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Distinctive Barriers to Antiretroviral Therapy Adherence among Non-adherent Adolescents Living with HIV in Botswana

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Abstract

Levels of adherence to HIV treatment are lower among adolescents compared with older and younger individuals receiving similar therapies. We purposely sampled the most and least adherent adolescents from a 300-adolescent longitudinal HIV treatment adherence study in Gaborone, Botswana. Multiple objective and subjective measures of adherence were available and study participants were selected based on sustained patterns of either excellent or poor adherence over a one-year period. Focus group discussions (FGD) and in-depth interviews (IDI) were conducted with the adolescents and a subset of their caregivers with the goal of revealing barriers and facilitators of adherence. Focus groups were segregated by adherence classification of the participants. Following coding of transcripts, matrices were developed based on participants' adherence classifications in order to clarify differences in themes generated by individuals with different adherence characteristics. 47 adolescents and 25 adults were included. The non-adherent adolescents were older than the adherent adolescents (median age 18 years (IQR 16–19) vs. 14 years (IQR 12–15 years)), with median time on treatment near 10 years in both groups.

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Competing interests
The authors have no competing interests to declare.

Interference with daily activities, concerns about stigma and discrimination, side effects, denial of HIV status, and food insecurity arose as challenges to adherence among both those who were consistently adherent and those who were poorly-adherent to their medications. Low outcome expectancy, treatment fatigue, mental health and substance use problems, and mismatches between desired and received social support were discussed only among poorly adherent adolescents and their caregivers. Challenges raised only among adolescents and caregivers in the non-adherent groups are hypothesis-generating, identifying areas that may have a greater contribution to poor outcomes than challenges faced by both adherent and non-adherent adolescents. The contribution of these factors to poor outcomes should be explored in future studies.

Keywords

outcome expectancy; supervision; treatment fatigue; social support; miscarried helping

Introduction

Adolescents represent a challenge to HIV care programs as they have higher rates of suboptimal treatment adherence and virologic treatment failure than both younger children and adults (Evans et al., 2013; Kahana et al., 2015; Kim, Gerver, Fidler, & Ward, 2014; Nachega et al., 2009; Nglazi et al., 2012). Tragically, adolescents are the only group for whom AIDS-related deaths increased during 2005–2012, with a startling estimated 50% increase in adolescent deaths contrasting with a 32% decrease in AIDS-related deaths among all other age groups (Idele et al., 2014). Limited research has been conducted on the facilitators and barriers to ART adherence among adolescents living with HIV in high-prevalence settings.

A systematic review of adolescents living with HIV in nine low- and middle-income countries found several factors associated with ART adherence including knowledge of serostatus, family structure, complexity of ART regimens, and health care and environmental factors such as rural versus urban settings (Hudelson & Cluver, 2015). In sub-Saharan Africa, commonly cited barriers to ART adherence included fear of disclosure, anticipated stigma, treatment longevity, and preference for traditional medicine (Denison et al., 2015; Nyogea et al., 2015). While prior research has identified facilitators and barriers to adherence among adolescents in general, prior qualitative studies have not benefited from correlation with longitudinal adherence data from the participating adolescents. We explored barriers and facilitators of adherence among adolescents who were identified as being among the best adherers and adolescents identified as being among the worst adherers in a longitudinal study which defined adherence using multiple measures including viral load and microelectronic monitor data.

Methods

Participants

The study was conducted at the Botswana-Baylor Children's Clinical Centre of Excellence among HIV-infected adolescents/young adults and their adult caregivers. Adolescents/young

adults ("adolescents") from a 300-patient longitudinal adherence study which enrolled 10–19 year olds were purposely sampled if they were among the most or least adherent patients in the cohort. Defining adolescents' adherence patterns to allow for purposive sampling for this qualitative study was one of the *a priori* reasons for establishing the longitudinal cohort. Other aims included describing changes in adherence over time across the adolescent age spectrum, identifying potentially modifiable risk factors for poor adherence, and elucidating the utility of different adherence monitoring strategies in adolescents on ART (Eby et al., 2015; Ioannides et al., 2016; Lowenthal, Marukutira, Tshume, Chapman, Anabwani, et al., 2015; Lowenthal, Marukutira, Tshume, Chapman, Nachega, et al., 2015; Okatch et al., 2016). "Adherent" adolescents maintained HIV virologic suppression during 12 month follow-up with quarterly viral load measurements and maintained at least 95% adherence by all adherence measures at all time points (self-report based on 4-day recall, parent-report based on 4-day recall, pill count, medication:possession ratio, and Medication Event Monitoring System (MEMS) microelectronic medication cap data). "Non-adherent" adolescents met ≥two of the following criteria: (1) mean adherence by self-report in the lowest 20% of all subjects, (2) mean adherence by MEMS cap data in the lowest 20% of all subjects, (3) viral load > 1000 copies/mL. Eligible caregivers were identified by each adolescent as the adult most responsible for assisting with medications. IDIs were conducted when participants couldn't take part in the FGD (e.g. due to the adolescent not yet having been told his or her HIV status or due to scheduling issues). The oldest "adolescent" was enrolled in the observational adherence study at the age of 19 years and had reached his 21st birthday at the time of participation in the qualitative study reported here.

IRB approval was received from the University of Botswana, Botswana Health Research Development Committee, University of Pennsylvania, and Baylor College of Medicine prior to the study. All caregivers and adolescents ≥18 years of age provided written informed consent and adolescents <18 years of age provided written assent.

Data Collection

Data collection was carried out between April 2014 and February 2015 by three investigators from the University of Botswana who were not known to the adolescents prior to the study. The FGD and IDI followed a semi-structured guide with open-ended questions and suggested probes related to barriers and facilitators of adherence. Sessions were conducted in Setswana or English in a private conference or classroom in the same building where the adolescents receive their clinical care. We aimed to include 6–8 participants per FGD. Sessions were audio recorded, transcribed verbatim, translated into English when necessary, and reviewed for accuracy by multiple investigators. Copies of the interview and focus group guides are available as online supplements. The guides remained the same in all sessions, but probes were adapted to clarify emerging themes.

Analysis

Transcripts were uploaded into NVivo 9 (Richards, 1999) and analyzed inductively such that categories, themes, and eventually theories emerged from the data. A draft codebook was created by the lead author after review of the first twelve transcripts and was revised through meetings with all investigators. The codebook was revised as new themes emerged. All

transcripts were coded independently by two coders who met periodically with the senior author to discuss and resolve discrepancies. Data were continuously analyzed throughout collection until thematic saturation was achieved. Matrices were developed based on participants' adherence classifications to clarify differences in themes generated by individuals with different adherence characteristics. Data were also stratified by method of collection (FGD vs IDI) to assess for differences in themes generated based on collection strategy.

Results

Participant demographics

The cutoff for the lowest 20% adherence as measured with MEMS caps during the first 12 months of follow-up was 87.5%. Fewer than 20% of adolescents had self-reported adherence <100%. 47 adolescents and 25 caregivers participated. Fewer caregivers were involved because thematic saturation occurred among adult participants with fewer discussions than required for the adolescents. Characteristics of the participants are outlined in Table 1. All but one of the adolescents were thought to have been infected with HIV perinatally or through breastfeeding.

Barriers and Facilitators of adherence identified by adolescents and their caregivers

Described facilitators of adherence did not differ between adherent and non-adherent participants. Social support, personal acceptance of HIV status and individual responsibility for medication adherence, a history of HIV-related medical complications, and a daily routine with reminders were all described as helpful to adherence. Similarly, some barriers to medication adherence were identified by adolescents and caregivers in both adherent and non-adherent groups. These included medication-taking interfering with daily activities, stigma and discrimination, side effects, denial of HIV status, and lack of resources such as food insecurity. Table 2 outlines barriers and facilitators to adherence that were identified by both adherent and non-adherent participants.

Several adherence barriers, however, were discussed only by non-adherent adolescents and their caregivers. These included low outcome expectancy, treatment fatigue, problems with mental health and substance abuse, and weak social support systems.

Barriers Uniquely Identified by Non-adherent Participants

Below, barriers to adherence that were uniquely identified among non-adherent participants are briefly explored. Further details about each of these barriers is are outlined in Table 3.

Low Outcome Expectancy

With regards to medication-taking, outcome expectancy is what an individual believes will happen if (s)he takes the medications as recommended. In our study, only non-adherent adolescents expressed doubts about the utility of the medications.

Treatment fatigue

Non-adherent adolescents and their caregivers also highlighted the fact that they became tired of taking pills and often wondered when they would be able to stop taking medications. Both adolescents and caregivers spoke without prompting about desires for injectable ARVs which could be administered once every 3 months for convenience, like a locally-available contraceptive. In addition to discussing the daily difficulty of medication taking, some who struggle with non-adherence lamented the burden of frequent clinic visits. The grandmother of a 15 year old male expressed frustration and exhaustion both with regards to the changes she has seen in him during adolescence and the fact that a response to his non-adherence was to increase the frequency and rigor of his clinical visits. She blamed herself for the child's poor adherence, but was at a loss for what to do to support him. She said that her grandchild felt that adherence counseling was stressful: "He says 'these people are forever talking to me…I'm tired of it.'…my child feels that he is being worn out, being bullied, being followed around…like I am abusing him, the doctors are abusing him."

Mental health

Depression and suicidality were uniquely identified in non-adherent groups as barriers to medication adherence. Throughout the IDI and FGD, it was common for participants to express that they were "stressed" by the different facets of living with HIV, including adherence to the medication. However, some participants explicitly noted that adolescents experienced suicidal ideations because of their HIV.

Substance Abuse

Some caregivers expressed concern about older adolescents experimenting with alcohol and drugs, noting that at times the adolescents were too impaired to take their medications properly. While not reported as being common, "abuse of ARVs" was also mentioned by both adolescents and caregivers in the context of mixing ART with other drugs leading to a "better high."

Mismatch between desired and received support

The final unique theme that arose from the conversations with non-adherent adolescents was struggle with developing medical independence. Caregivers with poorly adherent adolescents reported struggling to balance monitoring the adolescents and equipping them with the skills to mature into self-sufficient adults.

Discussion

This study is unique in that facilitators and barriers of medication adherence were identified in the context of adolescents' adherence patterns, observed longitudinally over time using a variety of measures. Unique barriers were identified among non-adherent adolescents. This is hypothesis-generating, suggesting that these barriers may be important to the development and maintenance of insufficient medication-taking patterns.

Both adherent and non-adherent adolescents in our study frequently identified the purpose and importance of HIV medications, but the theme of low outcome expectancy only arose as

a barrier to adherence in conversations with non-adherent adolescents and their caregivers. Non-adherent adolescents in our study were older than adherent adolescents, but the duration of time on treatment was similar between groups. Thus, the reporting of treatment fatigue only among the poorly adherent adolescents could reflect differences driven by maturity and development rather than the duration of therapy. A recent systematic review of treatment fatigue among patients on ART suggests that the course of treatment fatigue may vary by developmental stage (Claborn, Meier, Miller, & Leffingwell, 2015). Similarly, in our study mental health problems and substance abuse were reported only among older, non-adherent adolescents, although a few younger adolescents expressed awareness of these issues in others. Factors other than age/developmental stage that lead to susceptibility to treatment fatigue, mental health problems, and substance abuse in certain individuals need to be better understood. Even now, however, we can screen for these challenges in individual patients to better target our interventions.

The type of support that is most beneficial for individual adolescents isn't always easy to ascertain. While the support of adult caregivers was both desired and beneficial to study participants, the extent of adult involvement in adolescents' HIV care is a complicated issue. Older non-adherent adolescents wanted to be trusted to take medications on their own and caregivers struggled to find a balance between trust and appropriate monitoring. Mismatch between desired and received support has been termed "miscarried helping" and has been identified in other pediatric chronic illnesses in which the good intentions of caregivers have deleterious effects on children's disease status and management (Fales, Essner, Harris, & Palermo, 2014; Vermaes, Gerris, & Janssens, 2007). Anderson and Coyne describe a paradigm for adolescents with diabetes in which conflict arises because caregivers think they know best. When health fails to improve, caregivers feel like they have failed, and this sense of disappointment is communicated both explicitly and implicitly to youth. Youth, in turn, feel blamed for their health problems and feel pressured to receive healthcare (Anderson B J, 1991). The dynamic of miscarried helping was similarly described in relationships between adolescents living with HIV and caregivers in our study and may be an important contributor to adolescent non-adherence.

We designed our study to have groups separated by adherence characteristics in order to allow participants to explore the barriers and facilitators of their adherence with individuals whose behaviors (or whose children's behaviors) was similar to their own. We aimed to include all eligible subjects in FGDs rather than IDIs when feasible. Because patients who could not take part in FGDs were clearly different from those who could (e.g. reasons for exclusion of adolescents from focus groups included lack of disclosure of HIV status to the adolescent), we chose to interview those individuals separately in order avoid losing the "voices" of those who could not or would not participate in a FGD. Furthermore, while separating participants by adherence characteristics allowed for detailed discussions among individuals with similar challenges, the methodology could have "hidden" similarities between individuals in different groups. Issues that were raised by the participants in response to open-ended questions might have been endorsed by individuals in other groups had one person in the group raised the topic. For example while suicidality was mentioned spontaneously (without probing) in multiple groups with non-adherent participants and none with adherent participants, our facilitators also did not probe for comments about suicidality

in adherent groups. Had they done so, it is possible that adherent participants also would have shared relevant experiences.

Additional limitations of the study include the fact that we only included adolescents who were at the “extremes” of adherence. Adolescents with more “average” adherence might have their own unique issues. The population of our clinical site is primarily perinatally HIV-infected. Therefore, our findings may not be applicable to the growing number of adolescents and young adults who are newly infected with HIV.

No unique facilitators of or barriers to adherence were identified among adherent participants. Low outcome expectancy, treatment fatigue, mental health and substance use problems, and mismatches between desired and received social support were discussed as barriers only in conversations with poorly adherent adolescents and their caregivers. Healthcare providers should consider exploring these factors among their adolescent patients who are struggling with adherence in order to identify potential areas for intervention. Further research is needed to clarify how prevalent these challenges are among adolescents who are poorly adherent to their treatment and to develop interventions to mitigate the more prevalent barriers. In particular, interventions that successfully address parent-child communication may help to resolve issues related to miscarried helping (Duke, Wagner, Ulrich, Freeman, & Harris, 2016; Fales et al., 2014; Palermo et al., 2016).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Characteristics of participants

Adolescents		
Characteristics	**Adherent (n=15)**	**Non-adherent (n=32)**
Median age in years (IQR)	14 (12–15)	18 (16–19)
Median (IQR) MEMS Adherence[1]	100 (99–100)	57 (28–72)
Female Sex	8 (53%)	17 (53%)
Median age at initiation of ARVs (IQR)	4.8 (2.8–5.8)	8.8 (6.0–11.1)
Main occupation		
Student	15 (100%)	30 (94%)
Works full-time	0	1 (3%)
Unemployed and out of school	0	1 (3%)
Orphan Status		
Non-orphan	11(73%)	17 (53%)
Single orphan (mother or father deceased)	3 (20%)	10 (31%)
Double orphan (mother and father deceased)	1 (7%)	5 (16%)
Baseline WHO clinical stage[2]		
1	1 (7%)	3 (9%)
2	2 (13%)	1 (3%)
3	9 (60%)	15 (47%)
4	3 (20%)	13 (41%)
WHO T-stage[3]		
1	13 (87%)	26 (81%)
2	0	1 (3%)
3	2 (13%)	2 (6%)
4	0	3 (10%)
Baseline WHO immunologic stage[4]	1 (7%)	1 (3%)
1	6 (40%)	9 (28%)
2	2 (13%)	1 (3%)
3	5 (33%)	19 (59%)
4	1 (7%)	2 (6%)
Unknown		

Adolescents		
Characteristics	**Adherent (n=15)**	**Non-adherent (n=32)**
Recent WHO immunologic stage[5]	13 (86%)	16 (50%)
1	1 (7%)	7 (22%)
2	1 (7%)	4 (13%)
3	0	5 (15%)
4		
Took part in a FGD (not IDI)	14 (93%)	25(78%)
Non-adherent criteria[6]		
Viral load >1000 copies/mL	0	29
MEMS adherence lowest 20%	0	29
Self-report adherence lowest 20%	0	10

Adult Caregivers		
Characteristics	**Adherent (n=11)**	**Non-adherent (n=14)**
Relationship to adolescents		
Aunt	2 (18%)	2 (14%)
Biological mother	6 (55%)	5 (36%)
Biological father	1 (9%)	1 (7%)
Female cousin	0	1 (7%)
Grandmother	1 (9%)	1 (7%)
Sister	0	1 (7%)
Uncle	0	2 (14%)
Step-mother	1 (9%)	0
Unspecified	0	1 (7%)
Age		
18–29 years	0	1 (7%)
30–39 years	1 (9%)	4 (29%)
40–49 years	6 (55%)	4 (29%)
50–59 years	3 (27%)	2 (14%)
60–69 years	1 (9%)	0
Withheld	0	3 (21%)
Female sex	10 (91%)	11 (79%)
HIV-infected		
Yes	9 (82%)	7 (50%)

Adult Caregivers		
Characteristics	**Adherent (n=11)**	**Non-adherent (n=14)**
No	2 (18%)	4 (29%)
Unknown or withheld	0	3 (21%)

[1] Median MEMS adherence based on the first year of study follow-up

[2] WHO clinical stages defined based on most severe HIV-related illness with 4 being most severe (WHO, 2007)

[3] WHO T-stage defined as the most severe HIV-related illness in the past 6 months

[4] WHO immunologic stage defined as most severe immunologic suppression with 4 being most severe (WHO, 2007)

[5] Recent WHO immunologic stage defined by CD4+ T-lymphocyte count within the last 6 months

[6] Of the 32 non-adherent adolescents involved in the study, 4 met all 3 non-adherence criteria

Table 2:

Barriers and Facilitators to Adherence that were Common to both Adherent and Non-adherent Adolescents

Facilitators of Adherence		
Facilitator	**Examples**	**Illustrative Quotations**
Social Support * -Family -Peers	-providing for material needs -reminders to take ART -emotional support -role models -peer groups -peer mentoring	“My mother is my role model. She takes medicines every day for hypertension and I get motivated by her most of the time.” −13 year old non-adherent female “What helps most is the nature of our communication at home with the child. Communication brings unity between caretakers and helps the child to be reminded and motivated.” –father or a 14 year old adherent female “They should find someone who is their age and who is at the peak of everything when it comes to proper medication-taking so that they may be motivated by that peer to take their medicines well and tell them the problems they are encountering.” −21 year old non-adherent female 19 year old adherent male discussing friends coming with him for medical appointments: “They sacrifice their time to be with me. It shows that they care. And you get motivated when you are surrounded by people who care.”
Acceptance of HIV Status	-being motivated by past experiences with illness -understanding the purpose of ART -seeing medication-taking as the adolescents’ responsibility	“[The clinic staff] can come up with all these strategies [to improve medication adherence], but it depends on the individual if they have accepted [their HIV status]. That is when they can take their medicines well.” −17 year old non-adherent female
Daily Routine	-using reminders such as phone alarms and TV/radio programming -aligning schedule with that of others in the household -use of pill boxes	“If I haven’t taken them I can feel that. It feels like you know what there is something missing. I haven’t taken something. That is it’s like we are now addicted or what. Something is missing…That’s all that helps me.” −18 year old adherent female “I can just feel in my body that it’s time to take medicines. I never forget. When I fail to take them, it is always deliberate and intentional.” −16 year old non-adherent male “I am the one helping my child. I set an alarm on my phone and watch.” –mother of an adherent 13 year old female

Barriers to Adherence		
Barrier	**Examples**	**Illustrative Quotations**
Interference with daily activities	-school and work conflicts (e.g. rushing to school) -extra-curricular activities -timing of recreational activities (e.g. playing and losing track of time) -personal relationships	“Our kids love getting into relationships. When they are in that stage you cannot control them. She goes away and comes very late when her pill time has long passed. If you happen to call her when she is still with the lover she gets angry at you. Another thing is that she comes with friends for study group. That is a good thing, but the problem is when friends are around she is embarrassed to take her medicines because the friends do not know that she is taking medicines.” –father of 15 year old non-adherent female

Barriers to Adherence		
Barrier	**Examples**	**Illustrative Quotations**
Stigma and discrimination	-lack of disclosure outside the family due to fear of discrimination -self-stigmatization/feeling of isolation -separation of HIV services within the healthcare system	"when I am in school…I have a roommate. It is difficult to wake up and take the pills if I have not disclosed [my HIV status]. It's also a difficult thing to…disclose because people are judgmental." −20 year old non-adherent female "The big thing here is shame; that's why you see that they do not follow the doctors' instructions. It's shame. If my mate sees me taking pills, what will he say? How will they look at me? Because when this disease first started in Botswana, [the public] was truly afraid of it, and they shunned it. If someone suffered from it, they would not even enter that home." - mother of a 16 year old non-adherent male "I felt taking (my ARVs) made me different from other kids…I did not want to be treated differently because of my status instead of who I am." −21 year old adherent female
Side effects	-nausea and anticipatory nausea -diarrhea -increased appetite -fatigue -dizziness -rashes	"Sometimes when I have taken [the medications], a white foam-like substance is released in my throat which I have to spit. So when I think about them and that unpleasant substance, I just do not bother myself taking them." – 16 year old non-adherent male "when you are going to take your pills, when you think of the pills, you get nauseated before you take them." −13 year old non-adherent male
Denial of HIV status		"It is more difficult for adolescents who were born with the virus to accept [their HIV status]. So I think you should pay more attention to them because they do not know how they got [HIV]. Like my sister, she blames herself for her mother's death. Sometimes she does not really understand how she got the virus because she did not do anything to get it. She just found herself in this situation." –adult sister of 19 year old non-adherent female
Resource limitations	-food insecurity	"when I take them without eating they make me nauseated…in January, there was no food at home…I missed taking pills then because I had nothing to eat." −19 year old non-adherent female

* Social support from community members and school staff was only discussed as being lacking, usually because participants feared disclosing their/their child's HIV status outside of the household.

Table 3:

Barriers that were Unique to Non-adherent Adolescents

Barriers to Adherence		
Barrier	**Examples**	**Illustrative Quotations**
Low Outcome Expectancy	-belief that antiretrovirals don't improve their health -belief that antiretrovirals only improve their health when they are sick	"To tell the truth…I'm told by my mom and dad [when to take my medications]. But when I'm alone…when I don't take them, I'm just fine. So, when I'm alone I won't take them" −20 year old female "I do think teenagers have a problem because sometimes when they look (at themselves)…they think they are healed." – caregiver of a poorly adherent 13 year old female "They will not take their medications because they think, 'why is it that I have to take the medications when I am fine?...I will take them when I am ill again.' They judge themselves on their freshness [and if] their outward appearance is okay." −19 year old female "Some people completely believe in their churches or religions. A pastor or any church leader can tell someone to go and open the bottles to take out the pills and not swallow them by deceiving them that they will get healed."−12 year old male
Treatment Fatigue	-sense of exhaustion related to demands of medication-taking and healthcare -feeling that frequent clinic visits and adherence counseling are a burden rather than a help -overwhelmed by size and number of pills	"I am not taking my pills because every job has a retirement, and this one of taking pills has made me so exhausted that I want to take my retirement. That's why I do not take them."−16 year old male "It is very tiresome to take pills every day. I am tired. Very tired." −19 year old female
Mental Health	-depression -suicidality	"some people even commit suicide, some run away from home…when they are told about their status." – 13 year old male "some time back, she was suicidal. She wanted to die. So I guess she did not take the pills so she could die…she has [also] once been admitted after overdosing and trying to commit suicide." –caregiver of a 16 year old female -"Sometimes someone wants to commit suicide so they stop swallowing their pills." – 17 year old female -"said she thinks it's better to leave the world because…she sees no future for herself." –mother of a 15 year old female -"She says she hears herself saying that after all we are all going to die. Why should I be reminded that my situation is different from others [because of my HIV?] …We go [to the clinic] with hope that everything will be fine, but when we get there, [I am told] that if I don't take my medicine properly it's like at the end there is a death sentence. That is why she would say she wants to die just to see what will happen." -Father of a 17 year old female
Substance Abuse	-experimenting with alcohol and drugs -use of alcohol and drugs leading to	"Some smash (the ARVs) into powder and mix them with drinks or alcohol; some mix the powder with marijuana or tobacco. They say that when they mix tobacco and pills the

Barriers to Adherence		
Barrier	**Examples**	**Illustrative Quotations**
	impairment that impacts adherence -"abuse of ARVs"	effect is like that of cocaine and they feel high." −18 year old male "Some of them sell (the ARVs) because they say they can be mixed with marijuana to make a good drug." –mother of a 15 year old male
Mismatch between desired and received support	-supervision makes adolescent feel untrusted -lack of supervision makes adolescent feel unsupported -support of religious communities sometimes clashes with medical recommendations	"He knows that at 7:00 he is going to take his pills. When it's 6:55 and you tell him that he should not forget to take his pill...that doesn't settle well with him, that he is not trusted." –mother of a 16 year old male "At my home…they are not interested. Even now I come to the clinic alone. They do not even know the name of my pills…when it comes to my medicines, there is no support at all..." −20 year old male