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“Damaging what wasn’t damaged already:” Psychological tension and antiretroviral adherence among HIV-infected methadone-maintained drug users

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Abstract

Active drug use among HIV-infected persons is associated with poor adherence to highly active antiretroviral therapy (HAART) and sub-optimal treatment outcomes. To understand adherence experiences among HIV-infected drug users, we conducted semi-structured interviews with 15 participants in a randomized controlled trial evaluating the efficacy of directly observed HAART delivered in methadone maintenance clinics. Interviews were recorded, transcribed, and thematically analyzed. We identified negative and positive psychological themes associated with both drug use and adherence. Participants described tension between negative feelings (denial, shame, and perceived isolation) and positive feelings (acceptance, motivation, empowerment, and perceived connectedness), and they associated this tension with their own drug using and adherence behaviors. Sustained antiretroviral therapy adherence may require increased emphasis on understanding the psychological experience of HIV-infected drug users.

Keywords

Substance abuse; Methadone; Adherence; Qualitative; Shame

Introduction

Active drug use is associated with poor adherence to HAART, but HAART offered along with comprehensive substance abuse treatment improves outcomes (Malta, Magnanini, Strathdee, & Bastos, 2010). However, even among HIV-infected drug users attending methadone programs, ongoing drug use, poor social support, and depression are associated with inadequate adherence (Powers et al., 2003; Stein et al., 2000; Gonzalez, Batchelder, Psaros, & Safren, 2011; Avants, Margolin, Warburton, Hawkins, & Shi, 2001). Effective adherence interventions for HIV-infected substance abuse treatment patients must therefore target psychological relationships between drug use and adherence.

Psychological reasons for drug use include motivation to escape emotional pain (Zakrzewski & Hector, 2004) or feelings of vulnerability (Wiklund, Lindstrom, & Lindholm, 2006) and desire for self-enhancement (Kaplan & Meyerowitz, 1970). Negative emotions, such as shame and feelings of inadequacy, have also been associated with drug use (Merritt, 1997)

and may be exacerbated by HIV infection in a “double struggle” (Li, Wang, He, Fennie, & Williams, 2012). While drug use may alleviate short term emotional struggles, it exacerbates longer term negative emotions, perpetuating a “shame-addiction cycle” (Wiechelt, 2007). HIV-infected drugs users also experience stigma, or sense of devaluation because of a socially discredited condition (Weiss, Ramakrishna, & Somma, 2006; Room, 2005; Schomerus et al., 2011; Dean & Rud, 1984; Borchert & Rickabaugh, 1995). Stigma, in turn, is associated with poor adherence (Ware, Wyatt, & Tugenberg, 2006). To understand these relationships, we conducted a qualitative analysis among HIV-infected methadone patients enrolled in an adherence intervention.

Methods

We recruited participants from the Support for Treatment Adherence Research through Directly Observed Therapy (STAR*DOT) trial, (Berg, Litwin, Li, Heo, & Arnsten, 2011) which assessed the efficacy of DOT HAART in methadone clinics. Between 2008 and 2009, we conducted 20-45 minute interviews with STAR*DOT participants, focused on drug use, HAART adherence, and experience of participating in the trial.

Following Braun’s steps of qualitative analysis (Braun & Clarke, 2006) and elements of grounded theory (Glaser & Strauss, 1967), we identified general themes by open coding and then iteratively revising our coding structure. Two co-authors (AB and MB), blinded to each other’s codes, selectively coded interviews and brought discrepancies to the group for discussion.

Results

Fifteen adults completed interviews (Table 1). Participants had been HIV-infected for a mean of 15 years. Most (n=10) were taking HAART at least twice daily, and more than half (n=9) had no detectable HIV at the start of the trial.

We identified three negative and three positive psychological themes. Negative themes included: (1) denial and resistance, (2) shame, and (3) perceived isolation. Positive themes included: (1) acceptance of HIV and motivation to adhere, (2) empowerment, and (3) perceived connectedness. In most cases, participants described negative themes in relation to continued drug use or poor adherence, and positive themes in relation to decreasing drug use or good adherence. Each participant described tension between negative and positive psychological themes, often associated with changes in drug using or adherence behaviors.

Denial and resistance

Participants described feelings of denial, including difficulty accepting their HIV status or severity. These feelings were often associated with resistance to seek medical care or to adhere consistently, and were exacerbated by ongoing drug use.

“When I got the virus, I just shook it off - it didn’t matter nothing to me”
(Participant 10).

“[I] didn’t wanna take all that medicine they was trying to give me” (Participant 12).

“I’d still get high and I helped everybody else... I wasn’t thinking about myself once I got high... (Participant 9).

While several participants described their own experiences of denial and resistance, the majority (n=13) recounted others’ resistance.

“Some people ... won’t even take the [HIV] tests. Scared to know they got it.. they’re killing their own self” (Participant 7).

“A whole lot of them are still in denial ... they using drugs, crack ... [they] do what they want to do” (Participant 9).

Shame

Participants frequently described shame and low self-worth. In addition to feeling distressed or humiliated by past drug use or poor adherence, they also described feelings of self-blame.

“I wasn’t doing the right thing. I was just damaging whatever, you know, isn’t damaged in me already” (Participant 12).

“We did it to ourselves. I mean, maybe we end up nothing. We did it to ourselves...” (Participant 9).

Feelings of shame were linked to stigma associated with HIV. One participant reported that he stopped taking HAART at the methadone window because of shame and stigma.

“When you’re taking [HIV] medications at the [methadone] window, everybody on line behind you knows why. It’s like a little sign on your back that says, ‘I have HIV’” (Participant 8).

Perceived isolation

Almost all participants described feeling isolated and having few meaningful relationships. They attributed these feelings to alienation from family or loss of significant people from their lives. Many also felt that people were not genuinely interested in their well-being.

“A lot of my friends not here no more ’cause they stopped taking their [HAART]. They started using drugs again ...” (Participant 12).

“I don’t have anybody - my family lives upstate. Basically, I’m down here by myself. When they put me on the medication ... there was nobody asking me how are you feeling” (Participant 10).

Acceptance and motivation

Though all participants grappled with acknowledging HIV, a common theme emerged of accepting one’s HIV diagnosis and developing motivation to adhere.

“You can’t cover [HIV] up. I’m trying to live. That’s all I’m thinking about. I’m trying to survive.” (Participant 15).

“You have to open up. I mean, you still have a life regardless you know?” (Participant 9).

Several participants attributed acceptance of HIV and motivation to adhere to participation in the STAR*DOT trial.

“[The study] kept me abreast, things that I took for granted, questions that I probably thought about, but just overlooked.” (Participant 12).

Empowerment

All participants described growing confidence in their capacity to control their actions. Several described improvement in their ability to care for themselves.

“You have to maintain. You still live... There’s no giving up” (Participant 9).

“The STAR-DOT program reinforces my thoughts and my ability to keep struggling at this virus. This is one of the best opportuni[ties] I have...” (Participant 15).

Perceived connectedness

All participants described positive emotions associated with feeling connected to other people, and several reported family motivations to engage in care.

“Be strong, especially if you got a family or kids. You have to see them grow up” (Participant 9).

“I usually take [HAART] at home... and everybody in my family knows. All that does is make sure I’m taking [my medication]” (Participant 1).

Most participants reported one meaningful relationship (e.g., significant other or friend) and multiple participants reported feeling more equipped to care for another person than for themselves. All reported feeling connected to study staff, and many felt support from staff in their methadone clinics.

“My girlfriend has the virus and it helps me.. I make sure she takes her medications. I know by helping her I can help others...I can do what I need for me... but I can do more for others than I can do for myself” (Participant 10).

“My daughter has HIV also. We used to take our medications together... I have to keep on her to take her medications” (Participant 9).

Tension between negative and positive psychological themes

All participants reported both negative and positive emotions associated with drug use, and all revealed tension between these conflicting emotions. Some participants described movement between positive and negative states.

“I went back to college and then I just relapsed... I can’t stop once I start. I’ve tried 100 different ways.. and it might [work] for a while. Then I do drugs on the weekend then get ready for work on Monday. But then the weekends are getting longer and you start missing work” (Participant 5).

When describing movement between denial and motivation to adhere, participants acknowledged both internal psychological changes (acceptance of medical information and empowerment), and connectedness to others.

“I thought I was invincible. But now my mind is straight and I’m seeing that I wasn’t doing the right thing” (Participant 12).

“I was in denial at first. And then all of a sudden I got over it. It was easy for me to get over it because I have my family” (Participant 9).

Many participants felt the STAR*DOT trial facilitated movement from resistance to motivation.

“You get tired... take for granted being alive. Every time I do the survey, it keeps me aware that I should take this medicine. And, if I don’t, I might not be alive...it’s survival” (Participant 12).

Despite stigma associated with taking HAART at the methadone window, several participants described moving from reluctance to take HAART publicly to feeling empowered. For example, participant 12 reported that he would “rather take [HAART] at home” at the beginning of the STAR*DOT trial, but that later “[he] just didn’t care no more” about his peers’ perceptions.

Discussion

Our findings suggest that internal psychological tension is associated with both addiction (Zakrzewski & Hector, 2004; Wiklund, 2008; Merritt, 1997; Wiechelt, 2007) and adherence. We also observed that strengthening positive psychological themes facilitated movement from negative feelings and behaviors to positive ones. Specifically, stronger feelings of empowerment or connectedness enabled participants to reduce drug use and adhere to HAART. This suggests that a central challenge in maintaining adherence is effectively managing negative emotions and promoting positive psychological states.

The negative psychological themes we identified illustrate how the dual stigma associated with addiction and HIV affects adherence. HIV-infected drug users may internalize shame, which eventually becomes part of their identity (Cook et al., 2001; Gruenewald, Kemeny, Aziz, & Fahey, 2004). Repeated negative psychological experiences establish a flawed sense of self, lacking in self-worth (Bruce, Kresina, & Cance-Katz, 2010; Smith, Rossetto, & Peterson, 2008). This flawed sense of self may be reinforced by relapse to drug use and by failure to adhere. Breaking or reducing this negative cycle is essential to recovery from addiction, and may be essential for sustained adherence.

The positive psychological themes we identified represent adaptation to a challenging reality: acceptance of HIV status and motivation to adhere indefinitely to HAART. Increasing these positive feelings generally requires strong psychosocial support, which may be offered in the form of adherence counseling by skilled professionals. While it may not be possible for brief adherence interventions to address deeply rooted dysfunctional behavioral patterns, our results suggest that more emphasis on overcoming the shame-addiction cycle is likely to improve adherence among HIV-infected drug users.

A psychologically-oriented intervention may be needed to manage negative emotions, decrease shame, and promote social support and empowerment. Both mindfulness-based treatment and shame-focused acceptance and commitment therapy have been effective in reducing self-stigmatizing thoughts, promoting substance abuse treatment attendance, and decreasing drug use (Luoma, Kohlenberg, Hayes, & Fletcher, 2012). These studies, coupled with our findings, suggest that an intervention utilizing psychological strategies to overcome shame and self-stigmatization may improve adherence among HIV-infected drug users.

Despite our small sample, we have identified several important psychological constructs that are often difficult to assess (Wiechelt, 2007). Our findings highlight the need for clinicians to be aware of internal struggles between negative and positive emotions faced by HIV-infected drug users. Facilitating the resolution of these internal conflicts may increase the effectiveness of adherence interventions.

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Table 1

“Damaging what wasn’t damaged already:” Psychological tension and antiretroviral adherence among HIV-infected methadone-maintained drug users

Individual Demographics						
<u>ID</u>	<u>Gender</u>	<u>Age</u>	<u>Race/ Ethnicity</u>	<u>Education</u>	<u>Marital Status</u>	<u>Years with HIV</u>
1.	Male	57	Black Non-Hispanic	High School	Widowed	19
2.	Male	53	Black Non-Hispanic	Some College	Married/Living with Partner	15
3.	Female	52	White Non-Hispanic	Some High School	Widowed	19
4.	Male	47	Hispanic	High School	Single	7
5.	Male	46	Hispanic	Masters Degree	Divorced	21
6.	Male	54	Asian	Some College	Married/Living with Partner	19
7.	Male	53	Black Non-Hispanic	Some High School	Married/Living with Partner	13
8.	Female	45	White Non-Hispanic	Some College	Married/Living with Partner	6
9.	Female	50	Black Non-Hispanic	High School	Separated	6
10.	Male	54	White Non-Hispanic	High School	Single	23
11.	Female	42	Hispanic	High School	Divorced	11
12.	Male	58	Black Non-Hispanic	Some High School	Widowed	16
13.	Male	54	Hispanic	Some College	Single	21
14.	Male	52	Hispanic	Middle School	Single	15
15.	Female	43	Black Non-Hispanic	Some High School	Married/Living with Partner	18