

Integrative Health Promotion Model in Leprosy Prevention and Control Programs to Improve Quality of Life for Leprosy Survivors

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ABSTRACT

Objective: Leprosy is an infectious disease that causes highly complex problems from the medical aspect to social, economic, cultural, security, and national defence issues. This research aimed to develop and analyse the effect of an integrative model on leprosy prevention and control programs to improve the life quality of leprosy survivors.

Materials and Methods: This research was conducted in Madura, East Java, Indonesia. The study consists of 360 leprosy survivors. The exposed group in this study was a group of leprosy survivors living within the areas of the Ministry of Health's leprosy program, a total of 180 leprosy survivors. The unexposed groups were leprosy survivors living around the areas with the absence of Ministry of Health leprosy program, a total of 180 leprosy survivors.

Results: The quality of life has a direct and positive relationship with health status ($b = 0.56$; 95% CI = 0.14 to 1.00; $p = 0.010$), health status has a direct and positive relationship with healthy behavior ($b = 0.55$; 95% CI = 0.10 to 1.00; $p = 0.016$), healthy behavior has a direct and positive relationship with self-efficacy ($b = 0.91$; 95% CI = 0.38 to 1.44; $p = 0.001$), healthy behavior has a direct and positive relationship with family support ($b = 0.54$; 95% CI = 0.06 to 1.03; $p = 0.029$), healthy behavior has a direct and positive relationship with attitude ($b = 0.56$; 95% CI = 0.05 to 1.09; $p = 0.032$).

Conclusion: Health status, healthy behavior, self-efficacy, family support, attitude and community support related to improving quality of life for leprosy survivors.

Keywords: Leprosy survivors; quality of life; prevention and control (Siriraj Med J 2023; 75: 665-673)

INTRODUCTION

Leprosy is an infectious disease that causes extremely complex problems in not only a medical aspect but also social, economic, cultural, security and national security issues.^{1,2} The cases of leprosy worldwide are still profound. Based on data from the World Health Organization (WHO), about 0.2 per 10,000 population, with 208,619 new patients throughout 2018 were recorded. To date, there are still three countries severely fighting against leprosy, which are India, Brazil, and Indonesia.³

At present, Indonesia levels in the third place in terms of the number of leprosy patients worldwide, while East Java Province ranks the first across Indonesia.⁴ Based on data from the Directorate General of Disease Prevention and Control of the Ministry of Health of the Republic of Indonesia, the highest prevalence of leprosy in Indonesia happens in East Java. This province is the largest contributor of leprosy patients in Indonesia with 3,857 cases (28.44%). The province with the second highest leprosy cases is West Java with 2,612 cases (19.26%), and

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the third highest is Papua, with 1,582 cases (11.66%). Following are several provinces in Indonesia with the lowest number of cases, including Banten with 1,116 cases (8.23%), South Sulawesi with 1,086 cases (8.00%), West Papua with 978 cases (7.21%), Central Java 710 cases (5.23%), North Maluku 621 cases (4.57%), North Sulawesi with 507 cases (3.73%), and the lowest leprosy cases were in East Nusa Tenggara, with only 490 cases (3.61%).

Nationally, in 2014, there were 16,131 new cases of leprosy, consisting of 13,509 cases of the multibacillary type (83.74%) and 2,622 cases of paucibacillary type (16.25%), and the proportion of grade 2 disorder was 9.45 percent. This condition requires leprosy efforts for not only prevention but also integration of patients with society so that the life quality of the survivors does not go lower due to the various, a part from social resistance.⁵

East Java is an area with a high leprosy case in 2013-2020 which has achieved leprosy elimination in 2017 (the morbidity rate is 0.93 per 10,000), but there are still 10 regencies or cities that have not yet eliminated leprosy, which are Sumenep, Sampang, Pamekasan, Bangkalan, Probolinggo, Lumajang, Situbondo, Tuban, Jember, and Pasuruan. The highest cases happen around Madura and the north sea coast of East Java. Leprosy control in East Java is found in two areas, the east and west areas. At the end of 2020, Jember is expected to also reach leprosy elimination because the morbidity rate is approaching less than 1 per 10,000 population.

According to the strategic plan of the Indonesian Ministry of Health, all regencies or cities are targeted to have achieved leprosy elimination by 2024. The incidence of leprosy in East Java in 2013-2020 shows fluctuating data, due to changing individual and environmental health conditions. In 2013-2016, it exhibited a sloping curve. Then, in 2017 it increased up to the highest number of leprosy cases with 4,668 survivors. The curve decreased in 2017 to 2020 with 2,319 survivors.

Management of leprosy cases prioritizes early case and active case finding methods while prioritizing voluntary self-report. Community advocacy and mobilization, production of health promotion materials, health promotion campaigns, and self-reporting as well as examination of family members should be carried out. The number of leprosy cases covered has not yet reached the target. So far, information about leprosy is not widely understood.⁶ The clinical symptoms of leprosy are mostly perceived as white patches of numbness. Even though this information is a symptom of dry leprosy, early detection with other clinical signs needs to be made, not only on the symptoms of anaesthesia in the white spots.

In addition, it is necessary to provide proper information to the public about leprosy. In addition, the definition of contact adopted by officers is still limited to contact that occurs between family members in a single house. Furthermore, officers' understanding is fundamental, for example contact with neighbours (4-5 houses to the front, side, and back), social (school friends, work, and so on).⁷

The participation of the community is required to provide an appropriate management of leprosy. For example, health personnel in villages can be trained to provide education and health promotion about leprosy. The leprosy prevention and control program is still constrained due to limited competence of the health resources. Therefore, improvement in training for the health workers is on high demand.⁸ Coordination with other programs and other stakeholders also needs to be encouraged. Political commitment at the district/city level is still lacking, as represented from the lack of funds for the strategy implementation program to achieve the targeted coverage. Thus, it is necessary to create an integrated Neglected Tropical Diseases (NTD) program, for example in the aspects of advocacy and education to the community, drug distribution and case detection. Program planning needs to be made at the district/city level.⁹

Based on the background, the current health promotion for leprosy survivors is deemed to be ineffective. Therefore, it is necessary to change the strategy in the implementation of health promotion through policy revisions to ongoing health promotion programs to improve the life quality of leprosy survivors.

MATERIALS AND METHODS

This research was conducted in Madura, East Java, Indonesia. It employed a mixed method design in stages (sequential mixed methods). This was a cohort retrospective study, which aimed to examine the factors that influence healthy behavior, health status, and quality of life of leprosy survivors. Respondents in phase 1 used a 1:1 ratio between the exposed group and the unexposed groups. The exposed group in this study was a group of leprosy survivors living within the areas of the Ministry of Health's leprosy program, a total of 180 leprosy survivors. The Ministry of Health's leprosy program such as health promotion, surveillance, chemoprophylaxis; and management of leprosy. Health promotion for empower people to be able to play an active role in supporting behavior and environmental change as well as maintaining and improving health for leprosy prevention and control. Surveillance for the discovery of

leprosy survivors and early treatment and knowledge the magnitude of the problem in an area. Chemoprophylaxis to prevent transmission leprosy in people who have contact with leprosy survivors. Management of leprosy for treat leprosy survivors early and prevent disability due to leprosy. The unexposed groups were leprosy survivors living around the areas with the absence of Ministry of Health leprosy program, a total of 180 leprosy survivors. The independent variables in the study were health status, healthy behavior, family support, community support, attitudes and self-efficacy. The dependent one was the life quality of leprosy survivors. The data analysis adopted univariate analysis, bivariate analysis, and path analysis. The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work were appropriately investigated and resolved. The study was conducted according to the Declaration of Helsinki (as revised in 2013). The study was approved by institutional ethics board of Faculty of Medicine, Universitas Sebelas Maret, Surakarta, Indonesia (NO.: 80/UN27.06.6.1/KEP/EC/2021), and informed consent was obtained from all individual participants.

RESULTS

The results of the study involved the exposed and unexposed groups. The participants of this study were 360 respondents, divided into two groups: those who were exposed to the leprosy program and those who were not.

Table 1 shows the personal characteristics of the participants including the age of the respondents, gender, education and family income, knowledge. The results of the univariate analysis demonstrated that either the

exposed or the unexposed group to the leprosy program was mostly aged before 34 years, 126 respondents (70.00%) and 95 (52.78%) respectively. Correspondingly, in the gender variable, they were mostly male, 115 respondents (63.89%) in the exposed group and 94 respondents (52.22%) in the unexposed one.

In terms of education level, most of them, either in the exposed or unexposed group, are high school graduates, namely 125 respondents (69.44%) and 125 respondents (69.44%) respectively. The majority of the family income was below the regional minimum wage, 102 respondents (56.67%) and 107 (59.44%).

Table 2 shows the survivors in the group unexposed to the program mostly, 133 respondents (73.89%), had a negative attitudes (below the average value), while most of the exposed group, 104 respondents (57.78%), exhibited a positive knowledge (over the average value). In terms of self-efficacy, most of the unexposed group, 125 respondents (69.44%), showed a low self-efficacy, while most of the exposed one, 117 respondents (65.00%), had a high self-efficacy.

In the variable of family support, most of the families in the unexposed group, 150 respondents (83.33%), belonged to the weak category while that in the exposed one, majority of them, 111 respondents (61.67%), belonged to the strong category. Meanwhile, most of the community support variables in the unexposed group were weak, with 121 respondents (67.22%), while those in the exposed group, 114 respondents (63.33%), had a strong category.

In the healthy behavior variable, most of those in the unexposed group, 123 respondents (68.33%), belonged to the bad category, while in those in exposed group mostly had a good category, with 101 respondents

TABLE 1. Characteristics of the sample

No	Characteristics	Criteria	Not Exposed to Programs		Exposed Program	
			N	%	n	%
1	Age	< mean (34)	126	70.00	95	52.78
		≥ mean (34)	54	30.00	85	47.22
2	Gender	Male	115	63.89	94	52.22
		Female	65	36.11	85	47.78
3	Education	< Senior High School	125	69.44	125	69.44
		≥ Senior High School	55	30.56	55	30.56
4	Family income	< Regional minimum wage	102	56.67	73	40.56
		≥ Regional minimum wage	78	43.33	107	59.44

TABLE 2. Characteristics of the variable.

No	Characteristics	Criteria	Not Exposed to Programs		Exposed Program	
			n	%	n	%
1	Attitude	negative	133	73.89	76	42.22
		positive	47	26.11	104	57.78
2	Self-efficacy	low	125	69.44	63	35.00
		high	55	30.56	117	65.00
3	Family support	weak	150	83.33	69	38.33
		strong	30	16.67	111	61.67
4	Community support	weak	121	67.22	66	36.67
		strong	59	32.78	114	63.33
5	Healthy behavior	poor	123	68.33	79	43.89
		good	57	31.67	101	56.11
6	Health status	Very bad	114	63.33	100	55.56
		Good	66	36.67	80	44.44
7	Quality of life	< mean	143	79.44	76	42.22
		≥ average	37	20.56	104	57.78

(56.11%). Most of the health status variables in the both group, 114 respondents (63.33%) and 100 respondents (55.56%), were in a very bad category. In the quality-of-life variable, most of the participants, 143 respondents (79.44%), in the first group had a below average score while most of the participants, 104 respondents (57.78%), in the second group belonged to the good category.

Path analysis was intended to identify the number of measured variables, the number of endogenous variables, exogenous variables, and estimated parameters. At this stage, the degree of freedom (df) was calculated, which defined that path analysis could be carried out under the following conditions:

- Number of measured variables: 7
- Endogenous variables: 5 (attitude, self-efficacy, family support, community support, and healthy behavior)
- Exogenous variables: 2 (quality of life and health status)
- Number of parameters: 7

The degree of freedom formula is as follows:

$df = (\text{number of measured variables} \times (\text{number of measured variables} + 1) / 2 - (\text{endogenous variables} + \text{exogenous variables} + \text{number of parameters})) = (7 \times (7+1) / 2 - (5 + 2 + 7)) = (56 / 2) - 14 = 28 - 14 = 14.$

Path analysis can be done if $df \geq 0$, and in the model identification, the value of df was 14, and it was called

over identified path analysis. Therefore, path analysis could be obviously conducted.

Table 3 shows the results of calculations using the STATA 13 computer program software. Quality of life had a direct and positive relationship with health status. Leprosy survivors with good health status had a log odd of increasing quality of life 0.56 units higher than the leprosy survivors with very poor health status ($b = 0.56$; 95% CI = 0.14 to 1.00; $p = 0.010$).

Health status had a direct and positive relationship with healthy behavior. Leprosy survivors with good health behavior had a log odd of improving health status 0.55 units higher than the leprosy survivors with poor health behavior ($b = 0.55$; 95% CI = 0.10 to 1.00; $p = 0.016$).

Healthy behavior had a direct and positive relationship with self-efficacy. Leprosy survivors with high self-efficacy had a log odd of increasing healthy behavior 0.91 units higher than leprosy survivors with low self-efficacy ($b = 0.91$; 95% CI = 0.38 to 1.44; $p = 0.001$).

Healthy behavior had a direct and positive relationship with family support. Leprosy survivors with strong family support had a log odd of increasing healthy behavior 0.54 units higher than leprosy survivors with weak family support ($b = 0.54$; 95% CI = 0.06 to 1.03; $p = 0.029$).

Healthy behavior had a direct and positive relationship with attitude. Leprosy survivors with a positive attitude had a log odd of increasing healthy behavior 0.56 units

TABLE 3. Results of path analysis of integrative model influence on leprosy prevention and control to improve the quality of life of leprosy survivors.

Relationship of dependent and independent variables	Coefficient line	CI 95% Lower limit	Upper limit	p
Direct Effect				
Quality of life	←			
health status	0.56	0.14	1.00	0.010
Health status	←			
Healthy behavior	0.55	0.10	1.00	0.016
Healthy behavior	←			
self-efficacy	0.91	0.38	1.44	0.001
Family support	0.54	0.06	1.03	0.029
Attitude	0.56	0.05	1.09	0.032
Indirect Effect				
Family support	←			
Community support	0.96	0.53	1.40	<0.001
Attitude	←			
Community support	1.57	1.06	2.09	<0.001
N Observation = 360	description:			
df = 14	← = be connected			

* Signification $p \leq 0.05$

higher than leprosy survivors with a negative attitude ($b = 0.56$; 95% CI = 0.05 to 1.09; $p = 0.032$).

Community support was indirectly related to quality of life through family support. Leprosy survivors with strong community support had a log odd of having strong family support of 0.96 units higher than leprosy survivors who had a weak community support ($b = 0.96$; 95% CI = 0.53 to 1.40; $p < 0.001$).

Community support was indirectly related to quality of life through attitudes. Leprosy survivors with a strong community support had a log odd of having a positive attitude of 1.57 units higher than leprosy survivors with a weak community support ($b = 0.57$; 95% CI = 1.06 to 2.09; $p < 0.001$).

DISCUSSION

Based on the results, this study reveals that health status has a direct effect with quality of life. Leprosy and the physical deformities become sources of stigma and social isolation for patients and their families among society. The disability and stigma suffered by the patients play a major role in the decrease of life quality. In addition, the negative stigma of leprosy can hinder

community health programs related to the prevention, early diagnosis, therapy, and adherence to treatment of leprosy patients.¹⁰ People Affected by Leprosy in their lives experience physical health problems, psychological well-being disorders, social relationship disorders, and environmental problems. It can have a negative impact on the quality of life, such as mobility, interpersonal relationships, and other social activities.¹¹

Based on the research results, health status is a very complex point. It can be achieved optimally when the four factors - heredity, environment, behavior, and health services - are optimal. Once a single of them is disturbed (nonoptimal), the health status will be below optimal. For this reason, leprosy sufferers are expected to achieve good health status through internal and external factors, so they can improve their quality of life.

The result shows that healthy behavior has an indirect effect with quality of life through health status. Leprosy is a chronic disease caused by *Mycobacterium leprae* (M. leprae) infection, which first attacks the peripheral nerves, then attack the skin, oral mucosa, upper respiratory tract, reticuloendothelial system, eyes, muscles, bones, and testes except the central nervous system.¹² Health can be

achieved through behavioral change from unhealthy to the healthy behavior and creating a healthy environment in the family. According to Becker, the concept of healthy behavior is an extension of the behavioral concept developed by Bloom, which describes health behavior into three domains, which are health knowledge, health attitude, and health practice.

Healthy behavior affects one's physical, mental, and spiritual health. Mental health is a determinant of one's quality of life. One's mental health is good if he or she feels peaceful, calm, and happy with his life, and it will obviously affect the quality of life as well.¹³ A good mental health will improve the quality of life. Health workers are expected to be more optimal in conveying health promotion related to leprosy, such as by holding outreach about leprosy. The information obtained by the community can support the healthy behavior of leprosy survivors.¹⁴

The results show that self-efficacy has an indirect effect to quality of life through behavior and health status. Good self-efficacy can improve problem solving, reduce fear of failure, and promote enthusiasm.¹⁵ One's self-efficacy can be seen from several sources, from one's own experience, the experience of others, verbal persuasion, and physiological conditions. Self-efficacy can refer to the belief in improving the life quality of the survivors in dealing with the disease.¹⁶ The higher the self-efficacy, the stronger the coping in leprosy survivors.

The study result indicates that efficacy with all the aspects therein can improve the life quality of leprosy survivors through their behavior and health status. Therefore, self-efficacy is positively related to the quality of life of leprosy survivors. The higher the self-efficacy, the better the quality of life; the lower the self-efficacy, the worse the quality of life.

The result shows that family support has an indirect effect to the quality of life through healthy behavior. Family support is all assistance provided by family members to provide a sense of physical and psychological comfort to individuals who are depressed or stressed due to certain problems.¹⁷ A good family support for the leprosy survivors can reduce the stress and depression so that they feel a better quality of life. In a family, there are several functions to fulfil, one of which is a family care, taking care of the family members who are sick.¹⁸

The family support is expected to provide benefits or a stimulus for leprosy survivors in carrying out routine treatment. Leprosy patients whose families are not supportive might have a worse prognosis. Therefore, family plays a highly crucial role because their support can improve the life quality of leprosy survivors.¹⁹ Family

support consists of 4 indicators examined in this study, which include informational support, appraisal support, instrumental support, and emotional support. All aspects of family support are closely related one another.²⁰

Family support is a function of social ties that describe the level and quality of individuals that protect individuals from the consequences of stress.²¹ It can make them feel calm, cared for, increase self-confidence and competence. Health behavior can be formed due to the internal and external factors that play a role. These external factors include experience, facilities, and socio-culture, while internal factors include perceptions, knowledge, beliefs, desires, motivations, intentions, and attitudes.^{29,30}

The result of the study shows that attitude has an indirect effect with quality of life through healthy behavior. Leprosy sufferers who experience disabilities or (PCK) tend to live alone and reduce social activities with the surrounding environment. The disability problems due to leprosy will ultimately affect the life quality of the lepers.²⁴ The defects that occur affect the decrease in self-confidence of leprosy survivors, so they feel that they are not worthy among society. It causes withdrawal behavior from the surrounding environment, so that it affects the life quality of the lepers.²⁵

In this case, everyone has a set of standards within a person to judge what other people see or think. Although a former leper patient is medically considered cured, society remains considering him a leper. Even former lepers themselves often see the permanent physical disabilities they experience as a sign that they really have leprosy.²⁶ This condition affects the daily activities of leprosy sufferers to be disrupted, so it affect the life quality of lepers, such as physical health problems, psychological problems, social relations problems, and the environment. Negative attitudes and behavior of the community towards leprosy sufferers often cause leprosy sufferers to feel they do not have a place in their families and the community environment for the stigma and leprophobia which are heavily influenced by various understandings and misinformation from the community about leprosy, so this problem causes lepers.²⁷

The study results show that community support has an indirect effect to the quality of life through family support. Community support as a source of emotion, information or assistance provided by people around to deal with any problems encountered daily in life.²⁸ Community support comes from other people, such as friends, neighbours, co-workers, and others.^{29,30}

There is a feeling of anxiety experienced by leprosy survivors in the productive age group, which can limit daily activities such as meeting other people, gathering

with friends, and even working. Leprosy is a chronic disease that attacks any part of the body except the central nervous system. People who suffer from leprosy will certainly experience functional disorders of their bodies. It can lead to the lack of self-confidence due to the physical disabilities, so it can reduce their quality of life. For this reason, social support is vital to improve the life quality of leprosy survivors.³¹

The purpose of this study is to offer a conceptual model for developing a health promotion model, to improve the quality of life of leprosy survivors. The final model is a scheme of the health promotion model to reach the goal. This model is not only oriented to program performance for a moment. Sustainability of changes that can improve the quality of life at individual, family, and community levels, is way more important. This model is also community development, the process of which involves community support (cross-sectors). Each program involves a few institutions relevant to the issues by optimizing social capital through efforts to increase their active role in preventing and controlling the quality of life of leprosy survivors. Accordingly, this program is designed in the form of preventive promotion.

The efforts that can be designed to achieve the goal can be in the form of promotion and socialization, as well as communication about the quality of life of leprosy survivors. At the community level, high social capital plays an active role in supporting the quality of life of leprosy survivors. Through social capital, social support is further enhanced, so they feel stronger support and are able to improve the quality of life of leprosy survivors. The support is in the form of material support, informational support, and instrumental support. The higher the community support for leprosy survivors, the faster the change in healthy behavior of leprosy survivors.³²

With advances in technology in the areas of promotion, prevention, treatment, and health restoration including medical rehabilitation and socio-economic rehabilitation, treatment becomes more effective through an integrated approach, one of which is the collaboration model.³³ The mission of the leprosy control program is to cure and improve the quality of life of leprosy survivors. One's quality of life is not only measured from the aspect of his health, but also from other aspects such as social, economic, emotional, and human rights, so it is necessary to be integrated with related sectors.³⁴

The poor quality of life will affect the daily lives of leprosy survivors as well.³⁵ Leprosy survivors have a lot of roles, especially related to their role in society that experiences a change because leprosy survivors

find difficulty in socialization. Therefore, support at the community level is significant to help them adapt to themselves.³⁶

At the individual level, it is about how the individual can adapt and accept his disease to achieve a good quality of life. Leprosy affects all ages, male and female, and the most common age is young adults, those in the productive age. Leprosy, especially if it happens with disability, will create a bad stigma for the patient and their family. Thus, leprosy patients often experience difficulties in social interactions, going to school, working, and even having a family, which can reduce the patient's quality of life.³⁷

Continuous support from health workers and especially from the family is fundamental to restore self-confidence and at least erode self-stigma, so their quality of life becomes better. On the other hand, the group with low education is generally more indifferent to their illness or may be helpless and forced to accept the situation. The group is more closed and difficult to interview. They have a lot of other things to prioritize, such as working for a living. Thus, this group can pursue their lives, even though not optimal, and choose to avoid the environment. Self-stigma can be reduced, but social stigma remains attached to all subjects. There is still a need for continuous socialization of leprosy to the community so that social stigma can be eliminated so that the quality of life for leprosy patients will be even better.^{38,39}

CONCLUSION

Health status, healthy behavior, self-efficacy, family support, attitude and community support related to improving quality of life for leprosy survivors. The level of a one's quality of life is influenced by two factors, environmental and personal factors. Someone who lives around the depressed environment, coops up in a limited home environment, and has the opportunity to play a narrow social role will have a low quality of life, but if he or she can control the situation, he or she can participate in community life and various social interactions.

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