

## The Experiences of Leprosy Clients Attending Self-Care Groups During Community-Based Rehabilitation for Fulfilling Their Health Needs

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The experience of leprosy clients undergoing treatment in community-based rehabilitation (CBR) needs to be identified more deeply to reduce, prevent transmission and the disability it causes because it will impact the social life of leprosy clients in the community. The non-fulfillment of the needs of leprosy clients in the community will impact the conditions of transmission and disability of leprosy clients. We explored the experiences of leprosy clients attending self-care groups during CBR for identifying their health needs. A descriptive phenomenology study was performed among leprosy clients, families, and healthcare providers. Our study included 16 leprosy clients and their families and six healthcare providers. A triangulation method was performed to compare the third source data. Thematic analysis was used to identify the phenomenon of leprosy during CBR for fulfilling their health needs. We have identified five themes, including leprosy prevention efforts, self-care process and client treatment for leprosy, the needs of clients with leprosy during self-care at CBR, medication, and therapy during the CBR family support during rehabilitation and treatment. Therefore, fulfilling the needs for self-care, medication, and therapy during the rehabilitation period for leprosy clients in the community needs to be facilitated and fulfilled to support recovery. Furthermore, CBR designs that prioritize self-care aspects and are integrated with family care need to be developed in the future. All these approaches should be developed, adapted and validated in different settings with specific needs.

**Keywords:** Leprosy, Community Based Rehabilitation, Multidrug Therapy, Self-care

### Introduction

The incidence of leprosy is still relatively high in endemic tropical countries with various physical, psychological, economic, social, cultural, and

spiritual complexities during treatment in families and communities (Susanti et al 2018, Susanto 2013a). The complexity of the problem impacts the stigmatisation and discrimination of clients

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with leprosy and results in new problems that may impact transmission and disability (Susanto et al 2011, Susanto & Susumaningrum 2012, Susanto & Wantiyah 2015, Blok et al 2015, Reinart et al 2015, Gillini et al 2017). Therefore, comprehensive and programmed handling is needed to eliminate leprosy in the community (Huzzein et al 2015, Susanto 2013b) through active involvement of leprosy clients in fulfilling their needs during rehabilitation and treatment of leprosy in the community.

The incidence of leprosy in the world shows data with a total of 213,899 in 2014, including all countries with endemic priority, and in 2017 the number of new cases was 211,009 cases (Susanti et al 2018). The Southeast Asia region reported 71% of all global cases. These countries include India (120,334 cases) and Indonesia (17,017 cases), which contributed 92% of the cases in this region. Brazil, India and Indonesia account for 79.6% of all new cases detected globally (Huzzein et al 2015). The incidence of leprosy, which is still relatively high, requires treatment management through the provision of multi-drug therapy and monitoring programs in stages (Mahardita et al 2019, Susanto 2020) and is planned through community-based client rehabilitation to optimize their level of independence (Blok et al 2015, Gillini et al 2017).

One of the strategies implemented by the Indonesian government is rehabilitation for disabled people in general, which is Community Based Rehabilitation (CBR) (Susanto 2013b). The experience of leprosy clients undergoing treatment in CBR needs to be identified more deeply to reduce, prevent transmission and the disability it causes because it will impact the social life of leprosy clients in the community (Susanto & Wantiyah 2015). The non-fulfillment of the needs of leprosy clients in the community will impact the conditions of transmission and disability of

leprosy clients. For this reason, it is necessary to fulfill the needs of leprosy clients, both in physical, psychological, economic, social, cultural, and spiritual dimensions, while undergoing CBR treatment to facilitate finding nursing intervention inventions (Susanto et al 2011). For a nursing service model in the family and in the community in dealing with the problem of leprosy, so that the level of disability can be reduced and the stigma and discrimination against leprosy clients will be reduced during the CBR (Mahardita et al 2019, Susanto 2020). Therefore, this study aimed to explore the experiences of leprosy clients attending self-care groups during rehabilitation in the community for fulfilling their health needs in Indonesia. The phenomenon of leprosy clients during attending CBR was clarified using the triangulation method based on clients' leprosy and their families and healthcare providers in the public health center.

## **Material and Methods**

### ***Design:***

A descriptive phenomenology was used to explore the experiences of leprosy clients attending self-care group during rehabilitation in the community to fulfill their health needs in Indonesia. The meaning of client leprosy during CBR was explored in-depth (Susanto 2013a) to fulfill their self-care need in the community of Indonesia. This study was located in 3 public health areas, namely Rowotengah, Sumberbaru, and Ajung's Public Health Care. This research was conducted in 2020 for three months starting from June to August.

### ***Participants:***

Participants in this study were clients with leprosy and their families and healthcare providers in the public health center. The key informants in this study are healthcare providers who is responsible for implementing and managing leprosy in the

community. Then, the main informants in this study were clients with leprosy at the public health center who underwent treatment, clients who attended MDT treatment, clients with PB and MB types of leprosy, clients with 0 to 2 degrees of disabilities, adult clients and clients according to predetermined characteristics.

Meanwhile, additional informants in this study were households related by marriage that aim to create and maintain culture and improve individuals' physical, mental, emotional, and social development. Individuals in it can be seen from the interdependent interaction pattern to achieve common goals; they are the client's leprosy family. The sampling technique was used purposive sampling, purposive means to take respondent samples to determine the criteria desired by researchers. The researcher then selected three types of informants: key informants taken from 6 health workers, the primary informants were taken from leprosy clients totaling six people, and additional informants taken from the client's family or volunteer workers as many as 12 people. Our data-saturated among 18 leprosy clients and their families and six healthcare providers.

**Data collection:**

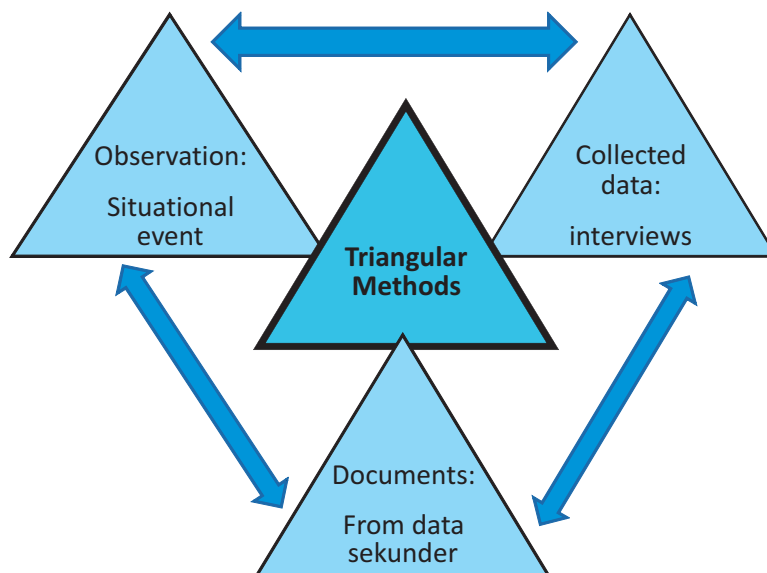
Data were collected using in-depth interviews, participant observation, and field notes for clients' leprosy (as primary informants) and their families (additional informants) and healthcare providers (as key informants) in the public health center. In-depth interviews were interviewed with the informants to see the leprosy treatment program; this method has captured the problem faced by the respondent and was not explored by other methods such as the motivation and support obtained by the client with leprosy. The researcher also performed an interview with the informants using the general question, "How are the efforts of the PHCs in overcoming leprosy

in the community?" The researcher observed leprosy nursing care services so far in facilitating the need for care and treatment during the CBR. The observations also found that clients looked happy when they received health services, especially from community officers who came to the house. Field notes are written documents of researchers derived from their observations, which specifically contain personal notes from various subjective responses and various interpretations of social processes. 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 participants' facial expressions, body language, and reactions when speaking.

**Ethical Consideration:** Ethical Review Board approved this study from Faculty of Dentistry, Universitas Jember with No. 913/UN25.8/KEPK/DL/2020. All of participants were explained the purpose of study, all approved the study and written informed consent of participants of their voluntary participation to attend this study was taken.

**Data Analysis:**

A triangulation method was performed to compare the third of source data (Fig. 1). This triangulation method approach was followed by observing the research subjects related to the questions that asked, after that, secondary data obtained from the public health center then conducting interviews with the intended respondents. Thematic analysis was used to identify the phenomenon of leprosy during CBR for fulfilling their health needs. To obtain reliable information truth and a complete picture of certain information, we used the data interview from the third kind of informants. Data from interviews and



**Fig. 1 : Triangulation Methods as a Step-in this Research**

observations, we were verbatim and transcript to analyze the thematic of the study. The researcher used different of three kinds of informants to check the accuracy of the information. Through various perspectives or views, the researcher hoped that results are closed to the truth will be obtained. Therefore, this stage of triangulation carried out if the correctness of the data or information obtained from the subject or research informants is doubtful.

## Results

**Characteristic of informants:** The characteristics of the key informants in this study were healthcare providers, which consisted of 3 general practitioners and 3 public health nurses (PHN). The age of the informants was between 30-48 years old with 4 of female and 2 of male. The work period at public health centers (PHCs) is between 5 - 8 years. The three PHNs are nurses in charge of the leprosy program at PHCs. Meanwhile, of the 18 main informants, clients of leprosy consisted of 10 men and 8 women aged

between 25 - 53 years. The length of diagnosed leprosy is between 8-24 months with the MDT treatment period between 4-12 months. A total of 11 clients were diagnosed as paucibacillary (PB) and 5 people with multibacillary leprosy (MB) with disability levels of 0 (5 clients), 1 (9 clients), and 2 (2 clients). Furthermore, additional informants, namely the client's family of leprosy who care for clients at home, consisted of 11 women and 5 men aged between 26 - 48 years. Most of the families who care for this are husband or wife partners of leprosy clients or their children. Henceforth, in delivering these results, we use the term healthcare providers with HCP (HCP 1-6), leprosy clients with CL (CL 1-16), and leprosy client families with FCL (FCL 1-16).

### **Theme 1 - Leprosy prevention efforts:**

Efforts made by the PHCs and the person in charge of the leprosy program by implementing a CBR approach include conducting counseling on leprosy. Therefore, the community were understands about leprosy both from the initial

symptoms that arise or how to treat it. In addition, the PHCs also conduct screening and even contact tracing.

“Prevention of leprosy in the community at the PHC so far, what we do first is that before going to the community, we coordinate with our cross-sectors to make our village leprosy groups do the first to provide counseling, then first the findings of leprosy patients, then after meeting we gather us provide counseling” (HCP 3).

“For the prevention of leprosy in the working area of the PHC has been carrying out activities called contact tracing, namely examining one patient to 20 people in the vicinity of 20 people in the vicinity, we carry out screening to find early symptoms of leprosy sufferers who have been recruiting cadres. Carry out for contact investigation activities or contact tracing if the cadre finds symptoms, then he will refer to the PHN at the PHCs for further examination” (HCP 4).

***Theme 2 - Self-care process and client treatment for leprosy:***

In the process of self-care efforts, PHCs always support and encourage leprosy clients to always take care of their health, especially when doing daily activities, so that they use personal safety facilities, so they don't get hurt. PHCs also formed an association for clients with leprosy to provide guidance on how to care for themselves and prevent further disability for leprosy patients. Furthermore, families and PHCs increased awareness of leprosy clients to carry out self-care independently. Leprosy clients take medication regularly at PHCs according to a predetermined schedule, then PHCs also collaborate with regional cadres to control leprosy clients, so they don't experience withdrawal, thus accelerating

recovery and reducing opportunities and avoiding disability. It was also observed that clients also looked happy when they received health services, especially from community officers who came to the house.

“The efforts of the PHCs in supporting group activities, especially for persons affected by leprosy, for their self-care, so in that group activity we always provide counseling regarding self-care for leprosy patients, especially leprosy patients with disabilities, there are injuries, how can they be? always take care when doing activities” (HCP 2).

“We are trying to form a group called the leprosy association group, this leprosy association group consists of leprosy clients, namely or members of patients who have recovered or who have been treated and there are usually presented every one month one time to be carried out which is called a disability examination, so that we can detect early for the level of our disability and at the same time we can get ways or how to prevent more severe disability for us” (CL 5).

“I came to PHN at PHCs to pick up the MDT medicine package according to schedule because I wanted to get well soon. Then PHN recorded the process of taking my medicine and gave a message related to possible side effects of the drug and how to report if there were side effects of this drug” (CL 11).

“If there is a drug dropout with a patient, then our family, as monitors taking MDT medication, will report to leprosy cadres at the village level because they are also monitors taking medication, for example, in the first time they don't take medication, the two clients take medication, then the health cadre visits the patient. after that, asked why

he didn't take the medicine. Then the PHCs followed up with these cadres together with PHN to directly conduct patient home visits" (FCL3).

***Theme 3 - The needs of clients with leprosy during self-care at CBR:***

Leprosy clients were taught to be independent in the process of caring for themselves and preventing the occurrence of more severe disability for leprosy clients. It seems to be a goal that must be achieved. The majority of leprosy clients can still carry out their daily routine activities normally. Based on the results of interviews with several leprosy client participants, they revealed that they can still carry out daily activities and even do work that they do routinely to make ends meet. Their families assist leprosy clients to carry out daily activities even to meet their needs. The role of the family for leprosy clients who experience difficulties like this is very important considering that the family is the closest person to the leprosy client who has to help the client with leprosy in carrying out activities such as bathing, eating, doing self-care and also medication and even doing the obligation to worship. In carrying out worship services, several leprosy clients experience difficulties so they do not carry out the worship.

"We teach independence with leprosy sufferers by teaching personal hygiene the cleanliness of the clean environment at home. Then if there is a disability, we train leprosy client to practice to minimize the more severe disabilities" (HCP 7).

"We really need nutritious food because leprosy requires high immunity, so we need to eat foods that are high in protein and calories" (CL18).

"I always time my rest and sleep well. Getting enough sleep at least 7 hours per day makes

the body fresh and speeds up the healing process" (CL 3).

"We in the self-care group were taught to do hand and foot care. We are taught to do at least 3 movements every day, namely soak and rub. We soak the feet or hands in warm water, then rub with a smooth pumice stone and after that grease them with lotion or oil. We do this to avoid disability" (CL9).

"When we go outside, we are asked to close our eyes, because we are very sensitive to light during the day. Then we also diligently control the ears and nose because they experience decreased sensation if it lasts a long time" (CL 15).

"As a caring family, I always provide support by reminding me to always keep clean, at least bathe 2 times a day. Then we also protect the home environment by maintaining adequate home ventilation, sunlight entering the house and avoiding humidity in the house" (FCL7).

***Theme 4 - Medication and therapy during the CBR:***

The treatment undertaken by clients with leprosy depends on the type of leprosy, leprosy drug resistance, and the degree of disability. PHN performs regular monthly nerve function checks. If there is a reaction to treatment, the monitoring family taking the medication will report the problem. For disabilities and wounds experienced by leprosy clients, treatment is carried out every two weeks through home visits or regular consultations by leprosy cadres.

"Drug packages are provided free of charge at PHCs, and clients and their families can take this drug package every month. When taking the drug, the HCP performs nerve function checks and monitors the side effects of the drug to avoid withdrawal" (HCP 5).

“PHN always regularly conducts home visits to control the occurrence of disabilities or problems taking medication. We always check our regular schedule for taking our medication. If you experience a withdrawal, a further examination is carried out and a prescription will be given to the doctor” (CL2).

“Family is always an active reminder or alarm for the client’s strict medication schedule. Besides that, we always remind clients not to forget to use personal protective equipment and be diligent in doing personal care” (FCL 18).

“Indeed, the drugs from the MDT package cause many side effects, but we have been told beforehand what kind of medication is taken and what possible reactions will occur. When taking drugs, we are given additional drugs to reduce these side effects that will arise. If the side effects did not decrease, we and our families were asked to report to the leprosy cadres and then referred by PHN to PHCs for further treatment” (CL 14).

***Theme 5 - Family support during rehabilitation and treatment:***

The family comprises of the closest persons who will directly assist leprosy clients in carrying out daily activities, motivating and praying for leprosy clients, and carrying out treatment.

“I invited and took them to PHCs for treatment. At the beginning, a complete examination was carried out and was declared leprosy. So, then every month I accompany the client for regular control and take the medicine every month to PHCs when it runs out” (FCL11).

“My family fully supports me to recover. My food, drink, and sleep rest are well catered for and cared for. I was always reminded to

take medication regularly. Besides that, my family’s support and prayers will always keep me strong and energized during the next year of treatment” (CL8).

“During this treatment period, PHCs were formed to provide self-care groups to strengthen themselves for leprosy clients and their families. So patients and families can exchange thoughts and experiences for the success of leprosy treatment facilitated by PHN at every meeting” (HCP 1).

**Interaction Between Themes**

In this study, the results obtained regarding exploring various needs of leprosy clients when carrying out rehabilitation in self-care groups in the community. In general, the informants revealed that leprosy clients have two needs that are considered fundamental. The first need is the need for the availability of leprosy drugs at the Public Health Centers which will certainly impact physical changes, namely improving the condition of leprosy clients. While the second fundamental need is motivation or encouragement from various parties around them. The leprosy clients have a close relationship with the stigmatization that is still negative towards leprosy clients who are currently still developing in the community, so that motivation needs to be done to leprosy clients to rebuild their positive mentality and enthusiasm to recover while undergoing rehabilitation in self-care groups in the community. Based on the explanation above, this research has implications for health services, especially in community nursing and the development of nursing science as a guide when carrying out the rehabilitation process in self-care groups in communities in various regions.

**Discussion**

The current study explored the experiences of leprosy clients attending self-care group during

CBR for fulfilling their health needs that the leprosy clients experience categorized for five themes, including leprosy prevention efforts, self-care process and client treatment for leprosy, the needs of clients with leprosy during self-care at CBR, medication and therapy during the CBR, and family support during rehabilitation and treatment. This phenomenon was reflected that during rehabilitation, the leprosy client needs self-care, treatment, and support to adhere to their medication.

Our finding identified that the majority of leprosy clients still believe that their disease can still be cured. The positive response shown by some leprosy clients is a good start to their healing process (Peters et al 2013). This is because the positive response they do will impact their enthusiasm for the healing process of the disease (Bergman et al 2018, Freitas et al 2017). Leprosy clients who show a positive response will have greater hope and a greater chance of recovery because they believe that the disease they are experiencing, namely leprosy, can be treated and cured again (Deepak et al 2013). Leprosy clients' needs motivation and also knowledge about leprosy, because if they experience depression it will have implications for their enthusiasm for self-care and also take medication (Susanto et al 2011, Susanto et al 2017), so that directly or indirectly it will ultimately impact probability of their cure.

Findings revealed that the majority of leprosy clients can still carry out their daily routine activities normally. Based on interviews with several leprosy clients, they revealed that they can still carry out daily activities and even do work that they do routinely to make ends meet. So, it can also be said that leprosy does not interfere with their activities in their daily lives, but what needs to be underlined is that it also depends on the severity or level of disability of leprosy they

experience (Garbin et al 2015, Heijnders 2004, Bahtiar et al 2020). In this regard, there are also leprosy clients who feel very disturbed by the disease so that they cannot carry out their daily activities as they should, usually leprosy clients are assisted by their families or their closest people to carry out daily activities even to fulfill their needs (Reinar et al 2015, Susanti et al 2018).

When undergoing treatment, family must meet the various needs of leprosy clients amid the disease they suffer, one of the things they need is the availability of free medicine from the PHCs, because always having these drugs can make clients able to treat leprosy. They suffer regularly (Peters et al 2015, Thangaraju et al 2018). However, clients with leprosy who do not suffer from severe forms of leprosy can still meet their own economic needs from working as usual. So based on the results of this study it can be said that the family or the closest person has an important role in fulfilling the needs of leprosy clients during self-care (Sasakawa, 2011, Padhi & Pradhan 2015). The family is the closest to the client of leprosy who will help leprosy clients fight their disease. The closest family does various ways to help cure leprosy clients, ranging from helping to carry out daily activities, helping to meet the economic needs of leprosy clients, and providing motivation to always carry out self-care and regular treatment (Fatmala 2016). The role of the family is very important for leprosy clients because with the presence of family and people around them, leprosy clients can be more motivated to carry out self-care and carry out regular medical treatment so that it increases their probability to recover.

### **Conclusion**

From the results of this study it can be concluded that leprosy clients during treatment require nursing therapy for fulfilling the needs of leprosy clients while undergoing Community-Based



Rehabilitation by means of routine treatment which aims to improve physical disabilities for leprosy clients so that they can get better and heal. In addition, motivation is also carried out for leprosy clients to be able to live clean as well as healthy life and also to be able to remain confident in carrying out daily activities, especially to carry out social activities with the community around them. Therefore, the fulfillment of the needs for self-care, medication, and therapy during the rehabilitation period for leprosy clients in the community needs to be facilitated and fulfilled in order to support recovery. Furthermore, CBR designs that prioritize self-care aspects and are integrated with family care need to be developed in the future.

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