

From the DEPARTMENT OF LEARNING, INFORMATICS,
MANAGEMENT AND ETHICS
Karolinska Institutet, Stockholm, Sweden

HIV-RELATED STIGMA IN THE ERA OF EFFICIENT TREATMENT - CONCEPTUALIZATION, MEASUREMENT AND RELATIONS TO HEALTH-RELATED QUALITY OF LIFE

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**Karolinska
Institutet**

Stockholm 2018

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ISBN 978-91-7676-986-7

Published by Karolinska Institutet

Printed by Eprint AB 2018

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HIV-related stigma in the era of efficient treatment - conceptualization, measurement and relations to health- related quality of life

THESIS FOR DOCTORAL DEGREE (Ph.D.)

To be publicly defended in Hillarp, Retzius väg 8, Solna

Friday May 4th, 2018, at 09.00 am

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*The dream is just to be simply me, that you are accepted for who you are
and aren't categorized by...which socks you have or what job or how much
money you make or if you have HIV*

/Study participant

ABSTRACT

The studies included in this thesis examined experiences of HIV-related stigma among persons living with HIV in the current era of efficient treatment.

Background Human immunodeficiency virus (HIV) has been a stigmatized condition since the beginning of the pandemic and people living with HIV who experience HIV-related stigma have been found to have lower health-related quality, also after the introduction of efficient treatment. HIV-related stigma has also been found to be a barrier to treatment and care. HIV has changed from being a deadly disease to a chronic condition where treatment is generally available, and people with efficient treatment are at extremely low risk of transmitting HIV to others. It is, however, unknown how people who are virally suppressed experience stigma related to HIV, and if stigma has consequences for their health-related quality of life.

Aim The overall aim of this thesis was to study self-reported stigma among people living with HIV in Sweden in the current era of efficient treatment. Further, the aim was to examine validity of the HIV stigma scale and to test the HIV stigma framework in a Swedish context where treatment is generally available.

Methods For measurement of experiences of HIV-related stigma we evaluated a Swedish version of the HIV stigma scale in a sample of 193 persons living with HIV in Sweden (44% female) (Paper I-III). Psychometric properties of the HIV stigma scale was also analyzed using data from people living with HIV in the United States and South India. The HIV stigma scale were then used, together with measures of health-related quality of life and adherence to treatment, to test hypothesized associations between stigma and lower health-related quality of life (as proposed in the HIV stigma framework by Earnshaw and Chaudoir [1]) for people living with HIV in a Swedish context (Paper IV). The experience of HIV-related stigma was explored using framework approach in analyzing individual interviews with 15 persons who were virally suppressed (8 women, 7 men) (Paper V). Health-related quality of life was compared to a general Swedish population and to a sample of men living with HIV 1993-1995 (not included in paper I-V).

Results The HIV stigma scale was found to be valid in general for measurement of stigma in the Swedish context, although some items, mostly belonging to the subscale Disclosure concerns had questionable psychometric properties (Paper I-III). To have disclosure concern was the aspect of stigma that was prominent among people living with HIV in Sweden (64% had disclosure concerns to a higher extent). The hypothesized relations in the HIV stigma framework was not confirmed in the Swedish context except for associations between internalized stigma and lower emotional wellbeing, and anticipated stigma and lower physical functioning (Paper IV). People who were virally suppressed did not think about their HIV

much in general. Still, some had been treated badly because of their HIV and they anticipated rejection or labeling if their HIV got known to others (Paper V). The health-related quality of life was found to be lower for people living with HIV in Sweden than for a Swedish general population, and equally low as for people living with HIV in Sweden 20 years ago.

Conclusion Although Sweden is in the front line regarding treatment, findings in this thesis indicate that the health-related quality of life seems not to have improved for people living with HIV in Sweden. HIV is still a stigmatized condition, even for persons who are virally suppressed. A majority of people living with HIV in Sweden have not experienced enacted stigma, but it is common to have concerns about when and to whom you should disclose your HIV.

LIST OF SCIENTIFIC PAPERS

- I. Lindberg M, Wettergren L, Wiklander M, Svedhem-Johansson V, Eriksson LE, (2014) *Psychometric Evaluation of the HIV Stigma Scale in a Swedish Context*, PLoS ONE, 9(12): 16
- II. Reinius M, Wettergren L, Wiklander M, Svedhem V, Ekström AM, Eriksson LE, (2017) *Development of a 12-item short version of the HIV Stigma Scale*, Health and Quality of Life Outcomes, 15(1): 115
- III. Reinius M, Rao D, Manhart L, Wiklander M, Svedhem V, Pryor J, Mayer R, Gaddist B, Kumar S, Mohanraj R, Jeyaseelan L, Wettergren L, Eriksson LE, (2018) *Differential item functioning for items in Berger's HIV stigma scale – an analysis of cohorts from Indian, Swedish and US contexts*, Quality of Life Research, DOI 10.1007/s11136-018-1841-4
- IV. Reinius M, Wiklander M, Wettergren L, Svedhem V, Eriksson LE, (2018) *The relationship between stigma and health-related quality of life in people living with HIV who have full access to antiretroviral treatment – an assessment of Earnshaw and Chaudoir's HIV stigma framework using empirical data*, AIDS and Behavior, DOI 10.1007/s10461-018-2041-5
- V. Reinius M, Zeluf G, Svedhem-Johansson V, Wettergren L, Wiklander M, Eriksson LE, *When the virus is undetectable – a reconceptualization of existing theory towards a new understanding of HIV-related stigma in the current era of efficient treatment*, In manuscript

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral treatment
CD 4	Cluster of differentiation 4
CFA	Confirmatory factor analysis
CFI	Comparative fit index
CI	Confidence interval
DIF	Differential item functioning
DNA	Deoxyribonucleic acid
EFA	Exploratory factor analysis
HIV	Human immunodeficiency virus
IRT	Item respons theory
MSM	Men who have sex with men
Msqr	Mean square
PLWH	People living with HIV
PrEP	Pre-exposure prophylaxis
RMSEA	Root mean squared error of approximation
RNA	Ribonucleic acid
SFS	Svensk författningssamling (Swedish code of statutes)
SWED-QUAL	The Swedish health-related quality of life survey
TLI	Tucker-Lewis index
US	United States
VL	Viral load

1 BACKGROUND

1.1 HIV HISTORY –FROM A WESTERN PERSPECTIVE

In 1981, the first official reports of what was later known as HIV/AIDS was published in the Morbidity and mortality weekly report by the Center for Disease control at the U.S. department of health and human services [2, 3]. Four, previously healthy young homosexual men, were described to have contracted pneumonia, extensive mucosal candidiasis and multiple viral infections. One of them also developed Kaposi's sarcoma [4]. Conclusions drawn at an early stage was that the syndrome could be sexually transmitted [4]. By 1982 the U.S. Center for Disease Control recommended to call the syndrome acquired immunodeficiency syndrome (AIDS) [5].

As AIDS was most common in men who had sex with men (MSM), early theories about the cause focused on "life style" issues, i.e. multiple sex partners and the syndrome was commonly known as the "gay plague" [5]. In Sweden, where the first person was diagnosed with AIDS in 1983, AIDS was initially noticed as a limited problem, only affecting gay men, and the press did not write much about the new syndrome until 1995, when a boy with hemophilia got infected through blood transfusion at a Swedish hospital [6]. In 1983, also heterosexual transmission of AIDS was reported and it started to become clear that AIDS was not a disease solely affecting gay men but that worldwide, 80% of new infections had been heterosexually transmitted, with the highest infection rates in countries in sub-Saharan Africa [5].

1.2 SWEDISH MEDIA REPORTS DURING THE 1980'S

According to Anna Ljung [6], who wrote a thesis on how Swedish press covered AIDS, Swedish media reports on AIDS increased after 1985, with a focus on certain "risk groups", i.e. groups referred to as homo- and bisexual men, prostitutes, drug addicts and African men [6]. Drastic actions to prevent infection were suggested (but not implemented), as a mandatory tattoo for people who were infected, a certain "license for sex" for those who were not infected [6], or to isolate people who were infected on an island [7]. On front page of a larger Swedish daily newspaper ("Dagens Nyheter") in 1987, a picture was displayed of how the body of a person who died of AIDS was handled. The body was covered in a black, plastic bag with large stickers labeled "smittorisk" ("contagious"). Next to the body two physicians were seen, wearing full protective equipment and the article that followed was titled "AIDS-epidemi på väg" ("AIDS epidemic on its way"). Ljung [6] concluded that the menacing picture of the AIDS epidemic, portrayed in media, had a negative effect on how people living with HIV was treated in health care and in society.

1.3 SWEDISH LAWS AND REGULATIONS

In Sweden, people living with HIV have legal protection against discrimination, as HIV counts as a disability in the law against discrimination (SFS 2008:567). At the same time, the

Swedish laws that control people living with HIV have been found to be among the most restrictive in the world [8]. HIV was included in the Swedish Law for communicable disease control (SFS 2004:168) in 1985 [6], which meant that people living with HIV, among other restrictions, became obliged to inform others about the infection if considerable risk of transmission occurred. The Swedish Law for communicable disease control made it possible to isolate people with HIV against their will and individuals have been convicted of abuse and given prison sentences because of not disclosing their HIV status to sexual partners [7]. Although the number of persons sentenced to prison each year is low, the consequences for the convicted individual are severe, especially for persons who have migrated to Sweden, who may be deported to their country of birth after served sentence [7].

In later years, based on the growing evidence on the minimal risk of transmission when persons are on ART [9, 10], the application of the law has changed, and from 2013 it is up to the treating physician to give individual restrictions, based on adherence and treatment results [11]. A report released by The Public Health Agency of Sweden in 2018 showed that physicians in HIV clinics have good knowledge in general about the minimal risk of transmission when persons are on ART. Eighty three percent of physicians had excluded one or more patients from the duty to inform sexual partners about their HIV [12].

The legal position in Sweden is still uncertain [12]. A person who was prosecuted for putting other persons in danger in 2013 (through unprotected sexual intercourse) was acquitted due to the extremely low risk of HIV transmission. However, a Supreme Court precedence from 2004 is still directive [12] but the Swedish Supreme Court have granted leave to appeal in the 2013 case, which might lead to a new precedence [12] (the Supreme Court trial is expected to take place in May 2018).

1.4 KNOWLEDGE AND ATTITUDES REGARDING HIV AMONG THE SWEDISH POPULATION

Knowledge and attitudes regarding HIV in the Swedish population has been regularly examined by The Public Health Agency of Sweden since 1987 [13]. In the latest survey, performed in 2016, 9 % answered that they would avoid close contact with a person that have HIV, compared to 52% that answered that they would avoid close contact in the survey conducted 1987. Around 18% in the 2016 survey agreed with the statement that persons with HIV should refrain from sexual contacts, compared to 66% who agreed to that statement in 1987. Although the situation seems to improve the authors of the 2016 report concluded that prejudice and stigma around HIV still exist in the Swedish society and that the knowledge regarding how treatment prevents HIV transmission is limited in the Swedish population [13].

1.5 HIV IN THE HUMAN BODY

The biological cause of AIDS was found in 1983 when a new human retrovirus was detected, later named HIV (Human immunodeficiency virus) [14]. The HIV virion contains two copies of RNA and a set of viral proteins, surrounded by a membrane [15] (Figure 1, right picture).

The proteins include enzymes that are essential in the HIV reproduction cycle (Figure 1, left picture); the reverse transcriptase that synthesizes RNA into DNA, the integrase that integrates viral DNA into the cell genome and the protease that cleaves the virus protein [16] before the HIV particle leaves the cell as a new virion.

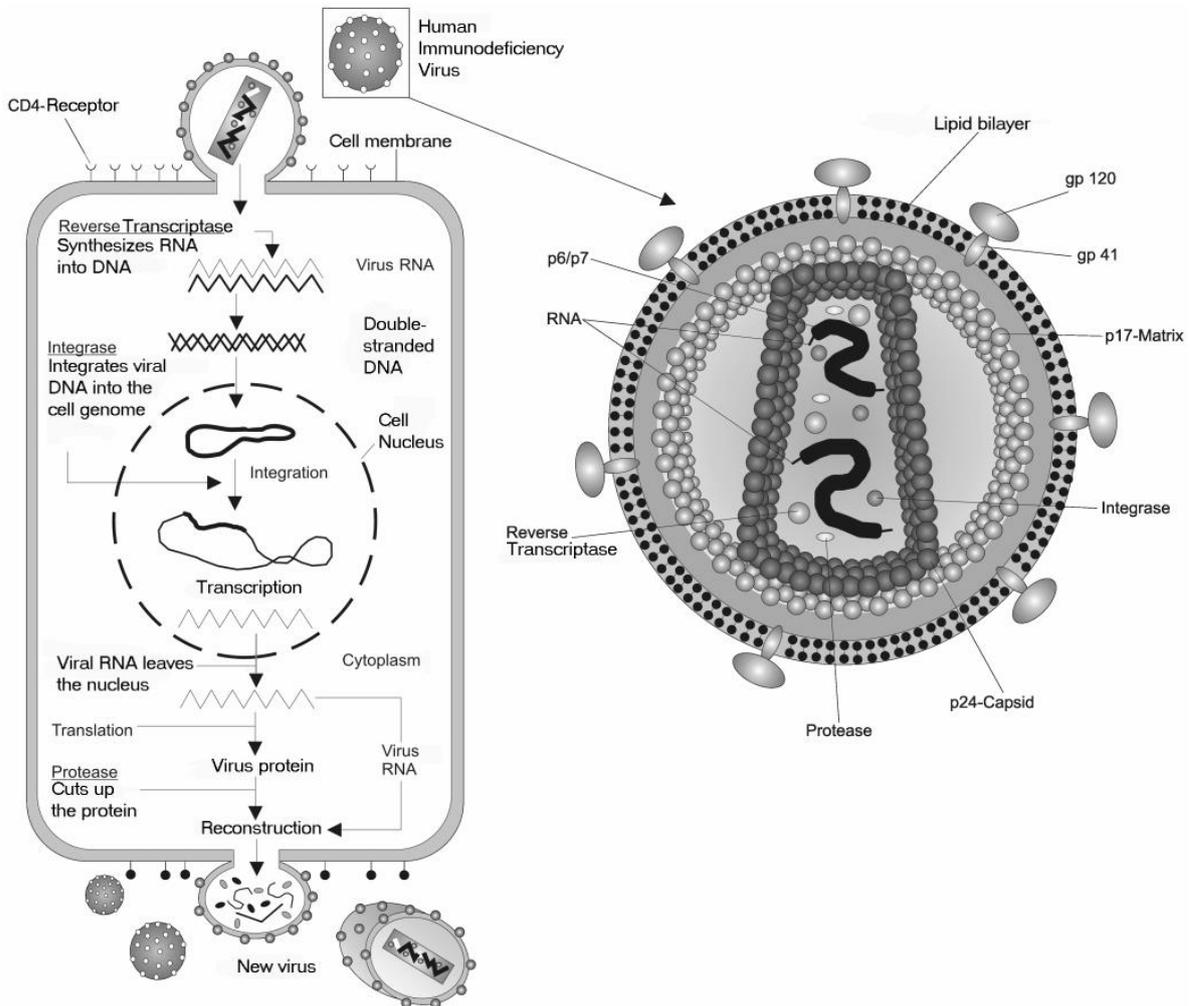


Figure 1. HIV reproduction cycle.

By Daniel Beyer, https://commons.wikimedia.org/wiki/File:HIV_gross_cycle_only.png, translated to English by Raul654, <https://commons.wikimedia.org/wiki/User:Raul654>, License CC BY-SA 3.0 <https://creativecommons.org/licenses/by-sa/3.0/>

1.5.1 Routes of transmission

The most common route of HIV transmission is when virus in semen or mucosal surfaces is transmitted through sexual contact [17]. The virus can also enter the human body through blood or be transmitted from mother to fetus/infant [17]. HIV cannot be transmitted through body fluids like saliva or tears. Without treatment the probability of acquiring HIV is highest through blood transfusion and mother-to-child transmission and regarding sexual route of transmission the risk is highest for receptive anal intercourse [18]. High viral load, as seen in

the acute and late phase (Figure 2), is a factor that may increase HIV transmission. The risk of acquiring HIV is also higher if one has genital ulcer disease [18].

1.5.2 HIV and the immune system

The major target cell for the HIV virion is the CD4⁺ T cell, which have a central role in the immune system. The virus disseminates rapidly within the first weeks after transmission (red graph in Figure 2) leading to acute HIV syndrome for a majority of people with HIV with flu-like symptoms [17]. In the absence of treatment, virus levels typically peak after three to four weeks and then declines and reach a steady state (Figure 2). As the blue graph (Figure 2) shows, persons with HIV progressively lose CD 4⁺ T cell in absence of treatment, which ultimately leads to opportunistic infections characterized as AIDS [17].

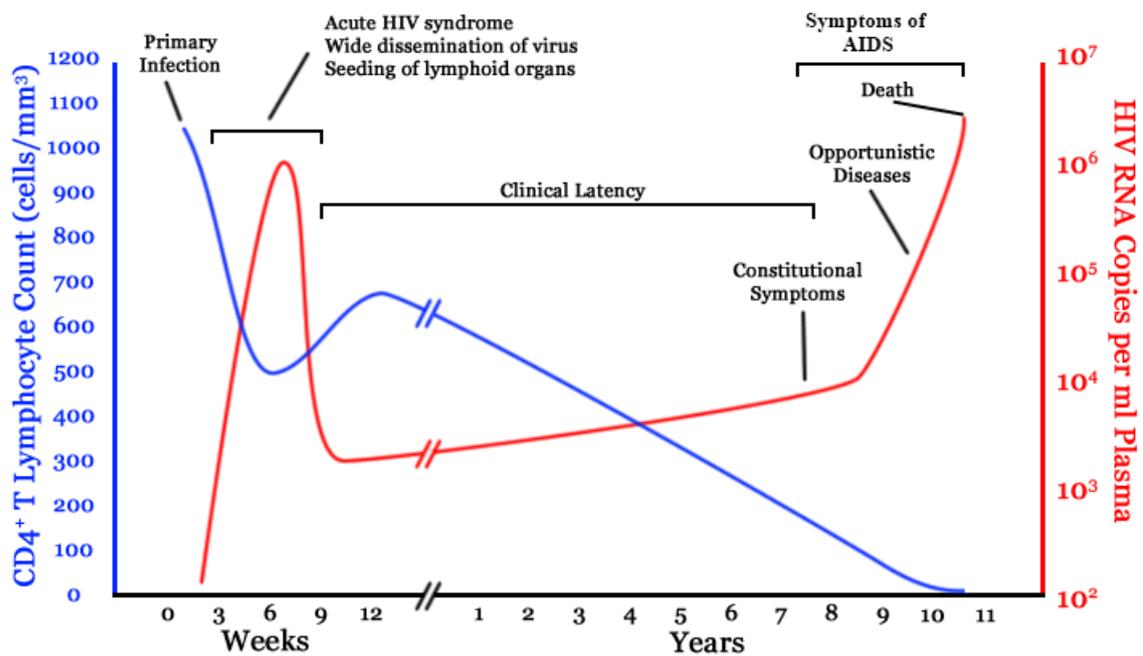


Figure 2. Graph showing HIV copies and CD4 counts in a human over the course of a treatment-naive HIV infection. By Jurema Oliveira - Based on Figure 1 in Pantaleo, G *et al.* [19], https://commons.wikimedia.org/wiki/Category:HIV_time_course , License CC BY-SA 3.0 <https://creativecommons.org/licenses/by-sa/3.0/>

1.6 ANTIRETROVIRAL TREATMENT

The introduction of combined antiretroviral treatment (ART) in 1996 made a dramatic change in morbidity and mortality related to HIV. HIV has changed from being a deadly disease to a chronic condition with life-expectancy of people living with HIV comparable to uninfected where treatment is generally available [20]. In combined antiretroviral treatment, different pharmaceuticals are combined to inhibit different steps of the viral life-cycle; i.e. the reverse transcriptase, integrase and protease (Figure 1) [21]. Although the first available treatments, had severe medical side effects, modern antiretroviral treatment are associated with minimal side effects [22]

According to Swedish treatment guidelines antiretroviral treatment is considered to be effective if the following criteria are fulfilled if viral load and adherence to treatment is monitored 2-4 times per year [20] and:

- Viral load of HIV RNA in blood plasma is continuously <50 copies/ml, at two successive measurements, 3-6 months apart [20].
- The person with HIV maintains a continuously high adherence to treatment [20]

1.6.1 Risk of HIV transmission when persons are virally suppressed

In 2008 the Swiss AIDS Commission announced what thereafter has been referred to as the Swiss statement; that people living with HIV who are on effective treatment should not be considered infectious through sexual contact (if certain criteria are fulfilled) [23]. The HIV prevention trials network (HPTN 052) study then provided more evidence regarding the risk of HIV transmission, when persons with HIV were virally suppressed [24]. The study followed 1763 couples, included 2007-2010, where one partner was HIV-positive and the other partner HIV-negative (i.g. a serodiscordant couple) at the beginning of the study. Couples were randomized into two groups, where the HIV-positive partner either got ART from the start, regardless of CD 4 levels, or received ART when CD 4 count went below 250 cells/ml. All couples were advised about the use of condoms. Early ART was associated with a 96% reduction in the risk of transmission through sexual contact compared to later start with ART [9, 25]. A recent meta-analysis pooled results from the HPTN 052 study with results from five other similar studies and showed that among 2848 serodiscordant couples where the person with HIV was virally suppressed, HIV had not been transmitted in any cases (rate of transmission = 0 per 100 person-years (95%CI=0-0.01)) [10].

The Public health Agency of Sweden released a statement in 2013 regarding risk of HIV transmission, based on the HPTN 52 study in combination with other observational studies [11, 20]. The risk of HIV transmission through sexual intercourse was stated to be minimal if the person with HIV were on effective ART and a condom was used throughout intercourse. The risk was considered to be very low also if a condom was not used. The risk of transmission through needle sharing when injecting drugs were considered to markedly reduced if the person with HIV were on effective ART [20]. The risk of mother-to-child transmission was considered to be less than 0.5% if the pregnant women had effective ART well in advance before the baby was born [20].

1.6.2 A residual problem in Sweden with late HIV diagnosis

Although Sweden has achieved the 90-90-90 goals [26] with a very high proportion of people living with HIV being diagnosed and efficiently treated, a key residual problem in the Swedish HIV epidemic have been that persons with HIV are diagnosed late (when CD4 counts <350 cells/ml or the person already had been diagnosed with an AIDS defining illness) [27, 28]. Johanna Brännström [29] concluded in her thesis about late HIV diagnosis in Sweden that more than half of Swedish patients with HIV were diagnosed late and that

older age and foreign origin was the two most important factors increasing the risk of late diagnosis.

1.7 A GLOBAL PERSPECTIVE

Great efforts have been and still are made to increase the access to antiretroviral treatment all over the world and in 2017 approximately 20.9 million out of the estimated 36.7 million people living with HIV worldwide had access to antiretroviral therapy. The majority of people diagnosed with HIV are living in Eastern and Southern Africa (19.4 million people, 59% women) and the rest is distributed as follows; 6.1 million in Western and Central Africa, 5.1 million in Asia and the Pacific, 1.8 million in Latin America, 310,000 in the Caribbean, 230,000 in Middle East and North Africa, 1.6 million in Eastern Europe and Central Asia and 2.1 million in Western and Central Europe and North America [30].

1.8 THE SWEDISH CONTEXT

Around 10,000 people have been diagnosed with HIV in Sweden since the beginning of the pandemic and 7532 were registered in clinical care in March 2018 according to the Swedish database InfCare HIV [31], which gives a prevalence of approximately 0.07%. Of these 39% were women and 61% men, 36% were born in Sweden and 64% in other countries. Route of transmission, as documented in InfCare HIV, was 31.1% homo/bisexual, 51% heterosexual, 5.3% intravenous drug use, 1.5% blood products, 2.9% mother-to-child transmission and 5.9% other/unknown [31]. When data was collected for this thesis in 2013 the number of people registered in clinical care was 6205 (38% female, 59% born in other countries than Sweden [31]).

Antiretroviral therapy is available, without any out-of-pocket costs, to all people living with HIV in Sweden and Sweden was the first country to achieve the Joint United Nations Program on HIV/AIDS (UNAIDS) 90-90-90 goal; that 90% of people living with HIV in a country should be diagnosed, 90% of these under treatment and 90% of these have an HIV RNA level of <50 copies/ml [32]. In March 2018 97.4% of persons registered in clinical care were under treatment and 94.7% of those were virally suppressed (HIV viral loads <50 copies/ml) [31].

1.9 CENTRAL CONCEPTS AND FRAMEWORKS

1.9.1 HIV-related stigma

In a statement presented for the United Nations general assembly in 1987, Jonathan M. Mann (director of the special program of AIDS at the World health organization) referred to, what he called, the third epidemic of AIDS [33]. The first epidemic was, according to Mann, the spread of the virus, followed by the second epidemic of people being diagnosed with AIDS. Following these epidemics came, relentlessly, the third epidemic, consisting of the economic, social, political and cultural response and reaction to AIDS [33]. Since the beginning of the pandemic, researchers have been tracking this third epidemic and often, but not always, referred to it as the stigma around HIV and AIDS.

1.9.1.1 The origin of the concept of social stigma

The word stigma is originally Greek and refers to a mark made on the skin by hot iron or by cutting/pricking, as a symbol of infamy [34]. When stigma is used in the context of HIV it, however, refers to a social stigma. The understanding of social stigma is often based on the work of E. Goffman [35] who described stigma as “an attribute that is deeply discrediting, that reduces the bearer from a whole person to a tainted, discounted one” (p 10-11). Based on his own experience of working within psychiatric hospitals, and with certain groups as people with a criminal background, he described the process when certain groups and individuals are being pointed out as abnormal in society. Goffman discussed the difference between a visible and a concealable stigma, where a visible stigma was thought to have a direct negative effect on the identity of the person who is stigmatized whilst an concealable stigma constantly would put the person in situations where he or she must decide whether to disclose the stigmatized attribute or not.

1.9.1.2 Towards a definition of HIV-related stigma

Although Goffman’s work “Stigma; notes on the management of spoiled identity” [35] have been proven useful in explaining social mechanisms related to a wide range of diseases, the concept of stigma have been found difficult to define [36, 37]. As Goffman described complex processes that appear when certain characteristics are found to be deviant, conceptual definitions of social stigma have often excluded parts of the process [36]. Stigma has, for example been defined as a characteristic [36], instead of a social process and it is common to separate stigma and discrimination [38], although discrimination can be understood as a part of the process of social stigma [37].

A comprehensive definition of social stigma in general has been presented by Link and Phelan [36], who stated that “stigma exists when elements of labeling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows the processes to unfold” (p382) [36]. Based on the definition by Link and Phelan [36] a conceptual framework for HIV-related stigma has been developed by Mahajan and colleagues [37]. However, there are also other frameworks for HIV-related stigma available and there is still a lack of consensus regarding how HIV-related stigma should be defined.

1.9.1.3 An addition of critical theory

A later contribution to theoretical frameworks around HIV-related stigma have been that HIV-related stigma not only occurs and is maintained on an individual level but also on a structural level within political and economic processes [39]. Parker and Aggleton [39] argued, inspired by Michel Foucault and Pierre Bourdieu, that power on a structural level not only maintains stigma but that stigma, with its processes of labelling and categorization also constitutes and helps to maintain structures of power. The Foucauldian perspective also brought a certain perspective on how stigma can be reduced, since Foucault throughout his work, put power in relation to resistance from the oppressed [40]. According to Parker and Aggleton [39] the most effective and powerful responses to the epidemic have taken place

when affected groups have mobilized themselves to fight back. Parker and Aggleton therefore requested interventions that may unleash the power of resistance in the stigmatized groups of people living with HIV [39].

1.9.1.4 How stigma is defined in this thesis

This thesis is not based on one single definition of HIV-related stigma. A theoretical framework (the HIV stigma framework, presented below) was used to examine individual experiences of HIV-related stigma and the HIV stigma scale (also presented below) was used for measurement of experiences of HIV-related stigma. The HIV stigma framework and the HIV stigma scale are based on slightly different understandings of how HIV-related stigma is constructed and maintained in society.

1.9.2 The HIV stigma framework

Earnshaw and Chaudoir [41] have, in a review of stigma measurements, called for clarity regarding conceptualization and measurement of HIV-related stigma. According to Earnshaw and Chaudoir [41] it is essential to distinguish between different aspects of how HIV-related stigma is experienced by the individual living with HIV, since different aspects of stigma not necessarily are associated with the same aspects of health-related quality of life.

Earnshaw and Chaudoir [41, 42] have presented a theoretical framework, the HIV stigma framework, that suggest that individual level stigma mechanisms for both people living with HIV and people who are uninfected can be elicited by the existence of HIV as a stigmatized “mark” [41]. These individual stigma mechanisms are all psychological responses to the knowledge that HIV is a socially devalued characteristic [41]. The HIV stigma framework was based on an understanding of stigma from Goffman [35], Link and Phelan [36] and Parker and Aggleton [39]. But in contrast to how stigma was defined by Link and Phelan [36], Earnshaw and Chaudoir (inspired by Deacon [43]) separated stigmatizing believes (i.e. Stigma in Figure 3) from stigmatization processes (i.e. Mechanisms in Figure 3).

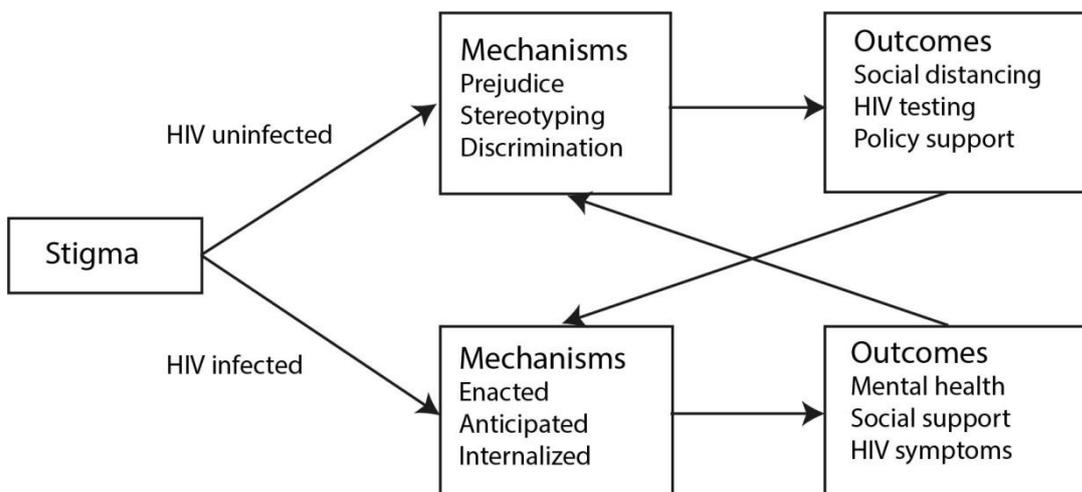


Figure 3. Earnshaw and Chaudoir’s [41] HIV stigma framework (adapted from Fig 1. Model of HIV stigma mechanisms [41])

The first mechanism for people living with HIV proposed by Earnshaw and Chaudoir [41] was enacted stigma; defined as when people living with HIV believe that they have experienced prejudice and discrimination from others in their community. The second mechanism, anticipated stigma, was defined as when people living with HIV anticipate experiencing prejudice and discrimination in the future [41]. Finally, the third stigma mechanism internalized stigma, represented when people living with HIV endorse negative feelings and beliefs associated with HIV about themselves [41]. Earnshaw et al have hypothesized that these stigma mechanisms could have different outcomes related to health and wellbeing for people living with HIV [42] (presented in Figure 4). In the HIV stigma framework *enacted stigma* along with *anticipated stigma*, was hypothesized to have a negative effect on physical aspects of quality of life, since both the fear of and experience of being stigmatized have been found to be stressful for the individual. *Anticipated stigma* was also hypothesized to affect medical adherence, since the HIV diagnosis can be revealed if someone recognize the person when he or she visit the hospital for a clinical appointment or takes his/her medicine. *Internalized stigma* was hypothesized to have a negative impact on the affective and emotional aspects of wellbeing for the individual, and also that a person with *internalized stigma* would feel less worthy than others and therefore not take their medicine or attend medical appointments. All these relations except the hypothesized path between anticipated stigma and behavioral health and wellbeing, have been confirmed in a North American context [42].

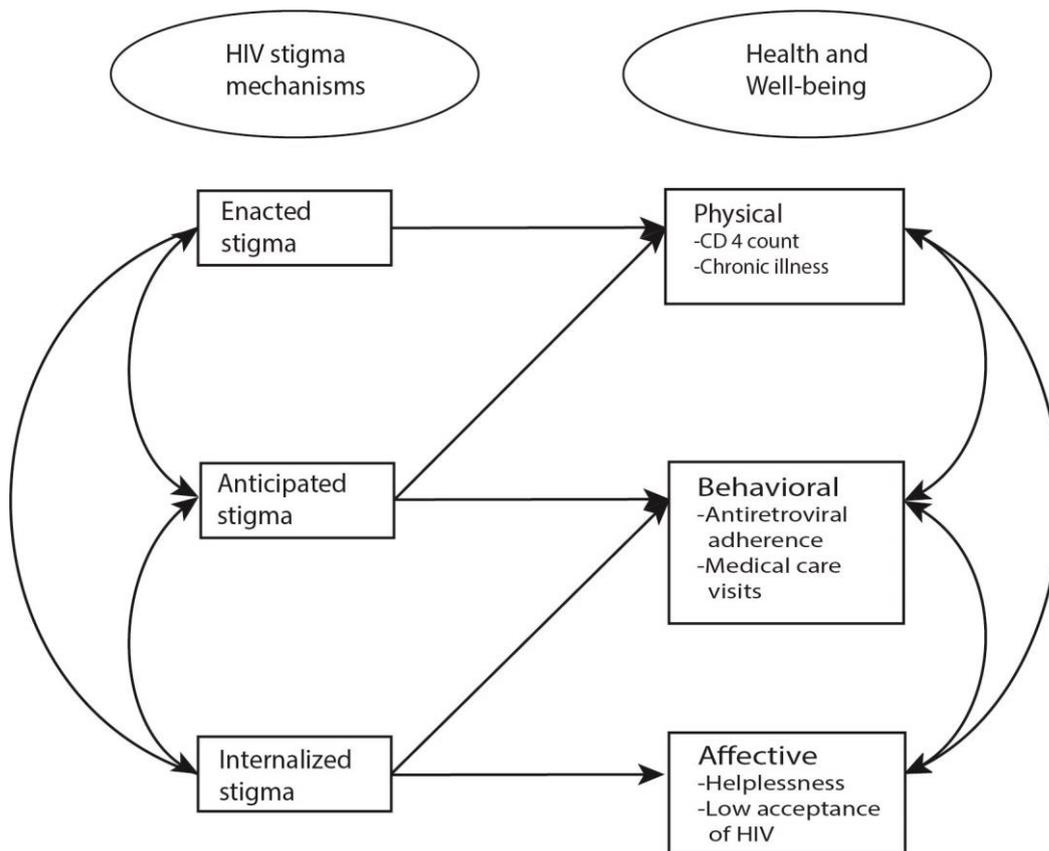


Figure 4. Earnshaw and Chaudoir's HIV stigma framework for people living with HIV [41, 42] (adapted from Fig 1. Hypothesized associations between HIV stigma mechanisms and health and wellbeing among PLWH [42])

1.9.3 Berger's HIV stigma scale

There are numerous patient-reported outcome instruments that measure different aspects of HIV-related stigma. In a review of measurements for HIV-related stigma, Earnshaw and Chaudoir [41] found sixteen instruments designed for measurement of how individuals living with HIV experienced stigma; four of these measure and differentiate between all three of their proposed stigma mechanisms (enacted, anticipated and internalized stigma). Of these four instruments, the HIV stigma scale by Berger et al [44] was the one most widely used [41].

The items in the HIV stigma scale were based on extensive literature review of research regarding social stigma in general and HIV-related stigma in specific. Based on major sources on HIV-related stigma, published between 1989 and 1993 Berger et al [44] developed a conceptual model of perceived stigma in people with HIV (Figure 5). Items were reviewed by experts on stigma from the disciplines of nursing, psychology and sociology and focused on content; special efforts were made to ensure that all aspects of HIV-related stigma that the authors could find in the literature were covered by the items. Items found to be irrelevant or in need of major revision were excluded. The questionnaire was then tested with exploratory factor analysis and a four-factor structure emerged. The authors interpreted the factors as (1)

personalized stigma (2) disclosure concerns, (3) concerns about public attitudes and (4) negative self-image [44].

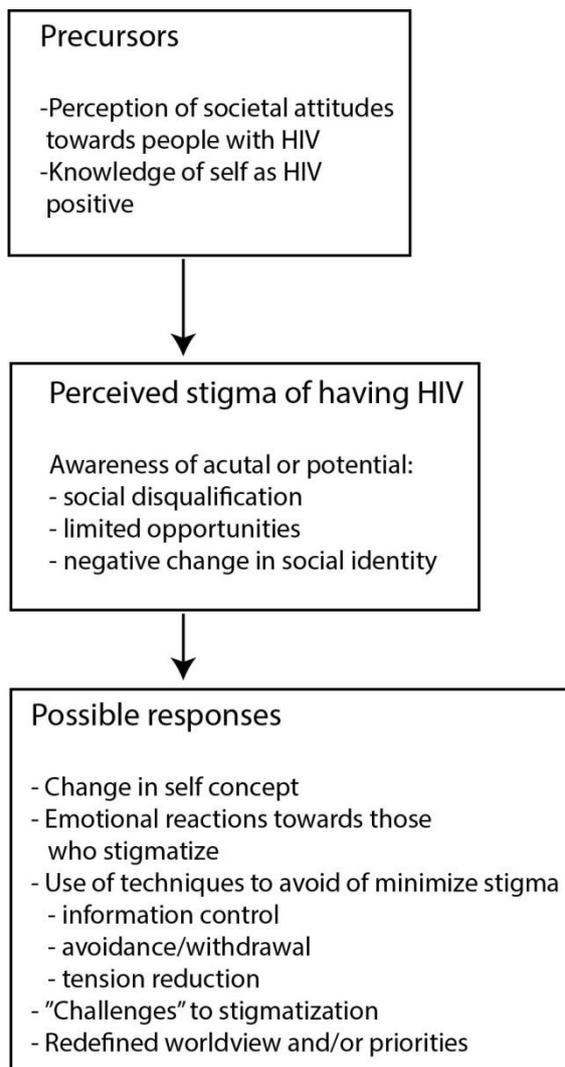


Figure 5. Berger's model of perceived stigma in people with HIV [44]

1.9.4 Disclosure

The concept of disclosure is central within theories that regard HIV-related stigma [45] (and concealable stigmatized identities in general). Often disclosure, as in being open with one's HIV status, is presented as something desirable, with benefits both for the individual with HIV and for the society, from a perspective of HIV prevention [38, 46]. A study on concealable stigmatized identities in general (but not on HIV), however, showed that for persons who had made their concealable stigmatized identity (e.g. mental condition, previous experience of rape or abuse, previous drug use) a central part of their identity had increased psychological distress [47].

Mayfield Arnold and colleagues [48] have presented three different pathways for the choice people living with HIV make regarding disclosure; (1) disclosure to everyone, (2) disclosure

to some and (3) disclosure to no one. According to Mayfield Arnold et al [48] the pathway of disclosure to some is the most common pathway among people living with HIV, as well as being the most complex one.

1.9.5 Health-related quality of life

Health-related quality of life is a multidimensional concept that usually involves emotional and physical aspects of the quality of life, as well as cognitive functioning and aspects regarding family and relations [49]. For people with HIV, in addition to the aspects generally included in the health-related quality of life dimensions, the following specific areas have also been found to be of significance; fatigue, pain, nausea and vomiting, sleep issues, sexual functioning and issues about disclosure; however, many instruments, including HIV-specific ones, do not cover all of these areas of significance [50, 51].

More than 20 years ago, between 1993 and 1995, Eriksson and colleagues [52] found that Swedish males living with HIV had significantly worse health-related quality of life, compared to a general Swedish male population. Both physical and emotional aspects of health-related quality of life were measured, including relations to family and partner as well as sexual functioning, using the Swedish health-related quality of life questionnaire (SWED-QUAL) [53]. Eriksson et al. [52] showed that especially dimensions of emotional well-being were affected.

1.9.6 Associations between HIV-related stigma and health-related quality of life

In reviews on correlates to HIV-related stigma that cover research in an American context up until 2007, HIV-related stigma has been found to have negative correlations to health-related quality of life, both to physical [54] and emotional [54, 55] aspects. HIV-related stigma has also been associated with decreased social support, lower income and lower age [54]. Also in later years, experiences of HIV-related stigma have been found to be associated with negatively affected quality of life for people living with HIV in a wide range of different countries [56-69]. In meta-analyses covering 64 publications from 1996-2013 associations were found between HIV-related stigma and higher rates of depression and lower social support. Weaker relationships were also found between HIV-related stigma and overall quality of life, physical health, anxiety, emotional and mental distress and sexual risk practices [70].

1.9.7 Associations between HIV-related stigma and antiretroviral adherence

Worldwide, stigma around HIV has been identified as a barrier to HIV testing and to care [38] and when UNAIDS has launched strategies for HIV prevention and treatment, ending HIV-related stigma has been high on the agenda [71]. Non-disclosure because of fear of stigma has been found to be a barrier to antiretroviral treatment [72-75] and internalized stigma has also been found to undermine people's adherence to treatment [72, 76]. However, a recent meta-analyses performed by Rueda et al [70] found no statistically significant

correlation between HIV-related stigma and adherence when bivariate results were pooled. But when potential confounders were accounted for in pooled multivariate analyses the results showed that people with experiences of HIV-related stigma were 32% less likely to be adherent to antiretroviral treatment [70].

1.10 RECENT STUDIES ABOUT THE LIFE SITUATION OF PEOPLE LIVING WITH HIV IN SWEDEN

In a recently published thesis, Desireé Ljungcrantz [77] has analyzed contemporary experiences of life with HIV. According to Ljungcrantz, the social dimensions of HIV are still severe, despite the favorable medical outcomes for people living with HIV. To become an HIV patient, for example, was found to be a performative process which was not optional for the individual. Through verbal and written information where the individual is referred to as HIV-infected, and through being included in a medical record and receiving HIV medical care the person with HIV becomes an object, according to Ljungcrantz, of care and control [77]. Although HIV was not described as a big factor in life for the persons interviewed, HIV became an obstacle in certain contexts; i.e. being part of a cooking team, bathing in a pool, or flirting in a bar, since other people's violent responses created negative experiences for the individual [77].

Health-related quality of life has been investigated among children living with HIV in Sweden. Rydström and colleagues [78-81] found that both children and their legal guardians rated the children's health-related quality of life as good but that they had concerns about disclosing their HIV to others. HIV could make daily life difficult; especially regarding the risk of being exposed to stigma [79-81] and experiences of HIV-related stigma was negatively associated to health-related quality of life [82]. The Swedish youths, living with HIV described how they refrained from sexual relations in order to maintain control over who that knew about their HIV. Some also questioned the obligation to inform potential sexual partners and said that the Swedish Law for communicable disease control needed to be changed [81].

The Public Health Agency of Sweden has also studied the health-related quality of life of people living with HIV in Sweden in the recent survey "Living with HIV in Sweden", performed in cooperation with a research group coordinated by Anna Mia Ekström [83]. The participants (1096 people living with HIV in Sweden, 29% female) reported their overall quality of life on a scale from 0-10, where higher values indicated better quality of life. Values of 7-8 were reported by 36% and 9-10 by 24%; the overall quality of life was thus regarded as good in general. However, almost one in five had not told anyone about their HIV and two aspects of HIV-related stigma (to have concerns about public attitudes and to have a negative self-image) was associated with a lower quality of life [83].

In the survey Living with HIV in Sweden, 49% of participants reported being sexually dissatisfied [83]. A majority (88%) of participants perceived the obligation to disclose one's HIV to a potential sexual partner as a barrier to engage in sexual relations and finding a long-

term partner [83]. Regarding those who were sexually dissatisfied, no significant difference was found between women, non-heterosexual men and heterosexual men [84].

1.11 TO LIVE WITH HIV WHEN HIV HAS BEEN “NORMALIZED”

From a biomedical perspective, it is clear that antiretroviral treatment has improved the lives of people living with HIV who have access to it [85-88]. Where antiretroviral treatment is generally available, HIV is now considered a chronic disease or long-term condition like many others [85, 87]. When I started my doctoral project in 2012, it was relatively unknown whether this biomedical normalization of HIV also would change how people living with HIV experienced their condition and further research was requested on what it meant to be virally suppressed [89].

Although some argued that the stigma around HIV would decrease when HIV was constructed as a chronic disease [90, 91], being on antiretroviral treatment has, on one hand, been found to, paradoxically, increase stigma, by making HIV visible (through daily medicine and visits to HIV-clinics) [92]. The years following the introduction of effective treatment have, on the other hand, also been referred to as “the big silence”, where people have stopped talking about HIV in general [93]. Questions remains whether antiretroviral treatment actually have made HIV less stigmatized, or if the treatment only made it possible for people with HIV to conceal their condition, thus avoiding enacted stigma [92].

During the last years, when I have been working with this thesis, research has been published showing that the subjective experience of living with HIV not necessarily improves when treatment becomes more effective [86-88]. A study performed in the United Kingdom showed ambiguous experiences, where HIV as a normalized condition existed alongside experiences of stigma, fear and shame [87].

In this thesis I have examined contemporary experiences of HIV-related stigma in Sweden, where treatment is generally available. I have been interested in if, and in that case, how people living with HIV in Sweden today experience HIV-related stigma and also if previously found correlations between stigma and lower health-related quality of life still occur when antiretroviral treatment is generally available.

2 AIMS

The overall aim of this thesis is to study self-reported stigma among people living with HIV in Sweden in the current era of efficient treatment. Further, the aim was to examine validity of the HIV stigma scale and to test the HIV stigma framework in a Swedish context where treatment is generally available.

The specific study aims were:

To evaluate the psychometric properties of the HIV stigma scale in a Swedish context with regard to construct validity, data quality and reliability (Paper I).

To develop a substantially shorter version of the HIV Stigma Scale with psychometric properties retained from the full-length scale (Paper II).

To examine whether items in the HIV Stigma Scale function differently with regard to gender and cultural background (Paper III).

To test the tenets of the HIV stigma framework and its potential covariates for persons living with HIV in Sweden (Paper IV).

To explore the experience of HIV-related stigma among people living with virally suppressed HIV in Sweden and to explore how these experiences correspond to the stigma mechanisms for people living with HIV in Earnshaw and Chaudoir's HIV stigma framework [41]. (Paper V).

3 METHODS

3.1 GENERAL STUDY DESIGN

My overall doctoral project was a mixed methods study, mainly consisting of a cross-sectional survey with people living with HIV in Sweden and a series of individual interviews with persons who were virally suppressed. Results from the cross-sectional survey have been published in four papers (Paper I-IV, republished in the later part of this thesis). Results from the interviews are published in this thesis as a manuscript (Paper V). Table 1 shows an overview over the papers included in this thesis, with design, instruments, participants and analytical methods. Psychometric properties of the HIV stigma scale [44] was examined in Paper I-III. The HIV stigma scale was then used in an empirical assessment of the HIV stigma framework in the Swedish context [41] (Paper IV) and the HIV stigma mechanisms [41] were explored in a qualitative interview study (Paper V).

Table 1. Overview over papers included in the thesis

Paper	Design	Instruments	Participants	Analytical method
I		The HIV stigma scale	132 PLWH* in Sweden (complete answers to the HIV stigma scale)	Classical test theory
II	Cross-sectional survey study	The HIV stigma scale	132 PLWH in Sweden (complete answers to the HIV stigma scale)	Classical and modern test theory, Item reduction
		The 12-item version of the HIV stigma scale	880 PLWH in Sweden (complete answers to the 12-item HIV stigma scale)	
III		The HIV stigma scale	193 PLWH in Sweden 660 PLWH in the US 250 PLWH in South India	Modern test theory, DIF-analysis
IV		The HIV stigma scale, SWED-QUAL, measures of viral load	173 PLWH in Sweden	Partial least squares structural equation modelling
V	Interview study	Individual in-depth interviews	15 Swedish persons with virally suppressed HIV	Content analysis with framework approach

*People living with HIV in Sweden

3.2 INSTRUMENTS

3.2.1 The Swedish version of the HIV stigma scale

Berger's HIV stigma scale [44] was translated to Swedish before I entered the project. The 40 items were translated independently from English to Swedish by three members of the research group. The three translated versions were compared and discussed and merged into a Swedish version of the HIV stigma scale, which was reviewed by a bilingual consultant. Minor changes were made before the items were translated back to English by a professional translator. Additional small changes were then conducted to ensure that the Swedish version of the items matched the English version. Cognitive interviews had been performed with a purposeful sample of people living with HIV in Sweden (7 men, 2 women, 3 born in Sweden, 6 born in other countries) and the participants had found the items relevant and comprehensive in general.

Appendix 1 shows the HIV stigma scale as it appeared in the questionnaire. The 40 items in the HIV stigma scale were statements that the participants could agree or disagree with on a four-point Likert scale (strongly disagree, disagree, agree, and strongly agree). There was no response alternative for "not applicable" or "do not want to answer". The last seventeen items in the questionnaire assume disclosure of one's HIV status, at least to some extent and prior to item 24 a text encouraged participants to imagine the situation, even if it had never happened to them. Response alternatives and the text prior to item 24 matched the original version of the HIV stigma scale [44].

3.2.2 SWED-QUAL

SWED-QUAL is a Swedish questionnaire designed to measure health-related quality of life. The instrument was developed by Brorsson, Ifver and Hays [53] using items from the US Medical Outcomes Study [94-96]. The questionnaire consists of 63 items that form two single-item and 11 multi-item scales, which are measures of different aspects of health-related quality of life. The scales with example of item in respective scale are shown in Table 2. Each item had a corresponding Likert scale with response alternatives and the responses for each item belonging to a scale were transformed into 0-100 scale indexes, with higher scores representing better health-related quality of life for all scales.

Table 2. Scales in SWED-QUAL with sample items.

Scale (number of items)	Sample item
Physical functioning (7)	Is your health today good enough that you can do the following activities? a. Strenuous activities. e.g., heavy manual work, strenuous sports
Mobility (1)	When you have errands outside your home, does someone have to assist you because of your health?
Satisfaction with physical ability (1)	How satisfied are you with your physical ability to do everything you want to do?
Pain (6)	Have you been bothered by aches and pain during the last week?
Role limitation because of physical health (3)	How often have your normal activities been interfered with because of your physical health during the last week?
Emotional wellbeing: Positive effect (6)	Do you agree or disagree with the following statements concerning your feelings during the last week? - I have felt harmony
Emotional wellbeing: Negative effect (6)	Do you agree or disagree with the following statements concerning your feelings during the last week? - I have felt sad
Role limitation because of emotional health (3)	How often have your normal activities been interfered with because of emotional problems during the last week?
Sleep (7)	Do you agree or disagree with the following statements concerning your sleep during the last week - I slept poorly
Satisfaction with family life (4)	Think about your family. How satisfied are you with the following aspects? - Cohension and mutual understanding
Relation to partner (6)	The following statements concern your relationship with your spouse or partner - We can talk with each other about almost everything
Sexual functioning (4)	Do you agree or disagree with the following statements? - I lack sexual interest
General health perception (9)	Do you agree or disagree with the following statements concerning your general health? - My health is as good as others my age

3.3 DATA SOURCES

The studies in this thesis are primarily based on two data collections within the project *Stigma and quality of life for people living with HIV*, which I have performed in collaboration with supervisors and colleagues; a cross-sectional survey investigating Stigma and health-related

quality of life for people living with HIV (paper I-IV) and a set of in-depth interviews (paper V). Data for participants in the survey was also retrieved from the national quality assurance registry InfCare HIV [97]. The 12-item version of the HIV stigma scale developed in paper II was used in the nation-wide survey Living with HIV in Sweden performed on behalf of the Public Health Agency of Sweden [83]; data from Living with HIV in Sweden was used to assess psychometric properties of the 12-item version of the HIV stigma scale (Paper II). In collaboration with researchers from the United states and India we performed secondary analyses (paper III) on the data that we had collected using the 40-item HIV stigma scale in combination with data collected with the HIV stigma scale in the US [98, 99] and South India [100].

3.3.1 Quantitative data

3.3.1.1 Stigma and quality of life for people living with HIV

A cross-sectional survey was distributed at the Karolinska University Hospital in Stockholm, Sweden from March through September 2013. In this thesis I will, from now on, refer to this survey as the Stigma and quality of life survey.

3.3.1.2 Inclusion criteria

Inclusion criteria were: (1) diagnosis with HIV and (2) 18 years of age and older (3) not first appointment at the clinic. We aimed to include a sample that was representative for the population of people living with HIV in Sweden, regarding gender, route of transmission and country of birth. The group of people living with HIV that were listed at the clinic when data collection took place reflected the population people living with HIV in Sweden regarding gender, route of transmission and country of birth. We therefore concluded that a consecutive inclusion of participants at that clinic would render a sample that was representative for people living with HIV in Sweden, except for that an overall majority of the participants would be living in an urban area.

3.3.1.3 Exclusion criteria

If a professional translator was needed for participation, but had not been booked, participants were excluded from the study. Individuals were also excluded if a nurse or physician opposed participation. Some females were already included in another ongoing study at the clinic and were therefor excluded from our survey. Some individuals, who were imprisoned for unknown reason, came to the clinic in handcuffs and with guards and were counted as excluded.

3.3.1.4 The questionnaire

The questionnaire, labeled “Questions about your health and life situation”, consisted of the Swedish health-related quality of life questionnaire (SWED-QUAL) [53] and Berger’s HIV stigma scale [44] (Appendix 1). The following questions were also included; “how old are you?”, “are you male or female?”, “in what country are you born?”, “what education best

applies to you?” and “how important is religion to you?” The questionnaire was available in Swedish and English and took approximately 30-45 minutes for persons who were fluid in Swedish or English to complete.

3.3.1.5 Strategies to enable participation

As a large proportion of eligible participants were not fluid in Swedish or English we had different alternatives prepared for how participants could be assisted when completing the questionnaire. Participants could either complete the questionnaire together with a professional translator or fill out the questionnaire with assistance from me or one of two research assistants involved in the data collection. We then sat down with the participant in a private room at the clinic and completed the questionnaire as a structured interview. The participant could ask questions, both about the meaning of certain words, but also about the structure of the questionnaire and response alternatives.

3.3.1.6 Procedures

From March to the end of June 2013 data collection was conducted on 26 different dates. On a day with data collection all persons that visited the clinic for a scheduled appointment, that matched inclusion criteria, were considered to be eligible for inclusion. I and one or two research assistants sat at a table near the reception and eligible participants were informed by the receptionist that we wanted to ask them to participate in a study. We gave eligible participants information about the study and gave interested participants written information about the study (Appendix 2) and a printed copy of the questionnaire. Participants could then sit down in the waiting room and complete the questionnaire before and/or after their appointment. Although that was not our initial intention, some participants wanted to take the questionnaire home and send it in by mail. We then started providing participants with prepaid envelopes so that they could mail questionnaires to us.

Fifty two individuals were excluded from the study, as summarized in figure 6. One hundred and twenty-three individuals declined participation (i.e. worried about secrecy, lack of time) and 40 individuals were not included due to administrative reasons (i.e. we did not have time to help them with the questionnaire, because we helped someone else). The response rate (44%) was calculated as individuals who returned a questionnaire (n=197) compared to eligible participants (n=441).

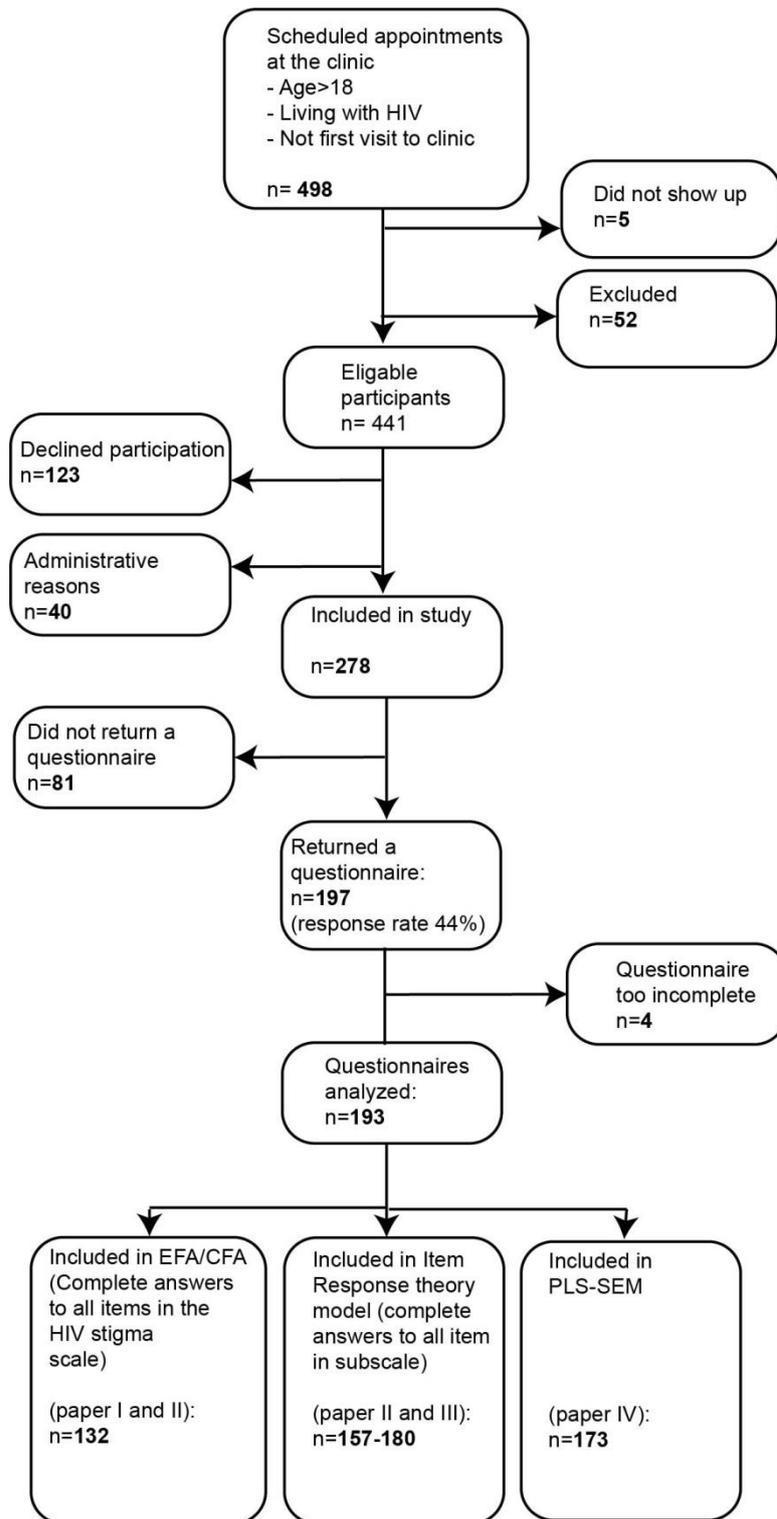


Figure 6. Flow chart over the process of inclusion in the Stigma and quality of life survey.

3.3.1.7 InfCare HIV

InfCare HIV is a national quality assurance registry, linked to the medical record, containing socio-demographic (gender, age, country of birth, estimated country of transmission, route of transmission) and biological data. For all participants included in the Stigma and quality of life survey that returned a questionnaire, the following information was retrieved from InfCare HIV; time point of first positive HIV serology, gender, route of transmission, CD4

cell count (lowest and most recent value), HIV viral loads (VL) and information about antiretroviral treatment. Patients were considered to be non-adherent to treatment if they had one viral one VL > 150 copies/ml or two or more consecutive VL > 50 copies/ml within the last 2 years of the condition with treatment ongoing at least 6 months prior to the evaluation period [101].

3.3.2 Qualitative interviews

Fifteen participants who were durably virally suppressed were recruited through purposeful sampling at the same clinic as where the survey was performed; we aimed to recruit a heterogeneous sample, regarding age, gender and country of origin. Individual face-to-face interviews were performed in conversational style by me (13 interviews) or by co-author Galit Zeluf (2 interviews). We had designed a schematic interview protocol, with topics aimed to frame the experience of HIV-related stigma, which we used if the participant did not talk about a topic spontaneously. Follow-up questions like “can you tell me more about that” and “how did you feel about it” were used as probes. Interviews were audio recorded and lasted between 23 and 129 minutes.

3.3.3 Data retrieved for secondary analyses

3.3.3.1 Living with HIV in Sweden

The study Living with HIV in Sweden was a nationwide survey on health-related quality of life of people living with HIV in Sweden, performed on behalf of the Public Health Agency of Sweden [83]. Data was collected 2013-2014 at 15 healthcare units for infectious diseases in Sweden, accounting for 75% of HIV care in the country, and at two needle and syringe exchange clinics [83]. The study Living with HIV in Sweden used the 12-item version of the HIV stigma scale that we had developed (paper II) to measure HIV-related. Item-level data from the participants that had answered all 12 items in the HIV stigma scale (n=880) was used in paper II in this thesis to evaluate the psychometric properties of the abbreviated instrument.

3.3.3.2 The Indian and United States cohorts

In 2013 we started collaboration with researchers from University of Washington, Dr Deepa Rao and Professor Lisa Manhart. Since they both had access to data collected with the HIV stigma scale, we decided to perform secondary analysis on our combined datasets. Since I was responsible for performing the analyses, I received their item-level data collected with the HIV stigma scale, together with a limited amount of sociodemographic variables. Gender, and to some extent age, were the only variables that were comparable over all three cohorts.

Data from the Indian cohort was collected in 2007 to 2008 in the state of Tamil Nadu, through networks caring for people living with HIV. Participants were residing in and around the cities Chennai and Vellore [100]. Data from the United States cohort was collected in three different states; Iowa [98], South Carolina [98] and Chicago, between 2005 and 2010.

3.3.4 Data used for comparison

3.3.4.1 Men living with HIV in Sweden 1993-1995

SWED-QUAL mean scores from men who completed the Stigma and quality of life survey were compared to earlier published mean scores from a population of men (n=72) living with HIV in Sweden [52]. These men completed SWED-QUAL between 1993 and 1995 before entering a pharmaceutical trial of an HIV vaccine. Mean age was 37 years (SD=9, range =22-64 years) and mean duration of HIV infection was 4.9 (SD=3.3, range =0.4-10). Route of transmission was primarily male to male sex (96%) and 94% of participants were classified as White (Ethnic group). Inclusion criteria were CD4 count $>200 \times 10^6$ cells/ml, absence of current acute disease, drug or alcohol abuse or neurological and psychiatric dysfunction that could interfere with participation in the study [52].

3.3.4.2 A Swedish general population 1991

SWED-QUAL mean scores from a Swedish general population were also used for comparison. Brorsson et al [53] distributed SWED-QUAL in 1991 to a random stratified sample from the Swedish general population (2366 individuals, age 18-83).

3.4 PARTICIPANTS

In the Stigma and quality of life survey, 193 individuals returned a questionnaire (44% female, 52% born in other countries than Sweden, mean age = 48.8, SD = 11.7, range = 19-83). Thirty-two participants had completed the questionnaire with assistance from me or another member of the research team, 8 participants had completed the questionnaire with assistance from a professional translator.

3.4.1 Paper I

Data used in paper I were responses to items in the HIV stigma scale from the Stigma and quality of life survey. Sociodemographic variables for all participants that returned a questionnaire (n=193) are presented in Table 3. For the exploratory factor analysis only participants who had completed all items in the HIV stigma scale were included (n=132, Table 3). We were concerned that a large proportion of the participants with missing answers in the Stigma and quality of life survey would be participants born in other countries than Sweden, but there was no statistical difference between the subsample of persons with complete answers to the HIV stigma scale and the sample of all persons returning a questionnaire (Table 3).

Table 3. The stigma and quality of life survey, categorical sociodemographic variables

Characteristics	Returned questionnaires n=193		Subsamples in analyses							
			EFA/CFA n=132 ^a		Differences between n=193 and n=132		PLS-SEM n=173 ^b		Differences between n=193 and n=173	
	n	%	n	%	$\chi^2(1)$	p	n	%	$\chi^2(1)$	p
Gender										
Female	85	44	55	42	0.41	0.522	74	43	0.11	0.745
Male	108	56	77	58			99	57		
Country of birth										
Sweden	93	48	64	49	0.04	0.845	84	49	0.02	0.884
Other country	100	52	67	51			89	51		
Non-adherent to ART	18	9	17	13	2.43	0.119	16	9	0.01	0.909
CD4 count<200x10 ⁶	8	4	7	5	0.58	0.445	7	4	<0.01	0.975
On antiretroviral	185	96	125	95	0.58	0.445	165	95	0.18	0.675
<hr/> $\chi^2(3)$ p <hr/>										
Education										
Elementary School	35	18	24	18	0.35	0.951	32	19	0.61	0.895
High	70	36	50	38			66	38		
College or	72	38	47	36			63	36		
Other/Unknown	16	8	11	8			12	7		
Route of Transmission^d										
Heterosexual	117	61	71	54	3.39	0.335	99	57	3.39	0.697
Homo/bisexual	52	27	44	33			51	30		
Intravenous drug	13	7	9	7			12	7		
Other/unknown	11	5	8	6			11	6		

^aParticipants with complete answers to all items in the HIV stigma scale

^bParticipants with enough items completed to be included in PLS-SEM

^cPersons not on treatment was not due to non-adherence. Treatment not initiated because of high CD4 count.

^dRoute of transmission as classified in InfCare HIV

3.4.2 Paper II

The results from the exploratory factor analysis from paper I with 132 participants were also used in Paper II. In the partial credit models we used a subsample of participants in the Stigma and quality of life survey that had answered all items in a subscale, (n= 157 for Personalized stigma, n=168 for Disclosure concerns, n=159 for Concerns about public attitudes and n=180 for negative self-image. To evaluate the psychometric properties of the 12-item version of the HIV stigma scale we retrieved item-level data from the study Living with HIV in Sweden [83]. Eight hundred eighty participants out of 1096 had completed all items in the HIV stigma scale. We found no statistical difference regarding gender between those who had completed all items in the HIV stigma scale and the total sample (26% female vs expected 29%, $\chi^2(1)= 3.79$, p=0.052).

3.4.3 Paper III

Participants in Paper III were people living with HIV in Sweden, South India and the United States. The Swedish cohort was the subsample used in the partial credit models in paper II. The Indian cohort consisted of people living with HIV (50% female) in the state of Tamil Nadu who completed the 40 items in the HIV stigma scale in 2007-2008. 150 participants were living in and around the city Chennai (urban area) and 100 were living in Vellore (semirural area) [100]. The US cohort consisted of people living with HIV (34 % female) who had completed the 40 items in the HIV stigma scale at different time points between 2005 and 2010. At the time of data collection the US participants lived in South Carolina (n=210), Iowa (n=331) and Chicago (n=62) [98, 99].

3.4.4 Paper IV

The participants in Paper IV were drawn from the Stigma and quality of life survey, (the same cohort as for Paper I-III). After calculating subscale scores for SWED-QUAL and the HIV stigma scale (with missing values imputed for the HIV stigma scale as earlier described) participants with missing data on variable level were excluded, leaving 173 participants for analyses. We found no statistical difference regarding characteristics between the subsample of 173 participants compared to the 193 who completed a questionnaire (Table 3).

3.4.5 Paper V

Fifteen persons who were living with HIV and who we knew were durably virally suppressed were interviewed. They were born in the different countries Eritrea, Uganda, Kenya, Gambia, Thailand, Philippines, Germany and Sweden, but they all had Swedish residency. Sociodemographic information about participants on a group level is presented in Table 4.

Table 4. Participants' characteristics

		n=15
Gender	Women	8
	Men	7
Country of birth	Sweden	6
	Other country	9
Age	30-39	1
	40-49	6
	50-59	6
	>60	2
HIV diagnosis before or after 1996*	Before 1996	4
	After 1996	11

*When combined antiretroviral treatment was introduced

3.5 STATISTICAL ANALYSIS

3.5.1 Psychometric properties of the HIV stigma scale in a Swedish context (Paper I-III)

Psychometric properties of the HIV stigma scale was examined in Paper I-III, with a focus on validity, which refers to the extent that an instrument measure what it is intended to measure

[102]. Paper I-III therefore gives information regarding to what extent it is reasonable to believe that the HIV stigma scale assess the experience of HIV-related stigma among people living with HIV in Sweden. A schematic overview over analyses performed within each paper with data sources used is presented in Table 5.

Table 5. Psychometric analyses performed within my doctoral project, sorted by data source used and with indication of paper where the analyses are published.

	Data source		
	The HIV stigma survey	Living with HIV in Sweden	American and Indian cohort
Content validity			
Data quality, missing values			
Differential item functioning	Paper III		Paper III
Criterion validity			
Convergent validity	Paper I		
Construct validity			
Exploratory factor analysis	Paper I	Paper II	Paper III
Confirmatory factor analysis		Paper II	Paper III
Distribution of scores within subscales	Paper I		
Corrected item-total correlation coefficients	Paper I	Paper II	
IRT evaluation of model fit	Paper II		
Floor and ceiling effects	Paper I	Paper II	
Evaluation of Likert scale	Paper I		
Reliability (Internal consistency)			
Cronbach's alpha	Paper I	Paper II	

3.5.2 The difference between classical and modern test theory

The HIV stigma scale was originally developed as a factor model with four latent variables intended to measure four different aspects of HIV-related stigma; the four subscales are treated as summated scales. Factor models and summated scores belong to classical test theory. In this thesis we have also used modern test theory, where a basic assumption is that items in a scale may vary in “difficulty” [102] [103]. With the subscale Disclosure concerns as example, there would be some items that even those with little Disclosure concerns would agree with and some items that only those with much Disclosure concerns would agree with.

3.5.3 Paper I

In Paper I we used classical test theory to evaluate content validity, criterion validity, construct validity and internal consistency of the HIV stigma scale in a Swedish context.

3.5.3.1 *Content validity*

Content validity was assessed to see whether items in the HIV stigma scale were sensible and reflected the experience of HIV-related stigma for people living with HIV in Sweden at the time of data collection for the HIV stigma survey [102]. We examined the rate of participants that had missing answers to items in the instrument and if more than 5% of participants had not completed an item we examined the content of that item further [104]. We also calculated floor and ceiling effects on a subscale level. If more than 15% of participants had maximum or minimum score on a subscale it could be suspected that the scale did not measure the entire range of the intended aspect of HIV-related stigma [105].

3.5.3.2 *Convergent validity*

We also assessed convergent validity, which concerns if an instrument can be empirically associated with external criteria [102]. We hypothesized that the measures of HIV-related stigma in the HIV stigma scale would be related to the SWED-QUAL scales Emotional wellbeing, with persons who had reported more experiences of HIV-related stigma reporting worse emotional well-being. Thus, we examined Spearman's rank correlations between HIV stigma scale scores and scores from the SWED-QUAL scales Emotional wellbeing: positive effect and Emotional wellbeing: negative effect and expected all correlations to be negative, since lower scores indicate worse health-related quality of life for all SWED-QUAL scales [53].

3.5.3.3 *Construct validity*

Construct validity concerns whether instruments measure the construct that it was intended to measure [102]. The HIV stigma scale was originally developed as a factor model using traditional psychometric theory and Berger et al. found that the items in the instrument related to four latent variables (sub scales) [44]. When testing the construct validity of the HIV stigma scale in a Swedish context therefore consisted in testing whether the four factor structure was confirmed also in a Swedish context. Construct validation primarily concerns dimensionality (i.e. do all items in a subscale relate to a single dimension), homogeneity (do all items in a subscale contribute equally to the subscale) and overlap between subscales [102].

To evaluate construct validity we replicated the factor analysis performed in the development of the original scale (alpha factoring, oblimin rotation) using item-level data from "the HIV stigma survey" to compare the psychometric properties of the instrument in a Swedish context. We used the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy (KMO) (expected to exceed 0.8) and Bartlett's test of sphericity (expected to be significant) [106] to evaluate if the data was suitable for a factor analysis.

In contrast to how Berger et al [44] handled the cross loading items, we decided to assign each item to one single subscale. If items cross loaded we assigned that item to the subscale that it had a higher loading with. When items had been assigned to subscales we calculated corrected item-total correlations, assessing how each item was correlated to the intended subscale to assess homogeneity. Corrected item-total correlations were considered acceptable if exceeding 0.4 and were also expected to have a variation in range [107].

3.5.3.4 Internal consistency

We calculated Cronbach's alpha for all subscales to assess internal consistency, and expected figures of > 0.7 if all items were adequately correlated to each other within a subscale.

3.5.4 Paper II

Paper II describes how we developed and evaluated a 12-item short version of the HIV stigma scale that was used to measure HIV-related stigma in the study Living with HIV in Sweden [83]. In the process of item selection we kept items with better psychometric properties and excluded items that functioned less well. Since we also wanted to preserve content validity we assessed which aspects of stigma that each of the subscales was intended to cover and tried to select a combination of item that covered as many aspects of stigma as possible.

3.5.4.1 Item reduction

The exploratory factor analysis from Paper I was used to assess which items that had lower loadings and which items that had high loadings on several subscales (i.e. cross loading items). Cross loading items or items that had low loadings to all subscales were not considered for the short version. We also used modern test theory (item response theory), where it is assumed that items have different "difficulty" level. We calculated partial credit models for all subscales where the items were hypothesized to represent more or less severe levels of the measure stigma aspect. Items that showed misfit towards the model (Mean square values > 1.2) were not considered for the short version. We discussed the remaining items in the research group and chose three high loading items per subscale that we thought represented the different aspects of stigma proposed by Berger et al [44] that the instrument should cover.

3.5.4.2 Evaluation of the 12-item version of the HIV stigma scale

The 12-item version of the HIV stigma scale was used in the study Living with HIV in Sweden and we used item-level data from that study to evaluate the psychometric properties of the abbreviated instrument. The 880 participants that had completed all 12 items in the HIV stigma scale were randomly divided into two samples of equal size. Item-level data from the first sample was analyzed in exploratory factor analysis (alpha factoring, oblimin rotation). We then specified a model with the 12 items loading to the intended subscales, without cross loadings, and used the second sample to perform a confirmatory factor analysis with maximum likelihood. Goodness of fit of the model to the data was evaluated with χ^2 -

testing (expected to be non-significant), RMSEA (expected to be below 0.5), and CFI and TLI (expected to exceed 0.9).

To compare psychometric properties between the 39-item version and the 12-item version of the HIV stigma scale we calculated corrected item-total correlations, Cronbach's alpha and floor and ceiling effects for the subscales in the 12-item version of the instrument.

3.5.5 Paper III

In Paper III we used data from the South Indian and the US cohort and compared psychometric properties between those cohorts and our Swedish cohort. Participants in all cohorts had answered the 40-item version of the HIV stigma scale, but based on our knowledge that the 40-item version of the HIV stigma scale had extensive cross loading in an American context we chose to only use 32 items included in an abbreviated version of the instrument, developed with an intention to remove cross loading items [108].

3.5.5.1 Dimensionality

We analyzed dimensionality of the subscales and assumed that the subscales separately would function as unidimensional constructs. We therefore specified factor models where all items in a subscale loaded onto one single factor and assessed model fit for subscales separately, and repeated this series of analyses for each cohort. In analysis we accounted for the ordinal nature of the data and fitted the models using weighted least squares means and variance (WLSMV) [109]. We also assessed dimensionality using the Empirical Kaiser Criterion [110].

3.5.5.2 Differential item functioning

We then examined if items in the 32-items version of the HIV stigma scale showed signs of differential item functioning (DIF) between the Swedish, South Indian and US cohorts. We also assessed DIF between men and women across all cohorts and replicated a DIF-analysis performed by Rao et al [98] where DIF was assessed between Black, non-Hispanic and White, non-Hispanic persons living with HIV. We used a combined ordinal logistic regression –IRT approach, as employed in the Lordif package [111] in R statistics. The logistic regression were performed in three steps where the first step consisted of a graded response model, with the probability for item responses calculated as a function of participants level of perceived stigma. In the second step group (i.e. cohort) was added as independent variable and in the third step an interaction term of group and latent trait level combined was added. Differences in pseudo R square values (nagelkerke) between step one and two was used to assess uniform DIF, with a constant effect for different levels of stigma. Differences in pseudo R square values between step two and three were used to assess non-uniform DIF, with an effect that differed depending on levels of stigma. Thresholds for when items should be flagged for DIF were based on Monte Carlo simulations of DIF-free samples. Impact of detected DIF on subscale scores was evaluated through scatter plots of the

difference between unadjusted IRT scores (with DIF) and adjusted IRT scores (adjusted for DIF). Differences exceeding 0.2 were considered to be salient [112].

3.5.6 Paper IV

3.5.6.1 Descriptive statistics for the HIV stigma scale

The Swedish version of the HIV stigma scale was used to measure different aspects of HIV-related stigma; Personalized stigma, Disclosure concerns, Concerns about public attitudes and Negative self-image. We calculated subscale scores for the four subscales in the HIV stigma scale by summarizing item scores across subscales. Missing values were imputed using multiple imputations if respondents had completed at least 50 % of items in a subscale. Since the subscales consist of 7, 8, 8 and 16 items respectively the subscale scores are not directly comparable across subscales. To generate descriptive statistics that was comparable across subscales we dichotomized the subscale scores into two categories; lower stigma and higher stigma. The cutoff-value was set to be half of the maximum range and the subscale scores were thus categorized as presented in table 6.

Table 6. Possible range for subscale scores in the HIV stigma scale and cutoff values for dichotomized categories.

HIV stigma Subscale	Possible range subscale score	Dichotomized categories (lower stigma/higher stigma)
Personalized stigma	16-64	16-40/41-64
Disclosure concerns	8-32	8-20/21-32
Concerns about public attitudes	7-28	7-17/18-28
Negative self-image	8-32	8-20/21-32

3.5.6.2 Comparison of SWED-QUAL scores

Scores for the 11 SWED-QUAL scales were transformed into scores from 0-100, with higher scores indicating better health-related quality of life for all scales. Since we were interested in knowing whether the health-related quality of life had improved with the use of modern antiretroviral treatment we excluded participants that was classified as non-adherent. SWED-QUAL scores from an age-adjusted subsample of men (age >64 and participants classified as non-adherent excluded) that completed the Stigma and quality of life survey was compared to the mean scores that Eriksson et al [52] reported for men living with HIV, measured 1993-1995. SWED-QUAL scores from a subsample of the Stigma and quality of life survey (participants classified as non-adherent excluded) were also compared to a Swedish general population, collected and published by Brorsson et al [53]. Two-tailed, one sample t-tests was

used for comparison since we did not have access to individual level data from the comparison groups. Differences were regarded significant at p-values below 0.05.

3.5.6.3 Empirical test of the HIV stigma framework

The HIV stigma framework [41, 42] is a theoretical model based on research on relations between HIV-related stigma and health-related quality of life and behavior. In the HIV stigma framework individual level stigma mechanisms are hypothesized to be differently related to health-related quality of life and behavior. Our hypothesis was that the part of the framework that regards people living with HIV would be valid also in a Swedish context, with a high proportion of people who are virally suppressed. To test this hypothesis we specified a path model, based on the HIV stigma framework. Since we did not have access to the exact same measures as Earnshaw et al [42] used in their empirical test of the framework we operationalized the concepts in the HIV stigma framework as shown in Table 7. We were interested in if the paths in the model differed depending on covariates. We therefor added age and a combined measure of gender and country of birth as potential covariates in the model, hypothesized to be correlated to measures of stigma and have a direct effect on measures of health and wellbeing. The path model was tested using partial least squares structural equation modeling (PLS-SEM) in smartPLS 3 [113]; significances were assessed through bootstrapping.

Table 7. Concepts in the HIV stigma framework and corresponding measures used in the present study

Concept in the HIV stigma framework	Description of concept as described by Earnshaw et al	Measure used in PLS-SEM (n items)	Brief description of measure used in the present study
Enacted stigma	“The degree to which PLWHA believe they have actually experienced prejudice and discrimination from others in their community” [41]	Personalized stigma ^a (16)	Perceived consequences of other people knowing about one’s HIV
Anticipated stigma	“The degree to which PLWHA expect that they will experience prejudice and discrimination from others in the future” [41]	Disclosure concerns ^a (8) Concerns with public attitudes ^a (7)	Concerns about disclosing one’s HIV status to others Concerns about other people’s opinion about HIV
Internalized stigma	“The degree to which PLWHA endorse the negative beliefs and feelings associated with HIV/AIDS about themselves” [41]	Negative self-image ^a (8)	Feeling of being unclean, not as good as others because of HIV
Physical health and wellbeing		Physical functioning ^b (7)	To what extent one’s health interferes with ability to perform physical activities
Behavioral health and wellbeing		Antiretroviral adherence	Non-adherence as defined by one VL>150 copies/ml or two or more consecutive VL >50 copies/ml within the last two years of the condition with treatment ongoing at least six months prior to the evaluation period
Affective health and wellbeing		Emotional wellbeing: negative effect ^b (6) Emotional wellbeing: positive effect ^b (6)	Negative feelings during the last week Positive feelings during the last week

^aSubscales of the HIV stigma scale [44]

^bSubscales of the SWED-QUAL [53]

3.6 QUALITATIVE ANALYSES

3.6.1 Paper V

The interviews were analyzed in a content analysis with framework approach [114, 115] with the HIV stigma mechanisms as predetermined codes. The interviews were transcribed by a professional transcriber and I and the second author of the paper listened to all interviews and read the transcripts to get familiar with the content. We wrote down ideas and thoughts that emerged and discussed the content in the interviews within the research team. Based on our notes we made a preliminary code index that we used when coding the interviews. Me and the second author coded interviews in parallel and discussed the coding index at weekly meetings. The coding index were changed during this time until we had coded all interviews and agreed on coding.

4 ETHICAL CONSIDERATIONS

All procedures described within this thesis were performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments [116].

4.1 ETHICAL PERMITS

When I started my doctoral project, Lars Eriksson was already involved in a project studying stigma and health-related quality of life among persons with resistant bacteria (MRSA); approved by the Regional Ethical Review Board in Stockholm, Sweden (2008/1794-31). Ethical approval for data collection with persons living with HIV in Sweden (the stigma and quality of life cohort) was approved as amendments to the study about MRSA (amendment 2013/335-32 for the survey and data retrieved from InfCare HIV and amendment 2017/222-32/1 for the individual interviews).

The study Living with HIV in Sweden was approved by the Regional Ethical Review Board in Stockholm, Sweden (3013/4:8).

Ethical permit for data collection in South India was granted by the Institutional Review Boards of the Christian Medical College, Vellore , ref IRB Min No 6946, and the University of Washington, Application no 37317 C. Ethical permits for data collection in Chicago, US, was granted by Northwestern University Institutional review board, IRB Project Number: STU00009286 with attached IRB authorization agreement. Ethical permit for data collection in Iowa and South Carolina, US, was granted by Northwestern University Institutional review board, IRB #2078-001, but the documentation has been recycled since more than seven years have passed since data collection (following US regulations). When Deepa Rao and Lisa Manhart shared their data with me, ethical permit was not needed since identifiers were removed from the data.

4.2 INFORMED CONSENT

Written information about the study was available in Swedish or English (Appendix 2) regarding the survey and in Swedish regarding the individual interviews. Potential participants were informed that participation was completely voluntary and that their care would not be affected if they declined to participate. When possible a professional translator translated the information for potential survey participants that did not understand Swedish or English.

4.3 PRIVACY AND CONFIDENTIALITY

All collected data was treated with confidentiality and data from the survey was only presented on a group level. I and other persons working with data collections had access to code numbers connected to InfCare HIV for potential participants during data collection. This code number could be used to access information about individual participants through InfCare HIV, but only by persons with a right to access the medical records. When data was entered into database, the InfCare HIV number was replaced by a new anonymous code. Some persons were concerned about confidentiality and did not want to sign the consent form with their name.

4.4 RISK, BURDENS AND BENEFITS

We identified a potential risk that participants would react negatively when answering the questionnaire or participating in interviews. If someone had been in need of support after participation, that person would have been referred to a social counselor at the clinic.

5 RESULTS

5.1 PAPER I

In this paper we used classical test theory to evaluate content validity, convergent validity, construct validity and internal consistency of the HIV stigma scale in a Swedish context. Results from the psychometric evaluations are presented in Table 8 (subscale level) and Table 9 (item level).

5.1.1 Content validity

The percentage of missing values exceeded 5% for 18 items (Table 9), of which 13 were items that assume that at least some persons, other than the participant and health professionals at the HIV clinic, knew about the participants HIV. Some participants had also written in the margin of these items that “nobody knows”. The highest rate (10.8%) of missing items was seen for item 5 (People with HIV lose their jobs when their employer find out) and some participants had written in the margin: “does this happen in Sweden?” Floor and ceiling effects were below 15% for all subscales (Table 8).

5.1.2 Convergent validity

As hypothesized we found all subscales in the HIV stigma scale to be negatively correlated to measures of Emotional wellbeing (Table 8). Effect sizes of correlation coefficients were moderate for Personalized stigma, Concerns about public attitudes and Negative self-image but small for Disclosure concerns.

5.1.3 Construct validity

The data was suitable for factor analyses with a KMO of 0.910 and a significant Bartlett's test of sphericity. Parallel analysis indicated a four factor solution with loading strengths for the four factor solution as presented in Table 9. Item 11 (It is easier to avoid new friendship than worry about telling someone) had no loadings exceeding 0.32 and we therefore decided to remove it from the instrument.

Figure 7. shows a matrix with correlations between items in the HIV stigma scale (darker red indicate a higher correlation coefficient). The items in the matrix are ordered after how we assigned items to subscales in the Swedish version of the HIV stigma scale. With an ideal factor structure items would be more strongly correlated within subscales and less correlated across subscales. As seen in Figure 7 this seems to be the case for the subscale Personalized stigma, but less clearly for other subscales.

The weighted summations of the item scores on each subscale (i.e. loading strength) are shown to the right of the correlation matrix in Figure 7. Although the correlation matrix showed overlap between latent variables in general, the factor analysis generated a somewhat clear four-factor structure. When Berger et al [44] developed the instrument all items but two had overlap between latent variables (loadings >0.32 for more than one latent variable). The Swedish version of the HIV stigma scale had considerably less overlap than when Berger et al analyzed the original version.

Corrected item-total correlations all exceeded 0.4 (Table 9) and also had a range within subscale, which indicated that the items measured a broadness of the aspect of stigma intended to measure.

5.1.4 Internal consistency

Cronbach's alpha for the subscales ranged from 0.87 to 0.96 (Table 3).

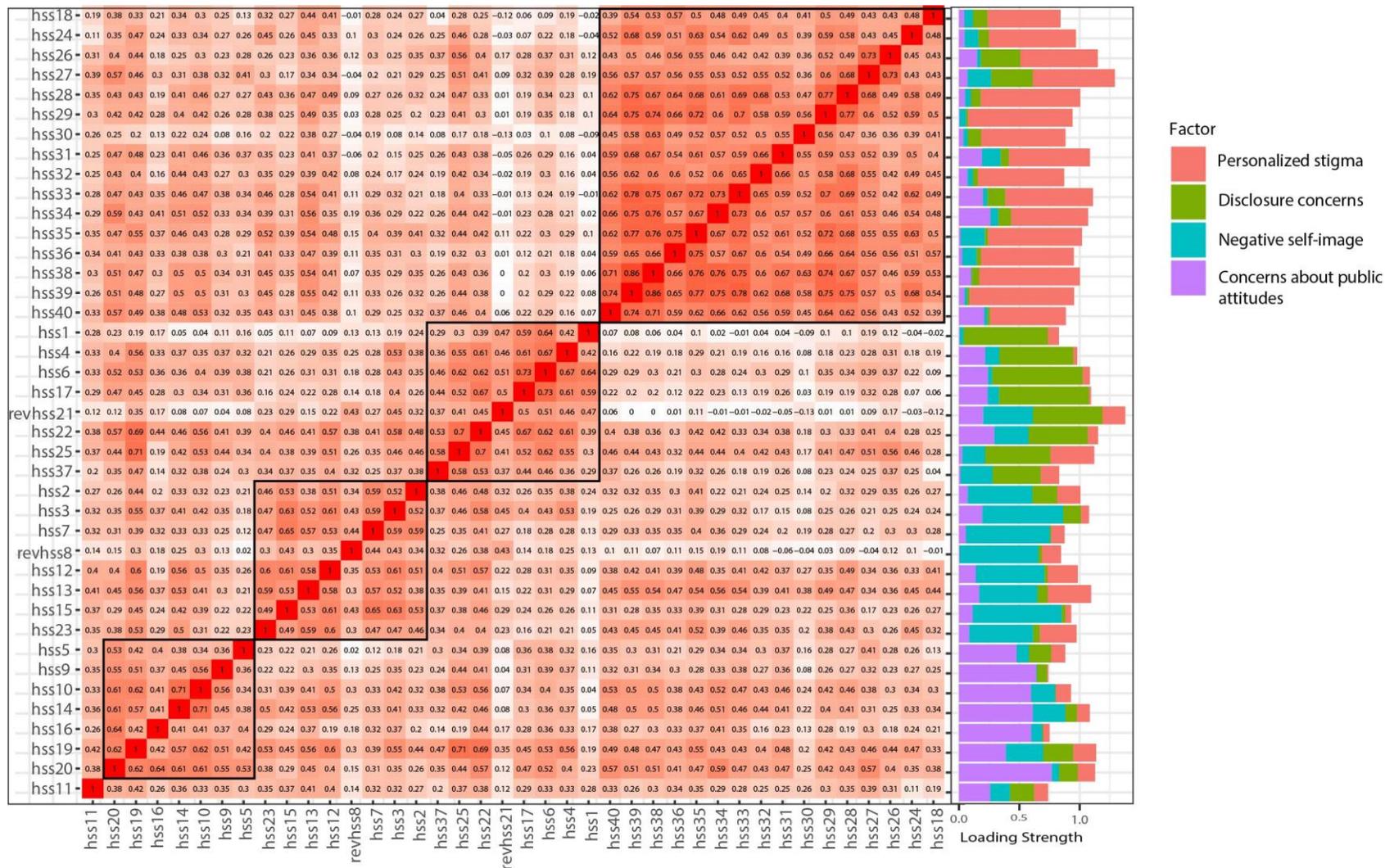


Figure 7. Correlations between items in the HIV stigma scale from Paper I. Darker red indicates higher correlation and black squares frame the items that were assigned to each subscale. Colored bars to the right are loading strengths from the factor analysis.

5.2 PAPER II

In paper II we described the development of an abbreviated version of the HIV stigma scale and tested the psychometric properties of the 12-item instrument.

5.2.1 Item reduction

Items for the 12-item version of the HIV stigma scale were selected from the 40-item version in a process of item reduction. As already reported in Paper I, item 11 had no loadings exceeding 0.32 and five items had loadings exceeding 0.32 on two subscales (Table 9). These items were not considered for the 12-item version of the HIV stigma scale. In addition to the classical psychometric analyses performed we also calculated partial credit models and assessed measures of item misfit. Items with mean square values exceeding 1.2 (Table 9) were not considered for the 12-item version of the instrument. From the remaining items we chose the items marked with grey background in Table 4 for the abbreviated version of the HIV stigma scale.

5.2.2 Evaluation of the 12-item version of the HIV stigma scale

Eigenvalues for the four factors were all above 1 and the 12-item version did not have cross loadings (Table 9). The confirmatory factor analysis showed standardized effects >0.7 for items on intended scales. Alternative fit measures indicated acceptable fit (CFI: 0.963, TLI: 0.950, RMSEA: 0.071). The χ^2 test was however statistically significant ($\chi^2 = 154.2$, DF=48, $p < 0.0001$) which indicated the model was inconsistent with the data.

The 12-item version had floor effects for the subscales Personalized stigma and Negative self-image. Ceiling effects in the 12-item version of the subscale were seen in the scale Disclosure concerns (Table 8). Cronbach's alpha was above 0.7 for all subscale, also in in the abbreviated version of the instrument (Table 8).

5.3 PAPER III

In paper III we compared psychometric properties for the HIV stigma scale between the Swedish Stigma and quality of life survey cohort and cohorts of people living with HIV in South India and the US.

5.3.1 Dimensionality

The subscales were treated as unidimensional constructs and the dimensionality was assessed with both confirmatory and exploratory methods. The confirmatory factor analyses supported the unidimensional models for Disclosure concerns and Concerns about public attitudes for the Indian Cohort and for Negative self-image for the Swedish cohort. For other subscales a significant χ^2 test indicated that the subscales might not be unidimensional in all contexts (Paper III, Table 2). According to the Empirical Kaiser Criterion 2 factors would be adequate

to retain from Disclosure concerns and Negative self-image regarding the South Indian cohort, and from Disclosure concerns regarding the Swedish cohort (Table 8).

5.3.2 Differential item functioning

Nine items were flagged for DIF between the Swedish, South Indian and US cohort (Table 9, one item in Personalized stigma, five items in Disclosure concerns, one item in Concerns about public attitudes and two items in Negative self-image). The DIF had a negligible impact on individual IRT scores for Personalized stigma, Concerns about public attitudes and Negative self-image. However, the DIF for Disclosure concerns did have a salient impact on individual IRT scores in the Swedish and South Indian cohort (Paper III, Figure 1). No salient DIF was found regarding gender.

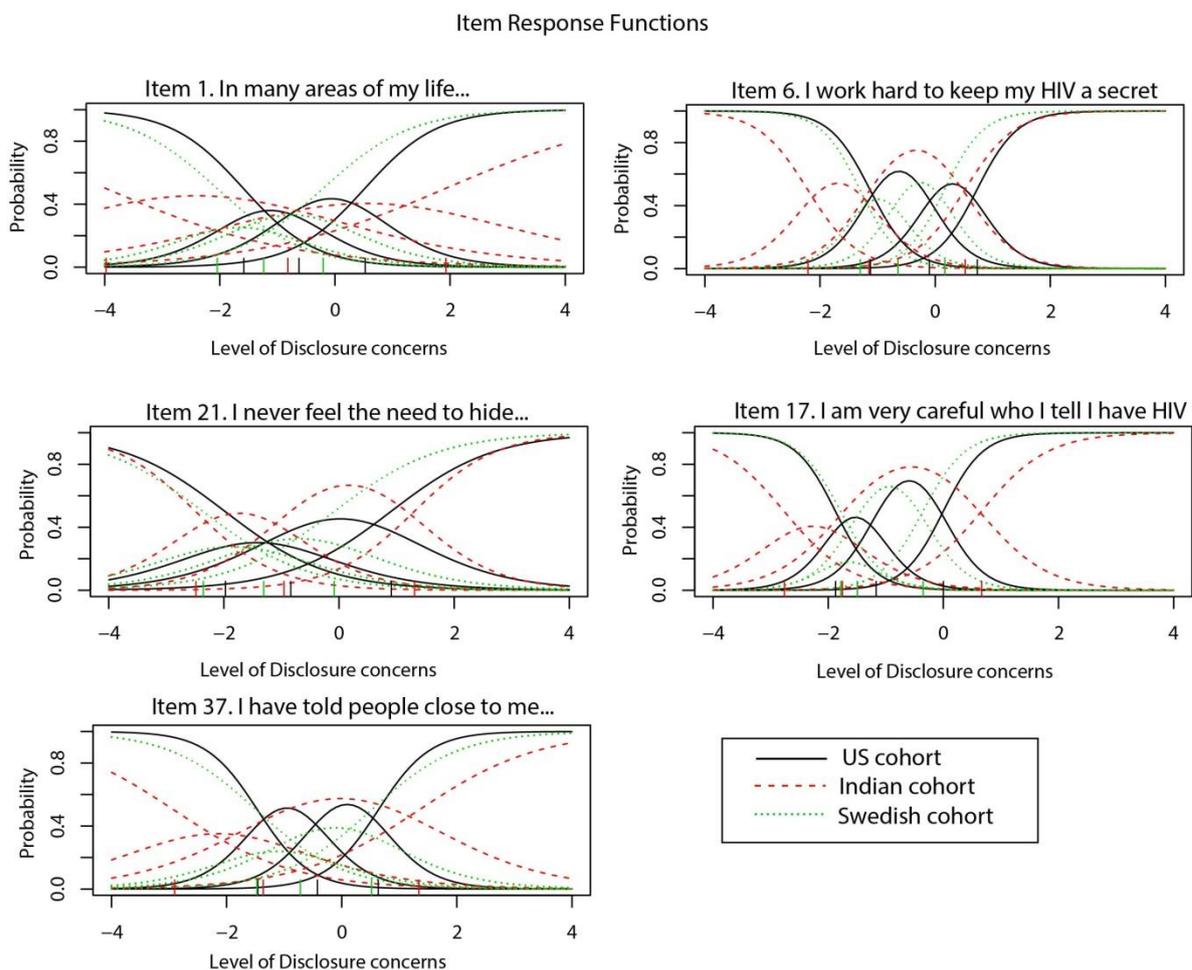


Figure 8. Item response functions for the items that were flagged for DIF within the subscale Disclosure concerns.

Item response functions for items within the subscale Disclosure concerns that were flagged for DIF are shown in Figure 8. These graphs show probabilities for participants with different level of Disclosure concerns to endorse the four response alternatives. If the items were without DIF the black, red and green lines would be identical. For item 1, 17, 21 and 37 the lines were, for some cohorts, flatter than expected, which may indicate a misfit towards data

in the item response theory model (i.e. the item did not function properly). Item 6 (I work hard to keep my HIV a secret) on the other hand, had item response functions that, by appearance, seemed to function well for countries separately, but functioned differently for separate countries (i.e. differential item functioning).

5.4 PSYCHOMETRIC PROPERTIES FOR THE HIV STIGMA SCALE (PAPER I-III)

Table 8 and 9 present combined results regarding psychometric properties for the HIV stigma scale from Paper I-III. The subscale level results (Table 8) indicate that the psychometric properties for Disclosure concerns may be questionable, with low correlations to Emotional wellbeing and results indicating multidimensionality. Some items measuring Disclosure concerns were also flagged for differential item functioning between the Swedish and South Indian cohort (Table 9).

On an item-level (Table 9) it was noteworthy that items measuring Personalized stigma in general had a rate of missing values exceeding 5%. Seven items in the subscale Personalized stigma also showed misfit towards the graded response (IRT) model. Results indicated that the two items that are positive statements in the HIV stigma scale (item 8 and item 21) were not functioning well. They were both flagged for differential item functioning, had poor fit to the graded response model and were only moderately correlated to their respective subscale. The same pattern, with low item-total correlation, misfit towards the IRT model and signs of differential item functioning, was, however, also seen for item 1 and 5, which were negative statements

Table 8. Subscale-level results from the psychometric evaluations of the HIV stigma scale.

Subscale	Correlations to emotional wellbeing (SWED-QUAL)		α	Floor/Ceiling effect (%)	Dimensionality ^a (Sweden/South India/US)
	Positive effect	Negative effect			
	39-item version (12-item version)				32-item version
Personalized stigma	-0.30*	-0.40*	0.96 (0.88)	5/2 (28/6)	1/1/1
Disclosure concerns	-0.24*	-0.21*	0.87 (0.84)	1/9 (6/22)	2/2/1
Concerns about public attitudes	-0.29*	-0.39*	0.88 (0.81)	2/3 (9/9)	1/1/1
Negative self-image	-0.43*	-0.49*	0.88 (0.80)	7/2 (24/5)	1/2/1

^a Numbers of factor proposed to retain according to Empirical Kaiser Criterion

*p<0.01

Table 9. Item-level results from the psychometric evaluations of the HIV stigma scale

Items (Full description in Appendix 1)	Item-total correlations	missing values%	Loading strengths from EFA ^a				Outfit Msqr	Infit Msqr	Items flagged for DIF ^c	
			1	2	3	4			Uniform	Non-uniform
Personalized stigma			39-item version (12-item version)						32-item version	
39 People seem afraid of me ...	0.88	7.7	0.866				0.49	0.51	-	-
29 People I care about stopped calling... ^b	0.81	5.2	0.864 (0.978)				0.59	0.66	-	-
38 People who know ...tend to ignore my good points	0.85	6.2	0.833				0.53	0.56	0.0115	-
28 Some people avoid touching me... ^b	0.79	5.2	0.824 (0.862)				0.65	0.75	-	-
35 I have stopped socializing with some people...	0.81	5.6	0.776				0.64	0.70	-	-
36 I have lost friends... ^b	0.79	7.2	0.770 (0.614)				0.75	0.87	-	-
33 People have physically backed away from me...	0.82	7.7	0.726				0.73	0.74	-	-
24 I have been hurt by how some people react...	0.67	5.6	0.721				1.34	1.27	-	-
32 People don't want me around their children...	0.74	5.6	0.714				0.98	1.01	-	-
30 People have told me that getting HIV is what I deserve...	0.65	4.6	0.700				1.16	1.38	-	-
27 As a rule, telling others... has been a mistake	0.68	5.6	0.677	0.344			1.16	1.21	-	-
31 Some people close to me are afraid others will reject them..	0.73	6.2	0.671				1.09	1.10	-	-
26 I regret having told some people...	0.63	4.6	0.642	0.327			1.68	1.51	-	-
34 Some people act as though it's my fault...	0.79	5.2	0.638				1.21	0.88	-	-
40 When people learn... they look for flaws in your character	0.76	7.7	0.627				1.26	0.98	-	-
18 Some people who know... have grown more distant	0.63	5.6	0.604				2.00	1.46	-	-
Disclosure concerns										
6 I work hard to keep my HIV a secret ^b	0.69	1.5		0.751 (-0.870)			0.58	0.63	0.0517	-
17 I am very careful who I tell I have HIV ^b	0.70	2.1		0.746 (-0.748)			0.64	0.69	0.0219	0.0181
1 In many areas of my life, no one knows...	0.53	2.1		0.696			1.56	1.14	0.0293	0.0204

21 (Reversed) I never feel the need to hide...	0.51	3.1		0.575	-0.411	1.33	1.29	0.0242	-
4 Telling someone I have HIV is risky ^b	0.69	2.6		0.614 (-0.764)		0.87	0.80	-	-
25 I worry that people who know... will tell others	0.68	3.6	0.362	0.542		0.84	0.86	-	-
22 I worry that people may judge me...	0.74	2.1		0.493		0.76	0.73	-	-
37 I have told people close to me to keep... HIV a secret	0.49	6.7		0.402		1.33	1.25	-	0.0191
Negative self-image									
15 Having HIV makes me feel that I'm a bad person	0.75	2.6			-0.737	0.67	0.73	-	-
7 I feel I am not as good a person as others... ^b	0.75	2.1			-0.698 (-0.663)	0.74	0.70	-	-
3 People's attitudes about HIV makes me feel worse... ^b	0.70	3.1			-0.665 (-0.758)	0.76	0.82	0.0174	-
8 (Reversed) I never feel ashamed...	0.40	1.0			-0.654	1.36	1.41	0.0502	-
12 Having HIV makes me feel unclean	0.72	2.6			-0.570	0.78	0.79	-	-
2 I feel guilty because I have HIV ^b	0.66	2.2			-0.532 (-0.759)	1.11	1.02	-	-
23 Having HIV in my body is disgusting...	0.66	2.6			-0.530	0.97	0.99	-	-
13 ... I feel set apart and isolated...	0.59	2.6	0.357		-0.484	0.98	0.97	-	-
Concerns about public attitudes									
20 Most people are uncomfortable.. ^b	0.79	5.7			-0.769 (0.604)	0.55	0.56	-	-
9 People with HIV are treated like outcasts ^b	0.63	4.6			-0.639 (0.705)	1.02	0.94	-	-
14 Most people think that a person with HIV is disgusting	0.69	4.6			-0.613	0.87	0.81	-	-
10 Most people believe that a person who has HIV is dirty ^b	0.68	4.1			-0.599 (0.783)	0.73	0.76	-	-
16 Most people with HIV are rejected when others find out	0.57	6.2			-0.598	1.05	1.08	-	-
5 People with HIV lose their jobs...	0.55	10.8			-0.477	1.24	1.21	0.0188	-
19 ... I worry about people discriminating against me	0.71	2.1			-0.389	0.93	0.84	-	-

^a Loadings below 0.32 not shown. Item 11 was excluded since all loadings were below 0.32.

^b Grey background indicate item selected for the 12-item version

^c Pseudo R square change (Nagelkerke)

5.5 PAPER IV

5.5.1 HIV-related stigma

The dichotomized scores for the HIV stigma scale are presented in Figure 8. Disclosure concerns was the aspect of stigma that most reported to experience; 64% of participants reported Disclosure concerns to a higher extent. 47% also reported Concerns about public attitudes to a higher extent. It was more uncommon to have experiences of Personalized stigma or to have a negative self-image. 32 % of the participants had experienced Personalized stigma to a higher extend, and 31% reported to have a Negative self-image to a higher extent.

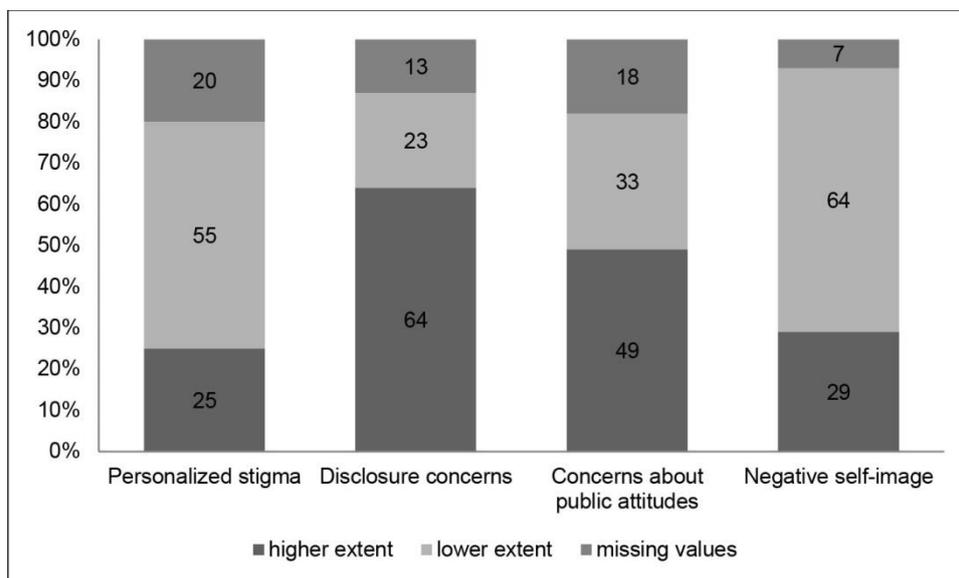


Figure 8. Percentage of participants in the survey that experienced stigma to a higher extent respectively lower extent.

5.5.2 Health-related quality of life

Figure 9 shows a comparison of SWED-QUAL scores between a subsample of men from the Stigma and quality of life survey cohort (age>64 and participants classified as non-adherent excluded) and mean scores from men living with HIV, data collected 1993-1995. Statistical differences in mean scores between males (1993-1995) and males (2013) were seen for only three of the scales; Physical functioning, Role limitations due to emotional health and Sexual function, where scores were significantly lower for males (2013).

Figure 10 shows a comparison of SWED-QUAL scores between a subsample for the Stigma and quality of life survey (participants classified as non-adherent excluded) and a Swedish general population, collected and published by Brorsson et al [53]

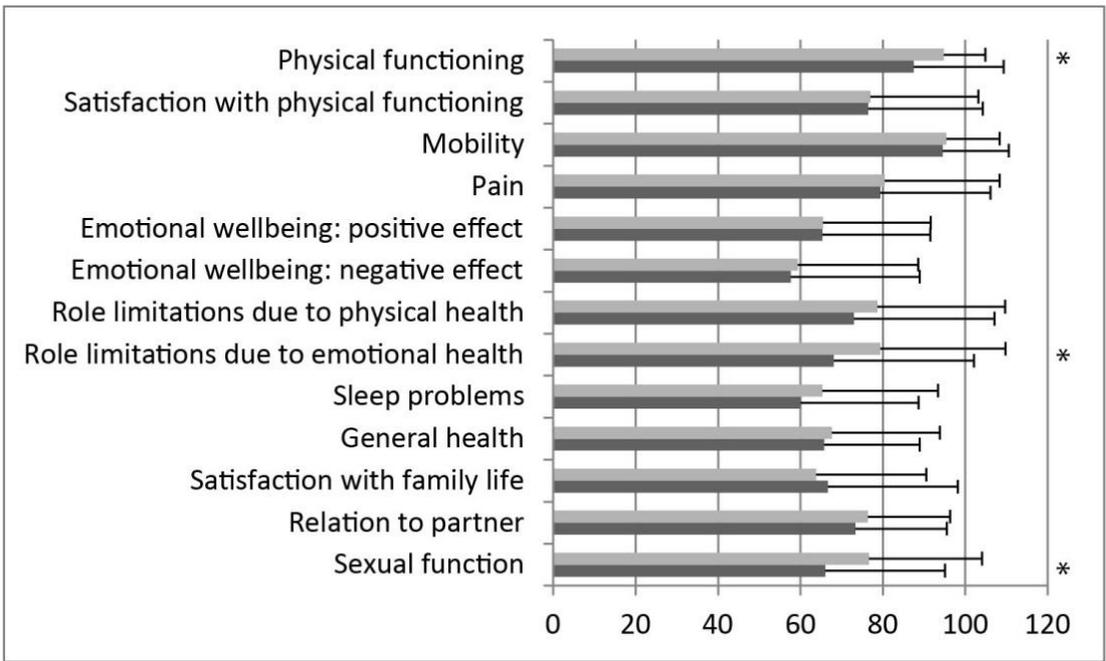


Figure 9. SWED-QUAL mean scores for males living with HIV. Results from 1993-1995 indicated with light grey bars and results from the Stigma and quality of life survey 2013 (age>64 and participants classified as non-adherent excluded) indicated with dark grey bars. Error bars indicate standard deviations.

*p<0.05

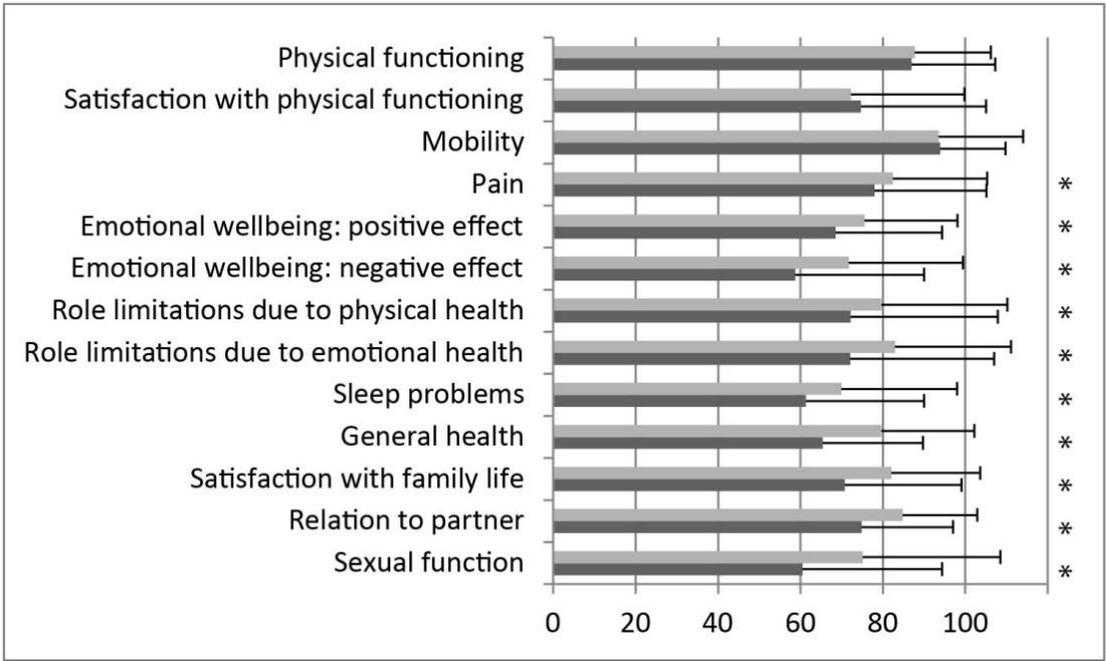


Figure 10. SWED-QUAL mean scores. Results from a Swedish general population indicated with light grey bars and results from people living with HIV from the Stigma and quality of life survey (participants classified as non-adherent excluded) indicated with dark grey bars.

Error bars indicate standard deviations.

*p<0.05

5.5.3 Relations between stigma and health-related quality of life in a Swedish context (Paper IV)

The result of the path analysis is shown in Figure 11. The subscales in the HIV stigma scale were intercorrelated, as expected. Correlations were also found between Physical functioning and Emotional wellbeing, both positive and negative effect. Physical functioning and Emotional wellbeing was not associated with adherence. Regarding relations between stigma and health and wellbeing only three of the hypothesized paths were confirmed. Concerns about public attitudes was associated with worse Physical functioning and Negative self-image was associated with lower Emotional well-being. In contrast to that hypothesized in the model Personalized stigma and Disclosure concerns was not related to Physical functioning and none of the measures of HIV-related stigma was associated with Antiretroviral adherence. Analysis of covariates (not shown in Figure 11.) showed that higher scores on the HIV stigma sub scales were associated with younger age. People of younger age were also significantly more likely to be non-adherent to antiretroviral treatment. Furthermore females, who had migrated to Sweden, had significantly more Concerns about public attitudes. Effect sizes of relations including covariates were small.

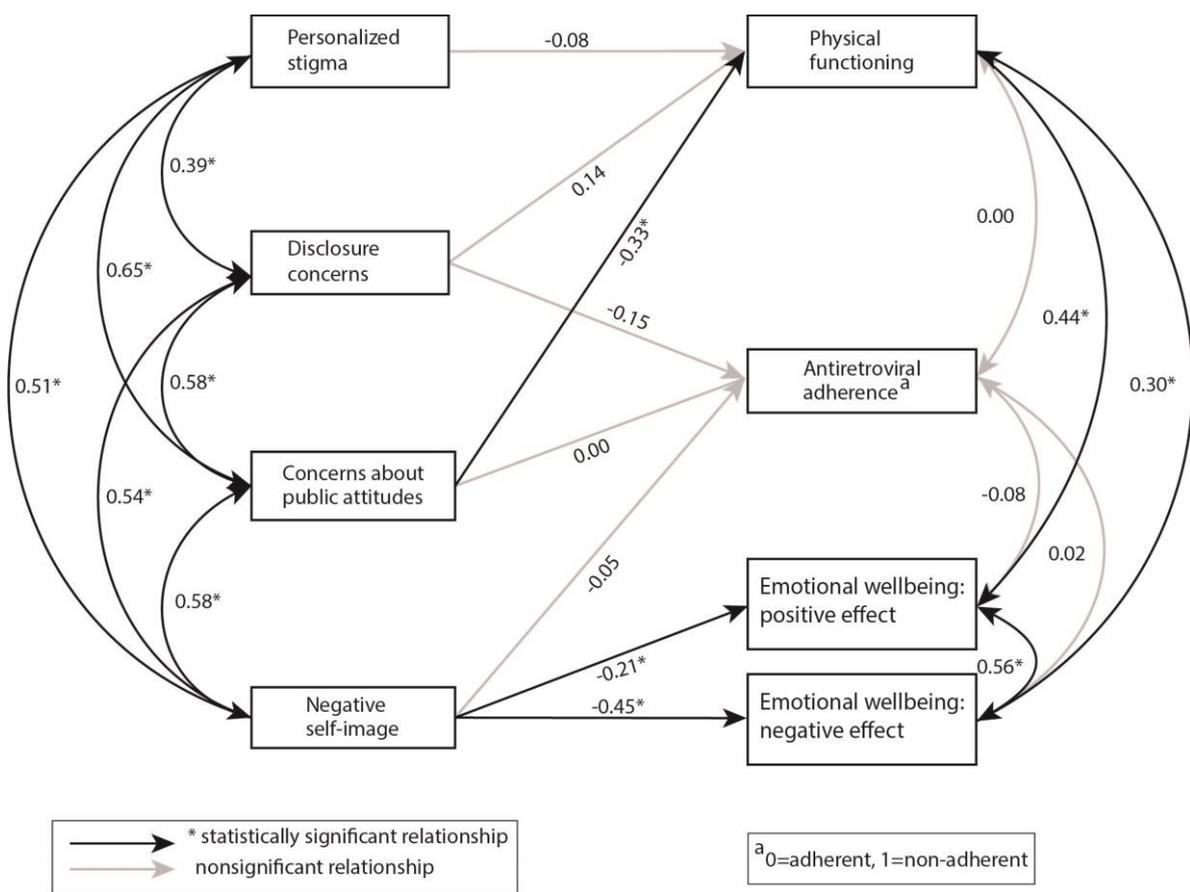


Figure 11. Results from the PLS-SEM analysis of a path model based on the HIV stigma framework. Boxes to the left are measures of HIV-related stigma and boxes to the right measures of health and wellbeing. Estimates next to two-way arrows represent correlation coefficients and estimates next to one-way arrows represent standardized direct effects. These estimates are calculated with covariates included in the path model, but covariates are excluded from this figure to facilitate interpretation.

5.6 MAIN FINDINGS PAPER V

Paper V described the experience of seven men and eight women living with virally suppressed HIV in Sweden.

Although the first period with HIV was described as a crisis, most participants described themselves as healthy and HIV as something that did not have a large impact on their lives. HIV was generally spoken about as something that the participants lived with but did not think about, except occasionally, when they took their medication, or when it came to sexual relations.

In daily life, that is, getting up in the morning and eating breakfast and all that, it doesn't affect me at all. It's just there and we live side by side. I take two pills at breakfast each morning ... But that's the case for many others who have different diagnoses so that ... I don't think there's anything strange about it at all. /Male participant

The social aspects of living with HIV were, however, described as more or less difficult. Some described that HIV today only affected social life when it came to meeting a new partner. *“It takes a bit of doing before you have told”,* a female participant described, *“before you know how they're going to deal with it. Otherwise it's nothing. Nothing strange”.*

Others described social life as hard and told stories about how they had refrained from all forms of close relationships.

“you just let everything be, that is staying in touch and making friends... You just get rid of everything, to get rid of the problem. You give up having a life.”/Male participant

This male participant, however, also described that he had found a way of living that he was satisfied with.

5.6.1 Stigma mechanisms

The negative social aspects of living with HIV that we interpreted as part of an individual experience of stigma related to HIV was categorized as enacted, anticipated or internalized stigma.

5.6.1.1 Enacted stigma

Participants told stories about how they had been treated badly by individuals who knew about their HIV; for example how they had been left by partners and blocked on social media. They also described how laws and regulations restricted their lives. A recurring comment in several interviews related to travel restrictions for people living with HIV and one participant described being denied access to fertility treatment. The obligation to tell a sexual partner about one's HIV was brought up in negative terms by some participants.

As the participants HIV status was often not known to others, stigma had not been enacted towards them directly. However, they told stories about how other people with HIV or other infections had been treated badly, as if those actions had affected themselves.

When you work with your colleagues and maybe someone comes in with an infection, maybe MRSA or ESBL, and they just say "oh that's disgusting", "Why do they come here?", "I don't want to go in there". People... Make me feel sick when I hear that they become... disgusted by infections. /Female participant.

One participant, whose closest community consisted of fellow countrymen and who had told no one about his HIV, said that he and his friends often talked about those who they knew had HIV; *"my friend said to me, he draw the joker, that's how we say it... people talk behind, not in front..."*

5.6.1.2 Anticipated stigma

Participants commonly described that they anticipated stigma in some specific contexts, but not in others. These contexts could be what one participant described as the homosexual world, a café where fellow countrymen gathered or the specific situation of disclosing to a partner. In these settings the participant described that they anticipated being rejected and treated badly if their HIV got disclosed.

It's a totally different situation in the homosexual world. There you're still labeled. We're so tough. We judge everyone really hard, we gay men, terribly hard. It's ...It's happened to me and I know people whose...conversations are deleted on those mobile apps, you get labeled as sick, in quotes, and all that kind of stuff, and it's really tough. It's really hard, so a lot of people are hesitant about being open. /Male participant

Apart from being treated badly by people who knew about their HIV, participants described that they anticipated that people who knew would tell others. A male participant described that if his HIV got known to one of his fellow countrymen, everybody within the community would know within a week; *"I can't be here", he said, "I going to move to another country. I can't live here...you know everyone will talk about me...so I just can't be comfortable here...I'm going to move tomorrow, I can't stay here"*.

Participants also described how they anticipated to be defined by their HIV if they were open and told others.

I'm so really torn because...it shouldn't matter...I'm first and foremost (participants name) and I'm also a whole lot of other things before I'm HIV, sort of. That's where it gets hard. Then I become HIV-(name)...and that's the question, do I want that? The dream is just to be simply (me), that's my dream, that you are accepted for who you are and aren't categorized by...which socks you have or what job or how much money you make or if you have HIV /Male participant

Participants also described that they made decisions about how and when they would tell that they had HIV in every new encounter. *"you sort of have to... come out every time to someone new.."*. HIV was sometimes described as private and sometimes as something that other people were not that interested in hearing about.

Participant described how they hid their medication or put the pills in a jar for vitamins. One participant described that he would wait until he was alone before he took his medicine. *"If I am together with friends, I won't take them, I just go home afterwards"*.

5.6.1.3 Internalized stigma

Most participants described that their HIV had not affected the way that they looked upon themselves. “*It's hasn't affected by self-image at all*”, a male participant said, “*I've never gotten into self-hatred or become self-destructive, more the opposite.*”

Some participants, however, described feelings of shame or embarrassment and described how they took self-made precautions to protect others. A female participant who worked with children described how she worried over transmitting HIV to them:

Now that I work with children, I worry so much. Darn, can I infect the kids? Every time I use ...gloves. If they fall or something. When I clean or wash that sore, I have to have gloves. Not for my sake, it's for her sake. If I see blood or anything, I run, lift up the child, and immediately put on gloves. /Female participant

6 DISUSSION

6.1 SUMMARY OF FINDINGS

People who were virally suppressed did not think about their HIV much in general, but some still experienced social life as difficult. Some had been treated badly because of their HIV and they anticipated rejection or labeling if their HIV got known to others. A majority of participants had not experienced enacted stigma, but it was common to have concerns about when and to whom you would disclose your HIV (64% of participants had disclosure concerns to a higher degree). It was also common to have concerns about public attitudes regarding HIV (49% had concerns about public attitudes to a higher extend). Although Sweden is in the front line regarding treatment, the results in this thesis indicate that the health-related quality of life does not seem to improve for people living with HIV in Sweden. Associations between stigma and lower health-related quality of life were in general, however, not confirmed in the Swedish context. Internalized stigma was found to be associated with lower emotional wellbeing and concerns about public attitudes with worse physical functioning. HIV-related stigma was in general experienced to a higher extent by persons of younger age and women, born in other countries than Sweden had, in general, more concerns about public attitudes. Persons who were non-adherent to treatment did not report stigma to a higher extent in general.

6.2 DISCUSSION OF MAIN FINDINGS

In the following sections I will discuss the main findings in the thesis under the following headlines: Conceptualization of HIV-related stigma, Measurement of HIV-related stigma and Relationships between HIV-related stigma and health-related quality of life.

6.2.1 Conceptualization of HIV-related stigma

6.2.1.1 *Internalized stigma*

In the individual interviews (Paper V) some participants described feelings of shame or embarrassment over their HIV. The stories were similar to how Earnshaw et al [42] defined internalized stigma (i.e. when people living with HIV endorse negative feelings and believes about HIV and applies them to themselves). Internalized stigma, as defined by Earnshaw et al [42] was also found to be consistent with the content in the items that constitutes the negative self-image subscale in the HIV stigma scale (Paper IV). Although only 29% of participants in the Stigma and quality of life survey reported to have a negative self-image to a higher extent, negative self-image was found to be associated to lower emotional wellbeing and we recognize this aspect of stigma to be important also in the era of efficient treatment.

6.2.1.2 *A mixed experience of enacted and anticipated stigma*

Based on findings in Paper V, I would argue that it may be difficult to always distinguish between anticipated stigma (i.e. expectations of discrimination, stereotyping and/or prejudice from others in the future [42]) and enacted stigma (i.e. experiences of discrimination, stereotyping and/or prejudice [42]). The experience of seeing other people being exposed to stigma (e.g. colleagues saying that a person with infection is disgusting) did not only result in participants anticipating that they would be exposed to stigma if their HIV got disclosed. They also described the event as something that happened to them directly (“it makes me feel sick”).

6.2.1.3 *Disclosure*

Disclosure and non-disclosure of one’s HIV was a central topic in the interviews (Paper V) and a majority (64%) of participants in the Stigma and quality of life survey reported Disclosure concerns to a higher extent (see above). In the interviews participants described how they anticipated being rejected or discriminated if their HIV got disclosed and a common reason for not disclosing was a fear that HIV would be the prime factor defining them as persons. Some participants, however, described other reasons for non-disclosure (e.g. “it shouldn’t matter”, “it’s private” or “people are not that interested) and it is of essence to recognize that non-disclosure of one’s HIV not always can be explained by fear of negative reactions from others. If HIV is a normalized chronic condition, it also becomes less relevant to tell people about one’s HIV status. Some participants had the approach that HIV was not a secret, but at the same time nothing that they told people about in general.

According to Goffman [35], a person with a concealable stigmatized identity will with every new encounter find her or himself in situations where he and she must decide whether to disclose or not, and how. Goffman also described a kind of etiquette of disclosure, as disclosure potentially makes other people uncomfortable. A socially accepted way to disclose may, according to Goffman, be to wait for a suitable opportunity and then calmly disclose in a way that saves present people from embarrassment [35].

6.2.2 Measurement of HIV-related stigma

Berger's HIV stigma scale was used for measurement of experiences of HIV-related stigma in paper IV and psychometric properties of the instrument was examined in paper I-III. Both a 39-item version was adapted for (Paper I) and a 12-item version developed (Paper II) and evaluated in the Swedish context.

6.2.2.1 Content validity

The items in the HIV stigma scale was originally generated through a thorough literature review of research regarding HIV-related stigma; items were intended to cover all aspects in Berger's conceptual model of perceived stigma in people living with HIV (Figure 5). I found the original item generating process performed by Berger et al [44] to be meticulous and judged to be in accordance with the protocol as describe by Fayers and Machin [102]. Since the Swedish version of the items matched the English version it may be expected that also the Swedish version covers Berger's conceptual model of perceived stigma in people living with HIV. The HIV stigma scale does, however, not entirely cover all HIV stigma mechanisms, as proposed in the HIV stigma framework [42]. The subscale Negative self-image was found to be consistent with the concept of Internalized stigma, and the subscale Personalized stigma with the concept Enacted stigma. The subscales Disclosure concerns and Concerns about public attitudes could, however, only been seen as proxy measures of the Anticipated stigma concept. As anticipated stigma has been defined as when people living with HIV anticipate experiencing prejudice and discrimination in the future [42], only one item (number 19. "Since learning I have HIV, I worry about people discriminating against me") reflects that aspect directly. However, based on my discussion regarding conceptualization of stigma above, I would suggest that the subscales Concerns about public attitudes and Disclosure concerns would have better content validity for how people who are virally suppressed experience stigma.

The differential item functioning (DIF) for items in the subscale Disclosure concerns might indicate that the concept of Disclosure concerns are not equivalent across different context. However, earlier research has shown that multidimensionality in a scale can be mistaken for DIF, if the scale is treated as unidimensional in analysis of DIF [129]. Based on the results of the psychometric analyses in Paper I-III, I would suggest that the differential item functioning, at least partially, can be explained by multidimensionality in the Disclosure concerns subscale.

Five percent of people living with HIV in Sweden had only disclosed their HIV to government agencies or health care personnel, according to the study Living with HIV in Sweden [83]. This could explain the high rate of missing answers to items in the HIV stigma scale that assumed disclosure to some extent and the subscale Personalized stigma may not be valid for persons who have not disclosed their HIV to others. High rates of missing answers to items in the subscale Personalized stigma has also been noted when the HIV stigma scale was used to measure stigma among children and youths living with HIV in Sweden [82, 117]

6.2.2.2 *Construct validity*

Both the 39-item version and the 12-item version of the HIV stigma scale had acceptable construct validity in general in the Swedish context. In fact, the instruments had better psychometric properties than the original 40-item HIV stigma scale with less cross loadings in the Swedish context. Some items, however, had less satisfactory psychometric properties and were therefore excluded from the 12 item version of the instrument. A limitation of the 12-item version of the instrument, however, was floor and ceiling effects that were not seen for the 39-item instrument.

Item 11 was excluded due to questionable psychometric properties when the Swedish version of the HIV stigma scale was presented in Paper I. However, Paper I-III together showed that more items were problematic and I would recommend considering if more items should be removed in future versions of the instrument (e.g. the reversed items 8. “I never feel ashamed of having HIV” and 21. “I never feel the need to hide the fact that I have HIV”). Items that cross load should also be removed (i.e. number 13. “Since learning I have HIV, I feel set apart and isolated from the rest of the world”, 25. “I worry that people who know I have HIV will tell others”, 26. “I regret having told some people that I have HIV” and 27. “As a rule, telling others that I have HIV has been a mistake”)

6.2.2.3 *The subscale Disclosure concerns*

The subscale Disclosure concerns stood out as a subscale with questionable psychometric properties. At the same time Disclosure concerns was that subscale that most participants had reported to a higher extent. When the HIV stigma scale was used with Swedish children and youths, the subscale Disclosure concerns had a Cronbach’s alpha of 0.55 [117]. The internal consistency of the subscale Disclosure concerns was also found to be low (Cronbach’s alpha=0.62) when the HIV stigma scale was used among people living with HIV in South India [100]. I would suggest that the low alpha for Disclosure concerns, detected in earlier studies, may be related to the multidimensionality found in Paper III. And as indicated in Paper II, Table 1, the subscale actually covers two aspects of Disclosure concerns; (1) worrying about own disclosure of one’s HIV, and (2) worrying that others will disclose one’s HIV. This was also recognized by Berger et al [44] when the instrument was first presented.

6.2.2.4 *Recommendations for future use of the HIV stigma scale in a Swedish context*

If the HIV stigma scale were to be used in a Swedish context again I would suggest using the abbreviated version. However, I recommend adding one item per subscale two prevent floor and ceiling effects. For each subscales I would suggest to add a high loading item with good psychometric properties according to results presented within this thesis (Table 9). The items would then constitute a 16-item scale, which I present in Appendix 3. In this proposed 16-item version the subscale Disclosure concerns is intended to measure the aspect of keeping one’s HIV a secret.

6.2.3 Associations between HIV-related stigma and health-related quality of life

6.2.3.1 Empirical test of the HIV stigma framework

Our basic hypothesis in this project was that HIV-related stigma would be associated to worse health-related quality of life for people living with HIV, also in the era of efficient treatment. The hypothesized relations in the HIV stigma framework were, however, not confirmed in the Swedish context except for associations between internalized stigma and lower emotional wellbeing, and anticipated stigma and lower physical functioning (Paper IV).

Standardized direct effects may be interpreted as effect sizes comparable to Cohens *d*, where values of 0.2–0.49 are interpreted as small, 0.5–0.79 as medium, and > 0.8 as large [130]. The effect size was therefore interpreted as low for associations found between anticipated stigma and lower physical functioning and between internalized stigma and lower emotional wellbeing.

6.2.3.2 Levels of health-related quality of life for people living with HIV in Sweden

The health-related quality of life was found to be lower for people living with HIV in Sweden than for a Swedish general population, and equally low or lower compared to men living with HIV in Sweden 20 years ago (see above). Regarding comparison to the Swedish general population it should be noted that the norm data was collected over 25 years ago [53], and I have not investigated whether the health-related quality of life for people in Sweden in general have changed during those last 25 years. Regarding comparison with men living with HIV 1993-1995 the samples were matched regarding age, but the proportion of participants being born in Sweden or born in other countries, as well as other variables that may have an impact on the health-related quality of life may have differed.

A main finding in the national study *Living with HIV in Sweden* was that people living with HIV in Sweden generally report high quality of life [83], which stands in contrast to the results presented in this thesis. Results that regard specific aspects of health-related quality of life are, however, more consistent between the two studies, as approximately 30 % of participants in *Living with HIV in Sweden* reported dissatisfaction with physical health, and emotional wellbeing [83]. Further on, findings from the interviews within this thesis indicate that also a person who's HIV have had a large impact on the social life (e.g. the male participant who said "you give up having a life") can have found a way to live a good life.

6.3 METHODOLOGICAL CONSIDERATIONS

6.3.1 Regarding data sources

A limitation with the Stigma and quality of life survey was that the questionnaire was distributed at one single hospital. Although the sample of patients listed at the clinic was judged representative for people living with HIV regarding gender and immigration status,

the majority of participants were likely to live in the same urban area. Repeated measures were not performed, thus limiting the study to be strictly cross-sectional.

The response rate for the Stigma and quality of life survey was 44%, which can be considered to be low. However, this should be viewed in regard to the fact that the response rate was calculated as the number of participants that completed a questionnaire divided with all eligible participants; we chose to have a wide definition of eligible, counting many participants as eligible even though we knew that they would have needed assistance to be able to complete the questionnaire and therefore were not possible to include because of no such assistance available at the time point of data collection.

The offer to complete the questionnaire together with a professional translator showed difficult to implement as translators needed to be booked well in advance. It was also time consuming to complete the questionnaire with a professional translator and some participants feared that a professional translator would be someone from their own community that would disclose their HIV status to common acquaintances.

6.3.1.1 Sample size

We aimed to include 200 participants in the Stigma and quality of life survey, based on a power calculation for detecting differences in SWED-QUAL scores compared to the Swedish general population. With an alpha criterion of $p < 0.05$ power was 0.99 to detect a difference of 10 score points (SD 30), representing a small effect size of 0.33, on the scale from 0-100 with a sample of 200. Also with the achieved sample size of 173 individuals included in comparison of SWED-QUAL scores the power was 0.99.

6.3.2 Regarding psychometric analyses (Paper I-III)

In quality of life research, validity is not a characteristic that a certain instrument can be proven to have [102] but can be understood as a constant process where more and more evidence is acquired regarding whether the instrument behave in the anticipated manner [102]. A strength in this thesis is the thorough examination of validity for the HIV stigma scale.

Validity is only one of several psychometric aspects that are important to assess for instruments. Other properties that should be satisfied for a measurement to be clinically useful are reliability, repeatability, sensitivity and responsiveness [102]. This thesis did not include any repeated measures and my ability to examine reliability, repeatability, sensitivity and responsiveness was therefore limited.

The sample size of 132 participants that completed all items in the HIV stigma scale, was considered to be sufficient for the exploratory factor analysis, since factors were over-determined and communalities ranged from 0.35 to 0.80 [118]. A sample size of 200 had, however, given a ratio of 1:5 of items compared to number of participants, which often has been suggested as a lower limit for sample size in exploratory factor analyses [106].

6.3.3 Regarding statistical analyses of stigma and health-related quality of life (Paper IV)

We chose to analyze the path model with PLS-SEM due to the relatively small sample size and variables being on different data level (ordinal, binary). PLS-SEM has been presented as a preferable alternative to covariance based SEM (CB-SEM) when sample sizes are small [119]. A widely used estimation method for sample size in PLS-SEM is that samples should be ten times larger than the maximum amount of paths linked to a latent variable in the model [119], which would give a minimum sample size of 80 for analysis of the path model in Paper IV. This method has however been questioned since it only works properly when standardized effects are large and an inversed square root method has been proposed to be more robust [128]. Using the inversed square root method in a retrospective calculation of sample size gives that standardized direct effects of 0.19 would be able to detect with a sample size of 171. The sample of 173 was therefore considered to be sufficient to detect associations of a small effect size (standardized direct effects >0.20).

Although validity for the HIV stigma scale was examined in Paper I-III, I have not evaluated validity for SWED-QUAL within my doctoral project. Sexual function and close relations are aspects of health-related quality of life that are highly relevant to assess for people living with HIV and SWED-QUAL include scales for measurement of family functioning, partner and sexual functioning. It is however, important to understand the limitations of these scales. The scale Family functioning asks the participant how satisfied they are with different aspects in regard to their family. As family is not defined within the scale I find it difficult to know what the participant has answered. The partner scale only applies to persons that have a partner and do not function as a measure for those who are single. The scale sexual functioning focus on the participants own sexual functioning, in form of one's own sexual interest, ability to relax and enjoy sex and ability to get sexually aroused and orgasm. My concern with these scales (family, partner, sexual functioning) regarding measurement of health-related quality of life for people living with HIV is that the items might miss aspects of not having a family/partner, or having concerns about disclosing HIV-status to potential partners.

Participants viral load was used as a proxy measure for adherence, and adherence (measured through self-reported number of missed doses) have been shown to have excellent concordance with viral load [120]. In the interviews (Paper V) participants, who all had viral loads <50 copies/ml, however, described how they stored their medication in jars for vitamins or postponed to take their medication until circumstances where they were alone. This might indicate that participants in the Stigma and quality of life survey who adjusted their treatment to avoid stigma (i.e. not fully adherent to dose timing), also were to be found among those classified as adherent.

As discussed earlier the subscales Disclosure concerns and Concerns about public attitudes are not direct measures of anticipated stigma, which might explain why the paths including these scales were not confirmed in the Swedish context. When Earnshaw and colleagues [42] performed their empirical test of the HIV stigma framework the items measuring enacted and

anticipated stigma where adapted from measures of HIV-related stigma developed by Visser et al [121], not Berger et al [44]. The items used by Earnshaw and colleagues covered enacted or anticipated actions of stigma from family members, social/community workers or health care workers [122].

6.3.4 Regarding qualitative analyses (Paper V)

Credibility of the analysis was enhanced through peer debriefing [123]; I presented preliminary results for research colleagues, not involved in the project, and at a meeting with a non-governmental organization for people living with HIV who asked critical questions, making us aware of our taken for granted biases. Credibility was further enhanced through the use of referential adequacy [123], as we postponed analysis of one interview until the analysis was finalized.

6.4 CONCLUDING REMARKS

HIV is still a stigmatized condition, even for persons who are virally suppressed. Although a majority of people living with HIV in Sweden have not experienced stigma enacted towards them, being aware of a stigma around HIV and seeing others with HIV being subject for stigma may also affect persons who have not disclosed. It is common to have concerns about when and to whom you should disclose your HIV. Although Sweden is in the front line regarding treatment, the health-related quality of life seems to not improve for people living with HIV in Sweden.

- The HIV stigma scale was, in general, found to be a valid measure of HIV-related stigma in Sweden. However, content validity was questionable for measure of anticipated stigma, as defined by Earnshaw and Chaudoir [41] and the subscale Disclosure concerns was found to have questionable psychometric properties.
- Personalized stigma was found to be consistent with the stigma mechanism enacted stigma. Hypothesized associations between enacted stigma and lower physical wellbeing was not confirmed. Personalized stigma was reported to a higher extent by 25% of people living with HIV in the Swedish cohort.
- Disclosure concerns were reported to a higher extent by 69% and Concerns about public attitudes was reported to a higher extent by 49% of people living with HIV in the Swedish cohort. Although the Disclosure concerns subscale had questionable psychometric properties, the individual interviews confirmed that questions about disclosure are central to people living with HIV in the era of efficient treatment.
- Negative self-image was found to be consistent with the stigma mechanism Internalized stigma and a negative association between internalized stigma and lower emotional wellbeing was confirmed. Negative self-image was reported to a higher extent by 29% of people living with HIV in the Swedish cohort.
- Hypothesized associations between stigma and adherence to treatment was not confirmed in general. However, participants described how they adjusted their treatment to keep their HIV a secret.

7 FUTURE PERSPECTIVES

The findings in this thesis gave limited answers to why the health-related quality of life for the participants was lower than for a general Swedish population. The Stigma and quality of life survey was conducted in 2013 and the interviews were performed in 2017. It is possible that some of the participants in the Stigma and quality of life survey had been informed by their physician that they were exempted from the obligation to inform potential sex partners about their HIV. It is, however, likely that most participants in the Stigma and quality of life survey were still obliged to inform their sex partners about their HIV, in accordance with the Swedish Law for communicable disease control (SFS 2004:168). In the interviews, many of the participants said that they had been exempted from the obligation to disclose and they talked about different approaches to disclosure.

I propose that the changes that have been made in the obligation to disclose one's HIV to others might change the stigma around HIV in Sweden. It could also improve the health-related quality of life for people living with HIV and it would be interesting to monitor the experiences of HIV-related stigma and the health-related quality of life among people living with HIV in Sweden over time to track these changes. I would suggest that The Public Health Agency performs a similar survey as Living with HIV in Sweden in a near future to capture changes over a five year period (before and after changes in the application of the Swedish Law for communicable disease control). Important measures from the study Living with HIV in Sweden to compare over time would be the overall question of quality of life, the specific questions regarding different aspects of life, the question regarding disclosure and the items in the HIV stigma scale. Due to the floor and ceiling effects in the 12-item version of the HIV stigma scale I would suggest using the proposed 16-item version of the HIV stigma scale in Appendix 3 for measurement of HIV-related stigma.

In this project we have deliberately avoided to use the word stigma in questionnaires and in interviews, since it may lack an evident meaning in the Swedish language. However, the word stigma is used in the most recent report from The Public Health Agency on the application of the Swedish Law for communicable disease control, where the Supreme Court precedence from 2004 is regarded as stigmatizing people living with HIV [12]. The word stigma is also used by Swedish activists and non-governmental organizations. Although I present suggestions for how HIV-related stigma can be conceptualized in the era of efficient treatment, I propose that much further work needs to be done regarding conceptualization of stigma both in general and specifically in a Swedish context. I suggest that people living with HIV in Sweden should be included in the process of defining the word.

When pre-exposure prophylaxis (PrEP) has been implemented in various countries, PrEP users have been identified as a new group that may be exposed to stigma and stigma has been identified as a barrier to PrEP [124-126]. PrEP is commonly recommended for people at very high risk of infection; a recommendation that in itself can be stigmatizing [131]. Stigma related to PrEP may be an important area to explore also in a Swedish context and it may be of essence to consider less stigmatizing guidelines when PrEP is implemented (i.e.

recommend PrEP for people who want to take responsibility for their sexual health) to avoid unnecessary stigmatization.

Finally, I have many times during this project thought about how it is to grow old with HIV. Participants have told me stories about how they control information, that HIV is private and that they fear rejection if their HIV status gets known to others. In their stories it has seemed relatively unproblematic to hide medication from others and living a life without other people knowing about one's HIV. I have wondered how those stories will evolve when people get older and might need care and support from others due to their old age.

8 CLINICAL IMPLICATIONS

People who do not get access to HIV testing, treatment and care will inevitably need a lot of care (both medical care and nursing interventions), but people who are virally suppressed gets prescription for their ART and comes for monitoring of treatment results 2-4 times/year. The participants in the interviews, however, described getting more support than just support related to treatment from their nurses, physicians and social counselors at the clinic. One participant, for example, described how finally, after years of worrying that she would transmit HIV to her children, a social counselor drank water from her glass and thus made her abruptly realize that she was not contagious.

According to the nursing theorist Dorothea Orem (as cited by Afaf Ibrahim Meleis [127]), patients may be in need of nursing care, not only for sufficient intake of air, water and food, or for seeking and securing appropriate medical assistance. Patients may also need assistance in (and here I have focused on areas I consider relevant for people who are virally suppressed) maintaining balance between solitude and social interactions, avoiding hazards, developing within social groups and accepting oneself to be in a particular state of health. As HIV still seems to be a stigmatized disease, patients will need special support regarding social life.

Findings in this thesis imply that younger persons may be more exposed to stigma than older. Further on, women born in other countries than Sweden may have more concerns about public attitudes. Targeted interventions for women born in other countries than Sweden and persons of lower age may therefore be warranted.

A large proportion of people living with HIV in Sweden have concerns regarding disclosing their HIV status to others. Although disclosure concerns was not found to be related to lower health and wellbeing, questions about disclosure can be brought up by people living with HIV in contact with health care. I have understood throughout this project that it sometimes can be complicated to advice patients regarding disclosure. Advice to disclose may have devastating consequences for individuals who may be rejected from their community. On the other hand, participants have shared experiences in the interviews of being surprised to get advised not to disclose. I would suggest that the topic of how to advice patients about disclosure /non-disclosure may be valuable to address in an open discussion among

caregivers at a clinic. It would also be valuable to include people living with HIV in that discussion.

9 ACKNOWLEDGEMENTS

Först vill jag tacka alla deltagare i den här studien. Mitt varmaste tack för att ni tog er tid att svara på enkäten och delta i intervjuer. Tack för att ni så generöst delade med er av era erfarenheter.

Jag vill också tacka Pernilla Albinsson, Lena Mattsson, Sofia Sandberg, Lise-Lott Njie och all annan personal på i56 som har arbetat med datainsamlingen. Ni har inte bara möjliggjort den här forskningen utan också fått mig att känna mig väldigt välkommen på kliniken. Tack till Dr Johanna Brännström för hjälp med rekrytering av deltagare.

Min huvudhandledare docent Lars Eriksson, du har varit den bästa huvudhandledare jag har kunnat tänka mig. Tack för att du trodde på min förmåga och för att du har fått mig att utvecklas så otroligt. Jag har lärt mig så mycket av dig. Tack också för att du så generöst har ordnat tillfällen för mig att resa och skapa nya kontakter i USA och också gett mig tillfällen för vila och koncentration vid olika skrivretreater. Jag kommer alltid minnas hur professionell du har varit i ditt sätt att stötta mig. Tack för allt du har lärt mig, för att jag har fått jobba med dig och för att du har kämpat och skrattat tillsammans med mig.

Docent Veronica Svedhem-Johansson, det har varit otroligt värdefullt för mig att få ha dig som handledare. Tack för allt du har lärt mig om hiv och om forskning i allmänhet, och för att du möjliggjort datainsamling för den här avhandlingen. Tack också för att du gav mig möjlighet att presentera forskningen på kursen för specialistläkare.

Docent Lena Wettergren, du har varit både min handledare, forskargrupsledare och på senare år även min studierektor. Tack för allt stöd, kloka tankar och oändligt många bra kommentarer i manuskript. Tack också för att du bidragit med din erfarenhet från KIs disputationskommitté.

Dr Maria Wiklander, jag hoppas att alla doktorander har en handledare som dig i sitt team. Tack för att du har sagt att jag är bra, också när jag har känt mig långtifrån bra.

Min mentor Dr Eva Joelsson-Alm, stort tack för alla våra fikastunder. Det har varit ovärderligt för mig att träffa dig regelbundet och höra dig säga att det går bra och att jag klarar av det.

Professor Carol Tishelman, vilken lycka det var att få komma till din forskargrupp och få ta del av all din kunskap. Tack för all hjälp med det kvalitativa manuskriptet och tack för att du tog med mig till Southampton.

Associate professor Deepa Rao and Professor Lisa Manhart, thank you so much for welcoming me and my family to Seattle and University of Washington. It was great to get an insight into an American University, and thank you so much for giving me the opportunity to present my research.

Thank you Professor Peter Griffiths and Dr Jane Ball for taking such great care of us when we visited you in Southampton. And thank you for valuable feedback on my research.

Marie Hultén och Mira Carlsson, som utförde enkätundersökningen som ligger till grund för den här avhandlingen tillsammans med mig. Tack för att ni tog er an uppgiften på ett så bra sätt. Jag är så tacksam för att det var just er som jag fick sitta med i entrén till i56 och inkludera deltagare.

Galit Zeluf, tack för att du lyste upp den sista delen i mitt doktorandprojekt. Det har varit fantastiskt roligt att skriva och analysera tillsammans med dig. Jag ser fram emot att färdigställa det sista i vårt kvalitativa manus.

Jenny McGreevy vill jag tacka för att du har språkgranskat artiklar och Lina Lindqvist för transkribering av intervjuer.

Dr Desirée Ljungcrantz, tack för givande och viktiga samtal om stigma och hiv. Jag tror och hoppas att vi kan hitta sammanhang i framtiden där vi kan fortsätta diskutera. Tack också för din avhandling som gav mig ny energi och inspiration precis när det behövdes.

Det finns några personer som har hjälpt mig extra mycket när jag haft frågor om statistik och kvantitativ analys. Tack Kimmo Sorjonen för en utmärkt kurs i multivariat analys, och tack för att du svarade på mina följdfrågor flera år efter kursens avslut. Tack Anders Kottorp för att du fick mig att testa modern testteori. Tack Mesfin Kassaye Tessma, för att du tog dig tid att delta på mitt övningsseminarium inför halvtid och gav ovärderliga förbättringsförslag. Tack Magnus Backheden, för hjälp med att reda ut mina Bayesiska analyser (som tyvärr inte fick plats i avhandlingen). Slutligen tack till Sara Runesdotter för alla kloka råd, jag har verkligen inspirerats av ditt förhållningssätt till kvantitativ analys.

Tack till Nationella forskarskolan i Vårdvetenskap, dels för finansiering av min doktorandtjänst men också för ett mycket givande forskarklimat. Tack till Lena Von Koch och Anders Kottorp som gav oss i hk 12 en så bra start. Tack till alla i hk 12. Det har varit så roligt att följa allas projekt och att se er försvara era avhandlingar med bravur, en efter en.

Jag vill tacka alla kollegor som jag hade i början av min doktorandtid, vid sektionen för omvårdnad på Ana 23. Tack forskargruppen som var HiP-LC när jag började; Lise-Lott Rydström, Gabriela Armuand, Jenny Nilsson, Anna Jervaeus, Claudia Lampic, Jeanette Winterling med flera.

Mats Christiansen, dig får jag tacka långt bak i tiden, för du var min handledare när jag fick stipendium en sommar för att gå KIs sommarforskarskola. Tack också för att du har velat läsa Sara Ahmed, Michel Foucault och Maggie Nelson med mig. Jag tycker att vår bokcirkel (läsa bok - ses och prata om något helt annat) är ett vinnande koncept!

Tack till Britta Berglund och Marie Iwarson. Ni fanns båda på Gastrocentrum när jag jobbade där. Tack för att ni såg och hjälpte mig att odla mitt intresse för forskning. Britta, du visste vad du pratade om när du sa att jag skulle hålla ögonen öppna för Nationella forskarskolan i Vårdvetenskap, så rätt du hade!

Tack till Maria Jirwe, som var min handledare under arbetet med c-uppsatsen och både då och senare har uppmuntrat och stöttat mig.

Tack till alla kollegor inom avdelningen för Innovativ vård. Tack för alla skratt och också en del tårar. Tack Kerstin Belqaid för alla fina samtal och för all hjälp inför disputationens ansökan. Tack Lisa Smeds Alenius för trevligt sällskap när vi åkte till Southampton. Tack Adrian Levitsky för gott sällskap i vårt fina hörnrum. Tack Max Kleijberg, Sophia Savage, Therese Johansson, Anna Forsberg, Britt-Marie Bernardson, Ida Goliath, ni är fantastiska och jag är så glad över att ha fått jobba med er. Rebecka Norman, tack för samtal om psykometri och annat. Tack Rikard Lindqvist, för trevliga luncher och goda råd och för att du såg hur trött jag var efter min föräldraledighet med Hanna... Det är

så sorligt att Olav inte finns längre. Tack Olav Lindqvist för all hjälp med min kvalitativa artikel. Sist jag såg dig sa du att det brukar vara kaos sista tiden innan disputationen. Tack Olav, det är kaos, ingenting kommer någonsin bli ordnat...

Tack till professor Mats Brommels och professor Carl Johan Sundberg, som har varit prefekter för LIME under den tid jag har varit här, tack för den kreativa arbetsmiljö som LIME har varit. Tack till alla kollegor på MMC och LIME för trevliga samtal, luncher och ovärderlig hjälp att navigera här i slutet, i djungeln av disputationsansökningar, mallar till inbjudningskort, hur man får håll i spikningsexen o.s.v. Särskilt vill jag nämna Sara Korlén, Marie Dahlberg, Georg Keel, Rafiq Muhammed, Mairi Jüriska, Charlotte Klinga, Mia von Knorring, Carolina Wannheden, Sara Tolf, Helena Strehlenert, Vibeke Sparring, Hanna Augustsson, Rebecka Mosson, David Ebbevi, Emma Granström, Kristina Palm, Ersida Mansoory och Karin Solberg Carlsson.

Jag har många vänner som stöttat mig under de här åren. Klara och Lotta, kära systrar, vad vi kämpar med livet och barnen och kampen. Tack för att ni finns där, om så ibland bara i en oändligt lång sms-tråd.

Anna Kaijser. Tack för kursen i akademisk överlevnad, för att du gett mig en inblick i hur forskarvärlden kan se ut utanför KI-bubblan och för att du finns kvar i mitt liv.

Matlaget, tack för all mat och trevliga samtal (som ibland också bara finns i en oändligt lång sms-tråd). När allt detta är klart är det min tur att bjuda in!

Barry och andra vänner som jag träffar för sällan (Johan!). Jag har inte glömt er, jag har bara haft lite mycket att göra...

Tack International Theatre Stockholm. Den resa som vi har gjort tillsammans är nästan lika lång som det här avhandlingsprojektet. Som tur är tar teaterprojektet inte slut. Ni har betytt otroligt mycket för mig under de här åren.

Tack till mamma Karin, pappa Håkan, mina svärföräldrar Ingrid och Lars-Gunnar för all stöttning med barn och vardagsliv. Och för att ni finns och är del av min familj! Tack till min bror Per för intressanta samtal om forskning, när detta är över kanske vi kan ses utan barn och prata klart..

Fredrik. *Under de dystra stunderna gnistrade mitt liv till...* Tack för att du hjälpte mig att formatera mitt CV så att jag kunde få den här doktorandtjänsten. Tack också för att du kunde förvandla mina tankar kring en omslagsbild till en faktisk bild. Tack för helgerna där du tog barnen till landet så att jag kunde jobba och tack för allt (vab och städ och ja.. du vet). Tack för att jag får leva med dig och dela allt som är roligt och allt som är svårt.

Otto och Hanna. Nu är mammas bok snart färdig. De här sista veckorna har jag jobbat mycket och längtat efter er. Jag hoppas att ni också har känt av att jag har mått bra under de här åren och att ni blir inspirerade en dag att själva göra något svårt men roligt!

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11 APPENDIX

11.1 APPENDIX 1 - THE HIV STIGMA SCALE

Experiences from living with HIV

This study asks about some of the social and emotional aspects of having HIV. For most of the questions, just circle the letters or numbers that go with your answer. There is no right or wrong answers. Feel free to write in comments as you go through the questions. This first set of questions asks about some of your experiences, feelings, and opinions as to how people with HIV feel and how they are treated. Please do your best to answer each question.

For each item, circle your answer: Strongly disagree (SD), disagree (D), agree (A), or strongly agree (SA).

	Strongly disagree (SD)	Disagree (D)	Agree (A)	Strongly agree (SA)
1. In many areas of my life, no one knows that I have HIV	SD	D	A	SA
2. I feel guilty because I have HIV	SD	D	A	SA
3. People's attitudes about HIV make me feel worse about myself	SD	D	A	SA
4. Telling someone I have HIV is risky	SD	D	A	SA
5. People with HIV lose their jobs when their employers find out	SD	D	A	SA
6. I work hard to keep my HIV a secret	SD	D	A	SA
7. I feel I am not as good a person as others because I have HIV	SD	D	A	SA
8. I never feel ashamed of having HIV	SD	D	A	SA
9. People with HIV are treated like outcasts	SD	D	A	SA

	Strongly disagree (SD)	Disagree (D)	Agree (A)	Strongly agree (SA)
10. Most people believe that a person who has HIV is dirty	SD	D	A	SA
11. It is easier to avoid new friendship than worry about telling someone that I have HIV	SD	D	A	SA
12. Having HIV makes me feel unclean	SD	D	A	SA
13. Since learning I have HIV, I feel set apart and isolated from the rest of the world	SD	D	A	SA
14. Most people think that a person with HIV is disgusting	SD	D	A	SA
15. Having HIV makes me feel like I'm a bad person	SD	D	A	SA
16. Most people with HIV are rejected when others find out	SD	D	A	SA
17. I am very careful who I tell that I have HIV	SD	D	A	SA
18. Some people who know I have HIV have grown more distant	SD	D	A	SA
19. Since learning I have HIV, I worry about people discriminating against me	SD	D	A	SA
20. Most people are uncomfortable around someone with HIV	SD	D	A	SA
21. I never feel the need to hide the fact that I have HIV	SD	D	A	SA
22. I worry that people may judge me when they learn I have HIV	SD	D	A	SA

23. Having HIV in my body is disgusting to me	SD	D	A	SA
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Many of the items in this next section assume that you have told other people that you have HIV, or that others know. This may not be true for you. If the item refers to something that has not actually happened to you, please imagine yourself in that situation. Then give your answer ("strongly disagree," "disagree," "agree," "strongly agree") based on how you think you would feel or how you think others would react to you.

	Strongly disagree (SD)	Disagree (D)	Agree (A)	Strongly agree (SA)
24. I have been hurt by how people reacted to learning I have HIV	SD	D	A	SA
25. I worry that people who know I have HIV will tell others	SD	D	A	SA
26. I regret having told some people that I have HIV	SD	D	A	SA
27. As a rule, telling others that I have HIV has been a mistake	SD	D	A	SA
28. Some people avoid touching me once they know I have HIV	SD	D	A	SA
29. People I care about stopped calling after learning I have HIV	SD	D	A	SA
30. People have told me that getting HIV is what I deserve for how I lived my life	SD	D	A	SA
31. Some people close to me are afraid others will reject them if it becomes known that I have HIV	SD	D	A	SA
32. People don't want me around their children once they know I have HIV	SD	D	A	SA

	Strongly disagree (SD)	Disagree (D)	Agree (A)	Strongly agree (SA)
33. People have physically backed away from me when they learn I have HIV	SD	D	A	SA
34. Some people act as though it's my fault I have HIV	SD	D	A	SA
35. I have stopped socializing with some people because of their reactions to my having HIV	SD	D	A	SA
36. I have lost friends by telling them I have HIV	SD	D	A	SA
37. I have told people close to me to keep the fact that I have HIV a secret	SD	D	A	SA
38. People who know I have HIV tend to ignore my good points	SD	D	A	SA
39. People seem afraid of me once they learn I have HIV	SD	D	A	SA
40. When people learn you have HIV, they look for flaws in your character	SD	D	A	SA

11.2 APPENDIX 2 – PATIENT INFORMATION

Living with long-term infections

We want to study the life conditions for people living with long-term infections. The goal is to inform policy makers and health care providers about the life conditions of people living with long-term infections to provide the best possible care and support.

Information about the study

The study involves answering questions in a questionnaire. It takes about 30-60 minutes to answer the questions and you do this before or after your appointment at the infection clinic. The questions are about your life, how you perceive your illness and how others treat you. One question regards religion. When you have filled in the questionnaire you return it in a sealed envelope. If you need assistance you can get help to fill in the answers to the questions. Background data about you and your illness will be collected from your medical record.

Your participation is completely voluntary and your care will not be affected if you decline to participate. Your answers and information from your medical records are handled with confidentiality. It's only project members who have access to the collected data, which is data without your name.

Responsible for the project

The project is collaboration between the Department of Infectious Diseases, Karolinska University Hospital and Karolinska Institutet. The data protection officer is Karolinska Institutet, Mats Gustafsson.

Questions about the study can be answered by your regular doctor or any signed.

Maria Lindberg
Nurse
08-524 839 20

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Nurse
08-58580000

Veronica Svedhem-Johansson
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08-58580000

Principal Investigator is Lars E. Eriksson, associate professor, Department of Neurobiology Care Sciences and Society, Division of Nursing, Karolinska Institutet, lars.eriksson@ki.se

Consent for participation in the study Living with long-term infections.

We here ask for your consent to participate in the study and to compile the answers from the questions with data from your medical records. All responses are anonymous.

Date: _____

Signature: _____

11.3 APPENDIX 3 – A PROPOSED 16-ITEM HIV STIGMA SCALE

Experiences from living with HIV

This study asks about some of the social and emotional aspects of having HIV. For most of the questions, just circle the letters or numbers that go with your answer. There is no right or wrong answers. Feel free to write in comments as you go through the questions. Please do your best to answer each question.
For each item, circle your answer: Strongly disagree (SD), disagree (D), agree (A), strongly agree (SA) or not applicable (NA).

	Strongly disagree (SD)	Disagree (D)	Agree (A)	Strongly agree (SA)	Not applicable (NA)
2. I feel guilty because I have HIV	SD	D	A	SA	NA
3. People's attitudes about HIV make me feel worse about myself	SD	D	A	SA	NA
4. Telling someone I have HIV is risky	SD	D	A	SA	NA
6. I work hard to keep my HIV a secret	SD	D	A	SA	NA
7. I feel I am not as good a person as others because I have HIV	SD	D	A	SA	NA
9. People with HIV are treated like outcasts	SD	D	A	SA	NA
10. Most people believe that a person who has HIV is dirty	SD	D	A	SA	NA
14. Most people think that a person with HIV is disgusting	SD	D	A	SA	NA
15. Having HIV makes me feel like I'm a bad person	SD	D	A	SA	NA

	Strongly disagree (SD)	Disagree (D)	Agree (A)	Strongly agree (SA)	Not applicable (NA)
17. I am very careful who I tell that I have HIV	SD	D	A	SA	NA
20. Most people are uncomfortable around someone with HIV	SD	D	A	SA	NA
22. I worry that people may judge me when they learn I have HIV	SD	D	A	SA	NA
28. Some people avoid touching me once they know I have HIV	SD	D	A	SA	NA
29. People I care about stopped calling after learning I have HIV	SD	D	A	SA	NA
36. I have lost friends by telling them I have HIV	SD	D	A	SA	NA
39. People seem afraid of me once they learn I have HIV	SD	D	A	SA	NA

Item 28, 29, 36, 39 =Personalized stigma

Item 4, 6, 17, 22 = Disclosure concerns

Item 9, 10, 14, 20 = Concerns about public attitudes

Item 2, 3, 7, 15 = Negative self-image