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Factors Associated with Quality of Life among People Living with HIV/AIDS in Kupang

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Abstract

It is known that HIV/AIDS remains a global health problem. Living with HIV/AIDS can have significant impacts on various aspects of life, including mental health, social relationships, and overall well-being. Addressing stigma and discrimination is crucial in improving the quality of life for people living with HIV/AIDS, along with providing access to proper medical care and support services. This study aims to investigate factors that impact the quality of life of people living with HIV/AIDS (PLWHA) in Kupang City, Indonesia from April 2023 to July 2023 in hospitals and NGOs in the city. The design of this study was a cross-sectional study. The study involved 98 respondents, who were PLWHA taking ARV therapy at Prof. Dr. WZ Johannes Public Hospital Kupang and Wirasakti Army Hospital Kupang. The data was collected using the Oslo Social Support Scale (OSSS-3) Questionnaire. This study found that most respondents have moderate social support. The study identified several factors significantly impacting the quality of life for HIV/AIDS patients such as social support (p 0.001), adherence to ARV therapy (p 0.000), depression levels (p 0.007), education level (p 0.002), income level (p 0.012), and the duration of the diagnosis (p 0.044). This study contributes to add valuable information for a comprehensive understanding of the multifaceted challenges faced by individuals living with HIV/AIDS, paving the way for targeted interventions and support strategies.

Keywords: AIDS, HIV, quality of life

Faktor-faktor yang Berhubungan dengan Kualitas Hidup Orang yang Hidup dengan HIV/AIDS di Kupang

Abstrak

Diketahui bahwa HIV/AIDS masih merupakan masalah kesehatan global. Hidup dengan HIV/AIDS berdampak pada banyak aspek kehidupan termasuk kesehatan mental, relasi sosial, dan kualitas hidup secara keseluruhan. Penting untuk mengatasi stigma dan diskriminasi sambil meningkatkan kualitas hidup orang dengan HIV/AIDS(ODHA) serta menyediakan akses pelayanan kesehatan yang mumpuni dan layanan pendukungnya. Tujuan penelitian ini untuk mengetahui faktor yang memengaruhi kualitas hidup ODHA di rumah sakit di Kota Kupang, Indonesia dari April 2023 hingga Juli 2023. Penelitian ini menggunakan desain potong lintang. Terdapat 98 responden ODHA yang mendapat terapi ARV di RSU Prof. Dr. WZ Johannes Kupang dan Rumah Sakit Tentara Wirasakti Kupang. Data yang diperoleh mengunakan kuesioner Oslo Social Support Scale (OSSS-3) menunjukkan bahwa kebanyakan responden memiliki dukungan sosial sedang. Faktor-faktor yang secara signifikan memengaruhi kualitas hidup ODHA yaitu dukungan sosial (p 0,001), kepatuhan terhadap terapi ARV (p 0,000), tingkat depresi (p 0,007), tingkat pendidikan (p 0,002), tingkat pendapatan (p 0,012), dan durasi diagnosis (p 0,044). Studi ini berkontribusi untuk menambah informasi berharga untuk pemahaman komprehensif tentang berbagai tantangan yang dihadapi oleh individu yang hidup dengan HIV/AIDS, membuka jalan bagi intervensi yang ditargetkan dan strategi dukungan.

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Kata Kunci: *AIDS, HIV, kualitas hidup*

Introduction

HIV/AIDS is a chronic disease that requires lifelong antiretroviral (ARV) treatment. According to the World Health Organization (WHO), HIV/AIDS is a global health problem with 40.1 million deaths since its discovery.[1] In Southeast Asia, there were 1.9 million HIV/AIDS patients, with 78,000 new cases reported in 2021, whilst in Indonesia there were 456,453 cumulative cases, with 36,902 new cases.[1]

Being living with HIV/AIDS can have an impact on the workforce, such as increased absenteeism and even decreased productivity. Currently there is no cure for HIV AIDS, which means that people living with the condition have to manage it throughout their lives. However, stigma and misconceptions surrounding HIV/AIDS persist. This can create additional challenges for people living with the disease.[2]

Stigma is a negative characteristic attached to a person by their environment. It can lead to discrimination, social isolation and loss of access to treatment and education. This can have a number of negative consequences for the individual. These include mood disorders, anxiety, cognitive impairment and even suicide.[3] Stigmatized people often hide their condition. This makes it more difficult for them to receive appropriate care and reduces their overall quality of life. [3]

The presence of co-morbidities such as sexually transmitted diseases (syphilis, condyloma acuminata), cardiovascular disease, type 2 diabetes mellitus and the need for hospitalization can also contribute to the increased stigma experienced by people living with HIV/AIDS. Stigma may be further exacerbated by fear of damaging relationships due to the diagnosis, leading to concealment of status. A cross-sectional study of 258 users of a specialized service in Minas Gerais, conducted between September 2014 and December 2015, showed that the majority of users were men between the ages of 40 and 49, single, with a low level of education and a low income. Stigma has an impact on the quality of life of PLWHA, increasing their feelings of guilt and shame, which can lead to depression, social isolation, treatment abandonment and clinical follow-up. This research has shown a significant relationship between level of education, duration of ARV therapy, stigma and quality of life of PLWHA.[4]

In Nusa Tenggara Timur, there were a cumulative total of 3,903 HIV/AIDS cases in 2022. After Sikka, Belu and Flores Timur, Kupang is the fourth city with 433 cases. Cumulated HIV/ AIDS cases in Indonesia were 456,453, which included 387,210 active cases and 36,902 new cases in 2021.[5–8] Nusa Tenggara Timur is next to other country, Timor Leste. There was no other HIV/AIDS quality of life study in Kupang, so we chose Kupang to represent factors affected HIV/AIDS patient’s quality of life.

Assessments of quality of life in developing countries have identified a number of factors that influence it, including gender, age, family situation, education, employment, income, viral and immunological status, symptoms, co-morbidities, mental health, social support and lifestyle choices. Community support can have a positive impact on quality of life, whereas stigma and discrimination have a negative impact, hindering engagement in health care and increasing depressive symptoms.[3,4,9]

In conclusion, HIV/AIDS remains a global health problem affecting millions of people worldwide. Living with HIV and AIDS may affect many aspects of people's lives, including mental health, social relationships and general wellness. Addressing stigma and discrimination, along with access to appropriate medical care and support services, is critical to improving the quality of life of people living with HIV/AIDS. There has been a gap in research on the differences between factors that have a significant impact on the quality of life of people living with HIV/AIDS (PLWHA). This study aimed to examine the associations between socio-demographic factors and quality of life of PLWHA in Kupang City.

Methods

The study design was a cross-sectional survey. It was conducted in hospitals and NGOs in the city from April to July 2023. The study population included all adult PLWHA in Kupang City who were available for interviewing during the specified period. Adult PLWHA in Kupang City who met the inclusion and exclusion criteria were included in the study sample. Eligible participants were defined as PLWHA aged 18 years or older under the inclusion criteria. In addition, potential participants had to be able to understand the Indonesian language and have the ability to follow the instructions given by the researchers. Willingness to participate as a respondent, demonstrated by signing the informed consent form, is essential to participate in the study. Conversely, the exclusion criteria outline specific conditions that would preclude individuals from participating. Patients with medical conditions that would prevent them from understanding or completing the questionnaire are excluded. Individuals with cognitive impairments that affect their understanding and response to the questionnaire will also be excluded from the study. The parameters for the selection of suitable participants in the research endeavor are defined by these inclusion and exclusion criteria. The researchers used snowball sampling to select the sample based on the specified criteria until the minimum sample size of 84 respondents was reached. We used Lemeshow to calculate the sample size[10] and calculated using an Android statistical software "Statistics and Sample Size Pro."[11]

We collected data from all 98 participants who met the inclusion and exclusion criteria. The WHOOL-BREF questionnaire was used in this study, which consists of 26 questions with a 5-point Likert scale. The data were analyzed using the Somer's D correlation for the ordinal to ordinal scale and the Coefficient of Contingency test for the variables of the nominal scale.[12,13] Ethical clearance accepted number 16/UN15.16/KEPK/2023.

Results

The study included 98 respondents, PLWHA receiving ARV therapy at RSUD Prof. WZ Johannes Kupang and RST Wirasakti Kupang. The characteristics of the respondents who participated in this study are shown in Table 1. The proportion of males was 55.1%. The age range varies widely from late adolescents to senior citizens, with the largest number of respondents in the early adulthood age group (26-35 years old). Of the 98 respondents involved in this study, approximately 63 people had other jobs, including self-employment. Most respondents in this study (53.1%) were high school graduates or equivalent, single (49%), and had incomes below one million rupiah (60.2%).

The study collected univariate data using the Oslo Social Support Scale (OSSS-3) and found that most respondents had moderate social support, while a smaller percentage had poor or good social support. Interviews revealed that some people living with HIV/AIDS did not disclose their status to those closest to them. The study also assessed antiretroviral (ARV) adherence, with the majority of respondents reporting high levels of adherence. Stigma was found to be experienced by 50% of respondents, with the assessment focusing on their perceptions of stigma. Symptoms of depression were present in 31.6% of respondents, with a range of severity levels. The length of time diagnosed varied, with the majority having been diagnosed for over 5 years. The study also assessed QoL using the WHOQOL-BREF questionnaire and found that most of those surveyed were experiencing a good QoL.

The Sommers D test and the Coefficient of Contingency test were used to analyse the bivariate analysis conducted in this study. The results of the analysis show that the factors that significantly affect the quality of life of people living with HIV/AIDS include social support (*p* 0.001), adherence to ARV therapy (*p* 0.000), level of depression symptoms (*p* 0.007), level of education (*p* 0.002), level of income (*p* 0.012) and length of time since diagnosis (*p* 0.044).

Table 1. Participant's Characteristics

Variable	n	%
Gender		
Female	44	44.9
Male	54	55.1
Age (years old)		
Late adolescence (1^7 - 25)	19	19.4
Early Adulthood (26 - 35)	38	38.8
Late Adulthood (36 - 45)	32	32.7
Early Elderly (46 - 55)	8	8.2
Elderly (>65)	1	1.0
Occupation		
Not working, student, housewife	34	34.7
CIVIL SERVANT	1	1.0
Non-civil servant/entrepreneur	56	57.1
Others	7	7.1
Education level (last graduated)		
Not graduated from primary school	2	2.0
Elementary School	6	6.1
Junior High School	16	16.3
Senior High School	52	53.1
University Degree	22	22.4
Marital Status		
Single	48	49.0
Married	31	31.6
Widower	19	19.4
Income Level (Rupiah)		
<1,000,000	59	60.2
1.000.000 – 3.000.000	32	32.7
3.000.000 – 5.000.000	5	5.1
>5.000.000	2	2.0
Total	98	100

Table 2. *Univariate data*

Variable	n	%
Social support		
Poor	22	22.4
Medium	42	42.9
Good	34	34.7
ARV Therapy adherence rate		
Low	24	24.5
Medium	15	15.3
High	59	60.2
Stigma		
Low	49	50
High	49	50
Depression Level		
Not depressed	67	68.4
Mild	11	11.2
Moderate	8	8.2
Severe	6	6.1
Very severe	6	6.1
Duration of diagnosis (year)		
<1	20	20.4
1-5	35	35.7
>5	43	43.9
Quality of Life		
Good	66	67.3
Poor	32	32.7

Table 3. Bivariate

Variable	QOL (p)
Social Support	0.001*
ARV Therapy Adherence	0.000*
Stigma 2 Categories	1.000*
Depression symptom Level	0.007*
Age	0.897*
Education Level	0.002*
Income Level	0.012*
Duration of Diagnosis	0.044*
Gender	0.874**
Occupation	0.227**
Marital Status	0.272**

** Somer's D Test ** Contingency Coefficient Test*

The Sommers D test and the Coefficient of Contingency test were used to analyse the bivariate analysis conducted in this study. The results of the analysis show that the factors that significantly affect the quality of life of people living with HIV/AIDS include social support (*p* 0.001), adherence to ARV therapy (*p* 0.000), level of depression symptoms (*p* 0.007), level of education (*p* 0.002), level of income (*p* 0.012) and length of time since diagnosis (*p* 0.044).

Discussion

There has been a gap in the research on the differences in the factors that significantly affect the quality of life of PLWHA. The aim of this study was to examine the association between socio-demographic factors and the quality of life of PLWHA in the city of Kupang. We found that social support, adherence to ARV therapy, depression symptom level, literacy level, income level and length of diagnosis had a significant impact on PLWHA QoL in Kupang.

The results of this study are in contrast to the results of the Wonogiri study, which showed a correlation between the symptoms of HIV disease and the quality of life of people with HIV/AIDS. Physical symptoms of HIV/AIDS disease burden patients. Asymptomatic patients have better physical quality of life, level of independence, and perception of overall quality of life and health than symptomatic patients.[14]

Social support was found to be associated with quality of life (QoL) among people living with HIV/AIDS in this study. In particular, higher social support was associated with better quality of life.[15] There are similarities between the results of this study and the study of 109 HIV/AIDS patients in Brazil by Miyada et al. In this study, the factors that had the most influence on the quality of life of people with HIV/AIDS were level of education, occupation, financial situation, ethnicity and symptoms of the disease. Brazil is a developing country like Indonesia. The population is similar in terms of age, socio-economic status, income and level of education. Sociodemographic factors and HIV/AIDS-related aspects affect HIV/AIDS patients' quality of life. Social support affects the quality of life of people living with HIV/AIDS. It is important to have someone who is willing to accompany, support, improve adherence to medication, lead a healthy lifestyle and improve quality of life. Counselling, support groups for mothers (living with HIV) and good nutrition are also needed to improve the quality of life of people living with HIV/AIDS. The Mediterranean Diet is proven to be an anti-inflammatory diet and good for people living with HIV/AIDS, with enough calories, enough protein, eating real food, avoiding processed foods, and eating enough fruits and vegetables. With good nutrition, PLWHA will increase their immune system to avoid opportunistic infections and prevent metabolic syndrome, cardiovascular disease, reduce comorbid and hospitalization, so it can reduce the morbidity and increase the quality of life of PLWHA.[16–18] With the development of community-based care models in some settings, support groups could provide an opportunity for PLHIV to share experiences, improve coping skills and become more involved in their care. Good nutrition with adequate protein intake of 1-2 g/kgBW, such as the Mediterranean diet, is an anti-inflammatory diet that supports HIV patients and many chronically ill patients to increase their immunity (CD4), prevent opportunistic infections, disease morbidity and hospitalization.

The level of depressive symptoms affects the quality of life of people living with HIV/AIDS because depression makes a person less enthusiastic about waking up and facing the day. Patients tend to be moody, sad and think of bad/negative things most of the day. Even in severe depression, patients have the desire or try to commit suicide out of despair. This disorder is caused by a neurotransmitter disorder in the brain in the form of insufficient serotonin and dopamine. It is also linked to stressors that can trigger a recurrence of depression and worsen depression symptoms. If accompanied by poor social support and not seeking immediate help in the form of counselling, psychotherapy (with a psychologist/psychiatrist) or medication from a psychiatrist, the condition and quality of life of patients will worsen.[19–21]

The level of education affects the quality of life of people living with HIV/AIDS, because with a low level of education it is difficult for patients to get a decent job, sufficient income, socio-economic and quality relationships, qualified support. The ability to think, innovate and fight to overcome problems is also limited in patients with low levels of education, making patients feel helpless and worsening their condition and poor quality of life.[20]

Income level affects the quality of life of PLWHA. Those living on low incomes could not afford to buy good food to eat. Especially in remote areas with distant health facilities, they cannot afford the necessary transport costs. Delayed treatment and failure to adhere also severely affect the quality of life of those living with HIV/AIDS.[22]

The duration of diagnosis has an impact on the quality of life of PLWHA because of poor adherence due to fatigue, tiredness or boredom. Nonadherence can increase opportunistic infections and organ damage. Post-tuberculosis obstruction syndrome with shortness of breath can have a negative impact on the quality of life of PLWHA.[23,24]

Adherence to ARV therapy affects the quality of life of HIV/AIDS patients, because if patients take ARV drugs daily, they will quickly achieve undetectable viral loads, elevated/normal CD4 levels, low opportunistic infections, so that patient mortality morbidity is greatly reduced, rarely hospitalized, so that patient quality of life improves.[25]

A meta-analytic study by Ghisvand et al. found some socio-demographic factors associated with poor quality of life among people living with HIV and AIDS: stigmatization, low socioeconomic status (poverty) and age below 35 years.[26] In this study, there was no evidence that stigma and age under 35 years had an impact on the quality of life of PWLHA.

The strengths of this study are that the sample size is sufficient for generalization to the population, the questionnaire is from the WHO and is valid, the bivariate analysis showed some significant associations and this research aim is met. Limitations of this study are variable questionnaire comprehension and recall bias, especially among low educated participants,

Conclusions

The study identified several factors that have a significant impact on the quality of life of people living with HIV/AIDS. These included social support (*p* 0.001), ARV adherence (*p* 0.000), depression symptoms (*p* 0.007), educational attainment (*p* 0.002), income (*p* 0.012) and duration of diagnosis (*p* 0.044). These findings provide valuable information to help understand the multiple challenges faced by people living with HIV/AIDS and to inform targeted interventions and support strategies.

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Conflict of Interest

There is no conflict of interest in this study

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