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The Physical, Emotional and Interpersonal Impact of HAART: Exploring the Realities of HIV Seropositive Individuals on Combination Therapy

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Abstract

The purpose of this qualitative study was to understand the impact of HAART on the lives of HIV seropositive men and women. The data demonstrate that the demands of these treatments are substantial, but that renewed health and hope for the future due to the implementation of HAART often overshadows the stress of the treatments on the physical, emotional and social well-being of the individuals. Practitioners should be keenly aware of the struggles faced by those on HAART, and provide multidimensional support to assure maximum effectiveness of these treatments in light of the realities of their clients' lives.

Keywords

HAART; health care; HIV; psychology; psychosocial

Introduction

MEDICAL advances in the treatment of HIV, notably the implementation of protease inhibitors as part of highly active antiretroviral therapy (HAART) in the late 1990s, have worked to increase life expectancies and to enhance the health of HIV seropositive (HIV+) individuals (e.g. decreases in viral load to undetectable levels in the blood and increases in CD4 cells in the immune system), resulting in a significant decrease in AIDS-related mortality (CDC, 1999; Cohen et al., 2002; Folch et al., 2002; Palella et al., 1998; Riley,

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Bangsberg, Guzman, Perry, & Moss, 2003; Valdiserri, 2003). Yet, the rate of decline for AIDS-related deaths has leveled off (Karon, Fleming, Steketee, & de Cock, 2001) and HAART has been shown to fail in over 50 percent of HIV seropositive (HIV+) individuals in clinical settings (Valdez et al., 1999).

While HAART has become the standard of care for people living with HIV, biomedical and behavioral researchers have minimal knowledge and understanding about the longer-term efficacy of HIV antiviral therapies. This uncertainty is due, in part, to the failure of these regimens even among people who initially respond to HAART (Brenner, Turner, & Wainberg, 2002; Clotet et al., 2002; Dionisio et al., 2001; Nicastrì et al., 2003; Roge, Katzenstein, Nielsen, & Gerstoft, 2003; Servais et al., 2002; van Vaerenbergh et al., 2002). Nonetheless, with the advent of recent treatment advances, HAART has provided a sense of optimism and hope to HIV+ individuals (Chan et al., 2003; Holmes & Pace, 2002; Kalichman, Nachimson, Cherry, & Williams, 1998; Lee, Solts, & Burns, 2002; Yallop, Lowth, Fitzgerald, Reid, & Morelli, 2002).

Connected to the optimism spurred by HIV treatment advances, the complexity and demands of the relationship between HAART and quality of life poses serious challenges for HIV+ individuals in relation to the physical, psychological and interpersonal realms of their lives (Coates, Ternoshok, & Mandel, 1984; Penedo et al., 2003; Rabkin, Ferrando, Lin, Sewell, & McElhiney, 2000). Much of the HIV prevention research has focused on health-related quality of life (HRQOL) due to the implementation of these treatments (Carrieri et al., 2003; Hays & Morales, 2001; Miners et al., 2001). Some researchers (Hays, Cunningham, Margot, & Beck, 1995) have found that HRQOL relates to a two-factor model: physical health (e.g. physical function, role function, freedom from pain, disability days and quality of sex life) and mental health (e.g. overall quality of life, emotional well-being, hopefulness, lack of loneliness, will to function, quality of family life, quality of friendships and cognitive function/distress). While recent research has demonstrated that individuals on HAART with advanced symptomatic AIDS reported an increase in CD4 count, body weight and serum albumin and ferritin levels, as well as a decrease in viral load and depression (Brechtel, Breitbart, Galiotta, Krivo, & Rosenfeld, 2001), other researchers have found that severe physical (Altice, Mostashari, & Friedland, 2001; Blanch et al., 2002; Gao, Nau, Rosenbluth, Scott, & Woodward, 2000; Oette et al., 2002) and emotional (Cook et al., 2002; Kalichman, Ramachandran, & Ostrow, 1998; Newshan, Bennett, & Holman, 2002; Rabkin & Ferrando, 1997) side effects of HAART may result in non-adherence to HIV antiviral medications. In fact, these complex HIV regimens (Cheever & Wu, 1999; Chesney et al., 2000; Durante et al., 2003; Giordano et al., 2003; Halkitis, Parsons, Wolitski, & Remien, 2003; Ickovics & Meade, 2002) require greater adherence than any other medical treatment (Rodriguez-Rosado, Jimenez-Nacher, Soriano, Anton, & Gonzalez-Lahoz, 1998).

In addition to the physical demands of HAART, the implementation of these therapies has social and psychological implications (Halkitis, Parsons et al., 2003). Successful adherences to these treatments is intimately linked to how prepared patients are to confront the effects of these medications (Wroe & Thomas, 2003). This is heightened by the fact that many HIV+ individuals already experience psychological distress in the forms of anxiety, depression and mood distress (Shor-Posner et al., 2003), which may be exacerbated by the dosing

requirements and physiological side effects of HAART. Even with the possibility of longer and healthier lives, people living with HIV in the age of HAART have been shown to experience the same psychological and existential issues that impact on psychological functioning, well-being and quality of life that existed prior to the development of these treatments (Schoennesson, 2002).

To assess the impact of HAART regimens on the lives of HIV+ individuals, we conducted a qualitative investigation and asked participants to describe their realities and experiences since HAART was implemented in their lives. In particular, we sought to contextualize the psychosocial and biomedical realities and to understand how HAART has changed the lives of HIV+ individuals.

Method

Procedure

Data were collected at a large AIDS service organization (ASO) serving over 8000 HIV seropositive individuals in a large north-eastern city of the United States. The sample was recruited using passive methodologies through the use of flyers posted throughout the ASO. The researchers screened potential participants using four criteria: (1) being 18 years old or over; (2) taking a protease inhibitor for at least six months; (3) gender; and (4) sexual orientation. The last two criteria were used to categorize the participants into four focus groups: women, heterosexual men and two groups of gay and bisexual men. These proportions reflected the composition of the clients being served at the ASO.

A set of three questions guided the discussion of the focus group; probes were used to obtain in-depth data regarding the constructs that were assessed. The questions focused on the participant's history of protease inhibitor-containing regimen, the impact of protease inhibitor-containing regimen for quality of life, the extent of adherence and reasons for non-adherence to their medication protocols and self-care strategies used to enhance adherence. Specifically, the questions that guided the discussion were as follows: (1) How familiar are you with HIV treatments and protease inhibitors? (2) To what extent do you adhere? What obstacles do you face? What strategies do you use to enhance adherence? (3) What impact have these protease inhibitors had on your life physically, emotionally and behaviorally? A member of the research team trained in qualitative methodologies and knowledgeable about HIV antiviral treatments facilitated each group. A second member of the research team served to keep field notes of the group's discussion. The facilitators were of the same gender as the participants in each of the groups. The focus groups were audiotaped after obtaining written consent from the participants.

The qualitative data were transcribed by an outside agency and were assessed for accuracy by comparing written transcripts to the audiotapes. After making corrections, the transcripts were reviewed and analyzed by a team of four research assistants. The entire team developed a two-level codebook based on their analyses of the transcripts and rooted in thematic coding procedures as outlined by Miles and Huberman (1984) and Patton (2000). The codebook was developed based on our exhaustive reading and discussion of the transcripts to identify all the possible themes that emerged. Once we developed the final set of codes, each

transcript was then coded separately by two different research assistants to assure inter-rater reliability. The level of agreement in coding within each of the four transcripts averaged 91.3 percent. When discrepancies in coding were evidenced, the coders met to discuss the disagreement. Modifications in the coding were made after the team had reached consensus.

Sample

Of the 50 clients who responded to the postings, 37 (74%) actually attended the focus groups. Of this number, 22 percent ($n = 8$) identified as female and 78 percent ($n = 29$) as male; the mean age of the sample was 42. Approximately 24 percent of the men identified as heterosexual and the remainder as gay or bisexual and all but one of the women identified as heterosexual. The sample was racially/ethnically diverse and reflected the population of AIDS clients at the ASO: 37.8 percent Black; 24.3 percent Latino/a; and 35.1 percent White. In terms of educational background, about 5 percent reported less than a high school degree, 76 percent a high school degree or some college education and 19 percent a bachelor's degree or higher. Further, 62 percent of the sample reported receiving disability benefits. The remainder either worked full- or part-time or was in school.

Measures

We used a semi-structured interview with probes to conduct the focus groups. The focus group questions focused on the participant's history with use of protease inhibitors and perceived changes on one's life since initiating HAART. Researchers used specific probes to assess the impact of protease inhibitors on the participant's quality of life.

Three main or first-level domains emerged and guided the data coding and each of these first-level codes included second-level domains. The thematic codes were as follows: (1) physical impact of protease inhibitor therapy including the second-level domains of positive and negative health outcomes; (2) psychological impact of protease inhibitor therapy including the second-level domains of changes in worldview and both positive and negative emotional reactions; and (3) interpersonal impact of HAART including the sub-domains of impact on relationships, including friends, family, coworkers and sexual partners. These themes emerged naturally from the questions that were posed in the interview. In addition, participants discussed the role of obstacles to and strategies for HIV adherence to antiviral therapies, which have been elaborated elsewhere (Halkitis & Kirton, 1999).

Results

We analyzed the qualitative data using the three primary domains discussed previously. As such, we assessed the physical, psychological and interpersonal impact of HAART and the interaction between these domains as they emerged across the discussions with gay and bisexual men, heterosexual men and women.

Physical impact

More so than any other area, the participants across all three groups very clearly articulated the impact of HAART on their physical health. These discussions involved both the positive effects of HAART on overall health, especially in light of disease progression, as well

as what was perceived to be the negative side effects of the medications. In terms of overall health, participants suggested that HAART increased their energy level, sexual desire and prevented the development of opportunistic infections. On the other hand, they also discussed the impact of side effects that included gastrointestinal distress, insomnia, dehydration, neuropathy, headaches and lypodistrophy.

Coding was used to determine the frequency of themes that emerged regarding the physical impact of treatments. Thus, we assessed each participant's statement in terms of our coding scheme to determine the relative importance ascribed to both positive and negative physical impacts. For the women, the negative side effects of HIV antiretroviral regimens served as a central factor in the group's discussion. All 38 times comments about physical impacts which emerged reflect the negative physical consequences of treatment. For both sets of men, heterosexual as well as gay and bisexual, the positive and negative effects were more equally cited. A summary of these themes is provided in Table 1.

One of the main themes that emerged, especially among the men of both sexual orientations, was that of increased physical health, improved blood markers and fewer opportunistic infections. Participants believed that improved health was directly related to HAART and indicated more AIDS-related complications prior to the initiation of combination therapy. In this regard, one gay man said:

I have had nothing but very excellent results. I had zero t-cells for about two years. I had CMV retinitis and a bunch of other things too. So, I've been in and out of the hospital and I've lost weight. When I started the protease inhibitors in October of last year, I didn't have any opportunistic infections at all. I just wanted to try the drug to increase my t-cells, which were zero, and the viral load was way up to 300,000. And, by the next blood test, which was about a month and a half, two months later, the t-cells went up to about 95, and the viral load had decreased to undetectable.

Also related to the effects on his blood markers, one heterosexual man commented, 'For about six months, I've been taking the protease inhibitors, Norvir, and everything. My t-cells are up. My viral load is down to 4000.'

Increased weight and prevention of wasting was perceived as a benefit of HAART and a direct result of combination therapy. For example, one heterosexual man noted, 'It's been pretty good for me. I was 149 pounds. Now, I'm 235 pounds. At 149 pounds, I was walking around like a scarecrow.' And a gay man noted, 'So I'm gaining weight, feeling better; and the doctor said it's because I'm on this combination.'

Another positive effect of HAART noted by the men with whom we spoke was increased physical strength. This higher level of energy was related to the ability to function more actively and in a more 'normal' fashion. One heterosexual man indicated this reality as follows, 'I can go to a party, I can dance, I can move around. I don't feel tired. I can have me some fun.' A gay participant attributed his perceived increase in energy to an increased appetite. He described the experience this way: 'And it's like, when I take it, it just makes me eat and gives me more energy, and it just keeps me running.'

In response to an increase in energy and general well-being in health, some participants, who had been on disability benefit, indicated a desire to return to work: 'So, now that I'm doing much better and feeling great. I've got to start putting my career back together, making all those contacts that I lost over the years, re-establishing myself in this world.'

However, many of the men expressed the prospect of returning to work after so many years as a daunting task. One gay participant communicated his feelings this way:

Something that I want to add is like, getting back to life together, I have some problems now because I been in this stage since '92. And now, I'm ready to go back to work. And I started going to interviews and sending my resume. Now, I have this gap between my last job and '97, and people say, 'What did you do between all these years?'

Both sets of men as well as the women indicated numerous negative physical impacts of being on HAART. For women, these negative impacts, which were essentially associated with side effects of the medications, were the most pronounced. For both gay and bisexual as well as heterosexual men, the side effects were counterbalanced by the positive physical impacts that were noted above. Side effects included gastrointestinal distress, neural and skin ailments and unbalanced water absorption. These problems associated with HAART were summarized by one woman as follows:

The first two or three months on meds was alright, and then all of a sudden, everything started. You know, I started getting allergic reactions to it. I started breaking out in blisters. My color started to get discolored.

Similarly, another participant noted the side effects and said, 'The Crixivan, I find, dries me out and I have dry skin. My skin gets so crinkled and you get a taste in your mouth like foam-tasting.'

Although the men in our study discussed these side effects less frequently, they did note some complications. For example, one of the gay men articulated his experience as follows: 'I started with the Crixivan. When I took the medicine, it felt like a bomb in my stomach. The nights, I couldn't sleep.' And another, describing the side effects of protease inhibitors, indicated how taking HAART interfered with his life:

I had a bad experience. I was on the Ritonavir and my body wasn't accepting that. The side effects were numbness around the mouth and loose stool. I went to work, and I had a real bad experience. My co-workers would try to talk to me and I couldn't talk back. And then I had problems with loose stools. I was coming from work and I went to the meat market, and as soon as I came out of the meat market, I lost control of my bowels.

Some men were unable to endure the negative side effects associated with some regimens:

And [the regimen] tore me up, you know. I started developing back pains and headaches. I couldn't sleep. I couldn't go to the bathroom. You know, my appetite was fluctuating, and I had to stop it . . . I couldn't take . . . I couldn't take the six. I never got to six. I took five. That was too much. I took four, and that was too much.

So, I started taking three, and that seemed to agree with me all right. And I'm doing okay.

Some participants deemed the negative impact of side effects less important because of the general improvement in health. However, for those who experienced continuous side effects with their treatment in light of limited improvement in their blood markers, the decision to continue treatment was less clear. In that regard, one gay man said:

You know first I was on Viracept and 3TC and d4T and I got neuropathy, then we took me off the d4T and started AZT and then I started to have nausea and headaches and diarrhea all the time. And now I am on Crixivan. And the whole time, no matter what, I'm feeling weak and sick and tired, and my viral load continues to be at like 4000 and my t-cells like 200 to 300. So now I wonder if it's all worth it.

Psychological impact

Participants also discussed the psychological impacts of HAART. In particular, many of the participants indicated that being on HAART had both positive and negative emotional side effects. In addition, participants spoke of a change in their worldview that was affected by the success as well as the long-term uncertainties of their medications. Frequencies of comments along these domains are indicated in Table 1.

As was the case when they spoke of the physical impact of HAART on their lives, participants across all three populations weighed more heavily on the negative mental health consequences of protease inhibitor treatments. Many participants expressed experiencing anxiety because of the medications, in particular, about missing doses of their medications. They also acknowledged the emotional impact of living while preparing to die, and spoke of memory loss and depression that they attributed, at least partially, to the regimen demands.

The renewed hope that some experienced due to improved health was not always viewed in the best possible light. For some, an improvement with health was associated with increased anxiety after preparing to die for so many years:

I think I'm much more riddled with anxiety since being on the protease inhibitors. I mean, sure, I was anxious about dying and the whole bit before. I think suddenly here's this life which, you know, for years I figured well, I'll be dead by then. And then suddenly, and there is this life to deal with.

This anxiety was also related to the uncertainty of the long-term effectiveness of the medications as well as the demands of adherence. In this view, one gay participant suggested, 'Well then you stop taking the medication and it [viral load] pops up again. When will it stop working? That's what I'm worried about.' Similarly, many spoke of the demands of adherence and their emotional concern about taking their doses 'off-schedule', which would lead to treatment failure. This theme emerged across all three populations and appeared to be foremost in the minds of the participants. One of the gay men commented on this matter as follows:

Last winter, I had a bad weekend, where I was, you know, doing illicit drugs, and just didn't take my pills and, for like two days. I went into a panic that everything was going to go all the way back up, and couldn't wait till we did the next viral load and t-cell count.

The anxiety about adherence interfered with the lives of several of the participants. One of the women with whom we spoke suggested this reality: 'I have stopped in the middle of sex to take my medicine. Once at a quarter to five, I was like, "Oh, wait, I've got to go take my Viracept." I'm a fanatic with my medicine.' One of the heterosexual men expressed his emotional fatigue of the constant need to take medications and said, 'But there's days that it does get me upset and don't want to take it . . . you know, it's just like I'm tired of it all.'

The importance of doctor–patient communication seemed to be a theme that emerged across all three groups. For some, being on HAART created fear in their lives. This fear was directly related to the uncertainty about how the medications actually work, distrust of the medical establishment, as well as their long-term effectiveness. One of the women expressed those feelings as follows: 'So like right now, I have a fear of these medications. I want to talk about that, and about what is happening to my body and I don't know what's happening. Some-times, my doctor tells me nothing.'

After disclosing some fears regarding the side effects of certain medications, one gay man described his physician's response this way: 'And I was saying earlier about my physician reading me the riot act. She said, "Listen, I'm trying to save your life man! And you ain't helping me none." ' One woman simply illustrated her frustration with her health care providers by stating, 'They don't advise you in anything.' While some participants felt discouraged with the lack of support and information they received from their doctor, another female participant highlighted the importance of her communicative relationship with her physician: 'I know my doctor. She broke everything down for me, everything from side effects to when she talked about how I felt about taking the medicine. You know we don't only have a doctor–patient relationship.'

For another gay male participant, the situation was worsened by conflicting information from different physicians, which seemed to undermine his faith in the advice of any one physician. 'And every doctor has a different opinion anyhow. As I said, my doctor said I can take Crixivan up to two hours after, and that counts as with food, whereas some doctors say after one hour, it's without food.' It seems that in some cases, a lack of communication, physician inattentiveness to patient needs and perceptions of misinformation enabled patient mistrust in their physician and their prescribed course of action.

While the negative emotional effects encompassed fears, anxieties and depressions, the participants also indicated that HAART provided a sense of control over their lives, a sense of happiness and a greater ability to manage HIV disease. Although these comments were few in number, they did demonstrate a type of optimism related to being on the treatment. This notion was best captured by one of the gay men as follows:

Look there was no hope like 3 or 4 years ago. I was sure I was going to die. When these drugs came out, it changed everything. Now my life is kind of normal, except for the pills. Now I'm kind of in control.

Both the positive and negative emotional effects of being on a protease inhibitor treatment changed the manner in which participants viewed the world and their lives. It also had an impact on their decision making as it related to the future, their hopes and their dreams. These ideas were expressed clearly by all three groups. For many, this change in worldview focused on living rather than dying, and on challenging HIV rather than letting the disease defeat them. One of the women said, 'Now listen, your medication has to be above anything else. Your life is priority. You want to live, and with these proteases, your living is possible.'

Similarly, one of the gay men noted the impact on his worldview:

I had really starting thinking about death when it was looming. I had retired. I had finally got my disability claim last spring. So it was like, okay, now it's time to start thinking about living towards death, not living towards life. And now I'm starting to live. I think about jobs, thinking about going back to school again, thinking about taking over old goals. I finally moved into my own apartment after several years of living in a residential hotel. So, I'm feeling hopeful and feeling promise.

In this regard, some spoke of changing habits in their lives such as recreational drug use, excessive alcohol consumption and the type of individuals with whom they socialized. One heterosexual man commented as follows: 'And when I started feeling better, I wanted to change things. I stopped smoking cigarettes. Hang with some positive people; leave the negative people alone.'

For some others, issues of returning to work and re-establishing their finances and careers were a direct impact of starting HAART. This reality, however, was both exciting and over-whelming. One of the gay men commented on this matter as follows:

It basically flipped my lifestyle over. Within four weeks after I started taking the medication, my viral level was undetectable. So I now feel I no longer have to worry about the virus. So now I can just go back to my old problem, and go try to find a job.

For another man, finances and returning to work created a sense of tension in his life:

It's changed my life, but now I have a whole bunch of additional problems, because I am going to live longer, which I did not expect to and I have spent all my money. I stopped working. I did a lot of giving up things because I was told that the prognosis wasn't good. So, now that I'm better I've got to pay all those bills that I ran up, and I've got to go back to work and earn some money to support myself, and start putting my career back together, making all those contacts that I lost over the years. And that's a very stressful situation.

Another gay participant found that remaining adherent interfered with his professional life in unexpected ways:

Yeah, I had to change my schedule too, because last week I had a real bad experience. Because I teach baton-twirling, and I teach a Core. And . . . and I have the pills in my bag, and my keys to my alarm was in my bag and it went off. And my students said, 'What is that? What is that?' 'Mind your business', you know, 'Don't worry about it.' Oh, I said it was my beeper and I had to take my bag and go around the school, because I had water in there to go ahead and take and come back. You know, and I'm like, 'Oh, shit. Now I've got to change the time on this thing because . . .' you know, with my class, you know, being in the class, you know, and stuff like that.

Having lived through the trauma of the AIDS epidemic, and the loss of so many loved ones, many gay men had lost hope and resigned themselves to death. The advent of effective drug therapies was a welcome blessing however, as it forced many men to re-evaluate their lives, as well as confront new, unforeseen obstacles:

So, I'm left now with this whole prospect of my life, like, gee, I'm going to live, everything's going to be okay. Now, what do I do? No, I'm just like, you have to pick up from where you left off years ago. And it's not an easy thing. And so, this is how taking medicines can help you live when you psychologically don't want to, or you decided well, do you want to continue when there's hope now, and there is real living left to do. And so taking medicines regularly comes into play.

Interpersonal impact

Being on HAART also was related to social realities and relationships in the participants' lives. Within this context, the participants across all three groups discussed the impact of HAART on their sexual lives as well as its interaction with the relationships they shared with their family, friends and colleagues. However, the impact on sexual relationships was most pronounced among the gay men in both groups; heterosexual men and women spoke less of this impact. The frequency of salient themes is provided in Table 1.

In terms of non-sexual relationships, participants discussed the stresses associated with balancing the relationships in their lives with the demands of their medication regimens, as well as their need for emotional support from family members. This was most pronounced among women in terms of their relationships with their children: 'This is hard on our kids. My daughter flipped when she saw me in the condition that I was in. She flipped, you know, and she's 16 years old.' Similarly, another woman spoke of her son's denial of her condition and of her medications:

I try to get Tony to understand about my meds but he wants no part of that. But anytime that I have tried to sit down and talk to him about it, he doesn't want to, and that's hard on me, because I can't hide it any more with the pills I have to take. The thing is, with him, if there's a show on and I say, 'Hey Tony, man, there's a show on about HIV.' He'll say, 'Mom, that's so depressing.' If I try to talk to him about certain things, he always has an excuse.

For some, being on HAART required the support of their families and friends. Reflecting on the positive impact of his wife on his adherence, one man said, 'Well my wife and I work

on that together. She tries to help me remember and that's a big help to me.' Similarly, one other heterosexual man talked about his increased need for support from the members of his ASO support group, 'I just got some friends from the support group that I am going to. And, we all try to help each other not forget our pills. So they either call me or I call them.'

However, for others, the presence of pills in their lives was a source of stress in social situations because it entailed disclosing their HIV status. One of the gay men reflected on that reality as follows:

There are certain times in social situations where it's hard to take them. For example, I went to my godson's birthday party during which I was supposed to take Crixivan, but I didn't because you know it was a party.

Similarly, another stated:

If I know I'm going out for brunch or something like that, I just carry the exact amount of pills, put them in my pocket, and I just take them. But when I don't want to take them around anyone else, I'll excuse myself, and go to the bathroom.

Finally, the gay men spoke quite clearly of the impact of HAART on their sexual relationships, their renewed interest in sex and their fear of infecting their partners in light of their renewed sexual drives. For some, the increase in sex drive was considered problematic in light of a desire for unprotected, condom-free sex. One man summarized these ideas as follows:

Well in the last few months I have been feeling a lot better, and so I've been going to my favorite bar two or three times a week, to hang out and sometimes for sex. I have met lots of guys. I don't know if they're positive or not and I haven't had unsafe sex except like I let them suck me and sometimes I cum in their mouth. And that feels really hot to me. But I don't know if that's safe or not. Every-one says it's okay, but I don't know.

For some other men, the possibility of infecting a sexual partner was an enormous concern. In response to this situation, several men made the decision that was summarized by one participant who said, 'I don't mind to tell somebody that I am HIV and on Crixivan, and I don't go to bed with anyone unless they are HIV too.'

For other men, the benefits of HAART left them with a renewed desire to protect themselves, now that they have been given a second chance at life. When asked if he continued to practice safer sex, one gay participant presented his ideas in this manner:

Oh, absolutely, sure. Absolutely. Because there are other diseases that you can catch. I'm not about to get gonorrhea, syphilis, hepatitis, or any other thing. That would only complicate my life, which I don't need at this point. I'm just getting everything in order.

Discussion

The data collected from the 37 HIV+ individuals in this qualitative investigation suggest a multifaceted psychological response to HAART. In part, the individuals with whom we

spoke indicated a sense of renewed health and hope for living due to the implementation of antiviral treatment. Tiamson (2002), similarly, notes that with the advent of HAART, individuals experienced 'resurrected lives'. Remien et al. (2003) indicate that some HIV+ individuals see treatments as 'life-savers', and as a source of hopefulness for the future. In our investigation, some of the participants expressed a sense of greater control over their lives and a sense of being able to maintain the virus and manage HIV disease. And, as has been noted elsewhere (Rabkin et al., 2000), reductions in psychological burdens of HIV have been attributed by some HIV seropositive individuals solely to the administration of these treatments regardless of treatment outcome. Such favorable changes in physical function, social function, mental health and energy have been noted in longitudinal investigations of individuals on HAART (Nieuwkerk et al., 2001).

However, our data also suggested that this optimism and the psychological relief expressed by some HIV+ individuals often were counterbalanced by the physical, emotional and interpersonal demands of these medication regimens. In particular, regardless of their gender or sexual orientation, the individuals in our study indicated that HAART placed heavy burdens on their physical beings due to the side effects of the treatments. This concern about the toxic effects has been cited as a source of ambivalence toward antiretroviral treatment (Remien et al., 2003). Further, uncertainty about the long-term effectiveness of the treatments, including the potential development of medication resistance served as a source of emotional burden to some of the participants in our study. In this regard, Saunders and Burgoyne (2002) have noted for those on HAART, quality of life is related to immunological and virological outcomes, thus suggesting the complex interrelationships that exist between the perceived effectiveness of treatments and the emotional or psychological burdens individuals may face. In our investigation, these feelings of uncertainty about the long-term effectiveness of treatment were exacerbated for those individuals who were extremely ill prior to the administration of treatment. And while our investigation suggests that the impact of HAART on quality of life may vary from person to person, we could not decipher why such variation occurred. It has, however, been suggested that personality traits may be associated with HIV-specific quality of life, and that HIV-specific quality of life may be impacted by HAART (Penedo et al., 2003). Future research in this area should thus attempt to disentangle person-level characteristics that may predispose individuals to the type of experience that they encounter while on HAART, and should be undertaken through individual rather than group-based interviews.

Another central theme that emerged in our study was with regard to the emotional burdens of HIV antiretroviral adherence. As has been documented extensively, adherence to HAART is a complex behavior that is impacted by numerous psychological, sociological and biomedical realities (Chesney et al., 2000; Cook et al., 2002; Diaz, Cisek, Nionne, & Tottenham, 1999; Halkitis, Parsons et al., 2003; Halkitis & Wilton, 1999; Ickovics & Meisler, 1996; Melbourne, 1999; Vanable, Ostrow, McKirnan, Taywaditep, & Hope, 2000; Weidle et al., 1999). Thus, attempting to balance the realities of HAART adherence within the structures of already burdened lives represented a major challenge for those with whom we spoke. Further, according to some of our participants, the dosing demands of the regimens were a source of elevated levels of stress due to the conflict they experienced in administering their medications in social situations. To this end, the demands of adherence

coupled with both the long- and short-term medical effects of the regimens has caused many clinicians to consider the optimal manner in which to prescribe and administer HIV treatment (Powderly, 2002).

Our study considers the psychosocial impact of HIV antiretroviral regimens on the social and emotional lives of those on treatment using approaches similar to those that have been used to understand barriers to adherence among gay men, women and injection drug users (Remien et al., 2003). Furthermore, since little is known about the impact of administering these treatments successfully (Fothegrill-Bourbonnais et al., 2002), investigations such as ours are crucial in order to help disentangle the complex array of factors that impact on the social, emotional and physical lives of HIV seropositive individuals. As Remien et al. (2003) note, there are numerous factors that influence the medication taking of individuals and thus clinicians and health care providers need to be aware of these complex factors. To this end, even historical events such as the disaster of 9/11 cannot go unnoticed in terms of the impact that such occurrences may have on the treatment lives of HIV seropositive individuals (Halkitis, Kutnick, Rosof, Slater, & Parsons, 2003).

Limitations

While our study is limited in generalizability due to the small sample size and the fact that all of our participants were clients of an ASO, the data are indicative of ideas and sentiments shared by those on HAART in the popular press (Grinberg, 1999). In addition, as our work was guided by qualitative methodologies, we believe that truth is not a simple correspondent relationship. Rather, we affirm that understanding the complex realities of those on HAART is best undertaken through hearing the words of the daily lived experiences of individuals on these treatments.

Given our recruitment within an ASO, it is possible that our participants provided a more positive view of HAART given that they were likely receiving support service within the community agency. For those without this level of support, the reality of being on HAART may in fact be more difficult than what our participants indicated. Furthermore, our sample was self-selected. While demographically this sample was similar in composition to the population served by the ASO, there may be under-lying factors that went unexplored with regard to the reasons that these individuals participated in this investigation. Moreover, individuals seeking service at a community agency may be fundamentally different from those who do not seek out this help. A more general sample of those on HAART might have provided slightly different findings.

Our work is further limited by the manner in which data were collected. While focus groups can provide an effective way for gathering information from groups of people, the social realities of such data collection may hamper more in-depth understandings that could be ascertained from individual interviews. Issues of social desirability are always present in social science research, and the format of the focus group may be such that the influence of social desirability is more greatly evidenced. To this end, the format of the focus groups did not allow us to individually correlate thoughts with the demographic characteristics of our participants.

The AIDS epidemic and accompanying treatments change continually. While our data certainly reflect realities of those on HAART today, it should be noted that the data were collected shortly after HAART became implemented in the late 1990s. None the less, we believe that the themes that we discuss are still evident and present in the lives of those taking antiviral treatments.

Finally, the reality of HAART for individuals in the United States is impacted by the social, political and economic realities of the country. Issues faced by those living with HIV in Africa and other poverty-stricken parts of the world are sure to be further exacerbated by lack of access to proper health care and appropriate treatments for the disease.

Conclusions

For those providing care to individuals with HIV and on HAART, the words of the participants in this investigation should be carefully considered. When prescribing medication regimens, health care providers should consider the realities of their patients' lives and customize each such that the medical benefits of the treatments are most realized. To achieve this end, physicians, nurses, psychologists, social workers and prevention staff must be keenly aware that while potentially prolonging the lives of individuals, HAART adds yet another layer of burden that may already be complex and demanding. We must consider that treatment with HAART does not occur in a vacuum, but within the structure of lives of people struggling to attain basic necessities, such as food, shelter and human compassion. Finally, we should take care to provide our clients with the social support necessary to maximize adherence to these treatments in order to realize full effectiveness. This represents an enormous task as numerous investigations of adherence have already demonstrated.

As we enter the third decade of AIDS, hope, optimism and complacency have permeated mainstream American society regarding HIV/AIDS. New, emerging challenges related to the fight against HIV/AIDS must be addressed if we are to capitalize upon past successes. New infections continue to occur, and co-infections with viruses such as Hepatitis C are more prevalent among the HIV seropositive (Human Resources and Services Administration, 1999). Feelings of complacency are partly to blame for this trend as it has been suggested that these advances in HAART have led to a false impression that the epidemic is over (Halkitis & Wilton, 1999; Kalichman et al., 1998; Miller et al., 2000; van de Ven, Kippax, Knox, Prestage, & Crawford, 1999; Vanable et al., 2000). Further, as the long-term effectiveness of treatment regimens becomes clearer, we should be even more proactive in assuring that those living with HIV and AIDS continue to receive necessary support and care. To do otherwise will make it impossible for patients to fully realize the benefits of their renewed health and the effectiveness of treatments on their physical, psychological and social well-being.

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Table 1.

Frequencies of emergent themes by group

Theme	Focus group			
	Gay men 1	Gay men 2	Heterosexual men	Women
Physical impact	30	36	43	38
Positive	12 (40.0%)	15 (41.7%)	19 (44.2%)	0 (0.00%)
Negative	18 (60.0%)	21 (58.3%)	24 (54.8%)	38 (100%)
Psychological impact	35	32	34	32
Positive	8 (22.9%)	6 (18.8%)	5 (14.7%)	10 (31.3%)
Negative	19 (54.3%)	20 (62.5%)	8 (23.5%)	16 (50.0%)
Worldview	8 (22.9%)	6 (18.8%)	21 (61.8%)	6 (18.8%)
Interpersonal impact	13	11	11	13
Sexual	10 (76.9%)	8 (72.7%)	5 (45.5%)	2 (15.4%)
Friendships/family/others	3 (23.1%)	3 (27.3%)	6 (54.5%)	11 (84.6%)