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Disclosure Decisions of Rural African American Men Living with HIV Disease

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Abstract

A qualitative study was conducted to explore disclosure decisions of rural African American (AA) men living with HIV disease. The sample consisted of 20 HIV-infected AA men living in the rural south, who had been diagnosed with HIV for at least six months. Audio taped semi-structured interviews were used for data collection. The men were questioned about who they had told about their disease, reactions to their disclosures, and their advice to others about disclosing. Findings showed initially the men did not disclose their disease to others, and many of them continued not to disclose. They were concerned about negative consequences, such as rejection, fear of contagion, and of the recipients telling others. If and when they disclosed, it was likely to be to sexual partners, immediate family members, and health care providers. Their decision not to disclose protected them from the possible negative reactions, but it also limited the amount of social and emotional support they received related to their HIV disease.

Keywords

disclosure; rural south; African American men

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The rural South has more than half of all rural cases of AIDS in the US and the most rapid growth in AIDS cases of all regions in 2003 (CDC, 2004). Rural residence compounds the difficulties faced by people with HIV/AIDS. Compared to people living in urban areas, rural residents are often less educated, more likely to be unemployed, and to lack health insurance. Access to care and services is poorer because of scarcity, distance, expense and lack of transportation. Very importantly, conservative cultural norms are common in rural areas, resulting in stigmatization of people with HIV disease. Thus they are reluctant to disclose their disease status, and less likely to use available services for fear of shunning or negative reactions (Crary, 2001; Whetten-Goldstein, Nguyen, & Heald, 2001). The always difficult issues of disclosing their disease status and to whom becomes an even greater burden than for people living where social norms are more liberal.

The purpose of this study, which is a component of a larger qualitative study on the experience of rural men living with HIV disease, was to understand the experience of southern rural African American (AA) men with HIV disease in disclosing their disease status.

Background/Review of Literature

Disclosure of being HIV positive is a difficult and important decision for all infected people (Levy et al, 1999; Holt, et al, 1998). However, it has also been identified to play a significant role in how individual's cope with their disease (Holt, et al, 1998; Perry et al, 1994). While disclosure can have positive effects on an individual's health, such as increased social support and decreased stress, it also has the potential for negative effects which are dependent upon

the recipient's response. For the majority of individuals with HIV, disclosure is stressful. There is a fear of rejection, discrimination, and abandonment (Sowell, Seals, Phillips, & Julious, 2003; Levy et al., 1999). Rather than the relief that is anticipated when one discloses to other, there are often regrets (Levy et al., 1999).

Regardless of the stress involved, the majority of people with HIV do eventually disclose to others (Levy, et al., 1999). The decision to disclose has been reported as a process beginning with the individual's adjustment to the diagnosis (Kimberly, Serovich, & Greene, 1995). This initial time is a period of personal adjustment to learning of their diagnosis. Other steps in the process include evaluating one's personal disclosure skills, deciding whom to tell, considering the recipient's circumstances, anticipating the recipient's reaction, and having a motivation to disclose. HIV infected individuals consider specific criteria of the recipient including not only their relationship to the person, but also the quality of that relationship, as well the perceived likelihood that the other person will keep the information confidential (Sowell, Seals, Phillips, & Julious, 2003). While disclosure is usually a reasoned decision, it also can be an emotion outburst (Levy, et al, 1999).

Part of the disclosure decision is the issue of to whom to disclose. The most likely identified recipients are sexual partners, close family members and friends, and health care providers. Studies on disclosure to sexual partners have identified that people with HIV disease do not consistently disclose to their sexual partners. In a review of the literature on male self disclosure to sexual partners, Sullivan (2005) reported that disclosure rates ranged from 67% to 88%. The disclosure rate decreased as the number of sexual partners increased. Indeed, individuals are supposedly required to inform their sexual partners when they are diagnosed. However, many HIV positive individuals do not tell all of their sexual partners, especially their casual sexual partners (Serovich & Mosack, 2003). White men are more likely to disclose to their sexual partners than AA or Latino men, and AA men are the least likely ethnic group to disclose to their partners (Stein, et al, 1998; Sullivan, 2005). Possibly there is more stigma, shame, and dishonor associated with HIV disease in the AA community.

The decision to disclose to family members is a difficult one that depends on the family members' role, the quality of the relationship, and the anticipated response (Kimberly et al, 1995). Anticipated responses include supportive, hostile, and ambivalent emotions. If a hostile or ambivalent response is anticipated, disclosure is less likely to occur. Actual responses by family members to HIV-disclosure have been reported to be complex and multidimensional (Serovich, Kimberly & Greene, 1998). Responses have been categorized as intellectual, physical, spiritual, relational, instrumental, and emotional, as well as negative or positive within each category. Factors influencing the family members response are not only the relationship, but also whether the family members has known other people with HIV/AIDS, how much they know about transmission, and whether they are prejudice toward people who are infected.

To access care, it is critical for HIV positive individuals disclose to their primary health care providers. Regardless, not all individuals do (Sankar & Jones, 2005), nor do they always disclose to other health care providers, such as counselors (Nelson & Brian, 1998).

Disclosure has been studied in both men and women (Murphy, Roberts, & Huffman, 2003; Levy, et al, 1999; Holt et al., 1998; Serovich, Kimberly, & Greene, 1998; Sowell, Seals, Phillips & Julius, 2003). Most of the studies on disclosure in men have focused on gay men. While the findings have many similarities, women have been reported to worry more about disclosing to their children. Women are reported to disclose to others sooner after their diagnosis than men. Also one study that included men and women reported that not disclosing to anyone was an exclusively male reaction (Levy, et al, 1999).

In the larger study to promote understanding of the lives of rural AA men living with HIV disease, a number of issues, concerns, and problems were identified. The men spoke extensively on problems related to disclosure, and they were identified as one of the major concerns and stressors for the men. Their experiences with disclosure will be described in this report.

Method

The research design is an adaptation of Parse's descriptive exploratory method, using a single semi-structured interview as the main data collection technique. This design is appropriate for eliciting rich data about participants' lives, including culture, communication styles, racism, and discrimination (Parse, 1996).

Procedure

An AA AIDS educator who worked in rural counties was consulted in developing the interview script, and in planning strategies to access the participants and conduct the interviews. Potential participants were identified by the consultant, case managers and Directors at the ASOs. They were asked of their interest in being in the study. If interested, permission to share their names and contact information with the researcher was obtained and forwarded to the researcher. The researcher then contacted the participants and arranged a mutually agreed upon time and place to meet for the interview. The majority of the meetings were at the ASOs in a private office. Prior to beginning the interview, the study purpose was explained to each potential participant. After obtaining informed consent, a Personal Information Form was used to collect demographic data and a brief medical history. These questions were read to the participants. The interviews were audiotaped and lasted approximately 2 hours. The men were paid for their participation and travel expenses.

Instruments

The Personal Information Form was designed specifically for this study. Participants were asked to provide standard demographic information on their age, education level, living arrangement, number of children, employment status, transportation needs, and income level. Related to their HIV disease, they were asked how long they had known that they were HIV positive, what medicines they were taking, where they were receiving care, and to rate their relationship with their health care provider.

A semi structured interview guide consisted of open-ended questions related to disclosing their HIV diagnosis. Probes were used as necessary to elicit descriptions and interpretations of their experiences. The questions related to disclosure addressed: a) who had been told, b) what were people's reactions, and c) what advice they would offer others in disclosing. Related to the disclosure questions, were questions about their family's response to their disease. The audiotapes of the interviews were transcribed verbatim for analysis. These transcripts were the primary data used in content analysis. Under each question, individual items of information were categorized and coded, and major themes were identified.

FINDINGS

Sample

The sample consisted of 20 men recruited from two ASOs serving rural areas in the south. The men had known that they had HIV disease for at least six months, and a positive HIV-antibody test was verified by the ASOs. Both of the ASOs offered HIV testing and counseling, case management services, and worked closely with clinics providing care to people with HIV disease.

The men's ages ranged from 31 to 54 years old. The majority (n=17, 85%) of the men had completed high school. While 11 (55%) of the men had some education beyond that, only 5 (25%) were college graduates. Three men (15%) were married and lived with their wives (only one of the wives was infected), 12 (60%) lived with a friend or relative, and 5 (25%) lived alone. Most (n=12, 60%) of the men had children, and four (20%) of them had children living with them. Many of the men's children were grown and living on their own. Seventeen (85%) of the men were unemployed. All of the men had been employed prior to their diagnosis of HIV, and the length of time since employment ranged from six months to over 10 years. Twelve (60%) of the men had health insurance, most of those had Medicaid. Only 11 (55%) of the men had their own means of transportation. The others depended on friends or relatives to take them places. All of the men reported an income of under \$20,000 a year, and 14 (70%) were under \$10,000. Seven (35%) of the men reported knowing "many" people with HIV disease, but most of them said only a few people. The people they knew included both males and females, and the majority of them were AA. The length of time the men had known that they were HIV positive ranged from 6 months to 20 years. Over half (n=11, 55%) of the men had known for over five years. The most likely mode of infection was sex with an infected man (n=10, 50%), followed by sex with an infected woman (n=5, 25%). Other modes included intravenous drug use, and sex with either an infected man or an infected woman. Half of the men were having symptoms related to HIV, the most common symptom was fatigue. The majority (n=18, 90%) of the men was on medications, but many of them were unsure of the names of their medications. Most of the men went to local clinics that were affiliated with the ASOs for their health care. Two (10%) went to Infectious Disease clinics in large cities. Their relationship with their health care provider was reported to be excellent by most of the men (Table 1).

Disclosure

When the participants were asked whom they had told that they had HIV disease, sexual partners were identified as the most likely people to be told, and the people who needed most to be informed. Most of the men stated that very few people had been told. The ones who were married talked about only telling their spouses and that together they made the decision not to tell others. One man stated, "I have only told my wife. Not my children or family. I don't think they would understand. I am afraid they would think I am contagious. They are not educated..... My wife's son lives with us and he does not know. My wife wants me to start telling people, but I tell her that I need more time." Another man who was engaged to be married talked about telling his fiancé, I told her immediately. I have not told anyone in the family or any of my friends." All of the men had told their partners if they were in a sexual relationship at the time of diagnosis, and most continued to do so. One man, who confessed that he did not disclose to all of his sexual partners, stated that he always used a condom. All of them said that they used condoms consistently in sexual relations. Several of the men said they had stopped having sex altogether.

All of the men said they told their health care providers about their HIV disease. Some of them spoke about health care providers needing to be told, and how they told providers other than their regular ones, such as providers in the Emergency Room and dentists.

After sexual partners family members were the next most likely group of people for the men to tell about their HIV disease. As one man commented "AIDS is such a taboo label that I am careful about who I tell and what I say. I don't talk about it, except with my family. You never know how people will react." Another man said, "I told my family immediately—the night I found out. I didn't tell my father, because he and my mother are not together. I told my mother, my grandmother, and my brother." There was a wide range of family members to whom they chose to disclose their HIV status, and the decision depended on the member's prior relationship with the participant. Mothers were the most likely family member to be told.

Fathers, siblings, grandparents, cousins, and children were also likely to have been told. One participant had not told his father, and they lived together. At the same time, many of the men chose not to tell certain family members, either because they feared their reaction or they wanted to protect the member from other people's negative reactions or from worrying about them. Some family members were chosen because they were health care providers (nurses) and the men felt like they knew about HIV disease. Several of the men talked about how they had planned the time to tell their families about their disease. Family reunions or get-togethers were chosen as the best time to disclose to their families. For example a participant stated "At first I kept it to myself for five or six years. I finally told my family at a family reunion." These families had all reacted positively and were supportive of the participants. Another man talked about disclosing to his sister, "She was my best friend so I decided to see how this works (to tell someone about having HIV disease). She was very supportive and did not have anything negative to say. She said we would find out what I needed to do. She said I still love you and I always will—you are my baby brother." Several of the men had had negative reactions when they told their family members, especially with the members telling other people. One man said he disclosed to his sister because he was close to her, but she betrayed him by telling her husband and son.

A few of the men referred to time being related to when they chose to disclose. Several of them had disclosed when they were ill. The longer they had known their diagnosis, the more likely they were to begin to disclose. Many of them spoke about the denial initially after their diagnosis. One commented, "I left my disease at the clinic." Very few of the men were totally open about their HIV disease, and all of them had known for over 10 years. The few who were open were happy with their decision to tell others. As one stated, "If I had it to do over, I would tell everyone from day one—the day I found out. I think my life would be better now. It took me too long. I did not know how people would react, but they reacted with love, and I could have had that all along."

Some of the men had told their friends about their disease, but most had not. Friends who had HIV disease were the ones most likely to be told. One man talked about deciding to disclose to a friend because the friend had HIV disease and was suicidal, "I decided to share with him and try to help him out. Now we can share with each other."

While many of the men attended church services, only one had told his pastor and the congregation. Going to church was identified as a source of strength in helping the men deal with their disease. However, it was not that the congregation offered support because of their disease, but the fellowship, rituals, and teachings that helped them deal with it.

Advice to Others—When asked what would be their advice to other people about disclosing their HIV status, the majority wanted to warn people to be careful about sharing the information, and to choose carefully the people to whom they disclose. As one man said, "Just tell the people who are closest to you, and the people it will effect or have a bearing on. Make sure to tell partners you choose to be involved with." Another one commented that people need to understand that it is a big decision to "put yourself out there." One man advised others, "Pray about it. Think long and hard about who this person is you are going to tell. The last thing, be prepared if the person goes out and tells it. You have to handle it if they do." One man's statement summarized the others' sentiments, but he added the importance of including about how the disease is being handled, "Choose people you can trust, someone you are close to, someone who is part of your life...Convince them that you are taking care of yourself and getting better, then they can accept what you are going through. If you are not helping yourself, they will not want to be around you."

While the majority had had positive, supportive reactions from others when they disclosed their disease status, they felt it was because of their careful choices about whom to tell. The families whom had been apprehensive initially, had become supportive over time, and received education about HIV disease. A few of the men had taken pamphlets to their families, or people they told, but most had not. One man spoke about how his family tried to educate him about his disease, and regularly sent him pamphlets and literature.

The rural area was identified as a barrier to disclosing their HIV status for a number of the men. As one said, “I haven’t told many people about my disease. Out here in the rural area people are not educated—they don’t understand. Here everybody knows everybody’s business. They still think HIV is a death sentence that gay people get.”

A number of the men acknowledged the importance of getting others educated about HIV disease, and felt an obligation to help. The ones who were open about their disease were involved in educational outreach programs from the ASOs. A few said they would not mind speaking to others if the program was in a different city or county where they were not known. Some felt that eventually they would become more comfortable sharing their disease status and experience with others.

Dealing with Families—Most of the men’s families were involved in their lives. Many of them had lived away from their family of origin when they were diagnosed, but had returned home when they became ill. The majority of the men lived with their family or near them. Sources of support from families included food, transportation, money, and emotional support. The families were large for many of the men, including a large number of siblings as well as other extended family members. One man complained that his family was overprotective, “I had to stop my family from calling me. My grandmother wanted to move in and take care of me. It is a good thing because I know they care, but sometimes I get annoyed.” The one need from family members that most of the men said they did not receive was the need to talk about their disease. They said their families were not comfortable talking about it or did not want to discuss it. For several of the men, their families were a source of stress. If the relationship had been stressful prior to the men’s diagnosis of HIV, the disease seemed to exacerbate it.

Living with HIV in a Rural Area

The men were questioned about special needs, advantages and disadvantage of living with HIV in a rural area. Most of the men identified education as a critical need for their rural community. As one man said, “There is still a lot of ignorance about AIDS here”. Another one said, “The people in small towns are uneducated about the virus. People look down on you real bad. They are not educated.” These concerns related to living in a rural area were major factors in disclosure decisions. Some of them spoke of trying to educate others, especially other people with HIV disease. The few men who were open about their diagnosis were willing to educate others whenever needed. Several others said they would be willing to educate others in private or out of town. The men suggested possible strategies to offer education, such as through the schools, churches, or a number to call. Some of the men felt like they needed access to more current information on treatment for the disease.

Several of the men identified the need for more emotional support for people living with HIV disease. Both ASOs had had support groups which were no longer functioning. One issue with the support groups had been that some people did not want to come to the ASO office. They talked about not having anyone to talk to about their disease. Many of them ended the interview wanting to meet with the researcher again and expressing how much it had helped them to be able to talk openly about their disease. They commented that they did not have anyone, other than the staff at the ASOs, with whom to talk about their disease. Again, the men’s disclosure decisions limited the amount of emotional support they received from others, such as friends.

The major source of help in dealing with their disease in their communities was the ASOs. They talked about visiting them at least once a month, while some of the men visited the several times a week. One man commented, "This agency helps me deal with this. I come in here two or three times a week. I see the staff and other people here." Another man said, "There are real good people here who go out of their way to help you." The men's case managers were at the ASOs. Often they met with them to apply for benefits or services, financial assistance, or referrals. Both ASOs had food banks for their clients. Plus the men felt that their confidentiality was safe at the ASOs.

Some of the men liked living in a rural area because of less pollution and crowding. Most of them were very satisfied with their health care, and did not feel like it would be any better in a city. Several of them had received health care in larger cities and did not feel that it had been better than what they were receiving. However, they did feel like cities probably offered more services, resources, and job opportunities. One problem for many of the men was transportation. The lack of public transportation made it difficult for the men not only to go for their health care, but to get around in general. Both ASOs offered transportation for their clients to get to their clinic appointments. One had a van and the other had volunteers or staff who drove the clients and were reimbursed for their gas.

The major disadvantage of living in a small town with HIV identified by the men was stigma. They worried about their privacy and confidentiality. Some of them worried about being seen at the clinic. They felt like people in larger towns were better educated and did not care as much about everyone else's business. Most felt that they would not have to be so careful about disclosure in an urban area.

DISCUSSION

The sample is small in this qualitative study, and was recruited from two southern ASOs which limit the generalizability of the findings. However, the strength of the study is the insights it provides into the lives and experiences of AA men with HIV disease, one of the most disproportionately impacted subgroups in the country. Also the men are from the south, the area of the country with most of the cases of HIV/AIDS.

Typical characteristics of other individuals with HIV disease in the rural southeast, most of the men had a high school education or less, were of low economic status, and had transportation difficulties (Whetten-Golstein, Nguyen, & Heald, 2001). Also similar to the rural residents in Heckman and colleagues' study (1998) comparing rural and urban people with HIV, the participants were likely to: 1) distance themselves from their infection, 2) receive less social support, 3) feel that there is community stigma related to HIV/AIDS, and 4) fear that their HIV status will be learned by others. A major difference with the men in this study from others was that most of them receive their health care locally, as opposed to traveling to other areas for better care or concerns about confidentiality (Mainous, Noble, Neill, & Matheny, 1996). While many of the men worried about their confidentiality, they voiced a trust in having it protected at the ASOs and the clinics. One man had commented "No one from here is going to say anything to anyone". The social support provided by the ASOs was a major factor in helping the men deal with and manage their disease. Not only were most of the men receiving their care locally, they were pleased with their care, and the majority reported having an excellent relationship with their healthcare provider, a critical factor in enhancing adherence to treatment (McPherson-Baker, Malow, Penedo, Schneiderman, & Klinas, 1996). In spite of reporting satisfaction with the care they were receiving, the majority of the men did not have basic information about disease progression, their viral loads and CD4 counts, which were routinely done at the clinics. There was a trust in the physicians to handle the treatment. Perhaps this was a strategy to distance themselves from their disease.

The decisions, concerns, and issues related to disclosing their HIV status to others are not unusual. There have been studies on disclosure of HIV status to sexual partners and family members (Kalichman & Nachimson, 1999; Kimberly, et al, 1995; Serovich & Mosack, 2003), employers and co-workers (Flesko, 2001), and the decision making process for women (Sowell, Seals, Phillips, & Jusius, 2003). While disclosure experiences and recommendations vary with individuals, relationships, and situations such as location or stage of illness, there are two common factors related to making the decision: 1) it is personal, and 2) it is difficult. In this study, the men's descriptions of living in a rural area where there is still ignorance related to HIV disease as well as a fear of people talking to others are certainly factors related to how they made decisions about disclosure. These factors are also related to the stigma that is associated with HIV disease that is feared by the men. From the beginning of the HIV/AIDS epidemic, the fact that HIV is transmitted through sexual and drug-use behavior has resulted in negativity, fear, and judgmental reactions to infected people. One strategy to combat stigma is education to increase knowledge and understanding of HIV disease (Valdiserri, 2002). The participants talked about the lack of HIV/AIDS knowledge in their communities as a major factor in their decision not to disclose their HIV status.

The decision of how and when to disclose one's HIV status to family members is common among all individuals with HIV disease (Serovich, Kimberly & Greene, 1998; Kimberly et al, 1995). Also, similar to findings in other studies (Cohn, Klein, Mohr, Van der Horst, & Weber, 1998), a number of the men in this study had returned to their rural home to be with their families after becoming infected with HIV or ill. While Heckman and colleagues (1998) reported that rural residents with HIV were likely to report low levels of social support from their families, most of the men in this study were pleased with the support they received from their families.

The men did not discuss telling their employers, a group often identified as needing to know one's HIV status (Flesko, 2001). Of course, most of the men were not working. However, even the ones who were working did not include employers as people who needed to know. Some even said it was better if employers did not know.

Implications

As individuals with HIV struggle with disclosure, there is a need for interventions to assist them with their decisions. They need to consider the benefits as well as the risks of disclosing to others. They need to be counseled about selected groups who need to be told (ie. sexual partners and IV drug use partners), as well as others who have been identified as supportive and helpful. HIV positive individuals also need assistance in developing plans for disclosure to increase the likelihood of a positive experience. Helping individuals with HIV disease anticipate questions, concerns, and needs of the people to whom they choose to disclose will assist them in being prepared to handle those issues. For example, the perceived lack of education was a major concern for the men in this study, and a reason given for not disclosing. Being prepared to educate recipients of disclosure with current, factual information on HIV, will help others to respond positively. The recipients will be more likely to be able to offer the needed emotional support, and to understand how HIV disease progresses and affects individuals. Recipients need clear information on HIV disease transmission, treatment, and progression to help them respond appropriately to people with it.

The rural men in this study were receiving medical care for their HIV disease. However, there is a need for further studies and interventions to address the needs and enhance the quality of life of their lives in relation to social support, disclosure decisions, and education of families, friends, and the community. The National Rural Health Association identified education as being fundamental to the prevention, control, and treatment of rural HIV/AIDS (1997). Strategies were suggested such as education of targeted groups in the communities, printed

materials, and continuing education for rural providers. The men, in this study, concur that community HIV education is lacking. Additionally they identified the critical need to educate not only individuals upon a diagnosis of HIV, but also to educate their families and friends. This education has the potential to increase their social support and ultimately enhance their quality of life.

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