Self-Care Practices of Rural People with HIV Disease

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Abstract

This qualitative study identified and explored the self-care behaviors of individuals with

HIV/AIDS who live in rural areas. Four audiotaped focus groups were conducted with nineteen

men and eight women in the rural South. Participants described activities used to take care of

themselves and help them to feel better. Data analysis revealed three categories: (1) dealing with

rural issues, (2) staying healthy, and (3) ways of taking care of self with HIV. Three

subcategories illustrated the concept of dealing with rural issues: (a) returning home, (b)

disclosing vs. not disclosing HIV status, and (c) obtaining care. The second category, staying

healthy, was portrayed by sub-categories of: (a) eating right, (b) exercising, (c) practicing safer

sex, (d) discontinuing drug usage, (e) keeping a positive attitude, and (f) staying busy. The third

category, taking care of self with HIV disease depicted sub-categories of participants'

descriptions of: (a) taking vs. not medications, (b) going to the doctor, (c) educating themselves

about HIV/AIDS, and (d) being involved with HIV/AIDS. This study has implications for health

care providers and community planners.

Keywords: HIV/AIDS, self-care, rural, focus group

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Self-Care Practices of Rural People with HIV Disease

During 1998, 48,269 persons were diagnosed with Acquired Immunodeficiency Syndrome (AIDS) in the United States, bringing the total number of reported AIDS cases to 688,200 (CDC, 1998). Since 1996 there has been a decrease in deaths among people with AIDS and in the occurrence of AIDS-defining opportunistic infections (AIDS-OI). The decline in AIDS related morbidity and mortality can be attributed to improved antiretroviral therapies (Pelalla et al. 1998). People surviving longer with HIV/AIDS reflect an increased prevalence of people living with HIV disease. There has not been a decrease in the incidence of HIV infection and increases are reported for minorities, women, and in some geographical areas. The South has experienced the most rapid growth in AIDS cases and has the highest incidence in the country (CDC, 1998).

The prevalence of AIDS continues to be highest in larger metropolitan areas, but the number of new cases in rural areas is increasing at a rate three times the rate of urban cases (CDC, 1993). The characteristics of exposure categories of rural individuals differ from the urban populations affected by the epidemic. Most of the rural cases are likely to be young, nonwhite, female, and live in poverty. The majority of these individuals acquired HIV through heterosexual behaviors (Berry, 1993; Rumley, Shappley, Waivers & Eisenfant, 1991; Sowell & Christiansen, 1996). The increase in prevalence of people living with HIV/AIDS in rural areas underscores the need for rural-based health care and service organizations that will meet growing needs for long-term support and service in this sector of the population (Heckman, Somlai, Kalichmam, Franzoi, & Kelly, 1998).

Although medical therapy is a primary mechanism for disease control, many individuals engage in self-initiated behaviors that are useful in maintaining health, quality of life, and

perceptions of wellbeing. These self-care practices aid individuals to live with HIV/AIDS as a chronic, but manageable disease. Previous studies have investigated the efficacy of self-care behaviors in samples of long-term survivors, women, and homosexual/bisexual men with HIV/AIDS. Consistently, the self-care activities reported have included health promotion activities, taking responsibility for one's health, and illness management as needed. A common belief that self-care activities positively influence health was identified among study participants (Barroso, 1995; Sowell, Moneyham, Guillory, Seals, Cohen, & Demi, 1997; Lovejoy, Freeman & Christianson, 1991; Valente, Saunders, & Uman, 1993). Although several studies were found investigating self-care activities in individuals with HIV, none were found related to those people who live in rural areas. The unique purpose of this study was to identify and explore self-care behaviors of individuals with HIV/AIDS who live in rural areas.

Participants

The sample for this study consisted of nineteen men and eight women who were HIV+ and who resided in the rural South. Participants ranged in age from 18-54 years with the majority falling in the 20s (8), 30s (9), and 40s (8) age range. Twenty-two were single, two were married, two were divorced and one was separated from his spouse. Most participants were unemployed. More than half were receiving some type of public assistance, for example, food stamps, Medicaid, or housing. Two participants received disability income. Four had no income. Twenty-two participants were African-American and five were Caucasian. Participants were recruited from Aids Service Organizations (ASOs).

Methodology

A focus group approach was used to investigate the shared meaning of the experience of engaging in health care activities. An advantage of this method is the stimulation and synergy

created as participants interact, hear other ideas or experiences, and have their own ideas and experiences validated (Stewart and Stamdasani, 1990; Kruger, 1995).

Four focus groups were conducted with 27 participants in two areas in the rural South. Local ASOs recruited participants after the researchers obtained approval for the study from the ASO Board of Directors and agency personnel. Group members met sample criteria of having been diagnosed with HIV/AIDS and of living in areas with rural zip codes. Group sizes ranged from five to eight participants, were racially mixed, and were comprised of both male and female participants. Group sessions were held at the ASOs either during regular clinic hours or on mornings when clinics were not being held. Informed consent was obtained prior to each session. Participants were told that their participation was voluntary and that data collected, as well as individual identity, would remain confidential. In addition, members agreed to keep other participants' identities confidential. Demographic data were obtained. Guidelines for group participation were presented and a semi-structured interview guide (Figure 1) was used to facilitate sequencing of questions and discussion regarding participant self-care practices. Additional clarifying questions were asked as deemed necessary by the researchers. Both researchers conducted audiotaped discussions and observational field notes were taken during the sessions. Group sessions lasted approximately 1 1/2 hours and participants were given a \$20 honorarium for their participation.

- Now that you are HIV+ what are some of the things you do to take care of yourself and help you feel better?
- How do these activities help or make a difference?
- Have you changed the way you take care of yourself since getting HIV? If so how?
- Are there things you would like to do to take care of yourself, but are unable to do them? If so, what are they and why?
- What would help you take better care of yourself?
- How would you prefer to get information about taking care of yourself? From whom?

Figure 1. Interview guide

Demographic data, verbatim transcripts, and field notes provided the data for analysis. Content analysis was used to analyze and interpret the data. Individual items were coded and categorized independently by each researcher after each group session. Major topics and issues related to each research question were identified. This material was coded then categorized independently by each researcher. The researchers then met to identify, discuss, compare, and collapse data into final categories. Low inference descriptors or the use of verbatim accounts of participant experiences were used in the description of findings to reduce threats to validity and reliability in this study (Field & Morse, 1985).

Findings

As part of focus group discussions participants were asked to describe activities they used to take care of themselves and help them to feel better. Three categories related to self-care practices consistently emerged during the sessions: (a) dealing with rural issues, (b) staying healthy and (c) ways of taking care of self with HIV (see Fig. 2).

Dealing with Rural Issues

Analysis of data by the researchers revealed that dealing with rural issues posed special concerns for the majority of participants. Three sub-categories were illustrative of this concept:

(a) returning home, (b) disclosing versus not disclosing HIV status, and, (c) obtaining care.

Returning Home. Returning home was a theme frequently encountered in the course of data analysis. Many individuals had lived in a metropolitan area, but had returned home to their rural areas after receiving a diagnosis of HIV. They returned home to be near their families. One participant stated, "I came home, not waiting to die, but to spend my last moments with my family." Some lived with their families, some did not, but all wanted to be in close proximity for emotional support. There was a sense of an overriding concern for later when health declined and they needed to be taken care of by others. Even those who had never lived far from home spoke of establishing closer relationships and having more contact with family members. One participant disclosed the importance of family when he said, "Once I found out that I had family love, I didn't care what other people said."

Disclosing vs. Not Disclosing HIV Status. For the majority of participants, not disclosing their HIV status was an important issue. They discussed not being able to tell their friends and relatives because they feared others would not understand and felt that they could not deal with the possible reactions to their revelations. As one participant stated, "No one really knows but my mama, cousin, and just my close friends. My father doesn't even know." They feared losing their relationships, being abandoned, being judged, or having their confidentiality violated. They feared the potentially stigmatizing effects of disclosure that could impact family members and significant others. Information shared could result in loss of jobs or housing.

There was a real sense that "everyone knows everyone else and their business" in a small town or

rural area. Some participants voiced being afraid to have prescriptions filled at the local pharmacy because employees would find out about their disease. They discussed hearing how people talked about HIV/AIDS and about how uneducated most people are in a small town and used this as a basis for the decision not to share their diagnoses.

Another frequently encountered issue related to disclosure was fear that their partners would leave them when they were informed of the HIV diagnosis. One participant stated: "I was scared to death. I thought for sure he was going to leave when he found out I had HIV...and it was just the opposite.... He said he had always loved me and it didn't make any difference.... I'm fortunate."

Participants who had known about their HIV status for a longer period of time were frequently more comfortable discussing their disease openly. However, many of these people also had positive experiences from others after disclosure and had made active choices not to deal with negative reactions.

Obtaining Care. The majority of participants had experienced difficulties at some point in obtaining medical care for their disease. Lack of transportation, lengthy distances, and time involved, made access to care a hardship. One participant lived 40 miles from the clinic and cared for a disabled sibling. He stated: "To get over here I have to plan a month in advance. From the time I leave today I will have to start planning how I'm going to get here for my next doctor's appointment."

At the time of the interview, all of the participants were receiving care at one of two clinics by physicians with expertise in the care of HIV patients. However, to get to one of the clinics, the physician was forced to travel, twice a month, from a city 60 miles away. The other facility held a special HIV clinic where a regular attending physician saw patients. There,

patients had the advantage of scheduling appointments between clinic visits as needed.

Participants were generally pleased with the care they were receiving for their illness.

- Dealing with Rural Issues
 - Returning home
 - o Disclosing vs. not disclosing HIV Status
 - Obtaining care
- Staying Healthy
 - Eating Right
 - Exercising
 - Practicing Safer Sex
 - Discontinuing Drug Usage
 - Keeping a Positive Attitude
 - Staying busy
- Taking Care of Self with HIV Disease
 - Taking vs. Not Taking Medications
 - o Going to the Doctor
 - Educating Themselves about HIV/AIDS

Being involved with HIV/AIDS Activities

Figure 2. Taking care of self: Strategies of individuals with HIV/AIDS living in a rural area

Staying Healthy

The second category that emerged during data analysis was that of staying healthy. This concept was portrayed by individual efforts to engage in a genuinely healthy lifestyle by incorporating health promotion and disease prevention activities. Six subcategories were identified from the researchers' interpretation of data. These were: (a) eating right, (b) exercising, (c) practicing safer sex, (d) discontinuing drug usage, (e) keeping a positive attitude, and (f) staying busy.

Eating Right. For the majority of the participants "eating right" meant eating regular meals and a balanced diet. There were no special diets, but rather, they spoke about eating what they enjoyed, such as southern cooked vegetables. Although not taken regularly, vitamins, minerals, and herbs were mentioned as being important dietary supplements. They spoke of

taking Cat's Claw, Saint John's Wort, beta-carotene, Vitamin B, garlic, Aloe Vera juice, mineral water, and multi-vitamins thinking that these preparations would increase their energy, elevate their moods, and increase their T-cell counts.

Exercising. All of the participants talked about the importance of exercising; however, most were not involved in regular routines. Walking was the most common activity engaged in by participants. For many, walking was a necessity because transportation was nonexistent. However, walking was enjoyed and produced added benefits of keeping them "in shape" and reducing stress. A few participants enjoyed other activities such as swimming, weight lifting, sit-ups, push-ups, and getting exercise at work. One participant regularly swam and did aerobics at the local YMCA, but he was in the minority as most did not engage in any type of organized exercise.

Practicing Safer Sex. Participants were all cognizant of the need to protect others from transmission of HIV as well as protecting themselves from acquiring other sexually transmitted diseases (STDs). For a few, abstinence was the only acceptable way to be sure of preventing exposure to STDs. However, most of them expressed a desire to be in a caring, monogamous relationship. Many were already in such a relationship and spoke of how comforting the relationship was to them.

Some partners refused to practice safe sex. Nevertheless, participants cited feeling guilty and worried about exposing their partners to the virus. One, whose husband was HIV negative, and who was pregnant at the time of the interview stated:

It's been real difficult because when we do have sex like in the middle of the night, a lot of times I will get woken up.. Then he feels kinda bad about it and scared and then he'll try to rationalize it. 'Well your T-cells are way up there and you don't have no viral load, so I'm fine and it doesn't make any difference.

Discontinuing Drug Usage. Several participants admitted to occasional marijuana usage as well as a previous history of cocaine and heroin abuse. They stated that they had discontinued drug use after finding out that they were HIV positive and felt "better since quitting." They discussed the need to take better care of themselves. Many participants drank alcohol (beer) and continued to smoke cigarettes in spite of their HIV diagnoses. They viewed these behaviors as social activities enjoyed with others.

Keeping a Positive Attitude. Participants discussed the importance of maintaining a positive attitude and "to not get depressed." They spoke of accepting the fact that they probably had a terminal illness but expressed the need to live and enjoy their lives within the limitations of the disease. There were many references to living one day at a time and to the importance of not dwelling on their disease. One individual stated: "Just because they say you are going to die, you have to look beyond that and live day to day."

For some, spiritual practices helped them to keep their disease in perspective and assisted them in maintaining a positive attitude. All participants professed to being Christians and spoke of the many spiritual practices that gave them comfort such as praying, meditating, reading the Bible, and having faith in a higher power. However, most individuals did not involve themselves in regular church activities in response to their HIV diagnoses. Those individuals who engaged

in organized religion, for example, attending services or singing in the choir, prior to their diagnoses, continued to do so.

Staying Busy. A strategy most of the participants identified as helping them to feel better was staying busy. A variety of activities were cited as being useful in keeping them from thinking about themselves and their diseases. For some, work was an enjoyable part of their lives. Others discussed engaging in activities that they enjoyed such as fishing, dancing, listening to music, going out with friends to parties or bars, or doing volunteer work. Whatever the activity, participants stressed the importance of "having fun."

Taking Care of Self with HIV Disease

The third category identified was taking care of self with HIV disease. Participants described behaviors used to take care of themselves that were specifically related to their HIV disease. All were under medical care, some for many years. All of them discussed the pros and cons of taking medications. Some insisted that not taking their medications helped them to feel better. Other self-care activities related to the HIV diagnosis included seeing the doctor, educating themselves about HIV, and becoming involved with HIV/AIDS activities.

Taking vs. Not Taking Medications. The third category identified was taking care of self with HIV disease. Participants described behaviors used to take care of themselves that were specifically related to their HIV disease. All were under medical care, some for many years. All of them discussed the pros and cons of taking medications. Some insisted that not taking their medications helped them to feel better. Other self-care activities related to the HIV diagnosis included seeing the doctor, educating themselves about HIV, and becoming involved with HIV/AIDS activities.

Only a few spoke of the benefits of taking medications. Those individuals had become accustomed to the routine and had been diagnosed longer. They referred to rising T-cell counts and lower viral loads, weight gain, and a general sense of feeling healthier as evidence of the efficacy of medication. However, they were in the minority.

Going to the Doctor. All participants were under the care of a physician and felt good about the care they were receiving. A few saw private physicians but most received care at an HIV care clinic. An overriding concern was the importance of having a physician who was knowledgeable concerning the treatment of HIV. Several participants noted that their doctors seemed to be knowledgeable about their disease, but did not seem as concerned about other problems they were experiencing, such as depression. Several participants stated that it bothered them to attend the clinic because everyone knew it was an HIV clinic.

Educating Themselves about HIV/AIDS. Participants discussed educating themselves about HIV disease in an effort to understand the disease and take better care of themselves. They acquired knowledge by asking the physician questions, "watching television", getting information at ASOs, talking to other people with HIV, going to the library, and attending the annual state HIV conference. However, in spite of attempts to educate themselves, most participants were deficient in knowledge related to their medication. They were unsure as to what the medication was, what it was for, why they were taking it or how it worked. They were also unclear about other important aspects of their illness such as T-cell counts, and viral loads.

Being Involved with HIV/AIDS. Being involved with HIV activities, such as attending support groups, serving on the local HIV Speakers Bureau, and volunteering at the local ASO helped rural participants to feel good about themselves while providing needed services. Under the direction of ASO personnel, support group members met twice a month, planned trips, meals,

and other enjoyable activities. Participants indicated that their work with the Speaker's Bureau provided them with enjoyable interactions and essential support from other group members. However, because they lived in a small town they noted the need for caution when doing presentations. Even when not active in the Speaker's Bureau the ASO was a positive experience for many participants. One stated, "I come in here in the foulest mood and it is like taking Valium...before I leave I either be smiling or in a better mood. The atmosphere here is so uplifting to me."

Discussion, Implications, and Recommendations

A limitation of this study, common to qualitative research, is the small sample size. However, results from four focus group discussions with individuals living with HIV/AIDS in a rural area indicate that participants contend with multiple issues consequent to living in a rural area. Similar to the findings of Heckman et al. (1998) who studied the psychosocial profiles of 276 persons with HIV/AIDS in both rural and urban areas, the present study found that rural people reported reduced access to care, more community stigma, and increased fear of disclosure of HIV serostatus. Congruent with the findings of Mainus and Matheny (1996), participants were more likely to travel to an urban area for testing and care because of confidentiality issues and a scarcity of physicians knowledgeable about HIV disease.

Similar to the findings of other investigators, (Heckman et al. 1998; Davis, Cameron, & Stapleton, 1992; Valente, Saunders, & Uman, 1993; Lovejoy, Freeman & Christianson, 1991; Sowell et al. 1997; Barroso, 1995) participants in this study described behaviors that were viewed as having a positive effect on their lives and on the progress of their diseases. These activities included those that were aimed at keeping themselves healthy as well as those targeted at retarding disease progression. Rather than viewing the behaviors as general health promotion

activities or disease management activities, they viewed these activities as positive actions that helped them to live more fully within the constraints of their illnesses. Other researchers also describe differences in self-care activities that are health related versus disease related (Gaskins & Brown, 1992; Barroso, 1995; Corbin & Strauss, 1985).

The migration of people with HIV/AIDS to rural areas has been described in the literature and has serious implications for funding and planning services. Because these individuals are often not included in state case figures, there is a resulting false perception concerning the prevalence of HIV/AIDS in an area and the extent of the associated problems (Davis, Cameron, & Stapleton, 1992). The community planning process supported by the CDC could be utilized to more accurately assess the HIV/AIDS epidemic in a particular area (CDC, 1998).

Access to care issues, such as lack of transportation, can be dealt with at the community level through involvement with local churches and others who are sympathetic to the needs of those with HIV/AIDS. The ASOs in this study frequently provided transportation that enabled individuals to participate in support groups.

The non-adherence to medical therapy reported by some participants is of particular concern to health care providers and community planners alike because of the consequences of jeopardizing future medical therapies as well as the increased likelihood of resulting resistant strains of HIV. Occurrences such as these would greatly increase the cost of health care and the need for community resources. Further study is needed to assess how people make decisions about adherence, strategies to enhance adherence, and the consequences of non-adherence on the health of the individual as relates to disease progression. The importance of health care providers involving patients in decisions concerning their care and treatment, while considering their beliefs and lifestyles, cannot be overestimated.

The importance of support groups to the participants has implications for rural areas. Nationally, ASOs have been formed to meet the various needs of individuals with HIV, often in a group setting. Greene, Berger, Reeves, Moffat, Standish, and Calabrese (1999) reviewed the literature on alternative and complementary therapies and activities engaged in by individuals with HIV, including attending support groups. The studies reviewed reported improved quality of life, hardiness, and perceived emotional support from individuals who attended support groups. ASOs and clinics which serve rural areas must be aware of the importance and positive outcomes related to support groups. Meetings need to be planned at times and places that rural members will be able to be involved. The participants in this study spoke about how much they enjoyed meeting with the support groups. They had the opportunity to talk openly about issues and to learn from one another.

Education of rural communities about HIV/AIDS is critical not only to enhance the lives of infected individuals but also to increase the awareness of the need for prevention of transmission. Community planning groups provide vital links that aid in this process (CDC, 1998). Sowell and Christiansen (1996) view education as the single most important strategy in decreasing the fear and stigma related to HIV in rural areas. Education is needed for health care providers practicing in rural areas, for families of HIV infected individuals, and for the general public. The National Rural Health Association (NRHA) (1997) concurs that education is fundamental to prevention, control and treatment of rural HIV/AIDS.

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