

# Experience of Persons Affected by Leprosy in Facing Psychosocial Problems: A Qualitative Method

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## ABSTRACT

**Background:** Leprosy is a tropical disease caused by *Mycobacterium leprae* and is characterized by damage to the skin and peripheral nerves due to direct contact with leprosy patients. Leprosy is one of the oldest diseases known to humanity, but significant gaps remain in the knowledge about this disease.

**Methods:** This research was designed with a qualitative approach using phenomenology study. The total number of participants was 16 participants. Data were collected using in-depth interview, and NVivo 10 was used to identify themes and patterns in further data.

**Results:** This research was conducted to explore the experience of persons affected by leprosy in facing psychosocial problems. The results of this study found three themes: Anxiety, Pulling away, Impaired self-concept

**Conclusion:** This study has provided a prevalence rate for psychosocial problems in this group of patients. Social stigma has an essential role in persuading psychological disorders in patients with Hansen's disease. For further researchers, the early detection and treatment of psychosocial disorders among these patients was powerful.

**Keywords:** Leprosy, Psychosocial, Phenomenology.

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## INTRODUCTION

Leprosy is a tropical disease caused by *Mycobacterium leprae* and is characterized by damage to the skin and peripheral nerves due to direct contact with leprosy patients<sup>1,2</sup>. WHO (World Health Organization) reported new case leprosy in 2018 as many as 184,212 cases from 13 countries, Indonesia belongs to the country that has a new case is 17,017. In East Java, The Leprosy case became the highest (4,013)<sup>3</sup>. Leprosy infects the eyes, hands and feet of the patient so that abnormalities arise, which result in limited daily activities of the patient until permanent disability occurs<sup>4,5</sup>. This disorder occurs not only in patients who stop therapy but also occurs in patients who even finish therapy<sup>5</sup>.

Psychosocial problems often occur in people with leprosy which can affect the psychological aspects of sufferers, such as depression, low self-esteem, anxiety, and withdrawal<sup>6</sup>. Psychosocial problems in people with leprosy cause a decrease in quality of life<sup>7,8</sup>. Lack of knowledge, community stigma against sufferers<sup>9,10</sup> and physical disability cause sufferers to feel challenging to get along with others so that sufferers feel ashamed to do activities and ostracized by the community<sup>11,12</sup>. According to<sup>7</sup> who conducted a systematic review of people affected by leprosy concluded that sufferers who had psychosocial problems but did not understand how they felt<sup>13</sup>. Quantitative research conducted by<sup>9</sup>, found that the psychological aspects and quality of life of people with leprosy will decrease. The same results obtained by<sup>14</sup> in leprosy sufferers will appear psychological disorders such as depression and anxiety disorders.

Problems related not only to individuals with leprosy but also to families of leprosy patients, namely psychosocial pressure and decreased financial income<sup>15</sup>.

Of the various problems faced by individuals who can overcome ability difficulties<sup>16</sup> with coping and good self-concept<sup>17</sup> to enable copying that is adaptable<sup>18</sup>.

Depressive disorders that are not treated immediately will cause a decrease in quality of life and even more significant disability<sup>19</sup>. To the extent that research conducted on people with leprosy only focuses on the cause of leprosy, but no research digs deeper into psychosocial issues. Psychosocial lepers also influence increased immunity. Based on the above problems, the purpose of this study is to explore psychosocial problems experienced by leprosy sufferers qualitatively phenomenology. The function of this research is to explore more in-depth the psychosocial aspects through the perspective of the sufferer.

## METHODS

**Study design**

A qualitative phenomenological research design was carried out to investigate the exploration of leprosy patients. Data were obtained from interviews with focus groups of leprosy patients about their experiences dealing with psychosocial problems. A structured interview protocol consisting of 10 open-ended questions was used.

## Population

This research was conducted in the working area of East Java Province. Participation in scheduled focus groups is voluntary and anonymous. Participants need to feel comfortable with the questions asked and answer them in Indonesian and Javanese, which are the most commonly used languages. Before data collection, each participant signed an informed consent form and gave oral consent to participate in this study.

**Table 1.** Participant Characteristics

Participant	Age	Gender	Duration of Treatment Program (Month)	Type of work	Level of education
P1	59	M	12	Farmers	elementary school
P2	48	M	12	Trader	elementary school
P3	27	M	12	Farmers	senior high school
P4	28	F	12	entrepreneur	junior high school
P5	50	F	12	entrepreneur	elementary school
P6	46	F	6	Farmers	elementary school
P7	36	F	6	Farmers	elementary school
P8	32	F	6	Farmers	elementary school
P9	34	F	6	Farmers	elementary school
P10	48	F	12	Farmers	elementary school
P11	38	M	12	Trader	senior high school
P12	44	M	6	Trader	junior high school
P13	37	M	6	Farmers	elementary school
P14	39	F	12	Farmers	elementary school
P15	41	F	12	Trader	junior high school
P16	35	M	6	Farmers	elementary school

### Validate findings

All transcripts were compared with the original audio file and then clarified to participants for review before analysis. Final analysis of the data was also sent via email to the participants for review. This post-interview interaction functions as a member check, which is considered by qualitative researchers as the most critical technique for building unbiased validity and, thus, credibility<sup>20</sup>.

### Analysis of findings

Audio recordings of each focus group are transcribed<sup>21</sup>. The researchers then independently grouped the data manually and then met together to discuss the themes and patterns identified. NVivo 10 was used to identify themes and patterns in further data. The last joint review of all transcripts, themes and patterns was completed and found to be consistent with the final analysis.

## RESULT

Participants explained the response to stressors as a way of expressing anxiety in the form of attitudes and behaviours caused by changes in health conditions in the form of physical disabilities and decreased bodily functions. The way participants express their discomfort with various forms of attitudes and behaviours, and it is implicit in the body language of participants in interacting with family and researchers to stimulate the emergence of psychosocial problems. The theme was identified based on subtheme 1) anxiety; 2) withdraw; 3) Impaired self-concept.

### 1) Anxiety

Participants explain anxiety as a form of discomfort from an unexpected condition. Participants described anxiety in the form of feelings of uneasiness, worry and even fear caused by changes in health status, to experiencing physical disability. In this subtheme, there are two categories identified, namely 1) anxiety symptoms; 2) intensity of anxiety.

**Table 2.** Overview of the themes and sub-themes

Theme	Sub-Theme
1. Anxiety	Symptoms of anxiety intensity of anxiety
2. Pulling away	Barriers to social interaction
3. Impaired self-concept	Body image Pride

#### a. Symptoms of Anxiety

Symptoms of anxiety often arise at the beginning of disability due to suffering from leprosy as a form of response to stressors. The following participant statements support this category:

*"My family and I are worried" (P2)*

*"I always feel scared" (P4) (P6)*

*"My mind" (P8)*

From the results of the above statement, it can be concluded that the participants experienced anxiety due to lack of knowledge about leprosy and healing the disease after the therapy program that was undertaken.

#### b. Anxiety intensity

The intensity of anxiety experienced by lepers with disabilities due to the disease often occurs in a certain period after leprosy was signed. The following participant statements support this category:

*"I often . . ." (P2) (P6) (P8)*

*"I always . . ." (P4)*

From the results of the above statement, it can be concluded that the participants experienced anxiety after learning about leprosy, but that anxiety disappeared overtime after undergoing regular treatment.

#### 2) Withdraw

Pulling out is described by participants as feeling reluctant to interact with others which are applied by choosing to stay at home and avoiding activities and routines that involve many people. Uncomfortable feelings accompanied by dislike of staring and dealing directly with others. In this sub-theme, there is one category that is identified, namely: 1) barriers to social interaction.

#### a. Barriers to social interaction

Barriers to social interaction experienced by lepers with disabilities due to illness because they are reluctant to interact with others in the environment around the house; this category is supported by participant statements as follows:

*"I also rarely leave the house, I feel I am not ready to meet other people" (P3) (P11)*

*"I do not want to be seen by others when sick" (P4)*

*"I prefer to stay at home" (P9)*

From the results of the above statement, it can be concluded that participants rarely interact, limit interaction and avoid interaction with others since being diagnosed with leprosy and experiencing disability due to the disease.

#### 3) Impaired self-concept

Participants describe the concept of self as a perception in seeing themselves, body shape and acceptance of changes in body conditions due to leprosy. The difficulty experienced by participants in seeing their body shape after experiencing disability is a feeling of refusing and hoping to be healed as before. In this subtheme, there are two categories found, namely: 1) body image; 2) self-esteem.

##### a. Body image

Changes in physical form due to leprosy experienced by participants are considered as deficiencies that trigger rejection of current health conditions. The following participant statements support this category:

*"Because of my body" (P5)*

*"My body is full of disease" (P7)*

*"Because my body has blackened skin" (P10)*

From the results of the above statement, it can be concluded that the participants are not confident and feel ashamed of their current body condition due to changes in body and skin condition after being diagnosed with leprosy.

##### b. Pride

The negative self-assessment conducted by the participant arises after seeing the condition of his health which has deteriorated due to suffering from leprosy. The following participant statements support this category:

*"I feel ashamed to meet new people and neighbours because of my body" (P5) (P7) (P10)*

From the results of the statement above, it can be concluded that the participants experienced a decrease in self-assessment since leprosy was affected as well as difficulty assessing themselves positively with the current health condition.

## DISCUSSION

This research explores the psychosocial aspects of leprosy sufferers. The results of this study indicate that lepers suffer from problems in the psychosocial aspects (anxiety, withdrawal, and self-concept disorders)<sup>22</sup>. Disorders in psychosocial aspects will affect the social life of sufferers, work, relationships with family and friends. The same results were obtained in a study conducted by van 't Noordende et al (2020), that people with the neglected tropical disease (NTD) will experience psychosocial problems<sup>17</sup>. Leprosy, which continues to be prevented in East Java, is still experiencing an increase; this is because of the habits of the people who lack the attitude to live clean and healthy. In addition, the lack of

awareness of the community to be open to facilitate data collection and provide further handling.

In this study, there was a self-concept disorder in people affected by leprosy shown by their lack of confidence, feeling ashamed of their condition, and feeling unfit to be in the midst of society<sup>23</sup>. This condition occurs because many of lepers have a disability on their bodies. In line with research that lepers suffer from self-concept disorder, this is shown by the presence of some who feel their ideal, self-identity, and low self-esteem<sup>24</sup>. Research conducted by Moura states that physical abnormalities can cause lepers to feel ashamed and anxious, making it difficult for lepers to live among the people. Barriers in communicating with the surrounding environment make sufferers withdraw from social life<sup>25</sup>.

In leprosy, patients withdraw due to disability, so they choose to remain silent and even choose to be in the house and do not want to be met by anyone<sup>8</sup>. Shyness to mingle and are reluctant to socialize lepers with the environment is a result of disabilities that affect daily activities, and the role of sufferers in the community also decreases<sup>26</sup>. The existence of a disability and decreased ability in daily activities make lepers suffer anxiety<sup>19</sup>. The emergence of worries, insomnia accompanies anxiety experienced by lepers in this study, fear of various frequencies, besides sufferers feel leprosy will result in disability and challenging to treat<sup>27</sup><sup>28</sup>. This is in line with the study of Somar et al. (2020) 10-20% of lepers will experience anxiety<sup>29</sup>. Anxiety experienced by sufferers varies greatly from general anxiety symptoms, obsessive-compulsive disorder (OCD) and panic. Based on research conducted by Li & Wang (2020) found that patients with physical disorders have a large percentage of experiencing anxiety<sup>14</sup>.

The results showed that most of the Responden was a farmer. Farmers are one of the risk factors of infectious leprosy and have a greater risk than other jobs<sup>30</sup>. Farmers and laborers are jobs that require large power, causing physical fatigue and physical stress, not infrequently causing a risk of trauma to the body tissues that can cause damage to the skin and nerve severe tissues. The condition will have an impact on changes in the immune response that can trigger the occurrence of ENL (Erythema Nodosum Leprosum)<sup>3</sup>.

The occurrence of psychosocial problems in people with leprosy is inseparable from the stigmas that arise in the community and the level of community knowledge about leprosy itself. This is reinforced which states that the negative stigma that occurs in lepers is directly proportional to the level of public knowledge. This affects the quality of life of lepers. The quality of life of people affected by leprosy will decrease this is influenced by negative stigma<sup>31</sup>. Handling of psychosocial aspects in people with leprosy needs to be done immediately because it will affect their quality of life<sup>7</sup>.

## CONCLUSION

There is an excellent need for sufferers of Hansen's disease who need comprehensive psychiatric treatment. This study has provided a prevalence rate for psychosocial problems in this group of patients. Social stigma has an important role in persuading psychological disorders in patients with Hansen's disease. The second part of the review shows the subtypes of psychosocial disorders that were found in this patient. for further researchers the early detection and treatment of

psychosocial disorders among these patients was powerful

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