

Life Experiences and Well-Being Among Children Born to Mothers Living With HIV in Two Provinces of Thailand

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Abstract

This study explores the complex experiences of children living with HIV (CLHIV) who were born to mothers living with HIV (MLHIV), particularly during their transition into adolescence and beyond, aiming to enhance their well-being. By investigating life experiences and determinants of well-being, the research seeks to uncover intricate challenges and offer insights into the factors influencing their well-being. The study uses a mixed-methods approach, combining a cross-sectional survey with structured tools and case studies involving in-depth interviews for a comprehensive analysis. The study settings encompass community and provincial hospitals in two provinces within Thailand's Central region, chosen for the presence of organizations supporting people living with HIV (PLHIV). The study examines well-being using standardized instruments: the Pictorial Thai Self-Esteem Scale (PTSS) and the PedsQL™ 4.0: Pediatric Quality of Life Inventory™ (Thai version). The findings illuminate various challenges faced by CLHIV, such as educational barriers, psychosocial difficulties, and stigma and discrimination rooted in past experiences. Recommendations emphasize the importance of quality education and employment opportunities, alongside addressing psychosocial challenges, to support the well-being of CLHIV. The study's outcomes provide valuable insights for policymakers, healthcare providers, and organizations working with CLHIV, guiding future interventions and policies to uplift this vulnerable population.

Keywords

Children; HIV; life experience; stigma and discrimination; well-being

Introduction

The introduction of highly active antiretroviral therapy (HAART) has significantly transformed the HIV treatment landscape, resulting in a substantial reduction of morbidity and mortality. Consequently, the global population of children living with HIV (CLHIV) born to Mothers Living with HIV (MLHIV) is expected to rise. With extended life expectancy, numerous CLHIV are entering adolescence and young adulthood, facing ongoing challenges, such as lifelong treatment and navigating societal biases.

However, concerns have been raised regarding the potential left behind of children in the ongoing fight against HIV (Essajee & Bains, 2023; United Nations Children's Fund [UNICEF], 2020). In 2022, the global provision of antiretroviral (ARV) therapy to CLHIV reached only 57%, highlighting a significant gap in treatment coverage compared to 77% of adults receiving ARV therapy (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2023b). This discrepancy falls considerably below the established global goal of attaining a treatment coverage rate of 95% (UNAIDS, 2021, 2023a). Research findings from Africa and Thailand indicate that the rate of loss to follow-up (LTFU) and mortality is more significant in adolescents compared to adults and young children (Amour et al., 2022; Kariminia et al., 2018; Teeraananchai et al., 2020). This underscores the immediate requirement for increased focus and support within HIV treatment programs during the crucial transition from childhood to adolescence and adulthood, aiming to improve the well-being of individuals living with HIV.

Understanding how children living with HIV (CLHIV) perceive and navigate their life experiences is essential for comprehending their life trajectories and for promoting their retention in healthcare and overall well-being. This study aims to provide critical insights into addressing the complex needs of CLHIV born to mothers living with HIV (MLHIV), particularly as they transition into adolescence and beyond, with the ultimate goal of enhancing their well-being.

Methods

This research adopts a retrospective mixed methods approach (Creswell, 2014) to comprehensively explore the life experiences and well-being of CLHIV born to MLHIV. Combining a cross-sectional survey with structured tools and case studies involving in-depth interviews and home visits, the study ensures a thorough analysis through triangulation.

Study settings

The study was conducted in community and provincial hospitals in two provinces within Thailand's central region. The selection of study sites was deliberate, considering the presence of non-governmental organizations (NGOs) and/or groups supporting people living with HIV (PLHIV) and providing psychosocial care for children living with HIV (CLHIV).

Study subjects

The study employed two data collection methods – a cross-sectional survey targeting out-patient CLHIV and their caregivers and case studies involving in-depth interviews and home visits of 15 CLHIV and their families. For the cross-sectional survey, 115 CLHIV aged 5–18 years receiving ARV were interviewed by questionnaire. Inclusion criteria for CLHIV in the cross-sectional survey were perinatal transmission diagnosis, ages 5 to 18 years, and voluntary permission. Case study participants were purposefully selected based on living arrangements, gender, and age, with a focus on the opinion of the healthcare provider at the ARV clinic and the caregivers' permission.

Tools

This study employed two standardized instruments to assess the well-being of children living with HIV (CLHIV): The Pictorial Thai Self-Esteem Scale (PTSS) (Phattharayuttawat et al., 2011) and the PedsQL™ 4.0: Pediatric Quality of Life Inventory™ (Thai version) (Varni et al., 2002).

- (1) The PTSS comprises 20 items across six domains, exhibiting strong reliability (Alpha coefficients 0.82–0.89) and a significant correlation with Rosenberg's self-esteem test ($r = 0.81$). Responses to items were scored from 1 to 4, with 1 indicating 'strongly disagree,' to a maximum of 4, "Strongly agree." Scores of all items were counted and summed. This calculation is for the positive items, but the score is the converse for the negative items. The total score of self-esteem was divided into three groups and can be interpreted as the extent of self-esteem for respondents as follows: Good: 61–80, Moderate: 41–60, and Bad: 20–40 (Phattharayuttawat et al., 2011).
- (2) The PedsQL™ 4.0 is a standardized tool designed to assess health-related quality of life (HRQOL) in healthy and healthy children and adolescents with various health conditions. This study utilized the PedsQL Generic Core Scales, a concise 23-item version suitable for ages 2–18. The questionnaire evaluates four dimensions: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). Responses are scored on a reverse scale, where 0 equals 100, 1 equals 75, 2 equals 50, 3 equals 25, and 4 equals 0. Higher scores indicate better HRQOL (Varni, 2024).

Data collection

Data collection occurred from December 2012 to May 2013. Trained interviewers conducted a cross-sectional survey within the ARV clinic premises. Selection criteria for case studies were communicated to healthcare providers, and consent was obtained before collecting data. Home interviews were conducted separately for caregivers and CLHIV, with a strong emphasis on confidentiality: audio recording and activities like drawing or playing facilitated openness.

Data management and analysis

Descriptive statistics (e.g., frequency, means, standard deviation) were used for the quantitative data to analyze general characteristics such as socio-demographic, clinical, and health status. Scores for self-esteem and PedsQL were calculated according to their guidelines. Statistical analyses were performed using SPSS 21. Qualitative data from case studies underwent content analysis, categorizing key study topics and exploring patterns and processes that improve children’s well-being.

Ethical considerations

The study anticipated potential discomfort for child respondents and implemented safeguards, including the right to refuse questions during the interview or terminate the interview at any time. Informed consent was obtained from all participants, and measures were implemented to prevent psychosocial harm. Confidentiality was prioritized, ensuring participant identities were protected and pseudonyms were used in the report. Ethical approval was obtained from the Institute for Population and Social Research, Mahidol University (COA. No. 2012/1-1-03).

Results

Population characteristics

The CLHIV’s characteristics were as follows: Among 115 respondents, 73 were females (63.5%), and 42 were males (36.5%). The largest age groups were 10–12 years (34.8%) and 13–15 years (31.3%), followed by < 9 years (17.4%) and 16–18 years (16.5%) (Table 1). The average age was 12.4 years ($SD = 3.0$), slightly higher for girls ($M = 12.5$; $SD = 3.0$) than boys ($M = 12.2$; $SD = 2.8$). Of these, 84.3% were enrolled in school, 13.9% had prior enrollment but were not attending during the study, and 1.7% were not in school due to age, citing reasons such as completing primary or lower secondary education, reluctance due to falling behind, and personal choice against further education (Table 2).

Table 1: Age Group of the CLHIV by Gender

Age group	Gender of children				Total	
	Male		Female		N	%
	N	%	N	%		
≤ 9 years	7	16.7	12	16.4	19	16.5
10–12 years	14	33.3	26	35.6	40	34.8
13–15 years	17	40.5	19	26.0	36	31.3
16–18 years	4	9.5	16	22.0	20	17.4
Total	42	100.0	73	100.0	115	100.0

Table 2: Education of CLHIV by Gender

Education	Gender of children				Total	
	Male		Female		N	%
	N	%	N	%		
No education	1	2.4	1	1.4	2	1.7
Not studying now, but had studied	7	16.7	9	12.3	16	13.9
Studying now	34	81.0	63	86.3	97	84.3
Total	42	100.0	73	100.0	115	100.0

The CLHIV caregivers' characteristics were as follows: Among 115 respondents, 93 were females (80.9%), and 22 were males (19.1%). Most fell into the 31–50 age range (33.0% aged 31–40 and 25.2% aged 41–50), with 17% classified as elderly (over 60 years), 14.8% aged 51–60, and 9.6% aged 30 or younger. The average caregiver age was 46 years ($SD = 13.9$). Parents constituted 43% of caregivers, followed by uncles/aunts (28%), grandparents (23%), and others (6%). 67.8% had completed only primary education, and 41.7% worked as casual laborers, with 18.2% reporting no occupation (Table 3). The average monthly income was 5,762 baht (approximately 192 US\$).

Table 3: Characteristics of the CLHIV Caregivers

	Total	
	N	%
Gender		
Male	22	19.1
Female	93	80.9
Total	115	100
Age group		
30 or less	11	9.6
31–40	38	33.0
41–50	29	25.2
51–60	17	14.8
Over 60	20	17.4
Total	115	100.0
Education		
Primary school (grades 1–6)	78	67.8
Secondary school (grade 7–9)	15	13.0
Secondary school (grade 7–9)	8	7.0
Vocational diploma/Bachelor's degree	4	3.5
No education/incomplete primary school	10	8.7
Total	115	100.0
Relationship		
Mother	38	33.0
Father	11	9.6
Grandmother/grandfather	27	23.5
Aunt/uncle	32	27.8
Older sister/older brother	4	3.5
Adopted mother/adopted father	3	2.6
Total	115	100.0
Occupation		
Farmer	17	14.8

	Total	
	N	%
Vending/retailing	21	18.3
Clerk/Staff	2	1.7
Causal laborer	48	41.7
Government officer	2	1.7
Daily wage (irregular income)	4	3.5
No occupation	21	18.3
Total	115	100.0

Life experiences

Long-term impact of child's illness and parental loss

The study underscores the enduring impact of parental loss, particularly before widespread Antiretroviral Therapy (ART) availability. About 70.5% of CLHIV born to MLHIV experienced parental loss, and about 81% of those older than 10 years were orphans (Table 4). On average, CLHIV was about 4 years old when their mother ($M = 4.2$; $SD = 2.9$) or father ($M = 4.0$; $SD = 2.7$) passed away.

Table 4: Parent's Survival Status by Age Group of the CLHIV

Survival status of parents	Current age group of the children				Total	
	<= 10 years		> 10 years		N	%
	N	%	N	%		
Still alive	17	52	14	17	31	27
Both passed away	2	6	35	43	37	32
Father passed away	10	30	17	21	27	23
Mother passed away	3	9	14	17	17	15
Unknown status	1	3	2	2	3	3
Total	33	100	82	100	115	100

Caregivers reported that 68% of CLHIV had experienced severe illnesses requiring hospitalization. Additionally, 96% of CLHIV were on ARV drugs, with 17% having interruptions in their treatment. It was noted that CLHIV over the age of 10 were reported to have discontinued their medication more than those aged 10 or younger (Table 5).

Table 5: Percentage of CLHIV Experiencing Severe Illness, ARV Treatment, and Treatment Interruptions by Age Group

Experience of illness and ARV therapy		Age group of children				Total	
		<= 10 years		> 10 years		N	%
		N	%	N	%		
CLHIV had ever been severely ill until admitted to the hospital	No	9	27	27	34	36	32
	Yes	24	72.7	53	66	77	68
	Total	33	100	80	100	113	100
CLHIV have taken ARV currently	No	0	0	4	5	4	4
	Yes	33	100	77	95	110	96
	Total	33	100	81	100	114	100

Experience of illness and ARV therapy	Age group of children				Total		
	<= 10 years		> 10 years		N	%	
	N	%	N	%			
CLHIV has ever stopped taking ARV	No	29	91	61	80	90	83
	Yes	3	9	15	19	18	17
	Total	32	100	76	100	108	100

Qualitative data highlights the role of caregivers and healthcare providers in ensuring regular treatment for younger children. However, as CLHIV enters adolescence, they face increased emotional volatility and diverse life events. Also, caregivers and healthcare providers often assume older children can self-manage, leading to situations where adolescents are entrusted with responsibilities, including medication adherence. This shift may contribute to lapses in treatment adherence.

Chat, a 14-year-old orphan boy, lives with his grandparents. His grandmother, despite being elderly and having limited reading abilities, consistently administered his medication during his childhood. The healthcare providers' clear separation of antiretroviral drugs (ARVs) into morning and evening doses facilitated her in this task. However, as Chat grew older, his caregiver let him go for resupply by himself, and he no longer needed his grandmother to monitor his ART compliance, which led to his non-compliance with doctor's appointments and subsequent initiation on second-line drugs.

Nop, an 18-year-old orphan boy who has not completed primary school, lost his motivation after the demise of his close uncle and father due to AIDS-related illnesses, leaving his grandmother as his sole caregiver. This transition prompted him to neglect his daily ARV dose, resulting in illness and hospitalization. Fortunately, the treatment improved his health, fostering an awareness of adherence's significance. Consequently, Nop now diligently follows a second-line ARV regimen.

Fear of death and psychosocial impact

The study underscores the psychosocial complexities confronting adolescent CLHIV, especially those recovering from severe illnesses and grappling with scarring concerns such as Persistent Pustular Eruptions (PPE). Furthermore, the study illuminates fears related to abandonment and premature death, underscoring the enduring impact of such adversities on the psychological well-being of affected children.

Lek, a 16-year-old girl, was orphaned by AIDS at the age of 3 to 4. She endured severe opportunistic infections (OIs), including a prolonged bout of PCP that preceded her initiation of antiretroviral therapy (ART). Subsequently, Lek experienced an adverse reaction to ARV drugs, leading to a month-long hospitalization. These health challenges have instilled in Lek a pervasive fear of premature death, particularly heightened when she is alone at home or in a hospital setting.

Phim, a 13-year-old orphan living with her aunt and grandmother, expressed her feelings: “I fear that my grandmother would be tired of looking after me; then I will be left alone. I am afraid she would say, ‘Let her be like that.’ My fear intensifies when she talks like this.” She recounted an incident when her grandmother once remarked, “Leave her like that; dead is dead.” Negative comments escalated during moments of her misbehavior, particularly when she deviated from her ARV medication schedule. Frustrated by her grandmother’s reminders, she occasionally deliberately skipped her ART dose.

HIV-Status disclosing the unspoken

The study investigates HIV disclosure, focusing on two different age groups of CLHIV and their awareness of their HIV status. Among CLHIV aged 10 years or older, 76% were reported to know their HIV status. At the same time, only 30% of CLHIV aged 10 years or younger were reported to be aware of their HIV status (Table 6).

Table 6: Child’s Age Group When They Learned About Their HIV+ Status

Age group	Whether child knows their HIV+ status			Total	
	No, and not suspect	No but suspect	Yes		
<= 10 years	N	15	6	9	30
	%	50	20	30	100
> 10 years	N	7	12	59	78
	%	9	15	76	100

The analysis of qualitative data reveals insights into the provision of psycho-emotional support after disclosure, highlighting the persistence of negative thoughts and feelings among Children Living with HIV (CLHIV).

Phim, a 13-year-old orphan girl living with her aunt and grandmother, initially experienced significant worry upon learning about her HIV+ status from her aunt. She felt different from her peers and constrained by the need to take ARV drugs before going anywhere. Additionally, she bears scars from PPE, which further exacerbates her concern about others questioning her skin condition. Phim’s uncertainties about having a romantic relationship are further complicated by the discouragement from her aunt and grandmother due to her HIV+ status. This adds an additional layer of emotional and social challenge to her experience, as societal attitudes and misconceptions about HIV – such as the belief that individuals with HIV should not have friends or romantic relationships – contribute to her feelings of isolation and hinder the pursuit of normal aspects of life.

Pat, an 11-year-old boy studying in Grade 5, lives with his parents and younger sister. He is an ordinary boy who enjoys play and fun, but his life took a turn upon discovering his HIV+ status. Initially saddened by this revelation, Pat finds comfort at the ART clinic, where he realizes he is not alone in his experience. Although he claims to worry less about being HIV+, his voice becomes quiet and somber when talking about the topic. In Pat's family, only his mother is aware of his HIV+ status, while his father and younger sister remain unaware, as they consider his condition to be a chronic illness requiring daily medication. He occasionally misses school due to monthly hospital visits for ARV resupply, leading to concerns from his teacher about falling behind in class. Despite these challenges, He confidently

manages his ARV treatment privately with his mother, while his father and sister are kept unaware of his infection.

The persistence of stigma and discrimination

Discrimination against Children Living with HIV (CLHIV) can occur in various settings like home, community, school, and service places. Quantitative Data shows that most discrimination happens outside the home, mainly in the community or school. This includes instances where friends tease them about their HIV status (17.4%) or their parent's HIV status (16.5%). Some CLHIV also face discrimination at service places, like being refused service because of HIV (6.1%). Discrimination at home is less common, such as being kept in a separate room (0.8%) or excluded from family meals (0.9%) (Table 7).

Table 7: Experience of Stigma and Discrimination Among CLHIV Reported by Their Caregivers

Item of discrimination		N	%
1. Being excluded from family meals alone or required to use a different set of food containers and utensils from others	No	114	99.1
	Yes	1	0.9
	Total	115	100.0
2. Being confined to a separate room or specific place (but in the same house)	No	113	98.2
	Yes	2	0.8
	Total	115	100.0
3. Isolated from family outside the house (but in the same compound)	No	115	100.0
	Yes	0	0.0
	Total	115	100.0
4. Being teased by friends at school or in the community about their HIV	No	87	75.6
	Yes	20	17.4
	Do not know	8	7.0
	Total	115	100.0
5. Being teased by friends at school or the community about parent's HIV status	No	88	76.5
	Yes	19	16.5
	Do not know	8	7.0
	Total	115	100.0
6. Being discriminated against or denied service due to HIV+ status	No	105	91.3
	Yes	7	6.1
	Do not know	3	2.6
	Total	115	97.3

Stigma and Discrimination at school can have lasting effects on CLHIV, affecting them even into adulthood. When discrimination leads to CLHIV being expelled from school, it can greatly limit their future opportunities. Qualitative data reveals that discrimination at school doesn't just come from peers but also from teachers, who may avoid physical contact with CLHIV or their belongings.

Kai, a 9-year-old orphan boy, lives with his grandparents and a 4-year-old sister who is not infected with HIV. He experienced stigmatization and teasing from peers after his mother's AIDS-related death revealed his HIV status. Due to frequent absences caused by opportunistic infections, his grandfather consulted the school principal. Despite efforts, his homeroom teacher, irrationally fearing HIV, refused to check his homework, leading to his withdrawal from school until HIV symptoms resolved.

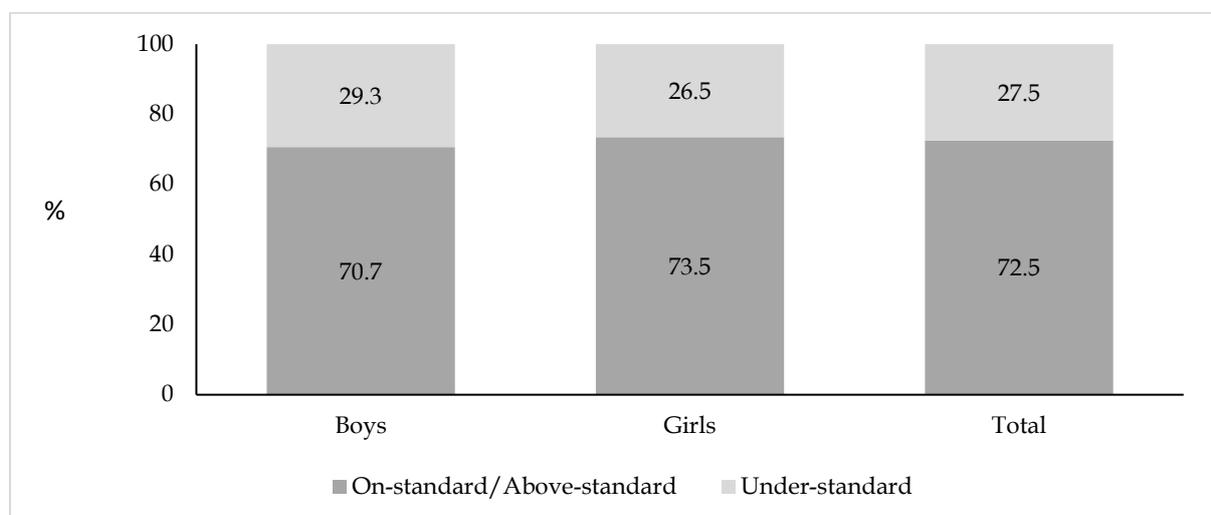
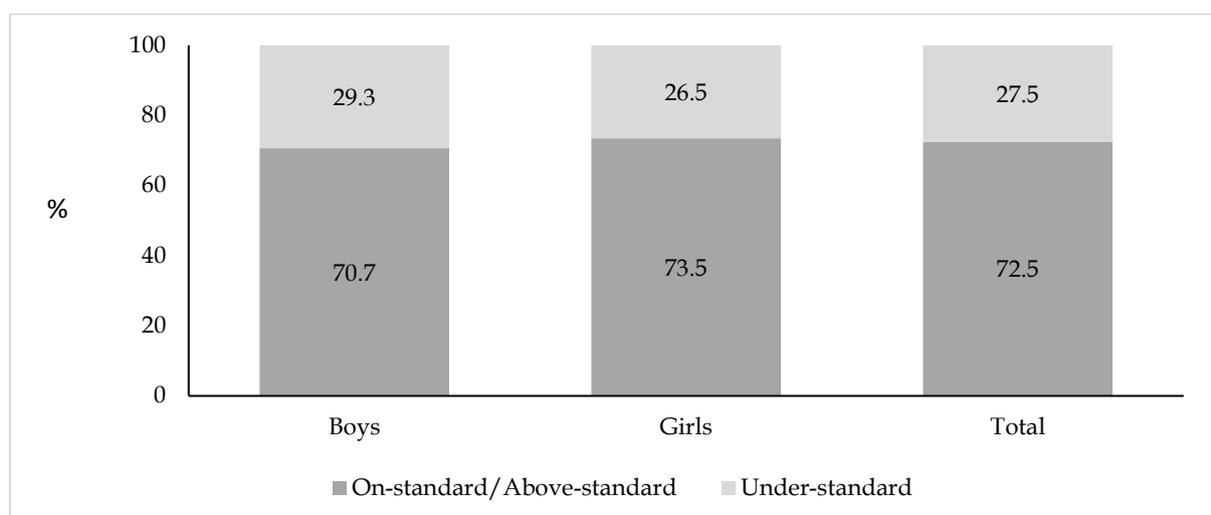
Understanding HIV among teachers can lead to greater empathy for Children Living with HIV (CLHIV). Teachers who are knowledgeable about HIV are often more understanding of the challenges faced by CLHIV, especially missing class due to frequent illnesses or the need for regular medication. Consequently, these teachers tend to offer special accommodations to CLHIV, such as being less strict in learning, homework, and exams than other students. However, this leniency can contribute to a delay in academic development among CLHIV as they progress through their education.

Noi, an 11-year-old girl entering Grade 6, lives with her father following her parents' divorce. While her father describes her as outwardly cheerful, she faces challenges with short-term memory, limited comprehension of lessons, and below-average reading and writing skills compared to her peers. Despite these academic difficulties, her teacher gives her passing grades, recognizing her as a "special student" due to her HIV+ status. The disclosure to the teacher is intended to secure understanding and support for her during periods of fatigue, hoping to avoid undue strictness or scolding that might cause her distress.

Bow, an 11-year-old girl, lives with her grandparents after her parents' divorce. She is fortunate because her grandparents, peers, and teachers accept her despite being a CLHIV. Aware of her situation, her teachers allowed her a day off each month for ART clinic visits and permitted occasional tardiness. She was proud of her routine and often woke up early to engage in various activities. She states, "On days when I am the class monitor, I go to school early. On that day, I visit the food shop in front of the school to eat rice porridge, then clean my classroom." Additionally, she wakes up early to prepare for a school sports competition, as she enjoys playing volleyball. Although her teachers are concerned about her health, they advised her to signal if she encounters any challenges, especially during volleyball, to avoid injury.

Child development in the shadow of HIV

Child development for CLHIV is complex, involving biological, psychological, and emotional changes. According to reference criteria for growth in children aged 0-18 years, the Department of Health, Ministry of Public Health, it was found that 28.6% of CLHIV were found to have below-standard height, and 27.5% had below-standard weight. Interestingly, a higher percentage of boys (34.2%) had below-average height compared to girls (25.4 %) (Figures 1-2). On average, the children's height was 141.9 centimeters ($SD = 14.2$), and their weight was 33.9 kilograms ($SD = 9.9$) (Table 8).

Figure 1: Child's Height for Age Compared to Standard Scale**Figure 2:** Child Weight for Age Compared to Standard Scale**Table 8:** Mean Height and Weight of the Children

Growth	Boys (<i>n</i> = 42)		Girls (<i>n</i> = 73)		Total (<i>n</i> = 115)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Height (cm)	142.5	16.0	141.6	13.2	141.9	14.2
Weight (kg)	32.9	9.9	34.4	9.9	33.9	9.9

Note: *M* = mean; *SD* = standard deviation

In general, adequate nutrition is crucial for the growth of all children, particularly during periods of illness. However, qualitative data indicate that many children, especially those facing challenging circumstances, such as low-income families or elderly caregivers, are not receiving sufficient nutrition. Some Children Living with HIV (CLHIV) encounter a loss of appetite due to illness, leading to inadequate nutritional intake and stunted growth.

Bow, an 11-year-old girl, lives with her grandparents after her parents' divorce. Like many children, she dislikes vegetables and prefers chicken, pork, and eggs. Her limited preference for bean sprouts and morning glory indicates that little effort has been made to encourage her to eat a wider variety of vegetables. The family's busy schedule, with her grandmother and father returning home late, often leaves her alone with her younger sister until 10 p.m., sometimes resulting in delayed dinners on those days.

Chat, a 14-year-old orphan boy, resides with his grandparents, both over 60 years old. Despite their affection, they may not be providing him with adequate care. His grandfather, who often arrives home late and inebriated, and his grandmother, who occasionally leaves him to prepare his meals, contribute to his limited diet of instant noodles or fried eggs. Recently, his appetite has diminished due to the effects of ARV drugs, possibly explaining his stunted growth compared to his peers.

Self-esteem of Children Living with HIV (CLHIV)

The Pictorial Thai Self-Esteem Scale (PTSS) was employed to assess children's self-esteem through a total score based on 20 items (Table 9). The overall self-esteem score was 60.2, which falls within the moderate range, indicating a slightly lower level of self-esteem among the children.

Table 9: Frequencies (%) for Items of PTSS

Items of PTSS		Strongly agree	Agree	Disagree	Strongly Disagree	Total
1. I am satisfied with my appearance	<i>N</i>	46	62	6	1	115
	%	40	54	5	1	100
2. My appearance is not different from others	<i>N</i>	34	70	8	3	115
	%	30	60	7	3	100
3. My appearance does not hinder my life	<i>N</i>	44	55	12	4	115
	%	38	48	10	4	100
4. I often feel that I am useless and incapable of doing anything as well as others	<i>N</i>	12	28	55	20	115
	%	10	24	48	18	100
5. I feel that I am good at some things which are not inferior to others	<i>N</i>	28	78	7	2	115
	%	24	68	6	2	100
6. I am not quite proud of myself	<i>N</i>	6	35	58	16	115
	%	15	30	51	14	100
7. I feel that I am worth at least as much as others	<i>N</i>	37	71	7	0	115
	%	32	62	6	0	100
8. Others want to be me	<i>N</i>	4	36	55	20	115
	%	4	31	48	17	100
9. I am unlucky, and I think that it will last a long time	<i>N</i>	1	26	69	19	115
	%	1	23	60	16	100
10. When a bad thing happens, I always think that it may not be bad for all things	<i>N</i>	19	58	32	6	115
	%	17	50	28	5	100
11. One day, I can do the things I want	<i>N</i>	50	64	1	0	115
	%	43	56	1	0	100
12. Other members of my family do not care for me	<i>N</i>	6	17	69	23	115
	%	5	15	60	20	100

Items of PTSS		Strongly agree	Agree	Disagree	Strongly Disagree	Total
13. If it is possible, I want to live in a separate place	<i>N</i>	27	67	14	7	115
	%	24	58	12	6	100
14. Mother and father are proud of me	<i>N</i>	38	73	3	1	115
	%	33	63	3	1	100
15. I am an important person in my family	<i>N</i>	35	70	8	2	115
	%	30	61	7	2	100
16. I feel lonely	<i>N</i>	10	15	66	24	115
	%	9	13	57	21	100
17. I have the capacity to work with others	<i>N</i>	39	69	7	0	115
	%	34	60	6	0	100
18. My friends often listen to my opinion	<i>N</i>	21	79	13	2	115
	%	18	69	11	2	100
19. I have as many friends as others my age	<i>N</i>	36	73	6	0	115
	%	31	64	5	0	100
20. Overall, I feel proud of myself	<i>N</i>	47	67	1	0	115
	%	41	58	1	0	100

The well-being of Children Living with HIV (CLHIV)

The overall PedQL score averaged 78.0 ($SD = 13.6$), with higher Physical Health scores than Psychosocial Health ($M = 82.6$, $SD = 15.5$, and $M = 75.4$, $SD = 15.0$, respectively). Within Psychosocial Health, School Functioning had the lowest average score. Particularly, items related to “Missing school to go to the doctor or hospital” ($M = 54.28$; $SD = 24.512$), “Missing school because of not feeling well” ($M = 65.54$; $SD = 25.905$), and “Forgetting things” ($M = 68.86$; $SD = 28.371$) within the School Functioning dimension showed the lowest average scores (Table 10). These findings shed light on specific challenges in the school-related aspects of psychosocial well-being among the studied population.

Table 10: Mean Score for Items of PedsQL 4.0 Among CLHIV

Item	Question	<i>N</i>	<i>M</i>	Min	Max	<i>SD</i>
Physical Functioning						
1.	Walking more than one block	115	82.6	0.0	100.0	26.1
2.	Running	113	82.7	0.0	100.0	26.1
3.	Participating in sports activity or exercise	115	88.0	0.0	100.0	23.9
4.	Lifting something heavy	115	74.4	0.0	100.0	29.1
5.	Taking a bath or shower by oneself	115	95.0	0.0	100.0	18.5
6.	Doing chores around the house	115	88.0	25.0	100.0	21.5
7.	Having pains or aches	115	73.0	0.0	100.0	27.5
8.	Low energy level	115	76.7	0.0	100.0	27.8
Emotional Functioning						
9.	Feeling afraid or scared	115	76.3	0.0	100.0	28.6
10.	Feeling sad or depressed	115	75.0	0.0	100.0	26.5
11.	Feeling angry	115	67.2	0.0	100.0	28.6
12.	Trouble sleeping	115	81.3	25.0	100.0	26.0
13.	Worrying about what will happen to oneself	115	79.8	0.0	100.0	27.7
Social Functioning						
14.	Getting along with other children	114	84.2	0.0	100.0	25.6
15.	Other children not wanting to be friends	115	83.0	0.0	100.0	27.0

Item	Question	N	M	Min	Max	SD
16.	Getting teased by other children	115	80.9	0.0	100.0	27.2
17.	Not able to do things that other children of the same age can do	115	85.2	0.0	100.0	22.9
18.	Keeping up when playing with other children	115	80.2	0.0	100.0	27.2
School Functioning						
19.	Paying attention in class	111	80.2	0.0	100.0	27.4
20.	Forgetting things	110	68.9	0.0	100.0	28.4
21.	Keeping up with schoolwork	111	72.1	0.0	100.0	28.6
22.	Missing school because of not feeling well	111	65.5	0.0	100.0	25.9
23.	Missing school to go to the doctor or hospital	111	54.3	0.0	100.0	24.5

Note: M = mean; SD = standard deviation

Additionally, through multiple regression analysis, this study examined factors influencing PedsQL scores, including attributes of children and caregivers, life experiences, and self-esteem. The results show significant associations between PedsQL scores and five variables: total score of PTSS, female gender, current ARV treatment, awareness of HIV status, and current enrollment in education (Table 11).

Table 11: Results of Multiple Regression Analysis Using Stepwise Method on Factors Influencing PedsQL Scores Among CLHIV

	B	Std. Error	Beta	t	Sig.	R ² Change
(Constant)	27.1322	13.5388		2.0040	0.0476	
Total score of PTSS	0.5782	0.1939	0.2542	2.9823	0.0036	0.093
Children are female	-8.8453	2.4050	-0.3136	-3.6779	0.0004	0.066
Children currently take ARV	11.5569	6.2879	0.1570	1.8380	0.0689	0.032
Children knew their HIV status	6.2797	2.4229	0.2246	2.5918	0.0109	0.033
Children are now studying	7.3858	3.3558	0.1940	2.2009	0.0299	0.034

Note: R = 0.509; R² change = 0.259; Adjusted R² = 0.224; Std. error = 12.087

Qualitative data highlights the crucial role of education in shaping these children's future well-being. Many children encounter difficulties continuing their education beyond primary grades, with some still struggling with basic literacy despite attending school. Stigma and discrimination during illness periods have led some to stop their education, creating a barrier to academic progress.

Enrolling in non-formal education programs is the next step for those who dropped out, but some face challenges. They may have to wait for years to be eligible, during which time they may stay home or work in agricultural labor, especially in rural areas. However, it was found that the longer they wait, the fewer opportunities they have to enroll in non-formal school due to diminishing motivation.

Su, a 13-year-old girl, has completed primary school and is residing with her visually impaired mother living with HIV. Unfortunately, she faces an educational barrier as her community has no secondary school. Previously, her mother worked as a laborer in sugar cane fields. Still, her deteriorating eyesight, attributed to AIDS, has led Su to take on the responsibility of working in the fields to sustain the

household. Despite performing tasks equivalent to adults, Su receives a lower daily wage of 140 baht than the adult rate of 170 baht.

Discussion

Based on the study findings, multiple regression results show determinants for quality of life using PedsQL scores, including the total score of PTTS (self-esteem), female gender, current ARV treatment, awareness of HIV status, and current enrollment in education. Additionally, a range of experiences impacts children's lives, including illness, parental loss, and developmental delays. Consequently, significant challenges emerge that affect the quality of life for these children.

Firstly, barriers are hindering the educational advancement of children living with HIV (CLHIV), leading to lower literacy levels compared to their HIV-negative counterparts. The loss of one or both parents due to AIDS often results in incomplete education or limited schooling, primarily up to the primary level, which subsequently affects their employment prospects. Being raised by older relatives with limited economic means further diminishes educational opportunities beyond primary school, despite the availability of educational scholarships. Addressing the academic capacity of CLHIV is crucial to ensure they can progress at least through Grade 9, taking into account delayed intellectual development (Boivin et al., 2018; van Wyhe, 2021) and prolonged school absences due to HIV-related illnesses. The study findings also highlight the impact of stigma and discrimination on their academic opportunities, leading to school dropout during periods of illness and some teachers and caregivers not providing adequate encouragement, potentially impeding their physical and educational development.

Secondly, the results outline various psychosocial problems and stigma and discrimination faced by CLHIV, such as fear of HIV-related illnesses and death, concerns about life expectancy, feelings of distinctiveness or isolation due to medication or sexual relationship restrictions, and apprehension about appearance changes caused by Opportunistic Infections (OIs), particularly scarring from persistent pustular eruptions. These psychosocial challenges are rooted in past experiences, such as the loss of parents or caregiving during severe parental illness and HIV-related stigma and discrimination. The daily regimen of taking antiretroviral (ARV) drugs can also create a sense of distinctiveness, leading to concerns about others suspecting or knowing about their HIV+ status.

Moreover, the issue of psychological and mental health is paramount (Ayano et al., 2021), as evidenced by existing studies linking mental health to HIV outcomes (Laurenzi et al., 2020; Olashore et al., 2023). Poor mental health directly affects the well-being of adolescents and young adults living with HIV, impacting their ability and motivation to seek healthcare and adhere to treatment regimens. The slower decline in HIV-associated mortality among adolescents compared to other populations underscores the urgent need for adequate support, care, monitoring, and adherence strategies tailored to this vulnerable population (Mugglin et al., 2019; Vreeman et al., 2015; World Health Organization [WHO], 2023). The insecurity and stigma faced by HIV-infected adolescents directly impact their fundamental need for love and belonging, which profoundly affects their lifestyle and worldview. Although access to ARVs has significantly improved, the issues of stigma, lifestyle, and perception of the world by these adolescents remain underexplored. These areas required

targeted interventions to address the health and well-being of CLHIV adequately (Lee et al., 2023).

Strengths and limitations

This study's strength lies in its mixed-methods approach, employing both quantitative and qualitative data to comprehensively reflect the experiences and quality of life of children living with HIV (CLHIV). By integrating structured surveys and in-depth interviews, the research captures a holistic view of the challenges and needs of CLHIV, providing nuanced insights that purely quantitative or qualitative studies might miss.

This study has two fundamental limitations. First, the lack of data from uninfected children prevents direct comparisons in quality of life, limiting the ability to fully contextualize the unique challenges faced by CLHIV. Second, the research was conducted in only two provinces in central Thailand, which may restrict the generalizability of the findings to other regions. While the data offers a detailed understanding of CLHIV's experiences and quality of life in these areas, the results may not reflect conditions in regions with different socio-economic, cultural, or healthcare contexts.

Conclusion

The findings of this study highlight the profound impact of past HIV-related life experiences on child development and the future of CLHIV. Recommendations for supporting the well-being of CLHIV born to MLHIV center on critical challenges, such as the imperative for quality education and employment opportunities. Policymakers and local administrative organizations are urged to devise ongoing education and meaningful employment strategies, fostering self-sufficiency and well-being among CLHIV. The importance of addressing psychosocial challenges, especially the fear of illness and death, is underscored, emphasizing the need for healthcare providers to reassess and strengthen self-esteem through practical psychosocial activities. The results of multiple regression provide determinants for quality of life using PedsQL scores, including a total score of PTTS (self-esteem), female gender, current ARV treatment, awareness of HIV status, and current enrollment in education.

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