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eHealth for Stigma Reduction Efforts Designed to Improve Engagement in Care for People Living with HIV

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Abstract

Purpose of review: HIV-related stigma remains a significant barrier to engagement in care for persons living with HIV (PLWH) worldwide. This review examines the use of eHealth technologies for reducing stigma as a pathway toward improved engagement in care for PLWH. We provide a brief overview of effective stigma reduction interventions for PLWH, both eHealth and others, identify gaps in the research on use of eHealth technologies for stigma reduction, and suggest potential research avenues moving forward.

Recent findings: The majority of HIV-related eHealth studies use technology to improve ART adherence. To date, few HIV-related eHealth studies have included any measurement of stigma.

Summary: Given the current narrow evidence base, further research is needed to determine whether eHealth technologies can help to reduce stigma and improve engagement in care for PLWH.

Keywords

HIV; stigma; eHealth; technology; HIV treatment engagement; intervention

Introduction

Considering the Joint United Nations Programme on HIV/AIDS ‘90-90-90’ treatment targets for people living with HIV (PLWH) [1], behavioral interventions for HIV are now directly focusing on engagement in care outcomes. This three-part target strategy states that by 2020:

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Compliance with Ethics Guidelines

Conflict of Interest

The authors declare that they have no competing interests.

Human and Animal Rights and Informed Consent

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90% of PLWH will know their status; 90% of those diagnosed will receive sustained antiretroviral therapy (ART); 90% of those receiving ART will reach viral suppression. Internalized stigma, or the degree to which PLWH endorse negative beliefs associated with HIV about themselves [2], continues to significantly impede optimal engagement in HIV care worldwide [3, 4]. Specifically, internalized stigma, as opposed to stigmas that operate in the public sphere, has a direct impact on individual's adherence behaviors [5]. Thus, HIV-related stigma reduction may positively impact the 90-90-90 targets. Accordingly, the HIV research field is shifting from examining stigma as a primary intervention outcome to exploring stigma reduction as a pathway toward improved engagement in care for PLWH [6].

Electronic health (eHealth) technologies, which comprise wide-ranging information and communication resources including text messaging, email, and internet-based tools such as videos, games, chat rooms, and social media [7], represent a novel and exciting platform for enhancing social connectedness. Thus, they are uniquely positioned to aid in delivery of stigma reduction interventions for improving care engagement in PLWH. Additionally, eHealth technologies may provide ideal resources for measuring stigmatizing attitudes in both research and clinical practice. Researchers have recently developed methods of measuring implicit and explicit stigma using validated instruments on electronic devices [8, 9], a tremendous milestone for studies conducted entirely through mobile technologies.

The potential benefits of eHealth interventions are manifold: not only do they align with the global public health agenda by generating access to evidence-based treatment for large numbers of individuals at potentially low costs [10], but they also address distance- and transportation-related barriers to treatment engagement by providing the opportunity to seek and receive care from the comfort of home. With PLWH in particular, eHealth can also confer benefits of protection via anonymity in settings with high levels of stigma against PLWH [11].

The purpose of this review is to examine the utility of using eHealth technologies to reduce stigma as a pathway towards improved engagement in care for PLWH. We provide a brief review the literature base on effective stigma reduction interventions for PLWH (delivered through both eHealth and non-eHealth approaches), identify current gaps in the research on use of eHealth technologies for stigma reduction, and suggest ways forward to strengthen this nascent yet important line of research as we continue to move towards the 90-90-90 targets.

Non-eHealth Approaches to Reduce HIV-Related Stigma: What Works?

In one existing review of traditionally delivered (i.e., non-electronic) HIV-related stigma reduction interventions, Brown, Macintyre, and Trujillo [12] identified 22 stigma reduction programs delivered in both high-income and low- and middle-income country (LMIC) settings. Four intervention categories for reducing HIV-related stigma — both in the public sphere among community members and internally for PLWH themselves — were identified: (1) *educational or information-based* strategies; (2) *contact* with affected persons; (3) *counseling* approaches; and (4) training in *coping skills* [12]. Interventions that target

education are among the most frequently implemented, and are generally designed to counter misinformation about PLWH by providing up-to-date knowledge on the biology of HIV/AIDS, modes of disease transmission, and methods for risk reduction. Education can be used with community members, to counter public stigma, as well as with PLWH themselves, to reduce internalized stigma. *Contact*-based interventions include direct (e.g., guided face-to-face discussions, shared social activities) and/or indirect (e.g., case vignettes, live or recorded testimonials from PLWH) social contact between community members and PLWH. Contact supports the reduction of stigma on bi-directionally, potentially reducing internalized stigma for PLWH and public stigma among community members. Increasing evidence supports use of contact-based interventions in improving attitudes and reducing stigma more broadly [13–15]. Corrigan, a leading anti-stigma researcher, identified contact as a key best practice of ‘Strategic Stigma Change’ [16] and theorized that development of personal relationships between community members and PLWH is a necessary means of dispelling misinformation, generating empathy, and humanizing HIV. The third and fourth strategies are used specifically to reduce internalized stigma carried by PLWH. *Counseling* approaches provide structure and support for attitudinal and behavioral change, while *coping skills* interventions help PLWH navigate stigmatizing situations individually or in groups by teaching behavioral techniques such as conflict diffusion, guided relaxation, and desensitization.

The Brown and colleagues review suggested that more research was necessary to determine the effectiveness of these approaches [12]. For instance, several studies that incorporated education-based interventions reported reductions in public stigmatizing attitudes and behaviors at follow-up. However, consistent with Corrigan’s suggestions [16], these changes trended in a superficial direction, with little-to-no change in deeper-seated fears regarding HIV or in attitudes over time. Contact-based interventions emerged as one of the more promising strategies, though only when combined with one or more additional intervention components.

In our own work to develop, test and evaluate an in person, group-based program to reduce internalized stigma in African American women living with HIV in the United States (US) (the UNITY workshop), we also noted the benefit of including additional methods such *active learning* and *modeling*, and perhaps most importantly, a focus on enhancing *social support* [17–20]. Our studies with the UNITY workshop have shown that social support and contact were key components of reducing stigma among African American women living with HIV, and most significantly, stigma reduction and increased social support were closely tied to decreases in HIV viral load.

Revisiting the evidence behind stigma’s potential impact on the 90-90-90 targets, several researchers have found specific associations between HIV-related stigma and antiretroviral therapy (ART) adherence. Katz and colleagues (2013) conducted a review of 23 studies that examined the association between stigma and adherence (on intrapersonal, interpersonal, and structural levels), and found that 75% of 20 cross-sectional studies demonstrated an association between stigma reduction and ART adherence. However, only three studies from the review examined associations between stigma reduction and adherence longitudinally,

two of which showed null findings. Thus, the authors refrained from drawing conclusions from the few available studies [21].

While several non-intervention studies have documented associations between stigma and engagement in care for PLWH [22–25], only one intervention study in Senegal evaluated the impact of a community- and health facility-level program for reducing enacted and perceived stigma and increasing engagement in HIV care services [26]. Stigma was measured in the context of service delivery for key populations at-risk for or currently living with HIV (Men who have Sex with Men (MSM) and Female Sex Workers (FSW)). The authors found a reduction in stigma, but did not examine its association with engagement in care. They also reported a 41% loss to follow up among MSM and 10% among FSW.

eHealth Technologies to Reduce HIV-Related Stigma

Given the benefit that SMS messaging and online chat rooms have for anonymous social support [27], different eHealth modalities have potential for targeting each of the mechanisms described above (education, contact, counseling and coping skills) to reduce HIV-related stigma for PLWH. In the general population, both computer- and web-based intervention packages have demonstrated effectiveness when used to provide psychoeducation and cognitive behavioral therapies to reduce emotional distress [28, 29]. In the HIV treatment and prevention field, the majority of published eHealth behavioral studies have used these technologies to promote ART adherence [30]. Few eHealth studies, however, have directly included measurement of stigma, either as primary or secondary outcome or as mediator. In one study in India, a brief (3-session), tablet-based intervention for reducing HIV stigma among healthcare staff is currently being evaluated, with the ultimate goal of improving the quality of providers' attitudes toward and treatment of PLWH [31]. The intervention combines educational content related to HIV stigma with contact, which is achieved via video vignettes depicting stigmatizing interactions between PLWH and healthcare staff. The intervention uses a video walkthrough of a healthcare facility and asks participants to identify locations within the healthcare setting where stigmatizing interactions might occur. Vignette cast members included actors, study staff, and three people openly living with HIV. Ultimately, participants obtain navigational assistance as well as contact via ehealth modalities.

In our own work on development of a behavioral stigma reduction intervention (The Positive Living Program) among African-immigrant PLWH in the US, we found that a tablet-based program was useful in reducing internalized stigma scores ($p = 0.2$) and depressive symptoms ($p < 0.01$) between intervention and 1-week follow up in a pilot feasibility study of 25 African immigrants [32]. The Positive Living Program intervention was based on an eHealth ART adherence program called Turning to Sunshine developed by Simoni and colleagues for use in China [33], as well as the UNITY workshop (as described above, UNITY uses an in person, group format) [17, 19]. The Positive Living Program presents elements of behavioral activation, problem solving, and other basic cognitive behavioral techniques in an online format. Videos from the UNITY workshop are incorporated into the Positive Living Program, which we developed to be delivered completely online. An online

physician helps the participant navigate the exercises, and an in person, health care worker assists the patient with any technical issues or program questions.

Outside of this work, investigators interested in developing feasible and effective eHealth interventions for improving medication adherence among PLWH have primarily explored questions regarding the feasibility of using technology for stigma reduction. In a qualitative study of transgender women and MSM in Thailand, researchers found that participants universally endorsed the idea of developing local eHealth resources to address internalized stigma related to HIV and improve public perceptions about HIV [34]. In another qualitative study, researchers identified desired content and features of a mobile app aimed at improving the healthcare needs of English and Spanish-speaking PLWH residing in the US [35]. While the purpose of these studies was gathering general information on HIV treatment, participants indicated that eHealth could be a useful avenue for enhancing social support, including chat forums, testimonials of lived experiences, and follow-up with personal outreach. Notably, a recent study found that PLWH from underserved populations in the US were willing to use smartphones for research [36], but found an inverse relationship between smartphone use and age, HIV stigma, social isolation, and other predictor variables.

More recent studies of eHealth interventions to promote ART adherence have begun to include measures of stigma. For example, the ongoing Mobile phone-based Approach for Health Improvement, Literacy and Adherence (MAHILA) trial study [37] is assessing the feasibility, acceptability, and preliminary efficacy of an eHealth intervention for enhancing self-care and ART adherence among HIV-infected women in India. In this study, investigators have included internalized stigma as a secondary outcome for analysis. Interestingly, in a recent Australian study of text messaging to improve HIV medication adherence, investigators did not find that text messaging was associated with ART adherence, but instead found that lower perceived stigma in PLWH was associated with increased adherence [38].

Conclusion

Given the exceedingly small evidence base on the effectiveness of eHealth interventions to reduce internalized stigma for PLWH, it is yet to be determined whether eHealth technologies can be effectively employed to improve engagement in care for this population. Relatedly, a salient theoretical and empirical question also remains: Can we effectively distill the essential mechanism of contact into electronic platforms for the purpose of reducing internalized stigma? On one hand, the speed, anonymity, availability, low cost, and convenience of eHealth technology indicate great theoretical promise for reducing stigma and helping PLWH engage in care. Yet, on the other hand, researchers have been asserting for years that, as we increase our reliance on technology for interpersonal connection in both personal and professional spheres, our dependence on this technology also fosters increased feelings of loneliness and isolation [39, 40]. It is possible that eHealth technologies may only create the illusion of interpersonal connectedness and support, while effectively diminishing critical opportunities for in-person, face-to-face interactions. In-person interactions provide key contexts for experiences of empathy through physical proximity and closeness, as well as generation and interpretation of facial expressions and body language,

which may serve as core mechanisms for stigma reduction. Furthermore, we must also acknowledge that technology can do little for people who experience severe stigma to the point of social isolation not only in physical domains, but also in the electronic world.

Despite the limitations inherent in use of eHealth technologies, their utility and potential benefits for stigma reduction and engagement in care for PLWH remain worthy of investigation. In thinking toward future research directions, several avenues for exploration emerge. First, future research studies would clearly benefit from an examination of eHealth for HIV-related stigma reduction and engagement in care, varying in-person and online treatment arms or using dismantling approaches to identify which aspects of interventions are helpful. Use of dismantling approaches (e.g., component analyses, single-case experimental designs) may be especially impactful, given our limited current knowledge of the active ingredients or core mechanisms underlying effective stigma reduction interventions both within and outside of the context of HIV [12]. Post-hoc qualitative methods may be an additional means of gathering participant feedback on the putative active ingredients of these interventions.

Second, future studies should contrast outcomes in varying populations to understand when, where, and for whom eHealth technologies can be of benefit for HIV-related stigma reduction. For example, it may be the case the eHealth technologies can entice isolated, social media users to leave their homes and engage in person social support, where stigma reduction may be most impactful. Carefully designed studies will be critical to learn the power and limitations of eHealth interventions for stigma reduction.

Third, though eHealth technologies may function as self-help resources for stigmatized PLWH, their utility for non-specialist or lay providers with limited-to-no prior experience in delivery of health services should also be examined. Smartphones and tablets, for instance, are highly portable, user-friendly devices that that may be accessed by lay healthcare providers who wish to regularly or intermittently reference digitally available intervention guides while providing clinical services in the field. Strategic use of these technologies by lay providers may have notable global health impact, given that 90% of the HIV burden exists in LMICs with chronic shortages of trained health workers [12].

Fourth, questions of intervention dosage also remain: online or smartphone-based interventions alone may be sufficient for some PLWH with internalized stigma. However, for others with higher needs, such interventions may serve as an entry point for future face-to-face interventions. This latter use of technology would be much like the stepped-care model of treatment used in Sweden with online Cognitive Behavioral Therapy [29], where patients participate in online treatment while waiting to receive in-person care from a psychotherapist. Those who find their emotional distress reduced after participation are instructed to remove themselves from the waitlist, while non-improvers remain in queue for in-person treatment.

In light of ongoing advances in biomedical and behavioral HIV prevention and treatment, the global community is beginning to fathom an HIV/AIDS-free generation for the first time in nearly thirty years. It is our hope that, within the next decade, novel intervention research

at the intersection of HIV, stigma reduction, and eHealth will allow us to continue narrowing the treatment gap in PLWH worldwide.

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** Note: Turkle, a leading psychologist directing current discourse on technology, provides a critical reflection on the intersections of technology, identity, and human empathy in her latest book.