

The Perception of People with HIV/AIDS against the Support of the Family in the City of Ternate 2017

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Abstract: Background: The situation faced by people with HIV/AIDS (PLWHA) is very complex, in addition to having to face the disease themselves; they also experience emotional distress and psychological stress. Therefore, people living with HIV need support of the family in improving the quality of life, good support emotionally, information, instrumental and appraisal. Ternate city is the area with the second HIV/AIDS sufferers' se region province of North Maluku. HIV/AIDS cases from the year 2007-2017 as much as 346 cases (206 HIV cases, AIDS 140 cases). The purpose of this research was to know the perception of people with HIV/AIDS against the family support in Ternate city of the year 2017. Method: This type of research is qualitative research with a retrospective case study approach. Research conducted in Ternate city in May until December 2017. The number of sample is 8 participants. The technique of data collection is by means of in-depth interviews. The results of the perception of people with HIV/AIDS against family support assessment and emotional family is still there. Informational support of families of people with HIV, and the perception of people with HIV/AIDS about support instrumental family that consists of financial support and the fulfillment of the needs of people with HIV (eat drink, chapter/BAK) It's been good. These results which are formulated the model family support based on the development of the theory of family support by Friedman. Themes and sub themes (categories) that are generated are listed in the model. This model was created with the name Family Support Model. Conclusion: Mmodel this is going to be a referral for family members with HIV/AIDS in providing support to people with HIV/AIDS to improve the quality of life.

Keywords: Family support, People living with HIV, HIV/AIDS, Perception

1. Introduction

Human Immunodeficiency Virus (HIV) is a virus that attacks the human immune system and can lead to AIDS. HIV invades a type of white blood cells that ward off infection (KPA, 2009). While the *Acquired Immune Deficiency Syndrome* (AIDS) is a collection of symptoms or disease caused by declining immune due to infection with the HIV virus. The Data indicates approximately 620 thousand people in Indonesia detected suffering from HIV, from the years 1987-2016 the number of deaths due to HIV in Indonesia reached 14,234. Risk factors the most current sufferers is the males, most transmission is heterosexual and most sufferers aged 30-39 years (UNAIDS, 2016; Kemenkes RI, 2016).

North Maluku are currently eighth in the ten provinces that had the highest prevalence (47.59%) as well as above national numbers (36.62%) with the amount of komulatif HIV/AIDS reached 928 sufferers in 2016 (Ditjen PP & PL Kemenkes RI, 2016). North Maluku it is one of the selected programs to combat HIV/AIDS by the Central Government in collaboration with the LKNU as well as the clinic Jasminee (VCT clinics at the Provincial Hospital of Dr H Chasan Boesoerie Ternate) in the accompanying people living with HIV as well as other high risk groups.

Ternate city is part of the North Maluku province of origin in Ternate City Health Office has a HIV/AIDS sufferers from the year 2007-2016 as much as 314 people. HIV cases among them as many as 216 cases of AIDS and as many as 198 cases. In the year 2017 findings the HIV/AIDS sufferers reaching 32 cases, with most sufferers is a housewife (Health Office of Ternate, 2017). Since January 2007, found at up to

now the number of sufferers in the city has reached 346 numbers of sufferers. Based on data from the NGO Rorano, from people with the disease the most are Housewives. The housewives with the number reaching 58 people, after the IRT second position, there are self-employed and civil servants. In addition, on the basis of age is the most productive age, i.e. between 25-49 years, as many as 262 people. Health Office (the city of Ternate, 2017; The NGO Rorano, 2017).

The situation faced by people with HIV/AIDS (PLWHA) very complex, in addition to having to face the disease themselves, they also experiencing emotional distress and psychological stress. For it is through therapy treatment compliance, taking the drug *antiretroviral* (ARV) is indispensable in order for people living with HIV do not break up the drug and not the case of resistance in her body. ARV therapy treatment approaches are not enough when just based on sheer ARV drug but necessary approach including granting plenary support (Nursalam and Ninuk, 2007). In addition compassion many sufferers of people living with HIV who lack the support of the family, this is due because of the high stigma associated with the disease of HIV/AIDS so that family members who This disease is often considered to have violated norms in family and embarrassing the family. In the end they often obscured and abandoned even the isolated from the environment (full moon & Haryanti, 2006).

Caring and affectionate family is one of the much-needed support for sufferers of HIV/AIDS (Nursalam & Kurniawati, 2007). The family as a *support system* that is the primary needed to develop an effective coping to adapt faced stressor

related diseases, both physical, psychological and social people living with HIV (Setiadi, 2008).

Nuraeni research results (2011) shows that a HIV/AIDS counselor reveals the main needs of people living with HIV are the ones closest to you like family. Only the family that is able to accept the conditions of the people living with HIV continues to accompany at difficult times, take the medication the doctor, help seeking and giving information about the disease of HIV/AIDS can make people living with HIV feel appreciated and his life became more meaningful. Thirteen of the 20 people living with HIV who examined, (65%) have family support at lower levels. Research results and Mohanna Kamath (2009) shows that family support can provide a positive impact against a decrease in interference in people living with HIV such as anxiety, stress, depression and a sense of solitude.

The purpose of this research is to know the perception of people with HIV/AIDS PLWHA against the family support in Ternate city of the year 2017.

2. Method of Research

This type of research is qualitative research with a retrospective case study approach. Research location is in the town of Ternate, North Maluku Province, May until November 2017. The populations of people living with HIV are all recorded in the health service of the city of Ternate. Retrieval technique using a *purposive sampling*, and is determined based on the criteria of inclusion. Large sample is 8 participants. The technique of data collection was by means of in-depth interviews (in depth interview). Data analysis was using qualitative data analysis.

3. Result

a. An overview of HIV/AIDS in the town of Ternate

North Maluku of eastern Indonesia is a region with a population of 1.142 million inhabitants (BPS, 2017). With a population that is so much, it's possible the population of North Maluku at risk of suffering from HIV/AIDS. Ternate city is part of the North Maluku province of origin in Ternate City Health Office has a HIV/AIDS sufferers from the year 2007-2016 as much as 314 people. With a total of 116 people as much as HIV and AIDS as many as 198 people.

In the year 2017 findings the HIV/AIDS sufferers reaching 32 cases, with most sufferers is a housewife (Health Office of Ternate, 2017). Since January 2007, found at up to now the number of sufferers in the city has reached 346 numbers of sufferers. Based on data from the NGO Rorano, from people with the disease the most are Housewives (IRT). The IRT with the number reaching 58 people, after the IRT second position, there are self-employed and civil servants. In addition, on the basis of age is the most productive age, i.e. between 25-49 years, as many as 262 persons (Health Office the city of Ternate, 2017)

There are two ways that is done by the hospitals and NGOs in linking HIV/AIDS sufferers in the city of Ternate, i.e. down checks and in cooperation with the Government of the

city of Ternate, open the services implemented in their respective community health centre as well as in the hospital.

b. An Overview of Participants

Participants are people with HIV/AIDS (PLWHA) were recorded in Ternate City Health Office and meet the inclusion criteria. Participant numbering were 8 people. Participants in this research-sex were women as much as men, and 2 male 6 people. The ages of the participants ranged from 23 to 32 years of age, with the status of married and unmarried persons 5 and 3 people. The lowest and highest education was high school undergraduate. Participants consist of private employees, housewives, jobless, honorary and civil servant. Participants are married as many as 5 people and 3 people aren't married. Route were history data, participants as much as 3 people using syringes and 5 people through sex.

When do participants choose where to interview he did interviews, based on participants' comfort level, because the data or information provided is confidential (*Confidentiality*). There are a few places that made the location of the interview at the jasmine clinic accompanied by counselors and the NGO Rorano.

Participants get privacy and secrecy (*Confidentiality*). Therefore, participants are given an initial identity code which later became the participant of the first (P1), the participant of the second (P2), the third Participant (P3), Fourth (P4) Participants of the fifth (P5), Participants to the six (P6), Participant of the seven (P7), and the Participants of the eighth (8th). The code is based on the participants' level of data retrieval.

c. The Results of Data Analysis

1) Identify the Perceptions of people living With HIV Family Assessment Support.

Family assessment support focuses on individuals who are positive coping. The perception of people living with HIV against family assessment support gave rise to two themes namely family response towards people living with HIV and problem solving strategies. Formula two this theme is the result of the analysis of the interview respondents.

The theme of family response gave rise to four (4) categories i.e. *denial* (family rejection), *sadness* (sad), *anger* (temper), *bargaining* (bargaining), *acceptance* (acceptance by the family). The theme of the problem solving strategy gave rise to the three categories namely scold, spiritual motivation, parental support, the support of a partner.

2) Identify the Perception of Family Informational Support people living With HIV.

The perception of people living with HIV against informational family support gave rise to two themes namely collection information. Collected information means families looking for HIV/AIDS-related information, while the information gives it means families who gather such information may be disclosed to those HIV/AIDS sufferers.

The first theme on collected information gave rise to three (3) categories are broken according to the meaning of the

statement to the respondent, i.e. the search for information in the Internet, seek information from counselors and information from peers (people living with HIV), whereas the second theme regarding the information giver gave rise to four (4) categories in which the best treatment, medication, regularity of Information management stress and information about the disease.

3) Identify the Perceptions of PEOPLE LIVING With HIV the Instrumental Support of the Family

The perception of people living with HIV against instrumental family support gave rise to two themes namely financial support and support basic human needs. Financial support means that the cost of the care and needs of people living with HIV are associated with cost supported by the family. And support basic human needs means that people living with HIV need support in the form of sustenance, mobilization treatment and elimination.

The first theme is regarding financial support gave rise to three (3) categories are sorted according to the meaning of the statement to the respondent, that is, the cost of treatment of parents, medical expenses of spouse and personal medical expenses, while the second theme regarding the need basic human gave rise to four (4) categories i.e. needs sustenance, elimination needs, the need for mobilization and the need for the provision of drugs.

4) Identify the Perception of PLWHA Emotional Support of Family

Identification of PLWHA's perceptions towards emotional support derived from family which brings up three themes of mental reinforcement, a sense of empathy and family protection. Strengthening mental i.e. family gives confidence and life expectancy, whereas empathy is meant is the families join the feel the suffering of sufferers. While the protection of the family means giving a sense of security and to protect sufferers of the disorder.

The first theme on strengthening mentally bring up four (4) categories were sorted according in accordance to the meaning of the statement of the respondent, i.e. not discrimination, the spiritual life, the principle of reinforcement, self-motivation. The second theme is about empathy gave rise to three (3) categories i.e. compassion, depression, participated the same suffering. While the theme into three namely family protections gave rise to four (4) categories maintain confidentiality, face stigma, maintain health, and advice on building, maintaining health.

4. Discussion

The results of this research obtained 8 respondents people with HIV/AIDS (PLWHA). The eighth interview respondents in a very varied. There were some respondents who chose to interview in the clinic and in the Office of the NGO. Place of interview is determined based on the respondent's level of comfort in providing family support related information.

Based on the results of the interviews to people living with HIV, people living with HIV against that perception obtained

support the assessment of families earned that support families obtained still Nothing worse, marked by the response of the families refused, angry, disappointed to restrict the activities of people living with HIV because of embarrassment with his condition and is regarded as the bearer of sustenance. Supports informational of the family towards people living with HIV are considered sufficient. The families of people living with HIV attempt to understand her condition by trying to seek information from counselors and the internet. From the information obtained, people family living with HIV can help the recovery process by reminding will order medications and possible complications that arise. Family support was informational so that it can be fulfilled.

The perception of people living with HIV was about support instrumental family who acquired the good people living with HIV. Most sources of financial supporting come from parents and spouse husband/wife of people living with HIV. The families was also involved in the fulfillment of the basic needs of people living with HIV, namely, providing sustenance, helps chapter/bak and help provide a remedy. And the perception of people living with HIV about emotional support from families that received by people living with HIV are still a bad category because most sources of emotional support people living with HIV comes from himself, other than that the family tried to keep the confidentiality status of people living with HIV, so the impact on the sense of careful people living with HIV in socializing.

Hacyl perception of people living with HIV against the family support can be made a family support model that depicts the family's support towards people living with HIV, and can be used as a guide/guide for stakeholders in addressing members families with people living with HIV. All eight respondents provide information about family support both in terms of assessment support informational support, support, instrumental and emotional support. From the results of the interview and after further analysis gave rise to the theme of each variable support. There is a theme that brings out the categories that are the aspects of family support towards people living with HIV. The existing categories and themes later developed into a model based on the theory of support families affected by *Friedman*.

Determination of the theme of each variable family was support above. The result determined based on interviews with people living with HIV. Support assessment gave rise to the category of family response and problem solving strategies. Support informational gave rise to two themes, namely as family information and as a giver of information to people living with HIV. Instrumental support, there are two themes, namely financial support and support basic human needs. Emotional support gave rise to 3 categories i.e. mental strengthening, empathy and protection of the family. All the themes that have been specified will bring up categories (subtheme).

The formation of the theory of the development of family support in the form of a model called the *family support model*. This model developed includes support assessment

(*assessment support*), endorsements informational (*informational support*), endorsements instrumental (*instrumental support*) and emotional support (*emotional support*). (green light) and *good support* inner box (dark green). *Bad support* is a level of family support that are still bad. *Moderate support* is the level of adaptation of the family in providing support to people living with HIV. And *good support* is level with the support given to the family of the best HIV/AIDS. *Family support model* this gives time to family members to understand the people living with HIV sufferers, especially physical or mental health of the people living with HIV who can contribute to satisfaction and happiness of the sufferers themselves. This Model also gives a positive understanding of family to HIV/AIDS sufferers as reference reading materials and to improve the quality of life of people living with HIV. Because not all people living with HIV get good support from family due to stigma, this is in line with the research Kusuma (2011) i.e. 51 people (55.4%) have family support. The results of the same study also found by Nirmal (2008), namely 63 people (58%) have family support.

1) Assessment Support

Assessment support is support that occurs when there is a positive assessment against the expression of the individual. The family acts as an intermediary in problem solving as well as a facilitator in solving the problem at hand. The support and care of family is a form of positive award is given to individuals (Friendman, 2010).

Family assessment Support consists of two themes, namely the family and response strategy for solving problems. Family response extremely influential towards the level of depression sufferers. In the early stages, the sufferer's family expressed suffering HIV/AIDS sufferer refused, sad and angry. This was confirmed by Djoerban (2007), said that the families of patients who are HIV/AIDS diagnosed cannot accept the fact that one of the family members suffering from HIV/AIDS. So it appears that brought the stigma against sufferers. Stigma also results in people living with HIV often feel *feeling blue* (loneliness, despair, anxiety and depression) so that it can be said that the quality of life of people living with HIV in terms of psychological outcomes. This is due to ignorance and incomprehension of the family about the disease HIV/AIDS. Novianandra (2014), that the existences of the respondent who get family support outcomes are affected by a lack of understanding or knowledge of the family about the disease HIV/AIDS.

The second assessment was support themes namely problem solving strategies. Categories that appear is scold, ask the help of counselors, spiritual motivation and motivation of parents. This is in line with research Hardiansyah (2011) recommends that can increase the quality of life of people living with HIV then the families should be able to provide support to people living with HIV can also be granting information, assistance, support religious behavior so that people living with HIV feel cared for, valued and loved. According to Oluwagbemiga (2007) States those HIV-positive patients who got the motivation of parents will experience symptoms of depression that are lighter.

2) Instrumental Support

According to Oluwagbemiga (2007) States that HIV-positive patients who got the motivation of parents will experience symptoms of depression that are lighter. Related research results the instrumental support one's family gave rise to two themes, namely financial support and support the fulfillment of basic human needs. Financial support is family support relating to the cost of care and treatment as well as the costs of necessities needed by PEOPLE LIVING with HIV sufferers. Support the fulfillment of basic human needs is a hereditary elements needed by sufferers in maintaining physiological as well as psychological balance, aiming to sustain life and health.

This is in line with the phrase Budiarti (2016), that this form of instrumental help support directly like a financial provision for medical treatment or giving of material directly. This form of instrumental helps support directly like caring, dropping off Dick and prepare medicines.

3) Support Informasional

Support informational consists of families as givers of information and collection information. Support information is very important for people living with HIV as information about diseases that face how to care and treatment the prognosis of his illness, the fulfillment of nutrition and prevent contagion (Irwanto *et al*, 2008).

Sheiley (1995) also suggests that this type of information include the support network of communication and responsibilities including giving a solution of the problem, advice, direction, advice or feedback on what to do. One suggestion about the doctor and the actions that should be done is a specific form of support against the stressor sufferer. While research Setyoadi (2010) about the expectations of the people living with HIV against support information providing the best care and treatment to sufferers of HIV/AIDS can be a means of solving the problems encountered the sufferers.

4) Emotional Support

Based on the results of the study respondents emotional support of family that produced three themes viz. strengthening mental from the family to the sufferer, a sense of empathy and protection of the family party on the environment both from society and family other major.

According to the Brown *et al* (2001) that emotional support is urgently needed by people living with HIV that comes from family and people nearby as well as the community. The emotional support of family is also important with regard to stigma received resulting in discrimination as well as isolation worsens the condition of people living with HIV either physical or psychic.

Support in the form of warmth, caring and empathy from people nearby then the people living with HIV will feel cared for. Furthermore these feelings will liberate people living with HIV on the feelings that he still means a lot to his closest people and gave rise to the feeling that he deserves to live and keep people living with HIV from negative thoughts or suicide (Astuti & Budiyan, 2015).

Meanwhile families maintain the confidentiality protection, family protection response is considered bad because families worrying about the identity of the respondent known to the communities that result in bad against a good name and effort on the run. The results of the research of Li Li (2008) about the impact of stigma in China by people who know the identity of the status of people living with HIV cause embarrassment in the family, loss of self-esteem, family, family relationships and the disorders and social networks wider family. The magnitude of the social pressures endured by families resulting from the presence of one of the family members who suffer from HIV/AIDS provide an influence on other family members to help each other and give a sense of the other family members.

5. Conclusion

People perception living with HIV/AIDS (PLWHA) against the support assessment families in the town of Ternate obtained that support families obtained is still there is the bad response, characterized by a family that refused, angry, disappointed to restrict the activities of people living with HIV because of embarrassment with his condition and is regarded as the bearer of sustenance. This resulted in lately recovery process health and opportunity for people living with HIV. This is due to ignorance and incomprehension of the family about the disease HIV/AIDS.

Supports informational of the family towards people living with HIV are considered sufficient. The families of people living with HIV attempt to understand her condition by trying to seek information from counselors and the internet. From the information obtained, people living with HIV can help the recovery process by reminding will order medications and possible complications that arise. Family support is informational so that it can be fulfilled.

The perception of people living with HIV about support instrumental family retrieved people living with HIV either. Most of the sources of financially supporting come from parents and spouse husband/wife of people living with HIV. The families was also involved in the fulfillment of the basic needs of people living with HIV, namely, providing sustenance, helps chapter and help provide a remedy.

The perception of people living with HIV about emotional support from families that received by people living with HIV are still a bad category because most sources of emotional support people living with HIV comes from himself, other than that the family tried to keep the confidentiality status of people living with HIV, so the impact on the sense of careful people living with HIV in socializing.

From the results of the analysis thus formulated various forms of family support i.e. support assessment, support informational, support instrumental and emotional support have an effect on quality of life of people living with HIV. The more good family support, then the nice quality of life of people living with HIV anyway. While most of the acquired

forms of support people living with HIV is bad, therefore later mapped in an effective model of the development of the theory of Friedman. This model was given the name "*family support models*".

Family Support Model the support consists of the assessment that is the response of families and problem solving strategies. Support informational consists of families as the collection and the information. Instrumental support consists of financial support and support basic human needs. And emotional support is composed of mental reinforcement, empathy and protection of the family. This model has 3 levels of family support, i.e., *bad support* (outer box), *moderate support* (middle box) and *good support* (the inner box). Increasingly in the direction of the inner box, then the family support towards people living with HIV is getting better (Model 44 pages). This model was as one alternative for the stakeholders especially families in dealing with people living with HIV.

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