Negotiating stigma in health care: disclosure and the role of electronic health records

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The widespread implementation of electronic health records facilitates information sharing which can create new challenges for stigma management and disclosure during the clinical encounter. Building on theories of stigma management, we analysed 30 in-depth qualitative interviews of sexual minority men in the USA to explore how they perceived the role of electronic health records in the clinical encounter in general and for disclosure in particular. Participants expressed concerns about privacy but also saw potential benefits to electronic health records. Some thought the greater information accessibility of electronic health records was beneficial to them and their health care, but others worried about confidentiality and the potential for reinforcing stigma. Similarly, while some thought electronic health records improved communication with providers, others experienced the electronic health record as a barrier to open and trusting communication. New information technologies are changing health-care encounters, but present a double-edged sword that underscores the challenge of negotiating health care for stigmatised individuals. It remains to be seen if information technology will enhance care for all or further alienate already apprehensive health seekers from disclosing personal health information.

Keywords: disclosure; sexual minority men; health information technology; privacy; stigma

Introduction

The clinical-medical encounter is a key site in the development and understanding of the concept of stigma and practices of stigma management (Charmaz, 1991; Goffman, 1963; Schneider & Conrad, 1980; Thoits, 2011). For individuals with a socially stigmatised attribute, such as a sexual minority status, management includes the challenge of deciding whether, when, and how to disclose potentially stigmatising information (see also Clair, Beatty, & Maclean, 2005). These individuals come to clinical encounters with concerns about confidentiality and trust (Mechanic & Meyer, 2000; Ozawa & Sripad, 2014) and must contend with sometimes contradictory demands of communicating health-care needs while managing stigma and disclosure (Dindia, 1998). Such challenges affect decisions about whether to disclose personal and health information when seeking care (Cain, 1991; Willging, Salvador, & Kano, 2006).
Whereas the process and implications of stigma management in the clinical encounter have been well studied, less is known about how changes in the organisation and delivery of health care might influence patient disclosure of information. For example, new health information technologies, such as electronic health records, have great potential to improve care, yet they also can change the way providers and patients interact (Rouf, Whittle, Lu, & Schwartz, 2007; Wright, 2011). Given that electronic health records are meant to increase information access across health-care providers, one challenge raised by them is the patient’s ability to manage information disclosure to providers (Campos-Castillo & Anthony, 2014; Wright, 2011). Such challenges can be particularly acute for people worried about stigma management in clinical encounters.

In this article, we analyse qualitative interview data gathered in the USA from a purposive sample of 30 sexual minority men (gay, bisexual men, and other men who have sex with men). We explore how these individuals think about and experience disclosures of sexual identity and other associated behaviours that may be perceived as stigmatising, such as sex and health risk behaviours, and HIV status in clinical encounters and also how they perceive the role of electronic health records in clinical encounters in general and for disclosures in particular. We discuss the implications of our analysis for patients concerned about stigma and for vulnerable patients more generally. We also consider how to ensure that new tools like electronic health records can be used to improve rather than harm patient–provider interactions to increase overall quality of care.

Electronic health records, communication, and confidentiality

Over the past decade, health information technology has become more prevalent throughout health-care systems worldwide (Adler-Milstein, Ronchi, Cohen, Winn, & Jha, 2014). In the USA, this was spurred by the Health Information Technology for Economic and Clinical Health Act, commonly referred to as the HITECH Act, which has invested billions of dollars to support the adoption and “meaningful use” of electronic health records in ways that improve the quality of care (Bailey, 2011). Congress passed this Act as part of the American Recovery and Reinvestment Act of 2009, which, in part, provided this money to increase incentives for providers to move from older medical records systems to certified electronic health records (see Blumenthal, 2010).

Electronic health records have indeed been shown to improve quality of care in hospitals (Appari, Johnson, & Anthony, 2012) and recent evidence suggests benefits of electronic health records for improved communication between patients and providers (Delbanco et al., 2012). But other research suggests more mixed effects of electronic health records on communication (Irani, Middleton, Marfatia, Omana, & D’Amico, 2009; Zwaanswijk, Verheij, Wiesman, & Friele, 2011). For example, electronic health records can depersonalise the clinical encounter (Heidt, 2006). Some critics also suggest that electronic health records can limit providers’ attention to the nuances of patient histories in ways that could compromise care (Berg, 1998; Cochran, 2010). Others have found that technological changes that alter communication patterns and information flows in the clinical encounter affect patient trust in providers (Cook & Stepanikova, 2008; Mechanic, 1998).

Electronic health records also can affect patients’ concerns about the privacy and confidentiality of their information (Campos-Castillo & Anthony, 2014). Generally in health care, most patients assume that their providers protect confidentiality and use sensitive information appropriately, which are core elements of trust (Hall et al., 2002; Ozawa & Sripad, 2014). However, recent public surveys find that many people have serious concerns about both the privacy and security of health information in electronic health record systems (Dimitropoulos, Patel, Scheffler, & Posnack, 2011; Undem, 2010). Concerns about greater information sharing and accessibility
via electronic health records may be particularly salient for those concerned about stigma as these individuals are known to come to clinical encounters with heightened concerns about confidentiality and trust (Dew et al., 2007; Mechanic & Meyer, 2000; Verhaeghe & Bracke, 2011).

**Stigma management and disclosure in health care**

The concept of stigma generally refers to socially interpreted discrediting attributes that can harm an individual’s social status, reputation, or identity (Goffman, 1963). These attributes might be apparent or concealed physical characteristics of the body (e.g. obesity, disease), related to social group membership (e.g. sexual minority status), or to behaviour (e.g. illegal substance use) that have the potential to elicit prejudicial or discriminatory reaction when revealed to others (Link & Phelan, 2001). Stigma, or being stigmatised, is harmful for individuals because it leads to stereotyping, status loss, and discrimination (Link & Phelan, 2001). Thus, to understand and remedy the consequences of social stigma, proponents of the labelling perspective have long sought to identify, define, and analyse the social interactions of stigmatised groups to understand stigma management strategies (e.g. Anspach, 1979; Goffman, 1963; Schneider & Conrad, 1980; Thoits, 2011) and also how groups with concealable stigma may hide these attributes from others (Dindia, 1998).

According to Modified Labelling Theory, internalisation of stigmatised identities also varies such that individuals will utilise different ways to cope with a stigmatised identity (Link, Mirotznik, & Cullen, 1991). Two coping strategies are secrecy and selective disclosure, which both include concealing a stigmatised label from others to avoid negative consequences (Link et al., 1991). Given the negative consequences of being stigmatised, people with these attributes, particularly nonvisible attributes such as sexuality, think strategically about whether, when, and how to disclose related information (see also Saunders, 2014; Wagner et al., 2013).

Accordingly, patients’ concerns about their health-care provider’s reaction to stigmatising information can also influence whether, when, and how they use health services. These expectations of negative health-care interactions create reluctance to disclose personal information to providers (Marks et al., 1992). For example, lesbian, gay, and bisexual individuals as well as other men who have sex with men may not choose to disclose same-sex sexual identity or behaviour to their health-care providers in fear that judgments about their sexual orientation will influence the kind of health care they receive (Nelson et al., 2010; Ramchand, Fox, Wolitski, Stall, & Valdiserri, 2008). Past studies have also found that patients with other nonvisible stigmatising health conditions, such as HIV/AIDS, substance abuse disorders, and mental illness, are similarly reluctant to disclose health information to providers (Wolitski & Fenton, 2011). Nondisclosure of these stigmatising attributes is often influenced by previous negative interactions with health-care providers and by perceptions of health-care settings as threatening (Eliason & Schope, 2001). However, this process may also be based on an individual’s perception of the ratio of costs to benefits of disclosure (Holmes & River, 1998). For example, individuals may find it therapeutic or beneficial to disclose potentially stigmatising information to one party over another (Herman, 1993), such as when an individual discloses her/his sexual health history to a physician, but not to co-workers (Limandri, 1989). The logic is that some benefit may be derived from disclosure and that this may outweigh the potential for prejudice and discrimination (Dindia, 1998; Dindia & Tieu, 1996).

As disclosure decisions and trust may be interrelated (Clair et al., 2005) and multi-dimensional, related to perceptions of caregivers’ interpersonal skills and competency, expectations of confidentiality (Mechanic & Meyer, 2000), and systems (institutional) trust (Ozawa & Sripad, 2014), individuals may also be particularly sensitive to macro-level changes in health care that affect interaction in the clinical encounter and information sharing as these changes
may be perceived to reinforce, rather than neutralise, stigma. In their extensive examination of stigma, Link and Phelan (2001) discuss that much of the research on stigma focuses on individual perceptions of micro-level interactions, but too little research examines the sources and consequences of these more macro-level exclusions that may perpetuate stigma.

For patients concerned about stigma management and the disclosure of potentially discrediting information, if electronic health records negatively affect interaction during the clinical encounter or perceptions of confidentiality or trust in providers, they could decrease patients’ willingness to disclose information or to seek care altogether. Alternatively, if electronic health records have the potential to enhance health-care communication and interaction among clinicians and their patients, there may also be an opportunity to transform health care for groups who have these experiences. As such, we sought to explore how patients at risk of experiencing stigma view the role of electronic health records in health care.

Methods
We conducted in-depth qualitative interviews with a purposive sample of sexual minority men (gay, bisexual, and other men who have sex with men) \((n = 30)\) in a large northeastern city in the USA. Prior to data collection, we received approval to conduct this research from the authors’ affiliate institutional review board. Participation was voluntary and confidential with no names or other identifying information gathered from participants (all names referenced below are pseudonyms). We recruited interview participants via advertisement through a research centre that studies sexual minority health and social issues. Because the men involved in research at this centre identified themselves as sexual minorities, we based our recruitment efforts within the centre to insure interview participants met our selection criteria. Subsequently, we employed an additional snowball sampling strategy whereby initial interview participants informed other sexual minority acquaintances of the opportunity to participate. We continued recruitment until we thought we had reached saturation (Morse, Barrett, Mayan, Olson, & Spiers, 2002) regarding our key themes of privacy, confidentiality, and trust, experiences of disclosure and interaction in clinical encounters, and how electronic health records affected those perceptions and experiences. During interviews, we asked participants to describe their perceptions of confidentiality in health care as they related to personal and health information, medical records, and the patient–provider relationship. We asked them to describe their experience and views concerning disclosures of sexual identity and other associated behaviour that may be perceived as stigmatising, such as sex and health-risk behaviours, and HIV status in clinical encounters. We define a clinical encounter as any direct patient–provider interaction occurring in the course of a patient’s care. We then asked interview participants to consider the privacy and confidentiality implications of electronic health records. We defined electronic health records for participants as “medical records that are stored in a computer data base and accessed and reviewed on a computer rather than paper”. Here participants reported what they thought might be positive and negative aspects of electronic health records. We then asked interview participants to recount specific experiences where they felt electronic health records altered health-care experiences and interactions with health-care providers. Finally, we asked participants to discuss their opinions of electronic health records in clinical encounters and in health care more generally.

Sample characteristics
The men we interviewed ranged in age from 18 to 61 years old (mean age 31 years, median age 30 years). Per the aims of the study, however, we opted to collect only a limited amount of social and
demographic information in order to limit identifying markers that may inhibit participants from recounting experiences with disclosure and stigma. We did not ask participants to volunteer their race and ethnicity, although interviewer observational notes suggests the sample was likely to identify as racially and ethnically diverse. However, we did not systematically record these observations. We did ask participants to volunteer their employment status. Thirteen were currently employed, 8 were unemployed, and 9 were students in college or continuing education. Participants reported using different health-care settings, including private and public community health centres or hospitals, as well as clinics specialising in gay men’s health issues. All reported they had previous interactions with providers who used electronic health records. All but one had seen a health-care provider in the previous 12 months. Some reported minimal experience with health care, whereas others had more elaborate health histories and experiences, including treatment for serious and stigmatising issues such as sexually transmitted infections (including HIV/AIDS), substance abuse, and mental health disorders.

**Analysis**

Interviews were transcribed, then coded and analysed using Atlas.ti, v7.0. In an effort to identify overarching themes, we used a deductive thematic analysis approach that involved simultaneous data collection and analysis, synthesising theory and data using analytic codes and memo making (Charmaz, 2006; Fereday & Muir-Cochrane, 2006). Following an iterative process, members of the research team thematically coded samples of interview data into categorically similar interview text references and then compared code classifications. During this stage, a broad range of agreed on codes were identified in an effort to catalogue interview data into topic driven classifications. The research team then established a final set of codes and the remainder of the interviews were then coded by the research team and finally analysed to elucidate patterns.

**Results**

**Stigma, disclosure, and trust**

Consistent with previous research, many of the sexual minority men that we interviewed reported managing stigma in health care either by avoiding care, seeking care from unknown providers to avoid information exposure, or limiting information disclosure during the clinical encounter. Participants reported that they had chosen not to disclose information to health-care providers for a variety of reasons at some point in their lifetime. They also noted not disclosing information in the more recent past due to a variety of concerns related the use of electronic health records (summarised in the following sections). Information not disclosed was consistent with concerns about stigma associated with being a sexual minority, including sexual orientation, sex-risk behaviours, history of sexually transmitted infections, and HIV-disease status. For some participants, selective disclosure was based on what they perceived as relevant information for the clinical encounter, particularly information about personal lives. For others, concerns about disclosure stemmed from general concerns about confidentiality and privacy during the clinical encounter and within clinical settings, leading some men to avoid care altogether. For example, James described how he avoided going to his hospital:

I had this … infection, but I did not want to go to the hospital because then I’m going to be in a room [with] like four other people waiting. … Someone could walk by and see or pull [the curtain] open or something. So I was like avoiding going to the doctors.

For Phillip, the social experience of going to his doctor’s office raised concern about the confidentiality of his health information. Phillip’s concerns stemmed from the variety of
interactions he had with clinic staff that may have connections to his family and others he knew in the community:

My family knows a lot of people and I felt like it [my HIV status] would leak [because] people talk. When [they’re] asking those questions and these receptionists, they don’t care. They don’t care who you are . . . They’ll be like, “oh I saw such and such and he has HIV”. So I [have not] disclosed that.

Phillip described not wanting to disclose health information to his own health-care provider, so he sought STD testing elsewhere. He said:

there have been times [when] . . . something in my body was hurting but I didn’t want to go through the guilt and sit in a doctor’s office and know that I’m not going to be fully honest with him, so he’s not going to give me the right diagnosis because I’m not going to tell him my status. . . . [so] I took a test at a hospital that’s not in my city . . .

Disclosure was also contingent on trust. Similar to the concerns above, another interview participant, Gabe, had concerns about disclosure given how crowded his clinic often was. Not only was it difficult to get an appointment to see his doctor, but he did not trust that the information he gave to his doctor could be kept confidential in that setting. However, nearly all of the participants said that trust was important in the patient–provider relationship and most said they currently had a provider they trusted. For these men, trust was based in how the doctor interacted with them and showed care for them and their confidential information, which in turn influenced their willingness to disclose sensitive information.

Despite reporting instances of stigma management through avoiding care and nondisclosure, most of the men were also deeply aware of the trade-offs they were making by doing so. Some chose not to disclose same-sex sexual identity or behaviour because it caused them personal discomfort, which sometimes led to avoiding health care all together. For others, it meant seeking care from someone other than his regular doctor, especially for health needs thought to be particularly stigmatising (e.g. sexually transmitted disease). However, they also recognised negative consequences from these stigma management strategies and over time many of the men said they became willing to disclose information to get the care they needed. Having these general experiences with stigma, disclosure, and trust in health care, we then asked participants to discuss (our primary focus) the role of electronic health records in shaping these expectations and encounters.

Electronic health records and disclosure

When asked to consider the privacy and confidentiality implications of electronic health records, participants reported mixed views. One type of concern about decreased privacy stemmed from perceptions that electronic health records are more accessible than paper records. That is, computerised records make it easier for more people to access the information, including not only more health-care providers, but also others outside of the medical team. For example, Dwight, who noted in his interview that he had concerns about disclosing personal information to any provider other than his doctor, worried that electronic health records increased access to his information:

[In] emergency rooms you see every nurse on every computer. Who knows how many doctors can just insert whatever password . . . for the entire facility and just pull up your records because you just happen to be there.

For those concerned about confidentiality, increased access afforded by electronic health records was problematic. For example, Terence, who noted in his interview that he disclosed only
information that he thought was pertinent to his health, described worries about his current doctor who is part of a large health system that includes many other providers and services. He thought the electronic health record, in particular, would enable others in his current health system to access his information. In an effort to maintain the confidentiality that he felt had been jeopardised by the use of electronic health records at his current health-care provider’s office, Terence opted to resolve this problem by seeking care elsewhere:

> With my [current] doctor, they don’t keep anything private … I think they [other people in the health system] have access [to my record] also. They can get access to all my information. … That’s why I’m switching doctors now, going back to my old doctor.

Similarly, Tom, who reported he had avoided going to the doctor in the past to avoid disclosing sex-risk behaviours, raised additional concerns about the electronic health record regarding where and to whom his information was going,

> [My doctor] could be looking at something [on the computer] and you don’t even know what they’re doing. … I don’t know who [he is] sending the information to. … Sometimes you could be seeing a [provider] fill out forms, but where are these forms being sent to or what are they being filled out for?

Some men also worried about risks to confidentiality from the electronic health record technology itself. Others raised general concerns about “hackers” and the possibility that any computer system is at risk of infiltration or damage. For Michael, that lack of trust in technology also extended to the trust he had in his provider to use that technology in a way that would protect rather than jeopardise his privacy:

> … [Electronic health records] very much affect my trust and … the way I think about my privacy of my records … I find it a little bit scary. … you trust your doctor not to say anything to other people … and you trust people not to be careless in terms of entering information, in terms of leaving perhaps your records on a screen just for other people to look at and that kind of stuff. You trust people to be scrupulous.

Michael’s lack of trust in the use of electronic health records stemmed from a basic distrust in technology in general as a way to secure private information. However, he also observed how his provider used technology in the clinical setting. In this way, anxiety over the potential negative implications of using technology in health settings, in part, was guided by how Michael observed his provider’s efforts to meet privacy expectations when utilising technology in clinical settings.

In contrast to those who worried about increased privacy risks from electronic health records, some thought that electronic health records were more secure than traditional paper records and provided greater confidentiality. According to Dwayne, “… [An electronic health record system] is pretty secure and protected through various levels of passwords and not anyone can get into the system”. Similarly, Travis thought the information contained in electronic records would be more complete and accurate:

> It’s a little bit more confidential when it’s just based [on] the hand straight to the computer … versus it [information] has to pass through these different sets of people before it reaches its destination. So it’s better in that way.

Overall, about half of the men interviewed considered electronic health records to be less secure than paper records and, thus, a greater risk of exposing their private information. For those who tried to manage stigma through limiting information exposure, the greater accessibility to their
records via electronic health records could make them even more reluctant to disclose information or even to seek care. Others worried about the technology itself posing a privacy risk. Yet, some of the concerns about electronic health records appeared related to how participant’s believed healthcare providers managed flows of information. For those who trusted their providers, they thought their information would be protected, sometimes despite fears of the inherent risks in information technology. In contrast to those who raised concerns about increased information accessibility of electronic health records, others thought they enabled greater security for their health information, which they consequently thought would enhance their privacy. For them, electronic health records do not pose a challenge for managing stigma through secrecy or selective disclosure, but instead may encourage greater engagement with the health-care system by providing further assurances that potentially discrediting information would not otherwise be revealed to others within and outside of clinical settings. Indeed, these proponents of electronic health records experienced and envisioned a situation where the management of health information in secure settings provided an opportunity to liberate them from concerns they had about disclosure.

Electronic health records and the clinical encounter

Beyond concerns about the accessibility of information, electronic health records also have the potential to transform the clinical encounter and patient–provider relationships (e.g. Wright, 2011). Although many of the men we interviewed recognised potential benefits from electronic health records, they also worried about how sensitive information conveyed in an electronic health record might stigmatise them through being labelled as a sexual minority or a person with risk behaviours. Commenting on the privacy of electronic health records specifically, Dwayne noted:

I think privacy could be a potential problem. I think that’s probably the biggest problem. … If you’re gay and you go to someone … 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.

For Dwayne, the electronic health record had the potential to narrowly label the health needs of sexual minority men like him, potentially subjecting him to unnecessary tests and/or limiting the care he received. The electronic health record, in particular, caused some alarm for Dwayne because he expected that any doctor would have access to what he thought of as privileged, private information. As a result, Dwayne believed that going to a clinic for a minor cold now meant having your sexuality revealed to others, potentially labelling and guiding treatment.

Gabe had a similar worry. For him, the electronic health record could label him and other men like him as a particular “type” of patient and therefore limit meaningful interaction during the clinical encounter:

… because the majority of the information is already on the computer, [providers] don’t need to listen to what the patient has to say. [Providers think], like, “oh well his medical history is there, [so] … I’m assuming he has this”; instead of listening to the symptoms coming out of the patient’s mouth.

In his interview, Gabe recounted that he thought he had been labelled in the past because of his doctors knowing his sexuality. Not only did Gabe think he was labelled narrowly by information in his record, he also thought the electronic health record created an impersonal environment in the clinical encounter, which further alienated him from his providers. This experience left Gabe questioning the utility of disclosure when electronic health records were being used. The electronic health record, in effect, motivated Gabe to remain silent during these interactions. He
articulated this frustration about electronic health records in the clinical encounter during the interview:

One of my doctors is like uh-huh, uh-huh and just [looks] at the computer, which [is] negative, just looking at the computer and not physically face to face. … I feel like it’s just a waste of time, what’s the point of waiting [to talk to] a person who’s not going to care? They’re not looking face to face. It seems like [they’re] just checking my body and not assuming it could be something else. [They] just think [my sexual behaviour] is the easiest thing [so they] are not even paying attention [to anything else].

Recall from above that Gabe also came to these encounters with concerns about disclosure due to the crowded nature of the health clinic from which he sought services. Together, Gabe’s observation of technology use by his providers, compounded by his concerns about the lack of confidentiality in what he thought were crowded health settings, culminated in a pessimistic view of his current health-care interaction.

Other men reported similar impersonalised interactions as a result of electronic health records used by their providers during a clinical visit. For example, Kevin said, “They [doctors] don’t look at me, they’re looking at the computer screen and talking to me. … we had a conversation where I was talking to the back of their head while they asked me questions.” Similarly, Phillip noted: “With the computer it’s kind of like click, click, look at you, click. [They] might ask you two questions.”

These comments ran in sharp contrast to others who felt that electronic health records could be beneficial in the clinical encounter. Some participants saw real benefits from electronic health records that were, surprisingly, exactly the same as those noted above as negative: ease of access to the entire medical record and improved communication between doctor and patient. For example, Matthew explained why access to information in the electronic health record would be beneficial:

If you were seeing a new doctor or a specialist, they will already have the information in front of them. It is very accessible to them, and it is accurate, presumably. So, you don’t have to go through the same things again.

Matthew valued the electronic health record for the same reasons that Dwayne (above) suggested they would limit the medical care of stigmatised individuals. Recall that Dwayne was concerned that information about his sexuality in the electronic health record would serve as a master status label, which could potentially follow him through each of his health-care interactions. In contrast, Matthew viewed this capability of the electronic health record as something that might make his care more efficient across the variety of health settings he traversed by giving providers access to all of his information. In addition, given that disclosing stigmatising information can be difficult and stressful, the relief of not having to do this with each new provider was seen as a real benefit. This liberated Mathew from contemplating the pros and cons of disclosure during every clinical interaction that he had. Interpersonal interactions did not so readily elicit these potential apprehensions to disclose, yet allowed Matthew to interact with his providers with the confidence that his information was secure and available while not having to disclose each time he sought care.

Other men also reported that electronic health records enhanced their interactions with doctors. Early in his interview, Nick expressed concerns about clinicians other than his doctor knowing personal information contained in his record. Yet, despite these worries, he saw the potential benefit of using electronic health records in clinical settings. Commenting on an interaction with a physician, Nick noted:
We were talking about the reason why I was there and different symptoms and she was typing it up on a screen right in front of me that I could see. I feel like in the past … they kind of write it behind a pad that I can’t see. So it was cool to be able to visually [see what was being entered into my record].

For others, like Steve, the electronic health record became an information tool to use together with his doctor:

… he’s right there at the computer and I’m like right here looking at it as he’s inputting stuff and we talk and he’s telling me “this is what happened” and “this is what it was looking like last time you were here and how things have improved from your previous visit” and things like that, which is good.

Overall, some men worried that electronic health records increased the likelihood that they would be labelled with negative consequences because their sexuality and sexual history would be readily available in the record. They worried it could limit interaction with and treatment by providers based on their sexual label. In addition, some explained that the use of electronic health records during the clinical encounter negatively affected their interactions and communication with health providers. Given the importance of communication for developing a trusting relationship with providers (Mechanic & Meyer, 2000), and for disclosure in clinical encounters (Greene, 2009), providers’ use of electronic health records in ways that interfere with rapport and communication can be particularly problematic for patients concerned about stigma. For those who sometimes manage stigma through limiting information disclosure, barriers to communication and trust increase the likelihood of nondisclosure in clinical encounters.

However, not all interviewees identified electronic health records as problematic. Some thought that accessibility to information in the record, even to new providers, was a benefit. Others enthusiastically endorsed the use of electronic health records in the clinical encounter. These men reported that the electronic health record, particularly when used by a provider who actively engaged them in the use of information, improved communication between them and their providers.

Discussion

Individuals at risk of stigma, many of whom reported that they sometimes withheld information from health providers for stigma management, see both pros and cons of electronic health records. Patients concerned about stigma are challenged by the use of new health information technologies like electronic health records because they affect such patients’ ability to manage disclosure of stigmatising information. Negotiating health seeking is already difficult for stigmatised individuals who recognise trade-offs from disclosing the information that may confer negative but also positive consequences to them (Link & Phelan, 2013). Given evidence that electronic health records increase patient nondisclosure because of privacy concerns (Campos-Castillo & Anthony, 2014), these technologies may be particularly problematic for patients already concerned about information sharing such as individuals concerned about stigma.

Thus, findings from this study have a dual significance for understanding the effects of electronic health records on consultations in general and, more specifically, on interactions involving groups that are prone to stigmatisation, including men from a sexual minority group. However, health seeking becomes a double-edged sword for stigmatised individuals, in particular, as they come to these encounters with concerns about disclosure, but must also rationalise disclosure as a necessary component to their care. Barring the negative consequences of disclosure due to stigma, such individuals would benefit from more focused care by disclosing pertinent information to providers. As such, stigma can be viewed as a “package deal” in health care as
Disclosure may offer both positive and negative consequences (Link & Phelan, 2013). Though health-care providers might expect all patients to readily disclose information about health status, lifestyle, and risk behaviours (Shim, 2010), patient decisions to disclose information are influenced by their concerns about stigma and past experiences, as well as by factors related to the nature of the relationship with the provider and to the interaction during the clinical encounter. Thus, the electronic health record has become an important component influencing how a patient must further negotiate disclosure decisions during clinical encounters.

Given the importance of communication and trust for disclosure in health care (Greene, 2009; Mechanic & Meyer, 2000), electronic health records might not only inhibit disclosure and the development of trust with providers, but also seriously compromise health care. Moreover, the variety of aspects of trust reported by participants ranged from interpersonal to systems (institutional) trust. Perceptions of trust in technology in general stemmed from one’s trust in how individuals were equipped to use technology. However, they also were guided by perceptions of technology security and the ability of health-care providers and institutions to securely maintain electronic health records.

Moreover, Shim (2010) suggests that there is a “cultural logic” about patient behaviour in clinical encounters which entails a “repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviours, and interactional styles cultivated by patients and clinicians alike” (p. 1). If patients do not display such attitudes and behaviours, including openness and willingness to share intimate information, they may receive lower quality care (Shim, 2010). If electronic health records impersonalise health-care encounters, they could further alienate already apprehensive patients, not only sexual minorities but also other groups who report distrust of health care, such as racial and ethnic minorities (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; LaVeist, Nickerson, & Bowie, 2000) or other patients with stigmatising health conditions (Ding et al., 2005).

Yet, for some, the fact that electronic health records enabled their health information to be disseminated across all their various health-care providers, facilitated rather than compromised their care. For others, simple gestures by providers during the clinical encounter, such as turning the computer screen around to share information, motivated participants to think positively about electronic health records and also appeared to facilitate collaborative communication during the clinical encounter. These findings support recent research that finds patients report improved communication with doctors and more engagement with their own care when they have greater accessibility to their medical records via electronic portals (Delbanco et al., 2012).

Taken together, our focus here on recent changes in health care through the introduction of electronic health records contributes to understanding the link between macro- and micro-level stigma processes (Link & Phelan, 2001). The electronic health record, which represents a major macro-level shift in the collection and governance of health information, can inadvertently result in compromised micro-level interactions between the provider and patient, potentially reinforcing or generating disparities among sexual minorities accessing health care. To the extent that electronic health records contribute to the labelling of particular patients in ways that allow stigmatisation and potentially limit rather than enhance care, they can contribute to the exclusions that lead to negative consequences for stigmatised patients. As health disparities stem from and may be exacerbated by differential diffusion of new technologies that affect health (Link & Phelan, 1995), new information technologies like electronic health records have the potential to affect disparities. Understanding how such technologies are used will be important in determining whether the impact of electronic health records will exacerbate rather than reduce these disparities.

Understanding how electronic health records are associated with stigmatising processes in the clinical encounter, as well as how those processes can be avoided, is important to prevent the “social exclusions” that could result, such as sexual minority men avoiding or being marginalised
in health care. Indeed, our findings suggest that if electronic health records are used in ways that enhance communication during patient–provider interactions, stigmatised individuals may benefit from their use. One could even envision a world where health information technologies enhance care for those patients most reluctant to disclose potentially stigmatising information by enabling new and different forms of communication and interaction with providers.

Given that this is one of the first studies to explore the explicit role that electronic health records play among those facing stigma, there are a number of limitations that future research should address. First, we did not differentiate between different kinds of sexual minority men (gay, bisexual, and other men who have sex with men). Gay men who identify as such, likely experience stigmatisation for very different reasons than those who do not identify as gay but engage in same-sex activity. Future research should explore how each of these groups differently manage and think about stigma and disclosure in healthcare settings that use electronic health records.

This study also did not explore whether or how perceptions vary by demographic differences. For example, the role of race/ethnicity in patient–provider interaction is well documented in the scientific and social science literature (Williams & Sternthal, 2010) as is the role that race and ethnicity play in health-care interactions and disclosure among sexual minorities in particular (Wilson & Yoshikawa, 2007). We did observe instances when the use of electronic health records intersected with concerns about the crowded nature of hospital settings, such as community health centres and hospital waiting rooms, suggesting that there may be instances when concerns about the use of electronic health records are compounded by concerns about the already impersonal nature of public health-care settings often navigated by individuals of low socio-economic status. These and other demographic factors may further shape the way that sexual minority men interact with health-care providers and can potentially affect perceptions of electronic health records as well. We encourage future research to examine whether and how patient demographic factors affect disclosure, confidentiality, and trust in light of electronic health records. More broadly, future research should also explore perceptions of technology among those experiencing other stigmatising health conditions, such as mental health symptoms, to more fully understand the potential benefits and harms from technologies like electronic health records.

As new information technologies transform not only health care, but social life in general, people with stigmatised attributes will face more complex stigma management decisions as they navigate whether, when, and how to disclose personal information across electronic networks and environments. If individuals managing stigma are to be empowered rather than harmed by new technologies, it is important to ensure that such technologies enable individuals to have confidence in, and some control over, the disclosure of their personal information. Also important for health care is the way new technologies, such as electronic health records, are implemented and used by providers. Ensuring the confidentiality that is essential to the patient–provider relationship will depend on policies and technologies, but also significantly on the communication practices of health-care providers during every day clinical encounters with patients.

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