

Self-Acceptance Among Leprosy Patients: A Qualitative Exploration of Personal and Social Challenges

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Abstract. Leprosy is a disease that affects physical and psychological aspects, impacting patients' overall psychological well-being. Self-acceptance is one of the factors that can affect their psychological well-being. This study aims to provide an overview of self-acceptance of leprosy patients at Bunda Pembantu Abadi Naob Hospital using a qualitative method with five subjects of leprosy patients that were undergoing treatment at the Hospital with criteria determined by purposive sampling techniques, then identifies three main themes to describe patients' self-acceptance; 1) psychological impact, 2) self-acceptance factors, and 3) treatment challenges. The data were analyzed using thematic analysis techniques. Despite the psychological impacts and treatment challenges, leprosy patients can achieve better self-acceptance through motivation, hospital treatment, religious coping, and social support. In addition, hospitals are encouraged to develop programs that enhance patients' self-acceptance and well-being with promotive and preventive efforts to improve early detection and suppress the transmission widely.

Keywords: *self-acceptance, psychological well-being, leprosy patients*

Abstrak. Kusta merupakan penyakit yang berdampak pada aspek fisik dan psikologis, sehingga memengaruhi kesejahteraan psikologis penderitanya. Penerimaan diri menjadi salah satu faktor penting dalam mendukung kesejahteraan mereka. Penelitian ini bertujuan untuk menggambarkan penerimaan diri pasien kusta di Rumah Sakit Bunda Pembantu Abadi Naob dengan pendekatan kualitatif dan subjek terdiri dari lima pasien yang dipilih melalui teknik purposive sampling, kemudian menghasilkan tiga tema utama yang mendeskripsikan penerimaan diri pada pasien: 1) dampak psikologis, 2) faktor-faktor penerimaan diri, dan 3) tantangan pengobatan. Data dianalisis menggunakan teknik analisis tematik. Meskipun menghadapi dampak psikologis dan tantangan pengobatan, pasien mampu mencapai penerimaan diri yang lebih baik melalui motivasi, perawatan medis, coping agama, dan dukungan sosial. Selain itu, rumah sakit diharapkan untuk mengembangkan program yang menumbuhkan penerimaan diri dan kesejahteraan pasien dengan upaya promotif dan preventif untuk meningkatkan deteksi dini dan menekan penularan secara luas.

Kata kunci: *Penerimaan Diri, Kesejahteraan Psikologis, Pasien Kusta*

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Introduction

Leprosy, also known as Morbus Hansen, is a chronic infectious disease caused by infection with the *Mycobacterium leprae*. This disease has a major affinity for peripheral nerves and skin, and can affect other organs of the body such as the eyes, upper airway mucosa, muscles, bones, and testicles (Kementarian Kesehatan RI, 2020). Transmission of this bacteria can be through the respiratory tract through splashes such as saliva or phlegm that comes out when coughing and sneezing. However, transmission requires close contact over a long period of time with leprosy patients who are not well treated (Siswanto. Asrianti, 2020).

According to World Health Organization (WHO) data, during 2021 there were 140.594 new cases of leprosy that have been reported globally. This figure increased significantly when compared to the previous year of 12.189 cases. Southeast Asia is the region with the highest number of new cases, namely 93.485 cases (WHO, 2023). According to data from the Ministry of Health of the Republic of Indonesia as of January 24, 2022, there were 13.487 cases of leprosy with 7.146 people with new cases. Indonesia is the number 3 contributor to leprosy cases in the world after India and Brazil. According to the Badan Pusat Statistik (BPS), the number of leprosy cases in 2018 recorded by district/city in East Nusa Tenggara Province (NTT) was 476 cases. Based on this data, Timor Tengah Utara Regency contributed as many as 25 cases of leprosy (BPS NTT, 2019).

Leprosy is a chronic infection that can cause disability in the skin, feet, hands, and fingers. Progressive and permanent skin lesions trigger self-isolation both physically and psychologically in leprosy patients. This can cause a negative impression on lepers. The negative impression received will last a lifetime even after undergoing treatment and recovering. Leprosy sufferers will be avoided or shunned

by society and their families because of the assumption that leprosy is a disease caused by curses, uses, sins, and heredity (Arianti & Suwanda, 2020). Therefore, this condition makes it more difficult for lepers to return to society and family.

A person diagnosed with leprosy will feel embarrassed, lose confidence, lose hope, and feel inferior due to the condition experienced (Jainudin & Astuti, 2022). Leprosy patients have awareness and concern about the negative attitudes of society so they tend to withdraw from social life. The inherent stigma makes it difficult for patients and former leprosy patients to carry out their daily activities (Lufianti et al., 2022). According to Rafferty, the stigma against leprosy patients affects disease knowledge and self-acceptance of leprosy patients (Putri et al., 2016). The less stigma society has against leprosy, the greater the self-acceptance of leprosy sufferers (Ertiandani, 2013).

Self-acceptance is a person's ability to accept the entirety of themselves unconditionally regardless of whether they have behaved intelligently, correctly, competently, and whether others approve, respect and love. Unconditional self-acceptance means that the person believes that he or she is valuable regardless of how others perceive him. In addition, the awareness that humans can be guilty and appear imperfect makes a person aware and accept their mistakes and shortcomings (Bernard, 2013).

Self-acceptance is the first dimension that helps leprosy patients achieve other dimensions of psychological well-being, namely positive relationships with others, independence, mastery of the environment, life goals, and personal growth (Jainudin & Astuti, 2022). This shows that high self-acceptance will affect psychological well-being in a positive direction. On the other hand, low self-acceptance can lead to many psychological problems in patients such as stress, anxiety, low self-esteem, lack of motivation to fight the disease as well as poor health management (Merlin et al., 2019). Even though there is a lot of research related to leprosy, most of the research has only focused on clinical conditions and very little research has tried to explore the experience of leprosy patients

psychologically, especially regarding the self-acceptance of leprosy patients. This study aims to find out the overview of self-acceptance of leprosy patients at the Bunda Pembantu Abadi Naob Hospital.

Method

This study uses a qualitative research design. The study has been conducted from April – July 2024 at the Naob Abadi Maid Hospital. The participants in this study are 5 people, namely YM, YS, MRY, NI, and YDT. The study participants were determined using a purposive sampling technique with special criteria, namely leprosy patients who were undergoing treatment at the Bunda Pembantu Abadi Naob Hospital.

Data were collected through semi-structured in-depth interviews. The collected data is then analyzed using thematic analysis methods. This research has received approval from the Research Ethics Commission of the Faculty of Public Health, Nusa Cendana University, with certificate number 2024112-KEPK.

Result

Based on the results of the analysis, there are 3 (three) main themes, which are psychological impact, namely stigma, rejection, and negative feelings about self. Self-acceptance factors that include motivation, hospital treatment, spiritual coping, and social support. Treatment challenges are disease knowledge, misdiagnosis, and alternative treatment.

Table 1.

Psychological Impact

Stigma	Leprosy is a curse
	Leprosy is considered a consequence of mistakes made in the past
Rejection	Unwillingness to accept food or drinks made by leprosy patients

	Restrictions on community participation such as religious activities in churches and other social activities
Negative feelings	Feeling regretful and sad about physical changes
	Feeling different from others
	Feeling scared and worried because of a reaction to leprosy medication

The results of the study revealed various forms of community stigma experienced by leprosy patients at Naob Hospital, namely avoidance of meeting or being physically close to leprosy patients, rejection and doubt of leprosy patients such as unwillingness to accept food or drinks made by leprosy patients, and also restrictions on community participation such as religious activities in churches and other social activities.

Table 2.

Self-acceptance factors

Motivation	Parenting responsibilities
	The need for self-activation
Treatment process at the hospital	Medical treatment in hospitals provides hope for recovery for leprosy patients
	The medical treatment process makes leprosy patients experience many positive changes both physically and psychologically
Religious coping	Leprosy patients see leprosy as a test from God that must be passed

	Leprosy and the treatment process in the hospital are interpreted by leprosy patients as an opportunity to rebuild a more personal relationship with God
Social Support	Family Support
	Peer support among leprosy patients

Faced with the disease experienced, leprosy patients are driven by various factors towards self-acceptance. These factors start from awareness of the existence of the disease, diagnosis, to the treatment process. These factors include the motivation that encourages leprosy patients to survive in life and the treatment process, medical treatment which then becomes a new hope in achieving recovery, the emergence of religious coping or hope and belief in the Almighty help, and support from people around leprosy patients.

Table 3.

Treatment Challenges

Disease knowledge	Low understanding of leprosy
Misdiagnosis	Leprosy is diagnosed as an allergic reaction and diabetes
	Misdiagnosis makes leprosy patients reluctant to seek medical treatment
Alternative medication	Traditional medication
	Cultural influences encourage the belief of leprosy patients in traditional medication

In living life, everyone certainly faces various challenges. Likewise with leprosy patients, in an effort to achieve recovery, there are various challenges faced. The results of the study show that in addition to social responses in the form of

stigma and rejection and other impacts, there are three main challenges faced by leprosy patients in the process of achieving recovery, namely knowledge about the disease experienced, misdiagnosis and the use of alternative medicine that is not scientifically proven to cure leprosy. These challenges along the way affect each other.

Discussion

As a contagious disease, leprosy has an impact on patients or people who have leprosy. The most common impact on leprosy patients is rejection due to stigma related to leprosy which is then followed by various other psychological impacts. Stigma is defined as a negative assessment of society towards a certain thing or behavior (Marpaung et al., 2022). Skin diseases, including leprosy, will attract attention and invite reactions from people around them because skin diseases look different from healthy skin (Astriningrum et al., 2013). This triggered the emergence of stigma and social labels in leprosy patients. Leprosy is often thought of as a curse and a consequence of mistakes made in the past, as stated by NI, MRY, and YS participants. Stigma against leprosy patients encourages the emergence of rejection in society, restrictions on social activities, and various forms of social exclusivity and discrimination. This stigma and treatment have an impact on the social behavior of leprosy patients, namely self-isolation or reluctance to build relationships and communicate with others (Lusli et al., 2015).

Stigma and social rejection coupled with the physical condition experienced by leprosy patients trigger the emergence of various psychological reactions in leprosy patients. Physical changes in leprosy patients are one of the factors that cause various negative psychological reactions such as the emergence of a negative physical self-concept. Like MRY participants who feel regretful and sad about the physical changes they experienced. Meanwhile, according to Morales-Roudrigoez, the concept of the physical self is one of the psychosocial factors of psychological well-being, including self-acceptance (Morales-Rodríguez et al., 2020). The

participant, YS, also stated the same thing and specifically felt different from others because of the changes that occurred in the face. Facial appearance is an important aspect in the perception of body appearance, so facial damage will cause psychopathology, namely feeling less and different from others and loss of confidence (Astriningrum et al., 2013). Berger states that one of the characteristics of self-acceptance is the feeling of equality or feeling no different from others (Denmark, 1973). Furthermore, the physical condition of leprosy patients affects their daily productivity. YM, one of the participants stated that since suffering from leprosy, YM's body has become weaker so it is difficult to do certain jobs. YS and MRY also stated that they must give their parents childcare and family responsibilities during the treatment process. In addition, NI admitted that she was behind people her age economically and educationally because NI had to undergo a healing process. These conditions trigger the appearance of feelings of helplessness in leprosy patients.

The appearance of psychological reactions in the form of negative feelings is also triggered by leprosy reactions in treatment in certain episodes. Leprosy reactions are considered unpredictable and painful (Putri et al., 2022). The leprosy reaction makes the patient feel difficult and worried as conveyed by the YDT participant that he feels worried due to the drug reaction which actually makes his body condition worse. This is also in line with other findings that show that at the time of the reaction, patients express a variety of emotions including confusion, sadness, anxiety, and anger (Putri et al., 2022). Other impacts of the condition experienced by leprosy patients are the inability to imagine the future, loss of hope, and the emergence of thoughts to end life (Marpaung et al., 2022).

Motivation is defined as the goal and reason for a person to do an action. In the treatment process, motivation is an important factor in starting treatment, dealing with complications, and participating in rehabilitation programs (Hosseini et al., 2021). Likewise, for leprosy patients in dealing with diseases and undergoing treatment, leprosy patients are encouraged by various motivations. There are

several reasons that encourage leprosy patients to achieve recovery. First, some duties and responsibilities that must be done. The view that duties and responsibilities are an obligation that must be completed encourages leprosy patients to achieve recovery in order to return to society and carry out these obligations. The research data showed that most participants were encouraged to recover by the responsibility of parenting. This encouragement is based on the existence of a need as in the theory of needs put forward by Abraham Maslow, namely the need for self-actualization or the need to be useful and reliable (Del Castillo, 2021). The need for self-activation is also what then encourages leprosy patients to be able to immediately return to life as before leprosy, namely to be able to work productively.

The treatment process at the hospital is also one of the factors for the self-acceptance of leprosy patients. Treatment provides hope for healing for people undergoing treatment (El-Haddad et al., 2020). After undergoing many efforts, medical treatment in hospitals provides hope for recovery for leprosy patients. The medical treatment process that is undergone makes leprosy patients experience many positive changes both physically and psychologically. These positive changes make leprosy patients feel more enthusiastic about undergoing the treatment process.

In undergoing the treatment process and facing the disease, the spirituality of leprosy patients plays an important role. The results of the study showed that leprosy patients saw the disease as a test from God that had to be passed. This belief fosters hope for healing and religious coping that makes leprosy patients optimistic and able to face the challenges and impacts arising from leprosy. This finding is in line with the results of research conducted by Roger and Hatala who found that religiosity functions as a source of personal hope and coping strategies (Roger & Hatala, 2018). The religiosity of leprosy patients also plays an important role in the process of changing the patient's perspective on themselves. On the other hand, leprosy and the treatment process in the hospital are interpreted by leprosy patients

as an opportunity to rebuild a more personal relationship with God. These findings are in line with other findings that suggest about religiosity as a moderating factor between chronic medical conditions and psychological well-being (Momtaz et al., 2012).

In addition to religious coping, the results of the study show that social support also plays an important role in the process of self-acceptance of leprosy patients. Social support, in this case, social concern is able to improve the self-concept of leprosy patients (Hamim et al., 2020) and good self-concept is closely related to good self-acceptance (Dewanti & Ibrahim, 2019). The results of the study show that social support is able to increase the confidence and expectations of leprosy patients in carrying out the treatment process. Sources of social support for leprosy patients include family support and support between fellow patients.

Family acceptance of the disease experienced by leprosy patients is a source of strength for leprosy patients in living their lives and the treatment process. Family acceptance makes leprosy patients feel strong in living life. In addition, support between fellow patients in the hospital is an important factor that encourages the enthusiasm of leprosy patients in undergoing treatment. Awareness of the need for social support encourages the emergence of support among fellow patients. The presence of fellow patients in hospitals and rehabilitation homes increases the confidence of leprosy patients because they do not feel "alone". The presence of fellow patients in hospitals and rehabilitation homes is a supporting factor for coping efforts because it allows them to exchange information, learn from each other and provide social support to each other according to their treatment and therapy experiences. These findings are also in line with findings on the effectiveness of chronic pain support groups which say that collective coping is able to reduce pain and encourage the group's ability to live better with the disease experienced (Finlay et al., 2018).

Knowledge is one of the factors that affect health behavior (Alves, 2024). Knowledge of the disease will affect the individual's attitude and behavior towards

the person. The results showed that leprosy patients lived in an environment that collectively had a low understanding of leprosy. Low understanding of leprosy in the community affects health-seeking behavior and slows down disease detection (Urgesa et al., 2020). This is in line with the findings of research that shows that at the beginning of the appearance of leprosy symptoms, lepers think that the disease experienced is an ordinary skin problem. In addition to slowing down disease detection, a poor understanding of leprosy also encourages and reinforces stigma against leprosy (Adhikari et al., 2014). To achieve self-acceptance, one needs to have an understanding or knowledge of oneself (Supraktiknya, 1995). Likewise, leprosy patients, on the way to achieving self-acceptance, need to understand themselves, including an understanding of the disease they are experiencing.

In addition to the problem of lack of knowledge about the disease, another challenge faced by lepers is misdiagnosis. Misdiagnosis is one of the problems that occur in many countries in the treatment of leprosy (Chen et al., 2023; Magnaterra et al., 2024; Neves et al., 2021). The study found that the participants had experience several types of misdiagnosis. MRY said he was diagnosed with an allergic reaction. On the other hand, NI said that he had been thought to have experienced diabetes. Misdiagnosis of leprosy will have an impact on inappropriate medical treatment. Study participants said that due to misdiagnosis, the prescribed medication did not make the patient recover. This affects patients' trust in medical treatment and become indifferent to the disease experienced.

Distrust in medical treatment due to misdiagnosis reinforced by a lack of understanding of leprosy makes lepers try alternative treatment methods that have not been scientifically proven to cure leprosy. Study findings show that the experience of misdiagnosis and not recovering after accessing medical health services makes lepers resort to traditional medicine. In addition to the result of misdiagnosis, cultural influences also encourage the belief of leprosy patients in traditional medicine. The belief that illness is the result of mistakes or sins committed in the past also strengthens the belief in traditional medicine and rituals.

This was also found in other research that said that culture is one of the factors that influence leprosy patients to be reluctant to follow a medical leprosy treatment program.

These challenges become problems that slow down the healing process. Slow diagnosis and treatment will worsen the patient's condition, increasing the risk of skin damage and physical disability due to leprosy (Bennett et al., 2008; Sinha et al., 2024). The physical condition of leprosy patients who worsen due to the disease is associated with low self-esteem (Astarani & Minarso, 2017). While self-esteem has a strong correlation with the self-acceptance of leprosy patients, the better the self-acceptance of leprosy patients, the higher the self-esteem of leprosy patients and vice versa (Astarani & Minarso, 2017).

There are several new findings in this study that can certainly enrich knowledge related to self-acceptance of leprosy patients. In several studies on chronic diseases, it was found that peer support is one of the factors that encourage patient self-acceptance, but so far there has been no research that specifically explains support between fellow leprosy patients and self-acceptance in Indonesia. The presence of fellow patients in hospitals and rehabilitation homes makes patients feel not alone and get information support based on the experiences they have gone through and emotional support during the treatment process so that they can accept the situation they are experiencing. Another interesting finding in the study is that the spiritual support and encouragement provided by hospitals encourage religious coping in leprosy patients. The rules and routines of prayer and worship in hospitals grow and improve the spiritual life of patients which also encourages religious coping in the face of leprosy.

Conclusion

Leprosy causes various psychological impacts on leprosy patients, namely the emergence of stigma and rejection followed by negative feelings about themselves. However, various factors encourage leprosy patients to achieve better self-acceptance: motivation, treatment in hospitals, religious coping, and social support. On the other hand, there are several challenges faced by leprosy patients in an effort to achieve recovery, namely lack of knowledge about the disease, misdiagnosis of leprosy and traditional medicine.

Suggestion

Leprosy patients are expected to improve their understanding of the disease and develop adaptive coping strategies such as positive thinking exercises and light physical activities such as exercise. The government is expected to increase efforts to promote and prevent leprosy in order to accelerate early detection. Hospitals in addition to providing medical services also need to consider psychological services and support to leprosy patients.

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