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HEALTH SERVICES OF NEGLECTED TROPICAL DISEASES IN JAYAPURA, PAPUA: A QUALITATIVE RESEARCH

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Abstract

Papua is one of the endemic areas for several neglected tropical diseases such as yaws, filariasis, and leprosy, but there are differences in the distribution of resources so that efforts to eradicate and eliminate tropical diseases require specific treatment strategies in each region. This study aimed to examine neglected tropical disease health services in Jayapura City. The research uses a qualitative approach with a case study design conducted in Jayapura City in June – October 2021. Data collection is carried out by in-depth interviews, document review, and focus group discussions. The research informants were 8 people consisting of the head of disease control, the head of the central health services, programmers, and patients. Results: The neglected tropical disease services in Jayapura City are focused on treatment and improving the quality of life on the social and psychological dimensions. Currently, the health department is still the sole player in the handling of neglected tropical diseases and is considered an “unsexy” disease, thereby reducing the interest of many parties to be treated. Screening activities to find new cases are decreasing. The scope of the screening is carried out only on family members without tracing the contact history of the patient. The double burden of health workers who are responsible as programmers occurs because they have to deal with several diseases with a wide working area. Strengthening screening for new case findings needs to be done by tracing contacts not only in the household but also on neighbors and contact history such as at school and work. Handling of neglected tropical disease cases needs to be encouraged to be evidence-based based on situational analysis of the incidence and prevalence of cases in each central health services working area.

Keywords: Neglected tropical diseases; health services; Papua

1. Introduction

The burden of tropical diseases is still being faced by Indonesia even though eradication of the disease has been carried out through adequate therapy (Kemenkes RI & UNDP, 2019). The dominant tropical diseases include tuberculosis, malaria and several neglected tropical diseases (NTDs), such as helminthiasis, filariasis, schistosomiasis, leprosy, leprosy and yaws. The term 'neglected' in neglected tropical diseases is due to the phenomenon that this tropical disease is not considered an important infectious disease to be resolved (Kusumasari, 2019). Neglected tropical diseases are a group of infectious diseases that occur mostly in tropical and subtropical regions (about 149 countries) that affect more than 1 billion people and harm developing countries economically (WHO, 2020).

Papua is one of the regions in Indonesia that has not achieved the elimination of several neglected tropical diseases such as leprosy and filariasis. The disability rate for type 2 leprosy in Papua is 11.35 per 100,000 population, which is

the highest in Indonesia. Likewise, filariasis cases were also the highest, reaching 3,615 cases (Kemenkes RI, 2021). Neglected tropical diseases cause changes and physical disturbances due to the disease process experienced which has an impact on other dimensions such as psychological, social, spiritual and cultural in patients, families. (Agustin, 2020).

Indonesia is an endemic country for several neglected tropical diseases, but there are differences in distribution so that efforts to eradicate and eliminate tropical diseases require specific treatment strategies in each region (Kemenkes RI & UNDP, 2019). Treatment of neglected tropical diseases is often faced with varying burdens of disease patterns, limited available interventions, lack of resources and community absorption, and inadequate case tracking (Marchal et al., 2011). Problems in the treatment of neglected tropical diseases are reflected in the treatment of several diseases. The low regional priority for yaws causes community support for yaws control programs to not be optimal. In the handling of leprosy, the leprosy

control program is still constrained by the ability of human resources that are not yet optimal. Stigma about leprosy is still widely found in society. On the other hand, the microscopic examination of filariasis is still constrained by the lack of human resources and the lack of human resources in case management (Kemenkes RI & UNDP, 2019).

Jayapura City is still dealing with efforts to control several neglected tropical diseases (Dinas Kesehatan Kota Jayapura, 2019). This is very concerning when compared to other areas that have achieved the elimination of leprosy and filariasis. The increase in cases still occurs in some districts with very limited case finding. This study aimed to examine neglected tropical disease health services in Jayapura City.

2. Method

Study setting

The study was conducted in Jayapura City, Papua, Indonesia, in June-October 2021. Jayapura City was chosen as the research location because this area is one of the areas in Papua with a high incidence of neglected tropical diseases, such as leprosy and filariasis. In 2018 the number of people with leprosy in Jayapura City was 368 people and filariasis was 3 people.

Data collection

In-depth interviews were conducted on 8 informants selected by purposive and snowball procedures. The research informants consisted of the head of the infectious disease control department, the head of the public health center, programmers, and patients. The main focus of the research interviews was limited to health services provided, program resources, community acceptance, and program integration. Before conducting interviews with informants, the researcher explained the purpose of the study and asked for informed consent. The researcher has obtained a certificate of ethics from KEPK Poltekkes Kemenkes Jayapura No. 045/KEPK-J/V/2021. Each informant signed a letter of willingness to be an informant. In-depth interviews used mobile phones as recording devices and notebooks to write down important relevant informants.

Data collection was also carried out with a focus group discussion (FGD) once with 6 informants. The FGD was conducted at the health office, attended by the field, the head of the public health center, programmers, and patients. The researcher explained the purpose of the FGD implementation and provided a

summary of the themes of the results to the participants as the discussion material. The FGD was guided by the researcher and provided opportunities for discussion participants to provide comments.

Data analysis

Qualitative data analysis was carried out to examine the meaning of the phenomenon of the focus of the research which was started at the time of data collection (Creswell, 2016). The recorded interview results were manually transcribed on Microsoft Office Word version 2013. The interview transcript was read to find the theme of the phenomenon. The interpretation of the meaning of the phenomenon of health care in neglected tropical diseases is presented in the form of quotations from the informants' original expressions and explanations. The researcher's efforts to maintain the validity of the findings are by doing perseverance in interviews and observations, finding cycles of similarity of data, checking among researchers and peers, triangulation, and adequacy of references (Bungin, 2007; Moleong, 2012).

3. Result and Discussion

The study of tropical health services was neglected in Jayapura City in the research on the dimensions of the disease program that had been carried out. The results of the study were examined on the types of health programs provided, acceptance of the program by the community, and aspects of the integration of neglected tropical disease service programs with other regional programs.

Services provided

The results showed that the health care program for neglected trophic disorders was focused on 4 aspects, namely health promotion, preventive, treatment, and rehabilitative programs. This is as conveyed by the following informants:

"...in general it's 4 attempts. We do this in every health service. There is health promotion, such as health education, prevention, prevention, yes. then for the sick, it is the curative treatment of patients. Then lastly, there is rehabilitation. Physical rehabilitation is just as social. Psychology too..." (Informant R, 44).

Health promotion and preventive services for tropical diseases are neglected such as counseling, especially for family members and contacts, leaflets, brochures. This activity is

routinely carried out by the public health center as an integrated communicable disease control program from the public health center level, the city health office to the provincial health office. These two efforts are called public health efforts which are carried out to prevent the community, especially families and people who have contact with sufferers from being infected. The aspect of improving environmental health is one of the important preventive efforts to do. Almost all neglected tropical diseases are related to unhealthy environmental conditions (Freeman et al., 2013; Hotez, 2017).

Curative activities are medical actions in the form of treatment for patients. Currently, all community health centers in Jayapura City have a special section or program to treat neglected tropical disease patients. The type of service provided begins with a diagnosis based on laboratory results and doctor's assessment, drug prescribing to assistance in taking medication for all patients. Each program or unit at the public health center has its schedule to monitor the progress of patient treatment. The duration of drug administration is following the established operational standards of disease treatment. Meanwhile, from the rehabilitative aspect, the efforts made are strengthening the quality of life in physical, social, and psychological dimensions (Spiegel et al., 2010). Aspects of the physical dimension are encouraged to increase the ability of physical mobility by minimizing limitations. In the social dimension, the elimination of stigma and eliminating discrimination at the individual, family, and community levels for sufferers and former sufferers (Litt, Baker, & Molyneux, 2012).

"...First, if the patient comes, we will still check. Doctors can see the symptoms anyway. Then asked to check in the lab. If it is positive that he has filariasis or leprosy, we will immediately enter it in the register data to prepare routine drugs. It already has the SOP..." (Informant M, 37)

Health services that also have high attention on health services for neglected tropical diseases are rehabilitative. Rehabilitative services are provided to patients, patients who have been declared cured, and their families. The rehabilitative aspect of the patient is to provide psychological support to the patient to strengthen self-confidence and have the courage to take treatment. The stigma aspect of society is one of the concerns that sufferers of tropical diseases tend to be neglected.

"...If the patient has recovered, they will return to the community. It's just that the stigma is there. Not only those who have recovered but also those who are still sick. It was given reinforcement. So you can be confident when you hang out. Even though the condition is usually limited. It's not like it's still healthy. The family especially..." (Informant M, 37)

For patients who have been declared cured, rehabilitation is carried out on the physical and psychological aspects. Physical rehabilitation to prevent the disability that affects their quality of life after being declared cured. Some neglected tropical diseases give physical scars to sufferers so that their quality of life is strengthened by assisting with assistive devices such as wheelchairs for former leprosy or filariasis sufferers.

"...yes.. there is a patient who is given a stick for assistive devices. There are also chairs... that's indeed a program, if you buy enough it's expensive for them..." (Informant M, 37)

Physical scars on former tropical disease sufferers are neglected in addition to causing limitations in their physical activities, but also causing limitations in aspects of their social life. For this reason, mentoring activities for former sufferers of neglected tropical diseases are still carried out to enable them socially and economically. Community groups were formed to provide a wide interaction space for former sufferers as well as a place for them to develop skills. This is as stated by the following informant.

"...we here have a special program. It's the gift of skills like making crafts. The members are all sufferers, some have recovered and are still joining. This activity is also supported by the public health center because it is also important to increase their enthusiasm. That's the motivation for psychology..." (Informant R, 44).

Units for making handicrafts are formed for patients or those who have been declared to have stopped treatment. Performance results can increase self-confidence in community social interactions, in limited conditions they can produce something of value.

Resources of program

The implementation of neglected tropical disease services is carried out at all levels, from the public health center to provincial health offices. Service resources consist of man, material, method, money, and time. Programmatically,

neglected health services are still listed as routine programs that must be carried out under the coordination and responsibility of the infectious disease control department at the health office and the public health center. This is as stated by the following informant.

"...The resources for health services for tropical diseases such as leprosy, filariasis, or others are already available, because it is a routine program in controlling infectious diseases. Every year it is planned. Because there are still cases in Jayapura City. We hold a lot of drugs and ingredients for examination in the laboratory..." (Informant R, 44).

However, the problem is the aspect of adequacy and distribution of both manpower and material. Even though neglected tropical diseases are still a routine program currently in health services, they are no longer a priority. Neglected tropical diseases are considered as "unsexy" diseases so that it reduces the interest of many parties to deal with them, this is different from the initial attention to neglected tropical diseases. This is as stated by the following informant.

"...It is admitted that there is still some public health center that is not available. No less actually. In the pharmacy warehouse, there is, because planning is according to need. But if the public health center doesn't ask for it, it won't be distributed either. Moreover, this disease is not like it used to be. In the past, it was always monitored whether there was available or not at the public health center..." (Informant N, 44)

The focus of current activities is to provide treatment to patients. Screening activities to find new cases are decreasing. The farthest reach that is usually done is only done on family members without tracing the contact history of the patient. This affects the provision of resources for neglected tropical disease services.

"...if want to focus, there should be a lot of it provided for screening, tracking contact. Because we have to admit that the discovery of new cases is still low. It's still far from the target... but we, as a screening tool, are also few available at the public health center. Because those who were screened were still few... at least only family..." (Informant M, 37).

Currently, from the aspect of human resources that are specifically involved in the service of neglected tropical diseases, it can be

said to be lacking, because there are still many health workers who treat more than 1 neglected tropical disease starting from screening, reporting to treatment recommendations. This causes health workers to experience limited coverage for all patients to the limited ability to deal with all existing problems. Apart from the problem of manpower, the same condition is felt in the material and budget aspects.

Finding new cases is still a challenge due to low screening and early detection (Spiegel et al., 2010). Neglected tropical diseases such as leprosy, yaws, and filariasis are still quite high in Jayapura City but the number of cases occurring in the community may be higher than reported. Early case discovery and the intensity of new case findings still rely on voluntary self-reporting, so it is necessary to encourage rapid case-finding tests and household contact checks. Knowledge updates about expanding the definition of contact are not only at home but also extended to neighbors and social relationships that have been carried out such as at work and school (Peeling, Boeras, & Nkengasong, 2017).

"...The problem is, of course, health workers. Like in our public health center, there are several cases but only 1 person is in charge. All the affairs are taken care of by 1 person. Starting from screening, monitoring treatment until every month you have to send a report to the health office. Unable..." (Informant P, 47).

The COVID-19 pandemic has greatly affected other health programs, including health services for neglected tropical diseases. The proportion of the health budget and health logistics is partly focused on handling the COVID-19 pandemic (Hotez, Fenwick, & Molyneux, 2021). The emergence of covid 19 as a new public health problem has given rise to all global policies that should not interfere with other disease interventions that require intervention, treatment systems and adequate human resources (Molyneux, Aboe, Isiyaku, & Bush, 2020).

Acceptance of the program by the community

The results of interviews with informants found that aspects of community acceptance were related to the suitability of the health service program provided to those felt needed by patients, aspects of satisfaction with services, to the potential of the community to maintain the continuity of treatment. The targets of health services in neglected tropical disease services are

patients, families, former sufferers, and the community. In general, patients do not know the type of illness they are suffering from until a diagnosis is issued from the public health center or other health facilities. This is as stated by the following informant.

"... I didn't know it was leprosy. But first, it looks like white appears and there is also red on the skin. Keep feeling like that. I went to the public health center and it turned out that they said it was leprosy..." (Informant A, 30).

"... many of our patients do not know that it is leprosy. They know it's just leprosy. Same with filariasis. Later they will be checked and then they will know..." (Informant R, 29).

After being diagnosed with a neglected tropical disease, the patient is given medication and monitored to monitor the progress of his treatment. The results of the interview found that some patients initially did not routinely / did not comply with treatment because they considered the symptoms they felt were normal. Until they return at a later date due to the increasing severity of the illness. Some patients come with conditions that are already severe so that maximum services are carried out to reduce the severity. This is as stated by the following informant.

"...At first, we thought it was just an ordinary skin disease. So use skin medicine like that. I was given medicine at the health center. But I didn't spend it because I didn't need it..." (Informant O, 44).

"... I went to the public health center when it started to get worse. It's starting to hurt, the legs are kind of heavy. When I checked at the public health center, they said it was elephantiasis... indeed someone in the family had it..." (Informant R, 29).

The results of interviews with patient informants found that they were satisfied with the health services provided. This is driven by the lack of choice but to accept the health services provided in the hope that it is the best for their condition. At the beginning of the treatment, the patient feels bored with the routine treatment that must be followed but the impact is felt to be insignificant. Until some patients decide not to continue medical treatment and seek alternative traditional medicine. In this condition, the role of health workers is very important in providing

education. As a result, some patients resumed treatment and showed adherence to treatment.

Compliance and sustainability of the neglected tropical disease treatment program are largely determined by family support. The results of the interview found that family support was like taking the family to take medicine at a health facility or being a companion in taking medicine.

"... the patient comes accompanied by the family. Some also come alone. But a lot of it was accompanied. If we monitor it at home too, we usually ask if the person who reminds us is the grandfather or does he have a relative..." (Informant O, 44).

In families who have accepted the patient's condition, they are the determinants of the continuity of treatment. Treatment is perceived as a family way of health problems suffered by their family members.

The integration of neglected tropical disease service programs

Health services for tropical diseases are neglected in Jayapura City in a complex manner, not only by the Health Service. The Health Office acts as the leading sector but in its implementation, it also involves related parties. The results of the interview found that currently in Jayapura City, NGOs are one of the parties that help patients in terms of improving their quality of life from social, economic, and religious aspects. This is as stated by the following informant.

"...the Health Office is responsible for health services in Jayapura City. Infectious and non-communicable diseases. Of course, everything is related to health. For neglected infectious diseases, there used to be a lot of joint activities with other agencies...because it's still a priority activity... if there are NGOs, yes. some special moves such as leprosy .." (Informant R, 44).

At the beginning of the initiation of the program for the elimination of several neglected tropical diseases, various relevant agencies were involved in handling this neglected tropical disease with different assignment domains according to the focus of the relevant agencies. This is as stated by the following informant.

Handling public health problems involves multidimensionality not only in the health aspect but also in other sectors (Ehrenberg et al., 2020). The phenomenon of the seriousness of all elements of the regional government for handling tropical diseases is neglected as shown by the

current fact with the covid 19 pandemic. All stakeholders, not only the health department, work hand in hand to carry out programs to prevent the transmission of covid 19 with various efforts such as reducing crowds, providing laundry facilities, hands, hand sanitizer, masks, and posters. It's the same with handling neglected tropical diseases, all stakeholders are assigned to campaign for the eradication of neglected tropical diseases which is the focus of their every activity such as including health messages or making banners.

"...Yes it is. Now back to their respective sectors... for those diseases, we have P2M. sometimes also invite other stakeholder but only socialize it..."
(Informant R, 44).

However, this condition has not continued to this day because neglected tropical management is no longer the main focus, so it has been handed over to the Health Office. In endemic areas, the lack of commitment and budgeting for program implementation is the main obstacle (Freeman et al., 2013). Partnerships with local governments are needed to regulate and define policies and budget support. The Department of Public Works is needed to help control environmental risk factors and provide clean water. Cooperation with the Ministry of Communication and Informatics is required for the dissemination of correct information. Cooperation with the private sector is needed to activate corporate social responsibility because most of the neglected tropical disease populations are in remote areas with low socioeconomic levels (Hotez, Bottazzi, Franco-Paredes, Ault, & Periago, 2008).

4. Conclusion and Sugestion

The health service program for neglected trophic disorders is focused on 4 aspects, namely health promotion, preventive, treatment, and rehabilitative programs. Even though neglected tropical diseases are still routine programs that currently exist in health services, they are no longer a priority. Neglected tropical diseases are considered un-sexy diseases, thereby reducing the interest of many parties to treat them. The focus of current activities is to provide treatment to patients. Screening activities to find new cases are decreasing. The farthest reach that is usually done is only done on family members without tracing the contact history of the patient. Some patients initially did not routinely/ did not comply with treatment because they considered the symptoms they felt were normal. Until they

return at a later date due to the increasing severity of the illness. Some patients come with conditions that are already severe so that maximum services are carried out to reduce the severity.

It is necessary to strengthen screening in the context of finding new cases by tracing contacts not only with household members but also with neighbors and contact history such as at school and work. Handling cases of neglected tropical diseases should be encouraged to be evidence-based based on situational analysis of the incidence and prevalence of cases. Determining the priority of problems at each public health center can of course be different according to the conditions of the work area, so it is necessary to analyze the situation and determine the program according to the health problems encountered. This is so that the implementation of case handling is more focused and measurable.

5. Acknowledgments

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6. References

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PAGE 1

PAGE 2

PAGE 3

PAGE 4

PAGE 5

PAGE 6