

THE URGENCY OF SOCIAL SUPPORT AS THE PREVENTION OF LOST TO FOLLOW-UP (LTFU) STRATEGY ON PEOPLE LIVING WITH HIV/AIDS (PLWHA) IN GARUT REGENCY, WEST JAVA, INDONESIA

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Abstract

The social support received by people living with HIV/AIDS (PLWHA) plays a very important role in increasing their self-confidence and meaning of life and enabling them to continue their lives. The purpose of this study is to describe the social support received by PLWHA in Garut Regency as a strategy that can be used to prevent lost of follow-up antiretroviral therapy for PLWHA. This study uses a qualitative descriptive method. The informant selection technique in this study used purposive sampling, with the number of informants obtained reaching as many as 10 people. Data collection in this study was obtained from in-depth interviews, observation, and documentation studies. The location of this research was Garut Regency. The study results indicate that LTFU is a big challenge for PLWHA. First, the side effects that are caused by PLWHA make PLWHA feel uncomfortable. PLWHA prefer to stop taking medication because they are unable to overcome the side effects of ARV therapy. Second, the stigma and discrimination attached to PLWHA also make them lazy to continue their treatment because they are embarrassed and do not want to get stigma and discrimination, which makes PLWHA choose to stop their treatment. Social support, especially from family members, played a major role in PLWHA's being able to consistently undergo ARV therapy. The family member who knows about PLWHA's condition helps remind PLWHA to always take medication and check their health condition routinely at the hospital. In addition, social support from NGOs also plays an important role in helping PLWHA get access to affordable or free health services. Social support from buddies at NGOs who are also HIV-positive turned out to be very helpful for PLWHA in accepting their condition as HIV-positive people. It can be concluded that social support strengthens PLWHA to be able to continue their lives with more confidence, meaning, and stronger personalities in the middle of a society that still gives stigma and discrimination to PLWHA.

Keywords:

social support, PLWHA, strategy, LTFU, stigma, discrimination

INTRODUCTION

The World Health Organisation (WHO) has noted that there are around 38.4 million people living with HIV (PLWHA) worldwide in 2021. Of this number, the majority came from the African region, namely 25.6 million cases. Meanwhile, the cumulative number of HIV and AIDS cases in Indonesia until September 2022 reached 493,118 cases with a division of 351,109 cumulative HIV cases and 142,009 cumulative AIDS cases. Compared to 2021, there was an increase in the number of findings in AIDS cases by 769 cases. AIDS cases in Indonesia in 2021 were found to be 5,750 cases while in 2022 AIDS cases increased to 6,519 cases. In contrast, the number of HIV cases decreased compared to 2021. The number of HIV cases until September 2022 was found to be 36,665 cases and decreased by 237 cases when compared to HIV cases in 2021 which were found to be 36,902 cases (Ministry of Health, 2022).

The distribution of HIV-AIDS cases in West Java based on data from the West Java Health Office from January to June 2022, the areas with the highest AIDS cases are Cirebon City with 61 cases, Bandung City with 52 cases, Garut Regency with 35 cases, Subang Regency with 24 cases, Sukabumi City with 19 cases, and Ciamis with 7 cases (Abdussalam, 2022). However, the region in West Java that has experienced a significant increase in HIV-AIDS cases in the last two years is Garut Regency. Compared to 2018-2020 where the addition of HIV cases in Garut Regency was never more than 100 cases per year, while in 2021 114 new cases of HIV-AIDS were found, 11 cases were AIDS and 4 people died of AIDS. In 2022, 182 new HIV cases were found, 89 of which were AIDS and 2 people died of AIDS. Cumulatively, the

number of HIV-AIDS cases reached 1,004 people until December 2022 in Garut Regency. Of the total cumulative cases, 181 people (18%) have died, out of 823 PLWHA, only 722 people followed antiretroviral therapy, while 101 people dropped out (lost to follow up). Based on risk groups, 182 new HIV cases were identified in 2022, 57% of which came from the homosexual population, followed by 34% of the heterosexual population, and 6% of the bisexual population. It is known that the highest proportion of HIV infection in Garut Regency is due to risk factors from male sex male (MSM) and heterosexual behaviour (Putra, 2023).

The problems faced by people living with HIV/AIDS (PLWHA) are not only related to physical conditions, but also psychological, social and economic problems (Diyanayati, 2006; Poindexter, 2010). Physical problems such as weight loss, changes in appearance, skin diseases, lung disorders, tuberculosis, and others. Psychological problems such as stress, anxiety, fear, depression. Socio-economic problems such as experiencing stigma and discrimination, difficulty in paying for treatment (Indriani & Fauziah, 2017; Wahyu et al., 2012).

Physical problems in PLHIV caused by the lack of information about HIV/AIDS have an impact on the behaviour patterns of PLHIV in undergoing treatment. PLHIV with limited knowledge about HIV/AIDS trivialise the symptoms they experience and are indifferent to the condition of their disease. This greatly affects the recovery process of PLWHA. In addition, psychological problems in PLWHA not only affect PLWHA such as feeling sad, anxious, isolated, hopeless but also have an impact on the family of PLWHA where families who know their family members are

infected with HIV / AIDS feel sad, angry, confused, afraid which has an impact on family treatment of family members infected with HIV / AIDS (Rahakbauw, 2018).

Social support for PLWHA needs to be provided because it can increase self-confidence and develop the quality of life of PLWHA. Social support provided to PLHIV in the form of providing comfort, attention, appreciation, or in other forms greatly helps PLHIV in carrying out daily activities. Social support provided by the family can raise the mentality of PLHIV in continuing life, while social support provided by the environment helps PLHIV in living social life in the community so that PLHIV have the enthusiasm to resume their lives (Attari, 2018).

In a research conducted by Astuti and Budiyan (2010), it was found that there was a positive relationship between social support received and the meaning of life in PLWHA. Providing social support can provide understanding and awareness of the meaningfulness of life of PLWHA, especially when PLWHA experience pressure (Astuti & Budiyan, 2010). Another study conducted by Siddik (2018) also showed the same thing that there was a significant positive correlation between sincerity and social support for the meaningfulness of life in PLWHA. From the results of this study, it is known that the higher the social support provided to PLWHA, the higher the meaningfulness of life for PLWHA (Siddik et al., 2019). In another research conducted by Sumiyati and Hidayat (2022) related to the relationship of social support to quality of life in PLWHA where one aspect that affects quality of life is the meaningfulness of work shows that there is a relationship between social support and the quality of life of PLWHA (Sumiyati et al., 2022). Based on previous studies, it is known

that social support in PLWHA has a relationship in the meaningfulness of life of PLWHA. This research aimed to see an overview of the importance of social support as a strategy for people with HIV/AIDS in preventing lost to follow up related to treatment in people with HIV/AIDS at PKBI Garut Regency.

LITERATURE REVIEW

Social support has an important role in the quality of life of people with HIV / AIDS because PLWHA not only need treatment related to physical conditions and therapy. According to Nasronudin in (Azwan et al, 2015) one of the factors that has an important role in the quality of life of PLWHA is social support. The definition of social support contains an understanding as a comfort, attention, appreciation and assistance that a person feels from other people or other groups (Uchino, 2008). The formation of social support will make a person feel valued, loved and feel recognised and accepted in society so that it can trigger a better quality of life. Based on research journals (Munaing & Justika, 2020), social support has a significant effect on the quality of life of PLWHA and the value of social support affects the quality of life of PLWHA.

Social support is defined as helping actions obtained through social relationships (Norris, 1996). Nietzel et al (1998) say that social support is very important in various aspects of individual life, considering that individuals are social creatures who are always in contact with one another. Social support gives individuals the experience that they are loved, valued, and cared for. Attention and support from others will foster hope for a longer life while reducing individual anxiety. Conversely, the lack or unavailability of social support will make individuals feel worthless and isolated (Toifur and Prawitasari, 2003).

Social support can be derived from various sources such as family, partners (husband, wife, boyfriend), friends or companions, counsellors, and doctors or paramedics (Meyrowitz, 1980). There are four types of social support based on House (Semet, 1994), namely: 1) emotional support which includes expressions of empathy, care and concern for the person concerned; 2) informative support which includes providing advice, instructions, suggestions or feedback; 3) instrumental support, namely providing facilities and facilitating the goals to be achieved in the form of material, providing opportunities and time opportunities; 4) appreciation support or positive assessment, namely in the form of expressions of respect (appreciation) positive for someone, encouragement to move forward, giving appreciation for the efforts that have been made, providing feedback on results or achievements.

The existence of support from people such as family, spouses, good friends, fellow sufferers and friends who are not sufferers, counsellors, and doctors in the form of emotional support, information support, instrumental support, and self-assessment will give PLWHA the experience that they are loved, cared for, and cherished. These experiences lead PLHIV to a belief that they still matter to those closest to them. In addition, these experiences also make PLHIV realise that they still deserve to live despite having HIV. This reduces the thought of suicide (Astuti & Budiyan, 2010).

Antiretroviral treatment (ARV) is one way to reduce AIDS mortality, HIV-related morbidity, and improve the quality of life of people living with HIV/AIDS (PLWHA) (Ministry of Health, 2011; Mukarromah et al., 2021). ARV therapy for PLWHA has positive impacts such as improving health, reducing the risk of HIV virus transmission, and

extending the lives of PLWHA (Kurniawan et al., 2023). ARV therapy carried out routinely can effectively control HIV virus replication, improve immune function, and reduce mortality so that PLWHA have a higher life expectancy (Aglemyer et al, 2013).

Patient compliance in undergoing Antiretroviral (ARV) therapy can be influenced by several factors. According to previous studies, factors that influence PLWHA in carrying out ARV therapy are patient characteristics, physical form and side effects of drugs, availability of drugs, negative views or stigma from the community, PLWHA do not feel the severity of their health condition, knowledge, provision of motivation, improved health conditions after treatment, family support, the role of health workers and peer support groups (KDS), the environment, PLWHA's commitment to undergo treatment, perceptions of PLWHA, access to services, and adherence counselling services in undergoing ARV therapy (Marpaung, 2016; Rahmadani et al., 2017; Anok et al., 2018), 2017; Anok et al., 2018; Hestia, 2019; Mukarromah & Azinar, 2021).

Loss to follow up (LTFU) is a condition when people with HIV/AIDS stop taking Antiretroviral virus (ARV) drug therapy or in other words PLWHA who experience drug withdrawal. There are several factors that make PLWHA experience drug withdrawal based on previous studies. Research conducted by Arisudhana et al (2022) on the correlation of stigma with loss to follow up (LTFU) conditions in people with HIV/AIDS (PLWHA) showed a very significant relationship. In the study, it was explained that stigma has an impact on the success of PLWHA treatment and has the potential to six times affect PLWHA to experience drug withdrawal (Arisudhana & Artati, 2022).

Research conducted by Artati (2022) on the Survey Study of Lost to Follow Up in PLWHA in Badung Regency, Bali showed that out of 141 respondents, 47 respondents were found to be in a drug withdrawal condition (LTFU) with most PLWHA including LTFU being male. LTFU in the study was PLWHA who did not carry out ARV control and therapy for more than 3 months. In addition, the research also found that PLWHA who experienced LTFU in terms of educational characteristics were PLWHA with low levels of education and did not have good knowledge about drug adherence (Artati, 2022).

In a study conducted by Haerati (2019) related to LTFU in PLWHA in Bulukumba Regency, it is known that PLWHA who experience LTFU feel that ARV therapy does not provide benefits to their health conditions and prefer to drop out of drugs because they cannot withstand the side effects and boredom in undergoing ARV therapy. In addition, the study also illustrates that informants in Haerati's (2019) research who experienced LTFU did not get much support from their families because they were afraid of stigma and discrimination (Haerati et al., 2019).

Research with a similar theme conducted by Irmawati et al (2019) found that based on data from Yayasan Peduli Kelompok Dukungan Sebaya (YPKDS) in Makassar in 2015, out of 1,598 PLWHA undergoing ARV therapy, 406 PLWHA experienced LTFU. In addition, the study found that there were 2 variables associated with LTFU conditions in PLWHA, namely family support and side effects of ARV drugs. However, the conclusion of the study suggested that the side effects of ARV drugs were the most influential variable on the occurrence of LTFU among PLWHA (Irmawati & Masriadi, 2019).

Based on these previous researches, it is known that LTFU is a challenge in the treatment of PLWHA. There are several factors that influence PLWHA to experience LTFU, including low education, low knowledge of ARV treatment, lack of family support, and side effects of ARV drugs on PLWHA.

METHODOLOGY

This research used a qualitative method. The research data collection technique used in-depth interviews, observation, and documentation studies. The informant selection technique in this study used purposive sampling. The informants in this research were 4 people living with HIV/AIDS (PLWHA), 4 people living with HIV/AIDS (OHIDHA) who were family members/spouses/friends living together with PLWHA, and 2 representatives from the Indonesian Family Planning Association of Garut Regency which is an institution that provides services for PLWHA informants. The total number of informants in this study was 10 people.

RESULTS AND DISCUSSION

The results showed that the 4 informants with HIV/AIDS at PKBI received strong social support from their families. While 1 informant did not get social support because he lived alone. Based on House's concept (Semet, 1994) of social support, it can be grouped into 4 forms of social support, namely 1) emotional support which includes expressions of empathy, care and concern for the person concerned; 2) informative support which includes giving advice, instructions, suggestions or feedback; 3) instrumental support, namely providing facilities and facilitating the goals to be achieved in the form of material, providing opportunities and time opportunities; 4) appreciation support or

positive assessment in the form of expressions of respect (appreciation) positive for someone, encouragement to move forward, giving appreciation for the efforts that have been made, providing feedback on results or achievements.

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