



ISSN: 0975-833X

Available online at <http://www.journalcra.com>

INTERNATIONAL JOURNAL
OF CURRENT RESEARCH

International Journal of Current Research
Vol. 11, Issue, 10, pp.7715-7720, October, 2019

DOI: <https://doi.org/10.24941/ijcr.36885.10.2019>

RESEARCH ARTICLE

QUALITY OF LIFE OF THE BATAKNES HOUSEWIFE INFECTED HIV IN HKBP AIDS MINISTRY BALIGE NORTH SUMATERA: A QUALITATIVE STUDY

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ARTICLE INFO

Article History:

Received 24th July, 2019

Received in revised form

19th August, 2019

Accepted 15th September, 2019

Published online 30th October, 2019

Key Words:

Quality of life,
Housewives,
HKBP AIDS Ministry.

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Citation: Marika Julina Hutabarat, Rahayu Lubis and Erna Mutiara. 2019. "Quality of life of the Batakness housewife infected HIV in Hkbp AIDS ministry Balige North Sumatera: A Qualitative Study", *International Journal of Current Research*, 11, (10), 7715-7720.

INTRODUCTION

HIV is a virus that damages the body's immune system by breaking white blood cells to destroy the human immune system. The current HIV case is like an iceberg where the total number of patients announced is less than the total number of actual patients. The case means that the total sufferer of HIV infection is in fact still large and raises many health problems. The spread of HIV every year there is a very sharp increase, where the total number of HIV female patients in the world continues to increase, especially in reproductive age (Sarwono, 2007). Based on the 2016 UNAIDS WHO report (United Nations Acquired Immunodeficiency Syndrome World Health Organization) in 2016 said 36.7 million people were living with HIV in which 17.8 million were women, 16.7 million were men and 2.1 million were children (>15 years). From these data the highest is found in Africa with 25.6 million and then Southeast Asia 3.5 million and over 1.7 million women in Asia are living with HIV, out of 90 percent of women

ABSTRACT

Background: HIV continues to be a major global public health issue, UNAIDS having claimed more than 1,7 millions women in Asia living with HIV and 90% being infected from husband or their sexual partner. Huria Batak Kristen Protestan (HKBP) AIDS Ministry as church committee who handled HIV-AIDS cases claimed than 603 people living with HIV and 138 died from HIV related causes and 6,8% cases among Batakness housewives. Being people who living with HIV causes not only dealing with disease conditions but also a very discriminatory social stigma. This stigma and discrimination often causes a decline in the quality of life of housewives. **Objects:** To determine and explore the quality of life among Batakness housewives with HIV who take antiretroviral therapy in term of physical, social, psychological and environmental aspects. **Methods:** The research used qualitative method (cases study design), with 7 informants who take ARV therapy \geq a year in January to May 2019. The data were gathered by conducting in-depth interviews and documentary study and analyzed by using content analysis. **Results:** The result of the research showed that the QOL in physical aspects was good because the subjects realized the importance of maintaining physical health as PLHAs by taking ARV medicine on time so that there were no opportunistic infections that appeared. Social, psychological and environmental aspects it was low where the results of the study show that housewives with HIV lack social and social relationships and lack social support from their families and surrounding people which illustrates that there is still a lot of stigma and discrimination experienced by housewives. Negative stigma and discrimination were still experienced by Batakness housewives with HIV which had an impact on their low quality of life. **Conclusion:** It is recommended to increase good communication and community support especially a family to accept them to increase the quality of life among housewives who infected HIV.

contracting HIV from their sexual partners when working on sexual intercourse at a time long time (WHO, 2016). The country of Indonesia is a developing country in Southeast Asia which every year there is an increase in the total case of HIV. The number of HIV cases as of March 2017 amounted to 242,699 and AIDS by March 2017 was 87,453, where the highest was reported in the age group of 20-29 years at 31.4 percent, 30-39 years at 30.6 percent, 40-49 years as much as 12.8 percent, 50-59 years as many as four point percent and 15-19 years as much as two point seven percent (Kemenkes, 2017). The biggest outbreak techniques are heterosexual intercourse as much as 68 percent, injecting drug users (IDUs) as much as 11 percent, transmission through homosexuals as much as 4 percent, perinatal 3 percent. The accompanying opportunistic infection was TB 11,836 human and diarrhea totaling 7,277 human. The highest number of HIV according to work is 12,302 cases of HOUSEWIFE, 11,744 cases of non-professional workers, 11,176 cases of entrepreneurs, 4,062

cases of farmers / ranchers / fishermen, 3,840 unskilled laborers, 2,963 cases of sex workers, 2,263 cases of civil servants, 2,219 students 2,034 case (Kemenkes, 2017). The high case of HIV and AIDS in housewife, because in biological women there is a higher risk of contracting HIV and AIDS than men who do sex relationships with multipartners outside without securing a condom (Dachlia, *et al.*, 2010). This condition is quite alarming for efforts to eradicate HIV/AIDS in which housewives who have been considered as not at risk groups now have higher rates of HIV/AIDS cases than in commercial sex workers. Current efforts to eradicate HIV/AIDS are still focused on risk groups, for example commercial sex workers, homosexuals and injection drug users. The fact is that many women's assumptions are the originators and spreaders of HIV, so the community's perception of women infected with HIV is very negative (Van Hollen, 2010). From province data, the largest cases of HIV infection reporting up to June 2016 were DKI Jakarta (41,891 cases). The highest number of HIV and AIDS cases is in DKI Jakarta Province, followed by East Java Province, Province of Papua, West Java, Central Java, Bali, North Sumatra, Riau Islands, South Sulawesi and West Kalimantan (Kemenkes, 2016).

Statistical data on HIV/AIDS cases in North Sumatra Province ranks 7th out of 10 provinces with the most HIV / AIDS case data in Indonesia where as of January 2017 there were 8272 cases with 3,411 HIV sufferers and 4,861 AIDS sufferers (Sumatra Provincial Health Office North, 2017). Balige AIDS Ministry HKBP in Toba Samosir District is one of the committees that handles HIV and AIDS issues and provides special services for people with HIV and AIDS. Patients suffering from HIV and AIDS who are served by the Balige HKBP AIDS Ministry come from various areas around Toba Samosir Regency such as North Tapanuli Regency, Humbang Hasundutan Regency, Samosir Regency, Sibolga, Parapat and Toba Samosir District themselves. There were 603 cases of HIV AIDS from 2003 to January 2018 with details, 150 HIV cases and 453 AIDS cases, 423 men and 180 women (HKBP AIDS Ministry Balige, 2018). Of the 603 cases of HIV and AIDS in the Balige HKBP AIDS Ministry, 138 people have died and 465 are alive. A total of 107 people (17.7 percent) were housewives with details of 27 dead, 19 lost contact, 16 were referred out and still being served by HKBP AIDS Ministry Balige, 45 were there, and of 45 housewives 32 people are Batak people.

MATERIALS AND METHODS

Study design: This study was a qualitative study with case study. This study was conducted from February 2018 to completion.

Research subject: seven informants who volunteered to participant in this study where selected using purposive sampling. Inclusion criteria included: housewife who has undergone ARV therapy \geq 1 year, counselor at the HKBP AIDS Ministry, Health Program Holder, Community Leaders and Indigenous Leaders.

Data collection: Primary data in this study was obtained by conducting in-depth interviews to all informants. The purpose of the in-depth interview is to explore more information about quality of life of the Batakness housewife Infected HIV. Secondary data was indirectly obtained to complete the

required data, generally in the form of evidence, historical records or reports that have been arranged in an archive. This data was obtained from the HKBP AIDS Ministry Balige report. The instruments used in this study were in the form of stationery, notebooks, and recording devices.

Data analysis: Qualitative data analysis has three paths, namely data reduction, data presentation and conclusion drawing. Data reduction is an analysis that sharpens, classifies, discards unnecessary and organizes data in such a way that the final conclusions can be drawn from the data. How to reduce data: 1) strict selection of data; 2) summary or brief description; and 3) classify in a broader pattern. Presentation of data is an activity when a set of information is compiled, so there is a possibility of drawing conclusions and taking action. Form of qualitative data presentation: 1) narrative text, in the form of field notes; and 2) matrices, graphs, networks or charts. The final path is conclusion making, in this stage, the researcher makes a formula related to the principle of logic, adopts it as a research finding, then continues by reviewing repeatedly the existing data, grouping the data that has been formed and then concluded (Miles and Huberman, 1992).

RESULTS AND DISCUSSION

Quality of life housewives Physical Aspects

In the physical aspects of the seven informants experiencing different conditions, as many as five informants have shown symptoms of AIDS when taking an HIV test, as experienced by informant I:

"Increasingly thinner, only bones, often fever, weakness, lack of enthusiasm, fatigue, even when it's tuberculosis" (EM, 36 years).

According to Nursalam and Kurniawati (2007), clinical symptoms in the AIDS stage are divided into major and minor symptoms. Major symptoms consist of: weight loss $>$ 10% in three months; a long fever or more than three months; chronic diarrhea for more than one month continuously or continuously, and tuberculosis. Minor symptoms consist of: chronic cough for more than one month; infection of the mouth and throat caused by the fungus *Candida Albicans*. Persistent swollen lymph nodes, the appearance of shingles, recurring and itchy patches throughout the body. While two informants have not experienced significant physical changes because they quickly learned about their HIV status, as experienced by informant III:

"I haven't been to a physical change, because I look healthy, only my stressed mind makes me less appetite ..." (AN, 33 years).

Likewise experienced by informant VI:

"I haven't been to a physical change, because not long after we married my husband immediately AIDS and I immediately checked so quickly resolved ... but after I was positive we did have time to part, I returned to the parents' house ... because a stress I became increasingly emaciated and lacking ..." (KRS, 29 years).

Conditions as people with HIV/AIDS affect not only physical changes, but also lifestyle, where research shows that all informants have trouble sleeping and have no appetite,

"I was having trouble sleeping at the time, eating was also not appetizing, I was very stressed, why should I, while I'm not a bad person....." (RT, 41 years).

Not only because of the disease, but also the status as people with HIV/AIDS stress the informant so that it disrupts sleep patterns, as the informant said:

"Yes, it must have been difficult to sleep at the beginning ... because of the thought ... I often ask, why oh my god I got this disease, while many people are" selling themselves "but not affected ..." (AN, 33 years).

The results of this study showed the quality of life of housewives infected with HIV at the beginning of HIV diagnosis was low where physical conditions that made it impossible to perform activities, sleep discomfort, pain and fatigue differed after housewives had been on ARV therapy for more than one year, all informants said that the physical condition the more healthy, able to carry out activities, the better the quality of sleep, as the informant said:

"I'm getting healthier, more powerful, because my body is also more contained, can already move like most people ..." (FL, 33 years).

The spirit to stay healthy is also influenced by the desire to see children grow healthy. This is in line with the research of Oktavia et. al (2012) which states that women survive with the enthusiasm of following therapy because children still need love and try to make ends meet. Quality of life of housewives infected with HIV after consuming ARV drugs has improved, from the results of the study of five previous informants who have reached the AIDS stage, but after taking ARV therapy regularly and on time now the status is HIV, while two informants have not reached the AIDS stage when conducting tests blood, so that more quickly healed. From the physical aspect, basically most of the informants have good quality, have been able to carry out daily activities, good mobility, feel comfortable, consume ARV routinely, do not get tired, getting enough rest. Most of the informants have worked, with activities in the workplace making informants feel productive this has an impact on the quality of life of the housewives on the physical aspects (Hardiansyah, 2014). The results of this study are also in line with research conducted by Nojomi (2008) who said that good care and treatment can improve the quality of life of people with HIV/AIDS. It can be concluded that the quality of life of Housewives in terms of physical aspects is good or positive.

Quality of Life Housewives Social Aspects

The seven informants have different social activities. When not yet diagnosed with HIV all housewives carry out social activities related to the wider community especially as Batak women who are attached to the clan is an obligation to uphold the principle of Dalihan Na Tolu which means that in kinship relationships have a position when a woman brings her own husband's or clan. A Batak woman who has been married to a Batak custom then will continue to cling to the custom, so that when a Batak does not pay attention to the principle of Dalihan Na Tolu, he will be ostracized in the relationship of citizenship and social relations. The six informants were active in customary and social events before being diagnosed, attending

traditional parties, clans, arisan and partangiangan (church services in every ward).

"For the past 2 years, not anymore, because of shame, sometimes the impact on my family is also increasingly shunned ... but before I knew I was HIV, I always followed customary events from both my family and husband ..." (FL, 33 years)

Only one informant who did not attend the customary event even before knowing his HIV status, because of the behavior that likes to change partners so that the community is ostracized, causing informants to close themselves off from social events.

"Of course I ... I was almost expelled, so I don't have to participate in customs ... I haven't even participated in traditional events since then, because I used to change partners ..." (MS, 40 years)

This situation is reversed when the informant has learned about his HIV status and the surrounding community or neighbors know that the condition results in the informant closing himself out of social activities, no longer attending customary events and family gatherings. The feeling of shame, discrimination and stigma that is so negative makes the five informants no longer participate in social activities. Even after taking ARV therapy where the body's condition is healthy and can carry out daily activities it still does not make the informant active in social relations. Discrimination and stigma received by informants make informants close themselves from the social environment.

"Actually, I was found out at the beginning of HIV I'm still actively participating in parties, but because more and more people know that I have become lazy, it doesn't feel good to be stared at by people with uncomfortable views ... even though I'm healthy, I'm still afraid of socializing ... yes that's the stamp of people HIV still exists even though it is healthy ..." (LMM, 38 years).

As many as two informants continued to carry out social activities even after their HIV status and had received ARV therapy for more than one year, but both informants acknowledged that social activities were carried out because no one knew the HIV status except the nuclear family. The surrounding community did not know their HIV status, the two informants also said that conditions would be different if others found out, they would get stigma and discriminatory treatment.

"Well ... usually the clan favors are with the neighborhood party from the church, I still participate in the parties, well ... because no one knows ..." (AN, 33 years).

The results of this study indicate that HOUSEWIFE infected with HIV lack social support from the community, the community tends to provide negative stigma and discriminatory treatment.

"Wants the people to accept me and not blame my family ... don't be shunned ... those of us who suffer from HIV don't always be considered negative ... thankfully in this Committee there is a community of fellow HIV sufferers, so we encourage each other ..." (MS, 40 years).

"Apparently not yet, for example, my neighbors feel disgusted seeing me ... afraid of touching ... even though it is not contagious if only touching ... we are very discriminated ..." (RT, 41 years).

Armiyati (2015) states that the socialization problems experienced by HIV/AIDS patients are withdrawal, disruption of socialization, disruption of roles, concerns about relationships with partners, lifestyle changes, loss of enthusiasm due to restrictions and inhibitions. Hermawati (2012) on 100 HIV/AIDS patients who showed that 87.5% of patients experienced disruption in social interactions and socializing. Meanwhile, to improve the quality of life of people with HIV/AIDS, social support is very much needed. Nasronudin (2006) revealed that one factor that has an important role in the quality of life of people with HIV/AIDS is social support. Social support can be interpreted as a comfort, attention, appreciation, or assistance felt by individuals from other people or other groups (Uchino, 2004). With this social support, a person will feel valued, loved, and feel a part of the community, so that people living with HIV do not feel discriminated against which can later have a positive impact on their health.

Quality of Life Housewives Psychological Aspects

Family presence and family acceptance mean a lot to psychological informants and encourage informants to keep their spirits and live healthier and orderly, but it is undeniable that all informants say that anxiety about death and sadness is still felt today. Anxiety about the fate of children is also one of the factors that causes sadness for informants.

"I am very sad, what if I die, what is the fate of my children, sometimes I often cry at night...." (EM, 36 years).

"Feelings of wanting to die sometimes, Sadness times but now I'm already excited, especially if I see my child ..." (LMM, 38 years)

Sadness and lack of confidence appear when informants experience discriminatory treatment. Closing yourself and avoiding society is an informant's way of dealing with discriminatory treatment.

"Well often ... it was ostracized ... so there is indeed a plan for me if my child is about to enter school, we will just move, but my child is not inferior ..." (LMM, 38 years).

The informant's HIV status also influences spiritual activities, due to stigma and discrimination resulting in a decrease in spiritual activity

"I rarely go to church, especially now I'm embarrassed to go to church, sometimes when I'm out of town I just go to church because no one knows me, so I'm not ashamed but if in the village I don't go to church, but I always pray at home, ask forgiveness with God, this is my fault ..." (MS, 40 years).

Although spiritual activity is reduced, all informants continue to carry out their worship at home, according to the informants praying and surrendering to God can be done anywhere and anytime. Places of worship do not guarantee acceptance of people with HIV/AIDS, even discriminatory treatment can occur in places of worship.

"Initially after getting caught by HIV, I was lazy to go to church, blame God, feeling sorry for myself. But now that I have begun to feel healthy I worship at church even though the discrimination is still experienced, such as no one sitting in our chairs even though it is still suitable ... and still praying and worshipping at home because I believe that is what strengthens me to this day .." (FL, 33 years)

After taking ARV therapy where the body's condition is getting healthier and can carry out daily activities it still does not make the informant confident and still burdened with HIV status. Even though some informants have accepted their condition by being resigned but it is undeniable that all informants still feel sadness about their status, this shows the psychological burden felt by the informant. The sadness felt by people with HIV/AIDS is not only because of the virus in their bodies but the stigma they receive that they get discrimination from family and society. This is a barrier to the interpersonal system in people with HIV/AIDS so that they withdraw from the environment. Self-acceptance as people with HIV/AIDS also greatly affects the quality of life of people with HIV/AIDS, the results of the study indicate that three housewives have not been able to accept their conditions

"Well ... why did my husband's behavior go along with me ... is this a punishment from God ... I hope my children are healthy....." (EM, 36 years).

"Well ... how is it ... it's still very hard to accept this especially if it's a disease for life ..." (KRS, 29 years)

The other four informants were able to accept and surrender to God for their condition

"I can accept my condition, because I also feel that these are my sins ..." (MS, 40 years)

"Well ... I have resigned to God ..." (RT, 41 years)

"Well ... how well ... I can already accept ... so I will have to be enthusiastic for my children ..." (LMM, 38 years)

People with HIV/AIDS actually need support, not ostracized so that people with HIV/AIDS life expectancy becomes longer. Sarafino (2011) revealed that with social support a conducive environment will be created that can provide motivation and provide new insights for people with HIV/AIDS in facing their lives. This social support can minimize the psychosocial pressure felt by people with HIV/AIDS, so people with HIV/AIDS can have a better lifestyle and can provide a more positive response to their social environment. In addition, with this social support, people with HIV/AIDS will feel valued, loved, and feel a part of the community, so people with HIV/AIDS do not feel discriminated which can later have a positive impact on their health.

Quality of Life Housewives Environmental Aspects

Stigma and discrimination from the neighborhood make the informant uncomfortable to get along so the informant closes and is not open to the conditions experienced. Unlike when the informant is in the health service place, namely HKBP AIDS Ministry (HAM), the informant is very comfortable because it has a community of fellow people with HIV/AIDS making it easier for informants to tell stories and exchange ideas within the community, officials from HAM are also very supportive and encouraging to informants to stay enthusiastic and remind each other of the therapies they are still living.

Therefore, counselors and officials from HAM are like their own families for informants. One of the human rights tasks is treatment, acceptance and support to people with HIV/AIDS through anti-stigma and discrimination programs, VCT (Voluntary Counseling and Test), STI treatment (Sexually Transmitted Infections), provision of ARV drugs (Anti Retro Viral) and support to the people with HIV/AIDS community, truly rightly felt by the informant, the involvement of the informant in the activities carried out by HAM increased knowledge about HIV and AIDS, also increased the informant's enthusiasm in living life

"I got a lot of information about HIV in this committee, they patiently served our every complaint and I thank you very much to this committee, all the people are very kind, always encouraging ... and always reminding to take medicine and take medicine ... oh yes ... there are also many HIV sufferers here, we feel the same fate there are friends ... we are also often invited if there are activities in the Committee ... "(FL, 33 years). "I am very grateful to be able to seek treatment here, because the medication is free and even this committee service is very good, I am always reminded to regularly take my medication, there is also our community of fellow HIV, so I feel there is a friend to share ... if there are activities in We are always invited to this committee so that we increase our knowledge about HIV "(EM, 36 years).

Enjoying quality time such as recreation can also improve the quality of life, but not all informants can enjoy recreation, from the seven informants, as many as three informants who enjoy recreation and feel comfortable in any environment.

"Hahahhahahaha ... often with our husbands and children often walk or just enjoy the natural beauty of Lake Toba, after all we live in Ajibata, also close to Samosir well ... so we often walk ... "(AN, 33 years)

While four informants did not enjoy or did not even want to go to recreation due to fear of discriminatory treatment from the community. This happens because the lack of understanding of HIV and AIDS results in people who suffer from this disease are often excluded from the environment so that sufferers tend to shut down. The sadness felt by people with HIV/AIDS is not only because of the virus in their bodies but the stigma they receive that they get discrimination from family and society. This is a barrier to the interpersonal system in people with HIV/AIDS so that they withdraw from the environment. Environmental aspects where all informants feel comfortable only when they are in HKBP AIDS Ministry. In HAM, all informants can communicate openly with the counselor, and this greatly helps the spirit of life of the informant. Open communication for HIV sufferers is very important to build close relationships in daily interactions. Starting from open communication, will result in closer relationships, relationships that are based on emotional ties, support and attention. In the end, effective communication for HIV sufferers will be able to build positive self-concepts so that they can overcome despair, reduce the burden of life, feeling comforted and eager to live positively again (Salam, 2014).

Conclusion

The quality of life of Housewives viewed from the physical aspect when tested positive for HIV is negative (low) but then changes after taking ARV therapy for more than one year

where the quality of life of the housewives become positive (good) because the informant realizes the importance of maintaining physical health as people with HIV/AIDS by taking ARVs on time so that no opportunistic infections arise. A total of five housewives have negative (low) quality of life in terms of social, psychological, and environmental aspects where the results of the study show that housewives with HIV do not have social relations and lack of social support from outgoing members and also those around them that describe the still a lot of negative stigma and discriminatory treatment experienced by housewives. As many as two housewives have a positive quality of life (good) in terms of social and environmental aspects because they do not experience stigma and discrimination because the community does not know that both housewives are HIV sufferers, while psychological aspects are negative, because they cannot accept their conditions. Stigma and discriminatory treatment from the people around cause low quality of life of housewives. Social support from the surrounding community is needed by the housewives to improve their quality of life. The existence of the HKBP AIDS Ministry along with its programs and activities has greatly helped housewives batatkness infected with HIV to improve their quality of life

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