Research Article

Social Support and Quality of Life Patients with Acquired Immune Deficiency Syndrome

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Abstract.
Social support is a fundamental element of every individual's life. It promotes the feeling of being loved, valued, and respected, especially for the person with HIV/AIDS infection. Quality of life is the ability of an individual to have a good and regular life. Health and well-being are the key factors in gaining high quality of life. Therefore, to attain an appropriate quality of life, giving social support to patients with HIV/AIDS is compulsory. This research investigated the relationship between social support and HIV/AIDS patients' quality of life. This study used a correlational design associated with a cross-sectional approach. This research involved all of the patients with HIV/AIDS in Yayasan Cahaya Kasih Peduli AIDS WPA Turen. The data analysis used the Spearman rank correlation test. The finding of the research showed that 1 (2.2%) obtained less social support, 9 (20.0%) obtained sufficient social support, and 35 (77.8%) obtained optimal social support. However, life quality 1 (2.2%) assimilates low life quality, 10 (22.2%) assimilates an average life quality, and 34 (75.6%) assimilates a high life quality. The result from the Spearman rank correlation test appeared with the signification value (sig)= 0.000 < 0.05, and then H1 was accepted; hence it was discovered that there is a positive correlation between social support and quality of life in HIV/AIDS patients.

Keywords: social support, quality of life, and patients with HIV/AIDS

1. INTRODUCTION

HIV (Human Immunodeficiency Virus) is a virus that attacks white blood cells in the human immune system. At the same time, AIDS (Acquired Immunodeficiency Syndrome) is a symptom caused by HIV and is a collection of symptoms of the disease, namely a decreased immune system in humans (1). HIV attacks the immune system, especially CD4 cells (T cells), which help the immune system fight infection. Over time HIV will destroy these cells so that the body cannot fight infection and disease, the immune system becomes very weak, and opportunistic infections arise so that a person enters the condition of AIDS (2).

The epidemiology of people with HIV/AIDS in 2017 reported as many as 14,640 people infected with HIV, while AIDS was reported as many as 4,725. In 2018 the number of
people living with HIV was 37.9 million. In 2019 the number of HIV cases was reported as 11,081 people, while AIDS was reported as many as 1,536 people, and in 2020, the number of HIV nationally was 388,724 people (3). Based on the Health Office (Dinkes) records, the number of HIV/AIDS in Malang in 2018 was 508 cases. Meanwhile, the number of people with HIV/AIDS from 2005 to 2019 was 4,300. Malang City occupies the second position in East Java, with the most people with HIV/AIDS (4).

Stigma and discrimination against people living with HIV/AIDS can discourage them from carrying out their daily activities and is a challenge that, if not resolved, will hinder HIV/AIDS prevention programs and the access of people living with HIV/AIDS to enjoy human rights. The results of the research conducted by [ (5)1] show that stigma and discrimination, if not resolved, will hinder the response to people with HIV/AIDS where stigma and discrimination are felt by people with HIV/AIDS in health services, workplaces, families and the surrounding environment. 3.8% experienced delays in taking treatment due to stigma and discrimination, 75% felt sad because they were afraid of being positive for HIV/AIDS, 41% experienced depression, 49.2% turned on themselves, 47.5% felt ashamed of their condition, and 14.8% had suicidal ideation.

In principle, all national and local regulations regarding HIV/AIDS prohibit the practice of stigma and discrimination against people living with HIV/AIDS. Regulation of the Minister of Health Number 21 of 2013 concerning HIV/AIDS prevention was made, which aims to eliminate discrimination against people with HIV/AIDS by providing correct information and empowering people with HIV/AIDS (6).

The care and treatment of people with HIV are part of the health rights of people with HIV that the state must fulfill. Everyone’s right to health must be guaranteed in the Indonesian constitution as stated in article 28H paragraph (1) in the health law number 36 of 2009 concerning health (Health Law). The principle of confidentiality must be respected where if the patient does not wish not to be informed of their status to their partner or other people, the health worker may not disclose the patient’s status. Article 45 of Law No. 29 of 2004 concerning medical practice (6).

Social support is the support that is considered one of the factors to support a person’s recovery. The results of the research conducted by (7)show that social support is the support that can make people with HIV/AIDS enthusiastic in carrying out their lives. When people with HIV/AIDS do not get support from family, friends, or friends and the environment, they will feel isolated and faced with various problems, helpless, and not enthusiastic in carrying out their lives social support is found to be positively correlated with healing ($r = 660, p < 01$). Therefore, there is a relationship between social support to improve healing in people with HIV/AIDS.
Sources of social support come from the family, including husband, wife, children, parents, siblings or relatives, friends or friends, and the community. There are several types of social support, including emotional support, a sense of belonging, informational support, which increases awareness and knowledge, and instrumental support, which is helpful in everyday life (8). The research results (Subramanian, Mohan, Nandi, & Rajeshwari, 2020) show that 44% get support from family, 40.4% get support from their close friends, and almost two-thirds get support from other important people. While the results of research conducted by (10), 48.4% received emotional support, 63.4 received information support, 62.4 received award support, and 51.1% received instrument support, al.

Social support can make people with HIV/AIDS not turn on themselves, be more open to people, and express what they feel or need without being ashamed and afraid (11). The results of the research conducted by (5) showed that among people who get social support, 46.7% do not blame themselves and express what they feel. While the results of research conducted by (Roifah, Akbar, & Sudarsih, 2018) show that through social support, a person feels valued and loved, does not feel alone in dealing with all problems, and feels part of the scope of the family and the surrounding environment.

Lack of social support can impact people with HIV/AIDS, including their physical and psychological health. People with HIV/AIDS who are depressed will affect the immune system, reduce appetite, disrupt daily activities, and cause various diseases (Grieb, Kerrigan, Tepper, Ellen, & Sibinga, 2018). The results of the research conducted by (9) showed that social support could impact the physical health of people with HIV/AIDS, namely physical function, pain, role function, and energy. Social support for physical health in people with HIV/AIDS was positively related ($0.4352, p = 0.0433$). At the same time, the research results (8) showed that 56.17% of people have psychological well-being. People with HIV/AIDS who receive social support will have an impact on their psychology; namely, they do not experience pressure and are beneficial in maintaining their health, and there is a strong positive relationship between social and psychological support for people with HIV/AIDS ($r = 0.756$). If people with HIV/AIDS do not get social support, it will have an impact on various aspects of life. So this can interfere with the quality of life in people with HIV / AIDS (12).

Quality of life is a person's ability to get a decent and regular life in daily life. With a quality of life, people with HIV/AIDS experience better health and are more enthusiastic about living, so their survival time will be longer (14). The results of research (15) show that 57.6% have a good quality of life, and people with HIV/AIDS who have a good quality of life can take treatment, making it easier for them to live their lives. While 42.4% have
a poor quality of life, people with HIV/AIDS who have poor quality will find it challenging to carry out activities, do not have enough energy, often experience fatigue, and also do avoidance such as social withdrawal. In addition, people with HIV/AIDS feel helpless, anxious, hopeless, and tired quickly.

2. MATERIALS AND METHODS

The research design used in this research is correlational research (relation/association). This study uses a cross-sectional approach, an observational research design, to determine the independent and dependent variables simultaneously.

The population in this study was 45 patients with HIV/AIDS at the Cahya Kasih Cares AIDS Foundation WPA Turen. The sampling technique in this study uses total sampling, which is the number of samples taken equal to the population. The sample in this study amounted to 45 HIV/AIDS patients at the Cahya Kasih Peduli AIDS Foundation WPA Turen.

The independent variable in this study is social support. Social support is a support that can support someone’s recovery. Social support makes a person feel cared for, valued, respected, and loved. The indicators are Guidance, Reliable alliance, Reassurance of wort, Attachment, Social integration, and Opportunity of nurturance (Cutrona & Russel 1987, in).

The dependent variable in this study is Quality of Life. The individual’s ability to get a decent or regular life in daily life. The indicators are physical health, psychological, social relations, and environment (WHOQOL BRIEF from WHO (2004, in)).

This research was conducted in Turen District, Malang Regency, in September 2020. This study used a social support questionnaire, namely the Social Provision Scale from (20)in 1987, which was developed by (18). The social support questionnaire was tested for validity by Cutrona & Russel (in 18) on 30 respondents to find out demographic data and general description of research participants, and the results of the validity test were obtained with the correlation coefficient of all question items (r = -0.072-0.648).

This study used a questionnaire from the WHOQOL BREF in 2004 developed by (21). The quality of life questionnaire was tested for validity by (21)30 respondents, which showed the results of the instrument’s validity test with a validity coefficient value (p <0.05) with a substantial correlation coefficient value (r = 0.81 - 1.00).

The reliability test used in this study used a questionnaire, namely the social support questionnaire in the reliability test score of 0.842 by (22) and quality of life in the reliability...
test score of 0.882 by (21) using Cronbach’s Alpha formula with the help of a program in a computer value tool. Both the questions are Reliable.

In the study, this data analysis uses SPSS Statistics 25 application. Analysis bivariate uses Correlation Test Spearman Rank.

3. RESULTS

This data collection was carried out on September 13 to 15, 2020, at the Cahaya Kasih Peduli AIDS Foundation, WPA Turen. The respondents studied were people with HIV/AIDS, as many as 45 people. The results of this study will present the acquisition of data on respondent characteristics, including age, gender, education level, occupation, length of illness, suspected transmission, and social support for quality of life in people with HIV/AIDS. The results of the study are described as follows.

The research data obtained from the respondents in terms of the social support domain are presented in table 3.1:

<table>
<thead>
<tr>
<th>Domain</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>STS</td>
</tr>
<tr>
<td>Guidance</td>
<td>10</td>
</tr>
<tr>
<td>Reliable alliance</td>
<td>2</td>
</tr>
<tr>
<td>Reassurance of worth</td>
<td>12</td>
</tr>
<tr>
<td>Attachments</td>
<td>5</td>
</tr>
<tr>
<td>Social integration</td>
<td>2</td>
</tr>
<tr>
<td>Opportunity of nurturance</td>
<td>5</td>
</tr>
</tbody>
</table>

Based on the table above can be seen that percentage highest found in the Attachment domain at 35.6% and followed by the Reliable alliance domain at 33.9%, the Social integration domain at 30.0%, the opportunity of nurturance domain at 29.4%, the Guidance domain at 28.3% and the Reassurance domain of worth 26.7%.

Research data obtained from respondents in terms of the level of social support are presented in table 3.2:

<table>
<thead>
<tr>
<th>Domain</th>
<th>Percentage %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>STS</td>
</tr>
<tr>
<td>Guidance</td>
<td></td>
</tr>
<tr>
<td>Reliable alliance</td>
<td></td>
</tr>
<tr>
<td>Reassurance of worth</td>
<td></td>
</tr>
<tr>
<td>Attachments</td>
<td></td>
</tr>
<tr>
<td>Social integration</td>
<td></td>
</tr>
<tr>
<td>Opportunity of nurturance</td>
<td></td>
</tr>
</tbody>
</table>
TABLE 2: Levels of Social Support for People with HIV/AIDS at the Cahaya Kasih Peduli AIDS Foundation WPA Turen.

<table>
<thead>
<tr>
<th>Social Support</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less Support</td>
<td>1</td>
<td>2.2%</td>
</tr>
<tr>
<td>Enough Support</td>
<td>9</td>
<td>20.0%</td>
</tr>
<tr>
<td>Optimal Support</td>
<td>35</td>
<td>77.8%</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
<td>100%</td>
</tr>
</tbody>
</table>

have a score of 77.8%, which means that respondents predominantly have optimal social support.

The research data obtained from respondents in terms of the quality of life domain are presented in table 3.3:

TABLE 3: Domains of Quality of Life in People with HIV/AIDS at the Cahaya Kasih Peduli AIDS Foundation WPA Turen.

<table>
<thead>
<tr>
<th>Domain</th>
<th>N</th>
<th>mean</th>
<th>Standard Deviation</th>
<th>Percentage (100%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Low %</td>
</tr>
<tr>
<td>Health Physique</td>
<td>45</td>
<td>2.33</td>
<td>522</td>
<td>1</td>
</tr>
<tr>
<td>Psychological</td>
<td>45</td>
<td>2.58</td>
<td>543</td>
<td>1</td>
</tr>
<tr>
<td>Social Relations</td>
<td>45</td>
<td>2.51</td>
<td>589</td>
<td>2</td>
</tr>
<tr>
<td>Environment</td>
<td>45</td>
<td>2.38</td>
<td>535</td>
<td>1</td>
</tr>
</tbody>
</table>

Based on the table above, it can be seen that on a scale of 0-100, the score for each domain of quality of life in the physical health domain has a mean of 2.33 with a standard deviation value of 522, the percentage score is 62.2%, which means that respondents are dominated by moderate physical health, domain psychology has a mean of 2.58 with a standard deviation of 543, a score percentage of 60.0% is obtained, which means that respondents are dominated by high psychology, the social relation’s domain has a mean of 2.51 with a standard deviation of 589, which means that the percentage score is 55.6%, which means that Respondents are dominated by having high social relations and the environmental domain has a mean of 2.38 with a standard deviation value of 535. The percentage score is 57.8%, which means that respondents are dominated by a moderate environment.

The research data obtained from respondents in terms of the level of quality of life are presented in table 3.4:

Based on the table above, it is known that the results of the quality of life for people with HIV/AIDS at the Cahaya Kasih Peduli AIDS Foundation in WPA Turen have a score
The distribution of respondents based on social support for the quality of life of people living with HIV/AIDS at the Cahaya Kasih Foundation for AIDS Cares WPA is presented in table 3.5:

**TABLE 5: Relationship of Social Support to Quality of Life of People Living with HIV/AIDS at Yayasan Cahaya Kasih Peduli AIDS WPA Turen.**

<table>
<thead>
<tr>
<th>Social Support</th>
<th>Correlation Coefficient</th>
<th>Quality of Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sig. (2-tailed)</td>
<td>1.000</td>
<td>0.726 **</td>
</tr>
<tr>
<td>N</td>
<td>45</td>
<td>45</td>
</tr>
<tr>
<td><strong>. Correlation is significant at the 0.01 level (2-tailed).</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on the table above using the *Spearman Rank* Correlation Test it is known that, the significance value (p) is 0.000 where the value is smaller than < 0.05 (p<α) which means H1 is accepted so that there is a relationship between social support and quality of life for HIV/AIDS at the Cahaya Kasih Peduli AIDS Foundation WPA Turen. The value of the correlation coefficient in this study was 0.726, which means a strong and positive relationship, meaning that the higher the social support, the higher the quality of life for people with HIV/AIDS.

### 4. DISCUSSION

This study categorizes social support into two categories, namely good and bad. Based on the results of the study, it was found that 45 respondents at the Cahaya Kasih Cares AIDS Foundation WPA Turen, namely 1 (2.2%) received less support, 9 (20.0%) received sufficient support, and 35 (77.8%) received support. Optimal. Respondents who get a
lot of optimal social support, this is because the results of the study prove that as many as 35.6% of respondents get attachment support where there is support from at least one person to be able to share solutions and information. This agrees with research conducted by (13) in his research stating that social support plays an important role in people with HIV/AIDS in carrying out their daily lives, namely the existence of social closeness. This closeness is made to someone in interaction, such as assisting.

From the results of the research on social support in chapter V table 3.1, the highest percentage is found in the attachment domain (attachment) of 35.6%, the majority of respondents expressed positive responses to items, it can be proven in points 2, 11, 17, and 21. One of them is in item 11, ”I have a close relationship that gives me a feeling of security and well-being,” with the respondent answering “appropriately,” which indicates that the respondent gets emotional support from at least one person to be able to share solutions and information. In addition, respondents indicated that there is a guarantee of someone who can help them when they are having difficulties and need assistance in providing access to health services or someone who can be relied on if needed. This can be demonstrated by looking at points 1, 10, 11, and 23, one of which is point 1: ”There is someone I rely on to help if I need it,” where respondents answered ” Appropriately,” where respondents are in the reliable alliance domain (guaranteed that someone is there to help), obtained a percentage of 33.9%.

In the domain of social integration (social integration), respondents received a positive response; namely, some people enjoy social activities and have concern and trust in them, which is 30.0%, this can be proven in points 5, 8, 14, 22, one of which is in Item 5 ”there are people who enjoy the same social activities as I do” with the respondent answering ”appropriately.” In points 4, 7, 15, and 24, one of which is ”there are people - people who depend on me for aid,” respondents correctly responded, indicating that the feeling of a need felt by others within the opportunity of nurturance domain (the opportunity to love) can be proven.

In addition, respondents get support from people when they are experiencing problems, both in providing advice, and information and also awards contained in the guidance domain (guidance) obtained a percentage of 28.3% can be proven in points 3, 12, 16, 19 one of which is in point 16 ”there are people I can trust to give me advice when I am having problems” with the respondent answering ”appropriately”. This shows that there is the support given to them. While in the domain of reassurance of worth (self-esteem) of 26.7%, it can be proven in points 6, 9, 13, 20, one of which is in point 13 ”I have relationships with other people who recognize my competence and skills” with respondents answering ”according to “So it shows that respondents get a positive
response where there are people who value their abilities and consider themselves competent.

According to (8) when someone has a problem he is facing, then a person needs to get social support from other people such as family, friends, or friends and the community environment. Some social support includes emotional support, which is a sense of belonging, information support that increases awareness and knowledge, and instrumental support is assistance in everyday life, according to Myers (in, (23) the factor that can lead to the formation of social support is empathy, where providing support to someone is the existence of social relationships so that they can reduce the problems they are facing.

Based on the results of the study, it was found that the 45 respondents at the Cahaya Kasih Cares AIDS Foundation WPA Turen 1 (2.2%) had low quality of life, 10 (22.2%) had moderate quality of life, and 34 (75.6%) get a high quality of life. Respondents who get a low quality of life, this can be proven in the question contained in item 20 "how satisfied are you with your personal/social relationship?" and item 26, "how often do you have negative feelings such as feeling blue (lonely) despair, anxiety and depression?". Agree with the research conducted by (15). when people with HIV/AIDS have a low quality of life, it will be difficult for them to carry out activities, do not have enough energy, often experience fatigue and avoid social withdrawal. In addition, people with HIV/AIDS feel helpless, anxious, hopeless, and tired quickly. In addition, according to research conducted by (24)people with HIV / AIDS who get a high quality of life, this is because they get support from family, friends, or friends and the surrounding environment. Quality of life is the view or feeling of people with HIV/AIDS on their functional abilities as a result of being infected with HIV/AIDS, such as physical health, psychological conditions, level of independence, social relationships, and individual relationships with their environment. People with HIV/AIDS who have a high quality of life can influence their treatment and ease of living.

According to the research's findings in Provisions Of section table 3.3, the psychological domain, with an average score of 2.58 and a percentage score of 60.0%, has the highest average score of the question points. Psychological health is defined as health-related to psychology, such as anxiety, depression, feeling afraid, or an unpleasant condition in him due to the disease he was experiencing. The domain of social relations, with an average score of 2.51 and a percentage score of 55.6%, is next. The social relationship is a condition that describes a person's relationship with others, such as sex with their partners, family, and relationships with people around them; the environmental domain is 2.38, with a percentage score of 40.0%. The relationship with the environment
describes the state of the home environment, the opportunity to receive information, care, and security, and how satisfied patients are with their health services and the physical domain is 2.33 with a percentage score of 33.5%, according to WHOQOL-BREF (2004, in (21)). Physical health is health related to the state of the human body. Good physical health in this research is seen from making daily activities, sleeping patterns, and taking medication.

Factors that affect the quality of life, according to (25), include family support, namely support given to family members when family members are in good health or sick. Therefore, the family is the main role in providing support to family members, support from friends or friends, namely support given or mutual support between others when healthy or sick and support from the environment, namely support given to a person or individual. Social support makes a person feel valued, loved, and respected. So this can affect a person’s quality of life. According (26) to other factors that can affect the quality of life in addition to sociodemographic characteristics, stress, and coping abilities, social support can also affect a person’s quality of life. Social support is an effort to assist others that aims to improve the quality of mental health and increase self-confidence.

Based on the Spearman Rank Correlation Test used to analyze the data, the significant value (p) = 0.000, where the value is less than 0.05 (p ), was determined. It indicates that H1 is accepted, supporting the hypothesis that, at the WPA Cahaya Kasih Cares AIDS Foundation, there is a link between social support and high quality of life for those living with HIV/AIDS. This is in line with Heniyuniarti’s (2014) assertion in (27) that social support significantly impacts the quality of life for those living with HIV/AIDS. In addition, social support has a strong impact on improving the quality of life for people with HIV/AIDS, where when a person gets social support, they have the opportunity to get a good quality of life.

People with HIV/AIDS need social support as the main support system, social support can minimize the pressure experienced by people with HIV/AIDS, both physically and psychologically. The social support provided to people with HIV/AIDS will improve their lives and provide a positive response to their social environment. In addition, social support is an effective strategy to improve the health and well-being of people living with HIV/AIDS (28).

Quality of life in people with HIV/AIDS is very important to note because HIV/AIDS is a chronic, progressive disease that can cause physical, psychological, and social problems in people with HIV/AIDS. This agrees with the research(27) that the quality of life is the level of well-being felt by a person with the quality of life that can make a person feel satisfaction in living his life in both physical health and psychological and
social relationships. Therefore, it is crucial to provide persons with HIV/AIDS with social support since it can help them feel more motivated to live their everyday lives, take their medications, and manage stress, among other things.

5. CONCLUSION

The researchers drew the following conclusions based on the research on the relationship of social support to the quality of life of HIV/AIDS at the Cahaya Kasih Peduli AIDS Foundation, WPA Turen. First, People living with HIV/AIDS at the Cahaya Kasih Care Foundation for AIDS WPA Turen fall into the category of optimal social support. Second, people living with HIV/AIDS at the Cahaya Kasih Cares Foundation for AIDS WPA Turen fall into the high quality of life category. Third, there was a relationship between social support and quality of life in people with HIV/AIDS at the Cahaya Kasih Cares Foundation for AIDS WPA Turen.

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References


