The social experience of living with HIV as a gay man in Sweden

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Abstract

The experience of living as HIV positive constitutes a mixture of social phenomenon which affects individuals in various ways diverging between countries and regions of the world. The purpose of this exploratory study was to investigate how gay men in Sweden’s larger urban cities experience living with the disease, focusing on social exclusion, disclosure decisions and social relations. Using phenomenology, textual data was analysed from in-depth interviews with 14 HIV positive gay men. This research proves that stigma associated with HIV is a major stressor for the individuals serving as a barrier affecting their quality of life. The prevalence of stigma manifests itself via personalised, disclosure decisions, fear, and environmental attitude. Social exclusion was experienced due to being HIV positive and various factors impact disclose decisions, such as second disclosure. Stigma was especially experienced via online communication on dating apps such as Grindr, making it more difficult for the participants to make new connections. A structural change in how gay men have sex has been noticed in line with advancement in medicines, resulting in an increased engagement in unprotected sex. Findings also suggest divided opinions about the obligation to inform while agreeing that the law needs to be modified.

Keywords

HIV, AIDS, gay men, stigma, social exclusion, disclosure decisions, obligation to inform, structural change, dating apps, Sweden
# Table of Contents

- **Introduction** ........................................................................................................... 1
- **Empirical Background** ......................................................................................... 3
- **Theory and Research review** .................................................................................. 3
  - *Previous research* ................................................................................................. 3
  - *Sociological view and understanding of living as HIV positive* ......................... 4
  - *Stigmatisation* ........................................................................................................ 5
  - *Conceptualised types of stigma* ............................................................................ 7
  - *Filling the gap on HIV research* .......................................................................... 8
  - *A subjective and objective understanding* .......................................................... 9
- **Research design** ..................................................................................................... 10
  - *Justification for research design* ........................................................................ 12
- **Methodology and Data** .......................................................................................... 13
  - *Data analysis procedures* .................................................................................... 15
  - *Sample* .................................................................................................................. 16
  - *Ethical issues* ........................................................................................................ 17
  - *Methodological concerns* .................................................................................... 18
- **Data analysis and results** ........................................................................................ 19
  - *Stigma - towards HIV and HIV positive individuals* ......................................... 20
  - *Social exclusion* .................................................................................................... 27
  - *Disclosure decisions* .............................................................................................. 28
  - *Structural change* .................................................................................................. 34
  - *Obligation to inform* ............................................................................................. 36
- **Final Discussion** ...................................................................................................... 39
- **References** .............................................................................................................. 46
  - *Published references* ............................................................................................ 46
  - *Un-published references* ....................................................................................... 47
Introduction

In 2015 The Public Health Agency of Sweden (Folkhälsomyndigheten, 2017) reported approximately 12 000 cases of HIV\(^1\) infections in Sweden since 1983, when AIDS became notifiable according to the diseases act. It is globally acknowledged that the study of HIV constitutes a compound social phenomenon, which includes underlying interrelation between factors such as multiple social, economic, political, cultural and environmental factors varying across countries, making it sociologically interesting to investigate. This study will aim to qualitatively explore the experience of individuals living as HIV-positive in Sweden’s bigger cities. One could state that HIV is a chronic disease in some European countries, while in some African countries it is a deadly disease (Reinado and Hernández 2015).

At present HIV/AIDS has reached epidemic proportions and it is recognised that this epidemic does have an impact on the lifestyles, practices and subjectivities of a population (Reinado and Hernández 2015). This can of course be distinguished depending on where the study takes place. However, it is necessary to study by utilising implements that enlighten a more qualitative in-depth knowledge of the phenomenon of disclosure decisions and social exclusions that living with HIV could induce, and to be able to explain any potential variation in experience according to these terms. This topic is also interesting to study because previous studies investigating stigma related to HIV disclosure are few and each is limited in several ways. This further indicates, there is a need to produce qualitative information to help conduct the design of prevention policies to avoid that individuals are being exposed to potential discrimination and stigmatisation (Reinado and Hernández 2015).

\(^1\) HIV stands for human immunodeficiency virus, which attacks cells of the immune system, leading to a loss of immune function, and if untreated could lead to acquired immunodeficiency syndrome i.e. AIDS.
Therefore, the purpose of this study is to analyse:

- *The experience of living as HIV positive and how it affects social relations, social exclusion and work?*
- *And to investigate; how this may influence disclosure decisions for these individuals?*

The study will thus aim to answer HIV’s role in relation to social exclusion and investigate potential reasons for individuals choosing to disclose or not disclose their HIV status to people in their vicinity.

To fully understand the immensity of this epidemic it is important to both consider numbers of persons affected, and the emotional impact of living with HIV. An HIV diagnosis has the prospect to serve as a traumatic factor for people, and individuals often adduce the moment of diagnosis as powerful, and often experiences symptoms of intense stress (Ostrom R, et al. 2006; Rodkjaer et al. 2011). Further, levels of trauma related to an HIV diagnosis may be in part assigned to the extent and salience of stigma and disclosure experienced by the persons living with HIV. An eventual presence of HIV stigma, an unwished-for attribute that leads to a diminution of a person’s status in society minimises ability to make HIV disclosure decisions and increasing fear of following negative reactions from any support systems (Ostrom R, et al. 2006; Zeligman et al. 2017). Interlinking social policies to the experience of living with HIV as the illness posing continuous uncertainties, it is essential to relate the experience of living as HIV positive to the ongoing Swedish debate and law from 1985 (Prop. 1985/86:13), about the obligation to provide information\(^2\) should be abolished or not. Thus, if and how this would make a difference to individuals life’s, when it comes to stigma, disclosure, social exclusion and open mindedness for the disease.

Consequently, social sciences have started to analyse the vast dimensions established in relation to the HIV phenomenon, with an emphasis on producing knowledge for its understanding and comprehension. The epidemiological method has been the guiding reference for an average of the approaches in the study of issues concerning HIV. By declaring this, it is worth pointing out that, the epidemiological method cannot comprehend with the intricacy of the HIV phenomenon on its own. Tackling this approach from another

\(^2\) Informationsplikten
angle, with phenomenology and narrative research will make it possible to address the intricacy of the problem. For instance, a positivist method will suffer from not being able to grasp the qualitative aspects of living with an HIV diagnosis. Thus, while examining epidemiological studies a gap is found, where a lack of the subjective aspects of the diagnosed as well as social policies and any cultural factors that are influencing the HIV is somewhat bypassed. Phenomenological sociology thus constitutes a crucial conceptual tool for approaching the study of HIV. A theoretical angle like this makes it possible to capture the subjective meanings that individuals attach to their actions and experiences (Reinado and Hernández 2015).

**Empirical Background**

The history of HIV/AIDS dates back over three decades, and it includes a series of significant changes to the disease over this time. Most noticeable are these changes in regard to treatment and effective care. Zeligman et al. (2017) writes that in the United States alone nearly 1.1 million people are living with HIV/AIDS leading to the disease reaching epidemic proportions. The public Health Agency of Sweden has over a five-year period leading up to 2015 approximately reported an average number of 455 new cases of HIV infections yearly. Today nearly 7000 individuals are living with a diagnosed HIV infection in Sweden, which means a prevalence of about 74 persons per 100 000 (Folkhälsomyndigheten 2017). To put this in a global perspective, according to UNAIDS (2015) report, it is estimated that 36.7 million people were living with HIV worldwide. The number has increased since the previous years, largely due to people gaining access to treatment which raises their life expectancy.

**Theory and Research review**

**Previous research**

Work in prevention and elimination of HIV has been one of the most difficult challenges for
public health worldwide. The HIV pandemic constitutes a social problem on many
dimensions and is a complex social phenomenon that is difficult to address (Reinado and
Hernández, 2015). The knowledge about HIV and AIDS is incessantly increasing and since
the HIV epidemic was recognised, research has continuously reported on new findings on the
HIV infection progress, about diagnostics, routes of transmission, treatments and so forth.
This knowledge and experience is the foundation for the preventive work primarily focused
on reducing the spread of HIV but also to assert the rights of victims not to be socially
excluded and discriminated against. Previous research confirms that the level of perceived
stigma will be positively linked with reasons for non-disclosure and negatively linked with
reasons for disclosure (Ostrom R, et al. 2006). In addition to the trauma associated with an
HIV diagnosis, the presence of HIV stigma has shown to be an undesirable attribute that leads
to a reduction of an individual’s status in society (Goffman, 1963). It has further been shown
to profoundly change the lives of people living with HIV. Contemplation of disclosure might
comprise the possibility of gathering emotional or contributory support, in contrast however,
it may also subject them to rejection (Draimin, 1993). In turn, disclosure to others also
minimises the ability to control second hand disclosure by others, which further increases
vulnerability (Murphy D, et al. 2002). Setting the new findings on HIV infections and routes
of transmission aside for the moment, this topic is sociologically relevant because it is
affecting both individual’s behaviours, actions and how society is functioning. Knowledge of
HIV experience is also important for understanding diversity of lived experience, how
identifies are formed, how social relations are impacted and how social exclusion take place.
Further, HIV disclosure is an important step in delivering the right care to individuals. As
many choose to not disclose about their status, it complicates the availability of sufficient
health care (Thapa S. et. al. 2018; Zeligman et al. 2017).

Sociological view and understanding of living as
HIV positive

The sociological discipline moulds a fundamental tool in generating knowledge for a deeper
understanding of living with HIV. Especially, in terms of how it is aimed towards explaining
and understanding a groups joint behaviour within a social context, and the importance of
actions and the multi-causality of phenomena. On top of that, sociology stipulates multiple
aspects for the study of behaviour towards and with HIV (Reinado and Hernández, 2015).
Even if the actual number of diagnosed people in Sweden is comparably small, there are still those who are infected (approximately 455 cases) every year (Folkhälsomyndigheten 2017). Some individuals are in the labour market at the time they receive their diagnose, and occasionally it becomes known at their place of work, which sometimes evokes a big commotion. This is due to the question being filled with anxiety, not only for the person being diagnosed but also for the surroundings, colleagues, friends and families etc. which ought to have an impact on willingness to disclose (Ostrom R, et al. 2006). Consequently, it is necessary to raise this topic from a sociological perspective, educate and inform from the persons affected point of view. It is also important to treat this judiciously and with great care to be able to reduce the negative effects of social exclusion, disclosure and stigma that potentially could arise for all those affected (SAN, 1996).

**Stigmatisation**

Stigma can be described as “the situation of the individual who is disqualified from full social acceptance” (Goffman 1963: xxi). The concept of stigma brings up important questions and confronts challenges such as discrimination and segregation, and is therefore highly relevant even in modern times, shedding light on the contexts of individuals that are unable to accommodate to the standards that society expects and refers to as “normal”. Based on preconceived notions regarding HIV-positive persons, stigmatisation could influence disclosure decisions (Guy A, et al. 2018) and investigators have pointed out that the disclosure decision making process highly decides upon individuals weighing the pros and cons associated with disclosure (Ostrom R, et al. 2006; Armistead L. et al. 2001; Black & Miles, 2002; Serovich J, 2001). Sources of stigma often include fear of illness, fear of transmission and fear of death. In connection to HIV/AIDS, fear of becoming ill, contagion, and death are recurrent reactions among health workers and colleagues as well as outlook of the general population (Brown et al. 2003).

In societies, there is a tendency to categorise people and their attributes which has become the natural for each and own of these categories. The term “category” is absolute abstract and can be posed to anyone with a certain stigma, and social contexts decide the categories of people likely to be encountered there. This behaviour could potentially lead to groups of people being exposed to exclusion based on category of belonging. The socialising patterns allow us to deal with anticipated others without special observance or reflection. When someone new comes
into our presence, then, first appearances are likely to make it possible for us to foresee the persons category and attribute i.e. the individual’s social identity. Although, HIV is not possible to identify by the eye, it can presume to play a part for the individual when it comes to disclosure and social exclusion. The category and attributes could be proved to possess the persons actual social identity. Evidence are not unlikely to arise that an individual in possession of an attribute that stands out from others in the category of persons available, and of less eligible kind, would be considered bad, dangerous or weak (Goffman, 1963). This way of seeing things, and ascribing attributes and categorising others can easily be put in parity with Du Bois’ (2004) way of thinking that it goes beyond the mere physical. A widespread feeling of aversion, which could go so far that it keeps him out of reasonable employment, specific public conveniences, and amusements. Thus, it does not make a difference if the attribute is visual or not for oneself, if one is not fully socially accepted, or prescribed a categorisation against ones will. When a minority for instance, suffer all these little differences of how to be treated, and continually be discriminated and insulted, results in an overall feeling that this group of people cannot live to their fullest potential. The difference is that Du Bois calls it a problem instead of a stigma, but then being stigmatised can be seen as a problem to the one being exposed to stigma (Calhoun, et al. 2012).

In regard to categorising, there is a usual misunderstanding and confusion. It is evidential that the members of a particular stigma category such as HIV positives will be inclined to together constitute small social groups whose members all originate from the category, and supposedly exposed to the same or a similar stigma. These groups themselves being subject to an overall organisation to diverse degrees. Being a member of a certain category also means that the individual has an increased likelihood of coming into contact with other members, perhaps by experiencing a common reception or phenomenon and even forming a relationship as a result. Therefore, can a categorisation work as to arrange its members to group-formation and relationships (Goffman, 1963).

Goffman’s exposition entails a basic condition that the stigmatised person has to make a choice regarding the attributes that makes one different from others. This means that one can either control the information by letting the “normal” as Goffman (1963:14) puts it, in on their secret. If it is not part of the body and therefore visual such as the case for HIV positives, pretending to be normal whilst nurturing the knowledge that the stigma separates them from
the others, or they can let it be known and manage the tension of the outcome (Goffman, 1963). The stigmatised person may have attempted to keep what differs from others a secret and feels unsure about being able to do so, or because of the surroundings not being aware of the condition and is making a painful effort not to reveal anything. Furthermore, the stigmatised person may feel as not having a choice but to keep what differs from others to oneself because of feeling uncomfortable or uncertain of how it may be perceived in terms of social exclusion and disclosure. This particular reasoning can be related to modern life and how we present ourselves when we for instance, find ourselves in work related contexts. Even though a stigmatisation might not necessarily be grounded in the way we conduct or portray ourselves during an interview or a presentation of ourselves, there are certain things many individuals do “hide” or at least try not to “show”, in the case of getting rejected. The feeling of unsureness whether the other person will accept you or expose you for discrimination could be very straining and stressful for the person in question (Rodkjaer et al. 2011).

**Conceptualised types of stigma**

Zeligman et al. (2017) explains how stigma can be experienced in three different ways. Namely, enacted stigma, internalised stigma and felt-normative stigma. To describe these in a more detailed manner, the term enacted stigma has been used to refer to apparent acts of discrimination directed at a person because of their participation in a stigmatised group. Internalised stigma, on the other hand occurs when the stigmatised individual has accepted the experienced stigma as valid. Lastly, normative or perceived stigma as more current work also call it can be interpreted as more subjective, as it describes an individuals’ personal perception of stigma being present in their lives to a degree of being expected and thereby normalised. Presently, perceived stigma for instance, refers to a persons’ awareness of stereotypes, with the occurring belief that negative consequences will take place if others became aware of their HIV status, for instance, second disclosure.

The field of stigma can be further enlightened with layers of destructive self-image, personalised stigma, and public attitudes measuring internalised, perceived and enacted stigma, as mentioned above, respectively (Zeligman et al. 2017; Brown et al. 2003). Making it important to produce qualitative information from a subjective point of view and add to the general knowledge about HIV’s impact on people’s daily life. Each separate form of stigma may be uniquely felt by HIV positives, while also collectively providing to negative mental
health results. Stigma related to HIV is often mentioned as a serious stressor (Rodkjaer et al. 2011), often undermining care providers work, treating these individuals (Brown et al. 2003). Goffman’s (1963) work on stigma argues that stigma is not unique to HIV/AIDS, however, one could mention four aspects linked with the virus increasing the risk of potentially stigma for HIV positive individuals. These include (1) the disease is perceived as the bearer’s fault. This in turn due to transmission being primarily through behaviours which are seen as voluntary. (2) The virus is perceived as unalterable and in cases also fatal. (3) The virus is contagious, and finally (4) in particular cases the disease may be visible (e.g. someone with advanced AIDS shows physical symptoms). Thereto, Zeligman et al. (2017) and Rodkjaer et al. (2011) argues that, HIV stigma is often stressed due to being added upon other stigmatised areas such as drug use, sexual promiscuity, or homosexuality, causing a doubled effect. Such a heavy presence of HIV stigma is tough for individuals, since its potential escalation of the physiological burden of living with HIV.

Having disputed that stigma has a strong relationship with HIV, it is also able to influence mental and physical health concerns in terms of anxiety, shame, medication adherence and isolation (Zeligman et al. 2017; Thapa S. et. al. 2018). This in turn, might possibly lead to social exclusion and fear of disclosure for people living with HIV. However, it is less obvious what role specific types of stigma play, especially as they relate back to the adduced moment of impact and potential trauma of receiving an HIV diagnosis.

**Filling the gap on HIV research**

There is limited research regarding the impact of stigma on HIV positive individuals, especially when it comes to their experiences in society, and the decision of disclosure (Ostrom R, et al. 2006). Notably limited are studies performed in the context of the Swedish society. However, the few that exist, conducted in countries other than Sweden do suffer from limitations when looking at stigma. Therefore, it is important for further investigation, and need for a broader understanding of the phenomenon. Because knowledge does not only create a sense of awareness but it also normalises factors that could lead to stigma that is linked to HIV and being HIV positive.

Phenomenological sociology and theories of stigma focuses on how meanings are created in the individual’s consciousness. This could be described in terms of how experiences influence
and form part of the interrelationships created between individuals in everyday life and how these meanings can unfold to the observer. In a sensitive research field and with a topic such as HIV stigma theory can be applied for studying social phenomenon about the virus. Social representation of HIV is therefore, highly relevant to understanding the lived perceptions and meanings attached to the virus by the general public (Reinado and Hernández, 2015). Alternative approaches from international studies (Maria J, et al. 2014) shows that stigmatised individuals are not passive recipients of negative attitudes and discrimination, on the contrary, they interpret, cope with, and react to stigma in many ways. One way is that stigmatised persons alleviate stigma by group identification. Another theoretical approach is that gay men of different birth cohorts may differ significantly in their health and identity development (Hammack P, et al. 2018). Studies performed in Sweden has focused on the distribution and transmission of HIV (Neogi, U, et al. 2017) and motivators and barriers to getting tested for HIV (Persson, K, et al. 2016).

A subjective and objective understanding

There are a few key notions that are essential to bring up when dealing with a topic as HIV. A lifeworld concept originated from a Husserlian elucidation and further developed by Schutz (1993) and phenomenological sociology, is fundamental for understanding the reality of the world of common-sense, social action and interaction. The concept stresses a state of affairs in which the world is seen, and where the world is lived. The intersubjective social world is what is inhabited by the individual in daily life, by ascribing a natural attitude. The lifeworld is easier to comprehend by thinking of it characterised as being an intersubjective and public world for oneself, and something that is shared and attainable to everyone. One of its most recognisable characteristics is that it is a pre-existing world for the individual. It is an intersubjective world that already is set up before the person has been infected with HIV, or even born for that matter, given to the person to orientate. It creates an outlook that embraces all possible ways of living and experiencing. Where actions of humans in their human contexts are performed, and of constructing a social life, transcending the crucial experience of a person. In the course of HIV research, theories such as this has been applied to the study and understanding of the different perceptions and meanings of the virus a person goes through, and most importantly its influence on how people live and experience the disease (Reinado and Hernández, 2015).
Intersubjectivity is important for grasping the reciprocal understanding that goes on between individuals during their interaction. Alfred Schutz (1993) defines this as simultaneity, meaning one grasps the subjectivity of the alter ego concurrently as experiencing one owns consciousness. This concept is based on the social world and lifeworld, where the intersubjective world, is one that is common to all. The subjective world is however, not just put together by what is received by senses through such as stigma or exclusion due to the disease, but also of subjects and interpretations of those sensations. This means that, depending on how an individual interprets the surrounding world based on experience, and the factors that condition the surrounding world, and that allows to change or maintain the individual’s interpretations and actions (Reinado and Hernández, 2015).

Research design

A Phenomenological approach is suitable for studies like this as it describes the common meaning for several individuals of their life experiences of a concept and phenomenon as HIV. The phenomenological method and data collection through asking the participants’ questions is thus about collecting subjective information (Thomas and Thomas, 1928). The author will focus on what the participants have in common as they experience phenomenon’s such as decisions on whether to disclose their HIV status and how it affects social relations, social exclusion and thus being exposed to potential stigma and discrimination. By applying a phenomenological method to the study, it will benefit the researcher to diminish individual experiences with a phenomenon to a description of the universal essence (Creswell, 2013). That is, to be able to present a grasp of the very essence of the experience and thereby be able to fully identify a phenomenon and object of human experience, through qualitative research.

Good research practice should encourage high-quality research and be used as an underlying goal (Gustafson et al. 2006). Within a sensitive research field as HIV and research questions such as to analyse the experience of living as HIV positive and how it affects social relations, social exclusion and work? And to investigate how this may influence disclosure decisions for these individuals? A qualitative approach is preferred as it helps to investigate personal experience through interviews of how HIV positive individuals feel they are being perceived
and treated. The researcher will collect data through interviews from individuals and develop a composite description of the essence of the experience for the individuals taking part in the study. As mentioned, this study is targeting a sensitive field and group of individuals sharing delicate information about themselves and their lives, it is hugely important to protect their privacy. A section regarding how the author has dealt with ethics in relation to the participants taking part in this research will be discussed further on.

The author will be using a semi structured interview guide with exploratory questions, as this will leave room for the possibility of changing order between the questions. A semi open structure permits the author in addition to the interview guide to ask follow-up questions as well (Bryman, 2011). The main route the informants will be contacted is via HIV voluntary organisations in Sweden’s larger cities. The justification for sample selection is to provide a broader picture of the experience, independent of where the participants live. Although, the sights of bigger cities in Sweden will more likely be easier to meet informants, mainly due to organisations location, it does not close the possibility of receiving data from participants about how they experience being HIV positive outside the cities, in smaller societies as well. The researcher is hoping to gain honest and reliable data of true experiences and how they might vary across cities and regions in Sweden. The author will target a certain group, using purposeful sampling and the inclusionary criteria is that the participants are gay, HIV positive and over 18 years of age and has lived in Sweden for at least 1 year (to have had time to experience the Swedish context). Worth pointing out as a limitation of this research is that the study will not be able to generalise the experience for all individuals, which is neither the aim of the research, as the experience might predominantly be subjective.

The goal of good research interviewing is to build trust and to rapport with the participants so that they feel comfortable and confident in sharing things they would otherwise not share with anyone, emphasising the need to respect the participants privacy. Building a safe research context allows the informants to talk openly about sensitive issues in their lives, issues that they previously have not discussed or had any intention of sharing. For the researcher is it essential to inform how sharing information like this can be beneficial for the participant, but it may also lead to the informants disclose their HIV status on others in their vicinity without being prepared to do so. The researcher must therefore, also be prepared on receiving information about the participants’ private lives and to handle this in a trustworthy way.
Information which they may not have wished to talk about, had it not been for the character of the interview and the mutual trust established between the researcher and the interviewed. While treasuring the many benefits of such trusting and open research context, one must critically question whether the informants have disclosed something they may not have intended, or were not emotionally prepared to, and how this information should be treated further in the research process (Skovdal & Abebe, 2012).

The author will mainly focus on the description of what the participants experienced and how they experienced it (Creswell, 2013). The author will justify and encourage the conduction of interviews as the main source of data collection for the study by seeing interviews as a divergence between information that describes actual conditions, and how a condition actually is. But also, information about how someone is experiencing a certain context, to simplify one can separate the conditions by relating to them as objective and subjective information. Hence, it is the ones in questions personal opinions, experiences, values and interpretations that are of interest, especially from a sociological point of view, because these are aspects that to a high degree control a person’s behaviour and actions (Andersson, 1985). Seemingly, it is the subjective information that will help the researcher to answer the research questions. Consequently, what seem to be subjective information can despite its flaws be a valuable source for research that wish for a description of a sensitive topic such as the social experience of HIV positives (Ibid) and material for continued research.

**Justification for research design**

Phenomenological tradition as mentioned earlier has a well-fortified philosophical element to it, deeply rooted in Edmund Husserl’s (1859-1938) writings. The research design is particularly popular in the social- and health sciences, especially in sociology, making it a perfect fit for this study. Philosophical assumptions stand on some common grounds as phenomenology, seemingly the life experiences of individuals, the view that these experiences are conscious ones, and also the development of descriptions of the heart of these experiences, and thus not explanations or analyses. Husserl coined the suspending term “epoche”, meaning a philosophy without presuppositions. A phenomenological approach thus, is to remove all judgements about what is real i.e. the natural attitude until they are founded on a more indubitable foundation. The idea of intentionality of consciousness will drive the study forward and that consciousness is consistently directed toward an object. Reality of an object
then is entangled to one’s consciousness of it. Evidently, reality, according to Husserl, is split not into subjects and objects, but into the dual Cartesian nature of both subjects and objects as they appear in consciousness. The reality of social exclusion or stigma is thus, only perceived through the meaning of the experience of the person (Creswell, 2013). A phenomenological research design will not only help to explore the experience of HIV positives, phrased in terms of a single concept, it will also ensure that the research is grounded in life experience. The approach is further supported by the gathering of in-depth and detailed interviews of individuals living as HIV positive as opposed to if standard survey methods were conducted (Woodgate et al. 2017). Moreover, the research design of phenomenological is used in this study because it offers the opportunity to comprehend innate individual’s frames of reference and experiences of reality (Ibid). By using phenomenology, the authors concern is to understand rather than causality or explanation of the phenomenon of living with HIV.

The exploration will take its course with a targeted group of individuals who have all experienced the phenomenon and fill the criteria for participating in the study. The researcher will aim for participants with a high degree of heterogeneity, to increase variation of individuals and identities. The data collection will through interviews focus on individuals who has experienced the same phenomenon. The analysis of the data will pin on following systematic procedures that shifts from the narrow units of analysis such as significant statements, topics and patterns, and on to broader units, continuing to comprehensive descriptions that encapsulates the two aspects of what the individual has experienced and how this have been experienced (Creswell, 2013).

Methodology and Data

A phenomenological approach has guided the research design and an abductive exposition has been utilised. To gain subjective knowledge of how living with HIV may affect the participants behaviour in terms of social relations, social exclusion and how this impact their decisions to disclose, in-depth interviews were performed. This will contribute to qualitative research on how life is experienced living as HIV positive gay men in Sweden. As a research methodology, using a qualitative research method to study the experience of
living as HIV positive infuses an additional element to the explanatory capability that the author need to explore and investigate in this research. The author used a qualitative descriptive design, steered by sociological theory, utilising in-depth interview data collection method and a thematic content analysis to present the data. Further, it allows the author to advance and apply the participants interpersonal and subjective adeptness to the research explanatory processes. Consequently, by using an interpretative phenomenological analysis (IPA) approach, the author is adding dimensions due to the bonding connection that the approach allows for the author to develop with the participants. IPA further gives a better opportunity to understand the innermost reflection of the life experiences of the interviewees (Rohleder et al. 2017; Alase, 2017). Moreover, a participant-adapted approach allows the interviewees to express themselves and their experiences in line with the aim of the study in a subjective manner, i.e. without any distortion or diversion. By using the IPA approach in a qualitative research study recapitulate the fact that its central objective and substance are to investigate the life experiences of the ones contributing with data to the study and grant them to narrate the research findings through their experiences (Alase, 2017).

The interview guide was developed over a longer period to precise and aim the questions to be able to answer the research questions posed. A semi structured interview guide was thus used and followed in the same manner during the interviews. The questions were based upon three broader themes that derive directly from the purpose and research questions; i) Background and identity, ii) Participation in society, iii) HIV specific questions and were also followed in the same order. An in vivo process has been used meaning that the five themes described further on emerged from the open-ended interview questions and the three broader themes stated above which developed the interview guide relate back to the literature used for this study. The three broader themes were further developed into sub-themes where more detailed and specific questions were produced. Further, the open-ended questions allow the participants to freely interpret and identify what is of key relevance and of most importance for them and their life experience in terms of living as HIV positive in Sweden. Questions such as “When were you diagnosed, and how was it for you?” and “What aspects do you consider before disclosing about your status?” and “Could you please describe if you have ever felt out of place or treated different for being HIV positive?” make room for the participants to reflect and to bring up certain aspects before these questions were specifically asked about. The respondents might bring up contexts where they had felt socially excluded,
stigmatised or discussing their trail of thoughts when it comes to disclose about being HIV positive. This might grant the author the opportunity to, during questions where needed ask follow-up questions about the themes as, “could you please give an example” or “could you please describe this situation or feeling a bit further?” still keeping a profile as an interviewer at a lowest. This would allow for making the interview itself appear and feel like a conversation where the participant is in charge and the interviewer merely steering the conversation. If for instance, (although it very rarely happened), the interviewee does not bring up any of the main themes that the author wants to cover, more targeted questions according to the themes could be asked, such as “How did this make you feel?”. In turn, this would work as a pathway to ask more specific questions about what the participants then brought up, allowing for a deeper subjective context of the participants experience of being HIV positive in terms of both disclosure decisions and social relations.

Data analysis procedures

The analyse was performed after the interviews were collected and transcribed. The interviews were transcribed simultaneously during the process of which new interviewees were being contacted and interviewed. All transcripts were imported into Excel for coding and writing the analysis by systematically identifying recurrent themes amongst the interviews. The data from each interview was sorted into five different themes that were found which connected the interviews. Specific attention has been devoted to identifying and make use of techniques to avoid influence of the authors own subjective perceptions on the subject. This has been accomplished by asking open ended questions and merely guide the interview in a way that would answer the research questions and by incorporating analytical theories which is believed to generate a more truth worthy and systematic analysis based on the subjective experience of the respondents.

Once meeting the participants, the author realised that the easiest way to gain access to other participants was to ask if the respondent knew other HIV positive gay men that wanted to share their life experience and take part in the study by being interviewed. However, this was something the author wanted to avoid as social network clusters would give biased answers and possibly too alike experiences. Thus, none of the interviewees had a direct or private contact knowledgeable to the author, snowballing selection has therefore not been used.
Sample

The life experiences of gay men, living in Sweden’s bigger cities were here considered as the empirical data guiding the analysis. The author contacted health clinics where the individuals first got diagnosed, HIV voluntary organisation and individuals directly via online dating sites and smartphone applications such as QX or Scruff, either by email or messages. Further, flyers with information about the study along with the authors contact details were also put up in the healthcare clinics and HIV voluntary organisations. However, no responses or respondents were accessed via the health clinics, as the author did not manage to establish any sources or connections via this route. Therefore, the main route of contacting participants was accomplished via HIV voluntary organisations. Once a direct contact was established between the author and participant, the contact was mainly held by email and on occasion over the phone. Date and times for the interviews where then set up mainly in regard to when it suited the respondents and the author could find time to travel between the cities. The interviews where held at the participants preference and convenience, usually they took place either at the participants home, office or at a quieter place in public, such as cafés or libraries.

In total 14 interviews were performed in two cities and saturation was achieved. The name of the two cities will not be revealed in the study to protect the participants privacy. All the interviews were recorded, where 8 was conducted in one city and 6 in the other. The response rate was somewhat higher in one of the cities, where individuals seemed more at ease and willing to participate in the study by being interviewed and the organisations more helpful to refer the author to HIV positive individuals. This might come as a consequence of that in the city were less interviews were conducted, the organisations do not have the same need for exposure and that people are more discreet about themselves, not wanting to reveal their identity and HIV status. This was particularly illustrated by that the author on several occasions was asked to perform the interview over the phone or by sending the questions on paper as a survey by individuals from this city, whereas that was never the case in the city with a larger representation. The participants were aged between 20 and 60 and have lived as HIV positive between 6 months and up to 27 years. The author believes that, a wide range of years lived as HIV positive is important for this study as it then includes a broader scope of what it is like to be living as HIV positive in Sweden, but also to see the differences before and after the medication came as this could change the surroundings view on individuals living as HIV positive. Further, it could also have an impact on disclosure decisions and how
social relations is perceived by these individuals and if it has changed over time along with that medication became available.

The interviews lasted for 1 hour and 15 minutes till 1 hour and 50 minutes. However, during the interviews, if the author noticed that the length of the interview would go much past the agreed time frame, the author would simply ask if the respondent had more time which was always appreciated and never an issue. Reflected upon as a consequence of the participants seeming to enjoy the conversation, simultaneously as to seeing the need for the research. The transcribing of the interviews where thus, very long and detailed, with reactions of emotions, pauses and thoughtfulness noted. The non-verbal reactions will therefore also be relevant for including in the analysis. Each interview took around two days to transcribe. The quotations in the analyse section will involve one or more of the participants, referenced by age groups to increase the participants anonymity.

**Ethical issues**

It has been widely debated amongst sociologists to what degree information about the aim and focus of the research should be provided to the respondents. This made the author question how deeply to inform about the purpose of the study prior to the interviews. When healthcare clinics, organisations and the interviewees were contacted, they more often than not wanted information about the author himself and about the study. The author made the decision to inform about oneself and of the soul aim and purpose of the thesis, but choose not to disclose any of the interview questions as to avoid preconceived answers when the interviews took place. Additionally, in this way the author made sure that the informants were not handed too much insight in the event that the purpose of the study would be skewed from what was initially thought and in regard to the process of allowing the empirical material to drive the analysis forward. Dealing with ethical issues on a sensitive subject like HIV entail making sure the participants remain anonymous throughout the research, the author will address this issue by never using any real names in the thesis or throughout the data collecting process nor reveal the names of the cities where the interviews where performed. Further, all material that could possibly trace back to the participants will be stored safely once the work is finalised. The author had to secure actual permission and interests of all those taking part in the study. The respondents were thus informed that the participation was completely voluntary and that they have the right to terminate their participation whenever, until the work is finished. It was
also explained that the study could be in their interest too and that this qualitative research will contribute to the general knowledge of living as HIV positive and the importance of research being conducted within this field. All the respondents were thereby informed of the subject and purpose of the study and all have been granted anonymity. A consent form was either signed by the participants or verbally agreed upon beforehand which was then also recorded once the interview started. Moreover, it was important to not misuse, or misinterpret any of the information discovered where a moral responsibility should be taken towards the participants. This will come to pass by making the participants see what is going to be published beforehand, letting them have a chance to accept what is intended to be published if they so wish. Only one respondent questioned that the interview was being recorded, however after explaining that the tool was only being used by the author at a later stage to transcribe the interview a go ahead to record the interview was given. Furthermore, it was explained that the conversation and recordings will be kept private and treated with the most respect, and being destroyed once the thesis has been published. As the study deals with a sensitive subject and puts the participants anonymity at a “risk” of exposure, it is important that their privacy and courage to participate is treated righteous.

As participants, typically are guaranteed their anonymity, there is a recognition that such formal measures are insufficient and in some cases, do not suffice as research project ethics. Research that directly affects individuals should therefore not solely be grounded on dominant and de-contextualized understanding of ethics. An issue that should be addressed by the researcher negotiating reflexivity and through conversing with the concerned will help to build trust and a way to bridge global and local understanding of research ethics (Skovdal & Abbe, 2012). Finally, when it comes to research ethics, activities in society and in particular conducting information on a sensitive topic such as HIV need to be subordinate human rights. Researchers as well as research have important roles in societies, which puts additional demands on them that needs to be considered at all stages. Demands such as to handle source data with substantial care and to retain and archive them in cases, where they are available for researchers that did not contribute to collecting the data themselves.

**Methodological concerns**

A difficulty noticed by the author was how to evaluate and situate the subjective life experience of each participant in parity with society’s outlook on HIV and HIV positive gay
men. Yet, with a qualitative approach and 14 interviews being conducted a generalisation would not be the aim of the study. Nonetheless, the analysis will present a truthful picture of how the participants have experienced living as HIV positive in the Swedish society. By analysing the interviews new research will emerge and this will be specifically highlighted upon in the discussion of this thesis.

The complications that might arise for the researcher is how to interpret what the participant express by weighing in both what is conveyed through the verbal- as well as the bodily language. Further, it is important to be on board with that the researcher is sending the same oral and bodily signals back to the participant. Thus, meaning mimics, tone and fidgeting gives away a superior or uninterested impression making it difficult for the researcher to create a mutual trustworthy atmosphere with the participant. Moreover, it is worth pointing out that the participant ought to feel that what is being told is well noticed and at the same time appreciated. Meaning the researcher has to with eye contact and mimics showing encourage and empathy for the participants opinions throughout the interview (Andersson, 1985), which was bared in mind before and during the interviews. Another problematic issue that might emerge while collecting the data and performing semi open interviews is if the researcher initiates the investigation with a relatively clear focus, instead of a general desire to explore an area such as the experience of living with HIV, or focusing too much on the research questions. To overcome this form of complication, the researcher might have to consider a more unstructured form of interviewing (Bryman, 2011). If the plan of reaching participants fails, the researcher will have to resort to finding other sources where informants are willing to take part in the study. Perhaps, widening the inclusionary criteria, by for instance not just focusing on gay men, considering snowball sampling, or using informants from more than “two” communities. Keeping in mind, the heterogeneity and variation of identities amongst the participants might change from this.

Data analysis and results

As previous research confirms that the level of perceived stigma is positively related with reasons for not disclosing being HIV positive and lead to social exclusion, the participants could reflect upon underlying logics of this structure in a subjective manner. As such, future
decisions to disclose being HIV positive is formed by prior disclosure experiences (Guy A, et al. 2018). Consequently, existing HIV stigma has shown to be an unwelcome feature which lowers an individual’s status in society (Ostrom R, et al. 2006; Goffman, 1963). The author will in this section address how the participants describe their life situations and analyse how the interviews will contribute with further depth and understanding of the phenomenon of what it is like to be living as an HIV positive gay man in Sweden. This will be done in aspect to how living with HIV may impact social exclusion and how stigma may influence disclosure decisions for these individuals (Ostrom R, et al. 2006). Emphasis will be laid upon the five themes that were discovered during the transcribing of the interviews. These include (i) Stigma, (ii) Social exclusion, (iii) disclosure decisions, (iii) Structural change and (iv) Obligation to inform and will follow in the same order. The section will further account for how living as HIV positive may (or may not) induce possible obstacles and limitations described by the participants. The interviews where performed in Swedish and English and those performed in Swedish have been translated word for word by the author.

**Stigma - towards HIV and HIV positive individuals**

Nearly all the participants revealed during the interview that they have felt stigmatised or have experienced discrimination when they have disclosed being HIV positive. The author was told similar stories about how the participants has been neglected, rejected and stigmatised against once they disclosed their status. By not being able to disclose about one’s HIV status apart from the doctors would lead to living a very isolated life. Very few tends to disclose about being HIV positive and respondents revealed how some do not even tell their friends. Even when the respondents explained that they have an undetectable viral load. They still experience rejection, in addition to being referred to as non-healthy due to being HIV positive. The concept of stigma as Goffman (1963) describes it, is a context of individuals that are unable to accommodate to the standards that society expects and refers to as “normal”. This could be put in parity with the participants revealing themselves as being referred to as “healthy” (or not) i.e. meaning that if the person is HIV positive would not be seen as healthy, which certainly undermines their potential as being seen as and accommodate to the standards that society expects and sees as “normal”.

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3 By undetectable means that the antiretroviral treatment has brought the level of virus in the body to such low levels that blood tests cannot detect the virus, and there is no risk of passing on HIV.
The interviewees disclosed how they had experienced rejection from people being scared of their HIV status and have avoided them. In the transcript below stigma is displayed from not knowing how HIV transmits. They also told the author how they afterwards have had to explain how HIV transmits and that they were undetectable, having to calm the other person down. Placing this in a broader context, one participant discussed how this was just one situation, but maybe reflecting a whole society. The participants also admitted that they had felt hurt of how they have been treated. This type of rejection could be linked to Zeligman et al’s (2017) three types of conceptualised stigma and a form of enacted stigma, where an apparent act of stigma has been directed at a person by being categorised into a group consisting of HIV positives.

Many people have avoided me because of my HIV. One time I met a guy and he was a psychologist, really hot and we had sex. Then one day he phoned me and said, it was really nice meeting you but I want to ask you something, -are you healthy? And I said, what do you mean by healthy? Well, you know. -Are you positive or negative? I told him that I was positive, and he went crazy. I mean, we are talking about a psychologist and a great situation and he was educated and we all have access to information about this. So, there was an hour-long conversation, I crossed the whole city on the train speaking to him explaining the whole thing about HIV and how it transmits and how I am not infectious and so on as I am on treatment. Then he thanked me and said that is good, now I can relax, -I had no idea. So, I hope that we can meet again he said and I was like -Yeah, of course. We never spoke again. He was around 45 years so it was not a younger person. However, I don’t know if this reflects a society or whole group in society, but that is the reality at least of one situation and person. It is a context of discrimination or stigmatisation. Your ego does get hurt. (Aged 30-40)

There were more stories that depicts the lack of knowledge of how HIV transmits, emphasising a situation where people have been scared by just being in the same company as someone being HIV positive. When the social surrounding impose stigma like this, it may lead to that HIV positive individuals choose not to reveal their status or lead to living a more isolated life by not engaging in activities where one might be exposed to stigma or of feeling hurt (Guy A, et al. 2018). If HIV positive individuals start isolating themselves due to their HIV status, the risk is that the stigma become internalised and thereby also in worst case scenario validated by the person. This in turn, could lead to that the struggle of fighting stigma becomes more difficult, not just for the person himself but also in society.

Once I was with my classmate and his sisters’ kid and we were canoeing and afterwards I
was told that the sister had been scared to death by me sitting in the same canoe as her children, as if I was going to infect them with HIV. And my classmate just got so angry with his sister and thought she was just being super dumb. But I didn’t know this until afterwards but still it didn’t feel alright at all. (Aged 40-50)

The phenomenon of being HIV positive and undetectable has not always made it easier for the participants to meet other men. The following script reveals how the participant has been rejected and had people saying that they did not want anything to do with them (HIV positives). So, even if the person is positive and undetectable, rejection and discrimination was experienced due to being HIV positive regardless if there is no risk of transmitting the disease. One could propose that stigma perpetuates irrespective of blood tests cannot detect the virus.

This guy was a doctor we were chatting and we were supposed to meet for sex. So, I was like okay before we meet I need to tell you -I'm positive undetectable, and he was like -No I'm sorry this change everything. I don't want to meet you I don't want to have anything to do with you. I was not okay, I'm telling you I'm undetectable and you are a doctor so you have to be educated about this, if you're not you can go online and Google it........ I would definitely take the license of that doctor, he doesn't deserve to be a doctor. He might be a good doctor but saying that being a doctor to someone is wrong. After a while I understood, it's your life and you choose what to do but saying that you are scared is wrong when there is no need to be scared. (Aged 30-40)

There were also scripts where participants admitted a sense of caution and fear when travelling, having to disclose their HIV status and being exposed to potential stigma. Here is an obvious example on the impact of stigma as one participant had dealt with it by not disclosing his HIV status on health declarations when crossing boarders or travelling to other countries. The stigma of not feeling welcome into another country has hit the participant hard. There is also that fear when you have crossed boarders or countries when you have felt like I'm not really welcome here as HIV positive, and that has been hard. I have had to lie and pretend that is raining and even signed false health declarations. Not false ones, but I have lied on them. Which hasn’t always felt that great to be honest. But as the globe trotter I am I have realised I might as well lie, because they wouldn’t have understood anyway. That’s what I have thought and then you just have to keep up a good appearance. (Aged 40-50)

Pervading the interviews was the stigma faced online especially on dating apps and in
particular on Grindr, when either trying to find a casual partner or meet someone for something long-term. There had even been fear of getting infected through hugging, that is how deep the stigma lies. The impression received was that people in general are ignorant or poorly informed on how HIV transmit. Some also expressed themselves as undetectable and thereby will not be able to transmit HIV, still stigma and rejection was experienced. There also seemed to be a divergence how HIV is regarded between certain age groups where individuals in ages 40-50 might relate to the 70’s mass epidemic compared to those who are younger. As this age group might also self-stigmatise for being gay.

...Yes, especially online when one has tried to find a casual partner. Then I have experienced stigma. People haven’t known about if one can give another one a hug for instance, without being infected. Online there has been a lot of stigma. In the gay community, in certain age groups there is a stigmatisation within the gay community. I don’t have the 70s mass epidemic in my thoughts and therefore I think the stigma is much more widespread in those aged 40-50. Also, they might carry the stigma of just being gay too. (Aged 20-30)

Another participant further described the stigma faced online and questioned the smart phone application of Grindr’s option of declaring if one is HIV positive or negative. An option that distinguishes individuals according to HIV status, in an exclusionary point of view. The option itself is seen as highly stigmatising and tough for HIV positives to deal with, questioning the logic behind, if it is to ease HIV negatives to avoid HIV positives?

One thing I have reacted upon is that Grindr wants you to declare if you are negative or positive. That I think is highly stigmatising and actually, a though thing. I mean what is the thought behind it? Is for them who are negative to be able to avoid the positive ones, or for the positive ones to find positive ones? I don’t know. That is something I have reacted negative towards. There are HIV negative people who are afraid of it. I have experienced being rejected exclusively because I am positive. That is the way it is. It does affect me if there was someone you wanted to meet. But then again it wasn’t to be, there are more gays. Laughs. (Aged 40-50)

The same trail of thought on why Grindr want you to declare your HIV status was reflected upon by another respondent, perceptualizing the distinguish between HIV positive and negatives. Questions were raised about whether a person who declares themselves as HIV negative would change this information if one would become positive? The participant further explained how he had written to Grindr and questioned the need for people to be categorised even more. This gesture typifies how the option to distinguish individuals by being either
positive or negative can be hurtful and hugely stigmatising a group of individuals.

*When people state that they are not positive or ticking that box on the dating apps. Would they actually change that if they became positive, I don’t think so? Then why state anything if it is not important. I actually wrote to Grindr saying why is this important and why do we have to be categorised even more? I never got an answer though. I think that if people were to become positive I think this box would just disappear.* (Aged 40-50)

A participant in his thirties who is very social described how the stigma on Grindr can play tricks on your mind. One can create a whole world on there that does not reflect the true picture of what the world looks like. If people can cut one out of their visibility some people will, due to stigma and fear of HIV. The participant explained how these situations have made him struggle with Grindr.

*I have experienced a lot of stigmatisation. Especially on Grindr. I mean Grindr can fuck up your mind, honestly. Especially for people like me who are intense and very social. You create a whole world on there that does not exist. Therefore, I have a boyfriend now, so I can breathe. There was a guy I met and I said I'm positive and undetectable, but he just cut me right off. Just like that. I mean there are treatments against HIV. But being infected with other diseases are much easier than HIV. I have struggled or battled against Grindr.* (Aged 30-40)

Another participant goes deeper into analysing the behaviour on Grindr, stating that people rather seem to meet people who do not know, or do not disclose their status. This has been noticed by people saying that they would prefer having sex with someone who does not reveal their HIV status, as the potential “threat” of being transmitted is not there. This behaviour could in fact lead to that fewer individuals want to be honest about their HIV status due to the impact of stigma. Thus, the stigma that does exist will remain, by individuals not being able to be honest about themselves and by not breaking stereotypical norms of what is normal, healthy or acceptable.

*It is interesting if you go online on Grindr and talk to people you like, they would prefer sex with someone they don't know anything about, than having sex with someone who is actually honest and tells them that he has HIV and it's not a potential threat towards them. It is interesting if you try to analyse it, that kind of behaviour. So, you're saying that you don't want to sleep with someone who is undetectable and who is openly telling you that there is no need for you to be concerned and we will use condom as well, than having something with someone who is not telling you. I cannot understand that kind of thinking.* (Aged 30-40)

Several of the participants admit having felt discriminated and stigmatised in a professional
sphere as well. Disclosing how they have felt mistreated when needing to be attended and cared for at hospitals. On occasion it has even gone as far as the staff not giving care once finding out about the participant being HIV positive due to stigma. Most of these feelings have come afterwards, when the person has had time to reflect on how they have been treated and also realised that this was due to being HIV positive. A situation that emphasise how HIV impact social exclusion even in a professional context.

*I have experienced that nurses when having applied for healthcare never have come back after having found out that I was positive. But I didn’t realise that at the time because I was feeling so ill, but in time I have thought more rational and realised that was the case. I was just lying there hoping someone would come back to care for me, but then no one ever did. That was difficult for me. I mean how were they thinking, like healthcare staff not being able to act professionally. That is scary.* (Aged 30-40)

There was more than one participant who had experienced stigma within the healthcare system when getting diagnosed. The participant describes it as it was like going back to the 80’s again, especially when it came to receive the council’s guidelines for HIV positives. When reading the guidelines along with a patronising demeanour from the curator, the respondent was chocked that the guidelines said not to share a toothbrush with somebody else, which was also questioned by the respondent. The council’s guidelines which were written only a few months back felt stigmatising to this participant.

*When I got to see the curator working at the hospital who’s not very good at her job, I experienced a huge stigmatisation, she had a mind-set of how one should behave. Then when I got the council’s guidelines for when one is HIV positive, the council put a huge stamp on how things should be. Like who you should tell and what obligations one has and so on. It said for example at the bottom of the page that you should not share a toothbrush with anyone and this was last autumn. I was like my god, what does it say? This is 21th century, and it actually said I shouldn’t share a toothbrush with anyone! When I met the curator the next time I confronted her about it, saying that the last sentence on this paper to me is going back to the 80s again, have we not come any further after all? She couldn’t answer the question about why that was stated like that in the guidelines, and said they were written 6 months before this. I mean there is research on this area, very much, and there is need for more. To me it is super weird that the healthcare system put a thing like this on their guideline as to how one should behave.* (Aged 40-50)

One respondent told the interviewer about an incident that he had experienced at a Swedish
airport. He was informed that Swedish law says that everyone needs to know about one’s health status, regardless of who this person or institution was. In this script stigma against HIV go as far as it is intruding in one’s privacy and right to remain a person rather than becoming one’s disease. This example shows that even individuals working in authority positions are poorly informed and educated within this area.

When I arrived at the airport the police told me that -Here we have I have a law that says everyone needs to know about your health status. So basically, that means that if I get into a cab will the cab driver need to know about my HIV status. I mean people will make mistakes just because they're not well informed. But here even the police officers at the airport told me I had to disclose to everyone that I'm HIV positive. (Aged 30-40)

Another participant faced stigma when applying for a job, where the director was worried and scared about employing someone who is HIV-positive. Believing that someone who is HIV positive could be a threat to the others by working in the company. Thus, the impact of stigma, will make it difficult for anyone living with HIV to be open about their status (Ostrom R, et al 2006), as it might jeopardise the chances of being employed.

I had a job interview and the director who was interviewing me said -okay let me check something and then he was opening his email. I had previously sent an email explaining everything that had happened to me asking for a job, because someone told me I could easily get a contract with him. Then he said - But here it says you are HIV-positive. He was like - Should I be scared about you working in my company and a threat towards the other employees. I said -Why would I be a threat to the other employees? I'm just a colleague with them. But then when I replay the whole situation up until that point we had a perfect interview and everything was great. The he said -Maybe you should wait and then you should call me and we can see. I'm not sure that was the right excuse. (Aged 30-40)

One respondent revealed how he had been questioned about being able to do his trade of work because of his HIV status, although saying it has not been a big issue for him. However, questioning one’s ability to work with food due to being HIV positive reflects stigma, ignorance and lack of knowledge about HIV but also respect towards the person in general. A mind-set that shift focus from the person and instead the person identifies with the disease.

At work it hasn’t really been a problem however there have been uncertain comments on occasion about if one should really work with food and so on. They come from colleagues wondering if I really could work with food because I’m HIV positive. But that is pure lack of knowledge about HIV. (Aged 20-30)
Social exclusion

When the participants disclosed about their status they were being exposed to social exclusion from making new connections, no matter if it concerned friendships or sexual meetings. There is still an obvious fear and stigma of HIV in the Swedish society, which leads to an exclusion of HIV positive individuals. The participants were in particular subjects for rejection and social exclusion if they disclosed their HIV status before meeting a potential friend or sexual partner. Reflecting a context where the mutual interest is based on one being HIV positive and this person is affected negatively.

People that I know have been like yeah okay it is not a big deal. But the rest of them are like sorry no I don't want to have anything to do with you. When it comes to Friendship no, I don't have time for friendships I have enough friends. But when it comes to go on a date then it's like a problem and especially if it comes to having sex, then it's like no, if you tell in the start then it's like no sorry there is no interest in the situation. (Aged 30-40)

One respondent has noticed the lack of knowledge about HIV amongst gay people in Sweden and admits this contributes to fear and rejection towards HIV positives. He further compares the lack of knowledge in a broader context, and points out dissimilarities in the knowledge between different countries and regions. By disclosing about being HIV positive the participants are more likely to be socially excluded.

I have noticed that gay men generally in Sweden are very badly informed and stigmatising the group in various occasions. If I were to disclose there would be many who would say thank you very much, but I’m leaving. I’ve noticed this on dating apps and so on. People are scared and you can see a difference in how cultural it is. If you get south of Denmark or south of Malmö, then people are better informed. People know a lot more and one knows how the medicine can work as prevention. Because that discussion has never been here and probably not going to be here either actually. (Aged 40-50)

One participant shared how him and his ex-partner had felt socially excluded at a christening they were invited to, being questioned about how they lived their life. A life that was seen different from the hetero normative outlook society portrays. By not having children, a house and a dog, the couple did not fit in and where socially excluded from conversing. Thus, even in contexts where the participant was included they were still exposed to social exclusion.

My ex and I went to a christening once where we felt excluded because it was so hetero normative and we felt really uncomfortable. Whatever we tried to talk about there was no one
who engaged in the conversation because we lived such a different life according to them. So, they didn’t want to have a conversation. They could not see that there was another way of living or that we were so open about ourselves. It was like if you don’t have two kids a house and a dog well then you don’t fit in here. They questioned us saying -Do you really lie about relaxing on Sundays? That is something we couldn’t do. Do you spend your money on clothes, interior design or travelling? We wouldn’t agree with that, laughs. It was so obvious that we don’t do things the way you do and whatever we do, we do for the kids. Laughs. They were marking that constantly or else they went quiet. (Aged 40-50)

Another respondent who were open about himself at work, described how he was socially excluded from the group dynamic by never getting invited to socialise with his colleagues. Describing how he was left out from having lunch or grab a drink after work with his colleagues and how the group seemed to enjoy excluding others. However, the participant accepted this behaviour by thinking that he did not belong in a group where people behave like that. By accepting social exclusion, a perceived form of stigma is evident, where the participant is aware of stereotypical behaviour from a groups dynamic.

I have felt socially excluded at work. They were a group and I was never included in that group. And they didn’t allow me to get into their group. They never asked me if I wanted to go with them and grab a beer or like when we were having lunch at work sitting like ten people at a long table. They liked the feeling of the group being just them and they excluded people. I never confronted them about it, instead I felt like, well if they do not want to socialise with me when we’re having lunch or never asked me anything about me. Then I do not belong there either and then I do not want to get in there. I did get a feeling I was excluded. (Aged 40-50)

Disclosure decisions

All of the participants discussed how stigma does influence disclosure decisions for them. In nearly all of the discussions second disclosure was an important factor and consideration before deciding to disclose their HIV status and to whom, which included the fear of beingouted and people finding out one’s HIV status without one’s knowledge. Many of the respondents spoke about how they would not be able to tell anyone at work in case of doors being shut on their careers due to potential stigma. Some of the participants feared other people’s reactions of finding out that they were HIV positive and that fear very much still exist. Disclosure decisions thus become more difficult due to people being scared of HIV.
Today maybe it is different, but still, I can think that we are not completely there yet. I still know people who are pretty much still scared. Like just the other day, you know, I think that you can’t disclose anything if we have the same friends or are in the same company with someone else. That is the fear that still exists. (Aged 40-50)

The subjective perception of stigma is described by the participant below. Stating that he makes it to a stigma himself by not disclosing at work, by worrying that it will or could affect his career due to people being scared or unsupportive. Here the fear that the information will be shared inappropriately is a distinct factor impacting disclosure decisions.

I make it to a stigma myself as I haven’t disclosed at work. I don’t really care about it but I haven’t told anyone. I have mainly disclosed to other gay people. I haven’t disclosed at the office, because I am worried it will hurt my career in that sense I might not be promoted and so on. Some people do find it scary, that’s why I don’t disclose, it could hinder me. The worry about being outed, I haven’t personally but maybe that is the reason for why people don’t disclose about their status. Because they are scared of being outed, second disclosure. I have considered this myself. I choose to whom I disclose too. It does affect the decision to disclose. (Aged 40-50)

A few of the participants had disclosed at work, but did not get the consideration or understanding they were hoping for. “My employer did not understand what it was about”. This justify the participant above’s reasoning for not disclosing at work. Events like these would lead to that HIV positive individuals refrain from disclosing at work again or the next time, contributing to a less informed society where only what is considered “normal” is accepted.

At one workplace I said I had some problems with my memory due to the HIV and the medicines. It was 2005, and I had disclosed but in the end my employer didn’t understand what it was about. They expected just as much from me as from anybody else. My boss got so frustrated, because if I don’t write things down it could be so that I will forget. (Aged 40-50)

One of the respondents described how he had disclosed to his closest friends, and what factors he consider important before disclosing on his HIV status. The participant spoke about how disclosing one’s status meant that the shame of being HIV positive was removed and that one then did not have to think about whether to disclose or not. This respondent explained seeing disclosing more as principle and that the true picture of society should not be disguised nor stigmatised. However, when meeting someone, factors such as if he was seriously interested in this man and if he should take the risk of being rejected was considered before disclosing.
All my closest friends know that I am HIV positive now. I choose to disclose because I don’t think there is something that one should have to be ashamed of and thereby keeping it a secret. I might not have had the need for my surroundings to know but I have been strongly against that no one should find out, so maybe there has been more of a principle like that…… I don’t think anything should be stigmatised in society. You should be able to talk to your friends about everything. So, I thought I should tell them and not because I had the need to tell them…… If I am seriously interested in a guy, then it is a question whether I shall dare taking the risk of being rejected and I have to think is this someone I’m actually interested in? (Aged 20-30)

One participant discussed how it must be his own decision of when and to whom to disclose that he is HIV positive. Still, the surrounding does not always accept that, by getting angry that the participant had not disclosed about being positive from the start. Here it is evident that stigma influence disclosure decisions when one is feeling disrespected by not owning the right to disclose whenever one would like to.

Once when I was travelling around the world, and at that one time I was sitting at night and I disclosed my HIV status and some German got angry that I hadn’t said anything from the beginning. I said I have the right to disclose whenever I want to and it doesn’t affect you. At that time, I felt disrespected. I make that decision when to disclose and it was at that time when it perhaps was more difficult for me. I mean it must be up to you whenever you want to tell someone, whether its cancer or diabetes or whatever. But yeah, it’s not as juicy saying you have diabetes as HIV. The exclamation mark is bigger for HIV. (Aged 40-50)

One of the participants compared living with HIV and disclosing about one’s status before and after the medicine came. Stating that is was more difficult to disclose then than it is now. In modern times, it is more of a chronic disease like any other, compared to before when it was considered a deadly disease. It is not a question of living or dying anymore. However, he explained that there is still a long way to go in terms of overcoming stigma when it comes to disclosing being HIV positive.

As there were no medicines at that time, I had to disclose that I was carrying an infectious disease that is going to kill me. Maybe not that fun to disclose actually, but maybe for me it helped to disclose just to that person. That feeling when everyone feels sorry for one because one is going to die, euu. On the other hand, nowadays it might not be as interesting anymore due to that there is not a question of living or dying, not in the same way as back then. I guess, overall this it’s a good thing, that the interest has cooled down. It has become a
chronic disease like all the others medically. But on the stigmatisation side there is still a long way to go. (Aged 40-50)

Others revealed how people would not be acceptant or understand when they disclosed their HIV status, and would ask follow-up questions they did not want to, or have the energy to answer. Occasionally this was reason enough for the participants not to disclose being HIV positive. Although, the reactions have changed over time and is more relaxed nowadays, it does not necessarily mean the participant disclose his status without hesitation.

Today, I still think that HIV isn’t something that you easily disclose. I have done it on occasion just to see people reactions and it’s not in the same way the same reaction today as it was back then in terms of that it is more relaxed, which is probably good. I can see a change in that way, but it doesn’t mean that I just disclose my status just like that. Sometimes you choose not to disclose because you don’t want to answer their follow up questions, sometimes you don’t have the time and energy to answer or explain or even hold a shorter lecture as has happened sometimes regardless if you want or not. (Aged 40-50)

When participants disclosed about their HIV status they faced strange questions such as, what is going to happen with you now and are you infectious? Which indicates a lack of knowledge about HIV from their surroundings. But simultaneously the participant revealed that there are still a lot of ignorance within the gay community when it comes to HIV.

I found some reactions strange when I disclosed to people asking how did it happen and what is going to happen now? Are you infectious? Those questions came from friends and relatives. I was lucky I had knowledge about HIV before, I knew about it. Maybe it’s only gay people who talks about HIV, I don’t know. But the one’s asking me those questions certainly didn’t know much about it. Within the gay community there is still a lot of taboo and violence and ignorance when it comes to HIV. I started thinking about my life and the quality of my life. (Aged 30-40)

One participant talked about how he decided to disclose depending on if he had the energy for it. Further, he explained that in the end it is openness that will defeat stigma against HIV positive individuals. Stating that when disclosing one should not make things more complicated than they are, one must try and make it easier for oneself.

It depends on what mood I’m in and if I have the energy for it. Really, I don’t believe that you should set the bar too high. The more people who have met someone who wants to disclose about their status the better it is for everyone living with HIV. Silence is never a pro, it is openness who in the end is going to make the stigmatisation disappear eventually. Quietness
doesn’t but openness does. One shouldn’t complicate thing that aren’t complicated. It’s not easy in day-to-day life, but one should try and make it easier, not complicate things. (Aged 50-60)

One thing the participants had in common before deciding to whom to disclose was that they evaluated the person receiving the information life situation and if they had any knowledge about HIV. All participants put the person receiving the information feelings before their own when it came to disclose. Consequently, not having anybody to open up to or to talk to apart from someone from the healthcare might add another dimension of social exclusion, and thus stigma unquestionably influences disclosure decisions for the participants. Further, for these individuals, by always taking other people’s opinions and emotions into account before their own, is another difficulty that must be considered before disclosing about one’s HIV status.

It has happened that when I’ve disclosed about me having HIV, people have just gone quiet. They just don’t know what to say or do and it has gotten awkward. It has happened when I’ve been invited to parties and I’ve been excited about meeting new people and so on. Then they have asked what I do and I’ve been completely open and then it just doesn’t go down very well and it becomes awkward. I decided to disclose to my parents the same day I was diagnosed. My parents didn’t think that I should disclose to my siblings at all at first. They were very emotional both of them and it was the first time I ever saw my dad cry. That one of his sons could die before him he could never have imagined. They were also scared to death that our relatives were to find out because then they would have been bad parents for not having protected me. (Aged 40-50)

One participant discussed how he has not disclosed to his sister because it would become difficult for her and in her marriage. This shows that the participants put others need before their own which affect their disclosure decisions, and thereby also creates a distance between the participant and those one would like to disclose to. The fear of second disclosure is also a factor for not disclosing in this script.

I haven’t told my sister because it's a difficult situation and in her marriage. She might be okay with everything but her husband, my brother-in-law is actually what my parents would like to have as a son, so he is the same as my parents and that complicates a lot. I'm not sure how long my sister can keep the secret, it will be a burden for her knowing something and not being able to talk about it with her husband and I don't want to put her in that situation. (Aged 30-40)

The participants also considered factors before disclosing and they included if the person
could handle the information, if the person had any knowledge about HIV, if the person had too much going on in their life or if the individual could keep this information to themselves. This was something the participants in one way or another went through before disclosing on their status. The participants also realised that after disclosing being HIV positive, people often put one into a category, where one loses one’s name and instead becomes the disease. 

Before I disclose to someone I think of where this person is in life. Do they have any knowledge about how it is with today’s medicine or not? Do they still have that image of how it was in the 80s? Do I experience that they do have that picture then I don’t disclose?

Because I have noticed that people more often like to put one into a certain category then. As soon as I disclose to someone that I am HIV positive they put me into a category. I’m not [name] anymore, I am HIV positive then [name] unfortunately. That is difficult, when people don’t have the knowledge, shall I then have to sit down and explain to people how it is? I’m like no, that is not me, I don’t mind doing that if people are willing to listen. A friend that I have disclosed to, said -Now you must be careful with what you do. Putting the responsibility on me, like you have to think about everyone else, somewhat off telling. Then I felt like it is not worth to be questioned or having my behaviour questioned. How I live my life is no other people’s business. (Aged 40-50)

The participants also considered whether the person they disclosed to could talk about the information received or if they would just get too upset and perhaps break down.

When it comes to disclosure I consider if this is people who have experienced things and are they reciprocal to that I have HIV? Can we actually talk about it without them breaking down? Can they take it in without them just react from themselves? Or do they have preconceptions about people living with HIV or preconceptions about people in general. If so then I tend to not disclose. (Aged 40-50)

Another factor that the respondents went through before disclosing about their HIV status is whether it was the right time for the person to receiving the information. Again, others need would come before the participants needs.

I have disclosed to my siblings and some friends. I am very open and don’t have a problem disclosing about my HIV status but, I haven’t told my parents. I think they know or would understand, but I haven’t told them. Maybe next year, or the year after I haven’t decided. I don’t know why I haven’t told them. I have thought about it but, my dad’s wife is battling cancer right now, so no now is not the time. My mother, yeah maybe, but there hasn’t been the right moment. (Aged 30-40)
The following script describes a societal hierarchy between those who are HIV positive and those who are HIV negative. This reflects a feeling of social exclusion from the rest of society because of one’s HIV status. In the script below the participant cement the notion of fear, stigma and lack of knowledge in society which leads to that HIV positive individuals are closing in and choosing not to disclose. The respondent further explains how being HIV positive will lower an individual’s status in society and if one does not have the tools to prevent isolation from society, it will become very difficult those persons.

There are the surroundings which defines stigma for us who knows about our HIV status. It is from the beginning a hierarchy between those who are negative and those who are positive. There became a selection where I as positive came in lower position from the start. As a white man I come pretty far in society, but as HIV positive there is a set back and as a gay man as well. That’s the way society look at us living with HIV. In politics and judicial we haven’t come that far. It is only for those few knowing how HIV actually transmits. There is a stigma surrounding HIV and it hits people. Ignorance and lack of knowledge is still reproduced, even among younger people who didn’t even live during the time where there was no medicine, still the fear exists among this group. The norm of society goes so deep down that one is closing in on oneself. If you have been so exposed, to the silence as I have, once I have disclosed about my status, you close yourself automatically and think maybe I should not say anything. If you don’t have the tools to get out of this, it becomes very difficult for some. With no people around you to talk about apart from the doctors then you will live a very isolated life due to the HIV. There are actually very few who decides to disclose about their status, I know many who don’t even tell their friends. (Aged 40-50)

**Structural change**

A structural change has been noticed from the participants where a change in how gay men have sex during the last years in line with the medication working so well and preventing HIV from being transferring from one to another. However, this structural change to a more frequent condom-less sex only seem to happen in situations when both parts are on board with how HIV transmits. Thus, stigma still persists as people want to meet someone they refer to as healthy, which accordingly do not include HIV positives, as everything that has to do with HIV is rejected.

…. Yes, amongst HIV positive gay men there has been a structural change. There is ok to not
use condoms. But then there is a big group both older and younger who still wants to meet a healthy guy. Then when they write you notice that everything that has to do with HIV is rejected; there is no question about that. Even when people are looking for a partner they can’t imagine being with someone positive. On some dating apps I have stated that I am positive and then I already remove some of the guys who don’t accept me as I am. Minorities don’t like other minorities within the minority, so there is stigmatisation within the gay community as well so to speak. Because everyone wants to be considered as normal as possible. (Aged 40-50)

Several of the participants compared the same structural change by not using protection alongside the advancement in medical prevention, many do not practice safe sex as a result. Describing the situation of not having to use protection when having sex with someone as an immunity, which further explains a structural change towards a less rigid way of using condoms. However, it will also impact the previous notions mentioned of an inclusionary and exclusionary scenario. Where HIV positives and HIV negative individuals are further distinguished. Adding that, living with HIV has changed since the medication came, and receiving a positive answer is nowadays not nearly the same as before the availability of medicine. It has changed from a deadly disease to a chronic disease.

You don’t have to use condoms if you don’t want too. Condoms are a barrier I believe. People can do what they like nowadays, without taking any real risks anymore. I don’t believe contracting HIV nowadays is that a huge thing anymore. But it’s easy for me to say who has lived a few years without access to medication at all. It’s not a big deal getting diagnosed with HIV today. But it might be a bit unfair as, a diagnose today still affects your life, although I can think it’s a piece of cake, but maybe I shouldn’t say that to others. Which is completely unfair to those who just come out as positives, but I think well maybe it’s not that bad, nowadays. There are worse things. But I can’t say that but I can carefully try and explain that when I was diagnosed there was no medicine. So maybe in that way yes. Another thing, if I was to have sex with someone positive then I am protected, I can’t get his HIV if you know what I mean, that closeness of unprotected sex is nice. (Aged 40-50)

There is a lot of people having sex now without using protection, because of the medicines. There has been a change mentally but one can still relate to the fear that existed ten years ago. But a lot of people don’t have “safe sex” anymore. So, there is two elements and groups that have increased in their behaviour. It is complexed. (Aged 30-40)
There are also encounters that look for HIV positive men for safe sex without the use of condoms. But this only applies for those who find it safer to have unprotected sex with HIV positives rather than HIV negatives and for those who have come to terms with that undetectable HIV positives cannot transmit the virus. The mentality of getting an HIV infection has also seemed to change as one respondent reasoned “if it happens it happens”.

I can see a structural change, in that sense that some people even look for positive men instead of negative men. There has been a change, from a deadly disease to a more chronic one. Some people find it safer to have sex with positive men than negative ones. I knew it might happen that I became positive, but I was like if it happens it happens. (Aged 40-50)

The participants expressed emotions of strength, frustration, and laughter but also sadness and a sense of longing for closeness and being cared for by a loved one, once reflecting over their experience of living as HIV positive.

I do sometimes miss the feeling closeness and physical contact and so on. I have to say, I do. But I don’t think I am rejecting it.... I can really miss that, and having someone who likes you, yes, I can really miss that. (Aged 40-50)

For me it is important with love and to fall in love with someone. It was important when I met my ex as I was living as HIV positive, because I knew people were scared. But he wasn’t. He chose love, and that was very special. (Aged 40-50)

Obligation to inform

The author also talked to the respondents about their outlook on the obligation to inform and how the removal of this law would make a difference for them. During the interviews there were divided opinions on whether the law should be kept or not. However, all participants agreed that the law need to be looked over and modified in line with today’s advancements when it comes to medication. At the moment the participants explained that, the law contributes to social exclusion of HIV positive individuals. Zeligman et al’s (2017) third type of stigma, felt-normative stigma could be put in parity with this law, where the law itself has reached a degree to where it has become normalised, and therefore no change or modification of the law has been put in practice since the advancement in preventive medicines has come into use.

Sometimes when I have been rejected by the ones I have told, as before we had the obligation
to inform 100%. And people who been scared to death, that classic thing like, - we have not done anything. Then it has felt hard, like I am scared meat. You don’t want people to be afraid of one. (Aged 40-50)

A couple of the participants explained how a removal of the law would make it easier to go on dates and meeting a partner as right now the law emphasises the already difficult decision of when to disclose to someone. The obligation to inform also hinder the participants of choosing to whom to disclose. Thus, the law contradicts a person’s right to be anonymous as it forces the respondents to disclose about their HIV status because it must be disclosed.

If the law was removed, going on dates would be much easier for me. Because right now, you don’t know if you should disclose on the first, or third date or first time you kiss each other. [Paus]. Or sleep over at someone’s. It is so difficult to draw the line of when to disclose about something like this. Because it has to be disclosed. But it feels wrong to disclose having the first coffee together. Like hi my name is [name] and I have HIV. (Aged 30-40)

I think the law should be changed completely and remove the regulations completely around this. The law has made you feel forced to disclose, I can’t decide for myself when and to whom to disclose. (Aged 40-50)

A couple of participants agreed on that the law should be kept at least a few more years as they believed more research has to be done, pointing towards a lack of societal discourse about how the law is outlined.

The law is still there, because it talks too little about it. There is no societal discourse about it there is too little research on it. There is too much ignorance and a too little knowledge about it. (Aged 20-30)

I think it is good. I think one should still tell at least for a few more years until there has been made more research on this. But when you know that you can’t infect someone with a good run of medication then I think the obligation to inform can be lifted. In a relationship you should disclose, but not for every contact. (Aged 20-30)

The participants discussed how the law needs to be adapted to when its needed, indicating that when someone is put at risk the law needs to be there. But its focus should be on the actual risks instead of on the individuals who are not a risk of transmitting HIV to somebody else.

I don’t think the law should be removed, but it needs to be adapted to when it is needed. The law has changed for those who are well treated. It should still be there if someone is putting
someone else at risk. But maybe it needs to be changed a bit further, targeting the risks instead. (Aged 40-50)

One respondent was admitting that regardless of the obligation to inform, once he was undetectable he will not disclose his HIV status before any sexual encounters as it would more often than not lead to rejection. Stating that HIV is still a label and people are still scared. Hence, by not disclosing the respondent would avoid stigma and social exclusion.

_I have reflected on this since I got diagnosed. When I know that the viral levels are undetectable, when the medicine has kicked in. I will most likely not tell people I have sex with. Yes, that is a breach against the law, by not informing. But I think as it is still such a label and that people are still scared, and then I think it has to go like 10-15 years until people catch up cognitively where I am. Where one knows that when the viral load is undetectable there is no scientific proof that I should infect anyone else and thereby no reason for disclosing._ (Aged 40-50)

There are also complications for the participants how to correspond to the law when making new connections with individuals. The respondent revealed how he wanted to be like everyone else and not be reject due to being honest about himself. These participants brought for instance up, questions of when to disclose? And reflecting on if it was going to be something more long-term with a person they meet?

_It is amazing that the law is partly removed I think. You can have one-night stands without informing, that’s a benefit. But on the other hand, if you meet a man that you’d like to get together with again after you still have to inform. And then I or he can think that why didn’t I say from the start? So, it doesn’t have to mean that it is always that much easier. You still have to disclose about your status if you want to live in a relationship I believe.......You do want to be like everyone else. No one wants to be rejected and having to say something that could make you get rejected._ (Aged 40-50)

Now since I'm not obligated to tell them I would say I will ask myself what is going to be with this person if it's only for sex and nothing else then I will definitely not say anything. But if I think that things are moving towards something serious then I would consider myself just disclosing my status and see what happens after. (Aged 30-40)

Participants called the obligation to inform a control by the system which induces stigma and exclusion for HIV positives. They also discussed the law from their angle and how it should be looked over. The participants view of the law as it is stated now is that, the law targets the group (HIV positives) and not about HIV itself as it does not oblige from the one who might
get infected. The doctors say it is not intruding on one’s private life it is rather about a disease and an epidemic and that is why the law is there. However, it does not correspond to the medication that is available.

One could say that one is being discriminated just because they have targeted my group, but it is not about HIV. Instead it is about that one should not transmit another STD’s. It doesn’t add up. I think there should be or exist a disease control if you are risking someone else’s health. But it should oblige from the one who might get infected if so. (Aged 40-50)

It is another way of control, there is logic behind it. We all have the right to our anonymity. The system doesn’t have the right to go into our private sphere.....The doctors would say it’s not about your private life it’s about a disease and an epidemic. But if it is about an epidemic, can we really call HIV with its treatments an epidemic 2018? It’s a step that is obsolete so to speak. Information is our best tool our weapon to fight stigma. Societies needs more love, empowered people need more information and knowledge about HIV, and how it works. (Aged 30-40)

Final Discussion

This thesis aim is to contribute to the knowledge about and filling the gap in qualitative research on how life is experienced living as a HIV positive gay man in Sweden. This has been achieved in the context of stigma and disclosure decision by posing the questions; how living as HIV positive effects social relations, social exclusion and work? And how this may influence disclosure decisions for these individuals? The participants experiences were surprisingly similar regardless of place of residence. However, in one of the cities the participants where easier to get in contact with and more at ease with opening up and talk about themselves compared to respondents from the other city. Surprising to the author was also the persisting prevalence of stigma towards HIV and HIV positive individuals in Sweden. Findings show that all the participants have experienced stigma due to being HIV positive in different ways. The stigma experienced could on the one hand come via social relations such as family members, friends or people in their vicinity. On the other hand, stigma was experienced when the participants where in need of healthcare, or when the respondents tried to meet a partner. Rejection and stigma was experienced from educated persons such as
doctors, nurses or psychologists. When healthcare was needed, stigma was impelled by staff not wanting to attend or care for the individual and it was also experienced in a professional sphere at the participants place of work. However, the results also show that stigma has been experienced online, via smartphone applications that depict bodies under the glass of screens as Penny (2014) points out, and the application of Grindr is one such system. Seemingly, it is important to remember that, the presentations of gay maleness proliferating on systems as Grindr are not works or a consequence of Grindr itself necessarily, but the creation of gay men using the application. Therefore, one could say that there is a self-stigmatisation within the gay community and as one of the participants so profoundly stated that “minorities don't like minorities within the minority” and this comes as a result of that everyone wants to be considered as normal as possible. Stigma as Goffman (1963) states, does raise questions and confronts challenges such as discrimination and segregation (offline and online), emphasising the context of individuals that are unable to live up to the standards that society expects and refers to as normative. As many of the respondents admitted a longing for closeness and physical contact, a question could be asked if the prevalence of apps like Grindr has rather worked as an obstacle in gay men’s quest of experiencing love? Penny (2014) writes that gay people have come to expect that smartphone apps will bring them affection and sexual gratification at steady pace. However, this affection which is received is ought to be numbed by the interface and its reductive tropes. Affection and intimacy cannot be perfectly translated or situated into the comparatively limited combinations of bodies under the glass provided by the app. Perhaps applications such as Grindr has made it easier for gay men to get in contact with other gay men, but then the exposition of potential stigma must have increased exponentially. Seemingly, the knowledge about HIV and HIV positive individuals is increasing, this research suggests that preventive work has not come as far as asserting the rights of victims for not being socially excluded nor discriminated against. By adding an option to disclose if you are HIV positive or negative on a system as Grindr, the finger will work as a narcissistic controlling tool, and could symbolise the user’s internal judgements to the point of decisive action. This means that the finger so to speak work as and decides what external objects are to be included or excluded from a self-created world (Penny, 2014). Thus, it adds another dimension which suggests affecting HIV positive individuals negatively, reducing their ease or willingness to integrate or to disclose their status online. Which in turn will work as a loop hole reproducing stigma by keeping HIV hidden and separated from what is seen a “normal”, “healthy” or attractive in a hierarchal manner. Being HIV positive thus,
more often than not fit into the sphere of what does not “make the cut”. By enabling functions such as online blocking and by exposing oneself for possible rejection underneath the glass, a world is constructed accordingly to the benefit of the user through the personal screen so that only those best matching the user's wishes appear. Thus, a numb, unfeeling finger and a god over their smartphone world, is a closed-circuit (Penny, 2014). At least so it seems, when inclusionary and exclusionary options of what is real and true in an offline world is chosen to be filtered on online dating apps such as Grindr.

HIV remains a highly stigmatised illness (Murphy et al. 2002), it has shown both in this research and in previous (Zeligman et al. 2017) that HIV tremendously change the lives of people living as HIV positive in Sweden. Contemplation of whether to disclose one’s HIV status comprise both the possibility of gathering emotional and contributory support (Draimin, 1993), while it also exposes oneself to social exclusion. Stigma plays a significant role for disclosure decisions in particular in regard to whom and when to disclose (Thapa S. et. al. 2018). Findings show that when respondents disclosed about their status they were exposed to social exclusion in terms of making new connections with other individuals.

Decisions about disclosure have proven to be a vital concern and a decisive factor for HIV related stress (Rodkjaer et al.2011). When the participants disclosed about their status they were being exposed to social exclusion from making new connections, no matter if it concerned friendships or sexual meetings. This shows that there is still an obvious fear and stigma of HIV in the Swedish society, which leads to exclusion of HIV positive individuals. Underlying reasons for this is possibly a lack of knowledge about HIV, not just amongst gay men themselves but also in comparison to individuals fitting in under the norm of society. Moreover, there seem to be a difference in experiencing stigma as a minority by a minority, compared to facing stigma as a minority by the majority. This stigma does not quite have the same impact, as it does not imply social exclusion of oneself in the same manner as both minorities are categorised differently from what society refers to as “normal”. A couple of the interviewees who strategically disclosed their HIV status to everyone in their vicinity, had simply a strategy of always being honest about their HIV status, refusing to hide the disease and in that way, counteract stigma and stereotypical norms of what is normal. However, the strategy was not tantamount with being easy. It imposed on the individual’s an oscillation of thoughts on how and when to disclose to other people, contributing to immense stress. Finding shows that disclosing ones HIV status is both and acute and recurrent stressor, implying that disclosure decisions has a dual meaning by working both as a stressor and a
mechanism by which the participants had to cope with their infection. The initiate thought from the participants had been that their surrounding network must accept them as they were if they were still to be part of the respondent’s life. This attitude, apart from evoking stress also exposed the respondents to social exclusion, if their friends and family could not accept them as they are. However, this way of reasoning, by disclosing to everyone, relived the participants from living with secrets and the stress linked to concerns about “who have I told?” and “who will find out?”, which was often the case when the participants discussed worries about disclosing their HIV status at work, being at risk of second disclosure. The feeling of unsureness whether the other person will accept you or expose you for discrimination does burden the person in question. However, most of the respondents would agree that a non-accepting would lead to a parting of ways. The participants decision to disclose to others thereby minimised their ability to control second disclosure by others, which further exposed them increased vulnerability. It was not uncommon for the respondents to have people in their surroundings who did not accept their status, which led to that some of their constellation of friendships and family came to change during the disclosure process. Second disclosure was a significant stressor as some of the interviewees raised concerns about being treated differently at work due to being HIV positive, in terms of missed career opportunities, promotions or being socially excluded. For participants who had disclosed at work the latter was a fact, where social exclusion from an in-group perspective was noticed, further speculations cannot completely rule out that promotions or other career opportunities might have gone unnoticed.

Based on preconceived notions regarding how HIV positives are perceived, stigma does influence disclosure decisions (Ostrom R, et al. 2006) which this study confirms. Findings also suggest that various forms of stigma do in fact play a significant role in how the participants view their diagnosis. Consequently, a conclusion can be drawn that concerns such as fear of second disclosure or viewing oneself in a negative light due to being HIV positive, does influence disclosure decisions. This was particularly noticeable as one of the respondents referred to oneself as “scared meat” once having been rejected after disclosing, reporting that people have been afraid, even though no physical contact has been shared. Another participant discussed stigmatising one self’s HIV status in terms of not disclosing at work, predominantly due to worries about it hurting one’s career by not being promoted. This could also be seen as a protection taken by the participant by not putting oneself at risk to be socially excluded or outed through second disclosure at work. By carefully choosing whom to disclose to, stigma

42
in a professional sphere as well as in a private context certainly affect the respondent’s decision to disclose being HIV positive. Moreover, these findings confirm Ostrom et al's (2006) research, that the level of perceived stigma is positively linked with reasons for non-disclosure and negatively linked with reasons for disclosure.

A shifting perception and attitude about HIV has been noticed by the participants, although a reduction in fear and risk perception has been perceived, stigma towards HIV and HIV positives are still prevailing in the Swedish society. However, HIV may be more frequently associated with other chronic diseases such as asthma or diabetes nowadays, rather than viewed as a death sentence, this view however, seems to mainly be held by the ones being positive, as there still is a large stigmatisation against this group. In this research the participants revealed themselves as being referred to as healthy or unhealthy due to their HIV infection. Goffman (1963) argued that the concept of being categorised as something diverging from what society expects and refers to as “normal” creates a societal hierarchy where those being HIV positive are undermined individuals being HIV negative. This structural change of being regarded as undermined includes a more frequent engaging in condom-less sex and the respondents admitted that a large group of individuals wanted to meet “healthy guys” which did not include those being HIV positive. In turn, this would mean that the structural change by engaging in condom-less sex will be limited to mainly include HIV positive individuals. As the stigma experienced by the participants was perceived in form of that HIV negative individuals wanted to meet “healthy guys” regardless of engaging in protected or unprotected sex. “Everything” was described as being related to HIV and when people are looking for a long-term commitment one could not imagine being with someone who was HIV positive.

In recent times dating apps have made the option available to declare whether one is positive or negative, exasperating the situation and the divergence between HIV positives and negatives in terms of both, social exclusion and making it more difficult for HIV positives to find a partner. The medicines are another factor which has driven the structural change of more frequent unprotected sex, and even if a mental change of how HIV transmits has been noticed, the participants still related back to the fear of HIV that existed in the past. A complex behaviour has thus occurred between two groups distinguished by a blood disease which prevails no matter if one has an undetectable viral load or is HIV negative. On the one hand, the author believes that the structural change in addition to a mental change has had a
positive impact when it comes to reducing stigma against HIV and HIV positives. Especially, if awareness of transmission risks has increased along with the belief that HIV is no longer the worst outcome and instead being regarded as a chronic disease rather than a death sentence. However, on the other hand, evident was that there was still a sense of longing for physical contact and in finding love and a partner amongst the participants. Having said that, the shift may have come with a setback as the structural change may have implied difficulties in finding love for HIV positives by highlighting further differences between the two groups.

The findings also revealed divided opinions from the participants whether the obligation to inform was to be removed or not, and if the law was removed how this would make a difference for these individuals. First it has to be emphasised that, all participants agreed upon that the law which was put in power 1985 (Prop. 1985/86:13), needed to be looked over and modified according to today’s advancements in terms of medication. Because, the law as it is stated according to the respondents, does engender social exclusion of HIV positive individuals. The rejection the participants experienced due to having to disclose their HIV status was admitted to at times having felt hard. This rejection was also experienced without involving any physical contact which undermines how the law impose social exclusion. The law also made it complicated on when to disclose to someone, questions such as whether to disclose on a first date? Or the first time physical contact had been made? Regardless of when, according to the law it has to be disclosed at some point. But disclosing on a first date, one's HIV status may make it more difficult to establish a long-term connection with someone as stigma against HIV positives and fear of HIV still exists in the Swedish society and in addition, HIV and being HIV positive is something that still falls outside of what is regarded as normal. According to this research a conclusion can thus be drawn, that going on a date and possibly finding a partner as HIV positive would be easier if the law was to be removed. Evident was also that the participants related the obligation to inform as a form of control by the system which induced stigma and social exclusion for them. The right for anonymity should entail everybody, and this law is viewed as an intrusion in the participant’s private sphere. Moreover, while the doctors oppose to this and mean the law is about a disease and an epidemic. Can we call HIV with its advancement in treatments an epidemic in the Swedish society 2018? Information and knowledge about HIV is thus without a doubt the best tool to tackle the stigma that exists towards people living with HIV. In the end, individuals need to feel loved, not discriminated against. Empowered people need more information and
knowledge about HIV, and from HIV positives themselves to gain a first-hand experience of what it is like to live as HIV positive. In turn, this could lead to that the obligation to provide information will either be modified or removed completely and that stigma against HIV positive individuals is reduced.

Future research could ask questions about the development of interventions to combat stigma. For instance, how are group identities formed in relation to HIV? How nations or societies can induce empathy for HIV positive individuals to successfully reduce stigma? Or via conventions which prevent segregation and group identities forming, while simultaneously increasing positive attitudes towards HIV in general. These suggestions have potential to ease the disclosure process for HIV positives whilst reduce social exclusion and negative impact on how social relations are formed. Further, one would expect that stigma against HIV and HIV positives may decrease with increased visibility of HIV. However, is this actually the case? As the visibility of HIV has become more prominent on dating apps, such as Grindr, stigma has rather increased and worked as a barrier for the participants in this study. This could be an interesting area for future research. Moreover, if the disclosure process comes without fear of stigma and that the information will be shared inappropriately, the understanding and availability of adequate health care would increase. Considering negative self-image received by surrounding attitudes, counsellors could battle HIV positives self-stigmatising in addition to validate and normalise such emotions within the person. Also, further information, education and training of health professionals on the social context around sexual norms is essential. In conclusion, targeting dating apps with interventions, including awareness and counselling options could aid in conveying complacency associated with shifting perceptions of HIV, by raising awareness of the social and psychological entanglements of an HIV diagnosis.
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