20. Adaptive Strategy of Women`s Leprosy in Indonesia

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Adaptive Strategy of Women`s Leprosy in Indonesia

Psychic Experience of Women with Leprosy in Living a Community Life

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ABSTRACT

This study aims to explore the psychological burden of leprosy women and their adaptive strategies. Leprosy has a destructive character and is opportunistic in nature, so that it becomes a burden for women because of the defects in the body and the resulting beauty crown. The study was conducted at the Center for Public Health in Eastern Indonesia with a purposive sampling method on 17 leprosy women. The interview became the most dominant instrument, and the results were analyzed by Phenomenological Analytical Interpretation. The result: mental stress is part of everyday life; physical conditions that are far from aesthetic value; guarantee of happiness that is difficult to obtain by sufferers; it is necessary to find a method to surrender to the trials received. The final conclusion shows that the psycho-emotional suffering caused by leprosy can be reduced through efforts to surrender to the trials received, to obey God's commands in any situation and to His servants to always try and pray and remain steadfast in maintaining the role, function and duty as a woman even though constrained by leprosy that accompanies.

Keywords: Adaptive strategy, women with leprosy, psychic experience, Indonesia

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INTRODUCTION

Women experience many problems when suffering from leprosy, because the characteristics of the disease are very destructive to the body and are opportunistic, thus placing them as a frightening monster for women [1], [2]. Besides affecting the physical condition [3], leprosy can also damage the beauty crown [4]. The Weekly Epidemiological Record notes that leprosy endemic disproportionately affects the permanent disability of women in the world, namely 34% of the leprosy population at the end of 2019 [5], and around 17.3% of sufferers in Indonesia also experience permanent disabilities with the proportion experienced more than men [6]. In fact, other studies have reported sexual harassment of women with leprosy [7].

Based on the experience of the sufferer, leprosy can be a very heavy burden, because it accepts physical, psychological and social consequences based on the severity of the disease [4]. Some sufferers then try to balance physical and social stresses, but women with leprosy do not yet have enough ability to meet the demands of society, so the adaptation strategy chosen tends to be mal-adaptive [8], [9], even though it is very much needed to improve their mental health [10].

Leprosy is always associated with traumatic events, depression and anxiety which can cause psycho-emotional problems [11], [12]. This is experienced by leprosy women throughout their lives [10], so they sometimes find it difficult to be the best in their lives [13]. This is what requires the sufferer to be able to adapt to a stressful environment [14]. Regarding the perceived challenges, there are several differences depending on their own expectations [15] and their relationships in family and society (Bakare et al., 2015; Nasrudin et al., 2018) and depending on their values and beliefs to recover [10].

In general, women with leprosy feel the burden of suffering which is always associated with social stigma, attitudes of self-stigmatization and discrimination [18], [19]. This atmosphere greatly affects their quality of life [20], [21], so that the leprosy status they receive is very painful {Formatting Citation}. These various problems make it difficult for all lepers to get out of the problems they face and there is a demand for the ability to be independent in overcoming their disease [25], [27].

Even interactions in groups that produce negative perceptions of leprosy can affect their environment [28] and sufferers are also not ready to engage in self-care practices, so they are often late for treatment [29] which leads to permanent disability [30]. Based on the description above, the need for mental nursing services, especially religious spiritual nursing practice to overcome their psycho-emotional problems, is overall very important to be presented so that people with leprosy are free from physical and psychological and social pressure [31], [32], and women with leprosy are no exception. Through religious spiritual practice, this study aims to examine the psychological experiences of women with leprosy in living in society.

RESEARCH METHODS

This study uses qualitative phenomenology to explore leprosy women about their psychological burden and adaptation strategies as meaningful experiences [33], [34]. The process of recruiting participants used a purposive sampling technique among outpatients. At the Public Health Center, researchers meet with health workers to confirm potential participants by checking participant data, medical diagnoses and drugs given to ensure the correctness of participants who match the WHO classification of leprosy patients, including patients who qualify as respondents.

Researchers have determined the inclusion criteria in this study, namely: (1) leprosy women who are registered at the Community Health Center, (2) Multi Baccilare leprosy type, (3) Still actively undergoing treatment programs. Data collection on the selected sample was carried out until it reached data saturation, and data saturation was achieved in the 17th sample, because it could no longer find new information [35].

Before collecting the data, the researcher has prepared an interview guide to remind the researcher of the topic and ensure that all the main topics have been studied in depth, related to their psychological burden and adaptation strategies as a meaningful experience and prepare data recording devices and ensure data recording devices are ready to use after through various trials. Following the informed written consent terms, each participant participates in a recorded, semi-structured interview. Interviews were conducted in September 2019 - February 2020. Researchers conducted in-depth, semi-structured face-to-face interviews with women (wives) in a semi-structured manner in the hope of obtaining complete data, interviews were conducted individually in the hope of gaining a deeper understanding of the experience in accordance with what is I'm researching [36].

Data analysis used the Interpretative Phenomenology Analysis approach [37]. Through a selective approach, interview transcripts and field notes are carefully matched and repeated to find actual themes by reading sentences carefully, then categorizing important words that are interrelated [38]. Along with this concern, researchers maintain openness through reflecting on various interpretations to monitor assumptions and bias through the triangulation process with participants [35]. Researchers seek to gain understanding and engagement with texts related to the phenomenon under study. Each analyzed sentence is confronted with the data in the note field. Furthermore, through the inductive approach method, a thematic analysis is carried out. These themes are then reconstructed into descriptions of experiences experienced by women (wives) with their husbands suffering from sexual dysfunction [39].

This research has also fulfilled the elements of qualitative research principles. Oral and written information regarding the purpose of the interview study, procedures and the right to refuse or withdraw at any time was provided to all participants. There is no identity on the participants and the results of the interview are stored together with the data. Anonymity and confidentiality were secured by labeling the interview transcript with the interview number and participant identification key [38].

LITERATURE REVIEW

Several studies related to public perceptions of leprosy in general and the impact felt by lepers have been carried out. Among them, a study conducted by Marahatta et al (2018) explained that the community views leprosy as a frightening disease, this has an impact on leprosy sufferers who are shunned by the community, so that this condition causes lepers to be far from an established job and difficult to find partners and obstacles in social interactions [27]. Meanwhile, others highlighted the experiences of leprosy women related to the burden they feel on the dimensions of their life, including the fulfillment of their sexual needs. Among them are research conducted by Noordende et al. (2016), explained that leprosy women are very vulnerable to violent behavior and sexual harassment in their domestic life [7].

The study related to the impact of leprosy on women is broadly explained through a systematic review of the study by Somar et al. (2020), which explains that besides the stigma the sufferer feels, it is also experienced by his family. According to this study, the impact of stigma that is received can cause psycho-emotional problems and is felt by leprosy women and their children [10]. The results of the research of Jatimi et al. (2020), concludes that after leprosy sufferers go through various kinds of stressors, they make themselves a tough person through various adaptations. This adaptation includes taking lessons, being an energetic and creative person, like to help others and always having active coping and adaptive conditions that are unpredictable, being more productive and showing helpful behavior for others [40].

RESEARCH RESULT

A total of 17 participants in this study with participant ages between 14 - 65 years, all of whom were Multi Bassiler type leprosy. The burden of disease that is felt due to leprosy is summarized in four main themes: (a) Mental stress is a part of daily life, (b) Physical conditions that are far from aesthetic values (c) Guarantee of happiness that is hard to come by, (d) Trying to find a point certain to surrender to God for the suffering that befell him.

Mental stress is a part of everyday life

This sub-section reveals the heavy burden of leprosy sufferers which is an inseparable part of their cognitive assessment. The following are the expressions of several participants regarding leprosy:

> "... I had to live with this long tenure, even though I had to go through many obstacles, especially ridicule from people, so I recovered quickly" (P. 10).

> "... I always have to do self-care every day so that it doesn't spread to other people, and I have to provide free time and sometimes miss what opportunities I should get" (P.6).

In addition, the shadow of the impact of leprosy and the accompanying disability can defeat the disease itself, so that it feels very painful. One participant stated:

> "... everywhere I have to carry my disability ... I have to think again to shake hands with people because of my disability (contracted fingers)" (P.3).

> "I sometimes have difficulty answering questions about my disability, so I say that the disability in my hands is due to being scalded" (P. 12).

> "I am afraid that people do not want to buy my wares (home industry: crackers), because I suffer from this disease, and I respond by selling this merchandise online, so I keep my house a secret" (P. 17).

> "I am saddened by the story of my son who was always shunned by his friends because of the illness I was suffering from. I am very disappointed, because my child is the victim of his friend's taunts" (P.4).

Stigma and discrimination are ghosts for women affected by leprosy, so that not many people are willing to use their energy and ignore their abilities. Several participants expressed their complaints:

"Until now I am unemployed, because no one wants to give me my job. When I was about to be accepted at work, I was told to ask for a health certificate by the company ... so that I was not accepted as an employee." (P. 15).

"Actually, I wanted to help my husband by looking for a job ... I was refused to be a shop assistant because my hand was disabled" (P. 2).

"I was forced to leave my job, because I was suffering from this disease and I only concentrated on healing the disease. (P. 13). Some leprosy women also stigmatize themselves so that they feel excessive fear of losing their future, here are their opinions:

"I am still young, I don't have a husband, I will give up if no one wants to marry me. I asked myself, is there anyone who wants to marry someone like me? " (P. 8).

"I am afraid that my husband will find out about my illness, surely he will be disappointed and will leave me. If I take medicine, I have to make an appointment with the health worker, I must recover from this disease without my husband knowing." (P. 11).

"My husband once suspected that my disease was leprosy. When I first went to the doctor in practice, the doctor said that my disease was due to sun allergies. If the doctor didn't say that, then it would be a different story." (P. 9).

"When I sleep at night, I turn off the lights. So that my husband doesn't feel uncomfortable and doesn't know what spots are on my body. I don't want my husband to leave." (P. 4).

Physical conditions that are far from aesthetic value

During the interview, some participants did not question the pain they had suffered, but what they thought was the physical impact they had received. As a woman, beauty is the crown of life, but due to changes in body shape from the risk of leprosy, some participants experienced impaired self-image. Several participants expressed the physical burden they received:

"I also feel uncomfortable with my skin, which looks dry. Using any moisturizer still looks shiny. But if left untreated, then this skin looks dry scaly (skin on the feet). " (P.16).

"The sores on the soles of my feet are always watery and smelly, and they smell bad. I am sad when I meet many people." (P,14).

"Is this defect (hand contracture) not going back all the way?" (P. 7)

"When I started to have red spots on my face, I was shocked and weak. It seems that the facial skin care I have been doing is useless. So, at the first time the red spots appeared, I was afraid to go out of the house." (P. 15).

Failure to achieve beauty and the role that the body represents has dashed hopes of being attractive and alluring. Some of the participants expressed their psychological burden.

"I can only regret, since there are red spots on my cheeks. I am not beautiful anymore. I feel embarrassed, if I meet old friends. " (P.13).

"I am ashamed to wear jewelry with this deformed hand. It felt like there was something else about me. " (P. 12).

"I am ashamed to meet many people, because my skin is not what it used to be, and if I take medicine, I have to make an appointment with the health worker in the morning or afternoon, waiting for the service to finish." (P.10)

Various attempts have been made to maintain the beauty of her body. Due to the influence of the permanent disability from leprosy, so that people with leprosy feel that their efforts are not satisfactory, several participants revealed:

"I always use oil to keep my skin moisturised according to the advice from health workers. By following these suggestions, the benefits I get are not there. My skin always looks dirty because it looks smooth and shiny. " (P. 16).

"The various powders I use can't get rid of the red spots on my face." (P. 13).

Guarantee of happiness that is hard to come by

This finding reflects an unpleasant emotional atmosphere, because it dissolves in prolonged sadness due to the apportunistic and destructive nature of leprosy. From this existing stigma, several participants expressed the constraints in their environment:

"Friends who used to be close to me now rarely see me. Maybe afraid of catching it, knowing my illness. " (P.8).

"My children were unusual in seeing me before. I am sad now, because they stay away from me, since knowing the condition of this disease. " (P. 4).

"My relatives are now far away. They are afraid of catching my illness. When discussing inheritance, I was only told the results, without inviting me, even though I have the right to express my opinion. " (P.2).

On the other hand, some respondents felt more suffering as a result of the leprosy they suffered, so they tried to hide the disease: Several participants revealed:

"Sometimes I feel that I am not human, so I think that I will leave my home and be away from my family." (P.6).

"My family is embarrassed because I have this disease (leprosy). Now my family rarely takes part in an activity called "Jamaah Yasinan", because I am

> ashamed of the leprosy that I have experienced. " (P. 7).
>
> "Until now, my children and nephews don't know about the leprosy that I have. Only my husband knows, and I will keep this until I recover from this disease. " (P.12).
>
> Some of the participants also felt a deep sadness as a result of losing the role of mother of their children. Some of the participants also expressed their wishes:
> "I really wish I could caress, sit side by side and joke with the children, but he keeps avoiding, feeling scared because I have this disease (leprosy), even though I gave birth to him." (P.15).
>
> "I was forced not to give my milk (ASI) to my child who is 5 months old. I replace it with formula milk. My baby is being cared for by my husband and oldest child. " (P.14).

Looking for a certain point to surrender to God for all suffering

This section reflects the spiritual approach of the leper as a starting point to find the true meaning of life for the test given by God. For the majority of sufferers, it is assumed that an approach to spirituality can produce a place to accept oneself unconditionally as an extension of God. Some of the participants tried to take a religious approach, among others, it can be seen in the following expression:

> "God gave the disease and I believe God also gave the medicine. For me, this is a test that I must go through, and I still have to try so that I can get the medicine that can cure my disease. " (P. 13).
>
> "If I die from leprosy, then I will accept it as God's destiny and I sincerely accept it and I must live it." (P.14).
>
> "For me, this illness that I suffer is a warning from God to me, so I have to get closer to God." (P.11).

The state of sincerity in accepting leprosy is the meeting point between life's journey and God's destiny. One participant said that the ordeal given to him was a sign that God loved him. The following are excerpts from the interview:

> "I believe God is with us. I sincerely accept this trial. God's trials will not exceed the abilities of a servant. " (P.16).
>
> Furthermore, another participant said:
> "I believe that God has other plans for me, and those plans must be for my good. I sincerely accept this trial; I hope I will get closer to God. " (P.13).
>
> "Let everyone hate me, but I believe God really loves me. Maybe this is the best way for me, so I have to accept it as it is. " (P.5).
> The religious approach is the key to all assessments of human actions, then trying and praying are God's commands that must be carried out. One participant strongly believes in the teachings of religion, that humans are only tasked with seeking healing and not healing disease:
>
> "The religion I believe has taught me to accept what is inside of me. My religion also always recommends making every effort and praying that my disease will be quickly removed from my body so that it will heal. " (P.7).
>
> One of the other participants put it this way:
> "God has given disease, and there must be a cure. Hopefully the medicine given is right for me, so that I can recover. " (P.9).

DISCUSSION OF RESEARCH RESULTS

This study, which focuses on the psycho-emotional responses felt by leprosy women, aims to understand the burdens they feel and how to adapt them. This study brings a new color from previous studies that highlight the psycho-emotional burden, so that the impact of leprosy has influenced the aesthetic value of changes in body shape. In addition, physical, psychological and social stresses are an inseparable part of any narrative given during the interview. It also negatively affects the dynamics of their daily lives because of the prevailing social stigma. Changes in body structure which is one of the dominant factors in several problems in leprosy women, so that they feel very tortured due to changes in skin color [41], feel useless because the disease is accompanied by disabilities [22], [42]. Quality stressors to psycho-emotional responses, stigma and discrimination can result in prolonged psychological distress for people with HIV-AIDS [43]. The participants also felt the environmental conditions so strongly that they felt the social stigma and discrimination that had an effect on their psycho-emotionalism, such as losing their job, being refused a shop assistant because of their handicapped hands [25], [27].

However, one participant tried to fight social discrimination by selling merchandise online and hiding his home address. This is done to assist the husband in improving the family economy amidst threatening psychological pressures. Another finding from this study, some leprosy women attributed changes to the body with aesthetic values, so that they feel no longer beautiful after red patches stick to their faces, even though they have performed self-care. In addition, they also feel that it is not appropriate to use the ring with a contracted hand, which affects their self-concept. This is a major stressor for women who crave a beautiful and charming face to meet their social status needs in maintaining their existence when interacting with others (Bhattacharya, 2012; Kim & Lee, 2018), especially for women who still don't have a partner [47]. Thus, the changes that occur in the body, will be difficult for many women to accept, so that it can add to the burden of prolonged psycho-emotional suffering [4]. However, there are several attempts to maintain an ideal body in order to maintain their social status and have proven effective in improving their self-image, so they routinely go to the salon [48], and limb reconstruction surgery is not ideal [49], [50].

Apart from all that, this study has found other habits of women with leprosy, namely taking medicine when visitors are quiet or making an appointment with officers outside the clinic to check and take medicine. This can bring about a big change in the behavior of lepers in seeking treatment, who previously were lazy to come for treatment because of the psychological burden due to stigma and discrimination.

This study found that there were participants who felt helpless to get a partner. This is a very serious problem related to the future for women who do not have a partner [51]. One young participant expressed deep concern about the opportunity to find a partner due to leprosy, but this feeling is not felt by all women.

The results of other studies reported that women still feel happy and retain their "own" status into old age because of pursuing careers [52], as well as a lifestyle for women today [53], and as their choice of life [54]. In addition, unpleasant past experiences also affect their current life and the way they view their future, so that it is a major predictor of why women should maintain their solitary status [55].

Leprosy women who have had partners, some of the participants expressed their feelings about the potential for disability in the course of their disease which was felt to be very sad, where stigma and discrimination were part of a situation that could destroy their future [10]. Some of the participants expressed their concern that their husbands would divorce because of suffering from leprosy, so they tricked their husbands by not telling them about their illnesses and even one participant always turned off the bedroom light when together at night.

This is in line with the findings of other studies that report the efforts of leprosy women to maintain household integrity amidst the threat of divorce due to leprosy [7]. However, some of their husbands accept and support and remain loyal to their partner because of the presence of their child, so mental health nurses should be present to discuss the advantages and disadvantages when a couple separates because of their children [61], [64], discussing the chosen strategy for maintaining the integrity of the household [60], and discussing the appropriate actions to support the wife in getting cured of illness [[61].

Religious spiritual practice is the most effective strategy used by participants to overcome their psycho-emotional suffering. Participants tried to relate psycho-emotional suffering to their God by believing that it was God's will. This is in line with other research that supports a positive relationship between religious spiritual practice and emotional well-being for chronic diseases that have a high negative stressor effect (Ballew et al., 2012; Barakat et al., 2019; Bredle et al., 2011).

The majority of women in our study discussed efforts to find God's point by remaining resigned to the trials received and always praying and obeying God's commands. Spiritual and religious practices have also been identified as major coping strategies in the problem of psychological distress and are particularly appropriate for older women with leprosy (Lutfi et al.,). Leprosy patients often associate their illness with God's destiny and suggest self-management. In addition, religious spiritual values are very important to be practiced in nursing services to provide psycho-emotional support [67], [68].

CONCLUSION

This research focuses on the life experiences of leprosy women in the form of psychological burdens and how their adaptation strategies in increasing self-confidence due to leprosy. The disease has had an impact physically, psychologically and socially, thus affecting the pattern of life in society. Religious spiritual practice through resigning to the trials that are received, remaining obedient to carrying out God's commands in any situation and always praying, are very important to be applied in managing this psycho-emotional suffering. This shows that the adaptation of psycho-religious in leprosy women is able to pass tests and trials, which in the end all of them are returned to the greatness of God, and for His servants to always try and pray and remain firm in the belief in God's success and destiny, so that they can live life. better, more meaningful and more efficient

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