AN AUDIT OF SELF – AND CAREGIVER - REPORTED MEDICATION AND OTHER CONTEXTUAL CORRELATES OF ADHERENCE AMONG HIV INFECTED CHILDREN AND ADOLESCENTS IN A TEACHING HOSPITAL IN SOUTHWEST NIGERIA

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ABSTRACT

Non-adherence to Anti-retroviral therapy (ART) is common in all groups of treated individuals. For most patients, near-perfect adherence is necessary to achieve full viral suppression. There is a close relationship between adherence and HIV-related morbidity and mortality. This study evaluated self- and caregiver- reported adherence to ART, predictors and other contextual correlates of adherence among 132 children and adolescents with HIV infection at the University College Hospital, Ibadan, Nigeria. Pre-tested questionnaires were administered to 109 primary caregivers and a subgroup of adolescents (23) who assessed their own adherence. Data generated from the questionnaire were coded, entered and analyzed using SPSS 15.0. Most of the respondents (90%) reported excellent and good health status after commencement of therapy. The self-reported adherence to the specific timing for taking the medications was 72.7 %. The self reported adherence to number of doses of medications missed irrespective of specific timing of the dosing was 75%. The overall rate of self reported adherence was 74 %. The most reported reason for missed doses was care-giver not being around to give the drug. Majority of respondents needed a prompting strategy to ensure adherence to instructions. Over half of respondents had not disclosed the HIV status to anybody. Viral load, age, and child's relationship with Caregiver were identified as influencing adherence. Stigmatization and disclosure status were not associated with poor adherence. The details of the contextual

correlates of adherence in this study should be factored into appropriate intervention strategies which would promote adherence to ART.

INTRODUCTION

The nature of infection with HIV/AIDS has been changed since the widespread availability of potent triple combination therapy. It is well established that along with improved diagnostic measures such as HIV viral load testing, the advent of Highly Active Antiretroviral Therapy (HAART) – combination regimens of different antiretroviral medications has been critical to the ongoing success of controlling the viral replication in a given individual patient. HAART is related to significant reductions in morbidity and mortality; however, these complicated therapies require high levels of adherence by the patient.[1, 2] Few prescribed regimens are as complicated and challenging to an individual's daily life as HIV therapies.[3]

Pediatric adherence is especially challenging, and may be further complicated when delivered in resource-limited settings like Nigeria. As combination antiretroviral therapy becomes available to HIV-infected children in sub-Saharan Africa and other resource-limited settings, effective strategies for measuring and facilitating adherence are needed.

For both the individual and society, the impact of poor adherence and subsequent drug resistance may be severe. When the virus is not optimally suppressed, potentially fatal opportunistic infections may develop which can lead to AIDS-related mortality. In addition, when the virus is partially suppressed, as occurs with intermittent or incomplete adherence, drugs will suppress wild-type virus, but viruses with resistant mutations will be selected for. The result is selective replication of the mutant virus that is resistant to those drugs and may be cross-resistant to drugs in the same class.

This study evaluated self- and caregiver- reported adherence to Anti-Retroviral Therapy (ART), predictors and other contextual correlates of adherence among children and adolescents with HIV infection aged 3 to 18 years at the University College Hospital, Ibadan, Nigeria.

METHODS

Study Design, Setting and Population: A cross-sectional survey of HIV-infected children and adolescents on antiretroviral therapy using a structured pre-tested questionnaire

administered to the primary caregiver and a subgroup of adolescents who assessed their own adherence.

The setting was the Anti-retroviral therapy unit of the University College Hospital (UCH), Ibadan, Oyo State, located in the south western Nigeria. The hospital is 900-bed spaces and 163 examination couches, tertiary health facility with over 60 health departments offering health services to the residents of Oyo State and neighbouring States. The HIV/AIDS treatment centre took off in the hospital in 2004 with the provision of comprehensive HIV care services. Patients received formal pre-treatment adherence education/counseling sessions. They were also expected to visit the centre once a month for drug pick-up.

The study population included 132 HIV- infected children and adolescents that enrolled in the Antiretroviral clinic and commenced HAART in the UCH Ibadan, and come to the hospital for their regular drug refill and some of them for medical follow up and were between the ages of 3 and 18.The patients were consented to participate in the study.

Consented guardians who were biological parents, relatives or adoptive caregivers were included in the study.

Sample Size Calculation

The sample size (n) was calculated as follows :

$$n = \frac{N}{1 + N(e)^2}$$

Where : n = Sample size, N = Total patient's population enrolled and commenced ART in university college Hospital, Ibadan (estimated at 200 patients) as this facility has an average monthly enrolment of 10 new ART patients; e = the level of precision ($\pm$5%)

Therefore: $n = \frac{200}{1 + 200 (0.05)^2} = 133$

Data Collection

A structured questionnaire was designed and administered to gather information on socio-demographic characteristics and adherence related measures, Adherence was also measured using self report adherence measures included in the questionnaire. Medical records were inspected in order to collect additional clinical information about the patient. Adherence was measured over three day's recall of medication intake. A patient is considered in this study

non adherent if he missed more than one dose from his daily medication and did not adhere to specific timing of taking doses of the medication.

Data Analysis

Data generated from the questionnaire were coded, entered and analyzed using SPSS 15.0. Descriptive Statistics such as frequency distribution, simple percentages were used. Responses relating to adherence to specific timing for taking the medications (medication schedule) and the number of prescribed doses of medication missed were transformed into a 0-100 scale, in a manner that the higher the score the better the adherence. Self reported adherence was calculated as the mean scores of patients' adherence to the specific timing for taking the medications (medication schedule) and the number of prescribed doses of medications missed.

We examined any association between various variables and self reported adherence amongst participants using chi-square test. All reported P- values were 2 – sided, and P <0.05 was used to determine statistical significance, except where otherwise indicated.

Ethical consideration

The study participants were educated about the study, its benefits and their informed consent obtained before the commencement of the study .The approval of the head of the Unit was obtained before the commencement of the study.

We identified two main potential risks associated with this study. First, guardians might have felt uncomfortable discussing the HIV status of their children. Second, there could be accidental disclosure of HIV status to the child. However, these were dealt with by administering the Questionnaire to the caregiver and not to children below age fifteen. Furthermore, participants' responses were made completely anonymous, their identity remained confidential and responses were not linked to their names and addresses in any way.

RESULTS

Characteristics of the Study Participants

The study subjects was comprised of females 72 (54.5%) and male 60 (45.5%), between 3 and 18 years old. Almost all the subjects were in school, with about two third (66%) in primary school. The median age was 8.5 years. The persons who assessed the adherence were

majorly Caregivers (109; 82.6%) and Adolescent HIV infected patients (23; 17.4%) who assessed their own adherence. About 56.8% of the subjects were under the care of their biological parents and 25.8% had caregivers other than biological parents. The majority of the caregivers (55.0%) were still married, 32(29.4%) were widowed, 7(6.4%) were divorced. As regard religious affiliation, 77 (58.3%) were Christians. The majority of the caregivers were self employed (69%) and 107 (81.1%) of study subjects were domiciled within Ibadan. See Table 1 for details

Table 1 Characteristic of the Study Participants

Patients' Characteristics	Frequency	Percent (%)
Sex		
Male	60	45.5
Female	72	54.5
Age (years)		
3 - 6	37	28
7 – 10	44	33.3
11 – 14	24	18.2
15 – 18	27	20.5
Education		
Primary	87	66.0
Secondary	28	21.2
College/University	7	5.30
Vocational	7	5.30
None	3	2.20
Religion		
Christianity		
Moslem	77	58.3
Other	55	41.7
Domicile of child		
within Ibadan	107	81.1
outside Ibadan	25	18.9
Caregivers Characteristics (n=109)	Frequency	Percent %
Relationship with Caregiver		
Biological parent	75	68.8
Granny	25	22.9
Aunty	3	2.8
Uncle	2	1.8
Sister	3	2.8
Other	1	0.9
Gender		
Male	10	0.92
Female	99	90.8
Education		
Primary	36	33.0
Secondary	30	27.4
College/University	22	20.2

Postgraduate	2	2.0
none	19	17.4
Marital Status		
Single	10	9.2
Married	60	55.0
Divorced	7	6.4
Widow/Widower	32	29.4
Occupation		
Unemployed	15	13.8
Self employed	70	64.2
Civil Servant	18	16.5
School/College	6	5.5

Health Characteristics of Study Participants; Duration of Treatment and Health Status

Among all respondents, 58.4% reported commencement of HIV treatment in the past 1-5 years; 77.3% declared that patients had a poor state of health before commencement of treatment whilst only 8% reported a good state of health before commencement of therapy. Most of the respondents (90%) reported excellent and good health status after commencement of therapy; 87.8% reported that the patients were not hospitalized in the past one year and 60% reported that patients had HIV-1 viral load of 200 copies per ml. See Table 2 for details.

Table 2 Health and Treatment Status of study subjects

Characteristics	**All Respondents N=132 N (%)**	**Self Assessed patients (N-23) N (%)**
When was the HIV treatment started? Less than1 year 1 -5 years 6 – 10years Above 10 years	13 (10) 77 (58.4) 27(21.6) 13(10)	2 (8.7) 7 (30.5) 3 (13) 11(47.8)
State of health prior to commencement of the HIV medication Good Poor	30(22.7) 102(77.3)	12(54.5) 10(45.5)
Number of times hospitalized in the past one year None 1 – 2 3 – 4	116(87.8) 15(11.4) 1(0.8)	6(26) 16(69.6) 1(4.4)
HIV-1 viral load 200 copies per mL 200–10 000 copies per mL $\geq$10 000 copies per mL	79(60) 27(20.5) 26(19.5)	4(19) 6(28.6) 11(52.4)

Medication Adherence Assessment

The self-reported adherence to the specific timing for taking the medications (medication scale) was   72.7 % (range: 0%- 100%). Of the 132 respondents, 95(72%) reported $\geq$ 80% adherence to medication schedule. The self reported adherence to number of doses of **medications** missed irrespective of specific timing of the dosing was 75% (range 20%-100%). Of all respondents, 99(74.5%) reported $\geq$ 80% adherence to the prescribed doses of medications irrespective of the specific timing of the dosing. The mean self reported adherence is 74% $\pm$ 14.4%.

Regarding missed doses, 65.1% of subjects had not missed any dose; 14.5% had missed more than 4 doses; 60.6% always adhered to the specific timing for taking the medication; 20.5% sometimes missed the timing. Regarding reasons for missed doses, 23% missed their doses because they were away from home, 6.8% because of change in schedule, 6% because they ran out of medications, 6.8% because the child refused the medication; 8.3% were tired of giving/taking the medication; 6% because they needed to hide the medication. Table 3

Table 3 Medication Adherence Assessment

VARIABLES	FREQUENCY	%
Number of doses of medication missed		
None	86	65.1
1	13	9.8
2	8	6.1
3	6	4.5
>4	19	14.5
Do you adhere to the specific timing for taking the medication		
Always	80	60.6
Most of the time	15	11.4
Sometimes	27	20.5
Never	10	7.5
Total	132	100
Reasons for Missed Doses		
you are away from home	32	23
too busy with other things	6	4.5
change in schedule	9	6.8
dosing times are inconvenient	1	0.8
Ran out of medications	8	6.0
financial constraint	3	2.3
Care giver felt sick	2	1.5
Forgetfulness	1	0.8
Child felt sick	1	0.8

Got confused on how to give Medications	1	0.8
	1	0.8
Child refusal	9	6.8
Child was not available	4	3.0
Stress at home and in school were too much	3	2.3
Got tired of taking/giving medication	11	8.3
Needed to hide the medication	8	6.0

Knowledge and perception of ART management, Disclosure and Stigmatization

Regarding their understanding of the concept of the illness, 95% of all respondents understood whilst 100% of self-assessed patients understood the concept. On medication efficacy, 96% of all respondents and 87% of self-assessed patients believed ARTs were efficacious. Majority of the respondents (83.3%) needed a reminder or prompting strategy to ensure that they were giving / taking the drugs according to health providers' prescription .The most common of these were "triggers based on activities of daily living" (52%), buddy systems (19%), look at the time (15%) and set alarms (10%).

Regarding disclosure of HIV status, 54.6% of all respondents had not disclosed the HIV status to any other person whereas 45.4% had made disclosures to Spouses (45.4%), Relatives (20.3%), Neighbours (19.5%), and Pastor/Imam (3.9%). All respondents reported that 91.7% of the children did not know the reasons for taking the medications.

Regarding the issue of stigmatization, 82.4% of all respondents and 91.3% of self-assessed patients were not comfortable giving or taking medications when other people were present; 79.7% of all respondents and 82.6% of self-assessed patients needed to hide the medication so that others would not become suspicious. See Table 4 for details

Table 4 Knowledge and perception of ART management, Disclosure and Stigmatization

Variables Knowledge/Perception	All Respondents N=(132) No (%)	Self- assessed patients (N=23) No (%)
Do you understand the Concept of the illness Yes No	116(95) 6(5)	23(100)
Do you belief in the efficacy of the medication Yes No	120 (96) 5 (4)	20 (87) 1 (4.4)
Prompting for ART drugs required Yes	102(83.3)	23(100)

No	20 (16.7)	
Types of ART reminders		
Daily activity	63(56)	10 (43.5)
Buddy system	18(19)	5 (21.7)
Look at the time	18 (15)	4 (17.4)
Set alarm	11 (10)	3 (13)
Disclosure		
Disclosed to any other Person		
Yes	58(45.4)	6 (26)
No	70 (54.6)	17(74)
Have disclosed to		
Spouse	58(45.4)	N=6
Relatives	26 (20.3)	
Neighbour	25 (19.5)	6 (100)
Pastor/Imam	5(3.9)	
All	2(1.6)	
Does the child know the reason for taking drugs		
Yes	9(8.3)	2 (8.7)
No	100(91.7)	21 (91.3)
Stigmatization by the Participants		
Comfortable giving/taking the medication when other people are present		
Yes	22(17.6)	2(8.7)
No	103(82.4)	21(91.3)
Needed to hide the medication so that others will not become suspicious?		
Yes	98(79.7)	19(82.6)
No	25(20.3)	4(17.4)

Predictors of Adherence; Cross-tabulations

Tables 5a and 5b provide details of the variables that were examined for association with adherence among the children and the adolescents.

The overall adherence rate was 74%. Adherence rates tended to decline with age, with the worst adherence rates among 15- to 18-year-olds (64% overall, as compared with 83.7% for younger children). Similarly, Adherence rates tended to decline with viral load (Fig.1).

Adherence levels varied significantly by age (P = 0.04); those with an adult other than their biological parent as Caregiver had reduced odds of non-adherence (P = 0.03) as well as those that perceived the health status as being excellent or good after commencement of therapy (P = 0.02). We found no association with educational level of the patient or caregiver, gender, occupation, religion or domiciliation of respondents. Subjects who believed in the efficacy of the medication had significantly improved adherence (P=0.02).The factors that were

marginally associated with adherence were understanding the concept of adherence and the need for treatment (P= 0.07) and need to prompt the respondent for ART (0.08)

Table 5a Predictors of Adherence; Cross-tabulations

Predictors of Adherence	Adherence level	P-value
Age 3 – 6 years 7 – 10 years 11 – 14 years 15 – 18 years	37/132 (83.7%) 44/132(75.7%) 24/132(72.9%) 27/132(64%)	0.04*
Gender Male Female	60/132(73.6%) 72/132(74%)	0.14
Education Primary Secondary College/University Vocational None	87/132 (75%) 28/132 (73%) 7 /132 (70%) 7/132 (72%) 3/132 (74%)	0.13
Religion Christianity Islam	77/132(73.2%) 55/132(73.5%)	0.17
Domicile Within Ibadan Outside Ibadan	107/132(75%) 25/132(73%)	0.21
Relationship with Caregiver Biological Parent **Others**	75/109 (70%) 34/109(77%)	0.03*
HIV-1 Viral Load $\leq$200 copies per ml 200–10 000 copies per ml $\geq$10 000 copies per ml	79/132 (92%) 27/132(70%) 26/132(60%)	0.05 *
Knowledge of medication reason Yes No	9/109(74.0%) 100/109(74.6%)	0.24
Understand the concept of the illness Yes No	116/122(74.8.8%) 6/122(73.1%)	0.07
Prompting for ART drugs required Yes No	102/122(74%) 20/122 (72%)	0 .08
Belief in the efficacy of the Medication Yes No	120/125(78%) 5/125(60%)	0.04*

Table 5b Predictors of Adherence

Predictors of Adherence	Adherence level	P-value
Disclosure Status Yes No	70/128(74.6%) 58/128(73.6%)	0.16
Stigmatization; Take medication when others are Present Yes No	22/125(71%) 103/125(73%)	0.17
Stigmatization; Needed to hide medication Yes No	98/123(70%) 25/123(72%)	0.18
State of Health Prior to initiation of ART Good Poor	10/122(70%) 112/122(75%)	0.12
Number of times Hospitalized in the past one year None 1-2 times 3-4 times	96/119(80%) 15/119(75%) 8/119(60%)	0.14
Duration of Treatment <1 yr 1-5 yrs 6-10 yrs >10 yrs	13/113 (70%) 60/113 (72.4%) 27/113(70.6.6%) 27/113(70.6.6%)	0.16
State of health after commencement of therapy Excellent Good Fair	45/119(80%) 62/119(78%) 12/119 (75%)	0.02*
Relationship with Caregiver Biological Parents Others	75/109 (70%) 34/109(77%)	0.03*
Caregiver Gender Male Female	10(73.5%) 99(74%)	0.23
Caregiver Educational Level Primary Secondary College/University Postgraduate None	36(72%) 30(73%) 22(75%) 2(74%) 19(70%)	0.12
Caregiver Marital Status Single Married Divorced Widowed	10(72%) 60(77%) 7(70%) 32(75%)	0.15
Caregiver Occupation Unemployed	15(71.5%) 70(76%)	

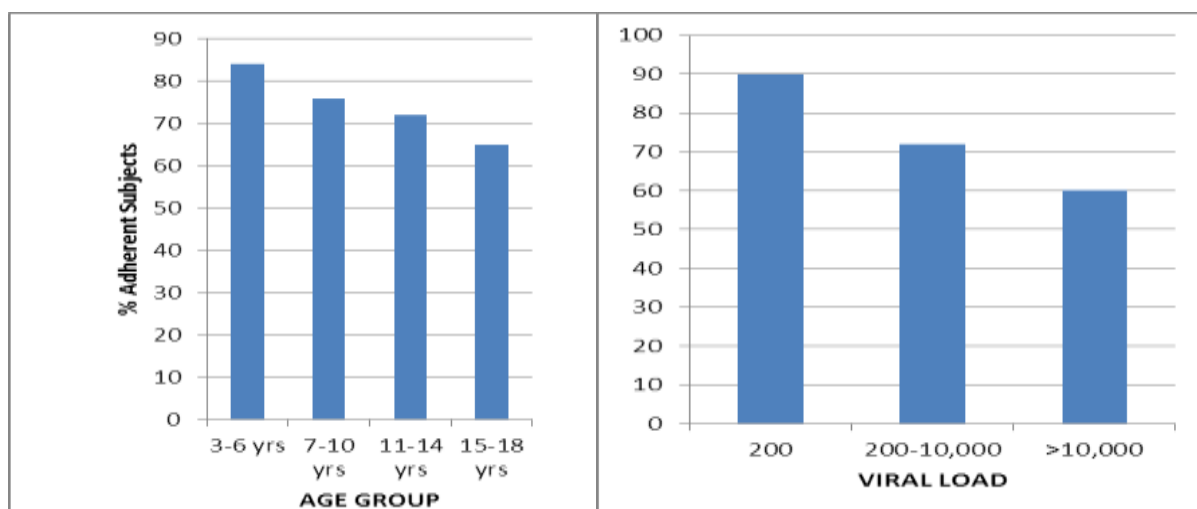| Self-employed | 18(75%) | 0.13 |
| Civil Servant | 6(70%) | |
| School/College | | |

Fig 1 Association   between Age, Viral Load   and Adherence

DISCUSSION

The female to male ratio of the HIV patients was 1:0.8 with a median age of 8.5 years. These are similar to other reports[4, 5] Care-givers, most of whom were married, self-employed biological parents were directly involved in the study.

The ratio of Christians to Moslems was 1:0.7 and majority lived within the city of Ibadan.

The health status of the respondents at the time of the study was assessed using treatment characteristic variables such as duration of the therapy, state of health prior to initiation of therapy and after commencement of therapy, number of times hospitalized in the past one year and the clinical marker.

More than half of the respondents reported from one to five years of duration of therapy, long enough to assess medication adherence and other correlates. A large majority of the respondents (92%) reported a poor state of health prior to initiation of therapy. However, most of the respondents (90%) reported excellent and good health status after commencement of therapy. This was corroborated with the report that majority (80.6%) of the patients were not hospitalized in the previous year before the study. More than half of the respondents (60%) reported HIV-1 viral load of 200 copies per ml The primary goal of treatment with ART is to prevent HIV-related morbidity and mortality. Many studies have shown a strong correlation between adherence and clinical outcomes and/or laboratory markers (notably CD4

count). Non-adherence has been found to diminish the immunological benefit of ART and increase AIDS-related morbidity, mortality, increased rate of hospitalization and longer hospital stays.[2]

Good adherence to antiretroviral therapy is necessary to achieve the best virological response, lower the risk that drug resistance will develop, and reduce morbidity and mortality.[6] Very high levels of adherence are required for full and durable virologic suppression.[1, 7, 8] The phenomenon of persistent clinical benefit despite virologic failure has been documented in a number of recent studies.[2]

In countries with broad access to effective ART, the clinical benefits have been found to be dramatic; progression to AIDS has been slowed down, there are now fewer hospitalized patients, and the age-adjusted death rate from HIV/AIDS has declined by more than 70%.[9] Adherence to ART has been described as both the major determinant and the Achilles' heel of this success.[2]

Adherence Reports

Antiretroviral adherence in young children and adolescents poses unique and formidable challenges. Young children may have particular difficulty taking medication. Adolescents may refuse to take medication as a manifestation of otherwise normal rebellious behavior. Furthermore, the crucial role of family support in pediatric adherence can be compromised by other associated burdens, such as low income, an HIV-infected parent, stigmatization, or unclear familial responsibilities regarding the child's medication adherence.[2]

In most studies, adherence refers solely to dose adherence, but successful treatment with ART also includes adhering to scheduling that accompanies many antiretroviral drugs.[10] Although it is generally acknowledged that self report measures tend to overestimate adherence, [4] the reports of missed medication doses would be expected to identify those non-adherent to medications.

In this study, scheduling and dose adherence were assessed and a combined indicator was made to determine the rate of adherence in the study area.

The self-reported adherence to the specific timing for taking the medications (medication scale) was 72.7 %. The self reported adherence to number of doses of medications missed

irrespective of specific timing of the dosing was 75%. The mean self reported adherence is (+ SD) is 74% + 14.4% in this study.

For most patients, near-perfect (>95%) adherence is necessary to achieve full and durable viral suppression. [1, 8, 11] In practice, this degree of adherence requires a patient on a twice-daily regimen not to miss or substantially delay more than 3 doses of antiretroviral medications per month. This degree of adherence is far greater than that commonly associated with other chronic diseases [12] and is quite difficult for most patients to maintain over the course of a lifelong illness.[1, 2]

The overall rate of self reported adherence in this study was 74 % which was quite below the 95% of adherence expected of these patients but higher in comparison with other studies.[13] Suboptimal adherence has been reported in a number of studies all over the world. [1, 7, 14-16] The reasons for improved adherence level in this hospital was that all the services rendered to these patients were at no cost which included free, regular and uninterrupted supply of quality anti-retroviral (ARV) drugs, medical laboratory tests and financial support.

Antiretroviral adherence is the second strongest predictor of progression to AIDS and death, after CD4 count.[14, 17] Incomplete adherence to ART, however, is common in all groups of treated individuals. The average rate of adherence to ART is approximately 70%, despite the fact that long-term viral suppression requires near-perfect adherence.[17, 18] The resulting virologic failure diminishes the potential for long-term clinical success. Drug-resistant strains of HIV selected through ongoing replication in the presence of ART also can be transmitted to uninfected or drug-naive patients, leaving them with fewer treatment options.[19] Non-adherence may eventually undermine the dramatic improvements in HIV-related health parameters seen in resource-rich countries and expected in developing countries as ART becomes more widely available.[2]

However, adherence is said not to be the only determinant of ART failure or success; other implicated factors include genetic differences in drug metabolism, severe baseline immune suppression, prior drug resistance, and concurrent opportunistic infections. What is significant about adherence is that it is one of few potentially alterable factors that impact outcomes for patients with HIV. Nonetheless, many health care providers are, in general, unskilled at assessing and improving medication adherence.[17, 20] The actual taking of

medication, which is regarded as the critical final step in the drug use process, is oftentimes neglected.[2]

Summarily, even without dedicated adherence programs, recent data suggest that patients in resource-poor settings like ours, have levels of adherence and virologic suppression that are equivalent to, or possibly better than, those seen in resource-rich settings. Financial barriers to access have been consistent predictor of incomplete adherence in resource-limited settings.[21] This underlies the advocacy for free or highly subsidized supplies of ARVs in resource-limited settings like ours. The consequences of non adherence are quite grave.[2]

Reasons for Non-Adherence

The most commonly reported reasons for missing doses in this cohort were caregiver being away from home (21.3%), got tired of taking/giving medication (8.3%), child refusing to take the medication (6%) and schedule change (6.8%). These findings may form a basis for improving clinical care of patients by developing an adherence programme that will adequately prepare patients and guardians prior to initiating treatment and provision of an ongoing ART adherence support.

The literature describes the common reasons why people miss medications and these include simply forgetting, being away from home, being too busy with other things, a schedule change, too many side effects, feeling sick or depressed, and running out of pills.[2, 22]

Devising strategies to promote adherence is very crucial in ART. The primary strategy taken by guardians together with their children to promote adherence in this study was a reminder. The study revealed that 83.3% of those reporting adherence required prompting or reminder to remember to take the pill. Subjects used a variety of tools and techniques to help them remember to take medications; the most common of these were "triggers based on activities of daily living".   The other strategies included the use of alarm, buddy systems and looking at the time '. These findings are consistent with other studies and empirically based literature.[23] The findings from this study substantiated the recommendation to use a number of tools to modify behavioral techniques and integrate medication taking into the HIV infected child's daily routine.

Reminder Devices are particularly important given that patents cite "simply forgot" as the primary reason for missed doses.[24] Common devices include alarms on watches, beepers, or

other electronic items that allow for multiple daily reminders. Calendars, paper or electronic, allow patients to document scheduled doses and note when they have been taken. Visual Medication Schedules, Medication Organizers (e.g., pillboxes, medisets), extra packages of pills at work or in the car, or an unmarked bottle for enhanced privacy have been recommended to enhance adherence.[2]

Disclosure of HIV status

A little over half of the respondents had not disclosed the HIV status to anybody as at the study time. The disclosures made were to close and intimate persons like spouses, relatives, friends, neighbours and spiritual leaders.

Disclosure of HIV status by the guardian to the child occurred in only one tenth of the participants; a majority of guardians did not disclose. Similar low disclosure rates have been reported elsewhere.[25-27] However, a similar study had reported a higher prevalence of disclosure (25%) which varied with age. The proportion of children who knew their status was greater among older children compared to young children.[5]

Pediatric HIV clinicians generally promote disclosure as a positive influence on adherence; however, the evidence from the literature is mixed.[28, 29] Several reasons have been adduced suggesting disclosure might be associated with non-adherence. For example, the negative effects of HIV-related stigma, including efforts to keep the diagnosis secret by hiding or not taking medicines, may impact adherence to therapy for disclosed children more than non-disclosed children. On the other hand, there are also reasons to believe disclosure may lead to improved adherence, including increased responsibility over medication-taking and better access to social support. In a longitudinal study, it was reported that approximately 58% of children and their caregivers reported that adherence improved post-disclosure; clinicians felt that adherence improved in only 25% of cases.[30] Complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence in another study.[26]

Pediatric HIV providers often recommend disclosure of HIV status to children as necessary to building trusting provider-patient and family relationships and developing disease management skills that facilitate adherence.[31] In the United States, recommendations for disclosure of HIV status to children endorse a gradual process of giving age-appropriate information as the child develops the cognitive and emotional maturity to process this

information[32] Globally, institutions such as the WHO have issued similar guidelines;[33] but there are few published data on standardized, culturally appropriate disclosure protocols in resource-limited settings. A recent review on disclosure of HIV status to children found that lower proportions of children in low- and middle-income countries (LMIC) knew their status compared to those in high-income countries and among those that did know, children in LMIC reported learning it at older ages[34] Of the 21 studies reviewed that reported prevalence of disclosure, median prevalence of disclosure among similarly aged children was 20% in studies conducted in LMIC and 43% in high-income countries, while median age of disclosure was 9.6 years in LMIC and 8.3 years in high-income countries[34]

Adherence Predictors

Identifying predictors of adherence is important for preventing regimen failure, increases in viral load, and subsequent viral resistance. In this study, a strong association was found between viral load and adherence to ART medications; both are based on a clear trend for improved adherence with decreasing levels of viral load. However, there remained a large number of subjects who reported non-adherence but had low viral load or who were completely adherent yet had higher viral load. It is possible that some of the latter subjects may have had previous treatment with less-than-optimal regimens, which may have resulted in drug resistance and suboptimal suppression of viral replication, despite maintaining good adherence. Greater difficulty in achieving optimal viral suppression in children as compared with adults is well recognized and has been attributed to higher baseline viral load and differences in viral dynamics. Other research in this area has also commented on the fact that fully adherent patients do not always achieve and maintain viral suppression. For example, a study noted that approximately half of the adherent subjects failed to achieve and maintain non- detectable viral loads, whereas 10% of non-adherent subjects did achieve viral load below detectable levels despite filling <_75% of ART prescriptions. The study suggested that this may be because of high initial viral loads in children, previous development of resistance, or use of regimens of insufficient potency[35] These observations suggest that the use of viral load detectability as the only way of validating adherence measures may not be ideal.

Multiple factors were identified in this study as influencing adherence in children and adolescents with HIV infection. Older age was associated with increased likelihood for non-adherence in this investigation, consistent with findings of another study[29] Studies of medication adherence in other chronic illnesses also indicated that adherence decreases over

time; older children and adolescents tend to exhibit poorer adherence than younger children.[36] This may be in part because parents may discontinue supervising disease management behaviors as a child becomes older.[37]

The child's relationship with the Caregiver was identified as a key factor in medication adherence. Children with a relative or other adult as caregiver reported better adherence than those cared for by a biological parent, perhaps because biological parents reveal intermittent adherence difficulties more readily than other caregivers.

In an adult study, an association was found between education level and adherence- where lower educational level was independently associated with having lower adherence.[18] Though this study reported high level of understanding of the concept of the illness and the need for treatment, the educational status was not associated with poor adherence, consistent with a previous study in Nigeria.[38]

In this study, health status and respondents' belief in the efficacy of the medication showed an association with adherence. An association with adherence was also demonstrated with respondents' belief in the efficacy and outcomes of the drug therapy; taking the drug will promote their health as good to be more adhering than those who perceived their health status to be poor. This finding is consistent with other studies that documented that patients who did not present with any symptoms or pain were more adhering than those with symptoms.[39] Although majority of the respondents understood the concept of the illness and the need for treatment, guardians were still experiencing some challenges since most of their children needed a reminder to take medication; other challenges included 'guardian being away from home, change in schedule, child not available. This suggests that high level knowledge alone among guardians is not adequate in obtaining an effective ART treatment in children.

A study had revealed that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence. Structural factors including poverty and stigma were found to be barriers to adherence even for children who had had complete disclosure and a supportive relationship with a parent.[26]

In a recent study, while disclosure status was not associated with adherence either reported on the clinical encounter form or by caregivers, disclosure was associated with child-reported adherence (p = .03) with disclosed children reporting more non-adherence than non-disclosed

children. Gender, primary caregiver, CD4%, duration of therapy, malnutrition and adherence were not associated with disclosure in multivariate regression[5]

In yet another study, there were no associations between disclosure status and clinical indicators like CD4 count. A study among Thai adolescents found that while disclosure was associated with CD4% below 30% in multivariate analysis, disclosure status was not associated with virologic outcomes[1] In contrast, a study in Romania found that children who did not know their HIV status were at higher risk for disease progression, measured by CD4 count decline and death compared to disclosed children[17]

It may be expected that stigmatization of HIV/AIDS patients by the society should contribute to non drug adherence, some patients and caregiver cannot give or take their drugs when other people are with them and some will even hide the drug so that other people will not become suspicious. This study reported more than half of the respondents(54.6%) did not disclose their HIV status because people living with HIV practice stigma management by choosing and limiting whom they disclose to in order to minimize the chance of negative reactions or rejection. However, stigmatization and disclosure status were not associated with poor adherence.

This study revealed that female guardians were dominating in providing support. Considering the importance of a family and/or relatives as a source of support in taking ART, [40] this finding suggests the need to motivate and involve biological fathers and male partners in sharing the responsibility in supporting HIV infected children.

CONCLUSION

The overall rate of self reported adherence was 74 % which was quite below 95% of adherence expected of these patients. The self-reported adherence to the specific timing for taking the medications (medication scale) was   72.7 %. The self reported adherence to number of doses of medications missed irrespective of specific timing of the dosing was 75%. Adherence rates tended to decline with age, with the worst adherence rates among 15- to 18-year-olds. Similarly, Adherence rates tended to decline with viral load.

The most commonly reported reasons for missing doses in this cohort were caregiver being away from home (21.3%), got tired of taking/giving medication (8.3%), child refusing to take the medication (6%) and schedule change (6.8%). Majority of the respondents needed a

prompting strategy to ensure adherence to instructions for medicating. The most common of these were "triggers based on activities of daily living" and buddy systems. A little over half of the respondents had not disclosed the HIV status to anybody as at the study time. The disclosures made were to close and intimate persons like spouses, relatives, friends, neighbours and spiritual leaders. Over 80% of respondents were not comfortable giving or taking medications when other people were present; over 79% of respondents needed to hide the medication so that others would not become suspicious.

In this study a strong association was found between viral load and adherence to ART Older age was associated with increased likelihood for non-adherence in this investigation, The child's relationship with the Caregiver was identified as a key factor in medication adherence; children with a relative or other adult as caregiver reported better adherence than those cared for by a biological parent. Though this study reported high level of understanding of the concept of the illness and the need for treatment, the educational status was not associated with poor adherence.

In this study, health status and respondents' belief in the efficacy of the medication showed an association with adherence. An association with adherence was also demonstrated with respondents' belief in the efficacy and outcomes of the drug therapy.

We found no association with educational level of the patient or caregiver, gender, occupation, religion or domiciliation of respondents. In this study, stigmatization and disclosure status were not associated with poor adherence This study revealed that female guardians were dominating in providing support. The revelations of the contextual correlates of adherence in this study should be structured into appropriate strategies for health care providers to use in providing support for both care-givers and HIV-infected adolescents towards promoting adherence to ART. This is against the backdrops that near-perfect (>95%) adherence is necessary to achieve full and durable viral suppression; antiretroviral adherence is the second strongest predictor of progression to AIDS and death; and the consequences of non adherence are very grave. There is, therefore, a very strong advocacy for free or highly subsidized supplies of ARVs in resource-limited settings like ours. In addition, access to free ART should be expanded.

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