

Psychological well being of families of people living with HIV/AIDS (PLWHA)

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ABSTRACT

Background: HIV/AIDS is a terminal disease that remains the leading cause of death worldwide, including in Indonesia. This disease has a wide impact, not only for sufferers but also for their social environment. Caregivers of people living with HIV/AIDS (PLWHA) often experience psychological distress, especially when they are not prepared to care for sick family members. Their ability to fulfill the five family duties in health is greatly influenced by their psychological well being.

Objectives: This study aims to describe the psychological well-being of caregivers of people living with HIV/AIDS (PLWHA) in Sumedang regency.

Methods: The method used in this research is descriptive quantitative. The sample in this study amounted to 196 respondents selected by simple random sampling technique. The instrument used was the Ryff Psychological Well-Being Scale, which has a validity range of 0.279 to 0.660 and a reliability score (Cronbach's Alpha) of 0.885.

Results: The results of the study showed that most caregivers (52.1%) were in the moderate psychological well-being category, while 47.9% were in the high category. Among the six dimensions of psychological well-being that were studied in this study, only purpose in life and personal growth were predominantly in the high category (50-60%). The demographic analysis revealed that most respondents were aged 20–55 years (M = 36.3, SD = 10.9), the majority were female (56.1%), and most worked as housewives (44.8%). The duration of caregiving was predominantly 1–5 years (61.7%; M = 2.7, SD = 2.5).

Conclusions: It can be concluded that most caregivers of People Living with HIV/AIDS (PLWHA) exhibit moderate levels of psychological well-being. This indicates that caregivers can generally accept their strengths and weaknesses, build positive relationships, adapt to their environment, set clear life goals, demonstrate independence, and engage in personal growth. Therefore, it is necessary to enhance family counseling programs within supportive care and treatment services, as well as strengthen family psychoeducation initiatives in nursing and healthcare institutions.

KEYWORD: AIDS; HIV; family caregiver; psychological well being

Article Info :

Article submitted on May 25, 2025

Article revised on August 14, 2025

Article accepted on October 29, 2025

Article Published on December 31, 2025

INTRODUCTION

HIV/AIDS remains a terminal illness and the fourth leading cause of death globally. According to the 2022 report by UNAIDS (Joint United Nations Programme on HIV/AIDS), approximately 74.9 million people have been infected with HIV, with around 32 million deaths attributed to AIDS-related illnesses (1). In Indonesia, the prevalence of HIV/AIDS remains high. Data from the Ministry of Health of the Republic of Indonesia (January-September 2023) recorded 515,455 cumulative cases, with West Java ranking fourth among the five provinces with the highest number of HIV cases. Of the total, West Java contributed around 8,307 HIV cases and 1,853 AIDS cases. Sumedang Regency, which is one of the buffer zones of the provincial capital, is also not free from HIV cases. In Sumedang District, 114 HIV/AIDS cases were recorded in 2019, which showed a significant increase compared to the previous year, when only 60 cases were recorded (2). The Sumedang Regency Health Service recorded 577 HIV cases from January 2021 to November 2024, with the main cause being MSM (men who have sex with men). This shows that the number of people living with HIV/AIDS (PLWHA) in Indonesia continues to experience a significant increase due to the rampant cases of free sex that occur in the community from at-risk groups (3).

HIV/AIDS can affect various problems in sufferers, both physically, psychologically, and socially (4). The most pronounced impact

on PLWHA and the surrounding environment is the destruction of social relationships, because the presence of this disease creates a barrier between PLWHA and the surrounding environment. The community often considers HIV/AIDS to be the result of bad morals or immoral behavior of an individual, resulting in discriminatory behavior from the community towards people and families with HIV/AIDS (5). This HIV/AIDS disease not only has an impact on PLWHA, but also has an impact on the surrounding environment, both the family and the surrounding community where PLWHA live (6). Therefore, the problems faced by PLWHA do not occur only after being diagnosed but are sustainable due to internal factors in themselves and external factors from other people's stigma towards their lives *kehidupannya* (7).

Ruth B. Freeman (1981) explained that health problems that occur in a family will be interrelated, so that when one member experiences health problems, the impact can be felt by other family members. With the bad stigma that arises in the community, it can complicate conditions in families with PLWHA. Families of people living with HIV/AIDS will experience a major impact on their lives which includes economic impact, psychological impact, and social impact (9). The economic impact felt by families with PLWHA will be even more severe if the infected are the parents in the family, because the family has a great responsibility in meeting the needs of the family, especially their children. This condition will complicate

the family's condition, because a decrease in health conditions can affect economic stability. The psychological impact can also be felt by families of PLWHA, namely in the form of fear and worry about losing family members, because HIV/AIDS is one of the terminal diseases that often results in death impact (6). Likewise, the social impact on families with PLWHA can be felt in the form of discrimination from the surrounding community. Although only one person in a family is diagnosed with HIV/AIDS, the community assumes that all family members have the potential to be affected by HIV/AIDS as well.

Cohen and Syme (1985) explain that individual psychological well-being is closely related to the social support received (9). Social support is a form of appreciation, attention, comfort and assistance that can be obtained from people around who become caregivers or caregivers, especially families. Families who become caregivers have an important task by providing social support to PLWHA, besides that the family also has a central role as a companion for PLWHA in carrying out daily life and the treatment process (10). Therefore, psychological well-being in the family must be considered because it will affect the five family tasks, especially tasks in the health sector to care for family members with HIV/AIDS. Bailon and Maglaya (1998) explained that the family has five important functions in the health sector, one of which is the health care function, which has a major influence on PLWHA (11). This is not only as a basic function inherent in the

family to maintain health, but also as preventive health care in caring for sick family members (11). A functional family is an important factor in helping to overcome health problems and improve the quality of life of family members who have health problems. If the caregiver experiences psychological problems, it will have a negative impact on the quality of assistance and quality of life for their sick family members (13).

Preliminary studies conducted by researchers at the Teratai Poli at Umar Wirahadikusumah Hospital regarding psychological problems in families with HIV/AIDS found that the length of time families accompany their family members infected with HIV/AIDS varies, from more than nine years to three months. Although the length of time of assistance varies, families of PLWHA have the same fears as the stigma that exists in the community. These fears often interfere with the psychological health of the family because they are afraid that they will be ostracized by the surrounding environment if they tell the condition of their family members. Thus, families find it difficult to express their feelings to others, feel worried about the condition of their family members, and are overwhelmed with the responsibility of caring for sick family members. Based on research by Najlawati and Purwaningsih (9), it was also found that the psychological well-being of an individual experiencing psychological problems can be influenced by the psychological well-being of the individual's family. Although numerous

studies have explored psychological well-being in people living with HIV/AIDS (PLWHA), there is a lack of research focusing specifically on the psychological well-being of their family members. In light of this gap, the present study aims to examine the psychological well-being of families with members diagnosed with HIV/AIDS to understand how it is manifested. Researchers feel this issue is important because psychological well-being in the family can affect the family process in caring for PLWHA. If the health care function of the family is hampered, it will cause PLWHA difficulties in the treatment process. This is because an individual who has a chronic disease such as HIV/AIDS requires assistance from the family in daily life and during the treatment process. Therefore, the aim of this study was to describe the psychological well-being of families of PLWHA in Sumedang Regency.

MATERIALS AND METHODS

This study employed a quantitative, descriptive design. The population consisted of families of people living with HIV/AIDS (PLWHA), totaling 320 individuals. The sample consisted of 196 literate caregivers of people living with HIV/AIDS who were proficient in using smartphones and were willing to participate in the study. Exclusion criteria included HIV/AIDS diagnosis, withdrawal from the study, or incomplete questionnaire completion. The sampling method employed a simple random sampling technique. Data collection took place over

approximately one month (March-April 2025) using the 42-item Psychological Well-Being Scale (PWBS), which was developed by Ryff. The questionnaire used had been translated into Indonesian and tested for validity and reliability. Five items were found to be invalid: items 4, 8, 31, 38, and 42. Valid items had correlation coefficients ranging from 0.279 to 0.660, while the invalid items had significance values greater than 0.05 or 0.01. Cronbach's alpha, a reliability testing method, yielded a coefficient of 0.885, indicating strong internal consistency. Items identified as invalid were removed from the instrument to ensure that only valid items were utilized in the data collection. The questionnaire employed a six-point Likert scale: strongly disagree, disagree, somewhat disagree, somewhat agree, agree, and strongly agree. The data obtained were assessed based on favorable and unfavorable item scoring. The results of the data that has been obtained will be assessed based on favorable and unfavorable. The scores obtained will be summed up and categorized according to the PWBS interpretation level, namely high ($\geq 4,01$), moderate (4,00 - 2,01), and low (2,00). This study obtained ethical approval from the Research Ethics Committee of Universitas Ngudi Waluyo with ethical clearance number 245/KEP/EC/UNW/2024 in 2024.

RESULTS AND DISCUSSION

RESULTS

Data on caregiver characteristics were used to determine the diversity of caregiver

backgrounds. The characteristics studied in this study include age, gender, religion, occupation, and length of time caring for

PLWHA. Based on the **Table 1** data collected, the following results were obtained:

Table 1. Characteristics of caregivers of people living with HIV/AIDS in Sumedang Regency (n=196)

Characteristics	Mean	Standard Deviation	Frequency	%
Age				
Adolescent	37.4	11.9	8	4
Adult			171	87.2
Elderly			17	8.6
Sex				
Male			86	43.8
Female			110	56.2
Religion				
Islam			196	100
Length of care				
< 1 year	2.7	2.5	39	19.9
1 – 5 years			121	61.7
> 5 years			36	18.4
Occupation				
Housewife			88	44.8
Enterpriser			32	16.3
Private Sector Employee			28	14.2
Laborer			21	10.7
Unemployed			18	9.1
Civil Servant			3	1.5
Student			3	1.5
Farmer			2	1
Sailor			1	0.5

Source: primary data 2025

Table 2. Psychological well being of caregivers of people living with HIV/AIDS in Sumedang Regency (n=196)

Psychological Well-Being Category	Frequency	%
High	94	47.9
Moderate	102	52.1
Low	0	0

Source: primary data 2025

Based on **Table 1**, the demographic analysis revealed that the majority of respondents in this study belonged to the age group of 20 to 55 years ($M=36.3$, $SD=10.9$); all respondents were Muslim; the majority of respondents were female with 110 people (56.1%); and the majority of respondents' occupations were housewives (44.8%). The length of time PLHIV have been assisted by caregivers was mostly in the range of 1 year to 5 years with a total of 121 people (61.7%,

$M=2.7$, $SD=2.5$), while the least number had assisted more than 5 years with 36 people (18.3%).

Based on **Table 2**, the results of the analysis of Psychological Well-Being in caregivers who accompany People with HIV/AIDS (PLWHA) show that most of them are in the moderate category (52.1%), while 94 other people scored in the high category (47.9%). Based on **Table 3**, the scores obtained by respondents vary, but they

Table 3. Psychological well being dimensions of caregivers of people living with HIV/AIDS in Sumedang Regency (n=196)

Psychological Well-Being Dimension	High		Moderate		Low	
	F	%	F	%	F	%
Autonomy	70	35.7	125	63.7	1	0.51
Environmental Mastery	75	38.2	120	61.2	1	0.51
Personal Growth	107	54.6	89	45.4	0	0
Positive Relation With Others	85	43.4	101	51.5	10	5.1
Purpose In Life	130	66.3	66	33.7	0	0
Self Acceptance	57	29	120	61.3	19	9.7

Source: primary data 2025

generally fall into the high and moderate categories. The study's results reveal that a significant portion of respondents scored in the high category in the dimensions of Personal Growth (54.5%) and *Purpose in Life* (66.3%).

Meanwhile, most respondents scored in the moderate category in the dimensions of *Autonomy* (63.7%), *Environmental Mastery* (61.2%), *Positive Relationships with Others* (51.5%), and *Self-Acceptance* (61.3%).

DISCUSSION

Based on the findings presented in **Table 2**, the psychological well-being of

caregivers of People Living with HIV/AIDS (PLWHA) in Sumedang Regency was predominantly in the moderate category (52.1%). This shows that families can adapt by accepting their own shortcomings and strengths in carrying out their duties as caregivers. Based on the study results, indicators of psychological well-being in the moderate category can be observed in caregivers who demonstrate acceptance of their strengths and weaknesses, maintain positive relationships with others and with PLWHA, are able to adapt and adjust their environment to suit themselves, have clear life goals, show independence, and possess

the capacity for continued self-development (14). Informal caregivers often do not perceive themselves as caregivers, instead viewing their responsibilities as a natural part of familial roles and relationships (15). However, this perception does not protect them from experiencing a heavy caregiving burden, which can increase stress, caregiving strain, and negative emotions such as fear and a persistently low mood (16). Stressful conditions have also been found to be associated with the onset of psychological symptoms among caregivers (17).

Positive psychological well-being is a description of the state of positive thoughts, feelings and strategies that a person has to assess their life and function well (18). Psychological well-being refers to how an individual lives a complete life and feels satisfied with the development of his life (19). Psychological well-being of the caregiver can be said to be good when viewed by considering the interaction between the caregiver's relationship with the care recipient. This can be influenced by the intensity of caregiving, living arrangements, age, and ethnicity of the caregiver (20). The intensity of caregiving for respondents in this study was said to be high, because most of the respondents were parents or spouses of PLWHA who lived under the same roof. Psychological well-being in caregivers is also closely linked to how they perceive their decision to assume caregiving responsibilities. If caregivers evaluate the caregiving situation positively, it is more likely to result in positive caregiving

outcomes (21). There are various factors that can influence the level of psychological well-being, both internal and external. Internal factors refer to influences that originate from within the individual, including age, gender, religiosity, personality, and stress. In this study, most respondents were in the age range of 20 to 55 years (87.2%), which falls within the adult age category. Details of these characteristics are provided in **Table 1**. This suggests that higher psychological well-being is associated with increasing age, especially among individuals who feel proud of their age group. These individuals tend to display a more optimistic attitude toward aging and the future, experience fewer negative emotions, feel more confident in their bodies, and show greater flexibility in setting goals (22). Ryff's (1989) research also revealed that age influences psychological well-being, as evidenced by increased autonomy and a stronger sense of purpose in life with advancing age (23).

The results presented in **Table 3** indicate that most caregivers scored in the moderate category ($n = 125$; 63.7%) and in the high category ($n = 70$; 35.7%) for the autonomy dimension. This shows that caregivers are able to determine their own destiny and believe in their own values. Autonomy or independence is a condition in which a person is able to believe in the values that exist within themselves, which can determine their own destiny and self-evaluation (23). In line with research Cook Maher et al., (24) which says that, this autonomy dimension

shows an individual is able to determine his own destiny and feel independence over himself.

Purpose in life is a crucial aspect of psychological well-being, and it can be shaped by age. This dimension reflects an individual's belief that their life, both past and present, has meaning and is guided by clear goals and objectives. Based on the research findings related to the purpose in life dimension, the majority of caregivers of People Living with HIV/AIDS (PLWHA) were classified in the high category ($n = 130$; 66.3%), while the remaining 33.7% were in the moderate category, as shown in **Table 3**. This shows that purpose in life has an important role in determining a good psychological well being in a person, but it can also play a role in the process of caring for PLWHA. Purpose in life is a situation where individuals have a direction, mission, life purpose that gives meaning to their life experiences (11) . In line with Ryff's (1989) opinion, which states that purpose in life is a dimension consisting of a sense of pursuing personally meaningful directions and goals (25). This sense of life purpose is also defined as the perception that life holds meaning and intentionality, rooted in the present and oriented toward the future (26). Understanding life purpose can be an important mediator in health and psychological well being, it also shows that life purpose results from caregivers who re-evaluate their priorities as a result of providing care (27). This is consistent with the findings of a study by Abshire Saylor et

al.,(28), which concluded that efforts to promote a sense of purpose in life and enhance social support systems can have significant implications for improving caregiver well-being and the quality of care.

Researchers also obtained research results showing that all respondents were Muslim (100%), but the level of religiosity of each individual was not studied. The results of Gonyea and O'Donnell found that caregivers who question God's power or do not have faith tend to feel overwhelmed, unable to meet the demands in life, feels that he is being punished by God, and sees a bleaker future. This is related to how individuals make meaning of their lives, so that they can improve their psychological well-being (30). Thus, religiosity is a factor that can affect the purpose in life dimension, because religiosity also plays an important role in how a person makes meaning of his life.

Gender also emerged as an influencing factor. The results indicated that the majority of respondents who were classified as having moderate psychological well-being were women ($n = 110$; 56.1%), predominantly working as housewives, as illustrated in **Table 1** . These findings are in line with the study by (19), it was reported that women tend to score higher in the dimensions of personal growth and positive relations with others, whereas men tend to score higher in self-acceptance and autonomy. The findings in **Table 3** show that caregivers' scores on the personal growth dimension were exclu-

sively in the high (54.6%) or moderate (45.4%) categories, with no participants in the low category. This suggests that caregivers are able to actualize their potential and evaluate their achievements, as this dimension reflects ongoing personal development and openness to new experiences (31). Personal growth also refers to individuals' continuous efforts to enhance their skills and improve their overall quality of life. Moreover, growth in caregivers is linked to effective family functioning and the receipt of adequate support from relatives and friends (32).

The dimension of positive relationships with others is another aspect of psychological well-being that is influenced by gender factors. According to Snyder (2002), this is due to a mindset that affects coping strategies and social activities, where women are more skilled at building interpersonal relationships compared to men (33). The majority of respondents in this study scored in the moderate category (51.5%), which indicates that a person has the ability to build good relationships, full of empathy, and mutual give and take in social interactions (34). The caregiving experience can be considered positive if it leads to an increase in self-esteem and the establishment of good relationships with others. One of the positive aspects felt by informal caregivers, namely feeling satisfied and useful for their sick family and characterized by a loving relationship between the caregiver and the recipient of care (16). Not only internal factors, but there are external factors that also affect a person's

psychological well being, namely socio-economic status. The findings presented in **Table 3** show that most respondents were housewives (44.8%), with a smaller proportion being unemployed (9.1%). There are studies that show that good psychological well-being has a close relationship with a person's economic situation, and in this case many are found in people who work compared to those who do not work (35). Failure in work can cause job stress that can trigger a decrease in psychological well being in an individual, which can ultimately damage performance and productivity at work (30). This socioeconomic status can affect several dimensions, including self acceptance, environmental mastery, and personal growth.

As reflected in **Table 3**, most respondents demonstrated acceptance of their condition and a positive attitude toward their caregiving responsibilities, with 61.3% scoring moderate and 29.0% scoring high on the self-acceptance dimension. In this dimension, only 19 people scored in the low category (9.7%). This shows that caregivers have accepted themselves as caregivers for their families diagnosed with HIV/AIDS. Thus, respondents are able to understand, appreciate and feel satisfied with the circumstances they have. Self-acceptance refers to a positive attitude toward all aspects of an individual's life—past, present, and future—and is considered a key indicator of mental health (36). Individuals with high self-acceptance are generally able to recognize and appreciate their strengths while also

acknowledging and accepting their limitations (37). In the Environmental Mastery dimension, the majority of respondents were in the moderate category (61.2%), followed by the high category (38.2%), with only one respondent (0.51%) in the low category, as presented in **Table 3**. This dimension examines how individuals master and have competence in managing their lives and environment. The study's results show that caregivers have successfully adapted to their environment and life. Environmental mastery involves shaping or creating various life contexts to meet psychological, practical, and physiological needs (15). According to Ryff (1989), Environmental mastery refers to an individual's ability to choose or create an environment that suits their personal needs and values (25). In addition to socioeconomic factors, the length of time of assistance can also play a role in the psychological caregiver, especially in the environmental mastery dimension. In this study, most of them have accompanied their families diagnosed with HIV/AIDS for 1 to 5 years (61.7%). The longer a person performs their duties as a caregiver, the higher the caregiver's ability to carry out the care process because they have a lot of experience (38).

Psychological well-being in caregivers is very important because it can be related to the process of caring for PLWHA. If caregivers experience psychological problems, it will adversely affect the quality of assistance and quality of life of their sick family members (13). All respondents can be said to be a

functional family, because they can help PLWHA in overcoming health problems and improving their quality of life (11). Adherence to taking medication in HIV/AIDS patients is the key to the success of the treatment process which can affect the life expectancy and quality of life of PLWHA (39). The success of the treatment process can be seen from the examination of the number of viral load levels, if the level of compliance is high, the viral load level will be better or even undetectable (40). The success of treatment is the result of a combination of individual factors, collective factors, biological factors, and social factors (39). One of the social factors influencing the success of antiretroviral (ARV) treatment in people living with HIV/AIDS (PLWHA) is family support. A study by Herawati et al., (41) found a significant relationship between family support and adherence to ARV medication in PLWHA. In this study, 78.4% of patients with strong family support adhered to their medication regimen, whereas those with inadequate family support were less likely to adhere to ARV treatment.

CONCLUSION AND RECOMMENDATION

This study reveals that the psychological well-being of family caregivers of people living with HIV/AIDS (PLWHA) in Sumedang Regency predominantly falls within the moderate to high categories. While dimensions such as purpose in life and personal growth exhibit higher levels of well-being, autonomy, environmental mastery, positive relationships with others, and self-

acceptance remain relatively lower among a small proportion of respondents. Future research is recommended to explore additional factors that influence the psychological well-being of PLWHA caregivers, including social support, coping strategies, and socioeconomic differences. The findings of this study can serve as a reference for HIV/AIDS support and treatment services in Sumedang Regency to enhance structured family counseling programs. Additionally, they can inform nursing institutions in developing targeted interventions to address psychosocial challenges within caregiving families.

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