The Concepts of Health and Illness of Children Living with HIV in Jakarta, Indonesia: Implications for Future Programs

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Abstract
Studies on children's concepts of health and illness have mostly focused on the views of healthy children. Since children living with HIV face different challenges, it is essential to gain a better understanding of their views on health and illness. A total of eleven children (5 boys,and 6 girls) participated in the study, ranging in age from 10 to 17 years old. They were in grades 5 to 11, with the exception of one child who was not attending school. The study used a guided drawing activity followed by a semi-structured interview. Thematic coding was used to analyze the interview data. Three categories emerged regarding the concepts of health and illness: biomedical, psychosocial, and healthy lifestyle representations. For children living with HIV, hospitals, hospitalization, medications, doctors, and symptoms of being sick were familiar concept for them. The children revealed the emotional fatigue from being regularly sick and hospitalized, as well as from being discriminated and having to pay medical bills as a consequence of poor health. On the other hand, the children also acknowledged the positive consequences of being healthy (e.g. playing without being discriminated, being able to celebrate birthdays). The study concluded that the ongoing health education programs for children with HIV should incorporate the positive consequences of being healthy, rather than focusing heavily on medical-related topics. A positive perspective may motivate these children to adhere to their medications and therefore improve their quality of life.

Keyword: *children living with HIV, concept of health, concept of illness, positive health behavior*

1. INTRODUCTION

Recent studies have focused on the views of healthy school-age children, rather than children with specific clinical conditions. Since children with chronic disease face different health challenges, it is therefore essential to gain a better understanding on their views on health and illness. It has been known that not only their lives are challenged with vulnerabilities and struggles against uncontrollable health factors (Israelsson-Skogsberg et al., 2018), but also their social lives are also affected, as they are unable to participate in certain activities and are dependent on others (Israelsson-Skogsberg et al., 2018). Such findings were not highlighted by studies on healthy school-age children.

To put things into the current context, it is important to highlight the specific situation in Indonesia. According to World Bank data, Indonesia has the highest number of children (aged 0-14) living with HIV in Southeast Asia, with a reported 18,000 cases in 2022 (The World Bank, 2022). Moreover, Indonesia ranks second in Asia, after India, in terms of the number of children

living with HIV (The World Bank, 2022). Apart from children's HIV status and clinical conditions (e.g., ARV resistance, length of treatment, comorbidities, etc.) and demographic factors (household size, parental history of substance abuse, caretaker's education, etc.), there are some of the HIV-specific challenges that affect children's current treatment.

Adolescents living with perinatally acquired HIV face a range of structural, familial, and psychosocial challenges that hinder

their long-term adherence to antiretroviral therapy (ART) (Mabasa et al., 2023). Structural barriers, such as food insecurity and transport difficulties, are significant factors. Many adolescents report an inability to take medication on an empty stomach, as food insecurity is pervasive in their households. Additionally, the high cost of transportation to clinics, compounded by the rural nature of the study area, limits access to healthcare services. Another critical structural challenge is the clash between clinic appointments and school activities, such as tests and exams, which often force adolescents to prioritize their education over their health (Mabasa et al., 2023). Additionally, familial factors also play a crucial role in adherence challenges. Adolescents often live in poverty-stricken households, relying on social grants that are insufficient to meet basic needs, including food. Orphanhood and disrupted family structures further exacerbate their vulnerability. Many adolescents are cared for by extended family members or grandparents who may lack the resources or capacity to provide consistent support. Crisis fostering, when takes place when relatives, community members or other guardians are obliged to take the children, instead of voluntarily opting to do so (Deininger et al., 2003), coupled with the lack of stability in their home lives frequently results in missed doses of medication and poor adherence to treatment plans (Mabasa et al., 2023; Richter & Rama, 2006). Psychosocial challenges add another layer of complexity. Adolescents are burdened by the secrecy surrounding their HIV status, driven by fear of stigma and discrimination (Nayar et al., 2014). The pressure to conceal their condition from friends, peers, and even extended family members leads to emotional distress and isolation. This secrecy often results in missed medication doses when adolescents are unable to take their treatment discreetly. The lack of mentors or accessible emotional support further compounds their struggles, leaving them to navigate the challenges of living with HIV largely on their own (Mabasa et al., 2023; Nayar et al., 2014). Limitations within the healthcare system also affect adherence. The absence of adolescent-friendly health services, such as flexible appointment schedules and welcoming clinic environments, discourages consistent engagement with healthcare providers. Additionally, some adolescents report difficulty in communicating with healthcare workers, who may not adequately address their unique needs or concerns. This disconnect can lead to reduced motivation to adhere to treatment and maintain consistent clinic visits (Mabasa et al., 2023).

Apart from these challenges, children's concept of what contributes to their illness could affect their health behavior, as some children went to the extent of blaming themselves for causing the disease, therefore felt responsible for their bad experiences (Blom, 2006). Children with HIV/AIDS may also think that they are sick because they are being punished for doing something wrong (Blom, 2006). In some other cases, those who are orphaned might also blame themselves for not being caring enough for their sick parents, and that they were evil that they cause the death

of their parents (Fabianova, 2011). As a consequence, the guilt might affect their help-seeking behavior, as some of them might fall into childhood depression or they just simply find themselves meaningless, causing them to stop nurturing themselves (Blom, 2006; Fabianova, 2011; Mburu et al., 2014). Understanding how HIV positive children perceive the concept of health and illness is therefore crucial in establishing the right material to lay foundation for positive health behavior and attitudes. Accordingly, the current research aims at describing the concept of health and illness as explained by children living with HIV, and how the knowledge from this research will enable us to come up with better future programs.

2. METHODS

2.1 Design

This study utilized a qualitative research design to explore the concepts of health and illness among children living with HIV through a combination of guided drawing activities and semi-structured interviews. Specifically, the study used the phenomenology approach as the study sought to describe the phenomenon by exploring the perspectives of those who have experienced it (Neubauer et al., 2019). The data collection process was planned to ensure that the children felt comfortable and safe throughout the procedure. Planning for data collection include preparation of information sheet, informed consent, assent form, drawing books, colored pencils, tape recorder, snacks, and interview guidelines. Data collection was done in Jakarta, Indonesia. Prior to the proper data collection, information sheet and informed consent were discussed with parents/caretakers. The parents and children were informed that the interview with the children was going to be recorded. A guided drawing activity followed by a semi-structured interview was done during proper data collection. The data in the study were analyzed by two methods. Interview data were analyzed by producing transcription of the recorded interview and coding of the emerging themes, whereas the sample drawing was analyzed by asking the following questions: "what or who is portrayed in the drawing?" and "what are the ideas and values expressed by what and how it was portrayed in the drawing?".

2.2 Participants

Inclusive criteria for the participants were being HIV positive and age 8 years old and older to be able to follow instructions. The participants of this study were recruited using the subjective purposeful sampling methods. The subjective purposeful sampling include the use of non-randomization method for participants selection (Stratton, 2024). Subjective purposeful sampling cannot fully represent the target population because it introduces unmeasurable sampling errors and biases (Stratton, 2024). Because subjective purposeful sampling lacks transferability, the findings from such research are only applicable to the specific participants in the study sample (Stratton, 2024). Children participated in this study were the beneficiaries of programs coordinated by a non-profit organization, Lentera Anak Pelangi (Lentera Anak Pelangi, 2024). Lentera Anak Pelangi provides health education classes for children and their parents/caretakers, home-visit and nutritional support, psychosocial support, ambulatory and medical support, capacity building

programs, and advocacy for the rights of children living with and affected by HIV (Lentera Anak Pelangi, 2024).

2.3 Instruments

As this study used guided drawing activity with young children, we only applied two main open questions to prompt the drawing activity. Each child was asked to first draw on one page the answer to this question: "What comes to your mind when you think of a healthy child?" Upon completion, the child was then asked to draw on another page the response to the question "What comes to your mind when you think of a sick child?" The child was informed beforehand that there is no right or wrong answer to the question, and he/she was allowed to use as much time as he/she needed. Upon submission of the drawings, the children were then interviewed with an open-ended question: "Can you tell me about the story of your drawing?" All interviews were done in Indonesian. It took approximately 45 minutes to one hour for each child to complete the activity. To maintain the credibility of this study, researchers did member checking in which we validated and confirm our interpretations back with the children. The process involved asking the children whether the findings or interpretations were accurately represented, and whether there were any additional insights that we could include in the analysis.

3. RESULTS

A total of 11 children, aged 10-17 years old who were in grade 5-11 (one child was out of school), and consisted of 6 girls and 5 boys participated in the study. The emerging themes on both the concepts of health and illness found in the study suggested a similar classifications to the study of Mouratidi, Bonoti, and Leondari (2015), in which we had three major categories formed: The biomedical, psychosocial, and healthy lifestyle representation (Mouratidi et al., 2016). Elaboration of the emerging themes are described below.

3.1 The Biomedical Concept of Health

From the biomedical perspective, health is represented by biological and medical processes, as well as the absence of diseases and symptoms.

First theme that emerged within this category was health was seen as the absence of symptoms of an illness, not having to be admitted to the hospital, or when one does not have to take medications. They shared:

> "*Healthy means one is not regularly admitted to the hospital, when one does not have to take medications*" (13 years old, grade 6, girl)

> "*Healthy is when one's body feels good...not having fever, not having many illnesses, never been admitted to the hospital*" (10 years old, grade 5, boy)

> "*Healthy means when you are not sick*" (15 years old, grade 10, boy)

Another theme that emerged within this perspective was the physical appearance of not looking sickly or unwell, instead the person should be and look energized. For example:

"*A healthy child is looking fresh, not looking like he/she is unenergized*" (15 years old, grade 10, boy)

Moreover, children did perceive having clean, tidy, and healthy home environment as one of the condition to being healthy. One child stated:

"*Healthy is when the home environment is clean, no mosquitoes, no mosquito larvae*" (11 years old, grade 5, boy)

3.2 The Psychosocial Concept of Health

Psychosocial view of health is essentially represented by the perception of being happy, cheerful, hopeful, and able to perform joyful activities.

Under this category, one child particularly mentioned about being healthy and having prolonged life and being able to enjoy activities with friends. As she described her drawing of a girl with a birthday cake, she explained:

"This is a girl celebrating her birthday. This is a birthday cake, and eggs, and birthday noodles. This girl was sickly when she was younger, she went back and forth being admitted to the hospital. I don't know what kind of sickness she had. When she grows up, she got healthier and healthier. She grows older and have a prolonged life. She could celebrate her birthday with her family and friends. When she was sick, she was just staying at home, she couldn't play. When she was healed, she could finally play with her friends…it is fun, you know" (16 years old, grade 11, girl)

Other prominent psychosocial theme was being able to do activities with friends and families. These children shared:

"*Healthy is when you can play, playing badminton, playing rounders. Healthy is also when you can enjoy playing with your friends*" (14 years old, grade 8, girl)

"*Healthy is when you can help your parents out (with chores)*" (11 years old, grade 5, boy)

In addition to being able to play with friends, one particular child mentioned the importance of playing without being distanced because of the disease he had. This child's HIV status was disclosed without his or his family's consent twice at two different schools in the past. He finally had to transfer to a new school. He shared his view:

"*Healthy is when I can play without being distanced by my friends. It happened to me twice in my previous schools. I was being distanced because of my disease, friends did not want to play with me, so I played by myself. When I was in school and others were having recess, I just sat quietly in my desk, sitting there, looking at my notes. It was so sad. Then when I told my grandmother, my grandmother told me that I have to be strong*" (12 years old, grade 5, boy).

Other theme that emerged under psychosocial view is being happy and grateful as they are healthy and able to live a longer life. A child shared:

"*He is happy, because he is still allowed by God to live his life although he is infected with a disease*" (12 years old, grade 5, boy)

3.3 The Healthy Lifestyle Representation

Healthy lifestyle representation is the range of activities that could potentially affect people's health. One major theme that emerged repeatedly on the issue of lifestyle was related to taking medications (ARV) regularly and adherently. Children stated:

"*Take medicine regularly, don't skip your medicines*" (13 years old, grade 6, girl)

"*He is healthy because he drinks his medications*" (12 years old, grade 5, boy)

Another theme that emerged under this category was the healthy diet. Healthy, according to this children, include eating a lot of food, eating fruits and vegetables, not eating junk food and street food/drinks, or food that contains coloring. In addition, children also mentioned the importance of taking care of one's body.

3.4 The Biomedical Concept of Illness

The biomedical concept of illness depicts medical and/or biological dimensions of illness.

The first biomedical theme that emerged was medical-related. The theme was surrounded on the issue of hospital, hospitalization, doctors, or medicine. They explained:

"*This girl is sick, and she went to the doctor. The doctor checked her, and this is her, taking her medications. There is syrup, pills, and also tablets. She goes in and out of the doctor's clinic, in and out of the hospital*" (16 years old, grade 11, girl)

"*Her health condition is dropping, and she is admitted to the hospital*" (16 years old, grade 10, girl)

The second biomedical theme was symptoms-related, as children explained symptoms of cold, fever, and tooth ache among others.

3.5 The Psychosocial Concept of Illness

The psychosocial concept of illness involves expressing feelings (e.g. sadness), social activities (e.g. unable to play) or any kind of abstract thoughts.

First theme under this category is illness as expressed by sadness. One particular girl expressed her fatigue of being sick. She said:

"*This child said "I don't want to be sick. It is tiring to be sick". She is tired, tired of being sick, of going in and out of the hospital*" (10 years old, grade 5, girl)

Other psychosocial theme emerged was the inability to perform enjoyable activities. Children stated:

"*When you are sick, you just stay at home, lying in bed, having no appetite*" (11 years old, grade 5, girl)

"*I don't want to be sick anymore, I want to be healthy, so I can play, so I can go to school*" (10 years old, grade 5, girl)

Apart from being sad, an abstract thought related to being sick was also shared by two children. They were aware of the cost of healthcare and procedures to benefit from the government insurance. They shared:

"*I don't want to go to the doctor. I don't have any money*" (12 years old, grade 5, boy)
"*This one is the queue line, the counter, and this is the person lining up. When you are sick, you have to line up at the counter*" (14 years old, grade 8, girl)

3.6 The Personal Lifestyle Representation of Illness

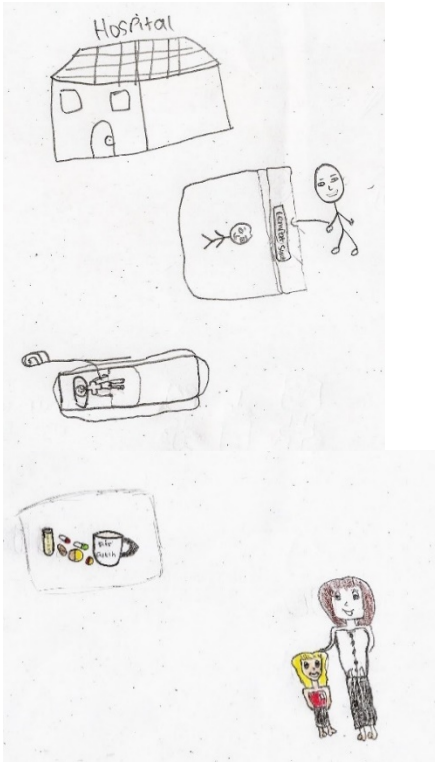
Personal lifestyle representation of illness depicts unhealthy attitudes and behaviors (e.g. nutrition, smoking, drugs, etc.). Children narrated various personal lifestyles related to the concept of illness: taking medications irregularly, dietary habit, not exercising, and having poor hygiene.

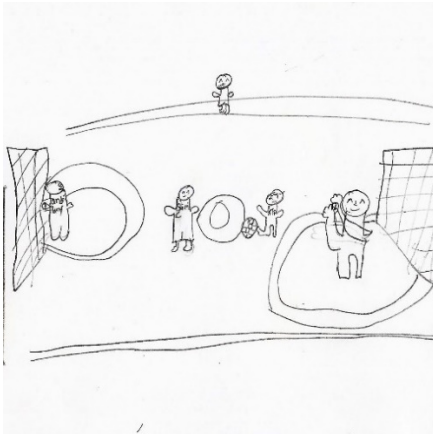
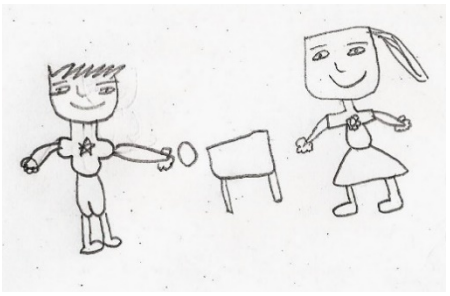
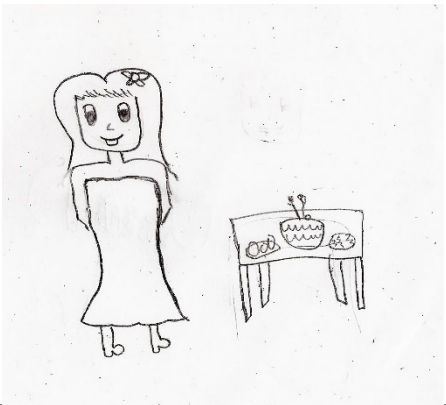
On the issue of taking medications irregularly, they explained:

"*Rarely takes the medication. It makes her drop*" (16 years old, grade 10, girl)
"*This is a sick child, she is just lying on her bed. She is sick because she does not take her medications*" (11 years old, grade 5, girl)

Some examples of the children's drawing based on the categories are as follows:

Table 1
Example of Children's Drawing on Health and Illness

Category	Perception of Health	Perception of Illness
Biomedical		

Category	Perception of Health	Perception of Illness
Psychosocial		
		
		
Personal Lifestyle		

No drawings were categorized as biomedical in the study. However, on drawings related to lifestyle, it was observed that medications were one of the elements along with the healthy food and fruits. On the other hand, there were plenty of elements of biomedical perspective of illness. The elements found include a child lying in bed, drawing of a hospital, a child with an IV attached while lying in bed, a child with runny nose, medications, and rotten teeth.

The psychosocial elements of health include group sports, smiley child or children, girl in the garden, playing with butterfly, and girl with birthday cake. On the contrary, the psychosocial elements of illness include sad and tearful child, and a child with an angry face. Lastly, personal lifestyle elements of health include taking medication, eating food, and drinking milk and water. On the other hand, none of the children drew a picture that could be classified as personal lifestyle related to illness.

4. DISCUSSION

The findings of the study added to the understanding of the concepts of health and illness. In particular, the study investigated the view of children with HIV on what health and illness mean to them.

HIV children in this study were familiar with biomedical aspect of health and illness. Many of them particularly mentioned hospital, hospitalization-related concepts, and drug-related concepts. As children with HIV suffer from uncommonly frequent sickness (Medscape, 2024), it is not surprising that hospitals, medications, doctors, and symptoms of being sick (coughing, fever, colds, etc.) are common concepts to them.

In addition to the finding of being able to play with friends, one particular child in this study mentioned the joy of playing with friends without being distanced. Interview with this child revealed that the child had experienced being discriminated against in two different schools in the past. Children with HIV are indeed prone to being discriminated and stigmatized at school (Kurpas et al., 2013). Part of their psychosocial concept therefore requires acceptance by their friends and being able to exercise their rights to participate in social activities. Furthermore, children in this study even expressed their gratitude to have lived despite the sickness and being able to celebrate the hope for the future. The psychosocial aspect of health therefore also commands acceptance of their own condition and having a hopeful outlook about their conditions.

Children with HIV in this study showed their knowledge on the importance of healthy lifestyle, including consuming healthy food and exercising. As children pick up health habits from their parents or caretakers, it is not uncommon that children's responses are also influenced by what has been taught to them (Savage et al., 2007).

Psychosocial aspect of illness involves expressing feelings (e.g. sadness), social activities (e.g. unable to play) or any kind of abstract thoughts (Mouratidi et al., 2016). As HIV affected children's psychosocial well-being (Giannattasio et al., 2011; Vranda & Mothi, 2013), children do relate being sick as being sad for not being able to play. In fact, one child discussed the emotional fatigue of being sick and being admitted to the hospital. Interestingly, the abstract thought of being ill was associated with being unable to afford physician fee and having to line up for medical

services despite of the sickness. These situations are common among children with HIV, especially in resource-limited settings like Indonesia (Callens et al., 2008).

The current health education classes to children with HIV are loaded with medical-related topics, such as taking ARV regularly, opportunistic infections, and the importance of nutrition and healthy lifestyle. Instead of highlighting the negative consequences of not adhering to the medications or poor diet and lifestyle, the current study recommends incorporating the rather positive consequences of being healthy to the modules. Positive consequences, such as being able to celebrate birthdays, being accepted among friends to play, being able to save money for the future instead of paying for medical bills, etc. will hopefully motivate children to adhere to their medications and therefore improve their quality of life. This study highlights the importance of incorporating positive health outcomes in program content. Children living with HIV are already familiar with the biomedical aspects of illness—such as hospitalizations, medications, and physical symptoms—but they also express the psychosocial benefits of health, such as being able to engage in social activities without discrimination and celebrating life milestones, like birthdays. To motivate adherence to medication and encourage healthy behavior, future programs should emphasize these positive aspects of health. By framing health education in a way that highlights the benefits of being healthy—such as enjoying playtime, participating in social circles, and avoiding the financial burden of medical expenses—children may feel more empowered to take control of their health. Additionally, programs should address the psychosocial needs of children, particularly in fostering environments that reduce stigma and discrimination.

Moreover, healthcare initiatives should work towards creating a sense of normalcy and inclusion for these children, promoting both physical health and emotional well-being. Incorporating narratives that reflect hope, acceptance, and positive self-identity can have a transformative impact on their outlook, potentially improving their quality of life. Therefore, future programs must balance medical information with an emphasis on the joy, freedom, and normalcy that a healthy lifestyle can bring, ultimately fostering a more holistic approach to health education for children living with HIV.Based on the findings from the study, several important recommendations for future programs can be drawn. First, health education for children living with HIV should shift toward emphasizing the positive outcomes of maintaining good health, rather than focusing solely on medical adherence and the consequences of illness. Children in the study associated health with joyful activities such as playing with friends, celebrating birthdays, and avoiding hospital stays. Incorporating these positive aspects into health education could encourage children to adhere to their treatments, fostering a hopeful outlook that motivates them to maintain their well-being.

Additionally, the study highlights the emotional toll that living with HIV can take on children, including feelings of isolation and sadness. To address this, future programs must include psychosocial support by teaching children coping mechanisms for dealing with stigma and stress. This can be achieved through activities such as art therapy or peer support groups, which can help build self-esteem and emotional resilience. Programs should also focus on reducing stigma in schools, as many children reported being ostracized by their peers due to their HIV status.

Community and school-based initiatives that educate staff and students about HIV can help create a more inclusive environment, allowing children to participate fully in social activities without fear of discrimination.

In an effort to provide education for parents and caregivers of children living with HIV, Yayasan Spiritia published two handbooks (Buku Saku) in 2014 and 2016 (Yayasan Spiritia, 2014, 2016). To our knowledge, these handbooks have not been updated since. For future handbooks, several key changes can be suggested. The inclusion of more positive imagery, such as children playing, attending school, or celebrating milestones like birthdays, would align with the study's emphasis on positive reinforcement. The language of the books should also be simplified to cater to younger readers, making complex medical concepts more accessible. Interactive elements, such as coloring activities or guided questions, could engage children more actively, allowing them to personalize their learning experience. Additionally, given the importance of peer relationships to these children, the books could include stories or advice on how to talk about HIV with friends, helping to build confidence in social interactions.

Lastly, the emotional aspect of living with HIV should not be overlooked. Since many children experience emotional fatigue from frequent illness, the books should include sections that encourage emotional expression, offering practical exercises for children to understand and manage their feelings. By integrating these changes, the books can become more engaging, supportive, and aligned with the real-life experiences and needs of children living with HIV, ultimately helping them to live healthier and more positive lives.

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