

Review Article: Systematic Review

STRESSORS IN LEPROSY WITH DISABILITY: A SYSTEMATIC REVIEW

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Abstract

Background: Psychological pressure on leprosy sufferers can be triggered by changes in individual health conditions that can cause stress. The stress experienced by leprosy sufferers can be reduced by identifying the causes of stress, to determine the right efforts to deal with psychological problems in leprosy sufferers.

Objective: This systematic review aims to determine the stressors in leprosy patients with disabilities.

Design: Database search includes Google Scholar, PubMed, and Researchgate from 18-21 November 2022 with the keywords Leprosy, disability, and stressor. The criteria for the selected articles are published in 2018-2022 with full text, in Indonesian and English. the Joanna Briggs Methodology model was used to analyze 15 selected articles to find the main themes in the preparation of the Qualitative Systematic Review.

Result: the results of the analysis of the articles that have been carried out show that the cause of stress in leprosy sufferers, there are three main themes identified, namely self-stigma as a psychological aspect, disability as a physical aspect, and public stigma as a stressor in a social aspect.

Conclusion: the findings show that the causes of stress in leprosy sufferers can come from psychological, physical, and social aspects that affect leprosy sufferers. this makes the three main themes that have been identified to help lepers to reduce stress.

Keywords: Stressors; Leprosy; Disability

INTRODUCTION

Leprosy sufferers who are in the community often experience psychological pressure after being diagnosed (Sekarningrum & Yunita, 2017) such as stress (Jatimi, Nenobais, et al., 2020), depression (Nugraheni, 2016), excessive worry (Jatimi, Yusuf, et al., 2020), and unhealthy social life (Grzybowski et

al., 2016). This psychological pressure can have an impact on the social life of lepers in the community (Dadun et al., 2017) which is characterized by withdrawal (Jatimi, Yusuf, et al., 2020), social isolation from the environment (Zamparoni, 2017) and discriminatory behavior from society (Sodik, 2016).

Discriminatory behavior from people in the community (Hidayat et al., 2020) as well as the labeling given by other people to people with leprosy triggers the emergence of psychosocial problems (Syahrul, 2019) such as impaired self-concept (Nugraheni, 2016), and hopelessness (Rodrigues Nóbrega Videres et al., 2016). This problem can affect the adherence of leprosy sufferers in undergoing therapy (Saputri et al., 2017). In addition, leprosy sufferers experience changes in health conditions and physical changes which are characterized by disability (Rismayanti et al., 2017).

Disabilities in leprosy sufferers occur along with the development of the disease after clinical symptoms appear (Widya et al., 2019). However, this can be overcome with appropriate treatment for new leprosy sufferers (Netherlands Leprosy Relief, 2018) to minimize disability. Disabilities suffered by individuals after adulthood (Govindharaj, Srinivasan, Darlong, et al., 2018) as well as disturbances in social life originating from the negative stigma of society (Van'T Noordende et al., 2020) can trigger psychological distress (Zaki et al., 2020) so it needs to be addressed.

The aim of this systematic review was to explore and summarize the stressors experienced by leprosy sufferers in society in various aspects based on the results of qualitative article conducted by researchers which described the various conditions of leprosy sufferers causing psychosocial problems.

METHODS

Design

This systematic review is a narrative synthesis of articles that uses the Joanna Briggs Methodology model for Qualitative Systematic Reviews (Efendi, 2019). Qualitative Evidence Synthesis (QES) analyzes data findings from published qualitative research to enable researchers to answer specific research questions by systematically reviewing evidence using the JBI method (see on table 1).

Search articles using databases including Google Scholar, PubMed, and Researchgate with the keywords disability, leprosy, and stressors. The next stage is to select articles according to the criteria, namely published in 2018-2022 with the complete text, in Indonesian and English, with inclusion criteria, namely the article discusses psychological problems in leprosy sufferers and their causes, leprosy sufferers are in the community and use research methods qualitative (see on table 2 and table 3). while the exclusion criteria were articles about lepers in general, with clinical problems and unpublished research.

Search for articles by researchers starts from 18 to 21 November 2022, with predetermined keywords. The researcher deleted 93 articles that were the same and irrelevant and not accessed fulltext, examined articles that met the criteria, and grouped them according to the results of the research to proceed to the discussion. This Systematic Review uses 15 selected articles that have been analyzed.

RESULTS

According to the review of the selected articles, three main themes regarding stressors in leprosy patients were identified, namely self-stigma, disability, and public stigma.

Self-Stigma

Stigma towards oneself occurs in leprosy sufferers due to failure to accept changes in health conditions, which triggers psychological pressure and results in stressful events for individuals (Jatimi, Yusuf, et al., 2020). The stress in question is in the form of psychological pressure which has an impact on the psychological health of lepers (Nugraheni, 2016). As the following statement;

Leprosy sufferers label themselves negatively (Jatimi, Yusuf, et al., 2020) (Rai et al., 2020).

Have negative perceptions of themselves (Muhammad Najmuddin, 2021).

And have feelings of self that are different from other people because of a diagnosis of leprosy (Van Netten et al., 2021)(Arisal et al., 2020).

Disability

Disability in leprosy sufferers is one of the causes of stress in the physical aspect which is part of changes in individual health status(Rismayanti et al., 2017). As the following statement;

Table 1. Joanna Briggs Institutecheck list

Criteria	(Jatimi, Yusuf, et al., 2020)	(Aditya, 2020)	(Muhammad Najmuddin, 2021)	(Jufriyanto et al., 2020)	(Hidayat et al., 2020)	(Nasir et al., 2022)	(Van Netten et al., 2021)	(Dako-Gyeke, 2018)	(Correia et al., 2019)	(van Wijk et al., 2021)	(Rai et al., 2020)	(Van'T Noordende et al., 2020)	(Gunnara et al., 2020)	(Arisal et al., 2020)	(Sa'diyah & Arsi, 2022)
Is there congruity between the stated philosophical perspective and research methodology?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and representation and analysis of data?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there congruity between the research methodology and interpretation result?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is there a statement locating the researcher culturally or theoretically?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the influence of the researcher on the research, and viceversa, addressed?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Are participants, and their voices, adequately represented?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body?	Yes	Unclear	Unclear	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Unclear	Unclear	Unclear
Do the conclusions drawn in the research report flow from the analysis, orinterpretation, of the data?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Total	10	9	9	10	10	10	10	10	9	10	10	10	9	9	9

Table 2. Study characteristics (Country, title & purpose)

Author (Year)	Country	Title	Purpose
(Jatimi, Yusuf, et al., 2020)	Indonesia	Leprosy Resilience with Disabilities Due to Illness: A Qualitative Study	to explore the experience of leprosy sufferers with disabilities to achieve resilience.
(Aditya, 2020)	Indonesia	Exploration of Active Coping in Leprosy Patients: Qualitative Methods	to explore in depth how to maintain active coping in leprosy patients
(Muhammad Najmuddin, 2021)	Indonesia	Stigma Against Leprosy: A Review of Interpersonal Communication	to identify self-stigma and public stigma related to leprosy in a review of interpersonal communication
(Jufriyanto et al., 2020)	Indonesia	Psychosocial Experiences in Ex-Leprosy Patients: A Qualitative Study	to identify the psychosocial experiences of ex leprosy in living their social life.
(Hidayat et al., 2020)	Indonesia	Phenomenology Study: Community Perception of Lush Disease In The Working Area of Puskesmas Talango	to identify in-depth information about people's perceptions of leprosy
(Nasir et al., 2022)	Indonesia	The life experience of leprosy families inmaintaining interaction patterns in the family to support healing in leprosy patients in Indonesian society. A phenomenologicalqualitative study	to identify how the experiences of family members as caregivers provide assistance to individuals with leprosy in improving healing and maintaining patterns ofinteraction in the family.
(Van Netten et al., 2021)	Nepal	Mental wellbeing among people affected by leprosyin the Terai region, Nepal	to our knowledge there have been no studies on the factors influencing mental wellbeing among peopleaffected by leprosy
(Dako-Gyeke, 2018)	Ghana	Courtesy stigma: A concealed consternation among caregivers of peopleaffected by leprosy	This study explored experiences of courtesy stigma among caregivers of people affected by leprosy
(Correia et al., 2019)	Nepal	“If you will counsel properly with love, they willlisten”: A qualitative analysis of leprosyaffected patients’ educational needs andcaregiver perceptions in Nepal	to explore the educational needs of leprosy affected patients in Nepal and compare them to the needs perceived by HCWs
(Van Wijk et al., 2021)	Colombia	Psychosocial burden of neglected tropicaldiseases in eastern Colombia: an explorativequalitative study in persons affected by leprosy,cutaneous leishmaniasis and Chagas disease	To explore the dimensions of stigma, mental distress and participation restriction related to the PSB experienced by people affected by CD, CL or leprosy
(Rai et al., 2020)	Indonesia	Qualitative Exploration of Experiences and Consequences of Health-related Stigma among Indonesians with HIV, Leprosy,Schizophrenia and Diabetes	to explore experiences and consequences of stigma among people affected by four health conditions relevant in Indonesia
(Van’T Noordende et al., 2020)	Ethiopia	The impact of leprosy, podoconiosis and lymphatic filariasis on family quality of life: A qualitative study in Northwest Ethiopia	looks at the impact of leprosy, podoconiosis and lymphatic filariasis on family quality of life.
(Gunnara et al., 2020)	Indonesia	Qualitative study of the existence of leprosy in Dendun Village, Mantang District, Bintan	To analyze the presence of lepers
(Arisal et al., 2020)	Indonesia	Social Discrimination of Children with Leprosy in Makassar City	To find out how the process, causes and impacts of discrimination in children with leprosy
(Sa’diyah & Arsi, 2022)	Indonesia	Social discrimination against former leprosy sufferers in the community	To find out the forms of discrimination received by leprosy sufferers and how to overcome them

Leprosy sufferers experience disabilities in adulthood so it is more difficult to achieve acceptance of changes in physical condition(Aditya, 2020)(Van Netten et al., 2021)(van Wijk et al., 2021)(Jatimi, Yusuf, et al., 2020).

Public Stigma

The negative stigma received by individuals in the community after being diagnosed with leprosy comes from the community around where they live, work, or

while using public facilities. As the following statement;

Leprosy sufferers receive a negative stigma from society(Muhammad Najmuddin, 2021)(Jufriyanto et al., 2020)(Hidayat et al., 2020)(Van Netten et al., 2021)(Dako-Gyeke et al., 2017)(van Wijk et al., 2021)(Rai et al., 2020)(Van et al., 2020)(Gunnara et al., 2020)(Sa'diyah & Arsi, 2022).

Table 3. Study characteristics (Research method)

Author (Year)	Design	Data Collection Method	Data Analysis Method
(Jatimi et al., 2020)	Qualitative research design	In-depth interviews used interview guidelines and field notes	Theme analysis
(Aditya, 2020)	Qualitative research design	In-depth interviews and field notes	Colaizzi data analysis
(Muhammad Najmuddin, 2021)	Qualitative research design	In-depth interviews	Themeanalysis
(Jufriyanto et al., 2020)	A phenomenological descriptive qualitative research method	In-depth interviews used interview guidelines and field notes	Colaizzi data analysis
(Hidayat et al., 2020)	Qualitative research	In-depth interviews used interview guidelines and field notes	Themeanalysis
(Nasir et al., 2022)	Qualitative research	Semi-structuredinterviews	Interpretative Phenomenology analysis
(Van Netten et al., 2021)	Aqualitative approach	Interviews	Themeanalysis
(Dako-Gyeke, 2018)	Aqualitative approach	In-depth interviews	Themeanalysis
(Correia et al., 2019)	Qualitative research	Semi directive interviews	the basic interpretative qualitative framework
(Van Wijk et al., 2021)	Qualitative research	Semi-structuredinterviews	Themeanalysis
(Rai et al., 2020)	Qualitative research	Interviews	Themeanalysis
(Van'T Noordende et al., 2020)	A cross-sectional design used a qualitative approach	Semi-structuredinterviews	Themeanalysis
(Gunnara et al., 2020)	Aqualitative approach	In-depth interviews	Content analysis
(Arisal et al., 2020)	Qualitative research	Observation, interviews and documentation	Descriptive analysis
(Sa'diyah & Arsi, 2022)	Qualitative research	Observation, interviews and documentation	Descriptive analysis

DISCUSSION

Psychosocial problems in leprosy sufferers are triggered by stressors in various aspects of individual life such as psychological aspects (Couto Dal Secco et al., 2017) which is characterized by the presence of stigma against oneself (Jatimi, Yusuf, et al., 2020), physical aspects such as disability (Rismayanti et al., 2017)(Widya et al., 2019), as well as social aspects such as negative stigma from society (Govindharaj, Srinivasan, & Darlong, 2018).

Stigma towards oneself in leprosy sufferers often shows maladaptive behavior such as labeling (Yudanagara, 2020) and discriminatory actions towards oneself (Ariani et al., 2019) which can trigger stress in individuals with leprosy (Nugraheni, 2016). Leprosy sufferers who exhibit stressful behavior are also caused by disabilities.

Disabilities that occur in new leprosy patients are often triggered by delays in treatment (Jaya Maulana & Arun, 2019) and diagnosis (Siregar & Ratnawati, 2018). These conditions can encourage individuals to experience stress caused by failure of self-acceptance (Widya et al., 2019) due to disability in adulthood. In addition, the disability in leprosy patients also has an impact on the social life of individuals (Irham et al., 2022).

The social interaction of leprosy sufferers with disabilities in the community is influenced by the presence of negative stigma from the public (Govindharaj, Srinivasan, & Darlong, 2018) which causes discomfort in the psychological aspect (Utami et al., 2017) such as the emergence of maladaptive behavior that shows signs of stress symptoms (Williams et al., 2019).

CONCLUSION

The identified stressors in leprosy sufferers consist of three aspects, namely psychological aspects such as self-stigma, physical aspects such as disability and social aspects that come from public stigma.

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CONFLICT OF INTEREST

There is no conflict of interest.

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AUTHOR CONTRIBUTION

Author 1:

Determining topics, analyzing data and compiling manuscripts.

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Help first author to find data.

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