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Barriers and Facilitators to Medication Adherence in a Southern Minority Population with HIV Disease

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Abstract

Adherence to HIV medications has been an important focus over the past decade, but little is known about adherence barriers and facilitators specifically in that part of the United States known as the Deep South. Characteristics of the region may affect factors associated with adherence related to the patient, the patient-provider relationship, and the environment. Twenty HIV-infected clients of a large public Infectious Diseases clinic in the Deep South participated in one of three focus groups; themes were identified by content analysis. Barriers included the perceived burden of extra planning, denial, life stress, difficult characteristics of the medicines, social stigma and shame. Facilitators included acceptance of the diagnosis, thinking about the consequences of not taking the medicines, prayer and spirituality, improvements in the medicines, and support from family and friends. In the South, faith and prayer may be strong facilitators that need to be considered when adapting existing adherence interventions.

Introduction

Advances during the last decade in the medical treatment of HIV disease have been remarkable. Since the onset of combination therapy in 1996, using protease inhibitors, treatment of HIV disease has theoretically been viewed as chronic care rather than terminal care. The primary limitation of these advances is the necessity that the individual adhere to a strict schedule of multiple medications to achieve long-term benefit. This problem has been of increasing concern because even the minimal level of adherence to prevent viral resistance places substantial demands on patients (Bangsberg et al., 2006; Bangsberg et al., 2000; Paterson et al., 2000). During the last several years, newly approved antiretroviral medications have offered improvements to early formulations by decreasing the number of medication administration times and/or the pill burden. Despite these improvements, adherence continues to be a problem.

Considerable research has described barriers to medication adherence experienced by HIV-infected individuals. These barriers fall into four major categories of factors related to the patient, the medication regimen, the relationship with the provider, and the environment (Ickovics & Meade, 2002; Ickovics & Meisler, 1997; Murphy, Roberts, Martin, Marelich, & Hoffman, 2000; Vervoort, Borleffs, Hoepelman, & Grypdonck, 2007). Examples in each of these categories include:

- Patient-related factors: literacy, substance abuse, health beliefs, depression,
- Regimen-related factors: side effects, treatment complexity, number of pills,
- Environment-related factors: beliefs of significant others, transportation, finances, and
- Provider-related factors: provider communication, the patient's ability to ask questions, clinic hours, accessibility.

Studies describing HIV adherence issues have been conducted primarily in major urban centers where the epidemic was first described in the United States. In the last decade, a shift in the epidemic to the rural South has been noted; yet less is known about HIV adherence issues in this region.

Cultural characteristics that are unique to the Deep South may introduce factors that influence adherence. These characteristics include the widespread nature of rural poverty, historical racism, conservative religiosity, lower education and literacy levels, and the poor overall health status seen in other chronic diseases such as diabetes and cardiovascular disease. In addition, HIV-infected individuals in the Deep South are mostly members of minority groups that are more likely to be isolated and stigmatized (Fowler-Brown, Ashkin, Corbie-Smith, Thaker, & Pathman, 2006; Hall, Li, & McKenna, 2005; Krawczyk, Funkhouser, Kilby, & Vermund, 2006; Napravnik et al., 2006; Pathman, Fowler-Brown, & Corbie-Smith, 2006; Pathman, Ricketts, & Konrad, 2006; Qian, Taylor, Fawal, & Vermund, 2006; Reif, Geonnotti, & Whetten, 2006; Whetten & Reif, 2006). There is, however, limited documentation of Southern patients’ descriptions of the barriers and facilitators regarding adherence to antiretroviral therapy (ART). Thus, the purpose of this study was to elicit perceived barriers and facilitators for HIV medication adherence in a primarily African American, low-income sample in Mississippi in order to support the development of an adherence intervention.

Methods

The sample was recruited from a large public Infectious Diseases clinic in Mississippi. Participants were recruited through flyers posted at the clinic and at a local medicine distribution site for the AIDS Drug Assistance Program (ADAP). Eligible individuals were English-speaking adults who were currently taking HIV medicines and willing to share their experiences in a group. Interested individuals signed an informed consent document and completed a demographic form. This study was approved by the institutional review board for the University of Mississippi Medical Center; each participant received a stipend of $30.

Twenty individuals were divided into three focus groups of 5−8 individuals per group. Focus groups were conducted in a conference room in the same building as the clinic but in a non-clinical area that afforded privacy and comfort. The groups were scheduled at various times of the day during three separate weeks, in order to meet varied schedules of participants. Each participant chose an identifier to protect individual confidentiality. Group leaders were health educators who had experience conducting focus groups. They were not part of the clinic's healthcare team in order to facilitate the participants’ willingness to share openly about healthcare issues. Although the Principal Investigator (PI) was a member of the healthcare team and her name was apparent on informational paperwork, she was not present during the focus groups.

The key questions used by the facilitator in each group to generate participant responses included the following:

◆ What makes it harder for you to take your HIV medications regularly?

◆ What makes it easier for you to take them regularly?

The focus group conversations were audio-recorded and transcribed verbatim; the transcriptions were reviewed for accuracy by the PI. Because the three groups had similar demographic characteristics, the data were grouped together. Data were downloaded to Atlas.*ti* (5.0) and sorted according to the first-level codes; through this process additional themes were identified. The PI, the group leaders, and collaborators' knowledgeable about HIV and the process of content analysis grouped the concepts into themes. Significant themes that emerged in each category were identified and verified with key informants, who were clinic-employed HIV-infected individuals. The key informants were fairly representative of the clinic population: 66% female, 100% African American, and with varied experiences living with HIV disease. Participants, themselves, were not contacted to verify themes due to lack of secured consent for this additional contact.

Results

Sample

Characteristics of the 20 participants can be seen in Table 1. Participants were predominantly African-American, and 40% were female. The clinic population as a whole was 86% African-American and 36% female, so the sample was representative of the entire clinic population.

Barriers and Facilitators

Barriers and facilitators identified from the focus groups are listed in Table 2. These will be discussed in categories, as barriers related to the patient, the regimen, the environment, and the provider-patient relationship. While this framework was not used as an *a priori* structure for content analysis, it offered a succinct method of comparing the data with data reported in the literature, as results are often expressed in these categories.

Patient-related barriers—Patient-related barriers included the perceived burden of extra planning, denial of HIV or the inability to accept the diagnosis, and life stress. Facilitators were acceptance of the diagnosis, thinking about the consequences of not taking the medicines, and prayer and spirituality.

The burden of extra planning included needing to remember to take the medicines and making life changes to accommodate the medicines. As one participant stated, "... my adjustment challenges were just simply to remember to take them two or three or four times a day. And to remember to carry them with me, and I wasn't always accessible to my meds because they were either at home or somewhere where I had forgotten to bring them along." The need to remember was perceived as an additional challenge requiring significant adjustment for patients.

Also, in recent years, the state's Medicaid program has put restrictions on the number and duration of medications that can be filled each month. This burden included trying to manage prescriptions in excess of the allowable number. As one participant said, "... if I only can receive five [prescriptions], it would help if they would [prescribe] a month and a half you know... That way some of the medicines will be given in this month and then the next month the other medicines that they couldn't get, they could get.... That way it would carry them over."

Although participants had low incomes, cost was not discussed as a barrier. As listed in the demographic questionnaire, focus group members were primarily covered by Medicaid ($3 per prescription per month) or enrolled in ADAP where medications were free at the local health department.

The difficulty accessing medications was not specifically stated, although extensive conversations occurred about the techniques that individuals used to maintain a supply of medicines: "keeping a stash wherever I go," and keeping a "stash two weeks ahead of [the] medicine so I'm not going to run out."

Denial, or the inability to accept the diagnosis of HIV was succinctly stated by one participant: "I was mad, and I was upset, and I was in denial. And it took me five years to tell anybody that was close to me. So I kept that to myself for a long time, and I was very angry. Right now, I still don't take [the medicines] like I should."

Life stress was another barrier included in descriptions of hectic lives. "Always ripping and running" due to jobs or family life was frequently mentioned as constraining adherence.

Patient-related facilitators—Conversely, patient-related facilitators included acceptance of the diagnosis, which was described as a continuum from simple acceptance to having a positive attitude about the medications and about the benefits of living longer. As one participant said, "This is your own responsibility. You know what you got. You know you got medicine to take. No matter what nobody else say or how peoples feel about it you got to take care of yourself first."

Thinking about the consequences of not taking the medicines was mentioned as a powerful facilitator. This was seen in conjunction with acceptance and having a positive attitude, rather than simply as fear of AIDS or death. One participant commented, "Then I had some friends to die of full-blown AIDS, and I looked around and seen what a horrible death that was. . . . And so I know I wanted to live, and I wouldn't want to send my family through that. So I knew I had to take my medicine and . . . I know I wants to live."

Participants discussed particular strategies they used to help them take medications on a regular basis. Reminder systems included charts, pill boxes, timers, and putting the medicines on a different shelf after they were taken. Developing routines was also considered helpful, e.g., making the medicines part of daily activities by combining the medicine-taking activity with something else that was done every day. This served to make taking medications a habit to ensure adherence on a typical day. Keeping medicines visually in sight was also mentioned as a way to remember.

Planning ahead was a recurrent theme, as participants mentioned several strategies for planning to prevent interruptions in medication availability. This was done by developing plans to refill medicines on a regular basis and by having a set of extra medicines at home. In addition, strategies were used to prevent forgetting when the participant was not at home, such as keeping the medicines for the next dose on a portable key ring and planning ahead when traveling, Strategies were also used to get all prescriptions covered by Medicaid, despite the limits placed by the state Medicaid program on the allowable number of prescriptions to be filled each month.

Prayer and spirituality were considered an important support. As one participant said, “I just want to be a living witness, that God has all power. He can do all things, and I put my faith and trust in Him.” Prayer was described as the ability to trust God to help them through difficulties and was described as a foundational support in managing medicines.

Regimen-related barriers—Regimen-related barriers were difficult characteristics of the medicines; facilitators included recent improvements in the medicines. Difficult characteristics of the medicines included side effects that made it difficult for participants to be adherent, as well as the number and size of pills. As one participant described, “It had to do with the quantity of the pills that were hard to get used to. They created nausea and diarrhea and fatigue.”

Regimen-related facilitators—Improvements in the medicines helped participants cope with complex schedules and the number of pills. Specifically, since an effective regimen of HIV medications includes three or more medications, the use of combination pills and medications that required a lower pill burden (decreased frequency of administration) made a significant difference. Fewer dietary restrictions also helped. Participants commented about the positive changes that the reduction in the number and complexity of medications had made in their lives.

Participants discussed strategies used to reduce side effects. Although the need to use these strategies might be perceived as a barrier that increased the burden of taking medicines, participants stated that attending to side effects allowed them to be adherent. As one participant said, “I'm not a big eater, so I had to – you know – get myself in the habit of eating three times a day because I needed that food to help me with that medicine. . . . If I didn't eat enough food, then I could tell because the medicine would kind of have like a little effect on me. I seemed nauseous, you know? And I would have to go and eat, eat something else.”

Environment-related barriers—Environment-related barriers centered on social stigma and shame, while facilitators included social support by family, friends, and the healthcare team. **Social stigma and shame** included aspects of social rejection and the loss of social relationships. As one participant described, “It wasn't hard for me to take my medicines; it was the thing that people would say. It wasn't really medically based. It was just personal ridicule and personal ignorance.” Part of this barrier was the perceived need to keep the HIV diagnosis private or hidden. For example, a participant said, “My company made it hard. You know, because I felt like I had to hide to take my medicine, you know? All, you know, for shame.” Another aspect of shame involved picking up medicines: “The embarrassment [made it harder to take my medicines]. Being ashamed to go and get my meds.”

This barrier of shame and social stigma related to personal feelings about self, personal relationships, and social relationships as well. This theme intersected with the theme of denial and difficulty in accepting the HIV diagnosis, raising the question of whether perceived social stigma made it more difficult to accept an HIV diagnosis, and contributed to attempts to deny its presence or impact in life.

Environment-related facilitators—Support from family and friends was seen as an environment-related facilitator because of reminders about medications and checking to make sure the pills were taken on time. “Well, they encourage me, like my folks have [said] ‘you took your medication today?’” Support from the healthcare provider was mentioned as helpful in identifying a tolerable combination of medications. Feeling free to call providers to ask questions or present problems was considered a positive influence on a person's ability to take medicines correctly.

Provider-related barriers and facilitators—No provider-related barriers were identified by this group of patients who were active in clinical care and taking medications. Support from healthcare providers, as mentioned as an environmental facilitator, could also be considered a provider-related facilitator.

Discussion

These focus groups were conducted to provide information specific to a southeastern United States, low-income, minority population regarding the barriers and facilitators that might need to be addressed in designing or adapting an adherence intervention. The researchers questioned whether adherence barriers and facilitators identified by members of this southeastern rural, poor, minority population might differ from those in the literature based on differences in characteristics of the culture of the Deep South.

It was anticipated that patient-related factors would include lack of knowledge about HIV due to rural isolation (Krawczyk et al., 2006), difficulties with coping with an HIV diagnosis due to lack of support in a stigmatizing culture (Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998), mental health barriers related to depression and substance abuse (Reif, Whetten, Lowe, & Ostermann, 2006), and increased stress related to high poverty (Reif, Geonnotti et al., 2006). Regimen-related factors were expected to be the same as in other regions of the country, since medications were primarily the same in all areas. Environment-related factors were expected to focus on poor social support related to stigma and isolation (Heckman, Somlai, Kalichman et al., 1998) as well as the limitations in access related to poverty (Heckman, Somlai, Peters et al., 1998; S. Reif, Whetten et al., 2006). Provider-related barriers were expected to include distrust of the healthcare system (Reif, Whetten, Ostermann, & Raper, 2006) as well as poor accessibility (Krawczyk et al., 2006; Napravnik et al., 2006; Pathman et al., 2006; Pathman et al., 2006)

Findings from this study revealed that patient-related barriers were more similar than dissimilar when compared to studies with other populations of HIV-infected individuals. These included problems with life stress and depression, as well as difficulty adjusting to the diagnosis of HIV and the accompanying denial. Vervoort, and colleagues (2007), in a metasynthesis of qualitative research on barriers to adherence, used the descriptor “moods” to include many of the components found in this study: depression, anger, anxiety.

Patient-related barriers mentioned in the literature include forgetting, especially when routines are altered (Vervoort et al., 2007). Another barrier in the literature was difficulty with medication access. While this was not specifically stated, it seems apparent that participants feared a lack of access or had experienced it and worked to prevent it from occurring again.

Regimen-related barriers were very similar to those identified in the literature as summarized by Vervoort et al. (2007); concerns about side effects and complexity of the regimen were clearly described by these participants. As medication regimens have become easier over the last decade, participants discussed how this barrier has decreased.

Environment-related barriers in both this Southern sample and in other regions (Vervoort et al., 2007) focused most often on privacy issues: shame and potential loss of social relationships were over-riding concerns. In addition, stigma was mentioned in this sample as a potential access difficulty related to the shame of picking up HIV medications.

No problems were identified in the focus groups regarding the patient-provider relationship, but these participants were all from one clinic where recruitment for the focus groups occurred. Although the group leaders were not part of the healthcare team, the PI was, and this may have minimized willingness to mention negative feelings. Support provided by providers was cited as a facilitator of adherence; this finding supports the work of other researchers on facilitators of adherence (Vervoort et al., 2007)

The facilitator identified in this study that was clearly different from those identified by Vervoort et al. (2007) included prayer and spirituality. Participants considered prayer and spirituality to be a source of internal support during times of distress. Spiritual activities have been shown to assist coping, particularly in the Southern United States (Coleman et al., 2006; Phillips & Sowell, 2000).

Limitations

Because this was a qualitative research design with a small, non-randomized sample drawn from one clinic, these results cannot be generalized. Although the characteristics of the current sample seem to be representative of the clinic population, potential bias exists, as there may be other factors that make this group different (e.g., accessibility to the clinic, desire to participate in a research study).

Conclusions

Knowledge of the barriers and facilitators to taking HIV medicines regularly can help clinic staff give patients the support they need to adhere to HIV medications. The similarities to barriers and facilitators identified in studies of other populations suggest that adherence interventions developed in urban Northern and Western areas may be transferable to the South, with some adjustments. For this Southern population, faith and prayer were especially strong facilitators that would need to be considered when adapting existing interventions. More research is needed to better understand the barriers that patients may experience when entering and continuing clinical care and starting antiretroviral medications. It is important to develop and test interventions to address reducing these barriers in order to improve patient outcomes.

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Table 1

Demographic Characteristics of the Sample (N = 20)

Characteristics	***N***	**%**
Ethnicity		
African American	16	80%
White	4	20%
Gender		
Female	8	40%
Male	12	60%
Heterosexual	14	70%
IDU[*] risk factor	1	5%
Income ≤ $10,000 per year	16	80%

[*] IDU = Intravenous drug use

Table 2

Barriers and Facilitators regarding Medication Adherence

Barriers
• The perceived burden of extra planning
• Denial, or the inability to accept the diagnosis of HIV
• Life stress
• Difficult characteristics of the medicines
• Social stigma and shame
Facilitators
• Acceptance of the diagnosis
• Thinking about the consequences of not taking the medicines
• Prayer and spirituality
• Improvements in the medicines
• Support from family and friends