



The Public and Leprosy Patients: A Theoretical Review of Peter L. Berger and Thomas Luckmann Social Construction

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ABSTRACT

The stigma of leprosy can generally be seen from two aspects, namely, self-stigma (such as shame and low self-esteem) and public stigma (such as societal prejudices), which are also related to the restriction of social participation and discrimination. Prejudice or assumptions are further reinforced by the presence of negative labels or stereotypes attached to an individual. The emergence of discriminatory actions is a result of the majority's assumptions or prejudices towards others. These assumptions or prejudices then become a form of differentiation in society. This research utilizes a qualitative method with the social construction approach of Peter L. Berger and Thomas Luckman. Data analysis is conducted in accordance with Berger's social construction theory, where social construction can be understood through the processes of externalization, objectification, and internalization. The results of this research indicate the existence of different constructions by each individual based on their level of information and experience. Firstly, society constructs leprosy patients as individuals cursed. Secondly, leprosy patients are constructed as sufferers of hereditary diseases. Thirdly, leprosy patients are constructed as sufferers of a highly contagious and dangerous disease. Fourthly, society constructs leprosy patients as individuals with a curable contagious disease.

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1. INTRODUCTION

Health and illness are biopsychosocial conditions integrated into human life. The concept of illness is related to three concepts in English, namely disease, illness, and sickness. Disease refers to a deviation whose symptoms are known through medical diagnosis. Illness is a psychological concept that refers to an individual's feelings, perceptions, or subjective experiences of their unwellness or the discomfort they feel in their body; this is an individualized experience. Meanwhile, sickness is a sociological concept that signifies the social acceptance of an individual as someone currently experiencing pain [1].

The last week of January is designated as the observance of World Leprosy Day, aiming to change public perceptions towards leprosy [2]. Leprosy remains a global health concern as it is one of the most feared infectious diseases by society. Leprosy is a chronic infectious disease that, if left untreated, leads to physical, psychological, and social disabilities [3]. Individuals suffering from leprosy and have experienced disabilities often face social stigma. Stigma is a social phenomenon that occurs when someone is labeled, stereotyped, and subjected to discrimination [4]. In this case, leprosy stigma can be defined as the negative characteristics attributed by a group of people to individuals affected by leprosy, and/or their families.

The stigmatization of leprosy can generally be observed from two aspects, namely, self-stigma (such as shame and low self-esteem) and public stigma (such as societal prejudices), which are also associated with the restriction of social participation and discrimination [5]. Leprosy stigma leads to the isolation of the

patients and even their families from society. Leprosy sufferers become marginalized, not accepted in their surroundings. Their social lives are hindered, and many even face rejection from their families, being abandoned by their partners.

Prejudice or assumptions are further strengthened by the presence of negative labels or stereotypes attached to an individual. Negative labels are often based on differing facts leading to similar patterns, thus, we tend to generalize someone based on their group. An individual acquires these negative labels or prejudices through the social influences occurring in society, neighbors, family, parents, school, media, and others [6].

Discrimination is a differential treatment carried out by an individual or a specific group to gain rights and services in society based on factors such as social class, skin color, ethnicity, religion, tribe, gender, nationality, and others. The emergence of discriminatory actions is a result of the assumptions or prejudices of an individual or majority group towards others. These assumptions or prejudices then become a form of differentiation in society. This difference stems from the fact that, as social beings, we naturally tend to associate with those who share commonalities with us. Prejudice often arises from ignorance, indifference, or excessive fear of these differences [7].

Leprosy has been known to humanity throughout history as a frightening disease due to the physical disabilities it causes. This is also explained in the Old Testament in Leviticus XIII-XIV, where leprosy is described as something unclean and a curse from God. As a consequence, the follow-up action is to cast out leprosy sufferers and not allow them to mingle with the community [8]. Erroneous societal beliefs about leprosy have contributed to unresolved issues related to the disease up to the present. These issues are not only experienced by individuals still afflicted by leprosy, but persist even after they have been declared cured, often leaving visible physical disabilities. These visible physical disabilities make it difficult for leprosy patients to escape societal discrimination. Ultimately, individuals cured of leprosy continue to face discriminatory actions from society, despite being declared healed by medical authorities and being non-contagious.

In Indonesia, leprosy patients are scattered across various regions. Deputy Minister of Health Dante stated in his address that there are currently 6 provinces that have not yet achieved leprosy elimination in Indonesia. The six provinces that have not yet reached the leprosy elimination target include North Sulawesi, Gorontalo, Maluku, North Maluku, Papua, and West Papua. Based on data compiled by the Ministry of Health as of January 24, 2022, the recorded number of registered leprosy cases is 13,487, with 7,146 new cases discovered. He mentioned that the prevalence of leprosy in these six provinces is still more than 1 per 10,000 population, meaning there is one leprosy patient for every 10,000 people in those areas [9]. Currently, the central government and local governments are making various efforts to eradicate leprosy for a leprosy-free Indonesia. However, the negative stigma and discrimination frequently exhibited by communities in various regions towards leprosy patients often hinder the early detection of cases. One such example is in Sampang Regency, which has the highest number of leprosy patients in East Java. The Sampang District Health Office acknowledges the challenges in preventing leprosy due to the prevailing negative stigma within the local community toward the disease.

The negative perceptions lead to leprosy patients being rejected and ignored by society, often experiencing isolation, losing their jobs, and becoming socially marginalized. As a result, some leprosy sufferers hide and avoid seeking treatment out of fear of being known by others. Thus, societal views become a crucial factor in efforts to eradicate leprosy in that area. The social construction theory proposed by Peter L. Berger and Thomas Luckmann serves as a reference to explore how social constructions can be formed. Everyday life holds and provides realities, as well as knowledge guiding daily behaviors. Daily life presents an objective reality interpreted by individuals or having subjective meanings. Thus, individuals become determinants in the socially constructed world based on their will. Individuals play a role as both creative production and reproduction media in constructing their social world.

Berger [10] They refer to it as the process of externalization, objectivation, and internalization. Externalization is the adaptation of oneself to the socio-cultural world as a human product. Biologically and socially, humans continue to grow and develop; hence, they continuously learn and work to build their survival. Externalization is the continuous pouring of human self into the world, both in physical and mental activities. Anthropologically, it is a necessity-humans always project themselves into the places they inhabit. Humans cannot be understood as isolated from their external world.

Berger and Luckmann's social construction theory-focuses on studying the relationship between human thought and the social context where those thoughts arise and develop. According to Peter L. Berger, the goal of social construction theory is to redefine the understanding of reality and knowledge within a social context. In this regard, sociological theory must be capable of providing an understanding that societal life is continually constructed. Everyday social phenomena in society are always a process that continues through the experiences of the community. Social reality is found in social influences manifested in actions.

2. RESEARCH METHODS

This research employs a qualitative research method with the aim of enabling the researcher to comprehend the phenomena experienced by the research subjects, such as behavior, perceptions, motivations, actions, and more. The qualitative method is utilized to obtain in-depth data, data that carries meaning. Meaningful data is the actual, certain data, representing a value behind the apparent data [11]. This research utilizes the social construction data analysis technique that aligns with the theories of Peter L. Berger and Thomas Luckman, involving the identification of externalization, objectivation, and internalization. In explaining the constructivist paradigm, social reality is seen as a social construction created by individuals. Individuals are free beings engaged in relationships with each other. Individuals play a determining role in the socially constructed world based on their will. Individuals are not victims of social facts but serve as creative media for both production and reproduction in constructing their social world [12].

3. RESULTS AND DISCUSSION

Understanding the Dialectics of Externalization, Objectivation, and Internalization

In an effort to understand the societal social construction towards leprosy patients, the researcher analyzes using the social construction theory proposed by Berger and Luckman. Everyday life stores and provides realities as well as knowledge guiding daily behaviors. This daily life presents an objective reality interpreted by individuals or having subjective meanings. Thus, individuals become determinants in the socially constructed world based on their will. Individuals play a role as both creative production and reproduction media in constructing their social world. The term 'social construction of reality' is defined as a social process through actions and interactions where individuals continuously create a reality that is subjectively owned and experienced collectively [13].

Social construction is a process of meaning-making carried out by each individual towards the environment and aspects beyond oneself, namely the subjective meaning of objective reality within the consciousness of individuals engaged in daily life activities. Berger and Luckman emphasize a dialectical view when examining the relationship between humans and society, where humans create society, and likewise, society creates humans, known as the processes of externalization, objectivation, and internalization.

Berger and Luckmann argue that social reality is not an entity that exists independently but is the result of a collective social interaction process performed by individuals in society. Humans actively attribute meaning to their experiences, shaping and maintaining concepts about reality. The process of forming social reality occurs through three stages [14]:

- 1) Externalization: Humans externalize social meanings through their actions and interactions.
- 2) Objectivation: These meanings detach from individuals and become stable objects within society.
- 3) Internalization: Individuals then internalize these meanings as part of their understanding of reality.

Berger and Luckmann's social construction theory-attempts to synthesize implicit social phenomena in three moments and introduces a construction of social reality that, from its origins, is the result of human creation, born from intersubjective interaction. Society is both an objective reality and a subjective reality. As an objective reality, society appears to exist outside of individuals and confronts them. Meanwhile, as a subjective reality, individuals exist within society as an inseparable part. In other words, individuals shape society, and society shapes individuals. Social reality is dual rather than singular, comprising subjective and objective realities. Objective reality exists outside of individuals, while subjective reality exists within them.

The common knowledge passed down through generations in society states that leprosy patients are considered cursed because either they or their families have violated traditional customs, such as engaging in intimate relations on the Prophet's birthday, engaging in daytime intimacy during the month of Ramadan, or engaging in intimacy with a woman who is menstruating.

Although initially accepted and acknowledged by society, not everyone ultimately considers leprosy patients as cursed. Public opinions vary among individuals, influenced by the information and shared experiences each person has with leprosy patients. Some communities still uphold the belief that leprosy patients are cursed, based on factors including the information available to that community.

The parties that contribute to influencing the construction of leprosy patients include; (1) Healthcare institutions, which provide socialization about the understanding and causes of leprosy, as well as its treatment methods; (2) Religious scholars, who deliver lectures on hadiths and the Quran, serving as references related to leprosy patients; (3) Information about leprosy is also obtained by some communities through accessing social media such as television, newspapers, the internet, as well as books or magazines.

Identify the Externalization Process

Externalization is the continuous process of pouring human self into the world, both in physical and mental activities. Anthropologically, it is a necessity that humans always express themselves in the places they inhabit. Humans cannot be understood as closed off from their external world. The process of

externalization in research marks the beginning of understanding social construction. Social construction is built based on discourses, realities, and policies prevalent in society.

In the externalization stage of this research, it is exemplified by the initial perspectives of society on leprosy. The initial viewpoint, known to the entire community, is the inherited information from previous generations stating that leprosy is a cursed disease caused by the patient or their family committing significant sins by violating the customary rules in the community. For instance, engaging in intimate activities on the Prophet Muhammad's birthday or during daylight hours in the month of Ramadan, or having relations with a woman during her menstruation. Since ancient times, the community has believed that if someone contracts leprosy at an old age, they must have violated one of these rules. Similarly, if someone develops leprosy at a young age, it is believed that they bear the sins of their parents who broke these customary rules.

Identify the Objectivation Process

At the stage of cultural objectivation created by humans, it then confronts its creator as something external to it or becomes an objective reality. In this case, humans or societies that create discourse will experience and feel what they themselves discourse. Through this stage, society becomes an objective reality. Objectivation is the result achieved, both mentally and physically, from human externalization activities. The everyday reality is objectivized by humans or understood as objective reality. Objectivation in society includes several elements such as institutions, roles, and identities.

The process of objectivation in this research is the community's view of leprosy patients according to the initial knowledge of the community about leprosy, which then becomes an objective reality. In this process of objectivation, the community's views on leprosy patients may vary, and these views are based on the knowledge and experiences they acquire, where the knowledge and experiences obtained by each individual differ from one another.

At this stage, several similar views were found among the informants, and they were classified into four categories, namely:

- 1) Objectivation of society that views leprosy patients as individuals under a curse.
- 2) Objectivation of society that views leprosy patients as sufferers of hereditary diseases.
- 3) Objectivation of society that views leprosy patients as sufferers of a dangerous contagious disease.
- 4) Objectivation of society that views leprosy patients as individuals with a curable contagious disease

In the first objectivation register, the community that views leprosy patients as cursed individuals belongs to the lower economic class, such as housewives and small traders. At this stage, the community believes that leprosy patients have been cursed, agreeing that they should be isolated to prevent the spread of leprosy to others. This belief is influenced by the fact that the community only receives information about leprosy based on statements that have existed in the community for a long time, stating that leprosy is a curse because the patient has committed a sin by violating prevailing customary rules. In this case, the community has not received medical information about leprosy through socialization from the health center.

The second objectivation is how the community views leprosy as an inherited disease. The middle-class community, including teachers and students, receives access to information about the medical explanation of leprosy. They obtain this information from various social media such as television, newspapers, books, and the internet. The community understands that the cause of leprosy is a bacterium resulting from an unclean lifestyle. In this context, the community no longer considers leprosy patients cursed, but they believe that leprosy is inherited. This belief is influenced by their experiences, as some of them have family members who have suffered from leprosy.

The community of the cleric, who have received health education about the causes of leprosy from healthcare professionals, no longer consider leprosy as a cursed disease. However, the information received is not optimal, so the community still does not fully understand the process of leprosy transmission. The information they obtain is based on the assumptions of the surrounding community regarding leprosy transmission, suggesting that leprosy is highly contagious and should be avoided. Additionally, they refer to a hadith that states, 'If you encounter someone suffering from leprosy, then run away.'

On the other hand, the upper-economic class community, consisting of professionals such as school principals, village heads, and council members, who have a better understanding of the causes, treatment, and transmission of leprosy, obtain information through socialization and various media such as television, newspapers, books, and the internet. This community views leprosy patients as individuals in distress, especially those they know who are mostly from the lower-economic class.

Identify the Internalization Process

The process of internalization is the reabsorption of the objective world into consciousness in such a way that an individual's subjective experience is influenced by the structures of the social world. Internalization is the moment when social reality is drawn into oneself, or social reality becomes subjective reality. Social reality exists within human beings, and through this process, an individual's self is identified

within the socio-cultural world [15].

In the internalization stage of this research, the researcher found that the subjective reality of the community regarding leprosy patients varied for each individual and was influenced by the stages of objectivation they had gone through. Although initially the initial knowledge of all communities was the same, namely that leprosy was a cursed or hereditary disease because the patient or their family was considered to have sinned by violating customary rules, eventually, after going through different stages of objectivation and obtaining various information, each community had different experiences. Therefore, in the internalization stage, different subjective realities were obtained from their initial views on leprosy patients. However, some communities still held onto the belief in the initial reality that leprosy patients were cursed.

New Construction Built in Society

The new constructions built by the community regarding leprosy patients can be categorized into four different constructions, namely:

Leprosy as One Affected by the Curse

The community that constructs leprosy patients as individuals under a curse tends to distance themselves from leprosy patients and their families. The community is indifferent and does not consider the presence of former leprosy patients in their vicinity. They want leprosy patients to be isolated and do not want them to return to their original homes because, even though leprosy patients have recovered, they are perceived no differently from current leprosy patients. This is due to the lack of new information they receive about leprosy. They only acknowledge their initial reality that leprosy is a cursed disease.

The community does not engage in any interaction with leprosy patients and their families. Although they are forced to accept the presence of leprosy patients in their living environment, they still socially isolate leprosy patients and their families. The community does not provide opportunities for leprosy patients to participate in any social activities.

Leprosy sufferers are sufferers of a hereditary disease

Unlike the community that regards leprosy patients as individuals cursed, the community that has received medical information about leprosy from various media such as television, newspapers, and the internet understands that leprosy is a contagious skin disease that can result in permanent disabilities if not promptly treated. However, they also learn that leprosy is not easily transmitted to others. They believe that leprosy patients declared cured cannot spread leprosy bacteria outside their bodies anymore, but they assume that there is a possibility that leprosy bacteria may still be present in the blood of former leprosy patients and could be passed on to their grandchildren later.

The objectivation stage in this case is that the community no longer sees leprosy patients as individuals under a curse, as they believe that a curse only applies when a disease cannot be explained medically. Here, the community perceives leprosy patients as individuals similar to those who are generally ill, needing attention to receive motivation for a quick recovery. In this context, they accept the presence of leprosy patients and interact with them because they realize that leprosy is not easily transmissible, especially if the patient has undergone treatment. However, they are reluctant to marry their children or grandchildren to former leprosy patients or the descendants of leprosy patients because they believe that even though leprosy patients have recovered and will not transmit leprosy to others, there is a possibility that the descendants of former leprosy patients will carry leprosy since birth.

Leprosy Sufferers Are Dangerous Infectious Diseases

The community that constructs leprosy patients as sufferers of a dangerously contagious disease. In the objectivation stage, the community gathers information from various media and socialization provided by health centers that leprosy is a chronic contagious disease caused by a specific bacterium that can develop due to unclean living habits. Here, the community also understands a story from the prophet where his people were cursed for their sins with diseases like leprosy, and a hadith advising to keep away from leprosy patients.

In this context, the community considers leprosy patients as individuals suffering from a dangerous contagious disease. Additionally, they view leprosy patients as very pitiful and repulsive, especially when observing the worsening condition of leprosy patients, experiencing deformities in the hands or feet, as well as white and reddish spots on the patient's body. The community believes that encountering leprosy patients will cause various disturbances within themselves, ranging from feelings of disgust, pity, fear of contagion, and various negative thoughts about leprosy patients.

In the internalization stage, the community ignores the presence of leprosy patients around them, avoiding interaction with them. If they accidentally meet on the street, they maintain a restrained attitude towards leprosy patients and try to ensure that the encounter and conversation do not last long.

Leprosy Sufferers Are Infectious Diseases That Can Be Cured

The community that constructs leprosy patients as sufferers of a curable contagious disease gains initial knowledge about leprosy as a cursed disease from their parents, then acquires information from various media and socialization provided by health centers, as well as information from neighbors and friends who work in healthcare professions. The community becomes aware of the medical truth about leprosy, describing it as a disease caused by a specific germ or bacteria due to poor personal and environmental hygiene. They also know that leprosy is not easily contagious; it requires years of intensive physical contact, and even then, if leprosy patients receive regular treatment, they won't pose a potential risk of transmitting leprosy.

In the objectivation stage, the community views leprosy patients as individuals who need attention and encouragement. They believe that leprosy patients won't easily transmit the disease if they adhere to regular treatment. Moreover, they maintain personal hygiene to avoid contracting the bacteria causing leprosy. Informants feel compassion for leprosy patients, most of whom belong to the lower economic class. Therefore, informants consider it crucial for leprosy patients who have undergone treatment, recovered, and returned to their routines, including earning a living.

In the internalization stage, the community engages in normal interactions with leprosy patients, offering encouragement and support for the patients to have the will to recover. After the patients are declared cured, informants encourage them to continue their work routines and other activities.

4. CONCLUSION

The social construction process of society towards leprosy patients is influenced by several factors, including new information obtained from socialization and various social media, lifestyle guidelines based on a specific understanding, as well as experiences shared with leprosy patients or former leprosy patients. Initially, the community possessed shared initial knowledge, referred to as objective reality, that leprosy is a cursed disease, where the patients or their families are considered to have committed a grave sin by violating prevailing customs. Through the process of objectivation, where the community's view of leprosy patients is influenced by various emerging information, ultimately, the community creates a different subjective reality from the initial reality they understood.

In the end, the community develops a new social construction that differs from the initial construction towards leprosy patients. While some communities still construct leprosy patients similarly to their initial understanding, i.e., that leprosy patients are cursed, three other distinct constructions are identified: leprosy patients as sufferers of an inherited disease, leprosy patients as sufferers of a dangerously contagious disease, and leprosy patients as sufferers of a generally curable contagious disease.

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