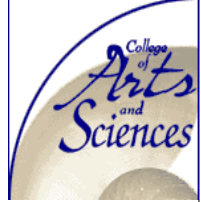




Treatment Adherence among Persons with HIV/AIDS

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Abstract

Adherence to highly active antiretroviral therapy (HAART) has received increasing attention in the scientific literature over the last five years. Much of the research in this area has been quantitative and focused on factors influencing adherence and measurement of adherence. Inductive approaches and qualitative approaches may be useful in the identification of additional influencing factors. Two qualitative focus groups examining patient perspectives of adherence were conducted. Interpretive phenomenological analysis revealed four major themes: coping, side effects, treatment regimen, and health care systems factors. The qualitative analysis supported the importance of a number of factors previously identified in the literature but also suggested additional factors that have received little attention and may be relevant to adherence to HAART.

Introduction

Although there are limited long-term data regarding treatment efficacy (Chesney, Morin & Sherr, 2000), highly active antiretroviral therapy (HAART) has been shown to be effective for treating individuals with HIV/AIDS. However, less than optimal HAART adherence rates among individuals with HIV/AIDS are of particular concern to the healthcare community. Non-adherence to HAART severely minimizes the therapy's potency and drug-resistant forms of HIV are more likely to develop. As a consequence, researchers are striving to implement systems that will bolster patient adherence to HAART and treatment efficacy (Chesney et al., 2000; Tsasis, 2001; Wagner et al., 2001).

A number of factors have been identified as correlates of adherence. Chesney et al. (2000) and Ickovics and Meisler (1997) found that complex medication regimens tended to discourage adherence, and adherence was more likely to occur when side effects were minimized. Psychological and physiological side effects were a major barrier in adherence (Chesney et al., 2000; Tsasis, 2001; Wagner et al., 2001; Ickovics & Meisler, 1997; Malow et al., 1998). Tsasis (2001) indicated that psychological conditions, including depression, affected patient adherence. Social support has repeatedly been identified as an integral component of adherence (Tsasis, 2001; Kempainen et al., 2001; Malow et al., 1998; Catz et al., 2000). The notion of spirituality, however, has not been addressed frequently in the literature (Chesney, et al., 2000; Tsasis, 2001; Wagner et al., 2001), but this may be a useful coping mechanism for patients. Research has also indicated that a key component to improving HAART adherence was improved patient-provider relationships (Tsasis, 2001; Ickovics & Meisler, 1997; Murphy et al., 2000). However, issues of barriers to access, such as transportation and the unavailability of insurance coverage, have not been addressed in the literature, but these concerns are worthy of investigation.

The majority of research pertaining to HAART adherence is quantitative in nature (Chesney et al., 2000; Tsasis, 2001; Wagner et al., 2001). Generally, adherence measures, including self-reports and pill counts, are useful but flawed (Chesney et al., 2000). Several theoretical models, including the Health Belief Model, Health Decision Model, and the Theory of Reasoned Action have been applied to non-adherence, but there is no widely accepted instrument for measuring adherence (Chesney et al., 2000; Tsasis, 2001; Wagner et al., 2001).

Introduction (Continued)

Furthermore, adherence has been measured by both patient report and provider report. According to Tsasis (2001), health care providers were highly unlikely to accurately report or predict patient adherence. Furthermore, when both patient and provider estimates of adherence are compared, agreement is low. Wagner et al. (2001) Catz et al. (2000) reported that there was consensus between patients and providers with regard to viral load and use of HAART. However, when substance use and depression were examined separately by patients and providers, consensus was nonexistent (Wagner et al., 2001). For example, a correlation between homelessness and patient adherence to HAART was established (Tsasis, 2001; Wagner et al., 2001) but providers did not identify a relationship between homelessness and HAART (Wagner et al., 2001). Nevertheless, data collected from patients and providers evaluating substance use, viral load, and depression are useful. In spite of the lack of patient-provider consensus, provider evaluation of substance use and depression are valid predictors of adherence (Wagner et al., 2001). This lack of consensus exacerbates the unavailability of a widely accepted measurement for assessing adherence to HAART. This also suggests the need for research that considers adherence from the patient's perspective and highlights the need for qualitative data that may improve the development of measures of adherence.

The present study sought to identify factors related to adherence from patients' perspectives, using qualitative methods to facilitate theory building.

Method

Participants

The sample consisted of two focus groups of participants who were HIV positive or had AIDS. The first group consisted of individuals who considered themselves to be successful with adherence. In the first group (n = 8), 38% were diagnosed with AIDS (n = 3), while 62% were HIV positive (n = 5). Participants in this group ranged from 28 to 63 years of age, with an average age of 46. The second group consisted of individuals who considered themselves to have difficulty with adherence. In the second group (n = 4), 75% had AIDS (n = 3) while 25% were HIV positive (n = 1). Participants in this group ranged from 27 to 45 years of age, with an average age of 39. Between the two groups, there were four female participants (33%) and eight male participants (67%). Overall, the groups were racially diverse (50% African American/Black; 33% Caucasian/White; 17% Native American).

Procedure

Following approval from the Institutional Review Board of the University of West Florida, participants were recruited through AIDS service organizations. Participants gave voluntary informed consent and financial compensation for their participation in the study. Two separate focus groups were established and held in discussion format. These sessions were audiotaped in accordance with informed consent procedures. In Group 1, eight participants, along with the researcher and three research assistants attended the 90-minute session regarding adherence to HIV medications. Group 2 was held in identical format, but with four participants, the researcher, and three research assistants.

Analysis

The audiotaped focus group sessions were transcribed and typed into two separate transcripts, one for each group. In the

Method (Continued)

multi-dimensional primary analysis, three independent raters analyzed copies of the transcripts in order to identify broad themes related to adherence. Using an Interpretive Phenomenological Analysis framework, superordinate and subordinate themes were identified independently by raters and discussed until consensus emerged regarding the major and minor categories. A coding sheet of recurrent themes derived from the focus groups was generated through this preliminary analysis. The credibility of this coding structure will be determined by inter-rater agreement on ongoing secondary analyses.

Results

Initial interpretive analysis of participant discussion of factors influencing adherence to treatment recommendations revealed four major themes, specifically coping, side effects, health care systems, and treatment regimen factors. Each of these superordinate themes was comprised of several subordinate themes. Coping factors consisted of spirituality, social support, self-efficacy beliefs, maladaptive coping behaviors, patient education and knowledge, emotional reactions, and perceptions of treatment regimens. (Table 1) Treatment regimen factors consisted of medication regimens, lifestyle changes, and non-traditional medicine approaches. (Table 2) Health care systems factors consisted of access to medical care, quality of medical care, and patient provider relationships. (Table 3) Side effect factors included psychological side effects, physiological side effects, and comorbid conditions. (Table 4) The coding structure shown in the table outlines the superordinate and subordinate themes.

Table 1

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| <p>COPING</p> <p><u>Spirituality</u></p> <ul style="list-style-type: none"> positive aspects of spirituality negative aspects of spirituality <p><u>Social Support</u></p> <ul style="list-style-type: none"> type of social support amount of social support availability of social support quality of social support negative aspects of social support <p><u>Maladaptive Coping Behaviors</u></p> <ul style="list-style-type: none"> substance abuse intentional avoidance of medication perception of medication side effects | <p><u>Self-Efficacy Beliefs</u></p> <ul style="list-style-type: none"> attitudes toward adherence cost/benefit analysis of adherence personal efficacy beliefs <p><u>Patient Education and Knowledge</u></p> <ul style="list-style-type: none"> knowledge of HIV/AIDS knowledge of health care system knowledge of personal health <p><u>Emotional Reactions</u></p> <ul style="list-style-type: none"> positive emotional reactions negative emotional reactions <p><u>Perceptions of Treatment Regimens</u></p> <ul style="list-style-type: none"> perception of medication efficacy |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Table 2

| | |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>TREATMENT REGIMENS</p> <p><u>Lifestyle Changes</u></p> <ul style="list-style-type: none"> smoking diet alcohol mental health services <p><u>Non-Traditional Medicine Approaches</u></p> <ul style="list-style-type: none"> Western (e.g., vitamins) Eastern (e.g., herbal, massage) | <p><u>Medication Regimens</u></p> <ul style="list-style-type: none"> complexity (e.g., number of pills, frequency of dosing) <p><u>Medication Regimens (Cont'd)</u></p> <ul style="list-style-type: none"> length of time on regimen (e.g., new versus long-standing) |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Results (Continued)

Table 3

| | |
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| <p>HEALTH CARE SYSTEM</p> <p><u>Access to Medical Care</u></p> <ul style="list-style-type: none"> insurance coverage availability of appropriate providers in area accessibility of provider barriers to access (e.g., transportation, child care) | <p><u>Patient/Provider Relationships</u></p> <ul style="list-style-type: none"> provider attributes patient attributes type of patient provider relationship (e.g., close, distant, oppositional) <p><u>Quality of Medical Care</u></p> <ul style="list-style-type: none"> technical quality of services provided manner in which services are provided |
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Table 4

| | |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>SIDE EFFECTS</p> <p><u>Psychological</u></p> <ul style="list-style-type: none"> emotional (e.g., depression, anxiety) behavioral (e.g., inability to eat, hyperactivity) psychophysiological (e.g., sleep, appetite, energy) cognitive (e.g., reduced mental clarity, forgetfulness) | <p><u>Physiological</u></p> <ul style="list-style-type: none"> gastrointestinal (e.g., nausea, vomiting, diarrhea) sensory (e.g., vision, hearing) somatosensory (e.g., numbness, pain) <p><u>Comorbid Conditions</u></p> <ul style="list-style-type: none"> medication interactions conditions caused by HIV medications (e.g., neuropathy) |
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Discussion

Previous literature has focused on treatment regimen factors, side effects, and several coping variables, such as social support. The importance of these factors was supported by the results of this qualitative investigation. For example, participants of this study identified regimen complexity, a factor frequently discussed in the literature. Similarly, alcohol and substance use problems were identified as factors related to non-adherence, which is also consistent with the literature. However, new themes were also identified through this study, such as spirituality and non-traditional medical approaches (e.g., herbs and massage). With regard to the health care system, factors such as access to medical care and barriers to access, such as transportation and the unavailability of insurance coverage, were also identified. Although the investigation included a small number of participants, the focus groups generated rich information that may help to identify factors related to adherence that have not previously been identified or examined quantitatively. This inductive approach may be useful for future investigations that attempt to develop explanatory models for adherence and measures of adherence.

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