

Socio-Cultural Factors in Family Independence Prevent the Transmission of Leprosy in Sampang, Madura Island

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Abstract

Introduction: Leprosy is an infectious disease that causes various problems, not only in medical terms but also extends to social, economic, cultural, security and social security issues. Efforts made to break the chain of transmission of leprosy cases focus more on individuals who have not focused on families that have a high transmission chain.

Purpose: The research aims to explore the social factors of social and cultural factors in influencing family independence in preventing transmission of leprosy, describing the independence of the family in preventing transmission of leprosy, then compiled an example of a culture-based family independence program model for the prevention of leprosy transmission in Sampang with a theoretical approach used namely Family Centered Nursing and the theory of Transcultural Nursing in the form of modules.

Method: This study uses a qualitative research approach. Data saturation until five participants were obtained who carried out data retrieval in an in-depth interview. Data analysis using the Collaizi analysis method.

Results: Identification found four main themes: ((1) Religious; (2) Social Factors; (3) Economic Factors; and (4) Cultural Value. Conclusions: The description of the independence of families who care for lepers is still influenced by many factors, especially tradition and culture, efforts to break the chain of transmission are also closely related to care efforts that still do not reflect preventive values.

Keywords: *Family Independence, Prevention of Transmission, Transcultural Nursing, Leprosy, Phenomenology Study.*

Introduction

Leprosy is an infectious disease that causes various serious problems that are very complex¹. The efforts cut of transmission of leprosy focused more on individuals or people affected by leprosy. Although, other factors such as families had a high risk of contracting leprosy if they have not been treated optimally². The leprosy transmission risk is higher in one family, because family

members are direct contact with patients every day and last for a long time³.

According to World Health Organization (WHO) in 2014 there were 213,899 new cases with an Incidence Rate (IR) of 3.78 per 100,000 population⁴. Indonesia is country with the third largest number of leprosy cases in the world, is 17,202 new cases with Incidence Rate (IR) of 6.73 per 100,000 population in 2015⁵. East Java is province in Indonesia which has the highest burden of leprosy, the number of new cases in 2015 about 4,013 cases with IR of 10.33 per 100,000 population and 335 cases of new leprosy (8.35%). Sampang in Madura Island as one of the districts in East Java Province which has the second highest prevalence of leprosy cases in Indonesia. Based on the profile of the Sampang District

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Health Office, it was stated that the New Case Detection Rate (NCDR) from 2014 to 2016 showed an increasing trend in cases every year.

Based on the interviews results with 10 leprosy patients, it was found that the first appeared like phlegm or ringworm, so it does not need to be treated. As ordinary skin disease does not need treatment because they are thinking that more often taking medication can poison the body. After learning that the disease suffered is leprosy, they have a stigma from the surrounding community. The existence of a culture that is believed by surrounding community can influence the perception and selection of care undertaken by patients⁶.

Families have ethnic and cultural diversity and have different acceptance of health problems, so that a guideline is needed to intervene in order to avoid cultural shock⁷. Madura's philosophy of obedience, submission and submission to the four main figures in life shows the strong role of parents as role models in the family. While the teacher is a figure in the community including ulama or kyaisabagai figures who can provide family support in caring for family members who experience health problems in a faithful and spiritual way⁸.

Family involvement is needed in helping to prevent transmission, since the family acts as a decision maker to prevent health problems and maintain or improve the health status of family members⁹. The inadequate role of the family is a factor that influences the transmission of leprosy in addition to dropping out from taking medication¹⁰. So that a deeper exploration is needed related to the problems of families with leprosy in which there are socio-cultural influences that can affect family health problems.

Method

The method used in this study is a qualitative research method using a phenomenological approach to explore family-based social and cultural independence towards prevention of leprosy transmission in Sampang district in depth from the subjectivity of participants who are directly involved in providing care to leprosy patients¹¹.

The number of participants in this study was until data saturation was obtained with predetermined inclusion and exclusion criteria. The inclusion criteria are for the nuclear family who live in the same house as leprosy patients and permanent residents in Sampang

regency, while the exclusion criteria are those who are affected by leprosy referred to the hospital or those who move to other regencies. So that there were 15 respondents with a purposive sampling technique¹².

Instruments used in the collection process are using interview guidelines, field notes (recording data obtained during interviews): such as participant and other expressions and recorders or voice recorders in the form of MP3 voice recorders. The validity of the recording device is done by using a test recording the sound of the researcher.

The process of data analysis in this study was carried out using the nine step data interpretation method¹². The method was chosen because the steps of data analysis in Collaizi are quite simple, clear and detailed to be used in this study.

Results

Participants in this study amounted to 15 (fifteen) participants as the main subject, which number corresponds to the saturation results obtained in the field. Fifteen families were interviewed about the independence process carried out while caring for family members who have leprosy to prevent transmission to other family members.

Table 1: Demography Partisipants

Characteristics	Frequency	Percentage
Family Caregiver		
Gender		
Female	6	40
Male	9	60
Marital Status		
Single	3	20
Married	12	80
Age		
Less 45 years	4	27
More 45 tahun	11	73
Education		
No school	2	13
Elementary school	5	33
Junior high school	7	47
Senior high school	1	7

In this study the researchers wanted to explore family-based social and cultural independence in the prevention of leprosy transmission in Sampang district. This study found 4 themes and 10 sub-themes (table 2).

Table 2: Theme and subtheme

No.	Themes	Subthemes
1.	Religious	1. Spiritual
		2. Diseases Views
		3. Cause
2.	Social Factors	1. Medication adherence
		2. Support
		3. Openness related to disease
3.	Economy Factors	1. The cost of needs
		2. The difficulty of access to health services
4.	Cultural Value	1. Discipline of therapy
		2. Course of the disease

Religious: From the religious themes there are three themes were spiritual, disease views and causes. The participants’ spiritual sub-themes was described by participants:

“Used to swell up to five months, after prayers on friday in the mosque” (Participant (P1)).

“Prayer of alone in the room” (P9).

The second sub-theme about the views of disease, along with the participant’s explanation regarding the theme:

“Infectious disease, but I am not clear”(P1-10).

The last sub-theme which was related to the causes of leprosy was presented by the participants :

“It’s like being used by people, cheating on the conditions said the shaman” (P12)

“Yes affected by the disease, he said he was exposed to a disease of the devil” (P7)

Social Factors: This social theme found three sub-themes were stigma, support and openness related to disease. The stigma sub-theme is presented by participants:

“Seeing it sad, every way out, people like not to get close” (P8)

The second sub-theme about support, along with participant’s explanation regarding the theme:

“His friends also comes, to encourage” (P5).

The third sub-theme regarding the openness of the disease is explained by participants:

“This is a disease that is routinely carried out by people, I don’t want all families to know”(P3).

Economic Factors: The theme of economic factors found two sub-themes were the cost of needs and the difficulty of access to health services. The cost of needs sub-theme was describe by partisipants:

“To meet daily needs just barely sir” (P10)

The next sub-theme about the difficulty of accessing health services was explained by participants as follows:

“I once took it to a health center, borrowed a neighbor’s bicycle. But it’s not good if you keep borrowing ”(P8).

Culturel Value: The theme of this cultural value found two sub themes were discipline of therapy and course of the disease. The discipline of therapy was described by participants :

“I was really tired, sir, but I want to get well. So that it continues to carry out this treatment” (P7).

The next sub-theme about course of the disease is explained by the participants:

“This is moving here now, first itchy continues to swell, so now it is like this. When Friday I bring it to prayer, once it is swollen pack, up to five month” (P13).

Discussion

This study similar with previous research has shown that 41% to 94% of patients want their doctors to deal with spiritual problems as a health solution¹³. The participants’ views regarding leprosy are also influenced by the religiosity they have. This is in line with previous research which stated that public knowledge about leprosy greatly influences perceptions, beliefs and attitudes¹⁴. Knowledge of leprosy also has a profound effect on the perceptions, beliefs and attitudes that participants will make to leprosy patients¹⁵. Religious patterns or beliefs about the mechanism of disease are closely related to knowledge, factors of experience and philosophy including religion¹⁶.

Beliefs held by individuals also play a role in choosing the right disease management¹⁶ Participants will believe treatment options according to what is considered right according to trust. Almost all participants chose non-medical treatment as the first treatment option. Most

individuals who have leprosy are advised by groups to undergo traditional medicine¹⁷. Traditional medicine is recognized as more affordable among livelihoods, more diverse and there is no partiality¹⁸. Traditional medicine is chosen because the cause of the disease is mostly due to curses and evil deeds or magic¹⁹. This explanation is similar of Visschedijk's research which states that leprosy control must be carried out more exclusively, especially related to mystical beliefs as one of the causes of leprosy²⁰.

Leprosy provides limitations in social relations. This research is in line with the previous study which stated that patients with leprosy experience an unsympathetic reaction, one of which is the rejection of the community regarding leprosy²¹. This distrust and rejection arises due to trigger stressors, namely the diagnosis of leprosy²². This situation causes the patient to experience social relations disorders in the form of a state of discrimination²³. So that continuous motivation and support for patients with leprosy is needed to have a positive impact on self-acceptance and constructiveness²⁴.

The next picture in the field of economics, which is often one of the crucial things. The existence of economic imbalances causes patients treated by participants to contribute to saving economic needs. This is one of the causes of the difficulty of access to health services. In line with the previous one which explains that health problems in population at risk one of them consists of risk factors that explain related economic problems²⁵.

The guidance of this research is on the concept of transcultural nursing, where the provision of nursing care with a cultural approach is competently carried out from infants to the elderly²⁶. Participants in this study are groups of people who have a strong cultural value in terms of organizing daily life. Culture has a central position related to social contact and spirituality. In the process of prevention, efforts to achieve the first cure need was continue therapy. Patients get the next rare diagnosis of leprosy that needs to be taken, namely undergoing treatment²⁴.

Leprosy is a disease that has a major impact on one's emotions^{27,28}. Previous studies related to leprosy also stated that patients with leprosy experience an unsympathetic reaction, one of them being rejection from the community²¹. This causes the emergence of feelings of sadness, worry, shame and resignation. Not infrequently also the patient becomes closed and chooses to remain silent at home.

Conclusion

Families as care giver who provide complete care still depend closely on the cultural values adopted. This tradition affects other factors such as social, economic and religious. Efforts to break the chain of transmission are also closely related to care efforts that still do not reflect preventive values.

Ethical Clearance: The present study was passed the ethical principal on the ethics committee of the Faculty of Nursing, Universitas Airlangga with certificate number: 1326-KEPK.

Conflict of Interest: None Declared

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