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**Citation:** Reinius, M., Andersson, G. Z., Svedhem, V., Wettergren, L., Wiklander, M. and Eriksson, L. E. ORCID: 0000-0001-5121-5325 (2021). Towards a new understanding of HIV-related stigma in the era of efficient treatment- A qualitative reconceptualization of existing theory. *Journal Of Advanced Nursing*, doi: 10.1111/jan.14774

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

Maria Reinius<sup>1,2</sup>  | Galit Zeluf Andersson<sup>3</sup> | Veronica Svedhem<sup>2,4</sup>  |  
Lena Wettergren<sup>5,6</sup>  | Maria Wiklander<sup>7</sup>  | Lars E. Eriksson<sup>1,2,8</sup> 

<sup>1</sup>Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, Stockholm, Sweden

<sup>2</sup>Department of Infectious Diseases, Karolinska University Hospital, Stockholm, Sweden

<sup>3</sup>Department of Public Health Sciences, Karolinska Institutet, Stockholm, Sweden

<sup>4</sup>Unit of Infectious Diseases, Department of Medicine Huddinge, Karolinska Institutet, Stockholm, Sweden

<sup>5</sup>Department of Women's and Children's Health, Karolinska Institutet, Stockholm, Sweden

<sup>6</sup>Department of Public Health and Caring Sciences, Uppsala University, Uppsala, Sweden

<sup>7</sup>Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Huddinge, Sweden

<sup>8</sup>School of Health Sciences, City, University of London, London, UK

## Correspondence

Maria Reinius, Department of Learning, Informatics, Management and Ethics, Karolinska Institutet, SE-171 77 Stockholm, Sweden.

## Funding information

This study was partly funded by the Doctoral School in Health Care Sciences, Karolinska Institutet.

## Abstract

**Aim:** To further develop Earnshaw and Chaudoir's HIV stigma framework by describing the experiences of HIV-related stigma among people living with viral suppression in a context where HIV is well controlled and to investigate how these experiences correspond to the stigma mechanisms of the framework.

**Design:** Qualitative study using interviews and a framework approach to analysis.

**Methods:** People living with virally suppressed HIV in Sweden were recruited through an outpatient clinic and interviewed about their experiences of social aspects of living with HIV. The interviews were audio recorded, transcribed and analysed using a framework approach.

**Results:** Fifteen participants (eight women and seven men, aged 30–64 years) were interviewed from March to September 2017. They described stigma around HIV as a barrier in many situations. Anticipated and enacted stigma were found to be more complex than is described in the existing literature. Being labelled as a person with HIV was found to be an important and persistent part of the stigma experience. Disclosure was found to be context-related and a result of a process of negotiating and weighing the relevance of disclosing HIV, perceiving HIV as a private matter and feeling a responsibility to disclose one's HIV status to others. An important reason for nondisclosure was to avoid being labelled with HIV, which would then become their most defining feature.

**Conclusions:** The HIV stigma framework could benefit from revision for people living with virally suppressed HIV.

**Implications:** The present findings, which indicate the role of health professionals in relation to disclosure and labelling, may guide nurses and other healthcare personnel in providing counselling and support for people who live with virally suppressed HIV and experience stigma.

## KEYWORDS

framework approach, HIV, HIV-related stigma, normalization, nursing, qualitative interviews, stigma

## 1 | INTRODUCTION AND AIM

Thanks to the development of antiretroviral treatment (ART) in the mid-90s, and its subsequently increased access, efficacy and efficiency, HIV has been reframed in global health policy as a manageable chronic disease (McGrath et al., 2014). There is an ongoing, mainly biomedical, discursive 'normalization' of HIV as being a chronic infectious disease like any other (Moyer & Hardon, 2014; Rodger et al., 2019). However, it has been shown that the biomedical progress is not always aligned with the realities and experiences of individuals living with HIV (Moyer & Hardon, 2014; Persson, 2013; Smith et al., 2017). HIV-related stigma has been shown to be a barrier to treatment and prevention (Langebeek et al., 2014; Rao et al., 2012) and to have a negative impact on both the physical and emotional aspects of quality of life (Andersson et al., 2019; Logie et al., 2011; Rueda et al., 2016; Rydstrom et al. (2016), Zeluf-Andersson et al., 2019) for people living with HIV.

In the present paper, we aim to describe the experiences of HIV-related stigma among people living with virally suppressed HIV in Sweden and investigate how these experiences correspond to the stigma mechanisms of Earnshaw and Chaudoir's (2009) HIV stigma framework, to further develop the framework.

## 2 | BACKGROUND

### 2.1 | The HIV stigma framework

In 2009, Earnshaw and Chaudoir called for clarity about how HIV-related stigma can be conceptualized and measured on an individual level. They presented the HIV stigma framework where the individual stigma mechanisms enacted, anticipated and internalized stigma are hypothesized to be related to a reduction in affective, behavioural and physical health and well-being for people living with HIV (Earnshaw & Chaudoir, 2009). Enacted stigma has been defined by Earnshaw and Chaudoir (2009) as referring to the degree that people living with HIV experience prejudice and discrimination, anticipated stigma refers to the degree that people living with HIV anticipate prejudice and discrimination from others and internalized stigma has been defined as when people living with HIV endorse negative beliefs and feelings about themselves associated with HIV/AIDS. The theoretical framework has been empirically confirmed in a North American context in a sample of people living with HIV where only a small proportion had effective treatment (Earnshaw et al., 2013).

### 2.2 | The framework in relation to virally suppressed individuals

The individual stigma mechanisms (enacted, anticipated and internalized stigma) have repeatedly been used as a theoretical framework in studies about stigma experience in people living with HIV (Turan et al., 2017, Vaughan et al., 2020). However, in the current era of treatment, viral suppression is increasingly common in parts of the world where treatment is generally available. There is a *dearth* of research investigating whether persons who are virally suppressed in a context where HIV treatments are easily accessed and free of charge experience stigma in the same way as described in the HIV stigma framework. Sweden is a low endemic country which in 2015 became the first country to achieve WHO's 90-90-90 target (Gisslen et al., 2016). In February 2020, 8,021 persons (39% female) were living with diagnosed HIV in Sweden and 98% of those on antiretroviral treatment had a viral load <150 copies/ml (InfCare HIV, 2020). We, therefore, suggest that Sweden is an appropriate setting to explore the experience(s) of people living with virally suppressed HIV. We recently performed an empirical test of the HIV stigma framework in a Swedish context using quantitative survey data from people living with HIV (Reinius et al., 2018). In the Swedish context, although it was common for people to have disclosure concerns, we showed that a majority of people living with HIV reported limited experiences of enacted stigma. In addition, when modelling the data according to the HIV stigma framework, only relationships between internalized stigma and emotional health, and to some extent relationships between anticipated stigma and physical health, could be confirmed (Reinius et al., 2018). With this empirical test in mind, we carried out the study presented below.

## 3 | THE STUDY

### 3.1 | Study design

This was a qualitative study using semi-structured interviews analysed with a framework approach.

### 3.2 | Participants

Participants were recruited at the outpatient clinic for infectious diseases at Karolinska University Hospital in Sweden using purposeful sampling (Patton, 2002). Research nurses recruited a group of virally suppressed persons living with HIV that was heterogeneous with regard to age, gender and country of birth. People living with HIV who

had been aware of their HIV status for  $\geq 1$  year, were durably virally suppressed (viral load  $< 150$  copies/ml at three time points during the last three years), and could speak and understand Swedish and/or English proficiently enough to participate in an interview were eligible for participation. Neither the recruiting research nurse nor the interviewing researchers had a clinical relationship with the participants.

### 3.3 | Data collection

Individual face-to-face semi-structured interviews in conversational form were conducted by a registered nurse and PhD student trained in interview techniques (female, born in Sweden) and a social scientist and PhD student experienced in qualitative interviewing (female, born outside Europe). The participants were able to choose the interview location, but all chose to be interviewed at their HIV outpatient clinic. A schematic interview protocol guided the conversation, with topics aimed to frame the experience of HIV-related stigma. After an initial question about how HIV affected their life, most participants began to describe experiences around the social aspects of having HIV. Follow-up questions such as 'can you tell me more about that' and 'how did you feel about that?' were asked to probe further. Interviews were audio-recorded and lasted between 23 and 129 min. We asked all participants to report sociodemographic data in the interview (age, gender, country of origin) and some participants also self-disclosed that they were gay, but we did not ask about sexual orientation or ethnicity in a systematic way.

### 3.4 | Ethical considerations

The participants received written and verbal information about the study with the opportunity to ask questions. They were also informed that they could withdraw at any time and that confidentiality was guaranteed. Written consent was obtained at the time of the interview. This study was performed in line with the principles of the Declaration of Helsinki. The Regional Ethical Review Board of Stockholm granted approval for the study.

### 3.5 | Data analysis

A framework approach, as described by Ritchie et al. (2003;1994) was used for analysis. Data analysis began with the first two authors listening to all interviews while reading and correcting transcripts to become familiar with the content. All co-authors read several transcripts and wrote down their initial understanding of the content. In the beginning of the process, this was done with open coding and emerging ideas and themes were noted and discussed in the research team. The process of analysis started by discussing how the content corresponded to each individual stigma mechanism

whereafter the material was coded as either related to enacted, anticipated or internalized stigma. If the content was not appropriate for the stigma mechanisms proposed by Earnshaw and Chaudoir (2009), new codes were inductively determined. This process generated a preliminary code index (Ritchie & Lewis, 2003) used to code 14 of the 15 transcripts in the data analysis software Nvivo version 11. The first and second author coded the same transcripts in a parallel process, comparing coding at weekly meetings and adjusting the index until agreement on coding was reached for all transcripts. The ongoing analysis was also presented and discussed at regular meetings including all co-authors.

Translated quotes from participants (in italics) are used to illustrate the findings. Irrelevant information and repetitions were removed from the quotes and indicated by (...) to facilitate readability, but with efforts to maintain the meaning. The quotes were translated from Swedish to English by a native English speaking researcher fluent in Swedish and external to the project group. Third-person plural pronouns are consistently used as gender-neutral nouns (singular) in the reporting of findings.

### 3.6 | Rigour

While two authors collaboratively conducted most of the analysis in cooperation, all co-authors were involved in the analytic process to some extent, which enhances trustworthiness (Lincoln & Guba, 1985) of the results. Credibility of the analysis was enhanced through peer debriefing (Lincoln & Guba, 1985), where the analysis was presented for research colleagues not involved in the project, people living with HIV and non-governmental organizations for people living with HIV who asked critical questions, making us aware of our preconceived biases. Analysis of one interview was postponed until the analysis of the remaining interviews was finalized for referential adequacy (Lincoln & Guba, 1985). The last interview was then analysed and the findings deemed stable.

## 4 | FINDINGS

First, background information about the participants is presented followed by their descriptions of the social aspects they have experienced of living with HIV, which are then discussed in relation to Earnshaw and Chaudoir's individual stigma mechanisms for people living with HIV: enacted, anticipated and internalized stigma.

### 4.1 | Background information about participants

Eight women and seven men (aged 30–64) were interviewed from March to September 2017. They all had Swedish residency, but were born in different countries: Eritrea, Gambia, Germany, Kenya, the Philippines, Uganda, Sweden and Thailand. Four participants received their HIV diagnosis before 1996, when antiretroviral

treatment was first introduced, and 11 participants were diagnosed between 1996 and 2015.

## 4.2 | Enacted stigma

In the present study, the data relating to these categories were found to be more complex than that described by Earnshaw and Chaudoir (2009), primarily because the stigma that participants described had not always been enacted towards them, but enacted towards other people living with HIV. Those who worked in healthcare settings, for example described how colleagues talked badly about patients with infections and how that affected them.

When you work with your colleagues and maybe someone comes in with an infection, maybe MRSA or ESBL, and they just say "oh that's disgusting", "Why do they come here?", "I don't want to go in there". People... make me feel sick when I hear that they become... disgusted by infections. (Participant #5)

In addition to describing situations they experienced directly, participants often incorporated other peoples' encounters with stigma as part of their own stigma experience. One participant, whose closest community consisted of fellow countrymen, said that they and their friends often talked about those who they knew had HIV; *my friend said to me, he drew the joker, that's how we say it... people talk behind your back, not to your face...* (Participant #3). This participant had not told anyone about their HIV.

The stigma experienced was not always enacted by other individuals. Participants also expressed how laws and regulations restricted their lives. One participant, for example, talked about not having access to fertility treatment in Sweden when wanting to have a baby. A recurring comment in several interviews related to different types of travel restrictions for people living with HIV.

The obligation to tell a sexual partner about one's HIV was brought up in negative terms by some participants. All participants had been informed by their physician in Sweden that, if they used a condom, they were exempted from the obligation to tell sexual partners about their HIV. Participants described how, despite this, they felt a responsibility to disclose their serostatus to sexual partners, as they would have wanted to know if someone they had sex with had HIV. Others reasoned differently, thinking that it was unnecessary to disclose to occasional sexual partners.

As long as I use protection, I don't have to disclose it, and ... I define it for myself, what is it for me? Is it...a sexual contact that's just going to be a sexual contact and it's just this time, because I want to and he wants to? Yeah, well then that's it...then we use protection and then I figure I don't have to inform the other person about it. (Participant #2).

Since Earnshaw and Chaudoir (2009) defined enacted stigma as acts of prejudice and discrimination, it was interesting to note that participants described being labelled as sick, or other people spreading that they have HIV, was perceived as negative actions performed by other people towards them. Although the participants described themselves as healthy, with HIV being a relatively small part of their lives, people around them sometimes categorized them as sick and told others about their HIV status without their permission. One participant said that a former spouse used the participant's HIV in conflicts, repeating what they considered to be an accusation: *you have HIV, you have HIV* (Participant #14). This participant talked about their child custody battle, saying their ex-spouse reported them to the Swedish social welfare authorities as being a bad parent because of their HIV status. The social welfare authorities made a home visit and wrote about their HIV in a report that was then shared with them and their present partner, who had not known about their HIV.

.. they came to us and of course checked up with one of those social service ladies. [...]And then X [new partner] was also there, and they came for a home visit and brought papers with them and X got to read about my background. Because Y [previous partner] had already said he would tell X I have HIV, so we wouldn't be able to live together because he could become [infected] too. Well, when I read it, I just saw how X's face was totally...well I knew, now it's over. (Participant #14)

Reflecting on the end of the relationship, the participant said: *it's kind of private, if anyone should disclose this it should be me, I should be the one telling. They have nothing to do with it.* One participant who used gay dating apps said that Swedish app culture was tough and judgmental when it came to HIV. Men commonly wrote '100% healthy' in their profile and requested that others state if they were healthy or not. The participant understood that the question really meant 'do you have HIV?' and they said that it made them angry since they deemed themselves to be in very good health. The participant described responding in an effort to make the other person reflect about what they were asking:

... that question always comes. It always comes, whether you like it or not, sort of "are you healthy"? And then I usually write yes, if it's in that context. But then I usually try to make it sort of more clear, or you can be a little clever, sort of, then and say something like "yeah, well I don't have a cold if that's what you mean" and then actually, well the other person has to explain then, what do you mean with this question, and it gets the person to start to think, what is it you are really saying and what do you want to know. (Participant #2).

### 4.3 | Anticipated stigma

Participants in the present study said that they anticipated being treated badly or that their children would be treated badly if others knew about their HIV. Although many elements in the narratives reflected anticipated stigma similar to that defined by Earnshaw and Chaudoir (2009), we also found elements that added more complexity to the concept.

Participants described anticipating prejudice not only from other specific individuals, but that they also found prejudice among the general public. Since it was common that other people did not know about the participant's HIV status, prejudice had not been enacted towards them directly but they described being aware of its existence.

One participant reflected over what Swedish people in general thought about HIV and said: *...it's everything from the early 80s and the gay plague and all that. That you can see from looking at someone if he has HIV or she does...It's seems you should be able to see it* (Participant #7).

Participants who had been diagnosed both before and after the introduction of effective treatment had memories of how HIV and AIDS were reported in Swedish newspapers and campaigns in the 1980s. One participant spoke of a Swedish campaign from the 1980s with advertisements in the subway trains, *Such really big letters, one single drop of saliva and the whole subway is [infected]* (Participant #7). The participants talked about these images as something that might still be present in people's minds today and that HIV may still be associated with death, AIDS, and the African epidemic with women and children dying. However, most participants said that peoples' negative opinions about HIV were changing, albeit slowly, and that HIV was less taboo and more accepted today.

Recurring themes in the participants' interviews were being unwillingly labelled as a person with HIV, losing control over who was informed about one's HIV and losing control over how you were perceived as a person. Participants said that it was important for them to have control over who knew about their HIV. They described thinking about how people would react and estimated the risk of people telling others about their HIV without their permission. As one participant said: *I really want to keep it to myself...I don't want to see how the person reacts...they'll feel sorry for me or 'you disgust me'. I just want to be left in peace* (Participant #14). Participants reported that in every new encounter or relationship they made decisions about whether to disclose and if so, about how and when to disclose. *But it's that a lot of people have a hard time with it, you sort of have to...you might say come out every time to someone new if you have a new relationship* (Participant #7). Participants commonly expressed that HIV was not a secret, but at the same time not something that you told people about. Some participants described HIV as a private issue or something that other people were not interested in hearing about. One participant described themselves as gradually becoming more open but said:

I'm really so torn because...it shouldn't matter...I'm first and foremost [name] and I'm also a whole lot of other things before I'm HIV, sort of. That's where it gets hard. Then I become HIV-[participant's name] ... and that's the question, do I want that? The dream is just to be simply [participant's name], that's my dream, that you are accepted for who you are and aren't categorized by...which socks you have or what job or how much money you make or if you have HIV. (Participant #2)

In the interviews, it was common for participants to describe anticipating stigma in some specific settings but not in others. One participant anticipated stigma only in what they called the 'homosexual world'. Everybody in 'the heterosexual world' knew about their HIV, but in the 'homosexual world' they expected to be judged and categorized as sick.

It's a totally different situation in the homosexual world. There you're still labeled. We're so tough. We judge everyone really hard, we gay men, terribly hard. It's ...It's happened to me and I know people whose... conversations are deleted on those mobile apps, you get labeled as sick, in quotes, and all that kind of stuff, and it's really tough. ... so a lot of people are hesitant about being open. (Participant #2)

They anticipated being blocked and judged on dating apps by potential partners before they got a chance to know them. Similar narratives were shared by some participants who had migrated to Sweden from sub-Saharan countries, but in such situations, fellow countrymen living in Sweden were said to be those participants anticipated being stigmatized by. One participant predicted that if one of their fellow countrymen knew, everybody in that community would know in a week, and they would have to leave the country because everybody would be talking about them. *I can't be here, they said, I'm going to move to another country. I can't live here...you know, everyone will talk about me...so I just can't be comfortable here...I'm going to move tomorrow, I can't stay here* (Participant #3). This participant continued, saying people would treat them badly even if knowledgeable about effective antiretroviral treatments, *Most people, they know but they don't want to...They don't have it in their heart to accept those kind of people*. The similarity between these participants' stories lies in the description of communities close to them (the 'homosexual world' and fellow countrymen) where information is thought to spread quickly and people risk being rejected.

Other participants anticipated stigma only when disclosing to a potential partner, which could be said to be the only situation in which they disclosed their HIV to others. One participant said that HIV only affected their life when it came to relationships: *Yeah, when it comes to relationships, there's a lot about relationships. Just that, otherwise it's perfect, my life is perfect* (Participant #13). This participant emphasized that they had only positive experiences of telling

a partner about their HIV: *It takes a bit of doing, before you have told them, before you know how they're going to deal with it. Otherwise it's nothing. Nothing strange. Because I would use a condom in any case to protect myself, so there's nothing weird about it, I think.*

Another specific setting where participants described anticipating stigma was their workplace. While participants did not speak directly of the risk of losing a job, descriptions were more centred on whether people in their workplace would react negatively. One participant, who worked with children in a Swedish daycare facility, spoke of how the parents would react if they knew about their HIV. *If they knew, I think it would be horrible, they'll look at you differently* (Participant #14).

On a structural level, some participants anticipated that it might be hard to travel to certain countries. Some participants did not seem concerned about this and said that they would lie about having HIV if they, for example, had to fill out an application for a visa. Other participants had stopped travelling because of the potential risk of having to show their medications in customs with the risk of being denied entry into the country.

#### 4.4 | Internalized stigma

Most participants did not describe feelings of guilt and shame, saying instead that their HIV had no impact on how they viewed themselves. *It's hasn't affected my self-image at all*, one participant said, *I've never gotten into self-hatred or become self-destructive, more the opposite* (Participant #2).

However, some participants described, in line with Earnshaw and Chaudoir's (2009) definition of internalized stigma, a variety of negative feelings and beliefs about themselves. While the content of such narratives reflecting internalized stigma could differ by participants, descriptions seemed to remain similar to those found by Earnshaw and colleagues (2009; 2013) before the full implementation of effective antiretroviral treatment.

One participant reported that they would be embarrassed if other people knew about their HIV. *It feels...embarrassing, shameful. That's how it feels* (Participant #14). Another described having had negative feelings towards people living with HIV before receiving their own diagnosis. When reporting that their fellow countrymen would treat them badly if they knew about their HIV, this participant said: *There's no room for someone HIV-positive...and if you tell me you're positive and I'm negative...almost worse. I won't say hello to you. We're like that* (Participant #3). Most descriptions categorized as internalized stigma contained ideas about being contagious that were not aligned with existing medical knowledge. Some participants had restricted their love life, avoiding finding new partners or preferring partners who also have HIV. Even though the participants were well-informed about their undetectable virus levels and the extremely low risk of transmitting HIV to others, some took their own precautions to protect others.

Now that I work with children, I worry so much.  
Darn, can I infect the kids? Every time I use...gloves.

If they fall or something. When I clean or wash the sore, I have to have gloves. Not for my sake, it's for their sake. If I see blood or anything, I run, lift up the child, and immediately put on gloves. (Participant #14)

## 5 | DISCUSSION

In this study, we sought to explore the experiences of HIV-related stigma among persons currently living with suppressed HIV and examine how these experiences fit with the HIV stigma framework by Earnshaw and Chaudoir (2009), developed prior to the advances in HIV treatment. Through framework analysis of interviews with persons who are virally suppressed, we suggest additional content and nuance in the individual stigma mechanisms (Earnshaw & Chaudoir, 2009), particularly with regard to enacted and anticipated stigma. The stigma mechanisms for people living with HIV are, according to Earnshaw and Chaudoir (2009), individual processes of stigmatization elicited by the existence of HIV as a stigmatized 'mark'. Analysis of our data suggests that it may not always be possible or desirable to limit stigma mechanisms to the experiences of discrete individuals without recognizing the strength and impact of relationships with other people. Several participants reported that the most immediate risk of stigma and rejection came from their own close community; for example, friends and family with the same country of origin, or from friends in the gay community. Although the stigma experience can differ between communities other studies have also shown that experiences of community stigma may lead to social rejection and isolation and in general have a very negative impact on persons' health and wellbeing (Fletcher et al., 2016, Turan et al., 2017).

Although the individual stigma mechanisms (Earnshaw & Chaudoir, 2009) build on Link and Phelan's (2001) definition of stigma, where the concept of labelling plays a central part, labelling is not included in mechanisms described by Earnshaw and Chaudoir (2009). The HIV stigma framework recognizes prejudice, stereotypes and discrimination as separate processes that may affect different types of outcomes (Earnshaw & Chaudoir, 2009) and we suggest that labelling be included as a fourth process. In the present study, labelling was central in the narratives categorized as both enacted and anticipated stigma and appears to be an intrinsic part of the individual level of HIV stigma conceptualization. In Link and Phelan's (2001) conceptualization of stigma, labelling, that is when other people distinguish and label a person as different, is the first component. We regard it as probably that, in the process of HIV becoming normalized, labelling will be the last persistent component of stigma. When people with HIV are no longer discriminated against or subjected to prejudice, the single act of labelling keeps them from feeling they are what Goffman (1963) referred to as a 'whole and usual person'.

The general experience of participants was that the biomedical realities of living with HIV today—taking medication once a day

and having unquantifiable viral levels—are not facts that are widely known in society. Participants often described how the old images of HIV as a deadly disease still shape many people's images of HIV. This is in line with other studies acknowledging several HIV discourses that seem to exist simultaneously in the contemporary era, creating tensions between the image of the hyper-infectious 'AIDS body' and images of the ordinary non-infectious body (McGrath et al., 2014; Persson, 2013; Rai et al., 2018). We want to highlight that most participants said that they felt healthy and that HIV was not a big part of their life. We consider such statements to be expressions of resilience, a feature of significance to protect the health of people living with HIV (Dulin et al., 2018).

While the issue of disclosure was central for study participants, it did not appear to be a prerequisite for participants to accept their HIV status or to live fulfilling lives. It was important for participants to control who knew about their HIV, partly to avoid being treated badly, but also to pursue that others perceived them as they perceived themselves. Some also said that HIV was private and that they did not think they would disclose it to everyone, even if HIV was totally accepted. Earlier literature has highlighted both potential costs of disclosure (Feigin et al., 2013; Murphy et al., 2016) and disclosure being beneficial to both the individual and the community (Paxton, 2002). Disclosure has been said to play a significant role in accepting and coping with HIV (Medley et al., 2004) and is considered an important step in receiving HIV-related social support. However, disclosure may be a risk factor for stigmatization (Chaudoir et al., 2011) and several key concepts about disclosure (e.g. that untold secrets are harmful and that the experience of telling secrets can be healing) have been questioned and discussed in recent research on HIV counselling (Mazanderani & Papparini, 2015; Nguyen, 2013). The present study indicates that people who are virally suppressed might have multiple, complex reasons for not disclosing their HIV. Our findings suggest that nondisclosure may be an action taken to prevent stigmatization, but also that disclosure is context-related and a result of negotiating and weighing the relevance of disclosing HIV, perceiving HIV as a private matter and the perceived responsibility of disclosure. Another significant reason for nondisclosure was, as mentioned earlier, to prevent being labelled and HIV becoming the prime factor defining them as persons.

## 5.1 | Limitations

We chose to work with framework approach since the method is suitable for thematic analysis of interview data and allows for building further on, adapting, refuting and expanding on existing knowledge while maintaining an explorative component (Gale et al., 2013). The use of predetermined codes in a framework approach may lead to confirmation bias. However, we did not only have a critical approach to the predetermined stigma mechanisms, but also coded inductively. It should be remembered that our aim was to use the material to critically examine and revise the stigma mechanisms. We found this critical use of the stigma mechanisms as predetermined

categories in a framework approach analysis beneficial, since existing evidence could be incorporated into the analysis thus preventing 'reinvention of the wheel'.

The present study focuses on experiences of HIV-related stigma. It is, however, common that people may also experience other stigma, for example related to gender, origin, sexuality, etc. This can lead to an experience of layered stigma, grounded in the intersections of stigmatized characteristics (Henrickson & Fisher, 2016). It is interesting to note that while layered stigma was occasionally alluded to, albeit in different words, participants maintained their focus on the experience of HIV-related stigma, despite some probing. Further specific investigation of layered stigma is a compelling issue for further study.

## 5.2 | Implications for care

It is known from earlier studies that internalizing stigma may be related to experiences of emotional distress and impaired quality of life, even for people who are virally suppressed (Reinius et al., 2018). It is therefore desirable that people experiencing internalized stigma related to living with HIV receive support and counselling from healthcare professionals; the findings from the present study may be helpful in identifying patients with internalized stigma. For example, patients may have prejudice about other people with HIV or take precautions that are not necessary from the perspective of communicable disease control. The healthcare system often has a central role in the mechanisms of disclosure and labelling about HIV. People living with HIV in Sweden were, up until 2013, obliged to disclose their HIV to sexual partners, but now they may be exempted from this obligation. This exemption is still, however, a decision for physicians to make based on the patient's adherence to treatment and treatment results (The Public Health Agency of Sweden, 2018). Indeed, earlier research has shown that healthcare providers working in non-HIV specific medical environments are more likely to enact stigma and uphold HIV-related stigma than are professionals more familiar with HIV care (Fisher & Henrickson, 2019). Swedish medical records are still being marked with warning labels for people living with HIV and, although this procedure is under evaluation, it is worth noting that this is a distinct act of labelling. We find it counterproductive to offer counselling to support people who experience negative consequences of stigma, and at the same time label people living with HIV through a distinguishing mark in the medical record, which, according to stigma theory, may constitute the very foundation of that stigma (Link & Phelan, 2001).

## 6 | CONCLUSIONS

The HIV stigma framework could benefit from revision for people living with virally suppressed HIV in a context where HIV treatment is easily accessed and free of charge. While internalized stigma seemed to remain similar to that described earlier by Earnshaw and colleagues



(2009), enacted and anticipated stigma were found to be more complex, primarily for two reasons. First, participants often incorporated other peoples' encounters with stigma into their own experience of stigma. Second, labelling was identified as an element of stigma that could exist independently to prejudice and discrimination. Disclosure was found to be context-related and a result of negotiating and weighing up the relevance of disclosing HIV, perceiving HIV as a private matter, and feeling a responsibility to disclose one's HIV status to others. An important reason for nondisclosure was to avoid being labelled and HIV becoming the prime factor defining them as persons.

## ACKNOWLEDGEMENTS

First of all, the authors would like to thank the participants that generously donated their time to be interviewed for this study. Thank you for so openly sharing your experiences. We would also like to acknowledge the contribution of the staff at the Infectious Disease Unit at the Karolinska University Hospital, especially research nurses Lena Mattsson and Sofia Sandberg, who assisted the research team in the recruitment phase. Professor Carol Tishelman gave invaluable insights regarding qualitative analysis during the work with this study, translated respondents' quotes from Swedish to English and also helped with proofreading.

## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.14774>.

## DATA AVAILABILITY STATEMENT

Research data are not shared.

## ORCID

Maria Reinius  <https://orcid.org/0000-0003-0864-8701>

Veronica Svedhem  <https://orcid.org/0000-0003-0845-1685>

Lena Wettergren  <https://orcid.org/0000-0003-1279-2191>

Maria Wiklander  <https://orcid.org/0000-0002-8250-3773>

Lars E. Eriksson  <https://orcid.org/0000-0001-5121-5325>

## REFERENCES

- Andersson, G. Z., Reinius, M., Eriksson, L. E., Svedhem, V., Esfahani, F. M., Deuba, K., Rao, D., Lyatuu, G. W., Giovenco, D., & Ekström, A. M. (2019). Stigma reduction interventions in people living with HIV to improve health-related quality of life. *Lancet HIV*, 7(2), e129–e140. [https://doi.org/10.1016/S2352-3018\(19\)30343-1](https://doi.org/10.1016/S2352-3018(19)30343-1)
- Chaudoir, S. R., Fisher, J. D., & Simoni, J. M. (2011). Understanding HIV disclosure: A review and application of the Disclosure Processes Model. *Social Science and Medicine*, 72(10), 1618–1629. <https://doi.org/10.1016/j.socscimed.2011.03.028>
- Dulin, A. J., Dale, S. K., Earnshaw, V. A., Fava, J. L., Mugavero, M. J., Napravnik, S., Hogan, J. W., Carey, M. P., & Howe, C. J. (2018). Resilience and HIV: A review of the definition and study of resilience. *AIDS Care*, 30(sup5), S6–S17. <https://doi.org/10.1080/09540121.2018.1515470>
- Earnshaw, V. A., & Chaudoir, S. R. (2009). From conceptualizing to measuring HIV stigma: A review of HIV stigma mechanism measures. *AIDS and Behavior*, 13(6), 1160–1177. <https://doi.org/10.1007/s10461-009-9593-3>
- Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: A test of the HIV stigma framework. *AIDS and Behavior*, 17(5), 1785–1795. <https://doi.org/10.1007/s10461-013-0437-9>
- Feigin, R., Sapir, Y., Patinkin, N., & Turner, D. (2013). Breaking through the silence: The experience of living with HIV-positive serostatus, and its implications on disclosure. *Social Work in Health Care*, 52(9), 826–845. <https://doi.org/10.1080/00981389.2013.827143>
- Fisher, M., & Henrickson, M. (2019). Are statutory protections sufficient to protect people living with HIV who are employed in the medical workplace? *Int J Healthc Manag*, 12(1), 75–80. <https://doi.org/10.1080/20479700.2017.1398387>
- Fletcher, F., Ingram, L. A., Kerr, J., Buchberg, M., Bogdan-Lovis, L., & Philpott-Jones, S. (2016). "She Told Them, Oh That Bitch Got AIDS": Experiences of multilevel HIV/AIDS-Related Stigma Among African American Women Living with HIV/AIDS in the South. *AIDS Patient Care and STDs*, 30(7), 349–356. <https://doi.org/10.1089/apc.2016.0026>
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13, 117. <https://doi.org/10.1186/1471-2288-13-117>
- Gisslén, M., Svedhem, V., Lindborg, L., Flamholc, L., Norrgren, H., Wendahl, S., Axelsson, M., & Sönnnerborg, A. (2016). Sweden, the first country to achieve the Joint United Nations Programme on HIV/AIDS (UNAIDS)/World Health Organization (WHO) 90–90–90 continuum of HIV care targets. *HIV Medicine*, 18(4), 305–307. <https://doi.org/10.1111/hiv.12431>
- Goffman, E. (1963). *Stigma; notes on the management of spoiled identity*. Prentice-Hall.
- Henrickson, M., & Fisher, M. (2016). 'Treating Africans differently': Using skin colour as proxy for HIV risk. *Journal of Clinical Nursing*, 25, 1941–1949. <https://doi.org/10.1111/jocn.13212>
- InfCareHIV. A National quality register. <https://qrcstockholm.se/register/anslutna-register/infcarehiv-och-infcarehepatit/>
- Langebeek, N., Gisolf, E. H., Reiss, P., Vervoort, S. C., Hafsteinsdóttir, T. B., Richter, C., Sprangers, M. A. G., & Nieuwkerk, P. T. (2014). Predictors and correlates of adherence to combination antiretroviral therapy (ART) for chronic HIV infection: A meta-analysis. *Bmc Medicine*, 12, 1–14. <https://doi.org/10.1186/s12916-014-0142-1>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385. <https://doi.org/10.1146/annurev.soc.27.1.363>
- Logie, C. H., James, L., Tharao, W., & Loutfy, M. R. (2011). HIV, gender, race, sexual orientation, and sex work: A qualitative study of intersectional stigma experienced by HIV-positive women in ontario, Canada. *PLoS Medicine*, 8(11), 12. <https://doi.org/10.1371/journal.pmed.1001124>
- Mazanderani, F., & Papparini, S. (2015). The stories we tell: Qualitative research interviews, talking technologies and the 'normalisation' of life with HIV. *Social Science & Medicine*, 131, 66–73. <https://doi.org/10.1016/j.socscimed.2015.02.041>
- McGrath, J. W., Winchester, M. S., Kaawa-Mafigiri, D., Walakira, E., Namutiibwa, F., Birungi, J., Ssendegyie, G., Nalwoga, A., Kyarikunda, E., Kisakye, S., Ayebazibwe, N., & Rwabukwali, C. B. (2014). Challenging the paradigm: Anthropological perspectives on HIV as a chronic disease. *Medical Anthropology*, 33(4), 303–317. <https://doi.org/10.1080/01459740.2014.892483>
- Medley, A., Garcia-Moreno, C., McGill, S., & Maman, S. (2004). Rates, barriers and outcomes of HIV serostatus disclosure among women

- in developing countries: Implications for prevention of mother-to-child transmission programmes. *Bulletin of the World Health Organization*, 82(4), 299–307.
- Moyer, E., & Hardon, A. (2014). A disease unlike any other? Why HIV remains exceptional in the age of treatment. *Medical Anthropology*, 33(4), 263–269. <https://doi.org/10.1080/01459740.2014.890618>
- Murphy, P. J., Hevey, D., O'Dea, S., Rathaille, N. N., & Mulcahy, F. (2016). Serostatus disclosure, stigma resistance, and identity management among HIV-positive gay men in Ireland. *Qualitative Health Research*, 26(11), 1459–1472. <https://doi.org/10.1177/1049732315606687>
- Nguyen, V. K. (2013). Counselling against HIV in Africa: A genealogy of confessional technologies. *Cult Health Sex*, 15(Suppl 4), S440–452. <https://doi.org/10.1080/13691058.2013.809146>
- Patton, M. Q., & Patton, M. Q. (2002). *Qualitative research and evaluation methods*. , 3rd ed. Sage Publications.
- Paxton, S. (2002). The paradox of public HIV disclosure. *AIDS Care*, 14(4), 559–567. <https://doi.org/10.1080/09540120208629674>
- Persson, A. (2013). Non/infectious corporealities: Tensions in the biomedical era of 'HIV normalisation'. *Sociology of Health & Illness*, 35(7), 1065–1079. <https://doi.org/10.1111/1467-9566.12023>
- Rai, T., Bruton, J., Day, S., & Ward, H. (2018). From activism to secrecy: Contemporary experiences of living with HIV in London in people diagnosed from 1986 to 2014. *Health Expectations*, 21(6), 1134–1141. <https://doi.org/10.1111/hex.12816>
- Rao, D., Feldman, B. J., Fredericksen, R. J., Crane, P. K., Simoni, J. M., Kitahata, M. M., & Crane, H. M. (2012). A structural equation model of HIV-related stigma, depressive symptoms, and medication adherence. *AIDS and Behavior*, 16(3), 711–716. <https://doi.org/10.1007/s10461-011-9915-0>
- Reinius, M., Wiklander, M., Wettergren, L., Svedhem, V., & Eriksson, L. E. (2018). The relationship between stigma and health-related quality of life in people living with HIV who have full access to antiretroviral treatment: An assessment of earnshaw and Chaudoir's HIV stigma framework using empirical data. *AIDS and Behavior*, 22(12), 3795–3806. <https://doi.org/10.1007/s10461-018-2041-5>
- Ritchie, J., & Lewis, J. (2003). *Qualitative research practice: A guide for social science students and researchers*. Sage Publications.
- Ritchie, J. S., & Liz, S. (1994). Qualitative data analysis for applied policy research. In A. B. Bryman & G. Robert (Eds.), *Analyzing qualitative data*. Routledge.
- Rodger, A. J., Cambiano, V., Bruun, T., Vernazza, P., Collins, S., Degen, O., Group, P. S. (2019). Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): Final results of a multicentre, prospective, observational study. *Lancet*, 393(10189), 2428–2438. [https://doi.org/10.1016/S0140-6736\(19\)30418-0](https://doi.org/10.1016/S0140-6736(19)30418-0)
- Rueda, S., Mitra, S., Chen, S., Gogolishvili, D., Globerman, J., Chambers, L., Wilson, M., Logie, C. H., Shi, Q., Morassaei, S., & Rourke, S. B. (2016). Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: A series of meta-analyses. *British Medical Journal Open*, 6(7), e011453. <https://doi.org/10.1136/bmjopen-2016-011453>
- Rydstrom, L. L., Wiklander, M., Naver, L., Ygge, B. M., & Eriksson, L. E. (2016). HIV-related stigma and health-related quality of life among children living with HIV in Sweden. *AIDS Care*, 28(5), 665–671. <https://doi.org/10.1080/09540121.2015.1120267>
- Smith, C., Cook, R., & Rohleder, P. (2017). 'When it comes to HIV, that's when you find out the genuinity of that love': The experience of disclosing a HIV+ status to an intimate partner. *J Health Psychol*, 24(8), 1011–1022. <https://doi.org/10.1177/1359105317691588>
- The Public Health Agency of Sweden (2018). Tillämpning av smittskyddslagens förhållningsregler vid hivinfektion. Retrieved from [www.folkhalsomyndigheten.se/publicerat-material](http://www.folkhalsomyndigheten.se/publicerat-material).
- Turan, B., Budhwani, H., Fazeli, P. L., Browning, W. R., Raper, J. L., Mugavero, M. J., & Turan, J. M. (2017). How does stigma affect people living with HIV? the mediating roles of internalized and anticipated HIV stigma in the effects of perceived community Stigma on health and psychosocial outcomes. *AIDS and Behavior*, 21(1), 283–291. <https://doi.org/10.1007/s10461-016-1451-5>
- Vaughan, E., Power, M., & Sixsmith, J. (2020). Experiences of stigma in healthcare settings by people living with HIV in Ireland: A qualitative study. *AIDS Care*, 32(9), 1162–1167. <https://doi.org/10.1080/09540121.2020.1781761>
- Zeluf-Andersson, G., Eriksson, L. E., Schonnesson, L. N., Hoijer, J., Manehall, P., & Ekstrom, A. M. (2019). Beyond viral suppression: The quality of life of people living with HIV in Sweden. *AIDS Care*, 31(4), 403–412. <https://doi.org/10.1080/09540121.2018.1545990>

**How to cite this article:** Reinius M, Zeluf Andersson G, Svedhem V, Wettergren L, Wiklander M, Eriksson LE. Towards a new understanding of HIV-related stigma in the era of efficient treatment- A qualitative reconceptualization of existing theory. *J Adv Nurs*. 2021;00:1-9. <https://doi.org/10.1111/jan.14774>

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