



Life Quality Perception of Positive HIV Sufferers in Semarang City

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Abstract

Human Immunodeficiency Virus (HIV) is still considered as a terrible, hard to be cured and even deadly disease by the society. Problems experienced by People Living with HIV (PLWH) will affect the quality of their life. This research is a qualitative research which focuses on the perception of the PLWH's quality of life in the Semarang city. Initial informant determined with purposive sampling techniques and to complete the further information, snowball sampling technique was used. The method used in the data collection was in-depth interviews with key informant that is 5 gay patients with HIV positive in the Semarang city and triangulation informants including families of PLWH, health workers providing services, *KPA* of Semarang City, and Peer Assistant Coordinator. The result showed that PLWH's perception regarding to their quality of life is good and satisfying. This is because PLWH in this study understand HIV very well, regularly take ARV, maintain a healthy lifestyle, attend the Peer Support Group, and get support from the family or friend. To continuously improve the quality of PLWH's life, program makers are advised to give counseling and health education towards the community about HIV so that the society will not have a misleading knowledge about HIV and they can participate in the prevention of HIV transmission as well as to the risky groups to continuously carry out routine HIV test and prevent the transmission of HIV.

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INTRODUCTION

In 2017 globally according to WHO data there were 36 million people suffering from HIV positive. There are as many as 25.7 million people living with HIV positive in the African Continent and the second position is the Asian region with the number of HIV positive sufferers reaching 3.5 million where the HIV positive antiretroviral coverage in Asia is only 51% (World Health Organization, 2018).

In Indonesia, the goal of the 2015-2019 National Strategy and Action Plan for the prevention of HIV and AIDS is to accelerate in reaching 3 zeros. The meaning of 3 Zero is zero new infections, zero deaths from AIDS, and zero stigma and discrimination. In 2017, according to WHO data, the State of Indonesia had an estimated number of 630,000 people with HIV and 39,000 deaths due to HIV (Ministry of Health, Republic of Indonesia, 2016; AIDS Commission, 2015).

In 2017 the Province of Central Java was included in the top 4 provinces with the highest HIV cases in Indonesia. The number of HIV cases in Central Java continues to increase. In 2017 there were 3,731 cases where previously in 2016 there were 1,867 cases and in 2015 there were 1,467 cases (Health of the Province of Central Java, 2017; Ministry of Health of the Republic of Indonesia, 2017).

As the capital of Central Java Province, Semarang City contributes to the incidence of HIV cases. In 2016 there were 488 HIV cases and in 2017 there were 534 HIV cases in Semarang City with the highest number occurring in the 25 - 45 years age group. Since 1995-2017, cumulatively, HIV cases in Semarang City have suffered more by men (57%) compared to women. This is because male mobility is higher than women, so men are more at risk of being infected with HIV. In addition, at this time there is also the phenomenon of Male Sex Workers (*PPS*) where *PPS* men in addition to serving opposite sex relationships also serve same-sex

relationships (Semarang City Health Profile, 2017).

In research (Naibaho, Triwahyuni, & Rantung, 2017) shows that the quality of life of people with HIV and AIDS is affected by physical, psychological, social and environmental changes after being diagnosed with HIV / AIDS. The decline in physical health is a stressor for people with HIV positive. In a study of the quality of life of HIV positive sufferers in Denpasar, the level of spirituality of HIV / AIDS patients at the Spirit Paramacitta Foundation in Denpasar mostly had low spirituality as many as 24 people (53%) with a mostly mediocre quality of life (51%) (Superkertia *et al.*, 2016).

The results of the study in Minangkabau stated as much as 59.4% of respondents received support from families and 57.5% of respondents had a good quality of life. This shows that if HIV sufferers have good family support they will have a good quality of life (Novrianda *et al.*, 2018).

The quality of life of people with HIV / AIDS is influenced by several things including social support, education level, duration of antiretroviral therapy (ARV), and stigma. According to a study stating that HIV sufferers who work experience stigma from their coworkers (Karkashadze *et al.*, 2017).

Poor quality of life experienced by sufferers is feeling the problem of stigma and discrimination where they feel shy, sad, and feel shunned by friends. This happens because of the lack of public understanding of HIV positive sufferers. In a study at Medan Veterans Clinic states that there is a significant relationship between depression, stigma, and fatigue with the quality of life of people with HIV / AIDS. This shows that stigma, depression and fatigue cause a decrease in the quality of life of people with HIV / AIDS (Lubis *et al.*, 2016).

Community stigma and discrimination against HIV positive sufferers discourages sufferers from interacting with the community and tends to shut down. The impact arising from the attitude of HIV positive people who

close themselves to the environment causes them to experience limitations in reaching health services and the support provided. This has an impact on their quality of life where with a low quality of life with the deteriorating physical, psychosocial, and emotional condition of HIV positive sufferers resulting in a decrease in the immune system of HIV positive sufferers so it is susceptible to infections such as pulmonary TB, herpes simplex, pneumonia, chronic diarrhea, lipomas, hepatitis C and neurological abnormalities (Katili *et al.*, 2012).

The purpose of this study is to explore deeply the perception of quality of life in HIV positive patients in the city of Semarang.

METHOD

This study used a qualitative research design using a descriptive analytic approach which is a study that aims to interpret phenomena that occur in research subjects such as behavior, motivation, perception, and action (Moleong, 2012).

In this study the informants were determined by researchers using purposive sampling techniques, namely techniques for determining informants with the conditions that have been determined. The number of initial informants determined at the beginning of this study were 5 MSM who were HIV positive patients in the city of Semarang.

In this study to meet the needs of informants and the addition of information developed using snowball sampling techniques where researchers are expected to get meaningful and complete data. Triangulation in this study is the family of HIV positive patients in Semarang City, Deputy Impementing Unit of the PEKA Foundation, health workers who provide health services to HIV positive patients in Semarang City and Semarang City AIDS Commission.

RESULTS AND DISCUSSION

The initial exploration of the informant knew the world of MSM (Male Sex) until he became infected with HIV

Based on the results of research to all informants regarding their initial exposure to the world of same-sex lovers (Male Sex Men) most of the informants stated that they knew or entered the world of MSM from the internet such as Facebook, Friendster, MIRC, mig33 and other chat applications. Starting from surfing the internet, they can make friends with anyone from anywhere in the world. Friendship that exists on social media and chat applications is getting closer and closer until finally a meeting is held. After the meeting they felt more comfortable until finally they had a further relationship, namely same-sex sexual relations without using a condom. In a study in Korea, it was common that bisexuals with HIV positive people were having sex and enjoying sexual relations without having a permanent partner (Jung, 2016).

In this study, data were obtained that the youngest informant was exposed to same-sex sexual when he was 10 years old. At that time the informant (I3) said that he was still in the 5th grade in a boarding school and was sexually abused by his senior. Whereas another informant (I1) said that he first got to know the world of MSM while sitting in the second grade of junior high school when he was 13 years old.

Same-sex sexual intercourse carried out by an MSM can be at risk of being infected with HIV when it is done at the age of ≤ 16 years, not using a condom and having sex with a partner of more than one person. They have sex without using a condom because they want to get a sensation and get paid (Sidjabat *et al.*, 2017).

In this study, informant I1 said that when he first worked as a sex worker, his pimp stated that it would be better if I1 did not use a condom because at that time he was a new commercial sex worker and so that I1 felt the sensation without using a condom. This is also

reinforced by research in Batang District which states that the practice of pimps has an effect on the use of condoms in sex workers (Atika, 2017).

Exploration of Life Quality Perception of HIV Positive Sufferers from the Spiritual Dimension

In this study all informants had been HIV positive with the lowest time being 4 years, they said they were not afraid of their future. They stated that they had accepted their current situation and really enjoyed their lives now. In a study in Denpasar there was a very strong relationship between the level of spirituality and the level of quality of life in people with HIV (Superkertia *et al.*, 2016). In the in-depth interviews, most of the informants stated that they were not afraid of death because they felt that they had enough faith and that they felt they were regularly taking ARVs and were always trying to live a healthy life so that when they died they would think it was because it was God's will. Based on the statement of triangulation informants (IT4) said that the acceptance phase of HIV positive sufferers at the start of being diagnosed is to reject. They feel shocked and do not accept the situation. They assume that this is not true and they feel fine. This usually happens for months until finally they can accept the situation. In other studies also mentioned that there is a significant relationship between the length of suffering from HIV with quality of life (Ethel *et al.*, 2016).

All informants in this study said that they were passionate about living their lives. This is because they get enthusiasm from family, friends, nurses and doctors who provide health services to them. Four main Muslim informants stated that they were still rarely to perform the five daily prayers, but they always carried out the Friday Prayers and the Prayers on Hari Raya. One main Christian informant (I4) stated that he regularly goes to church every Sunday. This is in line with research (Siddik & Uyun, 2017) which states that if HIV sufferers have positive thoughts

towards God, they will be more prosperous in life. In another study at the Semarang District Public Health Center stated that the spiritual needs of HIV sufferers obtained religious indicators as the main needs. This happens because HIV sufferers believe that through religion HIV sufferers can connect with God to ask for help and forgiveness. Through religion, sufferers of HIV can ease all inner conflicts within themselves to obtain peace.

Exploration of Life Quality Perception of HIV Positive Sufferers from the Physical Dimension

In in-depth interviews conducted by researchers, all informants stated that they did not feel any physical pain related to the HIV virus in their bodies. All informants stated that they did not experience physical pain that hindered their activities so far. The informants stated that they continued to carry out activities as usual, such as working, studying, hanging out with friends and doing sports. If they feel tired with their activities, they will rest for a while and then resume their activities. This is done because they are afraid that if they are too tired, they will drop out and not be able to carry out their activities to the full. In a study stated that most people with HIV continue to move like healthy people, for example work (Octavianity *et al.*, 2015). In carrying out activities most of the informants stated that they were satisfied and were serious about the work they were doing.

All informants in this study stated that they regularly took ARVs at the same time every day. When they first started taking ARVs they used an alarm as a reminder because in a study (Marlinda & Azinar, 2017) mentioned that the obstacle in consuming ARVs was that HIV positive sufferers forgot about their drinking schedule and experienced ARV side effects so they were reluctant to consume ARVs. Another study in Kupang also stated that one of the main factors causing HIV positive patients to be obedient in their treatment was behavior (Boro *et al.*, 2018).

All informants in this study realized the benefits of antiretroviral drugs that slowed the development of the HIV virus in their bodies so that their health could be better than before. They stated that they learned information about ARVs from health workers and Peer Support Groups (*KDS*). This is in line with research in the city of Semarang which states that peer support groups have a role for them to adhere to ARV therapy (Kamila & Siwiendrayanti, 2010).

The number of ARVs taken by informants was not the same. There is one informant (I4) who consumes 7 tablets a day, there are 2 informants (I2 and I3) who consume 4 tablets a day and 2 informants (I1 and I5) consume 1 tablet a day. This happened because all informants had experienced several ARV regimen changes. These changes occur because they do not fit into the previous regimen. Some informants experienced rashes on the skin, Hb dropped until there were those who experienced Stevens-Johnson syndrome. . This is what causes them to have to change regimens until finally finding a suitable for their bodies. However, at the beginning of the use of the regimen that is currently considered suitable even most of the informants experienced side effects from antiretroviral drugs, such as nausea, dizziness and weakness in the initial use. This was also corroborated by the statement of triangulation informants (IT3 / 39 Th) which stated that the side effects of ARVs commonly suffered by HIV positive sufferers were often dizziness, nausea and nightmares.

This is in line with research (Yuliandra *et al.*, 2017) which states that 100% of ARVs are used according to indications and doses and only 97.76% of patients receive appropriate ARVs. 10.11% of patients have the potential for drug interactions. Antiretroviral treatment requires the selection of the right drug to increase its efficacy. In another study, there was a relationship between the duration of ARV therapy ≥ 2 years with the quality of life of HIV sufferers (Handayani *et al.*, 2017).

In addition to antiretroviral drugs, of course HIV positive sufferers need good nutrition to support their daily activities. All informants in this study stated that there are no restrictions on food for HIV positive sufferers, the most important thing is clean and cooked food. Many bacteria are found in raw meat and vegetables. Though HIV sufferers are more susceptible to infections caused by bacteria. These infections more often cause septicemia (blood infection) in people with HIV (Spiritia Foundation, 2015).

In a study in Ghana mentioned that personal hygiene affects the incidence of diarrhea in HIV positive patients. Personal hygiene consisting of hand washing behavior, good sanitation, and proper drinking water will significantly reduce exposure and infections that cause diarrhea (Opoku *et al.*, 2018).

Exploration of Life Quality Perception of HIV Positive Sufferers from the Psychological Dimension

Negative feelings have certainly been experienced by HIV positive sufferers such as despair, anxiety, loneliness to depression. All informants in this study stated that they rarely experienced this. All informants said that the feeling that often arises is anxiety if they experience fatigue because their bodies are vulnerable and will easily drop. This is in line with research in Yogyakarta which states that perceptions that are felt seriously by HIV sufferers are decreased endurance and feel easy to feel weak (Mahmudah, 2018).

The worst negative feeling they have ever experienced was when they first learned that they were infected with HIV. However, now informants have risen from negative feelings thanks to the support of nurses and doctors who provide health services, peer support groups and families. This was also reinforced by triangulation informants (IT4) who stated that HIV sufferers would be motivated if they were willing to join peer support groups. All informants busied themselves with activities and always tried not

to be alone. This is in line with research (Sarikusuma *et al.*, 2012) which states that HIV positive sufferers who feel they have negative feelings will make an effort to keep themselves busy and look for a new atmosphere.

In in-depth interviews all informants stated that their lives were very meaningful. They revealed that even though they had been infected with the HIV virus, they felt that their lives were very meaningful because they could provide support to new HIV sufferers, still be able to work, still wanted to make parents happy and they also felt they didn't bother others.

All informants in this study stated that they received their bodies well. They stated that whatever gifts God had given them were grateful and considered it a gift. This is in line with research (Putri & Tobing, 2016) which states that HIV sufferers accept themselves by always being grateful, respecting themselves, helping others, optimistic and not wanting to be treated differently. Other studies also mention that HIV patients who are older are more able to accept themselves well compared to sufferers who are in their teens (Khasanah & Shanti, 2013).

Exploration of Life Quality Perception of HIV Positive Sufferers from the Social Dimension

The ability of HIV sufferers to get along, all HIV sufferers say that they get along with anyone. Most of the informants said that they rarely associate with the neighborhood. They feel more comfortable to hang out with people outside their place of residence such as sports friends, college friends and work colleagues. All informants stated that they would behave normally when hanging out, meaning they would not show pain and the informants would not disclose status to all friends. This is in line with research (Makmur, 2017) which states that HIV sufferers prefer not to talk about their situation in order to protect themselves. In a study in Surabaya, it was stated that most HIV sufferers received support from their foundation and partners because

sufferers kept their status from their families secret (Ningrum & Husna, 2014).

Mauritanian research (Boushab *et al.*, 2017) shows that 64% of HIV sufferers know their HIV status for more than a year and they refuse to disclose this information to whom. One informant (I4) stated that his family did not know that he was infected with HIV. So that he gets support only from friends and companions. This is in line with research (Latifah & Mulyana, 2017) which states that often HIV positive sufferers do not get support from family so that friends and companions play an important role in restoring the condition of HIV sufferers for the better.

In this study, the informants also received support from peer support groups, doctors and nurses who provided services as well as from their partners. For families of sufferers only a few family members know their status as HIV positive sufferers such as only mothers or sisters. This means that the support obtained by people with HIV from the social environment will affect the quality of life of people with HIV. An HIV sufferer faces a complex problem where they face HIV disease itself which can affect physiological changes in their body, but HIV sufferers also face psychological problems which can be in the form of stigma and discrimination. These things can have an impact on their quality of life.

Exploration of Life Quality Perception of HIV Positive Sufferers from the Environmental Dimension

In this study all informants stated that they had no difficulty in accessing information about HIV. They say that they can easily get information from the internet, the community, health services, health services or from the socialization or training that they follow. Through this easy access HIV sufferers are more empowered because of the knowledge they have. If they experience a problem then at least they understand what attitude they should take. They say if they experience health complaints they will find it easy to seek help,

such as consulting their assistants or going straight to health services. This is in line with the statement of the triangulation informant (IT4) which states that currently there are many NGOs that care about HIV / AIDS and Puskesmas that provide services on HIV which will facilitate HIV sufferers and can improve the quality of life of sufferers.

Information held by HIV positive sufferers affects the quality of life of HIV positive sufferers (Burhan *et al.*, 2014). Another study in Kupang City stated that MSM who suffer from HIV received support from their community and the AIDS Commission in the form of information and emotional support. They get information about HIV through the internet and counseling (Kana *et al.*, 2016).

All informants said that the response of their residence was good. Well, what is meant here is that all informants said that they were not yet open to their neighborhoods like neighbors. For the informants, it is not an important thing to tell about their health status to their neighborhood. Most informants said that they were not very familiar with the environment around their homes since they had not been diagnosed as HIV positive. They feel more comfortable hanging out with friends outside the neighborhood. All informants said that they lived in a good and clean environment. However, when researchers came to visit one of the informants' homes to conduct interviews with triangulation informants. Researchers observed the situation of the informant's residence (I2) located in a densely populated residential area in the city of Semarang. The family of informants stated that they currently live in rented houses and are accustomed to moving rented houses. The condition of the informant's house (I2) that the researchers observed was that the informant's house looked cramped and run-down where the rented walls were made of boards so that when conducting the research the researcher heard clearly the sound of the television next door. Narrow informants' houses looked dirty

because of the spatial arrangement. Upon entering the door of the informant's house, the researcher had to look down a little because the height of the house's door was not suitable and had no windows. Seeing this, researchers felt that the condition of the informant's house was less healthy for an HIV positive person. This is because with a decrease in immunity in an HIV positive person it will be susceptible to illness due to unhealthy environmental conditions such as coughing or skin diseases.

HIV positive sufferers say that they have easy access to health services. When they go to hospitals, health centers, or clinics to take ARVs, they get good and friendly service. They said they did not receive discrimination from health workers. In a study in the city of Semarang stated that there is a relationship of knowledge, access to services and support of officers to the regularity of patient visits to health care (Rahmatin & Azinar, 2017).

CONCLUSION AND SUGGESTION

Based on the description of the results of the above research conclusions can be taken as follows: HIV positive patients state that their quality of life in terms of the spiritual dimension, physical dimension, psychological dimension, social dimension, and environmental dimension are good. This is because all the informants have a good understanding of what HIV is, regularly taking ARVs, joining a Peer Support Group (*KDS*), maintaining a healthy lifestyle and getting a lot of support from their friends and family. In order to improve the quality of life of HIV positive sufferers, it is expected that program makers (Ministry of Health, Health Office and KPA) can empower positive HIV sufferers so that they are productive and feel that their lives are meaningful and provide preventative education and health education related to youth related groups healthy sex and avoid transmission of HIV / AIDS.

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