

Sexuality in women living with HIV

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For my daughters

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ABSTRACT

The overall aim was to investigate different aspects of sexuality in women living with HIV in Sweden. **Study I** was a meta-synthesis of 18 qualitative studies describing experiences of sexuality and reproduction in women living with HIV. A lines-of-argument synthesis showed that the women balanced the burden of HIV infection in relation to sexuality and reproduction. The burden was not constant but could be heavier or lighter. Conditions making the burden heavier were HIV being a barrier and feelings of fear and of loss. Motherhood, spiritual beliefs and supportive relationships made the HIV burden lighter. **Study II** was a qualitative study with a reflective lifeworld approach, comprising 18 interviewed women living with HIV in Sweden. The essence of the phenomenon sexuality and childbearing as experienced by the women was that the perceptions of HIV and its contagiousness profoundly influenced sexual habits and considerations in relation to pregnancy and childbirth. The constituents were; risk of transmission imposes demands on responsibility; the contagiousness of HIV limits sexuality and childbearing; knowledge about HIV transmission provides confident choices and decisions and to re-create sexuality and childbearing. **Studies III-IV** were retrospective cohort studies with data from the Swedish National Quality Assurance Registry InfCareHIV, between 2011-2016. InfCareHIV also contains a validated nine-item health questionnaire. **Study III** investigated whether having a suppressed viral load, HIV RNA < 50 copies/ml, was associated with sexual satisfaction. It further investigated associations with demographic variables and immunological function and changes in sexual satisfaction over time. The study comprised 3798 women and men living with HIV. No significant association between sexual satisfaction and HIV RNA levels was found. Women were more satisfied with their sexual life than men (51% vs 40%). Sexual satisfaction increased between 2011-2014 by 8% a year, which might be a result of the increased

knowledge of minimal sexual transmission and the concomitant changes in interpretations regarding the legal duty in Sweden to inform a sexual partner about an HIV diagnosis. **Study IV** investigated predictors of sexual satisfaction in women living with HIV in Sweden and its association with physical and psychological health. The study comprised 1292 women. Higher sexual satisfaction was associated with higher physical and psychological health. Predictors of greater sexual satisfaction were being born abroad and heterosexual contact as transmission route. Predictors of lower sexual satisfaction were higher age, more years since diagnosis and a longer time on antiretroviral treatment. **Conclusions:** The findings show the complexity of sexuality and that sexuality and childbearing are intertwined for women living with HIV. To be diagnosed with HIV impacts sexuality negatively. The extent of this impact varies and can be balanced with various challenges and resources that outline the woman's sexual wellbeing. Perceptions of being more or less contagious were a challenge of this kind. The women were dependent on their own and the surrounding people's knowledge of HIV and its contagiousness. The findings highlight the vulnerable situation for these women and contextual factors and health-related aspects influenced the ways in which these women experienced and enacted their sexuality and childbearing. Sexuality as part of health needs to be addressed to see the woman as a whole. This needs to be transferred and understood by healthcare professionals and all those who work with HIV in order to provide the right kind of intervention and support for women living with HIV.

Keywords: HIV, Sexuality, Childbearing, women

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SAMMANFATTNING PÅ SVENSKA

I slutet av 2017 uppskattades ca 36,9 miljoner människor leva med humant immunbristvirus (hiv). I Sverige lever ca 7500 personer med hiv varav 39% är kvinnor. Att leva med hiv som kvinna innebär att sexualiteten påverkas då hiv överförs bland annat genom sexuella kontakter och genom mor till barn. Det övergripande syftet med denna avhandling var att undersöka sexualitet och dess olika aspekter hos kvinnor som lever med hiv i Sverige. **Studie I** var en meta-syntes med 18 kvalitativa studier, inkluderandes 588 kvinnor som lever med hiv. Studien beskriver hur sexualitet och reproduktion upplevs av kvinnor som lever med hiv. En så kallad "lines-of-argument" syntes visade på att kvinnorna balanserar bördan av hiv i relation till sexualitet och reproduktion. Bördan av hiv var dock inte konstant, utan den kunde vara tyngre eller lättare. Faktorer som bidrog till att bördan blev tyngre var: HIV som ett hinder och känslor av rädsla och förlust. Moderskap, andlig tro och stödjande relationer bidrog däremot till att bördan av hiv blev lättare. **Studie II** var en kvalitativ studie, med reflekterande livsvärldsperspektiv som ansats. 18 kvinnor som lever med hiv i Sverige intervjuades om sina upplevelser av sexualitet och barnafödande. Resultaten visade att essensen av fenomenet sexualitet och barnafödande såsom det erfars av kvinnor som lever med hiv är att uppfattningar om hiv och dess smittsamhet starkt påverkar kvinnornas agerande och de val och beslut som görs i samband med graviditet och förlossning. De kontextuella delarna, de så kallade konstituenterna, av fenomenet var: krav på ansvar, smittan begränsar sexualitet och barnafödande, kunskap skapar trygga val och beslut samt att återskapa sexualitet och barnafödande. **Studie III-IV** var två retrospektiva kohortstudier. Data hämtades in från det svenska kvalitetsregistret InfCareHIV mellan år 2011-2016. I registret finns också en validerad hälsoenkät med nio frågor, varav en fråga handlar om sexuell tillfredsställelse (nöjdhet med sexualliv med eller utan partner). **Studie III** undersökte huruvida det fanns samband mellan undertryckta virusnivåer, HIV RNA < 50 kopior/ml, och sexuell tillfredsställelse. Studien undersökte också samband mellan sexuell tillfredsställelse, demografiska variabler och immunologisk funktion samt förändringar över tid i sexuell tillfredsställelse. 3798 kvinnor och män som lever med hiv i Sverige svarade på frågan om sexuell tillfredsställelse och inkluderades därmed i studien. Resultatet visar att det inte gick att påvisa något signifikant samband mellan sexuell tillfredsställelse och virusnivåer. Fler kvinnor än män svarade att de var nöjda med sitt sexualliv istället för missnöjda med sitt sexualliv (51% jämfört med 40%, $p < 0,001$). Den sexuella tillfredsställelsen ökade signifikant för hela gruppen mellan år 2011-2014 med 8% per år ($p < 0,0001$). Detta kan vara ett resultat av

en ökad kunskap om minimal risk för sexuell överföring av hiv samt att det samtidigt pågick en förändring i Sverige gällande tolkningen av lagen om den så kallade informationsplikten av en hiv-diagnos till en sexuell partner. **Studie IV** undersökte självrapporterad sexuell tillfredsställelse hos kvinnor som lever med hiv i Sverige, inklusive dess prediktorer. Den undersökte också sambandet mellan sexuell tillfredsställelse och fysisk och psykisk hälsa. 1292 kvinnor som lever med hiv svarade på frågan om sexuell tillfredsställelse och inkluderades därmed i studien. Det fanns ett starkt samband mellan högre sexuell tillfredsställelse och högre fysisk och psykisk hälsa. Prediktorer för att vara sexuell tillfredsställd var: att vara född utanför Sverige samt ha heterosexuell kontakt som överföringsväg istället för intravenös droganvändning som överföringsväg. Prediktorer för lägre sexuell tillfredsställelse var: högre ålder, fler år sedan diagnos och längre tid med antiretroviral behandling (ART). **Slutsatser:** Resultaten visar att sexualitet och barnafödande är sammanflätat hos kvinnor som lever med hiv. Att få en hiv-diagnos påverkar kvinnans sexualitet negativt. Denna negativa inverkan påverkas av både utmaningar och resurser relaterat till sexualitet och barnafödande. En sådan utmaning är uppfattningar om att känna sig mer eller mindre smittsam. Kvinnorna var beroende av sin egen och omgivande människors kunskap om hiv och dess smittsamhet. Resultaten visar hur sårbara kvinnor som lever med hiv i Sverige är vad gäller sexualitet och barnafödande och att faktorer såsom kontextuella och hälsorelaterade aspekter påverkade hur kvinnorna upplevde och levde ut sin sexualitet och sitt barnafödande. Sexualitet som en del av hälsa behöver lyftas inom vården för att hela kvinnan som lever med hiv ska ses. Detta gäller för all vårdpersonal och alla aktörer som arbetar med hiv för att rätt slags intervention och stöd ska kunna ges.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Carlsson-Lalloo, E., Rusner, M., Mellgren, Å. and Berg, M. 2016. Sexuality and Reproduction in HIV-Positive Women: A Meta-Synthesis. *AIDS Patient Care and STDs*. 30(2), 56-69.
- II. Carlsson-Lalloo, E., Berg, M., Mellgren, Å. and Rusner, M. 2018. Sexuality and childbearing as it is experienced by women living with HIV in Sweden—a lifeworld phenomenological study. *International Journal of Qualitative Studies on Health and Well-being*. 13:1, 1487760.
- III. Carlsson-Lalloo, E., Svedhem, V., Rusner, M., Berg, M. and Mellgren, Å. Sexual satisfaction in people living with HIV is not associated with HIV RNA levels – A national cohort study. Manuscript submitted
- IV. Carlsson-Lalloo, E., Berg, M., Rusner, M., Svedhem, V. and Mellgren, Å. Sexual satisfaction in women living with HIV is associated with physical and psychological health and antiretroviral treatment duration: A national cohort study. Manuscript submitted

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ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
AR 1	Autoregressive order
ART	Antiretroviral treatment
AZT	Analogue zidovudine
CASP	Critical Appraisal Skills Programme
CCR5	C-C chemokine receptor type 5
CD 4	Cluster of differentiation 4
CI	Confidence intervals
DNA	Deoxyribonucleic acid
FI	Fusion inhibitors
HIV	Human immunodeficiency virus
HIV 1	Human immunodeficiency virus-1 referred to as HIV
HIV 2	Human immunodeficiency virus-2
HIV RNA	Plasma HIV ribonucleic acid
HTPN	The HIV Prevention Trials Network
InfCareHIV	Swedish National Quality Assurance Registry InfCareHIV
Li-Sat	Life Satisfaction
NNRTI	Non-nucleoside reverse-transcriptase inhibitors
NRTI	Nucleoside reverse-transcriptase inhibitors
PI	Protease inhibitors
PREM	Patient Reported Experience Measures

PROM	Patient Reported Outcome Measures
QIC	Independence model criterion
RAV	Referensgruppen för antiviral terapi
RNA	Ribonucleic acid
RR	Relative risks
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

PREFACE

This thesis is written within the field of healthcare sciences. When talking to other people about HIV, risks of transmission, sexuality and this research, it has become clear to me that the public's knowledge relating to HIV, sexuality and childbearing is generally low.

The expectations are that the new knowledge provided in the thesis will help healthcare professionals, educators and politicians in their work with HIV. Hopefully, this thesis will draw attention to all the people living with HIV and spread knowledge about HIV, sexuality and childbearing.

I am a person who asks questions, every day. I want to experience and learn new things. So, when I became a nurse, it was natural for me to continue asking questions, every day. When I became an adult, I was fairly unused to talk about sexuality. In my work as a nurse for people living with HIV, I lacked the confidence to talk about sexuality. I soon realized that sexuality is part of health, for all people, but especially for people living with a disease that can be transferred by sexual contacts. For people living with HIV, sexuality was a very important part of health and also part of coping and being able to live with such a serious disease. I felt I was not able to provide good healthcare and help people achieve better health because of my lack of self-confidence to talk about sexuality. I therefore started to ask myself and my colleagues how we could support these people in these issues related to sexuality in order to provide better care. There were no clear answers to my questions.

I realized that standards and a solid knowledge of how to talk about sexuality could provide a good basis to talk about these issues. With knowledge, it was easier to be professional and not personal. With the support of a committed physician colleague and driven by my innate curiosity, the process began by asking research questions and finding answers. Due to the lack of research and to vulnerability and gender issues, the research became focused on women living with HIV.

1 INTRODUCTION

In order to understand the research area and topics associated with HIV in relation to sexuality, this introduction has two main sections. First, there is a description of the human immunodeficiency virus (HIV), HIV transmission, the occurrence of HIV globally and in Sweden, antiretroviral treatment (ART) and HIV transmission on ART. The second section introduces sexuality in women living with HIV, including the healthcare science perspective with the four core concepts of health, person, environment and caring.

Sexuality in this thesis includes sexual satisfaction and childbearing. Childbearing is a term used to define the process of planning and trying to conceive, getting pregnant, childbirth and the first year of motherhood¹. In order to minimize the stigma related to HIV, this thesis uses the term “women living with HIV” or “people living with HIV” as far as possible. These terms are recommended by The Joint United Nations Programme on HIV/AIDS (UNAIDS)².

1.1 HIV

In 1981, some previously healthy men in the United States presented unusual symptoms such as a pneumonia, called pneumocystis jiroveci pneumonia (formerly known as pneumocystis carinii pneumonia), and extensive mucosal candidiasis, caused by severe immunodeficiency³. It was caused by a retrovirus that was isolated in 1983 and subsequently named HIV (HIV-1)⁴.⁵ In 1986, a second virus, HIV-2, was found in West African patients with acquired immunodeficiency syndrome (AIDS)⁶. HIV-2 is more spread in West Africa and is less transmissible than HIV-1 and the immunodeficiency in HIV-2 develops more slowly than HIV-1⁷. Currently, HIV-1 is dominant throughout the world and, in this thesis, the use of “HIV” refers to HIV-1.

HIV is a retrovirus and contains two copies of ribonucleic acid (RNA) that encode for viral proteins and enzymes, which are essential in the HIV reproduction cycle⁴. After the virus has entered in the body, it enters the CD 4 T-cell by binding to the CD4 T-cell receptor. After fusion, the reverse transcriptase synthesizes RNA into DNA, using integrase to integrate into the host cell genome. The protease then cleaves the virus protein, before a new HIV particle leaves the cell⁸. The replicative cycle is illustrated in Figure 2.

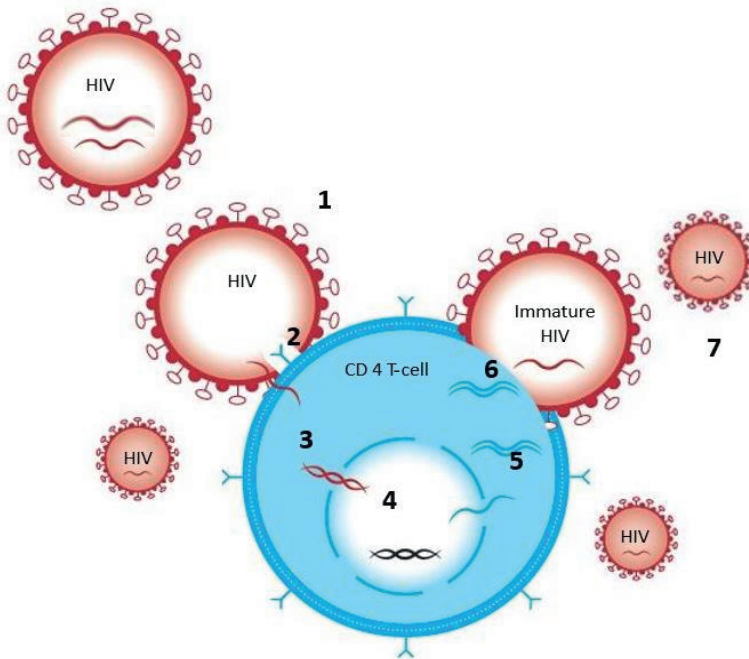


Figure 2: Illustration of the replicative cycle of HIV. 1. Binding/attachment of the HIV to the CD 4 T-cell receptor. 2. Fusion of HIV into the CD 4 T-cell. 3. Reverse transcription; inside the CD 4 T-cell, HIV is released and uses reverse transcription to convert its genetic material into HIV DNA. This allows HIV to enter the CD4 T-cell nucleus and combine with the genetic material of the cell. 4. Integration; inside the CD 4 T-cell nucleus, HIV integrates into the host DNA. 5. Replication; HIV begins to use the CD 4 T-cell to make long chains of HIV proteins which build blocks of more HIV. 6. Assembly; new HIV proteins and HIV RNA move to the surface and assemble immature viruses. 7. Budding; new immature viruses are released from the cell and the HIV protein called protease cleaves newly synthesized polyproteins to create a mature infectious virus. Figure by Jörgen Sahlén, source: ^{8,9}

1.1.1 HIV transmission

In the following section, HIV transmission and the natural course of HIV is explained when being treatment-naïve.

The most common way to acquire HIV is when the virus in semen or mucosal surfaces is transmitted by sexual contact ¹⁰. The highest risk of transmission is through blood transfusion and mother-to-child transmission. When it comes to the sexual route of transmission, the risk is highest for receptive anal intercourse ¹¹. Factors that may increase the risk of HIV transmission include sexually transmitted diseases, acute and late-stage HIV

infection and a high viral load. Factors that may reduce the risk include condom use, male circumcision, ART and pre-exposure prophylaxis ¹¹.

Following the transmission of HIV, about 50-70% of all infected people develop a primary infection, which is flu-like in symptoms ¹⁰. The HIV targets the CD 4 T-cell, which plays a central role in the immune system. During this acute phase, there are high levels of plasma HIV RNA and a prominent reduction of CD4 T-cells, in blood and in lymphoid organs ^{12, 13}. The chronic HIV infection results in the loss of CD4 T-cells, which ultimately leads to immune insufficiency with the risk of AIDS, defined by opportunistic infections, clinical symptoms or tumors and death. The time it takes to develop AIDS can vary between one and 20 years, but the median time, if untreated, is about 10 years ¹². Figure 1 illustrates how CD4 T-cells (blue color) and plasma HIV RNA levels (red color) change during the time after transmission.

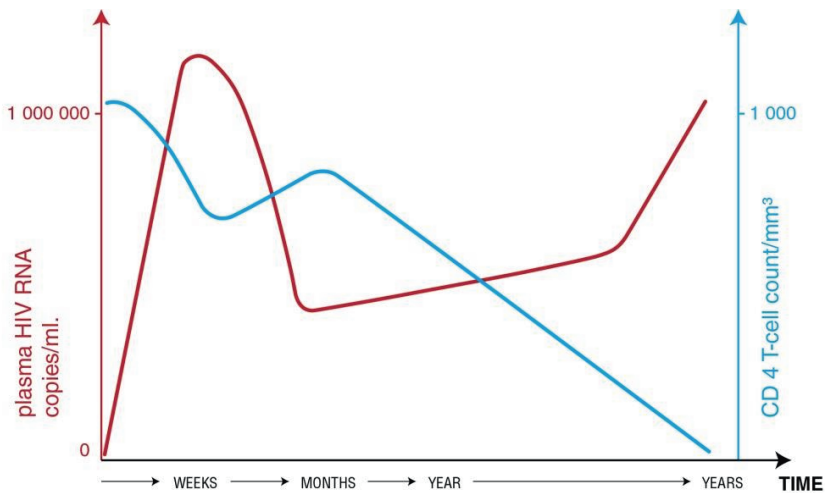


Figure 1: Illustration of plasma HIV RNA and CD4 T-cells during the time of a treatment-naïve HIV infection. Source ¹²

Mother-to-fetus/child transmission can occur intrauterinely during pregnancy, during birth, early after birth and through breastfeeding. In the absence of breastfeeding, 30% of infant HIV infections occur in utero and 70% during labor and delivery ¹⁴. When no other strategies are implemented to reduce the transmission of HIV other than not breastfeeding, the estimated risk of mother-to-child transmission is about 15–25% and, if the woman breastfeeds, the risk increases by 10-15% ¹⁴⁻¹⁷. Risk factors for HIV transmission via

breast milk when not being on ART include a high maternal viral load, advanced maternal immune deficiency and sore nipples caused, for example, by mastitis¹⁴. Moreover, the longer duration of breastfeeding or mixed feeding with solids are factors that increase the risk of HIV transmission^{18, 19}.

1.1.2 Occurrence of HIV globally and in Sweden

Since HIV was discovered, it continues to be a major global public health issue, where 77.3 million people have become infected with HIV since the start of the epidemic^{20, 21}. At the end of 2017, 36.9 million people were estimated to be living with HIV. Globally, more than 35 million people have died and, in 2017 alone, 940 000 people died from HIV-related causes²⁰.

Globally, in 2017, an estimated 1.8 million people became newly infected by HIV, where people in Africa accounted for more than two thirds of the new HIV infections²⁰. In 2016, young women and girls accounted for 59% of all new HIV infections among young persons aged 15-24²².

The African region is the most affected region, with an estimated 25.7 million people living with HIV²³. The estimated number of people living with HIV is distributed as follows: 19.6 million in Eastern and Southern Africa, 6.1 million in Western and Central Africa, 5.2 million in Asia and the Pacific, 2.2 million in Western and Central Europe and North America, 1.8 million in Latin America, 1.4 million in Eastern Europe and Central Asia, 310 000 in the Caribbean and 220 000 in the Middle East and North Africa²³.

In 1983, the first person was diagnosed with HIV in Sweden and, since then, approximately 10 000 people have been diagnosed with HIV in Sweden. The exact numbers and sociodemographic characteristics of the population living with HIV in Sweden have not been published. In the Swedish strategy for HIV prevention, people originating from high HIV endemic areas should be regarded as a key population, where extra attention should be paid to women, children and adolescent and transgender people in particular²⁴. According to a doctoral thesis on HIV-related stigma, 7532 patients (39% women) were registered in clinical care in March 2018, giving a prevalence of approximately 0.07%^{25, 26}. Of these, 36% were born in Sweden and 64% in other countries²⁶. Since the first case of HIV in Sweden, 51% were transmitted by heterosexual contact, 31% were men who have sex with men, 6% by people who inject drugs and 12% by other ways, such as mother-to-child transmission and blood products²⁷.

The Swedish Public Health Agency presented that 434 people were diagnosed with HIV in 2017 (273 men (63%), 161 women (37%))²⁸. In the

last ten years, a mean of 456 new cases of HIV infections a year have been reported. The reported mean age for individuals acquiring HIV was 37 years of age, with a range of 0-72 years. For women, the median age was 36 years, with a range of 0-72 years of age, and for men, the median age was 38 years, with a range of 0-71 years of age. Of the newly diagnosed cases 212 reported sexual contact with different sex as the route of transmission and 128 of the newly diagnosed were men who had had sex with men. Of the newly diagnosed, 20 were people who injected drugs and 14 were mother-to-child transmissions. The two most common countries in which HIV was transmitted outside Sweden were Thailand and Eritrea²⁸. The persons that were infected by mother-to-child transmission were most probably born outside Sweden, as Sweden has a mother-to-child transmission rate of < 0.5%²⁹.

1.1.3 Antiretroviral treatment (ART)

The first effective medicine against HIV, the nucleoside analogue, zidovudine (AZT), was introduced in 1987, followed by other nucleoside and nucleotide analogues^{30, 31}. In the mid-90s, combined therapy with three or more drugs from at least two different drug classes was introduced and this is also the current treatment recommendation worldwide^{32, 33}. The drug classes target specific steps in the HIV life cycle leading to a reduction in HIV RNA; nucleoside reverse-transcriptase inhibitors (NRTI), non-nucleoside reverse-transcriptase inhibitors (NNRTI), protease inhibitors (PI), integrase inhibitors, fusion inhibitors (FI) and CCR5 inhibitors³².

According to Swedish and international treatment guidelines, effective treatment, or being well treated, is defined as a plasma viral load of HIV RNA < 50 copies/ml at two consecutive measurements, three to six months apart, and that the person living with HIV maintains high adherence to treatment³⁴. After six months on effective treatment, the viral load has normally decreased to < 50 copies/ml. After starting ART, the CD 4 T-cells increase in number, Figure 3. As a result of the increased access to effective ART, HIV infection in terms of life expectancy is now regarded as a chronic, rather than a lethal, disease in well treated persons³⁵⁻³⁷, Figure 4.

Resistance to ART can develop through suboptimal drug concentration. All current antiretroviral drugs, including newer classes, risk becoming partially or fully inactive due to the emergence of drug-resistant virus³².

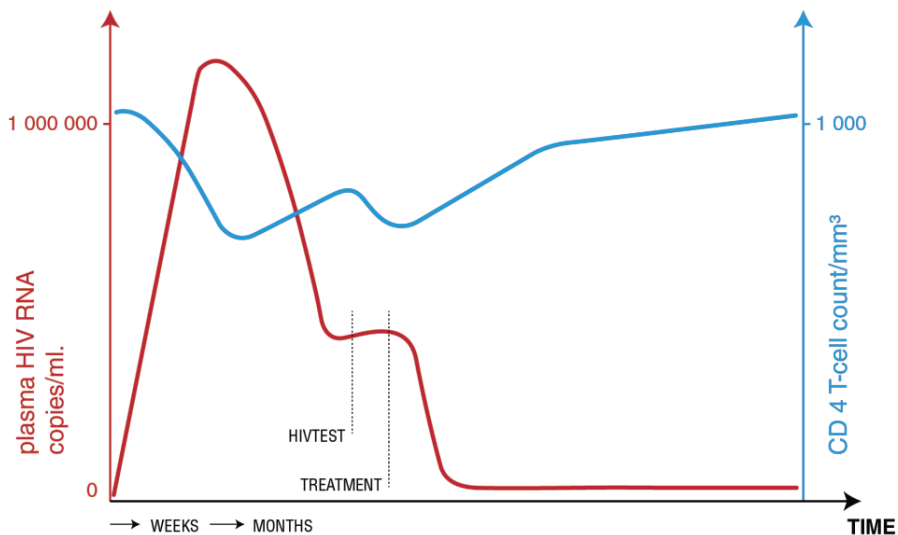


Figure 3. Illustration of an example of how HIV RNA plasma levels (red color) and CD 4 T-cell count (blue color) change after HIV testing and receiving effective ART. Source: ^{12, 38}

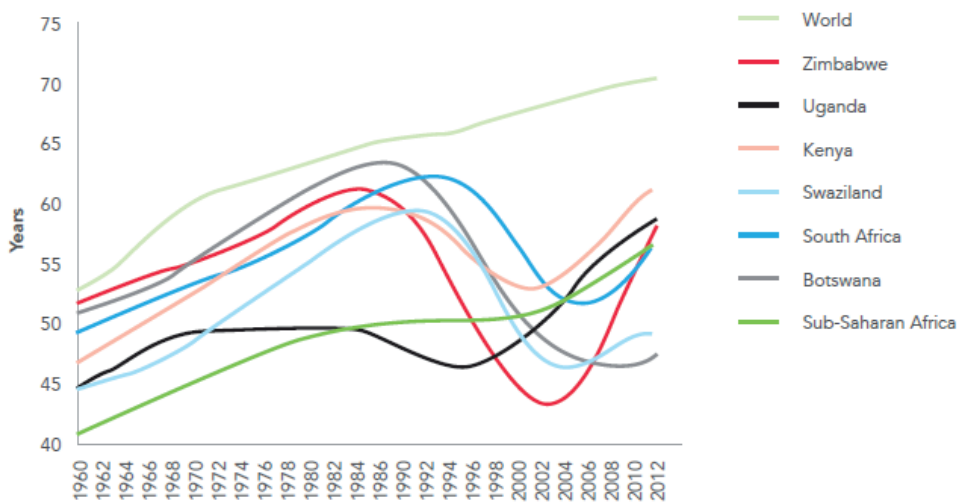


Figure 4. Trends for life expectancy since the introduction of ART globally and in selected countries. Source: ³⁹

The United Nations (UN) has set a 90-90-90 treatment target, stating that 90% of all people living with HIV will know their HIV status, that 90% of all people with an HIV diagnosis will receive ART and, of those receiving ART, 90% will have viral suppression³⁰. In 2017, the target had still not been reached globally, where 75% of all the people living with HIV knew their status and, of them, 79% were on ART, while, among people on ART, 81% were virally suppressed²³. Sweden was the first country in the world to achieve the 90-90-90 target in 2016⁴⁰.

1.1.4 HIV transmission on ART

ART suppresses the viral load which reduces the risk of HIV transmission and the rates of new infections have been reduced^{11, 41}. In 2008, the Swiss Commission announced that people living with HIV who were on effective ART were unable to transmit HIV through sexual contact. This has been referred to as “the Swiss Statement”⁴². More evidence has since been presented, showing a minimal risk of sexual transmission in conjunction with stable, well-functioning ART^{41, 43}. A meta-analysis found that, among 2848 sero-discordant couples, HIV had not been transmitted in any cases where the person living with HIV was virally suppressed⁴⁴. A systematic review concluded that the estimated risks of HIV acquisition from sexual exposure were attenuated by 99.2% by the dual use of condoms and antiretroviral treatment¹¹. The HTPN study provided more evidence and even questioned the risk of sexual transmission when people are on effective ART⁴⁵.

The risk of mother-to-child transmission has also decreased due to more available and effective ART²⁹. It is estimated that 77% of pregnant women living with HIV receive ART, with a varying coverage between different countries (from 2% to > 95%)^{20, 23}. There are no data on the risk of HIV transmission via breast milk in high-income countries⁴⁶. The risk of HIV transmission when being on ART while breastfeeding has in a study showed to be as low as 1,5%⁴⁷. By giving the infant antiretroviral prophylaxis, transmission can also decrease⁴⁸.

Around 60-80 children are born in Sweden every year to women living with HIV (≈ 0.05 - 0.07% of all babies born in Sweden in 2013⁴⁹) with a mother-to-child transmission rate of $< 0.5\%$ ²⁹. In Sweden, the strategy implemented to prevent mother-to-child transmission includes the following: screening for HIV among all pregnant women, routinely moderating plasma HIV RNA in the pregnant woman living with HIV, ART during pregnancy for the mother and antiretroviral prophylaxis to the infant for at least four weeks after childbirth²⁹. The updated recommendation for the treatment of pregnant women in 2017 stated that vaginal delivery was recommended for a well-

treated woman with HIV RNA < 150 copies/ml, regardless of gestational age, if no obstetric contraindications are present. Treatment during pregnancy should begin as soon as possible and should continue after delivery. Ongoing well-functioning HIV treatment at pregnancy start should usually be retained

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Women in Sweden should not breastfeed their infant ⁵⁰. Also in for example the United Kingdom, women are advised not to breastfeed, but women who have a suppressed viral load, present good adherence and choose to breastfeed should be supported and provided with information about breastfeeding ⁴⁶. Even though there is a low risk of transmission through breastfeeding in this situation, there is a requirement for extra maternal and infant clinical monitoring ⁴⁶. T-cells in breastmilk differ from blood lymphocytes which makes it easier for the HIV to replicate and turn the breastmilk into a residual source of infection ⁵¹. Information should be given about the “safer triangle” when breastfeeding, which means, in addition to having a suppressed virus, both the mother and the baby should have happy “tums” and the mother should have healthy breasts with no signs of infection ^{46, 52}.

1.2 Sexuality in woman living with HIV

Sexuality is defined by the World Health Organization (WHO) as:

“...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviors, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors”. ⁵³

As has previously been described, HIV can be transmitted either by sexual contact or by mother-to-child transmission. HIV affects different aspects of a woman’s sexuality and childbearing, which in turn influences overall health and wellbeing. For a woman, the journey of childbearing, from planning pregnancy to motherhood, cannot only be described as reproductive needs but must also be described as a great life transition ⁵⁴. Childbearing also includes childbirth, which is the process of giving birth to a child, and motherhood,

which is an ongoing process that typically starts in early pregnancy and continues through the first post-partum period ⁵⁵.

In what follows, sexuality in women living with HIV is described from a healthcare science perspective, including the four core concepts of health, person, environment and caring ⁵⁶⁻⁵⁸.

1.2.1 Health and HIV

According to the well-known definition from 1948, health is defined as a state of complete physical, mental and social wellbeing and not merely the absence of disease or an illness ^{59, 60}. This definition of health is also a basis for healthcare science. Health means being in balance and experiencing wellbeing ⁶¹. Furthermore, it has been stressed that health is relative and personal. What one person regards as healthy may be considered unhealthy by another person ^{62, 63}.

One part of overall health is sexual and reproductive health, where sexual health is defined by the WHO as:

“a state of physical, emotional, mental and social wellbeing in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled” ⁵³.

The link between sexual and reproductive health was stated in the 1994 United Nations International Conference on Population and Development ⁶⁴. Since then, sexual and reproductive health have been connected to one another and cannot only be explained and related to biology and reproduction ⁵⁴. Sexual and reproductive health includes the opportunity to have a satisfying sexual life which covers the whole life cycle.

Previous studies of women living with HIV have shown that living with HIV can reduce sexual function and arousal and cause feelings of being less attractive ^{65, 66}. There is also evidence that women even stop having sex, due to their HIV diagnosis ^{67, 68}. Quantitative reports and studies in Sweden have focused on associations between quality of life and sexual satisfaction in both women and men living with HIV and they have shown that lower sexual satisfaction was associated with lower quality of life ^{69, 70}.

Childbearing women, not only women living with HIV, are fragile⁵⁵. HIV has been shown to be an extra challenge when pregnant^{71, 72}. International studies have found that women living with HIV are worried about how to give birth without transmitting HIV to the fetus/infant^{71, 73, 74}. There is also uncertainty among women about the risks to the child in terms of HIV infection^{75, 76}.

Studies investigating experiences of childbearing in women living with HIV are missing in Sweden. However, one study, investigating social network, level of disclosure and knowledge about HIV in 47 parents of African origin living with HIV in Sweden, revealed that the single mothers in the study were an especially vulnerable group⁷⁷. They were more isolated, had a smaller network and had less knowledge of Swedish regulations about disclosing an HIV diagnosis⁷⁷.

1.2.2 The person living with HIV

A person in healthcare science is an individual in different caring contexts⁵⁷. The word “patient” is often used to refer to a person in need of care or a person that is in the healthcare system⁵⁶. All the studies in this thesis include patients and, in this thesis, the word “patient” refers to a person that is registered in the health care system⁵⁶. A patient refers to a role which can be changed and is considered reversible. The patient is always a unique person, but with an identity, who is considered to be an expert on him- or herself⁷⁸.

Studies show that HIV causes a change in sexuality, such as reduced intimacy, fears of infecting partners^{79, 80} and changes in body image^{81, 82}. HIV changes not only a woman’s sexuality but also her whole lived body. The so-called intersubjective world is accessed through the lived body, which is embedded and manifests itself through lived experiences⁸³. There is no thinking that is separate from the body, but the body, subject and world are interwoven⁸³. To obtain access to the experiences of the woman living with HIV, a lifeworld perspective can be used⁸⁴. The lifeworld can be explained as a world with meanings, where people experience and share the world in relation to each other.

1.2.3 HIV and the environment

The environment is the context of the person and there is always an interaction between humans and the environment⁸⁴. The environment is variable and consists of internal, external and social aspects⁵⁸. The context and environment can also be described in terms of other persons, a partner or a family member⁵⁷. This is also true for the woman living with HIV where the environment is the context in which she lives. She is dependent on social

structures, such as gender inequalities and knowledge levels, or on other persons such as a partner, friend or HIV organization. In some settings, different external and social factors can place women living with HIV at a higher risk of being affected by new HIV infections. A factor of this kind can be the lack of information on HIV prevention and how to protect oneself from HIV transmission²². There can also be lack of power in how to use this information in sexual relationships or marriages, which undermines women's ability to negotiate condom use and safer sex practices and places them at a higher risk of HIV transmission⁸⁵. Violence against women and girls increases the risk of acquiring HIV^{86,87}. Women working as sex workers are approximately 14 times more likely to be infected than other women of reproductive age with HIV⁸⁸.

In Sweden, HIV is included in the Swedish Law for Communicable Disease Control and is categorized as a disease that is dangerous to public health⁸⁹. The Communicable Diseases Act legally includes both rights and obligations for people living with HIV in Sweden (Appendix 1)⁵⁰. The law stipulates certain obligations in order to prevent HIV transmission, such as the obligation to use a condom in sexual encounters and the duty to inform a sexual partner of an HIV diagnosis. As a result of the new evidence of minimal risk of sexual transmission when being well treated on ART, the Swedish public health agency and Swedish reference group released a statement about HIV and sexual transmission in 2013^{34,90}. The interpretation and application of the law changed, which made it possible for the treating physician to remove the duty to inform about HIV in sexual encounters for people living with HIV when meeting certain criteria. The criteria were not to be diagnosed with other sexually transmitted infections, to display good adherence to ART and to have an undetectable plasma viral load (HIV RNA < 50 copies/ml) at two successive measurements, three to six months apart³⁴.

Countries other than Sweden have laws to prevent HIV transmission^{91, 92, 93}. In some countries, infringing a law of this kind is regarded as a criminal act and can even lead to imprisonment⁹⁴. The legal position in Sweden is uncertain, but the Swedish law has been criticized for being restrictive and increasing the stigmatization for an already vulnerable patient group^{93, 95, 96}. In a report on the quality of life of people living with HIV in Sweden, a total of 29% answered that they had been worried about being reported to the authorities or the police by a sexual partner⁶⁹. Some 75% reported that the duty to inform a sexual partner of an HIV diagnosis affected their sexual lives, while 88% reported that the duty to inform also prevented them from starting sexual relations or seeking a steady partner⁶⁹.

Stigma in the context of HIV refers to social stigma, a concept introduced in the early 1960s⁹⁷. For many people living with HIV, this stigma has a negative impact on their quality of life^{98, 99}. A literature review has shown that the consequences of HIV-related stigma may lead to mental illness and medication adherence issues¹⁰⁰. It can also result in difficulty being open about the diagnosis, which can in turn lead to isolation and feelings of being unsupported, which can have a significant impact on health and wellbeing⁵⁴. In women living with HIV, studies exploring stigma and sexuality have shown direct connections between stigma and psychological distress^{101, 102}. Studies in Sweden have also shown that stigmatization is associated with poor quality of life both in adults⁶⁹ and in children living with HIV¹⁰³. A dissertation in Sweden about self-reported stigma among women and men living with HIV in Sweden in the current era of efficient treatment showed that HIV is still a stigmatized condition, even for people that are virally suppressed²⁶.

1.2.4 Caring for people living with HIV

Caring is a way of communicating, including both talking and listening, as well as providing information and support⁵⁶. It involves seeing and understanding a patient as a whole person through close observation, precise listening and responsive questioning¹⁰⁴. Based on the observations, health and suffering are analyzed and explained, then plans and actions that directly address the patient's problem are drawn up in an attempt to facilitate better health for the patient⁶³.

All known people living with HIV in Sweden receive care at one of Sweden's 30 HIV centers¹⁰⁵. These HIV centers are differently organized and have varying numbers of registered patients. Care at the HIV centers is provided by a team of doctors, nurses and counselors.

For most people, receiving an HIV diagnosis is experienced as difficult. The HIV team needs to carefully plan the care of the newly diagnosed patient, based both on treatment guidelines and the personal needs of the patient. Information about HIV, ART and the transmission of HIV is given. Additional tests to exclude AIDS-related diseases or other diseases are made. Plasma HIV RNA and the CD 4 T-cell count are taken to monitor the HIV infection and these tests are also made regularly, according to national treatment guidelines. ART is started as soon as the patient is eligible, also according to national treatment guidelines³².

The care is compliant with national laws and guidelines regarding the care and treatment of HIV, such as the Communicable Diseases Act and national treatment guidelines^{32, 89}. All samples, visits, treatment and ART are free of charge, according to the Communicable Diseases Act⁸⁹. For pregnant women, the baseline program for maternity care, as well as the program for mothers with complications and risk, are followed¹⁰⁶. There are national treatment guidelines for pregnant women and for the fetus/infant^{29, 107}. In Europe, the European AIDS clinical society has developed European guidelines³³. The Swedish guidelines may differ slightly from these and other countries' guidelines, depending on political, social and economic differences.

Since 2008, all HIV centers have used the Swedish national quality assurance registry, InfCareHIV¹⁰⁵. In Sweden, more than 99% of all people diagnosed with HIV are registered in the InfCareHIV registry. The registry includes demographic, medical and health-related data. A clinical support tool containing a health questionnaire is included in the registry. The aim is to offer this health questionnaire to patients every year (Appendix 2).

The answers from the questionnaire, together with medical data, are shown in the support tool as a graphic for each patient and the graphic is used at meetings with the patient¹⁰⁸. The support tool can be used as a base for planning individual care. National standards governing how to perform, inform and follow up the health questionnaire are developed by the steering committee of the InfCareHIV.

The graphic in the support tool includes a graph where the red line refers to plasma HIV RNA levels, the blue line refers to the CD 4 T-cell count and the colored vertical stripes refer to ART. The x-axis refers to time and shows how long the patient has been diagnosed with HIV, the date of HIV-RNA and CD 4 T-cell tests, the date of changes in ART and the date of answering the health questionnaire. The answers to the health questionnaire are colored boxes, shown below the graph. For questions about physical, psychological and sexual health, the box with the green light appears when patients answer that they are satisfied or very satisfied, the yellow light appears when the patients answer rather satisfied or rather unsatisfied and the red light appears when the answer is unsatisfied and very unsatisfied. For side-effects, the green light appears when patients answer that they are not troubled by side-effects, the yellow light appears when they are troubled and the red light appears when they are very troubled by side-effects. The question about taking part in planning is green when the patients answer that they always feel involved, yellow when they answer that they sometimes feel involved

and red when they answer that they are seldom or never involved. The question about missed doses is only green when the patients report no missed doses and the light turns red when one or more missed doses are reported in the past week. The last question on the questionnaire about satisfaction with care is not shown in the support tool. An example of a patient's support tool is illustrated in Figure 5.

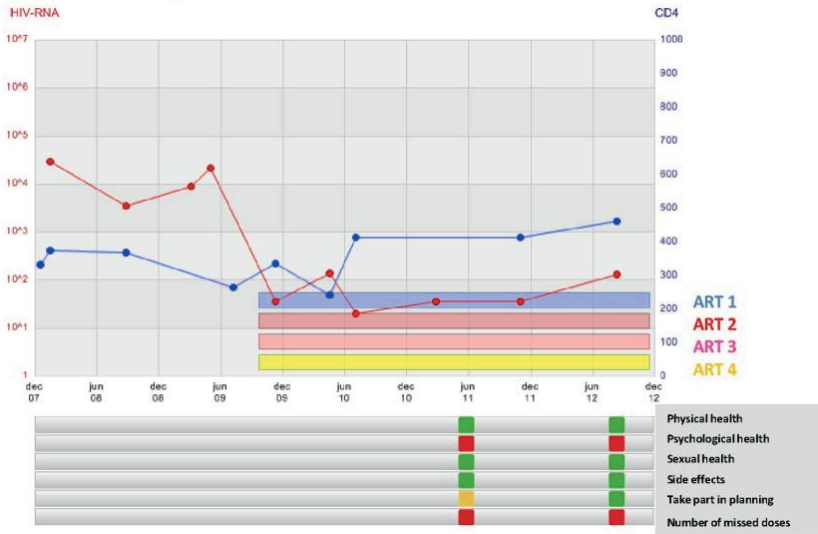


Figure 5. An example of how a patient's support tool appears in the InfCareHIV registry. This patient has been on ART for about three years and the viral load has been reduced, but it is not fully suppressed (< 50 copies/ml). The CD 4 T-cell counts are increasing slowly. In the last health questionnaire, the patient reported dissatisfaction with psychological health and also the missed number of doses, which might explain the suboptimal treatment. The reasons that the patient is not optimally treated should be further investigated. Source: ¹⁰⁸

2 RATIONALE

For women living with HIV, sexuality and childbearing can be complicated. HIV can reduce sexual function and sexual arousal and can also make women living with HIV feel less attractive. Due to a combination of biological factors and gender-based inequalities, women are also particularly vulnerable to HIV transmission. Furthermore, woman living with HIV in Sweden has to consider specific laws in relation to HIV affecting their sexuality and childbearing.

A satisfying sexuality and to have the possibility to be pregnant and give birth are essential elements of a healthy life. To live with a disease that is transmitted by sexual contact and by mother-to-child transmission and also can have serious consequences, make sexuality and childbearing an important part of these women's daily lives and wellbeing. However, in Sweden sexuality in women living with HIV has only been explored to a limited extent. In order to develop evidence-based care for women living with HIV in Sweden, there is need of more research. Both about their experiences in relation to sexuality and childbearing, as whether there are associations between sexual satisfaction and health-related issues.

3 AIM

The overall aim was to investigate different aspects of sexuality in women living with HIV in Sweden. In order to realize the aim of the thesis, four studies were performed.

3.1 Specific aims

Study 1: To synthesize HIV-positive women's experiences of sexuality and reproduction as described in qualitative studies

Study 2: To describe the meanings of sexuality and childbearing as it is experienced by women living with HIV in Sweden

Study 3: To investigate whether having a suppressed viral load, (HIV RNA <50 cop/mL) was associated with higher sexual satisfaction. Further, it investigated associations with demographic variables, immunological function and changes in sexual satisfaction over time

Study 4: To investigate self-reported sexual satisfaction in women living with HIV in Sweden, including its predictors and its association with physical and psychological health

4 METHODS

In this thesis, sexuality in women living with HIV has been investigated from different perspectives and with the use of different scientific methods. In Studies I and II, qualitative methods were used, while Studies III and IV were performed with quantitative methods.

4.1 Research design

The thesis consists of four studies from three data collections. Study I was a meta-synthesis that synthesized sexuality and reproduction as described in qualitative studies. Sexuality and reproduction can appear to be a wide-ranging phenomenon and, to obtain a better overview of what had been done in the research field, a meta-synthesis was performed. No qualitative Swedish study had been published and so no such study could be included in the meta-synthesis. Therefore, in Study II sexuality and childbearing as it was experienced by women living with HIV in Sweden was explored. An interview study using a reflective lifeworld approach was conducted. To further confirm and investigate the findings in the qualitative studies, two quantitative studies were performed. Studies III and IV were retrospective observational register cohort studies based on data from InfCareHIV, including a validated health questionnaire, in 2011-2016. Study III investigated the association between sexual satisfaction, suppressed viral load (risk of transmission) and changes over time in women and men living with HIV in Sweden. Study IV investigated sexual satisfaction, including its predictors, and its association with physical and psychological health in women living with HIV in Sweden.

An overview of the general research designs of the four studies is presented in Table 1.

Table 1. Overview of methodological research design, Studies I-IV

Study	Design	Data collection	Participants	Data analysis
I	Meta-synthesis of published qualitative studies	Systematic database search in the CINAHL and Medline databases	18 qualitative studies comprising 588 women from six countries	Quality assessment by Critical Appraisal Skills Programme (CASP) and meta-ethnography
II	Reflective life-world approach based on phenomenological philosophy	Meaning-oriented interviews	18 women \geq 18 years of age in the region of Västra Götaland	Meaning-oriented analysis with phenomenological lifeworld analysis
III	Observational retrospective register-based cohort studies	Nine-item validated health questionnaire and selected patient variables from InfCare HIV, in 2011-2016	3798 patients \geq 18 years of age, answering the question about sexual satisfaction in 6705 health questionnaires	Statistical analyses; associations and differences over time in univariable and multivariable models
IV			1292 women \geq 18 years of age, answering the question about sexual satisfaction in 2444 health questionnaires	Statistical analyses; associations in univariable and multivariable models

4.2 Study 1

A meta-synthesis was performed to synthesize HIV-positive women's experiences of sexuality and reproduction, as described in qualitative studies.

A meta-synthesis is research on research synthesizing the findings of previous primary researchers' qualitative studies¹⁰⁹. The emphasis in meta-synthesis is on rigorous study selection, including contexts and populations,

and on a careful interpretation of the results across the included studies. The method is designed to generate new integrated theoretical insights, as well as hypotheses that can be tested and used in further research^{110, 111}. This combination of interpreting findings from systematically selected studies in a particular subject area shares methodological similarities with its quantitative equivalent, meta-analysis¹¹².

4.2.1 Data collection and participants

Two systematic searches, one for sexuality and one for reproduction in women living with HIV, were performed in the Cinahl and Medline databases. The inclusion criteria were scientifically peer-reviewed qualitative studies including women living with HIV > 18 years of age. The exclusion criteria were studies carried out in countries in the African and Asian continents, studies using quantitative or mixed methods, studies including both sexes and studies that only included sex workers. There was no language or time restriction.

All studies matching the purpose of the study and meeting the inclusion criteria were assessed for quality using the Critical Appraisal Skills Programme (CASP)¹¹³. CASP grew out of the work of the Critical Appraisal Skills Programme in Oxford, which began in 1993 to help health-care decision-makers understand scientific evidence¹¹⁴. It provides a framework which approaches research in three steps with the following questions; 1. Is the study valid? 2. What are the results? and 3. Are the results useful?

In this thesis, the checklist for qualitative studies was used¹¹⁴. It consists of ten questions that assess different aspects of quality in qualitative studies¹¹³. The answer to each question was graded on a scale of 0-2 points, where 2 represents the highest quality. Consequently, each study could obtain a score of 0 to 20 points, where 20 points represents the highest quality. The whole checklist is attached as Appendix 3.

4.2.2 Data analysis

The analytic method used was meta-ethnography, as described by Noblit and Hare¹¹⁵, which includes seven overlapping steps. The steps are repeated as the synthesis proceeds, determining how included studies are related, by a process of translating them into one another¹¹⁵.

The analysis is inspired by grounded theory that is determined by “theoretical saturation”, which is reached when the emerging theory or hypothesis is unchanging¹¹⁶. The included studies can relate to each other differently; reciprocal translations that add findings from different studies together,

refutational translations where study results are in opposition, or lines-of-argument synthesis where parts of a process of comparative analysis generate a new theoretic model to explain the whole. In this study, the principles of lines-of-argument synthesis were followed¹¹⁵. The final synthesis of the translations describes a higher level of interpretative understanding and presents a new interpreted result, regarded as a complete study in itself^{109,115}.

The analysis started with each of the included studies being read several times by all the authors. In the repeated readings, descriptions and interpretations were extracted from the studies. Categories in each finding were identified, as well as meaning units and key words in their descriptions. Through a process of constant comparisons, the findings in each study were compared and contrasted and inter-relationships were identified. In a comparative process from meta (synthesis) to detail (individual study findings), themes emerged. Underlying uniformities were also found to enable reformulation until saturation was reached, in that the themes became stable and were shown to cover all the study findings. From details to wholeness, the new synthesis was tested by returning to the primary studies.

4.3 Study II

Meanings of sexuality and childbearing, as they are experienced by women living with HIV in Sweden, were explored using a reflective lifeworld approach. Reflective lifeworld research is described by Dahlberg, Dahlberg and Nyström and is based on phenomenological philosophy⁸⁴.

The reflective lifeworld approach contains methodological principles such as openness, flexibility and bridling¹¹⁷. Bridling is a methodological principle where the researchers need to embody a phenomenological attitude, which means adopting an openness and flexibility towards the explored phenomenon⁸⁴. Bridling is a reflective attitude aiming to slow down the process of understanding as a whole and making what is not directly visible become visible. It includes restraining the pre-understanding and avoiding the act of defining what is undefinable¹¹⁸. This is fundamental to research validity and transferability in studies with a design of this kind¹¹⁹.

4.3.1 Data collection and participants

The inclusion criteria for the study were women living with known HIV, age ≥ 18 years, English- or Swedish-speaking and women living in the western region of Sweden. The exclusion criteria were women newly diagnosed with HIV (within six months), and/or with an ongoing crisis reaction or women with serious mental illness. The participants in the study were chosen

strategically to reflect the variety of the participants' experiences of the explored phenomenon and also to present the group of women living with HIV in Sweden. Women with different backgrounds, such as age, years living with HIV, having a partner or not or experience of being a mother, were therefore considered when selecting the participants.

All (five) HIV centers in the region of Västra Götaland participated in the study. Women meeting the inclusion criteria were invited to participate in the study by a nurse, medical counselor or physician. The women also received oral and written information. If they were interested in participating in the study, the women were contacted and given a more comprehensive description of the purpose of the study. A total of 23 women were interested in participating. Five of the women were not included for the following reasons: two did not come to the appointment, two regretted participation and one woman did not want to be recorded. Consequently, 18 women from three HIV centers were included.

The participants had an age range of 30-60 years and they had been diagnosed with HIV between 1992 and 2015. The participants originated from nine different countries distributed as follows; African country (n=9 women), Sweden (n=7), Asian country (n=2). Their family status varied, including whether or not they had a partner (n=13 women with a partner) and where some of the partners were living with HIV. In order to protect the integrity and identity of the women living with HIV, a detailed table of the included women cannot be presented.

Individual phenomenon-oriented interviews were conducted between September 2015 and April 2016. The setting was chosen by the woman. Three interviews were conducted in English, to include women who had not lived in Sweden for a long period of time. The interviews took between 42 and 101 minutes.

The interviews began with an open broad-based question: "What is it like living with HIV?". The focus during the interview was then to gain access to personal experiences of the phenomenon. Questions such as "How do you experience your sexuality?" and "What is it like to be pregnant and living with HIV?" were asked. In order to encourage reflection and develop richer illustrations of the experiences, follow-up questions were asked, such as "Can you please give an example of that experience?". The interviews were recorded digitally and the Swedish interviews were transcribed verbatim in Swedish, while the English interviews were transcribed verbatim in English.

The translated text was reviewed for language, for grammar and spelling, by a native English speaker.

4.3.2 Data analysis

A reflective lifeworld research analysis, as described by Dahlberg, Dahlberg and Nyström ⁸⁴, was conducted to describe the meaning structure of the phenomenon. The description of the phenomenon, the meaning structure, is a unity of its invariant part, the essence, and its variances of the essence, the so-called constituents.

The analysis followed a process which began with the whole, then analyzed its parts and, finally, reconstructed the whole to understand the meaning structure of the phenomenon. The first step was a thorough reading of the transcribed interviews in order to become acquainted with the data material. Next, attention was directed at parts of the interviews to discover nuances of meaning. The meaning units, which can be a word, a sentence, or a longer piece of text, relevant to experiences of the phenomenon, were identified. A computer program, NVivo 11 ¹²⁰, was used to organize the data material. Meanings in the units were described by some words and were then compared, to find differences and similarities, and lastly grouped into clusters. This is a preliminary analysis stage, designed to elucidate the essence of the phenomenon.

The researchers tried to understand each meaning as a figure against the background of the others, where the method of bridling allowed them to slow down the process of understanding the phenomenon and, in this way, allow its meanings to show themselves. When the meanings relevant to the phenomenon had been identified and no inconsistencies could be found, the essence emerged by a process and movement between the parts and the whole. The essence was then expressed and described. Further, the final stage was to describe the variances of the essence that were present in the data in the more contextual nuances of the phenomenon, the so-called constituents ⁸⁴.

4.4 Studies III-IV

Two quantitative studies investigating sexual satisfaction, first in women and men living with HIV in Sweden and then in women living with HIV in Sweden, were performed.

4.4.1 Data collection and participants

Study III and Study IV were retrospective observational cohort studies based on data from the Swedish InfCareHIV registry cohort between 2011 and 2016.

The Swedish national quality assurance registry InfCareHIV

The InfCareHIV registry includes a database and a clinical support tool ¹⁰⁸. The database covers socio-demographic variables (gender, age, country of birth, estimated country of transmission, route of transmission), biological data (date of first positive HIV serology, CD4 cell count, plasma and cerebrospinal fluid HIV RNA and serostatus of hepatitis C virus and hepatitis B virus), ART history and information about HIV drug resistance. Since 2011, the support tool has included a self-reported nine-item health questionnaire.

The health questionnaire assesses self-reported Patient Reported Outcome Measurements (PROMs) and Patient Reported Experience Measurements (PREMs). Questions 1-3 cover satisfaction with physical health, psychological well-being and satisfaction with sexual life (with or without a partner). The questions regarding physical and psychological health as well as sexual satisfaction are adapted from the life satisfaction (Li-sat) scale with answers presented on a Likert scale, as follows; very unsatisfied, unsatisfied, rather unsatisfied, rather satisfied, satisfied and very satisfied ¹²¹. Question 4 covers side-effects and missed doses. Question 5 covers feelings of involvement in care and question 6 covers satisfaction with care. The whole health questionnaire (English and Swedish version) is presented in Appendix 2, while the Li-Sat scale (Swedish version) ¹²² can be found in Appendix 4. The health questionnaire was developed by the steering committee of the quality registry, together with a project team with members representing a wide range of disciplines, all active in HIV care and treatment. The health questionnaire was validated by test-retest and showed good agreement for physical, psychological and sexual health items. A further description of how the health questionnaire was developed and validated is given by Marrone et al. ¹⁰⁸.

The health questionnaire is designed to be offered annually to the patients. It is available as a web- or paper-based version, presented in both Swedish and English, or it can be translated into other languages by a professional interpreter.

Study III

The study included all women and men ≥ 18 years of age answering the question about sexual satisfaction in the health questionnaire in 2011-2016. The following sociodemographic and medical variables were used: gender, age at diagnosis, age at registry visit, time since diagnosis (years), route of transmission (heterosexual contact, homo/bisexual contact, intravenous drug use, unknown/other, blood products, mother to child), origin (Sweden or abroad), on treatment or not, ART duration (time on ART), plasma HIV RNA, CD 4 T-cell count and CD 4 T-cell nadir (lowest measured value). Changes in sexual satisfaction were based on calendar time in years between 2011-2016, age when filling in the health questionnaire and years since diagnosis.

In 2011-2016, 7998 individuals were registered in InfCareHIV. The health questionnaire was offered to 4,241 (53% of total InfCareHIV cohort) patients and 4,080 patients answered it. A total of 3798 patients (34% women, 66% men) answered a total of 6705 questionnaires. These patients corresponded to 47.5 % of the total Swedish InfCareHIV cohort during this period, Figure 6.

Study IV

The study included all women ≥ 18 years of age answering the question on sexual satisfaction in the health questionnaire in 2011-2016. The following sociodemographic and medical variables were used: age at diagnosis, age when answering the questionnaire, years since diagnosis, calendar year when answering the questionnaire, transmission route (heterosexual contact, homo/bisexual contact, intravenous drug use, unknown/other, blood products, mother to child), origin, on ART or not and ART duration (time on ART). For descriptive data, plasma HIV RNA and CD 4 cell count were used.

In 2011-2016, 3022 women were registered in InfCareHIV. The health questionnaire was offered to 1522 women and 1441 women answered the health questionnaire (94.7%). The question on sexual satisfaction was not answered by 149 women (10.3%) and a total of 1292 women (89.7%) answered the question on sexual satisfaction in a total of 2444 questionnaires, Figure 6.

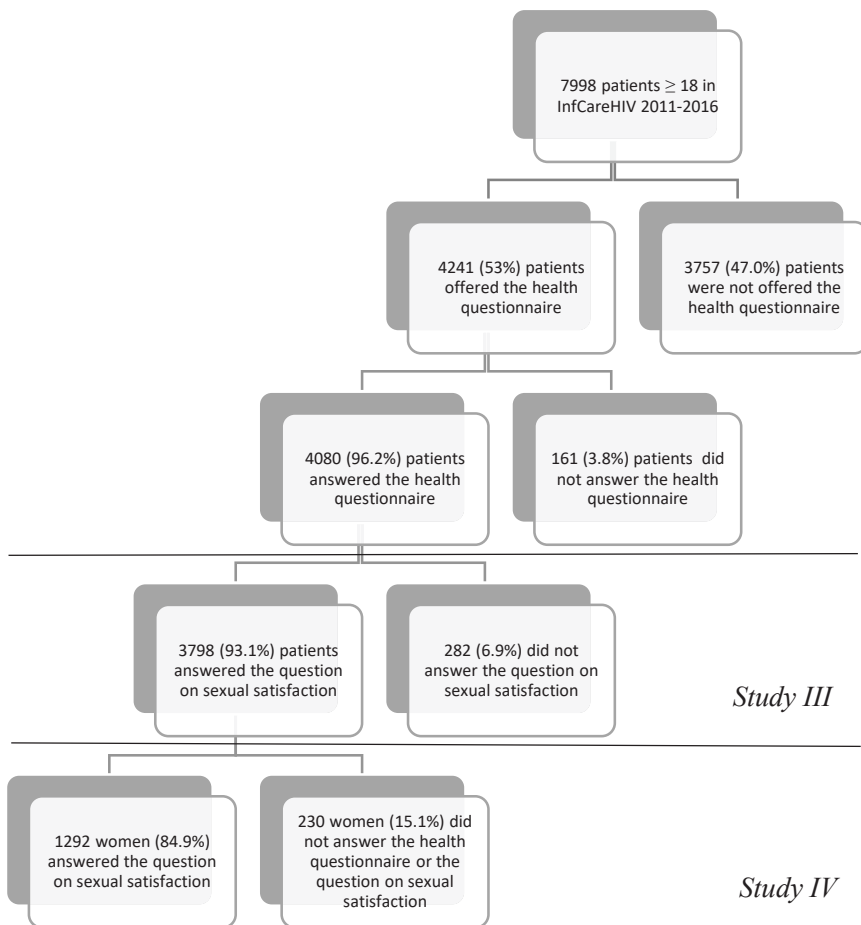


Figure 6. Flowchart illustrating the inclusion of the study populations in Study III and Study IV.

4.4.2 Data analysis

The analysis followed a pre-specified statistical analysis plan. Differences between two groups were identified using Fisher’s exact test for dichotomous variables, the chi-square test for non-ordered variables and the Mann-Whitney U test for continuous variables.

Individuals on ART > 6 months were dichotomized into two groups according to treatment result and having suppressed viral load (HIV RNA < 50 copies/ml) or not (\geq 50 copies/ml). HIV RNA was also analyzed as a continuous variable after \log_{10} transformation to achieve linear relation to the outcome variable.

The answers to the questions on physical and psychological health and sexual satisfaction were dichotomized into not satisfied (corresponding to Likert-scale answers: very unsatisfied, unsatisfied, rather unsatisfied, and rather satisfied) and satisfied (corresponding to Likert-scale answers: satisfied and very satisfied), in accordance with other Swedish studies examining sexual satisfaction using the Li-sat scale^{123, 124}.

To adjust for repeated answers on the health questionnaire and for within-patient correlations, generalized estimating equation models were used. Associations were tested in a univariable model. A multivariable model was then performed using backward regression. The covariance structure that fitted the data best was selected for each variable based on the lowest Quasi-likelihood under the Independence model Criterion (QIC) as a goodness-of-fit measurement. Compound symmetry and autoregressive order 1 (AR (1)) structures were tested. The linear, piecewise linear and quadratic function of time-scale variables were investigated.

In Study IV, after the univariable analyses, the multivariable analyses changed to a post-hoc multivariable analysis. In the original multivariable model, years since diagnosis was a stronger association variable than years on ART. However, years on ART was considered to be a better clinical explanatory variable and it was therefore included in a post-hoc multivariable model instead of years since diagnosis. Psychological and physical health were strongly correlated and physical health no longer contributed significantly to a better explanation of the parameter of sexual satisfaction and was consequently not analyzed in the multivariable model.

From these analyses, the estimated proportion of patients reporting sexual satisfaction per category and with log-link function relative risks (RR) with 95% confidence intervals (CI) were presented along with associated p-values. All the tests were two-tailed and conducted at the 0.05 significance level. All the analyses were performed using SAS software version 9.4¹²⁵.

Missing values were presented as not registered in the explanation of the cohort. In the univariable analysis, the missing values were not included for each variable. In the multivariable analyses, the questionnaire could not be included if a variable was missing. In Study III, a total of 278 (3.7%) of 6705

health questionnaires were excluded from the multivariable analysis. In Study IV, a total of 26 (1.1%) of 2444 health questionnaires were excluded from the multivariable analysis.

5 ETHICAL CONSIDERATIONS

All studies followed the Helsinki Declaration ¹²⁶.

Study I did not require ethical approval. However, each qualitative study was examined and assessed for ethical reasoning by the CASP criteria ¹¹⁴.

Study II was approved by the Regional Ethical Committee in Gothenburg 150810, Dnr: 591-15. The participants in the study were informed orally and in writing and individual written consent was obtained from all participants. Voluntary participation in the research was underlined. Studies about experiences of sexuality are regarded as sensitive, since the participants may experience discomfort related to private emotions and experiences. Participants were offered an appointment with a counselor at the clinic after the interview, if needed. One member of the research team of the study did not recruit or interview any patient that had been cared for by her at the clinic, in order to avoid a power balance between the participant and researcher. Special consideration also had to be taken to avoid exposing any of the included participants when presenting the included participating women of the study.

Studies III-IV: According to the Patient Data Act in Sweden, studies of data from national quality registries do not require the written consent of each registered patient ¹²⁷. In the studies, only registry data were used. The studies were approved by the Regional Ethical Committee in Gothenburg, 160421, Dnr: 293-16, and by the steering committee for InfCare HIV. All included patients were informed and agreed to be registered in the InfCare HIV registry. Choosing the focus in a special group in research can lead to the group that is not included feeling discriminated against and excluded. Of the two studies, one included both women and men and one included only women.

This thesis bridges an important gap in our knowledge of sexuality in women living with HIV, but, to some extent, also for both women and men living with HIV. People with origins other than Sweden can sometimes be excluded from research, due to not having enough Swedish language skills. The studies included in this thesis comprised a large number of women and men born outside Sweden.

Special care must be taken with studies of sexuality or ethnicity in Sweden. The risks in these studies have been carefully assessed, as have the benefits.

The importance and benefits of addressing sexuality in women living with HIV must be regarded as high.

6 RESULTS

6.1 Study I

The results of the meta-synthesis, the aim of which was to synthesize HIV-positive women's experiences of sexuality and reproduction, as described in qualitative studies, are presented in two parts. First, the result of the meta-synthesis presents a summary and a description of the context of the included studies. It then presents the analysis, resulting in a lines-of-argument synthesis of the included studies.

The search string in the Cinahl and Medline databases generated a total of 35676 records, including duplicates, up to March 2014. A total of 701 records remained after excluding duplicates or records fulfilling exclusion criteria. Titles and abstracts were read to further eliminate studies, resulting in 47 articles being read in full. Of these, 30 articles were further excluded.

The remaining 17 articles were assessed for quality using CASP¹¹³. Conflicts in assessments were identified and discussed before assessment agreement. This resulted in two of the full-text articles being excluded. From the reference lists of the 15 included studies, four additional full-text articles were quality-assessed using CASP. Of them, three studies were included. The procedure is described in Study 1. Table 2 shows the summarized assessment of CASP of the included studies.

A total of 18 studies, comprising 588 (n=4 to n=158) interviewed women living with HIV, were included in this lines-of-argument analysis^{66, 72, 73, 75, 76, 79-81, 128-137}. All the authors performed the analysis of the included studies. The studies were published from 1997 to 2012 and performed in six countries: USA (n=11), Canada (n=2), UK (n=2), Australia (n=1), Ireland (n=1) and Brazil (n=1).

Table 2. Summarized CASP assessment

Study presented in alphabetical order	CASP question number										CASP summarized
	1	2	3	4	5	6	7	8	9	10	
Barnes & Murphy, 2009	2	2	2	2	0	2	2	2	2	2	18
De Almeida et al., 2010	2	2	1	2	0	0	2	0	0	0	9
De Lacey et al., 2005	2	2	2	2	2	0	2	2	2	2	18
Giles et al., 2009	2	2	2	2	2	0	2	2	2	2	18
Gurevich et al., 2007	2	2	2	2	2	0	0	0	2	0	14
Ingram & Hutchinson, 2000	2	2	2	2	2	0	2	0	2	2	16
Jackson et al., 1999	2	2	2	2	2	0	2	0	0	0	12
Keegan et al., 2005	2	2	2	2	2	0	2	2	2	2	18
Kelly et al., 2012	2	2	2	2	2	0	2	2	2	2	18
Kirshenbaum et al., 2004	2	2	2	2	2	0	2	2	2	2	18
Psaros et al., 2012	2	2	2	2	2	2	2	2	2	2	20
Richter et al., 2002	2	2	1	2	2	2	2	2	2	2	19
Sanders, 2008	2	2	2	2	2	0	2	2	2	2	18
Sanders, 2009	2	2	2	2	2	0	2	2	2	2	18
Siegel et al., 2006	2	2	2	2	2	0	2	2	2	2	18
Siegel & Schrimshaw, 2001	2	2	2	2	2	0	2	2	2	2	18
Sowell & Misener, 1997	2	2	2	2	2	0	2	2	2	2	18
Wesley et al., 2000	2	2	2	2	2	0	2	2	2	2	18

The lines-of-argument synthesis showed that the women were balancing the burden of HIV infection in relation to sexuality and reproduction. The burden was not, however, constant; it could be heavier or lighter and was expressed as a kind of balancing act, Figure 7. Conditions making the HIV burden

heavier were HIV as a barrier, feelings of fear and feelings of loss, whereas motherhood, spiritual beliefs and supportive relationships made the HIV burden lighter.

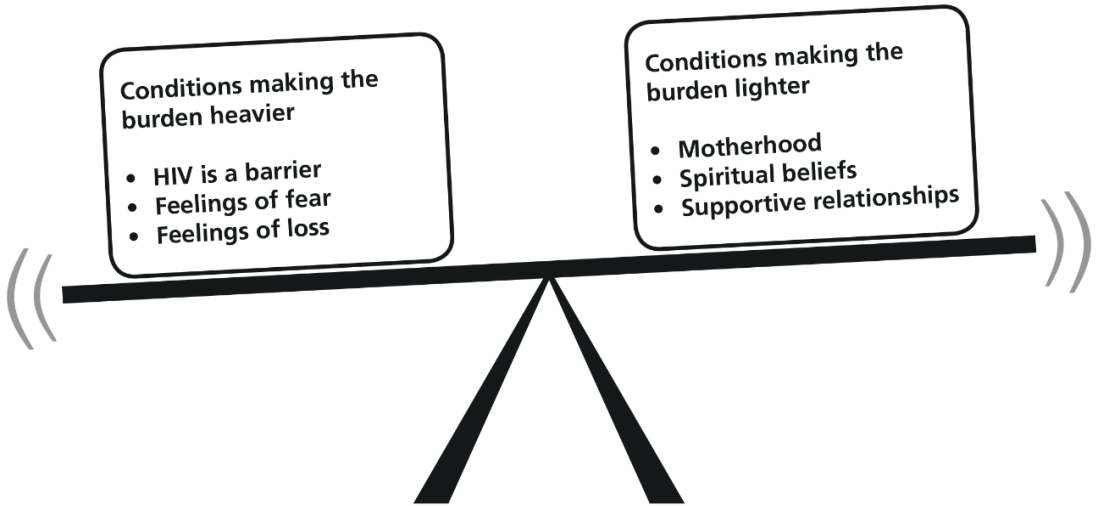


Figure 7. The balancing act for women to bear the burden of living with HIV in relation to sexuality and reproduction

6.2 Study II

The results of this study, the aim of which was to describe the phenomenon of sexuality and childbearing as it is experienced by women living with HIV in Sweden, are presented in parts. The meaning structure of the phenomenon, sexuality and childbearing, as experienced by women living with HIV in Sweden, is first presented in its invariant part, the essence, followed by a description of four identified constituents which further describe the variances within the phenomenon.

The essence of the phenomenon was that perceptions of HIV and its contagiousness profoundly influence sexual habits and considerations in relation to pregnancy and childbirth. The perceptions of the potential risk of transmitting HIV and its severe consequences permeated different aspects of sexuality and childbearing, such as thoughts, expectations, choices, decisions and actions. HIV, sexuality and childbearing were intertwined, as HIV can be transmitted through sexual intercourse or mother-to-child transmission.

Despite a low risk of sexual transmission, the risk of transferring the virus to a partner or child created feelings of fear and insecurity in relation to sexual habits, pregnancy and childbirth. Furthermore, the perceptions of HIV and its contagiousness were also present in the environment, such as members of society and healthcare professionals, thus influencing the women's perceptions. The perceptions were consequently formed by a combination of knowledge of HIV and transmission and interpretations by the woman herself, by those with whom she had a relationship and by those in her environment. The perceptions deeply impacted the women and made them dependent on their own knowledge but also on the knowledge of HIV and transmission in their environment and their decision-making in relation to sexuality and childbearing.

The constituents were; risk of transmission imposes demands on responsibility; the contagiousness of HIV limits sexuality and childbearing; knowledge about HIV transmission provides confident choices and decisions and to re-create sexuality and childbearing. The perceptions of being contagious, which for the woman meant seeing herself as a person who could transmit HIV, placed a feeling of responsibility on these women. This feeling of responsibility was both legal and moral, in relation to sexuality and childbearing. The perceptions of being contagious were experienced as being limiting, which was described through feelings of not having opportunities to choose freely how to perform sexual activities, to freely choose a partner, or not being able to choose if, when and how to become pregnant. The relationship between perceptions of HIV and its contagiousness and knowledge of the risk of HIV transmission was also shown through lived experiences of sexuality and childbearing. There was a dependency between the woman and her own knowledge of the risk of the sexual transmission of HIV, but also on the knowledge of others in her environment, such as a partner or healthcare provider. Deeper knowledge thus seemed to work against stigmatization and its negative consequences. A deeper understanding and greater knowledge of HIV and the risk of transmission provided a basis for making secure choices and decisions in relation to sexual habits, pregnancy and childbirth for the women. In a process of learning how to cope with the virus, the re-creation of sexuality and childbearing could begin. This re-created sexuality was not so negatively influenced by the perceptions of being contagious.

6.3 Study III

The study investigated whether having suppressed viral load, (HIV RNA < 50 copies/ml) was associated with higher sexual satisfaction. Further it investigated associations with demographic variables, immunological function and changes over time in sexual satisfaction.

A total of 3798 patients (34% women) were included, corresponding to 47.5% of the total Swedish InfCareHIV cohort during this period. The majority, 92.7%, were on ART and, of the patients who had been on ART for > 6 months, 2996 patients, 93.8%, had HIV RNA < 50 copies/ml.

The results from the univariable analysis of the association between sexual satisfaction revealed no differences in sexual satisfaction with regards to HIV RNA levels or between individuals with HIV RNA < 50 copies/ml compared to those with HIV RNA ≥ 50 copies/ml ($p= 0.74$). Figure 8 illustrates the distribution of proportions of HIV RNA levels in the two groups with HIV RNA < 50 copies/ml and HIV RNA ≥ 50 copies/ml for patients on ART > six months.

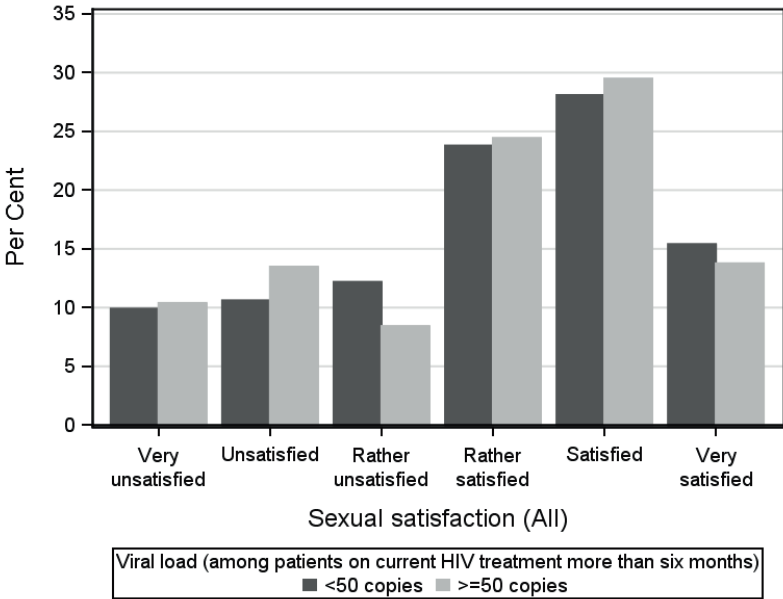


Figure 8. Percentage of individuals with HIV RNA < 50 copies/ml or ≥ 50 copies/ml by each answer on the Likert scale for the question on sexual satisfaction.

Overall, 43% of the cohort were satisfied with their sexual life (women, 51% compared with 40% of the men) (RR 1.30 [95% CI: 1.22-1.38], $p<0.0001$). People with heterosexual sexual contact as the route of transmission were more satisfied with their sexual life, 48%, compared with those with homo/bisexual sexual contact as route of transmission, 39% (RR 1.23 [95% CI: 1.16-1.33], $p<0.0001$). People born outside Sweden were more likely to be satisfied with their sexual life compared with people from Sweden (RR 1.26 [95% CI: 1.18-1.34], $p<0.0001$). Sexual satisfaction and age at diagnosis were associated with less satisfaction for every 10-year increase (RR 0.93 [95% CI: 0.91-0.96], $p<0.0001$), with a cut-off at 60 years of age.

For every increase in age of 10 years, sexual satisfaction was 11% lower in the < 70 years of age group (RR 0.89 [95% CI: 0.87-0.92], $p<0.0001$), but, in the age group between 70 and 80 years, sexual satisfaction was reported as being 45% higher (RR 1.45 [95% CI: 1.02-2.05], $p=0.039$), Figure 9.

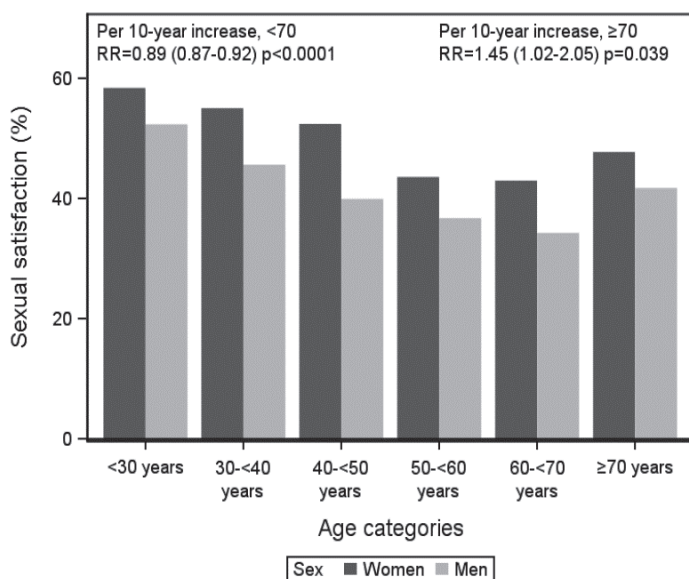


Figure 9. Self-reported sexual satisfaction for women and men by age when answering question about sexual satisfaction.

Sexual satisfaction was lower by 10% for each 10-year increase in time since HIV diagnosis (RR 0.90 [95% CI: 0.86-0.93], $p<0.0001$). For every five years on ART, sexual satisfaction decreased (RR 0.95 [95% CI: 0.93-0.98], $p<0.0001$). There was a significant increase in sexual satisfaction between 2011 and 2014 of 8% (RR 1.08 [95% CI: 1.04-1.11], $p<0.0001$) per year.

In the multivariable analysis, the following associations were still significant; the increase in sexual satisfaction over the period 2011-2014 (RR 1.05 [95% CI: 1.02-1.08], $p=0.0007$), the difference between women and men in sexual satisfaction (RR 1.17 [95% CI: 1.10-1.24], $p<0.0001$), the association between sexual satisfaction and age at diagnosis for those aged ≤ 60 years (RR 0.94 [95% CI: 0.91-0.97], $p<0.0001$) and the association between sexual satisfaction and years since HIV diagnosis (RR 0.88 [95% CI: 0.84-0.91], $p<0.0001$).

6.4 Study IV

The study investigated self-reported sexual satisfaction in women living with HIV in Sweden, including its predictors and its association with physical and psychological health. A total of 1292 women answered the question on sexual satisfaction at least once during this period, in a total of 2444 questionnaires. The mean age of the women was 42.1 (SD 9.7) years and heterosexual contact was the most common transmission route (86.2%), followed by injecting drugs as route of transmission (5.3%). The majority of the women (79.5%) were born outside Sweden. The majority of the women, 93.2%, were on ART. Of those who were on ART for > 6 months, 92.6% had HIV RNA < 50 copies/ml.

In the univariable analysis, greater sexual satisfaction was significantly associated with both greater physical and psychological health. Women who were “very satisfied” with physical health had a 78.0% increase in the probability of being sexually satisfied compared with those answering “very unsatisfied” with physical health (RR 1.78 [95% CI 1.36-2.34], $p<0.0001$). Women who were “very satisfied” with psychological health had a 125% increase in the probability of being sexually satisfied compared with those answering “very unsatisfied” with psychological health (RR 2.25 [95% CI 1.67-3.04], $p<0.0001$), Figure 10.

Predictors of a greater likelihood of being sexually satisfied were women born abroad compared with women born in Sweden (RR 1.13 [95% CI: 1.00-1.28], $p=0.047$), women in whom HIV had been transmitted by heterosexual contact compared with women in whom HIV had been transmitted by injecting drugs (RR 1.31 [95% CI: 1.04-1.64], $p=0.019$) and age > 60 years when receiving the HIV diagnosis compared with women < 60 years (RR 2.40 [95% CI: 2.00-2.87], $p<0.0001$). Predictors of less sexual satisfaction

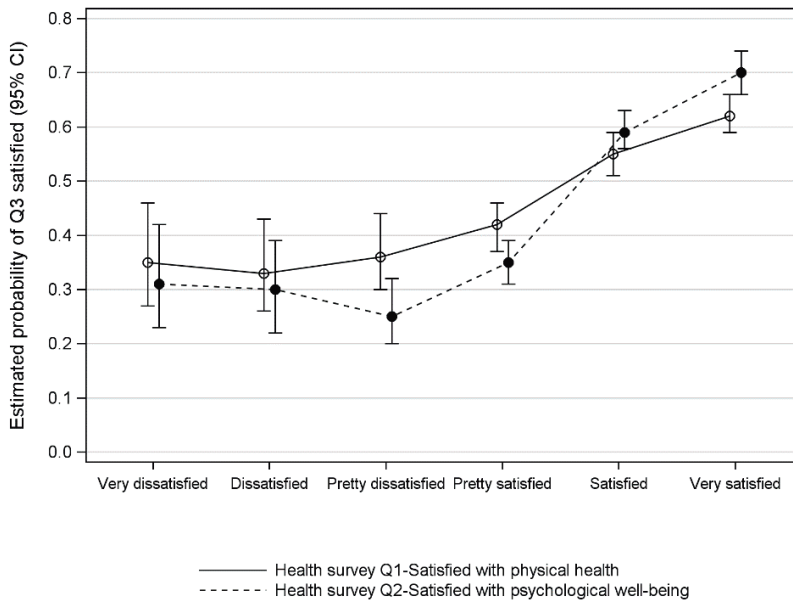


Figure 10. Estimated probability of being sexually satisfied (corresponding to Likert-scale responses: satisfied and very satisfied) for different answers to items relating to physical and psychological health among women.

were higher age when answering the questionnaire (for every ten-year increase (RR 0.92 [95% CI: 0.88-0.97], $p=0.0013$), more years living with an HIV diagnosis (for every ten-year increase (RR 0.90 [95% CI: 0.84-0.96], $p=0.0015$)) and longer time on ART (for every five-year increase on ART (RR 0.96 [95% CI 0.92-1.00], $p=0.032$)).

In the post-hoc multivariable analysis, the following associations remained significant; age at diagnosis for all ages (age ≤ 60 RR 0.95 [95% CI 0.91-0.99], $p=0.018$; age > 60 RR 1.94 [95% CI 1.63-2.31], $p<0.0001$), sexual satisfaction and calendar year 2011-2015 with a one-year increase (RR 1.06 [1.03-1.09], $p=0.0003$), sexual satisfaction and years on ART (RR 0.88 [95% CI 0.83-0.95], $p=0.006$) and association between sexual satisfaction and psychological wellbeing for all answers on the Likert scale (overall $p<0.0001$).

7 DISCUSSION

7.1 General discussion of main findings

The findings in the four studies (Studies I-IV) conducted as parts of this thesis identify and describe different aspects of sexuality in women living with HIV.

7.1.1 Sexuality as part of health in women living with HIV

The findings illuminate the complexity of sexuality in women living with HIV. HIV, sexuality and childbearing are intertwined, as HIV can be transmitted by sexual intercourse or by mother-to-child transmission. Sexuality and childbearing are integrated parts of all dimensions of health and wellbeing in women living with HIV, which thus confirms WHO's definition of sexuality⁵³. The findings show that HIV not only affects the body physically, with the risk of infections and symptoms, but that it also has psychological and social effects that have an impact on the women's sexuality. This impact of HIV on the sexuality of women living with HIV permeates actions, plans and decisions in relation to sexuality and childbearing, such as starting a new sexual relationship or planning to get pregnant. As sexuality and childbearing are part of being a woman, this impact on sexuality and childbearing affects the whole woman existentially.

As a consequence, the four core concepts of healthcare science, health, person, environment and caring, cannot be seen or described as separate entities in relation to sexuality in our findings but more as essentials that merge into one another. As part of healthcare which aims to see and include the whole woman, sexuality, sexual satisfaction and childbearing, together with all the other aspects of health, such as physical and psychological needs, need to be addressed for women living with HIV to promote overall health and wellbeing.

Health and wellbeing have been described as a movement¹³⁸. HIV was in Study I described as a burden in relation to sexuality and reproduction, where the burden was not constant but was a balancing act between conditions making the burden heavier or lighter. This goes in line with the definition of wellbeing as a balance point between physical, psychological and social challenges and resources in individuals¹³⁹. This fluctuating state of wellbeing applies to the finding in this thesis of challenges and resources relating to sexuality in women living with HIV. In this thesis, however, there is a

pronounced focus of the whole of these women's experiences and descriptions of health, person, environment and caring as part of sexuality in women living with HIV.

In the findings, HIV was referred to as something negative that limited sexuality and childbearing. This negative impact could, however, be balanced by the different aspects of sexuality identified and described in the findings as challenges or resources for the woman in relation to sexuality and childbearing. Perceptions about being more or less contagious and being treated differently, together with aspects related to time, were challenges for these women in terms of sexuality. Knowledge of HIV transmission, acceptance and feeling normal and being supported were, however, resources for the women when it came to sexuality. Women were dependent on knowledge relating to HIV and transmission, not only their own but also that of people with whom they had a relationship.

In the following section, the challenges and resources regarding sexuality in women living with HIV will be described and discussed.

7.1.2 Challenges regarding sexuality in women living with HIV

Perceptions of being more or less contagious

Since HIV can be transmitted by sexual intercourse or by mother-to-child transmission, together with the risk of severe consequences of HIV, this made the contagiousness one of the most prominent challenges regarding sexuality for women living with HIV. These perceptions of being more or less contagious permeated different aspects of sexuality and childbearing, such as thoughts, expectations, choices, decisions and actions (Study I, Study II). To use the word "contagious" should be avoided according to UNAIDS², but this was the word that was one used by the women themselves (Study II). The perceptions of being more or less contagious generated specific needs in relation to sexuality, such as knowing how to practice safer sex, or not transmitting HIV to a fetus/infant (Study I, Study II), which has been reported in previous research on women living with HIV^{65, 140, 141}.

However, this thesis has been written during a period in which the view of HIV and risk of transmission is changing^{34, 142}. After the data collection in our studies was completed, more evidence of the minimal risk of sexual transmission has been published, questioning whether sexual transmission is even possible with a suppressed viral load⁴⁵. Study III investigated if suppressed viral load was associated with sexual satisfaction as the findings in Study II showed that feelings of not being contagious had a positive effect on their sexuality. However, the result of Study III showed that viral load did

not have any association with sexual satisfaction and was therefore not a sufficient variable to measure sexual satisfaction. A recent study from France of people living with HIV revealed that as many as 68.0% of the respondents living with HIV feared transmitting HIV, even though 87.5% of the respondents reported an undetectable viral load¹⁴³. This potential fear, or the perception of being more or less contagious, cannot only be eliminated by presenting a suppressed viral load, it has to come from within each individual, as an understanding that being well treated also means that you cannot transmit HIV sexually. Consequently, the potential fear of transmission appears to be an important factor in relation to sexuality for all people living with HIV.

Being treated differently

The women had experiences or fears of being treated differently by a partner, friends or even healthcare professionals. This was often based on real experiences of being treated differently (Study I, Study II).

One of the explanations of being treated differently or being rejected was the experience of stigmatization. In spite of the medical success of ART, people living with HIV in Sweden still experience stigmatization²⁶. In studies, stigmatization has been described as complicating not only in people's sexual lives¹⁴⁴, but has also a negative impact on quality of life^{100, 101} for people living with HIV. Stigmatization has been shown to increase medication adherence issues¹⁴⁵ and sexual risk behavior among people living with HIV^{102, 146}. Stigmatization is described in the studies (Study I, Study II) as prejudice and misconceptions about HIV and transmission and that lack of knowledge in society can result in the unkind and unjust treatment. The Public Health Agency of Sweden regularly examines public knowledge and attitudes relating to HIV in Sweden. In 2016, the study revealed that there was still insecurity about HIV transmission¹⁴⁷. Some 60% of the respondents thought HIV could be transmitted by insect bites and 61% thought it could be transmitted by saliva¹⁴⁷. It is known since earlier that a lack of knowledge about HIV transmission and the power to request safer sex make people more vulnerable to acquiring HIV⁸⁵. This is problematic in some parts of the world, where only three in every 10 adolescent girls and young women aged 15-24 years have a comprehensive and accurate knowledge of HIV and how to protect themselves¹⁴⁸. HIV stigmatization is therefore still an important issue to women living with HIV. Disclosing or revealing an HIV diagnosis appears to be difficult for many women and healthcare professionals need to support disclosure¹⁴⁹.

The women also had experiences of experienced being treated differently in their contact with healthcare, which is in line with international studies^{75, 150}.

Some women had even been questioned about their right to become pregnant (Study I, Study II), which appears to occur in healthcare systems in other countries as well ^{75, 151}. In study II there were also experiences of HIV centers interpreting the regulations about preventing HIV differently, which led to insecurity about the risks of sexual transmission. The knowledge level in Swedish healthcare about HIV and transmission has been revealed to vary in primary care ¹⁵², a result also showed in Study II. Some women in Study II also experienced injustice in the form of not receiving help with assisted insemination. The Swedish law differs from that in Denmark, for example, when it comes to obtaining help with assisted artificial insemination ¹⁵³. The finding of being treated unfair cannot be assumed to be valid for all people living with HIV in Sweden, but should still be a reminder of how important it is to work evidence-based so equitable healthcare can be provided.

Another explanation that the women had experiences of being treated differently was by some women explained to be related to the Communicable Diseases Act (Study II). In study III we found that sexual satisfaction increased in the cohort during the years 2011-2015, even though the increase was only significant to 2014 for all people. The data collection took place during a period of change regarding the legal obligation to inform a partner of HIV ^{34, 90} and the implementation of the interpretation of the law in Sweden has been widespread, especially among people who live with HIV and at the HIV centers ⁹⁶. In 2018, a report from the Swedish Public Health Agency showed that, among treating physicians, knowledge of the minimal risk of HIV transmission in people living with HIV who are well treated is high ⁹⁶. The same report showed that, among people living with HIV, six in ten reported having had a conversation with their treating physician about exemption from the obligation to inform sex partners. However, in this investigation, most were men (92%), and there was an underrepresentation of people born outside Sweden, as well as women, in comparison with all the people living with diagnosed HIV in Sweden ⁹⁶. Additionally, another study in Sweden showed that single mothers had less knowledge of Swedish regulations about disclosing an HIV diagnosis compared to other parents with African origin ⁷⁷. A sub analysis in women and men of the finding in Study III of the yearly increase of sexual satisfaction (data not published) revealed that men's increase in sexual satisfaction lasted between 2011 and 2014, and the increase among women lasted between 2011 and 2015. Consequently, this might indicate that women receive information later than men or understand the information about HIV and transmission later than men. The reason for this might be that more women in higher extent are born abroad and have more difficulty understanding information due to a lack of language skills. It is of the utmost importance that all people living with HIV, regardless of their sexual orientation, gender or social status, should be

informed about HIV and transmission in a way that is individually designed for that person's unique needs.

Aspects related to time

Even though ART has reduced mortality, the result in Study IV showed that more years on ART had a negative impact on sexual satisfaction. There is no data or sub-analyses of sexual satisfaction and side-effects, although a recent study in Sweden reported significantly higher all-cause mortality in well treated people living with HIV compared with an HIV-negative control group¹⁵⁴. Mortality was reduced by 76% among well treated people compared with untreated and unsuccessfully treated people living with HIV, but people who were well treated and on ART were three times more likely to die compared with HIV-negative controls¹⁵⁴. The study concludes that the mortality was caused by immune activation, chronic low-grade inflammation, coagulation disorders, and/or lipid disturbances, as well as lifestyle risk factors such as smoking¹⁵⁴. This shows that there are still health-related issues in people living with HIV, even when being on effective ART, which need to be further investigated.

The quantitative studies showed that more years living with HIV affected sexual satisfaction negatively (Study III, Study IV). On the contrary, however, the findings in Study II described how time could lead to acceptance and a chance of rebuilding sexuality. These aspects related to time might not necessarily only be associated with HIV specifically, but they can probably also be experienced by people living with other different chronic illnesses. Studies of other groups with chronic illnesses also report lower sexual satisfaction due to body changes or psychological distress^{155, 156}. The experience of good health and sexual satisfaction has also been reported for people in general^{157, 158, 159, 160}. The results from study III therefore suggest that not only the specific impacts of living with HIV seem to affect sexual satisfaction, but also the overall health.

Higher age was associated with decreases sexual satisfaction (Study IV). Both older women and men living with HIV have reported having less sexual satisfaction^{161, 162}. In spite of this, the relationship between sexual satisfaction and age is not clear and other factors, such as relationship status, may also be more important than age^{81, 163, 164}. Interestingly, in this cohort, we saw that satisfaction with sexual life increased at over 70 years of age, for both men and women. Reasons for this might be a feeling of sexual freedom, which has been described in a qualitative study of African American women living with HIV¹⁶⁵. Furthermore, a large study conducted between 1971 and 2001 in Sweden showed that sexual satisfaction among 70-year-old people has increased over time, especially for women, from 41% in 1971 to 62% in 2001

¹⁶⁶. A review of sexual expression in later life in a general population suggests that women and men remain sexually active into their 70s and 80s and that age-related physical changes do not necessarily lead to a decline in sexual functioning; in fact, good physical and mental health, positive attitudes toward sex in later life, and access to a healthy partner are all associated with continued sexual activity ¹⁶⁷. Consequently, all these findings confirm the importance of seeing sexuality as something that encompasses a person's entire life and therefore needs to be continuously discussed with people living with HIV, regardless of age.

The group of women were younger than the group of men, which might explain why more women than men were sexually satisfied (Study III). However, there were also more differences between the groups that could affect sexual satisfaction. More of the women were born outside Sweden and they also had better psychological health compared to men. Also the distribution of the route of transmission differed between men and women in the study. People can though have different expectations of their sexuality and value it as more or less important ^{168, 169}. Economic and work-related factors ¹⁷⁰, are also associated with sexual satisfaction for people living with HIV, factors that are not investigated in this study. It is therefore probably not only the gender, if a person is a woman or a man, but instead individual psychological and physical health-related issues that are the factors affecting sexual satisfaction in these people.

7.1.3 Resources regarding sexuality in women living with HIV

Knowledge of HIV transmission

The women in the findings were dependent on their level of knowledge, their partner's, society's or on healthcare professionals'. The yearly increase of sexual satisfaction (Study III) might be a consequence of the new knowledge of the minimal risk of HIV transmission and the changes in the interpretation of the Swedish law relating to the obligation to inform a partner about an HIV diagnosis. Consequently people living with HIV should be systematically and repeatedly informed that, when efficiently treated, they cannot transmit HIV. This individual understanding can also be helped by external factors such as the public's view of not consider HIV as transmittable when having effective ART ¹⁴².

There was a lack of knowledge regarding mother-to-child transmission and especially about breastfeeding (Study II). In Sweden, the recommendation is not to breastfeed, but the women were aware that it was possible to breastfeed in other countries. There is a need for information about breastfeeding and, if the woman wants to breastfeed, the right information

about risks and how to prevent transmission to the baby is required. There is also a need for information about ART, HIV transmission and, if necessary, individual guidance on safer sex practices.

There was also a desire to talk more about sexuality and childbearing in the findings (Study I, Study II), a desire which has been reported in other settings as well^{171, 172}. Studies report the difficulty associated with talking about these issues in health care¹⁷³. A recent study of doctors working with patients with HIV in Sweden showed that the doctors needed more knowledge about how to talk about these issues with their patients⁹⁶, even though doctors working with HIV patients are expected to inform their patients about these issues due to the Communicable Diseases Act⁵⁰.

The findings reveal a need for more in-depth knowledge, not only in the healthcare system but also in society. Many of the attitudes to HIV were formed in the 1980s and since then they have not progressed much and are therefore influencing the lives of people living with HIV²⁶. There is a need to provide more public information about HIV and its transmission and in this way increase the general knowledge of HIV, thereby reducing prejudice and the stigmatization of people living with HIV.

Acceptance and feeling normal

Acceptance appears to be a wide concept, including acceptance of the disease, acceptance from the environment and acceptance of a change in sexuality (Study I, Study II).

The description of HIV as something that complicates sexuality has previously been reported^{67, 69, 70, 101, 174}. HIV was experienced as something that limits women's opportunities in both sexuality and childbearing (Study I, Study II). To be given a diagnosis of HIV was experienced by many women as a negative change in sexuality (Study I, Study II). This negative change has been revealed^{66, 70} and it can even lead to people stopping having sex^{68, 80}. The feeling of HIV as a burden was experienced (Study I), but the women also experienced themselves as being a burden, and did not want to transfer HIV to others (Study II). This made the women feel different and not normal.

Another factor that made the women not to feel normal were the negative consequences of not being able to breastfeed a baby (Study I, Study II), which have been described in other studies^{175, 176}. To not have the ability to choose the way of giving birth, for example, was also experienced negatively (Study I, Study II). Today women living with HIV in Sweden can have a vaginal birth, a guideline which was changed during the study period. It is

possible this would have effect in the narratives of the included women in the studies.

Motherhood was experienced as a strengthening condition and had a social value which made the women feel more normal (Study I, Study II). The importance of becoming a mother has also been reported in previous studies of women living with HIV ¹⁷⁷. There is no data on number of children or pregnancies for women living with HIV in Sweden. Childbearing and pregnancy intentions among women living with HIV should be explored in Sweden.

Being supported

The definition of social support is multidimensional and includes the provision of instrumental aid, information and emotional sustenance and affirmation ¹⁷⁸. The findings showed different needs to be supported, such as having a supportive partner (Study I, Study II), spiritual beliefs (Study I), HIV organizations or healthcare professionals (Study I, Study II).

Studies of people living with HIV have emphasized the importance of being in a relationship when it comes to sexual satisfaction ^{164, 179, 180}. There is no data about relationship status in the quantitative studies (Study III, Study IV), however another study of people living with HIV in Sweden presented that 62% of the women were in a relationship, compared to 55% of the men ⁷⁰. Partners should be encouraged to be actively engaged and discuss HIV, sexuality, reproduction and minimal risk of transmission. In doing so women's sexual and reproductive health and rights can be promoted and strengthened ¹⁸¹.

Spiritual belief has also been confirmed by other studies in people living with HIV ¹⁸² and might be something healthcare professionals miss addressing as a facilitator of achieving wellbeing. Another resource for women living with HIV was support from an HIV organization (Study I, Study II). Although there appeared to be a lack of confidence among some women to attend meetings, the women in contact with the organizations experienced support in the form of sharing experiences and obtaining information and knowledge about HIV.

In the findings, the healthcare professionals were described as supporters and even sometimes as family members (Study I, Study II). The findings showed how healthcare providers can have an impact on feelings of acceptance and the women in our study highlighted the importance of maintaining a good relationship with a healthcare provider (Study I, Study II). If women lack support from family members, support from healthcare providers may be

even more important. As is also reported in Study II, the report explains that physicians at the HIV centers have special positions as sources of information for people living with HIV. During pregnancy, the need for support and feeling safe is maintained through reliance on medical and technological information as a way to maintain control and ensure safe passage⁵⁵.

Healthcare professionals also have to confirm to women living with HIV that it can have severe consequences and that the perceptions of contagiousness affect their sexuality, health and wellbeing. Sexuality and childbearing need to be integrated as essential components in the clinical assessments of women living with HIV in order to empower and encourage women and improve their healthcare and wellbeing. High rates of depression have been found among women living with HIV^{183, 184} and it has also been shown that depression is negatively associated with poorer sexual function and a reduced power balance in their sexual relationships^{164, 185, 186}. Anxiety and depression have been shown in studies to reduce sexual satisfaction in both women and men living with HIV^{161, 164, 187, 188}. It is therefore recommended to consider social and psychological needs to help women living with HIV to enjoy better health and wellbeing and that people living with HIV should be routinely screened for depressive symptoms,^{28, 33}.

The fulfilment of sexuality and childbearing is tied to the extent to which human rights are respected, protected and fulfilled^{189, 190}. Work on sexual and reproductive rights should be included in national laws, international human rights documents and other consensus statements which recognize human rights related to the enjoyment of sexual health and the expression of sexuality^{53, 54, 189}. The findings in the thesis suggest future improvements for health care providers to support women living with HIV. There seem to be a need of more standardized way of addressing sexuality with women living with HIV. This goes in line with a recent report that showed that many of the treating physicians in HIV care stated that it was rare to have written clinical guidelines on the topics that should be addressed when meeting HIV patients⁹⁶. Consequently people living with HIV should be regularly informed about the risk of HIV transmission and viral load^{143, 174}. The information that is given has to be adjusted to individual needs and healthcare providers also have to give instructions on ways to cope with negative feelings of living with HIV⁵⁴. In Sweden, the health questionnaire in the InfCareHIV registry should continue to be used. It has now been developed and also includes questions about whether or not a patient smokes. Health questionnaires like this can be a good example of a standardized tool that can be used in the meeting with patients.

7.2 Methodological considerations

In order to match the overall aim of this thesis, both qualitative and quantitative methods were chosen. The methods were chosen to represent different angles in order to understand the different aspects of sexuality in women living with HIV. The mixed methods in the thesis enable us to find an understanding of different methods, but they may limit an in-depth knowledge of each specific method ¹⁹¹. Sexuality is complex and exploring sexuality using many different methods may be regarded as a strength.

Quality in qualitative research can be described as trustworthiness, which refers to four important criteria; credibility/internal validity, dependability, transferability/external validity and confirmability ¹⁹². Quality in quantitative research focuses mainly on two criteria: validity and reliability ¹⁹¹.

Credibility in Study I was established and strengthened by using two databases in the systematic literature search. The method, meta-ethnography developed by Noblit and Hare, accepts interpretative studies of all kinds, which matched the aim of the study. Moreover, a multidisciplinary team interpreted and analyzed data, in order to illuminate blind spots in the analysis process. Strongly connected to internal validity is dependability in qualitative research as it is an important part of trustworthiness.

The studies included in the meta-synthesis were conducted before 1997, when ART was not widely used or accessible (Study I). This might have made the burden of HIV heavier in these contexts. Since ART has reduced the morbidity and mortality of HIV infection and reduced the risk of sexual and mother-to-child transmission, this would probably have reduced the burden of fear for some of these women in the studies. In spite of this, recent studies show that, even though they are on effective ART, people living with HIV still have a fear of transmitting HIV ¹⁴³.

To enhance credibility in Study II the participants represented the group of women living with HIV in Sweden. To ensure a wide representation of the phenomenon, a strategic collection of the participants in the study was made. Women who spoke English were also included. To further strengthen the credibility, interviews were followed up and assessed in order to improve the interview technique. This generated more richness in the data and ensured that both visible and invisible sides of the phenomenon were presented ^{84, 118}.

To establish internal validity in the quantitative studies, statistical models were adjusted for dependency for repeated answers in the health questionnaire (Study III, Study IV). Repeated measurements of participants

may lead to bias when filling in the health questionnaire, which could be regarded as a kind of intervention. The correlations between the repeated measurements for each patient were controlled and adjusted for using a generalized estimated equation. Something that has to be discussed in observational studies is the direction of causality, which is not clear. This is especially the case when it comes to the more explanatory variables such as physical and psychological health in our studies. We therefore also suggest that sexual satisfaction might lead to an improvement in psychological health, considering all the evidence in the findings showing that sexuality is an important part of overall health and wellbeing.

Selection bias refers to the problem that differences between groups exist and may interact with the independent variable. It is possible that the people living with HIV who agreed to participate in the studies were those who also experienced better health and had greater control over their HIV. It could also be presumed that the people who, to a lesser degree, take advantage of care, or have low adherence to ART are also those who did not answer the questionnaire. In spite of this, comparisons with the people who were not included in Study III and Study IV showed that the people who replied were a good representation of the HIV cohort.

The meta-synthesis excluded studies carried out in countries on the African and Asian continents, due to sometimes low accessibility to ART and issues related to high poverty (Study 1). This might impact external validity and it might therefore not be possible to generalize the results of the study to all populations.

External validity and the question of generalization relates to how well the explored phenomenon is represented (Study II). If the strategic collection explained earlier made it possible to generate an essence, the explored phenomenon is thought to be represented¹⁹¹. The meaning structure of the explored phenomenon in Study 2, in particular the essence, could probably also be applied to men living with HIV and also to people living with HIV in other countries. The constituents describe a more contextual aspect and might therefore not be as applicable to men to such a high degree, or to women living with HIV in other countries. What might have affected the generalization in Study 2 was that no women who originated from Eastern Europe, Australia, or the American continent were included. Nor did we include any women with a history of drug abuse. Sweden has a very low prevalence of patients who originate from these parts of the world, as well as a very low prevalence of people living with HIV that inject drugs.

In reflective lifeworld research, confirmability is strengthened by an openness to the phenomenon, meaning that the researcher sees the phenomenon as it is. Dahlberg et al. assess the quality of research in terms of validity, objectivity and transferability⁸⁴ (Study II). This involves setting previous knowledge and assumptions aside, such as well-known theories and prior experiences, and instead being open to and aware of new aspects or explanations. This is called bridling and it was used during the interviews and also in the analysis process. It is also fundamental to the transferability of the research¹¹⁹.

The external validity of Study III and Study IV refers to the importance of a wide presentation of the participants. It is a strength in these studies that so many women and also people born outside Sweden are included. The questionnaire could be answered as a paper version or in a web version. It was also available in English or in Swedish or could be translated by a professional interpreter. The reliability of the health questionnaire was validated in 2016 by asking 57 patients to answer it twice with one month in between, in a test-retest¹⁰⁸. It showed good agreement for satisfaction with physical, psychological and sexual health items¹⁰⁸. Additionally has the health questionnaire been completed by many people, which generated extensive data material and making these studies to two of the largest studies in Sweden among people living with HIV.

The variable of sexual satisfaction is a subjective experience that can mean different things to different people and be of more or less importance to different people¹⁶⁸. There is no conceptual definition of sexual satisfaction and its meanings and sexual satisfaction would need to be validated in qualitative research. This might affect the content validity and other variables would perhaps have been more suitable, or even another instrument measuring quality of life. The question about sexual life has, however, been developed on the life satisfaction scale, and used in studies examining sexual satisfaction^{123, 124}. These two studies do not present results for people living with HIV, but they can be used as reference material as a control group.

The categorization of the variables or sociodemographic explanations can be problematic when using data from a quality registry. In the quality registry, all participants are referred to as women or men. However, we acknowledge that this assumption may be incorrect whereas a report on 1096 people living with HIV in Sweden showed that more than 1% stated a gender identity other than woman or man⁶⁹. The same problem applies to the term “route of transmission”, which might be perceived as identifying these people according to sexual practice or if they are using drugs. It is a reminder of the importance of that even though a registry and research studies are using these

terms, the way or ways a person practices sex does not identify who that person is.

8 CONCLUSIONS

This thesis provides a deeper and more profound knowledge of different aspects of sexuality in women living with HIV in Sweden. It can be concluded that:

- Sexuality is complex, and that sexuality and childbearing are intertwined for women living with HIV.
- The impact of HIV affects the whole women existentially. A HIV diagnosis is followed by challenges, which influence and permeate many of the actions, plans and decisions in relation to sexuality and childbearing for these women. This negative impact can be balanced by resources regarding sexuality and childbearing in these women.
- Clinical markers of HIV, such as viral load, are not enough to predict sexual satisfaction and sexuality, but contextual factors, health-related aspects and other social and cultural conditions, instead primarily influence the ways in which women experience and enact their sexuality.
- Women living with HIV are dependent on their own level of knowledge about HIV, transmission and sexuality, and also on their partner's, society's or on healthcare professionals' knowledge about these issues. The women need more information about breastfeeding, ART, HIV transmission and, if necessary, individual guidance on safe sex practices.
- All people living with HIV should be regularly informed about the risk of HIV transmission and viral load. This has to be done on individual level so there is an understanding that being well treated also means that you cannot transmit HIV sexually. There is also a need for information to the public and to healthcare professionals about HIV and the minimal risk of transmission.
- As part of the HIV healthcare, which aims to meet and include the whole woman, her sexuality including sexual satisfaction and childbearing, together with all other aspects of health, need to be addressed. There is a need to talk about sexuality and childbearing and also to include an eventual partner in these meetings.
- Healthcare providers and all other actors working with HIV need to consider social and psychological needs to help women living with HIV in order to provide the right kind of interventions and support.
- Healthcare professionals possess a position of power when it comes to information about HIV and transmission. The Swedish healthcare could work together with other actors, such as patient organisations or churches to provide social support for people living with HIV.

9 FUTURE PERSPECTIVES

Identifying the kind of support women living with HIV need, both social and professional support, could add important knowledge for healthcare professionals. A previous study in Sweden has shown that women living with HIV experience less support than men ¹⁹³. This could be explored and described in both qualitative studies and quantitative studies.

Paying attention to the women's increased vulnerability due to their HIV and empowering these women so they can make safe decisions about sexuality and childbearing is important. Women living with HIV are also particularly vulnerable to sexual discrimination compared with men living with HIV ⁶⁵. This imbalance of power in relationships when living with a chronic disease needs further investigation, not only for women living with HIV but also for other groups with chronic illnesses.

The importance of a partner in relation to sexuality, and also to the achievement of health and wellbeing, should be further explored for people living with HIV. Qualitative studies exploring the experiences of a partner living with a woman or man with HIV could further identify areas that healthcare professionals need to address in order to support these people. Quantitative studies could further investigate the associations between sexual satisfaction, relationship status and other health-related parameters.

Childbearing and pregnancy intentions among all the people living with HIV should be explored in Sweden. Not only women but also all the other people living with HIV may want to experience parenthood. The Swedish Communicable Diseases Act makes it difficult to obtain assisted insemination. Adoption is also more difficult for people with HIV. The work to develop strategies for sexual and reproductive health and rights for these people needs to be driven forward and continued on.

The fulfilment of sexuality and childbearing is linked to the extent to which human rights are respected, protected and fulfilled. Work on sexual and reproductive rights should be included in national laws, international human rights documents and other consensus statements so that they recognize human rights related to the enjoyment of sexual health and expression of sexuality.

Sexual satisfaction means different things to different people. A validation of sexual satisfaction should be described in qualitative studies. All the studies performed in this thesis should be performed in groups of all kinds: men, transgender, and people living with hepatitis C or hepatitis B. There is a need

to talk to patients about sexuality and issues related to sexuality to improve health.

ART has to be taken every day for the rest of a person's life, so the effects of being on ART for a long time have not yet been sufficiently assessed. The impact on sexual satisfaction caused by side-effects needs to be further investigated.

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APPENDIX

Appendix contains:

Appendix 1: Patient information, rights and rules of conduct. County Medical Officers' infection prevention sheet.

Appendix 2: The Health Questionnaire in English and in Swedish

Appendix 3: Critical Appraisal Skills Programme (CASP), the check-list

Appendix 4: Life-satisfaction scale (Li-Sat-11) in Swedish

HIV

Patient information, rights and rules of conduct. County Medical Officers' infection prevention sheet.

Why have you been given this information?

You have been, or are suspected of having been, infected with HIV. This sheet provides information about HIV, how it can be treated and what you need to do.

What is HIV?

HIV is a virus that affects your immune system. There is now medication that, if taken correctly, reduces the amount of the virus present in the body and potentially enables a person with HIV to live a long and healthy life. If the medication is taken correctly, the risk of infecting someone else with HIV is very low. There is no cure for the HIV infection; even with stable treatment, the virus is still present in the body. If an infected person does not receive treatment, their body's immune defence is weakened after a while and uncommon infections or cancer can develop. This latter stage is called AIDS. Most people with HIV today will never develop AIDS.

How is HIV spread?

Most people with HIV have acquired it as a result of unprotected sex, either vaginal sex or anal sex, and sometimes oral sex. Blood containing HIV is very infectious, and HIV can be transmitted from one person to another during a blood transfusion or a needlestick or if they use the same syringes or other injecting equipment. There is also a risk of infection if blood containing HIV comes into contact with mucous membranes in the eyes, nose or mouth or with a wound. Effective HIV treatment drastically reduces the risk of contagion, but does not completely eliminate the risk of infection. HIV can be transmitted from mother to child during pregnancy, birth and breastfeeding. If a mother is known to have HIV, it is possible almost completely to eliminate the risk to the child through medication and by not breastfeeding.

When is HIV not transmitted?

HIV is not passed on by hugging, kissing or cuddling. Tears, urine, faeces, vomit and catarrh containing no blood are not infectious either. Blood coming into contact with undamaged skin does not present a risk of infection.

Rights

According to the Swedish Communicable Diseases Act (Smittskyddslagen), testing for, clinic visits for and treatment of HIV are free.

You are also entitled to the psychosocial support you may need in order to deal with the disease. Your doctor should advise you on how to avoid putting others at risk of infection. You should not be treated less favourably because you are living with HIV. HIV is covered by the Swedish Discrimination Act (Diskrimineringslagen) under the issue of discrimination on the grounds of disability.

Professional activities

HIV infection will not normally result in restrictions to your studies or professional activities.

Pregnancy and breastfeeding

You can get help to enable you/your partner to conceive with a minimal risk of infection to your partner or your child. Women with HIV must not breastfeed.

Children with HIV

The parent/carer and child will receive information on protecting against infection via the doctor providing treatment, and this information will gradually be adapted as the child gets older. Children living with HIV have the same entitlement to childcare and schooling as other children, but may have special needs which have to be taken into account. The doctor providing the treatment or the County Medical Officer can provide the preschool with information if parents/carers grant consent to this. When the child starts school, the school healthcare service will be informed.

Condoms for vaginal sex, anal sex and oral sex

Condoms provide good protection against HIV and other sexually transmitted diseases and must always be worn throughout the entire sex session. It is probable that female condoms also work, but this method has not been evaluated scientifically. In the case of stable treatment, condoms must still be worn during anal and/or vaginal sex so as to reduce the risk of passing on HIV as much as possible.

Preventive drug therapy

If there is a chance that you have infected someone through sexual contact as a result of a condom not providing protection, through contact with your blood or in some other manner, it is possible to give preventive drug therapy, known as post-exposure prophylaxis (PEP). This must begin as quickly as possible. Contact the doctor providing treatment or an infection clinic/24-hour service as soon as possible.

Contact tracing

It is very important to identify people with HIV so that they can get treatment and prevent the infection being passed on to others. If you have HIV, you must, therefore, name the person or people who may have infected you or whom you may have infected. These may be people with whom you have had sex or other sexual contact, people with whom you have shared syringes, and in some cases family members. Contact tracing is performed by the doctor providing treatment, a counsellor or a nurse at the clinic. Anything you tell the contact tracing officer is confidential. The people you name will not be told who you are. They will only be told that they must get tested.

Blood must always be handled as infectious

- Anyone who may come into contact with your blood while changing wound dressings or the like must wear gloves
- Bloody material must be well wrapped before being discarded. Clothes can be machine-washed.
- *If anyone gets your blood in their eyes, nose or mouth, flush immediately with water. You must inform the person that your blood is infected with HIV and that they must get in touch with your doctor or with an infection clinic/24-hour service as soon as possible.*

Rules of conduct which you should follow so as not to infect anyone else

HIV is a public health hazard according to the Swedish Communicable Diseases Act. You are, therefore, obliged to protect other people from the risk of infection. If a risk of infection arises, you must disclose your illness to the other person. Below is a list of the rules of conduct for preventing infection based on the areas covered by the law. Most of these rules apply to anyone with HIV, while others are specific to your situation and may also change over time. It is the doctor treating you who decides which of the following rules of conduct should apply in your particular case.

1. *Restrictions may apply in respect of your work or participation in other activities where there is a risk of infection.*
2. *You must not donate blood, organs or tissue for transplantation.*
3. *If you use syringes/needles/other injecting equipment for medical purposes, you must not let other people use them.*
4. *If you use syringes/needles to inject drugs or the like, you must not let other people use them. You must not share mixing cups either. All injecting equipment must be stored and discarded so that it does not place others at risk of infection.*
5. *You must disclose that your blood is infectious when you seek dental or medical care where personnel may come into contact with your blood, for example while taking samples or performing surgery/procedures.*
6. *If you want a tattoo, to have your ears pierced or have any other treatment involving the use of sharp tools and where bleeding may occur, e.g. body piercing, you must disclose that your blood is infectious before the procedure is carried out.*
7. *You must inform your sexual partner that you are infected with HIV before sexual contact which presents a risk of transmission of HIV. There is a risk of such infection during all types of oral, vaginal and anal sex. As condoms can break, you must disclose your HIV status even if you are planning to use condoms. You must use condoms during sex where the penis is inserted in the vagina, the rectum or the mouth. During other sexual contact, a female condom must be used. If you are on stable treatment, condoms must still be used during vaginal and/or anal sex.*
8. *You must not share personal care items such as razors or toothbrushes with other people.*
9. *You must attend the repeat visits which your doctor considers necessary.*

If you have been given a rule of conduct which you think is wrong, you can contact the County Medical Officer in your county.

The Health Questionnaire in English

Please tick the appropriate box for each statement

1. How satisfied are you with your physical health?

Very unsatisfied	Unsatisfied	Rather unsatisfied	Rather satisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How satisfied are you with your psychological wellbeing?

Very unsatisfied	Unsatisfied	Rather unsatisfied	Rather satisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. How satisfied are you with your sexual life (regardless if you have sex with a partner or on your own)?

Very unsatisfied	Unsatisfied	Rather unsatisfied	Rather satisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4a. Are you currently taking HIV medication?

Yes → Go to question 4b. No → Go to question 5.

4b. Do you experience any side effects?

Yes → Go to question 4c. No → Go to question 4d.

4c. To what extent are you troubled by medical side effects?

Very troubled	Troubled	Rather troubled	Not very troubled	Not at all troubled
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4d. How many doses have you missed the last week?

0 1-2 3 or more doses

5: Do you feel involved in the planning and realization of your HIV care and treatment?

Never	Seldom	Sometimes	Always
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. How satisfied are you with the quality of care provided at your HIV clinic?

Very unsatisfied	Unsatisfied	Rather unsatisfied	Rather satisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your participation!

Hälsoenkät Kvalitetsregistret InfCareHIV

För varje fråga, sätt ett kryss i den ruta som stämmer bäst in på Dig.

1. Hur nöjd är du med din kroppsliga hälsa?

Mycket missnöjd	Missnöjd	Ganska Missnöjd	Ganska nöjd	Nöjd	Mycket nöjd
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Hur nöjd är du med din psykiska hälsa (välmående)?

Mycket missnöjd	Missnöjd	Ganska Missnöjd	Ganska nöjd	Nöjd	Mycket nöjd
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Hur nöjd är du med ditt sexualliv (med eller utan partner)?

Mycket missnöjd	Missnöjd	Ganska Missnöjd	Ganska nöjd	Nöjd	Mycket nöjd
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4a. Tar du hiv-mediciner?

Ja → Gå till fråga 4b. Nej → Gå till fråga 5.

4b. Upplever du för närvarande några biverkningar?

Ja → Gå till fråga 4c. Nej → Gå till fråga 4d.

4c. I vilken utsträckning är du besvärad av biverkningarna?

Mycket besvärad	Besvärad	Ganska besvärad	Inte särskilt besvärad	Inte alls besvärad
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4d. Hur många doser har du missat sista veckan?

0 doser 1-2 doser Mer än 3 doser

5: Känner du dig delaktig i planering och genomförande av din hiv-vård/behandling?

Stämmer inte alls	Stämmer dåligt	Stämmer delvis	Stämmer helt
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Hur nöjd är du med den vård du får vid din hiv-mottagning?

Mycket missnöjd	Missnöjd	Ganska Missnöjd	Ganska nöjd	Nöjd	Mycket nöjd
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Tack för Din medverkan!

Critical Appraisal Skills Programme (CASP)

making sense of evidence

10 questions to help you make sense of qualitative research

This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is *not a definitive guide* and extensive further reading is recommended.

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

- **Rigour: has a thorough and appropriate approach been applied to key research methods in the study?**
- **Credibility: are the findings well presented and meaningful?**
- **Relevance: how useful are the findings to you and your organisation?**

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

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Screening Questions

1. Was there a clear statement of the aims of the research?

Yes

No

Consider:

- *what the goal of the research was*
 - *why it is important*
 - *its relevance*
-

2. Is a qualitative methodology appropriate?

Yes

No

Consider:

- *if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*
-

Is it worth continuing?

Detailed questions

.....

Appropriate research design

3. Was the research design appropriate to address the aims of the research?

Write comments here

Consider:

- *if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)*
-

Sampling

4. Was the recruitment strategy appropriate to the aims of the research?

Write comments here

Consider:

- *if the researcher has explained how the participants were selected*
 - *if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study*
 - *if there are any discussions around recruitment (e.g. why some people chose not to take part)*
-

.....

Data collection

5. Were the data collected in a way that addressed the research issue?

Write comments here

Consider:

- if the setting for data collection was justified
- if it is clear how data were collected (e.g. focus group, semi-structured interview etc)
- if the researcher has justified the methods chosen
- if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?)
- if methods were modified during the study. If so, has the researcher explained how and why?
- if the form of data is clear (e.g. tape recordings, video material, notes etc)
- if the researcher has discussed saturation of data

.....

Reflexivity (research partnership relations/recognition of researcher bias)

6. Has the relationship between researcher and participants been adequately considered?

Write comments here

Consider whether it is clear:

- if the researcher critically examined their own role, potential bias and influence during:
 - formulation of research questions
 - data collection, including sample recruitment and choice of location
- how the researcher responded to events during the study and whether they considered the implications of any changes in the research design

.....

Ethical Issues

7. Have ethical issues been taken into consideration?

Write comments here

Consider:

- if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- if approval has been sought from the ethics committee

Data Analysis

8. Was the data analysis sufficiently rigorous?

Write comments here

Consider:

- if there is an in-depth description of the analysis process
- if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- if sufficient data are presented to support the findings
- to what extent contradictory data are taken into account
- whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Findings

9. Is there a clear statement of findings?

Write comments here

Consider:

- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researcher's arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
- if the findings are discussed in relation to the original research questions

Value of the research

10. How valuable is the research?

Write comments here

Consider:

- if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- if they identify new areas where research is necessary
- if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

NRS Frågeformulär Tillvalsinstrument (LiSat-11)

Datum när formuläret ifylldes: _____

Personnummer: _____

Efternamn: _____

Förnamn: _____

Li-Sat-11

Hur tillfredsstäld är Du med olika aspekter på Ditt liv?

För var och en av dessa frågor vill vi att Du ringar in en siffra från 1 till 6, eller markera med kryss i tom ruta (gäller påstående under 8 och 9). Använd skalan nedan för att göra dina val.

1	2	3	4	5	6
Mycket otillfredsställande	Otillfredsställande	Ganska otillfredsställande	Ganska tillfredsställande	Tillfredsställande	Mycket tillfredsställande
1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6
<input type="checkbox"/>					
1	2	3	4	5	6
<input type="checkbox"/>					
1	2	3	4	5	6
1	2	3	4	5	6

