

Research Article

# Analytical Observation: Relationship between the Disability Degree and Life Quality in Leprosy Patient in Lhokseumawe City

Putri Alvina Sofia Adila Nafsiah<sup>1\*</sup>, Rizka Sofia<sup>2</sup>, Mohamad Mimbar Topik<sup>3</sup>

- <sup>1</sup> Medical Study Programme, Faculty of Medicine, Universitas Malikussaleh, Indonesia;  
e-mail : [putrialvinasofia@gmail.com](mailto:putrialvinasofia@gmail.com)
- <sup>2</sup> Departement of Parasitology, Faculty of Medicine, Universitas Malikussaleh, Indonesia;  
e-mail : [drizkasofia@gmail.com](mailto:drizkasofia@gmail.com)
- <sup>3</sup> Departement of Dermatology and Venereology, Faculty of Medicine, Universitas Malikussaleh, Indonesia;  
e-mail : [drmimbar@unimal.ac.id](mailto:drmimbar@unimal.ac.id)
- \* Corresponding Author : [putrialvinasofia@gmail.com](mailto:putrialvinasofia@gmail.com)

**Abstract:** Leprosy can make patients experience loss of sensation in the body and if not treated properly it can cause irreversible disability and reduce the quality of life of patients. The purpose of this study was to analyse the relationship between the level of disability and the quality of life of leprosy patients in Lhokseumawe city. This is an analytical observational designed with cross-sectional study. The sampling technique was total sampling. Data analysis was carried out with the Spearman correlation test. Based on the results of the analysis test, it was found that the p-value ranged from 0.000-0.004 and the r-value ranged from (-0.499)-(-0.765). There is a significant relationship between the level of disability and the quality of life of leprosy patients in each domain item assessed with a significant strength of relationship and negative correlation direction indicating that the higher the level of disability of the patient, the lower the quality of life.

**Keywords:** Dermatovenereology; Disability Degree; Leprosy; Life Quality; Public Health.

## 1. Introduction

Leprosy is an infection caused by *Mycobacterium leprae* that causes chronic granulomatous inflammation of the skin and peripheral nerves, resulting in loss of sensation in the body. The predilection of leprosy is peripheral nerves, but it can also affect the skin, oral mucosa, upper respiratory tract, reticuloendothelial system, eyes, bones, muscles, nose, and testicles, except for the central nervous system (Kang et al. 2019). Loss of sensation in the body is one form of disability experienced by almost all leprosy patients and is irreversible. This is due to the long course of leprosy and lack of awareness about the disease, which leads to delayed early diagnosis and supports the progression of the disease towards physical disability, functional, psychological, and social impairment, and ultimately affects the quality of life of patients. The disabilities experienced by leprosy patients create a negative stigma in society, making it difficult for them to be accepted even after they have been declared cured (Chowdhury and Chakraborty 2017).

Many similar research has been done previously (Menaldi 2018) used mixed methods, namely quantitative method with completion of the Dermatology Life Quality Index (DLQI) questionnaire and qualitative method in the form of in-depth interviews for his research about to evaluate the quality of life of leprosy patients at the skin and venereal disease clinic Dr. Cipto Mangunkusumo Hospital in Jakarta. (Meiningtyas and Hargono 2018) used primary and secondary data to collect data and used the WHOQOL-BREF questionnaire to analyse quality of life and the social support questionnaire to analyse social support. While (Yuliati, Baroya, and Ririanty 2017) collected data using the WHOQOL-BREF questionnaire to assess

Received: December 23, 2025

Revised: January 31, 2025

Accepted: February 15, 2026

Online Available: February 18, 2026

Curr. Ver.: February 18, 2026



Copyright: © 2025 by the authors.

Submitted for possible open

access publication under the

terms and conditions of the

Creative Commons Attribution

(CC BY SA) license

(<https://creativecommons.org/licenses/by-sa/4.0/>)

differences in the quality of life of elderly people living in the community in elderly social services.

The weaknesses for DLQI are: (1) Not Relevant for All Age/Social Groups. Some items, especially those related to work or sexual difficulties, may not be relevant to certain groups, such as the elderly, retirees, or widows/widowers. (2) No Sleep Disorder Domain. The DLQI does not specifically ask about sleep difficulties, even though sleep disorders are often an important factor in the decline in quality of life of patients with skin diseases. (3) Limited Focus on Physical Aspects. This questionnaire focuses more on physical limitations caused by skin conditions and does not delve deeply into psychological (mental) health aspects. (4) Less Sensitive to Mild Diseases. The DLQI is considered inadequate for measuring changes in quality of life in patients with mild skin diseases. For its strength, DLQI is simple and quick to complete. The DLQI consists of only 10 questions covering various aspects of life (symptoms, daily activities, recreation, work/school, personal relationships, and treatment). Patients usually only need 1-2 minutes to complete it. It is also universal for skin diseases. It can be used for various skin conditions, not limited to one type of disease. Besides that, DLQI is easy to interpret. The final score (0-30) provides a clear picture of how much the skin disease affects the patient's life (ranging from "no impact" to "very significant") (Zou et al. 2024).

Meanwhile, WHOQOL-BREF strength includes high validity and reliability. This instrument is internationally recognised, has good internal consistency (Cronbach's alpha > 0.7), and is valid for various clinical conditions and general populations. It also has holistic measurement (4 Domains). It measures four important domains of quality of life simultaneously: physical, psychological, social, and environmental. The WHOQOL-BREF also cross-cultural, available in many languages and adapted to various cultures, including an Indonesian version, making it relevant to local contexts. But WHOQOL-BREF also has its weakness too, for example, it has limited depth of information due to its brevity, this questionnaire is not as detailed as the longer version (WHOQOL-100), so it may not capture the specific nuances of individual experiences (World Health Organization 2022).

Disability is often experienced by the majority of leprosy patients before receiving treatment, due to a lack of awareness and knowledge among patients and their families about early detection of leprosy. The fear of disability and discrimination experienced by patients causes them to change their behavior and try to hide themselves and reduce their social activities in their environment, which ultimately affects their quality of life (Utama 2018). Therefore, the purpose of this study is to analyze the relationship between the level of disability and the quality of life (QoL) of leprosy patients in Lhokseumawe City.

## 2. Literature Review

### Leprosy

Leprosy also known as Hansen's disease, is a chronic granulomatous inflammatory disease caused by *Mycobacterium leprae*, which primarily attacks skin tissue and peripheral nerves (Chalmers et al. 2010). If not treated promptly and appropriately, leprosy can cause disability in sufferers and become an obstacle in living in society and fulfilling their social and economic needs. The risk factors of leprosy includes: Educational level, medication adherence, duration of contact, age, gender, economic conditions (Utama 2018).

### Disability

According to WHO and International Classification of Functioning (ICF) disability is a condition in which there is a limitation in a person's body that makes it difficult for that person to perform certain activities and interact with the world around them. There is three scope, namely: Impairment (which is a decrease in the function of a person's body or mental function. Activity limitation (which is an abstacle in the performance of tasks or actions by an individual). Participation restrictions (which are disturbances in a person's involvement in their social life (Centers and Disease Control for Prevention 2020).

Classification of disability levels in patients leprosy. There are three categories. In level 0 it means the patient do not have any abnormalities and disabilities. In level 1 the patient have nerve damage due to invisible sensory, such as loss of touch sensation in the hands and feet and loss of sensitivity in the eyes. In level 2 disability means visible damage to the eyes, hands or feet (Centers and Disease Control for Prevention 2020).

### Quality of Life

Quality of life is defined by the WHO as an individual's perception of their life and their ability to achieve their life expectations and goals in accordance with the standards that exist

in society wherever they are. Meanwhile, according to the CDC, quality of life focuses more on an individual's perception of their physical and mental condition and its relationship to their health and social support and social status in society (Endarti 2015).

To measure an individual's quality of life, the WHO has developed the WHO Quality of Life (QoL) instrument, which is a shortened version of the WHOQOL-100 and has been translated into various languages. The WHOQOL-BREF instrument consists of 26 questions and covers 4 domains that represent all aspects of life. The four domains are: 1) physical health, consisting of 7 questions; 2) psychological, consisting of 6 questions; 3) social relationships, consisting of 3 questions; and 4) environment, consisting of 8 questions, as well as 2 questions that assess overall quality of life (Resmiya and H.Misbach 2019).

### 3. Proposed Method

This is an analytical observational designed with cross-sectional study approach with clinical ethics clearance issued from the Ethical Commission, Faculty of Medicine at Malikussaleh University in Lhokseumawe, with number 39/KEPK/FKUNIMAL-RSUCM/2023. The data source for this study was primary data obtained through direct interviews with respondents using the WHOQoL-BREF questionnaire. The study was conducted from April to July 2023. The population in this study consisted of all leprosy patients who had been treated at sub-district health centers in Lhokseumawe City, totaling 31 people. The total sample in this study was 31 people same as population. The independent variable in this study was the level of disability of leprosy patients, while the dependent variable was quality of life. Sampling was conducted using total sampling. Data analysis was performed using univariate analysis of the characteristics of the research respondents, the level of disability and quality of life of leprosy patients, and bivariate analysis was performed to see the relationship between the level of disability and the quality of life of leprosy patients using the Spearman's correlation test. The questionnaire used in this study was the World Health Organization Quality of Life (WHOQoL-BREF), which consists of four domains, namely physical health, psychological health, social health, and environmental health. Data analysis in this study was conducted by summing the scores obtained in each domain for each respondent, then transforming them from the raw score table to a scale of 0-100. According to the WHO, the interpretation is as follows: 0–20 for very poor quality of life, 21–40 for poor quality of life, 41–60 for moderate quality of life, 61–80 for good quality of life, and 81–100 for very good quality of life.

### 4. Results and Discussion

#### Characteristics of Leprosy Patients

Table 1. Characteristic of Leprosy patients.

Characteristics	Frequency (n)	Percentage (%)
<b>Age</b>		
0-1 month	0	0,0%
1 month-1 years	0	0,0%
1-12 years	2	6,5%
13-17 years	3	9,6%
18-65 years	22	71,0%
Over 65 years old	4	12,9%
<b>Gender</b>		
Male	19	61,3%
Female	12	38,7%
<b>Marital status</b>		
Married	9	29,0%
Unmarried	22	71,0%
<b>Highest level of education</b>		
Low education	21	67,7%
Higher education	10	32,3%

The characteristics of patients in this study were based on age, gender, marital status, and highest level of education. Table 1 shows that the majority of patients were aged 18-65 years, totaling 22 people (71.0%), the majority of patients were male, totaling 19 people

(61.3%), the majority of respondents were unmarried, namely 22 people (71.0%), and the majority of patients' final education was in the low education category, namely 21 people (67.7%).

These results are in line with the research by (Anastasia Porong, Sahli, and Asrianto 2020), which shows that the characteristics of leprosy patients at the Abepantai Community Health Center are the highest percentage in the 15-45 age group, and research conducted by (Rinawati and Alimansur 2017) on patients in the Inpatient Ward of the Kediri Leprosy Hospital shows that the most common age in this study is 40-65 years. This age is influenced by a person's level of productivity and mobility, which is related to the individual's immune system, which also begins to decline with age. Furthermore, leprosy cases are often found in the young adult age group, partly due to the very long incubation period of leprosy, which causes new leprosy patients to be diagnosed between the ages of 15 and 60 (Anastasia Porong et al. 2020; Fikria 2015; Rinawati and Alimansur 2017).

The frequency distribution based on the gender of respondents in this study shows that cases of leprosy among male respondents are higher than among female respondents. This is in line with the research data presented by (Catrina, Warjiman, and Rusmegawati 2017), which states that men are more likely to engage in strenuous physical activities that cause fatigue and can weaken their immune system, which also puts them at risk of disability due to leprosy-induced numbness (Catrina et al. 2017).

The frequency distribution based on marital status in this study shows that the majority of respondents were unmarried, totaling 22 respondents. Interviews with leprosy patients revealed that unmarried patients either had not married due to fear of being abandoned if their leprosy was discovered, or had been married but divorced after being diagnosed with leprosy. This is in line with the research by (Slamet, Sukandar, and Gondodiputro 2015), which states that marital status cannot be counted as support for a leprosy patient. This is because people suffering from leprosy have excessive fears when diagnosed with leprosy. A husband fears that his wife will not be able to accept his new condition and will not be able to provide for his wife and children. Similarly, if the wife is affected, she fears that she will not be able to fulfill her husband's needs, so the leprosy patient divorces his partner. This is also supported by research by (Noordende et al. 2016), which shows that 3 out of 5 respondents with leprosy faced additional problems when receiving treatment or when they were first diagnosed. Common problems include biological partners refusing to have any sexual relations at all for fear of contracting the disease, creating distance and sometimes even sleeping separately, and in many cases abandoning their partners for fear of contracting leprosy (Noordende et al. 2016).

This study shows that the highest frequency distribution of patient education levels out of a total of 31 cases was 21 patients in the low education category (67.7%). This is in line with (Fahik, Wahjoedi, and Supardi 2014) study, which states that the majority of respondents in his study were in the uneducated and elementary school education groups (81%). Formal education level itself is the intellectual foundation of a person, which is related to the fact that the higher and broader a person's knowledge, the easier it is for them to manage the information provided. While those with a low level of knowledge will find it difficult to prevent disease, due to their low awareness of seeking treatment and difficulty in understanding and following instructions from health workers, causing their leprosy condition to worsen (Fahik et al. 2014).

### Overview of Patient Disability Levels

**Table 2.** Overview of patient disability levels.

Disability levels	Frequency (n)	Percentage (%)
0	10	32,3%
1	15	48,4%
2	6	19,4%
<b>Total</b>	<b>31</b>	<b>100%</b>

The results of this study obtained data on the level of disability experienced by leprosy patients in Lhokseumawe City, with the highest number of patients experiencing level 1 disability, totaling 15 patients (48.4%), followed by 6 patients (19.4%) with level 2 disability. This is in line with research conducted by (Purwanto 2013) on the discovery of new leprosy patients and the level of disability in Lampung, which stated that there were 36 respondents who experienced level 1 and 2 disabilities (9.02%) (Purwanto 2013). These results can also be

used as evaluation material for the Indonesian Minister of Health's regulations for each region regarding leprosy elimination achievement indicators, which show that the existing P2 leprosy program in Aceh has not been successful, where one of the indicators for achieving the P2 leprosy program target is a level 2 disability rate in each region of <5%. The figure of 19.4% for patients with grade 2 disability in Lhokseumawe City means that it is almost four times higher than the tolerance limit of the existing leprosy control program (Kementrian Kesehatan Republik Indonesia 2019).

Previous research on factors associated with the disability rate of leprosy patients at the Lhokseumawe City Health Center in 2016-2020 by (Maulina, Zakiyya, and Mellaratna 2023) stated that there are several factors that contribute to the incidence of leprosy, including productive age, gender, and education. Males are almost twice as likely as females to suffer physical disability due to leprosy. These results are also in line with research by (Henry et al. 2016), which states that level 2 disability is higher in males than in females. This difference is caused by the social behavior of patients and their reluctance to access health services, as well as the fact that men more often ignore the symptoms of leprosy and only seek health services after the disease has progressed to a more advanced stage with worse manifestations (Henry et al. 2016; Maulina et al. 2023).

Education is also one of the factors that determine a person's knowledge. If an individual's knowledge of a disease is high, then that individual will seek treatment for themselves and take steps to prevent the disease. A low level of education results in a delay in seeking treatment and diagnosis of the disease, which can cause the disability of leprosy patients to become more severe (Salju and Muntasir 2018).

### Overview of Patient's Quality of Life

**Table 3.** Overview of patient quality of life.

Quality of life domain	Mean $\pm$ SD
Physical health	50,19 $\pm$ 13,35
Psychological health	38,61 $\pm$ 12,57
Social relationships	38,84 $\pm$ 16,97
Enviromental health	39,65 $\pm$ 9,43

The results of research conducted on leprosy patients in Lhokseumawe City found that the scores for each domain of quality of life for leprosy patients in Lhokseumawe City had a mean $\pm$ SD between 38.61 $\pm$ 12.57 and 50.19 $\pm$ 13.35. This indicates that the quality of life of patients is in the poor category. The lowest average score was in the psychological domain at 38.61 $\pm$ 12.57, followed by the social relations domain at 38.84 $\pm$ 16.97, then the environmental health domain at 39.65 $\pm$ 9.43, and the physical health domain at 50.19 $\pm$ 13.35. showing that the psychological domain is the most significant factor affecting patients' quality of life in this study, followed by the social relations domain, the environmental health domain, and the physical health domain.

The results of the study conducted on leprosy patients in Lhokseumawe City show that the majority of leprosy respondents who were patients in this study described a poor quality of life in each domain assessed. In this study, many patients complained of psychological problems, such as the stigma they received from the community, followed by feelings of shame about their physical condition. Most also complained of living with insufficient money to meet their daily needs. This was compounded by the fact that the majority of patients had a low level of education, which reduced their chances of finding work and lowered their satisfaction with life.

According to the World Health Organization Quality of Life (WHOQoL), quality of life is a person's personal functional condition, including physical health, namely daily activities, rest needs, dependence on medical assistance, sleep anxiety, energy and fatigue, mobility, and work capacity. Psychological health includes positive and negative feelings, physical appearance and image, thinking, learning and concentration, memory and self-esteem, and personal confidence. Social relationships include support from friends and family, environmental conditions, personal relationships, and sexual activity. Environmental conditions include physical safety, freedom, transportation, security, environmental health, financial resources, and social care(Yuliati et al. 2017).

The results of this study are also in line with research conducted by (Savassi et al. 2014) "Quality of life of leprosy sequelae patients living in a former leprosarium under home care".

Based on the results of this study, it was found that leprosy patients have a poor quality of life, particularly in the psychological, physical, and environmental domains. This is due to low values of self-esteem and work ability among leprosy patients, but in the social relations domain, they show a good quality of life. This is in line with another study by (Brouwers et al. 2011), which showed that people with leprosy have a poorer quality of life than healthy people. This is due to self-imposed restrictions on activities, low participation in society, and stigma, which cause sufferers to have a poor quality of life.

Research conducted by (Meiningtyas and Hargono 2018) states that the variables of age, education level, and social support have a significant relationship with the quality of life of leprosy patients at Sumberglagah Hospital in Mojokerto, where leprosy patients who have high social support can improve their quality of life. Research by (Menaldi 2018) on the quality of life of leprosy patients at the skin and venereal disease clinic at Dr. Cipto Mangunkusumo Hospital found that the youth age group had a poorer quality of life (54%) compared to the older age group, and respondents with a final education level of elementary school had a poorer quality of life (60.87%) compared to those with a final education level of bachelor's degree. and by (Geetha, Dhanalakshmi, and Judie 2015) on A Study To Assess the Impact Of Leprosy on Quality of Life Among Leprosy Patients in Government Rehabilitation Home at Paranur showed that 63% of males had a poor quality of life and 74.1% of respondents with a low level of education had a poor quality of life .

**The Relationship Between Degree of Disability and Patient Quality of Life**

**Table 4.** The relationship between degree of disability and patient quality of life physical health domain.

	<b>P value</b>	<b>r-value</b>
Degree of disability Physical health domain	0,000	-0,705

Based on the correlation of Spearman test between the disability degree and life quality of leprosy in Table 4, it was found that the Spearman correlation p-value was 0.000 ( $p < 0.01$ ), which means that  $H_0$  was rejected. Therefore, it can be concluded that there is a significant relationship between disability and the physical domain of quality of life in leprosy patients. The correlation coefficient value obtained was -0.705, indicating that there is a strong relationship between the degree of disability and the physical domain of quality of life in leprosy patients.

**Table 5.** The relationship between degree of disability and patient quality of life psychological health domain.

	<b>P value</b>	<b>r-value</b>
Degree of disability Psychological health domain	0,001	-0,562

Based on the correlation of Spearman test between the disability degree and life quality of leprosy in Table 5, it was found that the Spearman's correlation p-value was 0.001 ( $p < 0.01$ ), which means that  $H_0$  was rejected. Therefore, it can be concluded that there is a significant relationship between disability and the psychological domain of quality of life in leprosy patients. The correlation coefficient value obtained was -0.562, indicating that there is a strong relationship between the degree of disability and the psychological domain of quality of life in leprosy patients. The negative correlation direction means that the higher the degree of disability experienced by leprosy patients, the lower their quality of life.

**Table 1 .** The relationship between degree of disability and quality of life of patients social relationship domain.

	<b>P value</b>	<b>r-value</b>
Degree of disability Social Relationship Domain	0.004	-0.499

Based on the correlation of Spearman test between the disability degree and life quality of leprosy in Table 6, it was found that the Spearman's correlation p-value was 0.004 ( $p < 0.01$ ), which means that  $H_0$  was rejected. Therefore, it can be concluded that there is a significant relationship between disability and the social relations domain of quality of life in leprosy patients. The correlation coefficient value obtained was -0.499, indicating that there is a moderate relationship between the degree of disability and the social relations domain of leprosy patients' quality of life, with a negative correlation direction, meaning that the higher the degree of disability experienced by leprosy patients, the lower their quality of life.

**Table 2 .** The relationship between Disability Level and Quality of Life of Patients in the Environmental Domain.

	P value	r-value
Degree of disability Environmental domain	0.002	-0.528

Based on the correlation of Spearman test between the disability degree and life quality of leprosy in Table 7, it was found that the Spearman correlation p-value was 0.002 ( $p < 0.01$ ), which means that  $H_0$  is rejected. Therefore, it can be concluded that there is a significant relationship between disability and the environmental domain of quality of life in leprosy patients. The correlation coefficient value obtained was -0.528, indicating that there is a strong relationship between the degree of disability and the environmental domain of quality of life of leprosy patients with a negative correlation direction, meaning that the higher the degree of disability experienced by leprosy patients, the lower their quality of life.

The results of this study indicate that the level of disability in leprosy patients strongly influences the decline in their quality of life in three domains, namely the psychological domain, the social relations domain, and the environmental health domain, and correlates with the overall quality of life domain assessed. This is in line with the results of a study by (Govindharaj, Srinivasan, and Darlong 2018) which states that people affected by leprosy with disability have lower average scores in all four domains, where the results of the study show a significant difference in the quality of life of those with disabilities, with lower final scores for people with disabilities (Govindharaj et al. 2018).

Interviews conducted during the study revealed that many leprosy patients lost their confidence to return to work as they did before they contracted leprosy, and the appearance of spots made patients tend to withdraw from their environment. In addition, the disabilities experienced by leprosy patients can also cause them to be ostracized by those around them, including relatives, and ultimately worsen their quality of life.

This study also found patients who had a history of close contact with family members, which was suspected to have contributed to the transmission of leprosy to family members due to close contact within the household. During the interviews, the researchers found a patient who was a child and then discovered signs of numbness on his mother. It was found that the patient had not been taking the medication regularly prescribed by the community health centre. Furthermore, due to a lack of awareness on the part of the patient and their family, as well as the patient's belief that this disease is a curse, the patient did not take preventive measures for their family members.

The patient with leprosy had grade 1 disability, which did not involve physical abnormalities but only sensory disturbances and decreased visual acuity. However, in grade 2 disability, the disability is very visible, both physically in the form of sensory and motor nerve disorders accompanied by decreased visual acuity, so that the most significant factor affecting the quality of life of a leprosy patient is grade 2 disability. This is in line with research conducted by (Utama 2018) on the relationship between disability and quality of life (quality of life) in leprosy patients who are RFT in Babat Jerawat Benowo, Surabaya, which shows that 23 out of 44 leprosy respondents are in the poor quality of life category (52.3%) and 19 out of 32 leprosy patients with grade 2 disability have a poor quality of life (59.4%). The high number of patients with poor quality of life is due to the fact that most of the patients who were respondents experienced disability, making it difficult for them to adapt to their environment and find work. In addition, the tendency of patients to isolate themselves makes it difficult for them to meet their daily needs and improve their quality of life (Utama 2018).

The results of the cross-tabulation of patient interviews show that the quality of life of respondents in the social relations domain is dominated by patients with poor quality of life, namely 15 respondents (48.4%), 7 of whom have a disability level of 1, but the number is still

greater for those with a disability level of 2, namely 4 out of a total of 6 people. The social relations domain itself is described in terms of personal relationships, social support, and sexual activity. In the patients in this study, it was found that only a few received social support from their environment and relatives who were willing to accept their condition after being diagnosed with leprosy. In fact, it was not uncommon for patients to be abandoned by their partners after they were found to have leprosy. The results of this study are in line with the study by (Refitlianti and Isfandiari 2018) on "The relationship between family support and quality of life in leprosy patients with level 2 disability", which found that emotional support was on average low in 51.7% of cases. This is due to the lack of support from those closest to leprosy patients. For people of productive age, the need for close relationships with others, whether through supportive friendships or marriage, must be fulfilled in order for humans to have a better quality of life (Noordende et al. 2016; Refitlianti and Isfandiari 2018).

The results of the cross-tabulation of patient interviews revealed that the quality of life of respondents in the physical health domain was dominated by patients with moderate quality of life, namely 13 respondents (41.9%). The results of interviews with leprosy patients showed that patients did not have much trouble preventing pain caused by leprosy, nor did it prevent them from doing physical activities at home. This was because the spots caused by leprosy were numb, so in general, they did not prevent patients from doing activities due to pain. The physical health domain itself consists of: ability to perform activities in daily life, dependence on medical drugs, energy and fatigue, mobility, discomfort and pain, and quality of rest. Regarding the quality of sleep of patients at the time of the interview, there were slight disturbances in their sleep quality, including frequent waking at night or being unable to close their eyes for hours. This was because patients sometimes felt anxiety in their lives about leprosy and worries about being abandoned or distanced by those closest to them.

This is also related to the results of the cross-tabulation of patient interviews regarding the quality of life of leprosy patients in the psychological domain. The quality of life of leprosy patients in Lhokseumawe City in the psychological domain was mostly in the poor quality of life category, namely 17 people (54.9%), 10 of whom were patients with a disability level of 1 and 3 patients with a disability level of 2 who had poor quality of life, while 3 others had a very poor quality of life. The psychological domain itself covers the following aspects: body shape and appearance, negative emotions, self-esteem, personal beliefs and spirituality, as well as memory, learning, thinking and concentration. Interviews with leprosy patients in Lhokseumawe City revealed that patients had concentration problems due to concerns about their body shape and appearance, as well as the constant fear of being ostracised or gossiped about, which caused them to withdraw from their environment. This is in line with research by (Jufrizal and Nurhasanah 2019) which found that 127 out of 200 respondents experienced negative stigma from the community. This is due to the community's lack of knowledge about the transmission process of leprosy, causing them to be very afraid of contracting the disease (Jufrizal and Nurhasanah 2019). According to (Putra, Mudatsir, and Tahlil 2017), the support provided by the family itself can enable family members to function well with their abilities, thereby improving individual health. Quoted from Friedman et al, there are four types of family support, namely emotional support, appreciation, caring for someone, and providing encouragement to keep moving forward (Putra et al. 2017).

The results of the cross-tabulation of patient interviews indicate that the quality of life of respondents in the environmental health domain is dominated by patients with poor quality of life, amounting to 15 respondents (48.4%). The environmental health domain includes: financial resources, sense of security, physical freedom and comfort, healthy home environment (including water, pollution, traffic, circulation and cleanliness), opportunities to obtain new information and skills, and transportation safety. The results of this study are in line with research by (Kesuma 2015), which states that 14 patients (21.2%) with poor economic conditions suffer from leprosy, which is more than the 8 patients (12.1%) with good economic conditions who suffer from leprosy. The Spearman's correlation test results of the study showed a significance level of 0.002 ( $p < 0.01$ ), indicating that there is a significant relationship between economic conditions and the incidence of leprosy in a person. An individual's personal hygiene, including their primary environment, is also a primary prevention factor against leprosy, as poor personal hygiene can become a breeding ground for leprosy bacteria (Kesuma 2015).

## 5. Conclusion

The conclusion of the research hypothesis test obtained a p-value of 0.000 and an r-value of (-0.705) in the physical health domain, a p-value of 0.001 and an r-value of (-0.562) in the psychological domain, a p-value of 0.004 and an r-value of (-0.499) in the social relations domain, and a p-value of 0.002 and an r-value of (-0.528) in the environmental health domain, which overall means that there is a significant relationship between the level of disability and the quality of life of leprosy patients in each item of the domain assessed with a significant strength of relationship and a negative correlation direction, indicating that the higher the disability of patients, the lower the quality of life of leprosy patients in Lhokseumawe City.

A limitation of this study is the strong negative stigma attached to leprosy patients, who are believed to be afflicted by a curse or to have broken a serious oath. This makes it difficult for patients to open up to researchers during the initial visit for initiation, making it difficult to obtain data about their families or past. In future research, it is hoped that leprosy patients can be better educated that this disease is not a curse, so that they do not need to withdraw and feel ashamed to mingle in society. They should also not refuse to go to the health center for complete treatment because they feel ashamed. Recommendations for future research include continuing to follow up on leprosy patients in Lhokseumawe periodically to see whether the number of patients has increased and whether their quality of life has improved or worsened.

**Author Contributions:** Author one was the lead author of the journal and a researcher who went directly into the field to examine leprosy patients and directly assess their quality of life. Authors 2 and 3 provided guidance and input throughout the research process.

**Funding:** “This research received no external funding”

**Acknowledgments:** The researcher declare gratitude for all the respondents who assisted in the completion of this study, as well as the Faculty of Medicine at Malikussaleh University in Aceh.

**Conflicts of Interest:** “The authors declare no conflict of interest.”

## References

- Anastasia Porong, L. M., Sahli, I. T., & Asrianto. (2020). Karakteristik penderita kusta di Puskesmas Abepantai Kota Jayapura tahun 2020. *Gema Kesehatan*, 12(1), 1–6. <https://doi.org/10.47539/gk.v12i1.126>
- Brouwers, C., van Brakel, W. H., Cornielje, H., Pokhrel, P., Dhakal, K. P., & Banstola, N. (2011). Quality of life, perceived stigma, activity and participation of people with leprosy-related disabilities in South-East Nepal. *Asia Pacific Disability and Rehabilitation Journal*, 22(1), 16–34. <https://doi.org/10.5463/dcid.v22i1.15>
- Catrina, P., Warjiman, & Rusmegawati. (2017). Faktor-faktor yang berhubungan dengan tingkat kecacatan klien kusta. *Jurnal Keperawatan Suaka Insan*, 1(1), 68–80. <https://doi.org/10.20527/dk.v5i1.3634>
- Centers for Disease Control and Prevention. (2020). *Disability and health overview*.
- Chalmers, R., Barker, J., Griffiths, C., Bleiker, T., & Creamer, D. (2010). *Rook's textbook of dermatology* (9th ed., Vol. 1). Blackwell Publishing.
- Chowdhury, S., & Chakraborty, P. P. (2017). Grade 2 disability among leprosy patients: A pilot study from an endemic area of central India. *Journal of Family Medicine and Primary Care*, 6(2), 169–170.
- Endarti, A. T. (2015). Kualitas hidup kesehatan: Konsep, model, dan penggunaan. *Jurnal Ilmiah Kesehatan*, 7(2), 97–108.
- Fahik, A., Wahjoedi, I., & Supardi, F. (2014). Prevalensi kusta pausibasiler dan multibasiler berdasarkan karakteristik kepadatan hunian, riwayat kontak, sosial ekonomi di Kabupaten Belu Provinsi Nusa Tenggara Timur. *Jurnal Kesehatan Masyarakat*, 7(1), 155–160.
- Fikria, I. (2015). *Karakteristik pasien kusta di RSUD Tangerang tahun 2011*.
- Geetha, K., Dhanalakshmi, A., & Judie, A. (2015). A study to assess the impact of leprosy on quality of life among leprosy patients in government rehabilitation home at Paranur. *International Journal of Pharmaceutical and Clinical Research*, 7(6), 466–468.
- Govindharaj, P., Srinivasan, S., & Darlong, J. (2018). Quality of life of people affected with leprosy disability living in Purulia, West Bengal. *International Journal of Health Sciences and Research*, 8(2), 221–225.
- Henry, M., Galan, N., Teasdale, K., Prado, R., Amar, H., Rays, M. S., Roberts, L., Siqueira, P., de Wildt, G., Virmond, M., & Das, P. K. (2016). Factors contributing to the delay in diagnosis and continued transmission of leprosy in Brazil: An explorative, quantitative, questionnaire-based study. *PLoS Neglected Tropical Diseases*, 10(3), 1–12. <https://doi.org/10.1371/journal.pntd.0004542>
- Jufrizal, & Nurhasanah. (2019). Stigma masyarakat pada penderita kusta. *Idea Nursing Journal*, 10(1), 27–31.
- Kang, S., Amagai, M., Bruckner, A. L., Enk, A. H., Margolis, D. J., McMichael, A. J., & Orringer, J. S. (2019). *Fitzpatrick's dermatology* (9th ed., Vol. 1). McGraw-Hill Education.
- Kementerian Kesehatan Republik Indonesia. (2019). *Peraturan Menteri Kesehatan Republik Indonesia Nomor 11 Tahun 2019 tentang penanggulangan kusta*.
- Kesuma, M. B. H. (2015). *Faktor-faktor yang berhubungan dengan kejadian kusta terhadap pasien kusta di RS Dr. Rivai Abdullah Sungaikundur*.
- Maulina, N., Zakiyya, N., & Mellaratna, W. P. (2023). Associated factors with disability levels in leprosy patients at health center working area Lhokseumawe City 2016–2020. 6, 100–108. <https://doi.org/10.31850/makes.v6i1.1956>

- Meiningtyas, D. E., & Hargono, A. (2018). Hubungan faktor demografi dan dukungan sosial dengan kualitas hidup pasien kusta multibasiler pasca multi drug therapy. *The Indonesian Journal of Public Health*, 13(2), 258–268. <https://doi.org/10.20473/ijph.v13i2.2018.258-268>
- Menaldi, S. L. S. W. (2018). Kualitas hidup pasien kusta di poliklinik kulit dan kelamin RS Dr. Cipto Mangunkusumo Jakarta: Kajian terhadap stigma sosial. *Electronic Journal Kedokteran Indonesia*, 6(3), 159–165. <https://doi.org/10.23886/ejki.6.10107>
- Noordende, A. T. van, van Brakel, W. H., Banstola, N., & Dhakal, K. P. (2016). The impact of leprosy on marital relationships and sexual health among married women in Eastern Nepal. *Journal of Tropical Medicine*, 2016, 1–9. <https://doi.org/10.1155/2016/4230235>
- Purwanto, H. (2013). Cara penemuan penderita kusta baru dan tingkat kecacatan di Provinsi Lampung. *Jurnal Kesehatan Lingkungan*, 4(2), 371–380.
- Putra, Y., Mudatsir, & Tahlil, T. (2017). Pengalaman keluarga dalam memberikan dukungan keluarga pada penderita kusta. *Jurnal Ilmu Keperawatan*, 5(2), 28–41.
- Refitianti, A., & Isfandiari, M. A. (2018). Hubungan dukungan keluarga terhadap kualitas hidup penderita kusta kecacatan tingkat 2. *Jurnal Ilmiah Kesehatan Media Husada*, 6(2), 159–174. <https://doi.org/10.33475/jikmh.v6i2.35>
- Resmiya, L., & Misbach, I. H. (2019). Pengembangan alat ukur kualitas hidup Indonesia. *Jurnal Psikologi Insight*, 17(1), 20–31. <https://doi.org/10.21009/plpb.171.04>
- Rinawati, F., & Alimansur, M. (2017). Meningkatkan harga diri pasien kusta dengan terapi kelompok. *Jurnal Ilmu Kesehatan*, 4(2), 59–63. <https://doi.org/10.32831/jik.v4i2.91>
- Salju, E. V., & Muntasir, L. P. R. (2018). Studi faktor-faktor yang berhubungan dengan kejadian penyakit kusta pada wilayah kerja Puskesmas Bakunase Kota Kupang tahun 2017. *Jurnal Info Kesehatan*, 16(2), 197–213. <https://doi.org/10.31965/infokes.Vol16.Iss2.223>
- Savassi, L. C. M., Bogutchi, T. R. S., Lima, A. C. L., & Modena, C. M. (2014). Quality of life of leprosy sequelae patients living in a former leprosarium under home care: Univariate analysis. *Quality of Life Research*, 23(4). <https://doi.org/10.1007/s11136-013-0590-7>
- Slamet, E. S., Sukandar, H., & Gondodiputro, S. (2015). Faktor-faktor yang mempengaruhi quality of life orang yang pernah mengalami kusta di Kabupaten Cirebon.
- Utama, A. P. W. (2018). *Hubungan tingkat kejadian kecacatan dengan kualitas hidup (quality of life) pada penderita kusta yang RFT (release from treatment) di Babat Jerawat Benowo Surabaya*.
- World Health Organization. (2022). *WHOQOL: Measuring quality of life*.
- Yuliati, A., Baroya, N., & Ririanty, M. (2017). Perbedaan kualitas hidup lansia yang tinggal di komunitas dengan di pelayanan sosial lanjut usia. *Jurnal Pustaka Kesehatan*, 2(1), 87–94.
- Zou, Q., Luo, Y., Hao, D., Li, M., & Jihui, C. (2024). Validation and application of the dermatology life quality index score, a modification of the DLQI score, in psoriasis patients. 3, 1–8. <https://doi.org/10.1186/s41043-024-00587-3>