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# Not Another Medication Adherence App: Critical Reflections on Addressing Public HIV-related Stigma Through Design

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People living with HIV experience a high level of stigma in our society. Public HIV-related stigma often leads to anxiety and depression and hinders access to social support and proper medical care. Technologies for HIV, however, have been mainly designed for treatment management and medication adherence rather than for helping people cope with public HIV-related stigma specifically. Drawing on empirical data obtained from semi-structured interviews and design activities with eight social workers and 29 people living with HIV, we unpack the ways in which needs for privacy and trust, intimacy, and social support create tensions around key coping strategies. Reflecting on these tensions, we present design implications and opportunities to empower people living with HIV to cope with public HIV-related stigma at the individual level.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; **Empirical studies in interaction design**.

Additional Key Words and Phrases: Technology for stigma; HIV-related stigma; stigma; coping strategy; people living with HIV; stigma tensions, privacy; intimacy; social support; peer-to-peer support.

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## 1 INTRODUCTION

People living with the Human Immunodeficiency Virus (HIV) report high levels of stigma in our society. Public HIV-related stigma, or the stigma that is enacted or generated by the negative perception of others about HIV, can have detrimental effects on an individual's psychological and physical well-being, often leading to crippling depression and anxiety [14, 22]. This is especially true when individuals face enactments of public stigma such as discrimination or social rejection [22]. Public HIV-related stigma can also hinder the exchange of social support [88] and access to proper medical care, as individuals fear disclosing that they live with HIV to others [14, 81, 95, 102].

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In this paper, we focus on public HIV-related stigma because this type of stigma has been found to be the most strongly associated with psychological distress, such as depression and anxiety, in people living with HIV [19, 22, 110]. Moreover, public HIV-related stigma can negatively affect medication adherence and access to proper treatment, as individuals living with HIV want to avoid disclosure of HIV status at all costs for fear of social rejection [19, 95, 102]. This type of stigma occurs in both industrialized and developing societies, but its effects are stronger in social groups where lack of education, cultural and gender norms may play a more significant role in devaluing the identities of people living with HIV [46, 82]. For instance, [79] found evidence of "stigma-related risk analysis" among HIV-positive couples in India. This analysis arose as a result of gender norms which kept men and women from disclosing their positive status (but for different reasons). Men would not disclose their status to their wives because they are expected to be the stable head of the household, while women would not disclose their status to their spouses for fear of abandonment and acute social rejection.

Despite the detrimental effects of public HIV-related stigma, technologies customized for people living with HIV have been created with the main focus on medication adherence and treatment management purposes (e.g., scheduling appointments with doctors and keeping track of their health stats). These technologies often result from research in the public health and medical research fields and rarely focus directly on aiding users to cope with public HIV-related stigma. Medication adherence apps are one such technology and are often used by people living with HIV to manage their treatment. Apps are commonly designed as notification systems that produce a sound or text message to remind users when they need to take their medication. While adherence to treatment and medication is indeed an important aspect of comprehensive HIV treatment, taking a pill is rarely the only means of ensuring well-being. Public HIV-related stigma is a complex and widespread social problem that warrants further research within the CHI and CSCW communities.

HIV researchers have begun to look beyond traditional approaches to designing for HIV, which frame people living with HIV as patients who must take pills to control their condition and avoid further transmission to others. More recent HCI work in HIV have largely focused on treatment management, but have started to also consider issues such as privacy and disclosure [65, 119], access to social support [39, 79, 106] and HIV-related stigma [46, 65, 121]. In particular, recent works have identified the use of social media platforms as beneficial to people living with HIV. These platforms assist those living with HIV in coping with public stigma by encouraging disclosure and access to social support. Yet, more research is needed in this area to identify negative effects or barriers that users may experience when using social media platforms. Research has shown that, in other stigmatized groups such as the LGBTQ+ community, social media platforms and related online technologies have replicated and even exacerbated tensions that these populations experience offline, such as discrimination and harassment [96, 118]. Similar research is needed to address the barriers faced online by people living with HIV.

We conducted semi-structured interviews with eight social workers and nine people living with HIV and gathered data via online activities with 19 people living with HIV. We found that our participants use social media-based technology to cope with public HIV-related stigma by disclosing their status and their experiences to others in order to access social support. However, this disclosure was given only after taking great precautions: participants reported using fake identities and resorting to anonymity for disclosure and social support exchange. They also reported experiencing tensions at the time of disclosure due to the negative effects of public HIV-related stigma. We discuss how these tensions could be addressed with current technology and propose directions for the design of future customized technology for the specific purpose of helping people cope with public HIV-related stigma.

This paper contributes to HCI research in the following ways. First, our work extends the literature to include the perspectives of a population that is difficult to gain access to. Second, it extends the literature on the use of online technology for people living with HIV by identifying and discussing the tensions that exist when using online technology to cope with public-HIV related stigma. Third, it proposes design implications for online technology that address the identified tensions, and that are informed by related work with stigmatized populations. Fourth, it builds on literature on the design of technology for people living with HIV, which moves beyond the traditional focus on medication adherence towards technology that empowers individuals to cope with public HIV-related stigma more directly. Lastly, this work proposes a more emphatic and respectful approach toward designing technologies for individuals coping with stigma.

In the following sections, we provide an overview of research in the HCI and CSCW fields with stigmatized populations as well as with people living with HIV. We then describe our methodology and findings derived from our empirical approach. Finally, we discuss design implications that could further mitigate the negative impact of public HIV-related stigma at the individual level and that are informed by engaging in discussion with related work in our field.

## 2 RELATED LITERATURE

Stigma is a social construct whereby individuals are discredited or perceived as of less value on the basis of perceptible "marks" that diverge from what is socially conceived as normal or morally correct [36, 69]. For example, a person with a physical disfigurement or certain occupations like sex work may generate stigmatizing views or sentiments from the public due to a different appearance in the first case, or the nature of their work in the second case. Individuals with certain medical conditions like urinary incontinence, depression, or sexually transmitted diseases (STDs) may also experience stigma [8]. In the literature, one common way to classify stigma is by determining its source. On the one hand, if the stigmatizing views come from the stigmatized individuals themselves, this type of stigma is known as *internalized stigma*. Internalized stigma refers to the negative attitudes or feelings of shame that individuals have about themselves [50]. *Public stigma*, on the other hand, refers to the discrediting sentiments, attitudes, or enactments of discrimination or violence directed at stigmatized individuals. Public stigma also occurs when the stigmatized individuals are aware of the likelihood that such sentiments, attitudes, or enactments may occur in a particular social context [22].

Research in the social sciences has often examined public stigma through the lens of coping strategies at the individual level (e.g., [22, 36, 62, 69]). Notably, Meisenbach [69] developed a theory of stigma-coping strategies based on prior research done with a diverse set of stigmatized populations, including people living with HIV (e.g., [19, 100]). In general, Meisenbach's coping strategies relevant to HIV could be put in two groups, those which are used when individuals *react* to public stigma, also known as reactive strategies (e.g., disclosure, non-disclosure or concealment of the stigmatized trait, bonding with others who share the stigmatized trait, and self-isolation); and those which are used when individuals *challenge* public stigma, also known as proactive strategies (e.g., reframing or reducing the offensiveness, denying or ignoring the stigmatizing trait) [100]. In particular, a common coping strategy used by people living with HIV is to hide or conceal by not disclosing that someone is living with HIV (also known as non-disclosure) [100]. Alternatively, people living with HIV may cope by disclosing their HIV status in order to access social support and proper medical care [19]. In particular, this activation of social support takes place via a highly selective disclosure process to trusted networks of people [9, 44, 88, 114]. Self-disclosure has been found to improve the physical and psychological health of people living with HIV [10, 87, 91, 115]. For example, by disclosing their status, people living with HIV can bond with other individuals going through a similar experience [10, 115] and help them transcend or reframe their situation

as an opportunity for personal growth [23]. Yet, public HIV-related stigma prevents people from disclosing, consequently affecting their access to social support [19, 22, 38, 88]. Thus, research to further explore how technology could empower people to use coping strategies at the individual level is needed.

## 2.1 Technology for Stigma

HCI researchers have conducted studies around designing and assessing technological interventions with a diverse array of stigmatized groups, including those with stigmatized medical conditions (e.g., eating disorders, mental illness, substance abuse) [3, 16, 29, 70, 72, 84, 86] homeless individuals [122, 123], individuals with disabilities [27, 45, 48, 49, 63, 71, 85, 93], victims of sexual violence [67, 108], and those with non-normative sexual orientation or gender identities [31, 34, 37, 96, 118]. In many cases, the concept of stigma has been reported as one of many traits of the population rather than the core problem to be addressed in the design space. However, a few recent works have examined how the design of technology can have an impact on public stigma and stigma-coping strategies more directly. For instance, [107, 108] showcase how technological interventions could aid with reframing and social bonding among sex workers in the UK. In their study, the researchers highlight how technology may also help reduce public stigma towards sex work by changing perceptions from tracking and controlling sex workers to protecting and helping them. This work certainly stands out from other studies conducted on female sex work (often in developing countries), which have mainly focused on evaluating technology that aims to control STD propagation.

A few other studies have explored the design of technologies that leverage coping strategies against public stigma based on a theory of stigma proposed by [69] like disclosure and concealment. For instance, [112] propose the creation of products that re-shape, conceal, or turn attention away from a stigmatizing trait. Examples of such designs include hearing aids that look and feel like regular earrings, or prosthetic devices that allow for faster running or movement.

Web-based technologies, such as blogs and social media, have allowed individuals to access information that is otherwise beyond reach as well as to form online relationships with others who share a stigmatized condition [26, 122]. The Internet has provided a means for stigmatized individuals to self-disclose information regarding their stigmatized conditions more easily without having to reveal their identities. Anonymous self-disclosure allows stigmatized individuals to experience the benefits of disclosure like decreased levels of stress and access to social support [8, 91].

Recent work by [1, 2] has explored how disclosure on social media among women who have experienced pregnancy loss can serve as an effective stigma-coping mechanism. Participants engaged in a reciprocal self-disclosure process in which users who disclose first can trigger future disclosures from others, further normalizing the stigmatized experience and promoting the exchange of social support among users. However, despite allowing stigmatized populations to access social support easily, research has also found that social media can replicate harmful interpersonal interactions and power dynamics that take place offline. For instance, members of the LGBTQ+ community can still experience the negative effects of stigmatizing language or exacerbation of conflicting and harassment behavior from other users in online platforms [96, 113, 118]. Additionally, social media can foster and even encourage harmful behavior and exacerbate the symptoms of a condition, such as when images or content promote unhealthy eating behaviors in online groups for people living with eating disorders [15, 29, 86]. Online platforms can also lead to greater social isolation and loneliness in people living with mental illness due to a dependence on social media for connection with others [47, 84].

## 2.2 Technology for HIV-related Stigma

Most existing research around HIV has addressed issues that are not directly related to stigma. The majority of technological interventions for HIV, which are often mobile phone-based, have focused on antiretroviral medication adherence via the implementation of systems based on alarms and reminders related to HIV treatment management (e.g., [43, 89, 99]). However, more recent HCI research has discussed the implications for technology design from a holistic perspective that goes beyond medication adherence and treatment management. For example, [101] reviewed several mobile applications for HIV prevention, testing, and management and noted the prevalence of stigmatizing language and visual signs in their graphical user interfaces that could lead to accidental disclosure of HIV status. Work by [79] with heterosexual couples living with HIV in India identified how privacy and disclosure control enable couples to maintain existing social relationships that could otherwise be affected negatively by accidental disclosure. They also highlighted the importance of further work needed in the field to improve and expedite peer-to-peer support, which would allow people living with HIV to seek and receive advice from others with similar lived experiences on how to navigate challenges in social relations and intimacy. In a similar vein, [46] discussed implications for technology design that may help people diagnosed with HIV restore their normal life. Their work is informed by a field study of an HIV outreach organization in India and also by technology design for life disruptions proposed by [66]. This approach highlights that “technologies that play a role in achieving a new normal must be designed in a way that prevents them from contributing to the stigma surrounding the events of a life disruption.” [66]. Viewed through this approach, designs should empower social capital by allowing people with HIV to connect and bond with others in order to facilitate social support exchange to cope with public HIV-related stigma.

More specifically, researchers have explored how people living with HIV use social media [35, 57] as well as online forums [6, 73, 74, 87, 106] to access social support in order to cope with stigma at the individual level via engaging in discussion with other users on such platforms. Moreover, these online technologies support public stigma coping strategies by providing perceived anonymity, which allows users to access computer-mediated social support that has proven to offer psychological and physical benefits to users in both cross-sectional [73, 74] and longitudinal [6] studies, and that those with higher levels of disclosure had better health-related outcomes than those with lower levels of disclosure [74]. In particular, more customized online forums for people living with HIV allow users to disclose and access social support in synchronous or asynchronous ways, allowing them to upload and interact with multimedia content such as audio [42], video, and images [5, 6, 92, 106].

Despite these advances, the barriers or negative impacts of public HIV-related stigma in the use of online technology by people living with HIV have been less explored. In particular, disclosure is affected in online platforms due to public stigma. For instance, in the case of sex social media for men who have sex with men, [119] explored the use and perception that users have towards an HIV status disclosure field. They found a *privacy unraveling effect* by which people living with HIV are less likely to select the value "HIV positive" in the disclosure field in the profiles due to fears of immediate rejection, yet non-disclosure of HIV status (leaving the field blank) led other users to assume a positive status of those profiles in which HIV status was not disclosed.

Recent research has begun to address public HIV-related stigma more directly. Though still focused on medication adherence, mobile apps have adopted design approaches that leveraged coping strategies against public HIV-related stigma, such as non-disclosure, and access to social support. For example, [65] and [52] have incorporated gamified user interface design that uses avatars and neutral-looking visual elements to avoid unintentional disclosure of HIV status when

the app is used in front of others (e.g., avoid using the color red, which has been linked to HIV). This design also provides access to social media-like and chat features for the exchange of social support. Yet, more research in our field is needed to look into the barriers for safe disclosure and access to social support that people living with HIV experience. Further, these barriers must be contextualized within the process of coping with public HIV-related stigma at the individual level via the use of online technology.

### 3 METHODOLOGY

We employed multiple methods to data collection, which included semi-structured interviews and activities deployed via the Asynchronous Remote Communities (ARC) method [58] during 2017 and 2018. The ARC method allows individuals to participate remotely regardless of location or time zone, helping to overcome barriers in access and recruitment [58].

The first author conducted semi-structured interviews with eight White female social workers from an HIV support center located in the Midwest region of the USA. The interview covered aspects of the roles and services provided by the support center, the use of technology, and focused on the effects of HIV-related stigma on their clients' lives. Then, with the aid of the support center for recruitment purposes, the first author contacted potential participants interested in being interviewed via phone and scheduled an in-person meeting. As detailed in Table 1, nine semi-structured interviews were conducted with individuals living with HIV (8 men, 1 woman) with different sexual orientations (3 heterosexual, 4 gay, 2 bisexual), race (2 Black, 7 White), and ages (20–70). All participants were residing in the Midwest region of the USA. The interviews lasted approximately one hour on average and took place in the HIV support center. The interviews with people living with HIV started with questions about their experiences living with HIV in general and then covered aspects of social support exchange, the impact of HIV-related stigma, and the use of technology to manage treatment and HIV-related stigma. Participants received a \$20 (USD) gift card as compensation for their time. Interviews were audio-recorded and transcribed verbatim. After transcription, all audio data were deleted.

We complemented the interview data with data gathered from ARC-based activities deployed in a previous study [60, 61] (ARC S1), which was conducted with 19 participants recruited from HIV support groups on Facebook. Participants were diverse in gender (11 men, 7 women, and 1 queer), sexual orientation (8 straight, 8 gay, and 3 bisexual), and age (20–60) and moderately diverse in race/ethnicity (12 White, 4 Hispanic/Latinx, 2 Asians, 1 African). As detailed in Table 1, thirteen participants were from the US, two were from the Philippines, and there was one participant from each of Mexico, Kenya, South Africa, and the UK. Additionally, eight participants (seven of whom also participated in the interviews described above) were recruited from the HIV support center mentioned earlier for a second ARC-based study (ARC S2).

The weekly activities for the ARC-based studies included online surveys and discussion elicited by artifacts such as photos and vignettes. The activities were varied and covered topics related to challenges living with HIV and managing HIV-related stigma with and without the use of technology<sup>1</sup>. Informed consent was discussed and signed in person for study S2 as well as via private chat and email for study S1. Participants received \$50 (USD) as compensation for their time. All of the data collected from the activities was exported, adapted, and organized in digital format for subsequent analysis in Dedoose.

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<sup>1</sup>More information on the ARC-based activities and procedures can be found in [60]

Study	P	Race/Ethnicity	Gender	Age	Sexual Ort.	Country
<b>ARC S1</b>	P1	Hispanic/Latina	woman	31-40	straight	USA
	P2	White	man	51-60	gay	USA
	P3	White	man	51-60	gay	USA
	P4	White	man	51-60	gay	USA
	P5	White	man	21-30	gay	USA
	P6	Hispanic/Latina	woman	51-60	straight	USA
	P7	White	man	21-30	gay	USA
	P8	Black	man	31-40	straight	Kenya
	P9	White	man	41-50	bisexual	USA
	P10	Hispanic/Latina	woman	51-60	straight	USA
	P11	Asian	man	21-30	gay	Philippines
	P12	Asian	queer	31-40	bisexual	Philippines
	P13	White	woman	41-50	bisexual	South Africa
	P14	White	woman	51-60	straight	USA
	P15	White	woman	51-60	straight	USA
	P16	White	man	31-40	straight	USA
	P17	Hispanic/Latino	man	21-30	gay	Mexico
	P18	White	man	31-40	gay	UK
	P19	White	woman	51-60	straight	USA
<b>ARC S2 &amp; Interview</b>	PL1	White	man	61-70	gay	USA
	PL2	White	man	51-60	gay	USA
	PL3	White	man	51-60	bisexual	USA
	PL4	Black	man	31-40	straight	USA
	PL5	White	woman	51-60	straight	USA
	PL6	White	man	51-60	bisexual	USA
	PL7**	White	man	41-50	gay	USA
	PL8	White	man	41-50	straight	USA
	PL9*	Black	man	21-30	gay	USA
	PL10*	White	man	31-40	gay	USA

Table 1. Demographics of participants living with HIV ( $N = 29$ ). P = participant code. \*Interview-only participant. \*\*ARC-only participant

### 3.1 Data Analysis

Based on thematic analysis guidelines suggested by [11], the first author and two co-authors completed an iterative open-coding analysis that included an initial round of data familiarization via inductive thematic analysis. Researchers met several times to identify, revise, and group the codes into emerging categories with the goal to identify instances of situations and experiences that related to HIV-related stigma in the data. In addition, a round of thematic analysis was conducted on the data with codes developed and adapted from Meisenbach's theoretical framework of coping strategies for public stigma [69] in order to refine codes further and identify initial emerging themes relating to coping strategies for public HIV-related stigma at the individual level. Based on the codes applied and memos produced on Dedoose, the first author produced affinity diagrams in order to triangulate codes across the different data sources as well as to further verify and refine salient themes using a constant comparative approach [18]. Finally, the first and second authors

discussed and revised all the codes and final themes by engaging in an iterative process of critical reflection, dialogue, and refinement.

### 3.2 Self-Disclosure and Ethical Considerations

As a member of the LGBTQ+ community, the first author has experienced the negative impact of stigma firsthand. Thus, the first author is committed to serving and working with those who experience high levels of stigma in their lives. Since 2017, the first author has volunteered at the HIV support center from which the social workers and a few of the participants living with HIV were recruited. Prior to data collection, the first author had been actively engaging with this community in order to better understand what living with HIV entails and how to better approach this community with respect and empathy. Social workers have not disclosed to the research team, whether they were living with HIV or not. We felt that asking about that would have created an unnecessary invasion of privacy as we wanted them to share their views based on their clients' lives and experiences rather than on their own. Finally, to protect participant privacy, we used pseudonyms in our Findings section. We did not use acronyms such as "PLH" when referring to people living with HIV as recommended in [111]. All protocols and procedures received IRB approval at the authors' affiliated university.

## 4 FINDINGS

Public HIV-related stigma was identified as the most salient type of stigma experienced by participants. In many cases, this type of stigma has affected participants' well-being in a more negative way than living with the virus itself:

*"I often say that it is no longer the virus that is killing us, we have treatment for that. There is another disease out there that is killing us. It's called stigma!" - Olivia (White, female, ARC S1-P13)<sup>2</sup>.*

Self-disclosure or non-self-disclosure of HIV status (heretofore referred to as disclosure or non-disclosure) was identified as the most common coping strategy used against public HIV-related stigma. On the one hand, participants indicated that disclosure of status allows them to access social support (mainly emotional and informational). Social support was viewed as a coping strategy in and of itself as it allows participants to bond with others sharing the stigmatized condition and to reframe the experience of living with HIV in a more positive light. On the other hand, non-disclosure of HIV status allows them to hide or conceal that they are living with HIV and thus avoid possible enactments of public HIV-related stigma like social rejection or violence. This disclosure/non-disclosure dichotomy poses tensions in relation to participants' needs of privacy, trust, intimacy, and social support in both offline and online settings (see Table 2). In the following subsections, we discuss these tensions around disclosure in more detail.

### 4.1 Disclosure Tensions around Privacy and Trust

Participants pointed out that those living with HIV do not always know whom they should disclose their status to. There were instances where participants thought they were required to disclose their status to others at work. After doing so, they received the backlash of stigma in the form of rumors, people talking behind their backs, and in a few cases, even being fired from their jobs. Social workers expressed that people living with HIV have a general lack of knowledge about appropriate times when HIV status disclosure is warranted. For example, Mia explained that many of their clients think that they should disclose their HIV status to potential employers:

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<sup>2</sup>Next to each quote, we have included the participant's pseudonym along with their race, self-reported gender, and whether the quote came from an ARC-based activity or interview.

Need	Tensions
Privacy & Trust	Disclosure vs. Enactments of Public HIV-related stigma Disclosure vs. Confidentiality Breach Non-Disclosure vs. Missed Stigma Reduction Advocacy
Intimacy	Disclosure vs. Social Rejection Non-Disclosure vs. Missed Intimacy Non-Disclosure vs. Facing Criminal Charges
Social Support	Disclosure vs. Confidentiality Breach Non-Disclosure vs. Missed Peer-to-peer Support

Table 2. Tensions between needs and coping strategies for public HIV-related stigma.

*"There is a lack of education. People who are living with HIV would call and say: 'I just got offered this job and I just don't know how I'm going to tell them that I am positive. But I don't really want to, how do I do that?', I'm like, you don't have to tell them you are positive. You sure don't! Then, they would say something like: 'Well, I'm working in the kitchen..', [and then I would ask if] their employers are practicing universal precautions and following OSHA rules? If they are, then you're good!" - Mia (White, woman, interview, social worker).*

In this sense, participants find it difficult to strike a balance between disclosing in order to access social support and protecting their privacy as well as against possible enactments of public HIV-related stigma like social rejection and violence. Participants highlighted that the 'coming out' process should be a personal decision made when someone is ready. Moreover, participants also explained that when giving advice to others, especially those who had been newly diagnosed, they suggest disclosure should be done with caution because once it is done, there is no going back. Participants suggested that such disclosure should take place firstly with previous sexual partners, secondly with other healthcare providers; and lastly, when they have come to terms with the fact that they are living with HIV, with family and close friends they trust.

Participants also mentioned that people living with HIV often use social media to disclose to others in weak-tied networks in order to avoid public stigma. In particular, HIV support groups on social media have served as the most commonly used type of technology for those who want to disclose their status and experiences living with HIV while minimizing the impact of public HIV-related stigma that they experience elsewhere in their lives. For example, Elijah highlighted the importance of social media in order to connect with others and access social support:

*"Facebook is a very useful tool for me to reach out to people who are not stigmatizing. I met many friendly people on Facebook that have been supporting me to get through." - Elijah (Asian, man, ARC S1-P11).*

Furthermore, social media platforms can also be used to advocate against and challenge public HIV-related stigma and further *normalize* terms like 'HIV' and 'AIDS.' This advocacy can reduce the stigma associated with the condition in the long term because it detaches HIV from notions or prejudices related to wrong or immoral behavior. In these cases, participants expressed a willingness to show others that HIV can impact anybody:

*"The only way to eradicate or to try to eradicate stigma is to speak out against it. There is an idea in people's head how someone with HIV looks [and] behaves, etc. By speaking out and sharing online, we can attempt to 'normalize' it, showing it can happen to any of us. You don't have to be [a] promiscuous gay [individual] or a drug addict to contract the*

*virus. There will always be a degree of stigma, but those who are able to speak out against it should do so! To speak up for those who cannot.*" - Anonymous survey respondent (ARC).

Yet, participants who prefer not to disclose their HIV status in person and who avoid places where they believe public HIV-related stigma might be enacted often leverage the anonymity of social media to access support. Participants mentioned that they disclose anonymously by using *separate online identities* (e.g., using a fake profile) and by being careful to avoid the sharing of information that could give away their real identity:

*"I have pseudonym on Facebook, I never post my real picture on Facebook, I never reveal my exact location on Facebook - I basically have an entirely different identity to lay low. I once had Facebook account with my face on it and my then coworkers found out and it was scary."* - Elijah (Asian, man, ARC S1-P11).

Participants often participate and engage in discussions on social media sharing experiences about living with HIV and dealing with stigma. Other times, however, they just *watch and observe* what others are saying and sharing on these platforms; this is often referred to as *lurking* [73]. We found an overall lack of trust of other users on the platform, especially those who are *lurkers*<sup>3</sup>. Participants are wary of them, as their identities, as well as their true intentions, are obscured. For instance, Scarlett mentioned that sometimes it could be a scary experience disclosing on such platforms:

*"The problem with online [social media] is that it's all so scary.. it's also anonymous. It's also.. Are they really who they say they are? Are they really? Some people aren't even positive!"* - Scarlett (White, woman, interview-PL5).

In some cases, especially when using their real profile information (e.g., real name), participants mentioned that they contact social media account owners directly via private email or messages asking them explicitly not to share their questions with others on their social media accounts. For instance, Logan uses his social media account to share information about living with HIV. He talked about being asked for anonymity by users seeking support and advice from him on Tumblr:

*"I run a Tumblr blog and I've received messages from people (who have contacted me under their username) who have asked questions regarding my experiences living with HIV, but they don't want our interactions to be shared on the blog because they don't want others to identify who they are."* - Logan (White, man, ARC S1-P5).

When using real identities, participants worry about the privacy and confidentiality of their disclosures. They explained that social media might not prevent others from sharing information from private or secret groups elsewhere. Members could still take screenshots of their interactions and share them on other platforms:

*"One thing people are still most concerned in social media with is the invasion of privacy. Who can see the posts? Could someone copy and re-post somewhere else what others wrote with their names visible? In closed or even secret groups you can STILL screenshot and re-post comments elsewhere. In developing new technology, that needs to be addressed too!"* - Susana (Latina, woman, ARC S1-P6).

In summary, participants explained that people living with HIV often lack the knowledge of how to disclose about their experiences living with HIV in a way that will not make them targets of public HIV-related stigma. To protect their confidentiality and access social support, participants join HIV support groups on social media using fake profiles. In contrast, when using their real

<sup>3</sup>Users who just read the comments and participation of others, but that do not participate or contribute themselves in an online group.

identities, they use social media to advocate against public HIV-related stigma and normalize the condition.

## 4.2 Disclosure Tensions Around Intimacy

Intimacy is an important and often unmet need among people living with HIV. Strong-tied connections with family members are an important source of support, yet participants expressed tensions when disclosing their status to close family members in offline or online settings. Participants mainly feared social rejection:

*"Coming out to family is the scariest thing most humans can ever face! You're risking the total rejection [from] people you most love and maybe even rely on for physical support."* - Lucas (White, man, ARC S1-P4).

In addition, forming romantic connections with others proves to be difficult, and a source of psychological distress. For instance, Scarlett expressed that a lack of romantic and sexual intimacy with others affects her considerably:

*"If I can't have sex, why am I staying alive? You follow me? What am I doing maintaining life if I can't go out and live? And it is depressing.. and there's a few times I did skip my [antiretroviral] medications cuz I figured, fuck it, I might as well die! I'm not doing anything with my life. Nobody loves me. I'm not loving anybody so what is there? What is life if you don't have that. I don't understand."* - Scarlett (White, woman, interview-PL5).

As the disclosure of HIV is often mandated by law in cases where sexual contact may occur, the timing of disclosure matters. However, participants often do not know the optimal time for disclosing their status and subsequently handling a potential rejection. For instance, Jackson explained that disclosure could happen at any point of the interaction with others for sexual purposes:

*"You know, some guys will wait until right before sex is about to happen and it's like oh by the way... other guys won't tell at all. and then some guys would be very very upfront like 'Hey, my name is bla bla and I'm HIV positive'. And so, finding the balance between when to disclose and then being able to handle the rejection that comes -and it does come-. That's a challenge!"* - Jackson (Black, man, interview-PL9).

On the one hand, some participants felt like they had to wait until progressing further into a relationship in order to educate the partner and decrease the likelihood of rejection. On the other hand, participants expressed that disclosing too late puts them at risk of facing criminal charges due to non-disclosure:

*"Well, I met a man and he was HIV negative and so ten days into meeting him I told him that I was HIV positive. I disclosed because I felt the relationship was going in that direction and as we all know, [name of state] is very strict on their laws. If you don't disclose you go to jail!"* - Scarlett (White, woman, interview-PL5).

Popular online dating platforms such as Grindr allow users to display their HIV status by filling out a disclosure field for this purpose. Yet, participants mentioned that they fear discrimination and social rejection when using such disclosure fields — or not using them — on their profiles. When not disclosing explicitly using this HIV status field, other users may assume that the owner of the profile is trying to hide a positive status. This situation is perceived by people living with HIV as a lack of control in the disclosure process. It is also seen as a missed opportunity to educate other users and possibly change their views on HIV prior to engaging in romantic and/or sexual intimacy:

*"It happens pretty regularly when I'm on any type of online platform trying to hook up. You know I reveal my status and it becomes this gamble of if the person is going to be willing to engage or if they are against it... So, most of the apps have now migrated to a system where you can disclose your status and put it inside of your profile. I think that this has hurt more than it has helped. And more hurt because it.. for those who are opposed to engaging with someone that is HIV positive, the lack of putting your status is a signal that you are positive, or by putting your status it definitely -or clearly signals- that you are HIV positive. And so, that person can choose not to engage with you prior to having any form of conversation that could have mediated some of his objections. It's basically like you had this giant bulls eye in your head. If you don't want to talk to that person you can steer clear from them. But, by limiting the conversation, you have also limited the access to changing an opinion." - Jackson (Black, man, interview-PL9).*

On the one hand, participants explained that even when they do not explicitly disclose their status via a disclosure field, they can still disclose via a private message and be blocked immediately. On the other hand, some people choose to display the text 'positive' in the disclosure field to *filter out* others who may reject them. Yet, those who disclose explicitly via a disclosure field still report experiencing the effect of public stigma due to other users not reading the contents of the HIV status disclosure field prior to contacting them:

*"I have my [HIV] status listed in my online profiles, so I rarely get negative comments. It's a way to screen these people out. still, plenty of people hit on you without reading." - Ethan (White, man, ARC S1-P2).*

In summary, intimacy is an important need for participants' well-being. Yet, participants reported that achieving intimacy with others can be challenging as potential discrimination and abrupt social rejection can likely occur. Consequently, participants highlighted the importance of *timing* when disclosing for intimacy. In contrast to what happens in offline settings, there is a lack of control of how the disclosure process unfolds in online settings. This is particularly the case of online platforms that display HIV status disclosure fields.

### **4.3 Disclosure Tensions Around Social Support**

As mentioned earlier, disclosure of HIV status can facilitate access to social support, which is an important coping mechanism against public HIV-related stigma. However, participants mentioned an overall lack of peer-to-peer support. Specifically, they mentioned a lack of mentors, who are meant to guide less-experienced individuals in navigating issues related to treatment and coping with public HIV-related stigma. Indeed, peer-to-peer support can be a source of encouragement and reassurance as it provides hope to those living with HIV. More importantly, this type of support allows people to re-frame the experience of living with HIV into a positive opportunity for personal growth by means of social comparison with others who have been successful at leading fruitful lives. For instance, Benjamin clarifies to others that HIV and AIDS are not the same thing, and that living with HIV is no longer a death sentence:

*"I get to tell others living with HIV my stories and experiences. And sometimes, I will get personal and I'll tell [them] that I do have HIV but not AIDS, and try to help and support them in that way; because I'm still alive! And you know, it's been ten years!" - Benjamin (White, man, interview-PL8).*

In many instances, participants expressed a desire to connect or bond with others who have *walked their path*. An equal sentiment is shared by those who have lived with HIV for more than a decade (also known as "survivors") who want to provide support to those newly diagnosed, or those who may not be able to speak for themselves:

*"We, long term survivors, need to lift up those who are not strong by organizing campaigns, support groups, and lending ourselves to counselling others. It's all good and well saying 'get tested and know your status', but then you test positive and then what? SUPPORT IS VITAL, ESPECIALLY FOR THOSE NEWLY DIAGNOSED. Yet, there is not nearly enough of this..."* - Anonymous survey respondent (ARC).

However, participants pointed out that it is not always easy to find peers who can act as mentors:

*"My family has been very understanding and supportive from the day I was diagnosed, but there was no one who could show me the way. As a result I nearly died."* - Anonymous survey respondent (ARC).

In particular, in the case of those newly diagnosed, mutual disclosure of status between the newly diagnosed and those with more experience living with HIV could serve as a pathway for effective social support exchange, especially if the person living with HIV for a longer period of time appears as a *role model* to the support-seeker. For example, Ethan shared a story about when he offered hope and advice to someone who had just received a diagnosis:

*"I got called in yesterday and had to go in and tell a young woman that she tested positive for HIV. I don't usually disclose my own status when I talk to patients, but when she said she was going to die it felt appropriate to let her know that I've had this for almost twenty-five years. At that moment, I could see [her] face visibly change. The question posed here was not about others, but about how HIV has impacted my own life. I guess in this instance, it's made my work-life easier. It's one thing to tell folks, 'You'll be OK.' It's quite another to be the evidence that gives someone hope."* - Ethan (White, man, ARC S1-P2).

In other cases, as in the situation described by Emma below, people living with HIV use social media to re-connect with others for support via mutual disclosure after one person finds out about the other's status. For instance, Emma described re-connecting with a former co-worker after reading his experiences with HIV on social media:

*"I reconnected with a former coworker in [location]. He had posted about his experience of being HIV positive. It turns out that we had been working together at same time and we were both positive, but we didn't know this about each other."* - Emma (White, woman, ARC S1-P19).

One of the challenges of finding social support is that support groups can take place as face-to-face support meetings. Participants mentioned that their ability to travel to meetings might be limited due to geographic location and lack of transportation, as is often the case of those who live in rural communities. Moreover, when attending these support groups, people living with HIV would like to bond with others who share characteristics in common other than living with HIV:

*"People living with HIV would like to have that client-to-client support level as well, but they genuinely don't really want to come to the meetings because they don't have a lot in common with other clients. You may have a 50-year-old White gay male and a 20-year-old African American female and a 35-year-old Latino. All in very different phases in their lives. Different socioeconomic [statuses], different religions, different everything. They don't actually find a lot of support from each other. Because they don't have anything in common other than living with HIV. One of the things that we really stress is that 'you are not your diagnosis'. So, if we say 'you are not your diagnosis', but we're throwing them together with these room full of people, [to say] support each other doesn't work."* - Ava (White, woman, interview, social worker).

Additionally, people living with HIV worry about the risk of breach of confidentiality in face-to-face groups. Consequently, they have turned to using online social media sites like Tumblr as well as private Facebook groups to gain access to social support from any location. In this manner, online groups help people living with HIV realize that they are not alone, while simultaneously offering the confidentiality that in-person groups lack. For example, Susana uses Facebook groups for people living with HIV to not feel alone in her journey as well as to access social support:

*"When I was still in the 'HIV closet' in 2016 due to family bias and HIV stigma, my only outreach for support was private Facebook groups for people with HIV. I was afraid to go to support groups in person and being outed as having HIV. The ability to use a cellphone to reach out across the world and know I was NOT ALONE in this journey was priceless." - Susana (Latina, woman, ARC S1-P6).*

Nevertheless, online platforms do not explicitly support social exchange or integrate a mentoring system. Participants mentioned that it is difficult to find suitable mentors on these platforms due to barriers to finding people who have lived similar experiences with HIV. For instance, with current technology, they cannot easily filter people by certain traits such as age, years of living with HIV, gender, etc. Moreover, as mentioned earlier, support seekers cannot verify who these other people really are. In many cases, people who join online communities could be lurkers who do not wish to disclose whether they are living with HIV or not. As a result, participants expressed the need for alternative mechanisms to find mentors. For example, one participant talked about the creation of a buddy system that could pair up mentors with support seekers:

*"I like the idea of an app creating a 'buddy system', wherein you could get randomly matched with people based off certain parameters (age, sex, sexuality, etc.) to create a 'friend' or 'mentor' system. An anonymous feature would be REALLY helpful to some people who aren't willing to disclose their information but have questions regarding their sex life, personal life, etc." - Logan (White, man, ARC S1-P5).*

In summary, participants mention that they lack access and worry about breach of confidentiality in the case of in-person support groups. Consequently, they turn to social media groups in order to access and exchange support, but these platforms also pose risks of breach of confidentiality and lack an effective peer-to-peer support exchange. In particular, participants wish to connect and bond with others, who share experiences beyond the fact of living with HIV, for mentorship and guidance. However, it is challenging for participants to find people in online platforms that can become suitable support providers and mentors.

#### **4.4 Potential Disparities of Public HIV-related Stigma Experiences**

Overall, the use of coping strategies and tensions reported above were consistent across all the participants. While we did not have sufficient data points for comparisons, we observed instances where public stigma experiences differ based on individual backgrounds. Participants from developing countries and those recruited locally in a more rural area reported experiencing more episodes of public HIV-related stigma in the forms of discrimination, social rejection, and enacted violence:

*"I have been stigmatized by dentists, internist and general practitioner, that should tell you everything about HIV stigma. [Location] is a hostile place for gay men. Can you imagine what things I should go through being gay and [positive] on a daily basis? I can't deal with stigma, it's too huge to deal with. I've been basically brushing it off and pretend that things are okay - which I know for a fact that they are not." - Elijah (Asian, man, ARC S1-P11).*

Participants who self-identified as gay men or women mentioned more often that the source of infection weighs on perceptions of public stigma, as the public may deem homosexuality and promiscuity immoral and thus exacerbate the effects of stigma. In particular, women felt that they are stigmatized more harshly due to the assumption that HIV must have been contracted via promiscuity and/or illicit drug use:

*"HIV is still regarded as a gay men's disease in the US. Too many of today's ads still have gay men as their target audiences which prolongs that association for the rest of us too. Older, heterosexual people get HIV too. They no longer worry about pregnancies and don't use condoms. I despise being categorized. Since I am not a man, the next logical assumption is drugs or sex. Neither of that is correct. I got HIV doing my job drawing blood. Most often that statement is met with disbelief, even by healthcare professionals. I do know it is NOT homosexual-prevalent in other parts of the world BUT definitely MSM [men who have sex with men] in the USA. Men do not judge each other men the way women are judged when it comes to sex." - Susana (Latina, woman, ARC S1-P6).*

Overall, women and gay men tended to be more worried about intimacy-related tensions, whereas participants in our studies who self-identified as men and straight tended to be more concerned about social rejection from family and work colleagues. Straight participants were more vocal and reported to be involved in activism and use of disclosure of status as a way to normalize HIV and thus lower public HIV-related stigma in their communities. Finally, straight men mentioned seeking informational support (i.e., advice) from others, whereas women and gay participants mentioned seeking emotional support (i.e., encouragement) more often. Although gay men and women use online technology to cope via disclosure and access to intimacy and social support, they stressed the need for technology to adapt to their particular intersectional needs. For instance, Luna expressed how technology should be fine-tuned for women living with HIV:

*"Me being a woman with HIV, I have different issues than a man. I would like to see more on how HIV affect us women differently. As you know, I use my tablet for most of my discussions, keeping up with my medicine, appointments, and much more. I would like to see an application [specifically designed] for women living with HIV." - Luna (Latina, woman, ARC S1-P10).*

In summary, these findings show that there are distinct groups of individuals experiencing the negative effects of public stigma with different intensity. Thus, the tensions of coping with public HIV-related stigma via disclosure and access to adequate social support are likely to be experienced with different degrees of intensity as well. In this sense, participants wish for technology that would take into account their particular situations and needs regarding geographic location, gender, and sexual orientation.

## 5 DISCUSSION

Our findings align with and further validate the use of coping strategies described by Meisenbach's stigma management theory [69] and in related research on public HIV-related stigma (e.g., [19, 100]). Participants engaged in reactive and proactive coping strategies depending on their circumstances. Yet, participants reported experiencing tensions when coping with public HIV-related stigma via self-disclosure while trying to meet their needs of privacy, trust, intimacy, and social support. The same tensions persist when participants turn to online technology. Often, in HCI research, the concept of stigma has been reported as yet another trait of the population or as one of many factors affecting an individual, rather than the main problem to be addressed. A common sentiment among

participants is that researchers as well as practitioners should focus less on the design of alarm-based medication adherence technologies, and should focus more on the design of technologies that could extend beyond HIV treatment to help users cope with stigma more directly.

In particular, our findings show that several technologies have been re-appropriated (i.e., used in ways for which their generic core designs were not specifically created) for helping individuals cope with public HIV-related stigma at the individual level. In this sense, we argue that technologies could be designed from the ground up to empower individuals living with HIV to cope with public HIV-related stigma by facilitating safer disclosure and peer-matching mechanisms. In the following subsections, we present a series of design implications informed by our findings and by related research that could help people living with HIV address the tensions surrounding public HIV-related stigma at the individual level.

## 5.1 Designing for Safe Disclosure

The *coming out* process of stigmatized identities (like those of a non-normative sexual orientation) often takes place online due to an increased perception of anonymity [8, 26, 31, 91]. The majority of participants reported using fake profiles or *alternate personas* when using online technology. Indeed, research has found that people use fake identities as a form of escapism that allows them to access support and navigate their identity formation process without social repercussions like the enactment of violence [24, 68, 94]. This aligns with the reactive coping strategy of concealment by which the stigmatized individual hides the stigmatized trait. We found that such concealment in online platforms goes beyond the stigmatized trait even to include the individual's identity. However, using fake profiles or identities can be beneficial up to a certain point. The coming out process and its benefits like interpersonal connection may have to be transferred offline in order to avoid identity conflict and social isolation, which could worsen the negative effects of stigma in people's lives [24, 47]. This is especially relevant for people living with HIV, for disclosure is regarded as an important gateway to social support [19, 88]. In this sense, the design of online platforms could afford a more controlled -and informed- disclosure process so that individuals may opt to reveal their real identities or transition from using fake identities to real ones whenever they are ready, extending the disclosure process to offline settings.

Prior research states that people living with HIV engage in a highly controlled and selective process when disclosing their status and experiences. This selection process is based on perceptions of public HIV-related stigma from others and weighing on the possibility of social rejection or judgment [9, 44, 88, 114]. Common recipients of such disclosures are often trusted family and close friends as well as healthcare providers [114]. Yet, despite engaging in this highly selective process of disclosure, we found that people living with HIV experience reduced control in the process of disclosure due to a lack of technological affordances. Our findings indicate that current technologies do not aid people in managing tensions around privacy and trust as a result of disclosure. We argue that technologies could be designed to further optimize disclosure in online settings. For instance, these technologies could allow users to reveal their real identities in a safer and more controlled fashion even to people in strong-tied networks such as family members and close friends, whose support is critical for coping with HIV-related stigma [114]. On the following subsections, we discuss technology that could be designed to enhance trust and give users more control over their disclosures.

*5.1.1 Disclosure and Trust.* Establishing trust in social media and engaging in "uncertainty reduction strategies" (such as online information-seeking) have been shown to facilitate health-related disclosures [56]. We found that participants are indeed willing to disclose more openly and widely on social media. However, they feel uncertain of the level of privacy that such online platforms can

provide as they are not sure of the identity of *the others* who may be monitoring their interactions online. The presence of other 'fake' users and lurkers create tensions at the time of disclosing as users feel suspicion of their true identities and intentions. Consequently, users tend to use fake profiles via which they can show alternative identities so that their real identities can be protected.

Ideally, social media groups designed for people living with HIV could include tools that could enhance disclosure control by allowing users to disclose to group members selectively. This disclosure affordance could be based on members' prior participation behavior or on the quality of their history of providing social support within the group. Such an affordance could make use of tools such as the browser extension developed by [41], which adds visual signifiers around a user's profile photo for social media sites like Twitter. These signifiers denote whether a user has generated toxic or misinforming tweets and effectively create *computationally-derived social signals*. Similarly, social media platforms could incorporate visual signifiers of group members' public profile activity regarding attitudes around HIV (e.g., an "ally" badge for members active in public HIV-friendly groups or pages), or attitudes regarding homosexuality and women. Ultimately, these types of signifiers could help users feel more comfortable in determining the extent of their disclosures to other group members.

Tools such as visual signifiers could help those living with HIV establish a *trust index*, which can be used to support partial or privileged disclosure (e.g., disclosure to only trusted individuals) in online settings. A trust index could help identify potentially trustworthy friends or groups using information such as the number of "likes" a person gives to content supportive of those living with stigmatized conditions, or the number of posts in a group which express support for those living with HIV. Such a trust index would need to be dynamically maintained and frequently updated, much like trust for a person grows or wanes over time in offline settings. For example, as the number of supportive messages exchanged or posted in a group increases, the trust index for that group increases in tandem.

Alternatively, when disclosure takes place in more public online groups where users could be interacting with people they interact with in the offline world (i.e., family members and close friends), users could receive a Just-In-Time Adaptive Intervention (JITAI) [77] that could coach users on how and under which circumstances they could safely disclose to strong or weak ties. For example, an avatar could encourage the user to invite disclosure recipients to private channels like encrypted chats. Additionally, the user could receive step-by-step guidance on safe disclosure via a conversational agent, a powerful tool that has been shown to encourage self-disclosure in certain contexts [51]. On the side of the disclosure recipient, platforms could be designed to guide recipients by providing information about how to support the discloser. This information could be tailored to the discloser's demographic background, including gender and sexual orientation, and could explain the negative effects of unsupportive responses and social rejection.

*5.1.2 Data Persistence.* Another aspect regarding lack of control over disclosure is the persistence of data in online platforms. Participants worry that their disclosures could be read, copied, and shared elsewhere at a later point without their permission. Indeed, [83] already talked about this limitation of privacy control in sociotechnical environments due to the permanency of data and the users' lack of control in how disclosed information could be interpreted and disseminated. Our findings also align with [117]'s findings regarding users experiencing tensions between privacy and disclosure with their contacts on Facebook due to the persistence of their data on the platform. In this sense, customized social media platforms could allow the expiration of sensitive disclosures via automated or manual processes aligned to the notions of *forgetting* and *obscuring* discussed by [55]. On the one hand, *forgetting* could encourage the design of sociotechnical systems that could avoid storing permanent data and giving users the possibility to delete their data permanently

if so they desire. On the other hand, *obscuring* could encourage the design of systems that make data untraceable and irretrievable at any point in time. Thus, search engines or other crawling systems would be prevented from indexing and listing pages or interactions in which sensitive disclosures may have occurred. In this way, users would be granted more control over who and when their sensitive data can be accessed and seen by others.

Another design implication could be allowing users on video-based social media to distort their voice or image, an affordance that has been suggested in work with vloggers talking about their experiences with chronic illness [57]. Such a design encourages a data-grounded construction of one's online identity and provides safeguards for exploring this identity in the context of coping with stigma.

## 5.2 Designing for Intimacy

In the case of social media platforms that include specific HIV status disclosure fields (e.g., platforms or apps that are used for romantic or sexual encounters), participants report a lack of control over the process and the timing of their HIV status disclosures due to the simplistic design of such disclosure fields. Participants reported experiencing discrimination and abrupt social rejection on these platforms based on the values entered in these fields without giving them a chance to control the timing or the way they wish to disclose their status to potential partners. Interestingly, even a blank HIV status field may signal to others that the user is HIV positive and thus risks immediate discrimination against the user. This is particularly the case for sex social media platforms for men who have sex with men [119]. Similarly, participants in our study also highlighted a missed opportunity to educate others because of the simplistic design of such disclosure fields.

*5.2.1 Enhanced Disclosure Control.* Designs for those living with HIV must allow for a better control of disclosure timing. Technologies that seek to optimize disclosure timing could pair moments of disclosure with educational material about HIV as suggested in [121] in order to potentially reduce enactments of public HIV-related stigma. [103] have already evidenced a reduction of public HIV-related stigma among young populations via the use of animated educational material. This approach would be particularly important for those users who engage in proactive coping strategies and who wish to disclose upfront and use such disclosure to challenge public stigma by reframing and normalizing HIV as well as filtering mechanisms for potential partners. Alternatively, these types of disclosure fields could be removed from user profiles and rather encourage the avoidance of stigmatizing language towards HIV and support those who are willing to engage and meet others in spite of HIV status. For instance, social media platforms could better regulate the use of stigmatizing language such as DDF-UB2 ("disease & drug free, you be too") in users' profiles in order to promote a culture of anti-stigmatization. This could be accomplished with automatic vetting systems similar to those already being used to monitor pornographic content in public photos in users' profiles and those for moderating content that promotes unhealthy eating behaviors [17].

Additionally, designs for those living with HIV could seek to reduce public HIV-related stigma by challenging stereotypes and increasing understanding and acceptance of HIV as a treatable and manageable health condition. For example, [54] and [40] have already reported how a mobile application uses "live stigma-free" badges on users' profiles in order to help normalize people living with HIV on the platform. These badges let others know that the badge-bearer has been educated about HIV and is against its associated public stigma. This type of design of online technology could further aid people living with HIV in using proactive coping strategies that reduce the offensiveness of the stigmatized condition by reframing HIV as an acceptable individual trait, and rather make negative behaviors toward people living with HIV unacceptable.

Finally, [120] found that users opting not to use and disclose HIV status by filling out a value in an HIV disclosure field may be perceived as undesirable behavior and promote assumptions regarding users' HIV status. In this sense, technologies could allow users to partially disclose HIV status (or any other information about their treatment, for that matter) by enabling ambiguous forms of disclosure decipherable only by those whom the user trusts. For example, [20] have explored the concepts of privacy and abstraction with the design of objects that convey health-related information via symbols and signifiers that are unrelated to a particular health condition. For instance, a design could display information by showing an animation composed of visual elements not related to HIV at all, like flowers in a garden (just as UbiFit garden did for fitness achievements [21]). In this scenario, the number or percentage of flowers growing in the garden could represent the strength of the user's immune system (a related health metric). Viewing this information in a public space would be low-risk, as nearby others would be unaware of the display's meaning. Such designs reduce concerns regarding accidental disclosure and possible enactments of public HIV-related stigma. This approach could also extend work that has explored interventions that prevent accidental disclosure to others via the use of visual metaphors or gamified user interfaces [13, 52, 65, 101, 106].

### 5.3 Designing for Bonding

People living with HIV cope with public HIV-related stigma by *bonding* and sharing experiential information with others who share the same condition [115]. Participants felt connected with those sharing their experiences. Indeed, [115] found that people living with HIV choose similar others as information sources. That is, they form ties with others who share their condition rather than race, social class, or geographic proximity to obtain experiential information or "wisdom and know-how gained through personal lived experience." Ultimately, the main motivation for acquiring information from peers living with the same condition is to learn how to live with HIV for as long and as well as possible. This is done by obtaining useful and practical information through personal stories and by engaging in social comparison with others with the same condition. Such comparisons can either encourage hope (upward comparison) or thankfulness that one's situation is better than another's (downward comparison) [115]. In particular, the bonding with others who have more experience and who act as mentors to support seekers constitute an important coping strategy against public HIV-related stigma. These bonding and mentoring experiences allow people to re-frame their situation and access social support resources.

*5.3.1 Enhanced Peer-to-Peer Social Support.* Bonding with others in online settings is challenging for people living with HIV. However, initial disclosure from others in an individual's online social circle may trigger or further promote disclosure from others, similar to how directed messages from strong ties bolster social support online [12]. Our findings align with literature that reports benefits on well-being among people living with HIV due to the activation of social support after disclosure has taken place in online groups [73, 74]. In particular, initial disclosure can foster mutual disclosure and further activate social support exchange on these platforms. Andalibi and Forte's framework for stigmatizing disclosure highlights "network-level reciprocal disclosure", a process that takes in which some social media users inspire other users to disclose as a consequence of the reduced perception of stigma [1, 2]. Similarly, we found that those living with HIV for longer tend to be the ones who disclose first in order to help normalize (and thus de-stigmatize) living with HIV. We argue that this social support exchange process helps people living with HIV shape a new identity that integrates HIV and that promotes the use of coping strategies more conducive to social support, such as disclosure, bonding, and reframing.

Reciprocal disclosure could allow support seekers to identify mentors whom they can engage with for social support exchange. As suggested by [1], social media platforms could make it easier for users to identify others who are willing to be mentors without explicit disclosure of HIV status taking place. For instance, platforms could include visual elements like badges on users' posts in order to indicate a willingness to provide support to others. Additionally, if the user who is willing to be a mentor allows it, a value showing the trust index discussed earlier could also be displayed in the user's profile.

Prior research has already shown the effectiveness of mentor-based technological interventions in improving treatment for stigmatized conditions like mental illness [98]. By providing interactions with supportive individuals who have the appropriate expertise, computer-mediated interventions can achieve better treatment adherence and user engagement [75]. Online platforms could include interactive educational resources to mentors, also known as stigma toolkits [78]. These toolkits include scenarios, stories, and guidelines that mentors could use to help others manage public HIV-related stigma. In addition, these toolkits could include audiovisual material that could deliver the content in a more engaging fashion [5, 92].

Finally, social media technology could include automated peer matching possibilities by allowing users to find mentors based on attributes such as age, gender, sexual orientation, geographic location, and other factors (similar to how online dating platforms operate) as well as on similar lived experiences that could maximize the benefit of the supportive interaction. These types of mentor-peer matching systems could offer potential matches based on the preference of use of coping strategies against public HIV-related stigma. For instance, people who prefer not to disclose their status at all could be matched with others who prefer to use the same coping strategy in order to exchange experiences and support.

#### **5.4 Towards the Design of Customized Technology for Stigma**

We argue that the design and development of technology to help people cope with public HIV-related stigma at the individual level would need to be aligned with people's personal needs of privacy, trust, intimacy, and peer-to-peer support. Moreover, these needs could also equate to their corresponding human values and thus be further explored by adopting a Value Sensitive Design approach [32, 33]. Value Sensitive Design predisposes researchers and practitioners to be more sensitive about direct and indirect stakeholders' values so that technologies are aligned with those values and thus minimize unintended consequences that the research process may have on a marginalized population. Moreover, critical [4] and social justice-oriented design [28] as well as *Queering* [55] are additional orientations that could be adopted to encourage researchers to consider broader and more complex systemic and structural issues within the problem space of HIV-related stigma.

Based on our findings and on prior research that has identified the negative impact of social media on marginalized and vulnerable populations, we encourage researchers and practitioners to consider how technologies could be replicating and, in some cases, worsening systemic issues surrounding HIV stigma that take place offline [28, 101]. For instance, design implications presented here could be adapted to the particular needs and values of those living with HIV living in rural areas and for those who identify as gay men or women, as the social repercussions (e.g., discrimination, violence) are worse for these groups than for other groups as reported in our findings. Additionally, gay men and women have been shown to fear disclosure and intimacy and face a multitude of challenges when accessing social support due to the social perceptions and assumptions of immoral behavior [22, 25, 46, 79, 88, 102, 116]. In this sense, for instance, technology should take into account that people living with HIV may want to disclose to bond and access social support, yet others may want to disclose in order to challenge public stigma and normalize the condition. At a minimum,

technology designers and developers should protect the confidentiality of data collected from users via the integration of strong encryption and security protocols. Moreover, it should be made clear to potential users how the data collected would be used or disseminated with any type of technological intervention [13, 101].

HIV-related stigma is a complex social phenomenon that cannot be solved or addressed through a singular solution. When designing new technology in such a space, researchers frequently adopt alternative design methodologies better fitted for exploring and critiquing design problem spaces. In the case of stigma, co-design and speculative design approaches [30] have been used by researchers in order to design new technology with stigmatized and vulnerable populations (e.g., [37, 90, 93]), including people living with HIV (e.g., [65]). The strength of these approaches is that they allow researchers to foreground participants' values and perspectives via a democratic and dialogic process without aiming for a particular solution [53, 76, 80, 104]. For example, [80] used a futuristic prototype in order to generate lively discussions around how a technological intervention could assist caregivers of people with dementia. Similarly, [76] used probes that consisted of science fiction narratives in order to co-design technologies with people living with chronic or recurrent urinary tract infections, and [37] co-designed technologies with transgender participants to overcome challenges related to gender identity expression. In our studies, participants have shown interest and excitement in proposing ideas for technologies that would help them cope with public HIV-related stigma. We encourage researchers to further identify ways to foster meaningful interactions with participants that could be generative of design.

Taken together, this research outlines additional ways in which stigmatized individuals could be supported through novel design interventions. Our study is not the first to do this, as conducting research with stigmatized populations is a growing area of inquiry within HCI. Recently, a number of workshops have been organized to discuss best practices regarding recruitment, data collection, and reporting when working with stigmatized populations (e.g., [59, 64, 105]). Yet, the main purpose of existing technology has not been to address stigma specifically, but rather stigma has been an additional contribution to the central design goal. Thus, we exhort our community to continue moving towards a stronger collaborative or participatory design model with stigmatized populations. This movement forward will require continued development of ethical commitments that ensure the establishment of trust among participants, designers, and researchers. At the minimum, this may mean giving participants a stronger voice and control over the design process by including them in discussions of how findings of their personal experiences are interpreted and how subsequent insights are generated. This may be a particularly useful approach in overcoming further stigmatization that can occur within the design process, such as when individuals' HIV status, rather than their holistic well-being, is placed in the foreground. We encourage designers to iterate on existing technologies and to pursue new technologies that could improve quality of life by addressing people's needs for privacy, trust, intimacy, and peer support beyond HIV-related experiences. Researchers must ensure that participants are treated with dignity and respect throughout the entire research and design process. Thus, we recommend that such guidelines be generated through continued dialogue during workshops and panels organized within our academic community that would further raise the voice and needs of marginalized and vulnerable populations, as suggested in [59, 64, 105].

## 5.5 Limitations

Although we recruited participants both locally and internationally, our sample is skewed towards participants being white, male, older than 40, and living in the US. Consequently, our findings on intersectionality are rather brief and should be considered with caution. In this sense, and as suggested by intersectional HCI literature [97], future design work should continue exploring

further and take into account intersectionality related to particular aspects such as gender, race, sexual orientation as well as the cultural background of participants. This approach helps ensure that technologies are fine-tuned to the unique values and needs of stigmatized individuals. In particular, we urge researchers to include more women (including transgender women) and people of color living with HIV as research reports that these populations experience harsher negative effects of public stigma in the form of psychological distress, enacted violence, harassment, and poor access to care [10, 25, 78, 88, 109].

Additionally, measurements of public HIV-related stigma done with Berger's scale [7] in participants enrolled for ARC-based studies revealed that participants experienced rather mild levels of public HIV-related stigma upon starting the studies. In addition, participants were recruited from an HIV support center (and interviews at the HIV support center) and also recruited from HIV support groups online. Consequently, there is a possibility that our recruitment procedures encouraged the participation of those who were not experiencing high levels of public HIV-related stigma in their lives and were connected to such offline or online support groups. Thus, further research in our field should strive to find ways to encourage participation as well as collaboration with those who are the most affected by HIV-related stigma and should incorporate their views into the technology design and assessment process.

## 6 CONCLUSION

People living with HIV need and use medication adherence tools. However, there is still a lack of tools that could help address the wide-ranging impacts of public HIV-related stigma on the HIV coping journey. Based on interviews and activities with people living with HIV and social workers, we identified several challenges and tensions that make coping with public HIV-related stigma particularly challenging. We also discussed possible design implications and directions for future research, including the co-creation of technologies that could be customized to address stigma-related tensions more holistically. We urge researchers in the HCI and CSCW communities to design beyond medication adherence applications and existing online platforms as they seek to minimize the deleterious impact of stigma in people's lives.

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## REFERENCES

- [1] Nazanin Andalibi. 2019. What Happens After Disclosing Stigmatized Experiences on Identified Social Media: Individual, Dyadic, and Social/Network Outcomes. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 137.
- [2] Nazanin Andalibi and Andrea Forte. 2018. Announcing pregnancy loss on Facebook: A decision-making framework for stigmatized disclosures on identified social network sites. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. 1–14.
- [3] Anna N Baglione, Maxine M Girard, Meagan Price, James Clawson, and Patrick C Shih. 2018. Modern bereavement: a model for complicated grief in the digital age. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. 1–12.
- [4] Jeffrey Bardzell and Shaowen Bardzell. 2013. What is critical about critical design?. In *Proceedings of the SIGCHI conference on human factors in computing systems*. ACM, 3297–3306.
- [5] Julie Barroso, Michael V Relf, Megan Scull Williams, Joyell Arscott, Elizabeth D Moore, Courtney Caiola, and Susan G Silva. 2014. A randomized controlled trial of the efficacy of a stigma reduction intervention for HIV-infected women in the Deep South. *AIDS patient care and STDs* 28, 9 (2014), 489–498.

- [6] JA Bauermeister, KE Muessig, S LeGrand, DD Flores, SK Choi, W Dong, G Sallabank, and LB Hightow-Weidman. 2019. HIV and sexuality stigma reduction through engagement in online forums: results from the HealthMPowerment intervention. *AIDS and behavior* 23, 3 (2019), 742–752.
- [7] Barbara E. Berger, Carol Estwing Ferrans, and Felissa R. Lashley. [n.d.]. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. 24, 6 ([n. d.]), 518–529. <https://doi.org/10.1002/nur.10011>
- [8] Magdalena Berger, Todd H Wagner, and Laurence C Baker. 2005. Internet use and stigmatized illness. *Social science & medicine* 61, 8 (2005), 1821–1827.
- [9] Beth Perry Black and Margaret Shandor Miles. 2002. Calculating the risks and benefits of disclosure in African American women who have HIV. *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 31, 6 (2002), 688–697.
- [10] Walter O Bockting, Michael H Miner, Rebecca E Swinburne Romine, Autumn Hamilton, and Eli Coleman. 2013. Stigma, mental health, and resilience in an online sample of the US transgender population. *American journal of public health* 103, 5 (2013), 943–951.
- [11] Virginia Braun and Victoria Clarke. 2006. Using thematic analysis in psychology. *Qualitative research in psychology* 3, 2 (2006), 77–101.
- [12] Moira Burke and Robert Kraut. 2013. Using Facebook after losing a job: Differential benefits of strong and weak ties. In *Proceedings of the 2013 Conference on Computer Supported Cooperative Work*. ACM, 1419–1430.
- [13] Adrian Bussone, Simone Stumpf, and George Buchanan. 2016. It feels like i'm managing myself: Hiv+ people tracking their personal health information. In *Proceedings of the 9th Nordic Conference on Human-Computer Interaction*. 1–10.
- [14] CDC. 2018. On the Fast-Track to end AIDS by 2030: Focus on location and population. [https://www.unaids.org/sites/default/files/media\\_asset/WAD2015\\_report\\_en\\_part01.pdf](https://www.unaids.org/sites/default/files/media_asset/WAD2015_report_en_part01.pdf). Accessed: 2018-03-20.
- [15] Stevie Chancellor, Zhiyuan Lin, and Munmun De Choudhury. 2016. " This Post Will Just Get Taken Down" Characterizing Removed Pro-Eating Disorder Social Media Content. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. 1157–1162.
- [16] Stevie Chancellor, Tanushree Mitra, and Munmun De Choudhury. 2016. Recovery amid pro-anorexia: Analysis of recovery in social media. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM, 2111–2123.
- [17] Stevie Chancellor, Jessica Annette Pater, Trustin Clear, Eric Gilbert, and Munmun De Choudhury. 2016. # thyghgapp: Instagram content moderation and lexical variation in pro-eating disorder communities. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. 1201–1213.
- [18] Kathy Charmaz. 2014. *Constructing grounded theory*. SAGE.
- [19] Margaret A Chesney and Ashley W Smith. 1999. Critical delays in HIV testing and care: The potential role of stigma. *American behavioral scientist* 42, 7 (1999), 1162–1174.
- [20] Sunny Consolvo, David W McDonald, and James A Landay. 2009. Theory-driven design strategies for technologies that support behavior change in everyday life. In *Proceedings of the SIGCHI conference on human factors in computing systems*. ACM, 405–414.
- [21] Sunny Consolvo, David W McDonald, Tammy Toscos, Mike Y Chen, Jon Froehlich, Beverly Harrison, Predrag Klasnja, Anthony LaMarca, Louis LeGrand, Ryan Libby, et al. 2008. Activity sensing in the wild: a field trial of ubifit garden. In *Proceedings of the SIGCHI conference on human factors in computing systems*. ACM, 1797–1806.
- [22] Patrick W Corrigan. 2014. *The stigma of disease and disability: Understanding causes and overcoming injustices*. American Psychological Association.
- [23] Doris D Coward. 1995. The lived experience of self-transcendence in women with AIDS. *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 24, 4 (1995), 314–320.
- [24] Maxwell Crowson and Anne Goulding. 2013. Virtually homosexual: Technoromanticism, demarginalisation and identity formation among homosexual males. *Computers in Human Behavior* 29, 5 (2013), A31–A39.
- [25] Caroline K Darlington and Sadie P Hutson. 2017. Understanding HIV-related stigma among women in the Southern United States: A literature review. *AIDS and Behavior* 21, 1 (2017), 12–26.
- [26] Samantha DeHaan, Laura E Kuper, Joshua C Magee, Lou Bigelow, and Brian S Mustanski. 2013. The interplay between online and offline explorations of identity, relationships, and sex: A mixed-methods study with LGBT youth. *Journal of Sex Research* 50, 5 (2013), 421–434.
- [27] Xianghua Ding, Patrick C Shih, and Ning Gu. 2017. Socially embedded work: A study of wheelchair users performing online crowd work in china. In *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing*. 642–654.
- [28] Lynn Dombrowski, Ellie Harmon, and Sarah Fox. 2016. Social justice-oriented interaction design: Outlining key design strategies and commitments. In *Proceedings of the 2016 ACM Conference on Designing Interactive Systems*. ACM, 656–671.
- [29] Elizabeth V Eikay and Kayla M Booth. 2017. Recovery and maintenance: how women with eating disorders use Instagram. *iConference 2017 Proceedings* (2017).

- [30] Chris Elsdén, David Chatting, Abigail C Durrant, Andrew Garbett, Bettina Nissen, John Vines, and David S Kirk. 2017. On speculative enactments. In *Proceedings of the 2017 CHI conference on human factors in computing systems*. ACM, 5386–5399.
- [31] Jesse Fox and Rachel Ralston. 2016. Queer identity online: Informal learning and teaching experiences of LGBTQ individuals on social media. *Computers in Human Behavior* 65 (2016), 635–642.
- [32] Batya Friedman and David G Hendry. 2019. *Value sensitive design: shaping technology with moral imagination*. MIT Press.
- [33] Batya Friedman, Peter Kahn, and Alan Borning. 2002. Value sensitive design: Theory and methods. *University of Washington technical report* 02–12 (2002).
- [34] Zheng Gao and Patrick C Shih. 2019. Communities of support: social support exchange in a HIV online forum. In *Proceedings of the Seventh International Symposium of Chinese CHI*. 37–43.
- [35] Anna Gaysynsky, Kathryn Romansky-Poulin, and Stephen Arpad. 2015. “My YAP Family”: analysis of a Facebook group for young adults living with HIV. *AIDS and Behavior* 19, 6 (2015), 947–962.
- [36] Erving Goffman. 2009. *Stigma: Notes on the management of spoiled identity*. Simon and Schuster.
- [37] Oliver L Haimson, Dyke Gorrell, Denny L Starks, and Zu Weinger. 2020. Designing Trans Technology: Defining Challenges and Envisioning Community-Centered Solutions. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–13.
- [38] Gregory M Herek. 1999. AIDS and stigma. *American behavioral scientist* 42, 7 (1999), 1106–1116.
- [39] Lisa B Hightow-Weidman, Kathryn E Muessig, Emily C Pike, Sara LeGrand, Nina Baltierra, Alvin Justin Rucker, and Patrick Wilson. 2015. HealthMpowerment. org: building community through a mobile-optimized, online health promotion intervention. *Health Education & Behavior* 42, 4 (2015), 493–499.
- [40] Jevan A Hutson, Jessie G Taft, Solon Barocas, and Karen Levy. 2018. Debiasing desire: Addressing bias & discrimination on intimate platforms. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (2018), 1–18.
- [41] Jane Im, Sonali Tandon, Eshwar Chandrasekharan, Taylor Denby, and Eric Gilbert. 2020. Synthesized Social Signals: Computationally-Derived Social Signals from Account Histories. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–12.
- [42] Aishwarya M Iyengar and Anirudha Joshi. 2013. Evaluating anonymous social networking for PLHA with social prototypes. In *Proceedings of the 3rd ACM Symposium on Computing for Development*. 1–2.
- [43] Anirudha Joshi, Mandar Rane, Debjani Roy, Nagraj Emmadi, Padma Srinivasan, N Kumarasamy, Sanjay Pujari, Davidson Solomon, Rashmi Rodrigues, DG Saple, et al. 2014. Supporting treatment of people living with HIV/AIDS in resource limited settings with IVRs. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 1595–1604.
- [44] Seth C Kalichman, Michael DiMarco, James Austin, Webster Luke, and Kari DiFonzo. 2003. Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of behavioral medicine* 26, 4 (2003), 315–332.
- [45] Bogoan Kim, Daehyoung Lee, Aehong Min, Seungwon Paik, Georgia C. Frey, Kyungsik Han, and Patrick C. Shih. 2020. PuzzleWalk: A theory-driven iterative design inquiry of a mobile game for promoting physical activity in adults with autism spectrum disorder. *PLoS ONE* (2020).
- [46] Neha Kumar, Azra Ismail, Samyukta Sherugar, and Rajesh Chandwani. [n.d.]. Restoration Work: Responding to Everyday Challenges of HIV Outreach. 3 ([n. d.]), 1–26. Issue CSCW. <https://doi.org/10.1145/3359156>
- [47] Aideen Lawlor and Jurek Kirakowski. 2014. Online support groups for mental health: A space for challenging self-stigma or a means of social avoidance? *Computers in Human Behavior* 32 (2014), 152–161.
- [48] Daehyoung Lee, Georgia Frey, Alison Cheng, and Patrick C Shih. 2018. Puzzle walk: A gamified mobile app to increase physical activity in adults with autism spectrum disorder. In *2018 10th International Conference on Virtual Worlds and Games for Serious Applications (VS-Games)*. IEEE, 1–4.
- [49] Daehyoung Lee, Georgia C. Frey, Aehong Min, Bogoan Kim, Donetta J. Cothran, Scott Bellini, Kyungsik Han, and Patrick C. Shih. 2020. Usability Inquiry of a Gamified Behavior Change App for Increasing Physical Activity and Reducing Sedentary Behavior in Adults with and without Autism Spectrum Disorder. *Health Informatics Journal* (2020).
- [50] Rachel S Lee, Arlene Kochman, and Kathleen J Sikkema. 2002. Internalized stigma among people living with HIV-AIDS. *AIDS and Behavior* 6, 4 (2002), 309–319.
- [51] Yi-Chieh Lee, Naomi Yamashita, Yun Huang, and Wai Fu. 2020. “I Hear You, I Feel You”: Encouraging Deep Self-Disclosure through a Chatbot (*CHI '20*). Association for Computing Machinery, New York, NY, USA, 1–12. <https://doi.org/10.1145/3313831.3376175>
- [52] Sara LeGrand, Kathryn E Muessig, Alyssa Platt, Karina Soni, Joseph R Egger, Nkechinyere Nwoko, Tobias McNulty, and Lisa B Hightow-Weidman. 2018. EPIC allies, a Gamified mobile phone APP to improve engagement in care, antiretroviral uptake, and adherence among young men who have sex with men and young transgender women who

- have sex with men: protocol for a randomized controlled trial. *JMIR research protocols* 7, 4 (2018), e94.
- [53] Roxanne Leitão. 2019. Anticipating Smart Home Security and Privacy Threats with Survivors of Intimate Partner Abuse. In *Proceedings of the 2019 on Designing Interactive Systems Conference*. ACM, 527–539.
- [54] Karen Levy and Solon Barocas. 2017. Designing against discrimination in online markets. *Berkeley Tech. LJ* 32 (2017), 1183.
- [55] Ann Light. 2011. HCI as heterodoxy: Technologies of identity and the queering of interaction with computers. *Interacting with Computers* 23, 5 (2011), 430–438.
- [56] Wan-Ying Lin, Xinzhi Zhang, Hayeon Song, and Kikuko Omori. 2016. Health information seeking in the Web 2.0 age: Trust in social media, uncertainty reduction, and self-disclosure. *Computers in Human Behavior* 56 (2016), 289–294.
- [57] Leslie S Liu, Jina Huh, Tina Neogi, Kori Inkpen, and Wanda Pratt. 2013. Health vlogger-viewer interaction in chronic illness management. In *Proceedings of the SIGCHI conference on Human factors in computing systems*. ACM, 49–58.
- [58] Haley MacLeod, Ben Jelen, Annu Prabhakar, Lora Oehlberg, Katie Siek, and Kay Connelly. 2016. Asynchronous remote communities (arc) for researching distributed populations. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*. ICST (Institute for Computer Sciences, Social-Informatics and ...), 1–8.
- [59] Juan F Maestre, Elizabeth V Eikey, Mark Warner, Svetlana Yarosh, Jessica Pater, Maia Jacobs, Gabriela Marcu, and Patrick C Shih. 2018. Conducting Research with Stigmatized Populations: Practices, Challenges, and Lessons Learned. In *Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing*. ACM, 385–392.
- [60] Juan F Maestre, K Cassie Kresnye, Julia C Dunbar, Ciabhan L Connelly, Katie A Siek, and Patrick C Shih. 2020. Conducting HCI Research with People Living with HIV Remotely: Lessons Learned and Best Practices. In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–8.
- [61] Juan F Maestre, Haley MacLeod, Ciabhan L Connelly, Julia C Dunbar, Jordan Beck, Katie A Siek, and Patrick C Shih. 2018. Defining through expansion: conducting asynchronous remote communities (arc) research with stigmatized groups. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems*. ACM, 557.
- [62] Brenda Major and Laurie T O'Brien. 2005. The social psychology of stigma. *Annu. Rev. Psychol.* 56 (2005), 393–421.
- [63] Meethu Malu and Leah Findlater. 2016. Toward accessible health and fitness tracking for people with mobility impairments. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*. 170–177.
- [64] Gabriela Marcu, Robin Brewer, Karina Caro, Juan Fernando Maestre, Kay H Connelly, Christina N Harrington, and Jesus Favela. 2019. Strategies for Inclusion in the Design of Pervasive Computing for Health and Wellbeing. *IEEE Pervasive Computing* 18, 1 (2019), 89–93.
- [65] Gabriela Marcu, Nadia Dowshen, Shuvaditya Saha, Ressa Reneth Sarreal, and Nazanin Andalibi. 2016. TreatYoSelf: Empathy-driven behavioral intervention for marginalized youth living with HIV. In *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*. ICST, 69–76.
- [66] Michael Massimi, Jill P Dimond, and Christopher A Le Dantec. 2012. Finding a new normal: the role of technology in life disruptions. In *Proceedings of the acm 2012 conference on computer supported cooperative work*. ACM, 719–728.
- [67] Tara Matthews, Kathleen O'Leary, Anna Turner, Manya Sleeper, Jill Palzkill Woelfer, Martin Shelton, Cori Manthorne, Elizabeth F Churchill, and Sunny Consolvo. 2017. Stories from survivors: Privacy & security practices when coping with intimate partner abuse. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 2189–2201.
- [68] Katelyn YA McKenna, Amie S Green, and Pamela K Smith. 2001. Demarginalizing the sexual self. *Journal of Sex Research* 38, 4 (2001), 302–311.
- [69] Rebecca J Meisenbach. 2010. Stigma management communication: A theory and agenda for applied research on how individuals manage moments of stigmatized identity. *Journal of Applied Communication Research* 38, 3 (2010), 268–292.
- [70] Aehong Min, Flannery Currin, Gustavo Razo, Kay Connelly, and Patrick C. Shih. 2020. Can I Take a Break? Facilitating In-Home Respite Care for Family Caregivers of Older Adults. In *American Medical Informatics Association Annual Symposium Proceedings*.
- [71] Aehong Min, Flannery Currin, Gustavo Razo, Kay Connelly, and Patrick C. Shih. 2020. Can I Take a Break? Facilitating In-Home Respite Care for Family Caregivers of Older Adults. In *American Medical Informatics Association Annual Symposium Proceedings*.
- [72] Aehong Min, Daehyoung Lee, Gege Gao, Stella Jeong, and Patrick C. Shih. 2020. Design and assessment of a personal breathalyzer intervention to support responsible drinking. *International Journal of Human Computer Studies* 137 (may 2020), 102382. <https://doi.org/10.1016/j.ijhcs.2019.102382>
- [73] Phoenix KH Mo and Neil S Coulson. 2010. Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of 'lurkers' and 'posters'. *Computers in Human Behavior* 26, 5 (2010), 1183–1193.

- [74] Phoenix KH Mo and Neil S Coulson. 2013. Online support group use and psychological health for individuals living with HIV/AIDS. *Patient Education and Counseling* 93, 3 (2013), 426–432.
- [75] David Mohr, Pim Cuijpers, and Kenneth Lehman. 2011. Supportive accountability: a model for providing human support to enhance adherence to eHealth interventions. *Journal of medical Internet research* 13, 1 (2011), e30.
- [76] Larissa Vivian Nägele, Merja Ryöppy, and Danielle Wilde. 2018. PDFi: participatory design fiction with vulnerable users. In *Proceedings of the 10th Nordic Conference on Human-Computer Interaction*. ACM, 819–831.
- [77] Inbal Nahum-Shani, Shawna N. Smith, Bonnie J. Spring, Linda M. Collins, Katie Witkiewitz, Ambuj Tewari, and Susan A. Murphy. 2016. Just-in-Time Adaptive Interventions (JITAs) in Mobile Health: Key Components and Design Principles for Ongoing Health Behavior Support. *Annals of Behavioral Medicine* (Sept. 2016). <https://doi.org/10.1007/s12160-016-9830-8>
- [78] Nastad. [n.d.]. Addressing Stigma: A blueprint for improving HIV/STD prevention and care outcomes for Black and Latino Gay Men. <https://www.nastad.org>. Accessed: 2019-01-12.
- [79] Meena Natarajan and Tapan Parikh. [n.d.]. Understanding barriers to information access and disclosure for HIV+ women. ACM Press, 143–152. <https://doi.org/10.1145/2516604.2516627>
- [80] Renee Noortman, Britta F Schulte, Paul Marshall, Saskia Bakker, and Anna L Cox. 2019. HawkEye-Deploying a Design Fiction Probe. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 422.
- [81] Laura Nyblade, Anne Stangl, Ellen Weiss, and Kim Ashburn. 2009. Combating HIV stigma in health care settings: what works? *Journal of the international AIDS Society* 12, 1 (2009), 15.
- [82] Erick Oduor, Carolyn Pang, Charles Wachira, Rachel K. E. Bellamy, Timothy Nyota, Sekou L. Remy, Aisha Walcott-Bryant, Wycliffe Omwanda, and Julius Mbeya. [n.d.]. Exploring Rural Community Practices in HIV Management for the Design of Technology for Hypertensive Patients Living with HIV. ACM Press, 1595–1606. <https://doi.org/10.1145/3322276.3322348>
- [83] Leysia Palen and Paul Dourish. 2003. Unpacking "privacy" for a networked world. In *Proceedings of the SIGCHI conference on Human factors in computing systems*. 129–136.
- [84] Sungkyu Park, Inyeop Kim, Sang Won Lee, Jaehyun Yoo, Bumseok Jeong, and Meeyoung Cha. 2015. Manifestation of depression and loneliness on social networks: a case study of young adults on Facebook. In *Proceedings of the 18th ACM conference on computer supported cooperative work & social computing*. 557–570.
- [85] Jeremiah Parry-Hill, Patrick C Shih, Jennifer Mankoff, and Daniel Ashbrook. 2017. Understanding volunteer at fabricators: opportunities and challenges in diy-at for others in e-nable. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 6184–6194.
- [86] Jessica A Pater, Oliver L Haimson, Nazanin Andalibi, and Elizabeth D Mynatt. 2016. "Hunger Hurts but Starving Works": Characterizing the presentation of eating disorders online. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 1185–1200.
- [87] Jennifer L Peterson. 2009. "You have to be positive." Social support processes of an online support group for men living with HIV. *Communication Studies* 60, 5 (2009), 526–541.
- [88] Jennifer L Peterson. 2010. The challenges of seeking and receiving support for women living with HIV. *Health Communication* 25, 5 (2010), 470–479.
- [89] Cristian Pop-Eleches, Harsha Thirumurthy, James P Habyarimana, Joshua G Zivin, Markus P Goldstein, Damien De Walque, Leslie Mackeen, Jessica Haberer, Sylvester Kimaiyo, John Sidle, et al. 2011. Mobile phone technologies improve adherence to antiretroviral treatment in a resource-limited setting: a randomized controlled trial of text message reminders. *AIDS (London, England)* 25, 6 (2011), 825.
- [90] Rob Procter, Trisha Greenhalgh, Joe Wherton, Paul Sugarhood, Mark Rouncefield, and Sue Hinder. 2014. The day-to-day co-production of ageing in place. *Computer Supported Cooperative Work (CSCW)* 23, 3 (2014), 245–267.
- [91] Stephen A Rains. 2014. The implications of stigma and anonymity for self-disclosure in health blogs. *Health communication* 29, 1 (2014), 23–31.
- [92] Michael V Relf, Megan Williams, and Julie Barroso. 2015. Voices of women facing HIV-related stigma in the deep south. *Journal of psychosocial nursing and mental health services* (2015).
- [93] Yann Riche and Wendy Mackay. 2010. PeerCare: supporting awareness of rhythms and routines for better aging in place. *Computer Supported Cooperative Work (CSCW)* 19, 1 (2010), 73–104.
- [94] Michael W Ross. 2005. Typing, doing, and being: Sexuality and the Internet. *Journal of sex research* 42, 4 (2005), 342–352.
- [95] Sergio Rueda, Sanjana Mitra, Shiyi Chen, David Gogolishvili, Jason Globerman, Lori Chambers, Mike Wilson, Carmen H Logie, Qiyun Shi, Sara Morassaei, et al. 2016. Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses. *BMJ open* 6, 7 (2016), e011453.
- [96] Morgan Klaus Scheuerman, Stacy M Branham, and Foad Hamidi. 2018. Safe spaces and safe places: Unpacking technology-mediated experiences of safety and harm with transgender people. *Proceedings of the ACM on Human-Computer Interaction* 2, CSCW (2018), 1–27.

- [97] Ari Schlesinger, W Keith Edwards, and Rebecca E Grinter. 2017. Intersectional HCI: Engaging identity through gender, race, and class. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 5412–5427.
- [98] Stephen M Schueller and David C Mohr. 2015. Initial field trial of a coach-supported web-based depression treatment. In *Proceedings of the 9th International Conference on Pervasive Computing Technologies for Healthcare*. ICST (Institute for Computer Sciences, Social-Informatics and ...), 25–28.
- [99] Anita Shet, Karthika Arumugam, Rashmi Rodrigues, Nirmala Rajagopalan, K Shubha, Tony Raj, George D'souza, and Ayesha De Costa. 2010. Designing a mobile phone-based intervention to promote adherence to antiretroviral therapy in South India. *AIDS and Behavior* 14, 3 (2010), 716–720.
- [100] Karolynn Siegel, Howard Lune, and Ilan H Meyer. 1998. Stigma management among gay/bisexual men with HIV/AIDS. *Qualitative Sociology* 21, 1 (1998), 3–24.
- [101] Aneesha Singh, Jo Gibbs, Claudia Estcourt, Pam Sonnenberg, and Ann Blandford. 2017. Are HIV smartphone apps and online interventions fit for purpose?. In *Proceedings of the 2017 international conference on digital health*. 6–15.
- [102] Peter J Smit, Michael Brady, Michael Carter, Ricardo Fernandes, Lance Lamore, Michael Meulbroek, Michel Ohayon, Tom Platteau, Peter Rehberg, Jürgen K Rockstroh, et al. 2012. HIV-related stigma within communities of gay men: a literature review. *AIDS care* 24, 4 (2012), 405–412.
- [103] Piya Sorcar, Benjamin Strauber, Prashant Loyalka, Neha Kumar, and Shelley Goldman. 2017. Sidestepping the elephant in the classroom: Using culturally localized technology to teach around taboos. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. 2792–2804.
- [104] Jen Southern, Rebecca Ellis, Maria Angela Ferrario, Ruth McNally, Rod Dillon, Will Simm, and Jon Whittle. 2014. Imaginative labour and relationships of care: Co-designing prototypes with vulnerable communities. *Technological Forecasting and Social Change* 84 (2014), 131–142.
- [105] Katta Spiel, Os Keyes, Ashley Marie Walker, Michael A DeVito, Jeremy Birnholtz, Emeline Brulé, Ann Light, Pınar Barlas, Jean Hardy, Alex Ahmed, et al. 2019. Queer (ing) HCI: Moving forward in theory and practice. In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*. 1–4.
- [106] Mary M Step, Jennifer McMillen Smith, Joshua Kratz, Julia Briggs, and Ann Avery. 2020. "Positive Peers": Function and Content Development of a Mobile App for Engaging and Retaining Young Adults in HIV Care. *JMIR formative research* 4, 1 (2020), e13495.
- [107] Angelika Strohmayer, Jenn Clamen, and Mary Laing. 2019. Technologies for Social Justice: Lessons from Sex Workers on the Front Lines (*CHI '19*). ACM, New York, NY, USA, Article 652, 14 pages. <https://doi.org/10.1145/3290605.3300882>
- [108] Angelika Strohmayer, Mary Laing, and Rob Comber. 2017. Technologies and social justice outcomes in sex work charities: Fighting stigma, saving lives. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*. ACM, 3352–3364.
- [109] Austin Toombs, Laura Devendorf, Patrick Shih, Elizabeth Kaziunas, David Nemer, Helena Mentis, and Laura Forlano. 2018. Sociotechnical Systems of Care. In *Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing*. 479–485.
- [110] Bulent Turan, Henna Budhwani, Pariya L Fazeli, Wesley R Browning, James L Raper, Michael J Mugavero, and Janet M Turan. 2017. How does stigma affect people living with HIV? The mediating roles of internalized and anticipated HIV stigma in the effects of perceived community stigma on health and psychosocial outcomes. *AIDS and Behavior* 21, 1 (2017), 283–291.
- [111] UNAIDS. 2019. Terminology Guidelines. [https://www.unaids.org/en/resources/documents/2015/2015\\_terminology\\_guidelines](https://www.unaids.org/en/resources/documents/2015/2015_terminology_guidelines). Accessed: 2019-08-15.
- [112] KRV Vaes, Pieter Jan Stappers, Achiel Standaert, and Kristine Desager. 2012. Contending stigma in product design: using insights from social psychology as a stepping stone for design strategies. In *Out of Control; Proceedings of the 8th International Conference on Design and Emotion, London, Great Britain, 11-14 Sept. 2012*. Central Saint Martins College of Arts and Design.
- [113] Chad Van De Wiele and Stephanie Tom Tong. 2014. Breaking boundaries: The uses & gratifications of Grindr. In *Proceedings of the 2014 ACM international joint conference on pervasive and ubiquitous computing*. 619–630.
- [114] Tiffany Veinot. 2009. "A lot of people didn't have a chance to support us because we never told them" Stigma management, information poverty and HIV/AIDS information/help networks. *Proceedings of the American Society for Information Science and Technology* 46, 1 (2009), 1–20.
- [115] Tiffany C Veinot. 2010. We have a lot of information to share with each other": Understanding the value of peer-based health information exchange. *Information Research* 15, 4 (2010), 15–4.
- [116] Tiffany C Veinot and Roma Harris. 2011. Talking about, knowing about HIV/AIDS in Canada: A rural-urban comparison. *The Journal of Rural Health* 27, 3 (2011), 310–318.
- [117] Jessica Vitak and Jinyoung Kim. 2014. "You can't block people offline" examining how facebook's affordances shape the disclosure process. In *Proceedings of the 17th ACM conference on Computer supported cooperative work & social computing*. 461–474.

- [118] Ashley Marie Walker and Michael A DeVito. 2020. "More gay'fits in better": Intracommunity Power Dynamics and Harms in Online LGBTQ+ Spaces. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–15.
- [119] Mark Warner, Andreas Gutmann, M Angela Sasse, and Ann Blandford. 2018. Privacy Unraveling Around Explicit HIV Status Disclosure Fields in the Online Geosocial Hookup App Grindr. *Proceedings of the ACM on Human-Computer Interaction 2*, CSCW (2018), 1–22.
- [120] Mark Warner, Agnieszka Kitkowska, Jo Gibbs, Juan F Maestre, and Ann Blandford. 2020. Evaluating'Prefer not to say'Around Sensitive Disclosures. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems*. 1–13.
- [121] Mark Warner, Juan F Maestre, Jo Gibbs, Chia-Fang Chung, and Ann Blandford. 2019. Signal Appropriation of Explicit HIV Status Disclosure Fields in Sex-Social Apps used by Gay and Bisexual Men. In *Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems*. ACM, 692.
- [122] Jill Palzkill Woelfer and David G Hendry. 2012. Homeless young people on social network sites. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. 2825–2834.
- [123] Jill Palzkill Woelfer, Amy Iverson, David G Hendry, Batya Friedman, and Brian T Gill. 2011. Improving the safety of homeless young people with mobile phones: Values, form and function. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 1707–1716.