

**PEOPLE AFFECTED BY LEPROSY NEEDS DURING REHABILITATION IN COMMUNITY:
STUDY OF HEALTH CARE PROVIDER PERCEPTIONS**

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ABSTRACT

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Health care providers (HCPs) in Public Health Center (PHCs) have essential role to fulfil the various complexities of physical, psychological, economic, and social needs among people affected by leprosy (PALs) during treatment in communities. The complexity of these needs is important to prevent the stigmatization and discrimination of PALs for transmission and disability during their rehabilitation. To explore the experience of HCPs for fulfilling the PALs needs during attending community based rehabilitation in PHCs of Jember regency, Indonesia. A descriptive phenomenology was performed to HCPs during July to August 2020. In depth interview was saturated to six of HCPs who were responsibility to care PALs in community. Data was analyzed using systematic coding to all of verbatim of participants. Regarding our in depth interview for six of HCPs, we were identified of three of themes which explained into seven of subthemes and sixteen of categories. The main themes were adherence to treatment efforts, treatment to solve social limitation, and caring for preventing disability. The experiences of HCPs in caring for PALs during community based rehabilitation were identified in three main themes, namely: efforts to maintain adherence to treatment, efforts to prevent social barriers, and basic care to prevent disability. Therefore, regular visits through home visits can be carried out on PALs so that MDT compliance is good and reduces side effects. The formation of self-care groups is indispensable in teaching basic care skills in an effort to prevent future disability.

BACKGROUND

Data from WHO in 2014 showed a number of 213,899 new cases were found with a case detection rate of 3 per 100,000 population, where 94% of leprosy cases were found from tropical countries, one of which is Indonesia (WHO, 2014) with the number of new cases in Indonesia of 16,131 (WHO, 2016). Leprosy is commonly found in several developing countries and is a health problem that can cause disability which results in disruption of the quality of human resources (Susanto, Sahar & Permatasari, 2014). The problem of leprosy which is very complex related to the life of leprosy clients that occurs physically, psychologically, and socially in the community requires a comprehensive treatment in the

community (Susanto, 2010). During multi drug therapy (MDT) treatment, people affected by leprosy (PALs) need a community-based rehabilitation program (CRP) (Ministry of Health Indonesia, 2012). However, various complex problems will arise during the CRP program due to discrimination and stigmatization of leprosy (Susanto, Dewi, Rahmawati, 2017). Therefore, the needs of leprosy clients while undergoing CRP need to be properly facilitated in an effort to support the success of their treatment and care.

Handling leprosy in the community as a population at risk is in accordance with the SDGs target in eradicating infectious diseases (WHO, 2018) and based on the Global Leprosy Strategy Agenda, it is hoped that in 2020 every country will be free from leprosy (WHO, 2016). On the other hand, clients of

leprosy in the community during the CRP experienced stigmatization (Garbin et al., 2015) due to a lack of knowledge and socialization to the community (Susanto, Sahar & Permatasari, 2011), resulting in low community participation in the eradication of leprosy and new sufferers are still found every year. This has an impact on treatment compliance and motivation to recover leprosy clients during MDT (Susanti et al., 2017), so that it will simultaneously result in more complex problems during the CRP.

The experience of PALs undergoing treatment in the CRP really needs to be identified more deeply to reduce, prevent transmission and the disability it causes, because it will have an impact on the social life of PALs in the community. The unfulfilled needs of leprosy clients in the community will have an impact on the conditions of transmission and disability of PALs (Huzzein, Rachmawati, Susanto, 2014). For this reason, it is necessary for health care providers (HCPs) in public health centers (PHCs) to fulfill the needs of PALs, both physical, psychological, economic, social, cultural and spiritual dimensions during CRP treatment in an effort to facilitate finding nursing intervention public health nursing service model in the family and in the community in dealing with leprosy problems. Therefore, the level of disability and reduction of stigma and discrimination against PALs will be reduced during the CRP. Furthermore, the aimed of this study want to explore the experience of HCPs for fulfilling the PALs needs during attending community based rehabilitation in PHCs of Jember regency, Indonesia.

METHODS

A phenomenology descriptive study was performed to HCPs among PHCs of Ajung, Rowotengah, and Sumber Baru of Jember regency of Indonesia. This study was conducted during July to August 2020. The reason the researcher chose the research location was based on three factors, namely: (i) Data for the leprosy program in 2011-2019 from Public Health Department of Jember, the most new cases were in the Sumberbaru, Ajung and Rowotengah; (ii) both of three PHCs provide good services based on the assessment of the Health Office of Jember, namely the existence of the self-care group and have potential participants who match the characteristics set by researchers, as well as easy access for researchers to participants.

Participants in this study were HCPs in PHCs. The number of samples in qualitative research can be stopped if the achievement of completeness

of the information or data required has been saturated with the required data or no new information is found (Afiyanti & Rachmawati, 2014). Qualitative research does not set standard rules for determining the minimum number of samples. The sampling technique in qualitative research uses purposive sampling, which is a technique based on the objectives of the study. The criterion of participants in this study, namely: (i) HCPs who are responsible for the implementation and management of leprosy in the community; (ii) HCPs are the person in charge of the leprosy program at the PHCs; and (iii) responsible for health development at the sub-district level. In this study, our data were saturated to six participants of HCPs in the PHCs.

Data were collected using in depth interview, participation observation and filed notes. In-depth interviews was conducted an interview with the PHCs to see the leprosy treatment program, the researcher also performed an interview with the HCPs using general question "How are the efforts of the PHCs in overcoming leprosy in the community?" If the HCPs is difficulted to answer, the researcher was used a specific question for interview guidelines (Table 1). Researcher was made observations on leprosy nursing care services so far in facilitating the need for care and treatment during the CRP. Field notes are written documents of researchers derived from the results of their observations which specifically contain personal notes of various subjective responses and various interpretations of social processes that the researcher encountered while collecting data, these field notes were also used for the interview method. What a researcher must do when writing field notes must be made in full, with an explanation of the date and time. When the interview field notes are needed, these notes are used to record the facial expressions, body language and reactions of the participants when speaking.

Researcher is the main instrument of research, namely as a human instrument in data collection. Where in this research, the tools used are in-depth interview guidelines which contain open questions, field notes, observation sheets, documentation and MP4 as a voice recording and image capture tool. This study was approved by Ethical Review Board from Faculty of Dentistry, Universitas Jember with No. 913/UN25.8/KEPK/DL/2020. All of participants were explained the study and written inform consent was approved by all of participants who were voluntary to attend this study.

Creswell 2013 in Afiyanti & Rachmawati (2014) analyzes data on a phenomenological approach

Table 1. Interview Guideline for Health Care Providers

No	Questions
1.	To tackle leprosy in the community, what efforts did you explain?
2.	If there is a withdrawal, what efforts do you explain?
3.	If there is a leprosy client who has economic difficulties, in this case the client is unable to take medicine at the health facility, what efforts do you do?
4.	Community-Based Rehabilitation is an effort to restore the functioning of people who experience disturbances or obstacles, both physically, mentally, psychologically, and socially, by relying on the role of family and community groups, as well as making use of various initiatives, potentials and community resources, whatever. the obstacles faced by the person in charge of the program related to the CRP?
5.	If there is stigmatization and discrimination against clients with leprosy, how do you overcome it?
6.	Self-care is important for leprosy client independence, what are your roles in the self-care group activities?
7.	What are the obstacles you experienced while caring for leprosy clients who are currently being treated and treated?
8.	How did you overcome these obstacles?
9.	What are your hopes for success in the treatment and care of leprosy?

Table 2. Characteristic of informant (n= 6)

Code informant	Gender	Age (year)	Length of caring leprosy program (year)
Informant 1 (P1)	Female	48	12
Informant 2 (P2)	Male	52	10
Informant 3 (P3)	Male	45	15
Informant 4 (P4)	Male	45	15
Informant 5 (P5)	Male	35	5
Informant 6 (P6)	Male	41	2

Table 3. Theme, subtheme, and categories of study

Theme	Subtheme	Category	
Adherence to treatment efforts	Motivation	Informational support	
		Accessibility of services	
	Home visit	Controlling treatment and side effect	
		Hygiene personal and environment	
		Nutrition needs	
Side effects of treatment	Explanation of information for side effects		
Resistance of treatment	Providing medicine to reduce side effect		
Treatment to solve social limitation	Stigma and discrimination	Continuing of examination	
		Re-treatment of MDR	
		Health education for family and community	
		Self-care group support	
Caring for prevent disability	Eyes care	Training for return to work	
		Foots care	Cleaning of eyes
			Soaking
			Scrubbing
		Rubbing	

using a systematic coding process. This process begins by listening to the verbal descriptions of the participants, followed by reading and re-reading the verbatim transcripts. Verbatim transcripts are the art of converting spoken words into text so that the message conveyed is exactly the same as what was said. Researchers analyzed specific statements and categorized them into clusters that would form a theme.

RESULTS

In this study, we were interviewed six of informant of HCPs using in depth interview. HCPs were responsible for the implementation and management of leprosy in the community. Majority of HCPs were male with age from 35 to 52 years old. Length of caring leprosy program more than 10 years, although two of informants were just 2 to 5 years to care of leprosy program in PHCs (Table 2).

Regarding our in depth interview, we were identified of three of themes which explained into seven of subthemes and sixteen of categories (Table 3). The main themes were adherence to treatment efforts, treatment to solve social limitation, and caring for preventing disability.

In this study, informants were tried to provide their services of PALs for Adherence to treatment efforts. They were performed to give a self-motivation, home visit, Side effects of treatment, and resistance of treatment. The description of these themes were regarding their quotes:

"..... In order for the patient to adhere to the treatment, I usually provide information support that confirms what treatment the patient will undergo and for how long" (P2)

".... if the patient's house is far from the PHCs, then usually we provide easy access for control to the remote of PHCs, so it's easy to take, so that the treatment continues" (P3)

"..... Patients will feel comfortable and calm if we always control the side effects of leprosy MDT treatment, they will comply with the treatment if these side effects can be treated immediately" (P1)

"..... When home visits are carried out to check whether the patient is adhering to treatment, we always remind him to maintain personal hygiene and the environment so that it is clean, so that leprosy transmission does not occur in families and communities" (P3)

".... because leprosy is an infectious disease caused by bacteria, we advise patients to fulfill their nutritional needs in a healthy manner and eat a variety of foods, preferably eating high-calorie and high-protein foods to support the healing process ..." (P6)

"..... patients who experience side effects of MDT administration, then we will provide side effect relievers such as Predisolone to reduce swelling in clients, generally they complain that their skin is getting blackened and swollen, so it has the potential to withdraw the drug" (P5)

"... Patients who experience withdrawal and from the results of follow-up examinations experience resistance to MDT drugs, so we will conduct referrals and consultations for repeat and continued treatment and the duration of treatment" (P4)

The PALs who diagnosed leprosy and undergoing for treatment were experienced for social limitation condition. This situation were related stigma and discrimination of PALS among communities which needed to solve condition, regarding this quotes:

"... so that families and communities have a positive view of PALs, then we continuously provide health education to families and communities that leprosy can be cured, as long as they comply with the treatment given, so that the transmission rate decreases in the community ..." (P1)

"... we set up a self-care group to provide basic care and support to fellow PALs, so that they can share and support each other as new families who share the same co-existence ..." (P5)

".... Sometimes we provide training for PALs in the hope that after they recover from leprosy, they can return to work and activities, so that they can still produce economically and be accepted in the community ..." (P3)

PALS are actively involved in self-care groups, so we teach them basic care in preventing further disability. We provide training on eye and foot care, such as the following quotes:

"... we teach patients to always check their eyes, such as redness and dry eyes. If your eyes are itchy, don't put them on, but just cover them with wet gauze and wash your eyes with clean running water. If they travel, they can use protective glasses and hats dur-

ing the day ..." (P2)

"For foot care, it can be done in three movements, namely soaking, scrubbing, and rubbing. We ask the patient to soak his feet to the limit of the knees with clean water for 15-20 minutes, while seeing whether the legs are injured or not. After that, the patient can lift his feet from the water in the bucket and then dry them using a towel, then rub them. If the sole of the foot feels rough, it can be rubbed with a fine stone so that the callus that is formed is eroded. The last step is smearing the feet with oil or skin Vaseline so that the skin does not become dry and keeps moisture away. (P1, P2, dan P6).

DISCUSSION

The results showed that the experiences of HCPs in providing care for PALs were reflected in three main themes, namely efforts to adhere to medication, efforts to overcome social conditions, and care to prevent disability. The findings of this theme have mostly been identified in several previous research themes, but the existence of PALs with all the complexities of life physically, psychologically, socially, economically, and culturally deserves to be identified and described in order to facilitate the treatment of PALs in families and communities.

PALs received MDT treatment according to the length of treatment and the type of leprosy. Generally, during MDT treatment, there were clients who were not adherent, experienced drug side effects, and dropped out of treatment. Multi Drug Therapy (MDT) is a treatment recommended by WHO for PB and MB leprosy clients which aims to break the chain of transmission, prevent drug resistance, increase regular treatment, shorten the treatment period and prevent disability or prevent the increase of disability (Kementerian Kesehatan RI, 2012). The length of treatment that the PB type leprosy client must undergo is for 9 months, while for the MB type leprosy client for 18 months (Widoyono, 2008). Therefore, it requires continuous monitoring and home visits for PALs receiving MDT treatment in order for the treatment to be effective and efficient.

Meanwhile, PALS who undergo leprosy treatment sometimes experience stigma and social discrimination in society. This can result in PALs withdrawing from social life, thereby interfering with the healing process. According to the Kementerian Kesehatan RI (2012), disability is a term used to describe three aspects, namely structural and functional damage, activity limitation, and participation problems.

These factors can be influenced by individual factors (age, gender, education, and occupation) and the environment (government policies, surrounding communities, and stigma and environmental conditions). Left untreated and untreated, leprosy will develop progressively, causing permanent damage to nerves, resulting in disabilities in limbs and eyes (Susanto, 2010). The negative public acceptance of leprosy clients has a negative impact on leprosy clients, namely resulting in a feeling of inferiority and depression towards the disease they suffer. Negative acceptance occurs due to the wrong perception in society about leprosy, that leprosy is a curse disease. The inherent stigma can have an impact on leprosy clients so that they have feelings of shame, low self-esteem and choose to withdraw more from society (Rahayu, 2009). Furthermore, providing family and social support and the presence of leprosy self-care groups can facilitate PALs in physical, psychological and social aspects of life. Therefore, the formation of self-care groups with various positive activities for PALs really needs to be developed in the community in supporting the treatment and care of PALs.

Meanwhile, PALs in the community also need to be facilitated in their economic and social life to support the treatment and care process. Leprosy can attack the productive age which can cause disability and have negative impacts such as unemployment (Kementerian Kesehatan RI, 2012). The physical impact caused by leprosy causes leprosy clients to find it difficult to get a job which results in physical and financial dependence that can lead to poverty. In addition, this economic impact is a sustainable impact caused by social impacts stemming from the stigma of society. Stigma is one of the important factors that cause social exclusion for people affected by health problems, without exception for clients with leprosy. People who have leprosy or related disorders, even families who live together also often experience problems in social participation. This can have far-reaching consequences, for example on work due to social exclusion, which will affect productivity at work so that it has a direct impact on the economic situation (Dadun, et al, 2017). Therefore, resettlement to work and provision of basic job training are indispensable for PALs for survival after treatment is complete.

Furthermore, leprophobia is the fear experienced by clients of leprosy in society. Leprophobia, lack of knowledge, and social isolation in the community towards leprosy clients cause social problems. Based on the research conducted (Susanto T, 2010), the results show that leprosy clients feel sad and dis-

appointed with themselves when they are diagnosed with leprosy. The existence of negative views (stigma) causes low community participation in the eradication of leprosy (Susanto, 2010). The high number of leprosy clients is a result of social rejection and self-acceptance of their body condition so that leprosy clients experience hopelessness, anxiety and feelings of depression. One of the anxiety experienced by leprosy clients is due to the fear of not being accepted because of the stigma circulating in society that leprosy is a curse and disgusting disease that can be transmitted (Chrisnina, 2015). Difficulty in relating or interacting can be triggered by uncomfortable feelings in social situations (Stuart & Gail, 2007). Therefore, gradual socialization and counseling can be carried out in the community to prevent leprosy stigma and discrimination in the community.

Finally, basic care can be taken on PALs to prevent disability. Basic eye and foot care can be done according to coaching in the self-care group. Rehabilitation in the medical field can be carried out through a treatment (care) carried out in conjunction with a leprosy elimination program through the Disability Prevention Program (DPP) or Prevention of Disability, Self-Care Group. Leprosy clients in this study follow the self-care group to get a good service for their situation based on the perception of meaning and meaning according to leprosy clients (Ministry of Health, 2012). Leprosy treatment can take place effectively and is accepted in the community, so clients with leprosy need a good rehabilitation need during treatment (Susanto, 2017). Rehabilitation of leprosy clients in the community can be realized in the formation of a social support group.

The results of this study can be used as the basis for community nursing care for the group at risk of leprosy. The experience of leprosy clients undergoing treatment can be used to determine primary, secondary, and tertiary preventive measures in the population at risk of leprosy by the Health Office and the PHCs. Primary prevention can be arranged based on the identification of clients' daily life patterns before undergoing treatment. Secondary prevention can be prepared based on the identification of actions taken by clients to overcome leprosy problems and the care performed by families for leprosy clients and care givers expected by leprosy clients. Tertiary prevention can be arranged based on identified client acceptance of leprosy treatment management.

CONCLUSION

The experiences of HCPs in caring for PALs

during community based rehabilitation were identified in three main themes, namely: efforts to maintain adherence to treatment, efforts to prevent social barriers, and basic care to prevent disability. During community-based rehabilitation, PALs need to facilitate the fulfillment of physical, psychological, social, economic and cultural needs in supporting MDT care and treatment. Therefore, regular visits through home visits can be carried out on PALs so that MDT compliance is good and reduces side effects. The formation of self-care groups is indispensable in teaching basic care skills in an effort to prevent future disability.

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