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To tell or not to tell: Why people with HIV share or don't share with their physicians whether they are taking their medications as prescribed

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Abstract

This qualitative study examines whether HIV-positive people ($N = 79$) tell their physicians whether they take antiretroviral treatment (ART) as prescribed and why. Interviews, analyzed with qualitative content-analysis, asked about taking/not taking ART and, if taking, whether they shared their reasons for non-adherence with their physician. Patients are more likely to inform physicians why they take than why they do not take ART ($p < 0.01$). Only half of those not taking ART shared the reasons for their decision with their physician. The six motives were: anticipation that physicians will not support the decision, cannot discuss feelings, lack of trust in physician's opinion, unable to discuss spiritual/moral issues, no need for physician to know, and not seen physician yet. Of those taking ART, 21% did not tell their physician why they missed doses. The five motives were: not viewed as important, physician not asking, not seen physician yet, rarely non-adherent, no indications in surrogate markers. A significant proportion of patients are not taking their medications as prescribed and are not telling their physicians. To facilitate the chance that patients communicate with their physicians, physicians need to ask and, while giving the patients medical information, create a non-judgmental, respectful atmosphere where patients feel comfortable sharing their personal view.

Introduction

Access to ART transformed HIV from being associated with imminent death to living with a chronic illness. However, there are still many unanswered questions about the optimal use of ART in treatment for HIV. For example, the best point to start or stop therapy for a given patient is uncertain, as reflected by the frequently changing guidelines found on the Department of Health and Human Services (US) (DHHS) website. The continuous debate on early versus late initiation of ART clearly reflects the lack of certainty in this area (Carrieri et al., 2003; Clerici et al., 2002; Gallant, 2004; Hirsch & Sterritt, 2003; Phillips et al., 2003; Volberding, 2000; Wood et al., 2005). Adherence has been described as the 'Achilles heel' of treatment success (Carrieri et al., 2003; Chesney, 2003; McPherson-Baker et al., 2005). Partial or poor adherence can lead to a rebound in viral replication, poorer survival rates and the mutation to treatment-resistant strains of HIV (Alberdi Leniz et al., 2004; Harrigan et al., 2005). Writing prescriptions is easy but in the end, regardless of what the physician wants, the patient makes the ultimate decision whether or not to take ART. Little is known about why patients share their individual reasons with the physician to accept or forgo the offer of ART or not to adhere to a prescribed regimen. Our qualitative study examines two questions: (1) why people living with HIV (PLWH) disclose or withhold the reasons for their decision from their physician, to

accept or reject the offer of ART and (2) why PLWH who have decided to take ART tell or don't tell their physicians their reasons for not taking their medications as prescribed.

Methods

Study population and sampling

The study was conducted as a sub-study of the longitudinal parent study on the psychology of health and long survival with HIV/AIDS (Ironson et al., 2001; Ironson et al., 2002; Ironson et al., 2005a; Ironson et al., 2005b). The longitudinal study started in March 1997 and recruited a diverse paid-volunteer sample from AIDS-organizations, doctors' offices, and community-events in southeast Florida. The main objective of the parent study was to examine the psychological and immunological factors associated with health maintenance in the face of HIV. The main inclusion criterion for the parent study was having CD4 levels between 150 and 500. The exclusion criteria were having a past or current AIDS defining symptom (CDC category C), active substance dependence or active psychotic symptoms.

Our sub-study was conducted between February and September 2003 and investigated 79 PLWH who should have been offered ART according to the US treatment guidelines laid down by the DHHS at that point in time, these included: (1) PLWH with symptoms ascribed to HIV infection and (2) asymptomatic PLWH with CD4 cells $<350/\text{mm}^3$ or plasma HIV RNA levels $>55,000$ copies/mL (by RT-PCR or bDNA). The only differences between sub-study and parent study participants were that all participants of the parent study in which ART was not yet indicated according to the DHHS guidelines were excluded from the sub-study. In addition, participants with active substance dependence (i.e. who had relapsed) or who had developed AIDS defining events were no longer excluded in the sub-study. The sample was representative of PLWH in Florida with respect to gender and ethnic groups and included not only middle-class gay white men but also a substantial proportion of African-American and Latino women and men (see Table I).

Study design and procedures

The local Institutional Review Board approved this study and all participants gave written informed consent. Self-report questionnaires on demographics (Table I) were sent out by mail approximately two weeks prior to the interview. At the appointment, the participants completed their medical information with the researcher (Table I). The AIDS Clinical Trials Group (ACTG) adherence questionnaire (ACTG, 2001) was filled out with the researcher to determine whether participants were on an ART regimen and, for those that were taking ART, to assess the reasons for non-adherence. Then the participants were interviewed about the reasons why they had decided to take or not to take ART and why they did or did not share these reasons with their physician. If they were on ART, they were asked if they had additional reasons for non-adherence that were not listed in the ACTG questionnaire. Again, participants explored why they did or did not share their reasons for non-adherence to ART as they reported on the ACTG questionnaire or in the interview with their physician. The duration of the interviews was between 30–60 minutes. Participants were compensated \$50 for each visit at the study center.

ACTG-adherence questionnaire

The standard self-reported adherence questionnaire of the ACTG (ACTG; 2001) is one of the simplest methods of assessing adherence to ART. However, self-report tends to overestimate the true extent of adherence by approximately 20% (Liu et al., 2001). The questionnaire asks patients to check a list of 14 items covering possible common reasons for which PLWH miss taking medications. The items are rated on a scale from 0 = 'never', 1 = 'rarely', 2 = 'sometimes' to 3 = 'often'. A sum-score was calculated for each reason by adding the frequency scale across

participants. The ACTG adherence questionnaire instructs not to ask participants who reported that they never skipped doses about their reasons for missing doses. However, in our study, the reasons for non-adherence were assessed in all participants taking ART, even if they indicated that they never skipped doses.

Qualitative content analysis

All semi-standardized interviews were performed by one of two trained interviewers and were audio-taped and transcribed. The transcribed interviews were analyzed with the method of qualitative content analysis (Mayring, 2000a; Mayring, 2000b). This approach offers an advantage over other qualitative approaches in that it allows both quantitative and qualitative operations. This method defines itself as an empirical, methodologically controlled analysis of texts, following content analytical rules and step-by-step models without rash quantification (Mayring, 2000a; Mayring, 2000b).

In the first step, the most comprehensive interviews were worked through by three independent researchers to find illustrating quotes and to develop tentative categories regarding the two research questions: what were the motives for sharing or not sharing the reasons with the physician for taking/not taking ART and, if taking ART, the reasons for not adhering to ART. In the team, the categories were reduced, selected and grouped into a hierarchical system. Next, a formative check of validity took place to detect and revise ill-defined categories. This resulted in coding categories and illustrative quotations.

After analysis of 21 interviews, it appeared that the analysis had reached theoretical saturation. The preliminary coding categories were used to assess independent inter-rater reliability for two raters using the first 21 interviews. Cohen's Kappa-coefficient (Hays, 1981) was calculated for the categorical data. In general, coefficients above 0.7 are considered as acceptable or even good (Bakeman & Gottmann, 1986). Independent inter-rater reliabilities for the categories of the first 21 interviews ranged between 0.81 and 1.

Next, using the coding categories, all 79 interviews were coded by three team members trained in consensual ratings (Mruck & Mey, 2000). The three raters first looked at the interview independently and then discussed their decision in the group.

Statistical analysis

Basic descriptive statistics were calculated for the demographic and medical characteristics: reasons to take or not to take ART, motives to share or not to share the reasons for the decision about ART with the physician, reasons for non-adherence and motives to share or not to share the reasons for the decision about ART with the physician.

Chi-square analysis was performed to examine which motives were associated with sharing/not sharing with the physician the reasons for not taking ART or not adhering to ART. A 2×2 table was constructed with each motive scored as present/absent versus telling/not telling the physician why they were not taking ART or not adhering to ART. To adjust for the small sample sizes, Fischer's exact tests were calculated, indicated as p_f .

The relationship between demographic and medical characteristics and telling/not telling the physician the reasons for the decision made about ART and the reasons for non-adherence were examined using chi-square and Fischer's exact tests for nominal dichotomous data and Student's t tests for ordinal and interval variables (with log transformed viral load copies/mL). For statistical evaluation, SPSS version 12 statistical software (SPSS Inc., Chicago, Illinois, USA) was used.

Results

Demographic and medical characteristics of the participants

Table I summarizes the demographic and medical characteristics of all 79 participants in our study. The sample was diverse with respect to gender (35.4% female), sexual orientation (53.2% heterosexual) and ethnicity (41.8% African-American, 27.8% Latino, 24.1% white, 6.3% other races). At the interview, 73.4% participants were taking ART (69.6% highly active combination, 3.8% less potent combination) and 26.6% were not taking ART. Over the past year, 27.8% of the participants had maintained ART, 35.4% had changed ART, 10.1% of participants had restarted ART, whereas 20.3% had stopped and 6.3% were ART-naïve at the interview. Overall, 32.9% (26/79) of participants had CD4 counts below 200 cells/mm³. Of the participants taking ART, 51.7% (30/58) still had a detectable viral load.

Reasons for the decision to take or not to take ART

Qualitative content analysis of semi-structured interviews identified ten criteria for the decision of whether or not to take ART: (1) surrogate markers (87.3%), (2) quality of life (84.3%), (3) knowledge/ beliefs about resistance (65.8%), (4) body-mind belief (64.6%), (5) side effects of ART (59.5%), (6) easy to take regimen (58.2%), (7) spirituality/worldview (58.2%), (8) drug resistance (40.5%), (9) experience of HIV/AIDS symptoms (39.2%) and (10) preference for complementary/alternative medicine (16.2% prefer but 50.6% use complementary/alternative medicine). Participants choosing not to take ART preferred alternative medicine ($\chi^2=14.50$, $df1$, $p_f=0.001$) and perceived a better psychosocial quality of life without taking ART ($t=2.95$, $df77$, $p=0.004$). Participants who stopped ART tolerated adverse effects of ART less well than those who continued ART ($t=2.28$, $df72$, $p=0.026$). Further details on the reasons for the decision to take or not to take ART in our study are published elsewhere (Kremer et al., 2004a; Kremer, 2005; Kremer et al., in press).

Motives to share or not to share the rationale for the decision about ART with the physician

Six motives were identified as to why most participants (78.5%) did share the reasons for their decision about ART with their physician and seven motives were identified as to why some participants (21.5%) did not share the reasons for their decision with their physician (Table II). Participants not taking ART were less likely to share the reasons for their decision with their physician than those accepting ART ($\chi^2=14.24$, $df1$, $p_f<0.001$). Less than half (47.6%) of the participants who chose not to take ART shared the reasons for their decision with their physician, whereas most participants taking ART did (87.9%). Compared to PLWH accepting ART, those rejecting ART were more likely to anticipate that the physician will not support the decision, to lack trust in their physician's opinion and to not discuss spiritual or moral issues with the physician but less likely to want to inform the physician and to have concerns.

Motives associated with sharing or not sharing the reasons for not taking ART with the physician

Table II gives an overview of the chi-square analyses between each motive (present/absent) and telling/not telling the physician. In the 21 participants not taking ART, three motives to share (want to inform physician, wants/trusts physician's opinion, presence of concerns) were significantly associated with telling the physician why they did not take ART. Four motives not to share (anticipation that physician will not support decision, lack of trust in physician's opinion, unable to discuss feelings, unable to discuss spiritual/moral issues with the physician) were significantly associated with not telling the physician why they did not take ART. 'The physician did not ask' was not given as a motive for the participants for not telling the physician why they were rejecting ART. In two participants, one of whom told the physician why he was not taking ART and one who did not, the laboratory reports alerted the physician.

Uncovering over-reporting of self-reported adherence using the ACTG-adherence questionnaire

One way of identifying over-reporting is to examine people whose self-report is discrepant with their viral load. Half of the participants (19/37) who reported that they did not miss any dose over the past month had a detectable viral load. The detectable viral load might, of course, be due to drug resistance. However, of the 19 participants with detectable viral load despite good adherence, 68.4% were not tested for drug resistance. Another discrepancy was that one-third of participants who reported initially that they never skipped medications (in the first section of the ACTG adherence questionnaire), gave reasons for non-adherence when asked the checklist from the ACTG with specific questions. The ACTG adherence questionnaire instructs researchers to skip the checklist for the reasons for missing doses if participants claim that they never skip doses.

Reasons for non-adherence

Overall, 77.6% of participants taking ART (45/58) reported reasons for missing doses. The six most frequent reasons for missing doses in the 45 participants were: (1) side effects (felt sick/ill from side effects ($n = 6$), felt like the drug was toxic or harmful ($n = 7$) and wanted to avoid side effects ($n = 9$; sum = 51), (2) were away from home ($n = 29$, sum = 45), (3) had a change in routine ($n = 25$, sum = 37), (4) slept through dose time ($n = 23$, sum = 31), (5) were busy with other things ($n = 24$, sum = 34) and (6) simply forgot ($n = 24$, sum = 33).

Less frequent reasons were: had a problem taking pills at specified times ($n = 15$, sum = 27), ran out of pills ($n = 13$, sum = 20), did not want others to notice them taking medications ($n = 6$, sum = 11), had too many pills to take ($n = 5$, sum = 11), felt depressed or overwhelmed ($n = 7$, sum = 10) and felt good ($n = 4$, sum = 5). The following further individual reasons for often missing doses, which were not listed in the ACTG-adherence questionnaire, were reported in the interview: detoxification from substance use ($n = 2$), just did not feel like taking it ($n = 2$), irritable bowel syndrome ($n = 1$) and nausea during pregnancy ($n = 1$).

Motives to share or not to share the reasons for non-adherence with the physician

Six motives were identified why most participants on ART (79.3%) did share the reasons for non-adherence with their physician and five related motives were identified for why some participants on ART (20.7%) did not share the reasons for non-adherence with their physician (Table III). The chi-square analyses between each motive (present/absent) and telling/not telling the physician are also shown in Table III. In the 58 participants taking ART, two motives to share (important to talk about adherence, physician asks) were significantly associated with discussing the reasons for non-adherence with the physician. Three motives not to share (not important to talk about adherence, physician did not ask, not seen physician yet) were significantly associated with not telling the physician why they missed doses.

Demographic and medical characteristics associated with sharing or not sharing with the physician the reasons for not taking or not adhering to ART

The higher the viral load log ($t = -2.52$, $df56$, $p = 0.015$) and the lower the CD4 counts ($t = 2.11$, $df56$, $p = 0.039$), the more participants communicated with their physician about non-adherence. The higher the income, the less participants shared their reasons for non-adherence with their physician ($t = 2.95$, $df56$, $p = 0.005$). Sharing/not sharing the reasons for not taking or not adhering to ART with the physician was not significantly associated with other demographic or medical characteristics from Table I.

Discussion

The major finding of our study, that patients usually tell their physicians why they take ART but often do not tell them why they do not take ART, has barely been examined in the literature. People living with HIV/AIDS who accept an ART regimen usually tell their physicians the reason for their decision because they want to inform their physician, trust their physician's opinion or have concerns about ART. However, half of the participants deciding not to take ART fail to share the reasons for their decision with their physicians, mainly because they anticipate that he/she will not support their decision, lack trust in the physician's opinion and are not able to discuss feelings, spiritual or moral issues.

The results of our study are consistent with two other smaller studies of PLWH. In one study (Laws et al., 2000), 10/56 PLWH did not fill in their prescriptions for ART, five told their physician and five did not. In a German study (Kremer et al., 2004b) 4/6 women did not tell their physician why they refused ART as they felt under pressure from their physicians to take ART but 5/5 men did communicate to their physicians why they refused ART, regardless of feeling under pressure or not. Although half of the PLWH did not tell their physicians why they refused to take their medications, in other chronic diseases not telling the physician seems to be even more common. In a study in general practice in the UK (Barry et al., 2000), 31/35 patients did not voice their agendas in consultation which led, in 14 cases, to unwanted prescriptions and non-use of prescriptions.

How can physicians encourage patients to communicate why they are not taking ART?

Before writing out a prescription for ART, physicians should assess patients' willingness, ability and readiness to take ART (Department of Health and Human Services, 2003; Fowler, 1998). It is also important to acknowledge patients' reluctance to take a certain class of antiretrovirals. For example, participants often expressed reluctance to take a protease inhibitor in the interview fearing the lipodystrophy syndrome, which is more likely in regimens including a protease inhibitor (Negredo et al., 1999).

A widely used framework for assessing an individual's willingness for behavioral change is the five-stage transtheoretical model (Prochaska & Diclemente, 1992). These stages include: pre-contemplation (considering taking ART), contemplation (thinking about taking ART but no commitment), preparation (firm intention to take ART), action (taking ART) and maintenance (adhering to ART).

Recognizing that health beliefs (e.g. the belief about the necessity for ART) are usually necessary to motivate people to move through the stages of change, physicians should assess the individual's current stage and provide the appropriate information and support in order to facilitate movement to the next stage. Particularly if a patient is not yet prepared to take ART, a patient's action may not be consistent with what their physician wished for them to do but physicians will often not be aware of this. Our results suggest that, to improve communication about the patient's reasons for the decision not to take ART, physicians should signal that they respect the patient's freedom of choice not to be treated with ART, even if they personally would not support their patient's decision from the medical point of view. Physicians should get across to their patients in a nonjudgmental way that they want to know if their patients decide to stop taking ART, particularly if patients are in an advanced stage of immune-depletion, as careful monitoring and close cooperation between patient and physician helps to take this step more safely. To quote the secret of success of one medical expert, 'I can join in any decision they take in the large spectrum. Not that I find it good or that I find it right; this isn't important at all—but it is important to make it clear that this is their body, their life, their infection.' (Kremer, 2001)

How can physicians encourage patients to communicate why they are not adhering to ART?

As important as assessing and re-assessing patient's readiness to take ART, is the physician's assessment of adherence to ART. A physician's estimate of the likelihood of a patient's adherence is an unreliable predictor of adherence (Crespo-Fierro, 1997). However, physicians are less prepared to prescribe ART in patients who exhibit a behavior or characteristic judged by the physician to lend itself to non-adherence (Bogart et al., 2001). Treatment guidelines recommend physicians assess and address patients' reasons for non-adherence on a regular basis rather than using their judgment of a patient's likelihood of adherence (Department of Health and Human Services, 2003). Our study can help guide physicians' assessments of these reasons.

Our study revealed the six most common reasons for non-adherence: side-effects of ART, being away from home, a change in daily routine, sleeping through dose time, being busy with other things and simply forgetting. Although these are consistent with other reports (Chesney et al., 2000; Gallant & Block, 1998; Golin et al., 2002; Walsh et al., 2001), as we note above, patients often don't disclose their physicians why they are missing doses—how then can the physician encourage the patient to communicate this information? The first step, informed by our study results, is being aware of when the patient is not likely to share this information, as in the following instances: (1) some patients don't feel it is important to talk to the physician about adherence, therefore physicians should always ask, (2) if patients have good surrogate markers, they are less likely to talk to their physician about missing doses, (3) patients who see their physicians rarely are less likely to talk about non-adherence, therefore regularly scheduled appointments are essential, (4) physicians should not assume that patients with a higher income are more likely to talk about missing doses; our data shows PLWH with a higher income may communicate less with their physicians about their reasons for non-adherence, feeling that this topic is less important. However, it should be noted that while no one has studied the relationship between income and telling physicians about missing doses, studies have shown that adherence to ART is not related to income (Golin et al., 2002; Paterson et al., 2000; Wenger et al., 1999) and (5) while patients do inform their physician if they run out of prescriptions, this is certainly something physicians should ask about routinely.

Improving use of the ACTG adherence questionnaire for patients' self-reports

Although self-reported adherence is often overestimated (Liu et al., 2001), a physician's guess of a patient's adherence is no better than chance (Paterson et al., 2000). Asking patients about their adherence does improve on a coin toss to predict adherence (Turner & Hecht, 2001). When patients report they adhere to medication, this may or may not be accurate. In contrast, if patients tell the physician that they are *not* adherent, it is most likely to be true. Patients' self-reports of the proportion of missed doses are related to viral load (Chesney et al., 2000; Ironson et al., 2005b). Although the ACTG adherence questionnaire is a self-report instrument, it might be useful for clinical practice. Our data shows that, even when people say that they don't miss doses, asking them a list of common reasons for missing doses often reveals non-adherence. Looking for discrepancies between self-reported adherence and viral load (as well as follow-up resistance tests) and asking for common reasons for missing doses (even in those who say they are adherent) and following up each reason with additional questions may be helpful in encouraging patients to discuss non-adherence. For example, running out of pills may be due to difficulties with money/insurance, or may be related to the patient's forgetting or to the physician's office not providing enough refill prescriptions. Each of these has different implications for treatment therefore physicians should regularly ask their patients about their adherence and whether they have enough medication and refill prescriptions.

Limitations

Because this was a cross-sectional study, the associations that were found between variables have to be considered as correlations and may not be causal. Due to the combined qualitative and quantitative nature of the study, the sample size was relatively small. The study is based on self-reports of adherence with the known unreliability of self-reports of adherence and the bias towards reporting better adherence (Golin et al., 2002).

Conclusion

Implications for clinical practice

Learning from the stories of PLWH, the following suggestions may open up communication with patients about their individual reasons not to take or not to adhere to ART (see Table IV). In summary, physicians should actively determine whether patients take their prescribed medication or not by creating a non-judgmental, respectful atmosphere where the patients feel comfortable sharing their personal view and by following the recommendations noted above. Ways of creating a non-judgmental atmosphere with patients include actively listening to their concerns, being genuinely interested in their views and acknowledging their struggle with a challenging choice; this also involves exercising restraint from pre-emptive reaction or from impulsively making negative comments. It is helpful to put aside one's own personal views and, instead, put oneself in the patient's shoes. Reflecting back, clarifying and making sure patients understand risks and benefits are key components of supporting patients in making an informed choice. It is important for physicians to indicate respect for the patient's choice (as long as it is an informed choice), even when the patient's decision conflicts with what is believed to be the most reasonable from the medical perspective.

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Table 1Demographic and medical characteristics (*N* = 79).

Characteristics	<i>n</i> (%)
Gender	
Male	51 (64.6)
Female	28 (35.4)
Sexual orientation	
Heterosexual	42 (53.2)
Homosexual/bisexual	37 (46.8)
Ethnicity	
African-American	33 (41.8)
Hispanic	22 (27.8)
Caucasian	19 (24.1)
Other	5 (6.3)
Income(\$)	
Less than 10,000/year	43 (54.4)
10,000–20,000/year	16 (20.3)
20,000–40,000/year	12 (15.2)
More than 40,000/year	8 (10.1)
Education	
Less than high school	16 (20.3)
High school	13 (16.5)
Trade school/ less than college	27 (34.2)
College graduate	23 (29.1)
Employment	
Full time	20 (25.3)
Part time	9 (11.4)
Student	4 (5.1)
Unemployed	16 (20.3)
Disability	30 (38.0)
Health insurance/drug access program	
Yes	73 (92.4)
No	6 (7.6)
Drug use (% past month)	
Marihuana (non-prescribed)	20 (25.3%)
Cocaine	13 (16.5%)
Other recreational drugs	13 (16.5%)
Antiretroviral treatment (actually taking)	
Yes	58 (73.4)
No	21 (26.6)
CDC Stage	
Category B symptoms past 6 months	16 (20.3)
Category C symptoms in past	11 (13.9)
CD4 nadir 200–350 cells/μl	20 (25.3)
CD4 nadir below 200 cells/μl	59 (74.4)
	<i>M</i> (<i>SD</i>)
Viral load copies/ml	37,858 (83,125)
CD4 cells/μl at interview	347.00 (227.65)
CD4 cell/μl nadir	149.95 (93.99)
Years since HIV diagnosis	11.14 (4.15)
Age	42.03 (7.88)

Table II

Motives to share or not to share the reasons for the decision about ART with the physician in participants taking versus not taking ART and 2×2 chi-square analysis of presence/absence of each motive × sharing/not sharing why *not* taking ART with physician.

Motive category	Illustrative quotations	Frequency in patients taking ART (n = 58) versus not taking ART (n = 21)(%)	X ² Df=1 (n = 21)
Motives to share reasons for the decision about ART			
Wants to inform physician	'I always inform them but I am the one who makes the decision.'	77.6 versus 38.1 **	14.22 ***
Wants/trusts physicians opinion	'I believe in her decisions. She is very good and she is a specialist.'	72.4 versus 38.1 **	8.24 **
Presence of concerns	'I was scared to take it (because of hepatitis C). I even have shown him a pamphlet that was saying that it will re-infect the liver.'	63.8 versus 23.8 **	7.22 **
To maintain a good relationship with physician	'My physician and I have had a special relationship for eleven years now, so he basically is like one of my closest friends.'	41.4 versus 28.6	4.30
Physician asks	'If she brings it up and talks about it, we talk about it.'	25.9 versus 23.8	2.76
Indications in surrogate markers	'I knew he was going to see it (not taking ART) in my labs.'	5.2 versus 9.5	0.01
Motives not to share reasons for the decision about ART			
Anticipation that physician will not support decision	(Patient who stopped ART) 'I told him that stopping ART is just something that dwells inside me. He didn't think it will agree with me in the long run.'	3.4 versus 42.9 ***	14.32 ***
Unable to discuss feelings	'When it comes to concerns, I can communicate better with my case managers, who many are either gay or HIV, so they have a deeper understanding of what it means.'	8.6 versus 23.8	9.55 *
Lack of trust in physician's opinion	'I don't really know if I can really trust a medication or a physician's opinion.'	1.7 versus 33.3 ***	5.97 **
Unable to discuss spiritual/moral issues	'As far as what my moral beliefs, no...I don't think it is pertinent for him.'	1.7 versus 23.8 **	5.97 *
No need for physician to know	'I don't think she (physician) needs to know about that (reasons for decision to restart).'	5.2 versus 9.5	2.01
Physician did not ask	'He didn't ask.'	6.9 versus 0	N/A
Has not seen physician yet	'I have not seen him.'	5.2 versus 4.8	0.96

*
p<0.05

**
p<0.01

p<0.001.

Table III

Motives to share or not to share the reasons for non-adherence to ART with the physician in patients taking ART and 2×2 chi-square analysis of presence/absence of each motive $\times$ sharing/not sharing why adhering to ART with physician.

Motive category	Illustrative quotations	Frequency ($n = 58$)(%)	χ^2 Df=1 ($n = 21$)
Motives to share reasons for non-adherence to ART			
Important to talk about adherence	'It is extremely important for the physician to know (the reasons for non-adherence).'	56.7	19.97***
Physician asks	'Because there was times that he (the physician) asked me, "Are you sure that you are taking the medications at the correct time?"'	29.3	0.627**
To maintain a good relationship	'It teaches me to be honest with myself and therefore be honest with someone else (the physician).'	15.5	2.77
Indications in surrogate markers	'When he got the genotype back, he knew I was resistant to the medication. What was going to say? I couldn't lie.'	13.8	2.42
Ran out of prescriptions	'I told my physician that I need a prescription for my medication, "If I don't have a prescription, I can't take the medication until I get the prescription from you."'	3.5	0.54
Motives not to share reasons for non-adherence to ART			
Not important to talk about adherence	'I thought this was none of his business.'	12.1	30.52***
Physician does not ask	'She never asks me specifics.'	6.9	16.47***
Not seen physician yet	'I need to. I haven't been to an appointment yet to talk to him about it.'	6.9	16.47***
Rarely/never happens	'I don't think it is worth bothering him about. I think that my compliance is pretty good.'	5.2	3.90*
No indications in surrogate markers	'We did not talk about it (reasons for non-adherence). We do talk about other things. I mean, she sees the lab work and she sees I am doing stable.'	1.8	0.64

*
pf<0.05

**
pf<0.01

pf<0.001.

Table IV

Suggestions for clinical practice.

Opening up the communication with patients about not taking ART as prescribed

- Establish a trustful, non-judgmental relationship.
 - Ask patients about their feelings about taking ART or not taking ART.
 - Ask patients about their concerns about ART.
 - Ask patients if their decision made about ART relates to their spiritual/moral beliefs.
 - Ask patients about their personal reasons for the decision whether or not to take ART.
 - Signal that you respect patients' rights to choose not take ART.
 - Assess reasons for non-adherence during every visit in all patients taking ART (checklist!).
 - Assess surrogate markers regularly.
 - Schedule regular appointments.
 - Don't write a prescription for ART before assessing patients' willingness, ability and readiness to take ART.
 - Don't let your patients run out of prescriptions.
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