

The Spiritual Distress of Adolescents "Men Sex Men"(MSM) Infected with HIV in Bandung

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ABSTRACT

Introduction: The prevalence of cases of HIV infection in the group of adolescents "Men Sex Men (MSM) in Indonesia has continued to increase from 2015 to 2019. The problem of decreasing physical health, feeling depressed, social stigma, stress and inconsistent behavior with religious values will create prolonged distress that hinders the quality of life. **Objectives:** The purpose of this study was to identify spiritual distress in adolescents infected with HIV with MSM. **Method:** This study was conducted with a cross-sectional approach to 84 young people living with HIV/AIDS. The sample selection technique used snowball sampling with a Spiritual questionnaire. Data analysis was conducted by using frequency distribution and Lambda test processed using a computer system. **Results:** The results showed that 56% were in a state of spirituality with no disturbance, 38.1% were in moderate spiritual distress, and 6% were severe spiritual distress. The SSI score mean of respondents was $16.3 \pm SD 4.9$. There was a correlation between the length of diagnosis and the incidence of spiritual distress with a p-value of 0.000 and a value of $r = 0.459$. Spiritual distress tended to occur a lot in the early days of being diagnosed with HIV. There was no correlation between age and the incidence of spiritual distress ($p = 0.097$). **Discussion:** This study showed that spiritual care support for adolescents MSM would help overcome existential problems related to HIV.

Keywords: adolescent spiritual distress, HIV, homosexual

ABSTRAK

Latar Belakang: Prevalensi kasus infeksi HIV pada kelompok remaja dengan Lelaki seks sesama Lelaki (LSL) di Indonesia terus mengalami peningkatan dari tahun 2015 – 2019. Permasalahan penurunan kesehatan fisik, perasaan tertekan, stress stigma sosial serta pertentangan perilaku dengan nilai-nilai agama akan menjadikan distress berkepanjangan yang menghambat peningkatan kualitas hidupnya. **Tujuan:** Tujuan penelitian ini adalah untuk mengidentifikasi distress spiritual pada Remaja terinfeksi HIV dengan LSL. **Metode:** Penelitian ini dilakukan dengan pendekatan cross sectional terhadap 84 remaja ODHA LSL. Tehnik pemilihan sampel menggunakan snowball sampling dengan kuesioner Spiritual Scale Injury. Analisis data menggunakan distribusi frekuensi dan Uji lambda yang diolah menggunakan sistem komputer. **Hasil:** Hasil penelitian menunjukkan 56 % berada pada kondisi spiritualitas tidak ada gangguan, 38,1 % menunjukkan distress spiritual sedang dan 6 % menunjukkan distress spiritual berat. Rata-rata skor SSI responden mean $16,3 \pm SD 4.9$. Terdapat korelasi antara lama terdiagnosa dengan kejadian distress spiritual dengan nilai $p 0,000$ dan nilai $r = 0,459$. Distress

*spiritual cenderung banyak terjadi pada awal awal terdiagnosa HIV. Tidak ada korelasi antara usia dengan kejadian distress spiritual ($p=0,097$). **Diskusi:** Penelitian ini menunjukkan bahwa dukungan spiritual care pada remaja LSL akan membantu mengatasi masalah eksistensial berkaitan dengan HIV.*

Kata kunci: *Distress spiritual, Remaja , HIV, Homoseksual*

INTRODUCTION

HIV (Human Immunodeficiency Virus) disease is still a problem in Indonesia. The incidence of HIV cases in Indonesia from 2005 to 2017 continues to increase every year, with an average increase of 14-15% (Pusdatin, 2017). West Java is the province with the third-highest HIV infection cases. Bandung was reported as the area with the highest number of HIV infections with 238 cases with a cumulative number of HIV cases as many as 2424 (Pusdatin, 2017). The discovery of new cases that continuously increase from 2015 to 2018 is the crucial population group of MSM at 15-25 years old (Ministry of Health, 2018; Pusdatin, 2017). The onset of HIV symptoms in late adolescence due to sexual intercourse outside of marriage occurs in early and middle adolescents (12-18 years). This showed a unique approach to the key population is needed to control the transmission of HIV.

The phenomenon of behavior deviation that occurs among adolescents will impact adolescent reproductive health worsening and HIV transmission. The psychological instability of adolescence, the development of sexual needs and the high influence of peers make the adolescents at risk of getting HIV transmission (Latif et al., 2018). The problems of adolescents infected with HIV will be faced with physical problems from their disease, psychological problems due to HIV stigma and the concealment of their deviant identity, as well as social problems that will be faced related to the stigma of HIV and MSM (Lyon et al., 2014; Savitri & Purwaningtyastuti, 2019). This puts adolescents MSM infected with HIV at risk of getting heavier health problems than other HIV patients.

Adolescents infected with HIV tend to use negative religious coping in overcoming their life

problems (Aisyah et al., 2020). The results of a preliminary study through the interview method with 5 Adolescent MSM showed negative religious coping during their illness and a tendency to separate their sexual behavior from matters of divinity or aspects of worship. This condition showed that the low level of spirituality of adolescents with HIV would impact decreasing their quality of life in the future.

The aspect of spirituality is a significant part of improving the quality of life. Spirituality is a source of strength used by individuals when dealing with emotional stress, physical illness, and even death (Dewi & Anugerah., 2020). The results showed that the higher the spirituality of people living with HIV AIDS (PLWHA), the better the immune status with a higher CD4 + value (Armiyati et al., 2015; Collein, 2010; Mariany et al., 2019). Low spiritual well-being is a predictor of depression in HIV patients (Lyon et al., 2014). Therefore, there is a tendency to use negative religious coping in the adolescent MSM group to identify spiritual distress. This spiritual distress condition is essential to be studied. According to this condition, it is necessary to identify the spiritual distress of adolescent MSM or PLWHA (People Living With HIV AIDS) in Bandung. It is important to study this spiritual distress as a tool for nurses or other health workers to improve the health status of HIV patients through consideration of spiritual need aspects. Spiritual distress that is not adequately resolved will impact more severe problems such as depression and suicidal feelings (Pinho et al., 2017). The results of this study will be helpful in developing intervention planning to fulfill spiritual needs in key population groups at risk of HIV AIDS transmission. The purpose of this study was to identify spiritual distress in adolescents infected with HIV with MSM.

METHODS

Research Design

This study used a quantitative design with a cross-sectional approach.

Population and Sample

The population in the study were adolescents infected with HIV and adolescents MSM in Bandung. The basis for calculating the sample in the study used the Slovin formula with the unknown proportion of adolescents with HIV/AIDS in Bandung so that the proportion value of 0.05 with a minimum sample size of 73 people was added with a dropout estimate of 10% (Dahlan, 2011). The number of respondents who participated in the study were 84 people.

The sampling technique in this study used snowball sampling, namely, the sampling technique was not random. Still, the sample selection was continued based on previous respondents until the sampling quota was met (Sugiyono, 2014). Given that a respondent group is a minority group whose sexual orientation identity is hidden. The inclusion criteria established in the sample selection were adolescents aged 15-24 years old, diagnosed with positive HIV and having a habit of MSM homosexual orientation. Screening for sexual orientation used the Kinsey scale instrument (Ramdan, 2018). The exclusion criteria set included adolescents with HIV who had a heterosexual orientation. The screening results of 97 people found 50 people who were purely homosexual and 34 people who had homosexual tendencies and 13 people were included in the exclusion criteria.

Instrument

The data collection technique was carried out using a questionnaire instrument. The first questionnaire consisted of a demographic data questionnaire covering age, sex, education, duration of HIV diagnosis. The spiritual distress assessment questionnaire was modified from the Islamic spiritual distress assessment instrument adapted from the Spiritual Injury Scale Instrument (Schultz et al., 2017). The questionnaires were consisted of 8

questions with a Likert scale consisting of (1) never; (2) rarely; (3) often (4) very often. The instrument charging time took 5 - 10 minutes. Interpretation of scores 25-32 showed symptoms of spiritual distress; 17-24 showed symptoms of mild spiritual distress, and a score of 8-16 indicated no disturbance / normal. To ensure the instrument's authenticity, the researcher has tested the validity and reliability of the instrument on adolescents living with HIV / AIDS in the West Bandung area as many as 15 adolescents. The instrument has an r product moment validity value (0.685-0.900) and a Cronbach alpha reliability value (0.923).

Research Procedure

Data collection was carried out in Bandung in collaboration with the Indonesian Puzzle Community as a companion community for PLWHA. The study was conducted from July to August 2020. Data was collected by filling in the google health survey questionnaire link <https://bit.ly/KesehatanODHA>

Data analysis

Data analysis used a computer program through the variate test and bivariate test. The univariate test was used to identify the spiritual distress and characteristics of the respondents through analysis of the distribution of frequencies and averages. The normality test of spiritual distress data using the Kolmogorov Smirnov test showed that the data was normally distributed with a significance value of 0.059 (p value > 0.05). The bivariate test was used to identify the correlation between the variable level of adolescent age and the old variable diagnosed with spiritual distress. Bivariate analysis used the Lambda test. The Lambda test is a correlation test used to connect the dependent variable and the independent variable, which has a categorical scale.

Ethical approval

This study has been approved by the Health Research Ethics Committee of STIKes Aisyiyah Bandung with Number 81 / KEP. 02 / STIKes-AB / VI / 2020.

RESULTS

Characteristics of Respondents

Characteristics of Adolescent MSM Respondents who participated in the study are described in Table 1.

Table 1. Characteristic of Adolescent MSM Respondents in Bandung

Variable	N	%	Mean ± SD
Age Early Adolescent	0	0	
Middle Adolescent	7	8,3	22 ± 1,8
Late Adolescent	77	91,7	
Religion Moslem	82	97,6	-
Christian	2	2,4	
The length of diagnosis			
≤1 year	25	29,8	2,3 ± 0,8
1-3 year	15	17,9	
>3years	44	52,4	

Table 1 showed that most adolescents MSM with HIV were in the late adolescent age range (18-24 years old) and 91.7% with an average age of 22 years. Most HIV-positive adolescents were

Muslim (97.6%) and almost half of respondents underwent the disease for more than 3 years with an average of 2 and 3 years.

Overview of the spiritual distress of adolescent MSM with HIV

Table 2 showed that most of the adolescents MSM in Bandung did not experience spiritual distress disorder (56%). Table 3 described spiritual aspect of respondent. The symptoms that were sometimes experienced were feelings of guilt towards the past (35.7%), feelings of grief for a long time (46.4%), feelings of hopelessness (47.6%) and feeling that life is meaningless and anxiety of imminent death (46%).

Table 2. Overview of the Spiritual Distress Levels of Adolescent with HIV AIDS

Spiritual Distress Levels	N	f(%)
No disturbance	47	56,0
Moderate spiritual distress	32	38,0
Severe spiritual distress	5	6,0

Table 3. Distribution of the spiritual distress frequency of adolescents with HIV AIDS in Bandung based on symptoms of spiritual distress

Spiritual Aspect	Never (%)	Sometimes (%)	Often (%)	Always (%)
Feeling of guilt in the past	10,7	34,5	35,7	19,0
Feeling of resentment	21,4	46,4	23,8	8,3
Feeling of sadness for a long time	9,5	45,2	36,9	8,3
Feeling of meaningless life	34,5	47,6	13,1	4,8
Feeling of hopelessness	34,5	47,6	13,1	4,8
Feeling that God is not being fair	53,6	31	14,3	1,2
Feeling doubtful about the greatness of God	78,6	11,9	9,5	0
Fear of death in the near future	23,8	46,4	20,2	9,5

Table 4. The relationship between age and duration of diagnosis and spiritual distress disorder

Variable	No Disturbance	Moderate Spiritual Distress	Severe Spiritual Distress	R	P
Age					
Middle Adolescent (15-18 years old)	1	5	2	0.108	0.097
Late Adolescent (19-24 years old)	46	27	3		
The length of diagnosis					
Less than one year	2	19	4		
Between 1 and 3 years	8	6	1	0,459	0.000
More than 3 years	32	7	0		

Table 4 described the relationship between the age of the respondents and the length of spiritual distress diagnosis on the respondents. The results showed no relationship between age and spiritual distress with a p-value of 0.097 ($p > 0.05$). The length of diagnosis has a relationship with spiritual distress disorder with a significance of $p < 0.000$ ($p < 0.005$) and moderate strength of correlation (OR 0.459). Table 4 showed that the highest incidence of spiritual distress was in the group of adolescents who were diagnosed for less than one year as many as 19 (59.3%) with moderate spiritual distress and 4 respondents (80%) experienced severe spiritual distress.

DISCUSSION

The results showed that half of the respondents (56%) did not experience spiritual distress. Spiritual distress is one of the nursing diagnostic labels (Indonesian Nursing Diagnosis Standards), which means a disturbance in a belief or value system in the form of difficulty integrating the meaning and purpose of life through an individual's relationship with himself, others, God and a power greater than oneself (PPNI, 2017; Schultz et al., 2017). Most of the respondents were adolescent MSM with HIV / AIDS who were already active in the community of PWLHA companion in Bandung. The activeness of respondents in social groups is one of the reasons why some respondents perceive themselves not to experience spiritual distress because of group support from people living with fellow HIV. This is in line with several studies that HIV-infected patients who are members of the companion community tend to have lower social anxiety and better self-defense (Savitri & Purwaningtyastuti, 2019).

A person's experience of spiritual distress is influenced by various factors including physical factors, cognitive factors and psychological factors. Physical factors are related to disturbed physical complaints experienced during their illness because the more physical complaints experienced tend to experience heavier spiritual distress (Roze des Ordon et al., 2018). This cognitive factor is related to a person's perception

or thoughts about what is experienced. If someone considers that the test experienced as a punishment from God, he tends to experience heavier spiritual distress (Aisyah et al., 2020; Alvariza et al., 2020; Roze des Ordon et al., 2018). Psychological factors are related to a person's anxiety condition. The use of negative religious coping tends to experience spiritual distress (Harris et al., 2018; Roze des Ordon et al., 2018; Stecz & Kocur, 2014). The opinions of some experts above have further strengthened the researcher that spiritual distress is closely related to a person's ability to interpret life events experienced.

The ability to interpret life experiences is closely related to the grieving phase experienced by the patient in relation to the length of time of disease diagnosis. The results showed that there was a relationship between the length of time being diagnosed with HIV disease and the incidence of spiritual distress with a p-value of 0.000 ($P < 0.05$). In this study, moderate spiritual distress was mostly experienced by the group of adolescents with HIV for less than 1 year as many as 59.3% (19 people) and severe spiritual distress as many as 80% (4 people). This showed that the incidence of spiritual distress occurred when the patient first found out that he was diagnosed with HIV. The results of this study were in line with the previous studies that experiences of spiritual distress occur during the first year of being diagnosed with chronic or terminal illness (Armiyati et al., 2015; Gall et al., 2009). A person who has just received information that he or she has a disease that is difficult to cure will experience a denial, angry, and bargaining phase before a person reaches the stage of receiving a diagnosis of the disease.

The meaning of a person for his life experiences is based on a person's developmental age. The results showed that the incidence of spiritual distress had no relationship with the level of adolescence with a p value of 0.097 ($p > 0.05$). Spiritual distress experiences can occur in middle and late adolescence age group. The results of this study were in line with Park et al. And Moko et al. That age differences do not differentiate between the incidence of spiritual distress in a person (Lyon

et al., 2014; Mako C, Galek K, 2006). Spiritual maturity in adolescence is not based on self-objective assessment, but still adapts to the beliefs of the values of people around their social environment such as family and peers (Sateemae et al., 2015).

The positive meaning of received social support is able to help adolescents free from feeling depressed over their life problems. However, this behavior is a form of tendency of negative religious coping patterns. Negative religious coping, namely the use of coping sources of social support, becomes more meaningful in overcoming negative feelings than spiritual support or sources of religious power (Aisyah et al., 2020; Ziapour et al., 2017). This situation only helps a person to be free from feelings of distress, but not spiritually well-being.

Spiritual well-being is formed by a sense of harmony, mutual closeness between oneself and others, nature and their god or the highest power (Ross et al., 2018; Shabani J, Hassan SA, Ahmad A, 2010). Spiritual well-being is formed from two aspects, namely religious and existential aspects. The aspect of religiosity is obtained through tranquility through a relationship with God, while the existential aspect is a harmonious relationship with himself and his environment (Ziapour et al., 2017). Group support among adolescent MSM gives harmony in the existential aspect, but the harmony in the aspect of religiosity has not been fulfilled. All respondents (100%) have a religion and most of the respondents (78%) have never doubted the greatness of God but do not make religious values as a primary source of behavior, especially in terms of sexual behavior. Spiritual distress occurs when two aspects of spiritual well-being are not fulfilled, while if only one aspect is fulfilled, the individual is said to be at risk of spiritual distress.

The risk of spiritual distress is a person at risk of experiencing a belief or value system disturbance in an individual or group in the form of losing strength, hope or the wrong meaning of life (Dewi et al., 2020; PPNI, 2017). The risk of spiritual distress occurs due to the inability to

interpret the situation that occurs in individuals in connecting with their spiritual sources in the form of worship or religious rituals. This is indicated by the results of the study that all respondents had 100% religious beliefs, and on the question of believing in the greatness of God, some respondents said they never doubted the greatness of God but to change sexual behavior following the guidance of religious teachings could not be done. A problem-solving mechanism in which a person believes there is divine help but no effort to increase the activity of getting closer to God will lead someone to the wrong spiritual meaning of life (Tanjung, 2016; Xu, 2016). Therefore, even though the spiritual distress score is low, it still requires the support of spiritual nursing interventions so a state of severe spiritual distress during the disease will not be occurred.

The results showed that few respondents experienced severe spiritual distress as many as 6% and moderate spiritual distress as many as 38%. A condition of spiritual distress is a condition in which a person is in a condition of difficulty interpreting the suffering experienced even to the point where he does not want to perform rituals of worship and there is a feeling of hatred with God (Dewi & Anugerah., 2020). Some literatures associate the term spiritual distress with "spiritual struggle" which includes aspects of emotion, aspects of relationships with others, and aspects of relationships with God (Carey & Hodgson, 2018; Roze des Ordonns et al., 2018). Symptoms of spiritual distress occur when there is difficulty in fulfilling one of the three domains, which appears in the form of regret, despair, anxiety, and isolation. This spiritual distress arises when a meaning crisis of a person occurs in interpreting his life, including aspects of hatred towards the past, anger towards the situation, feelings of sadness for himself, the meaninglessness of life, feeling God's injustice towards his life, doubting the greatness of God, and anxiety about being near with death (Roze des Ordonns et al., 2018; Schultz et al., 2017). This was in line with the results of the study that the spiritual aspects that are disturbed a lot are

feelings of guilt towards the past (35%), feelings of grief for a long time (45.2%), and anxiety about death in the near future (46%).

The role of nurses in assisting patients diagnosed with chronic or terminal illness in accompanying every phase of grieving is significant. The nurse must develop the patient's spirituality at every stage of the grieving phase to not fall into a state of spiritual distress. Aspects of spirituality and religiosity are beneficial for a patient in receiving a diagnosis of a disease that occurs to him (Lin et al., 2018; Pinho et al., 2017). Spirituality is the ability to interpret life experiences or events associated with the value system, belief, religion (Dewi & Anugerah., 2020; Yusuf et al., 2016). Spirituality is used as a bridge between feelings of hopelessness and the positive meaning of life. HIV patients who have high spirituality tend to have a better quality of life during their illness (Agustin, 2018; Carey & Hodgson, 2018).

CONCLUSION

According to the results of the study showed that most of the adolescent MSM group did not experience spiritual distress as many as 56%, experienced moderate spiritual distress as many as 38% and severe spiritual distress as many as 6%. The incidence of spiritual distress in adolescents is related to the length of diagnosis with a p-value of 0.000 ($p < 0.05$). Severe and moderate spiritual distress are common in patients diagnosed with HIV for less than one year. Improving the spirituality aspect of adolescent MSM since the start of being diagnosed with HIV is very necessary to improve the quality of life of HIV-infected patients.

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