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Research Article

Social Acceptance For Leprosy Infants: Case Study of Leprosy Village, in Balang Baru Village in Makassar City

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ABSTRACT

The study delves into societal perceptions and interactions with leprosy-affected individuals in Balang Baru's Leprosy Village, addressing the prevalent negative stigma that shapes their social relationships. While striving for a more inclusive social space, affected individuals often experience alienation, limiting their interactions. Utilizing qualitative methods, including observation, interviews, and documentation, the research focuses on individuals impacted by leprosy, former patients, and the local community. Findings reveal a contrasting dynamic: within Balang Baru, residents view affected individuals as ordinary, fostering acceptance due to shared experiences. However, external societal acceptance remains scarce, hindering their engagement beyond the community. This study underscores the disparities in perception and interaction between internal and external environments. The challenge ahead lies in integrating affected individuals into broader society, necessitating bridging the gap between localized acceptance and the broader societal stigma. Ultimately, the research emphasizes the need to facilitate the inclusion of leprosy-affected individuals in the wider society beyond their immediate community.

Introduction

Leprosy is still widely understood as a severe disease because it can be contagious. Indeed, individuals afflicted with leprosy are frequently subjected to stigmatization and may even be concealed because of the apprehension of transmission. Leprosy patients often exhibit skin irregularities or lesions, including discolored patches and numbness (Sermrittirong, S., & Van Brakel, W. H., 2014), making these patients appear frightening. Individuals lacking knowledge about leprosy often hold the misconception that the disease can be readily transmitted by those affected. However, leprosy is one of the diseases that is not easily transmitted.

According to the World Health Organization (2006), leprosy is one of the oldest, most feared, and most debilitating diseases of humanity. Leprosy is a chronic infectious disease that primarily affects peripheral nerves. Nonetheless, leprosy can impact various body tissues, including the skin, eyes, nose,

and other areas, except for the central nervous system (Ooi, W. W., & Srinivasan, J., 2004).

Leprosy has the potential to result in disabilities, which can hinder leprosy patients from fully integrating into their communities and meeting their socio-economic requirements (Martos-Casado, G., Vives-Cases, C., & Gil-González, D., 2022). Leprosy poses a multifaceted problem in Indonesia, contributing to a complex health issue. The prospect of leprosy-related disabilities frequently results in patients and their families grappling with the acceptance of the disease's reality (Roberts, C. A., 2020).

The presence of groups different from the general population tends to result in exclusion from society (Tamrin et al., 2022). They may even be shunned by their own families. Kopparty (1998) found that leprosy patients are at risk of being disowned by their families because it is undeniable that social stigma affects their family's status in society.

Even after being declared free of the disease and non-contagious by medical professionals, leprosy patients and their families in Jalan Dangko Kota Makassar continue to encounter challenges when it comes to reintegrating into conventional social settings. They must confront a range of societal stigmas. Nevertheless, the disabilities resulting from leprosy give rise to stigmatization and apprehension within the community (Lusli, M., Zweekhorst, M., Miranda-Galarza, B., Peters, R. M., Cummings, S., Seda, F. S., & Bunders, J. F., 2015).

According to Dinos, S., Stevens, S., Serfaty, M., Weich, S., & King, M. (2009), Stigma is a concept associated with feelings of shame, embarrassment, a sense of diminished self-worth, and fear arising from a particular circumstance or characteristic. Leprosy patients tend to hide their disease from both society and their families. Leprosy patients feel very scared and worried about their disease being known. Some patients try to work as if they are not sick. Some limit themselves and withdraw, paying no attention to their environment. In advanced societies, the stigma against leprosy patients is lower (Kalisch, 1972).

They avoid seeking treatment due to shame, which worsens their condition. Psychologically, they are burdened by their disease, compounded by the stigma in society. Their disease tends to result in disabilities, leading to loss of physical ability, self-confidence, and low quality of life, as well as fading social bonds. Stigma against leprosy patients further exacerbates their condition (Ulrich et al., 1993).

The limited empathy of society towards individuals with leprosy has led to the segregation of their living areas and social interactions. Individuals with leprosy and their families, especially their children residing around Jalan Dangko Kota Makassar, have had to make efforts to interact with their surrounding environment. In reality, reluctance towards leprosy is universal (Gussow, 2021).

Social stigma acts as an obstacle for the children of leprosy patients in their integration, causing many of them to remain indoors and have limited interaction with the community. In some cases, it even leads to their non-participation in school due to a sense of isolation (Roberts, C. A., 2020).

The negative social stigma surrounding leprosy must be eliminated. Leprosy is not a curse (Kaur & Van Brakel, 2002), Although the bacteria can spread through the air and through direct contact, leprosy transmission is not easy, and one needs prolonged contact, a dominant genetic factor, and susceptibility of the immune system to be affected by leprosy. Based on the description provided, the research aims to investigate the perceptions, social acceptance, and forms of interaction towards individuals affected by leprosy in the Leprosy Village of Balang Baru sub-district.

METHODS

A case study primarily centers on the examination of a specific instance within an event, which may encompass a tangible entity like an individual, a small group, an organization, or a partnership (Yin, 2003). Through the use of a case study, researchers can acquire current and firsthand data about the subject of inquiry (Ramoni et al., 2017).

This research falls under the category of instrumental case study because it aims to understand issues, problems, concerns, and explore a concept or illustrate a problem (Stake, 1995). The study uses the Kampung Kusta in Kelurahan Balang Baru, Kota Makassar, as the case unit to explore the concept of social acceptance among residents with leprosy. The informant selection in this study adheres to a purposive method, where the groups of informants serving as data sources are identified based on criteria that have been tailored to align with the research goals (Rai, N., & Thapa, B., 2015).

Data sources in this research are categorized into two main types: primary and secondary. Data collection techniques used in this study include interviews, observations, and document analysis. The data analysis technique employed consists of data reduction, data presentation, and conclusions. The data analysis process, according to Creswell (2016) involves efforts to interpret the data. The data analysis technique referred to here encompasses the researcher's efforts to collect data, organize data, manage and synthesize data, as well as to understand and decide on what is conveyed by the informants.

RESULTS AND DISCUSSION Community Perception of Leprosy Patients

Residents living in Kelurahan Balang Baru tend to no longer discriminate against individuals with leprosy. According to some informants, the majority of newcomers who entered the Leprosy Complex Jongaya initially only sought medical treatment. However, some of them felt comfortable after being accepted into the community and eventually decided to settle down. Residents living in the housing complex have never felt uncomfortable with leprosy patients. As a result, some leprosy patients who came from outside Sulawesi Island decided to settle by renting houses from local residents.

Some leprosy patients have adapted well to the community around the complex. Likewise, the surrounding community has responded positively to leprosy patients. They live like the general population, supporting and caring for each other. Their relationships break down the widespread assumption in society of the incompatibility between leprosy patients and those around them.

The Balang Baru community does not view leprosy as a curse or as highly contagious as many outsiders do. Consequently, the relationship between the community and leprosy patients is good. This is evidenced by the community's ease in socializing, providing rental services, living with leprosy patients, and even marrying the children of former leprosy patients. However, there have been no cases of leprosy transmission to spouses or children so far.

The shift in the community's mindset about leprosy is not independent of various actors. Those who play a significant role in providing understanding about leprosy to the community include the local government, either through cooperation with institutions or independently. One of the institutions that plays a crucial role in educating the community about leprosy is Permata. Within this institution, several former leprosy patients are actively working to eliminate the stigma and discrimination against leprosy patients. Both former leprosy patients and current leprosy patients are entitled to live and receive good treatment from the community.

The community perceives both former and current leprosy patients as ordinary human beings. They do not see the disease as a divine curse. The disease is also seen as not easily contagious when the community maintains hygiene. Thanks to this understanding, which is socialized by various parties to the community in Kelurahan Balang Baru, leprosy patients in the area do not face exclusion or negative stigma. In fact, some residents even marry into families with former or current leprosy patients.

Beliefs have a strong influence on an individual's perception of those around them (Aloudat et al., 2014). The perception of the surrounding community is influenced by their economic conditions and educational levels (Joseph & Rao, 1999). In this context, it can be understood that the community's perception of their environment still differs from the perception of the general community, especially outside their environment.

Community Acceptance of Leprosy Patients

Based on the results of interviews and observations, it was found that there is a difference in acceptance towards leprosy patients in their ingroup and out-group areas. Below, the author attempts to elaborate on this condition in the analysis of social acceptance.

Acceptance is seen as a problematic obstacle that must be overcome (Van de Poel, 2016). Despite the negative image of leprosy patients, many face rejection. DeWall & Bushman (2011) explain that social rejection is also related to specific desires. In this case, the community hopes to avoid the potential transmission of leprosy from survivors.

Hurlock (1997) defines social acceptance as the selection of an individual as a friend for an activity within a group where that person is a member. This is an index of success used by an individual to play a role in a social group and indicates the degree of liking other group members have to work or play with them. Wolsink (2018) acknowledges social acceptance as a set of dynamic processes and not spontaneous actions.

Another definition is provided by Parker & Asher, (1993), stating that social acceptance is a state where an individual is liked and accepted by other peers in the environment, and this kind of acceptance will create a sense of security. This aligns view that social acceptance is an individual's ability to be respected by other members of the group as a useful social partner (Berk, 2022). This ability includes a willingness to accept others, at least to be patient, calm, friendly, and so on. These

opinions focus more on social acceptance as being accepted by others or group members.

For individuals accepted by others or group members, they will be treated well by those individuals. Palande & Virmond, (2002) found that patients who had received medical treatment were more easily accepted than those who had not. However, they sometimes understand that rejection is a consequence they must accept. Silva, Albuquerque & Antunes (2014) explained that although they are socially excluded, they believe that their isolation is justified.

Rejection is closely related to the stigma leprosy patients face. Stigma among leprosy patients varies; older individuals, especially those without jobs and with low levels of education, are more vulnerable (Kaehler et al., 2015). Arole et al., (2002) found that stigma among leprosy patients is significantly determined by the community they are in. The combination of leprosy, physical limitations, and social stigma leads to limited participation, resulting in disability for leprosy patients and sometimes even begging for some individuals (Rafferty, 2005).

Fundamentally, the psychosocial needs of leprosy patients are the same worldwide. The most basic needs are self-acceptance, social acceptance, and community acceptance (Scott, 2000). Acceptance by society towards leprosy patients varies greatly. According to Wentzel, Jablansky & Scalise (2021), acceptance is also determined by an individual's achievements.

Acceptance is also determined by cultural norms (Volinn, 1983). Additionally, Varkevisser et al. (2009) believe that limited mobility, illiteracy, and low knowledge of leprosy appear to be important sociocultural factors explaining low social acceptance of leprosy patients. According to Gussow (1964), leprosy is one of the greatest challenges, especially for scientists. Therefore, social sciences need to investigate the acceptance process to apply more rigorous and stable methodologies and concepts (Wolsink, 2019).

The most fundamental acceptance is a social mechanism for improving the lives of leprosy patients. Eyanoer (2018) the better the community's acceptance of leprosy patients, the better their quality of life (Brown, 2006; Thilakavathi, 2012), so awareness of leprosy is needed to dispel misunderstandings about its transmission. The

better the social acceptance, the better the chances of leprosy patients improving their economic status (Lenka & Mahapatra, 2016).

Social acceptance is important, but prevention efforts are equally important (Sardana & Khurana, 2020). Leprosy control requires more efforts to create awareness and combat irrational fears that are still largely associated with the disease (Soomro et al., 2013).

Forms of Interaction between Leprosy Patients and the Community

The interaction of leprosy patients is determined by perception, as well as the extent of community acceptance. Based on findings regarding perception and acceptance, there appears to be a difference between perception and acceptance within their internal and external environments. Interaction, according to the researcher, is the most concrete factor to assess the progress of community acceptance of leprosy patients.

Interaction serves as the gateway to the socialization process of leprosy patients. Through interaction, they can feel their self-worth. Sociologically, self-worth is the interpretation of relational practices. According to Vanhalst et al. (2013), self-worth and loneliness mutually influence each other. The interaction between the local community and leprosy patients is harmonious. This is because the people living in the Jongaya complex and those residing around the complex understand that leprosy is not contagious when patients receive regular treatment.

People are no longer afraid to interact with leprosy patients. Leprosy patients are even invited to eat together at various events or community activities. The positive treatment by the community is highly motivating for leprosy patients to recover. This motivation can also enhance their self-awareness and self-esteem. As Leary, Cottrell & Phillips (2001) found, self-esteem is related to the extent to which a person feels accepted by specific individuals in their lives. Conversely, rejection of an individual can minimize their social development and skills (Odom et al., 2006).

The local community and leprosy patients often cooperate, help each other, and participate in various activities together. The community does not exhibit behavior that would hurt the feelings of leprosy patients. They socialize with leprosy patients just like they do with the rest of the

community. Over time, the community has dispelled the negative stigma associated with leprosy as their knowledge has grown.

Leprosy patients report having good interactions with the people in their surroundings. Similarly, the local community responds positively to leprosy patients in the Jongaya leprosy complex. Negative terms used in community conversations have contributed to perpetuating the negative image of patients.

According to Cooley (1983), who emphasizes the role of interaction in the socialization process, an individual's self-concept develops through interactions with others. The self that develops through interactions with others is called the "looking-glass self", which is formed through three stages:

- 1. Leprosy patients imagine how they are seen by others.
- 2. Leprosy patients imagine how others evaluate them.
- 3. How leprosy patients feel as a result of this evaluation.

From the concepts described above, it is clear that the interaction of leprosy patients depends on the role of interaction in the socialization process that occurs in the Jongaya leprosy complex. Acceptance of peers is simple but tends to increase with age in children (Slaughter, Dennis & Pritchard, 2002).

community and leprosy patients complement each other in interacting to create positive socialization. Unhealthy interactions can worsen the condition of leprosy patients. Therefore, to save and heal leprosy patients, the local community plays a crucial role, especially in social acceptance. Ultimately, social acceptance can encourage leprosy patients to engage in activities to meet their needs, just like any other members of society. Raphael et al. (2017) state that the ability to meet basic needs can enhance social acceptance and respect from community members not affected by leprosy.

Survivors of leprosy will be more easily accepted if they can play a social role in their surroundings. They cannot remain passive, accepting their fate and affirming the negative label placed on them (Anthony, Holmes & Wood, 2007).

Through educational activities on leprosy organized by various parties for leprosy patients,

former patients, and the surrounding community, social acceptance of leprosy patients has been influenced positively. Leprosy patients no longer face negative stigma, which increases their confidence and chances of recovery. Reducing stigma activities need to encourage education and health counseling programs (Arachchci et al., 2017). However, stigma reduction needs to be contextualized according to the socio-cultural conditions of each area. Leprosy is highly influenced by the social context in which its patients reside (Leano et al., 2019). Therefore, it is important to develop stigma reduction strategies that are context-specific (Ebenso et al., 2019).

As Ebenso, B. (2007) found, improvements in economic and living conditions influence the social interaction process, resulting in positive attitudes and positive changes. Additionally, family support can enhance participation in community activities. A broad intervention is needed to eliminate the stigma of leprosy and create an atmosphere of acceptance (Kazeem & Adegun, 2011).

The community in Balang Baru no longer isolates leprosy patients but instead shows empathy, making leprosy patients feel valued and respected. Furthermore, social rehabilitation, especially in terms of employment and mobility, is crucial for reducing stigmatization (Lesshafft et al., 2010).

In the end, the Balang Baru community can engage with leprosy patients in various community activities, even leading to marriages. As a result of this treatment, leprosy patients feel optimistic about continuing their lives and are more diligent about treatment. However, their interactions are mostly within their environment, which is influenced by different perceptions.

CONCLUSION

The community, especially in Balang Baru, views leprosy patients as ordinary human beings. This is because they have become accustomed to living alongside and interacting with leprosy patients in their area. Similarly, in terms of social acceptance, there are hardly any issues within their community. However, when interacting with the broader society, the situation is different. Their interactions are more frequent within their internal environment, and they tend to avoid more interactions with the outside world in line with their general perception. Through this research, it can be

concluded that perceptions, acceptance, and interactions differ between the environment where leprosy patients reside and the external environment. Ultimately, the challenge for leprosy patients in the future is when they are present in the broader society outside their community.

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