

ORIGINAL ARTICLE

Using social media as a platform to publicly disclose HIV status among people living with HIV: Control, identity, informing public dialogue

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Abstract

Disclosure of HIV status is usually considered a private encounter involving only a limited number of people at a time. Many people living with HIV are strategic about deciding in what contexts, using which approach, to whom, and to what extent they disclose HIV status. However, social media platforms provide opportunities for people to publicly disclose information about themselves to their networks. Utilising semi-structured interviews with people recently diagnosed with HIV in Australia, we explore how, why, and using what strategies people living with HIV use social media as a means of publicly disclosing positive HIV status. Participants placed importance on having control of how they framed their life with HIV and adopted strategies to control the audience to whom they disclosed. Public disclosure on social media helped participants come out of the 'serocloset', empowered identity affirmation, and enabled

The members of the RISE Study Team are listed in [Appendix](#) section.

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them to be voices for other people living with HIV to shift public dialogue. We conclude that public disclosure of a positive HIV status can strip HIV disclosure of being associated with delivering private and unpleasant information, and instead reframe living with HIV from a *responsibility* to disclose to a *right* to share.

KEYWORDS

Australia, disclosure, HIV, qualitative, social media

INTRODUCTION

As a highly stigmatised condition, HIV is assumed to require disclosure that is associated with delivering unpleasant and confidential information, potentially exposing people living with HIV to criminalisation and marginalisation (Evangelini & Wroe, 2017; Flowers & Davis, 2013; French et al., 2015; Kilty & Orsini, 2017; Race, 2010; Serovich et al., 2008; Squire, 2014). Social media technologies provide platforms for people to efficiently and immediately disclose day-to-day or deeply personal information about themselves (Bazarova & Choi, 2014; Gündüz, 2017). The architecture of such platforms may present opportunities for some people living with HIV to publicly disclose their positive HIV status, should they have the desire and access to do so. In this paper, we utilise semi-structured interviews with people diagnosed with HIV from 2016 in Australia to explore how they used social media to disclose their HIV positive status. We explore the role of social media in disclosing HIV, what strategies were adopted to disclose, and how social media can help us reimagine disclosure.

HIV and disclosure

Disclosure describes a process whereby people reveal personal information about themselves to others (Cozby, 1973). Some researchers have provided insight into the relational and social nature of HIV disclosure (Davis & Flowers, 2014; Flowers & Davis, 2013; Squire, 2014). These researchers argue that HIV disclosure is often relationally tailored and depends on the depth of connection between parties (Flowers & Davis, 2013). Disclosure can occur in many contexts—to clinicians, researchers, sexual and romantic partners, relatives, friends, as well as in support programs, the workplace, and through activism. HIV disclosure is often considered private (Flowers & Davis, 2013; Squire, 2014) and dialogic, shaped by social norms and conventions (Davis & Flowers, 2014; Squire, 2014). While HIV disclosure can be misinterpreted or met with ignorance and resistance, it can also be met with sympathy, concern, and affection. As HIV disclosure occurs between two or more individuals, it is subject to being interpreted by the people being disclosed to in ways shaped by their understandings of HIV and relationship with the discloser in sometimes unpredictable ways.

HIV disclosure is often considered a difficult process. People living with HIV commonly report rejection, abuse, stigma, mental stress, the relinquishment of control, concern for breaches of confidentiality, and potential exposure to criminalisation and isolation following disclosure

(Evangeli & Wroe, 2017; French et al., 2015; Kilty & Orsini, 2017; Race, 2010; Serovich et al., 2008; Squire, 2014). People living with HIV may choose to withhold disclosing HIV to maintain a protective silence or to project an identity whereby their HIV status is not a factor (Emlet, 2008; Kilty & Orsini, 2017; Squire, 2014). ‘Strategic (in)visibilities’ describes how many people living with HIV choose who they make their HIV status visible to depending on the relationship shared between parties, the trust involved in such relationships, and the potential personal, interpersonal, and social consequences of disclosing to particular people(s) (Davis & Flowers, 2014). Being strategic in terms of visibility includes deciding in what contexts, using which approach, and to what extent to disclose a positive HIV status. Although disclosing HIV can have negative consequences, disclosure can also facilitate access to treatment and care, foster supportive social bonds, improve self-esteem and wellbeing, release people living with HIV from shame, and have an empowering effect (Evangeli & Wroe, 2017; Paxton, 2002; Squire, 2014). People living with HIV may also disclose positive HIV status to educate others, reduce stigma, and prevent future infections (Emlet, 2008; Paxton, 2002; Squire, 2014).

Biomedical advancements may have made disclosure easier. These advancements mean that people living with HIV who have access to ongoing treatment can be non-infectious to sexual partners if they have sustained undetectable viral load (UVL), and can have a similar life expectancy to people not living with HIV (Bavinton et al., 2018; Cohen et al., 2011; Rodger et al., 2016). With these biomedical advancements, living with HIV can have little impact on day-to-day life for many people, thereby potentially reducing marginalisation, stigma, and othering (Hughes, 2017; Persson, 2016; Persson et al., 2017; Philpot et al., 2020; Squire, 2010, 2013). However, researchers have argued that the promise held by biomedical interventions to reduce stigma and support disclosure may not yet have been realised (Dong et al., 2020; Grace et al., 2021; Holt et al., 2018). Previous research has shown some HIV-negative people are sceptical about relying on UVL to prevent HIV and express fear of knowingly having sex with someone living with HIV (Grace et al., 2021; Holt et al., 2018). Similarly, despite advances in biomedical approaches to HIV prevention such as Pre-exposure Prophylaxis (PrEP) and treatment as prevention (TasP), people living with HIV report substantial stigma in response to disclosure, suspicion from sexual partners about their trustworthiness, and considerable labour when disclosing in sexual contexts (Dong et al., 2020). Biomedical advancements may also have compelled people living with HIV to be responsible HIV citizens by successfully maintaining UVL for the betterment of society. This potentially introduces new forms of HIV stigma and reinforces non-disclosure for those who cannot meet this ideal, even if barriers to obtaining treatment and UVL are systemic (Hueben-thal, 2017; Young et al., 2019). Conversely, biomedical technologies like PrEP may have somewhat bridged HIV stigma, with those using PrEP more likely to feel comfortable having sex with a person living with HIV with UVL (Holt et al., 2018; Van Dijk et al., 2021). Thus, under some conditions, biomedical advancements may cultivate a culture of disclosure.

Social media, disclosure, and identity

Social media can be broadly interpreted to include any online media that encourages engagement with content in a way that allows people to connect with their networks efficiently and immediately (Gündüz, 2017). While social media platforms have intended purposes, they may also be used creatively and diversely beyond such purposes. For example, Facebook is packaged for individuals to connect with their social networks, but may be reimagined as a means of staying up to date with ‘snack’ (i.e., easy and quick to read) news (Schäfer et al., 2017). Similarly,

geolocation-based 'hook-up' apps such as Grindr may be packaged for people to meet for sex or dating, but are also used to develop virtual or in-person friendships (Mowlabocus, 2016). Using social media, people can share information from mundane daily activities to deeply personal experiences and beliefs, to both intimate and unknown people (Bazarova & Choi, 2014; McConnell et al., 2018). In this paper, we focus on social media platforms that specifically encourage communication based on social networks, including Facebook and Instagram.

Social media invites new ways of imagining disclosure. Having the capacity to use social media as a means of disclosure challenges Jourard's (1971) characterisation of disclosure as a private and contained act that occurs within dyadic boundaries mostly between trusted individuals. Although there can be some selection of audience when using social media (e.g., private messaging), public posts made to social media networks may not involve carefully selected and trusted others, even though those within one's social media networks have been accepted into those networks by accepting 'friend' or 'follow' requests.

Social media also invites innovative ways of expressing one's identity, and is a platform through which people can portray a particular identity (Bazarova & Choi, 2014; Cunningham, 2013; Gündüz, 2017; Hogan, 2010; McConnell et al., 2018). Employing Goffman's concept of 'impression management', whereby people mould their appearance and behaviours to guide the impression they want to project to others, Cunningham (2013) argued that when people use social media, they are able to construct particular (often 'the best') versions of themselves, by such tactics as posting photos, liking pages or photos, participating in threads, writing posts, and commenting on others' posts. As well as serving as a platform to *express* identity, disclosing on social media may help users *rework* identity. Drawing on Foucault's concept of 'confessions', whereby people seek emotional liberation through truth telling rituals, Nguyen (2013) suggested that a confession (in the context of HIV counselling) is not about revealing already formed parts of the self to others, but is a process of finding and (re)producing the self. Friesen (2017) adapted the notion of 'the confession' to social media, arguing that disclosing on social media can be considered a 'confessional technology of the self'. According to Friesen, people not only use social media to disclose *about* themselves, but also to disclose *for* themselves as a means of finding or reworking their identity.

Kilty and Orsini (2017) further argue that 'confessing about' (or disclosing) HIV self can lift the emotional burden of a diagnosis and represent self-acceptance. By disclosing, a person may be seen to be acting as a responsible and trustworthy citizen, thereby claiming a 'redeemed' moral character after the 'shame' of their diagnosis. Confessions can have also social benefits. Foucault's (1978) concept of a 'confessional society' describes how confessing to others, especially in the public eye, may encourage others to share their own 'confessions.' Continued confessionals, sometimes manifesting as activism, have the potential to build movements and encourage change by communicating en masse the hope that it is safe to disclose without fear of negative consequences (Kilty & Orsini, 2017).

Social media platforms have features that allow communication with one's network, including: status/photo updates (a public written or photo post to everyone in one's network); wall posts (a direct post to someone else's profile); private messages to individuals; tagging in photos; and, commenting on posts. These features are a medium through which people can disclose information. When individuals do disclose, the feature they choose may depend on their motivations for, and expectations of, disclosing. In this paper, we focus on people living with HIV who used social media to publicly, and broadly, disclose their HIV status on social media platforms. We draw on components of Friesen's (2017) 'confessional technologies of the self' and Goffman's (1956) 'impression management' related specifically to identity management. In doing so, we explore

what purpose disclosing on social media serves for people living with HIV, what strategies they adopt to disclose, and how social media practices might reposition how HIV disclosure can be understood.

METHODS

Study setting

This prospective online cohort study of people living with HIV had a survey and interview component exploring recent experiences of being diagnosed with HIV in the biomedical prevention era. When the study commenced, participants completed a baseline survey and were invited to take part in an in-depth, semi-structured interview and an opt-in follow-up interview 1 year later. As the study progressed, participants were able to enrol directly into the interview component of the study without participating in the survey component. Ethics was approved by [removed for blind review]. Data collection occurred between January 2019 and February 2021.

Recruitment and eligibility

Eligibility included: aged at least 16 years, living in Australia, and diagnosed with HIV in 2016 or later. Recruitment for the broader cohort study occurred via self-referral (the participant could find the study online and self-enrol) or through referrals from HIV community organisations or sexual health clinics (organisations and clinics could directly enrol the participant to the cohort study with their permission). Once participants were able to directly enrol in the interview component of the study (and not need to take the survey), recruitment occurred via self-referral or a direct referral from HIV community organisations to the study team, who then contacted participants to arrange an interview.

Data collection

Interviews were semi-structured and took between 90 and 120 min. Interviews were conducted face-to-face or by telephone/videoconference (by authors 1 and 2), were audio recorded, then transcribed verbatim and de-identified. Participants chose pseudonyms to ensure confidentiality in reporting of data. Interviews covered: experience of diagnosis; HIV clinical care and treatment; formal and informal social support; sex and relationship history; likely source of HIV infection; HIV and sexual-health testing history; and life since diagnosis. Follow-up interviews explored any changes that had taken place in that time. Public disclosure on social media was initially not a prescribed topic but was identified among five participants during inductive analyses of first-round interviews. Public disclosure on social media was then added as a topic to be explored in follow-up interviews of all participants to identify whether this experience of disclosure occurred among others. Ultimately, this experience only occurred among the five participants who raised it in their first-round interviews and was explored in greater detail in their follow-up interviews.

Analysis

Analysis of the data set began with a close reading of each transcript to ensure familiarity with the data, with short summaries written for each interview. Drawing on reflexive thematic analysis (Braun & Clarke, 2019), members of the research team (authors 1 and 2) coded the materials using an inductive approach (Boyatzis, 1998) drawing on themes in the existing literature on HIV infection and diagnosis. Conceptual and descriptive codes were developed after reading a small number of interviews and discussions within the research team, who also read some interview transcripts. These codes were tested on the remaining material and supplementary codes were added. Analysis for this paper was primarily conducted by author. This paper draws on data from a sub-sample of five participants who used social media to publicly disclose their HIV status and was framed around the questions of how and why they had chosen to do so. All had participated in follow-up interviews, providing a total of 10 interviews for analysis. The authors did not physically see the posts made by participants, with all data for this analysis coming from interview transcripts and participants' recollections. To ensure data integrity, analyses were discussed by the broader research team at regular meetings involving five social researchers who together have decades of experience researching the needs and experiences of people living with HIV.

Total sample

Of 28 participants, 17 were cis-gay men, 5 were cis-heterosexual men, 4 were cis-bisexual men, and 2 were cis-heterosexual women. Median age was 32 years (Q1 28, Q3 41). The majority of participants lived in Victoria (9), New South Wales (8), or Queensland (7), and four lived in Tasmania, the Australian Capital Territory, or Western Australia. Most (18) were born in Australia. The rest were born in Latin America, Southeast Asia, East Asia, Western Europe, South Africa, or New Zealand. Most (21) participants reported their cultural/ethnic background as European (predominantly white European), four as Northeast or Southeast Asian, two as Latin American, and one as Aboriginal-Australian.

Current sample

This analysis focuses on 5 participants who had used social media to publicly disclose their HIV status—Jasper (32 years), Angus (28 years), Dexter (50 years), Flynn (27 years), and Percy (26 years). Although they were similar in age (median 33 years) to other study participants, participants in this sub-sample were different from the participant group as a whole in several ways. They were all gay or bisexual men. They all had white-European backgrounds and spoke English as their first language, whereas the broader participant group was somewhat more culturally and ethnically diverse. Participants in this sub-sample had all undertaken tertiary education, had Australian citizenship, and had access to subsidised clinical care and HIV treatments through Australia's universal healthcare scheme. All had accessed HIV care and support services since their diagnosis and were more involved than other study participants in HIV community organisations and politics (as professionals, activists, or volunteers). Participants included in this analysis all had UVL at the time of interviews and were confident their HIV status would have little impact on their day-to-day life, including sexual transmission.

FINDINGS

Following an initial description of participants' social media posts and what prompted them, we describe four key themes: framing the narrative; controlling the audience; coming out of the 'sero-closet'; and changing public discourse.

Description of participants' social media posts

Flynn, Angus, and Percy wrote Facebook posts, Dexter had an online blog that regularly documented his experience of living with HIV, with links on his Facebook profile, and Jasper posted a photo of his HIV medication to his Instagram story using the 'close friends' feature. In addition to social media, two participants had also written—or been the subject of—news or magazine articles about their HIV diagnosis. The content of each social media post reflected the architecture of each platform. The Facebook posts and the blog used written text and were generally lengthy. The Instagram story used visual images of HIV medication to disclose HIV status. In terms of timing, some had disclosed within a few months of their diagnosis, whereas others had disclosed a year or more after being diagnosed.

There were specific circumstances that prompted the Facebook posts and the online blog. One participant had been increasingly participating in HIV community organisations since his diagnosis and had an increasing desire to align himself with that community. One wanted to speak openly about his sexual assault and HIV diagnosis. One, who had a public profile as an advocate, wanted to provide clarity about the circumstances of his diagnosis. One had experienced a lack of support from sexual partners to whom he'd disclosed his HIV status, and found his own narrative becoming lost by having to focus on the needs of these men instead of his own. The blog was an opportunity for him to share his narrative. Finally, the Instagram story post appeared to be less 'sparked' by an event or experience so much as being more generally about sharing positive HIV status.

Framing the narrative

Keeping control of one's own narrative was key when disclosing on social media. Using social media afforded participants the time to construct a carefully considered post that was able to reach a broad audience. It was important to participants that they controlled what they said, how they said it, and how they positioned themselves in relation to their positive HIV diagnosis. As Flynn said, *'I'm the one pulling the lever. I can't control what happens downstream but as long as I can pull that lever.'* For example, Angus contrasted disclosing on Facebook against a situation where he could not control how he framed his narrative. On that occasion, the receptionist at a medical clinic had forced him to disclose his status to get an appointment as they rarely accepted new patients unless they met specific criteria, of which having HIV was one.

When it was a Facebook post, it was to people I could control. It was on my terms when I wanted to, rather than when I called to make an appointment, got quizzed on it [my HIV status] rather than being able to get to a point where I was comfortable before I told someone. If I had said, "I'm part of the target audience"... They should have just believed me rather than say, "Well, which one?" (Angus).

Here, Angus felt he had been forced to disclose his HIV status and that he had been stripped of control in determining to whom, when, and how he disclosed. Conversely, his post on Facebook was on his own terms, when and how he felt comfortable. Like Angus, Flynn described a situation that deprived him of control in disclosing his positive HIV status. Recalling the story of an acquaintance whose HIV diagnosis was publicly shown in the media without the opportunity for them to tailor the message, Flynn said:

After seeing his story being talked about in the media, his life was absolute hell through it, watching other people talk about his story, watching rumours swell around. And so I asked him what was his biggest regret. He's like, "My biggest regret was not controlling my own narrative. My biggest regret was losing my agency." And so I said, "Well, that's something I want to avoid."

By invoking examples that contradicted control, Flynn and Angus clarified that their HIV status should be theirs to share and that it could be damaging to their lives if others discussed their HIV status in ways they could not themselves frame. Conversely, having control provided them agency in expressing how they wanted to position their life with HIV, thus avoiding being negatively (or mis-)represented. That is, they had autonomy in portraying their life with HIV as happy and healthy despite the diagnosis of a health condition traditionally associated with ill health and a difficult life trajectory.

Control of narrative manifested in a different way for Percy. As well as projecting a positive version of living with HIV, Percy carefully framed his narrative by being selective about what information he made available. When Percy was diagnosed, his partner at the time was himself HIV-positive with detectable viral load. Percy was unaware of this and upon learning this information, believed he acquired HIV from his ex-partner. Percy was concerned that if he explained the timing of his diagnosis, he may implicate his ex-partner, which he did not want to do.

I had to be very careful because I was worried that the timeframe [of my diagnosis] meant people would have known who my partner was at that time. So I had to be careful of not outing him, and I didn't want it to be a blame kind of post. I wanted to put emphasis on the health and the medication for people who are HIV positive these days.

Rather than inviting potential blame onto his ex-partner through his post, Percy wanted to emphasise that due to HIV treatments people living with HIV could lead healthy lives. Whereas Angus and Flynn controlled their narratives as a means of positioning their lives with HIV and what it symbolised to them, Percy wanted to control the content of his post to protect the privacy of others.

Controlling the audience

For the most part, social media users can determine who they allow to view their posts. Participants could thereby control to whom they disclosed because they had actively selected who could view their social media accounts. Dexter, Flynn, and Percy did not place limits on who could see their posts. However, despite the broad audience reach of social media, Angus and Jasper included limits on who could see their posts and, in doing so, adopted a strategic approach towards disclosure. While Angus disallowed some high school friends from viewing his Facebook

post, Jasper used the ‘close friends’ feature on Instagram, thereby limiting the photo to those to whom he felt close and who might respond supportively. Even then, he posted a photo of his medication without explaining its purpose, so only people who knew about HIV medicines or who were interested enough to search the name of the medication would be likely to understand. Jasper said:

To understand the [Instagram] post, you either would need to be in the sector and know or have HIV, or you would have to double-take it. There were acquaintances that maybe don't even know me particularly well that follow me on Instagram. Those people would probably just pass through it and think I could be on antibiotics (Jasper).

Davis and Flowers (2014) described the concept of ‘strategic (in)visibilities’ in relation to HIV and online dating, arguing that many people living with HIV strategically choose to whom, using which approach, and to what extent they make their HIV status known. Jasper and Angus, who controlled who saw their content, and what and how much they could see, similarly adopted a strategic approach towards visibility of their public HIV disclosure. Their main intention was to exclude people who they considered insufficiently familiar or worthy of knowing about their positive HIV status, or those who might not respond favourably.

However, Jasper and Flynn also chose to disclose to family members before writing their posts because those family members had *too much* familiarity or worth to learn about their HIV diagnoses via social media. Here, the type of relationship shared between the discloser and disclosee determined how disclosure was conducted. For example, Angus said:

I came out to my mum via text message, and we had a discussion afterwards that she would have preferred that kind of conversation in person. I took that on board and made sure that it was family who were people that were told with a phone call rather than happening to scroll through it on Facebook or having someone contact them and say, “Have you seen what's on Facebook?” I think it's more personal, and having respect was a term that was used. To have kind of life-changing news delivered in person where possible or on the phone if not would be more appropriate. (Angus).

Angus explained that his family members deserved private one-on-one conversations. While social media allowed disclosure to disseminate to broad audiences, for Angus and Flynn to use this method with family members would be too impersonal and disrespectful of such close relationships.

Despite being strategic about to whom, when, and how they disclosed, participants understood they could not control how that information might be further disseminated, nor could they control how others responded to—or repurposed—the information. Mostly, participants recounted receiving support, sympathy, respect, and love from those to whom they had disclosed. These supportive responses were a benefit of disclosing on social media—because participants (mostly) knew, and were to some extent in control of, who they told. For participants in this analysis, it was easier to anticipate that they would receive positive feedback. However, they also spoke of some anxieties about, or expectations of, stigma and gossip. For example, Angus expected to have been unfriended by a few people on Facebook and Flynn was informed by friends that others were talking about his disclosure in their own private social media chats. Flynn also anticipated that his post would result in negative reactions beyond social media, stating:

I stopped going out. [I] definitely limited my social interactions. People noted a really marked difference in how I existed in the world. I'm not sure if me being out there would piss people off and they'd approach me... Like my biggest fear was being approached (Flynn).

Despite Flynn's fears, and even though he and others were aware that they could not control how their audiences received their disclosure, they frequently asserted the importance of sharing their narrative and disclosing their HIV status far outweighed any negative consequences after the posts were disseminated.

Coming out of the 'sero-closet'

Disclosing on social media released participants from what both Dexter and Flynn described as the 'sero-closet', an expression invoking the 'closets' LGBTIQ people have 'hidden in' so as not to be exposed and discriminated against, but reimagined for people living with HIV. Public disclosure meant participants no longer felt burdened by hiding their diagnosis from others, or as Percy said, feeling the need to 'hide a dirty little secret'. For example, Dexter said:

I'm told that I'm positive and all the advice I'm being given is basically you build yourself in your closet. And that just didn't gel with me. And so I started writing this blog and published it on Facebook, so people quite often see it. And I don't hold back. So I am quite open about being positive. I need to clarify that.

Earlier in his interview Dexter recalled how at a young age he was similarly resistant to hiding his sexual identity. After his HIV diagnosis, his clinicians, other peers living with HIV, and other (presumed HIV-negative) people who knew of his status had advised him to be selective and cautious about disclosure, and that once information was shared it was unretractable. This framing of HIV was difficult for Dexter to absorb; he did not understand why he should be required to hide these elements of himself. Publicly disclosing on social media allowed him to detach from the notion that living with HIV should be kept hidden, unshackling him from secrecy and having cathartic value.

Coming out of the 'sero-closet' through public disclosure also helped participants craft a narrative in which they were better understanding the meaning of their diagnosis by articulating their thoughts in the written word. Jasper found this process particularly useful when writing magazine articles linked to his Instagram account:

Writing for me is the way I process things and my emotions. My emotions don't naturally come to the surface. I have to put the work in to let me feel them. I feel like I have this natural kind of 'close off your emotions' reaction. And so it's not until I actually put work in to be like, 'Oh, how are you feeling?'

By writing, Jasper was able to emote in ways he would otherwise struggle to do, with the writing process helping him better understand his relationship to his HIV. The public nature of his articles and posts served an additional purpose of voicing his newfound clarity of identity. Friesen (2017) argued through the idea of 'confessional technologies of the self' that social media can be a platform for people to express who they are and how they relate to the world around

them, while simultaneously helping them better understand and transform themselves. In this sense, coming out of the 'sero-closet' on social media provided an opportunity for participants to (re)work their identity as a person living with HIV, to both express pride in themselves and to decipher what their diagnosis meant to them.

Changing public discourse

In the previous section, participants described the personal benefits of publicly disclosing on social media. However, participants also valued the benefits for society and other people living with HIV that publicly disclosing their own HIV status might have. That is, disclosing may change public dialogue about HIV, reframe society's (or at least their network's) understandings of what it means to live with HIV, and reduce HIV stigma. Participants were acutely aware that HIV stigma persisted even in the biomedical prevention era, and confronting this stigma was a particular concern when they were diagnosed. When recalling their diagnosis experience, all participants described a fear that they might be stigmatised and cast as immoral and irresponsible if exposed as living with HIV, or deemed less suitable as sexual or romantic possibilities. For these participants, this fear diminished over time (albeit over different periods for each participant), and they increasingly viewed using social media as an opportunity to undo stigma by creating a positive social dialogue about living with HIV. It was important to participants that they challenged stereotypes that cast people living with HIV as irresponsible, unhealthy, and undeserving of social citizenship. Percy stated:

One night I was just like, "Nuh. I really want to raise awareness and remove stigma." And I actually bit the bullet and posted a Facebook status. And that's kind of how I fully became out about it. I didn't want any more secrets... But it wasn't just like a coming-out status; it was very much a motivational speech in a way. It's kind of like, "It's not what it is today. Create your own future," you know. "Don't let things stop you." It was this whole thing and then I went on about stigma and stuff (Percy)

Here, Percy described wanting both to reduce stigma and to be a voice for other people living with HIV, asserting that living with HIV need not be a barrier to a fulfilling life. Percy explained in his post that it was *not* was a 'pity post' nor an attempt to receive validation. Rather than personal gain, Percy was instead focussed on helping people living with HIV and bettering society.

Disclosing on social media to change public dialogue had the benefit of reaching a large audience. Jasper said that in addition to avoiding multiple in-person conversations, disclosing on social media to such a wide audience downplayed the seriousness of HIV.

One of the things I don't like about disclosing in a Hollywood sense is that it gives it too much weight, as in it feeds into a very old idea of HIV. So it requires this 'sit down and brace yourself' moment. Whereas I felt the suggestive, social-media form was more saying, "Oh, this is a part of my life now," rather than like, "I have something horrible to tell you," which I feel the most referred to form of diagnosis is; kind of a sit down and one-on-one moment.

For Jasper, using social media stripped HIV disclosure of being associated with delivering unpleasant, tough, serious news that should be conducted selectively and secretly, which he

believed was an ‘old idea of HIV,’ before the proliferation of biomedical HIV prevention. The capacity to purport a healthy life and non-infectiousness due to achieving UVL played a key role not just in downplaying the seriousness of HIV, but also in helping participants position themselves and other people living with HIV as healthy and responsible. Recalling a night at a gay pride event in which he participated in a group known to be for people living with HIV, Flynn said:

I wanted to portray exactly how I was feeling [at the event]. And at that point, how was I feeling? Undetectable. Happy. Surrounded by loved ones. This is me living with HIV. So I wanted to portray that but I also wanted to do everyone in the positive community justice by portraying all of us as good, decent, healthy, hard-working people.

At this event, Flynn viewed himself as a symbolic vessel through which more positive rhetoric of HIV might be encouraged, and this same symbolism applied to his social media post (which was written in concert with his attendance at the event). Here, biomedical advancements contributed to a narrative that people living with HIV were non-infectious, healthy, responsible people, and should not be subjected to stigmatisation and shaming. Not only did having UVL make participants more willing to be public about their status, but it also held the potential to change public dialogue about living with HIV.

DISCUSSION

In this study, participants' disclosure of positive HIV status on social media enabled them to carefully construct a post that allowed them to edit their message as they crafted it (Bazarova & Choi, 2014; Treem & Leonardi, 2012). Similarly, the capacity to deliver a message to a broad, but controlled, audience using strategic (in)visibility was considered beneficial (Davis & Flowers, 2014). However, the information they shared on social media could extend beyond their intended audiences, thus reducing their control of the dissemination and interpretation of that information.

Drawing on Derlega and Grzelak's (1979) functional theory of disclosure, Bazarova and Choi (2014) argued that public status updates on Facebook are mainly constructed for social validation or venting about issues, though their study was not related to disclosure of specific health conditions and were aimed at more general status updates. In this sample, however, the concept of identity clarification, which aims to portray one's identity in particular ways, may be more appropriate. Goffman (1956) similarly posited that people manage the impressions of themselves so they appear in the best possible light. In this study, participants tended to position themselves on social media as happy and healthy despite a diagnosis that has negative connotations in society. The self-presentation participants adopted was oriented towards meaningful and potentially more revealing confessions of the self, and so it had relevance for notions of authenticity and honesty. According to Flowers and Davis (2013), due to how heavily HIV is freighted with representations of deviance, marginalisation, and secrecy, disclosure relates more to authenticity and honesty than is the case with many other health conditions. Participants' posts conveyed more than a clarification of identity. They publicly communicated deeply personal information, highlighting how they had incorporated their HIV diagnosis into their lives, rather than allowing it to marginalise them. Also, participants disclosed their status on social media as a means of learning about themselves and better understanding their relationship to their diagnosis. Both

Friesen (2017) and Nguyen (2013) argued that rather than revealing some kind of 'inner truth' about the self, the process of confessing or disclosing can help people discover and (re)form themselves. The architecture of the social media platforms available to participants allowed them to use mostly textual language to (re)construct and (re)shape their thoughts about their positive HIV status.

Some participants self-disclosed to change public dialogue about what it means to live with HIV. Here again, the findings of this study depart from those of Bazarova and Choi (2014), who argued that self-expression and social validation are motivators for disclosure on social media. Participants' actions instead reflect Derlega and Grzelak's (1979) notion of social control, which aims to control social outcomes in order to provide social benefits. HIV disclosure has traditionally been associated with delivering sensitive, unfavourable, private, and confidential information (Flaherty et al., 2014). Yet, evidenced in the social media strategies adopted by the present sample, HIV disclosure shifted from the realms of the private to one that was far more public. Participants' public act of disclosure effectively stripped HIV disclosure of being associated with delivering private and unpleasant news, challenging the notion that living with HIV should be kept hidden. Participants also disclosed their HIV narratives to act as a voice for other people living with HIV. In many advocacy contexts, HIV disclosure is likewise positioned as a condition of action, part of a 'speaking out' against stigma to change public dialogue (Robins, ; Rose, 2007; Squire, 2014). In publicly disclosing their positive HIV status and specifically stating that they wanted to reduce stigma and be a voice for other people living with HIV, participants implied claims to citizenship for all people living with HIV, to reclaim their legitimacy and recognition. According to Kilty and Orsini (2017), public disclosure indicates to other people living with HIV that it is safe to disclose, thereby potentially encouraging others to consider sharing their own stories and creating a 'confessional society' (Foucault, 1978).

Some people living with HIV assert these claims to legitimacy, recognition, and citizenship to change the discourses that cast them as a threat to society (Persson, 2016; Persson et al., 2017; Squire, 2010, 2014). In Australia, people living with HIV are obliged to disclose their HIV status to others if they: apply to become permanent residents; apply for life insurance; work in health-care and perform exposure-prone procedures; or work in the defence forces (Australian Federation of AIDS Organisations [AFAO], n.d.). Disclosure to sexual partners is required in some Australian states, and this is the case even if an individual living with HIV has UVL (AFAO, n.d.). Indeed, people not living with HIV often expect that people living with HIV should disclose their HIV status before sex, and people living with HIV often feel the burden of HIV prevention and disclosure falls on them, even in the biomedical era (van Bilsen et al., 2020). The architecture of hook-up apps such as Grindr have features that allow users to display their status online. Yet, this kind of incitement to disclose can expose people living with HIV to exclusion, stigma, criminalisation, and isolation (Evangeli & Wroe, 2017; Flowers & Davis, 2013; French et al., 2015; Race, 2010; Serovich et al., 2008; Squire, 2014). People living with HIV who choose not to disclose in this way are potentially positioned as withholding information that might have dangerous social consequences. Disclosure on social media can, however, provide a platform for people living with HIV to reassert control of their narratives, choosing how, when, and to whom to disclose. This can reframe positive HIV status from a responsibility to disclose to a right to share, encouraging agency and choice in disclosure. In this sample, participants took ownership of HIV disclosure not as a practice required out of legal necessity nor to ensure they had access to treatment and support. Rather, they used disclosure to speak about themselves to clarify their identities and to change how living with HIV is represented socially, legally, and politically.

HIV disclosure is generally considered to be relationally tailored and dependent on the connection shared between parties (Davis & Flowers, 2014; Flowers & Davis, 2013; Squire, 2014). While not in the context of HIV, however, Bazarova and Choi (2014) argue that status updates on Facebook are not directed towards relational development. Participants' public posts in this study were, for the most part, not tailored towards relations shared with specific individuals. They instead disseminated the messages to a broad audience. Though there were opportunities for people to respond through comments, likes, and messages, the posts offered few opportunities for the production of highly negotiated and dialogic encounters. As such, this specific form of HIV disclosure was not focussed on relational development and the conversational negotiations that stem from it. Indeed, some participants believed that using social media would be an inappropriate method when seeking to disclose for the purpose of relational development. This is because doing so would not properly respect the closeness of the relationships the participants shared with loved ones. So, although relational development was not a key motivation for publicly disclosing on social media, it was nonetheless a consideration for some participants in choosing to tell some people privately. These kinds of private one-one-one conversations about positive HIV status particularly applied to circumstances where someone might be directly influenced by disclosure, such as sexual or intimate relationship partners. In these contexts, issues such as HIV prevention require negotiation, and one-on-one conversations likely yield more beneficial results in such circumstances.

Despite the control participants executed in framing their positive HIV status, they acknowledged they could not control how the information was disseminated and how others might respond to it. Although people living with HIV can author their own stories when they disclose, they cannot author how people interpret and respond to their stories, and such interpretations have likely been shaped by both the social norms conditioning understandings of HIV, and the relationship shared between the discloser and disclosee(s) (Davis & Flowers, 2014; Squire, 2014). For the most part, responses from people within their online networks were encouraging, loving, and sympathetic. This likely reflects a benefit of using social media to publicly self-disclose—although the audience reach is broad, the direct audiences are nonetheless part of trusted or at least known networks. Nonetheless, disclosure on social media did expose participants to actual or anticipated stigma in both online and physical spaces, as well as having others gossip about their status. Such experiences indicate that HIV remains a highly stigmatised condition, continuing to be infused into the narratives of people living with HIV, even those of the men in this sample who were well-educated, had excellent access to HIV treatments, and were highly engaged within the HIV-positive community. Norms shape how information is disseminated, understood, and circulated (Davis & Flowers, 2014; Squire, 2014). One persistent norm regarding HIV is its stigmatised status, influencing how people living with HIV relate to their diagnosis (whether they embrace it and push back against stigma, feel shame about it, or otherwise), and how society positions people living with HIV.

Limitations

This was a sample of recently diagnosed, well-educated, undetectable people living with HIV who were actively involved in HIV community organisations, politics, and activism. They had access to subsidised HIV treatments and care and lived in confidence of their ongoing health and the manageability of HIV. As active members of the HIV-positive community, they also had motivations that made them more willing to publicly disclose their HIV status on social media.

Together, these circumstances mean that they are a select group of people living with HIV who had the desire and capacity to be public about their HIV status on social media. This is not an experience shared by all people living with HIV, many of whom might have less access to HIV treatments and care and may be less comfortable or motivated to publicly discuss their positive status. The study team did not have access to participants' social media posts and only analysed interview transcripts based on participants' own recollections of their posts. Future research might consider content analyses of social media posts in relation to disclosure and health, which may yield different interpretations about the meanings behind disclosure.

CONCLUSION

In this study, we have described how some people living with HIV use social media as a means of publicly disclosing their HIV status. The features within and nature of social media platforms allowed participants to carefully construct their HIV narrative in a manner they could control, and do so to broad but nonetheless strategically selected audiences. Personal benefits of publicly disclosing on social media were that it afforded opportunities for participants to express and rework their identities, as well as unshackle them from the burden of secrecy. A social benefit of public disclosure was that it challenged HIV stigma by stripping HIV of being associated with delivering unpleasant, private, and difficult information. We conclude that viewing HIV disclosure through the lens of social media allows us to consider how HIV might be reframed from a responsibility to disclose to a right to share, returning agency to people living with HIV.

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AUTHOR CONTRIBUTIONS

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DATA AVAILABILITY STATEMENT

Research data are not shared.

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APPENDIX

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