

The Psychosocial Impact of Disease Disclosure in Children with HIV: A Comparative Study

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ABSTRACT: HIV disease disclosure in children is complicated by the dynamic developmental goals which risk potential retaliation from the affected children. Such occurrences may affect the children's overall well-being, their outlook on life, therapy adherence, and social life. Disclosure of HIV status in children is meant to promote better understanding and allow them to be responsible to their body and health.

Our study aimed to discover the long-term psychosocial impact of HIV status disclosure in children receiving anti-retroviral therapy. A qualitative study was conducted from 1st June 2017 until 8th September 2017 among HIV-positive children on combination anti-retroviral therapy (cART) on-going routine follow-up in Department of Paediatrics, Hospital Tuanku Fauziah, Kangar, Perlis, Malaysia. Face-to-face interviews were conducted between the children and the team of investigators. Transcribed interview dialogues were subsequently coded for thematic analysis.

Data were collected from 6 out of 8 HIV-positive children on ART. Participants' mean age was 12.2 years old (standard deviation [SD] 2.11); three with disease disclosure, another three without. The average duration since the first session of disease disclosure was 14.7 months (SD 7.36). We found that disease-disclosed participants were more withdrawn with less than three outdoor activities per week. Disease-disclosed children also did not demonstrate any remorse or anger towards the parents despite the awareness and understanding of having contracted the disease via vertical transmission. Disease disclosure status, however did not substantially affect the children's compliance to ART medication. We found that our patients showed evidence of good therapy adherence regardless of disclosure status. The source of motivations for therapy adherence, however were on contrasting grounds related to their disclosure status.

As a conclusion, a perpetual clinical and social supportive network is warranted in the holistic management of children living with HIV to ensure positive upbringing towards promising personal growth.

Abbreviations: AIDS: acquired immune deficiency syndrome; HIV: human immunodeficiency virus

Keywords: Acquired immunodeficiency syndrome, HIV infections, qualitative research, pediatrics, Malaysia, disclosure.

1 INTRODUCTION

Infection with the human immunodeficiency virus (HIV) increases the susceptibility to life-threatening illnesses as the infection progressively incapacitates the host's immune system. People with HIV eventually succumb to the opportunistic infection as a result of the poor immunological response towards the invading pathogens.

Clinical observation has revealed that children with HIV progress to acquired immunodeficiency

syndrome (AIDS) more rapidly as compared to adults. Most of the children infected with HIV contracted the disease via vertical transmission due to exposure to maternal blood harbouring the virus. Elimination of paediatrics HIV cases is one of many UNAIDS main goals. [1] The prevention-of-mother-to-child-transmission (PMTCT) initiatives introduce the early initiation of anti-retroviral therapy earlier in pregnancy to reduce the maternal viral load, hence the risk of transmission to the foetus. Unfortunately, some children still contract the disease.

Children living with HIV remain largely overlooked. They were seen as a taboo and were prematurely judged for the disease they contracted without their consent. The negative public perception often engulfed them in inferiority complex and poor self-esteem despite having done nothing wrong in their conduct. Adding more salt to the wound, their parents would have contracted the disease earlier on and most would succumb to the disease during their children's early development in life. The children were then left to be cared for by the extended family members or ended up in welfare institution. Some were lucky to be cared for with the love and protection any child would deserve but most of them were treated inadequately and were prematurely judged for what the disease they carry. Most of them ended up being an object of repercussion from their own relatives and more so from the public. Their life canvas was already stained to begin with. The poor relational self-esteem was reflected onto the psychological disruption and social issues among these vulnerable children.[2]

The psychosocial impact of the disease is particularly more complicated with regards to the status of disease disclosure. From the early part of the children's lives, they were made to comply with the rigorous schedule of therapy without having known why. Their illness was often kept hidden from them until a certain age partly due to the caregiver's anxiety of disclosing the disease or the feeling of guilt. Gradually, the children were made to believe that they need to adhere to the therapy due to certain illnesses that are less provocative. The real problem will surface when the child is eventually revealed of their disease status, the horrifying details of the prognosis and their responsibility in preventing future transmission. Some will resort to retaliation and repercussive actions.[1] Upon disclosure, life will be seen futile and they will have very few motivations to live by then.

Hippocratic's oath held by clinicians upholds and honour a doctor's character of always providing comfort. Hence, it is a role not to be neglected in caring for the psychological well-being of the HIV-infected children. There is a paucity of literature studying the long-term effect of disease disclosure among children living with HIV. The aim of this qualitative research is to gain an in-depth understanding of the impact of disease disclosure and experience with treatment among the HIV-infected children and the overall disease bearing on their quality of life.

2 METHODOLOGY

A qualitative study was designed via face-to-face interview, recruiting all eight HIV-positive children receiving anti-retroviral treatment (ART) in Department of Paediatrics, Hospital Tuanku Fauziah, Perlis, Malaysia. The study was conducted from 1st June 2017 until 8th September 2017.

The interview sessions were conducted by three main investigators; each patient underwent a single session lasting between 20 to 30 minutes. Each investigator probed into different domain of questions that are closely related to their individual line of work. One paediatric medical officer, one clinical pharmacist, and one clinical counsellor were the investigators present at each interview session. Another independent investigator assisted to take field notes and facilitate the interview process.



Figure 1: Audio recording device Transcend MP330 8GB
Audio recording was taken during the entire session (Fig 1). The interview session was conducted in the routine clinic environment to create a safe and comfortable ambient allowing the patients to share and express their emotions more freely.

2.1 Participants

All eight paediatric HIV patients on combination anti-retroviral therapy (cART) in Hospital Tuanku Fauziah, Perlis, Malaysia were invited to participate in the study.

Inclusion criteria

All HIV-positive children receiving ART, on-going follow-up at paediatric HIV clinic, Department of Paediatrics, Hospital Tuanku Fauziah, Perlis, Malaysia from 1 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 who they themselves and/or the parents refused to participate.

2.2 Consent

All eligible participants were identified prior to their routine HIV clinic visit. Both the parents and the potential participants were approached prior to their medical consultation on their appointment day and details pertaining to the study were informed by one of the designated investigators.

Confidentiality of the identity during the study was assured during the briefing session. The parents and the potential participants were given adequate time to review the Patient Information Sheet (PIS) in detail and they were encouraged to clarify any questions with any of the investigators present at site. Both the parents and study participants were informed that they can withdraw from the study at any time and were assured of anonymity and confidentiality. Decision regarding participation in the study was given to the investigators 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.



Figure 2: Seating arrangement during the face-to-face interview between the patient (and guardian) and the interviewers

2.3 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 were used to outline the interview guide. This guide is to ensure that all interviews were conducted in a similar

manner and an identical set of questions were discussed at each interview session.

The interviews were conducted in Malay language to ease the participants in narrating their views as 5 participants were of Malay descent and another one participant is a Siamese with a good command of Malay language. Each interview lasted approximately 20 minutes. All interviews were audio-recorded with the written consent from the parents. Interviews were deemed completed 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.

2.4 Data analysis

Transcribed interviews were further subjected to thematic content analysis. The transcripts retrieved were analysed for relevant content to identify emerging new categories. Transcription of the interviews were entered into Microsoft Word 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 a series of discussion among the team of investigators until a consensus on the common emerging themes was reached.

2.5 Ethical consideration

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.

3 RESULTS

There were eight children living with HIV on anti-retroviral therapy (ART) in Hospital Tuanku Fauziah, Perlis, Malaysia and six of them participated in the study. The participants' mean age ($n = 6$) was 12.2 years, (standard deviation [SD] 2.11). Four of them were diagnosed in their toddler years and were presumed to contract the disease via vertical transmission as evident by positive maternal testing. Three out of the six children have been disclosed regarding their disease status in the presence of the legal guardian. Their disease status has been disclosed for at least 6 months prior to the conduct of the study.

Four out of six participants live with their nuclear family; three of them live with their biological

parents while another with deceased parents lives with the biological siblings. Another two participants live with the extended family members, were orphaned due to parental AIDS-related complication; one stays with the grandparents, while another lives with the maternal aunt's family. The average monthly household income among all study participants was MYR 900 per month (USD 220). The age range for the three disease-disclosed participants was between 12 – 15 years old whereas the age range for the non-disease disclosed participants was between 9 – 14 years old. Their duration of disease disclosure among the disease-disclosed participants ranges between six months to two years prior to the conduct of the study.

Our study found that the caregivers among the non-disclosed participants chose to divert the children's actual illness into commonly known, less provocative diseases. A 10-year-old non-disclosed participant, when being asked about her illness and why she needed to take medicine said, "Mom said I have leukaemia. So, I need to take the medication till I am older." Another 9-year old non-disclosed participant replied, "I have skin disease. My skin itches all the time. People cannot be in touch with my blood or else they will get the disease as well!". All of the participants agreed that adhering to routine follow-up and therapy will help them get better. A 10-year-old said, "I must come to every follow-up to get better. To listen to doctor's advice."

The source of motivation differed significantly between different disclosure status. The disease-disclosed participants ascribed their motivation to adhere to routine follow-up and strict drug regimen to the long term benefit of 'cure' from the disease. A 13-year-old disease-disclosed participant said, "I am taking the medications to help me get better." On the contrary, the source of motivation among the non-disclosed participants besets in the short term gain. 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."

We found that status of disease disclosure does not significantly affect treatment adherence. Both disease-disclosed and non-diseased disclosed participants demonstrated excellent compliance to anti-retroviral therapy as evident by the ability to recall the right dosage, timing of intake and the physical property of each of the medication that were only displayed to them in boxes. A 13-year-old disease-disclosed participant claimed that it does become easier to her to comply with the medication

after she has been told about her disease. Another 13-year-old disease-disclosed participant said, "I have never forgotten my medications. Even if I do, I would usually have taken them within an hour or so". Adding on to that, a 9-year-old non-disease disclosed participant reported, "Sometimes I did forget my medications when I go to play soccer. But I rarely forget them."

The status of disease disclosure ominously affected the degree of physical and social activities among the participants. The disease-disclosed participants preferred to stay at home after school and often make excuses to not join their peers for playful outings. "I rarely join my friends for outing. Sometimes we ride bicycle together. Maybe once a week or so," a 15-year-old disease-disclosed participant reported. They however, were not able to give the reason to their reluctance to go out and play. Furthermore, they admitted to feel shy to share the details of their disease with their friends regardless of the gender dynamics. Most of the disease-disclosed participants do not have a close friend at school and their academic performances were typically poor. They were ranked at the bottom of their classes at recent public examinations. In comparison, the non-disclosed participants were noticeably active in social and physical activities. A 9-year-old non-disease disclosed participant reported cheerfully, "I play soccer every day. I am the goalkeeper!". They performed fairly well in school as compared to their disease-disclosed counterparts. A 10-year-old non-disease disclosed participant boasted, "I got number 8 placement in my class twice during examination last year!"

4 DISCUSSION

Socio-demography

Our study recruited a total of six paediatric HIV patients on anti-retroviral therapy; four girls and two boys. Our patients were typically disclosed on their disease status by 13 to 14 years of age. A study by Vreeman et al. (2010) concluded that disease disclosure should be done at the appropriate age to address the children's developmental needs.[3] As they are growing up, their thinking process matures and would question to understand the need for them taking the medication. Four out of six patients were presumed to contract the disease via vertical transmission. This is in agreement to an observation made in South American region which found that HIV vertical transmission is difficult to curb as it involved complex multifactorial process with multiple social variables interplayed.[4]

Drug Compliance

There is no gold standard for assessing medication adherence in paediatric patients. Additionally, there is no specific recommended method to assist clinicians to measure compliance in paediatric HIV patients.[5] We found that compliance to antiretroviral therapy was excellent among our patients regardless of their disease disclosure status. Our finding resonated with another study by Sirikum, et al. (2014) which found that disease disclosure status had no bearing on therapy adherence [6] but contrasted another study which found that treatment for children with HIV is challenging due to the poor palatability of the medication and limited paediatrics formulation.[7] A 13-year-old disease disclosed participant admitted that it does become easier to comply with medications after the disclosure session. People generally abide better to rules when they were made to understand the principle behind it which generally corresponded to the normative social influence. All the six study participants acknowledged the crucial role of the family unit to reinforce the compliance to therapy. Children do respond better to their deemed authority, particularly the parents if they were involved throughout the children's developing years.

Motivation for therapy adherence and follow-up

The source of motivation for the two groups was significantly distinct. The disease-disclosed participants relate their adherence to therapy and follow-ups to the future 'cure' of their illness. Hopefulness and positive expectations about the future are associated with increased resilience and a positive adaptation to diseases.[8] The non-disclosed counterparts on the other hand, assume short-term gain as their motivation to oblige to follow-ups and therapy, such as to please the parents or simply because they enjoy the clinic ambient. The caregivers among those with non-disease disclosed often resort to avoid from disclosing the disease status to the children, partly due to guilt or fear of retaliation. As the children grow older with maturing thinking process, often there will be more unanswerable questions directed to their caregivers. Such avoidant coping has been shown to play a negative role in parenting and further threatens the family dynamics.[9] Hence, children should be encouraged to question about their illness and the caregivers should do their best to explain the details of the disease reflecting the children's level of thinking and anticipated acceptance. Positive enforcement is

therefore, crucial to promote resilience in a child from a younger age. This can be achieved through engaging family support and encouragement of good family relationships and communication.

Social activities and lifestyle

Disease-disclosed participants led a quiet life. They had few friends and preferred to stay at home. Social issues encircling disease-stricken children may arise from disrupted parent-child relationships, fear of being judged and misinformation regarding the disease process.[10] Furthermore, Asians generally do not readily communicate emotional problems due to anticipation of stigma. Such behaviour is found to be more prominent among the low- and middle-income nations [11-13]. Potential for improvement in the externalizing behaviours was seen with the advent of three-way regular interactive session of over 18-month period between the parents or the caregivers, trained social workers or health personnel and the children living with HIV themselves.[14] The program showed a promising result of increasing children's adaptive functioning, especially in communication and daily living skills.

In view of the external pressure, the children are at high risk for mental health problems and subsequent poor developmental outcomes.[15] All of the disease-disclosed participants contracted the disease via vertical transmission and they were well informed regarding that however, none did show any form 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]. The counsellor should also be wary of early signs of mental health problems such as depression and anxiety.

Disease-disclosed participants did not do well in school. A review by Sherr et al. (2014) found that HIV-affected children were found to have significantly lower IQ scores than control children aged 3–5 years old in Thailand.[16] Hence, a proper system to address optimal and holistic care for the children is necessary.

The mental health and overall wellbeing of children affected by HIV must be viewed with a forgiven stance. It is a dynamic process involving a number of biological variables including the executive function of the family to the surrounding community and background culture.[15]

Study Limitation

Department of Paediatrics, Hospital Tuanku Fauziah, Perlis, Malaysia caters for only eight HIV-infected children who are receiving combination antiretroviral treatment. This is a relatively small population, hence may limit the possible information retrieved.

5 CONCLUSION

HIV-affected children were found to be secondary to the non-affected children in a number of cognitive assessments, behavioural and developmental parameters.[16] Therefore, integrative effort is necessary to encourage optimal therapy adherence and provision of social support to reduce the risks for emotional and behavioural problems.[15] Poor academic performance among disease-disclosed patients will continue to reflect on their future, thus proper allocation of resources is warranted to improve the health system and promote holistic intervention.[17] Outreach programs such as the Family Strengthening Intervention (FSI) may act as a positive reinforcement in supporting families caring for HIV individuals. Family-oriented service establishment at all ART facilities with at least 1 day/week session have been recommended to promote positive coping resources among paediatrics HIV patients.[18] Such programs employs a support framework for families to gather and share experiences and difficulties they are dealing in life.

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