

Physical Disability Related to Self-Concept of Leprosy Patients in Kediri Leprosy Hospital

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ABSTRACT

Introduction

Leprosy is a disease that gives a huge stigma to the community, so that leprosy patients not only suffer physically but also shunned or isolated by the community. Leprosy with physical disability can interfere with the self-concept of leprosy patients aged 20-40 years (productive age).

Methods

The design of the study was a cross-sectional study. The population was leprosy patients in Specialty Leprosy Hospital Kediri and the sample of the study was 96 respondents. The independent variable was physical disabilities, and the dependent variable was self-concept. Data collection using observation and questionnaire, then analyzed by Mann-Whitney statistical test with a significant level $\alpha \leq 0.05$.

Results

The result showed that the leprosy patients in Kediri Leprosy Hospital had defect in first stage were 63 respondents (65,6%), and positive of self concept were 53 respondents (55,2%). The result of Mann-Whitney statistical test obtained $p = 0,000$, H_a was accepted and H_o was rejected. It meant, there was a significant correlation between the independent variable and the dependent variable.

Conclusion

Leprosy patients in the productive age of 20-40 years, more than half, experience physical disability level 1 and negative self-concept whereas demonstrate a positive self-concept. Physical disability in leprosy patients has a significant correlation on the decreased of self-concept among leprosy patients.

Keywords

Physical Disability; Self-Concept; Leprosy Patient

INTRODUCTION

Leprosy is a disease that gives a huge stigma to society, so that leprosy patients not only suffer from the disease, but also shunned or isolated by the community (1). Leprosy is a disease that is feared because it can occur ulceration, mutilation, and deformity (2). As a result, even though leprosy patients have been treated and declared medically cured, but physically disabled, the

leprosy predicate will remain attached to the rest of the patient's life, so that the lepers and their families will be shunned by the surrounding community (3).

The majority of leprosy patients come from India as many as 133,717 cases, Brazil 37,610 cases, and in Indonesia as many as 17,260 cases (WHO, 2010). In 2009, in Indonesia there were reported new cases of Multibacillary type (MB) as many as 14,227 cases and Paucibacillary (PB) types of 3,033 with the Newly Case Detection Rate (NCDR) of 7.49 per 100,000 population (4). In 2009, the province that had the highest proportion of disabled level 2 was East Java Province with 572 cases (11.64%) with Prevalence Rate (PR) 1.62 per 10,000 population. The number of new patients in 2008 was 4,912 cases, consisting of 4,323 cases of leprosy type Multibacillary (88.01%) and 589 cases of Paucibacillary type leprosy (11.99%) (4). According to observation and interview conducted by researcher in pre-study on 1-3 November 2012 in Kediri Leprosy Hospital from 30 respondents, patients with disability level 1 were 17 people (56.7%), 5 people (16.7%) had hand disability and 12 people (40%) had foot disability. Patients who experienced disability level 2 were 13 people (43.3%), namely 6 people (20%) experienced hand disability and 7 people (23.3%) experienced foot disability. Observation from patients, 28 people wore long-sleeved clothes or wear jackets, 2 outpatients who wore black glasses and hats to cover the affected body part.

The positive impact of some leprosy sufferers is that they can immediately accept the situation and immediately seek medical help, but there are those who try to reject the reality by seeking alternative help, including medical treatment for traditional healers, physicians and so on. The negative impact of leprosy sufferers who experience disability is feeling inferior to experiencing depression, being alone, holed up because of shame (5). Every change in health can be a stressor that influences self-concept (6). This self-concept disorder will not support the treatment process and recovery, on the contrary it will increase the risk of physical and psychosocial disability. Physical disability will affect the psychosocial condition of leprosy patients, this will get heavier if the leper is the foundation of life and livelihood for his family (5).

It is necessary to handle mental rehabilitation, rehabilitation of works and social rehabilitation for leprosy patients, mental guidance, must be attempted as early as possible for each sufferer, his family and the surrounding community (5). Based on these circumstances, the researcher needed to examine the self-concept of leprosy patients with physical disabilities in Kediri Leprosy Hospital.

METHODS

Based on the objective of the research the research design used was correlational using a cross-sectional approach. In this study, samples were taken of leprosy patients in the polyclinic in Kediri Leprosy Hospital who met the inclusion criteria. Number of leprosy patients at the clinic in Kediri Leprosy Hospital aged 20-40 years in 3 months, from July to September 2012 was 309 people, so that the average patients of the polyclinic per month was 103 people. The sample size of this study used an estimated proportion of 96 respondents using purposive sampling. The data collection in this study used the WHO (World Health Organization) disability level

observation sheet, and self-concept using a questionnaire adapted from Tennessee Self Concept Scale (TSCS), then analyzed using Mann-Whitney statistical test with significant $\alpha \leq 0.05$. Data collection was carried out on 1 February 2013 - 1 March 2013 in Kediri Leprosy Hospital at Veteran street no. 48 Kediri.

RESULT

Characteristics of leprosy patients based on sex in Kediri Leprosy Hospital, the majority (85.40%) of leprosy patients were male. Because men have heavier activities than women. Characteristics of leprosy patients based on the age of most leprosy patients aged 31-40 years (66.7%). Age 30-40 years including middle-aged adults, in this productive age there is an increase in physical activity. Characteristics of leprosy patients based on education were the most with high school graduation education (46.9%). Characteristics of leprosy patients based on duration of illness were mostly with illness duration > 6 months (74.0%). Characteristics of leprosy patients based on treatment were more than 50% of leprosy patients with RFT treatment (55.2%).

Characteristics of leprosy patients based on physical disability were more than 50% of leprosy patients with 1 physical disability, namely 63 respondents (65.6%). Based on the self-concept in Kediri Leprosy Hospital was more than 50% of leprosy patients experience positive self-concept (55.2%), and had a negative self-concept (44.8%).

Cross tabulation of physical disability and self-concept of leprosy patients showed that leprosy patients with disability 0 had positive self-concept (100%). Leprosy patients with disability 1 tend to have a positive self-concept (55.6%), and leprosy patients with disability 2 tend to have negative self-concept (83.3%).

DISCUSSION

Physical Disability of Leprosy Patients in Kediri Leprosy Hospital

The results of research on physical disability from the number of respondents as many as 96 people obtained the results of respondents who experienced disability 0 were 15 people (15.6%), respondents who experienced disability 1 were 63 people (65.6%), and respondents who experienced disability 2 were 18 people (18.8%). Based on the data above it can be concluded that more than 50% of respondents experienced physical disability 1, namely 63 respondents (65.6%).

Leprosy mainly attacks peripheral nerves, skin and other organs except the central nervous system which if not diagnosed and treated early can lead to disability (7). Leprosy disability according to WHO (World Health Organization) is divided into 3 levels of disability, namely disability 0, disability 1 and disability 2.

Based on the frequency distribution of research data on the characteristics of leprosy patients with disability level 1, the sexes are mostly male (85.40%). Based on the theory, hand and foot

disabilities are often found in men than women with a 2:1 disability ratio. Disability in men is related to activities carried out every day (8). Based on the results of research on physical disability at disability level 1 tends to occur more in respondents of male sex with working as laborers and farmers that have quite heavy physical activity.

The age characteristics of leprosy patients with disabilities 1 tend to occur at the age of 30-40 years (70.3%). Age 30-40 years including middle-aged adults, physical activity is increasing so that the incidence of disability in lepers is more frequent at this age. An increase in the level of disability in lepers can be caused by an increase of the patient's age. Increased age can cause the ability of the nervous system to decrease so that the motor nerve paralysis occurs (8). Disability level 1 can occur at the age of 30-40 years, it is possible because during the incubation period, the respondent did not know about early diagnosis of leprosy, and did not handle the signs and symptoms of leprosy he suffered. Age 30-40 years old is a productive age having responsibility for themselves and family, so that individual activities will increase at that age. This situation also resulted the increasing of physical disability that occurred in leprosy patients.

Educational characteristics of leprosy patients with disability 1 tend to occur in patients who do not take school (100%). The low level of education can result in slow treatment seeking and diagnosis of disease, this can lead to severe disability in lepers (8). The lower the level of education, the lower it tends to be in actualizing itself in obtaining information and knowledge about early diagnosis of the disease and its therapeutic treatment regimen.

The job characteristics of leprosy patients with disability 1 tend to occur in labors, and farmers. (1) state that heavy and rough work can result in more severe skin and nerve tissue damage. Jobs that require excessive physical activity can lead to severe physical disability (8). Work as a farmer and laborer physical activity tends to be heavier, so the works have a greater chance of triggering physical disability in leprosy.

The characteristics of the duration of leprosy patients with disability 1 tended to occur at > 6 months of illness (66.2%) and the characteristics of respondents with disability 1 were based on treatment, which tended to occur in RFT treatment (69.8%). There were 30% - 56% of new leprosy patients who had damaged nerve function (8). Leprosy suffered from 0-2 years of disability was 26.9%, suffered from leprosy for 2-5 years was 45.6% (9). Based on this, it can be concluded that the longer the illness, the physical disability will tend to be greater. The longer the time delay from the time the first signs are found to the start of treatment, the greater the risk of disability due to progressive nerve damage. So early diagnosis and treatment should prevent long-term complications (4). It was in accordance with the results of a study of leprosy patients with illness duration of > 6 months tended to occur in disability 1 and disability 2, while in the illness duration \leq 6 months occurred in disability 0. Treatment of RFT (Release From Treatment) is treatment that was done when finished in the treatment of MDT (Multi-drug Therapy) 6-9 months or 12-18 months without laboratory testing (7).

Self-Concept of Leprosy Patients in Kediri Leprosy Hospital

The results of research on self-concept, from the number of respondents as many as 96 people found that leprosy patients who experienced negative self-concept were as many as 43 people (44.8%) and leprosy patients who experienced positive self-concept as many as 53 people (55.2%).

Theoretically self-concept has a strong influence on one's behavior (10). Self-concept assessment according to Fitts Theory (1971), consists of 2 dimensions, namely internal and external dimensions. Self-concept consists of 2 characteristics namely positive self-concept and negative self-concept characteristics (11).

The age characteristics of leprosy patients with disability 1 tend to occur at the age of 30-40 years. Often physiological changes during middle adulthood impact on self-concept and body shape(12). According to psychosocial theory, the development of self-concept at the age of 20-40 years is having an intimate relationship with family and other people (13). According to researcher, respondents with ages 30-40 years old, at that age in general are individuals who are already independent and have a family (14). Families can be a support system for the stressors faced by patients suffering from leprosy, so that it can be a motivation in supporting the healing process holistically (bio-psycho-socio-spiritual) (15). Theoretically at the age of 20-40 years individuals will have a stable and positive feeling about themselves, experience the success of the role transition and increased responsibility (16). At the age of 20-40 years experience of formal and informal education, life experiences and opportunities to work can improve self-concept, problem-solving ability, and individual motor skills (12).

People with not working Job status can reduce stressors because the opportunities and intensity to interact with others tend to be less frequent, because more activities are done at home. Non-formal jobs such as labors and farmers tend to be more confident in the general environment compared to leprosy patients with formal or informal work, because the work environment and relationships are more limited.

The illness duration characteristics of leprosy patients with positive self-concept tend to have illness duration for 6 months. One of factors that influences self-concept is its experience, according Fitts theory (11). The process of pain with illness duration for ≤ 6 months affected the self-concept of leprosy patients, because they had undergone the stages of grief. Acute disease can make respondents begin to be able to adapt to change from a previously maladaptive self-concept to adaptive.

While the age characteristics of leprosy patients with negative self-concept were 20-29 years old, graduated from university and not schooling, self-employed and private employment, illness duration > 6 months, RFT (Release From Treatment) treatment and with severe reactions. At the age of 20-29 years are more likely to experience negative self-concept because at that age the respondent is not yet married so that the presence of leprosy experienced by leprosy patients can be an obstacle in achieving their dreams and future.

The educational characteristics of leprosy patients with negative self-concept are university education and not schooling. At the age of 20-40 years experience of formal and informal education, life experiences and opportunities to work can improve self-concept (12). Every change in health can be a stressor that influences self-concept (6). Psychologically, patients with a higher level of education, namely at the level of education, graduated from university tend to have a higher stressor than patients with lower levels of education. Patients with a high level of knowledge who suffer from leprosy will certainly tend to be shy and not confident in their environment or colleagues if other people know about their leprosy illness. Negative self-concept in leprosy patients with an education status was not finishing school, probably due to a lack of knowledge about leprosy, especially if supported by a lack of economic conditions. This condition will cause feelings of despair because of difficulties in fulfilling life's needs if suffering from leprosy even with physical disabilities.

Negative self-concept is on the work of entrepreneurs and private. Physical disability will affect the psychosocial condition of leprosy patients, this will get heavier if the leper is the foundation of life and livelihood for his family (5). Patients with formal or informal work, namely on self-employment and private employment tend to experience negative self-concept compared to patients with non-formal jobs. This is because in informal work that is actually an entrepreneur and private employment as service provider in their work having a higher stressor because they work to interact with the community. It showed that the sickness process especially in physical disability in leprosy patients gave impact of higher psychosocial disorders compared to patients with non-formal jobs. This condition can lead to a negative self-concept in formal worker patients with productive age.

The illness duration characteristics of leprosy patients with negative self-concept for about > 6 months. Chronic disease can lead to a diagnosis of self-concept disorder (17). The results showed that negative self-concept occurred in leprosy patients who experienced illness duration > 6 months. RFT treatment showed that leprosy suffered more than 6 months (chronic). Chronic diseases can cause self-concept disorder and cause stressors. The treatment effect of leprosy type RFT (Release From Treatment) is hyperpigmentation throughout the body, this can add to the stressor because it results in disruption of body image and self-esteem in leprosy patients.

According to Nursing Care in leprosy patients with self-concept disorder, interventions that can be performed by nurses include believing in the patient's identity, providing support to reduce anxiety levels, approaching patients in a way that does not demand, accepting and seeking clarification of verbal or non-verbal communication, preventing patients from self isolation, building simple routines for patients, orienting patients to reality, increasing activities and tasks that provide positive experiences, supporting patients in self-care. (6)

Relationship of Physical Disability with Self-Concept of Leprosy Patients in Kediri Leprosy Hospital

There is a relationship between physical disability and self-concept, with meaning of the higher physical disability, the lower the self-concept, whereas if the physical disability is lower then the self-concept is higher. Mann Whitney statistical test results based on the significance level

set $\alpha = 0.05$ obtained $p = 0.000$, where $p < \alpha$ which means that H_0 is rejected and H_a is accepted. So there was a significant relationship between physical disability and self-concept in leprosy patients in Specialty Leprosy Hospital Kediri. The table number Z was -4.838 meant that it had a significant difference in the level of correlation or strong relationship. The number of the Z table was negative that the two variables indicated the direction of the opposite direction. It showed that high physical disability caused a negative self-concept, and low physical disability caused a positive self-concept.

Humans are not seen merely from the physical aspect but are seen as holistic beings consisting of bio-psycho-socio-cultural and spiritual (18). Holistic is one of the concepts that underlie nursing actions that include physiological, psychological, sociocultural, and spiritual dimensions. This dimension is a unified whole, if one dimension is disturbed it will affect the other dimension (19). Every change in health can be a stressor that influences self-concept (6).

Based on the results of statistical tests obtained results on disability 0 experienced a positive self-concept (100.0%), the disability 1 experienced a self-concept that tended to be positive (54.8%), whereas in disability 2 tended to experience negative self-concept (83.3%). Based on the results of the study, it was found that the higher the level of disability in leprosy patients, the self-concept tended to be negative and vice versa. Leprosy patients with disability 0 had a positive self-concept because of the possibility of not feeling meaningful physical changes, so that patients could hide their illness to others and still be able to remain productive individuals. Leprosy patients with disability level 1 experienced positive self-concept. The concept of leprosy patients with disabilities 1 was likely to have changed from maladaptive to adaptive and able to be positively oriented to complete treatment.

Leprosy patients with disability 2 tend to have negative self-concept (83.3%). Self-concept is derived from new and previous experiences (6). Based on illness duration level disability level 2 had a longer time than disability level 0 or level 1. Chronic diseases can lead to a diagnosis of self-concept disorder (17). Physical disability level 2 is a permanent physical disability, can not return to normal. This theory is in accordance with the results of the study, that most (83.3%) respondents with physical disability level 2 in leprosy experienced negative self-concept. This can happen because at disability level 2 there are physiological changes such as drop-hand, drop-foot, etc. There are even some patients who have to undergo amputation in their productive age in the age range of 20-40 years. These conditions result in disruption of daily physical activity, disruption of body image, low self-esteem, loss of confidence, pessimism towards the future, and even antisocial, so that eventually psychosocial disorders occur with negative self-concept in the leprosy patient.

The results of cross tabulation between physical disability variables and self-concept of leprosy patients were found in disability 1 and disability 2 totaling 81 respondents, while for the percentage results obtained in physical disabilities 1 and 2 with positive self-concept totaling 43 respondents (53%) and physical disabilities 1 and 2 with negative self-concept totaling 38 respondents (47%). According to researcher in patients with disability 1 and 2 there were still patients who had a positive self-concept due to many influences. These influences are in

accordance with Fitts' theory, namely the external dimension, namely the physical self, the moral self, the personal self, the family self and the social self.

Medical treatment will be better if supported by non-medical rehabilitation. Non-medical rehabilitation includes mental rehabilitation, work rehabilitation and social rehabilitation can support the treatment of leprosy patients (5). This can support changes in self-concept to be adaptive by returning leprosy patients to be independent and productive individuals despite their physical limitations.

CONCLUSION

Leprosy patients in the productive age of 20-40 years more than 50% had a physical disability level 1 (65.6%), had a negative self-concept (44.8%) and had a positive self-concept (55.2%). Physical disability in leprosy patients was related to the decreased self-concept of leprosy patients.

The high incidence of disability in leprosy patients in the productive age needed to be attempted to prevent further physical disability with appropriate treatment and self-care in leprosy patients to prevent injury or wound to their limbs. Increased knowledge of leprosy patients in this prevention can be done by providing health education for patients and involving families. The results showed that self-concept related to physical disability especially in productive age leprosy patients needed to strive to improve self-concept through improving the life productivity of leprosy patients, some things that could be done were through vocational therapy by providing special skills that could increase life productivity.

Declarations

Authors' contributions

In this article, each author has its own contribution. Fidiana Kurniawati as main author and researcher, Erlin Kurnia, S.Kep, Ns., M.Kes as first supervisor, and Akde Triyoga, S.Kep., Ns as second supervisor.

Consent for publication

Not applicable

Availability of data and materials

The original data in this article will not be shared because author thinks its research privacy. If need more information, author can be contacted through the information about corresponding author above.

Competing interests

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