

DEVELOPMENT OF A SOCIAL NETWORK– BASED INTERVENTION TO OVERCOME MULTILEVEL BARRIERS TO ART ADHERENCE AMONG ADOLESCENTS IN BRAZIL

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Brazil's comprehensive HIV treatment program does not specifically address ART adherence challenges for adolescents—a group accounting for the largest number of incident HIV infections in Brazil. We conducted three focus groups with 24 adolescents (age 15–24) living with HIV in Rio de Janeiro, separately for cisgender men who have sex with men, heterosexual-identified cisgender men and women, and transgender women of any sexual orientation, and key informant interviews ($n = 7$) with infectious disease specialists and HIV/AIDS service organization staff. Content analysis identified socioecological barriers and facilitators to adherence, including individual (e.g., low knowledge, side effects, and substance use), interpersonal (e.g., stigma from partners and health care providers) and structural (e.g., transportation and medication access) barriers. Overlapping and unique barriers emerged by sexual/gender identity. A community-informed, theory-driven ART adherence intervention for adolescents that is organized around identity and leverages social networks has the potential to improve HIV treatment and health outcomes for Brazilian adolescents.

Keywords: adolescents, HIV, medication adherence, Brazil, men who have sex with men, transgender women

HIV infection among adolescents in Brazil is on the rise. A significant and growing population of adolescents in Brazil are acquiring and living with HIV. In 2017, 25.2% ($\approx 45,000$) of the newly diagnosed HIV/AIDS cases in Brazil were among in-

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dividuals between the ages of 15 and 24 (Department of Health Surveillance, 2017; Department of STD, AIDS, and Viral Hepatitis, 2012). It is likely that the number of adolescents living with HIV in Brazil is twice as high, although official age-stratified HIV prevalence data is not available. Accordingly, adolescents account for the largest number of incident HIV infections compared to any other age group (that is, 25 years or older) in Brazil (Department of Health Surveillance, 2017; Department of STD, AIDS, and Viral Hepatitis, 2012). Among adolescents, gay, bisexual, and other men who have sex with men (MSM) and transgender women (TW) are at even higher risk than their heterosexual peers (Saffier, Kawa, & Harling, 2017).

Antiretroviral therapy (ART) has resulted in precipitous declines in HIV-associated morbidity and mortality (Cascade Collaboration, 2000; Gortmaker et al., 2001; Hogg et al., 1998; Palella et al., 1998) in Brazil since universal coverage was instituted by the federal government in 1996 (Luz et al., 2016). Current guidelines direct first-line treatment of all HIV-positive persons with tenofovir, lamivudine, and efavirenz, regardless of CD4 count, with varying second-line regimens (Brazilian Ministry of Health, 2014). Although universal ART coverage has allowed for HIV-infected adolescents and young adults to manage their HIV as a chronic disease, maintaining high levels of adherence (> 90%) is crucial to treatment success (Bartlett, 2002; Chesney, 2003). Achieving such a high rate of adherence is challenging because regimens may include multiple medications with complex dosing schedules, food interactions and side effects that result in poor tolerability; as such, overall rates of ART adherence among adolescents is generally suboptimal (Murphy, Wilson, Durako, Muenz, & Belzer, 2001; Reisner et al., 2009). In a 2012 study in Brazil, 45.0% of adolescents between the ages of 13 and 20 were found to be non-adherent to ART medications (Crozatti et al., 2013; Ernesto et al., 2012), much lower than the 85–95% to optimize treatment gain (Garvie, Wilkins, & Young, 2010; Secord & Cotronei-Cascardo, 2007).

Poorer rates of adherence may be due to factors associated with the normal developmental trajectory of adolescence and young adulthood, including behavioral experimenting, risk taking, and facing a host of challenging choices with regard to romantic relationships, sexual behavior, substance use, and identity formation (Martin et al., 2014). The complexity of these multiple developmental factors are compounded for HIV-infected adolescents, who must navigate such development within the context of managing a chronic and stigmatizing disease (Bartlett, 2008). Research in the United States has found that common factors to poor adherence among adolescents include forgetting, pill burden, substance use, dropping out of school, and difficulties in coping with treatment (Secord & Cotronei-Cascardo, 2007). However, little is known about barriers specific to HIV-infected adolescents in Brazil and how these may differ for sexual and gender minority individuals (e.g., MSM and transgender women), where treatment regimens, access, and social influences may differ from the United States.

Even with the increase in HIV incidence among adolescents in Brazil, there is a paucity of specialized HIV prevention and care programs for young people specifically. The Programa Saúde e Prevenção nas Escolas is among the only government-sponsored programs which provides education about HIV risk behaviors to adolescents specifically, and is currently administered in only 10% of all Brazilian municipalities (Taquette, 2013). Globally several studies have demonstrated the efficacy of adherence interventions to improve ART adherence. One such evidence-based intervention, LifeSteps, uses principles of cognitive behavioral therapy and

is based on social cognitive theory (SCT), which specifies a core set of mechanisms that influence health behaviors with a primary emphasis on self-regulation and self-efficacy (Bandura, 1997, 2004). While LifeSteps has been adapted for a variety of populations and contexts (Daughters, Magidson, Schuster, & Safren, 2010; Psaros et al., 1999; Safren, Otto, & Worth, 1999; Safren et al., 2012; Shiu et al., 2013; Thurston et al., 2014), to the best of our knowledge, no evidence-based interventions exist to improve ART adherence among Brazilian HIV-infected adolescents. As such, the aim of the current study is to better understand barriers and facilitators to ART adherence, and potential differences by sexual and gender identity groups, and to gain input on intervention format and structure to inform the development of SCT-informed intervention for HIV-infected adolescents in Brazil.

METHODS

ETHICS STATEMENT

Study procedures were approved by the institutional review board (IRB) at the Instituto de Pesquisa Clínica Evandro Chagas (IPEC) IRB (Brazil) and the Comissão Nacional de Ética em Pesquisa (Brazil); the Brown University IRB ceded review of the protocol to the IPEC IRB. Prior to study enrollment, research staff met individually with potential participants to explain the purpose of the study, the voluntary nature of participation, and its risks and benefits and provided written informed consent before the start of data collection.

PARTICIPANTS AND PROCEDURES

A total of 24 HIV-infected adolescents from Rio de Janeiro, Brazil took part in semistructured focus group discussion in September 2017; focus groups were specific to MSM ($n = 10$), TW ($n = 8$), and heterosexual women and men ($n = 6$). Key informant interviews ($n = 7$) were also conducted with infectious disease specialists, senior management staff from HIV/AIDS service organizations, and HIV case managers who are knowledgeable and have firsthand experience working with HIV-infected adolescents in this setting. Recruitment for this qualitative study followed a selective sampling technique whereby study staff approached clinic patients at the study site who they thought would be willing to share their experiences in a focus group. They also posted fliers at local HIV/AIDS service organizations, hospitals, and clinics where HIV infected people receive care. The study site where participant visits took place was a clinical research institute that also provides HIV care. Eligible individuals were between the ages of 15 to 24 years, HIV infected, and self-identified as MSM, transgender woman, or heterosexual men and women. The focus groups lasted for approximately 2 hours and were conducted by trained research staff in a private space. Participants were compensated for their travel costs and provided food during the discussion. They were audio recorded, reviewed for identifying information and transcribed verbatim. Transcripts were translated into English by a bilingual staff person and independently assessed for accuracy and consistency.

DATA COLLECTION

Prior to the focus group, participants were given a brief interviewer-administered demographic questionnaire. The focus group was conducted in both Portuguese and English using a simultaneous translator and guided by a pre-established

set of open-ended questions and optional scripted probes. Interview guides were pilot tested with study staff and community advisory board members at the study site for cultural competency. The domains discussed and example probes used are as follows:

- (1) Medication knowledge: What do you know about your HIV medication? How do you know this?
- (2) Medication storage: Where do you usually keep your HIV medication? What are some of the problems you have with storing your HIV medication?
- (3) General barriers to adherence: How easy or difficult would you say it's been to take your medication on time? What activities can get in the way of taking medication?
- (4) Side effects and food: Have you ever felt ill or had a negative reaction to your HIV medication? Can you think back to a time when you may have avoided taking your HIV medication because of how it made you feel?
- (5) HIV care and access to medications: How do you obtain your HIV medication? What are some of the things that get in the way of you obtaining HIV medication?
- (6) Relationships: How much do young people living with HIV tell their friends about their HIV status? How could a young person's desire to keep their HIV status hidden from their friends or boyfriend/girlfriend affect their ability to take HIV medication?
- (7) Mood and substance use: Have you ever felt like not taking your HIV medication because you were unhappy or feeling angry? How might being under the influence of drugs or alcohol affect the decisions young people make?
- (8) How to take your medications: How have you developed the approaches you use to remember to take your HIV medication? What motivates you to take your medication?
- (9) Providing information: Do you think you could benefit from receiving guidance and information about how to take your HIV medication correctly? What are some advantages to meeting on your own with a counselor? What are some advantages of meeting with a group of people your own age?

The present analysis focused on barriers and facilitators to adherence and the development of an adolescent-specific adherence intervention.

DATA ANALYSIS

Data analysis was conducted by the U.S. investigators with close collaboration of staff members from the Brazil site using content coding based on key domains of the interview guide, in particular around the central themes of barriers and facilitators to ART adherence. Through frequent team meetings, categories were developed by the primary coder and the principal investigators based on the central focus group domains (described previously), and as a team, we developed summaries of the findings in each of these categories, paying particular attention to both convergent and divergent opinions on barriers and facilitators to ART adherence (Berkowitz, 1997; DeCuir-Gunby, Marshall, & McCulloch, 2011; Patton, 2005; Ryan & Bernard, 2003). To illustrate key themes, illustrative quotes were selected.

TABLE 1. Characteristics of Adolescent Focus Group Participants ($n = 24$)

	<i>n</i>	%
Race/color		25
White	7	29
Brown	11	46
Black	6	25
Education		
Fundamental V–IX	5	21
High school I–III	16	67
Superior	3	12
Currently working		
Yes	11	46
No	13	54
HIV transmission route		
Perinatal	5	21
Sexual	16	67
Unknown	3	12
Currently taking ARTs		
Yes	22	92
No	2	8
Self-reported adherence, past month		
100%	20	91
Less than 100%	2	9
Ever forget to take ARTs		
Yes	9	41
No	13	59
Ever stop taking ARTs if feel worse		
Yes	2	9
No	20	91
Missed any ART, past weekend		
Yes	3	14
No	19	86
Drugs gotten in way of taking ARTs, past month		
Yes	1	5
No	21	95
Alcohol gotten in way of taking ARTs, past month		
Yes	4	18
No	18	82
	Mean	SD
Age, in years	22.3	2.3
Age at HIV diagnosis, in years	17.1	7.4

RESULTS

Table 1 provides information on the socio-demographics, health and adherence reported by participants in the study. On average, participants were 22 years old ($SD = 2.3$). Approximately one quarter had a less than a high school education. Twenty-one percent were perinatally infected, 67% infected through sex with an HIV-infected person, and 12% did not know how they were infected. On average, participants were diagnosed with HIV at 17 years old ($SD = 7.4$). Twenty-two individuals (92%) were currently taking ART. Of those on ARTs, most ($n = 20$) reported being 100% adherent in the past month; however, 41% reported ever forgetting to take ARTs and 14% reported missing any ARTs in the past weekend.

Potential barriers to ART adherence among HIV-infected adolescents can be examined through a socioecological framework for health, including individual-,

TABLE 2. Individual Barriers to ART Adherence

Lack of knowledge
I have a friend. . . she turned out to be seropositive. So she started taking medication. Because of that she took the test again, they told her that she didn't have AIDS and she stopped taking the medication. How can this be possible if AIDS can't be cured? (TW Focus Group)
It depends a lot on the level of comprehension of that person and so regardless of how many times the clinician explains [information about HIV], exhaustively, what we see is that during another appointment, we notice that their understanding is lacking. (Key Informant)
Complex medication schedules
When I first started taking antiretrovirals, I would take five pills. One of them needed to be in the refrigerator . . . And now instead of five I take only three. And that helped me a lot...if it were only one, that would be even better, but three is already a big help. (Heterosexual Focus Group)
Side effects
Generally, I take [the medication] before bed. When I'm going to go out and drink, consume alcohol . . . I take it when I come home the next day . . . because I've already tried taking the medication 5 hours before doing anything and I always felt bad when I was out. (MSM Focus Group)
Depression
I went two years without treatment. At the time I was married and I stopped taking my medication altogether . . . It was all psychological, but I decided to get help and with therapy I started taking it again. First I started to treat my head, which wasn't doing well, so that I could then take care of my body. (Heterosexual Focus Group)
Concerns about interactions with drugs or alcohol
Like I said, I don't take it when I'm going out to drink. . . . I know that alcohol can interfere sometimes with the absorption of the medication in your body. So I avoid it. (MSM Focus Group)
If I take drugs all night I get scared to take my medication and have a heart attack, you know? For there to be a problem. Because I don't know . . . (TW focus group)

interpersonal-, and structural-level barriers. While presented separately, these levels can interact to further complicate ART utilization, and facilitators to adherence can also intercede at multiple levels to promote ART adherence among HIV-infected adolescents.

INDIVIDUAL BARRIERS

During focus group discussions, several common individual-level barriers to ART use were identified by all groups, including lack of knowledge, complex medication schedules, side effects, depression, and concerns about interactions with drugs or alcohol (see Table 2 for illustrative quotes).

While knowledge varied greatly, some participants, particularly in the focus group of transgender women, had substantial misinformation about HIV and AIDS. Participants conflated HIV with AIDS, and commented on the difficulty of obtaining information about their HIV medications. Key informants echoed this sentiment, highlighting that a lack of knowledge about HIV and HIV medications among some adolescents living with HIV can impact adherence.

Complex medication schedules were universally disliked by participants. Many individuals reported that they had to take multiple pills a day at different times, and it was difficult to fit this into their daily routines. Many reported trying to take it at the same time every day but often times they would not be able to or would forget at that time.

Side effects were noted as uncomfortable by many participants and impacted when and if they took their medications. Common side effects included nausea, dizziness, hot flashes, and memory loss. Participants reported that side effects varied between individuals and over time, and were sometimes remedied if they switched

TABLE 3. Interpersonal Barriers to ART Adherence

Lack of disclosure to sexual partners
Only people living with HIV know how to prevent it, how not to transmit it . . . And other people don't know, because they barely want to know about [HIV], they only think that it's wrong and that they don't want to have a relationship with people that have it. (MSM Focus Group)
Yesterday a boy came over to my house, and I knew he was going to sleep over. I had to hide my medication beforehand and hide it on top of the refrigerator under a rag. Because I was not going to take that bottle out in front of him . . . (TW Focus Group)
Stigma from family and friends
I live in my mom's house. My grandma doesn't know about my illness. My mom asked that I don't tell my grandma and grandpa. And the medication stays in a little box under my bed, under my pillow, I always keep it there. (MSM focus group)
So, I'm seropositive since I was born. I was on treatment, which my family didn't tell me I was seropositive. When I became a teenager, they got us together in a group...and explained why I was taking those medications that I asked about every day. . . . (Heterosexual Focus Group)
Health care stigma
I think it's prejudice. It's the prejudice that many hospitals have nowadays. It's the only reason that could stop a person from getting [their medication]. (TW Focus Group)
There are places where, to really be able to get your medication, you wait in line for what seems like a month. Because there is also a lot of prejudice toward seropositive people. It isn't easy! And it also isn't that . . . that the doctors . . . some doctors aren't prepared to treat that type of person. (TW Focus Group)
Because you already have the stigma of being trans, and even more from being positive. It's like when a transwoman goes to a clinic, many times, it's expected that she will be seropositive. So it's a double prejudice, one feeds off the other. (Key Informant)

medications. These side effects were most likely to cause skipped medication doses when they interfered with social activities.

Depression was also cited as a barrier to adherence, regardless of whether this depression was related to a participant's HIV diagnosis or not. Some participants discussed going for months, or even years, without taking medication because of mental health issues. Relatedly, drug and alcohol use was common, with some participants reporting that they use drugs to temporarily alleviate their depression. Though many participants reported that they take their medication even when they drink or use drugs, others were concerned about potential interactions between their medications and recreational substances and opted to modify their adherence schedule or forgo taking their ART altogether in order to accommodate drug or alcohol use. While this was discussed in all groups, drug use appeared more commonly reported and was cited as a bigger barrier in the focus groups with MSM and transgender women.

INTERPERSONAL BARRIERS

While some participants did not feel that their sexual or intimate partners acted as barriers to ART adherence, others discussed difficulties in disclosing their HIV status to their sexual partners and felt it necessary to hide their medication from partners to prevent accidentally revealing their serostatus (see Table 3 for illustrative quotes). Similarly, stigma around taking medication in front of family and friends was cited by all groups as an obstacle to adherence. In contrast to the other groups, many of the participants in the heterosexual focus group acquired HIV perinatally, and therefore, had grown up in an environment in which parents or other family members were aware of their HIV status, even when they were not. Those with family and friends that were not aware of their HIV status described hiding medication in their bedrooms and backpacks in order to avoid disclosing their HIV status.

TABLE 4. Structural Barriers to ART Adherence

Lack of affordable transportation
I have several cases currently of youths who are not coming to their appointments because they don't have money for transportation. (Key Informant)
The time I take to get to my health outpost is about two hours and another two hours to return. And then, two hours to go to my destination . . . to university or work . . . so I leave one day unscheduled during my week and let them know that I'll be absent because I need to pick up my medication or go to an appointment. (MSM Focus Group)
Difficulties with medication access
We get enough for 30 days . . . and we get it every 30 days. Because of that, the doctor advises you to go 5 days in advance to get it. And sometimes [the pharmacy staff] don't want to give it to you. (MSM Focus Group)
I'm from [city], I go to [clinic]. There is no AIDS medication there . . . There were months that there was medication, and other months when there was none. You already know that dying . . . I don't take it anymore. I only took it for a month. I went back and they were out of medication, and I just couldn't . . . (TW Focus Group)
Inconsistent care providers
And, in the case that the doctor doesn't know you, he wants to change your medication, because it's causing—I have a headache, a cold, pneumonia. He doesn't know our body. It interrupts our lives as well, because I work, I study, you know? (Heterosexual Focus Group)
Engagement in sex work
I'm afraid of a lot of things if I just take it on the street, understand? There are lots of [sex workers] . . . and if I take it and end up feeling weird, if I get hit with a bottle, or whatever it may be, something . . . (TW Focus Group)

Transgender women were the only group to report HIV-related stigma or discrimination by clinicians specifically which discourages them from accessing health care services, including pharmacies. Some transgender women discussed the need for more specialized, culturally competent HIV hospitals. Some key informants acknowledged that not all health care workers are equipped to work with persons living with HIV. Patients may feel uncomfortable talking to providers about HIV-related needs, or about asking clarifying questions, because of distrust of or discomfort with clinical staff.

STRUCTURAL BARRIERS

Participants in all focus groups discussed many structural barriers to ART adherence, including transportation, medication access, and inconsistent care providers (see Table 4 for illustrative quotes).

Transportation-related concerns, including the cost of public transportation to and from HIV-related medical appointments and the pharmacy, as well as length of commute, were universally cited as prominent barriers to adherence. Transportation-related barriers to care were especially pronounced for those who lived or divided their time in a different district than their regular health clinic.

Conflicting priorities, including school and work schedules, have made it difficult to refill a prescription. One participant noted that they were often able to commute to the clinic to fill their ART prescription only before the previous month's supply had run out; this often led to difficulties in obtaining the refill. Similarly, most participants noted that medication shortages were not common, but they had occurred in the past and prevented, delayed, or decreased the supply of pills received. At least one participant stopped taking their medication altogether because of inability to get their prescription filled at their local health outpost.

Inconsistent primary care providers were also cited as barriers to adherence. Participants remarked that it was difficult for their physicians to understand their medication needs because they often did not have the opportunity to remain under

TABLE 5. Suggestions for ART Adherence Intervention Content and Structure

Motivators for adherence
<i>Improved health and longevity</i>
At first I was, because I was judging myself, for the fact that I got this illness. But my desire to get to be ‘undetectable’, even when I was mad I would take [the medication]! (MSM Focus Group)
A person who is on antiretroviral treatment doesn’t transmit HIV to another person. So what you can’t do is not get treatment, or stop with your treatment. Because then you will run the risk of infecting your partner. (Heterosexual Focus Group)
What motivates me is that I’m going to gain weight. (TW Focus Group)
I take it because I’m afraid of dying! (TW Focus Group)
<i>Valuing a person’s life</i>
One method that we use a lot, personally, to incentivize someone to take their medication is to value them. To show how important they are...And each time that they notice that somebody else values their life, they start to take their medication more correctly. (MSM Focus Group)
<i>Strategies for adherence</i>
<i>Carrying medications with them</i>
So, my parents don’t know that I have it, so I carry [the medication] in my backpack always. I leave it in my backpack because I always leave with it wherever I go. And I think that it’s probably wrong to do that, but . . . (MSM Focus Group)
<i>Disguising pills</i>
I take it every night, but sometimes I’m with a friend, in a meeting, or whatever, I’m not alone, so I say ‘I forgot to take. . . my birth control pill’. I take it, and that’s it. (Heterosexual Focus Group)
Format and structure
<i>Individual vs. group sessions</i>
I think it is highly recommended to have both [individual and group sessions] for people. Speaking to just one person in which they can trust, which is important because you aren’t going to open up to strangers. And also a . . . group, to get information from others and also give them information. (MSM Focus Group)
I think that it is less embarrassing when everyone is there! You know that everyone has [HIV]! (TW Focus Group)
<i>Social networks</i>
But I think, since it’s a program. . . you need to create something social, from young person to young person, people living independently and together. (MSM Focus Group)
<i>Interventionist preferences</i>
I would prefer a woman, preferably a psychologist! (TW Focus Group)
A transgender woman that is seropositive. Like, as an example for us. Because with a man, it’ll be like ‘look’, we are all going to be embarrassed. (TW Focus Group)
<i>Text messages</i>
I think that through Whatsapp we should talk to our doctors, psychologist, or even with other participants. (MSM Focus Group)

the care of the same provider over a period of time. This led to changes in medication schemes which some participants thought were unnecessary.

The TW focus group, additionally, discussed unique barriers to adherence that were not mirrored by either the MSM or heterosexual focus groups, including how engagement in sex work impacted ART adherence. Among transgender women that reported engaging in street-based sex work, HIV medication was not taken because they did not want clients to potentially see their medications so they were left at home or because of the potential for side effects to interfere with their work or their safety while on the streets.

SUGGESTIONS FOR ART ADHERENCE INTERVENTION CONTENT AND STRUCTURE

Content: Motivators and Facilitators to Adherence. Participants that acquired HIV sexually commonly reported experiencing feelings of anger, frustration, or grief when they were first diagnosed (see Table 5 for illustrative quotes). These feelings served as a barrier to initial ART uptake, but were overcome in a variety of ways, including recognizing a commitment to one's own health, desire to protect partner's from acquiring HIV and have a healthy sex life, to look attractive, or to reach life goals. Participants also noted the importance of making a person feel valued and capable of living a full life in order to motivate HIV infected adolescents to take their ART medication.

Participants had a variety of strategies to help with medication adherence, including using cell phone alarms for reminders. Most participants agreed that setting a time to routinely take daily medication helped with adherence—though they would modify medication routines to accommodate competing priorities. For some participants, this involved taking their medication with a particular meal every day, or right before bed to avoid side effects. Among participants that were open about their HIV status with other individuals in their home, keeping medication in a visible location, such as by the refrigerator, provided a visual cue to take their daily medication. Among those participants that did not feel comfortable disclosing HIV status to their family, adherence strategies included keeping medication hidden in a bedroom dresser or in a backpack. Participants in all groups suggested various ways of disguising HIV medications, to make it easier to take medication in public. Suggestions included transferring the medication to a different container, pretending they were birth control pills, vitamins, weight-gain pills, or hormone pills.

Adolescents indicated that an intervention for HIV infected adolescents should be holistic and not solely focused on taking their pills every day. They suggested an intervention that includes counseling, advocacy, and education, and provides comprehensive services for youths living with HIV.

Format and Structure. Suggestions for medication adherence programs were offered by each group based off of previous experiences of participants with programs targeted toward adolescents living with HIV (see Table 5 for illustrative quotes). A general consensus described the desire for having a mix of individual and group sessions formed around sexual and gender minority identity, as evidenced by one participant's response to the facilitator probing about preference for individual vs. group intervention format. Participants suggested that they would benefit from having other young people living with HIV to support them. This was voiced particularly strongly among the young transgender women participants, who preferred a group of only transgender women (no cisgender men) living with HIV because it would reduce the shame of the disease. Adolescents also discussed the strength that could come from harnessing their existing social networks of HIV positive adolescents to enhance motivation for participation and retention into an adherence program, as well as method to support adherence.

Participants were split on the desire for who should lead the intervention. Some felt that professionals would be most appropriate, as they are respected and assumed to have greater knowledge. However, others felt that a peer—someone living with HIV—would be best as they could act as a role model for the youth.

Lastly, text message or text application communication was highlighted as a preferred method for dissemination of information and coordination, across groups. Participants indicated that messages should be in code in order to maintain privacy, but that these types of messages would be helpful reminders. Many already use alarms on their phones as daily reminders.

DISCUSSION

High ART adherence is crucial to treatment success—with the current regimens, those who are virally suppressed have a similar life expectancy as HIV uninfected individuals (Samji et al., 2013) and are unlikely to transmit HIV to an uninfected partner (Cohen et al., 2011; Das et al., 2010; Rodger et al., 2016). While Brazil has implemented universal access to ART medications for all HIV infected individuals and have demonstrated improvements in virologic outcomes (Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006), treatment interruptions are still common. In our sample of diverse HIV infected adolescents in Rio de Janeiro, Brazil, socioecological barriers to ART adherence and retention in HIV care were discussed. Overlapping and unique barriers emerged for the MSM, transgender women and heterosexual adolescent groups. Moreover, some of the common barriers across groups manifested differently for each group. For example, while participants in all groups discussed the role of depression, drug use, and stigma on ART use (Bhatti, Usman, & Kandi, 2016; Ingersoll, 2004; Rao et al., 2012; Turan et al., 2017; Wansink & Pope, 2014), adolescents in the heterosexual group—who were primarily perinatally infected—discussed ways that they overcame these barriers, while adolescents in the transgender women group were more likely to discuss not taking their ART when faced with these barriers. These differences are likely the result of a number of distinct influences: first, sexual and gender minority individuals often face HIV stigma that is compounded by stigma due to their sexual orientation and/or gender identity (Ganju & Saggurti, 2017; Jeffries et al., 2015); second, behaviorally infected adolescents discussed a sense of shame and self-stigma because of their HIV acquisition (MacDonell, Narr-King, Huszti, & Belzer, 2013; Thurston et al., 2014) which was not discussed by perinatally infected adolescents; and lastly, those who are perinatally infected discussed more family support, which likely mitigates some of the psychosocial risk factors and facilitates adherence (Mellins, Brackis-Cott, Dolezal, & Abrams, 2004; Poudel, Buchanan, Amiya, & Poudel-Tandukar, 2015). Regardless of sexual or gender identity, or whether perinatally or behaviorally infected, HIV-infected adolescents in Brazil will likely benefit from interventions that include evidence-based strategies to overcome barriers related to stigma and depression; but differences based on sexual and gender minority identity will need to be addressed.

Across all groups, side effects and complex medication schedules also emerged as substantial barriers to consistent ART adherence. Most participants reported side effects that got in the way of their daily activities, including severe nausea, light-headedness, and drowsiness. Combined with complex medication schedules (i.e., having to take multiple pills at different times of the day), these side effects can make it difficult to consistently take medications when daily life will not be disrupted. For some they were so disruptive that they halted treatment altogether, while others indicated that they skipped doses or altered their medication schedule to avoid unpleasant side effects during work, school, or social activities. Managing these barriers will likely require continued and improved relationships with clinic staff, including their

HIV doctors, in order to determine strategies to reduce side effects or explore new regimens that may have fewer side effects and be less complex.

Adolescents in this sample also discussed important motivators for overcoming many barriers to ART adherence. The commitment to their own health and the health of their partners was a primary motivation to taking ART—for some this was about looking attractive and having a healthy sex life in the short term, and for others this was about living longer and reaching life goals. This focus on the positive value of ART suggests the importance of an intervention that uses a strength-based and gain-framed messaging for ART adherence rather than fear-based, loss-framed messaging (Gallagher & Updegraff, 2011; Martin et al., 2014; Richardson et al., 2004; Slavin, Batrouney, & Murphy, 2007). Principles of motivational interviewing have been effective at transmitting these types of messages and improving adherence (Hill & Kavookjian, 2012), including among adolescents (Naar-King et al., 2009). Importantly, a large scale efficacy trial of motivational interviewing for ART adherence among adolescents showed significant improvements in viral load at 6-month follow up, but these improvements were not maintained at 9-month follow up. The researchers suggest that motivational interviewing may need to be combined with cognitive behavioral skill buildings to have long term benefits (Naar-King et al., 2009).

Specific strategies to facilitate adhering to ART medications included methods to overcome simply forgetting or to take medications when in unsupportive situations. Many of these suggestions, including setting cell phone reminders or hiding pills in other pill bottles, were simple yet practical, suggesting that an adherence intervention would require problem-solving strategies that are personalized. Importantly, adolescents also suggested that an intervention that included personalized text message reminders to take ARTs and attend appointments would be acceptable. While no published studies to our knowledge examine technology to improve ART adherence among adolescents, several studies have shown successful use of technology to improve ART adherence in adult populations. One recent study conducted with adults in sub-Saharan Africa, showed efficacy for a text message intervention for ART adherence among adults: 53% of participants receiving weekly text reminders achieved adherence of at least 90% during the 48 weeks of the study, compared with 40% of participants in the control group (Pop-Eleches et al., 2011). Similarly, a 2008 study in Sao Paulo, Brazil found that text messages were efficacious at reducing non-attendance rates at appointments at outpatient clinics (Da Costa, Salomao, Martha, Pisa, & Sigulem, 2010).

Adolescents in the focus groups also made suggestions regarding format and structure of the intervention. Participants, particularly those that identified as sexual and gender minorities, noted the importance of peer support and role-models; as such, social cohesion and group empowerment may be important considerations in development of an intervention for this group (Ballard & Syme, 2016; Riger, 1993; Speer, Jackson, & Peterson, 2001). Moreover, existing social networks should be leveraged for both participation and retention in an intervention and as a method of ongoing adherence support within an intervention (Latkin et al., 2013). Social networks provide sexual and gender minority HIV-infected adolescents, who might generally feel isolated and stigmatized, with mutual social support, define and enforce norms of socially acceptable behavior, and provide systems for disseminating information and resources (Funck-Brentano et al., 2005; Henwood et al., 2016; Mo & Coulson, 2008).

The results of this study should be interpreted in light of its limitations. Primarily, our study was constrained by a selection of HIV infected adolescents living in the larger Rio de Janeiro metropolitan area, and as such, may not represent the perspectives of all HIV adolescents in Brazil, particularly those outside a large urban area who might have different or more extreme barriers to ART adherence due to geography and marginalization. Additionally, because of the focus group format, we are not able to examine differences in barriers and facilitators to ART adherence by age, sexual behaviors, or other potentially important moderators. As the goal of the study was to obtain qualitative data, we were only able to obtain limited quantitative data to describe the sample.

Adherence to ART among HIV-infected adolescents in Brazil, as in other parts of the world, is suboptimal. Barriers to ART adherence are complex and multilevel. However, adolescents have organically discovered strategies to help them better adhere. A theory-driven ART adherence intervention that includes input from the community, leverages existing social networks among adolescents and draws on other adherence intervention among similar populations has the potential to improve treatment outcome and health status and reduce the population of HIV.

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