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Social Support for HIV AIDS Sufferers Who Experience Stigma and Discrimination: A Systematic Review

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ABSTRACT

HIV AIDS is one of the most stigmatized medical conditions, so PLWHA will face various obstacles and need support from their social environment. Stigmatization can hinder seeking medical care, concealing treatment status and non-compliance. This study aimed to explore the benefits of social support for PLHIV. Implementation of PRISMA guidelines in four databases (Pubmed, Science direct, Scopus, Proquest) using keywords, so that 17 articles were obtained from 2016 to 2020 study ranges, in English, and used qualitative, quantitative and mixed study designs. 1 article using field notes, 6 interviews and 10 articles using a questionnaire. Stigma and discrimination reduce the spirit of life which has an effect on the quality of life, so that it has a broad impact on aspects of life both physically, psychologically, socially and spiritually.

Social support has many benefits such as helping to manage emotional distress, increasing adherence to taking ARVs, improving coping and mental health.

Keywords: Social Support, HIV AIDS, Stigma, Discrimination

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BACKGROUND

Human Immunodeficiency Virus / Acquired Immune Deficiency Syndrome (HIV / AIDS) is one of the most stigmatized medical conditions globally despite efforts to reduce stigma in recent years. During the lifetime of people living with HIV AIDS (PLWHA) have experiences about stigma and discrimination associated with their HIV status. These attitudes and behaviors often arise from misinformation about HIV transmission routes and negative stereotypes as a specific disease in groups that engage in risky behavior such as multiple or same-sex partners and sharing drug injection equipment (Meanley et al., 2019). Stigma is a destructive social phenomenon because it refers to a process in which a group of individuals is labeled socially undesirable and these individuals are judged for behavior that is socially disgusting (Turan et al., 2018). Society thinks that people infected with HIV AIDS deserve punishment for their own actions. They also think that PLWHA are the ones who are responsible for transmitting HIV AIDS. This lack of understanding has led to excessive attitudes that do not support the lives of PLWHA (Lisnawati Lubis, Sori Muda Sarumpaet, 2016).

Globally 38.8 million people were living with Human Immunodeficiency Virus (HIV) at the end of 2015 and the epidemic burden varies widely between countries and regions (Gesesew et al., 2017). The PLWHI Asia Pacific Network (APN) survey, July 2001 and November 2002 described 80% of respondents reporting stigma and discrimination in society and 50% being served by health services. Another study showed that 105.92 (95%) of 239 PLHIV experienced stigma and a higher level of stigma was felt by younger PLHIV (Z. Li et al., 2018). The stigma of HIV-AIDS continues due to a variety of factors including misconceptions about HIV transmission, media coverage of the epidemic, lack of access to care, disability and prejudice against certain groups (Littleton et al., 2020). In many ways, stigma and discrimination have a much broader influence than the HIV virus itself. Stigma and discrimination not only affect the lives of people who are HIV positive, but also those who live around them, for example spouses, families, even carers or their companions. Stigma has a very serious impact on people who are HIV positive as well as efforts to control HIV as a whole (Lisnawati Lubis, Sori Muda Sarumpaet, 2016). HIV stigma negatively impacts three core areas of PLHA's life including mental and emotional well-being (i.e., management of thoughts and / or behaviors that prevent a person from coping with the demands of routine life, social well-being (i.e., the degree to which an individual feels socially supported and / or isolated social and physical well-being (ie, making decisions that ensure physical health to avoid diseases and conditions that cannot be prevented) (Littleton et al., 2020). Data obtained from 119 PLHIV in Spain, one-third experienced symptoms of anxiety and depression. The study revealed that 61% of PLWHA experience anxiety and 48% experience depression due to internal stigma (Garrido-Hernansaiz & Alonso-Tapia, 2020). PLHIV who experience very high levels of stigma and discrimination are a source of additional stress that makes them more vulnerable to psychological stress and can contribute to disease progression, term and a higher CD4 count and viral load (Garrido-Hernansaiz & Alonso-Tapia, 2020).

This stigma and discrimination often causes a decrease in the spirit of life which then has a dominant effect on the quality of life of PLWHA. The quality of life in HIV AIDS patients is very important to pay attention to because this infectious disease is chronic and progressive so that it has a wide impact on all aspects of life, both physical, psychological, social, and spiritual (Lisnawati Lubis, Sori Muda Sarumpaet, 2016). Social support is one of the interventions that can be provided in minimizing psychological symptoms and the negative effects of stigma (Jiang et al., 2019). In facing their lives, PLWHA will face

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various obstacles that must be faced and will need support from their social environment. Sarafino, argues that people who get social support believe that they are loved and cared for, valued and feel that they are valued, and become part of a group, such as part of a family, or community organization that can provide materials, services and protection that benefit everyone. when it is needed and when it is in danger. HIV disclosure is a prerequisite for obtaining social support for access to health care and can also help facilitate HIV prevention and safe sexual behavior. However, stigma has been shown to hinder disclosure among various populations. Social support can help individuals reduce stress, so that it affects the quality of life of PLWHA (Shrestha et al., 2019). On the other hand, social support can also facilitate disclosure, in which case HIV can be disclosed to certain groups such as spouses, children, family, and friends, and the timing of disclosure can be direct or gradual after diagnosis (Mao et al., 2018).

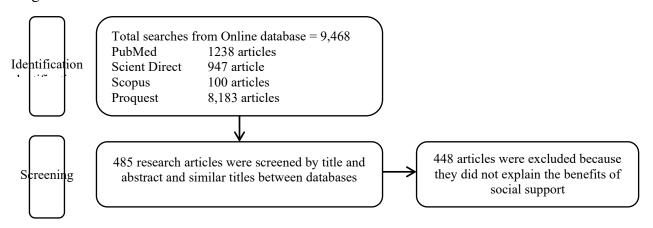
METHODS

This systematic review contains original articles that discuss the benefits of social support provided to HIV AIDS sufferers who experience stigma and discrimination. Systematic literature searches were carried out in several databases such as Pubmed, Science direct, Scopus and Proquest by entering the keywords "Social Support", "HIV AIDS", "Stigma", "Discrimination". The literature inclusion criteria are research with qualitative, quantitative and method methods. mixed, journal articles discussing social support provided to people living with HIV AIDS who experience stigma and discrimination, a 5-year study span between 2016 and 2021. All studies were in English and found 17 articles that matched the researchers' inclusion criteria and were used as systematic material. Exclusion criteria were literature reviews, discussion papers, comments, mini-reviews and stigma that did not focus on HIV AIDS patients.

RESULT

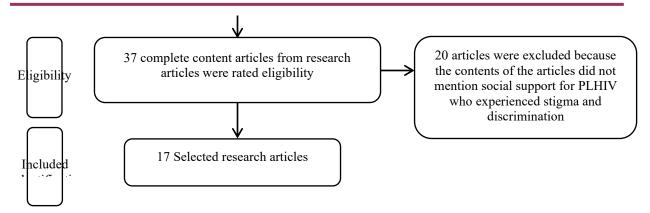
An initial literature search yielded 9,468 articles: 238 articles from PubMed, 947 articles from Science Direct, 100 articles from Scopus, and 8,183 articles from Proquest. The process of reviewing selected articles consists of three stages: reviewing the title, reviewing the abstract, and reviewing the research content. Thirty-seven articles were selected for review of the research content, and 20 of the 37 articles were excluded because the contents of the articles did not discuss the benefits of social support provided to PLHIV who experience stigma and discrimination. Seventeen articles that matched the inclusion and exclusion criteria were retained. The process of excavating and filtering articles is summarized in Figure 1.

Figure 1. Flow chart and article selection



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Research articles are limited from 2016 to 2020. All research articles consist of 11 quantitative studies, 5 qualitative studies and 1 mixed methods study. All studies used measuring instruments in the form of questionnaires and interviews. There are several measuring instruments used, including the Edinburgh Postnatal Depression Scale (EPDS) and the EuroQOL instrument consisting of 5- domains (EQ-5D. The total population in this study was 10,362 people with HIV AIDS (PLWHA). The research site was conducted in various countries, namely China, Namibia, India, South Africa, Ethiopia and Nepal.

The results showed that of the 17 articles social support had benefits in improving the quality of life of PLWHA, both directly and indirectly to overcome psychosocial factors (Chapman Lambert et al., 2020). One study explained that younger and older people living with HIV experience an HIV-related stigma that can harm relationships and weaken social support. Meanwhile, older people living with HIV / AIDS have experience in dealing with social pressures that have physical, psychological and social impacts (Rosenfeld & Anderson, 2020). Social support has an effect on increased coping, health behavior choices, increased emotional well-being and is also associated with higher ART adherence (Garfin et al., 2019) (Shrestha et al., 2019). Interventions that focus on providing social support can help PLWHA who have dropped out of care or who experience HIV treatment adherence challenges (Enriquez et al., 2019). Social support from others is an important driver of willingness to accept HIV testing, although in some cases this support is not seen. People who are seen as sources of social support are perceived as accepting, understanding, nonjudgmental, and trustworthy. Social support and stigma are closely linked and associated with depressive symptoms (Brittain et al., 2017). Stigma is a risk factor for depression (B = 0.295; p <001) and suicidal thoughts (B = 0.185; p <0.001) (J. Li et al., 2017). Only the availability of perceived support was directly associated with less depression (B = -0.182, p <0.001) (Casale et al., 2019), meaning that social support can withstand the negative effects of HIV-related stigma on poor psychosocial outcomes (Lipira et al., 2019). Other studies have also revealed that HIV-related stigma is the biggest risk factor and self-esteem is the biggest protective factor in relation to depressive symptoms (Kalomo, 2018).

Increasing personal self-esteem, resilience and social support can reduce the impact of perceived stigma on depressive symptoms among Chinese gays (Yan et al., 2019). Social support has an impact on health either by preventing potential stressors or by reducing the severity of reactions to stressors (Moodley & Kagee, 2019). Social support is also a potential mediator explaining the effect of disclosure on adherence (Mi et al., 2020). In particular, disclosure has effects on social, contextual, dyadic (eg, conjugal or family relationships), and clinical outcomes (eg medication adherence) through three possible mediation processes, including barrier reduction, social information change, and social support.

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Respondents who get higher social support are perceived to be more likely to disclose to their regular partners / partners, family or other people (Mao et al., 2018). It is also directly related to depression, stigma, and adherence, depression partially mediates the positive relationship between social support and self-efficacy as well as the negative relationship between stigma and self-efficacy (Jiang et al., 2019). A higher level of affectionate support can affect motivation in gaining access to care (estimated difference = 0.43, p <0.0001) (Chiao-Wen Lan, 2018). Meanwhile, other studies reveal that there is no significant relationship between social support and psychological distress. Interventions to increase social support may not be sufficient to improve the mental health of people living with HIV who experience HIV-related stigma (Parcesepe et al., 2018). The results of this study can be seen in Table 1.

Table 1. Summary of Social Support findings

	1. Summary of Social Su		n in i				
No.	Article Title, Author, Year	` U ,	Research Result				
	Variable, Instrument, Analysis)						
1.	'The own' and 'the wise' as social support for older people living with HIV in the United Kingdom (Rosenfeld & Anderson, 2020)		The life of elderly people with HIV has sufficient experience, and research reveals that an ODHA who has good social support will be very helpful in maintaining their health into old age.				
2.	Depression, social support, and stigma as predictors of quality of life over time: results from an Asha-based HIV AIDS intervention in India	(RCT) S: 100 female participants aged 18-50 years V: Depression, social support, HIV / AIDS stigma, quality of life	Stigma can cause depression which greatly affects the quality of life of PLWHA. Social support provided to PLWHA can improve individual coping in improving the quality of life such as adherence to treatment, increased health behavior choices, increased emotional well-being, and physiological stress				
	(Garfin et al., 2019)	I: Interview A: exploratory analysis	reduction responses.				
3.	Experiences of social support among persons seeking HIV testing (Moodley & Kagee, 2019)	D: Qualitative S: 15 HIV participants V: Experience, Social Support, HIV Test I: Interview	Participants reported that they could benefit from social support, which includes assistance in managing the emotional distress that would arise from a possible HIV-positive test result.				
		A: Thematic analysis					
4.	HIV Disclosure to Family Members and Medication Adherence: Role of Social Support and Self-efficacy (Mi et al., 2020)	D: Cross-Sectional S: 2987 participants V: Medication Adherence, Role of Social Support and Self- Efficacy I: Questionnaire A: independent-samples t-test or	Social support and self-acceptance can positively influence HIV disclosure and improve ART adherence in PLWHA.				
	(1111 00 all., 2020)	χ 2 test					
5.	coping, and stigma on the quality of life of people living with HIV in	D: Cross-Sectional S: 599 participants	By providing social support to stigmatized PLWHA, it can improve coping that focuses on problems and is useful for improving the quality of life of PLWHA.				

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6.	Social support, stigma, and HIV disclosure among parents living with HIV in Guangxi, China (Mao et al., 2018)	S: 1,254 Participants	Respondents who get higher social support are perceived to be more likely to disclose to their regular partners/partners, family, or other people. Perceived social support does not appear to be related to disclosure timing. Those who disclose in a shorter time after being diagnosed are more likely to disclose to their regular / partner. Interventions are needed to help reduce the negative effects of stigma felt at the family and community level and to help increase general perceived social support and emotional support especially among people with HIV, especially men and adults.
7.	Social support, stigma, and the mediating roles of depression on self-reported medication adherence of HAART recipients in China (Jiang et al., 2019)	D: Cross-Sectional S: 504 participants V: Social support, stigma, depression mediation, and medication adherence I: Questionnaire A: structural equation modeling analysis (SEM)	According to structural equation modeling, social support is directly linked to depression, stigma, and adherence; depression partially mediates the positive relationship between social support and efficacy of self-efficacy and the negative relationship between stigma and self-efficacy. Interventions are needed to improve mental health through mental health services such as social support, and increased confidence in self-acceptance.
8.	Suicidal thoughts and behaviour among South African adolescents living with HIV: Can social support buffer the impact of stigma? (Casale et al., 2019)	D: Quantitative S: Participants are 1053 adolescents aged 10-19 years V: thoughts, suicidal behavior, adolescence and social support I: Questionnaire A: Partial correlation, model- moderated mediation (Moderated mediation analysis)	Stigma was a risk factor for depression (B = 0.295 ; p < 001) and for suicidal thoughts and behavior (B = 0.185 ; p < 0.001). Only the availability of perceived support was directly associated with less depression (B = -0.182 , p < 0.01). However, both the availability of perceived support and participation of support groups contributed to the overall stress-buffering effect of moderating the direct and indirect relationships between stigma and suicidal thoughts and behavior.
9.		D: Quantitative Studies S: 522 Participants PLWHA V: Stigma, Social Support, and Access to care facilities I: Interview A: Linear analysis of mixed- effects regression models	Perceived levels of stigma and real, affectionate support were associated with access to care. In the main analysis, higher levels of perceived stigma were found to be significantly associated with lower rates of access to care (estimated difference = -0.08, p = 0.015). In contrast, internalized shyness was not associated with access to care (estimated difference = -0.01, p = 0.691). Higher levels of affectionate support were associated with higher levels of access to care (estimated difference = 0.43, p <0.0001). In contrast, intangible support was negatively associated with access to care (estimated difference = -0.17, p = 0.003). However, emotional support was not associated with access to care (estimated difference = 0.03, p = 0.373).
10.	Support, and Psychological	V: Stigma, Social Support, and	The social support provided was very different, most of the participants (85.2%) indicated that with social support, they had someone who could accompany them to the

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	(Parcesepe et al., 2018)	I: Interview A: Pearson Chi-squared tests	clinic. Likewise, 80.0% of the participants indicated that they have someone who can care for their children if they get sick. The lowest social support in relation to Financial Assistants. More than half of the participants reported that they had someone they could contact for minor, immediate assistance, such as going to the doctor or borrowing money (52.6%), or borrowing money specifically for medical emergencies (54.7%)
11.	Roles of Self-Stigma, Social Support, and Positive and Negative Affects as Determinants of Depressive Symptoms Among HIV Infected Men who have Sex with Men in China	S: 321 Participants	Social support has a positive effect so that it can reduce depression, while self-stigma has da negative effect on depression felt by PLWHA. Social support interventions can improve mental health among populations.
12.	(J. Li et al., 2017) Social Support, Stigma and Antenatal Depression Among HIV-Infected Pregnant Women in South Africa	S: 623 Participants V: Social Support, Stigma and Antenatal Depression I: Edinburgh Postnatal Depression	Social support and stigma are strongly associated with depressive symptoms. Stigma was observed to moderate the relationship between social support and depression scores; Lack of social support for
13.	(Brittain et al., 2017) Associations between HIV- related stigma, self-esteem, social support, and depressive symptoms in Namibia (Kalomo, 2018)	Scale (EPDS) A: Cronbach's alpha D: Cross-sectional survey S: 124 participants V: Stigma, self-esteem, social support, and depression I: Interview A: Least Squares (OLS) multivariate regression	people living with HIV who experience stigma can lead to depression. Correlation analysis revealed that HIV-related stigma, self-esteem, and social support were all significantly correlated with depression. Furthermore, the Ordinary Least Squares (OLS) regression analysis showed that HIV-related stigma was the biggest risk factor, and decreased self-esteem was one of
14.	Religiosity, Social Support, and Ethnic Identity: Exploring "Resilience Resources" for African-American Women Experiencing HIV-Related Stigma (Lipira et al., 2019)	D: Secondary analysis of baseline data (multisite randomized controlled trial) S: 226 participants V: Religiosity, Social Support, and Ethnicity I: Questionnaire A: Linear regression	the factors associated with depression. Among 226 African American women living with HIV, higher levels of HIV-related stigma were associated with higher depression. High reliability can reduce depression.
15.	Perceived Social Support Among Adults Struggling With Adherence to HIV Care and Treatment (Enriquez et al., 2019)	V: Social Support, compliance I: Field notes A: Pearson's product-moment correlation and Spearman's rank	HIV-positive adults who take ARVs feel a lack of social support. Interventions that focus on providing social support that can help PLHAs who have dropped out of care or who experience HIV treatment adherence challenges.
16.	HIV-related stigma, depression, and social support are associated with health-related quality of life among patients newly		Social support, depression, and HIV-related stigma were significantly associated with quality of life for PLHWA, with women experiencing more problems than men.

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	entering HIV care	I: EuroQOL instrument consists o 5- domains (EQ-5D	f
	(Chapman Lambert et al., 2020)	A: Cronbach's alpha	
17.	Association between perceived HIV stigma, socia support, resilience, selfesteem, and depressive symptoms among HIV-positive men who have sex with men (MSM) in Nanjing, China (Yan et al., 2019)	D: Cross-sectional survey <i>l</i> S: 374 participants V: stigma, social support, resilience, self-esteem, and depression I: Questionnaire A: Structural Equation Modeling (SEM)	Perceived stigma is directly associated with depressive symptoms. Perceived stigma also indirectly affects symptoms of depression through social support and self-esteem. Resilience is directly linked to self-esteem. Perceived HIV stigma can, directly and indirectly, influence depressive symptoms in HIV-positive gays. Increasing personal self-esteem, resilience, and social support can reduce the stigma impact on depressive symptoms among HIV-positive gays in
			China.

DISCUSSION

People living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) face many challenges including HIV-related stigma and mental health problems. In general, the perceived stigma refers to the individual's awareness of negative attitudes and community activities, while the internalized stigma shows negative thoughts and feelings internalized by a person or group. The stigma associated with HIV and discriminatory treatment of PLWHA remains common in many aspects of sufferers' lives, including health care. For example, people living with HIV / AIDS experience being judged by health care providers and are often rejected from services. HIV-related stigma is manifested at various social levels including among individuals, families and communities. The stigma associated with HIV is also reflected in government institutions, policies and practices. For example, a Namibian study revealed that PLWHA experience a stigma that results in them being rejected by community members, being refused jobs and often being forced to leave their homes (Kalomo, 2018). In addition, people who experience HIV-related stigma and discrimination report a variety of negative effects, including loss of income, isolation from the community, and inability to participate as productive members of society. Furthermore, HIV AIDS experts argue that many PLHIV rely heavily on social support networks as a means of dealing with physical illness and dealing with HIV-related stigma.

Social support refers to interpersonal transactions that involve one or more things such as: emotional problems, assistance with tools, information, or judgments. Many studies have shown that social support can help PLWHA balance emotions, and manage physical and psychological stress. However, because the dual stigma of HIV AIDS and homosexuality is usually marginalized in China, many PLWHA refuse to disclose their condition to others, even to people on their main social networks, such as close friends (Chen et al., 2019). Studies on the impact of social support among PLHIV in Thailand show that perceived social support has the potential to act as a buffer for crisis-related stress associated with AIDS positive status. People with higher perceived stigma and lower social support may be less resilient in stressful situations, and may have more negative emotions and less emotional flexibility (Yan et al., 2019). Other researchers stated that PLHIV who receive sustainable social support are more likely to experience a higher quality of life and a greater sense of self-worth (Kalomo, 2018). Self-esteem has been identified as an important coping trait. It may be common for those with high levels of stigma to be inferior and to become increasingly aloof and isolated, which in turn creates a downward spiral of worsening mental

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illness, such as depression. Consistent with previous findings, perceived stigma might impact depression by preventing gays from receiving social support. HIV-positive people may isolate themselves socially because of perceived stigma and this in turn reduces their opportunities for social support. As a result, those with lower social support may face more challenges when faced with adversity and be more susceptible to depression. Another finding suggests that disclosure to regular partners, family or other people is associated with higher levels of perceived social support (Mao et al., 2018). The importance of developing effective intervention strategies to reduce perceptions of HIV stigma among HIV-positive gays. Meanwhile, social support is a potentially modifiable variable that can also be targeted for intervention. An effective program is needed to increase social support (Yan et al., 2019).

HIV-Related Stigma

Taking into account the anticipatory stigma, nearly two-thirds (62.2%) of respondents expressed concern that people might avoid and not socialize / befriend if they knew or suspected that they were HIV-positive. Half (52.6%) of respondents who have children worry that their child will be angry or afraid if they know or suspect that the respondent is HIV positive and 42.8% of the respondents who have children report that they are worried that their child will be harassed or suspected and discriminated against by other people. Roughly half of the participants reported feeling embarrassed about being HIV-positive, completely worthless, and as if they were bringing a lot of trouble to their families (50.4, 48.0, and 46.4%, respectively). Sixteen percent of respondents reported experiencing HIV-related stigma in the previous three months. The type of stigma that was most commonly told was that God was punishing them, with 9.2% of respondents reporting the type of stigma that prevailed (Parcesepe et al., 2018).

Social Support

Social support varies according to experience. Most (85.2%) participants indicated that they may or certainly have someone to accompany them to the clinic if necessary. Likewise, 80.0% of participants indicated that they may or certainly have someone who can care for their children if they get sick. Social support is lowest in terms of financial assistance. More than half of the participants reported that they may or may have someone they can contact for immediate, small assistance, such as going to the doctor or borrowing money (52.6%), or borrowing money specifically for medical emergencies (54.7 %) (Parcesepe et al., 2018).

Psychological Disorders, Stigma, and Social Support

Psychological distress was significantly associated with all forms of HIV-related stigma assessed. There is a positive response relationship between anticipatory stigma and psychological distress. About 18.5% of those with low anticipatory stigma screened positive for severe psychological distress compared with 27.4% of those with moderate anticipatory stigma and 42.6% of those with high anticipatory stigma (p <0.0001). Similar positive relationships were observed between internalized stigma and psychological distress. More than half (58.3%) of respondents with a high level of internalized stigma reported severe psychological distress compared to 21.4 and 10.5% of those with moderate and low internalized stigma (p <0.0001). Those who reported having experienced HIV-related stigma had a significantly higher prevalence of severe psychological distress than those who did not report being stigmatized (41.2 vs 27.1%) (p = 0.0002). Social support was also significantly associated with psychological distress. Those who reported low social support

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were more likely to experience severe psychological distress than those who reported moderate or high social support (35.6, 27.1, and 25.5%, respectively) (p <0.0001) (Parcesepe et al., 2018).

CONCLUSION

Stigma is a major barrier to HIV prevention, care and treatment. Fear of stigma makes people less likely to get tested for HIV or delay disclosure of status to partners / families. As social beings, humans always interact with other humans to carry out various activities in their lives. With social support, PLWHA believes that they are loved and cared for, valued and feel valued, and become part of a group. The social support provided is very important, because it can build self-confidence and optimism in facing life in the future and improve the quality of life of PLWHA.

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CONFLICT OF INTEREST

There is no conflict of interest.

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