"I'm living with hiv, and today you'll get to hear my story"

How gay men living with hiv experience and perceive hiv-stigma

Anette Einan Enoksen

Master's Dissertation
Department of Psychology

UNIVERSITY OF OSLO

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Abstract

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Background and objectives: Since hiv's arrival, it has been a stigmatised illness. Since then, there have been great medical advancements, improving the prospects and life expectancies of those living with hiv. Surveys on individuals living with hiv suggest that the physical health and lives of this group has improved, but that stigmatisation remains an issue. There is little research on the experience of hiv-related stigma among gay men, a population overrepresented in the hiv population. The aim of this study was to investigate how hiv-related stigma is experienced and perceived by gay men living with hiv (GMLH), and how they deal with it. **Method**s: The study was done by interviewing 10 GMLH. The interviews were analysed through thematic analysis. **Results and conclusion:** Based on the narratives, the findings were organised into four themes, and discussed as followed: 'Encountered stigma', 'Living with a secret', 'Self-Perception' and 'A sense of responsibility'. Contexts, connections and implications of the findings are presented and discussed. Hiv-related stigmatisation is still experienced as an issue among some, but not all GMLH. Self-stigma is reported as being the most prevalent issue. Suggested applications of findings are presented.

Keywords: Hiv; stigma; gay men; thematic analysis

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Content

Introduction

"Hiv does not make people dangerous to know. So you can shake their
hands and give them a hug. Heaven knows they need it." (Princess Diana)

This is a quote by Princess Diana, who used her celebrity status to draw attention to a number of social issues, including hiv/AIDS (Brown, Nesse, Vonokur, & Smith, 2003; Brown & Basil, 2010). The fear of transmission that Diana was addressing in this quote, has been present since the first known cases of hiv. The believed threat of transmission, together with negative attitudes towards marginalised groups that are of heightened risk of transmission, have functioned as reasons for avoidance and stigmatisation towards individuals living with hiv (ILH; Herek, 2002).

Since 2001, Norway has adhered to several declarations aiming to prevent and improve physical and mental health, longevity, opportunities, and the overall life situation among ILH (The Ministries, 2009). Among the promises and aims related to stigmatisation is the commitment to eliminate all forms of discrimination towards ILH and other groups in particular risk of transmission (ibid.).

In Norway, the interventions related to declarations on discrimination and stigmatisation were found to be the least successfully implemented, and improved strategies were demanded (Econ, 2009). To fulfil this and other obligations stated in the EU and UN declarations related to prevention of hiv and improving the lives of ILH, the national hiv strategy "Acceptance and coping" was implemented for the time period of 2009-2014 (The Ministries, 2009). This strategy aimed at preventing transmission and promoting inclusion of ILH in society. At the time of the implementation of a new strategy of sexual healthy for 2017-2022 (Ministry of Health and Care Services, 2016), reductions in the number of hiv transmissions and improved outlook for ILH had been achieved, but challenges related to discrimination, stigmatisation and self-stigma were still found to be present, as well as a lack of hiv-related knowledge, especially related to risks of transmission. It was emphasised that updated knowledge on hiv, risk of infection and successful treatment is crucial for preventing stigmatisation and to ensure satisfactory services (ibid.). In this context, the Norwegian Directorate of Health provided subsidies towards projects aiming to secure that ILH are well taken care of in society (Regulation regarding grants for work related to hiv and more, 2016, § 1; The Norwegian Directorate of Health, 2016). As such, stigmatisation experienced by ILH is still on the agenda, despite improved medical treatment and improved outlook. However, there is little research investigating how stigmatisation is experienced and perceived among ILH belonging to

marginalised groups in the Norwegian society, and how they deal with potential stigmatisation. This study investigates this in the context of gay men, who are at heightened risk of transmission, and thus overrepresented in hiv statistics. This can create a better understanding on how to develop successful interventions and programs aimed at hiv stigma reduction and improving the lives of gay men living with hiv (GMLH).

Human Immunodeficiency Virus

Human immunodeficiency virus (hiv) weakens the body's natural immune system by reducing the body's CD4-cells, which support the immune system by fighting off infections (U.S. Department of Health and Human Services, 2017). If left untreated, hiv can develop into AIDS (acquired immunodeficiency syndrome), which is diagnosed when a patient develops one or more opportunistic illnesses (infections typically seen in individuals with weaker immune systems), or when the number of CD4-levels reaches below 200 cells/mm² (ibid.).

There is no effective cure against hiv, but since antiretroviral therapy (ART) was first introduced in 1996, (Palmisano & Vella, 2011) the treatment has been able to reduce the virus to undetectable viral loads, enabling ILH to live long and healthy lives (U.S. Department of Health and Human Services, 2017). This is also important for preventing transmission, as there have been no known instances of transmission from individuals with undetectable viral loads (U.S. Department of Health and Human Services, 2017; The Norwegian Medical Association, 2016). ILH with undetectable viral loads are therefore considered as safe from transmission when not having other STDs. Until 2016, ILH were advised to start treatment when their CD4-values reached to a level below 350 cells/mm² (The Norwegian Medical Association, 2016). New guidelines recommend that all patients adhere to treatment as soon as the diagnosis has been given, both because patients who adhere to early treatments have shown to have greater health benefits, and to prevent further transmission (ibid.).

Since the first diagnosed incidence of AIDS in Norway in 1983 (Brantsæter, Eikvam, Kjær & Åmsås, 2001), men who have sex with men (MSM) have been one of the main groups at risk for transmission, with a high rate of infection (Beyrer et al., 2013; Angeltvedt et al., 2012), and are overrepresented in hiv statistics in many countries around the world (Beyer et al, 2013). In 2015, 33% of new cases of hiv infections were MSM (National Institute of Public Health, 2016). This is the same prevalence as reported in 2006, where MSM were estimated to be 50 times as likely to have hiv compared to other men (Aavitsland & Nilsen, 2006).

In 2016, 6064 were living with hiv in Norway (National Institute of Public Health, 2017). Since the new recommendations of immediate treatment, the number of newly diagnosed

MSM who have been infected within the country have decreased (Ministry of Health and Care Services, 2016). Comprising 1989 of the cases, the number of transmitted MSM have decreased, but they are still overrepresented in these statistics.

The social construction of stigma

Society categorise people into groups where members of each group are expected to have similar attributes. This categorisation helps prepare for what may be expected from the individual in question, allowing us to deal with others without much attention. As we often meet strangers, this cognitive ability preserves energy and makes us able to detect signs of danger early, and without too much effort (Goffman, 1963). In interactions with strangers, we tend to anticipate strangers' attitudes and belongingness to a group based on first impression. We anticipate the stranger's *social identity*. The expectation or demands others have to an individual based on their social identity may be called their *virtual social identity*. However, categorizations and expectations may neither be right nor accurate. The category and attributes that the individual can prove to possess may therefore be called their *actual social identity*.

One is not normally aware of this cognitive process of categorization before there is a question on whether the expectations will be fulfilled or not, and we understand that we had expectations to begin with. Sometimes, an individual may be found to possess an undesirable attribute that does not concur with the expectations of the category of which the individual seemingly belongs. The individual is then reduced from being perceived as a whole and usual person to someone not fully human. This attribute is called a *stigma*. Herek (2002) defines stigma as '*an enduring condition, status, or attribute that is negatively valued by a society and whose possession consequently discredits and disadvantages an individual*', and this is the definition used in this study.

It is important to note that not all differences or undesirable attributes need to be an issue for stigmatisation, and not all discrepancies between virtual and actual social identity need to be negative. The stigmatised attribute does not have to be discreditable in all settings and groups. Rather, it depends on the participants and social norms of the social surroundings the individual finds itself. An illustration can be found from Goffman's (1963) book on Stigma:

> *'I can remember before now on more than one occasion, for instance, going into a public library near where I was living, and looking over my shoulder a couple of times before I actually went in just to make sure no one who knew me was standing about and seeing me do it'*

Going to the library is seen as normal or rather positive in many communities. Nevertheless, this is a quote by a professional criminal who tries to hide the fact that he is going to the library from a group where this behaviour may be seen as undesirable.

The stigmatised and the non-stigmatised are social roles, where the stigmatised has less power and resources than the non-stigmatised. The stigmatised is by definition seen as not quite human by the non-stigmatised. When someone is stigmatised, the non-stigmatised construct a cognitive stigma-theory that to them explains the stigmatised's inferiority by accounting for potential dangers represented by the stigmatised individual or group. This helps justify the prejudice or discriminating behaviour directed towards the stigmatised individual (Goffman, 1963). As the negative associations of the stigma is shared knowledge within society or a group that the individual finds him-/herself a part of, the devalued status of the stigmatised is known by everyone, and so both the stigmatised and the non-stigmatised are aware of the power differentiation between them (Herek, 2002; Goffman, 1963).

Goffman (1963) further differentiates between the discredited and the discreditable. The discredited are stigmatised individuals whose stigma is known to others, whereas the discreditable are individuals having a secret that they fear will result in stigmatisation if found out by others. As hiv is a concealable stigma, hiv-positive individuals can both be discreditable and discredited, depending on their level of openness about their condition.

Hiv-related stigma theory. Three types of hiv/AIDS-related stigma have been identified. Individuals living with hiv may experience self-stigma (Thomas, 2006), also referred to as internalised stigma (Berg & Ross, 2014), where the individual blames and depreciates him-/herself because of the illness. The individual might also fear that disclosure will lead to stigmatisation, which is called perceived stigma. Enacted stigma is when individuals are discriminated against based on their (actual or perceived) serostatus (Thomas, 2006).

Reasons for stigma may be many, but some factors may be particularly relevant to stigma related to hiv, as pointed out by Herek (2002). According to Herek (2002), hiv-related stigma may be further divided into two categories; namely instrumental stigma and symbolic stigma. Instrumental stigma stems from a need to protect oneself from hiv, and from fear of hiv as a potentially dangerous illness. Systematic stigma, is a way to express stigmatisation towards other groups associated with hiv. It has been argued that seropositive gay men may be particularly affected by hiv stigma because their condition is seen as self-inflicted by engaging in socially unacceptable sexual behaviour (Herek, 2002; Prieur, 1988). In this way, ILH who are already members of marginalised groups may experience double discrimination. They may not only be stigmatised based on their serostatus, but also for belonging to another socially devalued group (Bharat, 2001). This can increase anticipated stigma, as the affected individuals may fear stigmatisation based on both characteristics.

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Hiv and Stigma

Since the beginning, individuals with hiv/AIDS have been stigmatised through avoidance, exclusion, prejudice, discrimination, violence, and more (Herek, 2002). Hiv-related stigma may result in pain, isolation and struggle for the stigmatised, and have been shown to have an effect on hiv testing, risk reducing behaviour and seeking treatment after receiving a seropositive test result, (Chong, Mak, Tam, Zhu & Chung, 2017; Herek, 2002) and ART adherence (Brezing, Ferrara & Freudenreich, 2015; Katz et al., 2013). As poor adherence to treatment may result in resistance (The Norwegian Medical Association, 2016), stigmatisation may also result in serious consequences for transmission, and for the health of ILH.

Previous research on hiv-related stigma. The stigmatisation of individuals with hiv/AIDS has been seen all over the world (Liamputtong, 2013). In an American study, where seropositive gay men were interviewed about hiv stigma, they found that encounters of hiv stigmatisation were common, and that stigmatisation was experienced more within gay communities than in other arenas (Berg & Ross, 2014). Internalised negative feelings concerning their own serostatus seemed common amongst the interviewed participants. Many described hiv as a second closet, where many chose to keep the diagnosis secret to some extent. In another study on GMLH in San Francisco, a city described as having a politically active community for ILH and as being accepting towards hiv, they found that GMLH still struggle with stigmatisation. The distress that was mostly associated with hiv was related to relationships within the gay community, forming friendships and sexual relations, and serosorting (choosing partners based on their serostatus) (Skinta, Brandrett, Schenk, Wells & Dilley, 2014). A qualitative study on students, showed that levels of stigmatisation was higher when there is a belief that hiv is related to certain groups, such as prostitutes, drug users or homosexuals, than if they believed that it was an illness that could affect anyone, unrelated to a belongingness to particular social groups (Zefi, 2013).

As little research has been done in regards to the experiences of hiv-related stigmatisation among GMLH in Norway, it is hard to know whether the same would hold true in this country. Even though both America and Norway are Western countries, they still differ in culture and acceptance. In the social progress index from 2015, Norway was ranked as the country with highest social progress, with the United States as number 16, where social progress was defined as a '*the capacity of a society to meet the basic human needs of its citizens, establish the building blocks that allow citizens and communities to enhance and sustain the quality of their lives, and create the conditions for all individuals to reach their full potential*' (Porter &

Stern, 2015). Even though the scores did not vary equally on all aspects, Norway scored higher on *tolerance and inclusion*, including *tolerance for homosexuals*. Additionally, the Nordic countries and the Netherlands have been identified as having the least negative attitudes towards gays of all European countries (Štulhofer & Rimac, 2009). This is not to say that gays do not experience stigmatisation or harassment in Norway. On the contrary, as much as 58% report having experienced vocal harassment at some point, while 16% have experienced at least one instance of physical assault believed to have been a result of their attraction to other men (Angeltvedt et al., 2012). However, because of the double stigma that can be experienced by seropositive MSM, gay men living in in Norway may experience this stigma differently, compared to countries where the non-heterosexuals are more devalued by society. Also, as Norway scored higher on tolerance overall, it is also likely that other kinds of stigma, such as hiv stigma may differ from countries who score differently.

There is little research on hiv-related stigma that is focused on Norwegian GMLH. In a meta-analysis from 2010, no published qualitative articles on hiv stigma in Norway as the primary focus were found, even though hiv stigma was discovered to have been a theme in several other studies investigating other hiv-related phenomena (Olaussen, 2010). A literature search implies that the amount of qualitative research on hiv-related stigma is still lacking.

Despite the lack of exploration into how hiv stigma is experienced in Norwegian MSM, there are studies that prove this as an important research area in need of further investigation. Several Fafo-reports on Norwegian ILH have been conducted with different aims and focuses. Both quantitative and qualitative methods are applied in these reports. The 2008 report shows that there is a clear association between hiv-related knowledge and attitudes towards ILH (Mandal, Nuland & Grønningsæter, 2008). While there seems to be generally sufficient knowledge concerning how hiv transmits, there is a troubling lack of understanding about how it does not transmit. The belief that sharing a toilet with, or kissing an ILH, is as such deemed dangerous (ibid.). The most problematic attitudes and lowest levels of hiv-related knowledge were found among the eldest and the youngest of the participants.

The 2009 report on ILH's living conditions shows that some experience stigmatisation, while others do not (Grønningsæter, Mandal, Nuland & Haug, 2009). With a rather small participation, the report cannot be regarded as representative, but is rather a representation of some opinions present within this population, and the discussion on MSM as a separate group is limited. A more recent study investigating how hiv is perceived at the work place implies that the mentioned findings found in the Fafo reports are still valid (TNS, 2015), and further

support the connection between knowledge and negative attitudes.

In 2010, an internet survey was conducted on MSM across Europe. The Norwegian results were represented as a separate publication (Angeltvedt et al., 2012). Questions regarding hiv and hiv-related issues were included in the study's questionnaires. The study showed that most ILH were satisfied with their encounters with the health system, but the cause of those who were unsatisfied remained unclear. They also found no correlation between experiences of physical or verbal harassment and having hiv (ibid.). It is possible that the respondents who reported living with hiv did not experience violence related to their seropositive status, and there are several factors that may have contributed to these findings. Firstly, only a small percentage of the respondents described themselves as having a seropositive status, which may have influenced the results. Secondly, the phrasing of the question only referred to harassment believed to have resulted from someone knowing or believing that they were attracted to men. The question itself may therefore have excluded harassment where the respondents believed the harassment was targeting their seropositive status and not their sexual orientation. A person's seropositive status is also highly concealable, which may have affected others' opportunities to harass. At the same time, they found a correlation between hiv-related stigma and experienced harassment, where those who had experienced more harassment scored higher on hiv-related stigma, and 54% reported 'often' or 'very often' hearing someone saying something negative about ILH (ibid.).

In the World Health Organisation's (WHO) Treat 3 Million by 2005 Initiative, for improving hiv treatment in poor countries, it was predicted that: '*As hiv/AIDS becomes a disease that can be both prevented and treated, attitudes will change, and denial, stigma and discrimination will rapidly be reduced*' (WHO, 2003). Unfortunately, despite medical improvements, Norwegian reports on ILH argue that societal attitudes have not developed in line with the medical progress (Grønningsæter et al., 2009; Mandal et al., 2008; TNS, 2015).

Objectives of the Current Study

There is still little to no qualitative research on subjective experiences of hiv-related stigma among GMLH in Norway. The majority of the existing research, both qualitative and quantitative, also tend to deal with the hiv community as one. Whereas this may be beneficial for a number of purposes, the importance for group specific research should not be underestimated, where there has been shown to be important differences between the various groups diagnosed with hiv. Attempts to gain a better understanding of each group's challenges and needs should therefore be a priority, especially for populations who find themselves at

increased risk of transmission, such as MSM. Gaining more knowledge and understanding on how hiv stigma is experienced, perceived and dealt with by GMLH, will be helpful in developing interventions that may reduce hiv-related stigma in this group, and diminish negative effects caused by stigma. It is also believed that reductions in stigma will work as a preventative measure against hiv transmission and being proactive towards testing. Previous literature is mainly focused on negative experiences of stigmatisation, and there is as such little discussion on instances of lack of stigma or potential positive experiences related to living with hiv. The aim of this study is to fill this gap of knowledge on how stigma is experienced, perceived, and dealt with by GMLH in Norway today. This will be done through three subordinate research questions:

1) What are the GMLHs' experiences with social stigmatisation related to their serostatus, and how and from whom do they receive negative prejudice?
2) What are the GMLHs' experiences with internalised hiv negativity and self-stigma, and do they experience any positive aspects of the diagnosis?
3) How do GMLH potentially deal with hiv-related stigma?

Methods

This chapter will present information about the design and the procedures carried out in the study. This will also include methodological decisions made throughout the project, as well as ethical considerations.

Design

This qualitative study will investigate the experiences and perceptions of hiv-related stigma among 10 gay men living with hiv, and how they deal with potential stigma. By using a qualitative design and in-depth interviews, participants were encouraged to reflect on their experiences and their perceptions about the phenomenon. Other similar studies have used various approaches, such as Thematic Analysis (TA; Berg & Ross, 2014) and Interpretative Phenomenological Analysis (IPA; Skinta et al., 2014). Several approaches were considered for this study, such as IPA, Narrative Analysis and TA. In fact, IPA was originally chosen as a suitable approach for this study. IPA focuses on individuals' experiences and what meaning they attribute to those experiences. It was therefore perceived as an appropriate approach for investigating how GMLH attribute meaning to their experiences of stigma. However, after reviewing the data, it became apparent that important aspects of findings would be lost using this approach. The approach for analysis was therefore changed to TA.

TA is concerned with identifying patterns, also called themes, in data (Braun & Clarke, 2006). TA may be seen as a foundational approach, used as a basis for many other approaches, but it may also be used as an approach in its own right. As a novel approach, TA has been criticised for not having a set way to implement the method. Therefore, much work using TA has been criticised for not clarifying their analytic process sufficiently. However, if executed correctly, TA can be a useful and flexible approach. Braun and Clarke (2006) provides a framework on how to use TA more rigorously. This study has been based on these guidelines.

Epistemology

Epistemology is the theory of knowledge, and concerns what is regarded as knowledge, and what is seen as evidence for 'things' in the social world (Mason, 2002). This study relies on a social constructionist epistemology.

In Social constructionism, social reality is not seen as fixed or 'out there', but rather constructed by people through social processes and interpersonal interactions (Rogers, 2011). Social constructionism originates from a theory called the *sociology of knowledge*, first proposed in Berger and Luckman's (1967) *The Social Construction of Reality*. They theorised that social reality is constructed through three stages: externalisation, objectification and internalisation, which all work together in constant interplay.

Externalisation concerns how societies, culture and social groups make sense of the world, and through this, construct social worlds. Then, there is *objectification*, where those constructions progress into being perceived as truths or realities. Individuals will then get to know this social world, understand and adopt it by *internalising* it through processes of socialisation and enculturation. As an interpretive approach, social constructivism seeks to understand how people make sense of the world, why they experience it as such, and how their understanding of the world orientates their actions (Blaikie, 2010, as cited in Rogers, 2011, p.115). Social constructionism is also concerned with the consequences of social realities being constructed and how this affects how individuals behave and are treated (Rogers, 2011).

According to social constructivism then, the participants' narratives are not merely objective recollections of happenings, but rather representations of the participants' own perception of these happenings. How the experiences are perceived, remembered and told can be influenced in a number of ways, such as who they are communicating their narratives to, what they believe the listener expects from their narratives, other related experiences, social norms, the media, how hiv is perceived in society, and so on. Reflections of experiences may also change through time. The narratives provided by participants are thus not regarded as a

truth of experience, but rather a reflection of their own perceptions of their experiences at a given time. The narratives may therefore have been different if interviewed at another time. It is important to be aware of the plasticity of narratives, and the change of perspectives on experiences through time. This is not to undermine the importance of such research, but to emphasise what meaning may be attributed to the findings.

An important aspect of the social constructivist epistemology is the researcher's reflections on their own influence on research. Braun and Clarke (2006) emphasise the importance of acknowledging one's own effect on qualitative research, as all decisions made during the study are made by the researcher, and should be recognised as such. Just as everyone else, researchers inhabit a range of personal beliefs, attitudes and perceptions, which could influence the outcome of the study. The researcher forms the questions, and produce and discuss themes based on personal observation. In this way, results are not 'found' hidden in the data, but rather produced through careful observation of the data. The researcher will as such have a potential effect on all aspects of the study.

Participants and the Recruitment Process

Participants consisted of 10 gay men who were under treatment for hiv/AIDS during the time of the interviews. The requirements of participating in the study was belonging to the category of men-who-have-sex-with-men, being seropositive and presently undergoing medical treatment for hiv. Participants were mostly recruited through Aksept and HivNorway, both of which are organisations working with individuals affected by hiv/AIDS. These participants received information about the study through written information that was distributed by the two organisations and through encouragement from the organisations' staff to participate in the study. Some participants were approached through snowballing, as participants and one lecturer at the University of Oslo introduced the study to other potential participants. The participants contacted the researcher by phone or e-mail when they decided to participate in the study. All participants who took part in the study identified themselves as gay men. As men-who-have-sex-with-men is a broader term, covering a range of sexual orientations, for the purpose of this study, it was seen as more fitting to use the more specific, yet still accurate definition that was reported by the participants. The participants are therefore, in this study, referred to as gay men living with hiv or GMLH.

Research Materials

An interview guide was used during interviews to ensure that relevant topics were included (see appendix A). The questions mainly consisted of open ended questions, such as

'Can you tell me about when you grew up?', 'How has the medical treatment worked for you?' and 'If you could change something, what would you change?'. However, yes/no-questions were also included in the interview guide to introduce topics and to investigate the relevance of further questions before continuing with open-ended questions. An example of such a question was 'Do you feel that hiv has affected your dating-life?', where open follow-up questions were asked based on the participant's reply.

Questions for the interview guide were based on the researcher's prior knowledge obtained through the literature search that was done in the process of writing the research proposal, through conversations with staff at HivNorway, the Norwegian Directorate of Health, and the Norwegian Knowledge Center for the Health Services, and through conversations and suggestions from the project supervisor. Additionally, the interview guide was reviewed and edited between interviews for improvement. Due to the shared experience of being a member of two potentially stigmatised groups, and to assure context to their experiences, the interview guide contained questions regarding growing up as gay and living with hiv, as well as their experiences of hiv-related stigma. This is likely to have resulted in longer interviews and more extensive transcriptions. At the same time, it was helpful for the researcher to gain basic insight into their broader narratives, to better understand the implications of hiv stigma in each participant's life.

A recorder was used to record the interviews for further transcription. Transcription pedals and a transcription program (Olympia, DSS Player Standard Transcription Module) were used for a simpler and more effective transcription process. All recordings that were made were deleted after transcription by December 2016, and within two months of each interview. Interviews were only available and handled by the researcher and the supervisor.

Procedure

Interviews. The interviews were carried out August-October 2016. Two interviews took place at an office provided by HivNorge. All other interviews were held in an office at the University premises. When arriving for interviews, all participants received information regarding their participation and the study, both orally and in written form via an information sheet. Before participation, all interviewees signed a consent letter to confirm that they were willing to participate in the study and to ensure their rights as participants. Only the researcher and one participant was present during interviews. As interviews were semi-structured, the interview guide was simply used as a guide on topics of interest, whereas the order of topics varied, and further questions and more follow-up questions were added when seen as fit during

interviews. The interviews lasted between 1 hour and 2 hours and 40 minutes. After each interview, initial thoughts were noted down.

Transcription and the use of extracts. To enable analysis, all interviews were transcribed into written form. There are different ways to this. Some analytic approaches, such as Conversation Analysis, which is concerned with how individuals converse, demands highly detailed transcriptions, and are therefore dependent on detailed transcription systems, such as Jeffersonian transcription (Sullivan, Gibson & Riley, 2012). However, TA, which is more concerned with *what* is said rather than *how* it is said, does not require as detailed transcripts (ibid.). The transcripts were done through orthographic transcription, where all verbal utterances were transcribed together with other noises, such as coughs or laughter, or notes on behavior, such as crying or specific gestures. After analysis, all transcripts were edited to ensure readability for the reader. Words in brackets are words that are added to the transcripts for clarification. Additionally, the extracts included in the report were translated to English to concur with the language of the report. This translation also ensures greater anonymity on the participants' behalf, as the wording will be less personally identifiable.

As a qualitative study, the results and findings are presented by extracts from the interviews, rather than statistics, figures or graphs. While several extracts may be appropriate to demonstrate a finding, only the extracts that most clearly demonstrated the findings were used for the final product.

Analysis. Braun and Clarke (2006) have developed guidelines for conducting successful TA, where the analytical process consists of 6 stages. These stages were used as guidelines throughout the analytic process of this project.

Stage 1: Familiariation: The purpose of familiarisation is for the researcher to become familiar with the depth and breadth of the content of one's data. By personally collecting data and writing all transcripts, it ensured some familiarity with the data. In addition, after transcription, all transcripts were read and re-read, while interesting observations from the text and initial ideas were noted down.

Stage 2: Generating initial codes: All instances of interest were coded based on what was happening in that particular segment of the text. In this way, segments of text with similar content were given the same coding. One segment of text can have one or more codes, or none, when seemingly unrelated to the researched phenomenon. The coding was done manually on the right-hand side margin of printed transcripts. Analysis may be 'data-driven' or 'theory-driven', and the coding procedure will depend on this. As there is little research on stigma

experienced by seropositive gay men in Norway, a 'data-driven' approach was chosen, meaning that codes and themes were based on the data, not on previous research or theory. Because the transcripts contained data not directly relevant to the research question, coding was only done on parts of the transcriptions that were in some way related to hiv and hiv-related stigma. When coding was done, all extracts were sorted by code in a separate word document.

Stage 3: Searching for themes: Codes were grouped together to form themes. This was done by using small pieces of paper with code-names that were grouped together by apparent belongingness.

Stage 4: Reviewing themes: After generating themes based on codes, the themes were compared with the coded extracts and the original transcripts. Based on this, additional extracts were added to themes, some themes were divided or put together, or otherwise rearranged.

Stage 5: Defining and naming themes: In this stage attempts were made to define and refine the scope of each theme. Themes were named based on content.

Stage 6: Producing the report: This is considered the last section of analysis, where themes are written in the report. Explanatory extracts were selected to demonstrate the results. Because of the difference between spoken and written language, extracts included in the dissertation were edited for readability (see Transcription and the use of extracts).

Ethical Considerations

In all research, researchers and research institutions are obligated to ensure that their research is good, liable and ethical (The Norwegian National Research Ethics Committees, 2010), and maintaining ethically consistent research should be a consideration throughout the research process. Some ethical considerations were particularity relevant for this project.

Because of the sensitivity of the topic, and the potential vulnerability among participants, it has been particularly important to minimize potential strains on participants as resulting from participating in the study. Great effort has been made to ensure a high ethical standard throughout the entirety of the project, and to ensure that the product is presented in a manner that does not cast a negative light on the participants.

Because of the potential vulnerability of the target group, additional measures were taken to ensure that no one felt pressured to participate. Participants were given information from a third party, and had to contact the researcher themselves to sign up for the study (read Participants and the recruiting process). In this way, participants were allowed time to consider whether they wished to participate before making contact. Efforts were made to prepare for potential issues that could arise during or after data collection, to be able to maintain a safe

environment and take care of the participants as well as possible. Participants were informed about their right to stop the interview, and that they had the right to refrain from answering any question.

In studies relying on participants as sources of data, fully informed consent is crucial for ethical reasons (The Norwegian National Research Ethics Committees, 2010). Participants were therefore informed about the study before the interview. Information was provided two times in written form, first in the recruitment letter (see appendix B) and then in the information letter (see appendix C), and then one time in verbal form when receiving the information letter. Participants were ensured that the data would be anonymised and that they could withdraw from the study at any time (before, during or after the interview) without providing a reason for the withdrawal. Participants were encouraged to ask questions, if they had any, both before and after the interview. Additionally, they were provided with the contact information of both researcher and the project supervisor, and were prompted to make contact for any reason at all. None of the participants made contact after interviews.

To protect the participant's anonymity, their talk was anonymized, and personal information and highly specific utterances were either changed or excluded in the transcription. Data and consent forms were stored and locked away separately. Data was either stored in a safe or on a password-protected memory stick.

The study has been ethically evaluated and approved by the University of Oslo's Department of Psychology's internal research ethics committee (see appendix D) and the Data Protection Official for Research (NSD; see appendix E).

Results and discussion

Setting the Stage

The narratives provided by the participants showed great variety and high contrasts between experiences. We therefore want to set the stage by presenting two highly contrasting narratives given by the participants.

> *"I thought the world had progressed further, to put it mildly. So it ended up with the shutters shutting completely and actually ended with an overdose. I had lost everything I had worked so hard for, and decided that enough is enough. I went through every drawer and cupboard and found what I had of pain killers and what-not. Around four or five (in the morning), I took all the pills and swallowed, and it was the best feeling I've ever felt. Now I'm calm. Set free. I believe it was the easiest decision I think I've ever made. Because everything was just black. I didn't see any other way out. It was like it wasn't even a decision. There was no other way. Yeah, the shutters were shut completely. There weren't really thoughts of any other alternative. It was like, yeah, you're just sitting there and can't get rid of it, and it has only gone against me over and over, be it in love or now also at work, and so on. My career is now over, and so on. There's no way out now. Or. There was just one way out." (Liam)*

"... Experiencing that someone does not reject you as something poisonous, that sets the stage for how you experience it. So I had good experiences with being open from week one. It certainly isn't the opposite, in the way that hiv has created worries. Immediately, it was of course an element, but it got eliminated quite quickly by me having good experiences with being open. Like, I was thirty-something when I became hiv-positive, and when I was in my mid-thirties, I met a 24 year old guy whom I started dating, and who had studied psychology. And that experience of such an amazing, young and intelligent and oriented guy that didn't see my being hiv-positive as a problem. It kinda puts it all to shame in a way." (Sam)

The following chapters contain the results of the analysis and discussion of the findings. Through TA, five themes were identified as being related to how it is for GMLH to live with a stigmatised diagnosis. These themes were: 'Encountered stigma', 'Living with a Secret' 'Self-Perception' and 'A Sense of Responsibility'. In this section, these themes will be discussed.

Encountered Stigma

To better understand the concept of hiv-related stigma, we need to look at how and where this stigma occurs, what is experienced as good encounters and what is perceived as stigmatising. Today, hiv is not a visual or otherwise evident attribute, so for others to know about an individual's stigma, it must be disclosed. Participants provided descriptions of a wide range of experiences regarding others' reactions towards being exposed to information about their diagnosis. The findings will be discussed based on the type of relationship the participant had to the informed. Based on the participant's responses, the recipients of exposure have been divided into the following categories: family/friends, the public sphere, and the gay community. The public sphere is divided into strangers and encounters in professional settings, discussing encountered stigma at the work place and within the health care system. Additional social categories might have been included, such as school/academic networks, social services, etc., if questions about stigmatisation in specific contexts had been included in the interviews. The categories are based on the narratives of the participants. However, it is not suggested that these are the only contexts in which GMLH might encounter hiv-related stigmatisation.

Family and friends. The exposure to family, intimate partners and friends, collectively called intimates, seemed to be of great importance to most of the participants. According to the belongingness theory proposed by Baumeister and Leary (1995), a sense of belongingness is a fundamental innate human motivation, where human beings have an evolutionary drive to form and maintain interpersonal relationships that are positive in nature and where there is perceived mutual care for one another's wellbeing. Whereas the formation of social bonds is associated with positive emotions, dissolution of interpersonal relationships is defined as a primary source of negative emotions. Possibilities of losing one's relationship with important others create anxiety, and increased physiological arousal can even be seen when social rejection is imagined. Deficits in belongingness appear to have adverse effects, where both physical and psychological

issues are common among those lacking attachments to others (ibid.). Reactions from intimates may for this reason raise the most concern when it comes to exposure of stigmatisation.

Even though, when compared to strangers, families may be less likely to be put off by potentially stigmatising visual traits, it has been found that when an individual is discreditable (the attribute is not evident), their intimates may, like the stranger, be put off by the stigma (Goffman, 1963). Many participants, often described their intimates as those hardest to expose their diagnosis to:

> *"... it was decidedly hardest to tell my parents. It may be that it's the ones you care the most about (that are the hardest to tell). And as such, their reactions are also the most important. And friends are the family we choose for ourselves." (James)*

The majority of the participants described predominantly positive experiences of other's reactions to their diagnosis. James, reported being in a discordant relationship with his partner, meaning that they are of different serostatus. James' partner, family and friends all knew about his diagnosis, and he described positive experiences of telling his friends about his diagnosis.

> *"And then I have close friends. For example, one, yes, three or four that quickly comes to mind, that have handled it fine. Where it hasn't been an issue at all. They've only been concerned with me. 'How are you?', and 'Are you all right?' and 'Is there anything we can do', and so on. So, I've had many that have handled it in a very good way." (James)*

Most participants had similar experiences when exposing their diagnosis to intimates. Some of the factors that were often described when the participants described reactions as good were when the informed showed interest in their wellbeing and where they were not treated differently based on their diagnosis. Exposing the diagnosis may also result in positive consequences such as social support from close ones. All participants reported one or more negative experiences, whether it be from friends, family, work, sex partners or in the health care system. The extent of negative experiences varied. As will be demonstrated, James experienced the reactions from his family as being very different from the reactions from his friends.

> "One interesting reaction was my family. It hasn't been too many years since I told them about the hiv diagnosis. One of the very early things they asked about (was) 'What about Matthew? But what about your husband? Is he also infected?'. 'No', I said. 'He's not infected, so he's hiv-negative'. 'Really? Did he know about it when you first started dating and when you got married and everything?'. 'Yes', I said. '(He) knew from the very first day we met'. And then they said 'wow', they said. 'Wow we take our hats off for him', they said. And I've thought a lot about this afterwards. There was no one that took their hat off for me. They took their hats off for him. It really was quite revealing. About what kind of attitudes they have towards that kind of diagnosis. So I think they revealed themselves quite a bit at that point. (Laughs). In that way, at least. Imagine that he would want to be with me. Imagine that he would want to marry me then, when he knew I was infected. So that's something (I have) thought about a lot afterwards. And it's actually somewhat painful. I have no problem with understanding that reaction, or understand the thought. So, of course he deserves praise for dealing with it in a way that has also made me never feel contagious. So he deserves praise. But I think, they could have taken their hats off for the way I've handled it. And that's something they haven't said a word about. So, I think there you go. It's pretty obvious. And I don't think my family is particularly special. So I think it's a pretty normal attitude, I think." (James)

The main difference between the reactions received from James' friends and his family may be traced back to senses of value. Whereas his friends showed concern about *him*, his family displayed greater concern for his partner, emphasising the perceived gap in value between the two partners based on their serostatus. What may have been perceived by his family as being supportive, was perceived by James as signifying their altered perspective of him as an ILH. According to Goffman's (1963) stigma theory, the stigmatised is per definition perceived as less human. Additionally, the individual with a stigma is perceived by others as representing danger, and these perceptions of the stigmatised sometimes help rationalise and justify one's own discriminatory and stigmatising behaviour against the stigmatised (ibid.). What this perceived danger is related to may vary, and may include a fear of transmission or other physical threats, social consequences of socialising with the individual, personal discomfort, or other perceived threats related to the stigma. The perceived danger does not have to mirror reality, but is a way to justify stigmatisation towards the stigmatised.

However, how experiences with exposure are perceived is not merely black and white. In some cases, even rejection may not be considered a particularly negative reaction. Oliver emphasised the importance of accepting that people will have different reactions to the diagnosis, and to show understanding for others' need for time to process the news.

> *"It wasn't fear, but she said that she would have to consider this. (And then) I thought 'It's very honest when you come out as gay or as hiv-positive'. I used many, many years to gather the courage to say that I was gay. And I used many more years gathering courage to say to most people that I'm hiv-positive or living with hiv. So, I can't expect that you immediately drop everything and say 'Yay! That's great!'. Some will have a grieving reaction. Some will be shocked. Some may find it difficult. You have to give them time for that." (Oliver)*

On the other hand, even attempted displays of acceptance may go too far. Oliver described some people being so concerned about being accepting, that his personal space was neglected. Oliver had experienced this from a physician and from family members.

> *"I've been lucky. I haven't met anyone who have shunned me because I live with hiv. I mean, in my family it was almost gross, because everyone started licking my plate and my fork and my glass to show that they weren't afraid of it. I mean, it was really aggravating. Tell me it's completely fine." (Oliver)*

Reactions from intimates in the context of disclosure has now been discussed. However, there are more areas in which exposure of the diagnosis may affect the individual, despite an absence of a sense of belongingness. The next section will discuss exposure in the public sphere.

Public sphere. The Public Sphere consists of many levels, structures, institutions and so on. In this dissertation, the public sphere is divided into three parts: 'Strangers', 'Work', and the 'Health Care System', as these were the most discussed among the participants.

Strangers. The definition of strangers that is used here is the same as in the Oxford

Advanced Learner's Dictionary: 'a person that you do not know' (Hornby, 2005). Moreover, only encounters with strangers outside of work environments, the health care system and the gay community are discussed in this section, as individuals encountered in those settings are discussed separately. The participants talk little about their experiences with stigmatisation from total strangers outside of these settings, compared with individuals of greater personal value. It is unclear whether this is due to lower levels of experienced stigma from this social group or that participants talk less about it because these encounters generally have a smaller effect on them. It is also evident that the invisibility of hiv will prevent hiv stigma from happening with strangers, unless the diagnosis is somehow exposed. Whereas the belongingness theory proposes an inner drive to maintain close relationships, there is normally an absence of a close relationship with strangers to uphold. Therefore, the same concern for maintenance is not as present in encounters with strangers. However, it has been shown that under some conditions, strangers' opinions and feedback can still affect us.

One area of research investigating how strangers' opinions may affect others is found on trolling and cyber-bullying. Trolling is instances where individuals, often anonymously, leave provocative and offensive comments online to deliberately cause conflict amongst other readers, for no apparent purpose (Bishop, 2014; Buckels, Trapnell & Paulhus, 2014; Hopkinson, 2013; Fichman & Sanfilippo, 2015). Trolling may be distinguished from cyberbullying by its pointlessness, as cyberbullying often has a more obvious intent of abuse towards a victim (Buckels et al., 2014; Sengupta & Chaudhuri, 2010). The participants described the internet as one of the arenas where they can experience much stigma. Sam said this about encounters online:

> *"And so online you can experience rabid reactions. But I haven't really experienced that face-to-face in any big way. It almost revolves around, no, not entirely, but mainly about anonymous profiles, and people who don't stand up for who they are." (Sam)*

It was sometimes unclear in what context online stigma was experienced. Several participants had profiles on dating-sites in which their diagnosis was publicly exposed by choice, and it is unclear whether the stigma they experienced online was predominantly experienced in these contexts or on other online arenas.

Even though participants generally did not discuss many face-to-face encounters with strangers, some participants talked about this specifically. Jacob experienced an encounter with a stranger, where the stranger reacted belligerently when Jacob spoke with a friend on the phone about medical struggles related to his diagnosis. This encounter left its mark.

> *"And then there's another one on the bus who says that I have to be quiet and that I have to lower my volume. And I got a knot in my stomach, sort of an unpleasant feeling, and I asked him after I had hung*

up what he got upset about. Was it me talking loudly or was it what I was speaking about that was the problem? And then he said it was both. And meant that I had disgraced myself when I talked about private matters like that in a public space or 'on a bus where people can hear you and stuff'. And then I tried explaining to him that me having hiv is not a private matter to me, it's only a fact, nothing more. And I talked about my medicine. I didn't talk about anyone. I talked about my medicine. And he compared talking about hiv like describing the consistency of your faeces, and that he didn't think one should talk about any medical diagnosis at all in public. If I had talked about my insulin I don't think I would've had the same (laughs) reaction I imagine. And that feeling that (he) succeeded giving me, that feeling was something I hadn't felt in very long. And it is also something I've been through by being gay. That only in and of itself, or a part of one self, is provocative by itself. And that it is he that sets the agenda for what kind of stuff that is for me." (Jacob)

It is clear that stigmatisation from strangers can also have an impact on the stigmatised even when a future relationship is out of the question. Next, we will discuss the participants' encounters in professional settings.

Professional settings. Experiences described by participants from professional settings mostly involved encounters that were either work-related or related to meetings with the health care system. Typically, both environments involve expectations of some level of professionalism compared to encounters with individuals outside professional settings.

Work. At the time of the study, the participants were either working full-time, part-time, or were temporarily off work, which means all were either presently working or looking for work. Everyone diagnosed with hiv are protected by the Norwegian Anti-Discrimination and Accessibility Act, which states that it is illegal to discriminate or harass those living with a disability (The Norwegian Anti-Discrimination and Accessibility Act, 2013). It states that discrimination is illegal differential treatment where an individual is treated worse or ends up in a lesser position than others because of their disability. Differential treatment is only legal when it serves a practical purpose, is necessary for that purpose and is intended and suited to uphold the purpose of the law. Employers are therefore bound by Norwegian law to ensure equality for those living with hiv. Some participants reported being open about their diagnosis at their present work place, while others had not told their superior or colleagues about their diagnosis. Several of the participants were involved in hiv-related work at the time of the interviews. One of the participants, Barry, had been working with hiv-related work for years, and did not believe that his diagnosis affected his work situation.

> *"I mean, when it comes to work it's never been an issue, so to say. Again, you don't know when you apply for a new job if, I mean, are you put away because they think 'Oh no, we don't want a chronic working with us', or that 'It may be unpleasant. Here we work with people'? Not that there's supposed to be any risk of infection, but it is kind of like keeping up appearances in that those who are doing the hiring have probably googled and seen what you've said and done previously. So it could be something, but anyway, when they talk in interviews and in prior jobs that I've had, it's never been a subject that's been a problem." (Barry)*

Unfortunately, not all participants had the same experience. Liam, a prior salesman on his way up the ladder, experienced that his diagnosis resulted in severe consequences.

> *"So, I was just called in to my boss five minutes before I'm heading off to a department meeting, and I'm informed that I'm losing my position as leader, because she didn't see any future considering I had the illness I had. And then my world fell apart." (Liam)*

There is very little Norwegian research on discrimination in the work place among ILH. A report on ILH's living conditions and attitudes (Grønningsæter et al., 2009), showed that 66% of the respondents had not told anyone at their work place about their diagnosis, and interviews illustrated both negative and positive experiences following disclosure at work, but with more negative than positive experiences. A total of 79 out of 96 of the study's respondents reported not disclosing at work because they saw it as a private matter, but a common reason for not disclosing was also being afraid of negative consequences, such as losing their job, social exclusion or reduced career opportunities. A more recent study of people's attitudes towards ILH in the work place shows that 70% did not perceive it particularly dangerous to work with a colleague living with hiv, where 50% would take some precaution in relation to physical contact. About 24% rated it not likely or not at all likely that they would react by thinking that it's not that dangerous if they were to learn that a colleague had hiv (TNS, 2015). Even though these numbers show that a clear majority perceives working with ILH as unproblematic, the work place is still an arena where stigmatisation can be likely to occur. Despite seemingly predominantly positive attitudes towards ILH, only 21 % thought ILH were suitable for all jobs, with almost 1 in 4 people believing it problematic for ILH to work as nurses.

The health care system. All participants had some level of contact with the health system, as MSM living with hiv are advised to attend check-ups every 3rd to 6th months (The Norwegian Medical Association, 2016). It is important to note here that the participants predominantly seemed satisfied with the treatment received from health care professionals. Health care settings do here include settings where participants as patients receive health-related services for one of the following purposes: physical health, mental health or dental care.

> *"But for me personally, I've always been really lucky, and great follow-up, and I've had all the help I've needed. I have absolutely nothing to complain about." (Liam)*

While most participants had similar reports, some participants were unsatisfied with aspects of their treatment in the health care system. Some of the factors mentioned when describing negative experiences with health care professionals were being treated differently than other patients, being asked invasive and unrelated questions, top-down attitudes from general practitioners (GPs), not being given important information regarding treatment, nervous

and anxious health care workers, exaggerated acceptance (resulting in invasion of privacy), little psychological follow-up, and in other ways showing an incapability to act on the patient's needs. The two following examples show two different cases of what may be perceived as unfortunate encounters. Jacob, who was very young at the time of his diagnosis, described his meeting with health care workers when receiving the diagnosis:

> *"It was perceived like it was really good treatment at that point, (but) later there's like this bitter taste in your mouth when you later just, 'Wow, the treatment wasn't really that good'. Because you are so grateful for what, no matter what you get of support in that kind of situation. So, you think later, 'Well, maybe not so good'. Because she asked me about 'But didn't you expect that x and x would yield positive results?'. (Then) I said, 'No, I absolutely did not'. Then 'No, but what I was thinking about was, with the amount of sexual partners you have had'. And she asked me if I'd had feelings for every person I've had sex with, which is completely irrelevant, (and) doesn't have anything to do with anything." (Jacob)*

Oliver, who had had the same dentist for years at the time of the diagnosis, remembered receiving threats when his dentist heard about his diagnosis:

> *"I'm afraid to call the dentist that I've always had in my family, so my mother calls and says 'we're just informing that Oliver has been informed that he is hiv-positive'. Then my mother calls me back and says 'she would like to call you'. So I say, 'How nice'. And I'm sure she would say 'how sad' or. But then she rails at me. That I've put her life, her husband's life, her kid's lives-. 'I'm in a car with children on my way home from hiv testing' and 'Have you infected them with hiv then I'm going to make your life hell! And these friends you've referred to me, are they also hiv-positive?'. I mean, I was devastated. This is a professional person that is supposed to take, what's it called, precautions, against all eventualities. 'I remember when you (had) wounds', she said, meaning I had wounds on my hand. I had cut myself. 'Well, I thought, I knew you were gay'. I mean she completely railed at me. I changed dentists and forced my entire family to change dentists as well." (Oliver)*

Looking at Norwegian statistics, 74% are rating their treatment at hospitals as somewhat satisfactory or very satisfactory, while 79% say the same for out-patient clinics. Only about 5% rate their treatment at hospitals as somewhat or very dissatisfactory, both in hospitals and out-patient clinics. This suggests that the treatment of ILH can be considered good in hospitals and clinics (Grønningsæter et al., 2009). The ratings were, however, much lower for treatment received from GPs, with 60% rating their treatment as satisfactory, and around 12% were dissatisfied with their treatment. The same statistics also show that patients are generally more dissatisfied with information received from GPs compared with information received at hospitals and clinics. It was speculated that the lower scores on treatment satisfaction in GP consultations resulted from their treatment being much more reliant on each physician's knowledge, understanding and experience with working with hiv, as compared to clinics that are specialised for dealing with ILH. At the same time, fewer health professionals say that they would be likely to take greater precautions around someone with hiv, compared with individuals from other sectors (TNS, 2016). This implies that there is less unreasonable fear of transmission among health professionals, compared to non-health professionals. Still, 33 percent said that they would.

Even though participants did give examples of negative treatment, most of the participants still considered their overall treatment from health care workers as satisfactory. Nevertheless, these narratives show that there is still room for improvement on how to meet and support those living with hiv.

The gay community. The gay community can be seen as part of the public sphere, but will be discussed separately for a number of reasons. The gay community is a social arena that is likely to be less available to their heterosexual peers, and has unique relevance to our group of interest. Other reasons for investigating this community separately are the distinctiveness of social norms and social scripts, and the relevance to gay men's dating opportunities.

The stigma situation in the gay community was described as being different than in the rest of society by the majority of the participants. Some experienced it as a divided community when it came to attitudes towards individuals living with hiv. Mark was one of the participants that explained this division:

> *"I feel that there are two groups there. Because there are many of those who are really ugly. And that is quite strange really when you think about that you are in that click of people who really should take care of each other the best, but don't. That is one of the things that amazes me the most, really. That gay men are the worst. I mean, the most evil-minded group I know towards the hiv-positive. And I just don't get it. How can they hear this thing, and then just regurgitate it further as if you don't get it. It can kill you socially depending on who you hang out with. And then there's the group that are well read and think that, 'Oh well, but it's fine'." (Mark)*

The internet and dating apps were important instruments for getting in contact with others for many of the participants. Gaysir seemed to be the most used dating site, and participants used it to find dates and sex-partners. This website makes it possible to easily report one's serostatus if desired, but also have closed groups for those living with hiv where their personal profiles are not visible. Such dating sites are also an arena that can make one vulnerable for negative reactions from other MSM. Liam explains:

> *"Well, you see those debates on Gaysir for example. So, those who are not hiv-positive. It's kind of like those who have hiv have the plague and should be put on a deserted island. And that is probably because they feel that it is so close and threatening. If they have unprotected sex then they can contract it. I mean, a lot of the things that are written there is pretty bad and it's quite narrow minded and downright ugly. And all of this is kind of coming from your own people. And like, if I have been on a date and stuff, and they didn't know that coming in in a way, then I've been shunned pretty much every time. They back off even if we know today that you can't be infected etc. If you're undergoing successful treatment and stuff. Most people can't handle it." (Liam)*

While some experienced no difference in attitudes between the gay community and the rest of society, most defined the gay community as where they meet most stigmatisation. That the stigma against seropositive gay men is experienced as worse among their own may be seen as a paradox, especially since this particular group is of increased risk of being transmitted by

hiv. James talked about this paradox and what he believed to be the reason behind the stronger sense of stigma in the gay community.

> *"I think I've felt that often in the gay community hiv-positives have been badly handled. And maybe even more stigmatised than on the outside. And it's kind of like a paradox. One should think that there you would be greeted with open arms and understood and stuff, so I'm thinking that thaaaat's. It's been some negative things around it. And I think that maybe it's got something to do with gays living more with a kind of threat surrounding that transmission. Because it is overrepresented in our community. So, it is this kind of threat that you live with all the time. And I think that when you suddenly stand in front of someone hiv-positive, then suddenly the virus gets so close, and so alive, so seems more real. Personified. And then I think that a lot of people back off, because it's simply too uncomfortable. The threat that in a way's just there and up there floating, it gets so near and so real and so dangerous when it's right there in front of you. Especially if I'm in a setting where you might wanna think about having sex." (James)*

MSM generally have more knowledge about hiv, and has been a target group of campaigns for hiv prevention due to increased risk of transmission (The Ministries, 2009; The Ministry of Health and Care Services, 1999). With more knowledge and being of greater risk of getting hiv, it might seem likely that the gay community may be particularly suited to positively meet those living with hiv. However, previous research has also shown that GMLH experience challenges in this community (Berg & Ross, 2014; Chong et al., 2017). A study showed that American GMLH experienced most stigma in gay communities (Berg & Ross, 2014). The Norway gay community has also been described as both including and judiciary. (Fangen, Grønningsæter, Lorentzen & Øverås, 2002; Grønningsæter et al., 2009). The gay community has been categorised as being demanding through expectations of overall success, through expectations of intelligence, good looks, good economy, and so on. Hiv may therefore interfere with the high expectations of an impeccable façade (Grønningsæter et al., 2009).

What is important to take away about the encountered stigma experienced by GMLH, is that they may have different encounters of stigmatisation, and that stigmatisation may be experienced in a wide range of social contexts where the diagnosis is disclosed. While some participants described their lives as heavily influenced by stigmatisation, others seemed to have been spared from such incidences. However, as long as there is an actual or perceived risk of stigmatisation, a fear of stigmatisation may consequently have great influence on ILH's lives and choices, one of which is whether to tell others that they are living with hiv.

Living with a Secret

When a person's stigma is not immediately apparent and unknown to others, the challenge of the discreditable is not to manage tension during social interactions, but to manage the information of his differentness (Goffman, 1963). Through information management, the individual in question will reflect on questions such as whether to disclose the information, whether to lie, who to tell, and how, when and where to disclose their differentness. This theme

investigates participants' talk on: 1. the closet-metaphor used to describe the secrecy of living with a hidden differentness, 2. the emotional implications of living with a secret, and 3. the decision-making process on whether to tell others about ones' differentness.

A central concept in this theme is disclosure, which is believed to have relevance to stigma (de Vries, Koppen, Lopez & Foppen, 2016; Li, Chen & Yu, 2016). Disclosure may be voluntary by self-disclosure (where the ILH tell others about the diagnosis himself), involuntary (where others, who are aware of the serostatus of the ILH, disclose this information without the permission of the ILH) or mandatory (relevant in some countries) (Greeff et al., 2008). The primary focus of this discussion is self-disclosure, and is in this context restricted to selectively revealed disclosure of personal information that is revealed only under certain circumstances and is done by verbal communication (Goodstein & Reinecker, 1974; in Chelune et al., 1979). The personal information revealed in this context is being someone living with hiv.

The two closets. Growing up gay had influenced the experience of being diagnosed with hiv for many participants. Participants compared this event with being thrown back into a second closet. This refers to the first closet as the gay closet that often is used as a metaphor for non-heterosexuals wanting their sexual orientation to remain a secret, but the closet metaphor may also be used to describe individuals who want to keep some other fact than their sexual orientation secret (Hornby, 2005). Whether the participants saw themselves as having gone through this process or not, the participants referred to coming out of the closet as a gradual process, as opposed to a onetime event. *"Coming out is a long process, so the first person I came out to was a friend when I was eleven I think. And since then it's been a process"*, Jacob explained. Thus, the processes associated with the closet metaphor is regarded here as the period in which one deals with information management of a personal stigma, or is somehow not open about this personal information towards other persons they would have revealed the information to, if it was not for the disadvantageous nature of the differentness. Some participants said that they do not tell *everyone* they meet about their diagnosis, but would mention it without problem when appropriate. These individuals would be considered out of the closet, when they do no longer engage in information management to keep their information secret.

As both homosexuality and hiv may be regarded as stigmas, many will refrain from telling others about this personal information, due to consequences that could occur from disclosing such information. Keeping their diagnosis secret makes it possible to avoid stigmatisation, and may contribute to maintaining a sense of privacy and normality (Herek, 2002). However, keeping a secret of personal significance can be stressful, and disrupting

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relationships and avoiding others may be deemed necessary to avoid disclosure, resulting in less social support. For many, the recurrent position of being closeted may be experienced as a setback, where they have to re-experience the concerns related to living with a stigma. *"It's kind of like coming out of the closet one more time"*, James said. *"You've first gone through that gay closet and come out of it and it landed quite well, and was kind of done with it. And then I go through the same process again"*.

Liam also described it as a great setback: "*You get tired of living a double life. Finally you have come out of the closet, and then you end up in a vault instead. It's kind of hard when you've lived all your life and finally come out, and then you kind of end up in something worse"*.

The closet metaphor has been found in other studies as well. In an American study, they found that most participants referred to their diagnosis as a second closet (Berg & Ross, 2014). Maybe because of the similarity between living in the two closets, participants seemed to agree that experiences from being gay can have an influence on the experiences of living with hiv.

> *"Well, as a gay man, I believe you have a kind of existential experience of having hit the wall regarding central expectations towards life, which is very transferrable. Coming out as gay. Coming out as hiv-positive was quite, as I've said, transferrable." (Sam)*

Perhaps therefore, it may not be surprising that experiences from disclosing their sexual orientation might also have influenced their decision-making on disclosure. For instance, bad experiences of disclosure may prolong the process of coming out.

> *"I think the reason that it took so many years for me to tell them (my parents) was that it was fresh in my mind how telling them about my homosexuality had been. I remember that they took it so badly, and it was terrible and it was so sad, and there was no end to it. So, I think it's affected my decision when it comes to telling about the diagnosis. So, that was clearly the hardest… Telling my parents." (James)*

Despite potential setbacks of another stigma, some participants describe the gay closet as contributing with useful tools and experiences that have strengthened their capacity to overcome new challenges. This, either by being an experience that have prepared them for future hardships in general, or because of the similarity of the two processes. Jacob explains how the gay closet has helped him with his new stigma:

> *"It is the baggage that I carry. Hard times that's been. So I kind of thought that it felt like I was prepared, even if that sounds funny, for getting hiv. When you get hiv, it's totally crucial what kind of baggage you carry with you, and where you are in life. What experiences you have from before, if you've experienced hardships before, how you've handled it and stuff. You've already gained some tools. So I had that already from before. So I knew already then that I'd want to be totally open about being hiv-positive." (Jacob)*

Posttraumatic growth may happen after traumatic events through understanding one's own reactions, tolerating one's own feelings, a sense of control, and available resources (Stige, 2016). It is possible that this personal growth can be transferred to new potentially traumatising events, which may help GMLH to better handle their new situation, due to previously having

gone through the same kind of struggles. Homosexuals tend to be more open about their diagnosis than heterosexuals (Grønningsæter et al., 2009). A possible reason may be that they are influenced by previous experiences of being closeted. Homosexual ILWH also tend to consult psychologists more often than their heterosexual peers (Grønningsæter et al., 2009).

Living a double life. If wanting a stigma to remain hidden, the discreditable must engage in sustained information management, which often includes morally disreputable actions, such as cover-ups and lies. Even though secrecy can be a protective measure against experienced stigmatisation (because it makes the differentness apparent to others), secrecy may by itself be experienced as a burden. From the participants' narratives, it is clear that both the fear of being exposed and the active attempt to hide their differentness can be exhausting burdens for those carrying such a secret. Oliver's narrative portrays how the fear of being exposed may foster self-destructive behaviour. He went to great length to prevent what he believed could portray signs of hiv, and thus unveil his secret:

"I know how people look like that used medications in the 80's. They look different. I was scared to death in the beginning of ending up looking like that. That's why I didn't want to use medications either. The medications we have today don't have those kinds of side effects, where the subcutaneous fat and everything melts away. I started forcing myself to eat. Because I thought 'I can't look ill, I can't look ill, I can't'. So I gained a lot of weight. It didn't look good and it wasn't healthy. It took many years before I dared to lose weight. Had to be thick. Because then I didn't look like that." (Oliver)

There are many reasons for ILH to not disclose their serostatus, typically linked to the negative consequences they may face if the diagnosis is to be known by others. Reasons may be fear of stigmatisation and discrimination, fear of disruption of close relationships, protecting others or protecting oneself from undesirable emotional implications, loss of privacy, or other undesired changes (Greeff, 2013, p.85). Nevertheless, several participants described living with a secret as burdensome or exhausting. "*I've been carrying this for a long time. And it's also a burden to carry around, you know. It is. So it's wearing us down"*, James says.

Liam also described how the secrecy has affected him: "*I am tired of walking around keeping things hidden and hushing things down and come with excuses and stupid explanation and stuff all the time because of this hiv and everything. It's exhausting"*.

Non-disclosure has been linked to a number of psychological limitations, such as shame, doubt, worry, fear, futility, anxiety, depression, anger and hurt (Greeff, 2013, p. 87; Grønningsæter et al., 2009). It is therefore clear that, although non-disclosure may be a protective measure against potential negative consequences, non-disclosure is also likely to be accompanied by negative emotional implications of keeping a secret. Therefore, many will argue that the psychological implications of keeping it secret may be harder to carry than facing

potential consequences of disclosure. Still, it is important to consider that disclosure may not always be most beneficial in all circumstances. A contrast to stories showing the burdensome nature of a double life, was those describing their secret as creating little to no personal concern. *"Things like that are very private. And I choose myself who I wanna tell who I tell. But I've chosen not to say anything at home. I think that will only cause pain and create concern. More concern than what is necessary. Because I live well with it"*, Caleb says about why he doesn't tell his parents about the diagnosis. At the far end of the scale is the perception of secrets as positive "addition" to life, here portrayed by these two participants:

> *"But I've kept it from my mom and those. I did that for quite a lot of years. And then it was a little like, it was still before I started my medications. So, it was a little like, ok, taking extra care when I went home on vacation. Pay attention to my toothbrush, pay attention to my razors, paying attention. Then I suddenly had to really engage in hiding it a little. It could be something that made me sad. And then it could be something that, well, almost actually was a little exciting. That was my own thing. Because I've always been so open about everything that's mine."* (Adam)

> *"I think all people should have a secret that they keep for themselves. I believe it gives a nuance in life… That you also can take with you. It doesn't have to be something negative. Why the hell does everyone need to know everything about anyone? … Ridiculous. It's naïve and narrow minded, if you're gonna say it in a subjective way. It's foolishness. It's foolishness. It's not necessary that everyone knows everything about anyone. (ahem). And I think it can be good to have something you don't tell everyone."* (William)

There seems to be very little research on potential positive aspects of living with secrets or what characterises those who hold these perceptions. This has potential for interesting future research. Some participants paint a picture of being little affected by living with secrets, whereas others describe great relief after sharing their burden. A clear example of this was provided by Oliver, who portrayed great relief from sharing his experiences with others:

> *"I'd made up my mind then. Out, and then I'm gonna say it. I cried a lot then. A little from the relief of finally daring to say it. More and more letting go from carrying it on my own and the fear. Carry something that is so difficult is fucking hard. And then I was asked to join as a peer at the hospital, where they've got a coping course for the newly diagnosed. I said yes to it then. It took me a step further towards letting go of the control. Then I've held some lectures for students, and it's really the biggest high I've ever had, where I was standing in front of a hundred faces as myself. Saying my name and 'I'm living with hiv, and today you'll get to hear my story'. I was high for three days, and then I slept for two. Because I didn't sleep. I was all, I mean, I thought it was so fantastic to let it go. Ah, finally gone."* (Oliver)

In a Dutch study, 70% of respondents reported feeling stronger after telling others about their diagnosis. This was in turn positively correlated with the employers considerations in relation to their health and participating in activist work (de Vries et al., 2016), both of which depends on some level of disclosure. This shows the influence of both disclosure and having the opportunity to participate in related work. Feeling stronger, facilitation and participation in hiv-related work are just some reasons to disclose. Other reasons being developing or improving close relationships, receive understanding, social support, feelings of moral obligation, change others' perceptions, or to fulfilling personal needs. (Greeff, 2013, p. 85; de Vries et al., 2016).

As described by Oliver, the emotional implications of disclosure may be substantially positive for ILH. While non-disclosure can prevent stigmatisation and discrimination, disclosure is viewed as the only way to receive social support for hiv-related challenges they may encounter. ILH must therefore risk stigmatisation to gain social support for dealing with stigmatising reactions (Stutterheim et al., 2011). In a report on Norwegian ILH (Grønningsæter et al., 2009), almost half of the respondents reported feelings of isolation. With the knowledge of the necessity of disclosure for social support, it may not be surprising that disclosure is linked to increased quality of life, compared to individuals who have not disclosed their diagnosis. Disclosure is also an important part of demystifying the diagnosis in the community. ILH have therefore been encouraged to disclose as a preventative measure against stigmatisation in the community, because it has been shown both in international and national studies that hiv-related knowledge or knowing someone living with hiv predicts less prejudice against ILH (TNS, 2015; Zefi, 2013). With the complexity of disclosure and the seriousness of potential personal consequences resulting from their choices, it is important that ILH themselves are free to consider and choose their own strategies of openness. We will further discuss the process of disclosure, and how the participants of this study have chosen to deal with this issue.

The process of disclosing one's secret. All participants in this study reported some level of openness. All had therefore disclosed their diagnosis to *someone*. The level of outness differed greatly between the participants, ranging from only having disclosed their diagnosis to a couple of people to identifying themselves as ILH in the media. It should be stated here, that this study is less likely to entice individuals who want to remain hidden, and the represented outness of the participants in this study is therefore not likely to be representative for the general population of GMLH. Nevertheless, the participants' narratives reveal that their pace and process of reaching their current level of openness at the time of the interviews differed greatly. One such contrast may be perceived by investigating the narratives of Jacob and Oliver. Jacob said he already knew that he wanted to be open about his diagnosis when he was diagnosed.

> *"It's all those experiences that makes you reflect on how you want to live your life. And also this about freedom. How very important it is for me to feel free. I didn't want into another hiv closet, and knew how it had been earlier in my life, and that that was not any alternative or something that I wanted." (Jacob)*

In contrast, Oliver, who kept his diagnosis a secret for years, did not want to tell anyone about his diagnosis out of fear of potential costs of doing so. He was ready to risk his own health by not telling anyone about his suspicions of having contracted hiv, despite declining health.

> *"So I got ill in 2010. I started getting some discomfort in my legs, but didn't dare then to tell people that I thought it was hiv that now was making its move. I had lived with it for many years then. It got worse and worse, and in the end I wasn't able to walk any longer. Then I was in and out of hospital for months,*

assessing for MS, cancer, tumours. I mean, they looked for everything. Then I got really scared, so I hit the wall hard, and I ended up at a mental institution. Was hospitalized there for a while. During my stay, I went back and forth to the hospital. And then they suddenly said 'you know what. We'll take an hiv test too'... Then, well, then they had to move me from the open to the closed ward, because I thought 'Now they'll all get to know about it. Everyone will disown me. Everyone will disown me." (Oliver)

A Norwegian report has indicated that 55 % had told someone about their diagnosis just after learning about their seropositive status, and 80% had told someone within a year. Only 8% did not tell anyone within the first 5 years (Grønningsæter et al., 2009). Even though the study is not regarded as representative for the Norwegian population of GMLH, it indicates that ILH are likely to disclose their serostatus to someone, enabling them to receive social support. However, it also shows that ILH often disclose to a limited number of individuals, as 61% reported having told 0 to 10 individuals about their diagnosis.

It may also be worth considering the non-linear nature of coming out of the closet, as some participants described becoming more aware of whom to tell following a period of increased outness. Mark experienced that he lost control over the information, where the diagnosis was exposed to individuals he did not want to know about it, and did therefore make him more conscious about whom to tell:

"I've gone back and forth. First, for a while, I was very open. But because of that, people got to know who I didn't want to know. I actually met a boy that I really liked a lot. And then it was this girl who wasn't that nice to me. She was a little fond of gossip. So, she got drunk and then she told this gossip to him. And it wasn't right, because if I'm not able to say it myself, then you can't really go on dating, because then he gets scared away. And that's what happened." (Mark)

While James considered himself quite open towards most people, he had chosen not to tell about his diagnosis at his current work place, fearing that this may interfere with his chances of getting steady employment.

"I kind of had good practice in being open quite early, because I moved to France to a new environment, where no one knew me. So, then it was quite easy to be open. But then we moved back here. And I've told close friends and family about the diagnosis. I've been open at some places I've worked. I'm not open where I work now. So, there I haven't told anyone about the diagnosis. So I've actually gone a bit back into the closet, after having come back again. Yes, so I've become a little more careful about who I'm telling actually. So, in a way I've gone a little bit back into this hiv closet. Because I must think strategically. I must be careful so that it doesn't spoil my chances of getting a steady job and stuff like that. And that's a pity." (James)

The narrative by James shows that restrictions or decisions on disclosure in one's environment or situation may not be consistent with decisions of disclosure in other situations. As portrayed here, he described a retreat into the closet in work-situations, but considered himself out of the closet in other regards. Who the participants choose to disclose their diagnosis to is often a result of personal strategies or solutions to disclosure, which is also illustrated by Grønningsæter et al. (2009). One such solution, among others mentioned by Adam, was dealing with the diagnosis as any type of intimate information:

"Because I don't say it. Do you tell anyone that you've got gonorrhoea? (…) You don't say it. But if you did have gonorrhoea and you had to tell that you had gonorrhoea, then you wouldn't feel well about it. But you don't tell anyone. It's exactly the same thing. You can choose not to tell." (Adam)

Caleb described his solution to disclosure, and the reasons behind it:

"But some have chosen the same solution as I have. I'm actually quite open, but I'm gonna tell it myself. If you ask, you'll get an answer. And I don't have to tell, because as long as I don't die from it you don't have to know about it either. It just creates worries. For everyone else. For me there's no worries. And that's why I've chosen to do it this way. But it varies a lot. Some live completely openly." (Caleb)

The decision of whether to disclose may be based on a combination of such strategies, and the reasons behind their strategies may vary. Stigmatisation was described by the participants as one important reason for selective disclosure or non-disclosure. Adam positioned himself as sceptical towards disclosure, because you expose yourself to stigmatisation.

"Have you tried to ask someone out there what they think of hiv-positive people? Honestly. There must be something not quite right with you if you want to expose yourself to something like that[1]. It's not for me (laughs). I do know some people who stand forward as open. No. I'm not <u>that</u> much of a masochist. They don't meet any attitudes, because they can't see it when people back off. And then they become like 'what are they saying now?'. They're getting insecure. They're creating a situation where they themselves are the bad guys. And I don't think that's very smart." (Adam)

Similar utterances were observed in another study, where participants showed negative attitudes towards embracing hiv fully or raised questions when ILH chose openness when other options were available (Murphy, Hevey, O'Dea, Rahaille and Mulcahy, 2016). These participants often viewed those taking part in hiv-positive communities and who talked openly about their serostatus as deserving of stigmatisation and exclusion. The proposed reason given for these rejections of disclosure and embracement was a way to reject the possibility to be defined by hiv (ibid.). It is clear from the participants' narratives that finding a working strategy for disclosure is complicated, and there is a lot of considerations that needed to be considered. As said by Liam; *"I can't really seem to find the solution. There are limitations no matter how you try to look at it"*. Several participants portrayed that telling sex-partners may be considered as one of the biggest concerns when it comes to disclosing one's diagnosis (together with intimates). In addition to factors relevant to all telling-scenarios, there were additional worries and factors coming into play in dating-situations. This is Mark's reply when asked who he felt was the hardest to disclose to: *"It's hardest when you meet someone. Because you don't know when to say it. When is the right time? This thing about timing. I mean, everything about it is so damned difficult"*. Only a couple of participants said that they strived to always tell their sex-partners, while other participants said that they generally didn't tell or that it depended on

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[1] Loosely translated from the Norwegian idiom '<u>Det</u> er for spesielt interesserte'.

the situation or who they were with. As Liam said, one of the main considerations is timing. Oliver is one of the participants that brought this up during the interview:

> *"When are you gonna tell? Is it before intercourse? After? Is it just a one-night-stand? Am I gonna tell it then? We as hiv-positive talk a lot about this. And then it's like, 'if two months pass, then he might love me enough, so then it will be OK', but if you say it in the beginning it's easier to say that you can't handle it. So, I can understand that. When is the right time? It's never the right time, and it's always the right time. There'll never be a right time to tell people about something difficult. I mean, you just have to make the decision. Now I'm gonna tell that person. Oh no, he'll have his birthday tomorrow. I can't ruin his birthday. It's never the right time. That's why it's always the right time. Because it'll be like this. It's a nice day, it's a bad day. There's an exam in two days. I mean (laughs). Just say it! If that's what you want!" (Oliver)*

The quality of the relationship seemed to affect both the disclosure process and disclosure outcomes in partners. Smith, Cook and Rohleder (2017) found that relationships that were rated as positive before disclosure predicted positive outcomes of disclosure, while relationships where the diagnosed did not feel psychologically safe or there was an authority difference between partners, the outcome tended to be negative. Meanwhile, trusting relationships tended to delay disclosure, and it was suggested that this was because they had more to lose by negative disclosure outcomes. However, disclosures in trustful relationships often increased emotional closeness, and in cases of breakups, the discloser was less likely to perceive this as the cause of the breakup. During casual sex, there may be less at stake than in romantic relationships. Still, the partner will often not have gotten the opportunity to create a sense of closeness, and may therefore increase the chance of a negative reaction. Jacob explained another reason why disclosure for sex-partners may be particularly complicated:

> *"But what is there to tell? I mean, I can tell you that I <u>have</u> hiv, but there's no danger to you. By that, I'm sending you the message that you have to say something before you have sex, and then they think something like 'yeah, but he's most likely telling me this because there's a reason. That there's some kind of risk that I'll get hiv'. First, you create that reaction, and the you've supposed to create the reaction that there's no risk. It's really strange." (Jacob)*

The complicated nature of the disclosure-situations towards sex- and dating partners in particular seems to potentially become a burden that can create worry and make an impact in GMLHs' intimate lives. Several participants described present or previous struggles due to additional worries related to this subject. Their uncertainty could often be imputed to their fear of negative consequences, such as rejection, no sex, killing the mood, losing control of the information (e.g. by gossip), being blamed by sex partners for not telling or putting them at risk, breaking perceived moral codes, and fear of being hurt. Some participants reported finding it harder to find love, less sex, and fewer instances where they have chosen to bring partners home after a night out, and related this to issues of disclosure and fear of stigmatisation.

> *"I don't think I'm as comfortable taking home whomever anymore. It's just that you open up for someone else. You become vulnerable, so to speak. Even more. But it's coming from that. So, I think I have less, or*

> *not less sex. Or yes, yes, I think I have less sex, but the situation is a little more difficult. I think this thing limits you. Or with hiv, I mean." (Mark)*

It is important to note that this description did not fit all participants, as some participants reported more sex and little worry regarding disclosure in such settings. Several participants also talked about the tendency of GMLH to seek out other seropositive sex partners, also called serosorting. Several participants reported relying on serosorting at some point after being diagnosed, but for many, this was only or a while. Serosorting is among others brought up in Liam's description of how his sexual life had changed after diagnosis:

> *"Well… I have in a way pulled away in a way. I never bring anyone home after a night out or anything or flirt with people I meet out or anything. If I'm gonna meet someone for sex, it's someone in the same situation, so to speak. I overlook feelings and stuff. And only have sex-meetings with some just to, well, it's safe, because they are in the same situation. So then you can avoid questions and so on." (Liam)*

Barry described how this 'trend' of serosorting may also introduce insecurities regarding the intention of other GMLH that makes an approach.

> *"I've also had people who have, well, simply made a move because I've got hiv and because they don't wanna share their diagnosis with others. So they choose someone they feel that they can share the diagnosis with or feel secure or something like that. Sometimes you get these thoughts, like, do you get picked out in that way too? Are you picked out by other hiv-positive people because you're hiv-positive yourself? Sometimes I feel that I get very provoked when someone contacts me about having sex with me just because I am hiv-positive and they are hiv-positive. Just like, 'noo'. And I'm like, 'yikes. Are you gonna limit yourself <u>that</u> much?' First, you're gay, and then you're gonna be out and open and then you're again gonna … look in an even smaller pond of people to have sex with. It's just like, 'it's not gonna work'. It doesn't make sense. So then you simply have to just 'no. This doesn't work'. You have to get out of it." (Barry)*

Even those living with partners acknowledged the complications of disclosure in sex- and dating situations, and having a partner was therefore described as a protective measure against having to deal with it.

> *"Often when they know stuff like that, people get afraid. I know that for a lot of people, especially people who are single and may be out trying to find partners and such. It's a huge problem. And this, when are you gonna tell? Are you gonna tell right away then you meet someone you like? Or are you supposed to wait and see? And it might be harder to say it the longer you wait. I've worked a lot with this question. and I know it's a huge topic. So, I feel that I've been very lucky actually. Because I met my husband this early after the transmission. In that way I feel that I've been quite lucky. I'm the one who's responsible for telling, you know. It's been a heavy burden to carry. Now I've been lucky in a way, since I found a partner that I wanted to marry quite early. I do have friends, also hiv-positive friends, who are single and who have been for many, many years. And I think that responsibility feels heavier then. Because I'm not dating any longer and stuff (laughs). I don't have that burden." (James)*

The perception of disclosure in the gay community as particularly complicated may not be surprising when many perceive the gay community to be particularly stigmatising towards ILH. Nevertheless, disclosure may also lead to positive outcomes. Like Jacob said; *"It can also be better, because it does really become more intimate and more sincere when it's about a matter like that, and it can become a very, very nice encounter"*. Several participants described how

disclosure can create trust within relationships. Barry talked about two other potential positive consequence of disclosing to potential sex-partners, namely an opportunity for familiarisation with the potential sex-partner's attitudes and prevention of future blame or drama:

"You get to see whether people have any thoughts about it themselves. If they actually reflect on what risk is, because it's very nice to know that people know what sexually transmitted infections are and how they can be transmitted. And that maybe they are conscious about testing and that they are conscious about being responsible for their own sexual health. And you often get to know these things if you say that you've got hiv. And it's also that I can relax then. Because then I know that there won't come any shit further down the road, like, 'you didn't tell' or 'you should have done' or, well, some bullshit where people want to put the blame on me, because they don't what they should do when it comes to their own sexuality, to say it bluntly. Their own sexual health." (Barry)

Despite all the potential negative consequences of disclosure, Oliver was clear on what he believed to be the best solution, and didn't believe that hiv had to affect one's dating opportunities:

"As people who are hiv-positive we think it does (have an effect on dating). But I am a good example, showing that it doesn't. Try. Get hurt. You go on a date, 'fuck no, she's got dandruff or ugly teeth or flat breasts. I mean, we get rejected for everything. I just think it's a little more difficult, because this is infectious and a little sexual, so it's a little harder when being rejected, or we experience it as harder. But it's this about 'when are you gonna tell? That's something we hiv-positive people talk a lot about together." (Oliver)

As illustrated so far, ILH may encounter a range of different reactions from their surroundings when choosing to disclose, and there are numerous reasons for and against disclosing one's diagnosis, many of which are related to possible stigmatisation. Another factor that may both influence disclosure is self-perception, which will be discussed next.

Self-Perception

This theme will investigate participants' reports on how living with a stigmatised diagnosis influence self-evaluation, including hiv identity, internalised hiv-negativity and self-stigma, and suggestions on how to improve self-perception.

Hiv as part of one's identity. Several participants describe implications of secrecy on personal identity, where the secrecy is described as living a double life or wearing a mask, preventing them from being who they really are. A few participants anticipated and seemed to develop an hiv identity prior to the diagnosis. Some studies describe the time of diagnosis as the starting point of the development of an hiv identity (Flower & Davis, 2013), while others argue that it happens after an individual suspect being seropositive (Baumgartner, 2007; Sandstrom, 1990). The latter complies better with our results, where it is clear that it is not necessary with an official diagnosis for identity development to occur.

Whereas an incorporation of hiv as part of one's identity seems to be clear, how this is done, and how it is dealt with seems to differ between participants. Caleb considered himself

relatively open about his diagnosis, but could remember previously having two profiles on Gaysir: one regular profile and one hiv profile. His descriptions imply a divided identity. He talked about this in relation to himself and others.

> *"(I) have a profile at Geysir, and I ran two profiles there. And then I had one of those hidden profiles on the hiv pages. Or the hiv-positive club, which is a closed group. 'No, I'm not gonna bother with this anymore', I thought. 'I'm me, and that's it'. So I deleted this fake profile. Or maybe not fake, but the one where I had no picture. And then I used that one, the one I've always used. I just felt very conscious about having that hiv-profile, and then I had the Caleb-profile. And that, to juggle those two, it's mentally demanding. Physically as well. No. That wasn't how I wanted it. But I also see many at my own age and younger too… really hiding it. I mean, they choose to hide it. But not in my social circle though. I'm thinking like, but I couldn't have lived like that. Because it must be so straining. It must be terribly exhausting to walk around and pretend something. To play that game with two cards. You know. It must be terribly hard. Because it's been several people who have come over to me. I use a normal picture on my profile. A little like 'I saw you on that'. 'O yea, you did?'. 'But you mustn't tell anyone'. 'No no no'. You know, it's so many like that. It's so hard, because I'm thinking 'Can't you just be yourself?'. And then I see some of those that I've met during the last years now, who's come over to me, admittedly, and told me that they're behind that profile, 'I'm behind that profile'. Then I think, 'so tiring'. Because it's like, 'you can't tell anyone, blablabla'. And, of course I don't do it. But I'm thinking, how do you even manage? Right… It's a little sad. And I think it's tiring, you know, to play with-. And it is too. Pretending something. And wearing those masks, you know." (Caleb)*

 This extract suggests an adaption of hiv as part of one's identity, as keeping the diagnosis hidden is perceived as not being able to fully be one self. Pretending to 'pass' as 'normal' is also compared with wearing a mask, further illustrating the nature of a hidden identity.

One participant, Liam, described how he felt that having hiv connected him to a group of individuals that are sexually reckless and people who have got hiv due to self-taken risk.

> *"I wanna find someone that I can live my life with, and a lot of people with hiv, and who are in these (online) groups a least, are only after living out quite crazy sex fantasies, more or less. It's a group that I don't want to be a part of, so to say. The few people that's got it, where you're able to arrange a date, are both looking for open relationships or something else." (Liam)*

There are at least four observations to pay particular attention to in this extract. One, is the portrayal of the stereotypical view of GMLH. Two, is that the characteristics that are used to describe other GMLH are portrayed as being of a negative nature. Three, although Liam is a GMLH himself, his experience is that the general population of GMLH are different than he is. Four, it is clear that the perceived behaviour of other GMLH has consequences on his behalf, through complicating the search for a suitable partner. The tendency to prescribe negative and stigmatising attributes to other ILH, but excluding oneself from the same negative attributes, were also observed in a study investigating GMLH (Murphy et al., 2016). They noted that in such discourse, other GMLH may be seen as those that may be the rightful targets of stigma. Still, this comparison with other GMLH implies an adoption of a new identity based on living with hiv, albeit perceived as a different one than what they believe is typical for other ILH.

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These extracts may show that commonly known associations and stereotypes have created a conscious attempt to distance oneself from these associations.

Several participants described either having had personality changes after receiving the diagnosis, or describing hiv as being a part of their identity all together. Some participants seemed to be concerned with not wanting others to define them by their diagnosis, emphasising being 'more than hiv' and being unique despite living with hiv. Like Oliver said *"I'm living with hiv, but I am not hiv-positive. I don't wanna be the diagnosis"*. A couple of participants did view hiv as a part of their identity, but seemed to consider it at the same basis as their other attributes. *"I've never understood what they mean by 'I'm more than hiv' or 'You're not just hiv'. No, of course not. But I'm that too. So, what's the deal? Yes, I am hiv-positive and not just that of course. But just as much"*, Sam said. The magnitude of the hiv identity, namely how important the hiv identity it is for one's self-concept, may be described in two ways: by centrality and by salience (Quinn & Earnshaw, 2011). Oliver and Sam portray two variations of identity centrality; the extent to which an individual perceives something about themselves to be defining who they are as a person (ibid.). Quinn and Earnshaw (2001) found that centrality of a concealable stigmatised identity (CSI) seems to increase psychological stress (ibid.). However, the study researched students with a range of different CSIs, not hiv specifically. In contrast, another study showed that found that centrality of hiv identity had a resilient effect, where hiv symptoms were increased through experienced stress only when centralisation of an hiv identity was reported as low (Earnshaw, Lang, Lippitt, Jin and Chaudior, 2015). What may be responsible for the contrasting findings is unclear. However, it might indicate that there is something unique in the centrality of an hiv identity compared with other CSIs.

Salience is the frequency by which an individual think about their concealable stigmatised identity, unrelated to whether the thoughts are of a positive, negative or neutral nature. Salience may be affected by behaviours or symptoms that may impose thoughts in the direction of the stigma. For our participants, for instance, thoughts about hiv must happen at a regular basis to ensure ART adherence and regular medical check-ups. The same behaviours may increase chances of involuntary disclosure. In this way, salience may be both positive and negative, where it may increase anticipated stigma, but also improve adherence to medications.

Baumgartner (2007) found evidence for a process with two turnovers of identity after diagnosis. Often starting when diagnosed, they found that the respondent's perception of themselves as healthy individuals was challenged, and that they started 'developing' a new

identity as someone living with hiv, in a context where hiv is perceived as a stigma in society. This challenges perception on personal health may be what is described by James:

> *"And my self-image is that I can do it and that it's no problem. And then it's become obvious that the self-image isn't right, yeah, it's not right. And it's not right when it comes to how my body reacts. And that's been scary." (James)*

The first stage is associated with shock and denial. When getting to a point where having to deal with the situation, they reach the first turning point, continuing to the second stage, referred to as the *Immersion stage*. Having to deal with the diagnosis, the hiv identity is described as being central, the individual may become preoccupied by hiv, and perceiving hiv as a dominant identity. The stage consists of gaining experience within the hiv community and information seeking, which may be followed by a strong desire to teach. Teaching others about hiv as a self-proclaimed responsibility will be further discussed in theme 4: Responsibilities.

The second turning point, progressing to the *Integration-stage*, is described as following an event that makes the ILH reassess their immersion in hiv. Two reasons for this change were new and advanced medications enabling better life prospects, or burnouts resulting from going through the immersion-stage. The integration stage is characterised by realisation of being more than hiv, starting to balance life and activities in a manner consistent with their new perception of self. If the cases of burnouts described by participants resulted in a changed identity towards an immersion stage is unclear, and does therefore neither prove nor disprove the three stages of Baumgartner's (2007) identity turning points. Nevertheless, as emphasised by Baumgartner (ibid.), people may stay in one stage without progressing to the next stage of identity. The medical improvements of ART may have made it increasingly possible to progress between stages. It should be pointed out here that there should not be a goal in itself to progress from one stage to another, as long as the ILH is content with their own self-perception.

We have now seen that hiv is not merely a diagnosis, but is also implemented onto the diagnosed's identity. We will further discuss how this implementation of identity may have severe implications when it is accompanied by negative associations with such identities.

Internalised hiv negativity and self-stigma. Similar to internalised homophobia (negative feelings about homosexuality in gays), which is believed to stem from gays and lesbians internalising society's negative views of their sexual orientation onto their own identity (Mayfield, 2001), ILH may internalise stigmatising views of hiv, which in turn results in negative views of self (Berg &Ross, 2014; Herek, 2002; Lewis, 1998; Lee, Kochman & Sikkema, 2002). This phenomenon is called self-stigma, and results in negative thoughts about self, and may include seeing oneself as repulsive, contagious, filthy, unwanted/undesirable,

poisonous, deviant, as a disappointment to the family or similar (ibid.). Most participants reported having negative thoughts about self in relation to their diagnosis at some point after receiving the diagnosis (one participant referred to this as medical side effects, as suicidal thoughts ceased when changing medications). *"I just thought I was disgusting, infectious and dirty"*, Oliver explained, when talking about his relationship with his own body and sexuality in previous years. He continues; *"I stopped being sexual, because I wouldn't do what he had done. Had problems with my own body. Just thought I was disgusting, infectious, dirty"*. Several informants described the stigma they have against themselves as the biggest stigma of all.

> *"I think self-stigma is the biggest stigma. Expected stigma is number two. And the experienced stigma… rarely. But stigma, yes. But it lies within us. Or in me who lives with hiv. Has been the thing that has affected me the most." (Oliver)*

As much as 38% of participants in the 2009 Fafo-report say that they feel contagious, and therefore distance themselves from others, which might contribute to the high prevalence of isolation felt amongst ILH (Grønningsæter et al., 2009). Self-stigma is a barrier for disclosure (Lee, 2002), and may thus prevent both social support and positive encounters that can contradict expected stigmatising attitudes that they believe others inhabit towards themselves and others living with hiv. When disclosing, self-stigma is likely to increase sensitivity to stigmatisation from others simply due to awareness of the differentness (Chesney & Smith, 1999). However, 20% reported that they felt more taken care of by others because of their diagnosis (Grønningsæter et al., 2009). Whether these numbers are portraying beliefs before and after disclosure is not evident in the report. Internalising negative attitudes from their surroundings and from negative expectations or experiences in the social world may potentially have severe consequences on self-perception and behaviours, as narrated by Oliver:

> *"Struggled a lot mentally. Didn't want to touch people any more. Hug. I mean, my mom wasn't allowed to touch my clothes. Tried taking my life several times. I started cutting myself. A totally destructive life style. Got in contact with an hiv organisation. Or, was forced to the hiv organisation by the mental institution. Thank god." (Oliver)*

Self-stigma has been shown to be related to several kinds of ill-health, such as contributing to depression, anxiety and hopelessness (Lee et al., 2002). Lee et al.'s (2002) results also show that those scoring high on internalised hiv stigma were more likely to have received negative responses to disclosure and were less likely to ever have attended support groups for ILH. This means that those who need this support the most are those who are the least likely to seek help. This is important to note, as a sense of isolation is common among ILH, and because social support often is important in dealing with hiv. Self-stigma was negatively associated with perceived social support, and positive action coping. It was

positively correlated with grief, passive problem solving, self-destructive escape coping, and spiritual help coping. The authors suggested that these correlations may result from failure in adapting successfully to a life with hiv (ibid.). However, they acknowledge that causal interpretations cannot be made, and the effects may be caused by other variables not included in the study. Self-stigma has also been found to be related to increased sexual risk behaviour (Burnham et al., 2016; Lee et al., 2002), meaning that self-stigma also has the potential consequences for further transmission where infection is possible.

Hiv was not only portrayed negatively by the participants. On the contrary, even though all participants seemed to agree that a life without hiv would be preferred, they could describe something positive about having the diagnosis when asked, a few describing hiv as a positive change in their lives, often based on personal growth resulting from getting the diagnosis. Two examples of this were portrayed by these men:

> *"For most people, the people I know, will say the exact same thing. Because it's the best thing that has ever happened. Because every day I spend time with my own thoughts. And I never did that before." (Adam)*

> *"I think it's a big liberation project. Because hiv has basically contributed to, for me, to live with my sexuality with more openness and made me more self-accepting that I've ever been. So to me, hiv isn't an illness. I think it's a liberation." (Sam)*

The issue arises when the views on hiv are predominantly negative, and when participants pass these negative views onto their own self-perception. It is not apparent what contributes to the more optimistic focus among some participants, but a better understanding of this might help in the work of promoting and improving mental health and self-perceptions in ILH.

Some of the participant's self-perception seemed unaffected by experienced stigmatisation.

> *"And it's OK for me today if you 'you know what, ugh, are you gay and hiv-positive? I don't want anything to do with you'. 'Fuck you'. I mean, I don't think it hurts me anymore. I don't want anything to do with such narrow minded people". (Oliver)*

This extract shows typical talk related to ways in which stigmatisation does not have to affect self-perception. Several participants show signs of the same strategy, where there seems to be a chosen perception of stigmatisation as being a representation of other's shortcomings, as opposed to being something that reflects their value as GMLH. The authors did not succeed in finding other research mentioning this strategy. We will now discuss what may improve self-evaluation, based on the narratives provided by participants.

Improving self-perception. During interviews, participants mentioned a range of factors that may be preventative or assisting improvements in self-perception. There might be

many other factors that may influence self-perception among gay men living with hiv. These are only a summary of some of the more noticeable factors that were observed in the data.

> *"I remember that I thought right away that this would not stop my plans. So I'm kind of a survivor, I believe. So, I think I decided quite quickly. It was the feeling that 'OK, this wasn't great but it's not gonna stop my plans." (James)*

The use of the label *survivor*, here described by James, may be important. Although related to another context, the use of survivor instead of labels such as 'rape victims' or 'persons who have gone through cancer treatment', has received increased interest (Chaung & Delabbro, 2016; Morris et al, 2014; Papendick & Bohner, 2017). This because positive associations such as strength, activity, optimism and positive coping are connected to the word 'survivor', as opposed to 'victim' or 'patient', which carry more negative and passive associations (Papendick & Bohner, 2017). Perceiving oneself as a survivor might therefore improve self-perception, shifting the perception of self as a passive victim of failing health and circumstances to an active survivor who thrives through the hardships they face. In a study of cancer patients, they found that one didn't become a survivor by being diagnosed with cancer, but it was rather an identity that was adapted over time. Those who did identify as survivors had advantages such as a better quality of life and mental wellbeing, and had a positive influence of their participation in cancer-related activities (Chaung & Delabbro, 2016). Of course, the term survivor will not be preferred by everyone (Morris et al, 2014) and caution should be made to anticipate that this is right for all. Still, it seems to have potential benefits for those who choose to identify as one.

Others referred to personal factors, such as acceptance and positive attitudes, as important resources for developing or maintaining a healthy perception of self. An important part, Mark explained, is seeing one's own value: *"So, I guess that's what it's about, that dark period. To accept this. But you are a fantastic person. So, it's OK"*.

Information, knowledge and experiences were also deemed crucial for the perception of one's situation. As demonstrated by the narratives of Liam and Sam (see Setting the stage), both positive and negative experiences may affect how you view your situation and yourself.

A good network and social support was also stated as important. This support might be received from anyone, from friends, family, therapists or others in the same situation. Caleb summarized some factors he deemed necessary for dealing effectively with a life with hiv:

> *"It's easier to be hiv-positive, and go out meeting people I think. Because you need character. You need balls. You gotta have self-confidence. You need a network around you for you to be able to be relaxed about it. You need that." (Caleb)*

The majority of the participants generally reported improvements in their self-perception with time. *"I don't walk around being proud of being gay or hiv-positive, but I'm*

not ashamed anymore either. Because I've done that for a long time. I'm done with that", Oliver said. This is consistent with the findings of Lee et al. (2002), where individuals that were rated high on self-stigma had been more recently diagnosed than those low on self-stigma. What caused this correlation is not evident, but possible explanations may be greater social support following disclosure, having gained more positive experiences, or getting more experienced in dealing with the diagnosis, and thus decrease their negative sense of self. Attempts to find what strengthens healthy self-concepts and decrease self-stigma in ILH should be a priority.

A Sense of Responsibility

Participants were asked whether they felt some kind of responsibility, as a result of living with hiv. Participants provided both relevant answers following this question and at other points during the interview on their sense of responsibility. It was clear that the topic of responsibility was a concern that many had reflected on prior to engaging in the study. A sense of responsibility stretches across different situations and different kinds of responsibility. How a sense of responsibility was experienced and expressed by the participants also varied between the participants, and some participants reported personal growth through their sense of responsibility. This theme will investigate the participant's views on responsibilities resulting from being diagnosed with hiv. The results and discussion consist of the following sections: 'Protecting others from harm', 'Being blamed', and 'Altruistic responsibilities'.

Protecting others. Responsibilities mentioned by the participants both seemed to be related to transmission of having a transmittable disease and responsibilities that are more related to the stigmatisation associated with the diagnosis. *"You have to take responsibility for your own health. And other's too. That's important. At least I think so. Trying the best I can"*, Caleb said about his responsibilities towards others.

One dominant concern was the fear of inflicting psychological harm on others. The seemingly predominant focus on the psychological harm, as opposed to the physical harm of others (through transmission), may be a result of ART and the new guidelines recommending early treatment. Due to the effectiveness of these medications, the participants, who are all on successful treatment, are no longer likely to transmit hiv to others, ultimately decreasing the preoccupation of this concern. Still, most participants reported having had or having concerns regarding how their stigmatised diagnosis may affect those around them.

Oliver's narrative portrayed many years of secrecy and worries of becoming a burden for others that exceeded that of fears of transmission. *"I was afraid of worrying others with my condition. That I was gonna be yet another burden for them. The biggest burden was obviously*

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on me, but I was very concerned about not burdening others". Exactly what kind of harm they were concerned with inflicting on others is only sometimes addressed by the participants, but there were several potential stressors that may have influenced those associated with individuals with a stigma.

According to Goffman (1963), mere contact with a stigmatised individual may potentially inflict stigmatisation on those socialising with the stigmatised. This phenomenon is called associated stigma. Additionally, ILH may be worried that others' knowledge of their condition may produce unnecessary concern, worrying about the person's health or how the ILH will be met in society. Responsibilities to protect their loved ones from harm and worry has been found as a potential barrier to disclosure (Greeff, 2013, p. 86) and concerns of others becoming concerned on their behalf seems to be the biggest worry when it comes to disclosure (Grønningsæter, 2009). In some cases, there seemed to be a fear of merely inducing stigmatising feelings in others, not only for their own discomfort, but also on others' behalf. With the fear of transferring any form of discomfort onto others because of their own diagnosis, some outlined having spent great efforts into keeping it from happening. Oliver explained how, even after disclosure, he used measures to avoid reminding his partner about having a partner who is living with hiv.

> *"In the beginning, when we lived together, I was also like that. Like, was hoping that-, rather wanted him to like be outside in the garden or something, so that I could hurry to take my tablet, so he wouldn't be reminded that he lives with someone who's got hiv. But that was in my head. He doesn't give a fuck about that." (Oliver)*

During interviews, simple beverages were offered to the participants on a self-serve basis. Oliver explained how also situations like these had previously been accompanied by worries and a sense of responsibility to keep others from discomfort.

> *"I thought about it when you said 'there is', you know (pointing at a stack of plastic cups on the table). Earlier, I wouldn't have taken it. Then I'd ask you to hand me a glass, but I hadn't liked to take it. That 'would she think it's gross that I touch the glasses' and stuff. I mean, I started doing that a bit." (Oliver)*

While ILH on successful medical treatment are considered non-infectious, participants in committed relationships described responsibilities and measures taken to create and maintain their partner's sense of safety in being part of a discordant relationship. This could involve making sure that the partner is properly informed, making sure that the partner feels safe in sex situations or making considerations in public arenas if relevant. James had lived with his partner for many years. Still, his partner's sense of safety was considered more important than the possibility of an improved sexual life for them both, as long as there was a possibility that his partner could somehow suffer from any suggestions of improvement.

"We've actually always, and actually up till today used condoms during intercourse. I don't really like condom sex (laughing). I prefer without (laugh). I prefer without (laugh). It's maybe put a small damper on the sex that I have with my husband. You know, it's only him I have sex with, but I do wish we could drop that condom. I think I could have had better sex then. And we could actually do that, now when I'm not infectious like that. But I haven't brought it up either. So, I don't really wanna-. Knowing that it works and works OK then I think that I, like, don't want to pressure him or pressure him in a way. That he then maybe will refuse to do it or he will maybe feel pressured to say yes if he maybe actually doesn't want to. And I think it would be much better if it had come from him. If he had brought it up and said 'listen, I don't think we need it any more'. But he hasn't done that. So I'm thinking, you know, why put on that small burden, the insecurity on this then, when I actually strictly don't need to. So I'm thinking that if this is a kind of safety that it gives the both of us. Maybe especially for him. A better feeling of security, you know, then I think, then that must be good." (James)

The interesting aspect of this extract, is that it shows how he put himself and his needs second, positioning his partner's potential needs as more important than his own. Such narratives may portray feelings of being to blame or being of less worth. Therefore, the mere questions of change towards something that may benefit them both, still seem too risky because it may inflict discomfort upon an *innocent* partner.

Being blamed. In all encounters with new potential partners, whether it's of a casual or of a more serious nature, the question of whether to disclose or not to disclose their diagnosis presents itself. When it came to disclosure in sexual contexts, frustration was expressed about how they experienced that potential sex partners expected them to be completely responsible not only for their own sexual health, but also the sexual health of others. As Barry explained, some potential sex partners who are hiv-negative see their seropositive status as a valid reason to let go of their own responsibilities of taking care of their own sexual health.

"If you ask people very explicitly about it, then I think the answer will be that 'well yes, I understand that, and I do want me to be responsible for myself and my own health. But when it comes up, like, who should do it, then it's a little, like, you can end up with, like, 'I didn't get that information from anyone telling me that that was how it was. It was no one that asked me if I wanted to take an hiv test. It was no one who I had sex with who told me that they had a sexually transmitted infection, and still I end up at the clinic and test positive for stuff", you know. And then it's like, what happened here? I mean, where were you in all of this? And then it's kind of this thing about, like, no one took care of me, and that feeling of 'yes, but I need to do it' vanish. And those people I don't get. Because most often-, in society we individualise ourselves more and more, but when it comes to this sexual thing, we don't talk about and it doesn't exist, and it's someone else…. It's a little, it's strange." (Barry)

According to The Norwegian Penal Code, it is illegal to transmit or put others at risk of transmission from a dangerous contagious disease, except in cases where the person that is contaminated or been at risk of being contaminated is a spouse or cohabitant that has agreed to be exposed to such danger (The Norwegian Penal Code, 2009, §§ 237-238). The fear of transmission, and the potential of legal prosecution after not disclosing the diagnosis, therefore seems to have been important reasons for disclosure. In 2016, there was implemented new guidelines stating that individuals diagnosed with hiv are recommended to start treatment as early as possible (The Norwegian Medical Association, 2016). With successful treatment,

patients are considered as safe from transmission. Therefore, as risks of transmission has been an important reason for disclosure, both for personal and legal reasons, this consideration may become less significant in their decision making on whether to tell others about their diagnosis. Several participants described a Norwegian court case as a turning point regarding their legal responsibility of disclosure for sex-partners. Adam explains what happened:

> *"It was a trial in Stavanger. (It) dealt with a man who had abused a minor. And where the parents then went to court against him for having exposed their child for hiv transmission. But what one of these, was it the batsman or was it the attorney or whomever it was, became interested in during the trial was: When a woman can give birth to a child without transmitting the virus to her baby. When a man can make his wife pregnant without transmitting the virus. And then you're going to trial to be prosecuted for transmission? Nonsense! To have used protection, that is to take the medications every day. That is what we must <u>dare</u> to say. The medications work. The trial in Stavanger says so." (Adam)*

This case was perceived as evidence showing that the medical treatment is working so sufficiently that they would not be prosecuted or receive formal sanctions as a resulting from non-disclosure or transmission. Still, participants described a reluctance in the health care system to confirm the effects of the medical treatment, which participants said contributes to maintain social stigmatisation and unnecessary expectations on their behalf.

The reluctance to confirm the medical effects can also, as James explained, give rise to uncertainty about the validation of the argued medical success, creating insecurities in sexual settings.

> *"It doesn't help, in a way, to know that the risk of transmission is extremely low, because nor has anyone said that there's no risk of transmission. And that is what I'm quite critical about when it comes to so-called experts here at home. Because they are so veeeery much reserved when it comes to removing that risk of transmission. Because they don't dare to say it. Because then, you know, think about what will happen then. So, in that way they are very conservative these medical practitioners today. And I don't think that anyone has not told us that you can't infect others. Like, 'You have now, and you are well and healthy, and your tests and everything, and no infections. Go on! You can't infect anyone. It's impossible'. I think, if we had been able to hear that, then I think much of that burden that many walk around and carry, I think it would have been lifted off. Because it is none of us that wish to infect anyone, you know. So that's that. And also I think sometimes when I get so upset about this debate, and maybe not too much now, but earlier. When it's been up, like this kind of attitude where people believe that people with hiv is spreading this, you know, and wish to infect someone. That we are dangerous in a way. You know. Those are such hopeless attitudes. So, no. It's so much around this transmission, you know, and fear and stuff like that." (James)*

According to Persson, Ellard and Newman (2016) the preoccupation on serodiscordant couples in the context of sexual risk behaviour and risk management in research and literature, is an additional factor that contributes to upholding the notion of those living with hiv as unsafe and unwanted partners for seronegative individuals. The authors emphasised that this kind of research provide useful and important information, but that the unnuanced picture and lack of attempts to challenge the so called sero-divide, contributes to the issue described by James. They further proposed that we may be heading towards a shift, where stigmatising discourses

and preoccupations of risk can be countered with authoritative validations of safe sex through ART, and points towards the growing use of hiv-related designations, such as 'undetectable', 'hiv equal' and 'hiv neutral'. The ultimate goal here would be to ensure that hiv is not portrayed as a bigger issue than it has to be for those living with the diagnosis. There seemed to be a notion that some health care professionals work against ILH in this debate. Adam expressed that the reluctance to affirm the medical effects of ART, despite evidence showing no transmission during successful treatment, result in decreased trust in the medical system.

> *"The group that they say is spreading hiv, is the group that cannot spread it. What are they talking about? They are accusing us for something we cannot do. They lose their credibility. In that group they say they're not stigmatising, that is what they do. And they have stigmatised us so far on the side. I'm not even interested in coming back." (Adam)*

Although only a few participants reported this relationship between reluctance of endorsing the medical effect and the perceived trustworthiness towards medical staff in general, it may still be an important finding. As patients are fully dependent on medical staff to be able to adhere to their treatment, even if only a few individuals avoid contacting medical staff either before or after the diagnosis, it may have consequences for hiv testing, medical adherence, transmission, and physical health.

It is clear after speaking with the participants that the improved and immediate medical treatment and increased knowledge on confirmed medical effects in the general public, especially the gay community, can influence the sense of safety for GMLH and those around them, as well as influence the expectations or received responsibilities related to others' safety. As illustrated by Barry, issues of disclosure and sex seem to move from a mandatory responsibility to a decision made based on other means:

> *"So there are some things that has changed during the time that I've had the hiv diagnosis is that during the first years I didn't get any medications, and had, like, yea, quite a lot of anxiety when it comes to infecting someone. So, what you've actually left with now is kind of that 'No, it's no problem'. And now you've also got PREP, so now that fear has kind of disappeared completely, because now there's yet another tool there for hiv-negatives to use for taking responsibility for their own sexual health. So, well, that sense of responsibility has kind of disappeared." (Barry)*

Helping others: A large number of participants described a personal responsibility to somehow contribute to hiv-related work. In contrast to other responsibilities, the responsibility to help others in the same situation was predominantly described as positive or as a responsibility they were willing to take. Oliver, who was active in hiv-related work, explained:

> *"I have never been an activist and I don't intend to, but I feel that it's important for me to spread knowledge about something that has been affecting my life in such a major way. To better and improve the circumstances for <u>others</u> who get the diagnosis. So, there it is some responsibility. But it's positive." (Oliver)*

The underlying mechanisms that may be conducive to this wish to contribute can be many, but as discussed in theme 3, one theory is that it may be a part of the process of adapting to a new identity. A reoccurring reason provided by the participants, was wanting to feel responsible for improving the lives of others living with hiv. Jacob was involved in hiv-related work, and said there was no alternative than to stay involved in this work.

> *"I have also been able to learn and get to know a lot of nice people too, or this engagement also, has grown. And that I have the opportunity to be a voice for many people that do not have the same opportunity to get their voices heard." (Jacob)*

Knowing that there are many others who do not have the same resources or opportunities as themselves to be open about their diagnosis was one of the reasons provided for feeling responsible for contributing to a better situation for others that live with hiv, and to fight against discrimination and prejudice. *"But I have felt it as a duty that I, as I actually am resourceful, that I can do something when it is so many people that are not able to, I have felt responsible. More as a duty even, to contribute"*, Jacob explained.

In other words, participants showed signs of wanting to improve the stigma-situation themselves, and saw this as a responsibility towards other ILH. Only Adam positioned himself negatively to contributions made by ILH in relations to hiv-related work.

> *"There are some people that have been so called front figures. Those who are pleased by being front figures. I don't think that's right. I don't believe <u>we</u> should represent ourselves. It must take it's time. Everything new takes generations to change. It's not something that can happen suddenly, and then everything is all right. Freddy Mercury came out towards the end. Does that help? He looked terminally ill and dangerous. That doesn't help much, does it? It's scaring the shit out of people. A lot. A lot of those. It's wrong. Because in their heads, they're not coming <u>forward</u>. They're selling themselves. They want PR. It's the wrong people. And then they're trying to milk the case. It quickly becomes a cliché. So, it must, it must go its course. And then we must have some idiots like you who take care of it. It must be someone who are genuinely interested in it. <u>Genuinely</u> interested. Gets involved and looks into it." (Adam)*

For many, like Sam, engagement in hiv-related work seemed to signify more than a mandatory responsibility, but also an opportunity of increased self-worth: *"It's a responsibility that I'll gladly take. Being strong enough to carry that responsibility. It does provide you with a good feeling about self. So, it gives you a feeling that works as a contrast against that infection"*.

The "helper" therapy principle, proposed by Riessman (1965), suggests that 'helpers' also benefit from helping fellow sufferers. Having individuals who live with or have overcome some problem to help others who are struggling with the same issue, has long been implemented in social and health-related work. This principle is central in the 12-steps of Anonymous Alcoholics, but is also relevant to other issues, such as medical conditions, such as hiv, mental health issues or similar (Pagano, Post & Johnson, 2011). This principle has obvious parallels with the concept of the 'wounded healer', which is the notion that those who have overcome

difficulties, may be particularly sensitive and adept in assisting fellow sufferers (Melkman, Mor-Salwo, Mangold, Zeleller & Benbenishty, 2015). According to the helper therapy principle, individuals with previously experienced issues may benefit from the helper role, and the experienced benefits will in turn result in them becoming more effective workers and better helpers for recipients (Riessman, 1965). The helpers may benefit in a number of ways, such as rehabilitating effects of helping fellow sufferers, improved mental and physical health, a sense of belongingness and social support, improved self-image and overall increased quality of life (Riessman 1965, Pagano et al., 2011, Melkman et al., 2015). In addition, helpers may benefit from working with fellow sufferers through 'self-persuasion through persuading others', where the helper may change opinions or views by working with others in the same situation through reflection. Additionally, the implicit thesis that "I must be well if I help others", may provide support in a helper-situation (Riessman, 1965). Benefits of helping have been shown even in cases where the participants have been aware of the objectives of the study, and helpers may have greater, or at least just as many, benefits as the recipient (Riessman, 1965; Brown, Basil & Bocarnea, 2003; Schwartz & Sendor, 1999).

'The desire to educate' was the main contribution participants mentioned as an important preventative factor that they would like to assist with, and some participants, such as Barry, did already contribute to this work.

> *"Yeah, well, (one) of the reasons for having worked with it for a long time is, well, a kind of responsibility for making it visible, that people actually live very fine lives also with hiv. And that it is the only thing that I believe will work, also preventative, is that people can see that you exist and that one is outside, one is in social media, one is moving around where people have sex, so that they can actually see that you are present." (Barry)*

The belief in demystifying the condition and increasing knowledge among people was more or less mentioned by all participants in one way or another as crucial for the preventative work on decreasing hiv-related stigmatisation. According to the helper theory principle, teaching can provide a lot of the same benefits as described above. The theory also implies that teaching maybe beneficial through the concept of learning through teaching, as they need to be familiar with the topic of which they are lecturing, in addition to other academic sets that may emerge (Riessman, 1965). It is worth mentioning that the positive effects of helping fellow sufferers may diminish if the helper perceive the recipients as being less than themselves, or if being overwhelmed by the work (Pagano et al., 2011). Even though it is clear that engaging as a resource can have important positive effects for GMLH, some participants have found it hard to find the balance between their own capacity and work load. Jacob was one of them:

"All those things combined became too much. The circumstances had changed and I can't lecture anymore, so I quit. And I had, like, a period of time where I could cry from nothing and didn't understand that was wrong with me. And also it didn't correspond at all with my own self-image and what I thought I was capable, or what capacity I had. Then it was better again. So then I talked with them (at the hiv organisation) before I started working there. And then you had to go through a conversation. For that moment it helped. I didn't know what I'd do with my wish to participate. Because there is no alternative for not engaging myself at all. But how am I supposed to interpret my body, or how am I gonna know what I can do or not do? Because I don't know myself. But then I came to the conclusion that I'll just try and take it easy and stuff. And then I started to work at the hiv organisation, and it's going great." (Jacob)

Wounded healers have been criticised for passing on their own unmet emotional needs onto help-receivers, and for being at increased risk of burnouts and vicarious trauma, where the helpers get emotional reactions resulting from traumatic stories told by their clients (Melkman et al., 2015; Pagano et al., 2011). Caution should therefore be provided so that wounded healers are not overwhelmed by this work through empathetic over-arousal, which may cause burnouts, and encourage and guide helpers towards maintain a balanced lifestyle, where they take care of themselves before others (Pagano et al., 2011). We also suggest that it should be made clear to helpers that seeking help will not be regarded as unfit for their role as helpers. Because of the clear advantages of engagement among GMLH, guidance and advice on different variations of contributions and facilitation could be shown to be helpful to maximise the positive outcomes of this activity. Helping GMLH find meaning in their lives through participation can be a preventative measure in a population associated with increased ill mental health.

Summary of findings and research implications

This study has investigated how GMLH experience hiv stigma. Through thematic analysis, it was found that GMLH may experience stigma through negative encounters, through involuntarily living a double life, through responsibilities following the diagnosis, and through self-evaluation and self-stigma. It was also found that there are great gaps between the amount of stigma reported, whom they receive stigmatisation from, how it is experienced, and how they deal with it. Olaussen (2010) categorised experiences of stigma into eight themes: shame, blame, fear of transmission, prejudice/stereotyping, social avoidance/isolation, breach of confidentiality, meeting with the health sector, and openness/secrecy. All these categories were mentioned by one or more participants in this study, but other factors, such as rejection, discrimination and loss of opportunities were also mentioned.

Based on the nrratives, it seems that identity development is central to how encountered stigmatisation is experienced, how they perceive themselves, and how they deal with stigmatisation. From suspecting having hiv or being diagnosed with hiv, there seems to be an integration of hiv onto personal identity. With no previous experience on what it means to be

an ILH, they need to figure out who they are with their new identity, how comprehensive the implications of hiv will be, and how their new 'self' will fit into society. The development of a new identity involves evaluations of self with the new stigma, and this is largely influenced by society's views and attitudes related to hiv. As someone living with a stigma, they are aware of the stigmatising view of others regarding their stigma, and of the social devaluation of their new identity. As we have seen, the internalisation of society's negative views and self-stigma may have huge implications on disclosure, how stigmatisation is perceived and how it is dealt with. At the same time, ILH will have to find out how their new identity will be met by others, and how others will respond will not be known before disclosure. Their challenge then, is to navigate and find strategies on disclosure that fit their perceived moral obligations, as well as minimise harm or costs imposed on self or others. The implications of disclosure, non-disclosure or selective disclosure seem to vary, along with reasons given for their chosen strategies. It is clear that for some, disclosure is about being able to be who you are, while others perceive non-disclosure as a way to protect others or self from harm.

The findings of this study show that GMLH have different needs, and that there is a need for preventative interventions to target enacted stigma, as well as negative self-perceptions amongst GMLH. Earnshaw et al. (2015) found that resources in terms of social support, adaptive coping and hiv identity centrality can be effective against anticipated stigma, but failed to have a resilient effect on stress resulting from enacted stigma. This suggests that different measures are needed to tackle the complexity of hiv-related stigma. Interventions aimed at preventing hiv-related stigma should therefore have multiple focuses: to decrease enacted stigma by targeting the general public and the health system, as well as strengthening personal resources in ILH to target prevention of anticipated stigma and self-stigma.

A Norwegian survey (TNS, 2015) showed a lack of knowledge regarding hiv. The survey and other research has shown a significant relationship between hiv-related knowledge and relations to ILH, and attitudes towards ILH (Mandal et al., 2008; TNS, 2015), where knowing ILH or having more hiv-related knowledge predict less stigmatising attitudes. An especially interesting finding is that fear against hiv seems to increase with age, with the exception of those younger than the age of 30 (Mandal et al., 2008). Despite being the generation that has been sexually active during a time with available ART-medication, they seem to have less knowledgeable compared to their older peers, increasing the stigma in this age group. There is a clear need for more knowledge on all arenas; about hiv, how it transmits, and just as importantly how it does not transmit, and what it means to live with hiv. In our

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interviews, the gay community was generally rated as the area in which most stigmatisation was experienced, and a division in the gay community became apparent. As suggested by participants, this division may be due to fear among gay men of contracting hiv, and there seems to be a need to increase knowledge within this community. There seems to be a lacking awareness on the fact that those receiving ART have an undetectable viral load, and that this leaves them sexually non-infectious. This is described by participants as contributing to uphold at least a part of the complications of disclosure and stigmatisation found in gay communities, where GMLH seem to still be viewed as poisonous and dangerous among some. An important part of prevention then will be for health professionals and others in similar lines of work to maintain a terminology and communicate hiv and ILH in terms consistent with the present medical regime. A raising awareness of the non-contagiousness of hiv when on successful medical treatment could be a way to prevent ILH from unnecessary fear of transmission, but also reduce fear in others. This may also potentially strengthen people's self-perceived responsibilities of taking care of one's own sexual health, from becoming aware that those most likely to transmit hiv are those who themselves are unaware of their condition. More research should also investigate whether there are more reasons for the division seen in the gay community, marked by differences in behaviours and attitudes towards those living with hiv.

Just as importantly, we need to find ways to improve self-perception and decrease anticipated stigma, or rather alter self-destructive beliefs and attitudes towards self, which seems to be even more common than encountered stigma. These factors will also affect the impact of enacted stigma. The participants provided several factors as factors of resilience, including self-definition, personality factors, social support, hiv-related knowledge and positive experiences. It is of great importance to find ways to improve self-perception that can be implemented into interventions aimed at reducing stigmatisation. More in-depth research should focus on the positive aspects gained by living with concealable stigmas and investigate what contributes to positive and optimistic attitudes towards the stigma and the future among those living with hiv. Furthermore, psychological follow ups should be implemented into the treatment of those diagnosed with hiv, as the psychological implications of living with hiv and stigmatisation, as opposed to physical or medical concerns, were rated by all participants as the most exhausting and invading issues resulting from living with hiv.

Limitations

There are several limitations to this study that should be considered. As is typical for qualitative research, the study is in no way intended to be representative for all GMLH. Still, it

is worth reflecting on that all participants were willing participants who were available in the Oslo area, and all were recruited through hiv-related organisations. It is therefore even more unlikely to be representative in relation to GMLH with other demographic backgrounds. Due to the sensitive nature of the subject, and because many in this population would like their identity to remain hidden, it is also likely that those less open will be less likely to participate. Additionally, due to a limited time frame, this study consisted of ten participants. A higher number of participants might have provided a wider range of narratives. Nevertheless, we feel that participants provided a good variety of narratives, and we feel that a certain saturation of the data was achieved, as similarities between narratives were easily observed at the later stages of the interviewing process.

Keeping in mind that as the researcher is a white female in her twenties, this may potentially have influenced the data in several ways, and it might have influenced how the participants related to the researcher. Not being a member of the same reference group as the participants may also have prompted communication and increased acceptance for further questions. Some participants seemed to keep in mind the non-belongingness of the interviewer, and thoroughly explained aspects of the gay community that may be commonly known about among gay men, but maybe unknown to outsiders. In this way, the visible differences between the interviewer and the participants may have been an advantage.

Conclusion

The aim of this study was to find how hiv-related stigmatisation is experienced by GMLH. It was found that they experience it through encountered stigma in varying contexts and arenas, through having to deal with a hidden identity and issues related to disclosing or not disclosing this hidden identity, through negative self-perception, and through unwanted responsibilities. We have seen that stigmatisation, despite medical improvements, still exists, although not all report stigmatisation as a personal issue. Self-stigma was generally regarded as the biggest concern. An important finding is that GMLH are able to find positive associations with hiv, and there seems to potentially be several factors that might contribute to better the situation for GMLH. Still, there is a need for action, both to prevent stigmatising attitudes in the general public, and to prevent self-stigmatisation and anticipated stigmatisation in ILH. Suggestions for future research and interventional aims have been presented.

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