Trends in HIV Stigma Experienced by People Living with HIV in the Netherlands:

A Comparison of Cross-sectional Surveys over Time

Sarah E. Stutterheim, PhD^{1,2}, Kyran J. R. Kuijpers, BSc¹, Moon I. Waldén, BSc¹,

Renee N. N. Finkenflügel, MSc³, Pieter A. R. Brokx, BSc³, & Arjan E. R. Bos, PhD⁴

¹ Department of Work and Social Psychology, Maastricht University, Maastricht, the Netherlands

² Department of Health Promotion/Care and Public Health Research Institute, Maastricht, the Netherlands

³ The Dutch Association of People with HIV [HIV Vereniging], Amsterdam, the Netherlands

⁴ Faculty of Psychology, Open University of the Netherlands, Heerlen, the Netherlands

Author note

Sarah E. Stutterheim, ORCID: 0000-0001-9336-5022

Kyran J. R. Kuijpers, ORCID: 0000-0002-7453-6057

Moon I. Waldén, ORCID: 0000-0002-3008-7448

Renee N. N. Finkenflügel, ORCID: 0000-0003-2270-6066

Arjan E. R. Bos, ORCID: 0000-0003-1000-5852

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Correspondence concerning this article should be addressed to Sarah E. Stutterheim, Department of Work and Social Psychology, Faculty of Psychology and Neuroscience, Maastricht University, PO Box 616, 6200 MD, Maastricht, the Netherlands, s.stutterheim@maastrichtuniversity.nl

ABSTRACT

We investigated whether HIV stigma in the Netherlands has changed in recent years. We compared data on stigma settings and manifestations from 2007 ($n = 667$) and, specifically for the health care sector, 2009 ($n = 262$), to data acquired in 2019 and 2020 ($n = 258$). Results showed reductions in stigma from friends, family, acquaintances, at work, in the financial services sector, and in media. However, stigmatizing messages in media remained highly prevalent. Stigma in the LGBTQI+ community, with sexual partners, and while partying remained prevalent and, disconcertingly, relatively unchanged. Stigma in health care increased for a number of stigma manifestations, including physical distance, excessive preventive measures, awkward social interactions, avoidance, and unnecessary referrals. As expected, HIV stigma was positively related to psychological distress, and negatively related to social support and medication adherence. Further, most participants were familiar with U=U and PrEP, but 13.3% questioned the accuracy of U=U. Overall, the findings suggest that stigma reduction efforts should focus on reducing stigma in media, in the LGBTQI+ community and while dating, and in health care. In all of these contexts, a key message is U=U.

Keywords: HIV, stigma, media, LGBTQI+, health care, survey

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Stigmatization is a socially and culturally constructed process where a person is labelled as different and then devalued, resulting in status loss and discrimination (Link & Phelan, 2014; Pescosolido & Martin, 2015). It occurs in social interactions, reproduces social inequalities, and is perpetuated by social, economic, and political power (Link & Phelan, 2014). Since its onset in the 1980s, HIV has been a highly stigmatized condition (Chan, Mak, Ma, & Cheung, 2021; Stutterheim et al., 2014). This stigma has been driven by societal beliefs about the severity and contagiousness of HIV, perceptions that people who acquire HIV are blameworthy, and associations between HIV and behaviours that violate some individuals' norms such as sex between men, having multiple partners, drug use, and sex work (Stutterheim, Bos, van Kesteren, et al., 2012). As such, HIV stigma is both instrumental and symbolic (Maughan-Brown, 2010). Instrumental stigma is driven by fear of, for example, infection and death, while symbolic stigma is the result of negative moral judgments about behaviors associated with HIV and responsibility for acquiring HIV.

HIV stigma has highly detrimental consequences. It impacts the full treatment cascade - from testing to linkage to care, and through to treatment initiation and adherence, and, finally, viral suppression (Sullivan et al., 2020). It also, and importantly, has deleterious impacts on the quality of life of people living with HIV. Previous literature has demonstrated that HIV stigma can result in poorer psychological well-being, including depression and anxiety (Darlington & Hutson, 2017; Lowther, Selman, Harding, & Higginson, 2014), and is associated with lower self-esteem (Kalomo, 2018; Kay et al., 2018). Additionally, lower social support has been established as a correlate of stigma (Darlington & Hutson, 2017), and it has been tested as both a mediator and a moderator of the relationship between stigma and psychological distress (Breet, Kagee, & Seedat, 2014; Brener et al., 2020; Kondrat, Sullivan, Wilkins, Barrett, & Beerbower, 2018). Further, there is significant literature indicating that stigma can lead to detrimental health outcomes via poor treatment and clinic adherence (Katz et al., 2013; Sweeney & Venable, 2016).

HIV stigma is not a simple experience. In fact, it can manifest in many ways including avoidance, exclusion, rejection, blame, aggression, physical distance, indifference, and awkward social interactions (Darlington & Hutson, 2017; Stutterheim, Bos, Shiripinda, et al., 2012; Stutterheim et al., 2009). Additionally, it can occur in many contexts, settings, or domains including with families, with friends, in sexual relationships, in faith communities, at work, in the financial services sector, in schools, in the media, and in health care (Card et al., 2019; Chan et al., 2021; Smit et al., 2012; Stutterheim et al., 2009; Stutterheim et al., 2014).

Today, people living with HIV on successful antiretroviral therapy live long and healthy lives, and cannot transmit HIV to others, in the context of condomless sex or otherwise. When viral load is undetectable, HIV is untransmittable (U=U), and therefore not infectious (Deeks, Lewin, & Havlir, 2013). Also, new developments in HIV prevention, such as preexposure prophylaxis (PrEP), offer additional freedoms and possibilities (Garofalo, Kuhns, Reisner, & Mimiaga, 2016). With these developments in mind, and with the recognition that, currently, treated HIV is neither contagious nor severe, we might expect that HIV stigma has reduced in recent years.

Accordingly, we set out to investigate changes in HIV stigma as experienced by people living with HIV in the Netherlands. Specifically, we explored changes in the prevalence of HIV stigma manifestations and settings by comparing data from a cross-sectional survey study conducted in 2007 to an analogous survey conducted in 2019 and early 2020. We then honed in on one particular context, namely health care settings, where HIV stigma is particularly detrimental to wellbeing (Stutterheim et al., 2009), and can hinder access to care and treatment adherence (Chan et al., 2021). To do this, we compared cross-sectional data from a survey we conducted on the specific health care experiences of people living with HIV in the Netherlands in 2009 to analogous data acquired in 2019/2020. This allowed us to investigate changes in the reported prevalence of a number of manifestations of stigma specific to health care settings, such as refusal to care, unnecessary referrals to other health care providers, excessive protective measures, and breaches of confidentiality (Geter, Herron, & Sutton, 2018; Stutterheim et al., 2014).

Subsequently, we investigated the extent to which perceived HIV stigma among people with HIV in the Netherlands in 2020 is associated with established psychological, social, and health outcomes of HIV stigma experiences, namely psychological distress (including depression and anxiety), self-esteem, social support, and both treatment and clinic adherence. Lastly, we established the extent to which people with HIV are aware of U=U and PrEP, and, among those aware, the perceived impact of U=U and PrEP on their experience of having HIV. We found this to be important as both U=U and PrEP are considered to hold significant potential for HIV stigma reduction (Brown et al., 2017; Kalwicz et al., 2020; Wolff, Campbell, Tross, Weaver, & Des Jarlais, 2017).

METHODS

Participants and procedure

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In 2007 (May to October), 2009 (October), and then again in late 2019 and early 2020 (September to March), people living with HIV in the Netherlands were approached to complete cross-sectional national surveys on HIV stigma and its correlates. As reported in Stutterheim et al. (2009), participants in the 2007 pen-and-paper survey were approached by mail by the Dutch Association of People with HIV ($n = 1433$), in person by HIV nurses ($n = 823$), or they directly sought contact with the researchers when they heard about the study from others ($n = 3$). A total of 669 people returned the survey.

Then, based on findings of the 2007 survey showing that stigma in health care is detrimental to the wellbeing of people living with HIV (Stutterheim et al., 2009), we recruited people living with HIV again in October of 2009 to complete an online survey on health care specific manifestations of stigma ($n = 262$). As described in Stutterheim et al. (2014), these participants were drawn from an online panel of 342 people living with HIV hosted by the Dutch Association of People with HIV.

In late 2019 and early 2020 (hereafter referred to as the 2020 survey), people living with HIV were recruited once again to complete an online survey of HIV stigma settings and manifestations, also health care specific. These participants ($n = 258$) were recruited via an advertisement on the website of the Dutch Association of People with HIV, via HIV nurses during consultations using a recruitment folder, and via other civil society organizations who posted the advertisement on their website and distributed printed recruitment folders.

For all three surveys, inclusion criteria were having been diagnosed with HIV and being over 17 years of age. Informed consent was obtained and no monetary compensation was provided. Ethics approval was granted by the Ethics Review Committee at Maastricht University's Faculty of Psychology and Neuroscience (OZL_188_11_02_2018_S15) and this study was preregistered at OSF (<https://osf.io/vta8u>).

Measures

HIV stigma settings were measured in 2007 and 2020 using a 16-item index developed by Stutterheim et al. (2009) based on stigma literature and consultation with people living with HIV and HIV professionals. This index (displayed in the supplemental materials) measured 16 different settings (1 item per setting): immediate family, extended family, friends,

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other people living with HIV, sexual partner(s), work, general practitioner, dentist, hospitals, financial services sector, school, faith community, LGBTQI+ community, acquaintances while partying, leisure activities and hobbies, and media. Participants were asked to indicate whether they had experienced stigma in each of the settings in the past five years. Each item was measured on a five-point Likert scale ranging from 1 (never) to 5 (very often), and then recoded to 'never' or 'ever' experiencing stigma in that setting. In the event that the setting was not relevant or applicable for a participant, an answer option 'not applicable' was included.

HIV stigma manifestations were measured in 2007 and 2020 using an 11-item index developed by Stutterheim et al. (2009), also based on stigma literature and consultations with people living with HIV and HIV professionals. This index (displayed in the supplemental materials) measured 11 manifestations (1 item per manifestation): aggression, avoidance, awkward social interactions, being told to conceal HIV status from others, being told to disclose HIV status to others, blame, excessive kindness, excessive preventive measures, exclusion, increased physical distance, and indifference. Additionally, participants were asked if they had experienced 'sympathy and support'. For each manifestation, participants indicated if they had experienced that manifestation in the past five years with 'yes' or 'no'.

Health care specific manifestations of HIV stigma were measured in 2009 and 2020 using an index developed by Stutterheim et al. (2014) that was modelled on the HIV stigma manifestations index, and based on the literature on HIV stigma in health care and a focus group conducted with people living with HIV and HIV professionals. The index (displayed in the supplemental materials) measured 15 manifestations of HIV stigma in health care in 2009 and 16 in 2020 (1 item per manifestation). The overlapping manifestations were: aggression, avoidance, awkward social interactions, being advised to conceal HIV status, being advised to disclose HIV status, blame, excessive kindness, excessive preventive measures, increased physical distance, confidentiality breaches, differential protective measures, discouragement of care, refusal to care, and unnecessary referrals. In 2020, we added 'indifference' and 'exclusion', and removed 'rude and unkind behavior' based on feedback from the Association of People with HIV. Additionally, participants were asked if they had experienced 'sympathy and support' from health care professionals and whether they had avoided seeking health care because of negative interactions. For each manifestation, participants indicated if they had experienced that manifestation in the past five years with 'yes' or 'no'.

Perceived HIV stigma was measured in 2020 using the abbreviated 10-item version of the HIV stigma scale (Berger, Ferrans, & Lashley, 2001) validated by Wright et al. (2007). This scale measures personalized stigma, disclosure concerns, negative self-image, and public attitudes towards HIV. Answers were provided on a five-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). A higher score was indicative of more perceived HIV stigma. An example item is: “I have lost friends by telling them I have HIV”. In our study, Cronbach’s alpha was .90.

Psychological distress was measured in 2020 using the Mental Health Inventory (MHI), which includes subscales for depression, anxiety, positive affect, and behavioral control (Veit & Ware, 1983). The scale comprises 18 items, all of which were answered on a six-point scale ranging from 1 (none of the time) to 5 (all of the time). In our study, a higher score was indicative of more psychological distress. This scale has been used extensively and is considered both valid and reliable (Heubeck & Neill, 2000; Veit & Ware, 1983). An example item is: “Have you been anxious or worried?” Cronbach’s alpha in our 2020 study was .87.

Self-esteem was measured in 2020 with the Rosenberg Self-Esteem Scale (RSE) (Rosenberg, 1965). The RSE scale contains ten items that are scored on a four-point scale ranging from 1 (strongly disagree) to 4 (strongly agree). A higher score was indicative of greater self-esteem. An example item is: “I am able to do things as well as most other people”. The RSE is a frequently used and valid measure of self-esteem (Villalobos, 2015). Cronbach’s alpha was .83.

Social support was measured in 2020 using the 12-item short version of the Social Support List of Interactions (SSL-12) which measures the frequency of everyday support, social support in problem situations, and esteem support (Kempen & Van Eijk, 1995). Answers were provided on a four-point scale ranging from 1 (seldom or never) to 4 (very often). A higher score was indicative of more social support. An example item is: “Does it ever happen to you that people drop in for a visit?” This scale has good psychometric properties (Kempen & Van Eijk, 1995). Cronbach’s alpha in our study was .91.

Medication adherence was measured in 2020 using a 3-item measure developed and validated by Wilson et al. (2016). The first item assessed the number of days upon which ARVs were taken in the past 30 days by asking participants to indicate days missed and then deducting that from 30. The second measured adherence rating (“In the last 30 days, how good a job did you do at taking your HIV medication in the way you were supposed to?”) and answers were provided on a six-point scale ranging from 1 (very poor) to 6 (excellent). The third item measured frequency (“In the last 30 days, how

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often did you take your HIV medication in the way you were supposed to?”) and answers are provided on a 6-point scale ranging from 1 (never) to 6 (always).

Clinic adherence was measured in 2020 with a single item developed by the authors: “Have you missed any scheduled clinic visits with your HIV physician or nurse in the past year?” Participants answered ‘yes’ or ‘no’.

U=U awareness and impact were measured by asking participants to indicate the year in which they were first exposed to the U=U message, the source of that message (e.g., internist or HIV nurse, general practitioner, STI clinic, media, friend or acquaintance, Dutch Association of People with HIV), whether they believe that someone with an undetectable virus cannot transmit HIV to others (yes/no), and the extent to which knowing about U=U has impacted how they experience having HIV, which was measured on a seven point scale ranging from 1 (very negative) to 7 (very positive). These questions were developed by the Dutch Association of People with HIV.

PrEP awareness and impact were measured by asking participants to indicate the year in which they heard about PrEP and the extent to which knowing about PrEP has impacted how they experience having HIV, which was measured on a seven point scale ranging from 1 (very negative) to 7 (very positive). These questions were developed by the Dutch Association of People with HIV.

Demographic and background characteristics measured included gender, age, educational attainment, employment, relationship status, sexual orientation, ethnic background, and time since diagnosis.

Data analyses

Sample comparisons

We first compared demographic and background characteristics of participants in the 2020 survey to these characteristics in the 2007 and 2009 surveys by performing Pearson’s chi-square tests for gender, sexual orientation (straight, bisexual, gay), educational attainment (high school or less, high school and some vocational training, bachelor or more), employment, relationship status, and ethnic background (Dutch vs not Dutch). Sexual orientation follow-up tests were done with z-tests. Age and time since diagnosis were tested with independent sample t-tests.

HIV stigma settings and manifestations prevalence comparisons

We compared prevalence of stigma settings and manifestations (Table 1) between the 2007 and 2020 survey, and, for the health care sector manifestations (Table 2), between the 2009 and 2020 survey with Pearson's chi-square tests for each setting and manifestation. For all reported chi-square tests, the assumption of independence was met and there were no expected frequencies below 5.

Correlates of perceived stigma

To investigate the psychological, social, and health correlates of stigma, we first ascertained means, ranges, and standard deviations for all correlates measured (Table 3). For medication adherence, the score was calculated as outlined by Lauffenburger et al. (2020). We then calculated Pearson's correlations for all continuous variables, namely perceived stigma (as validated by Wright et al.), psychological distress (total score and individual subscales - depression, anxiety, behavioral control, and positive affect), self-esteem, social support, and medication adherence. For clinic adherence, we calculated a point-biserial correlation for missed clinic visits.

Then, we performed multiple regression analysis for psychological distress and medication adherence using the enter method (Table 4). Demographic and background characteristics were entered first (block 1), followed by perceived stigma (as validated by Wright et al.) and social support (block 2). To do this, we transformed age, perceived stigma, and social support into z-scores. Educational attainment and sexual orientation were transformed to dummy variables. The reference categories were respectively "high school or less" and "straight". As there appeared to be a quadratic relationship between social support and medication adherence, a quadratic term of social support was also included in the regression of medication adherence. We checked assumptions of linearity and homoskedasticity by plotting standardized predicted values against studentized residuals. We also checked predictors for abnormal tolerance, VIF, Cook's Distance, and Central Leverage Values, as indicated by Field (2018). Further, we checked studentized residuals for Normality. For all regression analyses, regression diagnostics did not reveal any conspicuous values. Normality tests of studentized residuals

showed that Normality was violated in the residuals of medication adherence, but due to the central limit theorem, we ascertained that this did not negatively affect the results (Field, 2018).

Descriptive analyses for U=U and PrEP awareness and impact

Lastly, we calculated descriptive statistics for U=U and PrEP awareness and impact.

RESULTS

Participant characteristics

2007 sample

In 2007, 667 participants were included in analyses. Of these, 86.2% were men ($n = 575$) and 13.8% were women ($n = 92$). Ages ranged from 17 to 75 with a mean age of 46.6 ($SD = 9.6$). Half had at least a bachelor's degree (49.5%; $n = 330$), 31.0% had a high school diploma and some vocational training ($n = 206$), and 19.5% had a high school diploma or less ($n = 130$). The majority self-identified as gay (79.5%; $n = 530$). Furthermore, 68.3% had paid employment ($n = 456$), 48.4% were in a relationship ($n = 323$), and 86.4% were of Dutch origin ($n = 576$). The mean time since diagnosis was 8.75 years ($SD = 6.0$).

2009 sample

Participants in the 2009 survey ($n = 262$) were also predominantly men (90.8%; $n = 238$). Ages ranged from 23 to 74 with a mean age of 47.3 years ($SD = 9.7$). Sixty percent had a bachelor's degree or more ($n = 157$), 25.9% a high school diploma and some vocational training ($n = 68$), 13.1% high school or less ($n = 34$), and data on educational attainment were missing for 3 participants. Again, the majority self-identified as gay (80.2%; $n = 210$) and of Dutch origin (90.1%; $n = 236$). About half were in a relationship (53.5%, $n = 99$). Mean time since diagnosis was 9.5 years ($SD = 6.6$).

2020 sample

In the 2020 survey ($n = 258$), 67.8% were men ($n = 175$), 26.4% were women ($n = 68$), 1.9% identified as transgender, genderqueer, or nonbinary ($n = 5$), 1.9% identified their gender as other ($n = 5$), and data were missing for a remaining 5 participants (1.9%). Ages ranged from 21 to 75 with a mean age of 49.4 ($SD = 12.0$). Regarding educational attainment, 58.6% had at least a bachelor's degree ($n = 151$), 26.4% had a high school diploma and some vocational training ($n = 68$), 13.2% had a high school diploma or less ($n = 34$), and data were missing for 5 participants (1.9%). More than half identified as gay (59.3%, $n = 153$), 29.5% as straight ($n = 76$), 7.4% as bisexual ($n = 19$), and data on sexual orientation were missing for 10 participants (3.9%). Most participants had paid employment (58.9%; $n = 152$), were in a relationship (58.9%; $n = 152$), and of Dutch origin (74.0%, $n = 191$). Mean time since diagnosis was 13.05 years ($SD = 8.7$).

Sample comparisons

Although the samples across the three surveys had relatively comparable demographic characteristics, some differences were established. Compared to the 2007 sample, the 2020 sample comprised more women ($p < .001$), was slightly older ($p < .001$), had less individuals that self-identified as gay ($p < .001$), had higher educational attainment ($p < .001$), lower rates of paid employment ($p = .011$), more individuals that are not of Dutch origin ($p < .001$), and a longer time since diagnosis ($p < .001$). Similarly, when compared to 2009 sample, the 2020 sample contained more women ($p < .001$), less individuals that self-identified as gay ($p < .001$), had higher educational attainment ($p = .002$), more individuals that are not of Dutch origin ($p < .001$), and a longer time since diagnosis ($p = .028$).

Stigma settings

Prevalence of stigma experiences across settings as ascertained in the 2020 and 2007 surveys are displayed in Table 1. In the 2020 survey, a substantial portion of participants had stigmatizing experiences with the media (70.9%, $n = 100$), in the LGBTQI+ community (58.6%, $n = 68$), with sexual partners (57.4%, $n = 89$), and while going out/partying (56.0%, $n = 61$). About a third of participants reported having experienced stigmatization in hospitals (34.3%, $n = 57$) and at the dentist (34.0%, $n = 48$), and 23.2% reported stigmatizing responses from their general practitioner ($n = 38$). Stigmatization from

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the financial services sector (34.3%, $n = 34$) was also experienced by about a third of participants, and about one in four had experienced stigma at work (28.8%, $n = 32$). Furthermore, 30.1% experienced stigmatizing responses from friends ($n = 50$), 25.6% with immediate family ($n = 40$), 27.6% with extended family ($n = 35$), and 25.0% with other people living with HIV ($n = 40$). Stigmatization in one's faith community (23.1%, $n = 9$), during leisure activities (21.1%, $n = 26$), and at school (11.9%, $n = 7$) were less common.

Compared to outcomes of the 2007 study, participants in the 2020 study reported significantly less stigmatizing experiences at work (52.0% vs. 28.8%; $p < .001$), in the financial services sector (58.4% vs. 34.3%; $p < .001$), in leisure activities (40.9% vs. 21.1%; $p < .001$), and in the media (79.1% vs. 70.9%; $p = .042$). Reductions were also noted for stigmatization from immediate family (34.8% vs. 25.6%; $p = .032$), extended family (39.0% vs. 27.6%; $p = .019$), and friends (39.3% vs. 30.1%; $p = .030$). Contrastingly, stigma experiences in hospital settings increased from 26.2% in 2007 to 34.3% in 2020 ($p = .037$). The remaining contexts showed no significant changes.

Table 1: Comparisons in the prevalence of stigma settings and manifestations from 2007 to 2020

	2020 %	2020 n	2020 Total n	2007 %	2007 N	2007 Total n	Chi square (df, n)	p -value
Settings								
Media	70.9	100	141	79.1	389	492	4.1 (1, $N = 633$)	.042*
LGBTQI+ community	58.6	68	116	66.7	290	435	2.6 (1, $N = 551$)	.107
Sexual partner(s)	57.4	89	155	51.9	295	568	1.5 (1, $N = 723$)	.225
Acquaintances from going out/partying	56.0	61	109	65.4	261	399	3.3 (1, $N = 508$)	.070
Hospital	34.3	57	166	26.2	170	649	4.4 (1, $N = 815$)	.037*
Dentist	34.0	48	141	28.8	150	521	1.5 (1, $N = 662$)	.227
General practitioner	23.2	38	164	19.2	124	646	1.3 (1, $N = 810$)	.256
Financial service sector	34.3	34	99	58.4	201	344	17.9 (1, $N = 443$)	.0001***
Work	28.8	32	111	52.0	193	371	18.5 (1, $N = 482$)	.0001***
Friends	30.1	50	166	39.3	238	605	4.7 (1, $N = 771$)	.030*
Immediate family	25.6	40	156	34.8	189	543	4.6 (1, $N = 669$)	.032*
Extended family	27.6	35	127	39.0	155	397	5.4 (1, $N = 524$)	.019*
People living with HIV	25.0	40	160	32.1	179	557	3.0 (1, $N = 717$)	.084
Faith community	23.1	9	39	33.6	46	137	1.6 (1, $N = 176$)	.212

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School	11.9	7	59	16.7	30	180	.8 (1, <i>N</i> = 239)	.376
Leisure activities/hobbies	21.1	26	123	40.9	175	428	16.1 (1, <i>N</i> = 551)	.0001***
Manifestations								
Aggression	15.6	25	160	8.6	56	653	7.2 (1, <i>N</i> = 813)	.008**
Avoidance	28.1	45	160	30.9	201	651	.5 (1, <i>N</i> = 811)	.498
Awkward social interactions	12.5	20	160	19.8	128	648	4.5 (1, <i>N</i> = 808)	.034*
Blame	31.9	51	160	38.2	250	655	2.2 (1, <i>N</i> = 815)	.139
Excessive kindness	14.4	23	160	19.4	178	653	2.2 (1, <i>N</i> = 815)	.142
Excessive preventive measures	19.4	31	160	29.5	191	648	6.6 (1, <i>N</i> = 808)	.010*
Exclusion	16.9	27	160	27.3	178	653	7.4 (1, <i>N</i> = 813)	.007**
Increased physical distance	30.6	49	160	34.4	224	652	.8 (1, <i>N</i> = 812)	.371
Indifference	31.3	50	160	28.7	186	648	.4 (1, <i>N</i> = 808)	.526
Told to conceal	33.1	53	160	54.1	353	653	22.5 (1, <i>N</i> = 813)	.0001***
Told to disclose	25.0	40	160	28.8	188	652	.9 (1, <i>N</i> = 812)	.333
<i>Sympathy and support</i>	84.4	135	160	91.1	597	655	6.4 (1, <i>N</i> = 815)	.011*

Note: * $p < .05$; ** $p < .01$; *** $p < .001$

Manifestations of stigma

Prevalence for specific manifestations ascertained in the 2020 and 2007 surveys are also displayed in Table 1. In the 2020 survey, being told to conceal HIV status (33.1%, $n = 53$), blame (31.9%, $n = 51$), indifference ($n = 50$), and increased physical distance (30.6%, $n = 49$) were most commonly reported, followed by avoidance (28.1%, $n = 45$), being told to disclose HIV status (25.0%, $n = 40$), excessive preventive measures (19.4%, $n = 31$), exclusion (16.9%, $n = 27$), aggression (15.6%, $n = 25$), excessive or exaggerated kindness (14.4%, $n = 23$), and awkward social interactions (12.5%, $n = 20$). Fortunately, 84.4% ($n = 135$) also reported experiencing sympathy and support from others. This, however, was reported significantly less frequently reported than it was reported in 2007, when 91.1% ($n = 597$) reported sympathy and support.

Comparisons between the 2007 and 2020 survey showed statistically significant reductions in being advised to conceal HIV status (54.1% vs. 33.1%; $p < .001$), excessive preventive measures (29.5% vs. 19.4%, $p = .010$), exclusion (27.3% vs. 16.9%; $p = .007$), and awkward social interactions (19.8% vs. 12.5%; $p = .034$). Disconcertingly, we also ascertained a significant increase in aggression (8.6% vs. 15.6%; $p = .007$).

Health care specific manifestations of stigma

Table 2 displays prevalence for specific manifestations in the health care sector. In 2020, increased physical distance (35.6%, $n = 72$) and excessive preventive measures (33.7%, $n = 68$) were most common, followed by awkward social interactions (22.8%, $n = 46$), the use of differential protective measures (22.3%, $n = 45$), and confidentiality breaches (18.3%, $n = 37$). The remaining manifestations were less common. Disconcertingly, 12.9% of participants ($n = 26$) reported having avoided health care because of stigmatizing responses in health care. Fortunately, 65.8% ($n = 133$) reported experiencing sympathy and support from health care providers.

Compared to the 2009 survey, there was a statistically significant increase in the reporting of increased physical distance (20.6% vs 36.6%; $p < .001$), excessive preventive measures (20.6% to 33.7%; $p = .003$), awkward social interactions (12.6% to 22.8%; $p = .004$), avoidance (6.1% to 16.3%; $p < .001$), and unnecessary referrals (5.3% to 11.9%; $p = .014$), and a statistically significant decrease in being advised to conceal HIV status (25.2% to 8.9%; $p < .001$). Additionally, sympathy and support from health care professionals reduced from 76.3% in 2009 to 65.8% in 2020 ($p = .008$).

Table 2: Comparisons in the prevalence of health care specific manifestations of stigma from 2007 to 2020

Health care sector manifestations	2020%	2020 N (of 202)	2009 %	2009 N (of 262)	Chi square (df, n)	p-value
Aggression	5.0	10	1.9	5	3.2 (1, N = 459)	.072
Avoidance	16.3	33	6.1	16	12.5 (1, N = 463)	.0001***
Awkward social interactions	22.8	46	12.6	33	8.4 (1, N = 464)	.004**
Blame	12.9	26	10.3	27	.6 (1, N = 459)	.431
Excessive kindness	12.9	26	8.4	22	2.2 (1, N = 459)	.134
Excessive preventive measures	33.7	68	20.6	54	9.1 (1, N = 458)	.003**
Increased physical distance	35.6	72	20.6	54	13.0 (1, N = 464)	.0001***
Advice to disclose	10.4	21	14.9	39	2.3 (1, N = 459)	.132
Advice to conceal	8.9	18	25.2	66	21.5 (1, N = 458)	.0001***
Confidentiality breaches	18.3	37	13.7	36	1.5 (1, N = 458)	.217
Differential protective measures	22.3	45	16.8	44	1.9 (1, N = 458)	.172
Discouragement of care	9.9	20	8.8	23	.1 (1, N = 458)	.738

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Refusal to care	8.4	17	6.9	18	.3 (1, N = 458)	.580
Unnecessary referrals	11.9	24	5.3	14	6.1 (1, N = 458)	.014*
Exclusion	5.9	12	Not measured			
Indifference	16.8	34	Not measured			
Rude and unkind behavior	Not measured		10.7	28		
<i>Sympathy and support</i>	65.8	133	76.3	200	6.9 (1, N = 462)	.008**
Care avoidance	12.9	26	11.8	31	.06 (1, N = 458)	.806

Note: * $p < .05$; ** $p < .01$; *** $p < .001$

Correlates of perceived stigma

Means, standard deviations, and correlations for the study variables are displayed in Table 3. Table 4 presents the regression analyses. For psychological distress, the model significantly predicted psychological distress, $R^2 = .31$, $F(12, 132) = 4.93$, $p < .001$. Adding perceived stigma and social support significantly improved model fit, $\Delta R^2 = .15$, $\Delta F(2, 132) = 14.54$, $p < .001$, but only perceived stigma remained significantly associated with psychological distress, $\beta = .38$, $t(131) = 4.38$, $p < .001$. For medication adherence, the final model significantly predicted medication adherence, $R^2 = .18$, $F(13, 130) = 2.25$, $p = .011$. Adding perceived stigma and social support significantly improved model fit, $\Delta R^2 = .12$, $\Delta F(3, 130) = 6.21$, $p = .001$. Perceived stigma did not remain significantly associated with medication adherence, $\beta = -.04$, $t(129) = -.44$, $p = .66$, while social support did, both for the linear term, $\beta = .29$, $t(129) = 3.35$, $p = .001$, as well as for the quadratic term, $\beta = -.24$, $t(129) = -2.81$, $p = .006$.

Table 3: Means, standard deviations, and correlations for 2020 study variables

	mean	range	SD	1	2	3	4	5	6	7	8	9	10
1. Perceived stigma (Wright et al.)	28.07	12.00-58.00	10.26	-									
2. Psychological distress (MHI)	47.48	6.67-97.78	13.68	.324**	-								
3. Depression (MHI subscale)	37.16	0.00-100.00	16.84	.417**	.835**	-							
4. Anxiety (MHI subscale)	41.58	8.00-100.00	18.57	.485**	.835**	.804**	-						
5. Behavioral control (MHI subscale)	47.21	5.00-95.00	17.64	.064	.774**	.445**	.413**	-					
6. Positive affect (MHI subscale)	66.83	5.00-100.00	17.80	-.237**	.518**	.171*	.088	.597**	-				
7. Self-esteem (RSE)	2.49	1.00-3.90	.44	-.094	-.502**	-.365**	-.220**	-.467**	-.600**	-			
8. Social support (SSL-12)	2.53	1.00-4.00	.62	-.282**	-.260**	-.316**	-.212**	-.162*	-0.025	.328**	-		

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9. Medication adherence (Wilson et al.)	92.22	31.11-100.00	11.98	-.197*	-.169*	-.220**	-.259**	-.001	.107	.085	.246**	-	
10. Clinic adherence ^a		0.00-1.00		-.027	-.146*	-.177*	-.174*	-.047	-.063	.142*	.093	.250**	-

Note: * $p < .05$ (2-tailed); ** $p < .01$ (2-tailed); ^aPoint-biserial correlation of missed visits versus no missed visits

Table 4: Hierarchical regression for psychological distress ($n = 145$) and medication adherence ($n = 144$) in 2020

Variable	Psychological distress (MHI)					Medication adherence (Wilson et al.)				
	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2	<i>B</i>	<i>SE B</i>	β	R^2	ΔR^2
Step 1				.16	.16**				.07	.07
Constant	31.31	5.89				88.63				
Gender (female)	8.84*	4.38	.29*			-3.21	4.06	-.12		
Bisexual	11.71*	5.21	.23*			-3.76	4.82	-.08		
Gay	13.02**	4.36	.46**			-4.88	4.04	-.20		
Age	-3.91**	1.39	-.29**			1.12	1.30	.09		
Partner	-.94	2.21	-.03			.47	2.05	.02		
Moderate education	4.84	3.72	.16			2.08	3.44	.08		
High education	3.43	3.45	.12			3.39	3.19	.14		
Dutch origin	6.34*	2.81	.20*			4.84	2.60	.17		
Paid employment	-7.40**	2.42	-.27**			1.28	2.24	.05		
Time since diagnosis	.10	.15	.07			.05	.14	.03		
Step 2				.31	.15***				.18	.12**
Constant	26.48	5.51				90.40				
Gender (female)	6.57	4.02	.22			-2.47	3.86	-.09		
Bisexual	9.19	4.78	.18			-1.91	4.61	-.04		
Gay	11.15**	4.00	.40**			-3.04	3.85	-.12		
Age	-3.91**	1.28	-.29**			.94	1.24	.08		
Partner	-1.26	2.02	-.05			1.11	1.95	.05		
Moderate education	5.01	3.40	.16			2.87	3.26	.11		
High education	5.83	3.18	.21			3.50	3.07	.14		
Dutch origin	8.82**	2.66	.28**			4.24	2.58	.15		
Paid employment	-5.73*	2.23	-.21*			.02	2.15	.00		
Time since diagnosis	.30	.14	.19			.01	.13	.01		
Perceived stigma (Wright et al.)	5.23***	1.19	.38***			-.50	1.15	-.04		
Social support (SSL- 12)	-1.69	1.08	-.12							
Social support (linear)						3.50**	1.04	.29**		
Social support (quadratic)						-2.14**	.76	-.24**		

Note: * $p < .05$. ** $p < .01$. *** $p < .001$

U=U and PrEP awareness and impact

Almost all participants (97.9%; $n = 190$) had heard of U=U, with about two thirds (63.7%; $n = 116$) reporting having learnt about U=U in the five years prior to survey completion (2015-2019; range 1997-2019), usually from an HIV health care provider (52.6%; $n = 100$), the Dutch Association of People with HIV (43.7%; $n = 83$), or the media (34.2%; $n = 65$). About half of those who knew about U=U indicated that it had a very positive impact on how they experience having HIV (48.1%, $n = 124$). However, among those aware of U=U, 13.3% ($n = 25$) were not yet convinced that someone with an undetectable

virus (viral load of less than 200) cannot transmit HIV to others. Most participants (94.2%, $n = 180$) were also aware of PrEP, with 80.4% ($n = 136$) having heard of PrEP in the five years prior to survey completion (2015-2020; range 2003-2020), and 37.2% ($n = 67$) claiming that knowing about PrEP has had a very positive impact on how they experience having HIV.

DISCUSSION

This study set out to investigate changes in the experience of HIV stigma over time among people living with HIV in the Netherlands. It also sought to confirm relevant psychological, social, and health correlates of stigma, and ascertain U=U and PrEP awareness and impact among people living with HIV in the Netherlands.

The results showed reductions in stigma experiences for a number of contexts, including work, the financial services sector, and in media. However, stigmatizing messages in media remained highly prevalent (70.9%). This is problematic as media sources have significant influence on the awareness, opinions, and behaviors of their audience (Card et al., 2019). Media shapes public perceptions and thus both reflects and contributes to stigma (Card et al., 2019; Chan et al., 2021). Media also has substantial impact on policy formation and agenda setting, though their framing and priming of topics like HIV, thereby also exercising influence on more structural sources of stigma (Card et al., 2019).

The results also showed that in close interpersonal contexts such as with family, friends, and acquaintances from leisure activities was reported significantly less in 2020 than in 2007. This is positive as families and friends are important sources of support for people living with HIV, and they contribute to better physical and psychological well-being (Öktem, 2015). In fact, in Stutterheim et al. (2009), we investigated the impact of a series of combinations of manifestations and settings, and established that four particular combinations contributed most to psychological distress; three of these occurred in a family context (avoidance, advice to conceal, and exaggerated kindness). Reductions in stigma in a context that has previously been established as particularly detrimental is thus a very positive development.

Disconcertingly, stigma in the LGBTQI+ community, with sexual partners, and while partying remained prevalent (56.0% - 58.6%) and relatively unchanged since we last measured this in 2007. This is problematic as the LGBTQI+ community is considered to be best acquainted with U=U and PrEP (Spinner et al., 2018), both of which are thought to

contribute to the normalization of HIV (Brown et al., 2017). Persistent stigma in LGBTQI+ communities may be because, historically and still now, people living with HIV are perceived to tarnish the reputation of the community by reinforcing negative stereotypes about LGBTQI+ communities (regarding, e.g., promiscuity and responsibility for HIV acquisition) (Smit et al., 2012), and this is evidenced by stigma-by-association (SBA) toward gay men. In a study by Broady and colleagues (2020), gay men reported significant SBA (71.9%), and those who had experienced SBA were more likely to reject partners because of their HIV status than those who had not experienced SBA. Also, partner vetting, defined as the practice of deciding how 'safe' a potential sexual partner is based on factors other than actual HIV status, has been reported to be commonplace, and this layers with other marginalized statuses such as race and class (Brown et al., 2017; Smit et al., 2012).

With regard to specific manifestations of stigma, our findings showed that excessive preventive measures, exclusion, and awkward social interactions were reported less frequently in 2020 than in 2007, as was being advised to conceal HIV status. Provision of support and sympathy also reduced. These changes may suggest greater normalization of HIV. However, it is important to be cognizant of the potential disconnect between the discourse of 'HIV is like any other condition' (normalcy) and the lived experiences of people living with HIV (Silva-Suárez, Rabionet, & Zorrilla, 2017), which remain marked by substantial stigma. HIV normalization discourse that promotes U=U is important but it should not be provided in ways that suggest that people living with HIV do not need support, particularly in light of the relationship between social support and medication adherence. Medication adherence is also impeded by aggression and violence (Hatcher, Smout, Turan, Christofides, & Stöckl, 2015), which we also ascertained to have increased from 2007 to 2020, albeit with limited statistical power.

Furthermore, an important finding of our study is that stigma in health care settings continues to occur (23.2% - 34.3%) across health care contexts (e.g., GPs, dentists), and was even reported to have increased in hospitals. Also, in the health care context, increased physical distance, excessive preventive measures, awkward social interactions, avoidance, and unnecessary referrals to other health care providers were reported more frequently in 2020 than in 2009. These manifestations appear to reflect instrumental rather than symbolic stigma (Maughan-Brown, 2010), which is in line with previous research indicating that health care providers do not tend to hold negative attitudes and moral judgment toward people living with HIV; rather, they experience a disproportionate fear of (occupational) infection (Davtyan, Olshansky, Brown, & Lakon, 2017; Geter et al., 2018; Stutterheim et al., 2014). This is the result of limited knowledge and experience,

and a lack of awareness about behaviors perceived as stigmatizing by people living with HIV (Davtyan et al., 2017; Stutterheim et al., 2014). Our findings on health care are in line with a growing body of literature demonstrating the pervasiveness of HIV stigma in health care contexts (Gagnon, 2015; Geter et al., 2018), and its highly detrimental impacts on access to, and quality of, care via, for example, non-disclosure of HIV status and care avoidance (Gagnon, 2015; Geter et al., 2018).

Also, in line with previous research (Stutterheim et al., 2011; Stutterheim, Bos, Shiripinda, et al., 2012; Stutterheim et al., 2009), our findings showed that perceived HIV stigma is positively related to psychological distress and negatively related to social support. This is supported by Chan et al. (2021)'s study of HIV stigma manifestations and their impacts among people living with HIV in Hong Kong, in which participants who experienced enacted stigma also reported greater psychological distress and lower life satisfaction. It is also in accordance with Darlington and Hutson's (2017) review of HIV stigma among women in the Southern United States. That review established that stigma is indeed positively related to depression and negatively related to social support. It also indicated self-esteem as a negative correlate of stigma, a finding that was not confirmed in our study. Similar to our findings, Kalomo (2018), in her study of HIV stigma, self-esteem, social support, and depression in Namibia, found no relationship between stigma and self-esteem.

Furthermore, our findings showed that, when controlling for background and demographic characteristics, perceived stigma remained a significant predictor of psychological distress, and while social support did not remain statistically significant in that model, together, perceived stigma and social support did explain significant variance. Additionally, in our study, we found, in accordance with previous literature (Been et al., 2016), that perceived stigma to be negatively related to medication adherence. This relationship is well established. Sweeney and Venable (2016), in their systematic review and synthesis, found substantial empirical evidence linking multiple forms of stigma (enacted, anticipated, internalized, or combination) to poorer medication adherence across diverse patient populations in a variety of countries. Additionally, Katz and colleagues (2013), in their systematic review and meta-synthesis, also concluded that HIV stigma undermines treatment adherence, often through reduced social support. Interestingly, in our study, stigma was not related to clinic adherence. This is potentially because poor adherence to clinic visits was infrequent in our sample.

Lastly, our findings showed that almost all participants were aware of U=U and PrEP, and that this awareness was perceived to have a positive impact on participants' experience of having HIV. Disconcertingly, 13.3% of people living with HIV surveyed in 2020 were not convinced that someone with an undetectable viral load cannot transmit HIV to others. This is in line with Rendina et al. (2020). In their large-scale study on the acceptability of U=U messaging, Redina et al. (2020) reported that 15.5% of sexual minority men with HIV in their study perceived U=U messages as somewhat or completely inaccurate. This speaks to the need to continue the spread of the U=U message, also among people living with HIV.

Implications

Evidently, our findings suggest that stigma reduction remains imperative in our efforts to end HIV and improve quality of life for people living with HIV. We recommend focusing specifically on those contexts where stigma has remained prevalent, and where stigma has not changed or has worsened in recent years. This means focusing on the media, the LGBTQI+ community and dating, and the health care sector.

With regard to the media, significant work can be done to reduce negative messaging about HIV and people living with HIV. Albeit in the context of PrEP stigma, Card et al. (2019) outlined a number of recommendations for reducing stigma in the media that can be applied to reducing HIV stigma as well. One is that researchers and civil society organizations invest in building relationships with journalists, and in developing effective communication skills that help journalists create content that is correct but also newsworthy. Another is the provision of evidence alongside expert opinions (via e.g. links to scientific articles) as this is more persuasive than expert opinion alone (Card et al., 2019). A key message that will contribute to reduced stigma in media is U=U. It is imperative that the current scientific consensus on viral load suppression and undetectability becomes newsworthy (Card et al., 2019).

Likewise, it remains important to continue to convey the message of U=U in the LGBTQI+ community. This is imperative as stigma in the LGBTQI+ community, with sexual partners, and while partying impedes (regular) testing and linkage to care (Brown et al., 2017; Smit et al., 2012), which is important not only for undiagnosed individuals but also for the success of biomedical HIV prevention, particularly PrEP (Gamarel et al., 2018). The tension between stigma and prevention is well documented (Brown et al., 2017; Smit et al., 2012), and it speaks to the need to address stigma not only

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within the LGBTQI+ community but also in prevention efforts and testing services for key populations (Brown et al., 2017; Card et al., 2019). For example, in many countries, access to PrEP is limited only to individuals who engage in condomless anal intercourse with multiple partners. Such restrictive criteria for access unintentionally reinforces stigma towards, and stereotypes about, people living with HIV (Brown et al., 2017). We need to ensure that prevention efforts, including biomedical prevention efforts, intentionally and explicitly tackle HIV stigma both for the sake of stigma reduction and for the success of prevention efforts (access, use, and scale up) (Brown et al., 2017). Furthermore, with a cure for HIV on the horizon, stigma reduction efforts in the LGBTQI+ community will become even more important (Wu et al., 2018). Community education programs that use evidence-based approaches to correcting misinformation, foregrounding U=U messages, taking the perspective of people living with HIV, and promoting empathy are imperative (Brown et al., 2017; Stutterheim & Ratcliffe, 2021).

Furthermore, stigma reduction efforts in health care contexts must be prioritized. Although most stigmatizing experiences in health care are episodic rather than ongoing (Gagnon, 2015), the impact of these experiences cannot be discounted, particularly given power differentials between health care providers and people living with HIV (Davtyan et al., 2017; Gagnon, 2015), and people living with HIV's corresponding increased vulnerability (Gagnon, 2015). Efforts to reduce stigma in health care would benefit from a socioecological approach that targets both the interpersonal and the structural level. Both clinical and non-clinical staff, especially those not working in HIV care, should be targeted (Gagnon, 2015; Geter et al., 2018). Interventions in health care should address fear of occupational exposure, and provide safe and non-judgmental opportunities to reflect on attitudes and beliefs about HIV and people living with HIV (Geter et al., 2018; Stutterheim et al., 2014). Again, U=U messaging is important as confidentiality breaches among health care providers are often justified via the rhetoric of 'risk management' (Gagnon, 2015; Stutterheim et al., 2014). On an organizational level, policy that explicitly addresses discriminatory practices and that prioritizes the provision of open, affirmative, and nonjudgmental care is important (Gagnon, 2015; Geter et al., 2018), and can be embedded broader quality of care efforts (Ikeda, Nyblade, Srithanaviboonchai, & Agins, 2019).

Limitations

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Our findings should be interpreted in light of some limitations. First, we did not take a longitudinal approach using one cohort to ascertain changes in stigma but rather compared stigma prevalence across samples that in many, but not all, ways were similar to one another. One difference was sample size. The sample size in 2007 was substantially larger than the sample size in 2020 but similar to the sample size in 2009. Another was study design. The 2007 survey was a pen-and-paper survey while the 2009 and 2020 surveys were online. Both of these factors may impact the comparability of prevalence rates between 2020 and 2007 and between 2020 and 2009. We highly recommend conducting a longitudinal study in which HIV stigma prevalence can be measured over time. A longitudinal study would also provide opportunities to better understand the relationships between stigma, psychological distress, social support, self-esteem, and adherence. In our study, this was measured cross-sectionally and thus the hypothesized direction of relationships in the regression models are assumed. With a longitudinal study, various pathways, as well as possible mediators or moderators, could be robustly explored. Another limitation relates to the composition of the study samples. In all three samples, a large proportion of participants self-identified as gay. This is unsurprising given that the HIV population in the Netherlands comprises predominantly men who have sex with men but it does limit the generalizability of the results. Given that other key populations in the Netherlands (e.g. people with a migration background, people with a history of substance use, people who identify as trans) tend to, in the Dutch context, experience greater marginalization as a result of both their HIV status and other intersectional identities, it may be possible that prevalence rates reported here are actually an underestimation.

Conclusion

In conclusion, this study explored changes in HIV stigma over time and ascertained that contexts currently most in need of stigma reduction interventions are the media, the LGBTQI+ community and dating, and the health care sector. Further reinforcing the need for stigma reduction interventions, this study also ascertained that perceived HIV stigma was positively related to psychological distress, and negatively related to social support and medication adherence in people living with HIV in the Netherlands. Lastly, this study established that U=U and PrEP awareness was high and perceived to have a positive impact on the experience of having HIV, but not all participants believed that undetectable indeed means untransmittable. Overall, the findings indicate that a key message in stigma reduction efforts should be U=U.

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Supplemental material: Indices for measuring HIV stigma settings and manifestations

HIV stigma settings index (2020)

The following questions are about the various situations in which people with HIV can experience negative reactions or stigmatization.

To what extent have you in the past 5 years experienced negative reactions to your HIV status in each of the following situations?

1. With my immediate family (parents, brothers, sisters, children)
2. With my extended family (grandparents, aunts, uncles, cousins, nephews, nieces)
3. With my friends
4. With other people with HIV
5. With my (sexual) partner(s)
6. At work
7. With my general practitioner (GP)
8. With my dentist
9. At the hospital
10. In the financial services sector (i.e. when applying for a loan, mortgage, insurance, etc.)
11. At school, college, university, etc.
12. In my religious community
13. In the LGBTI+ community
14. With my acquaintances that I know from going out/partying
15. With those I know from my leisure activities/hobbies
16. In the media

(Never, rarely, sometimes, often, very often, N/A; can be recoded as never, ever)

Are there any other situations in which you have experienced stigma? If so, please describe them here.

HIV stigma manifestations index (2020)

In this section, we ask you to first indicate whether or not you have experienced the reactions mentioned below in the past 5 years.

Have you, in the past 5 years, experienced that, because of your HIV status...

- ...people have maintained more physical distance from you than before?
- ...people have been awkward in their social contact with you (e.g. they make less eye contact, they hesitate or stutter while talking to you)?
- ...people reacted indifferently or didn't react at all when you told them that you have HIV?
- ...people avoided you because you have HIV?
- ...people have given you the impression that they think that your HIV status is your own fault?
- ...people have been overly nice and exaggeratedly kind?
- ...people have been aggressive towards you?
- ...people have excluded you from certain activities?
- ...people have taken excessive (hygienic) measures to protect themselves from HIV?
- ...people have urged you or told you that you must tell others about your HIV status?
- ...people have urged you or told you that you must *not* tell others about your HIV status?

(yes/no)

...people have been sympathetic and supportive?

(yes/no)

Health care specific HIV stigma manifestations index (2020)

These questions are about specific reactions to your HIV status from people working in the health care sector in the Netherlands. Please indicate whether or not you have, in the past 5 years, experienced the reactions mentioned below in the health care sector.

Have you, in the past 5 years, experienced that, because of your HIV status, people working in the health care sector in the Netherlands....

- ...have maintained more physical distance from you than before?
- ...have been awkward in their social contact with you (e.g. they make less eye contact, they hesitate or stutter while talking to you)?
- ...reacted indifferently or didn't react at all when you told them that you have HIV?
- ...avoided you because you have HIV?
- ...have given you the impression that they think that your HIV status is your own fault?
- ...have been overly nice and exaggeratedly kind?
- ...have been aggressive towards you?
- ...have excluded you from certain activities?
- ...have taken excessive (preventive) measures to protect themselves from HIV?
- ...have urged you or told you that you must tell others about your HIV status?
- ...have urged you or told you that you must not tell others about your HIV status?
- ...talked about, or told others about, your HIV status when they shouldn't have?
- ...denied you care, service or treatment?
- ...discouraged or reduced the care or service they provide?
- ...unnecessarily referred you to other health personnel?
- ...taken different precautions with you than with other patients (i.e. applying universal precautions with you and not with other patients)?

(yes/no)

- ...have been sympathetic and supportive?

(yes/no)

Have you ever avoided health care because you fear that people working in the health care sector will react negatively to your HIV status? (yes, no)