

# *The Effect of Individual, Family and Environmental Factors on Family Stigma with leprosy*

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**Abstract**—Stigma is assigning a sign or label of a negative undesirable characteristic which is not appropriate for the society. In addition, stigma in the family is resulted from the loss of family support in patients with leprosy (leprosy sufferer), by excluding and hiding them until the cessation of the treatment process. This condition will aggravate the process of early detection of patients with leprosy, self-stigma in patients with leprosy, disability and quality of life of patients and family members. The aim of this study is to analyze the patient, family and environmental factors that influence the family stigma on leprosy.

This study applied cross-sectional design while the study population was families of leprosy patients at six health centers for endemic leprosy in Jombang East Java and represent 49 families of leprosy patients. These samples included 39 families and sampling was with Multi-Stage Random Sampling. The hypotheses were tested by using Chi-Square with  $p$  value  $< 0.05$ . The results found that there were 29 (74.4%) family stigmas occurred, while hypotheses tests obtained from the individual factors included stigma individual, self-concept and disability level of leprosy patient influence on family stigma ( $P = 0.000$ ). Family factors include family support, family coping mechanisms, knowledge and family perception towards leprosy affecting the family stigma ( $P = 0.000$ ), whereas there was no effect of economic status on family stigma ( $P = 0.07$ ) and environmental factors affects the family stigma only as a social stigma ( $P = 0.007$ ) and there is no stigma attached by healthcare providers.

The conclusion is that the individual, family and environmental factors influence the occurrence of family stigma; therefore, the researchers recommend intervention in an attempt to overcome the family stigma attention on individuals, families and the environment.

**Keyword** : Individual, Family, Environment, stigma, leprosy

## I. INTRODUCTION

Leprosy (or Morbus Hansen) is a chronic disease caused by infection with *M. Leprae*, an obligate intracellular nature. It is one of the infectious diseases that pose a very complex problem. The problem is not only in terms of medical treatment, but also extends to social, economic, cultural and psychological areas. [1] Effects of social stigma towards families pose a problem for the family and affect the behavior of the family towards family members who suffer from leprosy. Furthermore, this results in the loss of family support to people with leprosy, exiling or hiding them until the cessation of with the leprosy treatment process as this disease is identified with emerges physical disability. Moreover, this will aggravate the process of early detection in patients with leprosy, their self-stigma, disability and their quality of life and all members of the family. [2] Stigma on leprosy patients may have an effect on all aspects of their life, such as physical impact, psychological, social and economic. [3]

The world's leprosy prevalence fell from more than five million cases in the mid-1980s to less than 200,000 cases in 2015. Treatment by using multidrug therapy (MDT) and the discovery of new cases was a key reduction of leprosy cases in the world. Indonesia is one of the countries with people having a high rate of leprosy disease. Data from the WHO reports, from 2005 through 2014, indicate Indonesia has always been in the third rank in the world after India and Brazil. In 2014, Indonesia had 17,025 new cases of leprosy, while, in 2014, the discovery of new cases of leprosy was 16, 856 cases and the number of second degree disabilities among new cases amounted to 9.37%, or 1.596. [4] Jombang had six endemic areas of leprosy. The highest number of deaths among leprosy patients during the last three years in the work area of Puskesmas Mayangan amounted to 30. In addition, most

patients with leprosy in Puskesmas Mayangan are over 15 years and have wet-type leprosy (multibacillary / MB) [5]. Based on the interview study conducted by researchers in March 1, 2016, data on 30 leprosy patients were obtained: 10% of patients had experience of a physical disability, 30% had psychiatric disorders and 60% had experienced psychosocial effects.

The high level of perceived stigma in the families due to having a member with leprosy increases family stigma and the stigma of society towards the family would cause problems for the family. The families need resources, support and a strong resistance to be able to perform their role in the treatment of families whose members have leprosy and reduce the social stigma to the family, the stigma of the family towards the lepers and self-stigma. The ability of the family in caring for leprosy patients is strongly influenced by patient factors, family factors and health service factors and health policy on the care and treatment of leprosy patients [6], [7]. The purpose of this study was to analyze the occurrence of family stigma and the relationship of individual factors, family factors and environmental factors with family stigma in Jombang.

**II. METHODS**

This study applied cross-sectional design and was conducted in June and July 2017. The study population was a family whose members have leprosy in six health centers with endemics in Jombang East Java, representing 49 families whose members have leprosy and have been diagnosed as a leprosy patient and are listed in the clinic registration data. These samples included 39 families, sampling was with Multi-Stage Random Sampling and the hypotheses were tested by using ChiSquare with pValue-value<0.05. The data collection method used a questionnaire by each family that was a respondent. Each family was represented by family members caring for patients with leprosy living in the family. Topics of assessment included: 1). Individual factors of the leper, 2). Family factors, 3). Environmental factors, and 4). Family stigma. The data collection of individual factors was the family's answers about the level of disability of patients based on WHO standards, patient self-concept, perceived stigma in patients with leprosy, age and gender. The data collection of family factors was their answers about the perceptions and knowledge of the family on leprosy, family economic status, family support, family coping mechanisms and family stigma. Assessment of an environmental factor is a result of the stigma of pengkajina health workers and social stigma against families was done by individual measurements using a questionnaire regarding the internalized stigma of mental illness (Seismic) scale [8]. Measurement instruments of stigma were family-based kosep stigma [9], the concept component of stigma and social stigma [6], [7], and the concept of family stigma [2] and modified by the use of explanatory Model Interview catalog (EMIC) stigma scale for community [8], [10] - [12]. The stigma question was about the family stigma towards a family whose members have leprosy. Measurement instruments and stigma among public health officials was based on the stigma concept of Link and Phelan (2001).The question regarding stigma was that felt by

the families from the officers and society towards a family member suffering from leprosy based on their perception. Data analysis was done gradually, including univariate analysis followed by bivariate, descriptive and analytic analysis. Bivariate analysis used frequency distribution while bivariate analysis used chi square test to see if eligible statistically, if it did not qualify the Fisher's Exact Test was used with pValue-value<0.05

**III. RESULT AND DISCUSSION**

*A. Influence of individual factors on the stigma of leprosy patients families*

Table 1 shows data obtained for individual factors that influence the leper's family stigma factors, including the level of disability (p = 0.001), self-concept of patients (p = 0.00) and the perceived stigma of patients (self-stigma) (p = 0.00). Factors of leprosy patients who do not have a relationship with the family stigma factors include age (p = 0.476) and gender (p = 0.693)

TABEL I. INDIVIDUAL, FAMILY AND ENVIRONMENTAL FACTOR OCCURRENCE OF FAMILY STIGMA

Variable	p
Individual factors	
a. Level of disability	0.001
b. Self-concept of patients	0.000
c. Self-stigma	0.000
d. Age	0.476
e. Gender	0.693
Family factors	
a. Families' coping mechanism	0.002
b. Family support	0.001
c. Family Knowledge	0.007
d. Family socioeconomic	0.074
Environmental factors	
a. Stigma by health provider	
b. Stigma by community/society	0.007

The self-concept factor of leprosy patients showed that 30.8% of individuals had a good self-concept and 25.6% had less self-concept of family stigma. Self-stigma variables showed that 56.4% of patients who undergo self-stigma stigmatize families plus people who have a disability with a rate of 51.3% for two stigmatized families. In general, people with leprosy feel inferior, distressed, have fear of the disease and the occurrence of disability, are afraid to face the family and society as acceptance of those less reasonable, so that people with leprosy who hide the pain of the family for their acceptance is less good. They are reluctant to seek treatment because of shame, apathy, and because disability means they cannot be independent so that they are burden to others (so become beggars or vagrants). [1] Self-image and ideal self can help the self-concept of leprosy patients return to the original, and tell the family about the illness early and not wait until the resulting disability, thus reducing family stress in caring for lepers. The research showed that patient and disease factors

influenced the onset of stigma in the family. These factors then caused early detection of leprosy and disability in people with leprosy, a factor masking pain conditions, either by individuals or families, and being too late to get therapy or treatment resulting in many leprosy patients suffering harm or disability which affects the emergence of the stigma [8], [13], [4], [14], [15].

The stigma about patients was not merely obtained from their environment, but also from themselves. In this case, some of the factors that cause internal stigma of self were the knowledge and perceptions of patients regarding the disease, its causes and the effects of leprosy, and social stigma or social groups, especially a stigmatized family or a patient's significant others. The effects of their internal stigma are psychological disorders such as impaired self-concept, fear, and mental disorders, as well as decreasing interest in medication and activities with social groups [11], [15] - [21].

#### *B. Influence of family factors on the occurrence of family stigma*

In Table 1, the data show that family factors that influence on the occurrence of stigma towards leprosy patients are family coping factor ( $p = 0.002$ ), family support ( $p = 0.001$ ), and knowledge of the family ( $p = 0.007$ ). Socioeconomic factors in the family do not have an influence on the family stigma ( $p = 0.074$ )

Family coping mechanisms reveal that 64, 1% the family, focused the stigma on emotional aspects and 10.3% on the problems. This shows that most family coping strategies are negative. This strategy impacts on the inability of the family in adapting towards perceived stigma from the community or society due to the family member with leprosy.

In this case, the internal source of coping consists of the family ability to be cohesive and integrated. Their integration requires control of the subsystem through the bond unity. Indeed, the most successful families in facing their problems were the most frequent integrated families where they had a strong responsibility towards their family member and collective goals.

Other coping resources are capable in modifying the flexibility of the necessity of family role. The family has to possess stress management in order to adapt to stigma; hence the balance in the family to stay awake and stay healthy [22]. In this case, for family supports in families who develop a stigma obtained 61.5% enough support and whole families support was 7.7% less stigmatized.

The high level of perceived stigma in the families due to their members with leprosy increases the internal stigma and problems. Therefore, families need resources, support and motivating their spirit so they are able to perform their role in caring for their members with leprosy and reducing the stigma in the family, family internal stigma and stigma towards the leprosy patient. Encouraging the spirit of the family through functioning of their existence includes three main components, namely: encouraging family value system and beliefs (family belief systems); strengthening the structure and function of the family as a unit or system (organization patterns), strengthening communication patterns and the system of family

strength in solving the problem (communication / problem-solving) [23] - [27]. Knowledge turns the family against leprosy stigma and also affects the family stigma toward their members with leprosy ( $p = 0.007$ ). Knowledge related to families with leprosy include: definition of the disease, the causes, modes of transmission, signs and symptoms, prevention and treatment. Knowledge and perception of the family of a disease or health problems will be a hedge against the emergence of stigma, the treatment process and behavioral health [3], [17], [18], [28] - [32].

#### *C. Influence of environmental factors and family stigma*

Table 1 shows the data found that factors of stigma from the health provider do not happen, while the stigma in society has an influence on the family stigma ( $p = 0.007$ )

The environment factor includes health workers and society. Based on the perception of family towards health providers, it was found that they do not have stigma towards the family and the leprosy patient. However, this study also showed that the stigma attached by the society or community reached 69.2%, which leads on to the perceived stigma towards the leprosy patient formed by their family. Indeed, bad presumptions in society regarding the patient or people with leprosy impacts on their family behavior towards them, such as they do not have a good coping mechanism, which leads to isolating the patient. If they do not have spiritual support, the family will have stress. In addition, bad presumption, unstable family coping and poor spiritual support cause family stress and they seek to obtain traditional medicine or a healer. The family also feels afraid of being expelled by the society, so they try to hide their member who has leprosy from society as well as being afraid of being contaminated [1], [2]. A study in India offered a description about persons with leprosy, stigma and disability in society [34]. In this study, as the family got stressed, they exiled their member with leprosy; hence, they (the person with leprosy) felt hurt and isolated by their own family.

The family is the entry point in the delivery of health services in the community, determining the risk of disruption due to the influence of lifestyle and environment. Meanwhile, the family strength and its involvement increases when a family member needs constant help because of their chronic health problems, such as in patients with leprosy. Healthcare for family members is the ability to take care of the family members from illness and for other family members to avoid becoming infected by the disease, as well as the interdependence between members of the family as a system, and improved family relationships with the environment [22].

#### IV. CONCLUSIONS

The occurrence of family stigma is influenced by various factors, such as individual, disease, family and environment. Meanwhile, age, sex factors, family socioeconomic factors and health workers factor did not affect the occurrence of family stigma of a leprosy patient. Finally, the factors obtained through this study are expected to be a basis in preventing and overcoming the stigma problem using an integrated approach

at the individual, family and community level as well as by policymakers.

### References

- [1] Kemenkes R.I. *Pedoman Nasional Program Pengendalian Penyakit Kusta* (Jakarta, 2012).
- [2] S. Park and KS Park, "Family Stigma: A Concept Analysis," *Asian Nurs. Res. (Korean. Soc. Nurs. Sci.)*, 8, no. 3 (2014): 165-171.
- [3] Rafferty, Joy. "Curing the stigma of leprosy," *Leprosy Review*, 76, no. 2(2005):119-126.
- [4] WHO. "Weekly epidemiological record épidémiologique Releve hebdomadaire," no. 36, pp. 461-476, 2015.
- [5] Dinas Kesehatan Kabupaten Jombang. *Profil Kesehatan Jombang Tahun 2015* (Jombang, 2015).
- [6] Link, B.G. and J.C. Phelan. "Conceptualizing Stigma," *Annual Review of Sociology*,27(2001):363-385,.
- [7] Link, B.G. and J.C. Phelan. "Labeling and stigma," in *Handbook of the Sociology of Mental Health*,2nd ed., ABE Carol S. Aneshensel., Jo C. Phelan., Ed. (New York London: Springer Dordrecht Heidelberg, 2013) 525-541.
- [8] ILEP. *Guidelines to reduce stigma*. London / Amsterdam: The International Federation of Anti-Leprosy Associations (ILEP) and the Netherlands Leprosy Relief (NLR), 2011.
- [9] Goffman, E. *Stigma: Notes on the Management of Spoiled Identity*. (United States of America: Prentice-Hall, Inc. Englewood Cliffs, 1963).
- [10] Weiss, M.G., J. Ramakrishna, and D. Somma. "Health-related stigma: rethinking concepts and interventions." *Psychol. Health Med.*, 11, no. 3, (2006):277-287.
- [11] Rensen, C., S. Bandyopadhyay, P.K. Gopal, and W.H. van Brakel. "Measuring leprosy-related stigma - a pilot study to validate a toolkit of instruments." *Disabil. Rehabil.*, 33, no. 9 (2011):711-719.
- [12] Van Brakel W.. "Measuring health-related stigma-A literature review," *Psychol. Health Med.*, 11, no. 3 (2006P: 307-334.
- [13] Geetha, K. A. Dhanalakshmi, and A. Judie. "A Study to Assess the Impact of Leprosy on Quality of Life Among Patients in Government Leprosy Rehabilitation Home at Paranur," *International Journal of Pharmaceutical and Clinical Research*. 7, no. 6 (2015): 466-468.
- [14] Cross, Hugh, Miriam Heijnders and Miwako Hosoda. *Guidelines to reduce stigma: Guide 3 A roadmap to stigma reduction: an empowerment intervention*. (London / Amsterdam: The International Federation of Anti-Leprosy Associations (ILEP) and the Netherlands Leprosy Relief (NLR), 2011) 1-30.
- [15] Adhikari, Bipin, Nils Kaehler., Robert S. Chapman, Shristi Raut, and Paul Roche. "Factors Affecting the Perceived Stigma in Leprosy Affected Persons in Western Nepal," *Plos One*, 8, no. 6 (2014):2-9.
- [16] Adhikari, Bipin, Nils Kaehler., Shristi Raut., Kapil Gyanwali and Robert Sedwick Chapman. "In Leprosy Stigma: A Qualitative Study Of Leprosy Patients affected At Green Pastures Hospital, Western Region Of Nepal." *Journal of Health Research*, 27, no. 5 (2013): 295-300.
- [17] Stephen, T., I. Selvaraj, and P.J. Parameswari. "Assessment of Knowledge, Attitude and Practice about leprosy among Patients and their families in a rural community in Tamil Nadu." *Indian Journal of Leprosy*, 86, no. 1 (2014): 7-14.
- [18] Peters, R.M.H., M. Lusli, B. Miranda-Galarza, W.H. Van Brakel, M.B.M. Zweekhorst, R. Damayanti, F.S.S.E. Seda, and J.F.G. Bunders. "The Meaning of Leprosy and Everyday Experiences: An Exploration in Cirebon, Indonesia." *Journal of Tropical Medicine*. (2013).
- [19] Lusli, M., M,B,M, Zweekhorst, B. Miranda-Galarza, R,M,H, Peters, S. Cummings, F,S,S,E ,Seda, and J,F,G, Bunders, "Dealing with Stigma: Experiences of Persons Affected by Disabilities and Leprosy." *Biomed Research International* , 2015 (2015).
- [20] Livingston, J.D., T. Milne, M.L. Fang, and E. Amari. "The effectiveness of interventions for reducing stigma related to substance use disorders: a systematic review." *Addiction*, 107, no.1 (2011): 39-50.
- [21] Berjot, S. "Stress and Coping with Discrimination and Stigmatization." *Frontiers in Psychology*, 2(2011): 1-13,.
- [22] Friedman, Marilyn, R., Vicky R. Bowden, and Elaine Jones. *Family Nursing: Research, Theory, And Practice*. 5th ed. (New Jersey: Prentice Hall, 2003).
- [23] Walsh, F. "Family resilience: A framework for clinical practice," *Fam. Process*, 42, no. 1 (2003): 1-18.
- [24] Walsh, F."Strengthening family resilience,2nd ed. (Guildford Press, 2006).
- [25] Walsh, F. *Spiritual Resource In Family Therapy*, 2nd ed. New York/London: Guildford Press, 2009).
- [26] Black, K., and M. Lobo. "Family Resilience Factors." *J. Fam. Nurs.*, 14, no. 1 (2008): 33-55.
- [27] Walsh, F. "Community-Based Practice Applications of a Family Resilience Framework" in *Handbook of Family Resilience*, ed D.S. Becvar (New York: Springer Science + Business Media, 2013), 65-82.
- [28] Wong, M.L. "Guest Editorial Programs Designing To Address Stigma in Leprosy: Issues and Challenges." *Global Health Governance*, 15, no. 2 (2004): 3-12.
- [29] Garbin, C.A.S., A.S.A. Garbin, M.E.O.G. Carloni, T.A.S. Rovida, and R.J. Martins. "The stigma and prejudice of leprosy: Influence on the human condition." *Rev. Soc. Bras. Med. Trop.*, 48, no. 2 (2015):194-201.
- [30] WHO. *Guidelines for strengthening participation of persons affected by leprosy in leprosy services*. (Geneva: WHO Publications, 2011).
- [31] Peters, R.M.H., M.E. Hofker, W.H. Van Brakel, and B.M. Marjolein. "Narratives Around concealment and Agency for Stigma- reduction: A Study of Women Affected by Leprosy in Cirebon District, Indonesia." *www.dcidj.org*, 25, no. 4 (2014): 5-21.
- [32] Maury, M., and P. Saunderson, "Social stigma: a comparative qualitative study of integrated and vertical approaches to leprosy care." *Leprosy Review*, 22, no.2.(2002): 186-196.

- [33] Pusat Data dan Informasi Kementerian Kesehatan RI. *Infodatin\_Kusta.Pdf*, (Jakarta, 2015).
- [34] Barrett, R. "Self-mortification and the stigma of Leprosy in Northern India." *Publ. information Med. Anthropol. Q.*, 19, no. 2 (2005): 216-30.