

ORIGINAL ARTICLES

FAMILY CAREGIVER-BASED PREVENTION AMONG AMONG LEPROSY PATIENTS IN SAMPANG DISTRICT

Achmad Ali Basri¹, Rachmat Hargono², Elida Ulfiana³, Merryana Adriani⁴, Retno Indarwati⁵, Setho Hadisuyatmana⁶, Nina Agustina⁷

1,3, 5,6,7 Faculty of Nursing, Universitas Airlangga, Indonesia

2,4 Faculty of Public Health, Universitas Airlangga, Indonesia

* Correspondence: ners.achmad.ali@gmail.com

Abstract

Disease with high stigma, leprosy has a totality effect in patient life. Families are components that a higher risk of contracting leprosy. Purpose of study to get prevention strategies for family caregiver that caring for leprosy patient based on culture in sampang district. A qualitative with phenomenology approach was applied in this study. We conducted the in-depth interview, group discussion forum and expert discussion to explore themes. Using the Collaizi analysis, 15 participants based on the saturation data were selected in this study. The results showed those 2 themes and 4 sub-themes in the study. The first themes such as discipline treatment with sub themes were medication adherence and prohibition during treatment. The second theme such as disease course with sub themes were perceived symptoms and treatment experience. Prevention family caregiver based in culture approach is needed for nurses and family caregiver, improve caring for leprosy patients' ability.

Keywords: Family caregiver, Transcultural Nursing, Leprosy, Phenomenology Study

International Journal of Nursing and Health Services (IJNHS), September 2019, Volume 2, Issue 4; Page 326-333

Received: 10 April 2019; Revised: 15 July 2019; Accepted: 30 July 2019

DOI 10.35654/ijnhs.v2i4.160

Introduction

Leprosy is a chronic infectious disease that is capable of causing damage to peripheral nerve tissue and has an effect on permanent limb deformity / disability, so that lepers suffer from poor social stigma among the community (1,2). Leprosy is known as non-contagious transmission, which is a condition where people are at high risk of contracting leprosy due to the frequency of interaction / contact which is quite intense with the source of leprosy germs (3).

The family is a component that has a higher risk of contracting leprosy, this is because family members are in direct contact with patients every day and last for a long time (4). According to Moet (2006) people who live and have household contacts with leprosy sufferers are at 4 times higher risk of contracting leprosy, this is due to the many exposure to germs containing *M. leprae* from lepers who affect the high levels of anti PGL-1 titers in a person (5).

According to the World Health Organization (WHO) recorded in 2015 the incidence of leprosy in the world amounted to 211,973 cases (0.2 cases per 10,000 inhabitants) (6) WHO, 2017 In 2015 Indonesia had a level 2 disability leprosy case of 1,687 cases (9.81%) and leprosy cases in children totaling 1,930 cases (11.22%) which indicate that the burden of leprosy in

Indonesia is still relatively high because it has not reached the national target of <5% of cases per 100,000 population (7).

Besides that, Indonesia is a country consisting of various ethnic groups with the most ethnic groups being Java, Sunda, Batak, and Madura(8). Madurese ethnicity is known to be very religious and the understanding of ethnic Madurese over Islamic teachings in its development goes hand in hand with its concrete cultural contextually. They are very obedient to religious leaders according to their motto, which is obedient to bhappa ', bhabhu', ghuru, rato (father, mother, teacher / religious figure, government employee)(9). 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.

As a disease that has a high stigma, leprosy has a uniform effect on the lives of patients, especially in culture (10,11). Family involvement is needed in helping care and preventing transmission, considering the family acts as a decision maker to prevent health problems and maintain or improve the health status of family members (12). When care is focused on the family, the effectiveness of care is proven to increase, so that leprosy can be cured and transmission can be prevented (13).

Objectives

This study aimed to explore family caregiver-based prevention that caring among leprosy in sampang district.

Methods

A phenomenology approach with in-depth interview and focus group discussion was applied in this study. After that, it was continued with Focus Group Discussion to develop a model of family independence in caring for leprosy patients based on culture.

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 technique.

Instruments used in the collection process are using interview guidelines, recorders or voice recorders in the form of MP3 voice recorders, and focus group discussion guidelines. The validity of the recording device is done by using a test recording the sound of the researcher. After that, a discussion was held with several sources of guidance instruments. More clearly the following description of the flow of research methods.

The process of data analysis in this study was carried out using the nine step data interpretation method according to. The method was chosen because the steps of data analysis in Collaizi are quite simple, clear and detailed to be used in this study. This study fulfills the ethical requirements of the study and has passed the ethical approved on the ethics committee of the Nursing Faculty of Airlangga University with certificate number: 1326-KEPK.

Results

Participant demographics

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 independence carried out while caring for family members who had leprosy to prevent transmission to other family members. Male and female participants with a age range of 25 years to 70 years. The level of education varies from not attending school to high school education. Participants were all Muslims, marital status: married, all Madurese participants, with a variety of work backgrounds, ranging from traders, farmers and breeders. Family members who participate in the lives of participants are parents, husband / wife, and children who live at home. The details of participants' details can be seen in the following table:

Table 1 Demography Characteristic Participants (N=15)

Characteristics	Frequency	Percentage
<i>Family Caregiver</i>		
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

Theme Analysis

In this study researchers only wanted to know the cultural values adopted by the family to produce a culture-based family development model.

No	Themes	Subthemes
1.	Disciplined treatment	1. Medication adherence 2. Prohibition during treatment
2.	Disease course	1. Perceived symptoms 2. Treatment experience

Disciplined treatment

We concluded that there were two subthemes were medication adherence and prohibition during treatment. Participants described the medication adherence:

Regular treatment, I routinely said I used to go to the shaman house sir (Participant (P) 3).

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

He sir, you have to know that the medicine must be taken thoroughly, don't be late, if recommended a day is taken 3 times, if he routinely takes medication, then often control may be a disease that will not be contagious (P9)

The second subtheme, prohibition during treatment was described by participants:

If it's forbidden like food that can't be eaten it's chicken, eggs, and noodles sir (P3)

Yes, there is no chicken meat should not be, but chicken meat is okay (P4)

Afraid to eat chicken and eggs, it is afraid of itching, bananas and sticky rice may not be too (P7)

Chicken fish, the egg is from the salvation of the dead (P10)

Disease Course

The disease course was divided into two subthemes: perceived symptoms and treatment experience. Participants described the subtheme “perceived symptoms”:

Nothing given sir, the blood flowed for five months (P10)

This moved here now, first feeling itchy and swollen. Then when Friday is used the worship is getting swollen (P12)

Participants described the subtheme of treatment experience:

I once borrowed a neighbor's bicycle to go to the health center's health service. Not yet to the puskesmas, the bicycle I used was damaged. I was confused because there was no tire patch, so I pushed to the puskesmas (P3).

I was brought up in the hospital for 4 days, then added blood 3, finished 3. now I have been healthy before. The doctor said that this has been cured no more control (P5)

Once a month, sir, I feel lazy. I only eat porridge. When I eat, I avoid people (P15)

The authors conducted a forum grup discussion activity with several participants to clarify the results of in-depth interviews that had been done before and add some new information that was not obtained in the previous stage.

The next stage is conducting expert discussions based on the results of in-depth interviews and forum grup discussion on the findings of the problems obtained. This expert discussion is intended to provide criticism and suggestions for program recommendations made by researchers to solve problems found based on the results of research that has been done.

No	Local Culture Implication	Recommendation	
		<i>Nursing Care Decision</i> (Maintenance, Negotiation, and Restructuring)	<i>Levels of Prevention</i>
1	“Rotten Meat”	Restructuring	<i>(Health promotion)</i> Program Topics: 1. Increased health behavior (health promotion, empowerment, and training) 2. Counseling 3. Health service policy
2	“Abstinence from food”	Restructuring	
3	“ <i>Long page</i> ”	Negotiation	
5	“Joining the clerics”	Negotiation	Early diagnosis and immediate treatment (Early diagnosis and prompt treatment) Disability limitation Program Topics: 1. Cross-sector coordination 2. Improving health services
6	“Dispose of bad luck”	Restructuring	<i>Rehabilitation</i> Program Topics: Rehabilitation (group therapy and work program)

Discussion

In accordance with the theory of transcultural nursing, the provision of nursing care with a cultural approach is competently carried out from infants to the elderly (14). 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 (15).

The theme of cultural values is an important thing that needs to be reviewed as the subject of this research. Anderson (1986) states that each culture has developed a health system that supports reciprocal relationships that do not fade in the prevailing view of life (16). Examined the reality of the daily life of lepers with a qualitative method of phenomenological approach (17). The response of leprosy individuals is influenced and shaped by cultural values (18). In this theme, it explains the discipline of therapy and the course of the disease which is influenced by the cultural values adopted. Participants view leprosy as a magical disease caused by the black sciences not as a health disorder. The healing process that goes through will also affect how leprosy patients undergo therapy with discipline and the rhythm of the journey of the disease being passed.

Disciplined treatment

Based on data obtained by the participants underwent disciplined treatment were avoiding the recommended taboos and undergoing therapy obediently. In accordance with the cultural values embraced, participants prefer non-medical therapies such as cleric, shaman and others to provide some restrictions that patients must avoid.

Participants stated that traditional medicine is the treatment most often chosen. From the treatment the treatment raises several restrictions and prohibitions that must be avoided. do non-medical treatment both independently and alternative medicine. This is done by participants before getting treatment or in line with the treatment they are undergoing. In this study, some information was obtained, that patients living with leprosy in the surrounding environment received restrictions regarding their condition. Abstinence obtained in the form of dietary restrictions, drinks and also behavior. Traditional medicine gives birth to a lot of advice or abstinence such as not being allowed to eat food that will aggravate the disease(19). This is reinforced by research Tumansery (2018) that the use of concoctions, messages, compresses and other treatments that are based on culture also requires self-preservation of certain restrictions(20).

After getting treatment that feels right according to what is needed, patients with leprosy need adherence treatment. Ways to minimize recurrence and negative reactions with medication adherence(21). Stimulus towards medication adherence is also needed and against social stigma, this is done to minimize the impact of disease on living patients(22). Analysis of the results of the two studies is consistent with this study, decision-making strategies are very important for underlying health-seeking behavior and the use of various methods of treatment by leprosy patients(23). In this case following the prescribed recommendations. Compliance with treatment is the main strategy to reduce the prognosis of leprosy that occurs in patients.

Disease Course

Based on the research conducted, it was revealed that the patient's disease course was influenced by the cultural values adopted by the community. As a society that is thick with culture and tradition, leprosy is often seen as a magical thing not as a medical disease. Participants as families who accompany and care for patients participate in the process of healing patients.

The sub-theme of the disease journey includes two things: the perceived symptoms and treatment experience. The participants explained that the symptoms of leprosy that appeared were not realized, suddenly and unknown. Patients often do not know what to do when symptoms of leprosy appear. Chronic symptoms of leprosy often afflict the most productive individuals which limit the activities and abilities of individuals to carry out their normal roles (18).

Clinical manifestations that vary in each individual with leprosy makes the response to cultural values also vary. The life of leprosy patients in the community who are treated independently lasts a long time, patients only feel the usual itching and spots like phlegm. Individuals infected with leprosy without clinical signs are often difficult to identify. The average incubation time of leprosy is estimated to be 2-5 years, but can take 20 years or more before clinical disease becomes clear after a person is infected (24).

Treatment experience becomes in the process of seeking health both medically and non-medically. Some patient participants finally had to undergo hospital treatment due to

conditions that were not possible. This is supported by the study of Singh and Madhavan (2015) which states that failure in traditional medicine to become medical treatment is taken as an option of treatment options(25). Another opinion that strengthens states that patients with leprosy receive treatment experience that makes patients have to return to medical treatment in hospitals (26).

Conclusion

This study can be concluded that a culture-based prevention family caregiver is needed by nurses in providing care to lepers who have a different local culture in each region. Assessment as the start of giving care needs to be done before the intervention is given, because holistic assessment can guide nurses to make interventions tailored to the specific needs of patients.

Acknowledgement

The authors would like to thank every lecture in Faculty of Nursing, Universitas Airlangga, Surabaya, Indonesia for the support to finish this paper

References

1. Rodrigues LC, Lockwood DNJ. Leprosy now: epidemiology, progress, challenges, and research gaps. *The Lancet infectious diseases*. 2011;11(6):464–70.
2. Spierings E, De Boer T, Zulianello L, Ottenhoff THM. Novel mechanisms in the immunopathogenesis of leprosy nerve damage: the role of Schwann cells, T cells and *Mycobacterium leprae*. *Immunology and cell biology*. 2000;78(4):349–55.
3. Carvalho APM, Fabri A da COC, Oliveira RC, Lana FCF. Factors associated with anti-phenolic glycolipid-I seropositivity among the household contacts of leprosy cases. *BMC infectious diseases*. 2015;15(1):219.
4. Barreto JG, Bisanzio D, de Souza Guimarães L, Spencer JS, Vazquez-Prokopec GM, Kitron U, et al. Spatial analysis spotlighting early childhood leprosy transmission in a hyperendemic municipality of the Brazilian Amazon region. *PLoS neglected tropical diseases*. 2014;8(2):e2665.
5. Moet FJ, Pahan D, Schuring RP, Oskam L, Richardus JH. Physical distance, genetic relationship, age, and leprosy classification are independent risk factors for leprosy in contacts of patients with leprosy. *The Journal of infectious diseases*. 2006;193(3):346–53.
6. Daniel OJ, Adejumo OA, Oritogun KS, Omosebi O, Kuye J, Onyemaechi S, et al. Leprosy disease burden, active transmission and late presentation at the lowest administrative level in Nigeria: A spatial approach. *Lepr Rev*. 2017;88:343–53.
7. KeMenKes RI. Profil kesehatan Indonesia tahun 2016. Jakarta: Kementerian Kesehatan Republik Indonesia. 2016;
8. Statistik BP. Indeks Pembangunan Manusia 2016. Jakarta (ID): Badan Pusat Statistik. 2017;
9. Wiyata AL. *Madura yang Patuh?; Kajian Antropologi Mengenai Budaya Madura*. Jakarta: Ceric-Fisip UI; 2003.
10. Adhikari B, Kaehler N, Raut S, Gyanwali K, Chapman RS. Stigma in leprosy: a qualitative study of leprosy affected patients at green pastures hospital, western region of Nepal. *J Health Res*. 2013;27(5):295–300.
11. Rinaldi A. The global campaign to eliminate leprosy. *PLoS medicine*. 2005;2(12):e341.

12. Friedman MM, Bowden VR, Jones E. Family nursing: Research, theory & practice. Pearson; 2003.
13. Supinganto A, Metri IK, Supriyanto I. Gambaran Peran Keluarga Dalam Bidang Kesehatan Terhadap Pencegahan Penularan TB Paru Di Kabupaten Lombok Barat. *Jurnal Penelitian UNRAM*. 2014;18(1).
14. Andrews MM, Boyle JS. Transcultural concepts in nursing care. Lippincott Williams & Wilkins; 2008.
15. Susanto T, Dewi EI, Rahmawati I. The experiences of people affected by leprosy who participated in self-care groups in the community : A qualitative study in Indonesia. *Lepr Rev*. 2017;88:543–53.
16. Anderson F. Antropologi kesehatan. UI-Press, Jakarta. 1986;
17. Nur Istifadah. Realitas kehidupan sehari-hari penderita kusta dalam lingkungan sosial (Studi Fenomenologi Pada Penderita Kusta di Rumah Sakit Kusta Kediri). *Jurnal Mahasiswa Sosiologi*. 2014;3(1).
18. Welsh TN, Wong L, Chandrasekharan S. Factors that affect action possibility judgments: The assumed abilities of other people. *Acta psychologica*. 2013;143(2):235–44.
19. Muspika M. Basis otoritas dalam praktik pengobatan akar paninggil (studi deskriptif tentang sistem kepercayaan dan tindakan sosial dalam proses pemilihan pengobatan tradisional di surabaya). Universitas airlangga; 2017.
20. Tumansery GS. Perawatan diri berbasis budaya selama masa nifas pada ibu postpartum. *Jurnal Ilmu Keperawatan*. 2018;6(1):47–56.
21. Susanto T, Aini L. Pengalaman Klien Dewasa Menjalani Perawatan Kusta di Wilayah Kerja Puskesmas Jenggawah Kabupaten Jember Jawa Timur: Studi Fenomenologi. Jawa Barat: Program Pasca Sarjana Fakultas Ilmu Keperawatan Universitas Indonesia. 2010;
22. Costa MD, Terra F de S, Costa RD, Lyon S, Costa AMDD, Antunes CM de F. Assessment of quality of life of patients with leprosy reactional states treated in a dermatology reference center. *Anais brasileiros de dermatologia*. 2012;87(1):26–35.
23. Singh S, Sinha AK, Banerjee BG, Jaswal N. The Health-Seeking Behavior of Leprosy Patients: An explanatory model. *Health, Culture and Society*. 2013;4(1):52–65.
24. Feenstra SG, Nahar Q, Pahan D, Oskam L, Richardus JH. A qualitative exploration of social contact patterns relevant to airborne infectious diseases in Northwest Bangladesh. *Journal of Health, Population and Nutrition*. 2013;31(4):424–34.
25. Singh A, Madhavan H. Traditional vs. non-traditional healing for minor and major morbidities in India: Uses, cost and quality comparisons. *Tropical Medicine and International Health*. 2015;20(9):1223–38.
26. Sutrisno FI. Hubungan Antara Dimensi Konsep Diri Dengan Interaksi Sosial Pada Penderita Kusta Di Rsud Kusta Donorojo Jepara. *FIKkeS*. 2014;7(1).