

Gay Males and Electronic Health Records: Privacy Perceptions, Age, and Negotiating Stigma

Authors

Timothy Stablein, PhD, ISTS Post-Doctoral Fellow, Department of Sociology, Dartmouth College, 109 Silsby Hall Hanover, NH 03755-3547, E-mail: Timothy.P.Stablein@Dartmouth.edu

Joseph Lorenzo Hall, PhD, Postdoctoral Research Fellow, NYU Steinhardt, Media, Culture and Communication, 239 Greene St., 3rd Floor, New York, NY 10003-6674, Email: joehall@nyu.edu

Helen Nissenbaum, PhD, Professor, NYU Steinhardt, Media, Culture and Communication 239 Greene St., 3rd Floor, New York, NY 10003-6674, Email: helen.nissenbaum@nyu.edu

Denise Anthony, PhD, Department of Sociology, Dartmouth College, 109 Silsby Hall Hanover, NH 03755-3547, Email: Denise.L.Anthony@Dartmouth.edu

Acknowledgements

The Authors would like to acknowledge the support, resources and helpful discussions of NYU's Center for Health, Identity, Behavior and Prevention Studies (CHIBPS), especially Perry Halkitis and Daniel Siconolfi. This publication was made possible by Grant Number HHS 90TR0003/01. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the HHS.

Abstract

In this paper, we explore how perceptions of electronic health records (EHR) and patient privacy shape information exchanges and health care delivery among individuals with histories, or at risk, of experiencing stigmatizing health conditions. We conducted in-depth qualitative interviews with a purposive sample of gay males (n= 24) who received care in a large northeastern city in the United States. The sample was stratified into two age groups; young adults, ages 19-26 (n=14), and adults, over the age of 30 (n=10). In this paper, we present preliminary findings from an ongoing study. By interviewing both younger and older groups, we sought to understand how different groups, with similar risks, experienced health care and the subsequent roles that health information technology (HIT), such as EHRs, played among groups more or less experienced with technology, health care settings, and delivery. Young adults also provided retrospective accounts of experiences with HIT and health care delivery when teenagers. Stigma management strategies for gay males, such as concealing information about sexuality or sexual activities from health care providers is consistent with the literature, however we find that the role of HIT alters this relationship further. Gay male recipients of health care must further negotiate the boundaries of patient/health care provider interactions in an effort to simultaneously protect perceived privacy threats offered by the use of EHRs, while they manage potential stigmas associated with being homosexual. We discuss how this process is influenced by age, experience with information technology, and associated health issues.

Key words

Gay Males, Age, Stigma, Privacy, Health, Technology

Introduction

Though the potential for electronic health records (EHR) to improve the quality of health care is generally understood (e.g. Davis et al. 2009; Goldzweig et al. 2009; Litvin 2007), researchers suggest that concerns about the confidentiality and privacy of EHRs may present significant barriers to their effective use (Appari and Johnson 2010; Hersh 2004; Litvin 2007; Swartz 2005). Surveys of patients and physician groups consider privacy protections to be essential in moving to EHRs (Wynia, Torres, and Lemieux 2011). To date, however, there is a lack of understanding concerning how access, privacy, and security change patient perceptions of protected health information and how these perceptions may influence the interactions they have with health care providers (Zwaanswijk et al. 2011).

Nowhere is this issue a more salient concern than among populations with histories, or at-risk, of stigmatizing health conditions. The problems associated with health stigma and stigma management strategies among people with illness and disease are well documented in the sociological literature (see for example Goffman 1963; Link and Phelan 2001; Siegel, Lune, and Meyer 1998; Thoits 2011; Weitz 1990). Not only do others treat those in stigmatized groups differently, people with stigmatized statuses are prone to internalizing deviant identities (see for example Link et al. 1989), which may influence decisions to conceal personal health information (Goffman 1963). In context to health seeking behavior, stigmatizing health conditions and provider's subsequent access to intimate knowledge, may influence the way these groups access and move through health care systems and services. For example, past studies have shown that patients with stigmatizing health conditions, such as HIV and AIDS, substance abuse disorders, and mental illness are more guarded when disclosing health information to their providers, family, and partners (Gaskins 2006; Willging, Salvador, and Kano 2006; Wolitski and Fenton

2011). However, recent efforts to modernize health information technology (HIT) may make these groups more or less likely to be forthcoming about health information and alter ways in which patient's negotiate stigmatized identities and interactions.

Building on theories and research concerning stigma, stigma management, and health, we explore how stigma affects information sharing. Specifically, we explore how individuals at risk of stigmatizing health conditions think about information sharing in health care and recent HIT innovations. We sought to understand how such individuals shared personal and health information with providers and what kind of concerns they had related to the use of HIT, such as EHRs, which have implications for how health information is shared. We address the persistent problem of stigma associated with gay men's health issues (Eliason and Schope 2001; Green 2008; Halkitis et al. 2011; Malebranche et al. 2004; National Research Council 2011). However, in the era of HIT, these persistent problems pose even greater challenges to the delivery of adequate and effective care to these populations. As such, we explore how patient privacy concerns, particularly related to stigmatizing health conditions, relate to perceptions of benefits and risks of EHRs and how these perceptions shape information exchanges, health care delivery, and interactions with health care providers.

We conducted in-depth qualitative interviews with a purposive sample of gay males (n=24) who received care in a large northeastern city, in the United States to explore perceptions of electronic health record (EHR) privacy among populations at higher risk of experiencing stigmatizing health conditions, such as HIV and AIDS. The sample was stratified into two age groups; young adults, ages 19-26 (N=14), and adults, over the age of 30 (N=10). By interviewing both younger and older groups, we sought to understand how different groups, with similar risks, experienced health care and the subsequent roles that HIT and privacy played among groups

more or less experienced with technology, health care settings, and delivery. Young adults also provided retrospective accounts of experiences with HIT and health care delivery when teenagers. This provided an added and related opportunity to explore how homosexual youth navigate health care and discussions of sexuality with health care providers. We suspected that younger at risk groups may hold different views of health privacy and HIT, and have different health care experiences to date compared to their older, at-risk counterparts.

Literature review

Negotiating health stigma and homosexuality

The lesbian, gay, bisexual, and transgender (LGBT) community are often targets of stigma because of their sexual and gender minority status (National Research Council 2011). This often leads LGBT individuals to withhold information from their health care providers in fear that judgments of sexual orientation will influence the kind of health care that they receive (Ramchand et al. 2008; Smith, Johnson, and Guenther 1985; Willging et al. 2006). Non-disclosure of personal health information related to sexual orientation is often influenced by previous negative interactions with health care providers and the perceptions of health care settings and providers as threatening and reinforcing of heterosexist stereotypes (Eliason and Schope 2001). Willging et al. (2006) suggests that LGBT individuals often will avoid professional care because they perceive “provider bias” against their sexual behaviors and gender identity and this is exacerbated by inadequate sensitivity to LGBT culture resulting in inappropriate care. In order to “pragmatically” navigate this embedded homophobia, they suggest that LGBT individuals may resort to non-disclosure of sexual preferences or may avoid care altogether. Willging et al. (2006) and others suggest that decisions to disclose may further

be complicated by geography, whereby individuals in rural settings will be less likely to disclose stigmatizing health information, such as LGBT orientation, sexual behavior, and knowledge of sexually transmitted diseases (Gaskins 2006) given patient's fear of personally knowing providers outside of clinical settings.

Wolitski and Fenton (2011) suggest that men who have sex with other men (MSM), in particular, who are uncomfortable with their sexuality, are also likely to not disclose their sexual behavior to health care providers and may avoid and/or delay HIV/STI testing (see also Malebranche et al. 2004; Mimiaga et al. 2009; Nelson et al. 2010). Non-disclosure of this information may also guide patient/provider interactions, whereby patients receive less focused care, such as prompts for the HIV tests, related to their elevated risk profile (Wall, Khosropour, and Sullivan 2010). Mimiaga et al.(2009) suggests that race also plays a significant role in decisions to disclose information and get tested HIV/STI tests. They suggest that although health care providers play a role in encouraging testing for minority MSM, they often lack the training necessary to meet the specific needs of this population (ibid.). This results in alienating minority MSM, which has the potential to lead to avoidance of care, disclosure, and testing.

Together, these perceptions inspire reluctance on the part of LGBT individuals and those at higher risk of experiencing stigmatizing health conditions to seek out health care and confide in health care providers. As we now enter into an age of new HIT innovations, such as EHRs, which continually shape the ways that health professionals collect, store, disclose, and use PHI, little is understood about the perceptions of these marginalized health care recipients towards changes in HIT and how such changes might affect the privacy of their health information.

Youth, young adults, and health privacy

Youth and young adults also have a variety of privacy concerns when using information technology, in general (Boyd and Hargittai 2010), and when seeking health care and confiding in their health care providers, in particular (Carlisle et al. 2006; Cheng et al. 1993; Thrall et al. 2000). However, to date, there have also been no studies, which explore the role that EHRs and subsequent health privacy perceptions play in health information exchanges among young patients and their providers.

Teen-aged youth, in particular, present a precariously situated population who, at once, must contend with their own private health concerns, while lacking many of the rights to privacy that are afforded to their adult counterparts (Weisleder 2004). As they approach young adulthood, teens have a variety of new health concerns, such as pregnancy, sexually transmitted diseases, and drug use which they wish to keep confidential and private from parents, caregivers, friends, classmates, teachers, and authority figures (Cheng et al. 1993). Like their older counterparts, LGBT youth are reluctant to disclose sexual orientation to health care providers (Allen et al. 1998). Moreover, Halkitis et al. (2011) suggest that young MSM, in particular who use drugs are much more likely to transmit STI/HIV. The ideal health care setting would have these populations coming for regular health care check-ups and testing to make sure any serious conditions or communicable diseases were treated as early as possible. Having drug-using gay youth neither disclose about MSM behavior or drug use may, therefore, only worsen the spread of these diseases amongst youths.

In order to receive effective care and treatment, youth must be willing to share personal health information and trust that their providers will keep information confidential. However, Carlisle, et al. (2006:133) suggests, “young people who are concerned that consultations may not

remain confidential are reluctant to consult their doctors, especially about sensitive issues.” Subsequently, pediatricians must respect these privacy concerns and build trust in patient confidentiality, while conforming to federal and state mandatory reporting and privacy laws. The negotiation process, which underlies these interactions, has the potential to compromise the effective delivery of health care to youth and emerging adults who may be concerned about the privacy of their health information.

Though Weisleder (2004) identifies doctor-patient confidentiality, in particular, as a precept of adolescent medicine, the emergence and proliferation of new HITs in current medical practice offer even greater challenges to assuring and maintaining patient privacy. To date, we know little about how EHRs and HIT will guide privacy perceptions and the delivery of quality care to youth concerned about the privacy of their health information as they enter into young adulthood. Though youth value the privacy of their personal health information (Carlisle et al. 2006; Cheng et al. 1993; Thrall et al. 2000), we understand little about how they will navigate hi-tech health care settings and if these experiences will differ from that of their older counterparts.

HIT and Privacy

Privacy has always been an important part of health care delivery and management. In recent decades, however, health care has undergone major technological changes, which has necessitated a reevaluation in ways of thinking about privacy and the formulation of new policies regarding the practice and protection of health information. One focus of health care privacy policy efforts for over a decade has been the conversion and transmission of protected health information (PHI) to electronic format. In 1996, the United States Congress enacted the Health Insurance Portability and Accountability Act (HIPAA) that included, among other provisions and

standards, an “administrative simplification” provision addressing the privacy and security of health information. Subsequently, the Department of Health and Human Services (HHS) adopted two rules to protect personal health information. The HIPAA Security Rule specifies a series of administrative, technical, physical, and organizational security standards to assure the confidentiality of electronic PHI. The HIPAA Privacy Rule sets national standards to protect individuals’ personal health information held by healthcare organizations that engage in transmitting patient data (e.g., health care providers, health insurance plans, health information clearinghouses) to health care providers. The Privacy Rule mandates appropriate safeguards to protect the privacy of personal health information, sets limits and conditions on the uses and disclosures of such information without patient authorization, and gives patients’ rights over their health information, including rights to examine and obtain a copy of their health records, and to request corrections. The HIPAA Privacy Rule became effective in April 2003 (i.e., relevant organizations were expected to be compliant with the Rule by this date) and the Security Rule became effective in April 2005 (see Appari and Johnson 2010). Recently, Congress passed the Health Information Technology for Economic and Clinical Health (HITECH) Act, as part of the American Recovery and Reinvestment Act of 2009, which, in part, provided tens of billions of dollars in increased incentives for providers to move from older medical records systems to certified EHRs (see Blumenthal 2010). HITECH also included more robust privacy protection of PHI by extending the privacy and security provisions of HIPAA and its regulations to business associates of covered entities, providing that organizations holding PHI on behalf of patients must give notice of privacy breaches to patients and increasing the amount of information providers have to provide to patients about disclosures of their PHI.

Though health care recipients in the United States hold these rights to private and protected health information, in an era of expanding technology, little is understood about the role that HIT plays in shaping people's perceptions of health information privacy and the way that HIT alters information exchanges and health care delivery. This is a particularly important consideration for individuals experiencing potentially stigmatizing health conditions, and for others wishing to conceal personal health information due to sexual orientation, related disease risk, or age.

Uncertainty about privacy protections and confidentiality, such as who has access to and use of electronic health data may lead marginalized groups, such as gay males, to withhold information, thus compromising a provider's ability to adequately and effectively deliver care and treatment. The added uncertainty of privacy protections offered through the use of EHRs raises questions about how patient interactions will be affected. Chiefly, for our purposes, will the use of EHRs affect privacy perceptions among gay males and, thus, the extent to which they communicate health information to their providers? Secondly, will the use of EHR's alter the way these groups interact with health care providers and, thus, change the way they manage stigma? In our analysis, which follows, we sought to understand how groups at higher risk of experiencing stigmatizing health conditions (we sample gay males) thought about privacy and the proliferation of EHRs in health care, and secondly, how these concerns, experiences, and the negotiation of stigma manifested themselves across different age groups.

Methods

We conducted in-depth qualitative interviews with a purposive sample of gay males (n=24) who received care in a large northeastern city in the United States to explore perceptions of

electronic health record (EHR) privacy among populations at higher risk of experiencing stigmatizing health conditions, such as HIV and AIDS. The sample was stratified into two age groups; young adults, ages 19-26 (N=14), and adults, over the age of 30 (N=10). We recruited interview participants via advertisement through a research center, which studies gay men's health and social issues. We subsequently employed a snowball sampling strategy whereby initial interview participants informed other similar acquaintances of our study. This yielded a sample of other similarly situated gay males linked through health service utilization and peer networks.

The decision to participate was voluntary and participation was confidential. To maintain confidentiality, interested parties were encouraged to contact a member of the study team via e-mail or phone in order to schedule an interview time. All interviews were conducted at said research center. At the time of the interview, we presented participants with a printed information sheet/consent form, which outlined participant rights and details about the study. Participants reviewed this information and gave verbal informed consent before the interview took place. Interviews lasted approximately 45 minutes to 1 hour. We paid each participant \$35.00 for their time.

We chose a qualitative interviewing strategy in order to explore privacy concerns among participants and to understand how different groups of gay males experienced and navigated health care delivery and systems. We also sought to understand how HIT shaped interactions that participants had with their health care providers and systems and the role that HIT played in information exchanges among sexual and gender minority groups more or less experienced with HIT, stigmatizing health conditions, and health care delivery. During interviews, we asked participants to describe their perceptions of privacy in general and as they related to health care,

medical records, and information technology. Participants described the importance and role of privacy within health care settings and the impact of HIT and EHRs, in particular, had on health care experiences to date. We electronically recorded, then transcribed and analyzed interview data. Two members of the research team thematically coded data into categorically similar interview text references and then compared code classifications to improve reliability.

Findings

Young adult and adult participants came from a variety of social and economic backgrounds. The older sample, in particular, had a greater diversity of health care experiences than their younger counterparts. The snowball sampling strategy yielded a high degree of older males who sought care at a local gay men's health and service center. This center catered to individuals who were uninsured and/or had specialized health care related needs typically associated with gay male populations. As such, in our older sub-sample we had the opportunity, not only to interview gay males, but also to interview a disproportionate number of men with health related issues, including HIV and AIDs.

Disclosure

Similar to the literature on non-disclosure, a number of participants in our sample indicated that they had not disclosed sexual orientation or personal health information to health care providers in the past. Non-disclosure was justified in a number of ways. Uncertainty about how health care providers used records to manage and share patient health information and how that information was made available to others not directly involved in their care led to non-disclosure among a number of older male participants experiencing stigmatizing health

conditions, such as HIV and AIDS. One participant noted that once he showed symptoms for HIV he went to another hospital in another city for an HIV test, fearing that the confidentiality of his record would be compromised, potentially jeopardizing personal relationships with other community members who worked in the hospital.

“I knew something was going on just in my bones. I was like ‘I think I have the virus’, I really think I do because I did my research and it was just all the symptoms. ... I took a test at a hospital that’s not in my city, so I knew what the results were...”

Younger participants also recounted experiences of non-disclosure of sexual orientation, sexual activity, and drug use, with pediatricians.

“When I was younger, I was a teenager, I wasn’t out to my parents yet and I was having sex with men and I didn’t tell my healthcare provider that I was gay because I didn’t know if they would tell my parents or not.”

“Yes [has withheld information from provider], you don’t want to come off as like the slutty person or you don’t want to come off as like the dirty person who doesn’t know how to take care of their hygiene or whatever just because of a small incident...”

Each group cited instances of non-disclosure. Older participants more often cited not disclosing sexual orientation and stigmatizing health information such as HIV status in fear that they would be judged by health care providers or that others within or outside the medical team would become aware of information present in their record. Older minority participants also discussed the significance of being both a minority and gay in predominantly white health care settings. The doubling up on these stigmas in the mostly-white health care setting compounded problems with disclosure.

Being so close to their teenage years, younger participants cited instances of withholding information because of embarrassment, or in fear that parents or caregivers would be altered to their behaviors or activities. These fears, however, did not appear to carry over into their young adulthood, as many described ceasing non-disclosure when they were no longer minors. This may be because a majority of the young adults interviewed lacked experience with significant illness, socially embarrassing health conditions or related health care experiences, which may have otherwise motivated them toward non-disclosure views as young adults. This is evidenced in statements made by younger participants that medical privacy was important, however unnecessary for them given their relatively uneventful health histories to date.

“Frankly, I don’t think there is anything really worth being protective about with my medical history, but that doesn’t mean I don’t care. I appreciate and feel better about the fact that I believe it is private.”

Though many adults and young adults expressed concerns about privacy risks related to the use of EHRs, a number of young adults also candidly expressed their confidence in the security of health information technology and the ability of EHRs to effectively maintain confidential health information to a greater degree than their older counterparts. This is not to say that youth lacked privacy concerns or concern for their health information. They expressed similar privacy concerns as their adult counterparts, however, fewer appeared moved to concern over the transition from paper to electronic records. Decisions to disclose may have also been influenced by the trust participants had in health care providers as was cited among many participants as an important factor in decisions to disclose health information.

The EHR and Privacy Perception

Participants in each age group cited a variety of similar advantages as well concerns regarding the use and privacy of EHRs. Overall, there was little consensus about whether or not EHRs posed greater privacy risks or compromised health care delivery. Participants cited a variety of contradictory views. Some suggested that HIT potentially offered more efficient, accessible records. A number of participants suggested that EHRs had the potential to facilitate in more engaging, thorough care, because they allowed health care providers more immediate and complete access to records. For example, EHRs offered health care providers an opportunity to access the record when needed in emergency situations. The interoperability of EHRs were cited as a positive attribute for these reasons. EHRs allowed health care providers access to centralized record systems, which provided clinicians with a fuller picture of a patient's health history. However, many of these cited positive aspects of EHR systems were identified as negative aspects for others. For example, some participants cited that EHRs were more secure and provided a greater deal of confidentiality than could be offered by traditional paper records systems. However, others cited EHRs as more vulnerable to security and privacy threats, were more prone to hacking, and were too accessible to others within and outside of the medical team.

Perceptions of privacy threat also pervaded the very organization and structure of the EHR. One participant remarked how EHRs produced unintended privacy breaches among gay males or MSM by inadvertently identifying sexual orientation otherwise undisclosed. This happened when specific health or illness information corresponded specifically to health issues experienced by gay males or MSM. The participant gave the example of individuals who had been treated for rectal Human papillomavirus (HPV). Since gay males and MSM are at higher

risk for this particular form of HPV, the participants suggested that providers reading the record did not need to have a cited sexual orientation within the record to pass judgments on patients.

Uncertainty and the trivialization of information exchange

Participants also cited that EHRs facilitated impersonal interactions with health care providers, which had consequences for how they experienced health care settings.

“I have encountered a doctor who was in a session, has sat there and asked me certain questions and then started typing on the computer and then comes back and it just seems very impersonal when they do that, like they’re just trying to gather information for the computer from you instead of actually trying to take care of your needs.

“They don’t look at me, they’re looking at the computer screen and talking to me. So I’m behind them. They’re sitting here. I’ve had two nurse practitioners in a row who work with me that way; we had a conversation where I was talking to the back of their head while they asked me questions. They would turn around occasionally if it was kind of like a really pertinent or really personal question.

Given they did not know how information was disseminated via the EHR, their use also facilitated in uncertainty about communicating personal health information to providers. One participant noted:

“If you’re looking over something on the computer and you’re sitting on the chair you’re not sure what they’re looking over on the computer. They could be looking at something and so you don’t even know what they’re doing. For example, me and you are sitting here

and the computer over there and you're typing and I'm sitting here, I don't know what you're typing. So I don't know who you're sending the information to.”

Each of these perceptions (that EHRs they create impersonal communication styles and uncertainty about what happens to information once it is entered into the EHR) has particular importance for understanding the experience of gay men seeking health care. The impersonality and uncertainty offered by the use of EHRs, and cited by participants as negative aspects of HIT in general, has the potential to further alienate already apprehensive sexual and gender minority groups from seeking health care and disclosing personal health information.

In addition, participants suggested that the EHR failed to conform to their specific health care needs. The EHR, at once, compromised their ability to effectively communicate information to health care providers and often did not allow for the recording of information specific to their circumstances. Participants recounted that the EHR, not only produced a greater sense of impersonality and uncertainty during interactions with providers, but also presented users with an inflexible and rigid system, which did not take their special or unique orientations and health circumstances into account. When commenting on his experiences with EHRs, one participant made this observation:

“...you have to fit these symptoms in like predetermined categories and it's kind of clumsy trying to figure out 'I can't type it in here - - like I don't know.' It doesn't seem like a very flexible system yet, [from] what I've seen of it.”

Another made this observation about the EHR:

“It creates a predisposed way of looking at health. You have to look it at through the records perspective and so it gets much more rigid than like in a paper one where there's blanks; lines where you can call them whatever you want.”

For these participants, EHR systems did not appear designed to record and manage the care of special needs, or high-risk patients who may have different sexual orientations or disease risks. This had the potential to lead to a disconnected record, which provided clinical diagnoses, but failed to take into consideration the qualitative experiences of patients with unique histories or circumstances.

“If you’re gay and you go to someone that’s more rural and they see that you have sex with men, they might instantly want to give you an HIV test when you just have strep throat. So, it’s like, I think there are issues around that with just them mentally decoding the things that aren’t actually there in your records. ...I think in that like the positive is the accessibility of how things could be expedited but the negative is the human factor that people are kind of like decoding the written script in a way that is through their personal value system lens.”

For these men, HIT and the role of EHRs further strip away the personal nature of health care delivery and require them to adopt routines, further trivializing their health experience, leading to increased stigma, and distorting what ought to be personalized care based on qualitative assessment.

Discussion and Conclusion

Due to stigma associated with gay men’s sexual orientation and health related risks, and illness, participants cited numerous occasions when they withheld sexual orientation and personal health information from providers, in fear of negative assessments from health care providers or information being leaked to significant others. Each age group expressed a similar concern about disclosing information. However, younger participants expressed a greater

confidence in the security of electronic health records. Participants across each age group cited a variety of positive and negative aspects of using EHRs. The perception that EHRs provided accessibility by more clinicians raised concerns for participants who feared that information in the EHR had a likelihood to be revealed to wider audiences within and outside the health care setting. This had implications for decisions to disclose personal health information for both younger and older groups.

Despite the EHRs ability to protect sensitive social information of patients, these concerns may contribute further, to not only non-disclosure, but also reluctance on the part of patients to seek out care. Participants suggested that privacy was not just about the data in EHRs but also about the patients' lifestyle and other information that could link otherwise innocuous data to something stigmatizing, such as sexual orientation (see the rectal HPV example above). One strategy to counter potential privacy breaches of personal information in the EHR might be for patients and primary physicians to identify inadvertent and indirect links, which produce potential privacy concerns and then specify what parts of their EHR they consider crucially private. However, this may limit the effectiveness of certain EHR components, which have the potential to improve health care outcomes.

Participants suggested that EHR use by health care providers created impersonal communication styles and uncertainty about what happens to information once it is entered into the record and also presented users with an inflexible and rigid system that did not take their special or unique orientations and health circumstances into account. This had the potential to lead to a disconnected record, which provided clinical diagnoses, but failed to take into consideration the qualitative experiences of patients with unique histories or circumstances.

Patients who assume precarious roles within health care systems, such as those with potentially stigmatizing sexual orientations or diseases may be further alienated from services, which systematically distort their lived experience. In this capacity, EHRs may further contribute to impersonality and uncertainty experienced by LGBT individuals seeking health services, detracting further from what Malebranche et al. (2004) suggest to be an already discriminating system of care.

With the advent of the EHR, there is a lack of clarity concerning how access, privacy, and security change doctor/patient interactions via the record. Subsequently, this has implications for the way patients manage interactions and relay information to health care providers. Withholding personal health information from health care providers will not only affect the quality of care they receive, but ultimately their health and the health of those with whom they come into contact.

References

- Allen, Laura B., Anita D. Glick (M.S.W.), Roberta K. Beach, and Kelly E. Naylor. 1998. "Adolescent Health Care Experience of Gay, Lesbian, and Bisexual Young Adults." *Journal of Adolescent Health* 23:212-220.
- Appari, Ajit and M. Eric Johnson. 2010. "Information Security Risk and Privacy in Healthcare: Current State of Research." *International Journal of Internet and Enterprise Management* 6:279-314.
- Blumenthal, David. 2010. "Launching Hitech." *New England Journal of Medicine* 362:382-385.
- Boyd, Danah and Eszter Hargittai. 2010. "Facebook Privacy Settings: Who Cares?" *First Monday*, Retrieved 8, 15
<http://firstmonday.org/htbin/cgiwrap/bin/ojs/index.php/fm/article/view/3086/2589>.
- Carlisle, Jane, D. Shickle, M. Cork, and A. McDonagh. 2006. "Concerns over Confidentiality May Deter Adolescents from Consulting Their Doctors. A Qualitative Exploration." *Journal of Medical Ethics* 32:133-137.
- Cheng, Tina L., Judith A. Savageau, Ann L. Sattler, and Thomas G. DeWitt. 1993. "Confidentiality in Health Care: A Survey of Knowledge, Perceptions, and Attitudes among High School Students." *Journal of the American Medical Association* 269:1404-1407.
- Davis, Karen, Michelle McEvoy Dotya, Katherine Sheab, and Kristof Stremikisa. 2009. "Health Information Technology and Physician Perceptions of Quality of Care and Satisfaction." *Health Policy* 90:239-246.

- Eliason, M. J. and R. Schope. 2001. "Does "Don't Ask Don't Tell" Apply to Health Care? Lesbian, Gay, and Bisexual People's Disclosure to Health Care Providers." *Journal of the Gay and Lesbian Medical Association* 5:125-134.
- Gaskins, Susan W. 2006. "Disclosure Decisions of Rural African American Men Living with Hiv Disease." *Journal of the Association of Nurses in AIDS care* 17:38-46.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of a Spoiled Identity*. Englewood Cliffs: Prentice Hall.
- Goldzweig, Caroline Lubick, Ali Towfigh, Margaret Maglione, and Paul G. Shekelle. 2009. "Costs and Benefits of Health Information Technology: New Trends from the Literature." *Health Affairs* 28:w282-w293.
- Green, Adam Isaiah. 2008. "Health and Sexual Status in an Urban Gay Enclave: An Application of the Stress Process Model." *Journal of Health and Social Behavior* 49:436-451.
- Halkitis, P. N., J. A. Pollock, M. K. Pappas, A. Dayton, R. W. Moeller, D. Siconolfi, and T. Solomon. 2011. "Substance Use in the Msm Population of New York City During the Era of Hiv/Aids." *Substance Use & Misuse* 46:264-273.
- Hersh, William. 2004. "Health Care Information Technology." *Journal of the American Medical Association* 292:2273-2274.
- Link, Bruce G., Francis T. Cullen, Elmer Struening, and Patrick E. Shrout. 1989. "A Modified Labeling Theory Approach to Mental Disorders: An Empirical Assessment." *American Sociological Review* 54:400-23.
- Link, Bruce G. and Jo C. Phelan. 2001. "Conceptualizing Stigma." *Annual Review of Sociology* 27:363-385.
- Litvin, Cara B. 2007. "In the Dark: The Case for Electronic Health Records." *New England Journal of Medicine* 356:2454-2455.
- Malebranche, D. J., J. L. Peterson, R. E. Fullilove, and R. W. Stackhouse. 2004. "Race and Sexual Identity: Perceptions About Medical Culture and Healthcare among Black Men Who Have Sex with Men." *Journal of the National Medical Association* 96:97-97.
- Mimiaga, Matthew J., Sari L. Reisner, Sean Bland, Margie Skeer, Kevin Cranston, Deborah Isenberg, Benny A. Vega, and Kenneth H. Mayer. 2009. "Health System and Personal Barriers Resulting in Decreased Utilization of Hiv and Std Testing Services among at-Risk Black Men Who Have Sex with Men in Massachusetts." *AIDS Patient Care and STDs* 23:825-835.
- National Research Council. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*. Washington, DC: The National Academies Press.
- Nelson, Kimberly M., Hanne Thiede, Stephen E. Hawes, Matthew R. Golden, Rebecca Hutcheson, James W. Carey, Ann Kurth, and Richard A. Jenkins. 2010. "Why the Wait? Delayed Hiv Diagnosis among Men Who Have Sex with Men." *Journal of Urban Health* 87:642-655.
- Ramchand, R., C. E. Fox, R. J. Wolitski, R. Stall, and R. O. Valdiserri. 2008. "Access to Optimal Care among Gay and Bisexual Men: Identifying Barriers and Promoting Culturally Competent Care." Pp. 355-355 in *Unequal Opportunity: Health Disparities Affecting Gay and Bisexual Men in the United States*: Oxford University Press, USA.
- Siegel, Karolynn, Howard Lune, and Ilan H. Meyer. 1998. "Stigma Management among Gay/Bisexual Men with Hiv/Aids." *Qualitative Sociology* 21:3-24.
- Smith, Elaine M., Susan R. Johnson, and Susan M. Guenther. 1985. "Health Care Attitudes and Experiences During Gynecologic Care among Lesbians and Bisexuals." *American Journal of Public Health* 75:1085-1087.
- Swartz, Nikki. 2005. "Electronic Medical Records' Risks Feared." *Information Management Journal* 39:9.
- Thoits, Peggy A. 2011. "Resisting the Stigma of Mental Illness." *Social Psychology Quarterly* 74:6-28.

- Thrall, Jeannie S., Lois McCloskey, Susan L. Ettner, Edward Rothman, Joan E. Tighe, and Jean Emans. 2000. "Confidentiality and Adolescents' Use of Providers for Health Information and for Pelvic Examinations." *Archives of Pediatrics & Adolescent Medicine* 154:885-892.
- Wall, Kristin M., Christine M. Khosropour, and Patrick S. Sullivan. 2010. "Offering of Hiv Screening to Men Who Have Sex with Men by Their Health Care Providers and Associated Factors." *Journal of the International Association of Physicians in AIDS Care (JIAPAC)* 9:284-288.
- Weisleder, Pedro. 2004. "The Right of Minors to Confidentiality and Informed Consent." *Journal of Child Neurology* 19:145-148.
- Weitz, Rose. 1990. "Living with the Stigma of Aids." *Qualitative Sociology* 13:23-38.
- Willging, Cathleen E., Melina Salvador, and Miria Kano. 2006. "Pragmatic Help Seeking: How Sexual and Gender Minority Groups Access Mental Health Care in a Rural State." *Psychiatric services (Washington, DC)* 57:871-871.
- Wolitski, R. J. and K. A. Fenton. 2011. "Sexual Health, Hiv, and Sexually Transmitted Infections among Gay, Bisexual, and Other Men Who Have Sex with Men in the United States." *AIDS and Behavior*:1-9.
- Wynia, Matthew K., Gretchen Williams Torres, and Josh Lemieux. 2011. "Many Physicians Are Willing to Use Patients' Electronic Personal Health Records, but Doctors Differ by Location, Gender, and Practice." *Health Affairs* 30:266-273.
- Zwaanswijk, Marieke, Robert A. Verheij, Floris J. Wiesman, and Roland D. Friele. 2011. "Benefits and Problems of Electronic Information Exchange as Perceived by Health Care Professionals: An Interview Study." *BMC Health Services Research* 11:256-256.