

Shared medical appointments and quality of life for children with HIV-AIDS

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Abstract

Background The human immunodeficiency virus (HIV) infects immune cells and weakens the immune system. There are 36.9 million HIV sufferers worldwide, with 1.8 million of them being children. Children with HIV and their parents may benefit from focus group discussions, also known as shared medical appointments (SMAs). SMAs represent an educational method capable of enhancing the quality of healthcare services. However, this method remains relatively under-researched in HIV/AIDS patients.

Objective To assess the impact of SMA on the quality of life of children with HIV-AIDS.

Methods This quasi-experimental study with a cross-sectional approach was carried out for 2 months. Subjects participated in SMAs, accompanied by a pediatrician as facilitator. Subjects filled three *Pediatric Quality of Life (PedsQL)* questionnaires (*Inventory 4.0*, *General Well-Being Scale 3.0*, and *Healthcare Satisfaction 3.0*), before and after attending SMAs. We compared the results.

Results There were 12 respondents, with the majority aged 5-10 years (50%), and a higher proportion of male than female (33.3%). The majority of boys had stage 3 HIV, while most girls had stage 2 HIV. According to the PedsQL Inventory module, the average quality of life for the physical aspect was the highest (83), while the lowest was observed in the school aspect (45). In the General Well-being module, the average emotional health scores were 84 before and 93 after SMAs, which were higher than the overall health scores (68 and 77 before and after SMAs, respectively). In the Healthcare Satisfaction module, the lowest average scores were in family satisfaction (52 before and 64 after SMAs), whereas the highest were in satisfaction with healthcare provider treatment (87 and 81 before and after SMAs, respectively). There was a significant increase before and after the SMAs in emotional health ($P=0.009$).

Conclusion An improvement in emotional health was observed based on the General Well-being module of the PedsQL before and after SMAs intervention. Thus, SMAs may potentially improve the quality of life for children with HIV-AIDS. [Paediatr Indones. 2024;64:60-5; DOI: 10.14238/pi64.1.2024.60-5].

Keywords: HIV; PedsQL; quality of life; children

The human immunodeficiency virus (HIV) infects cells of the immune system, damaging or destroying them and impeding their function, by attacking the CD4 molecules on immune cells which serve as receptors for HIV. Infection results in progressive deterioration of the immune system, leading to immune deficiency. The immune system is considered deficient when it can no longer fulfill its role in fighting infection and disease.¹ Infection may progress to acquired immune deficiency syndrome (AIDS), the final stage of HIV infection, marked by the emergence of various diseases that can usually be overcome by healthy immune systems.² The HIV transmission can occur through direct contact between the inner skin layers, mucous membranes, or the bloodstream with body fluids containing HIV, such as blood, semen, vaginal fluid, pre-seminal fluid, and breast milk. Blood transfusions, contaminated needles, materno-fetal contact during pregnancy, childbirth, or breastfeeding, as well as other forms of contact with body fluids can also facilitate HIV transmission.³

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Submitted January 24, 2021. Accepted February 27, 2024.

In 2017, the WHO reported that there were 36.9 million people living with HIV globally, of whom 25.7 million were in the African continent. In Southeast Asia, the WHO reported 3.5 million HIV cases. Pediatric HIV accounted for 180,000 new cases in 2017 and 110,000 deaths. The total number of AIDS cases from 1987 to December 2017 was 102,667, with the highest cumulative percentage of AIDS in the 20-29 year age group (32.5%).⁴ In Indonesia, the highest number of AIDS cases were found in Papua (19,729), East Java (18,243), Jakarta Capital Region (9,215), Central Java (8,170), Bali (7,441), and West Java (6,502).⁵ From 2013 to 2016 there were 1,547 people with HIV-AIDS in Lampung province, with 1,171 HIV-infected cases and 376 AIDS cases.⁶ During the same period, the prevalence of pediatric HIV-AIDS (>4 to 18 years) in Lampung was approximately 7-9% of all HIV cases.⁷

HIV-AIDS in children poses significant challenges, including physical, social, and emotional issues, ultimately affecting their overall well-being. Factors influencing the quality of life for children with HIV/AIDS include combination antiretroviral (ARV) therapy, enhanced healthcare services, social support (spiritual and welfare), and the severity of infection. However, adherence to ARV treatment in Indonesia remains notably low, ranging from 40% to 70%, falling well below the national target of 95% adherence.⁸ Various factors contribute to non-adherence, such as complex drug regimens, side effects, medication scheduling issues, competing priorities, fear of disclosure, lack of understanding the treatment, psychological distress, and distrust of medication. Hence, parental education is needed to improve their children's adherence to the treatment.⁹

Shared medical appointments (SMAs) are focus group discussions that represent an educational method capable of enhancing the quality of healthcare services. However, this method remains relatively under-researched in HIV/AIDS patients. In this study, we aimed to assess the impact of SMAs on the quality of life of children with HIV-AIDS.

Methods

This cross-sectional quasi-experimental study was conducted at the *Voluntary Counseling and Testing*

(VCT) Pediatric Clinic, Dr. H. Abdul Moeloek Hospital, Bandar Lampung, in August 2019. We included all children aged 0-17 years diagnosed with HIV-AIDS who were receiving ARV treatment at the study, whose parents provided written informed consent. Exclusion criteria were children who did not regularly come for treatment, dropped out of treatment, moved to another treatment center, or died during the study period.

Subjects' general characteristics and history of disease were recorded. The patients underwent physical examinations and their parents were asked to complete the three *PedsQL* questionnaires (*Inventory 4.0*, *General Well-Being Scale 3.0*, and *Healthcare Satisfaction 3.0*). Subjects then participated in SMAs. The theme of the SMA was predetermined by the researcher, focusing on introduction to HIV/AIDS in the first meeting, followed by discussions on the impact of HIV/AIDS on the child and the importance of medication adherence in the second session. Subjects were divided into three groups consisting of 4 subjects each. Subjects may be accompanied by parent or caregiver. Two meetings were held monthly, each lasting 90 minutes. During each session, a pediatrician acted as the facilitator. Facilitators posed brief questions as per intervention guidelines to stimulate discussions, while subjects engaged in dialogue by answering and asking questions, sharing experiences, and offering advice to one another. After two meetings, a reassessment of medical history and physical examination was conducted, and *PedsQL* questionnaires were again completed by parents.

After completing the post-intervention questionnaire, univariate analysis was conducted by calculating mean and median *PedsQL* scores. followed by an examination of the difference in quality of life before and after the intervention using the Wilcoxon test.

Results

Our subjects ranged in age from 2 years (two subjects) to 14 years (one subject). The majority of subjects were aged 5-10 years. Of 8 boys and 4 girls, all the boys had stage 3 HIV, while most girls had stage 2 HIV. **Table 1** describes the age and sex distribution of subjects.

The PedsQL Inventory 4.0 module consists of four parameters, namely, physical, emotional, social, and school functions. **Table 2** describes the mean and median scores of these four parameters in our subjects before and after the SMAs. According to this module, the average quality of life for the physical aspect was the highest (83), while the lowest was observed in the school aspect (45).

The PedsQL General Well-Being module includes two parameters, emotional health and overall health, as shown in **Table 3**. From the table, an improvement in emotional health and overall well-being was observed before and after SMA. The highest average scores were found in emotional health (84 and 93 before and after the SMAs, respectively).

The PedsQL Healthcare Satisfaction results are described in **Table 4**. The highest satisfaction score was observed regarding the treatment provided by healthcare personnel (technical skill point) with 87 prior to and 81 after the SMAs, while the lowest satisfaction score was related to family satisfaction (52 and 64 before and after the SMAs).

Wilcoxon test revealed a significant improvement in only a single parameter, emotional health ($P=0.009$)

from the PedsQL General Well-Being Scale (**Table 3**). None of the other parameters of any of the three scales showed a significant improvement.

Discussion

The WHO reported in 2017 that there were 36.9 million people living with HIV worldwide, including 1.8 million children under the age of 15. More than 90% of these children were infected through mother-to-child transmission (MTCT).¹⁰ According to the Mother-to-Child HIV Transmission Prevention Program, the proportion of HIV-positive pregnant women was 1.35%, and is expected to increase if not handled carefully.¹¹

Clinical stage in HIV patients can be used as a prognostic factor for quality of life and success of therapy. The clinical stage of HIV is based on the presence of opportunistic infectious diseases. However, quality of life in children with HIV might be improved by educating parents on the development, growth, and condition of the child.¹² Educational methods developed in several countries for patients with chronic diseases include the SMA method. SMAs involve periodic group visits of patients who share similar disease characteristics, fostering interaction, storytelling, listening, and learning from each other's cases. The SMAs method is devised to improve healthcare access, leverage peer support among chronic disease patients, reduce healthcare costs, and enhance satisfaction in chronic disease management among adult patients in various settings.¹³⁻¹⁴ However, this method has been less explored in children and adolescents. One instance is the study conducted by Mejino et al. in the Netherlands, focusing on children and adolescents with type-1 diabetes. Nonetheless, to date, there has not been any research conducted in

Table 1. Subject characteristics

Characteristics	(N=12)
Age by group	
< 5 years	3
5-10 years	6
>10 years	3
Gender	
Male	8
Female	4
HIV staging	
Stage 1	0
Stage 2	5
Stage 3	7
Stage 4	0

Table 2. PedsQL Inventory mean and median physical, emotional, social, and school function scores before and after SMAs

Function	Before SMAs		After SMAs		P value
	Mean (SD)	Median (range)	Mean (SD)	Median (range)	
Physical	83.85 (9.02)	87.5 (65.6-93.8)	83.85 (11.85)	85.94 (56.3-95)	0.755*
Emotional	75.00 (27.14)	85 (0-100)	79.16 (16.61)	81.25 (43.8-100)	0.575*
Social	79.58 (21.48)	77.5 (25-100)	72.77 (16.46)	77.5 (41.6-90)	0.305*
School	45.98 (38.86)	60.85 (0-100)	45.70 (36.30)	58.35 (0-91.7)	0.833*

*Wilcoxon test

Table 3. PedsQL General Well-Being before and after SMA: mean and median emotional and overall health scores

Health parameter	Before SMAs		After SMAs		P value
	Mean (SD)	Median (range)	Mean (SD)	Median (range)	
Emotional	84.68 (13.06)	87.5 (62.5-100)	93.04 (8.77)	95.8 (75-100)	0.009*
Overall	68.75 (26.38)	62.5 (25-100)	77.08 (16.71)	75 (50-100)	0.380*

*Wilcoxon test

Table 4. PedsQL Healthcare Satisfaction before and after SMA median scores

Satisfaction aspect	Before SMAs		After SMAs		P value
	Mean (SD)	Median (range)	Mean (SD)	Median (range)	
Information	72.92 (18.02)	70 (50-100)	74.58 (15.14)	77.5 (45-100)	0.734§
Inclusion of family	52.07 (20.16)	50 (12.5-93.7)	64.12 (15.88)	68.7 (37.5-81.7)	0.074*
Communication	74.58 (15.59)	75 (45-100)	76.25 (11.10)	75 (50-100)	0.788*
Technical skill	87.50 (17.20)	91.65 (50-100)	81.91 (13.23)	83.3 (58.3-100)	0.086*
Emotional needs	76.37 (25.73)	86.4 (25-100)	80.88 (18.41)	81.2 (31.3-100)	0.477*
Overall satisfaction	90.96 (13.98)	100 (58.3-100)	81.23 (15.55)	83.3 (50-100)	0.109*

*Wilcoxon test

Indonesia regarding the use of SMAs for HIV cases, neither in adults nor children.¹⁵ To this end, we held monthly discussions using the SMA technique with a predetermined theme. Prior to SMA and after two SMA sessions, we assessed participants' quality of life using three types of PedsQL questionnaires. PedsQL meets the requirements for instrument validity and reliability needed to assess quality of life. It has been demonstrated in various studies, is available in both generic and specific forms, can be filled out by children (self-report) or their parents/guardians (proxy report), is applicable across various age groups, and has been translated into multiple languages to facilitate its implementation.¹⁶ PedsQL is an acceptable and valid measure of health-related quality of life (HRQoL) in children.¹⁷

The PedsQL Inventory 4.0 questionnaire consists of four parameters, namely, physical, emotional, social, and school functions. There were no significant differences in any of the four parameters before and after SMAs. The PedsQL cut-off value for 'good quality of life' in children with chronic diseases under 8 years is 77, while for children over 8 years it is 70.¹⁸ As such, the physical, emotional, and social functions of our subjects were generally classified as good, even pre-SMA. A high score indicates that parents have provided optimal quality support to their children, success of therapy, both educational and pharmacological, and that disease stage is unlikely to

increase.¹⁹⁻²¹ However, for school function, the score of 45 is considered to be at risk of reduced quality of life. As such, our subjects were borderline at risk. Other studies have shown reliable internal consistency in the PedsQL Inventory 4.0 for children with HIV who receive treatment.

The PedsQL General Well-Being Scale 3.0 questionnaire is used to evaluate the emotions, including feeling comfortable with the disease, motivation from family or friends, and the belief that his future health is always optimal. Emotional health (motivation, health condition, feeling of comfort, feeling of pleasure) significantly increased from a mean of 84.6 before to 93 after SMAs (P=0.009). In contrast, the overall well-being score increased from 68.8 before to 77 after SMAs, but the difference was not statistically significant. The subjects' high scores indicate that their parents provide adequate support. Children with HIV often experience emotional disturbances due to the stigma attached to HIV. Emotional disturbances mostly occur in children with HIV over the age of 15 years, due to the importance of friendships in that age group, so education should be intensified and adjustments made.²²

The PedsQL Healthcare Satisfaction 3.0 questionnaire shows parental satisfaction with therapy. In addition, this questionnaire also assesses emotional needs and communication, especially for children with chronic conditions. This questionnaire

was found to be a reliable and valid instrument to assess parental satisfaction of their child's health care, especially for those with chronic diseases.^{23,24} We found no significant differences in any of the six parameters before and after SMAs. Overall, parents were satisfied with the therapy and care their children received, as indicated by mean scores >70, with regards to knowledge transfer, empathy, education, and pharmacological therapy.

The limitations of our study were the small sample size and limited number of SMA sessions. If SMAs is conducted for a longer duration (>6 months - 1 year), the results may indicate an improvement in the quality of life of children with HIV.

We conclude that two SMAs in one month increases the emotional health of children with HIV. Studies with a larger number of participants, with an extended duration and increased number of SMA sessions are needed to observe the effect of SMAs on quality of life.

Conflict of interest

None declared.

Funding acknowledgment

The authors received no specific grants from any funding agency in the public, commercial, or not-for-profit sectors.

References

1. World Health Organization. 2017. HIV/AIDS [cited 2019 January 7]. Available from: <https://www.who.int/features/qa/71/en/>.
2. Centers for Disease Control and Prevention. CDC: HIV in the United States. Statistics Overview, Statistics Center HIV/AIDS. HIV in the United States: At A Glance; 2014 [cited 2019 January 7]; Available from: <https://www.cdc.gov/hiv/statistics/overview/index.html>.
3. Rivera D. 2019. Pediatric HIV Infection. [cited 2019 January 2]. Available from: <http://emedicine.medscape.com/article/965086-overview#a0101>.
4. World Health Organization (WHO). 2018. HIV data and statistics [cited 2019 January 7]. Available from: <https://www.who.int/teams/global-hiv-hepatitis-and-stis-programmes/hiv-strategic-information/hiv-data-and-statistics>.
5. Ditjen PP & PL Kemenkes RI. Laporan Perkembangan HIV-AIDS dan Infeksi Menular Seksual (IMS) Triwulan IV Tahun 2017. Jakarta: Kemenkes RI; 2018.
6. Dinkes Kota Bandar Lampung. Layanan Komprehensif Berkesinambungan. Dinkes Kota Bandar Lampung. Bandar Lampung: Dinkes Bandar Lampung; 2016.
7. Dinkes Provinsi Lampung. Profil Kesehatan Provinsi Lampung. Lampung: Dinkes Provinsi Lampung; 2016.
8. Latif F. Efek samping obat terhadap kepatuhan pengobatan antiretroviral orang dengan HIV/AIDS. [Thesis]. Universitas Hasanuddin: Makassar; 2014.
9. Kementerian Kesehatan Republik Indonesia. Tata laksana klinis infeksi HIV dan terapi antiretroviral pada orang dewasa. Jakarta: Depkes RI; 2011.
10. UNAIDS. 2018. Global HIV statistics. [cited 2019 January 10]. Available from: https://www.unaids.org/sites/default/files/media_asset/unaid-data-2018_en.pdf
11. Kementerian Kesehatan Republik Indonesia, WHO. 2017. HIV Epidemiology Review Indonesia 2016. [cited 2019 January 10]. Available from: https://siha.kemkes.go.id/portal/files_upload/HIV_EPIDEMIOLOGY_REVIEW_INDONESIA_2016.pdf.
12. Khumsaen N, Aoup-Por W, Thammachak P. Factors influencing quality of life among people living with HIV (PLWH) in Suphanburi Province, Thailand. J Assoc Nurses AIDS Care. 2012;23:63-72. DOI: <https://doi.org/10.1016/j.jana.2011.01.003>
13. Rijswijk C, Zantinge E, Seesing F, Raats I, van Dulmen S. Shared and individual medical appointments for children and adolescents with type 1 diabetes; differences in topics discussed?. Patient Education and Counselling. 2010;79:351-5. DOI: <https://doi.org/10.1016/j.pec.2010.04.016>
14. Egger G, Binns A, Cole MA, Ewald D, Davies L, Meldrum H, et al. Shared medical appointment: an adjunct for chronic disease management in Australia? Aust Fam Physic. 2014;43:151-4. PMID: 24600680.
15. Mejino A, Noordman J, van Dulmen A. Shared medical appointments for children and adolescents with type 1 diabetes: perspectives and experiences of patients, parents, and health care providers. Adoles Health Med Therapeut 2012;3:75-83. DOI: <https://doi.org/10.2147/AHMT.S32417>
16. Muhaimin T, Utomo B, Utoyo DB, Kurniati N, Anugrahini T, Utami F, et al. Instrumen pengukuran kualitas hidup anak terinfeksi HIV. KesMas J Kesehatan Masyarakat Nasional. 2011;6:126-32. DOI: <https://doi.org/10.21109/kesmas.v6i3.103>

17. Banerjee T, Pensi T, Banerjee D. HRQoL in HIV-infected children using PedsQLTM 4.0 and comparison with uninfected children. *Qual Life Res.* 2010; 19: 803-812. DOI: <https://doi.org/10.1007/s11136-010-9643-3>
18. Huang IC, Thompson LA, Chi YY, Knapp CA, Revicki DA, Seid M, *et al.* The linkage between pediatric quality of life and health conditions: establishing clinically meaningful cutoff scores for the PedsQL. *ISPOR.* 2009; 13: 773-81. DOI: <https://doi.org/10.1111/j.1524-4733.2008.00487.x>
19. Bomba M, Nacinovich R, Oggiano S, Cassani M, Baushi L, Bertulli C, *et al.* Poor health-related quality of life and abnormal psychosocial adjustment in Italian children with perinatal HIV infection receiving highly active antiretroviral treatment. *AIDS Care.* 2010;22;858-65. DOI: <https://doi.org/10.1080/09540120903483018>
20. Li J, Yuan L, Wu Y, Luan Y, Hao Y. The Chinese version of the pediatric quality of life inventoryTM (PedsQLTM) healthcare satisfaction generic module (version 3.0): Psychometric evaluation. *Health Qual Life Outcomes.* 2013;11;113. DOI: <https://doi.org/10.1186/1477-7525-11-113>
21. Nkwata AK, Zalwango SK, Kizza FN, Sekandi JN, Mutanga J, Zhang M, *et al.* Quality of life among perinatally HIV-affected and HIV-unaffected school-aged and adolescent Ugandan children: a multi-dimensional assessment of wellbeing in the post-HAART era. *Qual Life Res.* 2017;26;2397-2408. DOI: <https://doi.org/10.1007/s11136-017-1597-2>
22. Punpanich W, Boon-Yasidhi V, Chokephaibulkit K, Prasitsuebsai W, Chantbuddhiwet U, Leowsrisook P, *et al.* Health-related quality of life of Thai children with HIV infection: A comparison of the Thai Quality of Life in Children (ThQLC) with the Pediatric Quality of Life InventoryTM version 4.0 (PedsQLTM 4.0) Generic Core Scales. *Qual Life Res.* 2010;19;1509-16. DOI: <https://doi.org/10.1007/s11136-010-9708-3>
23. Varni J, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. *Ambul Pediatr.* 2003;3;329-41. DOI: [https://doi.org/10.1367/1539-4409\(2003\)003<0329:tpaapp>2.0.co;2](https://doi.org/10.1367/1539-4409(2003)003<0329:tpaapp>2.0.co;2)
24. Xu T, Wu Z, Yan Z, Rou K, Duan S. Measuring health-related quality of life in children living in HIV/AIDS-affected families in rural areas in Yunnan, China: preliminary reliability and validity of the Chinese version of PedsQL 4.0 generic core scales. *J Acquir Immune Defic Syndr.* 2010;53;111-5. DOI: <https://doi.org/10.1097/QAI.0b013e3181c7dfa0>