# Patient and Provider Perspectives on HIV and HIV-Related Stigma in Dutch Health Care Settings

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# **Abstract**

Ensuring that people living with HIV (PLWH) feel accepted in health care settings is imperative. This mixed methods study explored the perspectives of PLWH and health professionals on their interactions. A total of 262 predominantly gay men of Dutch origin participated in a survey study of possible negative interactions with health professionals, and semi-structured interviews were subsequently conducted with 22 PLWH and 14 health professionals. Again, most PLWH were gay men of Dutch origin. All health professionals were Dutch. PLWH reported negative experiences with health professionals including awkward interactions, irrelevant questions, rude treatment, blame, pity, excessive or differential precautions, care refusal, unnecessary referrals, delayed treatment, poor support, and confidentiality breaches. They also reported positive experiences including equal treatment, being valued as a partner in one's health, social support provision, and confidentiality assurances. Health professionals reported having little experience with PLWH and only basic knowledge of HIV. They contended that PLWH are treated equally and that HIV is no longer stigmatized, but also reported fear of occupational infection, resulting in differential precautions. Additionally, they conveyed labeling PLWH's files to warn others, and curiosity regarding how patients acquired HIV. The findings suggest that there is a gap in perception between PLWH and health professionals regarding the extent to which negative interactions occur, and that these interactions should be improved. Implications for stigma reduction and care optimization are discussed.

#### Introduction

S INCE THE INTRODUCTION OF HIGHLY ACTIVE antiretroviral therapy, HIV has shifted from a fatal to a chronic medical condition. Despite significant improvements in life expectancy and quality of life, HIV remains burdensome, given the social and psychological implications of being infected with a virus that has been subjected to significant stigma. Stigma is defined as a discrediting social difference that results in devaluation or a 'spoiled social identity'. It occurs in social interactions and is reproduced by existing social inequalities and the exercise of power. Even today, HIV can yield anxiety about the potential for infection, generate fear given its previous association with death and wasting, and prompt moral judgments that assign responsibility for infection to those living with HIV. Additionally, people living with HIV (PLWH) are often associated with behaviors that are perceived by some to violate social norms, such as commercial sex work,

homosexuality, and intravenous drug use.<sup>7–9</sup> Combined, these perceptions contribute to PLWH feeling stigmatized, and, indeed, negative reactions to PLWH have been found to occur across a broad range of settings.<sup>10–13</sup> One such setting is health care.<sup>14,15</sup>

Previous research has documented stigmatizing beliefs and attitudes on the part of health care providers <sup>16–19</sup> and a lack of willingness to interact with, or care for, PLWH in hypothetical situations. <sup>18,20–22</sup> Additionally, actual discriminatory practices have been documented. These range from subtle to blatant and include awkward social interactions, increased physical distance, avoidance, unnecessary referrals to other health care providers, neglect, the discouragement of treatment regimens, contempt, testing without consent, blaming, excessive protective measures, the labeling of charts, beds, and/or rooms, breaches of confidentiality, refusal to treat, isolation in wards, and verbal abuse. <sup>15,23–27</sup> Such discriminatory acts have been found to occur in hospitals, doctor's

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offices, dental practices, ambulances, and pharmacies. <sup>15,24–26</sup> In fact, in a study previously conducted in the Netherlands, 26.2% of surveyed PLWH had experienced stigma in hospitals, 28.8% at their dentist's office, and 19.2% in their contact with a general practitioner. <sup>28</sup> In another study surveying PLWH in 14 European countries, 17% reported having experienced HIV-related discrimination from health professionals including non-HIV specialists (46%), dentists (39%), general practitioners (22%), and gynecologists (16%). <sup>29</sup>

Negative reactions to PLWH in health care settings, be they perceived to be or objectively the result of HIV-related stigma, are particularly problematic given PLWH's dependence on health care providers for necessary care and treatment and the fact that health care is one setting in which many PLWH feel obliged to disclose their status. 15,26 Perceived HIV-related stigma in health care can result in testing and treatment delays, avoidance of health services, and poorer quality care as a result of nondisclosure to health care providers. 30-35 In addition, perceived HIV-related stigma in health care settings can have detrimental psychological consequences, in part because perceived stigma, regardless of setting, negatively impacts psychological well-being, <sup>14,36,37</sup> but also because health care providers are what Goffman termed 'the wise'. They are expected to have knowledge about HIV and to not discriminate against PLWH. Unfortunately, previous research has shown that this is not always the case. 38-40

Research on the impact of HIV-related stigma in health care has shown that perceived stigmatization in health care settings is related to decreased patient satisfaction, psychological distress, low self-esteem, the feeling that one is undeserving of care, and diminished motivation to stay healthy, 14,31,41 while positive interactions between health care providers and PLWH have been found to contribute to better treatment adherence and health-related quality of life.42-45 Clearly, ensuring that PLWH feel accepted and treated equally in health care settings is imperative. This is particularly important as PLWH's reliance on health care providers and need for adequate health care services will, in the coming years, continue to grow as a result of aging demographics among PLWH. In fact, older PLWH will likely require more services more frequently than other elderly people as a result of possible accelerated aging, the complicated treatment of co-morbid conditions, and smaller informal social networks. 1,46

In the Netherlands, general practitioners (GPs) and STI clinics offer HIV testing. A test requested from a GP is subjected to an €360 own risk policy, while a test conducted at a clinic is always free. Upon receipt of a positive test result, patients are referred to specialized HIV care that includes the services of both an internist and an HIV nurse. A referral is necessary to receive any specialist care in the Netherlands. As such, GPs hold a strong gatekeeper role in the Dutch health care system. Once referred, PLWH visit their specialized HIV care providers on a regular basis. At the same time, they also maintain contact with their GP and other health professionals for issues not directly related to their HIV infection. Within HIV care, internists generally limit their consultations to medical aspects of HIV, while HIV nurses offer psychosocial support, particularly for treatment adherence, and function as liaisons between the internist and those offering primary care (GPs, social workers). All HIV care in the Netherlands is covered by a mandatory insurance package. In the absence of insurance, PLWH can still access care and antiretroviral treatment as they are entitled to that care by law. Additionally, no health professional can refuse care based on HIV status.

In a sequential mixed methods study, we explored both PLWH's experiences with health care providers and health care providers' perspectives on HIV and their professional interactions with patients with HIV in order to gain a comprehensive understanding of how PLWH and health care providers experience their interactions. Such an understanding is imperative to the effective promotion of positive patient-provider interactions. This mixed methods approach that combines qualitative and quantitative methodology and that looks at the perspectives of both PLWH and health professionals is something that, to our knowledge, has not previously been done.

#### Methods

In this sequential mixed methods study,<sup>48</sup> we first conducted a cross-sectional survey to determine the prevalence of negative interactions experienced by PLWH (n = 262) and then built upon those findings and more contextually explored both PLWH's (n = 22) and health professionals' (n = 14) perspectives on their interactions through a qualitative interview study that utilized a general inductive approach with thematic analyses.<sup>49</sup>

## Survey

The 262 survey study participants were drawn from an online panel of 342 PLWH recruited by the Dutch HIV Association (response rate = 76.6%). After providing informed consent, participants completed questions on the extent to which they had experienced 15 negative interactions (see Table 1) in their contact with doctors, nurses, dentists, other health care providers (e.g., pharmacists, physiotherapists, home care), and/or support staff. The negative interactions included in the survey were derived from the literature on HIV-related stigma in health care and from a focus group conducted with PLWH and HIV practitioners. In the survey, participants were also asked to indicate whether they had experienced sympathy and support from health professionals and whether they had avoided seeking health care as a result of negative interactions. Additionally, demographic data (i.e., age, gender, educational attainment, employment, ethnicity, sexual orientation, location, and family composition) and data on HIV-related characteristics (i.e., means of transmission, time since diagnosis, treatment status, current health status, and presence of visible symptoms) were obtained. Data were analyzed using SPSS 19.

The survey study participants were predominantly men (90.8%; n=238) from the Netherlands (90.1%; n=236) who self-identified as gay (80.2%; n=210). Ages ranged from 23 to 74 years 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); data on educational attainment were missing for three participants. Most had acquired HIV through sexual intercourse (92.7%; n=243) and the mean time since diagnosis was 9.5 years prior to survey completion (SD=6.6).

Table 1. Reported Prevalence of Negative Interactions, Sympathy and Support, and Care Avoidance (n=262)

	п	%	Physicians n	Physicians Physicians % % interaction total	Physicians % total	<i>Nurses</i> n	$Nurses \ \%$ interaction	Nurses 6% total	Other HCP n	Other HCP % interaction	Other HCP D % total	Dentists n	Dentists % interaction	Dentists % total	Support staff n	Support staff % interaction	Support staff % total
Physical distance Awkward social	54 33	20.6 12.6	22 20	40.7	8.4 7.6	14 13	25.9 39.4	5.3	15 19	27.8 57.6	5.7	28	51.9 30.3	10.7	13	24.1 24.2	5.0
ınteractıon Avoidance Blame	16 27	6.1	3	18.8 59.3	1.1	5 10	31.3	1.9	9	37.5 25.9	2.3	9 4	37.5 14.8	2.3	212	12.5	0.8
Rude and unkind behavior	28	10.7	10	35.7	3.8	∞	28.6	3.1	_	25.0	2.7	6	32.1	3.4	8	10.7	1:1
Excessive kindness Aggression	22	8.4	15	68.2	5.7	6 -	40.9	3.4	9 6	27.3	2.3	77	9.1	0.8	<i>∞</i> –	13.6	1.1
Advice to disclose	39	14.9	. 8.	46.2	6.9	20	51.3	7.6	1 1 - 5	17.9	2.7	1 = 9	28.2	2.4	00	0.0	0.0
Advice to conceal Breached	36	25.2 13.7	8 8	34.8 22.2	3.1	46 10	69.7 27.8	3.8	15	28.8 41.7	5.7	0 9	0.0 16.7	0.0	76	3.0 25.0	3.4
confidentiality Refusal to care Discouragement	18	6.9	96	33.3 39.1	2.3	0.4	11.1	0.8	93	16.7 39.1	1.1	6 4	50.0 17.4	3.4	0	0.0	0.0
of care Unnecessary	14	5.3	7	50.0	2.7	П	7.1	0.4	4	28.6	1.5	4	28.6	1.5	Т	7.1	0.4
reterrals Excessive	54	20.6	15	27.8	5.7	15	27.8	5.7	21	38.9	8.0	18	33.3	6.9	∞	14.8	3.1
measures Differential protective	4	16.8	6	20.5	3.4	∞	18.2	3.1	15	34.1	5.7	22	50.0	8.4	4	9.1	1.5
measures Sympathy and	200	76.3	156	78.0	59.5	167	83.5	63.7	81	40.5	30.9	62	31.0	23.7	42	21.0	16.0
Care avoidance	31	11.8															

Physicians include GPs, specialists, and interns. Nurses represent all nurses, specialized or not. Other HCP include pharmacists, physiotherapists, home care professionals, phlebotomists, etc. Support staff entail support staff in hospitals as well as dental and general practices.

The second and third columns display the absolute frequency and percentage of each interaction in the total sample.

TABLE 2. INTERVIEW TOPICS

PLWH	НСР
Mapping care network Per HCP, reactions to HIV status	General perceptions of HIV Estimation of HIV knowledge Previous contact with PLWH in work settings Reflection on that interaction or, if no experience, expectations in contact with PLWH Perceptions of colleagues' views on HIV and PLWH Rights and obligations of HCP and PLWH

#### Interviews

Interviews were semi-structured and conducted faceto-face at a location chosen by the participant, usually the participants' home (PLWH) or office (health professional). Interviews rather than other data collection methods such as group discussions (e.g., focus groups) were chosen as the most appropriate means as we set out to document individual rather than group perspectives on issues that not only can be considered sensitive issues reflecting vulnerability (e.g., experiences with stigmatization) but also because interviews allow more room to discuss behavior that is not always in accordance with social norms (e.g., health professional taking extra precautions with PLWH). Furthermore, given that both PLWH and health professionals are not easy to access due to, for example, a lack of openness about HIV status among PLWH and a lack of time among health professionals, interviews whereby the researchers could go to participants at a time and location of their choosing was considered more feasible than coordinating group discussions. 50-52

All interviews were preceded by informed consent, guided by a structured protocol with follow-up probes (see Table 2 for a list of interview topics for PLWH and health professionals), and followed by a short survey measuring the same demographic and, where applicable, HIV-related characteristics measured in the survey study.

For the interviews with PLWH (n=22), participants were recruited purposively by the interviewer, by HIV practitioners working in Dutch hospitals, through the Dutch HIV Association, and via snowball sampling. Inclusion criteria included having been diagnosed with HIV and having utilized the Dutch health care sector. We also intentionally sought to include a relatively equal number of PLWH living in urban centers as those living outside urban centers. The focus of the interview was participants' experiences regarding health care professionals' reactions to their HIV status. Interviews were approximately 1 h in length. Among PLWH, 17 were men (77.3%) and 5 were women (22.7%). Most were Dutch (90.9%, n = 20) and half lived in an urban center (50%; n = 11). In terms of sexual orientation, 16 self-identified as gay (72.7%) and 6 as straight (41.7%). Ages ranged from 27 to 66 with a mean age of 44.2 years (SD = 11.8). The majority had a bachelor's degree or more (59.1%; n=13), a little more than a quarter had a high school diploma and some vocational training (27.3%; n = 6), and 13.6% (n = 3) had high school or less. The greater majority had acquired HIV through sexual intercourse (93.9%; n = 20) and the mean time since diagnosis was 9.1 years prior to the interview (SD = 7.4).

For the interviews with health professionals (n=14), participants were recruited through snowball sampling and included physicians (i.e., general practitioners, an anaesthesiologist, a pediatrician, and a psychiatrist), (specialized) nurses, nursing assistants, a nurse manager, and a dentist. Inclusion criteria included currently working in the Dutch health care sector but not in specialized HIV care. The focus of the interview was experiences and expectations in interactions with PLWH. Interviews were approximately 30 min. All health professionals were Dutch. Ten were women (71.4%) and four were men (28.6%). Ages ranged from 24 to 66 with a mean age of 38.6 years (SD=11.7). All had a bachelor's degree or more.

All interviews were recorded with a digital voice recorder and transcribed verbatim. Data were subsequently processed with Microsoft Office Excel or QSR Nvivo 8. Each transcript was read thoroughly while listening to the corresponding recording to identify themes and establish categories to which text fragments were assigned in either Excel or Nvivo, depending on the coder (SS used Nvivo, LS used Excel). As coding occurred, categories and subcategories were developed and linked. A decision trail was maintained using annotations and memos. All emergent categories were documented, as were changes made to those categories, and the reasons for those changes. The coding structure was discussed throughout the coding process within the research group and preliminary findings were subsequently discussed with health professionals and PLWH to determine congruence with their experiences. Preliminary findings were also compared to findings in the empirical literature on HIV and health care. Additionally, because data collection and analyses were conducted in a parallel fashion and because data collection and analyses were conducted by the same two researchers (SS and LS), insights from preliminary analyses were carried back into and incorporated in the data collection process.

Ethical approval was provided by the Open University of the Netherlands' Faculty of Psychology and Educational Sciences (U2012/04530/NJA). No monetary compensation was provided for participation but interview participants received a gift.

## Results

## Patients' perspectives

Quantitative findings: Interaction prevalence rates and care avoidance. Of the 262 participants, 59.6% (n=156) had experienced at least one of the 15 negative interactions. A third of this group reported one kind of negative interaction (n=52; 33.3%) while a little more than one-fifth had experienced two kinds of negative interactions (n=35; 22.4%) and a little less than one-fifth had experienced three kinds of negative interactions (n=27; 17.3%). The remaining participants (n=42; 26.9%) had experienced four or more of the negative interactions with the frequencies generally dropping as the number of interactions increased. Frequencies for each of the 15 negative interactions in the total sample and

according to specific health care provider [i.e., physicians, nurses, other health care providers (e.g. pharmacists, physiotherapists, phlebotomists), dentists, and support staff] are displayed in Table 1. Fortunately, 76.3% of the participants (n = 200) also reported having received sympathy and support from health care professionals. Unfortunately, 11.8% of participants (n = 31) reported having avoided health care services and professionals as a result of negative interactions.

Qualitative findings: Negative experiences with health care. The interviews with PLWH demonstrated a number of negative experiences in interactions with health care professionals (described below and summarized in Table 3). Some of these were considered to be the result of how health care in the Netherlands is organized (access to specialized physicians requires a referral by a general practitioner; time allocated to individual patients is limited; physicians are stimulated to cut health care costs); others were attributed to HIV-related stigma. Sometimes this was explicit as is the case with blaming or the application of excessive protective measures. More frequently, perceived stigmatization was subtle as manifested in, for example, awkward social interactions. In these cases, participants often found it difficult to definitively attribute the negative interaction to stigmatization.

Awkward interactions and inappropriate behavior. Some participants reported awkward social interactions with health care providers: "I felt like they were uncomfortable. Yeah, uncomfortable. A silence like they are trying to find their words. It's short; just a moment but it gives me this sense like, uh, 'You are surprised by this or you struggle with this." (Jasmina, age 40, PLWH, low prevalence location; all names have been changed to protect the identity of participants; low prevalence locations included all locales outside of the four major urban centers of Amsterdam, Rotterdam, the Hague, and Utrecht).

Participants also conveyed having been asked *irrelevant questions* about their HIV status. Often, these questions pertained to how one had acquired HIV when this was unlikely to be important for care provision: "Every time I go to

the hospital, I have to explain so much and they ask about my HIV status. I doubt they ask someone with diabetes when they got it and how they got it. I think, 'That's none of your business.' That's not what I'm here for." (Hannah, age 35, PLWH, low prevalence location).

In addition, some participants reported *being treated rudely* by health care professionals because of their HIV status. One participant spoke of how his internist gave him his HIV diagnosis: "The internist said, 'Bingo.' He literally said, 'Bingo.' He didn't say, 'You're HIV-positive.' He just said, 'Bingo.' He didn't actually tell me that it [the test] was positive. He only said, 'Bingo.'" (Ronald, age 64, PLWH, low prevalence location).

Finally, some participants reported feeling *blamed for their HIV status*: "I had a feeling of, well, I felt a bit of an atmosphere of, 'What goes around comes around." (Melissa, age 40, PLWH, urban location; urban locations included Amsterdam, Rotterdam, the Hague, and Utrecht).

At the other end of the spectrum, some participants reported health care providers being excessively compassionate, so much so that they felt they were *being pitied*. One participant said, "He just looked at me for the first 5 minutes like, 'How awful!'" (Vincent, age 27, PLWH, urban location).

Excessive precautions and differential treatment. Participants further reported having been subjected to excessive or differential protective measures as a result of their HIV status: "I once, at the lab, had someone that, believe it or not, put on two pairs of gloves when that doesn't normally happen." (Hannah, age 35, PLWH, low prevalence location).

The data suggest that particularly dentists' and orthodontists' offices are inclined to take extra yet unnecessary precautions with HIV patients. This frequently manifests as booking HIV patients in at the end of the morning or the end of the day so that instruments can be thoroughly sterilized after the appointment: "I prefer to go first thing in the morning—straight out of bed, brush my teeth, and off I go to the dentist. Then it's over and done with but that can't happen anymore. He [the dentist] said, "The only problem [with

TABLE 3. SUMMARY OF QUALITATIVE RESULTS

PLWH HCP

Negative experiences:

- Awkward social interactions, irrelevant questions, rude treatment, blame, pity
- Excessive precautions and differential treatment
- Refusal or reluctance to provide care, unnecessary referrals, late diagnosis, treatment delays, insufficient support provision
- Confidentiality breaches, carelessness with confidentiality, inadequate discretion

Positive experiences:

- Equal treatment
- Extra attention
- Respect and partnership manifest as receiving adequate time, attentive listening, and complaints being taken seriously
- Social support provision
- Assurances of confidentiality

- Limited experience with PLWH
- Limited knowledge of HIV not considered problematic
- HIV seen as normalized, stigma not present
- Emotional reactions to HIV and PLWH experienced or observed
- Extra precautions taken to prevent occupational infection
- Awareness that differential precautions are discriminatory
- Labelling of files to warn other HCP
- Curiosity regarding how HIV was acquired and link to personal responsibility (although not expressed to patient)
- Awareness that attributions of personal responsibility are problematic

being HIV-positive] is that you have to come at the end of the day...because then all the instruments and everything can be thoroughly cleaned and sterilized.'...Nonsense! I mean, don't they use clean ones with everyone?" (Martin, age 54, PLWH, urban location).

Compromised care. In addition to awkward or inappropriate interactions and excessive or differential precautions, a number of participants reported incidents whereby care was refused based on HIV status or health professionals were otherwise reluctant to treat. In speaking about a physiotherapist, one participant claimed, "She said, 'I need to discuss this with the director of the health centre because, yeah, you are an HIV patient and I don't know if I can." Oh really?!?! I said, 'Forget it!'" (Ronald, age 64, PLWH, low prevalence location).

Additionally, a number of participants reported *being unnecessarily referred* to their internist for problems not explicitly related to their HIV infection which, in some cases, resulted in the internist sending them back to their referring physician: "If I talk to my internist about minor health complaints, he says, 'Those are not related to your HIV,' but when I get to my GP, he says, 'No' and it's then the other way around." (Alfred, age 50, PLWH, urban location).

Also, a number of participants reported not having received the care they needed. In fact, two participants reported that they had been *diagnosed much later* than they should have been. "I had to ask for an HIV test three times. I could have known four years earlier. I had weird complaints then." (Luka, age 27, PLWH, urban location).

Additionally, quite a few participants spoke of a reluctance on the part of their internist to prescribe antiretroviral medication when they felt that they needed to start treatment. "Participant: My mouth was full of blisters so I could only eat yoghurt and stuff. So I was, I was very thin. Really. I had become really skinny. And then I said to the internist, 'Give me the medication cuz I can't eat anything. Everything hurts.' In December, I got the medication. Interviewer: But then there were two months between when you said you wanted the medication — Participant: It was from May to December so that was seven months!" (Ronald, age 64, PLWH, low prevalence location).

The participants who reported *delays in receiving treatment* conveyed feeling as though they had not been taken seriously, as did participants reporting having to repeatedly remind their health care providers about contraindications between their HIV-related medication and their other medication: "I'm prescribed something that, if I read the instruction leaflet, I see that it doesn't combine well with this or that medication, and then I have to call myself, and I have to be watchful as to whether or not the medication can be taken together." (Hannah, age 35, PLWH, low prevalence location).

Some participants also conveyed *being insufficiently supported* by health care providers in dealing with having HIV, even within mental health care services: "They don't consider the consequences of having HIV at all. It's completely overlooked—at least that's my impression." (Kenny, age 28, PLWH, low prevalence location). A lack of support regarding how to proceed after one's diagnosis was also reported: "[My GP] called me once. That was 3 weeks after he told me [I have HIV]. He said, 'I think that you should go to the HIV clinic.' I said, 'I've already been three times.' I had to take care of that

myself." (Luka, age 27, PLWH, urban location). What this participant essentially felt was that he had been left to navigate a complicated health care process on his own.

Confidentiality concerns. Lastly, participants reported concerns regarding the protection of their confidentiality. Some reported explicit confidentiality breaches. Others reported carelessness on the part of health care professionals in maintaining confidentiality. Still others had concerns regarding the degree to which knowledge of their HIV status can be gained by others within a health care institution.

Not many explicit breaches of confidentiality were reported. However, one participant did report that, "They [nurses] stick notes on the outside of your chart that say you have HIV...It's really hurtful to, when I'm standing there in the queue, to see my file lying there. Who else has seen it?" (Hannah, age 35, PLWH, low prevalence location). More frequent than explicit breaches of confidentiality was carelessness in maintaining confidentiality: "[After I gave birth], a nurse came to my bed and started talking about how, yeah, the baby's medication needed to be considered and, at the time, my neighbor was visiting. She was sitting next to me on the bed. And she said, 'What kind of medication?'...You'd think she'd [the nurse] know and think, 'Oh, there's someone there at the bed and perhaps that person doesn't know.' On top of that, it was in my file. It said that I'm not open about it [HIV]." (Melissa, age 40, PLWH, urban location).

Study participants further reported having concerns that personnel whom they had not explicitly told about their HIV status in, for example, the hospital, at their GP's office, and at their dentist's office could find out by *accessing (electronic)* patient files. For example, one participant said, "So, even the receptionist—she saw in my file that I am HIV-positive. So everyone at my dentist's office can see that I have HIV while I only wanted to inform my dentist, no one else." (Liam, age 33, PLWH, low prevalence location).

Confidentiality concerns at pharmacies were also reported. Many pharmacies attempt to be discrete by bagging medication prior to the patient's arrival but not always. One participant reported, "She just started bagging it right there in front of everyone, saying the names [of the medication] while she did it." (Melissa, age 40, PLWH, urban location). Bagging medication ahead of time, however, can also be conspicuous and can make PWLH feel like everyone knows that they have a 'secret': "They are faxed that I need medication and they are there, ready to go, nicely packed in a bag, a pharmacy's bag but sometimes I need something else for my asthma and so they pass me the bag and then say, 'And here's the medication for your lungs' and those aren't in a bag. So, the people sitting there look and think, 'He has meds in a bag and then meds that aren't in the bag.' It's noticeable." (Leo, age 59, PLWH, low prevalence location).

Positive interactions in health care. In addition to negative interactions, participants reported many positive experiences in their interactions with health care professionals and expressed that, fortunately, the frequency of positive interactions was far greater than the frequency of negative reactions. These experiences are described below and summarized in Table 3.

Equal treatment. Participants reported, across a broad range of health care settings, positive experiences whereby they felt they had been treated like any other patient. One such setting was the blood sampling station: "I come there to have my blood taken and they do their job and that's that." (Vincent, age 27, PLWH, urban location). Another was the general practitioner's office: "[I was treated] really normal, nothing unusual. I haven't gotten the impression that they treat me any different." (Jasmina, age 40, PLWH, low prevalence location). Yet another setting was the pharmacy: "They just give me my medicine and I've never had the sense that they do something different or that they think it's weird." (Jacob, age 33, PLWH, low prevalence location). A number of participants also reported being treated normally at their dentist's office: "It wasn't a problem at all. He simply saw it as a medical condition and whether you have this or that, it doesn't matter. He gave no indication that he was shocked or thought, 'What am I supposed to do with this?'" (Benjamin, age 66, PLWH, urban location). Lastly, participants conveyed having been treated normally by medical specialists, such as a gynecologist: "I was treated just like any other woman who wants to get pregnant. And when I got pregnant, I was treated like any other pregnant woman." (Hannah, age 35, PLWH, low prevalence location).

Extra attention. In addition, participants reported having received extra attention because of their HIV and experiencing that attention as something positive. In fact, a number of participants provided examples of their health care providers going 'the extra mile' by being involved in and concerned about their unique situation as an HIV patient. For example, one participant reported that his internist had been very involved in his care during periods of hospitalization: "I found it reassuring to hear, after the fact, that my internist he had contact with the medical specialist in [regional hospital name removed] every day and followed up on everything and provided all sorts of advice and thought along about what needed to happen." (André, age 48, PLWH, urban location). Another spoke of a neurologist being very engaged in her treatment of neuropathy: "He was really concerned. I came there with symptoms of neuropathy. That, no doubt, has to do with HIV/AIDS or with the medication and he dealt with that really well in the sense that he did his utmost best to really figure out how severe things were and whether I had another neurological condition so he was really committed to understanding things. He even asked some doctor in [an urban teaching hospital]." (Joyce, age 55, PLWH, low prevalence location). Yet another participant explained that his GP said, "The next time you come, I want two consults booked so that I can spend more time on you." (Liam, age 33, PLWH, low prevalence location).

In addition to these examples, quite a few participants reported dentists, dental hygienists, and dental surgeons being very attentive and well informed regarding the fact that maintaining healthy teeth is particularly important for people with HIV: "My dentist, uh, he keeps a close eye on me and he doesn't let anything get out of hand. He, uhm, yeah, he always refers to it when he looks and, if he is going to do something where you're not sure if that's necessary, he always explains why he does it cuz he says, 'If you get complications with your mouth, this and that might happen.' [That is important] because my immune system isn't quite

where it should be." (Mark, age 50, PLWH, low prevalence location).

Pharmacies were also praised for being extra considerate: "I am always properly informed whenever I send them my prescription and if they run out of something, they call me saying, 'Hey, how much do you need? Do you need something now? If so, we'll order it somewhere else." (Hannah, age 35, PLWH, low prevalence location). Additionally, participants reported experiences whereby pharmacists were keen to check for potential interactions between drugs: "They pointed out that there's an interaction between the one and the other, and then you get this or that, so they think along with you." (Luka, age 27, PLWH, urban location).

Valuing the patient. Participants additionally conveyed interactions with health care providers whereby they felt respected and valued as a partner in the creation and maintenance of their well-being. Referring to his internist, one participant said, "He takes me as I am and lets me make my own choices and he understands." (Fred, age 51, PLWH, urban location). Receiving adequate time, listening carefully to health complaints, and taking those complaints seriously were also reported as positive interactions indicative of respect. One participant said, "It's really nice that you're heard and that you're taken seriously." (Benjamin, age 66, PLWH, urban location). Another reported being able to see her general practitioner whenever she needs to: "And it's always possible—right away. So, if I call, then I'm immediately the next patient. In that sense, the care I get is really good." (Hannah, age 35, PLWH, low prevalence location). Yet another participant spoke about being grateful that her general practitioner listens to her and does not automatically attribute health complaints to her HIV: "What I appreciate is that I'm not—see, I also go there for totally different things and, uhm, I'm happy that I can just talk about those things and that is not—you know, my condition isn't also part of it—there isn't the inclination to automatically link the two." (Jasmina, age 40, PLWH, low prevalence location).

Social support. Similarly, participants reported social support provision. In fact, particularly HIV nurses were perceived to be supportive and helpful. One participant said, "So, if there's something going on and I am struggling with something or whatever, I can always bring it up and talk about it with them. Yeah. They are always there for us." (Liam, age 33, PLWH, low prevalence location). Another said that his HIV nurse not only supports him but is also there for his family and friends: "My parents can also call her—or my friends even—if they have questions. My ex-partner also called her regularly to ask her how this or that works. So, she's not only there for me; she's also there for my whole network." (Luka, age 27, PLWH, urban location). Participants reported that receiving social support is particularly beneficial just after diagnosis and when dealing with negative reactions: "I think that you really need that. That if you are in these kinds of situations with HIV that you really need people that are positive about it." (Liam, age 33, PLWH, low prevalence location).

Assurances regarding confidentiality. Lastly, participants reported interactions in which their health care provider explicitly assured them that their confidentiality would be

maintained. In fact, two participants reported that their dentist was in some way connected to their social circle and that they had been concerned that their HIV status would come up in conversation. In both cases, the dentists reassured the participants that this would never happen: "He said, 'You're here in my chair and I have a duty to maintain professional confidentiality." (Mark, age 50, PLWH, low prevalence location).

## Health professionals' perspectives

Knowledge and experience with HIV. The health care providers interviewed reported having limited experience providing care to PLWH. Generally, they had had, at most, a handful of patients with HIV. This is not unsurprising given prevalence rates in the Netherlands. Most reported that, given the fact that their professional contact with PLWH is limited and that HIV is not their area of expertise, their knowledge regarding HIV is elementary: "Let's say, I know the basics but when it comes to the details or how that all works, my knowledge is limited." (Lori, age 24, nurse, urban location). This was not considered problematic: "I don't think I need to know the details of that stuff that the internist does." (Christine, age 39, physician, low prevalence location).

In discussing their perceptions of HIV and PLWH, most of these health care providers indicated that, in general, and thus also in their work environments, HIV has become relatively normalized. One professional said, "It's basically accepted—here in this office at least. It's not an issue, not even behind closed doors. We don't sit there and say, 'He's got HIV.'" (Matthew, age 50, dentist, low prevalence location). In fact, HIV-related stigma was considered to be a thing of the past. In the words of one participant, "It used to be—you know, with Freddy Mercury and that period, the eighties and nineties—it was like, 'Oh, that's deadly.' Fortunately, that's not the case anymore. It's more a chronic disease...It's become more accepted, better known. It's less frightening." (Peter, age 66, nurse, low prevalence location).

Emotional reactions. Despite the contention that HIV has become normalized and that fear in contact with PLWH has dissipated, some participants did report recently personally experiencing or, alternatively, observing a negative emotional reaction to PLWH, even if that reaction seems illogical. One participant, a dentist, said, "Initially, you're scared stiff. Then, you think, 'Oh shit!'...'I really hope I don't get this or that' but, yeah, obviously, it makes no sense...We have protocols about how sterile things have to be—the hygienic measures—so it shouldn't make a difference." (Matthew, age 50, dentist, low prevalence location). Similarly, a psychiatrist described emotional reactions to an innocuous injury in an interaction between a colleague and a PLWH: "Then you see that a colleague is in complete panic and there's no use telling them that the actual chance of infection is really small. At that moment, emotion prevails and then people are convinced that they are infected and then the fastest diagnostics are not fast enough. I have indeed seen someone get tested and have a rush put on it when there was absolutely no chance of infection. It was done just to reassure them. And then, the funny thing is that the order was specifically for HIV while there are all sorts of other diseases." (Hugo, age 32, physician, urban location).

Extra precautions. More frequent than negative emotional reactions in the form of fear or panic was a desire to be extra cautious and more alert in interactions with PLWH. In fact, the majority of participants used the words 'extra cautious', 'extra careful', or 'extra alert' when discussing professional interactions with PLWH: "Normally, you're careful but then [with a PLWH] you have this voice in the back of your mind that says, 'I really don't want to get this. I don't want to take this home with me, so to speak, so be extra careful!'" (Ria, age 24, nursing assistant, low prevalence location).

Although not quantifiable given the number of participants, this tendency appeared to be more prominent among nurses than among other health care providers, and a number of specialists did contend, without having been asked, that this tendency is indeed greater among nursing staff: "I'm less bothered by it but the assistants, if they have to take blood or something, they are extra alert." (Christine, age 39, physician, low prevalence location). Similarly, one participant said, "Right away, you can see that the nursing staff have already become a little more restrained in the care they provide. They, of course, follow the protocol to the tee, eh? Like, if they have to do an IV or if they have certain care duties, they are careful. Still, it, in some way or another, has a different feel and people are very alert." (Hugo, age 32, physician, urban location).

The data suggest that this desire to be extra careful or extra alert frequently compels health care providers to take protective measures with PLWH that they do not normally take with other patients. For example, many of the health care providers interviewed indicated that they tend not to wear gloves when inserting needles but that, with a PLWH, they would: "Indeed, I don't wear gloves but I would—I would if it was an HIV patient...The care provider is just protecting himself while he, albeit unjust, doesn't do that with someone else." (Niels, age 52, physician, low prevalence location). In a similar fashion, a dentist spoke of how his patients with HIV no longer have to come in at the end of the day not because they are treated like any other patient but because there is sufficient space to keep the room in which the PLWH was seen free for extra cleaning: "We don't do that anymore because we have more than one room so we can clean that room really well at any time. We do pay special attention to that. We're extra alert. We also have special disinfectant that we use for that. Normally, you wipe down the chair with alcohol. Then [after an HIV patient], we also use something that kills derivatives." (Matthew, age 50, dentist, low prevalence location). Unfortunately, some participants, including the above dentist, reported instances whereby the application of differential precautions with PLWH is, at least in their perception, formalized in protocol: "So, normally, it's like this: After the patient leaves, the room is cleaned according to a protocol, a standard protocol. If a HIV patient was treated, then all the hoses are cleaned again. The chair is completely wiped down. Basically, everything is cleaned extra well so that everything, uhm, to prevent any possible infection." (Matthew, age 50, dentist, low prevalence location).

Evidently the desire to be more careful or alert with PLWH is linked to a fear of potential infection and, although when handling blood products, a risk of infection is indeed present, it seems that this fear is disproportionate given the likelihood of infection. As described by one participant, "That alertness is not, definitely not, a, a, uh, a reproachful alertness or that

they, in itself, find it bothersome that someone like that is there, but you do notice that there's, uh, well, yeah, an alertness that a whole lot of other conditions with the same kind of risks don't get." (Hugo, age 32, physician, urban location). Again, this was considered to be rooted in the fear of HIV that was cultivated in the past: "That's because of that stress in the eighties and nineties. That's had such an enormous impact. It was paralyzing. I think that the fear was too great." (Anne, age 38, nurse, low prevalence location).

Furthermore, there was certainly an awareness among participants that the differential treatment of PLWH is problematic and reflective of discriminatory behavior. In fact, throughout the data, there are numerous examples in which participants reflected on the fact that such behaviour is illogical, unnecessary, and problematic. For example, one participant said, "Sometimes, I think to myself, 'How hypocritical is that?' because the woman lying next to that person could have anything. You just don't know. You should actually use the same procedure with every patient." (Ria, age 24, nursing assistant, low prevalence location).

Fortunately, many health care professionals, including those interviewed for this study, interact with PLWH no differently than they interact with other patients. For example, an anaesthesiologist said, "Look, I always wear gloves when doing an IV...so, for me, it's not any different...Right from the start, I learned to wear gloves when inserting a needle because you never know." (Ellin, age 33, physician, low prevalence location).

Labeling patient files. In addition to reporting the use of differential precautions, health care providers reported HIV patients' files being labeled in order to warn other providers about the potential risk of infection. As stated by one surgical nurse, "Usually, whenever I come in contact with those people [PLWH], there are big stickers saying 'HIVpositive. Be careful!'...The surgeons, they pick up instruments without gloves and they, they just walk into isolation rooms. They need to see 'Be careful!' on a chart in a big letters...because they just walk in. They don't look [at the charts]." (Ria, age 24, nursing assistant, low prevalence location). Another nurse recalled, "With, for example, the blood draw station in the hospital, it always said code 0 if it was an HIV patient and that is, of course, unbelievably stigmatizing too because it doesn't make sense. Why is it necessary? But it was always there, like 'Be extra alert and be careful,' a kind of warning." (Judith, age 39, nurse, low prevalence location).

Responsibility for infection. A number of health care providers indicated that, in contact with PLWH, they have found themselves curious about how that person acquired HIV. Frequently, this curiosity and the accompanying questions are linked to attributions of responsibility for HIV and this can, in some cases, manifest as blame. One nurse said that, in the past, "I always thought, 'How stupid could you be to get HIV?,' because you can prevent it. I was kind of judgmental. I was also really aware of it. I always wanted to know how they got it. Did they get it from a blood transfusion? Yeah? Then that's really sad because they had really bad luck. And I thought if someone had sex and did it really unsafely and especially with men who have sex with men. If they have anal sex without a condom, I thought,

'You're just a complete dolt!'" (Anne, age 38, nurse, low prevalence location).

Fortunately, most participants indicated that even if they were curious, they would not ask, and if they did somehow determine the means of infection, they would not express their opinions in that regard to the PLWH in question: "I do always try to approach them normally...but it's always there in the back of my mind." (Ria, age 24, nursing assistant, low prevalence location). However, this same nurse discussed how speculation about how a patient acquired HIV does occur, behind closed doors, among colleagues.

Again, health care providers were aware that curiosity and corresponding attributions of blame are problematic and can be construed as stigmatizing: "For me, it always raises questions about how one gets HIV, but I'm kind of ambivalent about that." (Hugo, age 32, physician, urban location).

#### Discussion

The findings of this mixed methods study have shown that PLWH in the Netherlands experience both positive and negative interactions with health professionals and have provided context for the occurrence of those interactions. When combined with the perspectives of health professionals, the findings suggest that there is a gap in perception between PLWH and health care providers regarding the extent to which negative interactions occur. PLWH conveyed a broad range of negative experiences, while health care providers felt that HIV has been relatively normalized and that HIV-related stigmatization is a thing of the past. At the same time, health care providers discussed behaviors that can easily be construed as stigmatizing to PLWH. It is important to consider this discrepancy in perception, particularly given the fact that it has been observed elsewhere by Feyissa and colleagues.<sup>38</sup> In their article on HIV in the Ethiopian health care sector, they discussed how PLWH felt they had been unnecessarily referred to other health professionals while health professionals claimed that referrals are made in an effort to optimize the quality of care. In that same study, discrepancies were also reported for issues pertaining to confidentiality. PLWH felt that their confidentiality had been breached, while health care providers claimed that unofficial disclosure to colleagues was necessary to facilitate health services delivery and to ensure that colleagues take necessary precautions with PLWH.

There are a number of possible explanations for this gap in perception. One is that some PLWH have high levels of stigma consciousness, defined as the expectation that one will be stereotyped, and therefore interpret behaviors as discriminatory when they are not necessarily rooted in prejudice or negative attitudes towards PLWH. 53-55 Li and colleagues, in their discussion of HIV-related avoidance attitudes among health care providers in China, claimed that health care providers' negative attitudes toward PLWH may be rooted in their own work stress or emotional exhaustion rather than in stigma and that a lack of willingness to care for PLWH may be a generalized negative attitude towards caring for patients. 41 Similarly, Manirankunda and colleagues, in their investigation of barriers to provider-initiated HIV testing in Flanders, Belgium, showed that health care providers are inhibited by a broad range of factors, including, ironically, a

fear of being perceived as acting in a discriminatory fashion.<sup>56</sup> We would contend that it is unlikely that all of the PLWH in our study had high levels of stigma consciousness. A more likely explanation is that some health care providers in the Netherlands lack an awareness of the kinds of behaviors that can be perceived as negative by PLWH. This is in line with Pisal et al.<sup>57</sup> In their focus group study, nurses described discriminatory actions but did not always perceive these as such. Interestingly, a lack of awareness that certain behaviors can be perceived as negative or stigmatizing has been found to be more common in health care providers who have, similar to our sample, limited experience interacting with PLWH. 58 In fact, most of the health care providers in our study did not express explicit negative attitudes about PLWH with accompanying moral judgments—something termed symbolic stigma.<sup>59</sup> Instead, most reported a fear of potential occupational infection resulting in the application of differential precautions and labeling of files. This is reflective of what is termed instrumental stigma.<sup>59</sup>

Thus, the issue does not appear primarily to be prejudice; the issue appears to be a disproportionate fear of infection, and indeed, in our study, health care providers showed a kind of ambivalence. On the one hand, they wanted to provide good care to patients. On the other, they wanted to protect themselves. Some were also aware of the problematic nature of differential treatment but nonetheless chose to protect themselves. Our contention is thus that behaviors perceived as stigmatizing by PLWH are unlikely intended as stigmatizing but rather the result of a lack of knowledge and experience. This is line with Hebl et al. 60 who claim that deficient knowledge and experience with people possessing a statistically infrequent stigmatized condition such as HIV in the Netherlands can result in 'unintended' stigmatizing behavior. Supporting this is our observation that negative interactions appeared to be more common in low prevalence areas where health care providers have less opportunities to interact with PLWH than in urban areas like Amsterdam, Rotterdam, the Hague, and Utrecht where prevalence is higher and health care professionals are more likely to come in contact with PLWH.

The contention that negative interactions between PLWH and health care providers are likely the result of unintended instrumental stigma resulting from limited knowledge and experience is well-supported in the literature. Sears and Ho demonstrated, in the US, that a lack of HIV expertise, inadequate training, and no prior experience in treating PLWH contributed to negative interactions. <sup>22</sup> Similarly, Bektas and Kulakaci found support for the relationship between experience and knowledge, on the one hand, and willingness to care, on the other, among nurses in Turkey, <sup>61</sup> as did Feyissa et al. in Ethiopia. <sup>38</sup>

Given that PLWH reported a range of negative experiences and HCP reported discriminatory behavior and given also that previous literature has shown that positive patient—provider relationships and adequate health service delivery are fundamental to treatment adherence and engagement in care, 45,62 we feel that efforts should be made to improve interactions between PLWH and health care professionals. This requires, in our opinion, multi-level and multi-faceted interventions that are theory and evidenced-based and that are developed in collaboration with the targeted end users. 33,37,63–66 We specifically recommend developing parallel

interventions that target PLWH and health care professionals simultaneously.

Keeping in mind current theory and evidence on stigma reduction and care optimization, we suggest that interventions geared to PLWH seek to enable processes of empowerment and develop resilience against negative interactions. PLWH can benefit from knowing their rights and obligations in health care settings, how to identify violations against those rights, and the kind of action that can be taken to deal with perceived discriminatory acts. 47,67–69 If negative interactions occur, resilience and coping skills can buffer against the negative impact of these experiences. 66,70–72 Interventions should thus facilitate the acquisition of advantageous coping skills like attributing negative interactions to ignorance, seeking social support, and positively reappraising negative experiences. 73–76

Again, leaning on the current literature in combination with our findings, we recommend that interventions geared to health care providers focus on increasing HIV-related knowledge and enabling opportunities for health care providers to gain experience in interacting with PLWH. Knowledge can be increased through the provision of information and educational materials. These materials should not only include information on the basics of HIV—thus how it is transmitted, its course, and its treatment—but also information that is specifically relevant for health care providers thus information on occupational risks, infection prevention measures, and postexposure prophylaxis. 19,38,57,77–79 We also recommend that interventions seek to sensitize health care providers to PLWH's rights and health care providers' obligations in their contact with PLWH as delineated in protocols, as has been suggested by other authors in other locales. 22,47,68,80,81

Possessing basic and health care sector specific knowledge about HIV and having an understanding of PLWH's rights can contribute to more positive interactions between PLWH and health care providers and better quality care, <sup>38,58</sup> but information provision alone is insufficient as knowledge does not automatically change attitudes. <sup>16,21,37,64,82</sup> It does, however, form the basis upon which informed attitudes are developed and is, therefore, central to positive changes in attitudes and behaviour. <sup>16,77</sup> Consequently, we consider the provision of information to be an important first but certainly not final step in creating and maintaining positive experiences for PLWH in health care.

Across a number of conditions, including HIV, there is extensive theoretical support for and empirical evidence showing that empathy promotes positive interactions and reduces stigmatization. <sup>33,41,66,71,83–87</sup> In fact, Lin and colleagues, in their study among service providers in China, found that more empathetic attitudes were negatively related to avoidance attitudes. <sup>88</sup> We therefore suggest that interventions with health care providers seek to induce empathy by creating an awareness of those behaviors reflecting unintended instrumental stigma (e.g., use of differential precautions, labelling of files) and the impact of such behaviors on PLWH. <sup>34</sup>

Empathy can also be cultivated by creating opportunities for contact between PLWH and health care providers, either directly or vicariously (e.g., through digital testimonials). We strongly recommend that interventions provide such opportunities as contact interventions have been found to not only promote empathy, but also correct misinformation, change stereotypes, and function as a means of acquiring experience

with PLWH, <sup>37,64,66,71,83,89–91</sup> and the empirical evidence linking experience with PLWH to positive interactions and stigma reduction is overwhelming. <sup>19,33,57,78–80,92,93</sup> Contact interventions are likely to be particularly valuable in low HIV prevalence areas.

We further recommend that interventions geared to health care providers offer opportunities for self-reflection on HIV-related beliefs, attitudes, and values in a safe and nonjudgmental environment. Interventionists may consider incorporating opportunities for self-reflection on stigmatized behaviors frequently associated with HIV such as homosexuality, commercial sex work, and drug use as addressing layered stigmas, if present, may yield even greater changes in negative attitudes. 16,95–98

Before interpersonal level interventions geared to PLWH and health care providers can be implemented, it is imperative that supportive structural conditions for the equal treatment of PLWH in the health care settings are in place. <sup>99,100</sup> This means that adequate national legislation, appropriate upto-date treatment protocols, and nondiscriminatory institutional policies are present, effectively conveyed, and easy to access for health care providers. <sup>18,38</sup> Additionally, institutional support for the consistent application of universal precautions and availability of post-exposure prophylaxis is important. <sup>33,38,80,82</sup> Failing this, interpersonal level interventions focusing on the interactions between PLWH and health care providers are futile. <sup>18</sup>

In addition to these recommendations for interventions, we suggest some directions for future research. First, in order to elaborate upon our qualitative findings with health care professionals and determine the extent to which these findings can be generalized across health care providers, we recommend conducting a quantitative survey study with various health care providers that measures HIV-related knowledge and attitudes in addition to willingness to care for PLWH, previous experience with PLWH, and empathy. Second, given the fact that most of the PLWH that participated in the survey or an interview were relatively welleducated gay men of Dutch origin, we suggest that future research on HIV in the health care sector explore the positive and stigmatizing experiences of other PLWH, such as immigrant PLWH from HIV endemic countries, to determine if their experiences are similar or unique. Third, given the paucity of research on experiences of HIV-related stigma in low prevalence locales, we suggest additional studies be conducted to better establish the contexts of HIV-related stigma in these areas, and that comparative studies look at differences and similarities in HIV-related stigma between health care settings in high and low prevalence areas.

In conclusion, this study has explored and outlined the perspectives of both PLWH and health care providers on their interactions in the patient-provider context, and demonstrated that perspectives differ and that interventions to improve interactions are not only worthwhile but important for the effective optimization of care provision to PLWH.

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