
Psychosocial Experiences in Ex-Leprosy Patients: A Qualitative Study

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ABSTRACT

Ex-leprosy is a leprosy patient who has undergone treatment and is declared cured from the results of a medical examination. The ex-leprosy left a number of psychological and social problems due to disability while suffering from leprosy and community stigma and caused them difficulty in re-socializing with the community. The aim of this study is to identify the psychosocial experiences of ex leprosy in living their social life. Method: This research is a phenomenological descriptive qualitative research method. The number of participants who participated in this study were twelve ex leprosy patients using the technique of purposive sampling. Data collection using in-depth interviews with interview guidelines and field notes then made verbatim and analyzed by the Collaizi method. Results: This study produced six main themes, namely: 1) Social stigma, 2) Support system, 3) Able to do activities, 4) Response to stress, 5) Coping strategies, and 6) Social support. Conclusion: Participants' social activity after recovering from leprosy has increased although there is still a stigma in some communities. Support from family and community is needed as well as good coping mechanisms so that ex leprosy patients can overcome psychosocial problems and emerge adaptive behavior.

Keywords : Psychosocial, Ex-leprosy, Self-acceptance

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BACKGROUND

Leprosy is a disease that is still a trending issue in the world of health. The effects of leprosy are physical disturbances to depression on maladaptive behavior (Singh, 2012; WHO, 2012). Leprosy affects the lives of every individual, family and their community (WHO, 2017). In addition, leprosy is a contagious disease so that it has other impacts in the form of psychological problems due to stigma and discrimination, as well as social and economic impacts due to the disabilities it causes (Depkes RI, 2012). The disability that occurs has an impact on the decrease in self-confidence of lepers so that they feel that they are useless and useful in society, this causes behavior to withdraw from the environment (Budyatna & Leila, 2011).

Psychosocial problems are mild mental disorders which, if left untreated, will lead to serious mental disorders such as depression and social isolation (Yusuf, Fitriyari, & Nihayati, 2015). Feelings of disappointment, fear, shame, insecurity, feeling useless, and fear of being excluded (self-stigma) are psychological problems that arise in leprosy patients. This is reinforced by public opinion (stigma) which causes people with leprosy and their families to be shunned and even ostracized by the community (Kemenkes, 2018). Although currently scientific information about leprosy is easy to obtain, so far the stigma that has emerged about leprosy by the community is still the same, most people consider leprosy to be a contagious disease, curses and sufferers must be exiled (Soedarjatmi, Istiarti, & Widagdo, 2009).

Leprosy sufferers who have completed their treatment series and are declared cured are still assigned the title of leprosy to themselves for life. Based on information obtained from a preliminary study through interviews with nurses holding the Leprosy Program at the Waru Pamekasan Community Health Center, in 2017 there were 21 patients suffering from leprosy with the Pauci bacillary (PB) and multi bacillary (MB) types. In 2018 there were 20 patients who were declared cured (hereinafter referred to as ex leprosy patients), 14 of them were still having difficulty socializing again in the community and 6 patients who were able to socialize again and were well accepted in the community. Supporting factors and psychosocial experiences in ex leprosy patients who can be re-accepted in their specific social environment have not been identified

WHO data (2017) states that Indonesia is currently still in the third rank in the world as the largest contributor to new leprosy sufferers after India and Brazil. Leprosy in Indonesia has achieved elimination, namely reducing the morbidity rate to less than 1 per 10,000 population. However, this disease is still a significant problem, as evidenced by the tendency of an increase in cases of 19,371 cases, besides that it was found that 10.23% had level 2 disabilities, namely disabilities that were visible to the eye, and as many as 11.97% of them were children (WHO, 2012).

The highest number of leprosy sufferers in Indonesia is in the province of East Java in the 2015-2017 period, but has a decrease in cases of 15.95% of the total number of incidents (Kemenkes, 2018). The prevalence of leprosy in East Java is known to be 1.018 people with the diversity between districts / cities of 1.342 people. Meanwhile, in Pamekasan, the prevalence of leprosy is still high, namely 3,105-4,128 people. (Prihantini, 2015). The Pamekasan Health Office stated that in 2017 there were 237 leprosy incidents, while in 2018 there was an increase to 368 cases of leprosy.

The social stigma of leprosy makes the condition of the sufferer's psychosocial development and behavior worse. When a person is diagnosed with leprosy, his normal psychological condition is affected. The negative reactions from family, friends, and the community worsened his declining moral and overall psychological state (Gopal, 2010).

Research on the effects of leprosy patients conducted in Brazil, found that psychological problems and social relationships are the most common aspects after physical health problems in someone suffering from leprosy (Leite, Arunda, & Vasconcelos, 2015). The survey conducted by the ministry of health in five districts in Indonesia (Subang, Malang, Gresik, Gowa, and Bone District) illustrates the discrimination experienced by leprosy sufferers both in the family environment, as well as in public facilities and services, such as being separated from a spouse (divorced), expelled or not accepted at work, rejected in schools, restaurants, places of worship, health services and other public facilities (Depkes RI, 2012).

Leprosy or Morbus Hansen is a chronic disease caused by infection with *Mycobacterium leprae* of the peripheral nerves, skin organs and mucosa of the upper respiratory tract. In the advanced phase this disease can attack other body organs except the central nervous system. When not addressed, it will cause disability in the form of lagophthalmus, claw hands, tissue damage to the fingers and toes. This occurs due to irreversible nerve damage in the face and extremities, motor and sensory (Kosasih, Wisnu, Daili, & Menaldi, 2011). In addition, leprosy is a contagious disease. Leprosy transmission has other impacts in the form of psychological problems due to stigma and discrimination, as well as social and economic impacts due to the disabilities it causes (Depkes RI, 2012). Psychological problems that occur in leprosy patients are anxiety, depression arising from lack of motivation, decreased physical abilities, inability to fulfill one's own needs, loss of roles in family and society as well as anxiety and low self-esteem (Brouwers, van Brakel, & Cornielje, 2011). Meanwhile, leprosy patients who are declared cured leave several psychological and social problems caused by disabilities during leprosy and community stigma. Research on the social acceptance of ex leprosy patients in the Sidoarjo area, East Java states that 65% of the community rejects the presence of ex leprosy patients on the grounds that they feel uncomfortable with their presence and there is community rejection of the participation of ex leprosy patients in events held in the social environment (Lesmana, 2014).

WHO's strategy in handling leprosy is by creating quality services for leprosy patients and reducing the burden of leprosy which is done not only by increasing early case detection but also by reducing disability, stigma and discrimination, as well as social and economic rehabilitation for leprosy patients (WHO, 2017). The Indonesian government has also carried out a leprosy eradication program which aims to reduce the burden of leprosy by reducing disease transmission, preventing disability in all new cases found through proper treatment and care, and eliminating social stigma in society (Kemenkes, 2018). After completing treatment, the ex-leprosy patients hope to be free from the problem of leprosy, namely the stigma and discrimination of the community (Pitakasari, 2012). In an effort to repeat this, the government created a rehabilitation program, namely through the Self-Care Group (KPD) which aims to return ex leprosy patients to be independent, productive and confident people (Kemenkes, 2018). However, in reality, there are still many ex leprosy patients who still experience stigma and discrimination. According to research in 2014, self-acceptance of ex leprosy sufferers has an important role so that they can return to socializing with the community (Oktaviandela, 2014)

The limited study of solving psychosocial problems in the socialization of ex-leprosy in the community led to researchers interested in examining this topic using Transactional theory (stress, appraisal and coping strategy) and self-acceptance theory with a qualitative phenomenological approach

MATERIALS AND METHODS

This study uses a qualitative research design with a phenomenological approach. The purpose of this study is to explore the psychosocial experiences of ex leprosy in socializing in the community. This research was conducted in February to May 2019 in the working area of the Pamekasan District Health Office. The participant must meet the following criteria : 1) Patients who have been diagnosed with leprosy and have undergone MDT treatment and are declared free of leprosy by the doctor, 2) adults (> 26 years old), 3) Able to communicate well. The participants who have fulfilled the inclusion and exclusion criteria, then conducted in-depth interviews using a semi-structured interview guide. Field notes were made during the interview. The interview process was recorded using a voice recorder. The data obtained is then made verbatim and analyzed by the Collaizi method.

Interview data were analyzed using thematic analysis and, research data analysis used a manual system because the vocabulary sorting used by participants had broad meanings and different meanings in each question. The following stages were occurred: 1) Describe the phenomenon under study; 2) Collect a description of the phenomenon through the opinions or statements of participants; 3) Read the entire description of the phenomena that have been submitted by all participants; 4) Reread the transcripts of interviews and quote meaningful statements from all participants; 5) Describe the meaning of significant statements; 6) Organize a continuous collection into the theme group; 7) Write a complete description; 8) Meet the participants to validate the description of the analysis results; and 9) Combine the validation results data into analysis description, to be added to the final description.

This Study has passed the examination of the Faculty of Health Research Ethics Commission of Airlangga University with a Code of ethics 1991-KEPK.

RESULTS

Table 1. Participant's Characteristics (n=12)

Code	Age	Gender	Marital status	Education	Job	Duration of illness (Month)
P1	53	M	Married	SD	Farmer	14
P2	29	M	Single	SMP	Unemployment	16
P3	42	M	Married	SD	Entrepreneur	13
P4	46	M	Married	SD	Entrepreneur	19
P5	39	M	Married	SMA	Trader	18
P6	26	F	Single	SMA	Student	14
P7	40	M	Married	SD	Farmer	14
P8	45	F	Married	SD	Unemployment	13
P9	51	M	Married	-	Farmer	18
P10	47	F	Married	SMA	Unemployment	14
P11	52	M	Married	SD	Entrepreneur	14
P12	49	M	Married	SMA	Farmer	19

P: Participants; M: Male; F: Female

Table 1 explains the participants in this study were 12 people. Based on table 4.1 the ages of the participants ranged from 26 years to 53 years. Most of the male participants, namely 9 people and 3 women. The majority of participants with family status were married and there were 2 participants who were not married. The level of education of the participants varied from not attending high school to high school. The occupations of the participants varied such as farmer, emtreperuner and trader, and only one participant is unemployment.

Table 2. Themes distribution

Themes	Sub-themes	Category
1. Social Stigma	Tupes of stigma	Discrimination Labeling
	Causes of stigma	Physical changes Decrease in function
2. Support system	Source	Family Public Health workers
	Types	Emotional support Instrumental support Informative support
3. Able to do activities	Work	The intensity increases Opening a business
	Physical needs	Mobilization Eating and drinking Rest
	Religious activity	Partners relationships Worship Social religious rituals
4. Response to Stress	Positive emotions	Happy Be grateful Free
	Negative emotions	Disappointed Worried Shame
5. Coping strategy	Problem focus	Confrontative Seeking social support Solving the problem
	Emotional focus	Self control Positive assessment Spiritual
6. Social support	Source	Public Government
	Types	Award support Instrumental support Informative support

Table 2 explains the psychosocial experience of ex leprosy patient in Pamekasan is divided into six major themes, namely: social stigma, support systems, ability to do activities, response to stress, coping strategies, and social support.

DISCUSSION

Theme 1: Social stigma

The first theme is the social stigma felt by the participants while living their daily lives after recovering from leprosy. This stigma is closely related to the perception and information obtained by the community regarding leprosy and the conditions of the participants themselves. Stigma is a common phenomenon and leprosy is often associated as a disease with a high acceptance of stigma (Govindharaj, 2018). Social stigma or public stigma is a part of stigma apart from self-stigma (Arachchi, Kumari, Wickramasinghe,

Kuruppu, & Pramuditha Madhavi, 2017). The social stigma experienced is classified into two, namely discrimination and labeling. Discriminatory treatment felt by participants such as being shunned by neighbors, ignored, and even mistreatment of the participants' children.

The results of the study revealed that the participants had difficulties in socializing in society because they experienced rejection and discrimination. Some participants stated that they are still shunned by some communities and are still considered contagious. This is in accordance with research which explains that the stigma that develops in society related to leprosy causes several problems for lepers themselves, such as being ostracized by the community, being ignored and difficulties in finding employment (Rahayu, 2011)

The causes of social stigma experienced by the participants include physical changes and decreased bodily functions. The physical condition of the ex leprosy patients changed according to whether they did MDT treatment quickly. Complications that arise as a result of physical damage include loss of touch sensation to disability in the extremities. The sooner leprosy cases are found and treated, the less the occurrence of disability.

Theme 2: Support systems

The support system theme has several sub-themes, the first is sources of support. The results of the study revealed that the participants received good support from their families, part of the community, which were their closest neighbors, as well as support from health workers. Family support for participants comes from the nuclear family, namely husband or wife, children and siblings. This is in accordance with the characteristics of the participants who are mostly married. Meanwhile, support from the community comes from the closest neighbors, community leaders such as local kyai, and village officials. Participants also received support from health workers, namely leprosy nurses, health center doctors and village midwives in carrying out daily life after leprosy.

In line with the research facts presented by Susanto et al (2017) that during leprosy and undergoing treatment. Individuals get full support from their own families. As well as interacting with families through discussions about the problems they are experiencing (Singh, 2012). Leprosy sufferers also really need social support from other people, be it from family, neighbors and health workers (Mahardita, Susanto, Wuryaningsih, & Deviantony, 2019). The role of health workers is very important in the welfare of individuals who suffer from disease (Tristiana, Kusnanto, Widyawati, Yusuf, & Fitryasari, 2016).

As people who have had leprosy, they should receive support from the surrounding environment. This is because their physical and mental conditions have not fully adapted to their environment. Family support has an important role because they are the main support group in the participants' lives.

Theme 3: Able to do activities

. The first sub-theme of the theme of being able to do activities is work. The results revealed that most of the participants returned to work after their productivity decreased during illness. They said that when it was declared cured slowly the participants' physical and mental problems recovered, so they could start working again. Participants also revealed that some of them are the head of the family so they have an obligation to support the family. Some of the participants returned to work as before they were sick, such as farmers, others opened other businesses according to the participants' abilities, such as trading and becoming motorcycle taxi drivers.

The results of the study stated that the majority of the participants had jobs as farmers, traders and the private sector. Job characteristics are closely related to changes in

the physical condition of participants after leprosy. The above matter is made clear by the research that the effects of leprosy such as disability that arise become a problem for doing heavy work (Schuller & Jackson., 2010). This condition has an impact on the daily activities of people with leprosy to be disrupted, so that the impact can affect the quality of life of people with leprosy including physical, psychological, social and environmental problems (Nugraheni, 2016). So that the disability that is owned makes heavy work a problem (Schuller & Jackson., 2010). Anticipating the inability to do heavy work, it is explained in research by Sillo et al (2016) that there is a compulsion to leave previous jobs and switch to other jobs that are suitable for their abilities.

Work is a social activity that must be carried out by participants considering that most of the participants are male and act as the head of the family. For ex lepers, working is a process of returning to a normal social life or called reintegration which aims to meet the economic needs of the participants. The term social and economic reintegration is intended to make persons affected by leprosy return to their original social and economic status, or to bring them back to their role in society so that they can live a normal good life, where this can be achieved through rehabilitation measures.

Theme 4: Response to stress

In this theme, it was found that the participants had several emotional responses that emerged when they were declared cured of leprosy. This psychological response theme covers 2 sub-themes, namely, positive emotional reactions and negative emotions.

The first sub-theme is a positive emotional response. The results of the study revealed that when the participants were declared cured of leprosy, the participants expressed their positive feelings. The first positive feelings are joy and happiness. This happiness is due to several reasons, namely because it can be healed and healthy, there is no need to take medicine, can work again, the body returns to health and the family becomes safe again. In addition to feeling happy, most of the participants also expressed gratitude to God for being given health again, their families continued to support them when they were sick and there were officers who were very helpful in the treatment process. Another feeling that arose when participants were declared cured was feeling free. This free feeling arises because the participants feel free from consuming drugs, and are free to do activities without any social obstacles.

Ex-lepers in life experience physical health problems, psychological health problems, social relationship disorders and environmental problems (Tsutsumi et al., 2007). The pressure that is faced by them which continues continuously also gives heavy mental stress, causing another psychological disorder called stress (Anna T. van 't Noordende, Aycheh, & Schippers, 2020). One of the effects of stress on ex leprosy patients is causing anxiety. Anxiety often occurs in lepers by showing tension, anger and worry (Muthuvel et al., 2017). These symptoms arise as a result of psychological pressure caused by disabilities and concerns about stigma in society (Barakat & Zaki, 2020). Emotional distress and anxiety cause ex lepers to experience a decrease in individual independence (Yusuf et al., 2015).

Themes 5 coping strategy

This is a process of participant coping mechanisms through continuous behavioral and cognitive changes in an effort to overcome internal and external demands that tire or exceed individual abilities. In the first sub-theme, coping strategies focus on problems. Coping is done if there is still the possibility of doing something to alleviate stress or in other words to reduce stress by directly dealing with the source of the stress or problem that occurs. Coping that arises includes confrontation, seeking social support and planning

problem solutions. Confrontations carried out by participants were such as reprimanding when someone discriminated against the participants to scolding those who were unkind to them. Another coping that emerges is seeking support, this is indicated by behavior such as asking for support and prayers from religious leaders such as Kyai or Ustadz as well as consulting health workers and Puskesmas. While coping that focuses on the last problem is solving problems such as returning to activities and being neighbors to reduce stigma.

The second sub-theme is coping which focuses on emotions where this is done by participants when they are unable to overcome existing problems and are only able to reduce emotional reactions that arise due to stress. Participants revealed that they used a self-control coping approach such as holding back shame, not thinking too much about the problems at hand and getting used to these problems. In addition, there is also coping using positive judgments such as self-introspection, stating this is destiny, and assuming this sick condition is not a sin, the last coping that arises is spiritual or the participants use their beliefs in religious matters to reduce emotional responses. They pray more, and participate in religious activities as a means of getting closer to God.

The way to deal with stressors positively in people with leprosy is to take advantage of social support from others around the individual (Dako-Gyeke, Asampong, & Oduro, 2017). Every leper expressed the importance of getting social support from others, be it from family, neighbors and health workers (Mahardita et al., 2019). Health workers play an important role in the welfare of individuals who suffer from disease (Tristiana et al., 2016)

Theme 6: Social support

The last theme is the hope of good social support from the community and government for solving problems faced by ex-lepers. Appreciation support includes the need for love, security, self-esteem, a sense of belonging. The need for love is a reflection of the meaning of the need for love that can provide life and psychological peace. The need for security and protection is divided into physical protection and psychological protection. The need for self-esteem and feelings of being valued by others is related to the desire to gain strength and gain achievement, self-confidence and recognition from others (Ardhiyanti, Yuliana, & Megasari, 2014).

Participants also expect the government to provide information support such as education on leprosy so as to reduce the community's stigma against leprosy patients. Other support that was conveyed by the participants was government assistance with materials and employment opportunities for those affected by leprosy, both those who are still on treatment and who have recovered. This is closely related to the economic participants, most of whom work as farmers and private workers. Research by Adhikari et al (2013) explains that the emergence of discrimination and isolation and work restrictions have an impact on increasing the economic burden that is carried. Rejection in the community with work related to food where the head of the community group thinks that leprosy can infect through eating or drinking (Peters et al., 2013). In line with research that explains that leprosy has also been known as an indication of low socioeconomic status, it often affects individuals with lower economic means (Adhikari, Kaehler, Raut, Marahatta, & K Gyanwali, 2014; Tsutsumi et al., 2007)

CONCLUSION

In this study, the following conclusions are obtained 1) Social stigma is the treatment of the community towards ex leprosy which includes discrimination and labeling, 2) The support system is the support obtained by ex lepers amidst the stigma problems

experienced, 3) Being able to do activities is the ability of ex lepers in live daily life, 4) The response to stress is the response of ex lepers to stress caused by the stigma of society, 5) Coping strategies are the mechanisms chosen by ex lepers in dealing with problems caused by stigma so that they can accept their conditions, and 6) Social support is the hope of ex lepers in dealing with problems that arise for leprosy patients

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