

## FACTORS DETERMINING DISCLOSURE BY PARENTS AMONG CHILDREN LIVING WITH HIV/AIDS ATTENDING THE CENTER OF EXCELLENCE IN KIGALI UNIVERSITY TEACHING HOSPITAL.

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### ABSTRACT

The increasing access to antiretroviral therapy (ART) and survival of HIV-infected children has raised challenges on disclosing HIV diagnosis to children. Many parents and guardians are reluctant to allow children living with HIV to know their status, arguing that they are too young and will not understand fully their circumstances causing emotional disturbances as a result. There are further concerns that children may blame their parents and ask questions on how they got the disease, even inadvertently "blurting out the secret" and thus exposing the family to stigma and discrimination. In this cross-sectional study, eligible children were recruited to participate. Data on these children was obtained from the electronic databases and completed with data extraction from the individual patient file. A sample of both parents and guardians who disclosed and those who did not disclose have been interviewed to identify the factors and reasons behind their decision-making process in addition to what they believe would improve their disclosure.

A total of 64% of HIV positive (HIV+) children had their status disclosed to them by parents while 35.8% did not. The majority of parents or guardians (80%) found that disclosing status improved adherence.

A large number of parents or guardians (67%) attended psychosocial support groups and accordingly disclosure status was highly associated with psychosocial support group attendance ( $p < 0.05$ ).

Disclosure and statistical tests showed that disclosure status was highly associated with CD4 outcomes ( $p < 0.05$ ). In addition, disclosure status was highly associated with viral load outcome ( $p < 0.05$ ). Moreover, 64.4% of children living with HIV underwent an increase of weight greater or equal 4 kg after disclosure and statistically disclosure status was highly associated with weight outcomes ( $p < 0.05$ ).

**Keywords:** Disclosure - HIV/AIDS - Children - KUTH

### RESUME

L'accès de plus en plus important à la thérapie antirétrovirale (ART) et de la survie des enfants infectés par le VIH a soulevé des problèmes sur la révélation de la séropositivité aux enfants. Beaucoup de parents / tuteurs sont réticents pour que les enfants vivant avec le VIH connaissent leur statut, en faisant valoir qu'ils sont trop jeunes, ne peuvent pas comprendre ce qui se passe, peuvent rencontrer des troubles émotionnels, par conséquent, peuvent blâmer leurs parents et poser des questions sur la façon dont ils ont contracté la maladie, et peuvent par inadvertance "laisser échapper le secret" exposant ainsi la famille de la stigmatisation et de la discrimination.

Dans cette étude transversale, les enfants admissibles ont été recrutés dans cette étude. Les données sur ces enfants ont été obtenues à partir des bases de données électroniques et complétées par extraction à partir des dossiers du malade. Un échantillon des parents / tuteurs qui ont révélé et ceux qui n'ont pas révélé la maladie aux enfants ont été interrogés afin d'identifier les facteurs et les raisons de leur décision et ce qu'ils croient permettrait d'améliorer leur communication.

Un total de 64% des enfants VIH+ a été révélé par les parents alors que 35,8% n'ont pas été révélé par les parents. La majorité des parents ou tuteurs (80%) trouve l'avantage de divulgation pour améliorer l'adhérence. L'avantage de faire la divulgation a été fortement associée à la divulgation des enfants par les parents ( $p < 0,05$ ).

Un grand nombre de parents ou tuteurs (67%) ont assisté aux groupes de soutien psychosocial et de l'état de divulgation a été fortement associée à la participation aux groupes de soutien psychosocial ( $p < 0,05$ ).

La Divulgation et le test statistique utilise ont montré que l'état de divulgation a été fortement associée aux résultats de CD4 résultats ( $p < 0,05$ ). En outre, l'état de divulgation a été fortement associée à l'issue de la charge virale ( $p < 0,05$ ). 64,4% des enfants vivant avec le VIH a connu une augmentation de poids supérieure ou égale à 4 kg après la divulgation et selon le test statistique, la divulgation a été fortement associée avec le poids des enfants ( $p < 0,05$ ).

**Mots clés:** Divulgation - VIH/SIDA - Enfants - CHUK

### INTRODUCTION

Human Immunodeficiency Virus infection/ Acquired Immunodeficiency Syndrome (HIV/AIDS) is one of the

public health challenges in the world. According to the UNAIDS report (2012) on the global AIDS epidemic, globally 34.0 million people were living with HIV at the end of 2011. Sub-Saharan Africa remains the most severely affected, with nearly 1 in every 20 adults (4.9%) living with HIV and accounting for 69% of the people living with HIV worldwide. In 2011, 1.7 million people died from AIDS-

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related causes worldwide. This represents a 24% decline in AIDS-related mortality compared with 2005 when 2.3 million deaths occurred.

While advantages of disclosing have been identified within the workplace to ensure that the employer creates a supportive environment for the employee living with HIV and AIDS, these advantages have not been translated into the home environment. Disclosure of sero-status to children is important because as an increasing number of children are born infected with HIV live to older ages, the question of when and how to talk with them about their illness becomes more crucial and due to the fact that HIV becomes more of a chronic disease and HIV positive people live longer, disclosure of HIV status is fundamental to the management of HIV infection especially for access and adherence to treatment (Hawk, 2007; Norman et al., 2007).

One potentially challenging experience for HIV positive parents is the process of disclosing their HIV status to children (Hawk, 2007). Studies conducted in well resourced settings have shown that parental disclosure of HIV status to children represents a major dilemma for HIV positive parents who struggle with decisions about whether and how to disclose their HIV status to their children (Murphy, 2008; Rwemisis et al., 2002; Schrimshaw & Siegel, 2002).

HIV positive parents must also meet the demands of children and mediate the negative impact of their illness upon their family (Murphy, 2008) this stated that it is essential to disclose illness status to children: "taking into consideration their age, psychosocial maturity, the complexity of family dynamics, and the clinical context" (AAP, 1999).

According to Shaffer (2001), disclosure of HIV status carries with it the threat of stigmatization and discrimination against the infected parent and her family. And living with a stigmatizing and chronic terminal illness, the decision to disclose HIV status is made with extreme caution. Suggesting that HIV positive parents weigh the pros and cons associated with disclosure given the social environment within which disclosure occurs.

Children with HIV disease have been called "the missing face of AIDS" because, more often than adults, they lack basic health care and they have been "missing from global and national policy discussions" (UNICEF, 2005). The parents of the children living with HIV/AIDS face difficulties with their own seropositivity and the anguish of seeing their child or children suffer (Chazal, 2005). This, on its own is traumatic enough. The feeling of blame and the fear of death make the situation worse. They may think that the child will blame them for giving him/her the disease and get worried about the welfare of the child/children after their death.

Disclosure to children is beneficial to their self-esteem and will help them to participate in their own medical treatment. As stated UNAIDS & WHO (2009), studies done elsewhere in Africa have identified age of the child, stigma and discrimination, fear that the children will tell

others and belief that the child has a right to know as being important determinants of disclosure; and the Rwanda treatment guidelines encourage disclosure to children beginning at 7 years. However, the researcher does not know how often and when exactly this is done exactly and the factors that determine this disclosure in Rwanda. This study aimed at identifying the facilitators and barriers of disclosure and the results target to surely contribute to the improvement of the care provided to children living with HIV.

The aim of this study is to determine factors influencing parental disclosure of children's HIV positive status.

## METHODS

This is a cross sectional study that lasted five months from June to October 2011. The study was conducted after obtaining approval from the Kigali University Teaching Hospital Scientific Research and Ethical Committee. Informed consent was obtained from each participant after giving a detailed explanation of the study purpose.

Study population was made by parents or guardians of children living with HIV/AIDS who were currently enrolled and followed up at the Center of Excellence of KUTH. Convenience sampling technique was used and 70 parents or children guardian met our section criteria.

Data were analyzed using descriptive and inferential statistics.

## RESULTS

Sociodemographic aspects for respondent such as education level, occupation, matrimonial status, residence location have been assessed: the majority of parents or guardians questioned in the study have a poor educational level: 53% had primary level while 17% were illiterate.

In 40% cases, the children live with their mother. Most of parents or guardians questioned in our study were people without monthly income: 30% are housewife while 30% others were unemployed. The majority of respondents (80%) came from the county to mean from the three districts of Kigali.

Children disclosure status revealed that 64% of children HIV+ were disclosed by parents while 35.8% were not disclosed by parents.

**Table 1:** Repartition of parents or guardians whose children are not yet disclosed according to the reason for no disclosure

Reason for no disclosure	Frequency	Percent
Fear of bad reaction after 10 disclosure	10	40
Fear to be challenged	15	60
<b>Total</b>	<b>25</b>	<b>100.0</b>

In view of the table above, most of parents or guardians whose children were not yet disclosed or 60%, it was on account of fear to be challenged.

**Table 2:** Relationship between no disclosure and reason for no disclosure

Child disclosure status	Reason for no disclosure		Total
	Fear of bad reaction after disclosure	Fear to be challenged	
Not disclosed	10	15	25

Chi-Square Tests (n= 25,  $\chi^2=74.000a$ , df=6; confidence level=95%, p=0.000)

Using Pearson chi square association test, reason for no disclosure mentioned were highly associated with fear to be challenged (p<0.05).

**Table 3:** Proportion of parents guardians of children living with HIV by psycho socio support group attendance

Psycho socio support group attendance	Frequency	Percent
Attended	47	67
No attended	23	33
<b>Total</b>	<b>70</b>	<b>100.0</b>

Most of parent or guardian whose children are living with HIV or 67% attended psychosocial support group.

**Table 4:** Impact of attending psycho social support group to disclosure

Disclosure status	psycho social support group attendance		Total
	Attended	No attended	
Not disclosed	17	8	25
Disclosed	30	15	45

Chi-Square Tests (n=45,  $\chi^2=58.481a$ , df=6; confidence level=95%, p=0.000)

Using Pearson chi square association test, disclosure status is highly associated with the psychosocial support group attendance (p<0.05)

**Table 5:** Distribution of children living with HIV followed up according to the CD4 evolution

CD4 evolution	Frequency	Percent
Increase greater than 100	15	33.3
Increase of 51-100	15	33.3
Increase of 1-50	15	33.3
<b>Total</b>	<b>45</b>	<b>100</b>

As shown in table above, most of children living with HIV followed up or 66.6% underwent an increase of CD4 greater or equal 51 cells after disclosure, including 33.3% who underwent an increase greater than 100.

**Table 6:** Distribution of children living with HIV followed up according to impact of disclosure on CD4 outcome

Child disclosure	CD4 evolution			
	increase greater than 100		increase of 51-100	
	greater than 100	increase of 1-50	100	Total
Not disclosed	8	9	8	25
Disclosed	15	15	15	45

Chi-Square Tests (n=45,  $\chi^2=74.054a$ , df=6; confidence level=95%, p=0.000,

Using Pearson chi square association test, disclosure is highly associated with CD4 outcome (p<0.05)

**Table 7:** Distribution of children living with HIV followed up according to the viral load evolution

Viral load evolution	Frequency	Percent
	Become undetectable	16
Stay undetectable	14	31.1
Still detectable	15	33.3
<b>Total</b>	<b>45</b>	<b>100.0</b>

In view of the table above, for children living with HIV followed up, 35.5% became undetectable after disclosure and 31.1% stay undetectable.

**Table 8:** Distribution of children living with HIV followed up according to impact of disclosure on viral load outcome

Child disclosure	Viral load evolution			
	become undetectable		still detectable	
	become undetectable	stay undetectable	still detectable	Total
Not disclosed	9	8	8	25
Disclosed	16	15	14	45

Chi-Square Tests (n=45,  $\chi^2=74.054a$ , df=6; confidence level=95%, Asymp. Sig. (2-sided)=0.000

Using Pearson chi square association test, disclosure status is highly associated with viral load outcome (p<0.05)

**Table 9:** Distribution of children living with HIV followed up according to the weigh evolution

Weigh evolution	Frequency	Percent
increase greater than 5 kg	15	33.3
increase of 4-5 kg	14	31.1
increase of 1-3 kg	16	35.5
<b>Total</b>	<b>45</b>	<b>100</b>

As shown in table above, most of children living with HIV followed up or 64.4% underwent an increase of weight

greater or equal 4 kg after disclosure, including 33.3% who underwent an increase greater than 5kg.

**Table 10:** Distribution of children living with HIV followed up according to impact of disclosure on weight outcome

Child status	disclosure		weight evolution		Total
	increase greater than 5kg	increase of 4-5kg	increase of 3kg	increase of 1-3kg	
Not disclosed	8	9	8	8	25
Disclosed	15	14	16	14	45

Chi-Square Tests (n=45,  $\chi^2=74.054a$ , df=6; confidence level=95%, p=0.000)

Using Pearson chi square association test, disclosure status is highly associated with weight outcome (p<0.05)

**Table 11:** Distribution of children living with HIV followed up according to the clinical signs evolution

Clinical sign evolution	Frequency	Percent
Disappear totally	32	71
Disappear partially	8	18
Worsen	5	11
<b>Total</b>	<b>45</b>	<b>100.0</b>

In view of the table above, for the most of children living with HIV followed up or 71%, their clinical signs disappear totally.

**Table 12:** Distribution of children living with HIV followed up according to impact of disclosure on clinical signs outcome

Child disclosure status	Clinical signs evolution			Total
	Disappear totally	Disappear partially	worsen	
Not disclosed	0	24	1	25
Disclosed	32	8	5	45

Chi-Square Tests (n=45,  $\chi^2=74.054a$ , df=6; confidence level=95%, p=0.000)

Using Pearson chi square association test, disclosure status is highly associated with clinical sign outcome (p<0.05).

**DISCUSSION**

Level of parental disclosure of children’s HIV positive status The results of our study in table showed that 64% of children HIV+ were disclosed by parents while 35.8% are not disclosed by parents. This level of parental disclosure of children’s HIV positive status is in line with the results from other studies.

In this regards, according to previous research (Lipson, 1994), data from several centers indicated that between 25% and 90% of school age children with HIV infection/AIDS have not been told that they are infected. (Grubman, 1995) reported 57% of children between 9 and 16, and (Cohen et al. 1997) found only 1 out of 20 children over age 10 were disclosed to; while (Wiener et al. 2007), reported that 41% of children between 5 and 18 were not told their diagnosis.

**Factors influencing disclosure**

The results of our study (Tables 4 and 5) report that most of parents or guardians whose children were not yet disclosed or 60%, this was on account of fear to be challenged by children and 40% on account of fear of bad reaction after disclosure. In this context, the results showed that no disclosure was highly associated with fear to be challenged by children and fear of bad reaction of children after disclosure (Pearson chi-square test, n=25, p=0.000).

In table 12, 13, the results of this study report that psychosocial support group constituted a factor influencing children disclosure by parent. Most of parent or guardian whose children were living with HIV or 67% attended psycho social support group and disclosure status was highly associated with the psycho social support group attendance.

Effects of disclosure on the clinical and biological outcomes of children living with HIV/AIDS

The results of our study show that disclosure impact on clinical and biological outcomes of children living with HIV/AIDS.

In this regards, 66.6% of children living with HIV followed up or underwent an increase of CD4 greater or equal 51 cells after disclosure and statistical test showed that disclosure status is highly associated with CD4 outcome.

For children living with HIV followed up, 35.5% became undetectable after disclosure and 31.1% stay undetectable and disclosure status is highly associated with viral load outcome.

For 64.4% of children living with HIV underwent an increase of weight greater or equal 4kg after disclosure and statistically disclosure status is highly associated with weight outcome.

For 71% of children living with HIV followed up, their clinical signs disappear totally and statistically disclosure status is highly associated with clinical sign outcome.

Our results are in line with the results provided by previous studies, in the sense that as said Munongo (2012), disclosure allowed improving clinical and biological children outcome two years after disclosure. In this context (Arun et al, 2006) reported in their study that disclosure improved clinical and biological children outcome for 72% of children living with HIV.

**CONCLUSION**

The purpose of this cross sectional study was to assess factors determining disclosure by parents among children living with HIV/AIDS attending the center of Excellence in

**KUTH**

The results from this study provided a significant contribution to current literature review to show factors contributing to children disclosure by parents such as attending psychosocial support group. Results of this study showed that the clinical and biological outcomes among children living with HIV/AIDS were highly associated with children disclosure status. Nevertheless results

from this study could not be generalized to all facilities in the country. That is why we suggest for further study, a research at national level, which could draw a general picture in Rwanda concerning the issue of disclosure by parent among children living with HIV.

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