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Family Support and Quality of Life among People Living with HIV/AIDS at WPA Turen Foundation: A Cross-Sectional Study

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Abstract

Background: HIV/AIDS is a chronic condition that affects physical, psychological, social, and spiritual well-being. People living with HIV/AIDS (PLHIV) in community-based foundation settings may experience different support dynamics from clinic-based populations because peer support and foundation accompaniment can coexist with limited family support.
Objective: This study aimed to analyze the relationship between family support and quality of life among PLHIV at the WPA Turen Foundation, Malang Regency.
Methods: An analytical cross-sectional study was conducted among 30 PLHIV recruited purposively from 59 registered clients at the WPA Turen Foundation. Data were collected using family support and quality-of-life questionnaires adapted from Kusuma (2011). Spearman's rho was used for bivariate analysis because the study variables were categorized/ordinal; findings were interpreted cautiously because of the small sample, purposive recruitment, and loss of information from dichotomizing total scores.
Results: Most respondents reported insufficient family support (60.0%), while 53.3% reported good quality of life. Based on the reported n = 30 and rho = 0.355, the association was modest and imprecise (approximate 95% CI: -0.01 to 0.63; p approximately 0.054). Therefore, the finding suggests a positive trend but should not be presented as strong or definitive evidence of a statistically significant association unless the authors provide a verified raw-data output showing otherwise.
Conclusion: Higher family support tended to be associated with better quality of life among PLHIV at the WPA Turen Foundation, but the small sample and imprecise correlation require cautious interpretation. Family education and counseling may be considered as future program components, but their effectiveness should be tested in larger studies that measure stigma, disclosure status, ART adherence, mental health, and foundation support.

Keywords: Family support, HIV/AIDS, people living with HIV/AIDS, quality of life, WPA Turen Foundation

INTRODUCTION

HIV/AIDS remains one of the most devastating chronic diseases and a persistent global public health concern. The human immunodeficiency virus (HIV) selectively targets CD4+ T-helper cells, progressively impairing the immune system and ultimately leading to acquired immune deficiency syndrome (AIDS)—a constellation of life-threatening symptoms resulting from the immune system's inability to combat opportunistic infections (1).

According to UNAIDS, 40.8 million people globally were living with HIV in 2024, 1.3 million people became newly infected, 630,000 people died from AIDS-related illnesses, and 31.6 million people were accessing antiretroviral therapy. Indonesian and local registry figures cited in this manuscript are from 2022; therefore, the epidemiological context should be interpreted according to the year and source of each dataset (2-4).

HIV/AIDS can affect physical, psychological, social, and spiritual domains of life (5). Physically, immune deterioration increases vulnerability to opportunistic infections (6). Psychosocially, some PLHIV experience stigma and discrimination from family members or the community, which may reduce service engagement and quality of life. Sensitive statements about stigma were therefore framed cautiously and supported by cited literature (7).

Previous Indonesian studies have reported impaired quality of life among PLHIV, although differences in setting, instrument, and cutoff criteria may limit direct comparison with the present study (8,9). Factors associated with quality of life include age, education, marital status, employment, ART adherence, depression, stigma, and social support (10). Family support is relevant because families may provide emotional, appraisal, informational, and instrumental support to PLHIV (11).

Kusuma (2011) reported that the majority of PLHIV in Indonesia perceived family support as non-supportive (55.4%), and that individuals who received supportive family engagement tended to demonstrate a significantly better quality of life (12). These findings are corroborated by several studies establishing a significant positive correlation between family support and quality of life in PLHIV (13–15).

Despite the growing body of literature, most prior studies have been conducted in clinical settings. Studies in community-based or foundation settings remain limited. The WPA Turen Foundation is relevant because clients may receive peer support and psychosocial accompaniment outside formal clinical services. A preliminary assessment conducted in March 2024 suggested concerns related to physical limitations, family rejection of healthcare involvement, and social discrimination; the sample size and procedure of this preliminary assessment should be documented by the authors or removed if not verifiable.

This study therefore aimed to analyze the relationship between family support and quality of life among PLHIV at the WPA Turen Foundation. The findings are intended to inform community nursing practice and generate hypotheses for future family-centered and foundation-supported interventions.

METHODS

Study Design and Setting

This study employed an analytical cross-sectional design. The research was conducted at the WPA Turen Foundation (Yayasan Warga Peduli AIDS/WPA Turen), located in Turen District, Malang Regency, East Java, Indonesia, in August 2024. The foundation, established on February 25, 2017, supported 59 registered PLHIV through health monitoring and psychosocial accompaniment programs during the study period.

Population and Sample

The study population comprised all 59 PLHIV registered at the WPA Turen Foundation. A total of 30 respondents were recruited using non-probability purposive sampling. Participants were included if they were willing to participate, aged 18 years or older, able to communicate clearly, and present at the foundation during data collection. Individuals absent during data collection were not included. This recruitment process may have selected clients who were more engaged with foundation services, and this potential selection bias is acknowledged as a limitation.

Research Instruments

Data were collected using three instruments. First, a demographic questionnaire gathered age, sex, educational level, marital status, duration since HIV diagnosis, and initials for temporary field identification. Initials were separated from questionnaire responses during data processing. Second, the family support questionnaire adapted from Kusuma (2011) consisted of 18 items covering emotional, instrumental, informational, appraisal, and social network support (12). Third, the quality-of-life questionnaire adapted from Kusuma (2011) consisted of 20 items covering physical, psychological, independence, social, environmental, and spiritual/personal-belief domains (12). Because these instruments were originally validated in a clinical setting, their fit

for a foundation/community setting should be interpreted cautiously.

Validity and Reliability

Both questionnaires were previously validated and assessed for reliability by Kusuma (2011) among patients at the Outpatient HIV/AIDS Clinic of Cipto Mangunkusumo National Hospital, Jakarta (12). The original family support questionnaire reported item-total correlations of r = 0.375-0.720 and Cronbach's alpha = 0.883, while the quality-of-life questionnaire reported item-total correlations of r = 0.302-0.811 and Cronbach's alpha = 0.893. Because these reliability estimates were not calculated from the present foundation sample, Cronbach's alpha for the current data should be added by the authors if raw data are available.

Data Analysis

Univariate analysis was performed to describe respondent characteristics and study variables. Bivariate analysis using Spearman's rho was conducted to examine the relationship between family support and quality of life. The analysis was bivariate and unadjusted for age, sex, marital status, duration since diagnosis, ART adherence, stigma, disclosure status, mental health, or foundation support. All analyses should report the actual IBM SPSS Statistics version used, not the Windows operating system.

Ethical Considerations

Ethical chronology requires author verification before resubmission: the manuscript reports data collection in August 2024, but the listed approval number is 2854/KEPK/UNIV-NHM/EC/IX/2025, which appears to indicate September 2025. The authors must confirm the correct approval date/number and ensure that ethical approval was obtained before data collection. Written informed consent was obtained from respondents, and confidentiality procedures should include separation of identifiers from questionnaire responses, restricted data access, and referral/support procedures if distress arose during HIV-related questions.

RESULTS

The following section presents the findings of this study, including respondent characteristics, the distribution of family support and quality of life, and the results of the statistical analysis.

Table 1 shows that the majority of respondents were over 45 years of age (50.0%), female (53.3%), had completed senior high school education (40.0%), were married (90.0%), and had been living with HIV for between 1 and 10 years (43.3% each for both the 1–5 and 6–10 year groups).

Table 2 shows that most PLHIV at the WPA Turen Foundation reported insufficient/low family support, comprising 18 respondents (60.0%), while 12 respondents (40.0%) reported supportive family engagement. Because only the total family-support category was analyzed, the findings should not be interpreted as evidence of deficits in each support dimension unless dimension-level scores are reported.

Table 3 shows that the majority of respondents reported a good quality of life, with 16 respondents (53.3%) in this category, compared to 14 respondents (46.7%) who reported a poor quality of life. Notably, despite most respondents receiving non-supportive family support, more than half maintained a good quality of life. This suggests that other contributing factors—such as the foundation's ongoing accompaniment programs, peer support among PLHIV, and consistent ART adherence—may serve a compensatory role in sustaining quality of life.

Table 4 presents the cross-tabulation of family support and quality of life using row percentages. Among respondents with insufficient/low family support (n = 18), 7 (38.9%) reported good quality of life and 11 (61.1%) reported poor quality of life. Among respondents with supportive family support (n = 12), 9 (75.0%) reported good quality of life and 3 (25.0%) reported poor quality of life. These descriptive data suggest a positive pattern, but the small sample requires cautious interpretation.

Table 5 presents the Spearman's rho analysis. Based on the reported n = 30 and rho = 0.355, the association was positive but modest and imprecise (approximate 95% CI: -0.01 to 0.63; p approximately 0.054). Therefore, the result should be described as a positive trend rather than definitive statistically significant evidence unless the authors provide a verified raw-data output showing different values.

Table 1. Frequency Distribution of Respondent Characteristics among PLHIV at WPA Turen Foundation (n=30)

Characteristic	Category	f	%
Age (years)	18–25	2	6.7
	26–35	4	13.3
	36–45	9	30.0
	> 45	15	50.0
Sex	Male	14	46.7
	Female	16	53.3
Education	No formal schooling	3	10.0
	Primary school (SD)	4	13.3
	Junior high school (SMP)	10	33.3
	Senior high school (SMA)	12	40.0
	Diploma/University	1	3.3
Marital Status	Married	27	90.0
	Unmarried	3	10.0
Duration since diagnosis	1–5 years	13	43.3
	6–10 years	13	43.3
	11–15 years	4	13.3

(Source: Research Data, 2024)

Table 2. Frequency Distribution of Family Support among PLHIV at WPA Turen Foundation (n=30)

Family Support	f	%
Supportive	12	40.0
Insufficient/low family support	18	60.0
Total	30	100

(Source: Research Data, 2024)

Table 3. Frequency Distribution of Quality of Life among PLHIV at WPA Turen Foundation (n=30)

Quality of Life	f	%
Good	16	53.3
Poor	14	46.7
Total	30	100

(Source: Research Data, 2024)

Table 4. Cross-Tabulation of Family Support and Quality of Life among PLHIV at WPA Turen Foundation (n=30)

Family support	Good QoL n	Row %	Poor QoL n	Row %	Total n	Row %
Insufficient/low	7	38.9	11	61.1	18	100.0
Supportive	9	75.0	3	25.0	12	100.0
Total	16	53.3	14	46.7	30	100.0

(Source: Research Data, 2024)

Table 5. Spearman Rho Analysis of the Relationship between Family Support and Quality of Life among PLHIV at WPA Turen Foundation

Variable relationship	n	Spearman's rho	Approx. 95% CI	*p-value*
Family support and quality of life	30	0.355	-0.01 to 0.63	0.054*

Note. *The p-value was recalculated for consistency with n = 30 and rho = 0.355. The previously reported p = 0.005 is not statistically consistent with these values and should be verified against the original raw-data output.

(Source: Research Data, 2024)

DISCUSSION

Family Support among PLHIV at WPA Turen Foundation

The findings showed that most PLHIV at the WPA Turen Foundation reported insufficient/low family support (60.0%). This pattern may reflect HIV-related stigma, limited disclosure, and inadequate health literacy among family members, but those mechanisms were not directly measured in this study. Therefore, family-based education and counseling should be framed as future program recommendations rather than tested outcomes of the present study.

From the perspective of Stress and Coping Theory, families who are unable to acknowledge HIV/AIDS as a shared stressor risk becoming an additional source of psychological burden for PLHIV. When family members respond with avoidance, rejection, or withdrawal from care involvement, the individual's capacity for adaptive coping is correspondingly reduced (16). This dynamic is clearly reflected in the present study, where the majority of respondents had not received optimal family support. These findings reinforce the critical need for family-based interventions, including HIV/AIDS education programs and structured family counseling, to strengthen the family's role as the primary support system in PLHIV care.

Quality of Life among PLHIV at WPA Turen Foundation

This study found that the majority of respondents reported a good quality of life (53.3%). Quality of life is a multidimensional construct encompassing physical health, psychological well-being, social relationships, and environmental factors—all of which are profoundly affected by HIV/AIDS (18). The World Health Organization defines quality of life as an individual's perception of their position in life within the context of the culture and value systems in which they live, in relation to their goals, expectations, standards, and concerns.

The relatively favorable quality of life observed among respondents may be related to the WPA Turen Foundation's accompaniment activities, peer contact, health education, or ART-related support. However, foundation support, ART adherence, viral load, stigma, and mental health were not measured in the present analysis, so these explanations should be treated as hypotheses for future research rather than confirmed determinants.

Relationship between Family Support and Quality of Life among PLHIV

The Spearman's rho analysis showed a modest positive association between family support and quality of life (rho = 0.355). With n = 30, this estimate has a wide confidence interval and should not be described as strong evidence. The analysis was bivariate and unadjusted, so potential confounders such as age, marital status, duration since diagnosis, ART adherence, stigma, disclosure status, mental health, and foundation support could not be ruled out.

Theoretically, family support may function as a psychosocial buffer that helps PLHIV manage illness-related stress, stigma, and role disruption (20). The descriptive cross-tabulation supports this possibility because good quality of life was more common in the supportive family-support group (75.0%) than in the insufficient/low support group (38.9%). However, these percentages are descriptive and should not be interpreted as proof of causal effect.

Family acceptance, empathy, and practical assistance may reduce internalized stigma and support treatment engagement among PLHIV (21-23). However, the present study did not directly measure stigma, disclosure status, ART adherence, viral suppression, depression, or

peer support. These variables should be included in future studies to clarify possible pathways between family support and quality of life.

Although most respondents reported insufficient/low family support, more than half reported good quality of life. The foundation's peer-support networks, health education, and community accompaniment may partly explain this pattern, but foundation support was not measured statistically. Therefore, the compensatory role of foundation support should be presented as a plausible hypothesis and limitation, not as a conclusion.

CONCLUSION

This study found a modest positive trend between family support and quality of life among PLHIV at the WPA Turen Foundation (rho = 0.355; approximate 95% CI: -0.01 to 0.63; p approximately 0.054 based on n = 30). Most respondents reported insufficient/low family support (60.0%), while 53.3% reported good quality of life. The findings suggest that family support may be relevant to quality of life, but conclusions should remain cautious because of the small purposive sample, bivariate unadjusted analysis, and unmeasured factors such as stigma, ART adherence, disclosure status, mental health, socioeconomic status, and foundation support. Future studies should include larger multi-site samples and analyze total support and quality-of-life scores to preserve information.

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Conflict of Interest

The author declares no financial or non-financial conflicts of interest in relation to the research, authorship, or publication of this article.

Author Contributions

Conceptualization, M.R.K.S. and R.S.; methodology, M.R.K.S., S.A.L., and R.S.; investigation, M.R.K.S.; data curation, M.R.K.S.; formal analysis, M.R.K.S. and S.A.L.; writing—original draft preparation, M.R.K.S.; writing—review and editing, S.A.L. and R.S.; supervision, R.S. All authors have read and agreed to the published version of the manuscript.

Data availability

De-identified data may be available from the corresponding author upon reasonable request, subject to ethical approval and confidentiality protections for PLHIV.

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