

Disclosure of HIV Status to Health Care Providers in the Netherlands

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Disclosure of HIV status to health care providers in the Netherlands: A qualitative study

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Abstract

We qualitatively investigated perspectives on HIV disclosure to health care providers (HCP) by people living with HIV (PLWH). Perspectives varied across PLWH and between PLWH and HCP. Some PLWH felt they should always disclose so that HCP could take necessary precautions or because disclosure optimized care. Others felt that disclosure was not an obligation but a courtesy. Still others felt that disclosure was unnecessary as all HCP should apply universal precautions or because HIV status was not relevant to care. Most HCP claimed they should be informed about patients' HIV status as this would reduce occupational risk of infection and improve care. HCP also felt that disclosure concerns by PLWH were unnecessary given the HCP duty of professional confidentiality. Some acknowledged that disclosure was not always necessary but still indicated wanting to be informed. Perspectives on HIV disclosure in health care settings differed substantially between PLWH and HCP.

Keywords: disclosure, health care, HIV, people living with HIV, stigma

Disclosure of HIV status to health care providers in the Netherlands: A qualitative study

People living with a concealable condition such as HIV are often in a position to decide if they will disclose their conditions in interactions with others. Generally, when determining whether to disclose, people living with HIV (PLWH) weigh the advantages and disadvantages of said disclosures (Serovich, Lim, & Mason, 2008; Stutterheim, Shiripinda, et al., 2011). A number of advantages to disclosure have been documented. These include increased provision of emotional and social support, better mental and physical health, greater adherence to antiretroviral therapy (ART), and increased CD4+ T cell counts (Chaudoir, Fisher, & Simoni, 2011; Heflinger & Hinshaw, 2010; Smith, Rossetto, & Peterson, 2008; Strachan, Bennett, Russo, & Roy-Byrne, 2007). On a broader level, disclosure has also been linked to safer sex and the reduction of public HIV-related stigma (Chaudoir et al., 2011; Obermeyer, Baijal, & Pegurri, 2011). However, disclosure can also have negative impacts. A significant body of literature has demonstrated a link between HIV status disclosure and stigmatization (Chaudoir et al., 2011; Logie & Gadalla, 2009; Stutterheim, Bos, et al., 2011) and, in parallel fashion, there are studies showing that concealing HIV can limit stigmatization (Emler, 2006; Richman & Hatzenbuehler, 2014; Smith et al., 2008; Stutterheim, Bos, et al., 2011).

Most of the literature on HIV disclosure has focused on voluntary disclosure or concealment, more generally or in the context of partners, family, or friends (Obermeyer et al., 2011; Parcesepe & Cabassa, 2013; Smith et al., 2008). A much smaller body of literature has looked at specific contexts for disclosure such as health care. In fact, to our knowledge, only a handful of studies have explored PLWH's perspectives on disclosure to health care providers (HCP; Bairan et al., 2007; Edwards, Palmer, Osbourne, & Scambler, 2013; Weatherburn, Keogh, Reid, Hammond, & Jessup, 2013) or HCP's perspectives on disclosure of HIV status by patients (Aultman & Borges, 2011; Mill et al., 2013).

Studying HIV status disclosure in health care settings is important because the experience of disclosure to HCP can be very different than the experience of disclosure to others (Chaudoir et al., 2011). Health care is a setting in which many PLWH feel obliged to disclose their status (Rintamaki, Scott, Kosenko, & Jensen, 2007; Rutledge, Abell, Padmore, & McCann, 2009) and also a setting in which PLWH often do not expect their disclosure to be met with negative reactions (Stutterheim et al., 2009). Unfortunately, negative responses to PLWH on the part of HCP do occur (Corrigan, Watson, & Miller, 2006; Jin et al., 2014; Philip, Chadee, & Yearwood, 2014; Pickles, King, & Belan, 2009; Rohleder & Lyons, 2015). In fact, in a study conducted in the United Kingdom, almost half of the PLWH who reported having experienced discrimination indicated that this discrimination involved a health care provider (Elford, Ibrahim, Bukutu, & Anderson, 2008). These kinds of experiences are highly detrimental to the mental and physical well-being of PLWH as manifested in increased psychological distress, poorer treatment adherence, and lower retention in care (Henry et al., 2015; Langebeek et al., 2014; Stutterheim et al., 2009).

Clearly, positive interactions between PLWH and HCP are vital, and an important step in optimizing interactions between PLWH and HCP is positive disclosure experiences. We therefore investigated both PLWH's and HCP's perspectives on the disclosure of HIV status in health care contexts and, in doing so, we paid particular attention to the reasons underlying those perspectives. Paralleling the perspectives of both PLWH and HCP in one study of disclosure is something that, to our knowledge, has not previously been done.

Method

Study Design and Context

PLWH's and HCP's perspectives on their interactions in health care settings were explored qualitatively using a general inductive approach with no formal methodological orientation. The Open University of the Netherlands' Faculty of Psychology and Educational

Sciences Ethics Board provided approval for this study.

The context in which our study was conducted was the Dutch health care sector. In the Netherlands, HIV prevalence rates are relatively low. As of June 2014, 19,989 people (0.1% of the population) were known to have HIV; 89% ($n = 17,750$) were enrolled in specialized care at one of the HIV treatment centers in the Netherlands. Of those enrolled in care, 91% ($n = 16,081$) were on ART and, of those on ART, 91% ($n = 14,602$) had an undetectable viral load (HIV Monitoring Foundation, 2014). Given low HIV prevalence and the presence of specialized HIV care in the Netherlands, most HCP working in the Dutch health care sector have, unless they are specialized in HIV care, limited, if any, contact with PLWH and, thus, also relatively limited HIV knowledge and experience (Stutterheim et al., 2014).

Sampling and Recruitment

In total, 22 PLWH and 14 HCP were recruited for our study. PLWH were recruited purposively by the interviewers (SS, LS), HIV practitioners in Dutch hospitals, and by the Dutch HIV Association, with some recruitment occurring via snowball sampling. HCP were recruited purposively by the research team who asked friends, family, and colleagues to bring them in contact with people who worked in the Dutch health care sector. Inclusion criteria were, for PLWH, having an HIV diagnosis, having previously received health care other than HIV care in the Netherlands, and an age of 18 years or older. For HCP, inclusion criteria were an age of 18 or older and working in the Dutch health care sector but not in HIV care, as those in HIV care would be likely to view disclosure in a fundamentally different light than those not working in HIV care. In recruiting HCP, we actively sought to include a diverse range of health care occupations.

All potential participants were contacted by telephone or email and then informed about the purpose of the interview, the context of the research as a whole, and the topics that would be discussed. Interviews were subsequently scheduled with either SS, who at the time

was a postdoctoral researcher with relatively extensive experience in conducting qualitative research on, among other subjects, disclosure, or LS, who was a Master's student conducting research under the supervision of SS. No potential participants declined.

Data Collection

Data were collected through single, face-to-face, semi-structured interviews that took place between September 2011 and May 2012 for PLWH and between January and March of 2012 for HCP. Interviews were conducted at a location deemed appropriate by the participant. This was generally the participant's home, office, or a restaurant. When interviews occurred in homes or offices, no other people were present. When interviews occurred in restaurants, other people were physically present but not part of the conversation.

All interviews were preceded by informed consent and guided by a structured protocol of interview topics with follow-up probes drafted by SS on the basis of the literature and previous research conducted on the disclosure of HIV status, and in collaboration with the other members of the research team. The structured protocol included an introduction wherein the interviewer reiterated the purpose of the interview, discussed confidentiality, outlined that participation was voluntary, and formally requested that the interview be recorded with a digital voice recorder. The topics subsequently covered in the interviews with PLWH included the kinds of health care professionals one comes in contact with, the extent to which one had disclosed to those professionals and why, reactions to disclosure, perspectives on the rights and obligations of PLWH and HCP regarding the disclosure of HIV, and ideas for improving interactions between PLWH and HCP. The topics discussed in the interviews with HCP were general thoughts about HIV, estimated knowledge regarding HIV, experiences and expectations in contact with PLWH as patients, perspectives on the rights and obligations of PLWH and HCP regarding the disclosure of HIV status, and ideas for improving interactions between PLWH and HCP. In this article, we report on the findings as they pertained to

disclosure. The data yielded from interviews with PLWH on reactions to disclosure and from interviews with HCP on their knowledge of HIV and experiences in caring for PLWH have been reported elsewhere (Stutterheim et al., 2014).

The interviews with PLWH were approximately 1 hour (range = 29:40 – 79:18) and the interviews with HCP were approximately 30 minutes (range 21:18 – 58:25). SS conducted 10 of the interviews with PLWH and all of the interviews with HCP; LS conducted the remaining 12 interviews with PLWH.

After interview completion, participants completed a short demographic survey measuring age, gender, educational attainment, employment, ethnicity, sexual orientation, location, and family composition, and, for PLWH, HIV-related characteristics such as means of transmission, time since diagnosis, treatment status, current health status, and presence of visible symptoms. No monetary compensation was provided for participation but participants were given a gift valued at approximately €15..

Immediately after each interview, the researcher took notes indicating impressions of the interview and ideas regarding interactions with the participant. The digital recordings were subsequently transcribed verbatim within a week of the interview having been conducted.

Data Analyses

Data derived from the 10 interviews with PLWH and all of the interviews with HCP conducted by SS were processed with QSR Nvivo 8 by SS. Data for the remaining 12 interviews with PLWH conducted by LS were processed in Microsoft Office Excel by LS.

In all analyses, each verbatim transcript was read thoroughly while listening to the corresponding recording to identify themes and determine categories to which text fragments could be assigned (i.e., thematic analyses). As coding occurred, categories and subcategories were developed and linked (Braun, Clarke, & Terry, 2015). The coding tree for disclosure was initiated with the parent nodes, *reasons for disclosure* and *reasons for concealment*, and

the various perspectives on disclosure that emerged from the data were added as children nodes. Using annotations and memos, a decision trail was maintained in which emergent categories within those initial nodes were documented, as were changes made to the categories and the motivation for changes (Polit & Beck, 2010). LS's first transcript was reviewed in detail by SS. Thereafter, SS and LS met regularly to review and compare coding structures and insights for the remaining data. When inconsistencies arose, these were discussed with members of the broader research group and the literature was consulted. Inconsistencies were not related to the content of the themes but rather the terminology used to capture the content.

After initial analyses, preliminary findings were compared to findings in the empirical literature on HIV and health care. They were also discussed within the research group, and with HCP and PLWH, to establish congruence with their experiences (i.e., member checks; Polit & Beck, 2010; Treharne & Riggs, 2015).

Results

Participant Characteristics

The PLWH sample included 17 men (77.3%) and 5 women (22.7%). Most were Dutch (90.9%, $n = 20$) with half living in an urban center (50%; $n = 11$). Of the participants, 16 (72.7%) self-identified as gay and 6 (27.3%) as straight. Ages ranged from 27 to 66 years 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 (27.3%; $n = 6$) had a high school diploma and some vocational training, and 13.6% ($n = 3$) had high school or less. Most had acquired HIV through sexual intercourse (93.9%; $n = 20$) and the mean time since diagnosis was 9.1 years ($SD = 7.4$).

The HCP interviewed included physicians (i.e., general practitioners, an anesthesiologist, a pediatrician, and a psychiatrist), specialized nurses, nursing assistants, a

nurse manager, and a dentist. All were Dutch; 10 were women (71.4%) and 4 were men (28.6%). Ages ranged from 24 to 66 years with a mean age of 38.6 years ($SD = 11.7$). All had a bachelor's degree or more.

PLWH's Perspectives

The extent to which PLWH felt they should disclose their HIV status to HCP varied, although most reported being quite open with HCP even if they were selective in their disclosure to family and friends. In fact, some participants claimed that *HCP should always be informed*: "I'm always open about it with medical personnel. I feel a kind of obligation to do that" (Melissa, age 40, PLWH; *note*: all names have been changed to protect the identity of participants).

A few participants reported *disclosing so that HCP take necessary precautions*: "Especially with doctors and nurses, I always tell them what I have because if they have to do certain things and need to protect themselves, they should know" (Benjamin, age 66, PLWH). In other cases, participants reported disclosing because disclosure *increases the likelihood that they will receive optimal health care*: "They need to get a clear picture of your general physical health and that is only possible if you tell them everything" (Vincent, age 27, PLWH).

A number of participants reported feeling that disclosure to HCP was *not a necessity nor an obligation but it was a courtesy*:

I don't think it has to be said because – don't get me wrong, I don't have a problem disclosing and I do - but I don't think people have to be "warned" because everyone should treat every patient as if he could potentially have HIV or something else like hepatitis B. (André, age 48, PLWH)

Indeed, some participants claimed that disclosure was unnecessary, as *all HCP should consistently apply universal precautions*:

As long as you work according to procedure, I don't need to tell you that I'm HIV positive. I know that things don't always go according to procedure and then that's difficult but then I think, "Is that my responsibility? Should I say something?" But I really think that if medical staff and, for example, my dentist, follow procedure, then I pose no risk in his practice. I think that people who aren't on medication and haven't been diagnosed but are HIV positive, they are a much greater risk than the people that are being treated and take their medication properly. (Hannah, age 35, PLWH)

Similarly, another participant, discussing his choice to conceal his status from his dentist, said the following:

You're supposed to work safely. I mean it's your responsibility. You're the ones messing around in my mouth so if you haven't done your work properly, that's your own fault and not mine. I mean, you know, I happen to know but there are plenty of people that don't know they're HIV positive. (Leo, age 59, PLWH)

Evidently, in determining whether or not to disclose, participants considered the degree to which knowledge of HIV status was important in that particular care context. Often, participants perceived risks to be absent and *knowledge of HIV status to contribute little to care provision*. One participant said, "I make conscious choices in the sense that I look at whether or not it is relevant for them" (Jasmina, age 40, PLWH). Another stated that in considering whether or not he should disclose to his physiotherapist, he thought, "What does it matter? ... It doesn't add anything. He can't do anything with the information. I mean, he only works with, uh, muscles and stuff so I figure it's not necessary for me to tell him" (Fred, age 51, PLWH).

HCP's Perspectives

The HCP interviewed were almost unanimously of the opinion that PLWH should always inform HCP about their HIV status: "I think that the whole team that is involved in

care should know” (Emma, age 30, physician). Generally, two reasons for disclosure were provided. The first and most prominent reason was that *disclosure reduces HCP’s occupational risk of infection*. Participants felt that “anyone that’s at risk, that could be at risk” should know (Katherine, age 64, nurse manager). As conveyed by one pediatrician, “We’re all involved in caring for that patient, so I think for the safety of the staff, that the whole team should know so also the nurses and the interns” (Emma, age 30, physician). Similarly, a general practitioner said, “I can’t think of a care provider for whom it wouldn’t be important to know” (Niels, age 52, physician).

The second reason why HCP felt that PLWH should disclose to all HCP was because *disclosure optimizes care provision*. One nurse said, “It’s important to know for the sake of the patient’s treatment” (Lori, age 24, nurse). Another said, in reference to disclosing to a dentist, “Just like if someone were on blood thinners, then the dentist should know that. It’s with stuff like that that I think, you can’t avoid that as an HIV patient, for the sake of your own health” (Judith, age 39, nurse). This sentiment was echoed in the following statement from a dentist:

The care that you receive is likely better if you inform care providers...If you come here and you say, “I have this or that,” even if someone says, “I have a severe form of cancer,” then we’re extra careful. We’ll go the extra mile. You don’t think, “Oh, he’s an idiot for getting this!” No, I just think then if you see a bad tooth, you’ll give that patient extra attention. (Matthew, age 50, dentist)

For an anesthesiologist, disclosure was considered particularly important:

It can have consequences for your own treatment. If I don’t know, I would give you a different dosage and then, I think, you can endanger yourself. So, I think it goes both ways. And, in any case, I think it’s important to have openness in the patient-provider relationship. You see, I have a duty of professional confidentiality and that’s there for

a good reason. (Ellin, age 33, physician)

Indeed, a number of participants referred to their *duty of professional confidentiality* when discussing disclosure of HIV status. They felt that knowing that they are obliged to maintain confidentiality should sufficiently alleviate any concerns PLWH had about their status being shared with others: “We’re not allowed to tell visitors or the family of a patient anything if the patient doesn’t want us to” (Lori, age 24, nurse).

At the same time, a few participants acknowledged that disclosure of HIV status might not always be necessary but that HCP would nonetheless *rather be informed than not informed*:

I once experienced that someone’s status wasn’t immediately conveyed. That person said it later himself and that was weird, you know? Immediately, there was a kind of unsafe feeling and people were like, “Oh, we should have been told,” as if someone had automatically come in contact with their blood and, uh, was walking around the ward with this extremely contagious thing. They really appreciate it if they are informed right away. (Hugo, age 32, physician)

This same participant reflected upon this desire to be informed:

You can ask yourself if it’s necessary, you know? I think – you see, it gives people a kind of false sense, eh, a false sense of security and false peace of mind, like, “Oh, yeah, I know it so I know how I’m supposed to deal with it,” but, at the same time, it also comes with a whole lot of panic. (Hugo, age 32, physician)

Discussion

Our study explored HIV status disclosure in health care settings from the perspective of both PLWH and HCP. Among the PLWH in our study, perspectives on disclosing one’s status to HCP varied. Some felt that HCP should always be informed so they could take the necessary precautions and/or because disclosure optimized care provision. Others felt that

they were not required or obliged to disclose but that disclosure was a courtesy. Still others felt that disclosure to HCP was unnecessary as all HCP should use universal precautions at all times or because knowledge of HIV status was not relevant to that care. This was in line with Edwards et al. (2013) who found that PLWH's disclosure to dentists in the United Kingdom varied from full disclosure to concealment. In that study, participants reported disclosing to their dentists to reduce transmission risk or to effectively prevent HIV-related oral disease. Reasons for concealing HIV status included anticipated stigma, in particular anticipated mistreatment and confidentiality breaches, and enacted stigma, specifically previous negative treatment after disclosure including care refusal. Edwards et al.'s (2013) participants also reported not disclosing because their dentists consistently applied universal precautions. Bairan et al. (2007) similarly reported the use of universal precautions and a lack of relevance to care provision as reasons for non-disclosure to HCP in the United States.

Interestingly, in our study, almost all of the HCP interviewed claimed that PLWH should always inform HCP of their HIV status as this reduced the occupational risk of infection and improved care. It appeared that, from the perspective of HCP, an apparent public health ethic was thought to take precedence over individual freedoms and patients' rights to privacy. The HCP in our study also reported feeling that disclosure concerns in PLWH were unnecessary given HCP's duties of professional confidentiality. Some HCP did acknowledge that disclosure was not always necessary but still indicated that they would rather know than not know.

Clearly, PLWH's and HCP's perspectives on disclosure differed. While PLWH appeared to vary in the degree to which they felt that they should disclose to HCP, many claimed that disclosure was unnecessary given universal precautions policies. In contrast, all HCP indicated wanting to be informed and most claimed that PLWH have an obligation to inform HCP so that HCP could take the necessary precautions or so that the patient could

receive adequate care. This was in line with a study by Aultman and Borgess (2011) in which medical students claimed that patients had an obligation to inform HCP of their HIV status so that they would receive proper treatment and so that HCP could protect themselves. Similarly, in a study conducted by Mill et al. (2013) with nurses in Sub-Saharan Africa and the Caribbean, participants reported that an awareness of the patient's HIV status was essential to the provision of appropriate and safe care.

Our study has several practical implications. First, our findings suggest that PLWH and HCP are often unaware of the fact that disclosure in health care is a choice. It is, therefore, important that both be made aware of their rights and obligations as they pertain to HIV status disclosure. Henry et al. (2015) argued that disclosure targets, as well as the time, place, and conditions under which disclosure occurred, should always be freely chosen by PLWH and, thus, an increased awareness of the voluntary nature of disclosure to HCP was imperative. This is particularly important in light of the fact that, in recent years, research has demonstrated how ART, when used correctly, can dramatically reduce heterosexual transmission rates (Loutfy et al., 2013; Vernazza, Hirschel, Bernasconi, & Flepp, 2008). This has been termed treatment as prevention. Given that needle stick transmission rates are lower than heterosexual transmission rates (Patel et al., 2014), it can be argued that the chances of an HCP becoming infected with HIV by means of needle stick injury with a PLWH adherent to ART is minimal, thus further reinforcing that disclosure can most certainly be a choice.

Further, Chaudoir et al. (2011) claimed that, for PLWH, disclosure was likely only beneficial when it alleviated the psychological stress of having to conceal or when it functioned to elicit some kind of support. If disclosure to HCP does neither, one must consider whether disclosure should happen at all. At the same time, there are situations in which disclosure to HCP is relevant to care provision (e.g., when drug interactions could occur). It is, therefore, important to increase PLWH's knowledge about when and with whom

disclosure of HIV status is relevant. Along similar lines, we contend that there is a need to increase awareness by HCP that there are PLWH who do not disclose and that universal precautions should always be employed regardless of whether or not HIV status is known. Furthermore, given that the way in which disclosure occurs impacts the response (Bos, Dijker, & Koomen, 2007; Chaudoir et al., 2011), we suggest that PLWH be counseled by HIV care nurses such that disclosure to other HCP would be more likely to generate a positive response and that HCP be made aware of the importance of adequately responding to the disclosure of sensitive information such as HIV status (Chaudoir & Quinn, 2010). Lastly, we contend that a supportive legal and institutional context for confidentiality must be present and manifest in policy and protocols (Yang, Zhang, Chan, & Reidpath, 2005). Failing this, individual and interpersonal level interventions will be ineffective.

Our findings should be interpreted in light of a study limitation that many of the PLWH in our study were gay men of Dutch origin who, generally, had been living with HIV for quite some time and who were, thus, potentially more likely to disclose their status to HCP than other PLWH. Despite our sample being representative of the PLWH population in the Netherlands regarding sexual orientation, age, and time since diagnosis (HIV Monitoring Foundation, 2014), future research should, nonetheless, explore the perspectives of other PLWH. In collective cultures where families are heavily involved in medical decision-making and care-giving, HCP's perspectives on confidentiality and PLWH's approaches to disclosure may be very different than those reported in our study (Obermeyer et al., 2011). Also, we believe that it is important to investigate the unique experiences of women. Research has shown that, more generally, gender impacted motivations to disclose and the reactions of others (Obermeyer et al., 2011), and that women were more likely to experience regret following disclosure (Henry et al., 2015). It would be interesting to see if these findings hold for disclosure in health care contexts. Further, age and time since diagnosis should be

considered in future studies of disclosure to HCP given Emlet's (2006) findings that PLWH older than 50 years were less likely to disclose to a number of targets, including nurses, and that PLWH who were diagnosed earlier were more likely to disclose. We also recommend that this qualitative study be followed by a quantitative study to document the prevalence of various perspectives on disclosure and, in the case of PLWH, their impact on actual disclosure.

In sum, our study has contributed to an understanding of disclosure in health care contexts by investigating both PLWH's and HCP's perspectives on disclosure of HIV status and the reasons underlying those perspectives, thus providing valuable input to improve interactions between PLWH and HCP.

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Key Considerations

- Perspectives on disclosure differ across PLWH and between PLWH and HCP.
- PLWH and HCP appear to often be unaware of the fact that disclosure in health care is a choice. It is, therefore, important that both be made aware of their rights and obligations as they pertain to HIV status disclosure.
- Given that the way in which disclosure occurs impacts the response, PLWH should be counseled by HIV care nurses so that their disclosures to other HCP are likely to generate a positive response. HCP should likewise be made aware of the importance of adequately responding to the disclosure of sensitive information such as HIV status.
- A supportive legal and institutional context for confidentiality must be present and manifest in policy and protocols.