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Development of a Directly Observed Therapy (DOT) Adherence Intervention for Adolescents with HIV-1: Application of Focus Group Methodology to Inform Design, Feasibility and Acceptability

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Abstract

Purpose—To obtain input from adolescents with HIV-1 infection to inform the design of a community-based modified directly observed therapy (MDOT) antiretroviral adherence intervention.

Methods—Pediatric AIDS Clinical Trials Group (PACTG) protocol 1036A conducted three focus groups with 17 adolescents aged 17 to 22 years (10 females, 65% African-American) from three geographically distinct US PACTG sites. Focus group sessions were scripted, audio-taped, and transcribed verbatim. A coding dictionary was developed and validated; Ethnograph v5.08 was used to summarize coded data across and within the three sites. Prevalent themes were identified via frequencies and are reported as percents.

Results—Adolescents specified: the MDOT provider should be familiar to the participant and empathic; the MDOT location should be mutually agreed upon, flexible, and private; and participant and provider communication should be bidirectional, preferably by phone. Ideally the MDOT program should be continued until adolescents independently demonstrate adherence and include a weaning phase as a test of skill-acquisition. The most commonly endorsed barrier to the proposed program was MDOT would be an invasion of privacy. Initially, following introduction to the purpose of the focus group, all but one adolescent expressed MDOT could benefit someone other than

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themselves; however, at conclusion of the focus group discussion, a significant shift in openness to the intervention occurred whereby 11 participants indicated they would consider participation in a MDOT program if offered.

Conclusions—Focus group feedback clarified the feasibility, logistics, and patient concerns about the design and implementation of a proposed MDOT intervention for adolescents with HIV-1 infection who struggle with medication adherence

Keywords

Adolescents; HIV; modified directly observed therapy (MDOT); focus group; adherence

Approximately 40,000 new cases of HIV infection are diagnosed in the US annually, half occurring among persons age 13–24 years [1]. HIV-infected youth face the challenge of managing HIV-1 disease the remainder of their lives. Thus, adolescents' life expectancy and quality are complicated by HIV treatment decisions and medication adherence in the years immediately following diagnosis.

Successful treatment and management of HIV-1 progression requires maintaining high levels of adherence to highly active antiretroviral therapy (HAART). Poor adherence is associated with increased viral load, enhanced HIV replication, development of drug-resistant HIV-strains and disease progression [2–4]. At least 90% adherence to HAART is required for successful viral suppression and sustaining optimal immune function [5–6]. Among adults, adherence rates range from 30–73%, considerably less than optimal [7–8]. Adolescents with HIV-1 on HAART show similar deficient adherence rates (28–72% non-adherence) [2,9–11]. Maintaining adequate antiretroviral adherence, therefore, is a common and significant problem, perhaps the biggest challenge to optimizing care particularly for youth self-managing their HIV.

Factors affecting adherence include the treatment regimen (i.e., complexity, number of pills/doses per day) [12], the disease itself (e.g., whether the disease is chronic or acute, symptomatic or not) [13–14], and patient characteristics (e.g. mental illness, substance use/abuse) [15–16]. Adolescents commonly cite forgetting to take medications at scheduled dose times as the primary reason for non-adherence [4,17]. Clinic staff utilize various adherence techniques to assist adolescents (e.g., reminder aids, calendars, pagers, alarms, and pill boxes) in addition to providing educational support or financial incentives with varying degree of success. As a result, youth with adherence problems are at increased risk to develop viral resistance to treatment and subsequent increased morbidity and mortality, making intervention to improve adherence difficulties in adolescents a critical component of care.

Directly observed therapy (DOT) successfully has improved treatment adherence in patients with tuberculosis (TB) [18], and is recommended as standard of care for pulmonary TB [19]. Despite differences between TB and HIV (e.g., mode of transmission, curability, duration of therapy), there is growing interest in MDOT as a potential intervention to improve HIV medication adherence [20–23]. Once-a-day HAART regimens make MDOT an increasingly attractive community-based intervention option to address adherence in the adolescent HIV-1 population.

Existing experience with the use of MDOT as an intervention to improve adherence to medication in HIV infected patients has been encouraging [21–26]. A number of studies have shown feasibility of providing community or center based MDOT to subsets of adult HIV infected patients such as those who are incarcerated [27–29], substance users [30–32], those with documented adherence problems or treatment naïve patients starting therapy [20–25,33–35]. However, none included adolescents. Three of four recently published randomized clinical

trials demonstrated efficacy of MDOT with adults in terms of improved medication adherence [26] or CD4 count/viral load [24–25] while one showed no difference of MDOT over the standard of care [35] in treatment naïve patients or for those whom no more than one HAART regimen had failed.

Goggin, et al [21] identified minimal requirements across 10 US MDOT provider programs to assist development of future programs. While MDOT generally demonstrates feasibility, acceptability, and success with adult populations treated across programs (most with co-morbid substance abuse, mental illness, and/or homelessness), questions remain as to the design and implementation of community-based MDOT programs in relation to duration, intensity, program logistics, ancillary/support services to be provided with MDOT, and determining who MDOT will benefit within target patient groups, such as adolescents with HIV-1.

Adolescence is a developmental period characterized by contextually-based risk behaviors, in which denial and invulnerability beliefs prevail, establishing one's identity and fitting in with one's peer group while separating from one's parents is essential. Adolescents are considerably overrepresented in those newly HIV-infected in the US and HIV interrupts the adolescent developmental trajectory at a time when youth may not be prepared to identify as HIV+, fully comprehend the consequential impact of their adolescent actions on their future treatment options let alone morbidity and mortality risks associated with non-adherence. Further, adolescents demonstrate significant difficulties with adherence [2,9–11], which creates a public health concern for potential transmission of resistant viral strains through high risk behaviors.

While MDOT has shown success with adults, each program was modified to meet the needs of the target patient population. A well-designed study of community-delivered MDOT tailored to the unique needs of this adolescent patient population may prove efficacious in not only improving adherence, immunologic function and viral suppression, but also may provide secondary psychosocial and public health benefits [21]. The relationship with MDOT outreach workers may provide adolescent patients much needed social and emotional support [27,29, 34], an especially important consideration for socially isolated or disenfranchised youth with HIV-1. Further, positive emotional support and related improved depression have been associated with increased adherence rates [36–38].

One must not assume what has shown feasibility with adult populations also will be feasible and acceptable to youth with HIV-1 as the contexts for their risk behaviors, adherence difficulties, and treatment needs may be very different. To design and implement effective adherence interventions for youth, information is needed from the adolescent patient group themselves. Rich and Ginsberg [39] assert qualitative research methodology is an essential first step in the development of effective intervention for adolescent health care. Qualitative research allows for collaborative exchange whereby youth provide insight into their lives and management of their illness by sharing their experiences, perceptions, beliefs, and understanding with clinical investigators to inform the development of the intervention [39]. In exchange, researchers learn from the perspective of youth what it is we need to know about them, what they need and want for their care, what they think will work for them, and what is required to help them invest in their own health care [39]. Including the teen perspective allows for greater likelihood of intervention success by targeting issues in contexts important to them.

Given the unique needs/barriers to adherence for adolescents, lack of a validated model to provide community based MDOT tested across different HIV infected adult patient populations, and the inability to translate the existing adult experience to adolescents, it was decided to first approach adolescents with HIV to solicit their opinions about creating an "adolescent friendly" MDOT model. To this end, focus groups were conducted as Part A of a

planned two-part study with the primary objective to obtain qualitative input from adolescents with HIV-1 infection acquired via high-risk behaviors to help inform the design and development of a proposed community-based MDOT adherence intervention feasibility and acceptability study (Part B). Presented herein is a summary of Pediatric AIDS Clinical Trials Group (PACTG) protocol 1036A.

Methods

Site and Subject Recruitment

Focus groups were conducted at three geographically distinct US PACTG sites (Los Angeles, CA, Memphis, TN, and Miami, FL), selected according to set criteria (e.g. established adolescent support group and a site facilitator with prior focus group experience). The protocol was reviewed and approved by each site's respective Institutional Review Board and informed consent was obtained for each participant. Participants aged 16 to 22 years, behaviorally-infected with HIV-1, currently prescribed or with a prior history of antiretroviral therapy, and non-pregnant were eligible for participation. Facilitators at each site recruited 5–10 adolescents with HIV-1 during regularly scheduled support group meetings announcing the date and time of the focus group in advance scheduled adjacent to a future support group meeting. Given previously noted concerns by youth reticent to meet other peers with HIV in clinic due to fear of disclosing their HIV status (e.g. "I might know them"), established support groups were utilized to involve youth already familiar and comfortable discussing HIV and nuances of HIV care openly with their peers in order to more readily generate conversation and depth of detail desired in response to the focus group inquiry.

Focus Group Methods

Participants first completed an anonymous questionnaire about demographics, experience with antiretroviral therapy (Table 1), and barriers to medication adherence (Table 2). Site staff with prior focus group experience, not otherwise affiliated with protocol development, served as focus group facilitators. A second staff member took notes in the event of recording equipment failure. A script was developed to lead discussions uniformly across sites to address the following topics: 1) MDOT provider characteristics; 2) MDOT interaction location and safety; 3) MDOT provider and participant communications; 4) MDOT interaction logistics; 5) MDOT intervention duration; 6) additional services to be provided during MDOT interactions; 7) MDOT feasibility and acceptability. To promote confidentiality, participants were asked not to use names during the focus group discussion. Each session lasted approximately two hours, was audio-taped and subsequently transcribed verbatim to ensure all salient information was captured. Two 1036A protocol team investigators independently listened to the audio tapes to validate the transcript, subsequent to which all tapes and handwritten notes were destroyed.

Data Analysis

Content analysis techniques were applied to identify repeated themes across the three focus group discussions. A coding dictionary corresponding to the focus group script question categories was developed as themes emerged from the data. Three secondary reviewers validated the derived coding scheme. Codes not validated by at least two secondary reviewers were dropped from the scheme. Ethnograph v5.08 qualitative software package was used to code blocks of relevant text, summarized across sites. Common themes were identified and are reported in order of prominence or how frequently each was mentioned by the youth.

Results

Participant Characteristics

Seventeen adolescents with HIV-1 participated, with each site enrolling a minimum five participants. Participant demographics (Table 1) were similar across sites and generally representative of the clinic population served (personal communication), thus data for all subjects were combined and are summarized as follows.

Barriers to Antiretroviral Medication Adherence

Thirteen of 17 participants provided information via anonymous survey about their experience with medication adherence and related barriers. Commonly endorsed barriers to adherence included not having a set daily routine (69%), falling asleep/sleeping through the dose time (62%), not having medications with them (41%), avoiding medication side effects (54%), or anticipatory nausea before taking them (54%, Table 2). Seven of 18 barriers endorsed related to lack of a daily routine, being too busy, or forgetting.

Identified themes (presented below) generated from focus group discussion in response to questions posed are summarized in Table 3. Themes are presented in order of prominence or relevance within the topic discussion.

MDOT Provider Characteristics

Characteristics discussed indicate the MDOT provider should be familiar to the participant, empathetic, a peer, and recognize boundaries of the relationship. For example, participants commented:

> "…Someone close to you to help you. I really don't believe a stranger can help you. Maybe someone that already know[s] you and how you are."

> "It should be somebody that you are comfortable with and that you can trust."

> "…my friend…because we are the same age going through the same thing. I feel more comfortable with her watching me take medicine."

Additional themes included respect, being a "people person", similar HIV status, and personal experience with chronic medications.

Location and Safety of MDOT Interactions

Discussion revealed the location should be: mutually agreeable to participant and MDOT provider, flexible, private or the participant's home. Comments related to location included:

> "Those two people need to decide where they are going to meet. I might tell my person to meet me in…and they might be [like] Hell no."

> "They should talk to see what would be good for them both"

In regard to privacy:

> "Nowhere where there are a lot of people, somewhere secluded – not too many [people] you know."

> "[Not] places where you think your friends are going, especially if you don't want them to know."

Communication Between MDOT Provider and Participant

Youth agreed communication should be bidirectional whereby the participant and MDOT provider could contact each other to facilitate communication, preferably by phone, as opposed to the provider having a phone and the participant a pager. Adolescents argued:

> "One can't have a cell phone and one can't have a beeper – they both need cell phones."

> "…Able to call the cell phone, that way, so they can at least let them know, 'Hey, I got a house full of people. Can you just call me instead of showing up?'"

Logistics of MDOT Interactions

Participants indicated the MDOT program must accommodate participant transience (i.e. frequent changes in residence), and participant travel should be minimized, for example:

> "I mean, if I am a participant…. to come pick you up, take you all the way to […] when you are in […] to watch you take your medicine for like less than ten seconds and drive you all the way back. I'm not going to; that is too tiring on my part."

> "What if they moved to another neighborhood, just a temporary neighborhood? You should give [the MDOT provider] the number so they can call you and make sure you took it…Until you get back to where they can watch you."

Participants also emphasized, while interactions should be scheduled, scheduling should remain flexible:

> "If it's scheduled, and you know it's not a good time, you would call the provider and let them know."

> "There should be communication…so you can figure out your schedule – kind of see how your day is going."

> "They should call…'Hey, is this a good time for me to come?' If not, the participant can let them know this is not a good time and for them to come around such and such time."

Duration of MDOT Intervention

Regarding duration, participants discussed MDOT should include a "weaning" phase, continuing until participants demonstrate adherence, or until participants decide they are ready to discontinue MDOT. Comments included:

> "There is the initial support of helping you take your medicine, and then it gradually come to the point where you are able to take it yourself without having anybody call you."

> "So this is like a training – to kind of train them to get used to taking medications, but once they start getting on track… it should be up to the participant to say, well, I think I'm okay. You don't have to come anymore, or, well, no I still need you a little bit."

> "The provider should set a time like, 'Hey, I am assigned to you for three months. So, [at] three months, if you feel like your motivation has picked back up and you are cool taking medications [and] you don't want me to come around, I won't come around anymore. Or if you feel like you want me to, I will still come around, but even if you feel like you don't want me to come around, I'm still always here.'"

Additional Services to be provided during MDOT Interaction

Participants discussed what other issues related to medication adherence the MDOT provider should help with during the MDOT interaction. Some participants felt the MDOT provider should offer other services such as case management:

> "I ain't got no income and I need them to help with my lights and stuff."

> "I think if your medications needs to go in a cooler, they should provide you with a cooler."

Others argued the program should provide MDOT exclusively:

> "Whenever the provider meet with the participant, make sure they both know, 'Hey, I'm only here to watch you take your medicine.'"

> "That person is only suppose to be there for [MDOT], for only one thing and that is to help you take your medications."

> "They should be able to refer you to somebody, instead of them trying to help."

Feasibility and Acceptance of MDOT Program

After the introduction period describing the focus group's purpose, participants provided initial thoughts about feasibility of a MDOT program in their clinic. Pre-focus group discussion centered on issues such as: The program would be ineffective, it should be optional, and it was deprecating. Adolescents commented:

> "My belief is if you are going to miss your medications or not take them or forget them or whatever, what is the point of you going out or having somebody waste their gas and drive all the way to you or you drive all the way to them and one you ain't home or you don't go, or you just don't feel like taking them? What is the point of going to all that trouble?"

> "If you don't take them at home, it is not going to make any difference if a stranger comes in and tells you that you have to take them."

Potential Barriers to MDOT Program

Participants also discussed potential problems implementing a community-based MDOT intervention. Participants frequently mentioned a major barrier would be feeling MDOT was an invasion of privacy, for example:

> " [This is] a potential problem…you are already opening up to them by letting them be involved one of your most private moments in your life."

> "A lot of people might be scared of other people watching you take [medications]. If they don't take them at home, like in front of their family, they are not going to take it in front of a stranger."

> "I have my own reasons why I don't take my medications and I keep that to myself. I don't tell a physician…in my mind that's not their damn business. I have my reasons and I don't want anybody telling me…I don't want to hear that."

To close the focus group discussion, participants again were asked, if they had problems taking antiretroviral medications as prescribed, would they consider MDOT as an option. When posed this question during the general discussion to introduce the purpose of the focus group at the beginning, 16 adolescents initially indicated MDOT would be good for someone other than themselves, however, by the end of the focus group discussion, 11 participants changed their

initial position stating they *would* consider taking part in a MDOT program if available, although emphasized MDOT should target only those with adherence problems:

> "For a person that really need[s] their medicines and are not taking them… Maybe it will work for them."

> "If you feel like you need it, if it sounds like a good idea, try it out. If you feel like you don't need it, forget about it."

> "It is a good idea for people that actually want help with their medicine. It would show they were making changes in their life for them to try to take their medicine right and I guess be adherent with it."

Discussion

The purpose of this focus group study, Part A of a planned two-part study, was to obtain information from adolescents with HIV-1 acquired through high-risk behaviors to inform the development of Part B, a proposed MDOT feasibility intervention study for whom these adolescents represent the targeted end-users for the to-be-developed MDOT program.

Utilization of qualitative research methodology is strongly encouraged when designing relevant and engaging interventions in adolescent health care [40]. In P1036A presented here, sites successfully recruited adequate numbers of participants who readily interacted and engaged one another in the facilitator-directed discussion providing varied, at times polar, opinions with regard to attitudes, experiences, potential barriers, and specific MDOT provider and logistical information about which study investigators desired to gain insight.

Youth expressed primary concerns related to MDOT provider characteristics, location/interaction logistics, and communication between participants and MDOT providers. Preference for the MDOT provider to be a peer was important, but not critical, as youth expressed greater importance in the MDOT provider being familiar (e.g. staff member), empathetic, knowledgeable about HIV, and experienced with chronic medications, although not necessarily HIV+ or on chronic medications themselves. Privacy was the greatest concern raised regarding MDOT location, and if a risk presents for privacy to be violated, the MDOT provider needs to remain flexible with last minute changes in location or time to meet. Participants expressed the need for communication to be bidirectional (preferably via cell phone) whereby either the participant or the MDOT provider could contact the other as needed, especially to communicate last minute changes (e.g. running late, selected location is no longer good, someone to whom HIV status is unknown is present). These findings add support to Goggin et al.'s [21] summary identifying essential MDOT program components for adults reported by providers of MDOT interventions and others [25,34]. Youth identified factors most important to consider in developing an MDOT program for adolescents with HIV-1 include the ability of the MDOT provider to relate to the participant, maintain confidentiality and protect the youth's privacy, and to be flexible with communication as to when, where and how MDOT will be delivered.

Given the level of participation in each focus group, the discussion progression, and the degree to which both pros and cons were expressed, participants, while initially expressing disinterest in MDOT as an intervention for themselves, demonstrated through their discussion, ultimate support for MDOT as both feasible and acceptable, belief youth similar to themselves would participate if available, and indicated MDOT would be helpful, as long as participation was optional for those with demonstrated adherence problems.

Additional information provided about MDOT logistics included: While the location should be mutually agreeable, flexibility and privacy of the location are important, the selected

location should be convenient for the participant, and ultimately, to meet in the participant's home is acceptable. Participants agreed a weaning phase should be included in MDOT, but when and how weaning occurs should be determined only when the participant demonstrates adherence to both observed and non-observed doses, and otherwise should continue until the participant indicates he/she is no longer interested in MDOT. While case management and lay counseling services were suggested for inclusion in MDOT interactions, virtually equally strong recommendation indicated MDOT should be restricted to observe medication ingestion and discuss medication and adherence issues only. Thus, case management services might best be provided independent of MDOT to meet concurrent support needs of youth with HIV-1.

The most salient observation of this study was participants' shift from their initial reluctance to consider MDOT for themselves. Following two hours of conversation with their peers, 11 of the 16 (69%) who initially indicated they would not consider MDOT for themselves, ultimately expressed they would consider MDOT if it were available. This observed shift in position emphasizes the manner in which MDOT initially is introduced will be extremely important. At first presentation, MDOT may be perceived as punitive when intended to be supportive, designed to increase perceived competence, success and autonomy with medications. How MDOT is presented, specifically individualized to the adolescent's needs, is an important consideration given initial reticence and heightened concerns about invasion of privacy.

While youth provided guidance regarding their preferences for several aspects to inform the development of a community-based MDOT program for adolescents with HIV-1, several factors remain to be assessed via experience when implementing Part B, the proposed MDOT intervention feasibility study, including factors to determine for which youth MDOT is appropriate, how long daily MDOT should last, how weaning should occur, how long MDOT should continue, and what additional services should be included within the MDOT program.

Limitations of this qualitative study potentially include the method by which recruitment occurred. Youth were recruited from already existing clinic-based support groups for adolescents with HIV-1 infection. Observationally, those non-adherent to medications often are non-adherent to medical appointments, including clinical services such as participation in support group. However, at the time of focus group participation, 35% of youth acknowledged not currently taking anti-HIV medications, discontinued due to adherence issues and potential related health risks; further, 47% of youth reported adherence difficulty at some point during the course of their treatment. Therefore, despite recruitment from established support groups, participants appear representative of those who struggle with antiretroviral medication adherence.

Another potential limitation of recruitment from support groups is selection bias via inclusion of youth who already self-seek support through their healthcare environment. Although these youth are believed to represent youth within their clinics, it cannot be assumed they are representative of youth who do not engage in their medical care, who may feel isolated and without support, and who otherwise have restricted access to care. Participation in a support group increases access to medical care providers and means to address psychosocial needs and reduce barriers, including those related to adherence. However, the presence of existing support services made the selected sites desirable as comprehensive care centers for the subsequently designed MDOT study to follow, recognizing from adult studies the relationship established with the MDOT worker provides an essential support need whereby ancillary support following the discontinuation of MDOT appears to be an important component of sustained adherence and health outcomes.

Another limitation, despite utilizing a script, discussion direction and content at all three sites varied somewhat dependent upon the facilitators' degree of redirection or encouragement of further discussion deviating from the provided script. Consequently, lingering on a topic, whether by allowing discussion to continue or a participant readdressing a personally important issue may have increased the frequency with which a theme was discussed. While this does not detract from the relevance and importance of themes discussed this observation may have limited in-depth discussion of other considerations or focused on potentially site-specific issues (e.g. available clinic and/or community-based factors) rather than generalizable to the adolescent population with behaviorally acquired HIV as a whole. Further, it is important to note, changes in speaker could not be identified from the transcripts alone, which only became apparent as problematic when developing the coding scheme after the tapes were destroyed. As a result, it was not possible to determine whether the frequency with which a particular theme emerged was because several discussants endorsed the same thought or whether a particular individual continued to revisit a theme of importance to him/her.

A significant contribution of this qualitative study is it is the first known to involve the input of the targeted consumer population, adolescents with HIV-1, of the proposed MDOT intervention at an informative stage prior to development. To our knowledge, previous MDOT feasibility studies did not incorporate the input of their adult consumers in the design and implementation of their programs. Youth who participated in PACTG P1036A provided valuable feedback and insight sharing with investigators their perspective regarding logistics, acceptability, and feasibility of a community-based MDOT intervention representative of those for whom the proposed intervention is intended. As a result, this study's findings were used to inform the development of a community-based MDOT intervention feasibility study for adolescents with HIV-1, PACTG protocol 1036B, a study for youth with noted anti-HIV medication adherence problems. A novel community-based MDOT model applied with an adolescent population has tremendous implications to address adherence problems and improve health outcomes for these youth. The developed MDOT program (to be reported on later), will be the first of its kind to be administered voluntarily in the community with adolescents with behaviorally acquired HIV-1, the success of which is likely enhanced as a result of designing the program based on direct input of youth for whom it is intended.

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Table 1

Demographic Characteristics

Characteristics	All three sites	
	Mean (SD)	Range
Age	19.93 (1.29)	17.6 – 22.5
Last grade in school	11.24 (1.20)	9 – 12
	n	%
Gender		
Male	7	41.2
Female	10	58.8
Race		
African-American	11	64.6
Caribbean Islander	2	11.8
Latino	2	11.8
Caucasian	1	5.9
Other	1	5.9
IV Drug Use		
Never used	12	70.6
Currently on ARV		
Yes	11	64.6
No	6	35.4
Adherence Problems		
Yes	8	47.1
No	8	47.1
Omitted	1	5.8

Table 2

Reported endorsement of barriers to medication adherence[a]

Barrier	*n*	*%*
Did not have a set daily routine	9	69.2
Fell asleep or slept through dose time	8	61.5
Did not have medications with them	7	53.8
Wanted to avoid side effects of medications	7	53.8
Felt sick or ill, so did not take medications	7	53.8
Simply forgot	6	46.2
Taking the medications reminded them of having HIV	6	46.2
Busy with other things	5	38.5
Did not like taste/texture	5	38.5
Could not swallow pills because were too big	4	30.8
Did not feel like taking medications	4	30.8
Already missed medications – blew it for the day	4	30.8
Did not want others to notice medications	4	30.8
Felt medications were toxic and/or harmful	3	23.1
Felt healthy, so did not take medications	3	23.1
Had too many pills to take	2	15.4
Felt medications had no positive effect	1	7.7
Change in daily routine	1	7.7
Confused about what and/or when to take medications	0	0.0
Had problems with special instructions for medications	0	0.0
Prescription not refilled	0	0.0

[a]Barrier questions omitted by 4 participants across all items, therefore n = 13 reported.

Table 3

Focus Group Summary Data to Inform MDOT Development.

Coding category		n	%
MDOT provider characteristics			
Person familiar to participant		23	13.5
Empathetic		22	12.9
Peer		18	10.6
Recognize boundaries, doesn't get too personal		17	10.0
Knowledgeable about HIV		13	7.6
Similar HIV status		12	7.1
Respectful of participant		12	7.1
Personal experience with chronic medications		10	5.9
Professional status		8	4.7
Ability to chose MDOT provider		8	4.7
Mature		7	4.1
People person		6	3.5
Same gender		6	3.5
Any gender		4	2.4
HIV diagnosis disclosed to MDOT provider		4	2.4
	Total	170	100.0
Location and safety of MDOT interactions			
Mutually agreeable to participant and MDOT provider		17	24.0
Flexible location, not always in the same place		14	19.7
Privacy is important		12	16.9
Home		10	14.1
Restaurant		5	7.0
Not at school		4	5.6
Clinic		4	5.6
Not a secluded area		2	2.8
Not gang territories		2	2.8
Not at a park		1	1.5
	Total	71	100.0
Communication between MDOT provider and participant			
Ability to call each other		15	30.0
Phone for both		14	28.0
Phone for MDOT provider, beeper for participant		9	18.0
Participant call only to reschedule		6	12.0
MDOT provider always available by phone		5	10.0
Text messaging		1	2.0
	Total	50	100.0
Logistics of MDOT interactions			
Must accommodate transience of the participant		7	24.1

Coding category		n	%
Scheduled		6	20.7
Flexible schedule		6	20.7
Travel should be minimal for participant		6	20.7
Waiting duration of 30–60 minutes of participant does not show		3	10.3
No weekends		1	3.5
	Total	29	100.0
Duration of MDOT intervention			
Wean		17	39.6
Until participant demonstrates adherence		13	30.2
Until participant chooses not to		9	20.9
Ongoing		4	9.3
	Total	43	100.0
Additional services to be provided during MDOT interactions			
Case Management services		17	37.0
Only MDOT service		12	26.1
Counseling		8	17.4
Pill swallowing training		4	8.7
Condoms given out		3	6.5
Medicaid/Medicare issues		2	4.3
	Total	46	100.0
Feasibility and acceptance of MDOT Program			
Ineffective, won't work		24	20.3
Should be optional		14	11.9
Depricating, treated like a child		12	10.2
Performance anxiety when someone watches		9	7.6
Helpful		9	7.6
If greater than one a day regimen, then also have reminder aids		9	7.6
Punitive		8	6.8
Education better than MDOT		6	5.1
Not effective with greater than one a day regimens		6	5.1
Self-efficacy, teachers you can do it		6	5.1
Develops dependency on MDOT provider		6	5.1
Self sufficiency better than MDOT		5	4.2
Effective with greater than one a day regimens		4	3.4
	Total	118	100.0
Potential barriers to MDOT Program			
Invasion of privacy		35	64.8
Too busy		7	12.9
Depends on program that is developed		5	9.3
Expensive		4	7.4

Coding category		n	%
MDOT provider characteristics most important to acceptance		3	5.6
	Total	54	100.0

[1]MDOT intervention and you	n	%(N)
Someone else, not me (prior to focus group discussion)	16	94.1
Would consider (at end of focus group discussion)	11	64.7
Only non-adherers	9	52.9

Note. n = frequency of theme discussed during session, Total used to calculate frequency of themes reported as percentages.

[1]*Note. n* = number of participants indicating response; % is proportion of total sample