

## ORIGINAL ARTICLE

# The relationship between family support and the quality of life of patients with seroconcordant HIV at the Pandian health center and Pamolokan health center, Sumenep Regency

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### ABSTRACT

**Introductions:** The HIV/AIDS endemic infected millions worldwide in 2019. Indonesia reported a very significant case of the disease, where East Java occupies the fourth position out of all the provinces. People who suffer from this disease (ODHA) are often associated with a poor quality of life. Family support is needed to control the patient's disease and improve the patient's quality of life. **Objectives:** This study aims to determine the relationship between family support and the quality of life of seroconcordant HIV patients. **Methods:** The study design used cross-sectional with a sample of 36 seroconcordant PLHIV patients and 32 people who met the inclusion criteria (living with family, married, and registered at the Sumenep District Health Center). The data collection instrument used the "family support" questionnaire and WHOQL-HIV Bref. The collected data were analyzed using the Rank Spearman technique at a significance level of 0.05. **Results:** The results of this study showed that more than half of the respondents (59.4%) received "good" family support; the majority of respondents (78.1%) have a "fairly good" quality of life; and there is a significant relationship between the two variables as evidenced by the  $p$ -value = 0.002 which has a "strong" relationship strength as evidenced by the correlation coefficient = 0.520 and has a unidirectional relationship as evidenced by the positive correlation coefficient. The more family support is improved, the quality of life of the respondents will increase. **Conclusion:** There is a significant, strong, and one-way relationship between family support and the quality of life of seroconcordant HIV patients. Families should increase their support for HIV patients to improve their quality of life in everyday life.

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## 1. Introduction

Human Immunodeficiency Virus (HIV) is a virus that attacks the immunity of the human body so that the body becomes weak to fight infection, and the effect will be an immune system deficiency. In comparison, Acquired Immunodeficiency Syndrome (AIDS) are conditions or symptom that arise when a person has an immune deficiency due to being attacked by the virus (Hasdianah & Dewi, 2014). The endemic of HIV and AIDS in 2019 was reported to have infected millions of people in various parts of the world. Data from the United Nations Program on HIV and AIDS (UNAIDS, 2019 in Kemenkes, 2020) states that hierarchically the human population infected

with HIV/AIDS occurs on several continents. As part of Southeast Asia, Indonesia is one of the countries with a high number of HIV/AIDS cases, namely 409,857 people with HIV cases and 127,873 people with AIDS cases (Kemenkes, 2020). East Java Province contributes a large number of HIV/AIDS cases; this province ranks third (100,132 cases) for HIV cases and fourth for AIDS cases (1,124 cases) of all provinces in Indonesia in the July – September 2020 period (Kemenkes, 2020).

Sumenep Regency, as one of the areas under the coordination of the province, reported 106 cases of HIV and 87 cases of AIDS (Dinkes Kab. Sumenep, 2019). The report stated there were no deaths. The latest cumulative HIV/AIDS data for 2020 was reported by the same institution as many as 51 people (33 men and 18 women) (Dinkes Kab. Sumenep, 2019). There are several Community Health Centers in Sumenep Regency that can serve HIV/AIDS patients, two of which are the Pandian Health Center and the Pamolokan Health Center. HIV/AIDS services in question are services in the context of pharmacological treatment, namely by administering Antiretroviral drugs (ARV). The number of respondents was 36 people (20 people from Pandian Health Center and 16 people from Pamolokan Health Center). This data is cumulative. Both HIV positive and suffering from AIDS symptoms, and the 36 respondents have a seroconcordant family background (a relationship between partners who have HIV/AIDS).

There are a number of common complications caused by HIV that a person suffers from, including tuberculosis (TB), toxoplasmosis, cytomegalovirus, cryptococcal meningitis, wasting syndrome, HIV-associated nephropathy (HIVAN), and neurological disorders (Verville, 2020). Therefore, the government has set a fundamental goal of controlling this disease, namely achieving Three Zero by 2030. The Three Zeros are meant as follows: no new HIV infections, no AIDS-related deaths, and no discrimination against sufferers (Kemenkes, 2013). The government has also developed a strategy to control the high number of HIV/AIDS cases. The strategy in question is the 90-90-90 strategy. The purpose of the 90-90-90 strategy is that 90% of people living with HIV/AIDS (PLWHA) already know the status of the HIV that infects them; 90% of PLWHA who already know their status receive antiretroviral treatment (ARV), and 90% of people living with HIV who have received antiretroviral therapy (ARV) experience suppression of the virus that infects them (Kemenkes, 2013). The process of controlling HIV/AIDS with antiretroviral treatment requires other aspects, one of which is support from elements of society, especially the family (Novrianda *et al.*, 2018).

Family support is an attitude or act of family acceptance of one of the other family members where the support includes several elements, including emotional, instrumental, informational, and appraisal support (Friedman, 2013). Family support in the context of health is the support provided by the family to other family members in the form of attitudes, actions, and acceptance of a family member suffering from a certain disease (Misgiyanto & Susilawati, 2014). People with HIV/AIDS, or what is commonly referred to as People with HIV AIDS (ODHA), really need support from their families in order to inhibit the rate of development or replication of the HIV that has infected or to inhibit chronic changes caused by infection with the virus which has weakened the body's immunity (Novrianda *et al.*, 2018).

The problem is, sometimes, the family support received by ODHA patients could be better, which causes their quality of life to be not ideal either. Even though this support can ultimately positively impact improving the quality of life for ODHA patients (Simboh, 2015). Quality of life, according to Hastuti (2016), is an understanding or understanding arising from a person's place in the culture and values in which he lives and how it relates to the dreams, goals, and standards set. And attention of others to him. Seanda's opinion states that quality of life is an individual's or someone's perception of his position in life, whether in a social, cultural, or other context (Jacob & Sanjaya, 2018).

The findings of Ramadhan (2018) showed that of the 41 HIV/AIDS patients (PLWHA) studied, the majority, or as many as 27 people (65.9%), received low-income family support. Meanwhile, the quality of life of most respondents, or 30 people (73.2%), is in the wrong category. Azizah, Ahmad, and Septianingrum's (2019) research also showed similar findings that of the 72

respondents of ODHA patients studied. They still showed a low percentage of family support, namely 17 people (23.61%); as a result, the quality of life for most of them (9 people or 12.5%) is in the less category; this was also reinforced by [Mustamu's research \(2019\)](#) which stated that out of the 30 respondents studied, as many as 11 people (36.7%) stated that they had insufficient family support. Then from these 11 people, as many as 6 (54%) people got a poor quality of life. Based on the phenomena and data above, this study aims to determine the relationship between family support and the quality of life of seroconcordant HIV patients.

## 2. METHODS

The cross-sectional research design is a form of research design used in this study. [Sugiyono \(2016\)](#) explained that a cross-sectional research design is a form of research design that aims to study the dynamics of the relationship (correlation) between two variables (independent variables and dependent variables) over a period that is not continuous or within a certain period. The two variables that will be examined or studied for their correlation dynamics are "family support" (the independent variable) and "quality of life of patients with serodiscordant ODHA" (the dependent variable). The population to be used in this study were 36 ODHA patients with seroconcordant criteria (patients infected with HIV/AIDS because one of their partners was infected with HIV/AIDS) who were at the Pandian Health Center and Pamolokan Health Center, Sumenep Regency. The sample that the researchers used in this study were 36 seroconcordant ODHA patients at the Pandian Health Center and Pamolokan Health Center, Sumenep Regency, with inclusion criteria (seroconcordant HIV/AIDS patients who live with their families, are married and registered at the Pandian and Pamolokan Health Centers, Sumenep Regency). This study used two family support questionnaire instruments and a quality-of-life questionnaire given to respondents through Google Forms; before filling out the questionnaire, the respondents first filled out informed consent as proof of their willingness to become respondents in this study.

## 3. Results and Discussion

The process of collecting and collecting research data was carried out for 11 days from 14-20 September 2022 to 32 respondents (seroconcordant ODHA patients) who were in the working area of two Pandian Health Centers and Pamolokan Health Center, Sumenep Regency. The number of samples initially (according to the researchers' initial observations in mid-October 2021) was 36 people. It is just that as many as four people did not meet the inclusion criteria because at the time this research was conducted (14-20 September 2022), their status was neither married nor partner, for reasons they had been divorced and the respondent's partner had died. The following are the results of this study:

Table 1 Characteristics of Family Support for Seroconcordant ODHA Patients

Category	F	%
Good	19	59,4
Average	13	40,6
Poor	0	0,00
Total	32	100

Table 1 above shows that more than half of the seroconcordant PLHIV patients (19 people or 59.4%) at the Pandian Health Center and Pamolokan Health Center in Sumenep Regency received "good" family support.

Table 2 Characteristics of the Quality of Life of Seroconcordant ODHA Patients

Category	F	%
Good	6	18,8
Average	25	78,1
Poor	1	3,1
Total	32	100

Table 2 above shows that most seroconcordant ODHA patients (25 people or 78.1%) at the Pandian Health Center and Pamolokan Health Center in Sumenep Regency have a "pretty good" quality of life.

Table 3 Results of Crosstabs Analysis and Rank Spearman

		Seroconcordant ODHA Quality of Life			Total	P-value	Coefficient Correlation
		Good	Average	Poor			
Family support	Good	6	13	0	19	0,002	0,520**
	Average	0	12	1			
	Poor	0	0	0			
<b>Total</b>		<b>6</b>	<b>25</b>	<b>1</b>	<b>32</b>		

Table 3 is the result of crosstabs analysis and Spearman's Rank, where each reinforces the other. Based on the results of the crosstabs analysis, as shown in Table 3, it was stated that of the 19 seroconcordant ODHA patients at the Pandian Health Center and Pamolokan Health Center who received "good" family support, the majority (13 people) had a "fairly good" quality of life and as many as six people have a "good" quality of life; and of the 13 seroconcordant ODHA patients who received "pretty good" family support, the majority (12 people) had a "pretty good" quality of life. Only one person had a "poor" quality of life. The better the family support obtained by seroconcordant ODHA patients, the better their quality of life. Furthermore, the results of the Rank Spearman correlation analysis with the help of the SPSS v.25 for Windows application stated three things, namely: a significance value (Sig. 2 tailed or P -value) is 0.002 which means that the two variables have a significant relationship; the coefficient correlation value is 0.520\*\* or 52%, which means that the two variables have a "moderate" relationship strength as the benchmark set by Sugiyono (2016), while two stars (\*\*) indicate that the relationship is considered significant at a level or significance level of 0, 01; and the number of correlation coefficients is positive (+), which means that the relationship between the two variables is in the same direction, which means that the more family support is improved, the quality of life of seroconcordant ODHA patients will increase. These results indicate that the alternative hypothesis (Ha) proposed at the study's beginning was declared accepted; this means that there is a significant, quite good, and one-way relationship between family support and the quality of life of seroconcordant ODHA patients at the Pandian Health Center and Pamolokan Health Center, Sumenep Regency.

The identification results of this study on family support variables stated that more than half of seroconcordant ODHA patients received 'good' family support. Family support consists of four indicators, indicators of emotional support, informational support, instrumental support, and assessment support; from the four indicators, there are three indicators with the highest percentage of patient answers that get high or good scores, namely emotional support with a percentage of 73.3% (good), informational support with a percentage of 72.4% (good) and appraisal support with a percentage of 73.7% (good). At least four factors influence these results, including emotional closeness, cultural background, social class, and spirituality.

These factors can be explained as follows: First, emotional closeness. Usually, family members with other family members have high emotional closeness. This emotional closeness allows the family to support other family members, especially when one of its members is sick (Wiyata, 2013). Families in the Madurese community, in general, and Sumenep, in particular, have good and even high emotional closeness with their family members—second, cultural background. Lasi (2018) states that cultural background can influence individual values, beliefs,

and habits, including providing support in seeking or implementing personal health. The Madurese, in general, including the Madurese in Sumenep Regency, besides seeking personal and family health with the help of medical personnel, also have local wisdom where they also believe in mystical powers from smart people or shamans. Apart from shamans, Madurese people also have a culture of drinking herbal medicine to cure illnesses (Mudjiono et al., 2015)—third, social class. Lasi (2018) states that people with relatively high or well-established social classes tend to give more attention or support than people with low social status. The researchers' observations showed that most respondents came from "respectable" families or had good social status with a relatively well-established economic level—fourth, spirituality. The spirituality of the Madurese people is mainly derived from Islam. God, as believed in Islam, is a source of strength and hope in healing diseases (Wiyata, 2013).

Furthermore, the results of research identification on the variable quality of life of seroconcordant ODHA patients showed a "good enough" category. Theoretically, ODHA patients with a good quality of life will have the following psychological signs: They will not experience depression, will not experience anxiety, and will not experience hopelessness in their lives (Rosnaini, Gabel, and Multazam, 2021). The researcher's short interviews with seroconcordant PLHIV patients in this study generally did not experience this negative psychological situation. Several factors influence the "good enough" quality of life: gender, age, education, occupation, marital status, and stigma.

These factors can be explained as follows: First, women are considered more able to survive HIV/AIDS infection than men. Women are considered that way because they have the sufficient ability (to be more independent and more accepting of their condition as ODHA patients) to live a life that is influenced by the results of their adaptation and ways of surviving (Rokhani & Mustafa, 2018). This theory is in line with the identifiable findings of this study which show that the majority of respondents are female, namely 24 people (75%). It is this majority of the female sex that allows their quality of life to be quite good. Second, age is another factor that affects the quality of life of seroconcordant ODHA patients. Theoretically, Ardianti (2015) states that the age variable is related to a person's life expectancy. The older a person is, the better their life expectancy will be. This study's findings indicate that most respondents are adults (20-60 years), namely 31 people (96.9%). Adult age shows excellent physical condition, which is different from old age, which is very susceptible to disease progression. When the organs in the body become dysfunctional due to aging, this will undoubtedly affect a person's health and quality of life, especially people with HIV/AIDS. Third, education also affects the quality of life of seroconcordant ODHA patients because, according to Monasel et al. (2022), individuals with a better education level tend to receive and seek related information about their illness and how to treat it. The identifiable findings of this study indicate that the majority of respondents (71.9%) completed their education at the high school level or its equivalent. This level of education is secondary education and cannot be said to be high educational attainment. Therefore, this middle level of education is very likely to affect the quality of life of respondents as ODHA patients, which this study stated were in the "fairly good" category. Fourth, marital status also affects the quality of life of seroconcordant ODHA patients because, according to Kusuma (2016), marital status ODHA patients will have adequate self-esteem and coping resources from their partners so that they will be able to develop adaptive coping mechanisms when facing stressors, This is in line with the identifiable findings of this study which show that overall, the respondents (100%) are married. Other research also shows that married individuals have a much better quality of life than those who are not married, either because they are not married or divorced (Afiyah, 2010). Fifth, work is also very likely to affect the quality of life of seroconcordant ODHA patients because working individuals tend to have good income or financial conditions, which allows them to fulfill their daily needs. The better the income and economic status, the opportunity and ability to meet life's needs will increase or be better (Saputra, 2019).

The identification findings of this study indicate that most respondents work as entrepreneurs/traders, namely 26 (81.3%). Working as an entrepreneur is one job that allows an

individual's income and financial status to increase; This is different from individuals who do not work. Sixth, the stigma of HIV/AIDS suffered by respondents tends to be another determining factor because, according to [Kusuma \(2016\)](#), HIV/AIDS is often negatively stigmatized and considered a disease that can be transmitted through regular physical contact where such perceptions can arise from a knowledge deficit. HIV/AIDS, especially in the local community, is considered a disease that is always assumed to be caused by free sex and can be transmitted. At least, that is what several respondents said when contacted by telephone. This negative stigma is very likely to affect the quality of life of those who, in this study, are stated to be "sufficient." This analysis is to the findings of [Mariany \(2019\)](#), which states that community stigma affects the quality of life of ODHA. In contrast, when community stigma is high, the quality of life for ODHA will tend to decrease.

Furthermore, the results of Spearman's Rank analysis in this study showed that there was a significant, substantial, and one-way relationship between family support and the quality of life of seroconcordant ODHA patients at the Pandian Health Center and Pamolokan Health Center, Sumenep Regency. There is a significant relationship between the two variables because the descriptive findings of this study indicate that the support provided by the family to seroconcordant ODHA patients is in the "good" category, and the quality of life of seroconcordant ODHA patients is descriptively in the "fairly good" category. It is logical if the statistical findings show a significant, solid, and positive relationship or in line with the consequence that if family support is further improved, the quality of life of seroconcordant ODHA patients will also increase.

Theoretically, family support for ODHA patients, including seroconcordant ODHA, can positively impact their quality of life ([Monasel et al., 2022](#)). When viewed in more detail based on the four family support models, three models have a high score. They are likely to influence the quality of life of seroconcordant ODHA patients, namely: emotional support with a percentage of 73.3% (good), informational support with a percentage of 72.4% (good), and assessment support with a percentage of 73.7% (good). The emotional support provided by the family to their members who have seroconcordant HIV/AIDS in this study was in the form of assistance during treatment, care for illness, love and affection during illness, good care, and provision of comfort when sad. Furthermore, informational support is in the form of assistance with information about daily activities, information about matters related to medicine, and information about prohibitions or taboos that must be avoided related to HIV/AIDS. Meanwhile, assessment support is in the form of explanations regarding dark matters related to HIV/AIDS, praise when carrying out medical advice, involvement in treatment decisions, involvement in decision-making on matters involving the family, involvement in social activities, and no restrictions on interaction with friends. The three family support models are considered to affect seroconcordant ODHA patients because they have a high percentage score.

The family gave high or good emotional and informational support and assessment or appreciation to family members who have HIV/AIDS, as explained in the previous subtitles, to help patients live their daily lives ([Missa, Manurung, and Sir, 2020](#)). ODHA patients who are given continuous emotional support will feel that they are still very much needed by their families, whether their wives, husbands, siblings, or parents. Furthermore, family support in the form of informational support provided to ODHA patients is critical because patients will feel that they are always welcome in their family environment; this is because the family always informs what they know about good and bad things for the patient. Meanwhile, support for evaluation or appreciation from the family is significant for ODHA patients because it will make patients feel valued, loved, and part of the family and society in general. Patients will not feel discriminated against because of their illness. The findings of this study are not a single phenomenon in similar studies. The findings of [Khairunnisa's research \(2015\)](#) stated that emotional and informational support was declared effective for life, including quality of life, for HIV/AIDS patients with an average score of 3, while another support (instrumental) was declared less effective with an average score of 2.

In general, family support is instrumental in improving the quality of life of ODHA; this is shown, for example, by the findings of [Kusuma's study \(2016\)](#), which stated that ODHA patients with family support in the non-supportive category are at two times the risk of having a poor quality of life. This is also supported by the findings of [Mustamu's research \(2019\)](#) which state that there is a significant relationship between family support and the quality of life of ODHA patients with p-value = 0.001. According to him, ODHA patients have a good quality of life because they also receive good support from their families. Apart from that, this research is also supported by the findings of [Khairunniza \(2020\)](#), which states that there is a significant relationship between family support and the quality of life of ODHA with a p-value = 0.009. According to him, these results show that positive family support can help ODHA deal with their health and psychological problems. Thus, the family is considered a party that has a vital role in improving the quality of life of ODHA.

Researchers argue that the family is the party closest to the patient. Family support for ODHA patients is very much needed as a support system that can be developed as a reasonable response or coping against stressors that arise, whether psychological, physical, or otherwise. Therefore, good family support is highly related to or influences the quality of life of seroconcordant ODHA patients. This analysis is also supported by [Carsita's analysis \(2019\)](#) which states that ODHA with high family support tends to have a better quality of life; this is because ODHA feels that their family supports them and considers their family as a good source of support for them so that feelings of security and comfort always appear in their daily lives.

#### 4. Conclusion

Based on the results of this study, it can be concluded that more than half of Seroconcordant HIV/AIDS patients at the Sumenep District Health Center receive good family support, and more than half of Sekonkordan HIV/AIDS patients have a relatively good quality of life. The higher the level of family support for seroconcordant HIV/AIDS patients, the quality of life of these patients will increase.

#### Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data, or human tissue must:

1. Participants or respondents in this study were previously given informed consent or a letter of consent to become respondents in this study and signed if the respondent agreed.
2. The ethical test for this research was carried out at the Health Research Ethics Commission (KEPK) Faculty of Dentistry, University of Jember with No.1780/UN25.8/KEPK/DL/2021

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