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Experiences of stigma amongst HIV-positive people encountering the healthcare system in Scandinavia: a systematic review.

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“I’m living with hiv, but I am not hiv-positive. I don’t wanna be the diagnosis”

(Anette Enoksen, 2018, p. 35)

Foreword

Since I can remember, I have had and special interest in HIV. As I grew up in the 90's I was lucky to have a mother who, from early on due to a friend of hers living with HIV, always made sure that my brothers and I knew how HIV did and did not transmit, and that it was not dangerous to be around said friend. As I grew older, I continued to educate myself finding the social and political history of HIV particularly interesting. The way, and why, societies and people reacted to HIV and the people living with it. I began noticing that information on HIV became of less importance in school compared to other diseases, disasters, and epidemics, as well as I became aware of other people's perceptions concerning HIV.

When studying for my bachelor's degree in nursing (2010-2012), neither HIV nor HIV-related stigma was a subject I remember being on the curriculum, other than HIV being briefly mentioned. However, we did learn about code of ethics for nurses and that one should not discriminate on people's gender, diagnosis, sexuality, ethnicity etc. I found it strange not learning more about HIV since there had been such an improvement in treatment and medication, which I found noteworthy for nurses to be aware of – as well as stigma as a phenomenon.

I knew early on in the master's degree program, that HIV and stigma was something I would like to explore further, and that I wanted to investigate how HIV and stigma is today in an era where many people living with HIV have access to medication, as well as there are many people not having access. How history has affected people getting diagnosed with HIV, and if there still are experiences of stigma, and what might be the reason and how we perhaps can reduce possible stigma experiences.

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This systematic review is my final thesis as part of a master's degree in public health at the University of Tromsø.

Abstract

Objective: This systematic review aims to investigate the experiences of HIV-related stigma among people living with HIV in Scandinavia

Introduction: Stigma has existed for centuries, with some groups of people being more prone to stigma than others, one example being people living with HIV. HIV-related stigma has existed from the beginning of the epidemic, 1980's, and may still be experienced after almost 40 years. HIV-related stigma may cause both physical and psychological illnesses and is seen as a barrier to treatment and medication adherence, as well as being an obstacle in the fight against HIV. The treatment and attitudes have changed since the 1980s, thus it is expected that people living with HIV should be treated as any other patients. This review attempts to explore the experiences of people living with HIV in relation to stigma and the health care system in modern times.

Inclusion criteria: This systematic review included studies dated between 2011 and 2021 that are conducted in the Scandinavian countries. Participants were living with HIV, and with focus on their experiences of stigma in relation to their diagnosis. If not solely focusing on the healthcare system, the included studies had to include experiences from the healthcare system. The studies had to be written in English or any of the Scandinavian languages (Swedish, Danish, and Norwegian).

Methods: The databases used to obtain relevant studies were Cinahl, Medline, PsychInfo, and Norart. Pubmed, google scholar and grey literature were used for supporting and background information. Articles included is written in English or any of the Scandinavian languages (Swedish, Danish, and Norwegian). Four studies were included in the review, three from Sweden, and one from Norway – all written in English. Last search was conducted in 10th of January 2022. When writing this review and conducting the search and critical appraisal JBI approach for systematic review were used, as well as the CASP-checklist and Finding What Works in Health Care: Standards for Systematic Reviews description on synthesizing body of evidence. This review explored only qualitative studies with in-depth interviews. One study was excluded due to methodological approach being quantitative, the other studies excluded were due to lack of information concerning stigma in the healthcare system.

Results: The studies reviewed did not primarily focus on experiences of stigma within the health care system/setting, however, they all reported to some extent situations and experiences of HIV-related stigma in their study. All the participants were living with HIV in

Sweden or in Norway and were both male and female. The review extracted 21 findings regarding experiences of HIV-related stigma in healthcare system. These was subcategorized into two sub-categories: *Experiences with health care providers* and *treatment*.

Conclusions: Across the reviewed studies, participants reported being fairly satisfied to satisfied with their experience in the healthcare system, however HIV-related stigma in the healthcare system in Scandinavia is still experienced. Experiences of HIV-related stigma has become evident in this review, and current literature support the evidence found.

Further research on HIV-related stigma in the health care in Norway, as well as further research on healthcare providers knowledge on HIV so as to determine where the knowledge gap lies.

List of Abbreviations and explanations

AIDS Acquired immune deficiency syndrome

CDC - U.S. Centers for Disease Control and Prevention

GRID - Gay related immune deficiency

Fafo - An independent social science foundation in Norway

FHI - Folkehelseinstituttet / Norwegian Institute of Public Health

Folkhälsomyndigheten - Public Health Agency of Sweden

HIV - Human Immunodeficiency Virus

PTSD - Post-traumatic stress disorder

Scandinavia - Norway, Sweden, Denmark

SSI - Statens serum Institut in Denmark

The Nordic Countries - Denmark, Norway, Sweden, Finland, and Iceland, as well as the Faroe Islands, Greenland, and Åland

UNAIDS - The Joint United Nations Programme on HIV/AIDS

WHO – World Health Organization

1 Introduction

Under current laws and guidelines, no patient, regardless of diagnosis, disease or illness should ever experience stigma whilst receiving care in the healthcare system. However, patient stories, both national and international describes situations that may be in breach with the patients right to diligent¹ care (1-3). Some key populations have been more visibly at risk for prejudice in the health and care services, such key populations includes people living with Human Immunodeficiency Virus (HIV), people using alcohol or drugs, and sex workers (1). This thesis aims to more closely explore if people living with HIV experience such prejudice and/or stigma in the Scandinavian healthcare system.

People living with HIV have a right to medical follow up and treatment in accordance with their needs. Anti-viral therapy should be followed up by their general practitioner and/or specialist regularly, depending on their adherence to and effect of treatment, and psychological follow up be provided according to their individual needs as well as psychological follow up (4). Furthermore, people living with HIV might contract other illnesses, be in need of vaccines, or have other health related needs which require assistance from the healthcare system (4). Unfortunately, there are studies showing that stigma is exhibited by healthcare professionals, and that negative experiences may result in discontinuing of treatment (5). Further, stigma has showed to be, from the beginning of the HIV pandemic, a barrier to both testing, treatment, and prevention (6).

Stigma refers to a deeply discreditable attribute, leading to prejudice or maltreatment (7). Stigma has existed for centuries, and some groups of people seem more prone to be exposed to stigma than others, e.g., people living with HIV (7, 8). Experience of stigma, in general, might result in several negative health outcomes that affect a person's quality of life (9). Stigma can be a significant source of stress and social disadvantage, as adding health inequalities (9). Stigma has been observed as a cause for mental illnesses such as depression, and might lead to feelings of guilt and shame, self-isolation (8, 9), as well as poor medical adherence, poorer health-related quality of life, and increased HIV symptoms (9). Stigma is

¹ *Diligent care* - providing health and care services that respects the patient's personal integrity and bodily autonomy (19)

still experienced today, and might not only occur in society in general, but within the healthcare system as well, resulting in people choosing not to seek medical treatment when needed (8).

Through a systematic literature review, the aim of this thesis is to gain better understanding of the experiences within the healthcare system of people living with HIV in Scandinavia, whether stigma is encountered, whether such experiences have changed over the years and what implications these experiences might have for healthcare providers and further research.

The thesis statement that has been developed to acquire more knowledge on experience of HIV-related stigma is:

Experiences of stigma amongst HIV-positive people encountering the healthcare system in Scandinavia: a systematic review.

The process of eliminating HIV-related stigma is a vital part of the international effort to end the AIDS-epidemic (1, 10). Investigating if, and to what extent, HIV-related stigma still is experienced in the healthcare system is essential to partake in this effort. With this information, it might be possible to identify the appropriate strategies needed to eliminate the possible stigma and give people living with HIV equitable healthcare, in accordance with the individuals needs and life situation.

An introduction and background regarding the human immunodeficiency virus (HIV), laws and guidelines in the Norwegian healthcare system relevant to the aim, and stigma as a phenomenon is first to be explored. Further, the thesis will investigate HIV and stigma, HIV-related stigma, and research relevant to these topics. Subsequently, the method and design are described preparatory to the results and findings of the review. Last, the thesis discussion of the findings in the context of relevant literature will be assessed before concluding.

1.1 Human immunodeficiency virus (HIV)

Human Immunodeficiency Virus (HIV) is a virus that attacks the body's immune system causing vulnerability to infections and diseases (8). Illnesses caused by HIV was first scientifically described as a possible new epidemic by the U.S. Centers for Disease Control and Prevention (CDC) in the summer of 1981 (11, 12). The clusters of rare diseases seemingly targeting the male gay communities were by 1982 being treated as a syndrome,

referred to as *gay related immune deficiency (GRID)* (13), and by the end of the year as *acquired immune deficiency syndrome (AIDS)* (12). However, the agent responsible for AIDS was not identified before May 1983, when a team of doctors at the Pasteur Institute in Paris reported to have isolated a retrovirus thought to be a possible cause of AIDS (8). The virus penetrates and infects the most important cells in our immune system, the CD4-T-lymphocytes (8), thus gradually causing an immune deficiency in the host leading to vulnerability to both innate and acquired diseases (8).

The late stage of HIV infection, Acquired Immune Deficiency Syndrome (AIDS), occurs when the virus has badly damaged the immune system (14), and is characterized by complications due to certain opportunistic infections and/or cancers that is particularly seen in patients with an immune deficiency (14). Also, opportunistic infections occur more frequently and are more severe in people with HIV due to their damaged immune system (8). Examples of such illnesses might be pneumonia caused by *Pneumocystis jirovecii*, esophagus fungal infection caused by *Candida*, retina infection caused by cytomegalovirus, and/or cancers such as Kaposi sarcoma and severe kinds of lymphoma (14). Homosexual men, men who have sex with men, hemophiliacs and intravenous drug users were the first known risk groups to contract HIV (8, 12).

In 1981, the first case of HIV-infection was registered in Denmark (15), Sweden registered their first case in 1982 (16), and in the beginning of 1983 the first case of an HIV infected individual was registered in Norway (8, 12). At that time there was a growing fear and anxiety for HIV in the society, as well as in the healthcare system (8, 12). No known treatment existed, and the possible pathways of transmission were unclear (8, 12). Microbiologists and laboratories refused to do blood work on patients if HIV were suspected (12). In Norway, there was suggestions of marking individuals with an HIV positive status with a heart shaped tattoo in their groin, and some people diagnosed with HIV were denied dental care (2, 12). In the early 2000 people living with HIV were still treated in isolation care when hospitalized, some were denied or given substandard dental care and treated poorly by healthcare workers (2).

HIV infiltrates all bodily tissue and organs, and can be detected in different levels in the saliva and other excreta (8). However, HIV is only transmittable from one human to another through blood, semen, and secretions from the mucous membranes of the cervix, vagina and the anal tract (8). There are three main routes of transmission; through sexual encounter, through blood transfusion or blood products, or through perinatal transmission, also referred to as "mother-to-child transmission" (8). Perinatal HIV transmission might occur either during pregnancy, birth and/or breastfeeding (8).

However, in 1996 it was discovered that if a pregnant woman living with HIV received proper medical treatment, the risk of transmission to the child was less than 1% (8). Until 2013 couples in Norway where one or both were living with HIV were denied assisted fertilization and referred to Denmark or England, countries where assisted fertilization treatment for people living with HIV had been conducted for years (8).

Individuals that have contracted HIV may still experience inherent guilt in relation to becoming infected or fear of infecting others (17). They might also experience that other people, both healthcare professionals and lay people, consider them as heavily promiscuous, and as a result have contracted HIV (17). From the discovery of effective medical treatment in 1996 there has been a radical improvement in HIV-care (17). There is still no effective cure against HIV, however, anti-retroviral treatment enables people living with HIV to live long and healthy lives as the treatment reduce the viral loads to undetectable (3, 18). Today sufficient treatment results in the virus not being communicable, and thus a person living with HIV receiving proper medical treatment will not risk infecting other people (3). Moreover, new and effective drugs have radically changed the life expectancy, quality of life and well-being for those living with HIV (17). So much so that HIV is no longer considered a death sentence, but a chronic disease much the same as other chronic diseases (17). However, Fafo, an independent social science foundation in Norway, published an updated report in 2009 that showed that there has not been the same progress in the aspects of openness, knowledge and attitudes in society, and stigma seem to still be attached to this diagnosis (2).

1.2 Laws and guidelines

Healthcare providers in Norway are bound by national laws and regulations, and there are professional guidelines provided by the Norwegian Directorate of Health², as well as guidelines such as codes of ethics for doctors, nurses, and other health care providers (19-22). Collectively they aim to protect the patients' rights and safety in the healthcare system.

The Norwegian Health Personnel Act of 2001 chapter two, article four on *Responsible conduct*, states that all healthcare personnel shall conduct their work in accordance with the requirements of professional responsibility and diligent care which can be expected based on their qualifications, the nature of the work and the context in which the care is taking place (23). The Norwegian Directorate of Health states that the duty of *diligent help* is understood as providing health and care services that respects the patient's personal integrity and bodily autonomy (24). This is to be expressed through the way the healthcare personnel act towards and communicate with the patient, as well as with their next of kin (24).

The Equality and Anti-Discrimination Act of 2017 chapter one and two describes that the purpose of the Act is to promote equality and prevent discrimination due to gender, pregnancy, leave in connection with childbirth or adoption, care responsibilities, ethnicity, religion, belief, disability, sexual orientation, gender identity, gender expression, age, or other significant characteristics of a person (25). The Equality and Anti-Discrimination Act's prohibition includes direct and indirect differential discrimination based on actual, assumed, former or future factors specified above (25). Furthermore, several medical professions have international codes of ethics, such as the International Code of Ethics for Nurses that states that inherent in nursing is respect for human rights, and that nursing care is respectful of, and unrestricted by, considerations of age, color, creed, culture, disability og illness, gender, sexual orientation, nationality, politics, race og social status (19).

However, national laws and regulations have themselves been responsible for stigma or persecution of people based on their diagnosis. The Penal Code articles 237 and 238 in the Norwegian Laws, and the previous Penal Code article 155, addresses the transmission of

² [Nasjonale anbefalinger, råd og pakkeforløp - Helsedirektoratet](#) – an overview of the national guidelines provided by the Norwegian Directorate of Health

diseases (8). Earlier versions of these articles have enclosed all dangerous or life-threatening communicable diseases, including HIV / AIDS (8). The articles made it possible to prosecute an individual if a potentially life threatening diseases was transmitted to another individual, and sanctioned with fines or imprisonment (26). In 2016 a revision group found that in the cases in which this section of the legislation were used in prosecution, it was often directed at people living with HIV (27). These sections of the law has, in many cases, caused anxiety, stress and fear among people living with HIV not only by emphasizing the risks of infecting other people but also that one could get prosecuted, fined and/or get imprisoned (2). In 2017 a revised Penal Code was made official and people living with a known HIV status who are either on treatment or using protection cannot be punished (28).

As a healthcare provider there are guidelines- and codes of ethics that embrace the norms, values and ideals for professional practice (29). The guidelines and ethics arise from the four tenets of medical ethics: to do good, to respect the patient's autonomy and rights, to do no harm and to exercise equal treatment (29). Examples being ethical guidelines for doctors (21), international code of ethics for nurses (19) and the revised Declaration of Geneva from 2017 (22) (29). These codes and guidelines is the foundation to how health care and services are to be conducted, including that health care providers not to discriminate, to show respect for the patient, and to secure equity of care and treatment (29). World Health Organization (WHO) and the European Council regulates and revise the ethical codes and regulations, such as the Declaration of Geneva, to minimize differences between the nations (29).

1.3 Stigma – Introduction

Stigma refers to a deeply discreditable attribute, and it might be a "mark" or aspect of the self that is socially devalued (7). However, it is the social interactions and relationships where this "mark" is constructed to reflect its possessor's tarnished character, and not solely the "mark" itself that is the reason for stigma (7).

Stigma has existed for centuries and some groups in society has been seen as to have a lower status than others (7, 8), thus being more prone to experience of stigma. Canadian sociologist and social psychologist Erving Goffman (1922-1982) defined the term stigma as "*an attribute that is deeply discrediting*" (7 p.13) and that this attribute might disqualify a person from full social acceptance (7). The social phenomenon of stigma may be ascribed to individuals with

specific attributes that might be devalued, a difference that in a negative context deviates from the norm (30). More so, Goffman (7) described three types of stigma; abominations of the body (physical deformities), blemishes of individual character (mental disorder, addiction, homosexuality, radical political behavior etc.) and tribal stigma (race, nation, religion) (7). These are differences that are frequently met with prejudice, discrimination and stereotyping (31). The stigma phenomenon is seen globally, and the stigmatizer often transfers blame to the individual or group that are stigmatized (30).

In their article *From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures* Valerie Earnshaw (social psychologist) and Stephenie Chaudoir (social health psychologist) (32) describes three mechanisms as to be important when exploring HIV-related stigma; enacted-, anticipated-, and internalized stigma (32). Enacted stigma is described as "the degree to which an individual believe they have experienced prejudice and discrimination from others in their community" (32, p.5). Anticipated stigma is "the degree of expecting experience of prejudice and discrimination from others, often based on previous experiences" (32, p.5). Internalized stigma is described as "the degree to which an individual endorses negative beliefs and feelings" (32, p.5), that is when negative beliefs and feelings become a part of their identity and image of self (32). These three mechanisms are, by Earnshaw and Chaudoir, seen in relation to HIV/AIDS (32). The mechanisms were earlier used to define central and distinct processes in which individuals in other stigmatized groups experienced stigma, and are considered highly relevant to the experiences of stigma among individuals living with HIV (32). Experiences of each of these mechanisms have shown to often have deleterious outcomes such as psychological distress and lowered well-being (enacted stigma), a reluctance to disclose their HIV status in fear of rejection (anticipated stigma) and poor psychological wellbeing such as depression (internalized stigma) (32).

In the study *Towards a new understanding of HIV-related stigma in the era of efficient treatment- A qualitative reconceptualization of existing theory* (2020) Maria Reinius et al. (33) argues that labelling, when other people distinguish and label a person as different, might play a central part in battling stigma (33). More so, that it might be the last persistent component of stigma in the process of HIV becoming normalized, and they suggest that

labelling is included as a fourth process to the HIV-stigma framework by Earnshaw and Chaudoir (33).

1.3.1 HIV and stigma - World

The Joint United Nations Programme on HIV/AIDS (UNAIDS) (1) has defined HIV-related stigma as negative beliefs, feelings and attitudes towards people living with HIV, groups and people associated with people living with HIV and other key populations at higher risk of HIV infection (1).

Certain types of diseases such as leprosy and sexual transmittable infections, e.g. Syphilis in the 1800s, have historically been cause to stigma experiences (8). Sexually transmittable infections have in many societies been seen as identifiers of low morals or proof of lack of self-control (8). Health problems related to socially unacceptable behavior such as drug use or sex work have been frowned upon by the population, but more importantly, also by health professionals (8). In other words, diseases that people have brought upon themselves are less worthy of social support or diligent medical care. The history of HIV/AIDS show this phenomenon most vividly (8). Already in 1987, the director of the WHO Global Program on AIDS, dr. Jonathan Mann, recognized the danger that stigma might pose to an effective response in the battle against HIV/AIDS (34). More so, groups that were, and still are, identified as key populations was already marginalized, stigmatized, or discriminated before the arrival of HIV(34). Research by Laura Nyblade et al. (2021) suggest that Dr. Manns recognition of the danger of HIV-stigma, it is still considered relevant, decades later (34).

With improved healthcare and effective medications, HIV is today considered a chronic or permanent condition but at the same time not forgetting that it is a life-long contagious infection with possibility of transmission if not adequately treated (2, 17). While there has been a decrease in new cases of the disease, and an improvement in healthcare and treatment, still, HIV-related stigma has shown to impact people living with HIV in different ways, and that might cause barriers in battling HIV (8, 34). In 2014 UNAIDS proclaimed three main targets, the 90-90-90 targets, to be achieved world-wide by 2020 with the ultimate goal of ending the AIDS epidemic (35). The 90-90-90 targets states that by 2020 90% of all people living with HIV will know their HIV status, 90% of all people diagnosed with HIV will receive treatment, and that 90% of all people receiving treatment will have viral suppression

(35). These targets has since been revised to be 95% for each target within the sub-population (key populations, men and women under/over age of 35, children, sub-national³, pregnant women) by 2030 (37). However, there are evidence showing that HIV-related stigma has been, and still is, a barrier to the achievements of each of the 90-90-90 targets by undermining HIV testing and its linkage to care, treatment adherence, and suppression of viral load (34).

HIV and AIDS stigma is recognized as complex and multifaceted with prejudice towards groups or lifestyles associated with HIV/AIDS as well as the fear of a contagious, life-threatening condition for which no cure exists (30). HIV-related stigma may be suffered as both internal (e.g. guilt, shame, low self-esteem- and image) and external (reactions and attitudes from the environment) (8). A literature review from the US (38) states that effects of HIV-related stigma may be linked to depression, post-traumatic stress disorder (PTSD) and risky sexual behavior as well as poorer medical adherence due to fear of undesired disclosure if medication has to be taken in public (38). Further, there has been detected a high prevalence of mental illness among individuals living with HIV which might lead to reduced quality of life (38). Stig Frøland, a Norwegian doctor specialized in infectious diseases and known for his involvement and experience with HIV/AIDS-related work, groups the negative aspects of HIV-related stigma into to two main areas (8). At an individual or group level, HIV-related stigma may cause a reduction in the quality of life, due to fear of exclusion both familial and from society in general and mental and physical health problems (8). At a societal level HIV-related stigma may obstruct the effort to end the epidemic when people that might be infected dare not get tested, or people living with HIV do not take the medicine as prescribed due to fear of getting revealed as HIV positive (8, 34). Treatment as prevention, including both post-exposure therapy (of people infected by HIV) and pre-exposure therapy (of people at high risk of becoming infected) is a vital part of the international effort (8, 35). However, reaching people at risk of either may be hindered by stigma.

³ Existing or occurring below a national level: relating to or being a group or region within a nation (Subnational, Merriam-Webster online dictionary)

1.3.2 HIV and stigma – Scandinavia

In the 2009 Fafo-report about experiences of living with HIV in Norway, including both surveys and in-depth interviews, there are indications that there has been a decrease in experiences of mental illnesses among people living with HIV (2). However, the study also identified that there still was individuals that experience depression, anxiety and fear of being open about their diagnosis due to possible experience of stigma (2). The in-depth interviews also disclosed that some interviewees experienced the healthcare personnel's attitudes and care in hospitals unsatisfactory (2). They reported experiences of excessive and unnecessary infection control regimes such as food and drinks served with disposable plates, cups and cutleries, suggestions to keep away from other patients and isolation care, and also a lack of knowledge about HIV from their general practitioner (2).

Regarding attitudes of the general public, a survey conducted in Norway in 2015 about HIV knowledge and attitudes in relation to life at work found that out of 1968 individuals, 6% said that it was unsafe to hug an HIV-positive person, 6% believed it was unsafe to shake hands, 32% of those registered in the survey as health workers felt it unsafe to kiss a person living with HIV, and 2 out of 10 employees found it unsafe to share toilets with individuals living with HIV (39). Further, almost 50% of the partaking participants found it likely to be more cautious when in contact with a person living with HIV (39). Similarly, Swedish and Danish reports (40, 41) found attitudes indicating that there still was a fear of sharing a glass of water, sharing toilet or a towel with a person living with HIV, and a feeling of it not being safe to kiss a person living with HIV. These are fairly current surveys, published in 2015-2017, two decades after effective treatment of HIV was discovered.

1.3.3 Incidence and prevalence of HIV in Norway, Sweden, and Denmark

The table below shows HIV transmissions sorted after route of transmission, registered in Norwegian Surveillance System for Communicable Diseases (MSIS) 1984- 2020 (42).

Year	Before	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	Total
Transmission route	2010											
Heterosexual	2231	155	142	124	130	138	120	115	101	100	66	3579
Transmission:												
- while residing in Norway	700	46	46	31	47	52	50	47	32	33	22	1163
- Prior to arrival to Norway	1531	109	96	93	83	86	70	68	69	67	44	2416
Homosexual	1369	97	76	98	107	70	87	88	73	61	63	2274
Intravenous drug use	564	10	11	8	7	8	8	7	6	8	8	656
Via blood/- blood products	47				1							48
Mother-to-child	63	4	7	1	3	2	2	2	6	2		93
Other/unknown	99	2	6	3	1	3	3	1	5	1		128
Total	4373	268	242	234	249	221	220	213	191	172	137	6778

Table 1 - HIV incidents in Norway 1984-2020 registered in MSIS

It was early considered homosexuals, men who have sex with men, intravenous drug users and sex workers as risk groups (8), which are still used as basis for the categories of incidents statistics from Norwegian Institute of Public Health (FHI). The table shows that among Norwegian residents diagnosed with HIV by 2010 or earlier, the most common way to become infected with HIV was through heterosexual transmission, with more than half of these cases being identified before, or upon arrival to Norway, either as asylum applicant, family reunions or individuals returning from travels abroad (42). The table shows that there has been an overall decrease in new, registered cases of HIV the last decade. Among Norwegian residents infected while residing in Norway, however, the majority of new cases has been among men having sex with men, shown in the table as homosexual transmission (42). Among men having sex with men the reduction in new cases is likely related to easier access to pre-exposure prophylaxis, introduced from 2017 (42). Cases of homosexual transmission is decreasing more rapidly among men born in Norway, indicating that broader efforts are needed to reach men with an immigrant background having sex with men (42).

Table 2 show the differences of route of transmission in Sweden from 2018 to 2020, and also total new incidents from 2013. The information is retrieved from Public Health Agency of Sweden (Folkhälsomyndigheten) (43).

Year	2013	2014	2015	2016	2017	2018	2019	2020	Total
Transmission route									
Heterosexual						212	204	139	555
Transmission: - while residing in Sweden - Prior to arrival to Sweden						29 180	27 173	22 117	
Homosexual						157	154	110	421
Intravenous drug use or via blood/-blood products						23	21	13	57
Mother-to-child									
Other/unknown						89	70	102	261
Total	461	481	451	430	434	481	449	364	3551

Table 2 – HIV incidents registered 2013 – 2020, Sweden

When looking at the similar table for Sweden, the most common transmission route is heterosexual transmission (43). As with the Norwegian statistics (42), most of those registered as transmitted through heterosexual transmission in Sweden were transmitted before entering the country (43). Folkhälsomyndigheten in Sweden publish yearly statistics over new incidents of HIV infection registered (43).

Statens Serum Institut (SSI) in Denmark publishes yearly, as Norway and Sweden, statistics of new diagnosed HIV incidents(44). It is different from the statistics published in Norway and Sweden (table 1 and 2), with the Danish table (table 3) only differentiating men and women. However, at their web site, they state that there were 110 incidents registered in Denmark, and 54 incidents registered before entering the country (44). 47 of those registered in 2020 were transmitted through heterosexual intercourse, 61 people were men who have sex with men, 1 intravenous drug user and 1 transmission route unknown (44).

Alder	2019				2020			
	Mænd	Kvinder	I alt	%	Mænd	Kvinder	I alt	%
0-4	0	0	0	0	0	1	1	1
5-14	0	0	0	0	0	1	1	1
15-19	1	0	1	1	2	1	3	2
20-24	7	1	8	4	8	1	9	5
25-29	29	8	37	19	13	3	16	10
30-39	36	13	49	26	39	9	48	29
40-49	36	11	47	25	29	7	36	22
50-59	26	10	36	19	22	6	28	17
60-69	6	2	8	4	12	1	13	8
70+	5	0	5	3	9	0	9	5
I alt	146	45	191	100	134	30	164	100

Table 3 - HIV incidents registered 2019 & 2020, Denmark

Despite the reduction in overall numbers of registered incidents, heterosexual transmission is now the most common form of transmission in Sweden and Norway according to the statistics (42, 43), and homosexual transmission in Denmark (44). A majority of the individuals living with HIV in Norway that are registered as transmitted heterosexually are foreigners entering the country, either as asylum applicant or family reunion, but also individuals traveling abroad (42), whereas that information is difficult to obtain precisely for Sweden and Denmark. By the end of 2020 there were 6778 people living with HIV in Norway; 4585 men and 2193 women (42). In Denmark, by the end of 2020, there were 6100 people living with HIV (44), whereas in Sweden there was approximately 8000 people registered as living with HIV (45).

1.4 HIV-related stigma and previous research

Stigma related to HIV are experienced all over the world (46), and there are studies that have investigated the possible effects of HIV-related stigma.

1.4.1 HIV-related stigma in Scandinavia

When searching literature on HIV-related stigma in Scandinavia, as well as the countries Norway, Sweden, and Denmark individually, there was very little qualitative research found. What knowledge that exist on HIV-related stigma in Scandinavia has mainly come from surveys and reports.

When researching literature for her masters dissertation on experiences of stigma among gay men in Norway, Anette Enoksen (2018) found little to no qualitative research on stigma

experiences among gay men living with HIV in Norway (3). A search for more current studies, revealed that there still are few published studies on the subject. The lack of qualitative research on HIV-related stigma might indicate that it may be of interest to research further. There have been, however, more studies conducted in Sweden than Norway and Denmark.

The Scandinavian countries have, individually, conducted surveys and published reports that shows similarities between the three countries regarding lack of knowledge on HIV and HIV-related stigma (39, 41, 47). HIV-related stigma both among the population in general and in the healthcare system has been observed, and there is seemingly a lack of knowledge concerning both transmission route and contagiousness of HIV (39, 41, 47). The report *Hiv og levekår – livet som hiv-smittet i Danmark in 2016*⁴ (2016) found that improved treatment of HIV did not have the desired effect of a reduction of associated stigma and discrimination (40). 15% of participants partaking in the survey had experienced discrimination in the Danish healthcare system – though not within the facilities that specialized in HIV (40). In the article *Combating HIV stigma in health care settings: what works?* (2009) three main causes of HIV-related stigma in healthcare system is stated: lack of awareness of what stigma looks like and why it is damaging; fear of casual contact as a result of incomplete knowledge about HIV and how it transmits; and the association of HIV with socially unacceptable behavior (46).

Lack of general knowledge on HIV is an important factor in causing stigma and discrimination towards people living with HIV (46). Both the Danish (2021), Swedish (2017) and Norwegian (2015) surveys shows that there was a lack of knowledge of HIV among the populace (39, 41, 47). Further, the knowledge gap was highest in the lower age range, i.e., people under the age of 30 (39, 41, 47). Additionally, both the Norwegian Fafo report *Fortsatt farlig å kysse? Kunnskap om og holdninger til hiv*⁵ (2008) and the Danish report *Hiv og levekår – livet som hiv-smittet i Danmark in 2016* states that there seems to not only be a lack of knowledge, but a lack of knowledge and understanding on how HIV *does not* transmit as

⁴ English title: HIV and living conditions – living life with HIV in Denmark in 2016

⁵ English version: [HIV in Norway: Knowledge and Attitudes | Fafo-report 2008:44](#)

well (17, 40). *Hiv i Sverige, En studie om kunskap, attityder och förhållningssätt till hiv i befolkningen*⁶ (2017) refers to a Swedish study that found that people living with HIV in Sweden were negatively influenced by the lack of knowledge in the Swedish society, and that it might lead to internalized stigma and low self-esteem (41). Furthermore, as a consequence of fear of being stigmatized one of five people living with HIV in Sweden choose not to disclose their HIV-status to other people – rather choosing to keep their HIV-status a secret (41).

Att leva med hiv i Sverige, En studie om livskvalitet hos personer som lever med hiv (2016), a qualitative study from Sweden found that 78% of the respondents (people living with HIV) reported that they worried about being open regarding their diagnosis, 55% reported concerns about reactions from society, 36% felt less worthy, guilt and lower self-esteem due to their diagnosis(48). More so, 30% had, to a large extent, experienced HIV-related stigma (48). The study concludes that stigma is still an issue and that it contributes in lower life quality among people living with HIV In Sweden (48).

A Danish press release from HIV-Danmark (a nationwide patient association for people living with, or who are close to people living with, HIV in Denmark), *Sundhedspersonale mangler vigtig viden om hiv*⁷ (2021), reports that eight of ten healthcare providers believe that well treated HIV is still transmittable, and that every fifth healthcare provider believes that it can transmit through saliva (47). Furthermore, 45% of the participants admits to being more precautionous, and 23% feel unsafe if their patient is living with HIV (47). Taking precautions such as wearing gloves, masks, and/or gowns when knowing their patient is living with HIV was also reported by the participants (47). Healthcare providers reported feeling unsafe due to a lack of knowledge, and 23% responded that the Danish healthcare system does not treat people living with HIV in the same way as other patients (47).

⁶ Contain English Summary: [HIV in Sweden, a study about knowledge, attitudes and approach to HIV in society \(folkhalsomyndigheten.se\)](https://www.folkhalsomyndigheten.se) –

⁷ Health care personnel lacks important knowledge on HIV

1.4.2 HIV-related stigma in the world

Stigma has, as described earlier, a great number of negative side effects. Reducing stigma related to HIV is regarded as an essential part of the effort to end the AIDS epidemic (1, 34). Reducing stigma, might work preventative against HIV transmission and proactive towards testing (3, 34). A study from Canada, *Re-thinking HIV-Related Stigma in Health Care Settings: A Qualitative Study* (2015), researching HIV-related stigma in the healthcare system, found, when searching for literature, that there are very few articles from Western Europe (49). However, the article highlights outcomes of stigma such as under par healthcare, lack of knowledge from healthcare professionals, negative attitudes, and people living with HIVs impact of ability and willingness to access healthcare and psychological well-being (49). Dr. Marilou Gagnon, professor in the UVic School of Nursing and scientist, suggests that there is a need for further studies on experiences of stigma and discrimination in healthcare systems as there have been few studies that has investigated this topic (49). More so, it is suggested that people living with HIV today faces different degrees of more subtle to overt forms of HIV-related stigma in healthcare settings (49). These can take the form of judgmental language, blaming and humiliation, moral disapproval, unnecessary precautions and assumptions (49).

Dr. Marilyn Gagnon's study (2015) found indications that people living with HIV continues to endure stigma and discrimination in healthcare (49). The study report these findings as consistent with research conducted in other industrialized countries (49). Further, prior to their in-depth interview study, dr. Marilou Gagnon conducted a literature review that supported the knowledge gap experienced (49). *Experiences of stigma in healthcare settings by people living with HIV in Ireland: a qualitative study* (2020), indicates continuing stigma and discrimination experiences across a variety of healthcare settings, and concludes that stigma remains a significant issue for many people living with HIV (50). The stigma experienced is categorized into anticipated, enacted and internalized stigma (50), as previously described, and that stigma is associated with health avoidance affecting disclosure of diagnosis, engagement with healthcare services, testing and adherence to medication (50). The same tendency towards health avoidance is described by Frøland (2014), in the Fafø report about HIV (2009), as well as negative psychological impacts such as depression and anxiety (2, 8).

2 Method

2.1 Design

The design chosen in this thesis is a systematic review of qualitative evidence. A qualitative systematic review aims to present an understanding of experiences and perceptions rather than assess effectiveness of an intervention (51). This method of research has shown to be applicable when researching topics within the healthcare (51). Qualitative data allow the researcher to reflect upon human experiences and cultural and social phenomena (52), hence, this method is to be considered important and applicable for this thesis.

The objective of this thesis is to investigate experiences of HIV-related stigma. Applying systematic review of qualitative evidence as a research method to this review might aid in discovering different categories of experiences and perceptions, and it might give the opportunity to identify if there still are experiences of stigma within the healthcare system.

2.2 Data collection

To explore the experiences of stigma qualitative studies have been chosen as an inclusion criteria, with qualitative studies including interpretive and critical studies that focuses on qualitative data, but not limited to, designs such as phenomenology, ethnography, and discourse analysis (52). This method is chosen with the purpose of collating evidence related to social interactions that occur within healthcare and to seek and establish insights into social, emotional and experienced phenomena (52), the phenomenon being HIV-related stigma. We have limited the time period to studies published between 2011 and 2021. Our reasoning for this being that we are interested in the experiences of patients at present, and with advances in testing and treatment, along with changes in societal attitudes one would expect experiences to be different to those in the earlier days of HIV and Aids.

The following lists the inclusion and exclusion criteria for this thesis.

Inclusion criteria

- Qualitative studies.
- Primarily studies on Norwegian residents/ health care system; subsequently including all of Scandinavia (Denmark, Sweden) if needed

- Focuses on experiences of stigma relating to HIV positive status
- English or Scandinavian language text
- Health-care setting
- Peer-reviewed journals
- Non-peer reviewed sources such as reports, surveys, interviews in newspapers, radio, podcasts etc. as well as grey literature such as unpublished studies, theses, conference proceedings, presentations, government documents (51)
- Databases: Cinahl, Medline and PsychInfo as well as the Norwegian database Norart
- Mainly studies published between 2011 to 2021.

Exclusion:

- Text written in other languages than English or Scandinavian
- Studies based outside Scandinavia/Norway
- Quantitative research

2.3 Search Process

2.3.1 Knowledge gap and preliminary search

As described above an exploration of literature on experiences of HIV-related stigma in healthcare system in Norway and Scandinavia, show some findings regarding attitudes and knowledge among the general population and amongst health professionals. However, there is a lack of research found regarding *subjective* experiences of HIV-related stigma among people living with HIV, and even less to find on experienced HIV-related stigma.

With this study we will try to explore what the literature has found about experiences of HIV-related stigma in the healthcare and healthcare system, as experienced by people living with HIV, primarily in Norway. We would like to explore whether there have been studies or research performed and whether there is a need for further in-depth research.

A preliminary search of the databases returned no previous reviews based on the Norwegian experience, and very few research articles in general. As our initial aim was to research experiences based only in Norway. However, the formal search returned similar results to the preliminary search, thus, since the Scandinavian countries are similar (53) we included Sweden and Denmark as well.

The three countries of Scandinavia has a history that goes centuries back, and until the dissolution of Norway's dissolution of the union with Sweden in 1905, Norway had been in union with Denmark(54). The similarities between the Scandinavian countries, because of these unions, have influenced the culture of the Scandinavian countries, and may aid in the applicability of possible findings to Norwegian experiences, and as such to be of relevance. Furthermore, the findings may also be applicable to each of the countries in Scandinavia. Together with the Nordic countries, Scandinavia strive to organize the health and welfare to be similar (55).

The Nordic welfare Center, an institution in the Nordic Council of Ministers' social and health sector, contribute to the development of welfare initiatives in the Nordic region (55). Furthermore, The Nordic co-operations welfare model, The Nordic model, provides citizens with welfare services and social safety net, including health services and hospitals (56). The Nordic model value compassion, tolerance, and the fact that humans are of equal worth as a basis, together with the idea of good health for all (56). These co-operations and institutions show that there are similarities between the Nordic countries. With that said, even though they are not the same countries, and ruled to a degree differently, Sweden, Denmark and Norway have more similarities than differences in both social cultures, and the healthcare system.

Furthermore, the reports and surveys, mentioned above, from Denmark, Sweden, and Norway (39-41) indicates that the attitudes and knowledge among the general population and health care providers in the Scandinavian countries are relatively similar (39-41), and one might expect that experiences of stigma therefore might be of higher comparability than data from i.e. North America.

2.3.2 Main search

JBIMES manual for evidence synthesis (JBIMES) recognize the importance of describing the search process for a systematic review (52), which we will explore in this section. The approved protocol for this thesis, JBIMES manual for evidence synthesis (JBIMES) (52), and *A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care* (2016) by Ashleigh Butler, Helen Hall, and Beverley Copnell was followed as a guide through the search process (51). Butler et al. (2016) states

that when conducting a systematic review the search has to be conducted in multiple databases, using the same search strategy for each database (51).

In dialogue with a librarian, the chosen databases for the search were Cinahl, Medline, PsychInfo and the Norwegian database Norart. Initially our focus was purely Norwegian setting, and a trial search was conducted with Norway as focus in all databases. The findings were, however, scarce. To obtain enough relevant articles to conduct a systematic review, the scope was therefore broadened to include all three Scandinavian countries.

The research statement was adjusted to now read:

Experiences of stigma amongst HIV-positive people encountering the healthcare system in Scandinavia: a systematic review.

A PICO table (51, 57), was used as a search tool, to clarify the literature search, as well as a table of search word and medical subject headings (MeSH terms). Since the aim is to investigate a phenomenon in a population in a certain context without focus on the outcome, the O in the Pico table was considered not relevant to this search or thesis.

Population	Phenomena of Interest	Context	Outcome
HIV Human immunodeficiency Virus	Experience* Personal experience* Stigma Social Stigma	Health care Norway Scandinavia	Not relevant

Search words	MeSH terms
HIV HIV-related stigma HIV infection* Aids Stigma Stigmatization Personal experience* Norway Scandinavia (Sweden, Norway, Denmark) Health care Health service Discrimination Quality of life	Human immunodeficiency virus, AIDS? Stigmas, Social stigma Stereotyping

The same search was conducted in each of the chosen databases. A search with each search-word individually was performed before OR was inserted between all the similar search-words. Then an "AND" were added to connect the different search-words, eventually combining every search term. If the searches got no hits, a narrower search combining to only the two words HIV and Stigma together with the name of the countries were conducted. In the databases where this was possible, the search-words were exploded to broaden the search. When conducting the search in the Norwegian databases the same search-words were utilized, however translated into Norwegian. There is an example below of how the searches were conducted together with an example from the search conducted in the database PsychInfo.

HIV OR HIV infection OR Aids OR Human immunodeficiency virus
 AND
 Stigma OR HIV-related stigma OR stereotyping OR Stigmatization OR discrimination
 AND
 Health care OR Health service
 AND Norway OR Sweden OR Denmark OR Scandinavia

▼ Search History (24)			
<input type="checkbox"/>	# ▲	Searches	Results
<input type="checkbox"/>	1	exp HIV/ or HIV.mp.	61254
<input type="checkbox"/>	2	Human Immunodeficiency virus.mp.	6668
<input type="checkbox"/>	3	exp Psychosexual Behavior/ or exp HIV/ or HIV infection.mp.	277773
<input type="checkbox"/>	4	exp "AIDS (Attitudes Toward)"/ or exp AIDS/	16195
<input type="checkbox"/>	5	exp Self-Stigma/ or stigma.mp. or exp Mental Health Stigma/ or exp Stigma/	30953
<input type="checkbox"/>	6	exp Discrimination/ or exp "Quality of Life"/ or stigmatization.mp.	104333
<input type="checkbox"/>	7	experience.mp.	436509
<input type="checkbox"/>	8	Norway.mp.	11658
<input type="checkbox"/>	9	scandinavia.mp.	834
<input type="checkbox"/>	10	(Norway or sweden or denmark or scandinavia).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	38634
<input type="checkbox"/>	11	exp "Quality of Care"/ or exp Health Care Delivery/ or exp Health Care Services/ or exp Health Personnel/	364466
<input type="checkbox"/>	12	stereotyping.mp. or exp Stereotyped Attitudes/	21141
<input type="checkbox"/>	13	1 or 2 or 4	61667
<input type="checkbox"/>	14	5 or 6 or 12	147729
<input type="checkbox"/>	15	13 and 14	7129
<input type="checkbox"/>	16	11 and 15	1267
<input type="checkbox"/>	17	8 and 16	0
<input type="checkbox"/>	18	10 and 16	1
<input type="checkbox"/>	19	9 and 16	0
<input type="checkbox"/>	20	11 and 13 and 14	1267
<input type="checkbox"/>	21	10 and 20	1
<input type="checkbox"/>	22	10 and 20	1
<input type="checkbox"/>	23	8 and 15	2
<input type="checkbox"/>	24	10 and 15	21

Table 4 -Example of search conducted in the database PsychInfo.

The literature search resulted in 134 articles that could be of interest, and all abstracts were read. 16 of the 134 abstracts were identified as potentially relevant. An excel-sheet (see table 5 for an excerpt, and appendix J for the whole table) were made to organize the inclusion criteria to make a clearer overview of relevant articles before reading them in full text. The inclusion criteria table made it clear that there was only one article that matched all the criteria, *Experiences of young adults growing up with innate or early acquired HIV infection--a qualitative study* (2018) (Rydström et al., 58). Very few articles were based in a healthcare setting, although many made mention of them.

Database (total search result)	Title (Authors)	Year	Method	People living with HIV	Norway or Scandinavia	Experience of stigma (HIV)	English or Scandinavian Language	Health Care setting	Peer-reviewed
Norart (15)									
Norart	How gay men living with HIV experience and perceive the HIV stigma: a qualitative study (Anette Enoksen, Bente Træen)	2018	Qualitative Study		Norway				Unsure, electronic article psykologisk.no derived from a master's dissertation
Norart	Bruk av metasyntese som metode for å syntetisere kvalitative forskning: et eksempel hvor HIV-stigma er brukt som tema (Camilla Olavsen)	2011	Metasyntese av kvalitative studier		Amerika				Unsure, journal article from Vård i Norden
Norart	Seks møter med hiv og stigma	2013			Norway				
Norart	Slipper å true med straff	2012			Norway				
Norart	Skam, stigma og HIV/AIDS	2004			Norway?				
Medline (88)									
Medline	Health workers and the human immunodeficiency virus: knowledge, attitudes and behavior. (G. Brattebo, T. Wisborg, and H. Sjursen)	1990	Quantitative questionnaire-based study		Norway				Public Health
Medline	Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld phenomenological study. (Ewa Carlsson-Lalloo, Marie Berg, Maria Åsa Mellgren, Marie Russer)	2018	Qualitative Study		Sweden	Mention			International Journal of Qualitative Studies on Health and Well-being
Medline	The Relationship Between Stigma and Health-Related Quality of Life in People Living with HIV Who Have Full Access to	2018	Qualitative Study		Sweden				Aids Behaviour
	Antiretroviral Treatment: An Assessment of Earnshaw and Chaudoir's HIV Stigma Framework Using Empirical Data. (Maria Reinius, Maria Wiklander, Lena Wettergren, Veronica Svedhem, Lars E. Eriksson)								
Medline	Experiences of young adults growing up with innate or early acquired HIV infection--a qualitative study. (Lise-Lott Rydström, Britt-Marie Ygge, Björn Tingberg, Lars Navær, Lars E Eriksson)	2018	Exploratory qualitative study		Sweden			Mention	Journal of Advanced Nursing

Table 5 - Excerpt of evaluation of relevance for the 16 articles found. See the whole table in the appendix J.

Of the 16 articles found relevant, three were not found in full text, hence, 13 of the 16 articles were read and evaluated (green – inclusion criteria detected, yellow – inclusion criteria not clear/uncertain, red – inclusion criteria not found), and five publications were first included in this review. Two were labeled as uncertain if should be included and six excluded.

Furthermore, a google search and review of the citations in the articles found gave a few relevant articles, however place of origin did not match the inclusion criteria, and these were therefore not included.

Since there were few articles, after reading them, that matched all the inclusion criteria's set to obtain relevant articles to explore the research statement *Experiences of stigma amongst HIV-positive people encountering the health care system in Scandinavia*, we chose to look beyond the main focus of the studies and included those that discussed the topic of stigma in healthcare to some degree. This resulted in five articles included. However, upon a second evaluation of the five included articles, one was excluded ending up with four included articles in this systematic review of literature.

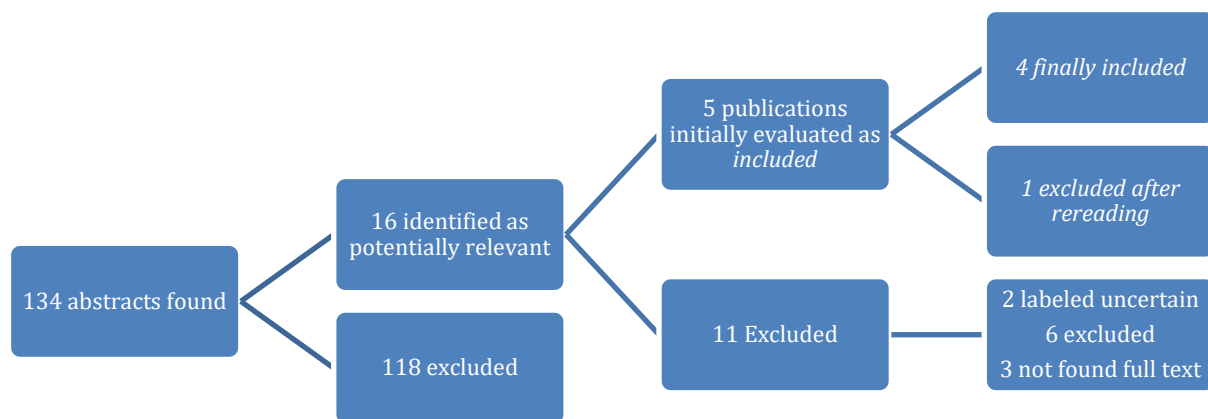


Figure 1 - Identification of relevant studies

The article excluded, *Public knowledge and attitudes to HIV: Research from three decades in Sweden* (2017), aimed to describe Swedish public attitudes and knowledge concerning HIV (59). At eight occasions between 1987 and 2011 questionnaires were distributed to a representative sample of the general public, exploring 27 questions regarding attitudes and knowledge about HIV (59). 10 000 individuals between 16-44 years of age responded (59). The study does not solely include people living with HIV or the experiences of stigma, however, it investigated the public's attitudes toward HIV as a diagnosis and the possible change in knowledge and attitudes during the mentioned period. Further, the study investigates stigma and possible stigma-reduction over time (59). Hence, the study contributes to a broader understanding of HIV-related stigma and thus provided useful insights, but was deemed not to qualify the inclusion criteria set for this review.

3 Results

3.1 Introduction

To critically appraise and synthesize the findings, we utilized three tools from different methods; a reminders table exemplified in Finding What Works in Health Care: Standards for Systematic Reviews (60), Critical Appraisal Skills Program (CASP) check-list (61), and the description of JBI manual for evidence synthesis (JBIMES) (52). Due to the included screening questions in the CASP-checklist (61), this check-list was chosen for use in the assessment of the quality of each study included in this review. Note that the score of dependability is followed by the JBIMES score of dependability (52) since CASP-checklist do not recommend scoring (61). Nevertheless, the JBIMES dependability questions is found to be similar to the CASP-checklist questions, however, the screening questions in the CASP-checklist aided in the thoroughness of the assessment. Before rating with the JBIMES score of dependability, the JBIMES list of questions were compared with the CASP-checklist, and then rated.

In this part of the thesis the four included studies will be introduced before investigating the reviewed studies characteristics of methodology, strengths, and limitations. First, we explore each of the study's methodology of characteristics such as type of study, participants, recruitment process and data collection including exclusion and inclusion criteria and timeframe as well as their analyzing method of choice. Further, we will explore strengths and limitations as well as self-reported strengths and limitations. There will be a short discussion to argue the quality of the four included studies before summarizing this segment with a conclusion.

3.2 Included studies

Four articles were included in this review to be explored further. Data was extracted from the studies including aim or purpose of the study, characteristics of the methodology, findings as well as findings relevant to this review. Shown in table 6 is an overview of the four articles included, and there will be a brief presentation of each of the studies together with a presentation of a shortened CASP-checklist. The full-length CASP-checklist is to be found in appendices E-H along with comments to the screening questions included in the CASP-checklist. Further exploring of the individual studies will be presented in section 3.2.

Title (Year) (Authors)	Method, design,	Country, number of participants and setting	Findings
<p>Towards a new understanding of HIV-related stigma in the era of efficient treatment - A qualitative reconceptualization of existing theory (2020) (Maria Reinius, Galit Zeluf Andersson, Veronica Svedhem, Lena Wettergren, Maria Wiklander, Lars E. Eriksson)</p>	<ul style="list-style-type: none"> - Qualitative study - In-depth, semi-structured interviews - Framework approach to analysis 	<ul style="list-style-type: none"> - Sweden - 15 participants, 8 women, 7 men - 30-64 years of age - Participants recruited in an outpatient clinic - Interview lasted from 23 and 129 minutes 	<ul style="list-style-type: none"> - Those who worked in healthcare settings described how colleagues talked badly about patients with infections and how that affected them. - Talked about not having access to fertility treatment in Sweden when wanting to have a baby. - Participants anticipated being treated badly or that their children would be treated badly if others knew about their HIV. - Described stigma as a barrier in many situations - Anticipated and enacted stigma were to be more complex than described in existing literature - Labelled as a person with HIV – important and persistent part of stigma experience - Disclosure found to be context-related, and participants weighed the relevance of disclosure – even in health care situations - Nondisclosure – avoid labelling - Experiences of people talking behind their backs or in negative context about other people living with HIV - The HIV stigma framework could benefit from revision - In addition to describing situations experienced directly, participants often incorporated other peoples’ encounters with stigma as part of their own stigma experience. <p>Findings similar across studies:</p> <ul style="list-style-type: none"> - Fear of losing control - Control as an important aspect regarding HIV - Felt responsibility to disclose status to others - Experiences of people talking behind their backs or in negative context
<p>Experiences of young adults growing up with innate or early acquired HIV infection--a qualitative study. (2013) (Lise-Lott Rydström, Britt-Marie Ygge, Björn Tingberg, Lars Navèr, Lars E Eriksson)</p>	<ul style="list-style-type: none"> - Exploratory qualitative study - Analyzed using qualitative content analysis 	<ul style="list-style-type: none"> - Sweden - 14 participants, 4 declined – 10 participants (5 male, 5 female) - 15-21 years of age - Recruited from clinic - Interview lasted from 45 to 90 minutes 	<ul style="list-style-type: none"> - Living with a dark secret - Participants hid their HIV status and only declared their status in healthcare situations to protect themselves from the risk of being stigmatized - Fear of being judged - Ignorance and prejudice were more harmful than the disease itself - Disclosure related to fear and insecurity - Participants expressed their worry that if their HIV status was discovered, they could be accused of unaccepted behavior in society - The potential spread of rumors (of HIV status) could lead to isolation, powerlessness, and alienation. - Some participants believed they could maintain control and decrease prejudice and ignorance by being open about their HIV infection. - The participants expressed their pediatric care for HIV treatment as fairly good. - Some of the participants relied heavily on their healthcare providers - Healthcare staff lacking sufficient skills and knowledge about HIV induced frustration and anger among the participants. - High quality of the health care providers was important because they mostly only felt safe to disclose their diagnosis to them - Health care professionals were viewed as an important aid in coping with HIV - Stigma and discrimination were a major issue – governing in participants decisions about how to live their lives

			<ul style="list-style-type: none"> - Maintaining secrecy and being partly open about HIV to avoid and protect the family from prejudice and negative attitudes. - Efforts to decrease stigma and discrimination, and disclosure matters were warranted, by the researchers, on the societal, community and family level <p>Findings similar across studies:</p> <ul style="list-style-type: none"> - Living with a dark secret - Related disclosure to fear and insecurity - Could be accused of unaccepted behavior in society - The potential spread of rumors linked to HIV infection - Maintaining secrecy and being partly open about HIV infection were strategies employed - Efforts to decrease stigma and discrimination, and disclosure matters were warranted, by the researchers, on the societal, community and family level
<p>Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld phenomenological study. (2018) (Ewa Carlsson-Laloo, Marie Berg, Åsa Mellgren, Marie Rusner)</p>	<ul style="list-style-type: none"> - Qualitative Study - Individual phenomenon-oriented interviews - Analyzed using phenomenological reflecting lifeworld analysis 	<ul style="list-style-type: none"> - Sweden - 23 females recruited, 18 included - 30-60 years of age - Recruited through 5 medical clinics (strategically) - Interview lasted from 42-101 minutes 	<ul style="list-style-type: none"> - Expectations about people's reactions and bad experiences of a partner leaving after learning about their partner's positive HIV status - Fear of being judged or rejected - Some participants feel that they should not get pregnant and have children - Feeling of receiving "unfair" treatment and discrimination, compared to HIV-negative women - Feelings of alienation - Belief that one is not able to obtain what all other women have: a home, a partner, a relationship, a child - A feeling of missing out on opportunities was common - Health care providers can have an impact on feelings of acceptance - Feelings of guilt and shame - Experiences of stigmatization due to perceptions of contagiousness and transmission - Feeling of lack of knowledge that leads to prejudice and misconceptions - Feeling of being questioned about their right to have a baby by the health workers - Level of self-perceived stigma in the health care system = feeling of not receiving equal health care - Perceptions about contagiousness are present health care professionals <p>Findings similar across studies:</p> <ul style="list-style-type: none"> - Expectations about people's reactions and bad experiences of a partner leaving after learning about their partner's positive HIV status - Experiences of stigmatization due to perceptions of contagiousness and transmission
<p>How gay men living with HIV experience and perceive the HIV stigma: a qualitative study (2018) (Anette Enoksen, Bente Træen)</p>	<ul style="list-style-type: none"> - Qualitative Study - In-depth, semi-structured interviews - Thematic analysis 	<ul style="list-style-type: none"> - Norway - 10 male participants - Recruited from Aksept and HIVNorge – organizations working with individuals affected by HIV and snowballing 	<ul style="list-style-type: none"> - Predominantly seemed satisfied with the treatment received - All participants reported one or more negative experiences (friends, family, work, sex partners or in the health care system) - Some participants described their lives as heavily influenced by stigmatization - Treated differently than other patients - Asked invasive and unrelated questions - Top-down attitudes from general practitioners (GPs), - Not being given important information regarding treatment - Nervous and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy), - Little psychological follow-up - Or in other ways showing an incapability to act on the patient's needs. - Anticipated stigma most common

		<p>- Interview lasted from 1 hour to 2 hours and 40 minutes</p>	<p>- Self-stigma was generally regarded as the biggest concern. - Great gaps among the stigma experienced, from whom, how it was experienced and how they dealt with it</p> <hr/> <p>Findings similar across studies:</p> <p>- From the participants' narratives, both the fear of being exposed and the active attempt to hide their differentness can be exhausting burdens for those carrying such a secret. - Several participants described living with a secret as burdensome or exhausting. - Need for demystifying the condition and increase knowledge to decrease stigma - Encountered stigma in varying contexts and arenas, through having to deal with a hidden identity and issues related to disclosing or not disclosing this hidden identity, through negative self-perception, and through unwanted responsibilities.</p>
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Table 6 - Overview of the included studies

Towards a new understanding of HIV-related stigma in the era of efficient treatment-A qualitative reconceptualization of existing theory (2020) by Maria Reinius, Galit Zeluf Andersson, Veronica Svedhem, Lena Wettergren, Maria Wiklander, Lars E. Eriksson (33) investigated how experiences of HIV-related stigma in Sweden corresponded Earnshaw and Chaudoir's HIV stigma framework(33). This was a qualitative study using semi-structured interviews analyzed with a framework approach aiming to discover whether Earnshaw and Chaudoir's HIV stigma framework needed revision to fit better to stigma-experiences today in countries where viral treatment is available and most people living with HIV are virally suppressed (33).

Table 7 - Shortened CASP-checklist and JBIMES dependability score (appendix E)

Towards a new understanding of HIV-related stigma in the era of efficient treatment-A qualitative reconceptualization of existing theory			
Maria Reinius, Galit Zeluf Andersson, Veronica Svedhem, Lena Wettergren, Maria Wiklander, Lars E. Eriksson			
Received 2020, accepted 2021 (Journal of advanced nursing)			
	Yes	Can't tell	No
Was there a clear statement of the aims of the research? <i>The aim was to describe the experiences of HIV-related stigma among people living with virally suppressed HIV in Sweden and investigate how these experiences correspond to the stigma mechanisms of Earnshaw and Chaudoir's (2009) HIV stigma framework, to further develop the framework.</i>			
Is a qualitative methodology appropriate			
Was the research design appropriate to address the aims of the research?			
Was the recruitment strategy appropriate to the aims of the research?			
Was the data collected in a way that addressed the research issue			
Has the relationship between researcher and participants been adequately considered?			
Have ethical issues been taken into consideration?			
Was the data analysis sufficiently rigorous?			
Is there a clear statement of findings?			
How valuable is the research?			
Dependability (following JBI ConQual score)	High		

Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study (2013) by Lise-Lott Rydström, Britt-Marie Ygge, Björn Tingberg, Lars Navèr, Lars E Eriksson (58) discovered a knowledge gap regarding the life situation for young adults living with HIV, and with their study aimed to explore the experiences on how it is growing up and living with HIV for young adults. This is an exploratory qualitative study with in-depth interviews(58).

Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study			
Lise-Lott Rydström, Britt-Marie Ygge, Björn Tingberg, Lars Navèr, Lars E Eriksson Accepted 2012 (Journal of advanced nursing)			
	Yes	Can't tell	No
Was there a clear statement of the aims of the research? <i>The aim of the study was to explore the experience of young adults growing up and living with HIV in urban Sweden.</i>			
Is a qualitative methodology appropriate			
Was the research design appropriate to address the aims of the research?			
Was the recruitment strategy appropriate to the aims of the research?			
Was the data collected in a way that addressed the research issue			
Has the relationship between researcher and participants been adequately considered?			
Have ethical issues been taken into consideration?			
Was the data analysis sufficiently rigorous?			
Is there a clear statement of findings?			
How valuable is the research?			
Dependability (following JBI ConQual score)	Moderate		

Table 8 - Shortened CASP-checklist and JBIMES dependability score (appendix F)

Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld phenomenological study (2018) by Ewa Carlsson-Lalloo, Marie Berg, Åsa Mellgren and Marie Rusner (62) aim to investigate experiences that women living with HIV have with regard to sexuality and childbearing(62). This qualitative study was attained by individual phenomenon-oriented interviews and analyzed using reflective lifeworld approach (62). The authors refer to *sexuality and childbearing* as the phenomenon to be in focus. This is reflected in their choice of phenomenological reflective lifeworld approach analysis and conducted phenomenon-oriented interviews(62). Further, with a phenomenological lifeworld analysis the goal is to describe and obtain the meaning structure, often referred to as *essence*, of a phenomenon, and variants of that essence as to understand the phenomenon(62, 63).

Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld phenomenological study			
Ewa Carlsson-Lalloo, Marie Berg, Åsa Mellgren & Marie Rusner			
Accepted and published 2018 (International Journal of Qualitative Studies on Health and Well-being)			
	Yes	Can't tell	No
Was there a clear statement of the aims of the research? <i>The aim was to describe the phenomenon sexuality and childbearing as experienced by women living with HIV in Sweden.</i>			
Is a qualitative methodology appropriate			
Was the research design appropriate to address the aims of the research?			
Was the recruitment strategy appropriate to the aims of the research?			
Was the data collected in a way that addressed the research issue			
Has the relationship between researcher and participants been adequately considered?			
Have ethical issues been taken into consideration?			
Was the data analysis sufficiently rigorous?			
Is there a clear statement of findings?			
How valuable is the research?			
Dependability (following JBI ConQual score)	High		

Table 9 - Shortened CASP-checklist and JBIMES dependability score (appendix G)

How gay men living with hiv experience and perceive hiv-stigma: a qualitative study (2018) by Anette Einan Enoksen, Bente Træen (supervisor) (3). This study aims to investigate how stigma is experienced, perceived and dealt with by gay men living with HIV (GMLH) in Norway (3). Further the aim is supported by three subordinate research questions:

- What are the GMLHs' experiences with social stigmatization related to their serostatus, and how and from whom do they receive negative prejudice? (3 p.8)
- What are the GMLHs' experiences with internalized HIV negativity and self-stigma, and do they experience any positive aspects of the diagnosis? (3 p.8)
- How do GMLH potentially deal with HIV-related stigma? (3 p.8)

This was a qualitative Study with in-depth, semi-structured interviews of ten gay men in Norway, analyzed using thematic analysis (3).

How gay men living with hiv experience and perceive hiv-stigma: a qualitative study			
Anette Einan Enoksen, Bente Træen			
Published 2018 (Scandinavian psychologist)			
(The version used in this thesis is her master's dissertation of which the article is based upon)			
	Yes	Can't tell	No
Was there a clear statement of the aims of the research? <i>The aim of this study was to investigate how HIV-related stigma is experienced and perceived by gay men living with HIV (GMLH), and how they deal with it.</i>			
Is a qualitative methodology appropriate			
Was the research design appropriate to address the aims of the research?			
Was the recruitment strategy appropriate to the aims of the research?			
Was the data collected in a way that addressed the research issue			
Has the relationship between researcher and participants been adequately considered?			
Have ethical issues been taken into consideration?			
Was the data analysis sufficiently rigorous?			
Is there a clear statement of findings?			
How valuable is the research?			
Dependability (following JBI ConQual score)	High		

Table 10 - Shortened CASP-checklist and JBIMES dependability score (appendix H)

3.2.1 Methodological characteristics

Finding What Works in Health Care: Standards for Systematic Reviews (60) recommendation on how to synthesize body of evidence is used to extract the information needed from each of the included studies with regard to their methodological characteristics (60). This section will describe the different studies regarding type (method and design), participants and study sizes, methods of recruitment, data collection, inclusions and exclusions made, timeframe and method used to analyze the data collected in the different articles.

Type of study

All four of the included articles were qualitative studies from Scandinavia conducted, written, and published between 2013 to 2021. All studies report to have been appropriately ethically approved. Enoksen (2018) conducted her study in Norway (3) whereas Rydström et al. (2012), Ewa Carlsson-Laloo et al. (2018) and Reinius et al. (2020) were conducted in Sweden (33, 58, 62).

In-depth interviews were conducted in all four studies, three of them being semi-structured whereas Carlsson-Laloo et al. (2018) conducted a phenomenon-orientated⁸ interview (3, 33, 58, 62). All the interviews were mainly open-ended, and the researchers or interviewer used an interview guide/protocol that the researchers had prepared prior to the interviews. Enoksen (2018) and Rydström et al. (2012) respectively reviewed and tested the guide/protocol to be able to edit it to become more precise with regard to the aim of the study, hence also increasing trustworthiness (3, 58). The interviews were conducted individually face-to-face and was recorded and transcribed shortly afterwards. The timeframe for each study was noted to range from 3 months (Enoksen, 3) of data collection at the shortest, and 8 months (Rydström et al., 58, Carlsson-Laloo et al., 62) at the longest.

Participants

The participants were found to be relevant to the individual studies regarding the individual aim of the different studies and their inclusion criteria. The number of participants differed

⁸ An approach based on phenomenological philosophy. To understand the essence (a structure of essential meanings) that makes the phenomenon (p. 11, Dahlberg 2006)

from 10 (Enoksen, 3) to 18 (Carlsson-Lalloo et al., 62) individuals living with HIV. One study included only male participants (Enoksen, 3), and one included only female participants (Carlsson-Lalloo et al., 62) whereas the remaining two articles were mixed gender (close to 50/50 male/female) (Reinius et al., 33, Rydström et al., 58). Two studies included adults 18 years and older, with an age spread of 30-60 years (Carlsson-Lalloo et al., 62) and 30-64 years (Reinius et al., 33). One study included participants 15 years and older (Rydström et al., 58), while the last study (Enoksen, 3) did not disclose the age span of the participants. The participants were either Norwegian or Swedish residents with different ethnic background such as Asian, African, and European. The participants were fluent in the language of country of residence (i.e., Swedish, or Norwegian) or English.

Route of transmission differed amongst the participants, including mother-to-child transmission, sexual transmission, other or unknown routes of transmission. Neither study reports how long each of the participants had lived with a confirmed diagnosis of HIV, although the inclusion criteria clarify that to be included the participant must have lived with a confirmed diagnosis of HIV for a minimum of 6 months at the shortest (Carlsson-Lalloo et al., 62). Sexual orientation was not addressed by the different researchers as a part of the interview questions, however, there were participants disclosing their sexual orientation to the interviewer voluntarily. In Enoksen's study, all the participants identified as gay men (3).

Recruitment

Purposeful (Reinius et al., 33), convenient (Rydström et al., 58), strategic (Carlsson-Lalloo et al., 62) sampling method was used in recruitment. Enoksen (2018) used, in addition to purposeful sampling, the snowballing method as well (Enoksen, 3). Participants were recruited from locations where the possibility to get participants was high (clinics/hospitals/non-governmental organizations). Hence, a majority of participants were recruited mainly through healthcare facilities or clinics that specialized in HIV or organizations working with HIV. Neither of the studies explained the reasoning behind the number of participants chosen to the study, however it was emphasized geographically relevance for applicability.

The number and type of locations chosen differed across the studies. Reinius et al. (2020, 33) and Rydström et al. (2013, 58) used only one location for recruitment whereas Carlsson-Lalloo et al. recruited participants from five different clinics (62). Enoksen (2018) also used a snowballing method as a part of the recruitment process for her study, i.e. recruited participants recruiting friends/contacts, as well as recruiting from organizations working with individuals affected by HIV (Aksept and HIVNorge) (3).

There was a total of 23 women interested in participating in Ewa Carlsson-Lalloo et al. (2018) study, however, five of them were not interviewed due to two not showing up, two changed their mind and one woman did not want to be recorded (62). Rydström et al. (2013) recruited 14 possible participants whereof four declined (58). Three young adults declined on advice from their parents, and one declined for the reason that he/she rather preferred not to think about their HIV-infection (58). Enoksen (2018) and Reinius et. al. (2020) did not report any declines or withdraws from their recruitment (3, 33).

All the participants included in the studies were given both spoken and written information of the study at the location, as well as a consent form to sign before the interview. If the participants were minors, their parent or parental guardian signed the consent form as well. The participants were informed of anonymization and further anonymized with pseudonyms when referred to or quoted in the study.

Participation in all studies was voluntary, with no financial benefits promised for this participation. Information on withdrawal from the study was also provided.

Data Collection

In-depth interviews were conducted in places chosen by the participant in three of the four studies. Enoksen (2018) does not clearly state whether the participant or the researcher chose the interview setting (3). The locations for the interviews could either be at the clinic, if recruited there, or wherever the participant felt safe for example at a café. Reinius et al. (2020) used a registered nurse and a PhD student trained in interview techniques together with a social scientist and PhD student experienced in qualitative interviewing as interviewers (33). Whether the two interviewers were in the research group were not clearly expressed (33). Rydström et al. (2013) used an external senior pediatric nurse as the interviewer (58),

whereas Ewa Carlsson-Lalloo et al. (2018) and Enoksen's (2018) interviews were conducted by the first author (3, 62). The researchers prepared a semi-structured interview guide/protocol to stay on topic. Enoksen (2018) and Rydström et al. (2013) reported testing the guide/protocol beforehand and/or changing it to fit more properly to their study objective whereas the other studies did not report whether this was conducted during their phase of interviewing (3, 58).

The widest difference in interview timeframe was seen in Reinius et. al.'s (2020) study with interviews lasting from 23 minutes to 129 minutes (33), whereas the three other studies conducted interviews lasting at least 45 minutes up to 2 hours and 40 minutes at the most in Enoksen's (2018) study (3). All the studies were audio-recorded, and the recordings were transcribed afterwards, however, neither of the authors reported the time between recording and transcribing the interviews.

There were some differences in the method of transcription. In all but Enoksen's (2018, 3) study the transcription was verified by a second author (33, 58, 62). Furthermore, everyone in Rydström et al. (2013), Ewa Carlsson-Lalloo et al. (2018) and Reinius et al. (2020) research team participated in the discussion of the transcribed interviews and the data analyzing process to some degree (33, 58, 62). Ewa Carlsson-Lalloo et al. (2018) had the translated transcription reviewed by a native English speaker (62). All authors states that the recordings and the transcriptions were deleted at the end of the study (33, 58, 62). Nevertheless, Enoksen (2018) also reported on how the recordings, transcriptions and consent forms were stored to protect the participants anonymity, and the use of a transcription program (Olympia, DSS Player Standard Transcription Module) for effectiveness of the process (3).

Inclusion/exclusion

Inclusion criteria and the number of criteria differed between the studies. Ewa Carlsson-Lalloo et al. (2018) and Enoksen (2018) included only one gender in their study, respectively one all female and one all male study (3, 62), whilst the other Rydström et al. (2013) and Reinius et al. (2020) were mixed gender studies (33, 58). Age as an inclusion criteria for the study were most visible in the study *Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study* (2013) where the aim was to investigate young adults living with HIV in Sweden, and they included younger individuals between 15

and 21 years of age (58). However, even if not mention specifically the minimum age in the other studies reviewed were 18, which are the legal age, in both Sweden and Norway, in which one does not need parental or guardian consent (64, 65). No inclusion or exclusion criteria regarding country of origin, or way of transmission were observed. One inclusion criterion across all studies was time lived with HIV. However, length lived with HIV were not specified rather participants had to have known their HIV status for at least 6 months. Reinius et al. (2020) reported an inclusion criterion of participants being virally suppressed, since the aim of the study were to understand HIV-related stigma in the era of efficient treatment (33). The participants viral load was not reported on in the other studies.

Exclusion criteria did not differ across the studies, and they were not many. All the studies had chosen to exclude newly diagnosed individual, individuals with ongoing crisis reaction and/or mental illness.

As mentioned in *recruitment* there were, in both Rydström et al. (2013) and Ewa Carlsson-Lalloo et al. (2018) studies, recruited more participants than were included in the final study (58, 62). The participants chose themselves not to participate and therefore withdraw from partaking in the studies, hence, there was not reported exclusion of participants done by the researchers due to inclusion/exclusion criteria.

Timeframe

The timeframe for each study was noted to range from 3 months, Enoksen (2018, 3), of data collection at the shortest, and 8 months, Carlsson-Lalloo et al. (2018) and Rydström et. Al. (2013), at the longest (58, 62). Reinius et al. (2020) did not report timeframe of their study (33). With this in mind, one might expect to see a large variation in participant numbers between the studies with short periods of data collection and those with longer periods. Nonetheless, there were two studies with 10 participants, Enoksen (2018, 3) and Rydström et. al. (2013), Reinius et al. (2020) study had 15 participants (33, 58), and Ewa Carlsson-Lalloo et al. (2018) had 18 participants (62).

Method of analysis

All four studies utilized different methods of analyzing the collected data: qualitative content analysis (Rydström et al., 58), reflecting lifeworld analysis (Carlsson-Lalloo et al., 62), thematic analysis (Enoksen, 3) and framework approach (Reinius et al., 33). Further, the studies differed in the depth of explaining their choice of method and the analyzing process.

In the study *Towards a new understanding of HIV-related stigma in the era of efficient treatment-A qualitative reconceptualization of existing theory* (2020) the aim was to investigate how experiences of HIV-related stigma correspond to the stigma mechanisms of Earnshaw and Chaudoir's HIV stigma framework, thus Reinius et. al (2020) used a framework approach and predetermined codes when analyzing their data (33). Having said that, Reinius et. al (2020) reports that predetermined coding may lead to confirmation bias, hence, they critically approached the coding process (33). Further, they did code inductively if the content were not applicable to the stigma mechanisms of Earnshaw and Chaudoir (32, 33). The research team read and discussed the transcriptions and discussed how the content corresponded with the stigma mechanisms before coding the material as related to either enacted, anticipated, or internalized stigma(33). Additionally, this study was the only study that got their analysis peer debriefed to make the authors aware of preconceived biases (33).

Both the first and second authors of the study *Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study* (2013) used qualitative content analysis which began with transcriptions being read both individually and together by the first and second author to achieve consensus (58). Further, meaning units were identified, condensed, and coded before sub-categorized (58). This resulted in five categories; to protect oneself from being stigmatized, to be in control, losses in life, but HIV is not a big deal, healthcare/healthcare providers, and belief in the future (58). Results were discussed with all the co-authors during the entire process (58). Rydström et al. (2013) reports that there are some linguistic changes were made to increase the clarity of the quotations without changing the content (58).

Phenomenological reflecting lifeworld analysis was used to analyze the collected data in the study *Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a*

lifeworld phenomenological study (2018) (62). This method was chosen as to best describe the meaning structure of the phenomenon *sexuality and childbearing* (62). The data was analyzed as a whole, then by parts before reconstructing the whole understand the meaning structure of the phenomenon (62). This process, as stated by the authors was to: "uncover particular nuances of meaning" (62, p.3). More so, "Meaning units—a word, a sentence, or a longer piece of text, relevant to experiences of the phenomenon, sexuality and childbearing—were identified" (62, p.3). To ensure trustworthiness, all the co-authors were involved in processing the results before final the final version (62).

Anette Enoksen (2018) conducted thematic analysis when analyzing the data collected in the study *How gay men living with hiv experience and perceive hiv-stigma: a qualitative study* (3). The choice of analyzing method were described using a analytical process consisting of six stages; familiarization, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (3).

Rydström et al. (2013) and Carlsson-Lalloo et al. (2018) did both report the use of computer program NVivo 11 (58, 62). Rydström et. al. (2013) reported that 14 of the 15 transcribed interviews were coded using NVivo 11, nevertheless, the first and second author coded the same transcripts at the same time as well as weekly comparing and adjusting the coding (33). Carlsson-Lalloo et al. (2018) utilized NVivo 11 to organize the data material rather than analyze (62).

All but one study, (Enoksen, 3), had several authors which all read the whole or parts of the transcriptions and discussed the findings and coding process. Carlsson-Lalloo et al. (2018) and Rydström et. al. (2013) also used a data program to organize data material (58, 62).

3.2.2 Strengths, limitations, and possible bias in the reviewed studies

With regard to reporting on their studies rigor and possible limitations only Reinius et. al. (2020, 33) and Rydström et al. (2013, 58) that discuss rigor, whereas all the studies report on possible limitations (3, 33, 58, 62). Rigor in qualitative studies may, however, be more difficult to maintain, assess, and demonstrate (66).

In *Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld phenomenological study* (2018) by Ewa Carlsson-Lalloo et al. describe the inclusion of many women not born in Sweden as a strength to the study (62). Further, they state this inclusion as a strength due to the broad variance of lived experiences of their explored phenomenon (62). To maintain and establish objectivity and validity throughout the research the researchers used a methodological principle of bridling⁹ (62, 63). In terms of limitations, the authors discuss that none of the participants were from eastern Europe, Australia, or the American continent, and that neither of participants had a history of drug abuse (62). Both limitations were assumed to be caused by the low prevalence of HIV infections in Sweden (62).

Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study (2013) by Rydström et al. report their limitation that even though the result ought to represent the experiences of young adults living with HIV in urban Sweden, it might not be applicable for young adults living in smaller communities lacking specialist care (58). However, the authors strived for a mixed sample with regard to age, sex, background (58). And they included two authors with no or limited experience with HIV infected youth or children so to minimize biased interpretation and results (58).

Reinius et al. (2020) report on rigor as well as limitations in their study *Towards a new understanding of HIV-related stigma in the era of efficient treatment-A qualitative reconceptualization of existing theory* (2020) (33). All co-authors were involved in the analyzing process and they conducted a peer-debriefing to discover possible preconceived bias and enhance credibility of the analysis (33). They postponed the analysis of one interview for referential adequacy (33). They discuss the limitation of using predetermined coding when analyzing and how they critically approached this method of analysis (33).

Anette Enoksen (2018) states several limitations to her study *How gay men living with hiv experience and perceive hiv-stigma: a qualitative study* (3). The study is not intended to be representative for all gay men living with HIV (3). More so, the study recruited men from

⁹ Bridling (a methodological principle) – "an understanding that not only takes care of the particular pre-understanding, but the understanding as a whole. We bridle the understanding so that we do not understand too quick, too careless, or slovenly, or in other words, that we do not make definite what is indefinite" (p.16, Dahlberg, 52)

Oslo area of Norway and might therefore not be representative for gay men living with HIV with other demographic backgrounds (3). Further, Enoksen report the possibility of a wider range of narratives if the time frame of her study, with the possibility of including more participants, were extended (3). Nevertheless, Enoksen argue that there was a good variety of narratives, and that the similarities was easily observed as a result of achieved saturation of data (3). Furthermore, Enoksen also reflects on how her being a white female in her 20s, and obviously not a member of the reference group, might influence the data collected (3).

Possibilities of bias – a short discussion

In a systematic review and critical appraisal, it is important to investigate the possibilities of bias as qualitative research may be criticized as being biased as well as being small scaled, anecdotal, and/or lacking rigor (66). Nevertheless, if the study is properly conducted the outcome may culminate to be unbiased, in depth, valid, reliable, credible and rigorous (66). In this section there will be a brief discussion on the reviewed studies possibilities of bias, as well as their credibility, reliability, and validity.

When reporting on the different methodological characteristics, the authors differed in the degree of the information given.

The nuances that might have appeared in the data collection, read, interpreted, and explained by the researchers, may be understood differently than what it originally meant when participant responded to the questions (66). Further, the researchers and the participants understanding of key concepts might not the same (66). In this review there is no observation of discussion whether researchers and participants conducted an agreement of key concepts prior to the interviews, or if the participants validated the data after it had been analyzed in any of the studies, which might have biased the results.

Moreover, the quality of the research depends on individual skills of data collection and may easily be influenced by personal biases and idiosyncrasies (66). Furthermore, the researchers presence during the data gathering may affect the participants responses as well (66). With that said, one might argue that the use of external interviewer, perhaps with experience of data collection, as Rydström et al. (2013, 58) and Reinius et al. (2020, 33) did, may lessen the possibility bias concerning the researcher's preunderstanding and/or previous knowledge to

the topic. Nevertheless, for the same reason bias may occur due to the lack of including/interpreting the responses with body language and other nuances that might be present during the interview (66). In the article *Presenting and Evaluating Qualitative Research* (2010, 66) Claire Anderson states that a qualitative researcher should consider how participants structured their responses as well as their feelings and reactions to the subject discussed, and the participants emotions, tone, nonverbal communication etc. (66). Both Rydström et al. (2013) and Reinius et al. (2020) conducted their study using external interviewer(s) in their data collection process (33, 58).

Respondent validation may provide feedback on the researchers' interpretations of the participant responses, and that might aid in an investigation of possible inconsistencies as well as challenge the researchers' assumptions (66). Furthermore, it provide an opportunity to re-analyze data, thus further strengthen of the study (66). Nevertheless, neither of the studies included in this review reported respondent validation, which could have strengthened their study's validity and perhaps clarified their results further.

Carlsson-Lalloo et al. (2018) were the only study using the wording feel/feels/feeling when describing and interpreting the collected data and responses (62). Enoksen (2018) reported writing down initial thoughts after each interview, as well as using a transcription program to enhance effectiveness (3). This has the potential for strengthening might the study when analyzing the data.

Layered stigma is described as having more than one "trait" that could lead to experiences of stigma (3, 33), and was mentioned in both Reinius et al. (2020) and Enoksen (2018) studies (3, 33). Being homosexual as well as living with HIV (3) or being of a minority ethnic group as well as living with HIV (33) is examples that may lead to experiences of layered stigma. Layered stigma might bias the participants response as they might not always know what the reason behind their experienced stigma or discrimination may be, and layered stigma might, therefore, impact the credibility of the findings. Reinius et al. (2020), however, state that participants stayed focused on, and responded to, experiences of HIV-related stigma despite touching upon layered stigma (33).

When studying an HIV-related stigma framework Reinius et al. (2020) found that participants to some degree described not only their experiences with HIV-related stigma, but also people

close to them, or examples of experiences of stigma they had heard of (33). This is not described or found in the other articles; however, this finding might be regarded as an important possible bias of subjective experience of HIV-related stigma. Further, it shows that HIV-related stigma is experienced beyond those who participated in the studies.

There is more than one method to use in qualitative research, each with their strengths and weaknesses. Nevertheless, the researchers have all chosen a method they felt appropriate for their research, and the authors all reasoned for their choice of method. Enoksen (2018) changed the method originally chosen, from interpretative phenomenological analysis to thematic analysis, arguing that it strengthen the data extraction and study itself (3). Even though the method, and the depth of describing the method, differed between studies, their method of choice appears to be reasoned for and described, aiding in strengthening the validity and reliability of their studies. All four studies reported findings relevant to their aim showing that their chosen method was the appropriate one.

All the studies aimed to investigate experiences of HIV-related stigma in either Sweden or Norway, however, neither of the studies discussed when nor where the participant got infected, or if the participant had gotten treatment outside Sweden or Norway prior to moving there. This not being discussed might bias the results and not give a clear result as to experiences while living in Sweden or Norway. With this said, previous experience of prejudice and discrimination might affect the degree in which one expect experiences of stigma (anticipated stigma) (32).

3.2.3 Conclusion of chapter 3

As the goal of critical appraisal is to assess the risk of bias with regard to the methodological quality as well as establish whether the studies has been conducted so as to minimize the possibilities of bias (52), this review has explored four studies further in their design, conduct and analysis.

As described in section 3.1 (page 24) the CASP checklist was chosen for use in the assessment of the quality of each study included in this review, and JBIMES score of dependability was, and a shortened checklist with the score of dependability is found in table seven through ten (pages 28-31). With the JBIMES score of dependability, three of the four

studies rated as of high dependability. *Experiences of young adults growing up with innate or early acquired HIV infection (2013)* was rated as moderate dependability. The four studies appear to be transparent regarding the different categories of characteristics of the methodology explored in chapter 3.2.1 (page 32). The CASP-checklist allowed for a deeper understanding of the reviewed studies. The studies are conducted thoroughly, no matter the differences in methodology.

There are both strengths and limitations regarding methodology of characteristics for the included studies. The different studies reasoned for how their chosen design is appropriate. The aim and subject of the individual studies were to some degree the same; aiming to explore the experiences of stigma among individuals living with HIV. There are differences in number of participants and timeframe across the individual studies, as well as the timeframe for the interviews differ within the individual studies, however, this is not considered a limitation.

No systematic errors necessitating the need for disregarding studies were found, and all the studies is found to be relevant and valid for further exploring on the findings they have reported on.

4 Findings

Findings were synthesized as per guidance in JBI manual of synthesizing (52) and Finding What Works in Health Care: Standards for Systematic Reviews (60). The aim of this review is to investigate the *experiences of stigma amongst HIV-positive people encountering the healthcare system in Scandinavia*. Since stigma is experienced both inside and outside the healthcare setting, the majority of the included reviews investigated this phenomenon in all settings. Our results focus on those pertaining to healthcare only.

Following the two sources of guidance might strengthen findings of this review. In this section the process used when extracting findings from the individual studies will be described, as well as the findings extracted. Further, it will investigate the relevance and applicability of the findings before concluding with a short summary of the findings.

4.1 Process

JBI manual of synthesizing emphasizes the importance of describing the process of extraction of findings (52). The process conducted in this review began with the reviewer (one) reading the different studies several times both on the computer as well as on paper. Notes were taken each time reading the different studies before retrieving extracts that could be considered possible findings. Further, the possible findings were written down in different documents and then compared to explore which findings were included and excluded when read and noted the different times.

Findings in this review was limited to participant quotes and the researchers' interpretation of the participants quotes as well as researchers' observations. Furthermore, extracts described by the researchers as findings regarding experience of stigma was extracted. Pertinent findings throughout the whole article were also included. When first extracting finding, all findings in relation to stigma that could be of relevance or directly relevant to healthcare system were extracted and written down in a reminders table exemplified in Finding What Works in Health Care: Standards for Systematic Reviews (60) (Appendices A-D).

As a part of the process color-coding was used to separate the findings in the reminders table. Findings related to the healthcare system was given the green color, findings similar across studies was given purple color, and findings that might be relevant although not specifically

relatable to healthcare system was given black color (Appendices A-D). The findings were evaluated using JBIMES levels of credibility (52), and relevant findings grouped into two categories: *HIV-related stigma outside the healthcare system* and *HIV-related stigma in healthcare system* solely based on the setting of the findings.

HIV-related stigma is experienced in everyday life of people living with HIV (1), and Earnshaw and Chaudoir's (2009) description of enacted stigma (the degree to which an individual believe they have experienced prejudice and discrimination previously) and anticipated stigma (the degree of expecting experience of prejudice and discrimination, often based on previous experiences) (32) might also have an influence on people living with HIV when seeking healthcare. Nyblade et al. (2009) report that enacted and anticipated stigma are associated with people not accessing care and treatment when needed (46). *HIV-related stigma outside the healthcare system* is therefore included in the extraction of findings as so to provide knowledge of experienced HIV-stigma in general. However, the findings are only presented briefly before moving on to HIV-related stigma in healthcare system.

The category *HIV-related stigma within the healthcare system* was sub-categorized into *Experiences with healthcare provider* and *Treatment* based on the degree of findings being relatable to a situation of treatment or in contact with a healthcare provider.

The findings that were considered of possible relevance for this review were organized in a table to make an overview as well as evaluating their credibility. The full table is to be found in appendix I. The extraction of findings supporting the objective of this study was complex considering this was not a topic in the articles read, however mentioned by the participants to some degree.

<i>Experiences of stigma amongst HIV-positive people encountering the healthcare system in Scandinavia.</i>			
Population: People living with HIV Phenomena of interest: Experiences of stigma Context: Healthcare system		SQ – supported by quotation U – Unequivocal C – Credible NS – Not supported	
Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study	Towards a new understanding of HIV-related stigma in the era of efficient treatment - A qualitative reconceptualization of existing theory	Sexuality and childbearing as it is experienced by women living with HIV in Sweden – a lifeworld phenomenological study	How gay men living with hiv experience and perceive hiv-stigma: a qualitative study
To protect themselves from the risk of being stigmatized, the participants hid their HIV status and only declared their status in healthcare situations (C)	Those who worked in healthcare settings described how colleagues talked badly about patients with infections and how that affected them. (SQ), (C)	Feeling of receiving “unfair” treatment and discrimination, compared to HIV-negative women (SQ), (C)	Predominantly seemed satisfied with the treatment received (SQ), (C)
Pediatric care for HIV treatment as fairly good (C)	Talked about not having access to fertility treatment in Sweden when wanting to have a baby. (NS)	Experiences of stigmatization due to perceptions of contagiousness and transmission (C)	All participants reported one or more negative experiences (friends, family, work, sex partners or in the health care system) (U) (SQ)
Relied heavily on their healthcare providers (SQ)	Described stigma as a barrier in many situations (SQ), (C)	Feeling of lack of knowledge that leads to prejudice and misconceptions (C)	Treated differently than other patients (SQ), (C)
Healthcare staff lacking sufficient skills and knowledge about HIV-induced frustration and anger (C)	Labelled as a person with HIV – important and persistent part of stigma experience (SQ), (C)	Feeling of being questioned about their right to have a baby by the health workers (C)	Great gaps among the stigma experienced, from whom, how it was experienced and how they dealt with it (C)
Felt safe to disclose their diagnosis to health care providers (C)	Disclosure found to be context-related, and participants weighed the relevance of disclosure – even in health care situations (C)	Level of self-perceived stigma in the health care system = feeling of not receiving equal health care (C)	Asked invasive and unrelated questions (SQ), (C)
Health care professionals were viewed as an important aid in coping with HIV and its consequences (C)		Perceptions of HIV being more contagious than it is, are present among health care professionals (C)	Top-down attitudes from general practitioners (GPs)
			Not being given important information regarding treatment - Nervous and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy) (SQ), (C)
			Or in other ways showing an incapability to act on the patient’s needs. (C)

Table 11 - Extracted findings and their score of credibility. The same table including findings outside the healthcare system is to find in appendix I

As table 11 illustrates the findings as well as their credibility score as described by JBI manual of synthesizing (52), the process continued with detection of similarities as to be able to synthesize findings into categories. Two main categories were found: *HIV-related stigma outside the healthcare settings* and *HIV-related stigma in healthcare system*. However, the aim of this thesis is to explore experiences of HIV-related stigma within the healthcare system, and thus one of the main categories are not to be explored other than with a brief insight to HIV-related stigma in general. *HIV-related stigma in the healthcare system* was sub-categorized into *Experiences with healthcare provider* and *Treatment*. To ensure that the findings are not being overanalyzed or change their original meaning by further decoding it was deduced that two sub-categories was satisfactory.

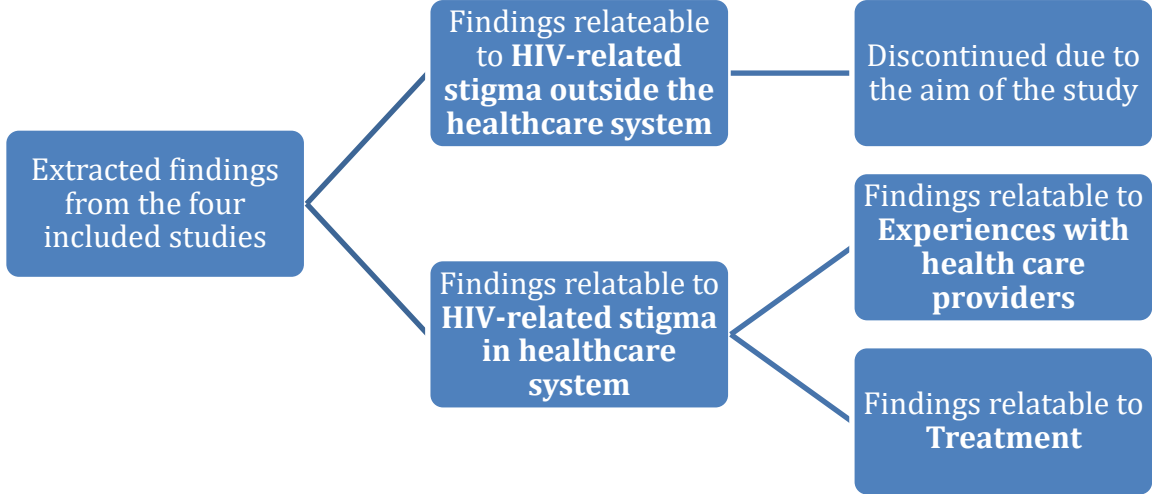


Table 12 - Overview of the groups of findings

4.1.1 HIV-related stigma

Experiences of, or fear of experiencing, HIV-related stigma and discrimination may make people living with HIV avoid seeking health care or health care settings altogether, they might also choose to withhold vital information in fear of being stigmatized (1). These actions may lead to inadequate care and treatment of people living with HIV (1). Furthermore, HIV-related stigma and discrimination is seen all over the world, and in the health care settings HIV-related stigma is regarded as one of the main obstacles to end the AIDS epidemic as a

public threat by 2030 (10). However, HIV-related stigma is found in every area of social life as well as in healthcare system (10), with that I mind, this section will briefly focus on the findings related to HIV stigma in general so as to better inform our understanding of experiences related to healthcare.

4.1.2 HIV-related stigma outside the healthcare system

Healthcare does not happen in a vacuum. The culture in which healthcare exists does not stop at the door of the hospital or doctor's office. These interactions will reflect current cultural norms (for instance the way one reacts to fear and anxiety of transmission) and so it is of importance to present these findings before moving onto the specifics of healthcare.

Whilst Enoksen (2018) found that some of the participants lived their life heavily influenced by stigmatization, others presented contradictory evidence of participants spared from incidences of HIV-related stigma (3). More so, the fear of being stigmatized, may as a result influence the life choices of individuals living with HIV, for instance whether to disclose their diagnosis in certain situations (3). Whether or not to disclose their HIV-diagnosis was relatable to fear and anxiety in people living with HIV, in which they might choose not to disclose their diagnosis if they did not see the relevance or need, hence reason for disclosure was weighed by relevance to the situation – also in health care situations (3, 33). On the other hand, it was also reported that participants felt a responsibility to disclose their HIV-diagnosis due to fear of transmission (58, 62).

Across all the studies reviewed there seem to be a feeling of living with a dark secret or descriptions of living with a hidden identity if not disclosing their diagnosis (3, 58). Further, that maintaining secrecy were strategies to avoid and be protected from prejudice and negative attitudes (3, 58), as well as being rejected as a possible partner (62). Even though findings revealed that some participants did not find it strenuous living with HIV as a secret, there were participants that reported the secrecy being burdensome and exhausting (3). Further, findings showed that participants reported that feelings of fear, anxiety and/or insecurity in relation to telling others about their HIV-diagnosis (3, 33, 58, 62). Carlsson-Laloo et al. (2018) reported participants felt a lack of knowledge in society which as a result could lead to prejudice and misconceptions, both in relation to transmission route and to the contagiousness (62). This is also seen in Rydström et al.'s (2013) study of young adults living

with HIV where some participants reported a fear of being accused of improper behavior in society and rumors being spread (58). Maintaining control, both over who was privy to their HIV status, as well as control over people's perceptions of the person was an important factor in Reinius et al.'s (2020) study (33), which was also seen among the young adults in Rydström et al.'s (2013) study (58).

Rumors being spread was a great concern among young adults living with HIV, as it reportedly, may lead to isolation, powerlessness, and alienation (58). This fear of being talked about behind their back was also described in Reinius et al. (2020) study, and supported by examples from a participant experience of being part of a conversation about other people living with HIV in a negative context, which resulted in an anticipation of how the participant is being treated and talked about when not there (33).

Across the studies it was found and concluded that stigma still was experienced by the participants, however, it was found that there were great gaps in the stigma experienced, from whom, how it was experienced and how they dealt with it (3). Stigma might not happen all the time or in every situation. However, Enoksen (2018) reported that all participants in her study had been exposed to one or more negative experiences of HIV-related stigma (3). Additionally, that HIV-related stigma could occur in work-related situations as well as it could be from friends, family or in the health care system (3).

Enacted-, anticipated-, and internalized stigma

As mentioned before Earnshaw and Chaudoir describes 3 stigma mechanisms as to be important when describing HIV-related stigma; enacted-, anticipated-, and internalized stigma (67). These mechanisms were recognized in the four studies reviewed when the researchers described their findings and results.

There were similarities across studies in that the majority of findings regarding HIV-related stigma in society in general could be defined as anticipated and/or internalized stigma, the least reported was of experiences that could be defined as enacted (3, 33, 58, 62). Not that this was not reported on, however, not as strongly experienced as anticipated and/or internalized stigma. Additionally, the studies reviewed all conclude with, or mention that, there is a need for an increase of knowledge, both in society as well as in the healthcare system, as a means to decrease the experience of stigma (3, 33, 58, 62). More so, they find it important to demystify

the condition and provide non-judgmental information about HIV and contagiousness, and a need for interventions (3, 33, 58, 62).

4.1.3 HIV-related stigma in healthcare system

The aim of this thesis is to explore if people living with HIV experience stigma in the healthcare system in Scandinavia. The studies reviewed did not primarily focus on experiences of stigma within the healthcare system, however, they all reported to some extent situations and experiences of HIV-related stigma in their study. The findings regarding HIV-related stigma in healthcare system is subcategorized into to sub-categories: *Experiences with health care providers* and *treatment* (table 12). There is a hierarchy chart in figure 2 below that present the findings from the included studies. Participants quotes reflecting the findings are also included.

There is one finding from the study *Towards a new understanding of HIV-related stigma in the era of efficient treatment* that scored *not supported* and marked read in table 11. And will therefore be excluded from further discussion.

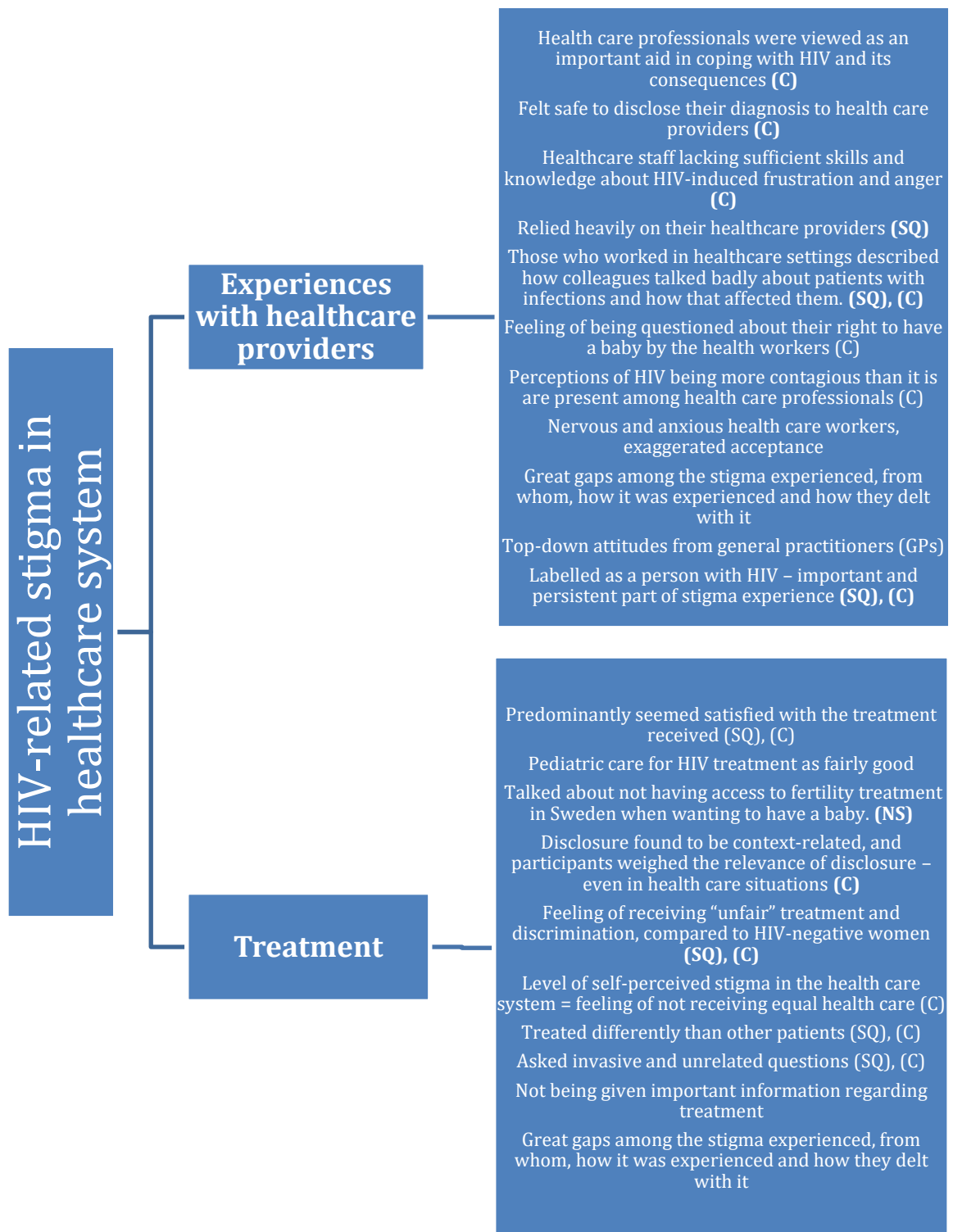


Figure 2 - Overview of synthesized and grouped findings

4.1.4 Experiences with healthcare providers

12 findings were identified in the sub-category *experience with health care providers*. They were all evaluated as credible findings guided by JBIMES Levels of credibility (52).

however, there were only three findings that were supported by quotation. JBIMES Levels of credibility includes three levels (52, p.55):

- **Unequivocal** (findings accompanied by an illustration that is beyond reasonable doubt and; therefore not open to challenge)
- **Credible** (findings accompanied by an illustration lacking clear association with it and therefore open to challenge)
- **Not Supported** (findings are not supported by the data)

Only three findings were supported by participant quotes.

Finding	Evidence	Quotes supporting the evidence
Health care professionals were viewed as an important aid in coping with HIV and its consequences (C) (SQ)	<p>For many of the participants, healthcare professionals were viewed as an important aid in coping with HIV infection and its consequences. (p. 1364 in Rydström et al.).</p> <p>Although most seemed satisfied with talking to their healthcare providers, others expressed a desire to have a contact outside the healthcare system. (p. 1361 in Rydström et al.).</p> <p>In fact, all participants mentioned the importance and necessity of having someone with whom they could talk about their life situation. Although most seemed satisfied with talking to their healthcare providers, others expressed a desire to have a contact outside the healthcare system. (p. 1361 in Rydström et al.).</p>	<p>Supported with example with social worker:</p> <p><i>"If I'm sad or feel alone, I would call my social worker for an appointment... we can meet and talk not only about the test results."</i></p> <p>And</p> <p><i>"No, I have not been feeling bad in that way. If you have to talk to the social worker, it feels as if you are a psycho."</i> (p. 1361 Rydström et al.)</p>
Felt safe to disclose their diagnosis to health care providers (C)	To protect themselves from the risk of being stigmatized, the participants hid their HIV status and only declared their status in healthcare situations. (p. 1360 in Rydström et al.)	Not supported by quotes
Healthcare staff lacking sufficient skills and knowledge about HIV-induced frustration and anger (C)	The need for healthcare professionals with appropriate knowledge concerning HIV was also expressed, as healthcare staff lacking sufficient skills and knowledge about HIV-induced frustration and anger among the participants. (p. 1362 in Rydström et al.)	Not supported by quotes
Relied heavily on their healthcare providers (SQ)	The participants rated their paediatric care for HIV treatment as fairly good; they had been well treated at the hospital and had some influence over their long-term care, such as setting the time for regular consultations. (p. 1361 in Rydström et al.)	Not supported by quotes
Those who worked in healthcare settings described how colleagues talked badly about patients with infections and how that affected them. (SQ), (C)	Those who worked in healthcare settings, for example described how colleagues talked badly about patients with infections and how that affected them. (p. 2475, Reinius et al.)	<i>"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."</i> (Participant #5) (p. 2475, Reinius et al.)

<p>Feeling of being questioned about their right to have a baby by the health workers (C)</p>	<p>Our findings reveal experiences of having a feeling of being questioned about the right to have a wish to become pregnant, even by health care providers, which also seems to occur in health care systems in the health care services provided in other countries. (p.8 Carlsson-Lalloo et al.)</p>	<p>Not supported by quotes</p>
<p>Perceptions of HIV being more contagious than it is, are present among health care professionals (C)</p>	<p>Information from HIV clinics and also other health care providers seems to have an impact on decision making and brings a sense of dignity to the choices that the women make. It also affects the perceptions of HIV transmission, which places health care providers in a position of power when it comes to information about HIV, guidelines and regulations. (p.6 Carlsson-Lalloo et al.)</p> <p>Lack of knowledge generates prejudices and misconceptions about HIV and transmission. Levels of knowledge about HIV and transmission in Sweden vary (SMI, 2012), and these also seem to vary within the health care system (Hall, Plantin, & Tornberg, 2017). According to our findings, the level of knowledge about HIV is experienced as being much better at HIV clinics than for health care in general. (p.8 Carlsson-Lalloo et al.)</p>	<p><i>"It can go very wrong depending on the information you get, how you express it"</i> (IP 12). (p.6 Carlsson-Lalloo et al.)</p>
<p>Nervous and anxious health care workers, exaggerated acceptance (C)</p>	<p>While most participants had similar reports, some participants were unsatisfied with aspects of their treatment in the health care system. Some of the factors mentioned when describing negative experiences with health care professionals were being treated differently than other patients, being asked invasive and unrelated questions, top-down attitudes from general practitioners (GPs), not being given important information regarding treatment, nervous and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy), little psychological follow-up, and in other ways showing an incapability to act on the patient's needs. (p. 20 Enoksen)</p>	<p>Not supported by quotes</p>
<p>Top-down attitudes from general practitioners (GPs) (C)</p>	<p>See the above verbatim text (p. 20 Enoksen)</p>	<p>Not supported by quotes</p>
<p>Great gaps among the stigma experienced, from whom, how it was experienced and how they dealt with it</p>	<p>It was also found that there are great gaps between the amount of stigma reported, whom they receive stigmatisation from, how it is experienced, and how they deal with it. (p. 20 Enoksen)</p>	<p>Not supported by quotes</p>
<p>Labelled as a person with HIV – important and persistent part of stigma experience (SQ), (C)</p>	<p>In the present study, labelling was central in the narratives categorized as both enacted and anticipated stigma and appears to be an intrinsic part of the individual level of HIV stigma conceptualization. (p. 2477, Reinius et al.)</p> <p>Recurring themes in the participants' interviews were being unwillingly labelled as a person with HIV, losing control over who was informed about one's HIV and losing control over how you were perceived as a person. (p. 2476, Reinius et al.)</p>	<p><i>"I'm really so torn because...it shouldn't matter...I'm first and foremost [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-[participant's name] ... and that's the question, do I want that? The dream is just to be simply [participant's name], 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."</i> (Participant #2) (p. 2476, Reinius et al.)</p>

Table 13 - Overview of evidence of findings (Experience with healthcare providers)

4.1.5 Treatment:

The second sub-category identified were *treatment* and the experience of the healthcare system as is. There were 9 findings identified in which all of them were evaluated as credible. Three findings were supported by quotations. They were all evaluated as credible findings guided by JBIMES Levels of credibility as described above (52).

Findings	Evidence	Quotes supporting the evidence
Predominantly seemed satisfied with the treatment received (SQ), (C)	It is important to note here that the participants predominantly seemed satisfied with the treatment received from health care professionals. (p.20 Enoksen) Even though participants did give examples of negative treatment, most of the participants still considered their overall treatment from health care workers as satisfactory. (p.22 Enoksen)	<i>“But for me personally, I’ve always been really lucky, and great follow-up, and I’ve had all the help I’ve needed. I have absolutely nothing to complain about.” (Liam)</i>
Pediatric care for HIV treatment as fairly good (C)	The participants rated their paediatric care for HIV treatment as fairly good; they had been well treated at the hospital and had some influence over their long-term care, such as setting the time for regular consultations. (1361 in Rydström et al.)	Not supported by quote
Disclosure found to be context-related, and participants weighed the relevance of disclosure – (even in health care situations?) (C)	Our findings suggest that nondisclosure may be an action taken to prevent stigmatization, but also that disclosure is context-related and a result of negotiating and weighing the relevance of disclosing HIV, perceiving HIV as a private matter and the perceived responsibility of disclosure. (p. 2478 Reinius et al.) The healthcare system often has a central role in the mechanisms of disclosure and labelling about HIV. (p. 2478 Reinius et al.) Participants reported that in every new encounter or relationship they made decisions about whether to disclose and if so, about how and when to disclose. (p. 2476 Reinius et al.)	No supportive quotes, however, it is interesting to know if this also is relatable in health care situations
Feeling of receiving “unfair” treatment and discrimination, compared to	There is also a feeling of receiving “unfair” (IP 7) treatment and discrimination, compared to HIV-negative women, when seeking help from the Swedish health care system,	The quote for which made the understanding of evidence is not included in the study. It would have been interesting to get the whole transcription on "unfair" treatment.

HIV-negative women (SQ?), (C)	with such services as artificial insemination and adoption. (p.7 Carlsson-Lalloo et al.)	
Level of self-perceived stigma in the health care system = feeling of not receiving equal health care (C)	Furthermore, it is also important to investigate the level of self-perceived stigmatization in the health care system as a grounds for providing equal care. (p.8 Carlsson-Lalloo et al.)	no supportive quotes, however, for this evidence to be reported there should be identified in the data collected and therefor included as a finding in this review
Treated differently than other patients (SQ), (C)	While most participants had similar reports, some participants were unsatisfied with aspects of their treatment in the health care system. Some of the factors mentioned when describing negative experiences with health care professionals were being treated differently than other patients, being asked invasive and unrelated questions, top-down attitudes from general practitioners (GPs), not being given important information regarding treatment, nervous and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy), little psychological follow-up, and in other ways showing an incapability to act on the patient's needs. (p. 20 Enoksen)	<i>"I'm afraid to call the dentist that I've always had in my family, so my mother calls and says 'we're just informing that Oliver has been informed that he is hiv-positive'. Then my mother calls me back and says 'she would like to call you'. So I say, 'How nice'. And I'm sure she would say 'how sad' or. But then she rails at me. That I've put her life, her husband's life, her kid's lives-. 'I'm in a car with children on my way home from hiv testing' and 'Have you infected them with hiv then I'm going to make your life hell! And these friends you've referred to me, are they also hiv-positive?'. I mean, I was devastated. This is a professional person that is supposed to take, what's it called, precautions, against all eventualities. 'I remember when you (had) wounds', she said, meaning I had wounds on my hand. I had cut myself. 'Well, I thought, I knew you were gay'. I mean she completely railed at me. I changed dentists and forced my entire family to change dentists as well."</i> (Oliver)
Asked invasive and unrelated questions (SQ), (C)	See the above verbatim text (p. 20 Enoksen)	<i>"It was perceived like it was really good treatment at that point, (but) later there's like this bitter taste in your mouth when you later just, 'Wow, the treatment wasn't really that good'. Because you are so grateful for what, no matter what you get of support in that kind of situation. So, you think later, 'Well, maybe not so good'. Because she asked me about 'But didn't you expect that x and x would yield positive results?'. (Then) I said, 'No, I absolutely did not'. Then 'No, but what I was thinking about was, with the amount of sexual partners you have had'. And she asked me if I'd had feelings for every person I've had sex with, which is completely irrelevant, (and) doesn't have anything to do with anything."</i> (Jacob)
Not being given important information regarding treatment (C)	Some of the factors mentioned when describing negative experiences with health care professionals were being treated differently than other patients, being asked invasive and unrelated questions, top-down attitudes from general practitioners (GPs), not being given important information regarding treatment, nervous and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy), little psychological follow-up, and in other ways showing an incapability to act on the patient's needs. (p. 20 Enoksen)	Not supported by quote

Great gaps among the stigma experienced, from whom, how it was experienced and how they dealt with it (C)	It was also found that there are great gaps between the amount of stigma reported, whom they receive stigmatisation from, how it is experienced, and how they deal with it. (p. 47 Enoksen)	Not supported by quote
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Table 14 - Overview of evidence of findings (Treatment)

4.1.5.1 Experiences with healthcare providers

Evidence and findings show that health care providers were viewed as an important aid in coping with HIV and its consequences, and findings suggest that people living with HIV and their reliance on their health care provider contributed to a feeling of safeness. However, a lack of sufficient skills and knowledge about HIV was also experienced, and it could generate feelings of frustration and anger, secrecy of diagnosis, and a feeling of being labelled.

Furthermore, a lack of sufficient skills and knowledge might result in unintended acts of stigma from health care providers, and thus experiences of stigma among people living with HIV. There was observed similarities in terms of health care providers wrongful perceptions of the contagiousness of HIV and how HIV transmits, which participants experienced as, for instance, health care providers being nervous and anxious, or expressing exaggerated acceptance that could lead to a feeling of invading the participants privacy. Nevertheless, HIV-related stigma was observed to occur episodic rather than continual when in contact with healthcare system.

4.1.5.2 Treatment

Evidence and findings also show that across the four studies reviewed participants seemed predominantly satisfied with the treatment received, however, there were experiences of being treated differently or not getting access to treatment i.e., fertility treatment. Further, it was found that the participants were asked invasive and unrelated questions, as well as a feeling of being labelled which may interfere with their perception of worthiness and self-esteem.

Experiences of unnecessary measures of precaution taken by the health care providers were also experienced such as double gloving. Furthermore, disclosure of the HIV-diagnosis seemed to be something that often were kept close to heart in fear of stigmatization, and participants weighed the relevance of disclosure to situations, and if that information was of necessity for the health care appointment. There was found experiences of receiving unequal treatment, compared to people not living with HIV, as well as not being given important

information regarding treatment. There was also found great gaps of experiences of HIV-related stigma.

In the studies reviewed it seems to be reported HIV-related stigma covering all three stigma mechanisms described by Earnshaw and Chaudoir; enacted-, anticipated-, and internalized stigma(67). However, there were experience of enacted stigma as well, though anticipated and internalized seemed to be the most experienced of the three stigma mechanisms.

5 Discussion

This thesis aims to undertake a systematic literature review to gain better understanding of the experience individuals living with HIV have with healthcare personnel in Norway/Scandinavia, if these have changed over the years and what implications such experiences might have for healthcare providers. The evidence was reviewed and on analysis was found to be related to two areas – *Experiences with health care providers* and *Treatment* – and will be further discussed.

5.1.1 HIV-related stigma in healthcare system

Experiences with healthcare providers

HIV-related stigma in the healthcare system has implications for treatment and the quality of care for people living with HIV (1). It may also result in people discontinuing their treatment, not getting the treatment they need or being reluctant to attend their appointments (1). Further, people that suspect being infected might avoid getting tested in fear of being stigmatized by health care providers (1).

This review found that people living with HIV were predominantly satisfied with their health care providers and that they felt safe in communication with them (58). Dr. Marilyn Gagnon (2015) also describe, in her study, that the overall experience, for people living with HIV, within the healthcare system was evaluated as "generally good" and "better than before" (49, p.709), thus supporting the findings in this review. Having said that, findings in this review also suggest that there are, to a degree, negative experiences related to HIV-related stigma when in the healthcare system. Experiences of HIV-related stigma correlates to the findings of the study *Att leva med hiv i Sverige, En studie om livskvalitet hos personer som lever med hiv* (2016), which found that the majority of the participants scored their interactions with health care providers as satisfactory, and 86% to 90% had confidence in their primary doctor and nurse (48). This was also seen in a Danish report, *Hiv og levekår - Livet som hiv-smittet i Danmark* (2016), as well (40). Nevertheless, it appeared that health care providers in the above mentioned study and report were health care providers within health care facilities specialized in HIV (40, 48), which may suggest that as long as the visited health care facility has the necessary knowledge about HIV, stigma may be avoided. *Re-thinking HIV-related Stigma in Health Care Settings: a qualitative study* (2015) also found that participants felt

more comfortable, safe and welcomed when using health care inside "HIV network" (healthcare system specialized in HIV), whereas going to a health care facility where there were no guarantee of health care providers having sufficient knowledge of HIV made participants feel uneasy and vulnerable (49). Participants in dr. Gagnon's study described health care settings outside the HIV-network to be more judgmental, less knowledgeable, competent and experienced (49).

Danish health care providers reported, in a survey conducted by YouGov¹⁰ on behalf of Hiv-Danmark (a nationwide patient association for people living with, or who are close to people living with, HIV in Denmark), a lack of knowledge about HIV that resulted in a press release¹¹ in 2021 stating that health care providers lack important knowledge on HIV (47). The press release stated that the younger health care providers expressed feeling the most unsafe in interaction with patients living with HIV (47). A lack of knowledge concerning HIV, together with factors such as a fear of HIV transmission and misconceptions about HIV and how it is and is not spread, is described by UNAIDS as factors to why health care workers exhibit stigma (1). Moreover, *Re-thinking HIV-related Stigma in Health Care Settings: a qualitative study* (2015) found that HIV-related stigma might impair the interactions with health care providers, and thus the quality of care (49). As a consequence of HIV-related stigma, people living with HIV may become fearful, anxious, defensive and hesitant when in contact with the healthcare system, if not entering specialized HIV facilities (49). Having said that, Carlsson-Laloo et al. (2018) observed an ambiguity among the participants between the need for, and importance of, providing specialized HIV care and the need to be treated in the same way as women who are not living with HIV (62).

Despite laws, guidelines, and regulations to prevent stigma and discrimination and ensure equity in treatment and care, this review found that people living with HIV still experience HIV-related stigma. The Norwegian Health Personnel Act of 2001 all health care personnel should conduct their work in accordance with the requirements of professional responsibility and diligent care, and thus provide health and care services that respects the patient's personal

¹⁰An international online research data and analytics technology group. [YouGov plc Corporate Homepage](#)

¹¹ [Pressemeddelelse_Sundhedspersonale-mangler-vigtig-viden-om-hiv_Hiv-DK.pdf \(hiv-danmark.dk\)](#)

integrity and bodily autonomy (23, 24). Furthermore, the Norwegian Directorate of Health clarify that work-related code of ethics should be used as guidance in the way of how diligent care is conducted (24). With that said, codes, regulations and guidelines for health care providers all states that health care providers are to ensure, among other things, respect for the patients autonomy, not to discriminate or in other ways give unfair treatment due to gender, sexuality, ethnicity, religious belief and more, and that they have a responsibility and accountability to obtain and maintain knowledge and practices concerning their profession so to conduct their work (19-22). Hence, all healthcare providers have a duty to maintain their clinical knowledge to allow for up-to-date treatment and ensure equity of care and treatment for all their patients.

Reinius et al. (2020) state in their study that in the Swedish health care system/setting, medical records are still marked with warning labels for people living with HIV(33). If this was something the participants knew of was unclear, and not reported on by the participants in the study. However, the participants did report a fear of disclosure due to fear of being labeled, although perhaps more metaphorically(33).

HIV has been associated with other groups of people that are already stigmatized, and a feeling of being labelled or treated different due to an HIV-diagnosis was found in several studies (33, 49, 68). Terms such as labeling and layered stigma¹² was found in the studies reviewed in this review. Layered stigma was observed in dr. Marilyn Gagnon's study (49) as participants expressed difficulties of separating stigmas already experienced due to being drug-users, homeless, sex-workers (49). Nonetheless, participants described being treated as if some of their rights had been taken away due to their diagnosis (49). One example given in the study was inadequate pain medication being offered, not offered at all, or denied to these patients due to a past with drug abuse (49).

The Patient and User Rights Act of 1999 (69) was designed to secure patients trust, ensuring respect, integrity, and dignity in interaction with the Norwegian healthcare system. With the aim that everyone interacting with the Norwegian healthcare system to

¹² Having more than one stigma-related "trait", thus not know for certain which "trait" are being stigmatized

experience equal healthcare regardless of, among other, diagnosis, ethnicity, gender (69). Equality and Anti-Discrimination Act of 2017 promote equality and prevention of discrimination due to gender, pregnancy, leave in connection with childbirth or adoption, care responsibilities, ethnicity, religion, belief, disability, sexual orientation, gender identity, gender expression, age, or other significant characteristics of a person (25). With this Act people living with HIV should not experience being treated differently than people living without HIV.

Treatment

Our findings shows that participants experienced being treated differently, asked questions unrelated to their treatment at that time and that they had a feeling of receiving unequal treatment compared to people not living with HIV. Similar findings were found in Ann P. Zukoski et al. (2009, 68) study from the U.S, where participants described feelings of being judged, disrespected or discriminated against when in contact with health care providers (68). However, this was not reported as to occur at every appointment or contact with the health care, as also seen in dr. Marilyn Gagnon's study (2015) where experiences of HIV-related stigma was observed to be episodic more than ongoing (49), supporting the findings of this study.

Furthermore, Zukoski et al. (2009, 68) found experiences of health care providers being intrusive and unnecessary questioned, which is also supported by Vaughan et al. (2020) and their study where participants expressed that health care professionals asked inappropriate and medically irrelevant questions as well as having judgmental attitudes (50). Similar findings are reflected in this review. Reflecting upon the codes of ethics, guidelines and regulations for health care providers, a health care provider should promote an environment in which the patients – and human – rights and values are respected, as well as provide a place for the patient to not fear judgment or other actions that infringe upon the patients integrity, or in some way or another is experienced as a violation (19-22).

Living with HIV as a secret was seen both in the reviewed studies as well as in *Hiv i Sverige, En studie om kunskap, attityder och förhållningssätt till hiv i befolkningen* (2017) and were reported as strategies to avoid and be protected from prejudice and negative attitudes (3, 41,

58), however, findings also revealed that there were participants that did not find it strenuous living with HIV as a secret (3). Nonetheless, World Health Organization (WHO) reports that secrecy is deemed to cause suboptimal adherence to treatment (70), and health care providers might be a facilitator to being more open about their diagnosis, and thus aid in reduction of HIV-related stigma.

Vaughan et al. (2020) found that patients living with HIV tended to be given appointments at the end of the day (50). The reasoning behind this was that this would allow for thorough sterilisation of any instruments used in their care (50). Other studies have documented similar findings, where people living with HIV experience of health care providers delaying care or refusing to provide care, as well as being clearly uncomfortable when providing care (49).

Gagnon (2015) and Vaughan et al. (2020) also found experiences of health care providers using double gloves, and other excessive precautionary measures (49, 50). These types of precaution is defined by UNAIDS as examples of how stigma might be exhibited, as well as using judgmental language, testing for HIV without consent, or breaching confidentiality (1), similar experiences is reported in studies, surveys and reports from the Scandinavian countries as well (2, 40, 48). Excessive use of protection, a feeling of unequal treatment, being treated differently and the feeling that the health care provider was unable to meet the needs of the patient were also found in this review (3, 33, 62).

It is important to mention that woman may experience HIV-related stigma in other ways than men, and they experience a greater burden of mental health conditions (71). Women in the United States and Canada reports higher level of HIV-related stigma than men living with HIV (71). Women living with HIV may experience stigma when seeking fertility treatment or in relation to disclosure of HIV-diagnosis when pregnant (71). The feeling of being questioned, by health care professionals, about the right to have a baby was found in two of the reviewed studies (33, 62). Carlsson-Lalloo et. al (2018) also found that negative expectations of society, and sometimes of health care professionals, often resulted in women living with HIV questioning whether they should get pregnant and have children at all (62).

5.1.2 Applicability and relevance of the findings

Stigma and discrimination might not be experienced at every interaction with the healthcare system. Nevertheless, current literature and studies finds that HIV-related stigma is still experienced.

5.1.2.1 Implication for health care

Our findings show that, despite regulations governing how healthcare professionals should treat patients with dignity and respect regardless of diagnosis, ethnicity, gender, sexuality etc., HIV-related stigma is still experienced. However, HIV-related stigma is experienced differently by those who are living with HIV, in different situations, and tend to occur sporadically as opposed to regularly, and experienced to a different degree.

People living with HIV may choose not to seek help in the healthcare system, not only for their HIV, but they might also avoid other services within the healthcare. Further, HIV-related stigma tends to be based on/grounded in outdated ideas and a lack of updated knowledge. Consequently, this has a negative impact on the life and quality of life of those living with HIV, medically, psychologically, and socially. Depression, anxiety, fear, self-isolation and a lower life quality and lower health-related quality of life was found expressed in this review. Treatment adherence is also seen to be reduced by HIV-related stigma, and people might choose not to get tested due to fear of being stigmatized (1). It is of importance that HIV-related stigma might discourage people living with (or who suspect they may be living with) HIV from seeking necessary testing and treatment (1).

As HIV-related stigma tends to be grounded in outdated ideas and a lack of updated knowledge among health care providers, as well as in society, this review found that it might be of importance to educate healthcare providers working outside health facilities specialized in HIV. To access better and safer healthcare, World Health Organization (WHO) emphasizes education and training against stigmatization and discrimination (70). Further, WHO recommends awareness training for clinical and non-clinical healthcare providers to improve care and experiences for people living with HIV (70).

Health care providers should strive to keep the patient from being asked unnecessary questions, avoid creating environments where patients might feel judged, disrespected, or

receiving unequal treatment, and thus secure a safe environment where stigma and discrimination is not experienced.

5.1.2.2 Implications for further research

With this review we do believe that there is a need for more information and education on HIV, and on stigma in general. Much can be solved with information and making of awareness, and aid in enlightenment of information one might unknowingly need. It is impossible to know everything about everything, and the prevalence of interaction with a person living with HIV in Norway is low. However, with improvement of treatment and care people living with HIV live longer, healthier, and they are reaching old age (2). As an example of a need for knowledge in the throughout the health care system, Fafos report *Aging with hiv* (2018), healthcare providers caring for elderly people will increasingly encounter people living with HIV, and thus have a need for up to date knowledge on HIV (72). People living with HIV will also experience health challenges when ageing, as the rest of the population, and basic knowledge should be obtained, both on HIV and on stigma, as stigma is applicable to other situations as well.

There is a global aim of eliminating experiences of HIV-related stigma in the healthcare system, and thus reducing the possible negative impact HIV-related stigma has on people living with HIV. As a consequence of reducing and eliminating HIV there might be a decrease in transmission, improvement of treatment and adherence, and promoting testing. Therefore, to obtain knowledge and develop strategies and interventions, we suggest further research on HIV-related stigma in the healthcare in Norway, as well as further research on healthcare providers knowledge on HIV so as to determine where the knowledge gap lies.

5.1.3 Strength of evidence from, and limitations of, the included studies

There are both strengths and limitations in the included studies. With the use of the CASP-checklist and score of dependability, it was assessed that the studies are conducted thoroughly, however different.

The score of dependability rated three of the four as of high dependability, which strengthen the evidence retrieved from the studies. However, *Experiences of young adults growing up with innate or early acquired HIV infection* (2013) was rated as moderate dependability due to some of the checklist questions were difficult to obtain a clear answer to. It was difficult to

find a clear statement of findings, which might be due to a broad aim of the study. All the studies predominantly supported their findings with quotes, nevertheless, there were findings that were not supported by quotes. However, the findings as such are supported by relevant literature from other countries, and thus regarded as relevant.

Reliability and *validity* are seen as important concepts in qualitative research (66). Exploring the reliability and validity make the possibility of assess the objectivity and credibility of the research (66). The critical appraisal and analyzing conclude that criteria for validity and reliability is fulfilled, and the reported information of the different studies are transparent. Further, self-reported limitations are reported on, thus the articles show honesty to their findings, and reproducibility of the data. Each study is strengthened with contradictory evidence, and there are variety in the experiences. The studies identify and include emerging/unanticipated themes – one example being Reinius et. al (2020) that report on coding deductively even though they used predetermined coding (33) - as to minimize bias.

In section 3.2.2 (page 38) possible biases was explored, and observed, and although it is difficult to assess the validity and reliability to a 100%, we do believe that there was no observation of severe bias in which the studies are not to be trusted.

5.1.4 Limitations to this review

The method chosen for this thesis is a systematic literature review. When reviewing and comparing studies it is generally recommended that the selection and reviewing of studies are conducted by at least two independent reviewers to increase trustworthiness and minimalize potential for error (51, 52, 60). As this is a master's dissertation there has only been one reviewer, guided by a supervisor. This might therefore represent a limitation/weakness to our work. Further, there is always a possibility that there are studies that have not been found and therefore not included in this review. The last search for this review was conducted in 10th of January 2022.

Further, as this thesis aiming to explore experienced HIV-related stigma in Scandinavia, the studies reviewed neither discussed when nor where the participant got infected, or if the participant had gotten treatment outside Sweden or Norway prior to moving there. This might bias this systematic review as findings reported as experienced stigma, might perhaps be

influenced by previous experienced stigma and it may have affected their interpretation and/or approach in certain situations in Sweden and Norway.

The data from the four included studies are collected from a smaller sample size due to the design of the studies being qualitative studies with in-depth interviews, and it is therefore difficult to generalize the findings to larger population. However, due to the similarities in Scandinavia (53), the findings might be transferable to all three countries even though there are only included studies from Sweden and Norway.

Refinement of the protocol

To obtain relevant article to conduct this review, there was a need of an adjustment of the thesis question originally sent in with the protocol. Initially our focus was purely Norway, however, the results were scarce, and so the scope was broadened to include the whole of Scandinavia (Norway, Denmark, and Sweden).

Even though the alternation of the objective gave more results as to relevant articles that could be included in this review, the findings were unfortunately rather scarce, and there was a need to adjust the inclusion criteria as well. Initially the included studies were to focus on HIV-related stigma in the healthcare system, and the alternation made it possible to include studies that mention HIV-related stigma in the health care system as well. Thus, we got the opportunity to include more studies even though they did not solely focus on HIV-related stigma.

In dialog with a librarian at University of Tromsø, the choice of databases for the search was altered. Pubmed was removed, and a Norwegian database, Norart, was included in the main search.

6 Conclusion

Although the extractions of findings focusing on healthcare system were to some degree complex and difficult, the findings suggest that there are experiences of stigma in the health care system. In the context of relevant literature, the findings in this review are supported. Across studies, participants reported being fairly satisfied to satisfied with their experience in the healthcare system, however there are experiences of HIV-related stigma in the healthcare

system in Scandinavia, and it might seem like it is due to a lack of sufficient knowledge and skills among health care providers.

The need for health care providers to have updated knowledge and skills appear to be of importance, as the opposite could lead to for instance anxiety and fear of experiencing being stigmatized which might result in further health related challenges and avoidance for the person living with HIV. This will also impact the health systems, and the public health. Experiences of HIV-related stigma has become evident both in this review and current literature from other countries support the evidence of experienced HIV-related stigma.

Further research on HIV-related stigma in the health care in Norway, as well as further research on healthcare providers knowledge on HIV so as to determine where the knowledge gap lies.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) has stated that, in order to overcome the HIV/AIDS epidemic, there is a need for elimination of stigma and discrimination towards people living with HIV (1).

Conflicts of interest

There is no conflict of interest

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7 References

1. UNAIDS. Evidence for eliminating HIV-related stigma and discrimination. <https://www.unaids.org/2020>.
2. Grønningsæter A, Mandal, R., Nuland, BR., Haug, H. . Fra holdninger til levekår, Liv med hiv i Norge 2009. Fafo; 2009.
3. Enoksen A, Traeen B. How gay men living with HIV experience and perceive the HIV stigma: A qualitative study. *Scandinavian Psychologist*. 2018;5.
4. Norsk forening for infeksjonsmedisin. Faglige retningslinjer for oppfølging og behandling av hiv. In: Den norske legeforening, editor. Oslo2022.
5. Sayles JN, Ryan GW, Silver JS, Sarkisian CA, Cunningham WE. Experiences of social stigma and implications for healthcare among a diverse population of HIV positive adults. *J Urban Health*. 2007;84(6):814-28.
6. Reinius M, Wiklander M, Wettergren L, Svedhem V, Eriksson LE. 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 Behav*. 2018;22(12):3795-806.
7. Goffman E. *Stigma : notes on the management of spoiled identity*. Harmondsworth: Penguin; 1968.
8. Frøland SS. *Aids-epidemien : nederlag, seire og nye utfordringer*. Oslo: Gyldendal; 2014.
9. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. *Am J Public Health*. 2013;103(5):813-21.
10. UNAIDS. Global partnerships for action to eliminate all forms of HIV-related stigma and discrimination 2018 [Available from: https://www.unaids.org/sites/default/files/media_asset/global-partnership-hiv-stigma-discrimination_en.pdf].
11. Curran JW, Jaffe, H.W. AIDS: the Early Years and CDC's Response. *Morbidity and Mortality Weekly Report (MMWR)*. 2011;60(04):64-9.
12. Evensen SA, Gradmann, C., Larsen, Ø., Nylenna, M. . Da hiv kom til Norge. *Michael Journal* 2010(7):12-157.
13. Altman L. New homosexual disorder worries health officials 1982 [Available from: https://ajph.aphapublications.org/doi/10.2105/AJPH.2021.306348#_i7].
14. Frøland SS. *Aids* [Leksikon]. snl.no: Store norske leksikon; [updated 2020; cited 2022]. Available from: <https://snl.snl.no/aids>.
15. Nygaard N. *Aids-epidemien i Danmark, ca 1981-1996* 2021 [cited 2022 20.05.2022]. Available from: <https://danmarkshistorien.dk/leksikon-og-kilder/vis/materiale/aids-epidemien-i-danmark-ca-1981-1996/>.
16. Folkhälsomyndigheten. I Sverige lever omkring 8000 personer med HIV idag.se: Folkhälsomyndigheten 2019 [cited 2022 20. May]. Available from: <http://www.hiv idag.se/hiv-i-sverige/>.
17. Mandal R, Nuland, BR., Grønningsæter, A.B. Fortsatt farlig å kysse? Kunnskap om og holdninger til hiv. Fafo; 2008.
18. Helsedirektoratet(HelseNorge). *Leve med HIV* HelseNorge.no2021 [updated 30.04.2021; cited 2022]. Available from: <https://www.helsenorge.no/sykdom/hiv-og-aids/leve-med-hiv/>.
19. ICN. *ICNs etiske regler for sykepleiere Switzerland*: International Council of Nurses; 2006 [Available from: <https://www.nsf.no/Content/2182991/seefile>].

20. Fellesorganisasjonen (FO). Yrkesetisk grunnlagsdokument www.fo.no: Fellesorganisasjonen; 2015 [cited 2022. Available from: <https://www.fo.no/getfile.php/1311735-1585635696/Dokumenter/Din%20profesjon/Brosjyrer/Yrkesetisk%20grunnlagsdokument.pdf>].
21. Den Norske Legeforening. Etiske regler for leger www.legeforeningen.no2021 [cited 2022. Available from: <https://www.legeforeningen.no/om-oss/Styrende-dokumenter/legeforeningens-lover-og-andre-organisatoriske-regler/etiske-regler-for-leger/>].
22. World Medical Association. WMA Declaration of Geneva www.wma.net2017 [cited 2022. Available from: <https://www.wma.net/policies-post/wma-declaration-of-geneva/>].
23. Helsepersonelloven – hpl. Lov om helsepersonell m.v. 1999-07-02-64 1999 [Available from: https://lovdata.no/dokument/NL/lov/1999-07-02-64#KAPITTEL_2].
24. Helsedirektoratet. Helsepersonelloven med kommentarer Oslo2018 [Available from: <https://www.helsedirektoratet.no/rundskriv/helsepersonelloven-med-kommentarer/krav-til-helsepersonells-yrkesutovelse#paragraf-4-forsvarlighet>].
25. Likestillings- og diskrimineringsloven. Lov om likestilling og forbud mot diskriminering m.v. 2017-06-16-51 (2017) [Available from: <https://lovdata.no/dokument/NL/lov/2017-06-16-51>].
26. Straffeloven. Lov om straff m.v. 2005-05-20-28 2005 [Available from: https://lovdata.no/dokument/NL/lov/2005-05-20-28/KAPITTEL_2-8#%C2%A7232].
27. Prop. 120 L. Endringer i straffeloven mv. (smitteoverføring og allmennfarlig smittespredning). In: Justis- o, beredskapsdepartementet, editor.: Regjeringen; 2016-2017.
28. Sekretariatet (HivNorge). Hiv og straffeloven HivNorge.no: HivNorge; 2021 [updated 04.11.2021; cited 2021 19.11]. Available from: <https://www.hivnorge.no/a-leve-med-hiv/hiv-og-juss/hiv-og-straffeloven-2/>.
29. Ursin L. Profesjonsetikk (medisin og helsefag) snl.no: Store Norske Leksikon; 2020 [cited 2022. Available from: https://sml.snl.no/profesjonsetikk_-_medisin_og_helsefag].
30. Sowell RL, Phillips KD. Understanding and responding to HIV/AIDS stigma and disclosure: an international challenge for mental health nurses. Issues Ment Health Nurs. 2010 june 31:394-402.
31. Sowell RL, Phillips KD. Understanding and responding to HIV/AIDS stigma and disclosure: an international challenge for mental health nurses. Issues in Mental Health Nursing. 2010;31(6):394-402 9p.
32. Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. AIDS Behav. 2009;13(6):1160-77.
33. Reinius M, Zeluf Andersson G, Svedhem V, Wettergren L, Wiklander M, Eriksson LE. Towards a new understanding of HIV-related stigma in the era of efficient treatment- A qualitative reconceptualization of existing theory. J Adv Nurs. 2021;77(5):2472-80.
34. Nyblade L, Mingkwan P, Stockton MA. Stigma reduction: an essential ingredient to ending AIDS by 2030. Lancet HIV. 2021;8(2):e106-e13.
35. UNAIDS. 90-90-90 An ambitious treatment target to help end the AIDS epidemic. Joint United Nations Programme on HIV/AIDS (UNAIDS); 2014.
36. Merriam-Webster. Subnational in Merriam-Webster.com dictionary 2022 [Available from: <https://www.merriam-webster.com/dictionary/subnational>].
37. UNAIDS. Understanding fast-track, accelerating action to end the AIDS epidemic by 2030. In: UNAIDS, editor.: Joint United Nations Programme on HIV/AIDS; 2015.

38. Whetten K, Reif, S., Whetten, R., Murphy-McMillan, L.K. Trauma, mental health, distrust, and stigma among HIV-positive persons: implications for effective care. *Psychosomatic medicine*. 2008(70(5)):531-8.
39. Helsedirektoratet. T. Arbeidstakere og arbeidsgivers holdninger til hiv i arbeidslivet Helsenorge.no: Helsedirektoratet; 2015 [Available from: <https://www.helsenorge.no/globalassets/dokumenter/arbeidstakere-og-arbeidsgiveres-holdninger-til-hiv-i-arbeidslivet-rapport.pdf>].
40. Dahl A. Hiv og levekår - Livet som hiv-smittet i Danmark. 2016 2016.
41. Folkhälsomyndigheten. Hiv i Sverige, En studie om kunskap, attityder och förhållningssätt till hiv i befolkningen. 2017.
42. Caugant D, Kløvstad, H., Nilsen, Ø., Olsen, A.O., Whittaker, R. . Årsrapport 2020 Overvåking av seksuelt overførbare infeksjoner Oslo: Folkehelseinstituttet, Område for smittevern moh; 2021.
43. Folkhälsomyndigheten. Hivinfektion – sjukdomsstatistik 2020 [cited 2022. Available from: <https://www.folkhalsomyndigheten.se/folkhalsorapportering-statistik/statistik-a-o/sjukdomsstatistik/hivinfektion/?p=93925#statistics-nav>].
44. Statens Serum Institut. HIV 2020 2020 [cited 2022. Available from: <https://en.ssi.dk/surveillance-and-preparedness/surveillance-in-denmark/annual-reports-on-disease-incidence/hiv-2020>].
45. Folkhälsomyndigheten. Sjukdomsinformation om hivinfektion 2020 [cited 2022. Available from: <https://www.folkhalsomyndigheten.se/smittskydd-beredskap/smittsamma-sjukdomar/hivinfektion/>].
46. Nyblade L, Stangl A, Weiss E, Ashburn K. Combating HIV stigma in health care settings: what works? *Journal of the International AIDS Society*. 2009;12(1):15.
47. Hiv-Danmark. Sundhedspersonale mangler vigtig viden om hiv (press release) København 2021 [updated 20.09.21. Available from: https://hiv-danmark.dk/wp-content/uploads/2021/10/Pressemeddelelse_Sundhedspersonale-mangler-vigtig-viden-om-hiv_Hiv-DK.pdf].
48. Folkhälsomyndigheten. Att leva med hiv i Sverige, En studie om livskvalitet hos personer som lever med hiv. 2016.
49. Gagnon M. Re-thinking HIV-Related Stigma in Health Care Settings: A Qualitative Study. *J Assoc Nurses AIDS Care*. 2015;26(6):703-19.
50. Vaughan E, Power M, Sixsmith J. Experiences of stigma in healthcare settings by people living with HIV in Ireland: a qualitative study. *AIDS Care*. 2020;32(9):1162-7.
51. Butler A, Hall H, Copnell B. *A Guide to Writing a Qualitative Systematic Review Protocol to Enhance Evidence-Based Practice in Nursing and Health Care*. [Oxford] :2016. p. 241-9.
52. Aromataris E, Munn, Z. (Editors). *JBIM Manual for Evidence Synthesis*: JBI; 2020. Available from: <https://synthesismanual.jbi.global>. <https://doi.org/10.46658/JBIMES-20-01>.
53. HealthManagement.org. Overview of the Healthcare Systems in the Nordic Countries. Country Focus: The Nordic Countries. 2010;4(1).
54. Wikipedia c. Scandinavia: Wikipedia, The Free Encyclopedia.; 2022 [Available from: <https://en.wikipedia.org/w/index.php?title=Scandinavia&oldid=1086132262>].
55. Nordic Welfare Center. A Nordic welfare model nordicwelfare.org: Nordic Welfare Center; [cited 2022. Available from: <https://nordicwelfare.org/en/about-us/>].
56. Herning L. Social policy and welfare www.norden.org: The Nordic Council and The Nordic Council of Ministers; [

57. Systematisk søking sokogskriv.no: Søk&Skriv; 2021 [updated 2021; cited 2022. Available from: <https://sokogskriv.no/soking/systematisk-soking.html#problemstilling>.
58. Rydström LL, Ygge BM, Tingberg B, Navèr L, Eriksson LE. Experiences of young adults growing up with innate or early acquired HIV infection--a qualitative study. *J Adv Nurs*. 2013;69(6):1357-65.
59. Plantin L, Wallander L, Mannheimer L. Public Knowledge and Attitudes to HIV: Research From Three Decades in Sweden. *International Journal of Sexual Health*. 2017;29(1):22-31.
60. Eden J LL, Berg A, et al., Standards for Synthesizing the Body of Evidence. In: (US) NAP, editor. *Finding What Works in Health Care: Standards for Systematic Reviews*. Washington (DC):2011.
61. Critical Appraisal Skills Programme. Casp qualitative check-list 2018 [cited 2022. Available from: https://casp-uk.b-cdn.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf.
62. Carlsson-Lalloo E, Berg M, Mellgren Å, Rusner M. Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld phenomenological study. *Int J Qual Stud Health Well-being*. 2018;13(1):1487760.
63. Dahlberg K. The essence of essences – the search for meaning structures in phenomenological analysis of lifeworld phenomena. *International Journal of Qualitative Studies on Health and Well-being*. 2006;1(1):11-9.
64. Wikipedia. Myndig 2022 [cited 2022. Available from: <https://sv.wikipedia.org/wiki/Myndig>.
65. Vergemålsloven. Lov om vergemål m.v. 2010-03-26-9 2010 [Available from: https://lovdata.no/dokument/NL/lov/2010-03-26-9/KAPITTEL_1#%C2%A72.
66. Anderson C. Presenting and evaluating qualitative research. *Am J Pharm Educ*. 2010;74(8):141.
67. Earnshaw VA, Chaudoir SR. From Conceptualizing to Measuring HIV Stigma: A Review of HIV Stigma Mechanism Measures. *AIDS and Behavior*. 2009;13(6):1160-77.
68. Zukoski AP, Thorburn S. Experiences of stigma and discrimination among adults living with HIV in a low HIV-prevalence context: a qualitative analysis. *AIDS Patient Care STDS*. 2009;23(4):267-76.
69. Pasient- og brukerrettighetsloven. Lov om pasient- og brukerrettigheter m.v. 1999-07-02-63 1999 [Available from: <https://lovdata.no/dokument/NL/lov/1999-07-02-63>.
70. World Health Organization. Consolidated guidelines on HIV prevention, testing, treatment, service delivery and monitoring: recommendations for a public health approach. Geneva; 2021.
71. Waldron EM, Burnett-Zeigler I, Wee V, Ng YW, Koenig LJ, Pederson AB, et al. Mental Health in Women Living With HIV: The Unique and Unmet Needs. *J Int Assoc Provid AIDS Care*. 2021;20:2325958220985665.
72. Grønningsæter BA, Hansen, L.S. . Om å bli eldre med hiv (Ageing with hiv). Fafo; 2018.

8 Appendix A – D:

Finding What Works in Health Care: Standards for Systematic Reviews description on synthesizing body of evidence - methodological characteristics

Following are the tables of the critical appraisal for each of the studies reviewed following Finding What Works in Health Care: Standards for Systematic Reviews description on synthesizing body of evidence - methodological characteristics (60).

A - Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study

B - Sexuality and childbearing as it is experienced by women living with HIV in Sweden – a lifeworld phenomenological study

C - Towards a new understanding of HIV-related stigma in the era of efficient treatment - A qualitative reconceptualization of existing theory

D - How gay men living with HIV experience and perceive the HIV stigma: a qualitative study

8.1 A - Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study

Describe the clinical and methodological characteristics of the included studies:

- Exploratory qualitative study
- Semi-structured interviews,
- Interview guide tested in two interviews before use – they were included in the study.
- Open conversation with interview guide as support. Follow-up questions asked when relevant
- Informed consent required either from participant or legal guardian
- Interviews performed by a nurse who were not involved in the participants regular treatment
- Both general questions of origin, family, living conditions etc., and more specific regarding stigma, sexuality and growing up in Sweden living with HIV.
- Tape-recorded with first author transcribing shortly after the interview

Analysis:

- Analyzed using qualitative content analysis
- Transcribed texts read by 1st and 2nd author individually and together
- Identified meaning units were compared and sub-categorized - 5 categories
- Participants has been anonymized to maintain confidentiality
- Some linguistic changes were made to increase clarity without changing the content

Rigor

- Strived to obtain a mixed sample regarding age, sex, and background
- The interviewer had no experience in data collection but experience working with children living with HIV – preunderstanding decreased
- To reduce data deviation, two authors were included that had very little or no clinical experiences with children and youth living with HIV

Aim:

Explore the experience of young adults growing up and living with HIV in urban Sweden

Sample size:

- 14 participants, 4 declined – 10 participants
- 5 male, 5 female – 8 had verified mother-to-child-transmission, 2 unknown transmission routes
- Six born in Sweden, 4 immigrants

Inclusion:

- Perinatal or early acquired HIV infection
- Been treated at a pediatric clinic in Sweden for more than 5 years
- Between 15-21 years

- Informed of his or hers HIV infection
- Understand and speak Swedish fluently

Exclusion:

not described

Timeframe:

January to august 2008

45 to 90 minutes

Findings:

- Living with a dark secret
- To protect themselves from the risk of being stigmatized, the participants hid their HIV status and only declared their status in healthcare situations.
- The participants seemed to use this silence as a strategy to avoid further stigmatization – fear of being judged for instance
- Ignorance and prejudice were more harmful than the disease itself
- Related disclosure to fear and insecurity
- The participants also expressed their worry that if their HIV status was discovered, they could be accused of unaccepted behavior in society
- The potential spread of rumors linked to HIV infection in the participants' small ethnic communities was one of their greatest concerns, as it could lead to isolation, powerlessness, and alienation.
- Participants believed that they could maintain control and decrease prejudice and ignorance among their peers by being open about their HIV infection.
- The participants rated their pediatric care for HIV treatment as fairly good.
- Some of the young adults relied heavily on their healthcare providers, including social workers, physicians, and nurses. They described the ease with which they could communicate with these professionals on any topic
- The need for healthcare professionals with appropriate knowledge concerning HIV was also expressed, as healthcare staff lacking sufficient skills and knowledge about HIV-induced frustration and anger among the participants.
- High quality of the health care providers was important because they mostly only felt safe to disclose their diagnosis to them
- Health care professionals were viewed as an important aid in coping with HIV and its consequences
- Stigma and discrimination were a major issue that governed the young adults in their decisions about how to live their lives
- Maintaining secrecy and being partly open about HIV infection were strategies employed by the participants to avoid and protect the family from prejudice and negative attitudes.
- Efforts to decrease stigma and discrimination, and disclosure matters are warranted on the societal, community and family level

8.2 B - Sexuality and childbearing as it is experienced by women living with HIV in Sweden – a lifeworld phenomenological study

Describe the clinical and methodological characteristics of the included studies:

- Qualitative study
- Individual phenomenon-oriented interviews, two in English
- Open conversation with interview guide as support. Follow-up questions asked when relevant
- Digitally recorded and transcribed verbatim
- First authors translation was verified by the other bilingual authors and the translated text was reviewed by a native English speaker

Analysis:

- Analyzed using phenomenological reflecting lifeworld analysis
- Describe the meaning structure of a phenomenon
- After analyzing as a whole, it was analyzed part by part to uncover nuances of meaning relevant to the aim
- Computer program (NVivo 11) used to organize data material to identify differences and similarities

Rigor

Aim:

Describe the phenomenon sexuality and childbearing as experienced by women living with HIV in Sweden

Sample size:

18 females (23 expressed interest, two did not meet, two changed their mind, one did not want the interview being recorded)

Went through clinics – oral og written information of the study

Inclusion:

- Women living with HIV
- Over 18 years of age
- Speaks Swedish or English

Exclusion:

- Diagnosed within 6 months
- Ongoing crisis reaction
- Serious mental illness

Timeframe:

September 2015 and April 2016

42-101 minutes interviews

Other relevant factors:

- Participants chosen strategically to present women living with HIV in Sweden – variety of age, years living with HIV, time lived in Sweden, having a partner or not, experiences of being a mother
- 30-60 years of age
- Diagnosed between 1992 and 2015
- Represented nine countries – seven born in Sweden the rest from Africa and Asia.
- Some of the women had partners, some of the partners lived with HIV themselves.
- Confidentiality assured. Identity and integrity protected
- Voluntary with possibilities to withdraw or discontinue without explanation
- Written consent
- No payment

Findings:

- “They often compare it [HIV] with diabetes. //But a patient with diabetes is not being seen as a source of infection or limits you from having sex or being close to people physically.”
- Expectations about people’s reactions and bad experiences of a partner leaving after learning about their partner’s positive HIV status can create a fear of being judged or rejected.
- Limitations in pregnancy for the women seem to exist because of the negative expectations of society, and even sometimes of some health care professionals, resulting in a sense that the women living with HIV have feelings of that they should not get pregnant and have children.
- There is also a feeling of receiving “unfair” (IP 7) treatment and discrimination, compared to HIV-negative women, when seeking help from the Swedish health care system, with such services as artificial insemination and adoption.
- Living with HIV can release feelings of alienation and a belief that one is not able to obtain what all other women have: a home, a partner, a relationship, a child, a normal life. A feeling of missing out on opportunities is common, and emotions of not being normal
- Results show how health care providers can have an impact on feelings of acceptance, and the women in our study highlight the importance of maintaining a good relationship with a health care provider. However, the findings in our study also show a sort of ambiguity between the need for and importance of providing specialized HIV care and the need to be treated in the same way as women who are not living with HIV.
- Strong feeling of responsibility to disclose status to partner
- The regulations relating to HIV are described by the women as existing for a reason but are experienced as placing the responsibility for the transmission of HIV on the person living with HIV, which seems to generate feelings of guilt and shame.

- HIV felt as a limitation in relation to sexuality and childbearing connected to experiences of stigmatization
- Experiences of stigmatization due to perceptions of contagiousness and transmission
- Feeling of lack of knowledge that leads to prejudice and misconceptions
- Feeling of being questioned about their right to have a baby by the health workers
- Mentions level of self-perceived stigma in the health care system as a grounds for providing equal health care
- These perceptions about contagiousness permeate thoughts, expectations, choices, decisions, and actions related to sexuality and childbearing. The perceptions are also present among members of society and health care professionals, thereby influencing the women's own perceptions.
- By providing education and non-judgmental information about HIV and its contagiousness to women, while also disseminating knowledge about HIV and its transmission in wider society and health care, the sexual and reproductive health and rights of women living with HIV can be strengthened (from conclusion)

8.3 C - Towards a new understanding of HIV-related stigma in the era of efficient treatment - A qualitative reconceptualization of existing theory

Describe the clinical and methodological characteristics of the included studies:

- Qualitative study using interviews and a framework approach to analysis
- Semi-structured interviews
- Participants recruited in an outpatient clinic
- Using purposeful sampling
- Neither research nurse nor the interview researcher had a clinical relationship with the participants
- Semi-structured interviews
- Schematic interview protocol to guide the interview
- Topics aimed to frame the experience of HIV-related stigma
- Audio-recorded
- Participants asked to report sociodemographic data (age, gender, country of origin)
- Sexual orientation was not asked, but some participants disclosed it
- Written and verbal information with opportunity to ask questions
- Confidentiality guaranteed
- Obtained written consent
- Ethically approved

Analysis:

- Framework approach
- All authors read several transcripts and wrote down their understanding of content
- Ideas and themes were noted and discussed
- Coded into enacted, anticipated, and internalized stigma
- Quotes translated from Swedish to English by an external to the research group
- Third-person plural pronouns are consistently used as gender-neutral
- If the content was not appropriate for the stigma mechanisms proposed by Earnshaw and Chaudoir (2009), new codes were inductively determined. This process generated a preliminary code index (Ritchie & Lewis, 2003) used to code 14 of the 15 transcripts in the data analysis software Nvivo version 11. The first and second author coded the same transcripts in a parallel process, comparing coding at weekly meetings and adjusting the index until agreement on coding was reached for all transcripts

Rigor

- All co-authors involved to some degree in the analysis

- Credibility of the analysis was enhanced through peer debriefing – analysis presented to colleagues not involved in the project, people living with HIV and non-gov org. for PLWH – to make the authors aware of preconceived biases
- Mentions of layered stigma due to experiences of other stigma related to f ex gender, origin, sexuality etc.

Limitation/bias**Aim:**

To use the material to critically examine and revise the stigma mechanisms

Sample size:

- 15 participants, 8 women, 7 men

Inclusion:

- Aware of their hiv-status for more than 1 year
- Durably virally suppressed
- Speak and understand Swedish and/or English

Exclusion: Not mentioned

Limitations:

- Mentions of other types of stigma i.e., gender, origin, sexuality which can lead to layered stigma
- Predetermined codes might lead to confirmation bias – authors state they had critically approach to this fact and coded inductively

Timeframe:

- 23 and 129 minutes

Other relevant factors:

- peer-reviewed
- 30 to 64 years of age
- All with Swedish residency, but born in different countries
- Laws and regulations as stigma (not having access to fertility treatment, restrictions when travelling)

Findings:

- Those who worked in healthcare settings, for example described how colleagues talked badly about patients with infections and how that affected them.
- Talked about not having access to fertility treatment in Sweden when wanting to have a baby.

- In addition to describing situations they experienced directly, participants often incorporated other peoples' encounters with stigma as part of their own stigma experience.
- Participants in the present study said that they anticipated being treated badly or that their children would be treated badly if others knew about their HIV.
- Being unwillingly labelled as a person with HIV, losing control over who was informed about one's HIV and losing control over how you were perceived as a person. Participants said that it was important for them to have control over who knew about their HIV.
- The HIV stigma framework could benefit from revision for people living with virally suppressed HIV in a context where HIV treatment is easily accessed and free of charge.
- Described stigma as a barrier in many situations
- Anticipated and enacted stigma were to be more complex than described in existing literature
- Labelled as a person with HIV – important and persistent part of stigma experience
- Disclosure found to be context-related, and participants weighed the relevance of disclosure – even in health care situations
- Felt responsibility to disclose status to others
- Important matter in nondisclosure – avoid labelling and hence avoid that to be the most defining feature
- Experiences of people talking behind their backs or in negative context about other PLWH when not knowing that the person also lives with HIV
- Control as an important aspect regarding HIV

8.4 D - How gay men living with HIV experience and perceive the HIV stigma: a qualitative study

Describe the clinical and methodological characteristics of the included studies:

- Qualitative design with in-depth, semi-structured interviews
- Interview guide to stay on topic. Mainly open-ended questions.
- Interview guide reviewed and edited between interviews
- Participants mostly recruited from Aksept and HIVNorge – organizations working with individuals affected by HIV
- Written information about the study handed out by the staff
- All participants identified themselves as gay men
- Interviews were recorded and transcribed – recordings were deleted after transcriptions
- Transcribed after the TA approach
- Oral and written information about the study while arriving. Signed written consent form
- Ethically evaluated and approved
- Anonymized
- Data and consent-forms were stored in a safe or password protected memory stick
- Includes self-reported limitations

Analysis:

- Thematic analysis based on 6 steps by Braun and Clarke – familiarization, generating initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report

Limitations:

- Participants were in two potentially stigmatized groups, gay and living with HIV
- Few participants – the study is not intended to be representative for all GMLH
- More participants might have resulted in wider range of narratives
- Only participants in the Oslo area – demographically not representative
- Limited timeframe
- Mentions that the researcher is a white female in her twenties and that it might have influenced the data – not being a member of the reference group, non-belongingness. Although this could also be of help for the interviewer due to the fact that the participants thoroughly explained aspects that might not be commonly known to "outsiders"

Aim:

To investigate how HIV-related stigma is experienced and perceived by gay men living with HIV, and how they deal with it.

Including their size:

- 10 participants

Inclusion:

- Men who have sex with men
- HIV- positive
- Presently undergoing treatment for HIV

Exclusion: Not mentioned**Timeframe:**

August to October 2016

1 to 2 hours and 40 minutes

Findings:

- All participants reported one or more negative experiences, whether it be from friends, family, work, sex partners or in the health care system.
- The participants described the internet as one of the arenas where they can experience much stigma (online dating for instance).
- *I talked about my medicine. And he compared talking about hiv like describing the consistency of your faeces, and that he didn't think one should talk about any medical diagnosis at all in public. If I had talked about my insulin I don't think I would've had the same (laughs) reaction I imagine.*
- *"So, I was just called in to my boss five minutes before I'm heading off to a department meeting, and I'm informed that I'm losing my position as leader, because she didn't see any future considering I had the illness I had. And then my world fell apart."*
- Predominantly seemed satisfied with the treatment received
- *"But for me personally, I've always been really lucky, and great follow-up, and I've had all the help I've needed. I have absolutely nothing to complain about."*
- Some of the factors mentioned when describing negative experiences with health care professionals were being treated differently than other patients, being asked invasive and unrelated questions, top-down attitudes from general practitioners (GPs), not being given important information regarding treatment, nervous and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy), little psychological follow-up, and in other ways showing an incapability to act on the patient's needs.
- While some experienced no difference in attitudes between the gay community and the rest of society, most defined the gay community as where they meet most stigmatisation.
- While some participants described their lives as heavily influenced by stigmatisation, others seemed to have been spared from such incidences. However, as long as there is an actual or perceived risk of stigmatisation, a fear of stigmatisation may consequently have great influence on ILH's lives and choices, one of which is whether to tell others that they are living with hiv.
- From the participants' narratives, both the fear of being exposed and the active attempt to hide their differentness can be exhausting burdens for those carrying such a secret.
- Several participants described living with a secret as burdensome or exhausting.

- Some participants paint a picture of being little affected by living with secrets, whereas others describe great relief after sharing their burden.
- James considered himself quite open towards most people, he had chosen not to talk about his diagnosis at his current workplace, fearing that this may interfere with his chances of getting steady employment.
- Need for demystifying the condition and increase knowledge to decrease stigma
- Great gaps among the stigma experienced, from whom, how it was experienced and how they dealt with it
- Most participants reported having negative thoughts about self in relation to their diagnosis at some point after receiving the diagnosis
- Anticipated stigma most common
- Self-stigma was generally regarded as the biggest concern.
- Different tactics needed to tackle the complexity of hiv-related stigma
- Multiple focused interventions might be helpful
- It was found that they experience it through encountered stigma in varying contexts and arenas, through having to deal with a hidden identity and issues related to disclosing or not disclosing this hidden identity, through negative self-perception, and through unwanted responsibilities. We have seen that stigmatisation, despite medical improvements, still exists, although not all report stigmatisation as a personal issue

Appendix E – H:

Critical Appraisal Skills Program (CASP) checklist

Following are the tables the critical appraisal for each of the studies reviewed following the Critical Appraisal Skills Program (CASP) checklist (61).

E - Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study

F - Sexuality and childbearing as it is experienced by women living with HIV in Sweden – a lifeworld phenomenological study

G - Towards a new understanding of HIV-related stigma in the era of efficient treatment - A qualitative reconceptualization of existing theory

H - How gay men living with HIV experience and perceive the HIV stigma: a qualitative study

8.5 E - Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study

Lise-Lott Rydström, Britt-Marie Ygge, Björn Tingberg, Lars Navèr, Lars E Eriksson

Accepted 2012 (Journal of advanced nursing)

	Yes	Can't tell/unclear	No
<p>Was there a clear statement of the aims of the research? <i>The aim of the study was to explore the experience of young adults growing up and living with HIV in urban Sweden.</i></p>			
<p>Comment: This is a very clear statement of the aim of the research. The paper describes a scarcity of studies focusing on the life situation of young adults living with HIV, not only in Sweden. As understood, the researchers discovered a knowledge gap regarding life situation and the need of this to direct the development of adequate care and interventions for this growing group. As the authors write, there are a new generation of HIV-infected children now reaching adulthood. The care and treatment are better, and they might expect to live a life with a chronic disease with long-life expectancy hence the need for adequate care and interventions. The relevance of this study is well reasoned.</p>			
<p>Is a qualitative methodology appropriate</p>			
<p>Comment: As to this study aiming to explore experiences of young adults, a qualitative method seems appropriate. Experiences are subjective and in-depth interviews might aid in deeper understanding and the possibility to ask further follow-up questions if needed.</p>			
<p>Was the research design appropriate to address the aims of the research?</p>			
<p>Comment: This is an exploratory qualitative study using qualitative content analysis. They describe it a systematic approach for describing a certain phenomenon by objective means without going further into explaining why this design is chosen. They do, however, describe the data analysis process.</p>			
<p>Was the recruitment strategy appropriate to the aims of the research?</p>			
<p>Comment: They wanted to achieve maximum variation in sex, age, and socio-cultural background. They wanted to include all the individuals that fit their inclusion criteria. Regarding the aim of the study, the recruitment strategy was appropriate. Although, they only included participants from only one clinic. It is not described whether there was a reason for not including from other clinics as well other than that the hospital clinic cares for a large number of HIV-infected children I Sweden. Even so, I do find the strategy appropriate.</p>			

	The recruitment process is described, as well as why some of the participants withdraw or did not partake in the study. 10 participants, mixed gender 50/50 and described as to background, age, who they lived with etc.		
Was the data collected in a way that addressed the research issue			
	<p>Comment:</p> <ul style="list-style-type: none"> • Semi-structured interviews performed by an external nurse who were not involved in the participants regular treatment • Performed at a location chosen by the participant • Open conversation with interview guide as support. Follow-up questions asked when relevant • A semi-structured interview guide created based on the preunderstanding of the first author’s extensive experience in the field of focus • Two pilot interviews conducted to test the usability of the interview guide –included in the study. • Both general questions of origin, family, living conditions etc., and more specific regarding stigma, sexuality and growing up in Sweden living with HIV. • Tape-recorded with first author transcribing shortly after the interview • Interview lasted between 45-90 minutes • I cannot find that data collected are collected in a way that do not address the research issue. 		
Has the relationship between researcher and participants been adequately considered?			
	<p>Comment:</p> <ul style="list-style-type: none"> • The authors state that the interviewer was an external nurse who were not involved in the participants regular treatment - unclear whether the research team knew of the participants more than the tape-recorded interviews. • They do write <i>our clinical side's complete sample of young adults that fulfilled inclusion criteria</i> which might indicate that they knew of the participants. However, this might also be the reason for using an external interviewer. • To reduce data deviation, two authors were included that had very little or no clinical experiences with children and youth living with HIV • The authors do state no conflict of interest 		

<p>Have ethical issues been taken into consideration?</p>	<p>Comment:</p> <ul style="list-style-type: none"> • Informed consent was obtained from all participants and in addition from the legal guardians for those younger than 18 years. • Ethical approval was granted by the Regional Ethical Review Board in Stockholm. • Informed that participation was strictly voluntary, and they could choose to terminate their participation at any stage without explanation or impact on their present or future care. • Interviews may give rise to thoughts and feelings that the participant may need help processing, all participants were offered support from the interviewer and, if necessary, referral to a counsellor. • Special efforts were made to ensure confidentiality when transcribing and presenting the material; participants' names were replaced with pseudonyms. 		
<p>Was the data analysis sufficiently rigorous?</p>			
	<p>Comment:</p> <ul style="list-style-type: none"> • Analyzed using qualitative content analysis • Transcribed texts read by 1st and 2nd author individually and together • Identified meaning units were compared and sub-categorized - 5 categories • The results were discussed among all co-authors during the entire analysis and writing process. • Strived to obtain a mixed sample regarding age, sex, and background • The interviewer had experience in data collection but not with working with children living with HIV – preunderstanding decreased • To reduce data deviation, two authors were included that had very little or no clinical experiences with children and youth living with HIV • Quotations used to illustrate results as well as to facilitate the readers judgment of credibility – which I can see reflected in the article • The article has a separate section describing how they strive for rigor and achieve trustworthiness. 		

	<ul style="list-style-type: none"> • Contradictory data are considered and there are examples if participants do not have the same thoughts and experiences. I cannot find that the authors have critically examined their own role, potential bias and influence during analysis and selection of data. They all work at the clinic participants are recruited from, but it is not stated their background. However, the whole research team are working together, and they have discussed categories and information extracted from the interviews as I can understand. 		
<p>Is there a clear statement of findings?</p>	<p>Comment: In the abstract, the findings are written as to be <i>the analysis revealed five categories illustrating the experiences of growing up and living with HIV in Sweden: (1) to protect oneself from the risk of being stigmatized; (2) to be in control; (3) losses in life, but HIV is not a big deal; (4) health care/healthcare providers; and (5) belief in the future.</i></p> <p>The findings do illustrate five categories that may discover what the study aimed to explore. I do not find it all too clear as a statement of findings just an overview. They did, however, find that a major issue was governing the participants life was stigma and discrimination – and this was within all the categories. Nonetheless, this is just one part of the life experienced by the young adults. As written before, the aim of the study is broad, and they might have gained if narrowed the aim more as to have a clear finding.</p> <p>They do, however, add to the paper an information box on what is already known, what this paper adds and implications for practice and/or policy. The part "What this paper adds" is more relevant to what might be their findings with this study. It is a clear statement.</p>		
<p>How valuable is the research?</p>	<p>Comment:</p> <ul style="list-style-type: none"> • The authors add to the paper an information box on what is already known, what this paper adds and implications for practice and/or policy. This clarifies the relevance of the study as well as the section with findings from the collected data. • I do believe that this information is relevant as to the era we live in today with treatment available and young people having a long-life expectancy in contrast to earlier. With that 		

we need to consider how to continue so that to offer proper care, interventions, and preventative measures to secure an as normal life as possible for those living with HIV.

- The authors are transparent as to the study having limitations regarding applicability of the results and that those experiences discovered might differ for young adults living in smaller communities lacking specialist care.

Contribution to existing knowledge or understanding:

This article has added an information box in which they have in short described what it adds to existing knowledge and what kind of implications this might have for practice and/or policy. The continuous fear of disclosure and other people's reactions except when in health care is important. There is a need for continuity among health care professionals as well as high quality care. The authors states that the findings of this study support the current knowledge. Young adult has a positive outlook on the future, however, growing up with and living with HIV as a young adult are related with issues surrounding secrecy and the struggle to avoid or cope with stigma and discrimination.

How are the findings relevant to my study?

To be a young adult is tough on its own, and it is important to include how and if they, when living with HIV, also experience stigma and discrimination. They have grown up in a time where treatment and knowledge has been available and, one might think that the fear, as shown in this study, would not have been experienced to that degree shown in the study.

8.6 F - Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld phenomenological study

Ewa Carlsson-Lalloo, Marie Berg, Åsa Mellgren & Marie Rusner

Accepted and published 2018 (International Journal of Qualitative Studies on Health and Well-being)

	Yes	Can't tell	No
<p>Was there a clear statement of the aims of the research? <i>The aim was to describe the phenomenon sexuality and childbearing as experienced by women living with HIV in Sweden.</i></p>			
<p>Comment: The aim of the study is clear and appropriately defined. It is made clear that their aim is to describe women with HIVs experiences about sexuality and childbearing. These women living in Sweden</p>			
<p>Is a qualitative methodology appropriate</p>			
<p>Comment: As it is a study of subjective experiences, qualitative method is appropriate to get a deeper understanding an nuances of it and what is experienced.</p>			
<p>Was the research design appropriate to address the aims of the research?</p>			
<p>Comment: The researchers used phenomenological reflective lifeworld approached. They have described the method/design thoroughly and with that argued that is the right design to get the aim of the study well explored</p>			
<p>Was the recruitment strategy appropriate to the aims of the research?</p>			
<p>Comment: They strategically chose their participants as to present women living with HIV in Sweden as well as to get a wide variety of experiences. To get the variety there was one inclusion criteria – women must be over 18 years of age, however, they excluded women with newly diagnosed HIV-infection and/or with ongoing crisis reaction and/or mental illness to reduce possibility of bias. The women chosen differed in age, years living with HIV, time lived in Sweden, cultural background, and the experience of being a mother. Researchers chose five clinics, and participants that were interested got contacted by first author to get more information. 23 women expressed interest. 5 were not interviewed and the authors described the reasoning as to why. 18 women across three clinics were interviews and it is described the variances of the participants.</p>			

	A limitation of the study is that no women were included who originated from Eastern Europe, Australia, or the American continent, nor did it include any women with a history of drug abuse.		
Was the data collected in a way that addressed the research issue			
	Comment: <ul style="list-style-type: none"> • Individual phenomenon-oriented interviews (first author as interviewer), two conducted in English • Participants chose location • The interviews lasted between 42 and 101 minutes. • Open conversation with interview guide as support. The interviews began with a broad open question: Follow-up questions asked when relevant. The research gives examples of questions asked as well as examples of follow-up questions • Digitally recorded and transcribed verbatim • First authors translation was verified by the other bilingual authors and the translated text was reviewed by a native English speaker 		
Has the relationship between researcher and participants been adequately considered?			
	Comment: It is stated that no potential conflict of interest was reported by the authors, however, there are no other comments if there are any relationships between researchers and participants		
Have ethical issues been taken into consideration?			
	Comment: <ul style="list-style-type: none"> • The study was approved by the Regional Ethical Review Board in Gothenburg, Sweden and conducted in accordance with the Helsinki Declaration. • Assured confidentiality and protection of integrity and identity • Participants were informed that their participation in the study was voluntary, and that they could withdraw or discontinue the participation at any point without explanation. • Participants signed consent form • Participants receive no payment 		
Was the data analysis sufficiently rigorous?			
	Comment: <ul style="list-style-type: none"> • Well described analyzing process – how it was conducted, and further meanings was also explained 		

	<ul style="list-style-type: none"> • After analyzing as a whole, it was analyzed part by part to uncover nuances of meaning relevant to the aim • Computer program (NVivo 11) used to organize data material to identify differences and similarities • Use of bridling (to establish objectivity and validity throughout the research) to continue process of discovery, reflecting and working through meanings • In final stage variance of essence was further described in more contextual nuances of the phenomenon • Results were processed by all authors before final version was defined to ensure trustworthiness as well as a professional English-speaking native-language editor checked the language. <p>Contradictory data are taken into account: There are not much data that exemplifies contradiction in perceived experience of stigma. There is mentioned a feeling of being normal or feeling of relief when being open about diagnosis, but also the fear of disclosure because of the unknown reaction from other people. Further the data shows a high feeling of contagiousness even though other studies show that being on treatment decreases contagiousness.</p>		
<p>Is there a clear statement of findings?</p>			
<p>How valuable is the research?</p>			<p>Contribution to existing knowledge or understanding:</p> <ul style="list-style-type: none"> • By providing education and non-judgmental information about HIV and its contagiousness to women, while also disseminating knowledge about HIV and its transmission in wider society and health care, the sexual and reproductive health and rights of women living with HIV can be strengthened. • Women living with HIV in Sweden experience legislation and regulations as old-fashioned and repressive • The level of knowledge about HIV is experienced as being much better at HIV clinics than for health care in general. • Need to provide more public information about HIV and its transmission and in that way increase the general knowledge about HIV, thereby decreasing prejudices and the stigmatization of people living with HIV.

Is there identified new areas where research is necessary:

- A need to enable and address issues connected with sexuality and childbearing to empower and encourage women living with HIV to be actively engaged in making confident choices and decisions about sexual habits, pregnancy, and childbirth.
- There is a knowledge gap about risk of mother-to-child-transmission of HIV when breastfeeding and suggested further research of risk in women on treatment for HIV.
- A need for deeper knowledge, not only in the health care system, but also in society. Lack of knowledge generates prejudices and misconceptions about HIV and transmission.
- The negative effects of stigmatization in the Swedish context must be further investigated to see whether there are differences between groups of people living with HIV in Sweden (gender, age, or cultural background etc.) and how they affect sexuality and childbearing and health and well-being for individuals living with HIV.
- Important to investigate the level of self-perceived stigmatization in the health care system as a ground for providing equal care.

May the finding be transferred to other populations:

They do compare the feelings of responsibility being similar to that of women with type 1 diabetes. There might more similarities as to diabetes type 1 is a chronic disease and HIV being life-long infectious disease.

How are the findings relevant to my study?

It was not many findings or quotations from the participants regarding experiences of stigma and discrimination regarding HIV. However, the authors do input indirectly that there are such experiences. They mention participants having a feeling of receiving “unfair” treatment and discrimination, compared to HIV-negative women, when seeking help from the Swedish health care system, with such services as artificial insemination and adoption. Which I understand as the participants having experienced stigmatization in health care systems even though not given examples of it. They indirectly describe an experience of lack of knowledge which inhibit participants, and other women living with HIV, to make confident choices and decisions about sexual habits, pregnancy, and childbirth. Further the authors describe health care professionals that sometimes has difficulties in explaining high or low risk of transmission in specific sexual situations. There are descriptions of health care providers being in positions of power when it comes to information about HIV and that the consequences are described as: *“It can go very wrong depending on the information you get, how you express it”*. I understand this quotation as to be a result of at least once

feeling some kind of stigmatization, as well as the sentence *being treated fairly and with respect are important factors in feeling normal and confirmed*. Further the authors states that their findings reveal experiences of having a feeling of being questioned about the right to have a wish to become pregnant, even by health care providers and that one should note that the level of self-perceived stigmatization in the health care system as a ground for providing equal care.

I find this article to be of partly relevant for my study and what I aim to deeper understand with this review. It is important to also look at it as an all-woman-focused study investigating sexuality and childbearing as well since there might be other feelings and situations that they experience compared to men living with HIV. Not that it makes it more or less important than other experiences of HIV-related stigma

8.7 G - Towards a new understanding of HIV-related stigma in the era of efficient treatment-A qualitative reconceptualization of existing theory

Maria Reinius, Galit Zeluf Andersson, Veronica Svedhem, Lena Wettergren, Maria Wiklander, Lars E. Eriksson

Received 2020, accepted 2021 (Journal of advanced nursing)

	Yes	Can't tell	No
<p>Was there a clear statement of the aims of the research? <i>The aim was to describe the experiences of HIV-related stigma among people living with virally suppressed HIV in Sweden and investigate how these experiences correspond to the stigma mechanisms of Earnshaw and Chaudoir's (2009) HIV stigma framework, to further develop the framework.</i></p>			
	<p>Comment:</p> <ul style="list-style-type: none"> • The goal of the study was to see if the mechanisms in an HIV-stigma framework corresponds with experiences of stigma among people living with HIV (PLWH) in Sweden. Those being virally suppressed due to the current era of available treatment. They were to investigate if PLWH experience the same kinds of stigma compared to the time when the framework was first developed. In 2020 in Sweden 98% of those who were living with HIV were on antiretroviral treatment and had a viral load <150 copies/ml. • It was performed an empirical test of the HIV-stigma framework prior to this study that found that it was reported limited experiences of enacted stigma as well as discovering relationships between different types of stigma to emotional and physical health. • With this study the authors want to discover if the framework need revision to fit better to stigma-experiences today in countries where viral treatment is available and most PLWH are virally suppressed. Their aim was to use the material to critically examine and revise the stigma mechanisms. • To critically examine and maybe revise frameworks to keep them up to date is important so that to increase the possibility of targeting stigma experiences and perhaps aid in reducing peoples' experiences of HIV-related stigma. And with the WHO's 90-90-90 target this is an era were hopefully most of the people living with HIV are virally suppressed. 		
<p>Is a qualitative methodology appropriate</p>			
	<p>Comment: This was a qualitative study using semi-structured interviews analyzed with a framework approach. Experiences in general, and experiences of stigma is subjective experiences and may be described in other words hence not always fit into a questionnaire. I believe that</p>		

	<p>qualitative research is an appropriate way to address the goal and aim for this research.</p>		
<p>Was the research design appropriate to address the aims of the research?</p>			
	<p>Comment: The researchers has described the choice of methodology and design thoroughly. A framework approach seems appropriate since the researchers are to investigate the correspondence between experienced stigma and HIV-stigma framework. The use of in-depth interviews and qualitative method seems appropriate to get a deeper understanding and knowledge of possible stigma experiences.</p>		
<p>Was the recruitment strategy appropriate to the aims of the research?</p>			
	<p>Comment: Purposeful sampling of participants from one clinic using an external research nurse. However, they chose to only include one clinic for the recruitment without giving a reason. This might have led to a limited amount of participants. They were all virally suppressed (viral load <150 copies/ml at three time points during the last three years) which is important for the aim. 15 participants were an heterogenous group regarding age, gender and country of birth which is further described.</p> <p>There are no comments on inclusion or exclusion criteria. There is no comment if there were participants that chose not to partake in the study.</p>		
<p>Was the data collected in a way that addressed the research issue</p>			
	<p>Comment:</p> <ul style="list-style-type: none"> • Individual face-to-face semi-structured interviews in conversational form. • Used two external interviewers with relevant background and experience in this kind of studies was expressed in the article • Used a schematic interview protocol guide with topics aimed to frame the experience of HIV-related stigma. • Examples of questions asked were given in the article, and if a need for follow-up questions with examples. Open-ended questions that are not leading or too narrow. Further description of the initial question and that it led to participants describing experiences of living with HIV. • The participants were able to choose the interview location which might have made the participants safer and more prone to be more open about their experiences. • Interviews were audio-recorded and lasted between 23 and 129 min. 		

	<ul style="list-style-type: none"> • They asked for sociodemographic data, however stating that neither sexual orientation nor ethnicity were asked in a systematic way. • There is no information on modifying the protocol/guide or testing it before use. However, they postponed analysis of one interview until finalizing the other interviews. This was done for referential adequacy. The interview was then analyzed, findings stable and included. 			
Has the relationship between researcher and participants been adequately considered?	<table border="1" data-bbox="454 533 1444 577"> <tr> <td style="width: 33%;"></td> <td style="width: 33%;"></td> <td style="width: 33%;"></td> </tr> </table> <p>Comment:</p> <ul style="list-style-type: none"> • Neither the recruiting research nurse nor the interviewers had a clinical relationship with the participants. • No further comments on the role of the rest of the research team other than the declaration of no conflict of interest. • Neither are there information, only assumptions (from me), that possible comments from the peer debriefing was followed if comments led to changes in the data, misconceptions, or other bias. 			
Have ethical issues been taken into consideration?	<table border="1" data-bbox="454 965 1444 1010"> <tr> <td style="width: 33%;"></td> <td style="width: 33%;"></td> <td style="width: 33%;"></td> </tr> </table> <p>Comment: The participants received written and verbal information about the study with the opportunity to ask questions. They were also informed that they could withdraw at any time and that confidentiality was guaranteed, and that it is anonymized. Written consent was obtained at the time of the interview. The paper states that <i>this study was performed in line with the principles of the Declaration of Helsinki. The Regional Ethical Review Board of Stockholm granted approval for the study.</i> With that information I do believe the information given on the ethical considerations are sufficient.</p>			
Was the data analysis sufficiently rigorous?	<table border="1" data-bbox="454 1397 1444 1442"> <tr> <td style="width: 33%;"></td> <td style="width: 33%;"></td> <td style="width: 33%;"></td> </tr> </table> <p>Comment:</p> <ul style="list-style-type: none"> • Included own section on rigors • Two main authors conducted most of the analysis in cooperation. However, all the co-authors were involved in the analytic process to some extent. • Weekly comparing of coding and adjusted the index until agreement on coding was reached for all transcripts. The ongoing analysis was also presented and discussed at regular meetings including all co-authors. • The authors do note that the use of predetermined codes in a framework approach may lead to confirmation bias. Further they 			

	<p>state that they had a critical approach to the predetermined stigma mechanisms, but also coded inductively.</p> <ul style="list-style-type: none"> • There is, in my opinion, a thorough description of the data analysis process, and how the researchers coded the data and extracted their findings. There is mentioned that irrelevant information and repetitions was removed to facilitate readability. • Furthermore, the authors mention <i>layered stigma</i>, however, their experience is that the participants maintained focus on HIV-related stigma. The authors describe that to strengthen credibility of the analysis they presented the data through peer debriefing for research colleagues not involved in the project, people living with HIV and non-governmental organizations for people living with HIV who asked critical questions, making the authors aware of possible preconceived biases. • Analysis of one interview was postponed until the analysis of the remaining interviews was finalized for referential adequacy. The last interview was then analyzed, and the findings deemed stable. <p>Contradictory data are taken into account: One participant reported that HIV only affected their life in relation to relationships, but otherwise they had only positive experiences when disclosing their status. Further, most of them reported HIV to not have impact on self-image – which is in contradiction to some other studies I have read - this was also represented in the finding but only by a few participants. My conclusion is that there is not much contradictory data in this article, however, this might not be that there is data excluded to support their aim, but more that there is a continuity in the experience of stigma and discrimination.</p> <p>Presenting their method of analyzing the data and what is removed as well as being transparent on limitations and possible factors that can lead to bias. Including a peer reviewing and critically approach the data and their own role, as well as stating, with explanation, the vulnerability for bias using predetermined coding and their method chosen they upheld an acceptable rigor to their analysis.</p>				
<p>Is there a clear statement of findings?</p>	<table border="1" data-bbox="454 1675 1444 1720"> <tr> <td style="width: 20%;"></td> <td style="width: 20%;"></td> <td style="width: 20%;"></td> <td style="width: 40%;"></td> </tr> </table> <ul style="list-style-type: none"> • In their conclusion they state that <i>"The HIV stigma framework could benefit from revision for people living with virally suppressed HIV in a context where HIV treatment is easily accessed and free of charge."</i> Which for me is a clear statement of findings. 				

	<ul style="list-style-type: none"> • The authors have collected their findings and grouped it into three main sections after the framework from 2009. The findings are discussed, and they state that <i>"Through framework analysis of interviews with persons who are virally suppressed, we suggest additional content and nuance in the individual stigma mechanisms (Earnshaw & Chaudoir, 2009), particularly with regard to enacted and anticipated stigma."</i> • They found that internalized stigma remained similar to that described in 2009, but that anticipated and enacted stigma were more complex. <p>Findings in this study is discussed in relation to the research question, and there is throughout the discussion mentioned findings in relation to the framework. What works as of the research conducted and what might improve the framework. When discussing the findings, the authors does mention the findings that are similar across the data, and they give examples and quotes to support their finding. If more than one participant shared similar experiences participant was mentioned in plural, however, not how many. I do feel that the findings are explicit and well documented and stated.</p>				
<p>How valuable is the research?</p>	<table border="1" data-bbox="462 1003 1066 1041"> <tr> <td style="width: 25%;"></td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> <td style="width: 25%;"></td> </tr> </table> <p>The researchers found that there was possibly a need for revising of the framework.</p> <p>Has included a section in which they describe the findings regarding implication of care.</p> <p>The authors suggest an additional content and nuance in the individual mechanisms with particularly regard to enacted and anticipated stigma. And that labelling is added as a fourth process since it was central in the narratives in both enacted and anticipated stigma. The authors recognize participants describing a lack of knowledge in society</p> <p>Contribution to existing knowledge or understanding:</p> <ul style="list-style-type: none"> • Anticipated and enacted stigma were to be more complex than described in existing literature • Participants often incorporated other peoples' encounters with stigma into their own experience of stigma. • Concept of labelling a person with HIV – important and persistent part of stigma experience. This is not included in the original framework <p>How are the findings relevant to my study?</p> <p>This study aimed to look at experiences that are related to HIV which I also aim to look at. However, findings regarding stigma in the health care</p>				

	<p>are scare, but nonetheless described. Those findings are useful for my study. Their finds included experiences of health care personnel talking badly about patients without knowing that their colleague has HIV which is both stigmatizing towards the colleague and the patients. Participants mentioned not having access to fertility treatment in Sweden when wanting to have a baby, although this might be a misunderstanding of information given and how it has been given, it still is an experience of stigma and/or discrimination because of their seropositive status.</p>
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8.8 H - How gay men living with hiv experience and perceive hiv-stigma: a qualitative study

Anette Einan Enoksen, Bente Træen

Published 2018 (Scandinavian psychologist)

(The version used in this thesis is her master's dissertation of which the article is based upon)

	Yes	Can't tell	No
<p>Was there a clear statement of the aims of the research?</p> <p><i>The aim of this study was to investigate how HIV-related stigma is experienced and perceived by gay men living with HIV (GMLH), and how they deal with it.</i></p>			
<p>Comment: As the authors aim with this study is to fill the gap of knowledge on how stigma is experienced, perceived and dealt with by gay men living with HIV in Norway, the statement of this study is clear. There was in 2018 and still are a knowledge gap in the experience of stigma among people living with HIV, hence this study is both relevant and important to contributing to filling the knowledge gap. The aim of the article is supported by three subordinate research questions:</p> <ol style="list-style-type: none"> 1) What are the GMLHs' experiences with social stigmatization related to their serostatus, and how and from whom do they receive negative prejudice? 2) What are the GMLHs' experiences with internalized HIV negativity and self-stigma, and do they experience any positive aspects of the diagnosis? 3) How do GMLH potentially deal with HIV-related stigma? 			
<p>Is a qualitative methodology appropriate</p>			
<p>Comment: To be able to investigate further the aim of this study a qualitative method is appropriate. With in-depth interviews one might obtain a deeper understanding of a subjective experience and if needed to probe further one are able to ask follow-up questions. The methodology is considered appropriate and right for this study.</p>			
<p>Was the research design appropriate to address the aims of the research?</p>			
<p>Comment: The research design is discussed and justified. There is mentioning that the author originally considered several designs for this study, however she found that this</p>			

	<p>design, thematic analysis, abled her to get more use of the data she had gathered. She therefore went from IPA to TA after collecting data. As she argues that important data would have been lost if used IPA, the switch to a different design was the right thing to do. In the description of the design chosen she argues both the positive and negative concerns using TA and justifies well the use of this design.</p>		
<p>Was the recruitment strategy appropriate to the aims of the research?</p>			
	<p>Comment: The author describes the recruitment process in that she mentions inclusion criteria (belonging to the category "men who have sex with men", being seropositive and presently undergoing treatment for HIV), where participants were recruited through (Aksept and HivNorge) although not using clinics only organizations working with individuals affected by HIV/AIDS. She does also mention snowballing as part of the recruitment. Participants got written information and had to contact the researcher. There are no mentions of any participants being excluded or withdrew themselves from the study.</p>		
<p>Was the data collected in a way that addressed the research issue</p>			
	<p>Comment:</p> <ul style="list-style-type: none"> • Semi-structured interviews • It is not clear if the participants were able to choose the setting of the interviews, although it is mentioned that they were conducted at the premises of the university and an office provided by HivNorge. • The researcher made an interview guide to ensure relevant topics to be included, and they were mainly open-ended questions. • Interview guide was simply used as a guide on topics of interest, whereas the order of topics varied, and further questions and more follow-up questions were added when seen as fit during 12 interviews. • Interview guide was revised and edited between interviews for improvement. It is not explained any further why this was done. There might be seen as the questions were not the same in every interview if revised and edited between interviews. 		

	<ul style="list-style-type: none"> • She includes examples of the questions used; however, those examples are more relevant as to get background information and ease up the conversation, not examples of questions that would be of help to the aim of this study. • The author/researcher addresses the possibility of being a member of two stigmatized groups (being gay and living with HIV) to avoid layered stigma and in that way get information on HIV-related stigma • A recorder was used to record the interviews for further transcription. Transcription pedals and a transcription program (Olympia, DSS Player Standard Transcription Module) were used for a simpler and more effective transcription process. • There is documented how the data analysis was carried through, with explanation on why this analyzing method was suitable for this study – for example the author/researchers states "TA, which is more concerned with <i>what</i> is said rather than <i>how</i> it is said, does not require as detailed transcripts." And that " the transcripts were done through orthographic transcription.". Further there are descriptions of six stages for conducting successful TA and that they were used as guidelines • The extracts included in the report were translated to English to concur with the language of the report. • The researcher/author states that there might be several extracts that appropriately may demonstrate a finding, however, only extracts that most clearly demonstrated the findings were used in the article
<p>Has the relationship between researcher and participants been adequately considered?</p>	<p>Comment: The researcher/author does state that the fact that she is a white, female in her twenties might have influenced the data in several ways and also how the participants related to the researcher. She is not a member of the same reference group, and this might have led to increased acceptance for further questioning and participants explaining more thoroughly. She states that the non-belongingness might therefore have been an advantage.</p>

	<p>While the author/researcher do document the limitations of her studies, there are no explaining of her background or how it might have affected the data and interpretation of data.</p>		
<p>Have ethical issues been taken into consideration?</p>			
	<p>Comment:</p> <ul style="list-style-type: none"> • The study has been ethically evaluated and approved by the University of Oslo’s Department of Psychology’s internal research ethics committee and the Data Protection Official for Research. • Participants were informed about their right to stop the interview, and that they had the right to refrain from answering any question. • Written and oral information and had to sign a written consent form • Participants were ensured that the data would be anonymized and that they could withdraw from the study at any time without providing a reason for the withdrawal. • All recordings that were made were deleted after transcription by December 2016, and within two months of each interview. • Interviews were only available and handled by the researcher and the supervisor. <p>I do believe that ethical considerations are taken into considerations throughout the study.</p>		
<p>Was the data analysis sufficiently rigorous?</p>			
	<p>Comment:</p> <ul style="list-style-type: none"> • As mentioned above the analysis process are well documented and the categories/themes used in the TA are explained. It is considered that there are sufficient data presented to support the findings, and there is explanation of extracts chosen in the final report. The researcher has critically examined her role and the potential bias and influence during the collection of data, however not during the analysis and selection of data. • There are extracts and examples of both those who experience stigma, and those who do not experience much stigma. However, there are to some degree an 		

	<p>experience of stigma among gay people living with HIV. There are examples of participants that are satisfied with the health care system and participants that are not. I do believe there is contradictory data considered.</p>		
<p>Is there a clear statement of findings?</p>			
	<ul style="list-style-type: none"> • There has been only one analyst analyzing the data. However, there has been a supervisor that has supervised the study. • Throughout, the findings are supported by extracts from the interviews • The findings are clearly relevant in relation to the research questions • From the article "Through thematic analysis, it was found that GMLH may experience stigma through negative encounters, through involuntarily living a double life, through responsibilities following the diagnosis, and through self-evaluation and self-stigma. It was also found that there are great gaps between the amount of stigma reported, whom they receive stigmatization from, how it is experienced, and how they deal with it. 		
<p>How valuable is the research?</p>			
	<p>Contribution to existing knowledge or understanding: This study contributes to existing knowledge that stigma is still experienced by people living with HIV, even in health care settings. This is supported by previous research and research outside Norway. Further the study also contributes to investigating the implications experiences of stigma might cause such as challenges with self-stigma, psychological implications, and a constant fear of disclosure. There are extracts that show that there are some individuals living with HIV that find it difficult to disclose, have a fear of being alienated and isolated as well as other stigmatizing behavior, whereas other adapts a fighting mode and become eager to fight the stigma that one might experience in society. As mentioned in other studies, it is suggested that interventions aimed at preventing HIV-related stigma should therefore have multiple focuses. This study mentions interventions to decrease enacted stigma by targeting the general public and the health system, as well as strengthening</p>		

	<p>personal resources in ILH to target prevention of anticipated stigma and self-stigma.</p> <p>An important finding in general is that psychological implications of living with HIV and stigmatization, as opposed to physical or medical concerns, were rated by all participants as the most exhausting and invading issues resulting from living with HIV.</p> <p>Is there identified new areas where research is necessary:</p> <p>As the study also revealed that stigma might, in certain situations, be a strength, the researcher/author suggest that one might conduct more in-depth research that investigates the positive aspects gained by living with concealable stigmas as well as what contributes to positive and optimistic attitudes towards the stigma and the future among those living with HIV.</p> <p>How are the findings relevant to my study?</p> <p>The study contributes with some information on how the health care system/settings are experienced in relation to stigma, by people living with HIV. It also contributes with information and extracts from interviews that are of relevance for my study. It does state that even though many of the participants are satisfied with how they are treated in the health care, there still are examples of stigmatization and behavior that are stigmatizing for the individual living with HIV. Furthermore, this is a study that was conducted a few years ago and conducted in Norway which is highly relevant for my study.</p>
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Appendix I - Findings and credibility score

Following are the tables of findings from each of the studies reviewed. This tables includes both findings outside the healthcare system and withing the healthcare system. The credibility score used is JBIMES score of credibility.

<i>Experiences of stigma amongst HIV-positive people encountering the health care system in Scandinavia.</i>			
Population: People living with HIV Phenomena of interest: Experiences of stigma Context: Healthcare system		Coding SQ – supported by quotation U – Unequivocal C – Credible NS – Not supported Health care – Green Outside Health care – Purple	
Experiences of young adults growing up with innate or early acquired HIV infection – a qualitative study	Towards a new understanding of HIV-related stigma in the era of efficient treatment - A qualitative reconceptualization of existing theory	Sexuality and childbearing as it is experienced by women living with HIV in Sweden – a lifeworld phenomenological study	How gay men living with hiv experience and perceive hiv-stigma: a qualitative study
Living with a dark secret (SQ), (U)	Those who worked in healthcare settings described how colleagues talked badly about patients with infections and how that affected them. (SQ), (C)	Expectations about people’s reactions and bad experiences of a partner leaving after learning about their partner’s positive HIV status (SQ), (C)	Predominantly seemed satisfied with the treatment received (SQ), (C)
To protect themselves from the risk of being stigmatized, the participants hid their HIV status	Talked about not having access to fertility treatment in Sweden when wanting to have a baby. (NS)	Fear of being judged or rejected (SQ), (C)	All participants reported one or more negative experiences (friends, family, work, sex partners or in the

and only declared their status in healthcare situations (C)			health care system) (U) (SQ)
Fear of being judged (C)	Participants anticipated being treated badly or that their children would be treated badly if others knew about their HIV. (SQ), (C)	Some participants feel that they should not get pregnant and have children (SQ), (C)	Some participants described their lives as heavily influenced by stigmatization
Ignorance and prejudice were more harmful than the disease itself (NS)	Described stigma as a barrier in many situations (SQ), (C)	Feeling of receiving “unfair” treatment and discrimination, compared to HIV-negative women (SQ), (C)	Treated differently than other patients (SQ), (C)
Related disclosure to fear and insecurity (C)	Anticipated and enacted stigma were to be more complex than described in existing literature (SQ), (C)	Feelings of alienation (C)	Asked invasive and unrelated questions (SQ), (C)
Pediatric care for HIV treatment as fairly good (C)	Labelled as a person with HIV – important and persistent part of stigma experience (SQ), (C)	Belief that one is not able to obtain what all other women have: a home, a partner, a relationship, a child (SQ and NS)	Top-down attitudes from general practitioners (GPs)
Could be accused of unaccepted behavior in society (SQ), (U)	Disclosure found to be context-related, and participants weighed the relevance of disclosure – even in health care situations (C)	A feeling of missing out on opportunities was common (SQ), (C)	Not being given important information regarding treatment - Nervous and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy) (SQ), (C)

The potential spread of rumors (of HIV status) could lead to isolation, powerlessness, and alienation. (SQ), (C)	Experiences of people talking behind their backs or in negative context about other people living with HIV (SQ), (C)	Feelings of guilt and shame (SQ), (C)	Or in other ways showing an incapability to act on the patient's needs. (NS)
Relied heavily on their healthcare providers (SQ)	The HIV stigma framework could benefit from revision (C)	Experiences of stigmatization due to perceptions of contagiousness and transmission (C)	Anticipated stigma most common
Healthcare staff lacking sufficient skills and knowledge about HIV-induced frustration and anger (C)	In addition to describing situations experienced directly, participants often incorporated other peoples' encounters with stigma as part of their own stigma experience. (SQ), (C)	Feeling of lack of knowledge that leads to prejudice and misconceptions (C)	Self-stigma was generally regarded as the biggest concern.
Felt safe to disclose their diagnosis to health care providers (C)		Feeling of being questioned about their right to have a baby by the health workers (C)	Great gaps among the stigma experienced, from whom, how it was experienced and how they dealt with it (C)
Health care professionals were viewed as an important aid in coping with HIV		Level of self-perceived stigma in the health care system = feeling of not	Living with a secret (SQ), (U)

and its consequences (C)		receiving equal health care (C)	
Stigma and discrimination were a major issue – governing in participants decisions about how to live their lives (C/NS)		Perceptions about contagiousness are present health care professionals (C)	
Maintaining secrecy and being partly open about HIV to avoid and protect the family from prejudice and negative attitudes (C)			
Efforts to decrease stigma and discrimination, and disclosure matters were warranted, by the researchers, on the societal, community and family level (U)			

Appendix J - Databases, search results and inclusion

Database (total search result)	Title (Authors)	Year	Method	People living with HIV	Norway or Scandinavia	Experience of stigma (HIV)	English or Scandinavian Language	Health Care setting	Peer-reviewed
Norart (15)									
Norart	How gay men living with HIV experience and perceive the HIV stigma: a qualitative study (Anette Enoksen, Bente Træen)	2018	Qualitative Study		Norway				Unsure, electronical article psykologisk.no derived from a master's dissertation
Norart	Bruk av metasyntese som metode for å syntetisere kvalitativ forskning : et eksempel hvor HIV-stigma er brukt som tema (Camilla Olaussen)	2011	Metasyntese av kvalitative studier		Amerika				Unsure, journal article from Vård I Norden
Norart	Seks møter med hiv og stigma	2013			Norway				
Norart	Slipper å true med straff	2012			Norway				
Norart	Skam, stigma og Hiv/aids	2004			Norway?				
Medline (88)									
Medline	Health workers and the human immunodeficiency virus: knowledge, ignorance and behavior. (G. Brattebo, T. Wisborg, and H. Sjursen)	1990	Quantitative questionnaire-based study		Norway				Public Health
Medline	Sexuality and childbearing as it is experienced by women living with HIV in Sweden: a lifeworld	2018	Qualitative Study		Sweden	Mention			International Journal of Qualitative Studies on Health and Well-being

	<p>phenomenological study.</p> <p>(Ewa Carlsson-Lalloo, Marie Berg, Åsa Mellgren, Marie Rusner)</p>								
Medline	<p>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.</p> <p>(Maria Reinius, Maria Wiklander, Lena Wettergren, Veronica Svedhem, Lars E. Eriksson)</p>	2018	Qualitative Study		Sweden				Aids Behaviour
Medline	<p>Experiences of young adults growing up with innate or early acquired HIV infection--a qualitative study.</p> <p>(Lise-Lott Rydström, Britt-Marie Ygge, Björn Tingberg, Lars Navèr, Lars E Eriksson)</p>	2013	Exploratory qualitative study		Sweden			Mention	Journal of Advanced Nursing
Medline	<p>Depression in patients with HIV is under-diagnosed: a cross-sectional study in Denmark.</p> <p>(L Rodkjaer, T Laursen, N Balle, M Sodemann)</p>	2009	Questionnaire-based study		Denmark				HIV Medicine
PsychInfo (21)									

PsychInfo	The Lion at the Gate: An HIV-Affected Caregiver Resists Stigma. (Cynthia Cannon Poindexter)	2005	Qualitative report of one interview		Sweden/America				Health and Social work.
PsychInfo	Towards a new understanding of HIV-related stigma in the era of efficient treatment - A qualitative reconceptualization of existing theory (Maria Reinius, Galit Zeluf Andersson, Veronica Svedhem, Lena Wettergren, Maria Wiklander, Lars E. Eriksson)	2021	Qualitative study		Sweden			Mention	Journal of Advanced Nursing
PsychInfo	Beyond viral suppression: The quality of life of people living with HIV in Sweden. (Galit Zeluf-Andersson, Lars E. Eriksson, Lena Nilsson Schönnesson, Jonas Höjjer, Peter Månehall, Anna Mia Ekström)	2018	Quantitative questionnaire-based study		Sweden				Aids Care
PsychInfo	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 (Maria Reinius, Maria Wiklander, Lena Wettergren,	2018	Qualitative Study		Sweden				Aids Behaviour

	Veronica Svedhem, Lars E. Eriksson)								
PsychInfo	Public knowledge and attitudes to HIV: Research from three decades in Sweden. (Lars Plantin, Lisa Wallander, Louise Mannheimer)	2017	Qualitative study		Sweden				International Journal of Sexual Health
PsychInfo	Quality of life in people with advanced HIV/AIDS in Norway. (Eli Haugen Bunch)	1998	Qualitative study		Norway				Western Journal of Nursing Research
<u>Cinahl (10)</u>									
Cinahl	Experiences of young adults growing up with innate or early acquired HIV infection - a qualitative study (Lise-Lott Rydström, Britt-Marie Ygge, Björn Tingberg, Lars Navè, Lars E Eriksson)	2013	Exploratory qualitative study		Sweden				Journal of Advanced Nursing
	Health system capacity to report on indicators fostering integrated people-centered HIV care: findings from six European countries	2019			Including Sweden				International Journal of Integrated Care
<u>Google-search and citations</u>									
Science Direct	Re-thinking HIV-Related Stigma in Health Care Settings: A Qualitative Study (Marilou Gagnon)	2015	Qualitative Study		Canada				JANAC: Journal of the Association of Nurses in AIDS Care
Science Direct	HIV Status Disclosure in the Workplace:	2017	Qualitative study		Netherlands			Health care providers	JANAC: Journal of the Association of

	<p>Positive and Stigmatizing Experiences of Health Care Workers Living with HIV</p> <p><i>(Sarah E. Stutterheim, Ronald Brands, Ineke Baas, Lilian Lechner, Gerjo Kok, Arjan E. R. Bos)</i></p>							living with HIV	Nurses in AIDS Care
BMC	<p>Monitoring progress towards the first UNAIDS 90-90-90 target in key populations living with HIV in Norway</p> <p><i>(Robert Whittaker, Kelsey K. Case, Øivind Nilsen, Hans Blystad, Susan Cowan, Hilde Kløvstad, Ard van Sighem)</i></p>	2020			Norway				BMC Infectious Diseases
Sage journals	<p>Mental Health in Women Living With HIV: The Unique and Unmet Needs</p> <p><i>(Elizabeth M. Waldron, Inger Burnett-Zeigler, Victoria Wee, Yiukee Warren Ng, Linda J. Koenig, Aderonke Bangbose Pederson, Evelyn Tomaszewski, Emily S. Miller)</i></p>	2021			US?				Journal of the International Association of Providers of AIDS Care (JIPAC)
Science Direct	<p>Stigma reduction interventions in people living with HIV to improve health-related quality of life</p> <p><i>(Maria Reinius, Lars E. Eriksson, Veronica Svedhem, Farhad Mazi Esfahani, Keshab Deuba, Deepa Rao, Goodluck Willey)</i></p>	2020	Systematic review (narrative focused)		Sweden				Lancet HIV

	<i>Lyatuu, Danielle Giovenco)</i>								
Pubmed	Experiences of stigma in healthcare settings by people living with HIV in Ireland: a qualitative study <i>(Elena Vaughan, Martin Power, Jane Sixsmith)</i>	2020			Ireland				Aids Care
Aidsonline	HIV-related stigma and psychological distress: the harmful effects of specific stigma manifestations in various social settings <i>(Sarah E. Stutterheim, John B. Pryor, Arjan E.R. Bos, Robert Hoogendijk, Peter Muris, Herman P. Schaalma)</i>	2009			Netherlands				AIDS
Web of science	Experiences of Stigma and Discrimination among Adults Living with HIV in a Low HIV-Prevalence Context: A Qualitative Analysis <i>(Ann P. Zukoski, Sheryl Thorburn,)</i>	2009			US?				AIDS Patient Care and STDs
	Is It Just Me? Experiences of HIV-Related Stigma (Not retrieved full text)	2009	Qualitative study (Journal of HIV/AIDS & Social Services)		US				
Web of science	Experiences of Social Stigma and Implications For Healthcare Among a Diverse Population of HIV Positive Adults	2007							Journal of Urban Health

	<i>(Jennifer N. Sayles, Gery W. Ryan, Junell S. Silver, Catherine A. Sarkisian, William E. Cunningham)</i>								
Web of science	Lessons on Stigma: Teaching about HIV/AIDS <i>(Bronwen Lichtenstein and Jamie DeCoster)</i>	2014			US				Teaching Sociology

