

## ORIGINAL ARTICLE

**IMPACT OF DISEASE DISCLOSURE IN PAEDIATRIC PATIENTS WITH HUMAN IMMUNODEFICIENCY VIRUS (HIV) IN HOSPITAL TUANKU FAUZIAH, MALAYSIA: A QUALITATIVE STUDY**

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**Abstract**

Progression to AIDS is more rapid in HIV-infected children. **Objective:** Our study aimed to investigate the effect of HIV status disclosure in children in terms of their perception of the illness, knowledge on their disease and medications and the overall impact on their quality of life. **Methods:** A qualitative study was conducted from 1st June 2017 till 8th September 2017 involving face-to-face interviews with HIV-positive children receiving combination anti-retroviral therapy (cART) under paediatric HIV clinic follow-up, Hospital Tuanku Fauziah, Kangar, Perlis. Transcribed interview dialogues were subsequently coded for analysis. **Results:** Data were collected from 6 out of 8 HIV-positive children on cART in Hospital Tuanku Fauziah, Perlis. Participants' mean age was 12.2 years (standard deviation [SD] 2.11); 3 with disease disclosure. Disease-disclosed participants with ironically poor knowledge on their disease emerged as the key theme in the study. Disease-disclosed participants were also noted to be more withdrawn with very few friends, if any. Disease disclosure status did not affect the patients' knowledge and compliance to medication. **Conclusion:** Assessment of patients' understanding after disease-disclosure session is crucial to encourage therapy adherence and prevention of future transmission. Re-appraisal of the healthcare policy with regards to holistic management of children living with HIV is warranted to attain positive social and developmental goal throughout their lives.

**Keywords:** HIV Infections, Qualitative Research, Paediatrics, Patient Compliance

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## Introduction

Progression to acquired immune deficiency syndrome (AIDS) is relatively more rapid in HIV-infected children than adults, thus World Health Organization (WHO) has recommended that all children living with HIV should be started on anti-retroviral therapy (ART), regardless of WHO clinical stage or mature T-helper cell (CD4+) count at diagnosis [1].

HIV status disease disclosure in paediatrics is fairly complicated due to its potential effect on patients' overall well-being, therapy adherence, and social relationships [2]. Disclosing HIV disease status in paediatric risks retaliation and repercussion as their labile emotion and immature thinking process are still developing. Hence, disclosure commonly depends on the parents' and children's anticipation, the clinician's judgment and the severity of the disease.

An improvement in health outcomes among youths with HIV is possible with corrective measures to address the fragmented clinical care in routine practice. This can be achieved by formalizing a multiagency collaboration in the management of paediatric HIV which is in keeping with the National HIV/AIDS Strategy for the United States of America (USA) [3]. A quality improvement project involving 200 study sites all over United States conducted in the year 2000 showed that substantial improvement in the quality of care can be achieved through collaboration with other agencies [4].

Quality of life among HIV-infected children may be affected by the strict drug regimen that the patients need to adhere to, thus,

several sets of questionnaires have been developed and validated to assess quality of life among HIV-infected individuals but they are exclusively for used in adults [5,6]. Policy changes and practice recommendation particularly in clarification of disclosure guidelines in children and its legal implications are needed to sustain good clinical practice [7]. Children are vulnerable to external pressure. The events throughout the years of their development will mould their future personality trait. Therefore, it is a critical social responsibility to guide them through to the positive track. There is currently no specifically defined age range for disclosure in HIV paediatric setting hence, the decision is largely dependent on the clinician's judgment and parental inclination. In certain circumstances, the children are not primed earlier hence resulted in poor acceptance and repercussive actions which further complicates treatment and follow-up adherence.

Despite encouragement by American Academy of Pediatrics to provide developmentally appropriate disclosure of HIV infection to children [8], there exist very few specific recommendations and guidelines to assist the clinicians particularly in limited resource setting [2]. The broad dimension of experience is difficult to be assessed quantitatively as there exists broad differences in belief, attitudes and behaviours, thus a qualitative approach is adopted in the study.

The aim of this study was to explore the impact of disease disclosure in paediatric HIV patients on ART pertaining to disease perception, patient's experiences with medication and disease impact on their quality of life.

## **Methodology**

### ***Study Design***

A qualitative study was conducted in Department of Paediatrics, Hospital Tuanku Fauziah, Perlis from 1st June 2017 till 8th September 2017 to gain an in-depth understanding of the impact of disease disclosure on patients' disease perception, experience with treatment and disease effect on their quality of life. All 8 HIV-positive children ongoing anti-retroviral treatment (ART) under paediatric HIV clinic follow-up, Hospital Tuanku Fauziah, Perlis were invited to join a one-to-one interview with the team of investigators.

The interviews were conducted by 3 main investigators; each probed into a different domain which was closely related to their individual line of work. One paediatric medical officer was in-charge on the scope of disease knowledge, 1 clinical pharmacist was in-charge on the scope of knowledge of medication, and 1 clinical counsellor was in-charge to probe into the social aspects and assessment of the quality of life. Another investigator assisted to take field notes and facilitate the interview process.

The interview session was conducted in the routine clinic environment to create a familiar ambient for the patients. This created a safe and comfortable environment which allowed the patients to share and express their emotions on personal issues more freely.

### ***Participants***

All 8 paediatric HIV patients from Hospital Tuanku Fauziah, Perlis who were on combination anti-retroviral therapy (cART) during the course of study were invited to participate in the study.

### ***Inclusion criteria***

All HIV-positive children started on ART, ongoing follow-up at HIV clinic, Department of Paediatrics, Hospital Tuanku Fauziah, Perlis from 1st June 2017 until 8th September 2017.

### ***Exclusion criteria***

Patients who were hospitalised and/or too-ill to participate (i.e. unable to establish a direct, two-way communication) and whom they themselves and/or the parents refused to participate.

### ***Consent***

All eligible participants were identified prior to their routine HIV clinic visit in Department of Paediatrics, Hospital Tuanku Fauziah, Perlis. Both the parents and potential participants were approached prior to their medical consultation on their routine appointment day and details pertaining to the study were informed.

Confidentiality of the identity during the study was assured. While waiting for the consultation, the parents and potential participants were allowed to review the Patient Information Sheet (PIS) in detail and were encouraged to clarify any questions with any of the investigators present on site. Both the parents and study participants were informed that they could withdraw from the study at any time and were also assured of anonymity and confidentiality. Decision regarding to participate in the study was given after their regular medical consultation.

Consent was taken prior to the conduct of the study. Written consent was retrieved from the parents and written assent was

retrieved from the patients if they are 13-17 years of age.

Only written consent from the parents and verbal consent from the patients were retrieved if the patients were less than 13 years of age. A copy of the PIS was given to the parents for keeping at the end of the interview session.

### ***Data Collection***

A standardised interview guide was constructed by the team of investigators for the purpose of the study. Information from other literatures, researchers' clinical knowledge and research experience was used to outline the interview guide. This guide was to ensure that all interviews were conducted in a similar manner and an identical set of questions were discussed during each interview session.

The interviews were conducted in Malay language to help the participants narrate their views as 5 participants were of Malay descent and another one participant was a Siamese with a good command of Malay language. Each interview lasted approximately 15-20 minutes. All interviews were audio-recorded with written consents from the parents. Interviews were deemed complete when consensus from all researchers was reached upon establishment of data categories. A saturation point was reached and no new information emerged after the 6th interview.

### ***Data Analysis***

Transcribed interviews were subjected to thematic content analysis. The transcripts were analyzed for relevant content to identify emerging categories. Transcription of the interviews was prepared in Microsoft Word format and translated into English by

the researchers. Each transcript was repeatedly compared across and within the participants to identify common themes. This was then followed by discussion among the team of investigators until consensus on the common emerging themes was reached.

### ***Ethics Approval***

This study received ethical approval from the Medical Research and Ethics Committee, Ministry of Health, Malaysia on 11th May 2017 with registration no.: NMRR-17-682-35411.

### ***Results***

Six out of eight HIV-infected children on ART participated in the study. The participants' mean age ( $n = 6$ ) was 12.2 years, (standard deviation [SD] 2.11). The mean age of disease-disclosed participants ( $n = 3$ ) was 13.3 years old (standard deviation [SD], 1.25) while the mean age of non-disease disclosed participants ( $n = 3$ ) was 11.0 years old (standard deviation [SD], 2.16). Among the disease-disclosed participants ( $n = 3$ ), the mean age for disease disclosure was 12.7 years old (standard deviation [SD], 1.70). Four of them were diagnosed during toddler years and presumed to contract the disease via vertical transmission. Disease-disclosed participants were informed of their disease status for at least 6 months prior to the conduct of the study. Four out of the six participants lived with the nuclear family; 3 of them lived with the biological parents while another lived with biological siblings. Another 2 participants with deceased parents due to AIDS-related complication lived with the extended family; 1 lived with the grandparents, while another lived with maternal aunt's family. The average household income among all study participants was MYR 900/month.

The age range for 3 disease-disclosed participants was between 12 – 15 years old. Their duration of disease disclosure ranged between 6 months to 2 years prior to the conduct of the study. Disease-disclosed participants demonstrated poor knowledge on the disease regardless of biological age and duration of disclosure. A 13-year-old who had been disclosed with her disease status 1 year ago said, “I don’t know what disease I am having or how I got it. I am not sure whether it can spread to others.” Similar response was received from a 15-year-old who had been disclosed regarding his disease status 2 years ago. All 3 participants who were disclosed with their disease status were not aware of how long they would need to continue on taking cART. A 12-year-old participant replied, “I need to continue the medication maybe for another year till I am in Form 1 (secondary school).” When asked regarding the reason they needed the medications, a 15-year-old replied, “because I am ill, so I need to take the medication. I will get a fever if I don’t take my medications regularly”.

The age range for the non-disease disclosed participants was between 9 to 14 years old. Apparently, the caregivers had diverted the children’s actual illness into commonly known diseases. A 10-year-old when being asked regarding her illness and why she needed the medicine said, “Mom said I have leukaemia. So, I need to take the medication till I am older.” A 9-year-old replied, “I have skin disease. People cannot be in touch with my blood or else they will get the disease as well!”. All of the participants agreed that complying with medical follow-up and adherence to therapy would help them get better. A 10-year-old said, “I must come to every scheduled follow-up to get better. To listen to doctor’s advice.”

Findings of the study demonstrated that status of disease disclosure did not affect their knowledge on the medications. Both groups of patients were not able to recall the specific names of the medications they were taking but complied with their strict treatment regimen and were well aware of the physical property of the medications.

Disease-disclosed participants exhibited excellent compliance to the treatment. A 13-year-old claimed it was easier to comply with her medication after she was told about her disease. A 13-year-old participant said, “I have never forgotten my medications. Even if I do, I would usually have taken them within an hour or so”.

Their non-disclosed counterparts exhibited an average-to-good compliance to therapy. A 9-year-old participant reported, “Sometimes I did forget my medications when I go to play soccer. But I rarely forget them.”

The source of motivation among the 2 groups of study participants differed significantly in terms of their goal of treatment. The disease-disclosed participants attributed their motivation to adherence to regular follow-up and strict regimen to the long term benefit of ‘cure’ from the disease. A 13-year-old participant said, “I am taking the medications to help me get better.”

The source of motivation among their non-disclosed counterparts lied in the short term benefit of seeking treatment. A 10-year-old participant stated, “I love coming to the clinic for the follow-ups, I like the air-conditioned, chilly rooms here.” Another reported, “I take medications because my mom tells me to.”

Degree of physical and social activities differed markedly among the 2 groups of the study participants. The disease-disclosed participants were typically home-bound and did not have routine social activities with their peers. "I rarely join my friends for a bicycle ride. Maybe once a week or so," a 15-year-old disease-disclosed participant reported. They were also shy to share the details of their disease with their friends, regardless of gender dynamics or social norm. Most of them do not have a close friend at school. Their academic performances were typically poor and were ranked at the bottom of their classes in recent public examinations.

The non-disclosed participants were noticeably active in social activities in comparison to their disease disclosed counterparts. A 9-year-old participant said, "I play soccer every day. I am the goalkeeper!". They performed fairly well in school as compared to their disease-disclosed friends. A 10-year-old participant boasted, "I got the 8th placement in my class twice in the examinations last year!".

Summary of the comparative evaluation between the disease-disclosed participants and non-disclosed participants is presented in Table 1.

**Table 1. Comparative evaluation of face-to-face interview in paediatrics HIV patients**

		<b>Perceived impact</b>	<b>Illustrative quotes</b>
<b>Knowledge on disease</b>	DD	Poor basic knowledge on disease despite being disclosed on disease by a qualified paediatrics medical officer	"I have bacteria in my body" "I don't know how I got the disease" "I do not know how the disease spread"
	NDD	The caregiver disclosed a different disease The caregiver disclosed the details of the disease but not the name	"Mommy said I have leukaemia. I need to take the medicine till I am older" "I have skin disease. People cannot be in touch with my blood or else they will get the disease as well!"
	DD	Good drug compliance	"I never forget my medicine. Even if I do, by the first hour I would have taken them" "I never forget to take my medicine. Even if I do, usually by half an hour I will have them taken" "It is easier for me to follow doctor's instruction to take up medicine when I know more about my illness"
	NDD	Average to good compliance	"Sometimes I do forget when I went to see soccer games" "I would always bring my medication together whenever I go back to Siam"
<b>Motivation for therapy adherence and follow-up</b>	DD	Family members	"I want to get better" "My sister always encourages me, advises me" "Because I love everyone around me"
	NDD	Family members Clinic environment	"Because mommy tells me to" "I love coming to the clinic, it's chilly"
	DD	Few close friends	"I am shy to tell my friends about my disease" "I do ride bicycles with my friends sometimes. Maybe once a week"
<b>Social activities</b>	NDD	Regularly involved with social activities	"I play soccer every day!" "Every weekend I would go to attend mini concert in Siam"

DD: Disease disclosed; NDD: non-disease disclosed

## **Discussion**

### ***Socio-demography***

The study participants involved young children and youths under paediatric HIV clinic follow-up in Hospital Tuanku Fauziah, Perlis. This typically corresponds to the nature of paediatrics care which caters from neonatal period till the grown age of 18-years-old.

Clinical observation in the field revealed that earlier disclosure is deemed necessary whenever the patient demonstrates poor compliance to therapy and disobedience to adhere to routine follow-up. Disclosing the disease status at appropriate age also addresses the children's developmental needs to understand as to why they are taking medication [2].

### ***Knowledge on disease***

Disease-disclosed participants with shockingly poor knowledge on their disease emerged as the key theme in the study. This strongly signifies a weakness in the healthcare system whereby the patients failed to integrate and assimilate information delivered to them during the disclosure session, particularly on the basic facts. Failure of the system to recognise this issue eventually defeats the purpose of disclosing the disease status in the first place.

Disease disclosure session was habitually done in the presence of supportive network. Certain centres practise group sessions for their patients where basic HIV information and adherence education were given gradually on multiple separate occasions. This is to ensure effective communication for disclosure-related messages to children is attained over time [9].

Disclosure of a different illness by the caregivers among the non-disclosed participants signalled the caregivers' concern about the potential negative impact of HIV status disclosure on the children or its effect on the family's social relationships. This includes disclosure repercussion such as violence, separations and withdrawal of support [2, 10-13].

### ***Knowledge of drug***

Participants from both the disease-disclosed and non-disclosed groups demonstrated good knowledge on their medication. They were able to recall the physical properties of each medication when only the packaging boxes were displayed to them. Dosing characteristics of the prescribed regimen also play a crucial role in promoting adherence [14]. The participants were also able to recall the correct dosage and frequency of each medication prescribed to them. This supported the crucial role of family support in managing children with chronic illnesses on strict drug regimen [15].

### ***Drug compliance***

Assessing adherence in paediatric population is challenging and currently there is no gold standard in terms of the assessment method [16]. Compliance to drug regimen was exceptionally high in both groups, regardless of their disease disclosure status. Our finding was supported by another study by Sirikum, et al. (2014) which found that disease disclosure status had no bearing on therapy adherence [17]. All of our participants acknowledged the primary role of family to reinforce therapy compliance. Our findings however, contrasted a review article by Steele and Grauer in 2003 studying 13 empirical papers on children's adherence to ART conducted between the years 1981 to 2002 which claimed that

therapy adherence in paediatrics was generally poor compared to adult patients [14]. The review paper however did not systematise the age of participants, the type of therapy regimen and the method of assessing treatment adherence.

### ***Motivation for therapy adherence and follow-up***

The source of motivation for the 2 groups was significantly distinct. The disease-disclosed participants related their adherence to therapy and follow-ups to the future cure of their illness while their non-disclosed counterparts assume short-term gain such as to please the parents or enjoying the clinic ambient, as their motivation to comply with follow-ups and treatment. Hence, children should be encouraged to incorporate behavioural modification strategies, such as the use of self-assigned medication calendars to boost a sense of responsibility and eventually therapy adherence.

### ***Social activities and lifestyle***

The lifestyle of disease-disclosed participants was not as lively compared to their non-disclosed counterparts. Being aware of their disease status possibly creates a barrier for them to experience life as carefree as the other children. A cross-sectional study conducted among adult HIV patients showed that their physical functioning and overall emotional well-being were worse than patients with other chronic illnesses [18]. Furthermore, Asians generally do not communicate emotional difficulties openly due to anticipation of stigma. This is especially true for low- and middle-income nations [19-21]. All of the disease-disclosed participants contracted the disease via vertical transmission and they were well informed regarding that however, none did show any forms of resentment

towards their parents. Thus, the possible interventional role of a clinical counsellor to address the unique developmental issues of adolescents may be planned in the future [3].

Disease-disclosed participants were less involved with social activities and did not even do well in school hence, a proper strategy to address optimal and holistic care for the children is necessary. Family-oriented service establishment at all ART facilities with at least 1 day/week session has been recommended to promote positive coping resources among paediatric HIV patients [22].

In the near future, steps must be made to ensure continual therapy adherence and better disease understanding among HIV-infected children. In addition, disclosure is best done in staggered steps, underlining the need for gender-specific disclosure-support approaches [13].

### **Limitation**

Our centre, by far, only caters for 8 HIV children on combination ART treatment. This is a relatively small population hence the diversity of information retrieved may not capture all possible feedbacks.

### **Conclusion**

Disease-disclosed participants with surprisingly poor knowledge on disease emerged as the key theme in the study. Effort must be made to re-assess patients' understanding after disease-disclosure session to encourage good therapy adherence and prevention of transmission. Improper management of poor coping behaviour and meagre academic performance among disease-disclosed patients will continue to reflect on their future, thus steps must be taken to improvise

health policy and allocate resources to improve the health system and promote holistic intervention. A guideline for HIV disease disclosure in paediatric setting is necessary to aid clinicians during the disclosure process as well as to safeguard the parties involved from any future legal implications.

### Abbreviations

AIDS: acquired immune deficiency syndrome, HIV: human immuno-deficiency virus

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### Conflict of Interest

The authors declare that there is no conflict of interest.

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