Digital Technologies and HIV Prevention and Care

Introduction

Digital technologies have had a transformative effect on every aspect of our lives, and the way that we access health information and health care is no exception. In particular, these tools offer exciting opportunities for HIV service providers to increase their own knowledge base, reach out to underserved members of the community, collaborate with colleagues, and help connect their clients with both HIV and STD testing and other prevention and care interventions.

Just last month, a small Rwandan trial reported that a $34 smartphone attachment appeared to quickly and accurately detect HIV and syphilis antibodies. While most digital innovations are not so dramatic, digital technologies are becoming an increasingly important part of the HIV prevention and care toolbox. This issue of Perspectives will examine some of the advantages and challenges of using these technologies, and review the growing field of research studies on their effectiveness.

A Variety of Tools

Most HIV prevention and care digital technologies are part of what is called “new media,” a collection of interactive digital platforms (such as Facebook, Twitter, and other social networking sites, texting, webinars, and wikis). New media offer myriad tools for connection, collaboration, and message delivery. But it’s important to pick the right tools for the audience you want to reach and the effect that you want to have. To help HIV service providers communicate effectively using new media, the website aids.gov offers an overview of these technologies in their section entitled “New Media Tools,” accessible here.

Research on Digital Technologies

New media represents a large collection of different, but often intersecting, technologies. This makes it challenging to evaluate the impact of new media as a whole on outcomes like sexual and injection-related behavior change. In the few review articles that have been published on the impact of new media on HIV prevention and care, authors have noted not only its enormous promise, but also the difficulty of comparing various types of new media such as texting vs. digital storytelling, across different intervention purposes such as increasing knowledge, improving medication adherence, or reducing behaviors that could transmit HIV.

A 2014 Columbia University review of eHealth (electronic health) interventions for HIV prevention in men who have sex with men (MSM) found a wide variety in both the type of interventions used, which made it impossible to group them together for analysis as a group, and in the quality of the articles that described these interventions. For example, some studies did not clearly describe...
the intervention, and some did not account for other factors besides the intervention that could have caused the outcome. The review’s authors conclude that digital HIV interventions (particularly those relating to prevention with HIV-negative people) are greatly under-researched. As researchers from the University of Minnesota who conducted the Men’s INTerNet Sex Studies (MINTS I and II, discussed below) put it, “While Internet studies are easy to conduct, they remain challenging to conduct rigorously and well.”

Although the evidence base of the field is new, and many studies are small, pilot studies that are designed to test feasibility rather than the efficacy, hopeful signs are emerging. The following studies, grouped by type of digital technology intervention, offer a sampling of the benefits and drawbacks of these approaches.

### Web-Based Videos and Interactive Educational Sites

Results of the Men’s Internet Sex Study (MINTS-II), published in 2010, suggested that “persuasive computing programs” can be an effective approach for delivering HIV prevention messages to men who have sex with men. The researchers randomized 650 MSM participants either to an online, interactive risk reduction intervention, or to a control group with no intervention. The intervention itself was multifaceted. Participants used a “hot sex” calculator related to decision making in dating; a virtual gym where they could explore body image concerns; an online chat simulation; and a reflective journey, among others. At the three-month follow-up, men in the intervention group reported a 16 percent greater reduction in unprotected anal sex than those in the control group (which also reduced its incidence of unprotected anal sex). There were no significant differences in behavior at the 12-month follow-up, suggesting that the effects of the intervention are time-limited.

A U.S. online randomized controlled trial (RCT) published in 2012 by Hirshfield and colleagues used a sampling frame of more than 600,000 MSM by recruiting through banner ads and emails from four MSM-oriented sexual networking sites. More than 3,000 eligible participants (of varying HIV statuses) were recruited, but only 53 percent (1,631) were retained throughout the intervention. There were five arms to the study: one group got no intervention (control); one got a prevention webpage, and three others were exposed to dramatic and documentary videos related to HIV risk, HIV testing, HIV status disclosure, and condom use. The three video arms (dramatic video, documentary video, both dramatic and documentary video) were pooled together for analysis because of the reduced size of each group by the study’s conclusion. Men in the pooled video group were significantly more likely to report that they had disclosed their HIV status to their last sexual partner than men in the control or webpage conditions. Both HIV-negative and HIV-positive men reported significant reductions in unprotected anal sex in both the pooled video and webpage conditions, as compared with controls. And, the authors report, “the most striking finding for HIV-positive men in the video condition was their significant reduction in unprotected anal intercourse (UAI) with HIV-negative or unknown status partners at follow-up compared to baseline. . . . It appears that this low intensity digital media intervention [five- and nine-minute videos] may have resonated most with sexually active HIV-positive MSM, who may not be reached by traditional offline prevention messages.”

### Texting Interventions

The Hookup is a California sexual health text messaging service for young people of varying sexual orientations between the ages of 13 and 24 years old. It is part of Teensource, a youth-focused sexual health website, and its objective is connecting young people with sexual and reproductive health information and services.

According to a 2014 evaluation study, the site had 2,477 weekly subscribers, who receive weekly sexual health tips, and can obtain local clinic referrals for youth-friendly free and low-cost HIV and other STD testing and reproductive health services. Subscribers are also linked to teensource.org.

A text-based survey of those subscribers yielded 832 respondents (34 percent), with 482 respondents (58 percent of all subscribers) completing the entire four-question survey (respondents were lost at each additional question after the first). Surveyors learned that 92 percent of respondents were girls, 8 percent boys, and that they were indeed reaching the target age and location range. Ninety percent of respondents stated that they had made some behavior change since they had joined the Hookup, including using condoms (33 percent) and getting tested for HIV and other STDs (15 percent). The authors note
that evaluation of the program was complicated by the loss of respondents with each survey question, as well as the program’s rule against using subscribers’ cell phone numbers for anything but text messaging.6

A large Australian sexual health clinic published results of its short messaging service (SMS) HIV/STD testing reminder program for HIV-negative MSM in 2011. Researchers found that members of the group receiving text reminders to retest were 4.4 times as likely as those in the comparison group who did not receive such reminders. Only 30 percent of the 1,084 men in the group that was reminded to retest were 4.4 times as likely as those in the comparison group who did not receive such reminders. Only 30 percent of the 1,084 men in the comparison group received HIV/STI retesting within a nine-month period, as compared to 64 percent of the 714 men in the group that was reminded to retest.7

A University of California, Los Angeles pilot study of 50 methamphetamine-using MSM found that using text messages over a two-week period allowed them to deliver real-time social support and health education messages to clients who might have been difficult to reach for face-to-face interventions.8 The study, published in 2012, included HIV-positive and HIV-negative participants who had both used methamphetamine and had unprotected anal sex with a non-primary partner in the previous two months, and who were not receiving substance abuse treatment. Researchers sent out both pre-written and extemporaneous text messages, and all were customized to the participant’s profile (for example, his HIV status, whether he met sexual partners online, and whether he used commercial sex venues).

At the baseline of the intervention, the greatest number of participants (43 percent) reported using methamphetamine “two to three times per week,” and at the two-month follow-up point, the greatest number (36 percent) reported using “two to three times per month.” In addition, 49 percent of participants reported that they had stopped using methamphetamine altogether by the two-month follow-up, as compared with 13 percent at baseline. Only 8 percent of participants reported injecting methamphetamine at follow-up, as compared to 21 percent at baseline. Regarding sexual behavior, participants reported unprotected anal sex with significantly fewer HIV-positive non-primary partners, and significantly less incidence of unprotected receptive anal sex with HIV-positive partners. They also reported significantly fewer HIV-negative unprotected anal sex partners, and fewer HIV-negative partners with whom they had UAI while using methamphetamine. Although the study was small, its retention rates were high, with 48 out of 50 participants (96 percent) completing the intervention and follow-up.

A 2013 systematic review of mHealth (mobile health) intervention studies by Catalani and colleagues found that among text messaging interventions for HIV prevention and care, those used to improve antiretroviral therapy adherence with HIV-positive people had the strongest evidence base, especially in areas with few resources.9 They note in particular a Kenyan study by Pop-Eleches and colleagues, published in 2011, which randomized 431 adults living with HIV into five conditions: control (no texts); short daily texts; short weekly texts; long daily texts; and long weekly texts.10 The researchers found that 16 percent more of participants in the weekly reminders group were adherent to their antiretroviral medications (defined as taking 90 percent or more of the prescribed doses) than those who had not received reminders. Participants receiving weekly texts were also significantly less likely to have a “treatment interruption,” defined as going more than 48 hours without a dose of medication.10

The Kenyan study authors note that daily reminders did not improve adherence more than no reminders, perhaps because they were considered intrusive. Although the longer texts included “words of encouragement,” these were not more effective than shorter texts. Such findings are echoed in a 2014 meta-analysis of randomized controlled trials to promote HIV medication adherence by Finitsis and colleagues, who note that the most successful antiretroviral adherence reminder programs appear to use less-than-daily messaging; encouraged two-way communication; and included personalized message content.11

**Partner Notification with E-Cards and Email**

Traditionally, partner notification services for sexually transmitted diseases were only done in person, or by telephone or mail. An individual would be diagnosed with HIV or another STD, and had the option of either telling sexual or needle-sharing partners themselves, or enlisting the help of a provider, who would use a public health investigator to make the notification, so that the partner can be tested and treated if necessary. In 2004, the San Francisco Department
of Public Health and the Internet Sexuality Information Service (ISIS Inc.) conducted a needs assessment around partner notification with MSM in San Francisco. They found that most men surveyed stated that they made sure that primary partners were notified, either by telling them themselves, or by using a public health investigator to let them know. However, they often did not inform casual sexual partners, and welcomed the idea of a simple and anonymous way to contact casual partners to let them know of their potential exposure.

In response, ISIS Inc. developed inSPOT.org as a peer-to-peer, web-based system of partner notification, which has the advantage of allowing people to contact partners whom they might only know by email. In 2006, the target customer audience for inSPOT was expanded to include people of different genders and sexual orientations. Data from a survey published in 2011 suggests that e-cards for partner notification may be less attractive to certain populations (such as heterosexuals in a large STD clinic in Colorado) than to other populations.

Although it has been around for more than 10 years, and has been replicated nationally and internationally, there have been few recent studies of the effectiveness of inSPOT—particularly with regard to HIV notifications. A 2008 article by Levine and colleagues reported that in 2006 and 2007, more than 23,000 e-cards were sent, including more than 2,200 for HIV (or 9 percent). But there are no data on what proportion of inSPOT’s users actually access HIV/STD testing because they received an e-card, or how many were ultimately diagnosed and treated. The very anonymity and access that make inSPOT an attractive option also make it difficult to assess as an effective intervention.

Rather than tracking what happens to inSPOT users and their partners directly to assess effectiveness, studies usually set up hypothetical situations to ask participants what they think they would do if they were diagnosed with an STD. A 2013 Seattle STD clinic study asked a convenience sample of 185 MSM about their preferred methods for partner notification, and how they might react if they were notified themselves. When asked how they would like to notify partners of an STD (and could choose multiple options), 62 percent said by phone, 33 percent said in person, 45 percent said by email, 33 percent said by e-card, and 33 percent said by text. Forty-five percent of men said that having the option of using e-cards would make it more likely that they would inform a sexual partner of an STD. However, fewer men said that they would likely seek treatment for an STD if they were informed by e-card (62 percent) than if informed by a sexual partner directly (86 percent).

What Advantages Does Digital Technology Offer?

Digital technologies offer some tremendous advantages over traditional means of finding audiences of people living with and at risk for HIV, connecting with them, delivering information, interventions, and other services to them, and ultimately tracking where resources continue to be most needed.

We’ve Got the Technology, and We Use It. The “digital divide” is shrinking. According to the Pew Research Center, as of January 2014, 87 percent of U.S. adults reported using the internet, 90 percent owned a cell phone, and 58 percent owned a smartphone. In 2013, 73 percent of adults, and 80 percent of adolescents use some form of social
media. Black Americans (62 percent) are less likely than White Americans (74 percent) to have broadband service at home, but are just as likely to have a smartphone.

Cost-Effectiveness. The tremendous rise in use of digital technology for HIV prevention and care comes at a time when both public health departments and community-based organizations face shrinking budgets, and as the health care industry continues to search for more cost-effective methods of service delivery. Some client interventions, which had previously been delivered exclusively face-to-face, are now delivered partially or completely through digital technology. In addition, some of the professional development for HIV test counselors and other service providers is achieved through webinars and podcasts, reducing the need for costly travel.

Rapid, Uniform (or Not) Dissemination of Information. Another advantage of both professional training tools and client interventions delivered through digital media is that some or all of the digital aspects (for example, streaming video) can be accessed quickly and replicated exactly, allowing for a uniformity of messaging to a statewide, national, or international audience. Conversely, some digital interventions can be more easily tailored to specific audiences, or to individuals, based on their responses.

Already Associated with Health and Sex. Many Americans already associate using the internet with taking care of their health, and with their sexual lives. In 2013, the Journal of the American Medical Association reported that 35 percent of Americans have used the internet to diagnose their own or someone else’s health concerns. Among Americans who use the internet, 72 percent said they had looked online for health information within the past year. Fifty-nine percent of Americans say that online dating is a good way to meet romantic partners, and smartphone geolocation apps such as Grindr, Scruff, Manhunt, and GROWLr are an important way that MSM, in particular, find both romantic and casual sexual partners. Digital interventions, can help engage large numbers of people, and may be especially helpful in engaging populations traditionally considered “hard to reach.” Gay, lesbian, bisexual, and transgender people are more likely to use social media and read blogs than their non-LGBT counterparts. LGBT youth use the internet to search out sexual health information, in part to avoid the stigma they feel when asking providers. Among internet users, Latino Americans are just as likely as White Americans and Black Americans to say they use social networking such as Facebook. Social media preferences, however, differ by race, ethnicity, and age, with 40 percent of Black American internet users aged 18 to 29 years old using Twitter (compared to 28 percent of White American young people). And young Americans, ages 12 to 29 years old use internet technology and social media the most. This suggests that digital interventions may be a natural way to deliver HIV prevention and care interventions to the groups most disproportionately burdened by HIV: young Black and Latino men who have sex with men.

Perception of Privacy. One reason that “hard-to-reach” populations may find digital interventions more appealing is that they can access them privately, without others being aware that they are doing so. People who have been stigmatized due to their identities as sexual minorities or people of color, and people who have experienced judgments from providers and others regarding sexual, drug-using, or other behaviors may be more comfortable disclosing their experiences honestly when they can do so without revealing personally identifying information.

Portability. Many people are never far from their mobile devices, so staying in touch with study participants, or text messaging a medication reminder can be done in a variety of settings, throughout the day.

What Challenges Remain?

New digital interventions bring with them not only the promise of greater access and engagement with target audiences but also new challenges. Additional research is needed to determine how to address many of these concerns:

Literacy. Most digital interventions require that participants read, although there are some computer-based interventions that read text to their audiences.

Confidentiality. There are a number of ways that confidentiality can be breached in the virtual world, just as in the physical one. Users of chat rooms or social media may not realize that many spaces are not set up to be secure or confidential. Someone besides the intended recipient of a message might see confidential information visible in an email or text. Agencies should always be sure that they are in compliance
with state and federal regulations related to the confidentiality of private health information, and should describe any limitations on such privacy clearly to their clients.

Unintended Consequences. When an internet intervention is set up, it is not always used the way the designers intended. Participants might use chat rooms or social media sites to sell sex or drugs. Or they might simply misunderstand the health information on the site and fail to protect themselves based on that misunderstanding.

Cost to Participants and Providers. Although many people now have mobile devices, the plans associated with them can be expensive, and people often switch to new mobile devices. Providers and researchers may have to give participants specific devices and data plans in order to engage them in interventions and retain them to follow-up.19

The start-up costs of developing web-based interventions can also be high, in terms of equipment, technology, and salary, and training costs for staff, and staff may be required to monitor pieces of the intervention, such as chat rooms or social media, to prevent unintended uses.19

Understanding Where Human Providers Fit In. Most HIV prevention and care interventions have been developed to be delivered by people. Increasingly, a combination of human and digital interaction together are used to teach, share stories, build skills, and collect information. But we may not know yet which components of an intervention are best delivered by a person, and which can best be delivered digitally.19

What Counselors Can Do

Here are a few of the many ways that HIV test counselors can maximize their use of digital technologies to benefit themselves and their clients:

Get the facts. The Centers for Disease Control and Prevention’s (CDC) HIV/AIDS website, http://www.cdc.gov/hiv/, is a great resource for everything from basic HIV information to the latest on types of HIV tests, and how HIV/AIDS is affecting different U.S. subpopulations.

Map your local epidemic. Know where (and which) people are most affected by HIV in your state and community. AIDSVu.org is an interactive online map that shows the national, state, and local prevalence of HIV in the United States. You can also examine the resources for HIV testing and care in a community, along with demographic factors, like race, ethnicity, sex, and age of people living with HIV, as well as social determinants of health, like income and educational levels.

Learn what works. You can find out about evidence-based interventions that are being used to prevent HIV infection and to optimize the health of people living with HIV by going to https://www.effectiveinterventions.org/. This is the CDC’s High Impact HIV Prevention website, devoted to interventions that have a strong demonstrated evidence base for their effectiveness. Many of these interventions themselves use a mix of human expertise and digital technology. You can also find out about opportunities for obtaining capacity-building services to help your agency implement High Impact Prevention interventions.

Know how to use social media to engage your community. Part of the goal of the aids.gov website is to help people who want to stop the spread of HIV learn to use new media to communicate their messages effectively.

Ask your clients how they use technology. Knowing how your clients use technology is an important part of how they navigate their worlds. Do they meet some or all of their partners online? If so, do they use a computer more often, or geolocation apps? How does hooking up online work or not work for them in terms of their own risk reduction goals? For example, where are the opportunities to communicate about HIV status or prevention strategies like condoms, PrEP, or other methods? Counselors can share strategies that other clients have used—for example, stating a preference for condom use, or frequent HIV/STD testing—and they can also tell clients that they want to learn from them what’s working and not working. Reflect back to your clients what you are hearing about the role that digital technology plays in their risk reduction. For example: “On one hand, Grindr has made it a lot easier to find partners to play with, but on the other it has actually made it harder to have conversations about protection,” or “You’ve always felt a little shy about talking about risk reduction, but being able to put your limits in your profile really helps.”

Let clients know about online HIV services. Several sites offer information about nearby HIV testing services. Some also offer additional services your clients may want: aids.gov also lists housing assistance, mental health,
and substance abuse services. Clients who have been diagnosed with HIV or an STD may want to notify partners through inSPOT. And clients in crisis who want to talk with someone have the option of either calling local or national suicide prevention phone lines or using Lifeline Crisis Chat.  

### Conclusion

Digital technologies and new media are so embedded in both our personal relationships and our working lives that many of us could not imagine managing either one without them. For HIV prevention and care professionals, choosing which interventions to use, and which digital and human technologies can best support our goals, remains the challenge. As the evidence base for some digital interventions is becoming clearer, there is no question that digital technologies offer HIV service providers and researchers unprecedented opportunities to learn, share our own expertise, and reach our communities.

### References

Review Questions

1. Hirshfield’s 2012 study with 600,000 MSM who either received no intervention (control), accessed a prevention webpage, or watched dramatic documentary videos related to HIV prevention and status disclosure, found that a) Only HIV-positive men reported significant reductions in unprotected anal sex in the webpage group as compared with controls; b) Men in the video group were significantly more likely to report that they had disclosed their HIV status to their last partner than in the control and webpage groups; c) There was no significant behavior change between all three groups; d) The intervention videos may have resonated most with sexually active HIV-negative MSM.

2. Research has shown that the most successful antiretroviral adherence medication programs use: a) less than daily messaging; b) personalized content; c) two-way communication; d) all of the above.

3. Which of the following statements is NOT true of inSPOT.org? a) It is a peer-to-peer web-based system of partner notification; b) The anonymity of inSPOT makes it easy to assess as an effective intervention; c) The platform allows people to contact partners who they might only know by email; d) There is no data on what proportion of inSPOT users actually access HIV/STD testing because they received an e-card.

4. Which of the following statements is an advantage of using digital technology? a) It allows for a uniformity of messaging to a statewide, national, or international audience; b) Most digital interventions require that participants read; c) Participants might misunderstand the health information on the site and fail to protect themselves; d) Internet interventions are not always used the way the designers intended.

5. The Center for Disease Control and Prevention’s High Impact HIV Prevention website, effectiveinterventions.org, is a resource for: a) learning where people are most affected by HIV in a specific state and community; b) locating testing and care services; c) learning about evidence-based interventions that are being used to prevent HIV infection; d) examining the demographic factors, like race, ethnicity, sex, and age of people living with HIV.

Discussion Questions

1. Which programs or interventions at your site utilize digital technology? Where do you think digital technology could be used more effectively?

2. What role does social media play in your site’s outreach and marketing campaigns? Is your site an active member of social networking sites like Facebook or Twitter?

3. During counseling sessions, how often does digital technology come up in discussions with your clients? Have you noticed a pattern in technology use and how it relates to you clients’ behavior?

4. What components of the interventions your site delivers would best be delivered by a person and which would best be delivered digitally?

5. Currently, digital HIV interventions are under researched. What study objectives would be most useful to future program planning? What questions do you have about interventions that rely on digital technology?

Answers

1. b 2. d
3. b 4. a
5. c