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Behavior of patients with leprosy in disability prevention through patients' self care: A literature review

Mujib Hannan

Doctoral Student, Faculty of Public Health, Universitas Airlangga, Surabaya, Indonesia

Hari Basuki Notobroto

Faculty of Public Health, Universitas Airlangga, Surabaya, Indonesia
Corresponding author email: haribasuki.n@fkm.unair.ac.id

Syaifurrahman Hidayat

Faculty of Health Science, Universitas Wiraraja, Madura, Indonesia

Elyk Dwi Mumpuningtias

Faculty of Health Science, Universitas Wiraraja, Madura, Indonesia

Siti Nur Hasina

Department of Nursing, Faculty of Nursing and Midwifery, Universitas Nahdlatul Ulama Surabaya, Surabaya, Indonesia

Abstract---Poor self-care in people with leprosy can cause progressive damage because leprosy attacks the peripheral nerves, skin, hands and feet and eyes, so patients need good self-care. It is necessary to increase the active role of sufferers to seek information about leprosy and to increase routine self-care habits to prevent disability. Aim of this study for reviewing the relevant literature available on the behavior of people with leprosy in preventing disability through patient self-care. Literature study in 2018-2022, data obtained from databases include Scopus, *JSTOR*, *Science Direct* with the keywords leprosy, self-care, disability, behavior, and prevention. This literature study found 28 articles that match the criteria inclusion and exclusion. From the review of the article it is known about behavior of people with leprosy in preventing disability through self care of patients. The results of the literature review show that there are five sub-findings, namely factors related to the incidence of leprosy, stigma about leprosy, incidence of disability, self-care practices of patients, and behavior of people with leprosy to prevent disability. Factors related to the incidence of leprosy are age, gender, social

contact, care, personal hygiene, knowledge, education, occupation, income, and house density. The stigma possessed by lepers believes that leprosy is inherited, and is associated with unclean blood which is shameful and not accepted in society. The stigma arises because of the lack of knowledge of patients about leprosy. Delay in diagnosis, poor self-care and lack of information cause disability in leprosy patients. Behavior of leprosy patients to get used to self-care and increase muscle strength can reduce disability.

Keywords-- Disability, Leprosy, Prevention, *Self Care*.

Introduction

Leprosy is an infectious skin disease, chronic (old) caused by leprosy bacteria (*Mycobacterium leprae*) which attacks the skin, peripheral nerves and can attack other body tissues. This disease is chronic and rarely causes death, but often causes disability in the sufferer. Patients with leprosy generally experience physical disorders in the form of *lagophthalmos*, mutilation, *absorption*, blindness, curly fingers, secondary infections in wounds experienced and physical abnormalities. The disability experienced by leprosy clients begins with the entry of *Mycobacterium leprae* bacilli into the body which then moves into the nervous tissue and enters *Schwann* cells, then leprosy bacteria will damage the function of sensory nerves, motor nerves, and autonomic nerves if not immediately do a medication and early treatment will cause signs of disability in leprosy clients (Eldiansyah et al, 2016). People with leprosy need to do self care to reduce the risk of disability (Nadhiroh et al, 2018).

Self-care constitutes an adult's continuing contribution to his or her extremity, health, and well-being. This self-care describes and explains the benefits of self-care to maintain life, health and well-being (Alligood, 2014). Patients with leprosy with poor care will cause leprosy to become progressive, leprosy can cause permanent damage to the skin, peripheral nerves, hands or feet and eyes, so that by increasing self care it can improve the health of leprosy sufferers (Ministry of Health of Indonesia 2018).

Self-care can be useful for people with leprosy in wound prevention, a strategy is needed to implement a self-care program and test the use of footwear for people with leprosy. (Ilozumba & Lilford, 2021). In line with the research conducted by Meima et al (2008) revealed that there is a relationship between self-care and the incidence of leprosy defects. This self-care effort can be done alone or together with other sufferers by forming a self-care group (SCG).

The research of Noratikasari et al (2020) shows that the assistance provided by the facilitator is good. The role of the Self Care Group (SCG) in the good category includes helping solve problems, providing advice, monitoring, and referring. Kusuma et al (2019) in his research stated that self-care empowerment training for people with leprosy based on support groups with family assistance was effective in increasing the ability to self-care at home. In line with the research conducted by Handaris et al (2021) that there is an influence of family

psychoeducation on self-care of leprosy survivors. It is necessary to increase the active role of sufferers to seek information about leprosy and to improve routine self-care habits to prevent disability.

This *Literature review* provides some insights and challenges for health care professionals in carrying out an interpersonal approach to the self-care habits of lepers. The purpose of this literature review is to review the relevant literature on the behavior of leprosy patients in preventing disability through self-care of patients.

Method

self care of patients. Article searches using the keywords “*leprosy*”, “*self-care*”, “*disability*”, “*behavior*” and “*prevention*” in the Scopus database, *JSTOR*, *Science Direct* obtained 2,855 articles published in 2018-2022 that are relevant to the topic, but only 28 articles meet the inclusion criteria. The exclusion criteria are as follows:

- (a) the article does not meet the components of a good article (consisting of Abstract, Introduction, Methods, Results, Discussions, Implications, and References);
- (b) the content of the article is not relevant to the topic.

The stages and methods that have been carried out are (Figure 1):

- a. Finding Sources for Literature Review Materials or Literature Studies.

This stage is done by looking for quality literature sources or research articles.

There are 38 journal articles

- b. Perform analysis with *critical appraisal* of journal articles that have been obtained
- c. Compile a summary of the article
- d. Pouring in literature review writing

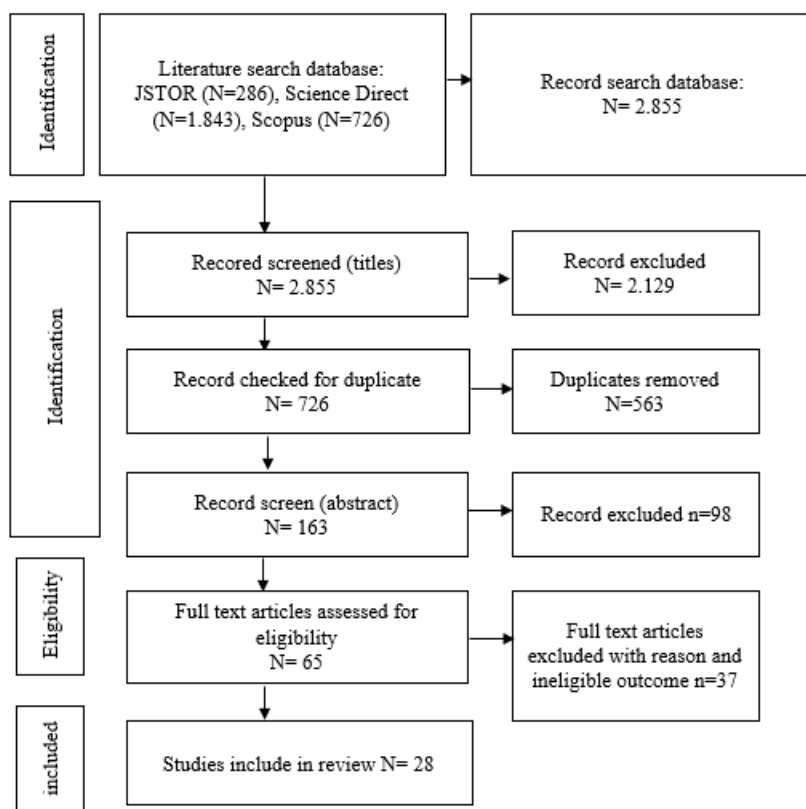


Figure 1. Flowchart Study or Article Selection for Systematic Review

Discussion

There are 2,855 articles identified on *Scopus*, *JSTOR*, and *Science Direct* databases with year of publication 2018-2022 relevant to the topic. Identification at stage *Records excluded* as many as 2,129 articles, *Duplicates removed* as many as 563 articles, and *Record excluded* as many as 98 articles, with the remaining 65 articles, then Eligibility data was carried out by categorizing *Full text articles excluded with reason and ineligible outcome* as many as 37 articles, finally a total of 28 articles research is taken for review associated with the behavior of leprosy patients in preventing disability through self care of patients.

Table 1
Study Characteristics and Findings

Author, Year	Country	Design	Subject	Aims
Owira Mallongi, Arry Pongtiku, AL antetampung, & Anwar Mallongi (2019)	Indonesia	Qualitative	6 people	To find out the stigma profile of leprosy sufferers in the district of

				Manokwari, West Papua Province
Ivaneliza Simionato De Assis, Thais Zamboni Berra, Luana Seles Alves, Antônio Carlos Viera Ramos, Luiz Henrique Arroyo, Danielle Talita Dos Santos, Marcos Augusto Moraes Arcoverde, Josilene Dália Alves, Juliane De Almeida Crispim, Flávia Menguetti Ciipriani5, Marco Andrey, Ione Carvalho Pinto, Carla Nunes And Ricardo Alexandre Ar êncio (2020)	<i>Brazil, Paraguay and Argentina</i>	<i>Ecological study</i>	New cases of leprosy reported in <i>Notifiable Disease Information System</i> (SI NAN) from 2003 to 2015	To analyze the dynamics of leprosy in order to identify areas at risk of disease and disability as well as places where health conditions are deteriorating.
Heloisy Alves De Medeiros Leano, Kleane Maria Da Fonseca Azevedo Araújo, Isabela De Caux Bueno, Eyleen Nabyla Alvarenga Niitsuma, And Francisco Carlos Félix Lana.,2019, in Portuguese, English or Spanish	Portugues e, English or Spanish	<i>Integrative review conducted in Lilacs, Medline, Scopus databases and SciELO online library with studies from 2000 to 2016</i>	Integrative review conducted in Lilacs, Medline, Scopus databases and SciELO online library with studies from 2000 to 2016	To investigate in the literature the relationship of socioeconomic factors to disease incidence and other outcomes associated with leprosy.
Thayza Miranda Pereira, Lucilane Maria Sales Da Silva, Maria Socorro De Araújo Dias, Lorena Dias Monteiro, Maria Rocineide Ferreira Da Silva, And Olga	Brazil	a time series study based on data from the Department of Informatic s of the	2,220 people	To analyze the temporal trends and epidemiologic al patterns of leprosy indicators in Sobral, rural municipality of Ceará

Maria De Alencar (2019)			Unified Health System		state, from 2001 to 2016.
Laily Hidayati, Harmayetty, Mahsus Ridwan (2019)	Indonesia		Analytical study with cross-sectional approach.	107 Orang	This study aims to identify the factors that contribute to the stigma of leprosy in the Madurese community in Indonesia.
Mingzhou Xiaohua, Ting Su, Ming Li, Daocheng (2019)	Xiong, Wang, Bin Yang, Li, And Zheng	China.	Cross-sectional	7230 people	This paper investigates the relationship between psychological health and quality of life (QOL) of Persons Affected by Leprosy (PAL) living in a community in Guangdong Province, China.
Paul Saunderson, Md, Mrcp, (2019)	United States		<i>Review articles</i>	leper	To know the approaches and challenges in leprosy prevention
Dadun Ruth, Wim Brakel, Irwanto, And Regeer (2019)	Dadun, MH Peters, H. Van Joske GF Bunders, Irwanto, And Barbara J.	Indonesia	<i>Mixed Method</i>	143 people	This paper describes the impact of socio-economic development interventions (SED) using a twin-track approach (two models of

					microcredit) to reduce the stigma of leprosy in Cirebon District, Indonesia.
Mariana Campos Da Rocha Feitosa, Ana Carina Stelko-Pereira, Karla Julianne Negreiros De Matos (2019)	Brazil	Quantitative	43 people		Describe and validate educational technology for adolescents about leprosy, focuses on preventing disease and reducing stigma.
Senthilkumar Ramasamy, Pitchaimani Govindharaj, Archana Kumar ¹ , Karthikeyan Govindasamy, Dan Annamma S John (2019)	India	Observational study	108 people		This study aims to assess and evaluate changes in social participation in leprosy patients after completing MDT.
Graham F Medley, David J Block, Ronald E. Crump, T. Déirdre Hollingsworth, Alison P. Galvani, Martial L. Ndeffo-Mbah, Travis C. Porco, And Jan Hendrik Richardus (2018)	India, Brazil, and Indonesia	<i>Quantitative modeling</i>	People with leprosy		The purpose of this supplement article is to summarize the main policy-relevant recommendations from the recent modeling of leprosy transmission
Ramadhan Tosepu, Joko Gunawan, Devi Savitri Effendy, and Fitri Rachmillah Fadmi	Indonesia	<i>Report Case</i>	75 new cases of MB and 28 new cases of PB		To find out the Stigma and increase in Leprosy Cases in

(2018)					Southeast Sulawesi Province, Indonesia
Anuj Steaven Rita Liesbeth And Jan Richardus (2018)	Tiwari, Dandel, Djupuri, Mieras, Hendrik	Indonesia	Three year prospective follow-up study	1900 residents in November 2014, November 2015 and November 2016.	The aim was to assess the operational feasibility of providing SDR 'blankets' across the population for leprosy prevention in remote communities on remote islands.
Peter Arielle Ann Anand, Mohammad Sarady Maung Barth-Lal Chuda Bhandari, Blaney, Bonenberger, Van Cross, Ansarul Nilanthi Zaahira Helena Eliane Deus Christa Burkard Anil Sambath Liesbeth Fareed Beatrice Blasdus Tiara Saunderson,	Steinmann, Cavaliero, Aerts, Sunil, Arif, Sao Ay, Tin Aye, Tanja Jaeggi, Nand Banstola, Mani David, Marc Wim Hugh VK Das, Fernando, Gani, Greter, Ignotti, Kamara, Kasang, Ko" Mm, Kumar, Lay, Mieras, Mirza, Mutayoba, Njako, Pakasi, Paul	Brazil, Cambodia, India, Indonesia, Myanmar, Nepal, Sri Lanka and Tanzania	Quantitative	Fieldwork related to the LPEP (<i>Leprosy Post-Exposure Prophylaxis</i>) program began gradually in India, Indonesia, Myanmar, Nepal, Sri Lanka and Tanzania in 2015 and in Brazil in 2016.	To generate evidence of feasibility and explore potential interventions in various epidemiological, cultural and health system conditions, a comprehensive Leprosy Post-Exposure Prophylaxis Program (LPEP) has been established.

Bakhuti Shengelia, Cairns S. Smith, Rene´ Sta´ Heli, Nayani Uriyarachchi, Tin Shwe, Anuj Tiwari, Millawage Supun D Wijesinghe, Jan Van Berkel, Bart Vander Plaetse, Marcos Virmond & Jan Hendrik Richardus (2018)					
Anwar Mallongi, Handayani, Makmur Selomo, Anwar Daud, Stang Abdul Rahman, Apollo Mattangang, and Abdul Muhith (2018)	Indonesia	Crosssecti onal analytics	All leprosy patients in Barru District in 2013- 2015.	1. To find out the spatial distributio n pattern of leprosy patients by using the Geographi c Informatio n System (GIS) and 2. Describe the risk factors associated with the incidence of leprosy in Barru District in 2013- 2015.	
Anna T. Van 'T Noordende, Ida J. Korfage, Suchitra Lisam, Mohammed A. Arif, Anil Kumar, Dan Wim H. Van Brake (2019)	India	<i>The study used a community -based cross- sectional design with a mixed- methods approach</i>	100 people	This study is a baseline study of the PEP++ project and aims to assess knowledge, attitudes and practices about leprosy in Fatehpur,	

					India.
Chinwe C. Eze, Ngozi Ekeke, Chukwuka Alphonsus, Linda Lehman, Joseph N. Chukwu, Charles C. Nwafor, Eileen Stillwaggon, Anthony O. Meka, Larry Sawers, Joy Ikebudu, Moses C. Anyim, And Kingsley N. Ukwaja (2021)	Nigeria	This study uses a quasi-experimental pretest/post-test design	40		The aim of this study was to assess the effectiveness of self-care practices on the cost of care, disability status and health-related quality of life
Anna T. Van'T Noordende, Moges Wubie Aycheh, Tesfaye Tadesse, Tanny Hagens, Eva Haverkort, and Alice P. Schippers (2021)	Ethiopia	Quantitative		Participants were selected using a convenience sampling. For people with podocniosis and LF, local health posts were visited and a list of eligible persons in the study area was prepared.	This study aims to develop and pilot a family-based intervention to support the prevention and self-management of leprosy, lymphatic filariasis and podocniosis-related disability in Ethiopia.
Natalia Hounsou A, Mersha Kinfeb, Maya Semraua, Oumer Alib, Abraham Tesfayeb, Asrat Mengisteb, Stephen Bremnerc, Abdulkadir Ahmedb, Abebaw Fekadub, And Gail Davey (2020)	Ethiopia	Implementation research studies		All patients who come to Gusha Health Center	to integrate a holistic package of physical, mental health and psychosocial health care for podocniosis, lymphatic filariasis and

					leprosy into routine health care in the Gusha cluster, Guagusa Shikudad district, northwest Ethiopia.
Lisanawork Kidist, Tsegaye Edessa (2019)	Girma, Bobosha, Hailu, & Negera	Ethiopia	A cross sectional study was conducted using quantitative methods.	424 leprosy patients	This study assessed the knowledge and practice of self-care of leprosy patients at the ALERT leprosy referral hospital in Ethiopia.
Marize Ventin, Fernanda Barbosaa, Christine Dos Raphaela Delmondes Do Nascimentoa, And Stephanie Steremberg D'Azevedoa (2018)	Conceição Limaa, Ribeiro Danielle Moura Santosa,	Brazil	Qualitative studies	24 people	To analyze self-care practices on the face, hands and feet performed by people affected by Hansen's disease.
Mirella Laragnoit Hespanhol, Marcel Dan Rocha-Figueiredo (2021)	Chaves Sidney Domingues, Lúcia Da Uchôa-	Brazil	qualitative study	4 patients diagnosed with leprosy and GIF 2 patients	The purpose of this article is to analyze the late diagnosis from the perspective of a therapeutic itinerary (IT) of symbolic cases.
Aleksandra Rosendo Santos, Rodrigues Souza	Dos Pâmela De Silva, Peter	Brazil	Retrospective cohort study and survival analysis	All newly diagnosed leprosy patients were	This study evaluates the possibilities and factors associated

Steinmann, And Eliane Ignotti (2020)				discharged from treatment between January 1, 2000 and December 31, 2017. (yes/no); complaints of leprosy during treatment (yes/no).	with the development of post-discharge PD rates among leprosy patients treated at Cáceres-MT, Brazil in the period of 2000 to 2017.
Wei-Hung Hsu, Wan-Ting Tsa, Sung-Jen Hunge, Hsin-Chung Cheng, Chung-Hua Hsueh, Tsung-Jung Ho, & Hao-Ping Chen (2019)	Taiwan	<i>Case reports</i>	one female patient and four male patients with a mean age of 86 years	to evaluate the role of mirror therapy in people with leprosy disabilities	
Mehak Singh, MD, And Manoj Pawar, MD (2019)	India	<i>case control</i>	24 people	Evaluating the efficacy of mirror therapy in leprosy patients with paresis.	
Jayanta Kumar Barua, Sumana Khan, Ananya Chandra, Arunima Dhabal, Saswati Halder (2021)	India	A retrospective note-based study	SPatients aged over 18 years who visited the leprosy clinic of a tertiary care institution in Kolkata, West Bengal, India, from 1 January 2019 to 30 June 2019.	To evaluate the clinical and epidemiological profile of adult leprosy patients attending a tertiary care hospital in eastern India for six months.	

Libardo Gomez, Colombia	Alberto Rivera, Yesenia Vidal, Jorge Bilbao, Christa Kasang, Sandra Parisi, Eva-Maria Schwienhorst-Stich And Karl Philipp Puchner (2018)	Colombia	Quantitative	249	To investigate factors associated with diagnostic delay.
Abraham Tesfaye Maya Semrau Oumer Ali Mersha Kinfe Mossie Tamiru Abebaw Fekadu Dan Gail Davey (2020)		Ethiopia	Qualitative	Three focus group discussions (community, health professionals, and policy makers), each consisting of 7-10 participants, and key informant interviews with 11 participants	This study describes the development of a comprehensive package of physical, mental health and psychosocial care for people with lymphedema of the lower limbs caused by podoconiosis, lymphatic filariasis (LF) or leprosy as part of the EndPoINT program in Ethiopia.

Table 2
Factors related to the incidence of leprosy

Writer	Findings
De Assis <i>et al.</i> (2020)	The risk of disability and worsening of leprosy is influenced by high population density and poverty, late diagnosis and inadequate clinical examination.
Leano <i>et al.</i> (2019)	Leprosy is strongly influenced by the social and socio-economic context associated with the incidence of leprosy, such as low-income families who have fewer resources to obtain nutritious food.

Pereira et al. (2019)	The high incidence of leprosy in endemic areas is related to adults, children, gender, social contacts, and care.
Xiong et al. (2019)	Psychological health of people with leprosy is related to physical, psychological, social, environmental, gender, age, occupation, and profession.
Saunderson (2019)	Household contacts have been considered a high-risk group for new leprosy cases and findings, often based on examination of people. They have an up to 8 times higher than average risk of developing leprosy over the next 4 to 5 years.
Medley et al. (2018)	Modeling studies have revealed a slow decline in new cases and the pool of undiagnosed infections.
Mallongi et al. (2018)	The risk factors that influence the occurrence of leprosy are distance, gender, personal hygiene, knowledge, contacts, socioeconomic, education, occupation, income, and house density.
Van et al. (2019)	low knowledge about leprosy and high levels of stigma and fear as well as the desire to maintain social distance with leprosy sufferers.
Hespanhol et al. (2021)	Lack of information about Hansen's disease and the inability of professionals to diagnose increase individual and collective risk, in addition to the negative impact on the daily life of the subject
Gómez et al. (2018)	The average delay in diagnosis of leprosy is 33.5 months. Approximately 14.9% of patients show visible deformity or damage <i>Disability Grade 2 (DG2)</i> at the time of diagnosis.

Table 3
Stigma about Leprosy

Writer	Findings
Indow et al. (2019)	Negative perceptions about leprosy are related to delays in treatment because sufferers do not know about leprosy.
Hidayati et al. (2019)	The stigma of leprosy is related to family and social factors, religious and philosophical factors as well as technology, economy, culture, education
Tosepu et al. (2018)	Leprosy is believed to be inherited and

	associated with the idea of unclean blood, which is shameful and not normally accepted in society.
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Table 4
Incidents of Disability

Writer	Findings
Ramasamy et al. (2019)	The majority of these 90 clients or 83% were multibacillary and 23% had Grade 2 disability at the time of diagnosis
Eze et al. (2021)	The average disability score at baseline was 22.3 severe disability (i.e. score 10-46)
AR Dos Santos et al. (2020)	Average time to progression of PD degree (<i>Physical Disability</i>) was 162 months for PB and 151 months for MB leprosy patients. The survival curves showed that 15 years after discharge from treatment, the probability of progression to the degree of PD was 35%, with no difference between PB and MB or age groups. Leprosy reactions and medical complaints registered in any form during treatment were identified as risk factors with a Hazard Ratio of 1.6 and 1.8, respectively.
Hsu et al. (2019)	Ulcers that do not heal are common in leprosy, which is one of the main causes of disability.

Table 5
Self Care Practices for People with Leprosy

Girma et al. (2019)	The score of respondents' knowledge is bad at 276 (65.1%) and good at 148 (34.9%). Knowledge level varied significantly with age group ($p < 0.01$), gender ($p < 0.01$), marital status ($p = 0.003$), educational status ($p < 0.01$) and income ($p < 0.01$). Approximately 77.4% of interviewed patients had poor self-care practice and only 22.6 patients had good self-care practice score ($p < 0.01$). Age ($p = 0.002$), previous disability due to leprosy ($p < 0.01$), knowledge about leprosy ($p = 0.038$) and income ($P = 0.028$), were significantly associated with
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	poor self-care practice.
Conceio et al. (2018)	Two categories emerged: Knowledge and implementation of self-care practices in Leprosy and the Singularity and challenges to self-care. The study found that respondents were aware of information about facial, hand and foot care, but reported difficulties such as low income to obtain materials for self-care, lack of time, and some lack of interest. Most of them have already shown some level of incompetence. Professional training working on empowering people facing illness, perception prevention guidelines and access to input for self-care is required

Table 6
Behavior of people with leprosy to prevent disability

Writer	Finding
Indow et al. (2019)	Interpersonal approach of health workers and families in supporting and motivating patients to perform <i>self care</i> properly, so that patients understand the importance of doing <i>self care</i> so that it can prevent the process of transmission on contact and can prevent the occurrence of defects.
Dadun et al. (2019)	SED (<i>socio economic development</i>) intervention affects the sustainability and improvement of leprosy programs
Feitosa et al. (2019)	Development of technology education (<i>board games</i>) has an effect on increasing knowledge as a way to promote students' knowledge about leprosy, reducing stigma, and it can be felt that technology is considered valid regarding its content and appearance in promoting knowledge change, especially about disease care and prevention.
Ramasamy et al. (2019)	MDT and steroid therapy can increase the participation rate of clients affected by leprosy, indicating that early detection and appropriate management will reduce the risk.
Tiwari et al. (2018)	There is a 50% reduction in leprosy among those who previously received SDR (<i>single dose of rifampicin</i>) compared to those who did not. Prevention of leprosy by giving rifampin

Steinmann et al. (2018)	Early detection, contact screening, <i>chemoprophylaxis</i> and administration of rifampicin effect in reducing the transmission of leprosy and the incidence of leprosy.
Eze et al. (2021)	behavior self-care habits of leprosy patients in reducing disability
Van'T Noordende et al. (2021)	Family-based interventions consist of self-management of persons with disabilities, awareness raising and socio-economic empowerment. Family quality of life improved significantly from 67.4 at baseline to 89.9 at advanced levels for family members and from 76.9 to 84.1 for affected persons. The level of stigma decreased significantly from 24.0 at baseline to 16, 7 at advanced levels, Activity level increased
Hounsoume et al. (2020)	Implementation activities include training events, workshops, awareness raising, self-help groups, supportive supervision, staffing and advisory board meetings. There was a 35% reduction in average disability score (measured using the World Health Organization Disability Assessment Schedule 2.0) and a 45% improvement in dermatology-specific QoL (measured using the Dermatology Quality of Life Index) at 3 months of advanced level compared to baseline. There was a reduction in the number of days with symptoms, days off from normal activity/work and days with reduced activity due to illness, all of which were statistically significant.
Hsu et al. (2019)	Jinchuang ointment provides a feasible, safe, simple and inexpensive method for treating leprosy ulcers. Due to its low cost, this traditional Chinese medicine may play an important role in treating leprosy in low-income countries in the future.
Singh & Pawar (2019)	Muscle strength in the mirror therapy group of participants increased sharply compared to the control group (post hoc Bonferroni $p = 0.027$). This study provides Class IV evidence that mirror therapy improves muscle strength in patients with leprosy associated paresis.
Barua et al. (2021)	the need to implement sustainable

	effective measures for the early diagnosis and treatment of leprosy to prevent disability, while raising awareness to ensure appropriate health-seeking behavior.
Tesfaye et al. (2021)	The holistic care package includes components that are applied at three levels of health: care system: health organization, facility, and community. Part of the care package is directed at strengthening capacity building, program management, community involvement, awareness raising, stigma reduction, morbidity management, disability prevention, follow-up visits, referral relationships, community-based rehabilitation, and monitoring and evaluation.

From *the literature reviews* above, it is divided into five sub-findings namely factors related to the incidence of leprosy, stigma about leprosy, the incidence of disability, the practice of *self-care* for patients, and the behavior of people with leprosy to prevent disability. Factors related to the incidence of leprosy are age, gender, social contact, and care (Pereira et al, 2019), as well as personal hygiene, knowledge, education, occupation, income, and house density (Mallongi et al, 2018).

The stigma of leprosy is related to family and social factors, religious and philosophical factors as well as technology, economy, culture, education (Hidayati et al., 2019). The stigma possessed by lepers believes that leprosy is inherited, and is associated with unclean blood which is shameful and not accepted in society. (Tosepu et al., 2018). The stigma arises because of the patient's lack of knowledge about leprosy which results in delays in diagnosis (Indow et al., 2019).

The need for active early case detection (Medley et al., 2018), the average delay in diagnosis of leprosy is 33.5 months and the patient has a grade 2 disability (Gomez L et al, 2018). Disability is associated with poor self-care (Girma L et al, 2019), where lack of care and the emergence of disability in leprosy patients are caused by lack of information (Hespanhol et al, 2021).

The importance of behavior of self-care habits of leprosy patients in decreasing disability (Eze CC *et al*, 2021), decreasing disability scores (Hounsoume N *et al*, 2020), and increasing muscle strength in leprosy patients with grade 2 disability (Singh M & Pawar M, 2019).

Behavior of people with leprosy in preventing disability through *Self Care* for patients with leprosy

Leprosy is a chronic *granulomatous* infectious disease caused by the obligate intracellular *M. leprae* organism. Initially, these bacteria attack the peripheral

nervous system, then attack the skin, mucosa, respiratory tract, reticuloendothelial system, eyes, muscles, bones, and testes. (Amiruddin, 2012). People with leprosy in general can experience disability, mutilation, ulceration, and others (Susmiati, 2021). If medication and treatment are not carried out early, it will cause disability in leprosy patients. Therefore, people with leprosy need to do good *self care* to minimize the impact of leprosy. *Self-care* is an activity to meet the needs of maintaining the life, health and well-being of individuals, whether sick or healthy, which is carried out by the individual himself (Alligood, 2014; Orem 2001).

The high incidence of leprosy in endemic areas is related to age (adults, children), gender, social contact, and care (Pereira et al, 2019). The risk factors that influence the occurrence of leprosy in the research conducted by Mallongi et al (2018) are distance, gender, personal hygiene, knowledge, contacts, socioeconomic, education, occupation, income, and house density. The impact of leprosy causes health, social, economic, cultural, security and national security problems (Kurniawan, 2019). Leprosy is chronic and often causes disability. The risk of disability and worsening condition of leprosy is influenced by delay in diagnosis and inadequate clinical examination (Ivaneliza et al, 2020). Research by Gomez L et al (2018) the average delay in diagnosis of leprosy is 33.5 months and leprosy sufferers experience deformity or disability at the time of diagnosis. The diagnosis is slow and do not seek treatment immediately after symptoms appear. Late diagnosis, diagnosis of grade 2 leprosy, and stigma are associated with the quality of life of people with leprosy (Lutosa et al, 2011). Disability can be prevented by early detection and improving the management of acute and chronic complications due to leprosy reactions so as to help fight the stigma and discrimination in people with leprosy. (Menaldi et al, 2016).

People with leprosy often feel stigma from the community, leprosy sufferers themselves, their families, and even some health workers. Stigma and discrimination from health workers still exist and can hinder the process of treating people with leprosy (Da Silva et al, 2017). Leprosy is believed inherited and associated with unclean blood, shameful, and not normally accepted in society (Tosepu et al, 2018). Research by Hidayati et al (2019) concluded that the stigma of leprosy is related to family and social factors, religious and philosophical factors as well as technology, economy, culture, and education. While the research by Van et al (2019) explains that low knowledge about leprosy causes high stigma and fear to keep a distance from people with leprosy. Indow et al (2019) explained that low knowledge about leprosy causes stigma and delays in carrying out treatment.

The results of the research by Girma L et al (2019) revealed that there was a relationship between age, disability, knowledge, and income with poor self-care. This is in line with the research of Hespanhol et al (2021) that the lack of information about leprosy and the delay of health workers in diagnosing cause less care, the emergence of stigma, and disability in people with leprosy. Meanwhile, research by Lima MCV et al (2018) explains that respondents know information about facial, hand, foot care, but are in a low economy so that they have difficulty in meeting materials for *self-care* and lack of time and interest.

There are several efforts in the care and treatment of leprosy to prevent transmission, disability, or reduce the impact of leprosy. Household contact with patients is a source of leprosy transmission (Romero Montoya *et al*, 2017). Research Tiwari *et al* (2018) there is a 50% reduction in leprosy among those who previously received SDR (Single Dose of Rifampicin) compared to those who did not receive, leprosy prevention can be done by giving rifampin. In line with the research of Steinmann *et al* (2018), namely early detection, contact screening, chemoprophylaxis and administration of rifampicin have an effect in reducing the transmission and incidence of leprosy. Immunological, molecular, and neurophysiological should be implemented to diagnose PNL (primary neural leprosy) for effective treatment in reducing disability (DF dos Santos *et al*, 2017).

Eze CC *et al* (2021) in their research carried out the effectiveness of *self-care* interventions with the results that there was a decrease in household costs for the treatment of patient morbidity and a decrease in disability after self-care intervention within 6 months and a decrease in scores in leprosy patients who continued the intervention until the end of the project that have severe disabilities. Van'T Noordende AT *et al* (2021) conducted a family-based intervention study for the prevention and self-management of disability due to leprosy, podoconiosis and lymphatic filariasis with the result that there was no significant improvement in eye and hand problems after the intervention. However, foot and leg disorders, number of acute attacks, lymphedema and shoe wear all increased significantly at advanced level. Besides that, the quality of life of families and affected persons improved significantly, levels of stigma decreased significantly, and activity levels increased but not significantly. Meanwhile, research by Hounsome N *et al* (2020) related to community-based care packages for patients with lymphatic filariasis, podoconiosis and leprosy, there are a 35% decrease in disability scores and a 45% increase in quality of life.

Various efforts of people with leprosy in preventing disability through *self care* such as being involved in SCG (*Self Care Groups*). The majority of respondents expressed satisfaction regarding their participation in SCG. People with leprosy find SCG useful in *self-care* for disability prevention and social participation (Deepak *et al.*, 2013). Research conducted by Hsu WH *et al* (2019) revealed that ulcers that do not heal are often found in people with leprosy which are one of the main causes of disability. In his study, there were 4 leprosy patients who had chronic ulcers that did not heal, then they were treated by giving Jinchuang ointment which is considered a feasible, safe, simple, and inexpensive method to treat leprosy ulcers. Due to its low cost, this traditional Chinese medicine may have an important role in treating leprosy in low-income countries in the future. While the research conducted Singh M & Pawar M (2019) explained that mirror therapy increase muscle strength in leprosy patients with grade 2 disability.

Barua *et al* (2021) in their research concluded that it is necessary to implement sustainable effective measures for early diagnosis and treatment of leprosy to prevent disability and increase awareness in seeking appropriate health services. Recommend to multi-professionals to carry out care and supervision of diseases and people with leprosy (Leano *et al*, 2019). This review found that there is a need for an interpersonal approach to health workers, families and social workers in supporting and motivating patients to perform self-care properly, so that patients

understand the importance of self-care so as to prevent the process of contact transmission and can prevent disability.

Conclusion

Leprosy is often overlooked because it rarely causes death. One of the bad effects of leprosy is disability. Efforts for people with leprosy in preventing disability through *Self Care* need an interpersonal approach including health workers, families, and social workers. Various interventions such as self-care groups and holistic care can be beneficial for people with leprosy in preventing disability and transmission so as to minimize the adverse effects of leprosy and break the chain of leprosy transmission.

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