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Changing HIV Treatment Expectancies: A Pilot Study

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Abstract

Beliefs about HIV treatment efficacy, adherence self-efficacy, and side effects management are related cross-sectionally to adherence to antiretroviral therapy (ART). However, the role of such expectancies held prior to the initiation of ART in unknown. The purpose of this study was to explore feasibility, satisfaction, and preliminary effect of an intervention to address HIV treatment expectancies. ART naïve participants (N=26) who were contemplating ART initiation were randomized to a single session group intervention or standard care control condition. The session included an exploration of expectancies; an education about ART efficacy, adherence, and side effects; and guided problem solving around adherence and side effects management. The pilot intervention was feasible and was rated highly satisfactory. Follow-up assessments demonstrated that intervention participants increased adherence self-efficacy and positive side effects expectancies relative to those in the control group (*p*s<.05). Findings have implications for nursing practice and further research in the area of HIV treatment expectancies and treatment readiness.

Keywords

HIV; AIDS; antiretroviral therapy; adherence; expectancies; treatment readiness

INTRODUCTION

The treatment decision-making process is complicated and varies among patients and providers (Allen, 1999; Meredith, Jeffe, Mundy, & Fraser, 2001; Russell et al., 2003), but the need for commitment by the patient to a course of treatment is paramount to successful management of HIV. While care delivery systems offer a range of services to address patient readiness to initiate treatment, there are no standardized approaches based on empirical evidence.

There is evidence from cross-sectional research with HIV+ adults on antiretroviral therapy (ART) that beliefs about treatment and self-efficacy for adherence are related to adherence and clinical outcome (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Demmer, 2003; Fogarty et al., 2002; Holmes & Pace, 2002; Johnson et al., 2003). However, it is unknown whether beliefs held once treatment has begun are the same as the expectancies the patient held before starting medications.

The purpose of this study is to evaluate a brief intervention to enhance treatment expectancies and readiness among treatment-naïve HIV+ patients contemplating initiation of ART.

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METHODS

Participants

Participants were recruited via flyers in clinics and agencies serving HIV+ clients in the San Francisco Bay Area. Participants were required to be at least 18 years of age, to provide written informed consent and medical documentation of HIV infection, and to self-report being ART-naïve but planning to initiate ART, indicated by a response of “very likely” or “definitely” when asked if they plan to begin taking ART in the next six months.

Procedures

Following phone screen for eligibility, interviews consisted of both interviewer- and self-administered questionnaires. The follow-up interview was similar in content and format to the baseline. After the baseline assessment, participants were randomized to the intervention or control condition and scheduled for their next visit.

The intervention was a single small group two-hour session with 5−6 participants, facilitated by a psychologist and an HIV clinical nurse. The overall goals of the intervention were to explore expectancies about (1) treatment outcomes, (2) side effects, (3) adherence self-efficacy, and (4) communicating with providers. Education was provided about (1) the role of medications in the replication of HIV, (2) the importance of adherence, (3) the likelihood of side effects, including strategies to manage side effects, and (4) the types of clinical gains commonly seen with ART. The facilitators led the group in brainstorming and problem solving around adherence and side effects management.

Participants were paid US$30 each for the baseline and follow up interviews and US$25 for participation in the session.

Measures

Background data included age, race/ethnicity, gender, sexual orientation, education, employment status, and income. Self-reported CD4 count, viral load, and time since HIV diagnosis were obtained.

Treatment expectancies were assessed with a version of the Beliefs About Medications Questionnaire (BMQ) (Horne, Weinman, & Hankins, 1999) adapted to assess potential consequences of medications. The BMQ assesses treatment representations of concern (e.g., “These medications will disrupt my life”) and necessity (e.g., “My health will depend on these medications”) and provides a scale score of each.

Positive side effects expectancies were assessed by a three-item scale created for this study: “ I am nervous or afraid of the side effects that I might have,” “I will be able to manage the side effects from my HIV medications,” and “I am ready to deal with the side effects that may occur.” Responses were on a five point Likert scale ranging from 1=strongly disagree to 5=strongly agree.

Adherence self-efficacy was assessed using a 12-item scale of patient confidence to carry out important treatment-related behaviors related to adhering to treatment plans, especially medication adherence, in the face of barriers. Reponses range from 0 (cannot do it at all) to 10 (certain you can do it). Alpha equals 0.91 for this scale (Johnson *et al.*, 2003). Participants in the intervention condition answered a set of Likert items assessing intervention satisfaction, likelihood of recommending someone to such a program, and whether additional sessions would have been helpful. Space was provided for written comments.

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Data Analysis

We computed T-test analyses to compare the average change scores from baseline to follow-up between the intervention and control groups on BMQ Necessity and Concerns scores, Adherence Self Efficacy, and Positive Side Effects Expectancies.

RESULTS

Of the 26 individuals who completed the baseline assessment, 23 completed the follow up assessment (88% retention). Of the 14 randomized to the intervention, all 11 who attended an intervention session completed the follow-up assessment. One participant from the control condition was excluded from analysis because he began ART prior to follow up. Participant demographic and background descriptors are presented in Table 1. Although all participants reported intentions to initiate ART, there was a wide range of time participants knew their HIV status, from 2−208 months. Similarly, CD4 counts varied widely, from 49 to 1110, indicating a range of illness progression.

Feasibility and Satisfaction

Recruiting participants for the pilot study was minimally resource- and time-intensive. Participants were challenging to retain, however, with 3 participants lost to follow up immediately upon completion of the baseline interview. Furthermore, several respondents in the intervention indicated less certainty of their plans to initiate ART than they had previously indicated in the phone screen. Among the 11 participants who attended the intervention, ten rated the experience as “good” or “excellent” while one rated it as “fair.” Eight of 11 indicated that they were “very likely” or “extremely likely” to recommend such a program to friends who are contemplating ART, whereas one said “somewhat likely” and two that they would be “unlikely,” and 8 reported that more than one session would have been helpful. Additional comments provided by some indicated that the wide range of participants provided diverse perspectives, but limited the depth of content covered.

Changes from baseline to follow-up

There were no differences between groups in treatment expectancies scores on the BMQ from baseline to follow-up. On the BMQ Necessity scale, the intervention group increased a mean of 0.36 points whereas the control group increased an average of 1.0 point. On the BMQ Concerns scale both groups decreased minimally; 1.36 for intervention and .91 for control. On the positive side effects expectancies measure, the intervention group increased by 1.7 points on average while the control group decreased by .55 points ($p<.05$). Similarly, the intervention group increased adherence self-efficacy by a mean difference score of 5.3 as compared to a decrease in self-efficacy in the control group of 5.5 points ($p<.05$).

DISCUSSION

Decision-making about medications is an issue which participants reported needing more support and information. The intervention was rated as satisfying, and most participants thought that more than one session would be helpful.

Although we did not see large differences in response to the intervention on administered measures, the directions of the changes in adherence self efficacy and positive side effects expectancies are encouraging. Given that the intervention was a single session, more intensive interventions may magnify these results and thus have clinical benefit for patients initiating ART. Nonetheless, these results support the notion that intervention prior to the initiation of ART can influence expectancies.

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Experiences with this pilot provide guidance for expanding this intervention for future research. Participants indicated a positive impact of the supportive environment of the group setting, but reported it difficult to discuss individuals' specific questions about their own circumstances within the constraints of a single session. Further, the range of knowledge of HIV treatment issues precluded more complex discussions of issues of antiretroviral resistance and clinical decision-making. For this reason, we believe that a combination of group and individual sessions would provide greater support, information, and individual attention than can be achieved by a single group session.

Participants expressed strong concerns about side effects, often presenting fatalistic expectations accompanied by anecdotal, catastrophic stories of people with debilitating side effects. Validating such concerns and balancing extreme stories with evidence that some people do not experience serious side effects and, among those who do, many learn to manage them effectively was well-received. Greater attention to side effect-related expectancies and proactive side effect management instruction would likely enhance this benefit. Other areas of interest to participants included information about how providers use treatment guidelines in determining initiation of therapy, guidance for how to communicate with providers, the importance of adherence, and the role of medications in HIV disclosure. Related to the last point, several expressed concern that by starting medications, they risk others learning their HIV status, which is consistent with our prior work demonstrating interactions of medication-taking and serostatus disclosure (Klitzman *et al.*, In Press).

Limitations of note include the small sample size and heterogeneity of group members, and the lack of availability of established, validated multi-dimensional measures of HIV treatment expectancies.

In conclusion, our intervention shows feasibility and satisfaction and demonstrates promising trends in important outcomes. Future steps to continue this work will involve the development and testing of a more comprehensive intervention utilizing a combination of group and individual sessions. Outcomes of interest from a larger trial may include uptake of ART, medication adherence, disease progression, provider relations, quality of life, and successful side effects management.

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Table 1

Participant Characteristics

Variable	n	% of sample	Mean (SD)	Range
Overall (N=22)				
Age (Years)	22		38.8 Years	25−57 Years
Gender				
Male	14	63.6		
Female	5	22.7		
Transgender	3	13.6		
Ethnicity				
Black/African American	11	50.0		
Hispanic/Latino	3	13.6		
White	6	27.3		
Other	2	9.1		
Employment Status				
Working	8	36.4		
Not Working	14	63.6		
Sexual Orientation				
Heterosexual	4	18.2		
Homosexual	11	50.0		
Bisexual	5	22.7		
Other/Not Sure	2	9.0		
Education				
< High School	2	9.1		
High School	5	22.7		
Some College	7	31.8		
College Grad.	8	36.4		
CD4 Count	19		561(260)	49−1110
Viral load				
Undetectable	3	13.6		
Detectable	14	63.6		
Unknown	5	22.7		
Months Positive	22		67.7(56.7)	2−204