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Social Functioning of People with HIV/ AIDS (PLWHA) Receiving Antiretroviral Therapy in the City of Bengkulu

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Abstract: The problem in the research is the low number of people with HIV/AIDS (PLWHA) who take antiretroviral drug therapy in Bengkulu City. This occurs because of shame and fear of being stigmatized and discriminated against if other people find out about their status, causing their social functioning to be disrupted (Social Dyscpunction). The purpose of the study was to determine the benefits of antiretroviral drug therapy for people with HIV/AIDS (ODHA) in Bengkulu City on their social functioning. The research uses applied research methods, this research approach uses qualitative research. The research informants were 8 people with HIV/AIDS (ODHA), determined by the snowball sampling technique because the group or person as an informant could not be identified. Data collection techniques include observation, in-depth interviews, and documentation. The results of the research show that there are many benefits for people with HIV/AIDS (PLWHA) who take antiretroviral drug therapy in terms of their social functioning. The physical condition is healthier because antiretroviral drug therapy makes the immune system of PLWHA stable so that the development of viruses can be prevented. Psychologically, people with HIV/AIDS (PLWHA) become better because the therapy process provides a lot of knowledge about HIV/AIDS, thus eliminating fear and worry about the disease they suffer from, ultimately making PLWHA more confident and able to socialize and be able to carry out their social roles or functions. Based on the results of the research, researchers recommend that PLWHA with new status should immediately undergo antiretroviral drug therapy. It is also necessary to carry out interventions to empower families to always provide support to PLWHA, and make efforts to prevent and treat depression problems so that PLWHA remains empowered.

Keywords: Social Functioning, PLWHA, Antiretroviral Therapy

Introduction

HIV/AIDS (Human Immunodeficiency/Acquired Immune Deficiency Syndrome) is not only a sensitive issue in the health sector, moreover, it is quite broad in touching the social realm because it has an impact on a person's social functioning. HIV is also an international issue because HIV has attacked many people all over the world. AIDS cannot be cured, but the life expectancy of PLWHA can be extended with ARV (antiretroviral) treatment. This treatment can increase the immunity of PLWHA so that their quality of life increases (Spiritia, 2006).

Since antiretroviral drugs (ARVs) were discovered and widely used, HIV has entered a new chapter in its history, from being a highly deadly infectious disease to now being a chronic disease that, if managed properly, will give sufferers the same life expectancy as those who do not have the virus in their bodies. At the beginning of the epidemic, most people diagnosed with HIV had a low life expectancy. The number of PLHIV who die of HIV exceeds the number of those who die of cancer. But since the ARV era, the number of AIDS-related deaths has dropped drastically (Boneya, 2024).

Before carrying out ARV therapy, every PLHA must first undergo VCT (Voluntary Counseling and Testing). VCT is the entry point to provide care, support, and treatment for PLWHA. VCT is also a model for providing comprehensive information and support to change risky behavior and prevent transmission of HIV/AIDS (Haruddin, et al. 2007). Counseling is carried out before and after testing to diagnose HIV/AIDS, if a positive test result is obtained, counseling will lead to care, ARV therapy, and other supporting services (Choudhary, 2024).

The cumulative number of HIV cases in Indonesia will reach around 526,841 people by 2023. Of that number, around 429,215 people have been detected or know their HIV status, while there are still around 100,000 people who have not been detected and have the potential to transmit HIV to the community. New HIV cases in housewives also continue to increase, with around 35% of total transmission occurring in this group, and more than 14,000 children aged 1-14 years are recorded as HIV positive (Ministry of Health).

Meanwhile, Bengkulu Province and City contributed HIV/AIDS data as follows: Kasus Penyakit Menurut Kabupaten/Kota dan Jenis Penyakit di Provinsi Bengkulu, 2023 Terakhir Diperbarui : 22 Februari 2024 **⇔** Bagikan Cari data statistil Freeze judul kolom

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Bengkulu Province now has several ARV therapy health services, namely, M. Yunus Bengkulu Hospital, Bengkulu City Decline Health Center, Kandang City Health Center Bengkulu City, and Rejang Lebong Hospital, and there are several PKM in Bengkulu City which are currently providing HIV counseling and testing services, namely

Beringin Raya, Suka Merindu, Ratu Agung, Padang Serai, Pasar Ikan, Lingkar Timur, Basuki Rahmat and PKM Jalan Gedang, but not all of them provide ARV provision services (Jacobson, 2024).

The issue of HIV/AIDS has always been a frightening polemic, this becomes even more frightening when policies, health services, stigma, and so on do not take sides. The public's ignorance about HIV/AIDS results in low public access to health services, whereas knowing the HIV/AIDS status of a person early can improve the quality of life better so that the death rate can be suppressed (Woldegeorgis, 2024).

From this background, the researcher was interested in researching the benefits of antiretroviral drug therapy for the social functioning of people with HIV/AIDS (PLWHA). the formulation of this problem is: How are the benefits of antiretroviral therapy for the social functioning of people with HIV/AIDS (PLWHA)?

Theoretical Basis

HIV / AIDS

HIV is the abbreviation of Human Immunodeficiency Virus, HIV is a virus that can cause AIDS. HIV attacks the human body's immune system so that the body becomes weak in fighting infection. In other words, the presence of this virus in the body will cause deficiency (immune system deficiency) (LKNU 2013).

People who have been infected with HIV in the first few years have not shown any symptoms so physically they may look no different from healthy people, but have great potential as a source of transmission, meaning they can transmit the infection to others. Entering the 5 to 10-year period, an HIV sufferer begins to show symptoms of various diseases that arise due to low body immunity. In this condition, the person is referred to as an AIDS sufferer (Motivator Training Module for HIV/AIDS Prevention in the Islamic Religious Sector, 2000).

AIDS stands for Acquired Immunodeficiency Syndrome. Syndrome, which in Indonesian is syndrome, is a collection of symptoms and signs of a disease. Immuno means immunity while Acquired means acquired or obtained. In this case, "acquired" means that AIDS is not a hereditary disease. AIDS can be interpreted as a collection of signs or symptoms of a disease due to the loss or decline of a person's immune system. AIDS is the terminal phase (end) of HIV infection (Training Module for Motivators for Handling HIV/AIDS in the Islamic Religious Sector, 2000).

For an HIV sufferer or AIDS sufferer, a mild illness can have fatal consequences, for example, influenza. In healthy people, this disease will heal by itself in less than one week, even if it is not treated at all as long as the sufferer eats and gets enough rest. **People with** HIV and AIDS sufferers can die from other infectious diseases that attack their bodies due to their compromised immune systems (opportunistic infections).

The figure of someone suffering from HIV/AIDS is often seen as a representation (image) of human moral decline. This systemic process of marginalization is what makes sufferers become aliens (strangers) in their environment. Discrimination against sufferers occurs almost all over the world. Expulsion, isolation, and dismissal are the consequences for PLWHA who reveal their status (Jangkar 2006). It was clear in the decision of the UN

session that specifically discussed HIV/AIDS in 2001 that it was necessary to expand services, care, and support for PLWHA and protect their human rights (National AIDS Commission, 2004).

In English, people infected with HIV/AIDS are called PLWHA (People Living with HIV/AIDS), while in Indonesia this category is called PLWHA (People with HIV/AIDS) and OHIDA (People living with HIV/AIDS) both their families and their environment. PLWHA are people who suffer from HIV/AIDS who are physically the same as those of us who do not suffer from HIV/AIDS, it cannot be seen from the naked eye whether someone is suffering from HIV/AIDS or not Ardhiyanti et al (2015). PLWHA (People Living with HIV/AIDS) are a source of factual information regarding HIV/AIDS because PLWHA has direct experience with HIV/AIDs (Aubrey 2004).

Antiretroviral Therapy

The use of ARVs in Indonesia began in 1990 using patented medicines, only in November 2001 using generic medicines. Kimia Farma itself was only able to produce generic ARVs at the end of 2003, so ARV drugs have been available free of charge since 2004. ARVs or antiretrovirals are drugs designed to inhibit the development of HIV/AIDS in the sufferer's body. The drug (ARV) does not kill the virus but can slow the growth of the virus, the time the virus grows is slowed down, as is HIV disease. Because HIV is a retrovirus, these drugs are usually called antiretroviral therapy (Spiritia, 2006).

The main goal of ARV therapy is to maximize and sustain the viral load, restore or maintain immunological function, improve quality of life, and reduce morbidity and mortality (Silvia Andreson 2006 in Syafrizal 2011).

Spiritia (2013) stated several benefits of antiretroviral therapy (ARV) as follows:

- Inhibits the progression of HIV disease
- Increases the number of CD4 cells in the body
- Reduces the number of viruses in the blood
- Feeling better
- NNRTI (Non-nucleoside reverse transcriptase inhibitors).
- NRTI (Nucleoside reverse transcriptase inhibitors).
- Protease inhibitors.
- Entry inhibitors.
- Integrase inhibitors.

Social Functioning

The concept of social functioning generally refers to the ability of an individual, family or community to carry out social roles in their environment, because in this case, social functioning refers to how an individual or group carries out life tasks and fulfills their needs (Trickey, 2024).

This is in line with the opinion of Thackeray and Farley 1991, p.19 (in Edi Suharto, 2006, p.28) defining social functioning as the ability of people (individuals, families, groups or communities) and social systems (institutions and social networks) to fulfill their needs. or responding to basic needs, carrying out social roles, and dealing with

shocks and pressures (shocks and stresses) Another opinion that provides an understanding of social functioning, namely Achlis (in Dedy Haryanto, 200, p.18) says that "social functioning refers to the methods used by a person as an individual or as a collective as a family, organization, community or social unit in behaving. or acting in carrying out life tasks and meeting their needs," Achlis further said that social functioning is showing balance, mutual exchange, mutual reinforcement, and mutual adaptation between people individually and collectively with their environment.

Achlis added about the social functionality regarding:

- a. Ability to display several social roles and task roles
- b. The ability to solve problems and the ability to use oneself as well as the ability to explore and utilize the resources available in one's environment/people as well as the ability to create new resources to overcome obstacles to self-realization.

The explanation above says that social functioning is seen as the ability to meet needs. Everyone is always faced with efforts to meet their needs. Therefore, social functioning also refers to the methods used by individuals and groups to meet their life needs. Many experts have given their opinions regarding the types of human needs in general. Neil Gilbert and Harry Specht in their book entitled The Emergence of Social Welfare and Social Work state that human needs can be grouped into S parts:

- a. Physical Needs
- b. Emotional Needs
- c. Intellectual Needs
- d. Spiritual Needs
- e. Social Needs

The concept of social functioning essentially refers to the "capabilities" of an individual, family or community in carrying out social roles in their environment. This conception puts forward the value that humans are the subject of all life processes and activities; that humans have abilities and potential that can be developed in the process of assistance; that humans have and/or can reach, utilize, and mobilize the assets and resources that exist around them.

Thus, it can be concluded that the definition of social functioning refers to the way a person carries out life tasks, solves problems, and fulfills their needs. Therefore, to carry out these aspects of social functioning, social functioning is closely related to a person's social role and social status in the social environment or society.

Suppose a person can carry out a role (rights and obligations) by his social status. In that case, that person is said to be capable of social functioning, conversely, if he is unable to carry out or perform a role by his social status, then that person is said to be socially dysfunctional.

Methodology

This research aims to determine the benefits of antiretroviral drug therapy for people living with HIV/AIDS (PLWHA) in Bengkulu City in carrying out their social roles (social functioning). This research approach uses a qualitative assessment. Qualitative

research methods refer to research procedures that produce descriptive data, namely what people say both verbally and in writing, what people do, fundamentally depends on human observations in their area and relating to those people in their language and events. Limitations in this research are the social Functioning of People with HIV/AIDS and ARV (Antiretroviral) drug therapy. The method of determining informants is the snowball sampling method. Snowball sampling is an option because the group or people as respondents cannot be determined. The research focus, informants for the research were PLWHA who were taking antiretroviral drug therapy in Bengkulu City. Data collection techniques include observation, in-depth interviews, and documentation studies. Data analysis techniques are carried out before entering the field, during the field and after completing the field (Miles and Huberman model of data analysis in the field).

Result and Discussion

1. Physical Health of PLWHA

 Table 1 Frequency of Informants' Illness Before and After ARV Therapy (per three months)

No	Initial	Frequency of Illness (every three months)	
		Before ARV Therapy	After ARV Therapy
11	FR	1-2 times (fever, TB, IO, mouth	1-2 times (fever, mouth ulcers and
		ulcers, and prolonged cough and	cough, and cold) not too long, and CD4
		cold) and CD4 fluctuates (under	stable
		200)	
22	AP	1-3 times (fever, diarrhea, and	1 time (mouth ulcers/cold) not too long
		prolonged mouth sores), and CD4	and CD4 was stable and even increased
	D.C.	fluctuates	4.2 Ti (TI 1 1 2 11 2 1)
33	RS	1-3 Times (Fever, Diarrhea, Mouth	1-2 Times (Thrush and Cold Cough) not
		ulcers, Cough, and prolonged cold)	too long and CD4 is stable
4.4	ED	and CD4 fluctuates	1 times (mostly release and colds) not to
44	FB	1-2 times (fever, diarrhea, mouth	1 time (mouth ulcers and colds) not too
		ulcers, and prolonged cough and cold) and CD4 fluctuates (under	long and CD4 stable
		200)	
56	TY	1-3 times (fever, diarrhea, mouth	1-2 times (fever and mouth ulcers) not
		ulcers, and prolonged cough and	too long and CD4 stable
		cold), and CD4 fluctuates	O
67	MZ	1-2 Times (Fever, TB, Thrush,	1-2 Times (Fever and Cough and Cold)
		Diarrhea, and Long-term Cough	not too long and CD4 stable
		and Cold), and CD4 fluctuates	
		(often below 200)	
88	UJ	1-4 Times (Fever, TB, IO, Mouth	1-3 Times (Fever, TB, Mouth Ulcers,
		ulcers, Diarrhea, and long-term	Diarrhea, and Cough Cold) not too long,
		cough and colds), and CD4	and CD4 is stable
		fluctuates (often below 200)	
Source: Research results February 19_29 2024			

Source: Research results February 19–29 2024

The table above explains that after following ARV therapy, the informants no longer felt excessive physical symptoms, and the quality of health of PLWHA was much better after following ARV therapy compared to when they had not participated in ARV therapy. It is known that the physical condition of PLWHA in research before

taking ARV therapy, 37.5% of informants did not feel excessive physical symptoms, only felt tired quickly and had a lack of appetite, while 62.5% of informants experienced complaints due to opportunistic infections (IO), fungus, canker sores and prolonged diarrhea and even had to be hospitalized for quite a long time because he had complications with other diseases so that his physical condition was very thin, dull and weak. After taking part in ARV therapy, all informants said that the frequency of pain (physical condition) they felt was much better than before taking ARV therapy. Behaviors carried out to maintain personal health by getting used to healthy behaviors such as not going out at night, maintaining personal and environmental cleanliness, and being obedient and obedient to ARV therapy.

2. Psychological Health of PLWHA

Good mental health is a condition when the mind is in a peaceful and calm state, allowing us to enjoy everyday life and appreciate others around us. A person who has a healthy mentality can use his abilities or potential to the maximum in facing life's challenges, as well as establishing positive relationships with other people. On the other hand, people whose mental health is disturbed will experience disturbances in mood, thinking ability, and emotional control which can ultimately lead to bad behavior.

Before ARV therapy, all informants stated that their psychological health was less stable (easily angered, easily offended, fearful, and blaming themselves and others) because they did not know much about HIV/AIDS, all they knew was that it was a deadly disease, and they were afraid of death. In addition, the psychological burden experienced was still having to hide their status from their families, because they were afraid of being expelled by their families, this was experienced by 37.5% of informants. There were 25% of informants who still denied the illness they were suffering from (disbelief), and 37.5% of informants were burdened because they were thinking about the fate of their children in the future, as well as being afraid of infecting their partners and those closest to them.

When a PLWHA first finds out that they are HIV positive they become stressed, feel sorry for themselves, regret the actions they did previously, and also blame circumstances that were not in their favor, of course, this makes the psychological condition of a PLWHA become disturbed, as did the informants in the research 100% The informant had experienced stress and denied his status as a PLWHA.

Many changes occur for PLWHA who decide to take part. Many changes occurred for PLWHA who decided to take ARV therapy, as was done by the informants in this study after they took ARV therapy and joined the Bengkulu+ KDS at the Kipas Foundation, 37.5% of PLWHA dared to convince their HIV-negative partners to married and had children because they had received knowledge of VCT, ARV, PMVCT and other information about HIV/AIDS, apart from that they had also attended training and strengthened mental abilities so that some had open status (12.5%). Apart from that, 62.5% of informants were also able to accept their status as PLWHA, starting to understand the lifestyle they would live, namely complying with

ARV therapy and living a healthy lifestyle, as well as behaving well for themselves. So that the psychology of PLWHA when they get to know VCT and ARV therapy becomes better, that they can continue to live their lives carrying out their roles like other people who are not PLWHA, as long as they have good behavior, have a healthy lifestyle and adhere to ARV therapy, and check their CD4 regularly. according to the doctor's advice

3. Independence of PLWHA

In general, independence is an attitude that allows a person to act freely, do something based on his encouragement, and the ability to regulate himself, by his rights and obligations so that he can solve the problems he faces without asking for help or depending on others and can be responsible for All decisions have been taken through various previous considerations.

The results of the research show that PLWHA experience helplessness (not being independent) when they are first diagnosed with HIV/AIDS. When someone is infected with HIV/AIDS, they will face various reductions in their potential or capacity for life, and their mobility will also be hampered. Ignorance and wrong knowledge about HIV/AIDS, one of the things that most often makes people infected with HIV/AIDS become independent is that they don't know the symptoms when HIV starts to infect them. As a result, they are late in receiving treatment, so they experience a declining health condition or serious illness which is characterized by the emergence of various opportunity infections at low immune levels (CD4) below 200, ultimately affecting the quality of life of PLWHA.

After following ARV therapy, all informants were still able to carry out their normal activities, because their health was relatively stable so they could still work and meet the needs of themselves and their families. It's just necessary to limit the type of work that is heavy and working hours that are too busy. Informants who are mothers can also continue to carry out their roles in caring for and educating children.

4. Social Relations of PLWHA

Interview data shows that 37.5% of PLWHA are married (have partners) who do not have the status of PLWHA so the husband-and-wife relationship is carried out using contraception (condoms), but this does not disrupt the harmony of their household, because before marriage this consequence has been conveyed by the partner and they accept it. Families and partners of PLWHA are expected to always accept the status of PLWHA as it is and support PLWHA in carrying out care and treatment.

As Lieberman (1992) stated, theoretically the existence of social support can reduce the tendency for events to occur which can cause stress. Social support will change an individual's perception of stressful events and therefore will reduce the potential for stress in the individual concerned.

PLWHA who experience discrimination tend to experience stress, suicidal ideation, and low quality of life and tend not to seek health services (Wingood, et al. 2007). Stigma is a dynamic process that is built from a pre-existing perception that

causes a violation of attitudes, beliefs, and values. PLWHA's views on social assessments of themselves Informants receive various assessments from their families, relatives, neighborhoods, peer groups, and workplaces. All families and relatives of informants can accept the reality of PLWHA status at different levels. 50% of informants stated that their families and relatives accept and do not give different treatment to others, but 50% of informants stated that they are different. Different treatment or what is often called stigma and discrimination experienced by PLWHA consists of the community environment and self-stigma.

In addition to the support of family and friends of KDS, the support of the government is very important in determining the fate of PLWHA. Currently, PLWHA's survival is very dependent on ARVs, so the availability of free ARVs and VCT services is necessary at all times. The hope for the future is that health equipment related to CD4 and blood screening examinations can be increased in each region. So far, PLWHA has received social and health insurance, their social insurance is provided by social institutions where they are grouped, and health insurance is in the form of free VCT and ARV. In addition to social security, PLWHA also often gets the opportunity for recreation and fun in monthly meetings held by KDS.

5. Environmental Support

The results of interviews with informants revealed that 87.5% of PLWHA's nuclear families knew their family members' status as PLWHA and 12.5% of PLWHA had open status (known to the environment). Of the 12.5% of PLWHA who have open status, they experience stigma and discrimination from those in the environment who know their status. Informant FR stated that while being treated in the hospital, he felt discriminated against by other patients, for example in terms of food provision, he used Styrofoam which was immediately thrown away after use, in addition in terms of service, nurses and doctors always used face and hand masks which were considered somewhat excessive. FR has just experienced this, his child has just been treated at a hospital because he has TB, he feels that the service provided by the medical team is different for his child, his child is being treated in an "isolation" room and the medical team that treats him always wears a mask which according to FR is too much. The hospital experience ultimately made PLWHA always close themselves off regarding their status in their family, neighbors, work environment, and the wider community.

PLWHA's views on the social assessment of themselves Informants received various assessments from their families, siblings, neighborhoods, peer groups, and workplaces. All of the informants' families and siblings were able to accept the reality of having PLWHA status at different levels. 50% of informants stated that their families and siblings accepted them and did not treat them differently from others, but 50% of informants stated differently.

6. Spiritual Life of PLWHA

The spiritual aspect has an important role in maintaining the quality of life of PLWHA (Braxton, et.al 2007). Spiritual aspects play a very important role in controlling a person's psychology. Spiritual, including the ability to find the meaning

of life and carry out worship by the religion one freely adheres to. PLWHA who realize that the disease they suffer from is a trial from God to test His people will increase their faith so that they improve themselves by getting closer to their God. This will impact the quality of life of PLWHA.

The spiritual aspect has an important role in maintaining the quality of life of PLWHA (Braxton, et. al 2007). Spiritual aspects play a very important role in influencing a person's psychology. Spiritual, including the ability to find the meaning of life and carry out worship in accord with the religion one freely adheres to. PLWHA who realize that the illness they are suffering from is a trial from God to test His people will increase their faith so that they improve themselves by getting closer to their God. This will influence the quality of life of PLWHA.

Conclusion

There are many benefits for HIV/AIDS sufferers (PLWHA) who undergo antiretroviral drug therapy in Bengkulu City, namely:

- 1. The physical condition of PLHIV who are undergoing antiretroviral drug therapy is healthier compared to PLHIV who have not and/or are not compliant with antiretroviral drug therapy.
- 2. Psychologically, the health of PLWHA who are taking antiretroviral drug therapy is more stable compared to PLWHA who have not or are not compliant with antiretroviral therapy. Emotionally stable, not easily angered, not blaming yourself or others, not afraid of death, and have good behavior so you can still socialize well in the social environment.
- 3. Learning from a regular treatment system, making PLWHA independent and responsible people, affects the daily lives of PLWHA, they continue to carry out their daily mobility as usual and they continue to work according to their type of work. PLWHA are still able to carry out their social roles within the family (as husband or wife) both in terms of personal relationships and sexual activities.
- 4. In addition to social support, namely family and friends of KDS, government support greatly determines the fate of PLWHA. The survival of PLWHA currently relies heavily on ARVs, so the availability of free ARVs and VCT services is necessary at all times. The length of time undergoing therapy also influences the understanding of HIV/AIDS which then makes PLWHA become better spiritually, illness often makes people closer to their creator.

Advice

The importance of antiretroviral drug therapy and routine and compliant VCT for PLWHA as soon as possible after being diagnosed with HIV, so that the quality of life and health of PLWHA can improve, so that they can continue to function socially well. Compliance with antiretroviral drug therapy requires support from family, close friends, and the environment. For PLWHA to continue to function socially, they must feel safe in their living environment by not avoiding, isolating, and not rejecting their existence, providing support to PLWHA in the form of providing information, behavioral or material assistance so that PLWHA feel cared for, valued and loved. Interventions need to

be carried out to empower families to always provide support to PLWHA, families can also make efforts to prevent and treat depression problems to improve the quality of life of PLWHA. In addition, in the process of maintaining the social functioning of PLWHA, social workers are expected to help in terms of:

- 1. Increase public knowledge to solve problems faced by society, especially HIV/AIDS Problems.
- 2. Linking PLWHA with social service institutions.
- 3. Striving to improve the capacity of service institutions related to HIV/AIDS issues.
- 4. Contribute to the improvement of social policies and legislation related to social rehabilitation services for HIV/AIDS sufferers.

In addition, in carrying out their functions, social workers are expected to be able to:

- 1. Helping PLWHA use their abilities to carry out life tasks and solve their problems.
- 2. Helping PLWHA with relationship paths with service institutions.
- 3. Facilitate interaction between PLWHA with the service institutions needed and people within the service institutions.
- 4. Contribute to changes, improvements, and developments in social policies and legislation related to handling HIV/AIDS problems.
- 5. Equalize material resources for PLWHA in overcoming their problems. Align material resources for PLWHA to overcome their problems.
- 6. Act as an implementer of social control over PLWHA and the services provided.

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