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HIV PERSPECTIVES AFTER 25 YEARS

HIV Behavioral Research Online

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ABSTRACT *Internet access has caused a global revolution in the way people of all ages and genders interact. Many have turned to the Internet to seek love, companionship, and sex, prompting researchers to move behavioral studies online. The sexual behavior of men who have sex with men (MSM) has been more closely studied than that of any other group online given the abundance of gay-oriented websites and concerns about increasing transmission of HIV and other sexually transmitted infections. Not only does the Internet provide a new medium for the conduct of behavioral research and for participant recruitment into an array of research studies, it has the as yet unrealized potential to reach huge numbers of MSM with innovative harm reduction and prevention messages tailored to individualized needs, interests, and risk behavior. Internet-based research on sexual behavior has many advantages in rapidity of recruitment of diverse samples which include individuals unreachable through conventional methods (i.e., non-gay identified and geographically and socially isolated MSM, etc.). Internet-based research also presents some new methodologic challenges in study design, participant recruitment, survey implementation, and interpretation of results. In addition, there are ethical issues unique to online research including difficulties in verifying informed consent, obstacles to surveying minors, and the ability to assure anonymity. This paper presents a review of Internet-based research on sexual behavior in MSM, a general discussion of the methodologic and ethical challenges of Internet-based research, and recommendations for future interdisciplinary research.*

KEYWORDS *HIV transmission, Gay men, Internet, Ethics.*

INTRODUCTION

Most adults in the United States have regular access to the Internet, either through home, work/school, or both. In 2003, Neilsen/NetRatings, a company that

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compiles data on Internet usage around the world, estimated that 63% of Americans were using the Internet, an increase of 93% from 2000. During the last decade technological advances have made access to information easier and faster. Today, an average user can not only search the immense web database for topics of interest but also can exchange images, video, text, and voice messages with other users anywhere in the world in real time ("chat"). Not surprisingly, many individuals have turned to the Internet to seek love, companionship, and sex.[1,2]

Men who have sex with men (MSM) are avid users of the Internet for dating and sexual purposes, as documented both by the number of studies[3–15] and the increasing number of Internet services catering to MSM. Mainstream Internet providers, such as America OnLine (AOL), feature user-created chat rooms where MSM can easily find each other in rooms labeled, for instance, "m4m" and coded by geographical location (e.g., NYCm4m), HIV status (e.g., HIVm4m), ethnicity (e.g., Latinom4m), or more arcane names known only to the initiated [e.g., "Atlantabimm4bimm" (for bisexual married men)]. Sex-specific sites cater to niche sexual interests, from fetishes to bareback (without a condom) sex.

Understanding the impact of the Internet on sexual behavior demands not only exploring its use as an instrument through which people interact and data can be gathered but studying the medium itself with ethnographic approaches similar to those employed in the study of other, nonvirtual communities. This paper uses a review of the published literature on the relationship of Internet use to high risk sexual behavior in MSM to illustrate the importance of the Internet in HIV-related research and prevention activities and discusses in detail the methodologic and ethical challenges inherent to Internet research.

SEX AND THE INTERNET

It has been suggested that the Internet is an ideal medium for sexual pursuits as a result of the three A's—access, affordability, and anonymity.[1] Online chat rooms, websites, and listservs can be easily accessed by individuals from home computers, computers at work or school, Internet cafes, or public libraries. Although some Internet service providers (e.g., America OnLine) and some gay-oriented websites (e.g., Gay.com) charge a fee for full access, others are free. The use of email addresses and screen names, and the ability to sign up for certain websites and chat rooms without revealing any contact information results in a fairly anonymous world in which to initiate sexual contact.

A Google™ search on August 11, 2005, using the key words "online dating sites" produced 9,610,000 results demonstrating the enormous popularity of meeting potential partners online. Although there are sites for heterosexuals, bisexuals, gay men, and lesbians, few published studies have examined the behavior of heterosexuals who meet online.[4] A single survey of heterosexual women found that 77% of women who met an Internet partner for an in-person sexual encounter did not use a condom, suggesting that the accelerated intimacy of online relationships may be influencing decisions about condom use.[16] This phenomenon may be widespread among those who meet online.

MSM and Sex Online

MSM comprise one of the largest online communities and these men are significantly more likely to have sex with partners that they meet online than

heterosexual men and women.[5,11,17] Most studies show no difference between HIV-positive and HIV-negative MSM regarding their use of the Internet for finding sex partners.[3,17–20] In a study of MSM in the United Kingdom (UK), two thirds of gay men reported Internet use in any given month and over half the men living in London reported use in the past 48 h.[20] The proportion of MSM in the UK using the Internet to find sex partners significantly increased from 28% in 1999 to 66% in 2002. As the proportion of men using the Internet for sex increased, the proportion of those using public sex venues decreased.

The role of the Internet in finding sex partners for MSM, as well as the impact on unprotected sex and potential risk of HIV and other sexually transmitted infections (STIs), has been examined in a number of studies. Men can use the Internet to instantly identify and eventually meet with a large number of anonymous sex partners they might not meet otherwise, increasing their risk for HIV and other STIs.[4,21–23] Unlike public and commercial sex venues, where subtle gestures and nonverbal forms are used to communicate information regarding sexual interests and behaviors desired,[24–26] the Internet permits men to communicate explicitly through written text or even through the use of photos or streaming video.

The ability to conduct searches of online member profiles simplifies the process of identifying and interacting with potential sex partners who have desired qualities: physical characteristics (e.g., body type, penis size, presence or absence of body hair), preferred sexual practices (e.g., top versus bottom, oral versus anal, fetishistic behaviors), interest in condom use or nonuse (e.g., barebacking or BB, safe only), and even HIV status and interest in serosorting (e.g., "I'm Poz UB2", "Poz4Poz," "neg only").

Demographic and Behavioral Characteristics of MSM Online

Research on MSM who use the Internet to seek sex partners has revealed some consistent findings. Compared to others, men with online sex partners or who use chat rooms to find sex partners are younger,[3,17,19,20] more likely to have a previous STI,[11,18] to frequent public and commercial sex environments,[19,27] and to identify as non-gay and report sex with women.[19,20]

There are also some contradictory findings. Although some studies have found increased illicit drug use among Internet-using men, specifically poppers (nitrite inhalants), MDMA (ecstasy), crystal methamphetamine, and Viagra®,[3,27,28] others have found no differences in the use of these drugs.[8] With regard to demographic characteristics, it has been reported that men using the Internet for sex are more likely to be white[3,4,20,28–30] and have less education;[19] however, other studies have found no differences in race/ethnicity[8,17] or level of education.[3,17] Demographic characteristics have been shown to be dependent on the website men are recruited from; for example, men recruited from America Online tended to be older than those recruited from Gay.com.[29] Thus, contradictory findings related to race/ethnicity or education level in online research are likely to be the result of sampling bias.

Whether or not MSM who seek sex partners online engage in more sexual risk practices has been investigated but with contradictory results. Some have found that men using the Internet to find sex partners report a higher number of sex partners,[3,11,28] are more likely to have had sex with casual partners,[17,19,28] and report more unprotected sex.[3] Other studies, however, have found men using the Internet were more likely to report having used a condom for their most recent sexual encounter,[11] and some have found no differences in the rates of condom

use.[17,27] Men were equally likely to report unprotected sex with partners met online and offline in an online study of 1707 men from the US and Canada[31] and in a study of 4225 London men recruited online and offline.[32]

HIV and STI Transmission

When data from studies of online sexual activity are analyzed by serostatus, some additional findings emerge. HIV-positive men who meet sexual partners online are more likely to report unsafe anal intercourse with other positive men[8,20] and self-report a previous diagnosis of gonorrhea.[8] An online study in the US found that only 12% of HIV-positive men with more than one sex partner in the 6 months before the survey reported serosorting.[30] HIV-negative men with online partners are more likely to report having HIV-positive partners,[17] more likely to report unsafe anal sex with nonconcordant partners,[18] more likely to report receiving money or drugs for sex,[17] and report feeling less worry about HIV due to improved HIV treatments.[18] These findings are concerning because of the increased potential for HIV infection among HIV-negative men who use the Internet to find sex partners.

STI transmission has also been associated with online partnerships. In 1999, a syphilis outbreak among men in San Francisco was traced to users of a gay chat room.[22] Similar results have been reported in the UK, where increasing numbers of men testing positive for syphilis (the majority of whom were coinfected with HIV) reported meeting partners online.[21] In fact, Taylor et al.[28] surveyed men in Los Angeles County already diagnosed with syphilis and found that men who met partners online reported more sexual and drug use risk behaviors.

Outreach and Prevention

The Internet has been used to notify men of specific exposures to STIs as well as to make sexual health information more readily available. When a syphilis outbreak occurred in San Francisco in 1999, the Department of Health electronically contacted hundreds of gay chat room users to educate them regarding the outbreak and to provide information on obtaining a medical evaluation.[22] E-mail addresses were used to notify sex partners of possible exposure. Men surveyed after this intervention took place reported that such outreach was helpful and appropriate.

Many MSM access HIV prevention information online. A Netherlands study found that a safer sex website, an email-based question and answer program, and a safe sex chat room were the most preferred programs.[9] Men online in the UK also had favorable attitudes towards online health promotion.[33] In fact, most men (75%) thought that Internet sites should allow health workers into chat rooms, would click on a banner to find out about sexual health (78%), and were agreeable to engaging health workers online (84%).

HIV-positive men in London were more likely than other men to have used the Internet to obtain information about HIV and sexual health services and HIV treatments as well as to get information regarding recreational drugs and Viagra®.[8] Many HIV-positive men utilize the Internet to access health information and such use is associated with more active coping, empowerment, and social support.[34]

Men who seek sex online may be particularly in need of Internet-based HIV prevention because they tend to be better educated, insured, and less likely to be exposed to offline messages delivered through the public sector than others.[5] The Internet may also provide health educators access to men who would be resistant to in-person individual or group level prevention efforts. Further, since many HIV-positive men who use the Internet for sex are engaged in risk practices, delivering

HIV prevention messages through this medium targets those most at risk of transmitting HIV to their partners.

The Internet can be used to engage hard to reach men for online and offline (in-person) interventions. Success in targeting MSM from ethnic minority communities is growing, although white men remain overrepresented in many online studies. Using the Internet, Fernandez et al.[35,36] recruited 172 at-risk Hispanic MSM to enroll in a larger face-to-face intervention study.

Internet-based behavioral interventions have been successfully used for smoking cessation and to treat a variety of conditions including depression, chronic headaches, and tinnitus, but proven HIV prevention interventions have not yet been adapted for online use. Few systematic behavioral interventions have been developed and implemented[37,38] aside from using chat rooms to talk to gay men about HIV and safer sex and using banner ads to promote HIV and STI testing.

Education

For the first time, people of all ages, genders, and sexual orientation from anywhere in the world have access to current and accurate health information at the privacy of their own computer. Adolescents are one vulnerable population whose educational needs can be effectively supplemented online. There are excellent sites specifically targeted to adolescent sexual health that provide developmentally appropriate information in a supportive environment sponsored by organizations like Planned Parenthood and Advocates For Youth. Prudence is still required by the online information seeker, however, since not all information available is reliable or current.

METHODOLOGIC AND ETHICAL CHALLENGES OF INTERNET-BASED RESEARCH

As evidenced by the preceding section, the Internet is rapidly becoming an important medium for HIV-related behavioral research, particularly among MSM. However, like all recruitment methods, there are many sources of potential bias in online sampling in addition to some technological issues specific to the Internet.[39] The following sections discuss survey procedures that can be used to design, program, and implement methodologically sound online studies, regardless of the population of interest, and also highlight some important ethical considerations.

Recruitment and Retention of Participants

The advantages of web-based surveys compared to traditional recruitment methods include the ability to rapidly attain large sample sizes[40,41] and reach geographically dispersed and behaviorally isolated men.[14,30,42] Various methods of recruiting subjects online exist, with new strategies continually being developed. Active recruitment methods include solicitation through e-mail blasts, chat rooms, and instant messaging. Passive recruitment techniques include survey banner advertisements that rotate on target websites or hypertext links on search engines, both of which can link to a survey.[43]

There are some disadvantages, however, to online recruitment including missing data and duplicate enrollments. Internet-based research also has produced higher attrition rates than offline research, as there are fewer social constraints compared to in-person interviewing.[40] Using fast survey page loads, succinct and

understandable content and the most widely available and user-friendly software will likely reduce attrition.[44,45]

Depending on the type of online survey, different methods are appropriate to guard against completion of multiple surveys by participants. For surveys in which participants consent to disclose their e-mail and other personal information, techniques such as removing financial incentives, using Internet protocol (IP) addresses or e-mail addresses, cookies, or passwords can detect multiple surveys.[40] For anonymous surveys in which participants do not share personal information, the survey can request respondents to participate only once, remove incentives, and filter identical data during the data cleaning phase.[40] A recent anonymous study of MSM recruited online minimized the likelihood of multiple surveys by rotating its study banner ad through online chat rooms at the end of a string of other advertisements and blocked participants from book marking the survey.[30]

Validity of Data

With anonymous Internet surveys, threats to validity include the inability to verify the participants' identity or their responses. However, a growing number of studies indicate higher reporting of sexual risk and drug-using behaviors with computer-based compared to in-person surveys.[46–49] A recent survey comparing online and offline samples found that the online sample of HIV-negative and never-tested men was significantly more likely to report high risk sexual behavior than were men surveyed offline.[50] Internet-based surveys have the added advantage of eliminating interviewer bias and respondent social desirability bias.

Generalizability

Internet access varies by income, education, and race/ethnicity, suggesting the systematic exclusion of lower income groups from the potential benefits of research being conducted online.[51,52] However, this issue is complex. On the one hand, research indicates that those who have computer skills and access to participate in online surveys tend to be wealthier, educated white males.[2,52,53] On the other hand, an important factor to consider regarding the racial digital divide is cybergeography, which refers to sites that people visit and where researchers collect information and conduct research. Although lower income and minority groups may not be fully represented online, there is still a large presence on the Internet. Blackplanet.com, the largest national African American website, has almost 3.5 million unique visitors, most of whom self-identity as African American.[54]

MSM present a special problem when assessing the generalizability of survey findings. Since the population of MSM in the United States has never been enumerated, it is not possible to determine whether MSM that participate in online surveys are representative of the MSM population who use the Internet or of MSM in general. Two large-scale, MSM online studies linked to gay-oriented sites indicated that the majority of respondents were white, non-Hispanic, and educated.[30,31]

Technological Considerations

Rhodes et al.[41] state that the process of web-based data collection is simple, compared to mail-in and other traditional survey methods. This is partly true. Some advantages of web-based data collection include the ability to program variables and values ranges before the survey is implemented so that the survey is automatically transferred into a database eliminating the need for a separate data

entry step.[41] Unlike a self-administered written survey, in which the respondent has to negotiate skip patterns, a well-constructed online survey caters to the respondent, with preprogrammed skip patterns. However, considerable computer programming expertise is needed to create a successful online survey.

Technological reasons for missing data and dropouts may include respondents' lack of computer skills, poor survey design, and an incompatible web browser.[55] Although the cost of posting and running an online survey can be very low, there may be more expenses and time considerations involved in planning, programming, and implementing large-scale, web-based surveys, compared to traditional written surveys. Programming and pilot testing, establishing working relationships with websites, monitoring the survey to ensure proper functioning, and other technological planning considerations, such as having a secondary server to protect against power outages, are crucial for online studies.

Ethical Issues

The following section provides a general overview of some ethical considerations faced by those conducting Internet-based research. For a more detailed discussion, the reader is referred to the growing body of literature dedicated specifically to the ethical issues surrounding Internet based research.[51,53,56–66]

While some have argued that Internet-based research is inherently no more risky to human subjects than traditional research methods,[62] there are fundamental differences in the nature of human subject-related risks, the ability to assess those risks, and in the safeguards against them. The ethical principles involving research with human subjects have been formalized in federal regulation known as the Common Rule, which establishes guidelines for assessing risk to human subjects in research (http://ohsr.od.nih.gov/guidelines/45cfr46.html). Federal guidelines require that Institutional Review Boards apply a risk-benefit assessment when considering the merit of proposed research. The risk portion of the assessment involves being able to establish, among other things, whether the subjects are identifiable or anonymous, whether the behavior being assessed is public or private, and the degree of risk to the subjects posed by the research. Federal guidelines also require that protected groups (i.e., women, minorities, children) not be systematically excluded from the participation in research studies. Finally, Internet research poses unique considerations regarding the acquisition of informed consent from study subjects.

Identifiable versus Anonymous Information

There are several research methodologies currently being employed over the Internet, including online focus groups, online surveys, and content analysis of email and Web pages. Information collected anonymously poses inherently fewer risks to subjects than identifiable data. Assuring anonymity in online research can be more difficult than it would seem, particularly when the research involves the assessment of online behavior. For example, quoting exact text and including online pseudonyms can lead, directly or indirectly, back to individual user identities. It is therefore becoming common practice for researchers to disguise online pseudonyms and to modify quoted text when conducting this type of online research. Maintaining subject anonymity can also be complicated by the desire to compensate subjects for participation in online research. Some researchers have addressed this problem by issuing prepurchased online gift certificates with unique certification numbers to participants.[62]

Public versus Private Behavior

Central to the distinction between public versus private information is the *expectation of privacy* on the part of the research subject. This is a rapidly developing area in Internet research, with widespread opinion regarding the degree of privacy that Internet users can expect. Public behavior is generally not protected by Common Rule guidelines. Researchers do not have to obtain informed consent from subjects to report information related to behavior taking place in public. Some online forums afford little privacy, including unrestricted email distribution lists, online chat rooms, multiplayer games, and other forums designed for widespread public interaction. Individuals accessing these forums probably have no reasonable expectation of privacy, and it has been argued that their online behavior within these forums should be considered public and exempt from Common Rule regulations.[62,63,67,68] On the other hand, individuals accessing restricted membership forums with explicitly posted recording policies probably possess a reasonable expectation of privacy, and their behaviors are likely protected by Common Rule regulations.[62,63]

Researchers must also be aware that technology may factor into privacy expectations. Many Web sites create logs displaying the IP addresses of the machines accessing its sites. For individuals with exclusive use of a computer employing a fixed IP address, knowledge of the IP address can be equivalent to knowing its user. Individuals using machines with dynamic IP addresses (addresses assigned to machines as they are being used) are not identifiable by the IP address. These individuals may also possess higher privacy expectations.

Level of Risk

A primary difficulty with Internet-based research involves the challenge of assessing the level of risk to the individual. Internet research involves two primary types of risk: (1) risk associated with participation in the research itself; and (2) risk associated with breaches in confidentiality. Many types of Internet research involve minimal risk associated with participation in the research itself.[62] In fact, online surveys, observations, and experiments are often even less risky than studies employing traditional research forums, since it is typically much easier for online subjects to withdraw from the research. On the other hand, it is harder for researchers to monitor the status and condition of research subjects taking part in Internet-based research and is therefore harder for researchers to assess the impact participation is having on subjects. Internet researchers can minimize risks associated with study participation by posting web links to information sites and hotline numbers related to the study material at the end of the online survey[30] and by posting debriefing materials on study web sites following the end of the research period. This can also be an efficient method to keep subjects informed about the status of longitudinal research studies and results at the end of the study.

Compared to traditional research forums, the greatest risk associated with online research involves the potential for breaches in subject confidentiality. Identifying information can be inadvertently disclosed as study data are being collected or subsequent to data collection when data are being stored on computers connected to the Internet. Disclosure may be inadvertent or the deliberate result of efforts by computer hackers. Use of automated Web survey software helps minimize the risk of data being compromised during transmittal, although the best safeguards against confidentiality breaches are not to collect identifying information at all or to transmit and store identifying information in separate files linked only through code

numbers.[62] Other safeguards for researchers include configuring computers to permit access to study data by study team members only, using password protected directories, encrypting sensitive files, and routinely installing security patches on the operating systems of computers housing sensitive data. Importantly, there should be a direct relationship between the steps taken to ensure subject confidentiality and the sensitivity of the data being collected. Less precaution is needed when responses are anonymous or when the data being collected are innocuous. In fact, more elaborate security protocols may actually cause more concern among potential study participants, making them less willing to participate.[69]

Informed Consent

Federal regulation requires that written informed consent from research subjects be obtained when human subjects research is being conducted. This requirement can be difficult to achieve with online research; however, the written consent requirement can be waived for research involving minimal risk to subjects. An alternative in these cases is to have subjects click a button (or series of buttons) to signify that they have read the informed consent statement and that they agree to participate in the research. Internet-based informed consent procedures have the potential advantage of being interactive, multilayered, and constantly available for the subject to review.[57] However, the lack of interactivity between the researcher and the study subject makes it difficult for the researcher to determine whether or not the informed consent document was truly read and understood by the subject. Therefore, when informed consent is obtained without any interaction between the researcher and the subject, all aspects of the consent process should be made available online.[60]

Another challenge endemic to online research involves verifying information about the respondent. This can be especially problematic when parental consent is needed prior to participation in research involving minors.[64] In these cases, researchers can institute safeguards to decrease the likelihood that minors are feigning parental consent, such as requiring information typically available only to adults (i.e., credit card or drivers license numbers) or requiring that parents register with identity verification organizations such as VeriSign (http://www.verisign.com/products/asb/). It is important to note that researchers working with minors are also subject to the rules and regulations promulgated in the Children's Online Privacy Protection Act (1998) as well as all individual institutional review board policies and procedures.

Recommendations for an Interdisciplinary Research Agenda

The Internet has opened new frontiers in HIV behavioral research and prevention, but it also presents the researcher with a number of methodologic and ethical challenges. At the most basic level, the development of statistical techniques to enumerate, describe, and sample Internet populations is in its infancy. Few published studies have compared the response reliability/validity between online and in-person surveys; the generalizability of findings from online surveys remains difficult to assess. There are many large gaps in our knowledge of how and why people from adolescence through old age use the Internet to meet sexual partners. Little is known about the design and conduct, either from behavioral theory or technological standpoints, of online behavioral interventions most likely to elicit sexual behavior change. Since Internet-distributed self-help programs based on cognitive behavioral therapy appear to be effective in treating depression and other

conditions, adapting evidence-based HIV interventions to this medium is one of the most exciting new directions for research. The potential for creating low cost interventions capable of reaching any targeted population online is enormous. Future advances in Internet-based research will require that scientists from a variety of disciplines including survey research experts, biostatisticians, behavioral scientists, epidemiologists, ethicists, and computer scientists work together to take full advantage of this revolutionary technology.

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