Published in final edited form as:

J Appl Commun Res. 2015 October 1; 43(4): 450–467. doi:10.1080/00909882.2015.1083603.

A Communicative Analysis of a Sexual Health Screening Intervention Conducted in a Low-income Housing Complex

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Abstract

Providing free HIV screening within public housing sites offers the potential for increased participation of at-risk populations. Residential-based screening, however, raises concerns about privacy because of the stigma attached to HIV/AIDS and even to the testing for HIV. This study examined the effectiveness of offering HIV screening within a public housing high-rise in upstate New York. Through interviews with both women who obtained testing and those who did not, this study explored the tension between convenience and privacy concerns. The findings suggest that offering HIV screening where people live could encourage participation in the screenings, as well as lead to a destigmatization of HIV testing over time. Some women chose to eschew the convenience of on-site testing in favor of a more private venue for screening, whereas some women responded positively to the accessibility of on-site testing, using communicative strategies to manage privacy concerns.

Keywords

confidentiality/privacy; health care screening; marginalized populations; HIV/AIDS; stigma

The goals of public health prevention strategies with respect to HIV are to identify HIV-infected people, get them into treatment, and counsel them about ways to prevent the spread of the virus (U.S. Dept. of Health and Human Services, n.d.). However, an estimated 25 percent of people with HIV in the U.S. do not know they are infected (Kaiser Family Foundation, 2014). HIV-positive individuals who do not know their positive status are believed to cause half of new infections (Kimbrough et al., 2009). Though testing offers a way to increase early diagnosis, get people into treatment, and help prevent the spread of infection (Bowles et al., 2008), just over half (54%) of the adult population have been tested

for HIV (Kaiser Family Foundation, 2014). As part of a larger multi-year intervention to increase low-income women's access to reproductive and sexual health care, we participated in a program with a non-profit healthcare organization to offer HIV screening in the building where the women live. The purpose of this study is to understand the perceptions of women toward the on-site screening and to learn about their communicative strategies for managing privacy.

HIV Testing in the Community

Bringing HIV testing into the community, especially with the advent of newer rapid HIV testing techniques, has been an increasingly used strategy for providing services to hard-to-reach at-risk individuals (Bowles et al., 2008). Venues for conducting the testing appear to have an impact on the success of reaching at-risk populations. Some researchers have taken rapid oral HIV testing to locations that attract people at high risk for HIV infection, such as bars, bath houses and parks (Woods et al., 2008). However, some people refuse testing in outreach settings, citing among other reasons concerns about confidentiality of results (Bowles et al., 2008). Community-based health screenings and education programs offer convenience and the support of a community setting; however, concerns about confidentiality of accessing testing in a location where other members of one's community are present might be an issue. Perhaps for this reason, no previous studies were found describing an intervention that brought HIV testing into residential buildings.

Low-income communities, in which African Americans are disproportionately represented (United States Census Bureau, 2013), have been found to be particularly vulnerable to poor health and illness, including HIV. Despite representing only 12 percent of the U.S. population, African Americans account for around 44 percent of new HIV infections in 2010. African American women are 20 times more likely than white women and 5 times more likely than Hispanic women to acquire the HIV infection (Centers for Disease Control and Prevention, 2014).

Ethnic minority women not only have a higher risk of contracting HIV (Apanovitch, McCarthy, & Salovey, 2003; Gielen, O'Campo, Faden, & Eke, 1997), they may also face additional barriers to obtaining screenings for HIV, such as lack of transportation and health insurance (Kaiser Family Foundation, 2012). Social barriers such as stigma and associated concerns about confidentiality and privacy also serve as barriers to seeking testing (Young & Bendavid, 2010). The situation is further exacerbated for low-income minority women living in smaller urban and rural areas who might have fewer healthcare providers to choose from, more limited public transportation options, and greater privacy concerns as a result of densely connected social networks (Golden, 2014).

Researchers and public health professionals have been searching for more efficient ways to reach people at highest risk for HIV with testing and counseling services because only 1.3 percent of individuals who receive HIV tests each year are positive (Kimbrough et al., 2009). One strategy to reach HIV-positive individuals involves taking sexual health testing to settings where higher risk people are likely to be found, such as community clinics, homeless shelters and bars (Bowles et al., 2008; Sanchez & Sullivan, 2008). Providing free

HIV screening at public housing sites offers a similar potential for increased participation from the at-risk population because of convenience and the opportunity to take advantage of spur-of-the moment decision making regarding testing. However, residential-based screening also raises concerns about privacy because of the stigma attached to HIV/AIDS, which potentially extends even to the seeking of screening (Wolff et al., 2005). In fact, some research suggests that worry about confidentiality is a factor when women choose a testing location (Ransom, Siler, Peters, & Mauer, 2005).

The Stigma of HIV/AIDS

HIV stigma is conceptualized as “prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, and the individuals, groups, and communities with which they are associated” (Herek, 1999, p. 1107). Consequences of stigmatization can include rejection and disruption of interpersonal relationships (Leary & Schreindorfer, 1998). Historically, HIV has been highly stigmatized because of its negative association with death, homosexuality, drug abuse, and promiscuity (Herek & Glunt, 1988).

Testing is an important first step in making decisions about care, but potential stigmatization prevents many people from getting tested and receiving treatment (Chesney & Smith, 1999). Among the more than 1 million people living with HIV in the U.S., an estimated 16 percent are unaware that they are infected. Only 54 percent of U.S. adults aged 18–64 report having been tested for HIV, and many are diagnosed with HIV late in their illness (Kaiser Family Foundation, 2014).

The stigma of HIV is associated with individuals even only suspected of having the illness. Because of the intensity of the AIDS stigma, even being tested for the virus carries privacy risks, making it less likely that some individuals will seek testing or treatment (Peterson, 2010). In an effort to manage their privacy, individuals sometimes provide unrelated reasons for visiting to a health care facility or list HIV testing as a secondary reason for the visit to avoid the stigmatization associated with the disease (Young & Bendavid, 2010). In situations where HIV testing is the only service being provided, though, such dissembling about one’s reason for the visit is not an option.

Theoretical Framework

Communication Privacy Management Theory (CPM), originally developed to help explain family communication patterns in private disclosures (Petronio & Caughlin, 2006), is a useful analytical framework for this study. CPM has been extended to explain privacy management within online communities (Child, Pearson, & Petronio, 2009) and wider social networks (Smith & Hipper, 2010). Whether individuals are considering getting HIV testing or already know their status, they wish to reap the benefits of receiving services and support, but also guard their private information. The push and pull between needing to share information to obtain services and wishing to retain control over sensitive information highlights the dialectical nature of privacy. The theory explores how individuals negotiate between the need for privacy and the utility of openness (Caughlin & Petronio, 2004).

People consider private information as something they own and which they can bestow ownership of to others when they share that information (Petronio, 1991). Through telling others, a new metaphorical boundary is formed around the information that includes the people who are privy to it (Petronio, 2002). Within the inner sanctum of a clinic or testing location, the only people coming into possession of information regarding an individual's health are the client and the health care practitioner, who is bound by institutional rules to safeguard the client's privacy. However, in the hallway outside of a residential testing center, other residents are not bound by the same privacy rules as healthcare professionals. Although testing results remain private, gossip and speculation can arise among community members and become privacy concerns for the individual. Residents construe their neighbors in the public housing complex as constituting a communicative community, with overlapping social networks. This construal was evident in data collected in formative research that preceded the intervention project (Golden, 2014) and in interviews collected for this study.

Privacy rules are created to control the flow of information in CPM (Petronio, 2002). Rules can be influenced by such factors as culture, motivations, and the cost of revealing (Petronio & Caughlin, 2006). Boundary coordination operates through using privacy rules to first determine who will gain access to the private information. The border around the information expands through disclosure. Privacy rules also determine how much responsibility someone is being given over private information and how much information can be divulged to third parties, such as other people in their social network (Petronio & Caughlin, 2006). The strength of the network tie, as well as any institutional rules, will influence the level of control the person sharing the private information will have over the recipient.

In a case study of a patient health record confidentiality breach which extended CPM's primarily interpersonal focus to an organizational setting, it was revealed how differing rules for managing confidential information among managed care, healthcare providers, and the legal system resulted in the compromising of patient's privacy (Mattson & Brann, 2002). Similar concerns about confidentiality and privacy are possible when health services are offered within a dense residential setting. In such a situation, the boundaries around ownership of information may extend beyond the control of the individuals seeking healthcare services and the healthcare provider, forcing individuals to find additional ways to manage their privacy. This study applies CPM to examine the dialectical nature of the decision for minority women to get tested for HIV in a residential setting while maintaining their privacy. Seeking a better understanding of how women think about and manage the tensions that arise in this situation, we pose the following research questions:

RQ1: What understandings regarding the advantages and drawbacks of on-site HIV screening are displayed in the talk of women who are residents in the testing site?

RQ2: What communication strategies do the women report using to manage their privacy concerns around HIV screening in a residential setting?

Methodology

The research questions are explored using interpretive methods, specifically interviews, to understand the perspectives of women living in the community about the on-site HIV testing offered within the residential setting. Interpretive research methods are ideal for this study because they focus on “how” and “what” questions (Green & Thorogood, 2009) and provide a way to “get at the inner experience of participants, to determine how meanings are formed” (Corbin & Strauss, 2008, p. 12).

The Intervention

This analysis is based on data collected as part of an intervention offering HIV screening within a public housing high-rise building in a small city in upstate New York. This intervention, focusing specifically on HIV screening, was part of a larger project, referred to locally as the Women’s Health Project, whose purpose was to identify effective strategies for encouraging underserved women in a smaller urban setting to seek regular reproductive/sexual healthcare services. The project was a collaboration of our university-based research team with local health and human service organizations. We implemented bimonthly health education events, a taxi voucher program to provide transportation to local healthcare providers, and weekly outreach by adult peer health advocates and a member of the research team to offer safer sex supplies and health information. The HIV screening initiative grew out of a partnership with a local nonprofit that provides HIV/AIDS prevention services and direct support services. The nonprofit conducted the testing and provided the counseling. We provided some of the resources necessary to carry out the testing (i.e., our field office on the second floor of the high-rise served as a private setting for testing). Our goal was to examine why the testing initiative was successful or not in attracting participants from the perspective of community members. On the fourth Tuesday of each month, a date selected to coincide with a food pantry held in the building’s community room, the non-profit organization staffed a table in the community room, providing information about HIV and details about the free testing upstairs in the WHP field office. Peer outreach workers with the nonprofit organization distributed flyers about the screening to people waiting in the food pantry line. Posters announcing the screening were displayed in the high-rise building for several days. Individuals who wished to be tested went upstairs to sign up with a WHP staff member and then returned at a designated time to receive the screening service.

The free on-site testing was designed to offer residents convenience and time efficiencies. However, field observation and informal discussion with members of the community, combined with the fact that the testing was not utilized to capacity, suggested that there might be concerns of privacy and confidentiality with on-site testing.

Participants

Participants in this study were nearly all residents of the subsidized public housing building in which the testing took place. According to the building’s management, 79 percent of the residents have a household income at or below 30 percent of the median income for the county, which for a family of four means they have a household income of less than \$22,050. Fifty six percent of the building residents self-identify as African American, and

43.5 percent as white, of which 7 percent are Hispanic. A total of 32 women were interviewed. Fifteen of them had received free HIV screening within the housing complex. At the time they signed up for testing, they were informed of the opportunity to participate in a research interview. Consistent with other activities (such as community health education events) that were offered as part of the larger intervention project, women who participated in the intervention and then sat for an interview received a cash payment of \$25.

Following a preliminary analysis of the interviews with women who had participated in on-site testing, we determined that we also needed to understand the perspectives of women who had not utilized the testing services offered in the building. An additional 17 women were recruited while waiting in line for the weekly food pantry. Of those 17, it emerged that at least four of them had taken advantage of testing in the residential building, and an additional seven had been tested elsewhere. (The rest had either not sought testing or did not volunteer information about whether they had tested or where. To safeguard participants' privacy, we did not explicitly request this information.) These participants received a cash payment of \$15 for their participation in the interview, the smaller payment reflecting the fact that the women were participating in interviews only rather than an intervention activity and an interview. The research protocol received approval from the university's Institutional Review Board.

Data Collection

Women who received HIV screening and agreed to participate in an interview were interviewed in the project field office at a later date following screening. The women recruited from the food pantry were interviewed immediately after their agreement to participate in a private area of the building management office. Interviews consisted of semi-structured, open-ended questions and lasted 10 to 20 minutes on average. We audio-recorded and transcribed the interviews in their entirety, resulting in 214 pages of double-spaced transcripts.

We asked the women who received HIV testing services in the building how they heard about the available screening services, as well as what led to their decision to be tested. We also asked participants about their knowledge of additional screening services offered at the local county health department and their perceptions of what barriers women face when deciding to get tested at any location.

We asked the women recruited while waiting in line for the food pantry whether they were aware of the free HIV testing offered in the building and what might be advantages and drawbacks associated with on-site testing. We also asked them about their knowledge of additional screening services offered at the local county health department.

Data Analysis

Informed by principles of grounded theory methodology, this study was an iterative process of collection and analysis (via coding), as well as memoing to track the development of the researchers' ideas about the data (Corbin & Strauss, 2008). Existing research sensitized us to initial concepts and informed development of interview questions. Two of the authors open-coded the interviews independently and reconciled the coding. We developed a codebook

from the open coding and reviewed it with the third author, the project director. Analysis of the data from the initial rounds of interviews indicated that the women who had received HIV testing services in the building did not perceive any barriers to themselves getting tested, perhaps not surprisingly, because they were recruited while registering to be tested. Thus, to get a broader picture of how women in the building viewed the on-site testing opportunity, we determined that interviews should also be conducted with women who had not chosen to use the on-site testing service. This theoretical sampling as described by Charmaz (2006) enabled us to follow emergent themes. We then fully transcribed and open-coded the second round of interviews. We modified the codebook and then recoded the interviews separately using the codebooks and reconciled our coding. Analysis confirmed that with the data from the additional interviews, data saturation was achieved (Charmaz, 2006; Corbin & Strauss, 2008). Coding categories and emergent themes were discussed with the project director and refined throughout the process.

Findings and Interpretation

Bringing HIV testing into public housing of low-income minority and ethnic women offers a promising strategy for reaching more members of at-risk populations. The interviews provided evidence that, for some women, accessibility influenced their decision to be tested. For others, concerns about privacy and fear of stigmatization served as a potent barrier to the testing. Overall, the interviews reflected diverse understandings and expectations of privacy.

Our findings for Research Question 1 are organized into two main categories: ways in which interviewees positioned on-site testing as advantageous, and ways in which interviewees positioned on-site testing as problematic. It is important to note, though, that these categories of interview discourse do not necessarily align with the two categories of participants (those recruited while signing up to get screened, and those recruited at the food pantry). The same person often talked about both advantages and drawbacks to on-site testing. Therefore, the results do not reflect categories of people, but rather the variety of their interpretations and ways that they talk about screening services in their housing complex. Interviews frequently reflect participants' awareness of diverse views within their community. Participants offered explanations for themselves and also attempted to explain the behaviors of others. For example, many women said privacy concerns were particularly relevant for other people, but the privacy was adequate for themselves.

Advantages of Residential Testing

Nearly all of the women talked about the advantages of having free HIV testing conducted within the building where they lived. The advantages they articulated included convenience, privacy protections, a comfortable setting, and increased visibility for HIV screening.

Convenience—The convenience offered by free HIV testing within the residential complex removes several structural barriers, including transportation, insurance, time, and cost issues. Residents of the high-rise frequently talked about this convenience. “It’s convenient. You don’t have to leave the building” (Carla, a pseudonym). Of particular importance to this community is removing the need for transportation (Matsaganis & Golden, 2015). Many residents do not have cars, the city’s public transportation system is

minimal, and taxi rides are expensive relative to income and not always reliable. The lack of transportation typically makes it difficult for residents to access healthcare.

Privacy protections—Though some women cited lack of privacy as the reason they would not have testing done within the residential building, others stated that the on-site testing offers sufficient privacy. “It’s not done in the hallway. Nobody knows the outcome but you” (Helen). In discussing privacy issues, these participants focused on the confidentiality of results, not on whether people are seen going to get tested. “I mean, they see you walking in and out, but they don’t know your test results or anything like that because it’s private” (Martha). The women who found the amount of privacy offered by residential testing sufficient conveyed the opinion that they were confident that the results would be kept confidential. Just being seen getting tested was not a cause for concern or stigmatization.

Comfortable setting—Many of the women expressed a feeling of comfort in being able to be tested within their home setting and among people they know and trust. “I know the ladies that do it (the testing)...I trust them with my information where I don’t have to worry about them blasting it out” (Martha). The community outreach peers working with the nonprofit who help recruit people to be tested live in the building and are well known and liked. Staff members from a nonprofit organization located in a bigger city about 40 miles away conducted the actual screening and counseling. When asked if she would consider having the testing done within the building, one woman replied, “Sure. This is my home. I feel comfortable” (Denise).

Because women from the nonprofit organization conducted the testing, some women discussed the increased privacy that they felt and how this made them feel more comfortable than going to their doctor. These women said that they will continue to see the doctor and the doctor’s staff over the coming years, and the results of an HIV test were not something that the women felt comfortable sharing with their regular doctors. “Going to the doctor’s might be scarier for a doctor to tell you because you know it’s your doctor and they might look at you a different way” (Nadine).

The prospect of having one’s regular doctor conduct the testing was embarrassing to some women. They preferred the relative anonymity of having the testing conducted on-site by the nonprofit staff member who they might never see again. The women do not go on to discuss how or by whom they would be treated if their test results were positive. This might reflect an assumption of seeking treatment outside the immediate community, or perhaps their assessment of their own risk as low.

Visibility—Although some women complained of a lack of privacy with the on-site testing, others framed it as an advantage. For these participants, the fact that others are aware of who is getting tested was seen as a way to encourage others to get tested. Within this interpretive framework, on-site testing increases the visibility of the testing process, which encourages more participation. The fact that the testing took place on-site was a topic of discussion among the residents. For some women, the talk centered on encouraging others to get tested.

I say, “You know they’re having the testing done for AIDS and HIV, whatever that stuff is, HPV or stuff like that in (the Project office).” And they say, “Oh really?” I say, “Well, go check yourself out.” And a lot of times when I’m waiting, they’re there at the door (Opal).

If she sees more people going there and doing it or her friends or like a relative, “Like, listen, we can go there, I’ll help you go there, or I’ll take you there, and I’ll go with you” to help them go (Martha).

The higher visibility appears to help normalize the testing process and remove some of the stigma associated with testing. When residents of the high-rise see other residents entering the room during testing hours, they might think about participating themselves.

Drawbacks to Residential Testing

Despite the increased accessibility and convenience offered by on-site testing services, evidence from the interviews indicated that there were also drawbacks that contribute to the service’s underutilization. The concerns dealt with privacy and confidentiality issues and fell into two categories: whether testing results would be kept private; and whether other residents would observe individuals accessing the testing services, leaving them vulnerable to gossip and stigma.

Confidentiality of results—Confidentiality concerns arose from a distrust or uncertainty about whether testing results would remain private by the workers who were either signing them up or administering the testing. One woman explained, “People are worried about taking the test ‘cause they are not sure who’s going to see the results” (Georgia). This uncertainty is related to the fact that the town in which they lived was fairly small and many people knew each other. Another woman explained:

I keep saying like it’s a small town, like I’m nervous with that. Like I’m not nervous to take the test ‘cause I will take the test, but it’s just to go about it like the people who’s going to do it and stuff like that. I understand everybody say it’s confidential and stuff, but you still can’t take that chance with these people in here (Iris).

Guarding one’s test results is extremely important when dealing with the stigma of HIV/AIDS. If women had any suspicions that confidentiality might be an issue, they would not likely take advantage of the convenience.

Gossip and stigma—The privacy concerns that were brought up by the women in the study more often had to do with other people in the building who might see them going to get tested, due to the dense social structure of the building. One woman felt uncomfortable with the testing process because too many people showed up at once to get tested. Because there was only sexual health screening being offered within the testing room, it was obvious to those in attendance what everyone else was doing. She explained, “I mean like when I first went, there were six of us by the door, so we all knew who was there. So, and of course, there was a lot of talk” (Alice). Another woman concluded that it is not really private in the

building because everyone knows each other. Thus, she suggested that the only way to ensure privacy would be to offer the same services outside of the building.

Some participants reported that the lack of privacy left residents vulnerable to gossip. Through gossip, people are able to share information, and find out what is going on in their social networks (Brennan, 2009). It can cement social bonds, as well as influence others (Dunbar, 1996). One woman characterized the environment in the building as full of drama where “everybody knows everybody...and it’s not fun” (Carla). Residents were aware that stories tended to start out small and grew increasingly larger as they were passed around the building. It became easy to make assumptions about what a person had been up to and that they might have a problem. If a person was going to get tested, it must be because they either have something wrong with them or they think something could be wrong. Alice explained:

Well, a lot of times, especially when you live around this kind of area, when people see you going to get tested, right away, they want to say, “Oh, she must be sick or she must be doing this or...” ... A lot of people, they would probably like to have it more private. Here, when you go, everybody’s looking, everybody’s talking.

This sentiment was echoed by another woman who realized that sometimes it was inevitable to cross paths with people who live in the same building. Once people see a person signing up or entering or leaving the testing room, they were free to draw whatever conclusions they desired and share them with whomever they wished. “That’s what they’re going to think.... Because there’s a lot of ‘em be coming out down on the elevator, and they be looking, and they say, ‘What she doing in there? Something must be wrong’ (Felicia).

Gossip is not always the transmission of stigmatizing information, but it has social value as private information. Residents feel as though many threats exist to their privacy, whether the information being passed around is stigmatizing in nature or rather just an invasion of their privacy. Being talked about by members of the community and possibly being stigmatized by association with HIV/AIDS testing was suggested as a deterrent to testing. As one woman expressed, there is a fear of “being pushed aside” (Betty) if others suspect you have AIDS or judged by others for assumed risky sexual behaviors. “A lot of people then won’t go” (Martha) to get tested at all because they fear the negative judgment of others.

Communicative Management of Privacy Issues

Our findings for Research Question 2 suggest that participants talked about the testing in ways that demonstrated their active communicative management of the tensions between accessibility and privacy. Their strategies included dissembling about their actions, downplaying the gossip while positioning their own health as the paramount issue, and encouraging others to get tested (thus positioning screening as a destigmatized activity).

Dissembling about their actions—Several women talked about concealing from others in the community the real reason for their visit to either the WHP office or the Department of Health be screened for HIV. Denise said that she would simply lie. “You know, I didn’t go in there for that. That’s what I would have done. I didn’t go in for that. You don’t know what I did. I can always keep my mouth shut. They can assume what I went in there for.”

Though others might speculate what the visit was for, they would not have proof. However, they did note that at the Department of Health, dissembling about their real motive would be easier because “there are so many different offices in there, you never know where somebody is going” (Jeanne).

Positioning one’s own health as paramount—Several women positioned their concern for their health as outweighing any possible concern with what the gossipmongers might say. “If I had to be tested right here where everybody is watching, I wouldn’t care as long as I’m getting help to catch something on time” (Betty). Elaine was emphatic that her health takes precedence over gossip.

I ain’t no shame to get myself tested ‘cause I’m gonna make sure me is all right... It’s not no reason for me to get tested here. ‘Cause I don’t care who knows I’m coming. I know I’m being safe, and I know I’m clean, and I don’t have a disease. And I don’t got time for people saying this...I don’t worry about what people saying. Well, I’m gonna get tested and make sure my self is all right. I got good health.

The interpretive resources these participants drew on could be utilized as part of their own sensemaking processes; they could also be deployed interactionally with other residents to justify and defend their decision to obtain testing. Alice related how she took control of the negative gossip by sharing her good results. After she was tested, she went out to the courtyard where people sit and talk and announced her good results. Though initially, she was intimidated by the talk and didn’t want people to see her going to get tested, she later adopted the attitude that “I’d rather know my status than what they said...Where you live, it does put a lot of pressure on you. Because when I got my results, I went outside and held it up and said, “I’m free.” I did. Just to set the record straight. I’m free.” Knowing her status was more important to her than the gossip.

Encouraging testing—Several women discursively normalized or routinized the testing process, suggesting that everyone should get tested and know their status. They argued that if most people get tested, then testing does not stigmatize anyone. They often used the word “just” to talk about testing, which functions to minimize what follows. “It’s just making sure” (Helen), and “They just figure they want to know their status before they do anything with anybody else” (Martha). Use of the word “just” seems to indicate that to these women testing is not a “big deal.” Some women talked about getting tested routinely, every few months. Their doctors ask if they want to be tested as part of their regular routine, even in front of other people waiting in line. All of this points to a discursive normalization of the testing process. “So big deal. They’re going to be tested. At least you know that you want to be healthy...to make sure” (Carla).

One woman suggested that by offering the testing in the building, more people will see others going to get tested and will gain confidence to get tested themselves. By seeing other people do it, they will feel that it is more normal and routine behavior. Lenore said that she will teach her children to get tested regularly, and that she plans to bring her 14-year-old son along one day soon to get tested, thus modeling for him the normalization of testing. “My

son is 14, and I already told him, like he's going to come with me one day and get tested for HIV and everything else."

These communicative strategies for managing the issues of privacy suggest that it might be possible for testing to move toward becoming normalized within the building. The regularity of the testing and the visibility that people are getting tested, along with the presence of posters and peer educators doing outreach, might be contributing to a process of destigmatization of the testing process.

Discussion

As CPM theory would suggest, this study found that perceived confidentiality breaches regarding HIV testing in a dense residential setting forced women to find ways to manage their privacy. The evidence also confirms that there are not just structural barriers that need to be overcome to improve participation levels, but also social barriers, such as fear of stigmatization and concerns about gossip. We discuss below three areas of implications of our findings: First, social barriers might be ameliorated by developing a better understanding of how privacy concerns impact decision-making of participants and their communicative strategies for managing privacy. Second, our findings suggest that on-site testing enables potential results that could not be achieved through interventions in alternative settings. Finally, we discuss implications for practice.

The Impact of Privacy Concerns

Evidence from this study indicates that accessibility and the convenience of not having to travel far from home or take time off from work to obtain the testing influences some women when they are considering getting tested. Despite these advantages, the testing service not operating at full capacity suggests that other factors are at play. Although the density of the social ties in the community helps to spread the word about the availability of on-site testing, it might also work against the testing because of the sensitive nature of HIV/AIDS. The role that privacy management needs might play when the information at issue is of a sensitive nature should not be underestimated.

The interviews with women recruited from the food pantry confirmed that concerns about privacy are indeed an issue within the community. Most people prefer anonymity when getting tested for HIV, but this could not always be provided in a building where most people knew each other. Gossip was perceived to be inevitable once someone was spotted signing up or entering or leaving the testing room. Many women perceived that others in the building would assume a person was more likely to be HIV positive or to have engaged in high risk behavior simply if they were seen getting tested.

The women in the building had to deal with a tension between the open promotion and recruitment for HIV testing, and the desire to keep their sexual health private. As CPM suggests, the risk of putting yourself out there by being seen going to get tested is that others can use that information against you (Peterson, 2010). For some women in this study, this was definitely a concern. The fear of being stigmatized or "pushed aside" (Betty) was voiced frequently. In an effort to control their privacy about this sensitive issue, the women resorted

to multiple strategies, including choosing not to take advantage of the on-site testing because “you still can’t take that chance with these people in here” (Iris), preferring to seek testing elsewhere or going without. Other women found communicative strategies for managing their privacy in order to take advantage of the testing, such as taking control of the rumor-mill by sharing their results, choosing to dissemble about what they were doing in the testing room, or working to normalize the testing process by routinizing the practice.

Additional Advantages to Testing in a Residential Setting

Evidence from this study also suggests that locating the testing within a residential setting may provide opportunities for intervention gains that extend beyond the public health goals of performing larger numbers of sexual health screenings. These benefits could include changing how the residents perceive the meaning of the testing and promoting spur-of-the-moment decision-making by having recruiting for testing in the same place located on-site.

Changing the meaning of testing—The first benefit from offering testing in a residential setting could be a desensitization to the testing process that can occur when individuals see the promotional signage every month and observe others going to get routinely tested. This could progress to a change in how people in the community think about testing, perceiving it as more routine rather than something only those in trouble do. This process happens within the community, when community members interact and together make sense of their environment, and perhaps destigmatize testing. Ball-Rokeach, Kim, and Matei (2001) reference this type of interaction in describing the “interpersonal networks including family, friends, coworkers, and neighbors who share information about their daily lives, offer advice, and tell stories about the neighborhood” (p. 202). The interview data suggest that the community currently includes individuals who represent a range of interpretive positions with respect to what it means to see someone accessing sexual health testing. At one end of this continuum are individuals who make negative assumptions regarding the likelihood that the person getting tested has something wrong with them. At the other end of the continuum, we see a different interpretive framework, where women have already normalized the testing process and see it as a good thing. They might think that those who are not getting tested are not necessarily better people, but rather could be worried or in denial. In the middle are women who use the visibility of seeing others get tested as encouragement and confirmation that it is okay for them to get tested. Several women discussed how the visibility of the on-site testing encouraged others to get tested, and how taking the initiative themselves encouraged others to get tested. More data gathered over a longer period of time would be needed to draw more definite conclusions about this possible gain.

Locating testing within the residential environment could be a powerful way to destigmatize testing, but researchers and organizations engaged in health promotion should not expect this to happen overnight. It is an ongoing process as people find ways to talk about the testing within the community. The findings of this study suggest that people’s attitudes about testing could change as the community develops new ways of talking about and understanding getting tested for HIV where they live.

Providing testing on a “then and there” basis—Another advantage of on-site testing parallels related health communication research on workplace wellness programs (Watson & Gauthier, 2003) and points to the role of immediacy and convenience in encouraging new health-related behaviors. By locating recruiting efforts in the building lobby, interactions take place in which women are approached and offered testing then and there. This differs significantly from the situation where women have already made the decision to be tested prior to going to their doctor’s office or the county health department. The latter case requires that people receive a message advocating testing, make the decision to get tested and then get themselves to the institutional setting. They might see promotional materials or hear about the testing opportunity, but they do not interact with the testing organization until they arrive at that location. By having the recruiting and testing located within the same residential area, there are opportunities for residents to have one-on-one interactions with peer recruiters who live in the building, too. This contributes to the level of comfort, provides an opportunity for the peers to influence decision-making, and contributes to the process of destigmatization by regular exposure and the fact that the peers are part of the interpersonal sensemaking networks.

Implications for Practice

The findings of this study suggest that on-site testing and associated messages may encourage routinization of HIV testing within a community. This approach is in line with public health initiatives adopted by some states that recommend HIV testing be offered as part of prenatal care, emergency room visits, and annual wellness exams, as well as with national campaigns such as MTV’s GYT (Get Yourself Tested) campaign (MTV, n.d.) and the I Got Tested campaign (Greater than AIDS, n.d.). In addition, messages to promote on-site HIV testing could be fine-tuned with the goal of attracting increased participation. Specifically, signage to promote the events might be revised to speak about the routine of sexual health checkups (“Is it time for you to get rescreened for HIV?” “HIV Screening—it’s part of a healthy routine”) or the inclusiveness of the testing (“Don’t be the only one on your floor who doesn’t know her status!”). Additionally, peer educators could be coached about how to talk to women in ways that support the routinization and inclusiveness of testing.

The findings that there is a continuum of interpretive positions with respect to how women view the on-site testing suggest that messages could be developed to appeal to individuals along the spectrum. For example, women located near the middle of the continuum might respond better to words of encouragement and confirmation that getting tested for HIV is a standard part of caring for one’s health.

Privacy concerns must be dealt with in any type of health intervention. In this study, rules were implemented to protect people’s privacy. Measures were taken to maximize their privacy, such as the timing of when participants entered and exited the testing room. The women signed up and then received a specific time to come back for testing. No system is perfect, though, and there was no guarantee that people would not see each other accessing the testing. The peers who assisted the organization with the testing process lived in the community and were trusted. This made some of the women getting tested feel more

comfortable about being tested where they live. Practitioners must do what they can to ensure privacy, but the ultimate goal is to normalize testing, which will decrease the level of stigmatization associated with it.

In summary, on-site testing reaches women; they do use it, although it is not an immediate panacea for the problem of getting all potentially at-risk individuals to learn their status. The value of on-site testing, however, extends beyond the extremely significant public health outcome of getting testing. The particular communicative characteristics of the residential community setting can yield the double dividend of normalizing the testing process while reaching hard-to-reach individuals, which in turns leads to more screening.

Conclusion

The findings of this study suggest areas for further research. First, because this study was conducted within one subsidized housing complex in a small upstate New York community, which might limit the generalizability of its findings, evaluation of similar interventions in other communities should be conducted. Additional research in other locations would also be helpful in determining the effect of other environmental and societal factors on the usage of sexual health screening services.

In addition, longitudinal studies should be conducted to determine if bringing testing into residential areas has an impact on destigmatization over time. A closer look at the continuum of interpretive positions with respect to how women view the on-site testing would be a fruitful topic for further study. Does regular and prominent visibility of HIV testing within one's residence encourage women to move along a spectrum towards greater normalization of the testing? Finally, whereas the analysis presented here has focused on the privacy-accessibility dynamic, it was also the case that participants offered explanations other than privacy concerns for some women's choice not to be screened for HIV—predominantly fear of the results. As we have noted elsewhere (Golden & Pomerantz, 2014), women's assumptions regarding the potentially catastrophic impact of positive findings from reproductive and sexual health screenings can have a powerful negative influence on their decisions to obtain these screenings. Moreover, we concur with other researchers who have observed that many health communication interventions promoting screening tend to imply a scenario in which the individual obtaining screenings experiences the relief of receiving a clean bill of health rather than the more complicated scenario of dealing with positive results (Babrow & Kline, 2000; Johnson, 2012). Interventions that balance direct acknowledgement of the seriousness of potential positive findings, with reassurance that positive findings do not necessarily lead to catastrophic consequences (e.g., treatment is available for HIV) may be more effective in encouraging potentially at risk individuals to obtain screenings than “normalizing” discourse alone. This could contribute more effectively to reducing the disproportionate burden of HIV borne by low-income minority communities.

Acknowledgments

This research was supported by the National Institute on Minority Health and Health Disparities, National Institutes of Health (grant number P20MD003373). The content is solely the responsibility of the authors and does not

necessarily represent the official views of the National Institute on Minority Health and Health Disparities or the National Institutes of Health.

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