

The Live Experience of People with Leprosy

A Systematic Review of Qualitative Evidence

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Abstract: Leprosy is a disease caused by *Mycobacterium leprae* which affects the peripheral nerves. Until recently, there are few studies explore the lived experience of people with leprosy. In this study, the authors peer review relevant literature in numerous data. This systematic review was a patent synthesis of a qualitative study. Data collected with predefined keywords. The database used in this study were Scopus Medline, ProQuest, Elsevier, Science Direct, CINAHL, JSTOR, Sage Journal, Wiley Online Library, Springer Link, EBSCO Host, and Oxford Academic Journal. There are 15 studies included, consist of 12 qualitative studies and 3 mixed method studies. The main theme which often appears in each study identified as an understanding of leprosy, physical, health, psychological, stigma, social relation, economics, and activity. Aspects various studies showed multi aspect of lived experience among people with leprosy. Which is collected and served, that shows a diversity of life from people with leprosy. Addressing physics, psychological, social, economics, spiritual and environment would be a benefit to assist people with leprosy living on their daily life.

1 BACKGROUND

Leprosy or Morbus Hansen is a disease caused by *Mycobacterium leprae* (Bhat and Prakash, 2012). Leprosy is a chronic infectious disease that attacks nerves characterized by granulation, patches on the skin and visual impairment (Rodrigues, 2011). This disease has infected hundreds of thousands of people in each year (WHO, 2012). Infection transmission is most likely believed through nasal droplets and mouth droplets during close and frequent contact (Elamin, Stehr and Singh, 2012; MA *et al.*, 2012). Often in some cases found to be slowly detected resulting in unintended adverse effects of leprosy (Abedi, Javadi and Naji, 2013)

Over the last decade's leprosy control efforts have focused on disease healing, infection control, and disability prevention, the reported global elimination report has improved with decreasing leprosy (Price, 2017).

Disability caused by leprosy disrupts the functioning of the body, the individual, and the public relations, as experienced by individuals with disabilities (Van Brakel *et al.*, 2012; Chingu, Duncan and Amosun, 2013). The physical impairment suffer is nerve damage caused by chronic granulomatous inflammation (Wilder-Smith and Van Brakel, 2008).

Live Experience of leprosy people needs to be explored to understand their meaning of life.

Impairment of certain parts of the body can lead to an inability to engage in activities involving use, eyes, hands, feet, and limitations in social participation (Brandsma and Van Brakel, 2003). In fact, late diagnosis of leprosy leads to permanent disability disorders requiring sustainable self-care (Wilder-Smith and Van Brakel, 2008).

Table 1: WHO 2016 global leprosy update (World Health Organization, 2017).

WHO Region	Number of new cases detected		
	2014	2015	2016
Africa	18.597	20.004	19.384
Amerika	33.789	28.806	27.356
Eastern Mediterranean	2.342	2.167	2.834
South-East Asia	154.834	156.118	161.263
Western Pacific	4.337	3.645	3.914
Europe		18	32
Global Total	213.899	210.740	214.783

In addition to physical disturbance and activity limitations, people with leprosy tend to experience social stigma and discrimination that causes economic hardship (Ebenso *et al.*, 2007; Dijkstra, Brakel and Elteren, 2017). The other problems faced by people with leprosy from the psychosocial aspect

are challenging for the individual, the emergence of stigma, limitation in the participation of the community, the decrease in social interaction, the economic difficulties due to restrictions on activity due to disability, and the inability to keep the job (Heijnders, 2004; Rafferty, 2005; Santos *et al.*, 2015; Del'arco *et al.*, 2016). Stigma is not a new phenomenon in the problem of people with leprosy, but the form of self-stigma such as shame and decrease in self-esteem or even public stigma such as public prejudices associated with restrictions and discrimination in social participation (Reeder and Pryor, 2008; Weiss, 2008). This is supported by the finding that the symptoms associated with decreasing quality of life of people with leprosy, behaviour psychosocial worse and identified that daily activities are indicators that indicate significant value to the quality of life of health aspects for people with leprosy (Costa *et al.*, 2012; Singh, 2012; Lusli *et al.*, 2016).

Other negative effects have an impact on the point of view of social identity. Social identities are the individual's knowledge that they belong to a particular social group, in addition to personal interests and emotional attachment to being a part of a particular group (Taipel, 1978; Turner, 1999). Many factors influence a person's ability to achieve goals to overcome problems experienced, for example, diseases that are considered something that "interferes with life" can affect the individual response associated with the disease. The ability to accept the illness and the changes that arise in the social life of people with leprosy, as well as the strategies employed by individuals by doing mental exercises to help complete tasks during treatment can affect to individual expectations (Debats, 1996). It is important to understand that the individual's social identity tends to be strongly related to mental well-being defined as satisfaction, optimism and purpose in life, ability to control, control, possess, and feel social support and public expectations of hope for help in overcoming suffering and expectations related to social identity meaningful people, activities, and accomplishments (Mace *et al.*, 2014)

The purpose of this systematic review study is to synthesize the qualitative literature relating to the life experiences of people with leprosy. This synthesis will provide reinforcement, theoretical saturation, the main theme that emerges. Many qualitative studies of the life experiences of people with leprosy have not yet collected, reviewed, and synthesized existing evidence in a semantic way. To date, a thorough and rigorous review not only understands how people with leprosy live everyday life but also assess the feasibility of the literature and find gaps in future understanding and research with respect to the

phenomenon. The purpose of this study is to combine and synthesize qualitative evidence based on the life experiences of people with daily leprosy and how people with leprosy dealing life. The main question of this study: how is the life experience of people with leprosy in living their lives-day-to-day?

2 METHODS

2.1 Design

The design of this study is a systematic review of Qualitative of Evidence formulated to collect the relevant qualitative studies and comprehensive analysis. Guidelines on the systematic study of this review by using guidance Joanna Briggs Institute as Qualitative Systematic Review (The Joanna Briggs Institute, 2014). Joanna Briggs Institute's method guides the making as a guide to the process of article selection, search strategy, eligibility criteria, and information from data analysis. The synthesis of qualitative research provides a comprehensive perspective on the understanding and knowledge that exists in a particular area to guide evidence-based practice and identify gaps in a study (Sandelowski, Barroso and Voils, 2007). Systematic reviews can help to provide information and a fair overall impression of the themes highlighted in the literature and show gaps or recommendations for future research.

Table 2: Eligibility criteria.

Criteria	Inclusion	Exclusion
Study Design	Qualitative Approach Mixed Method	Quantitative Approach
Concept	Live Experience	psychiatric
Population	People with leprosy	Health worker associated with leprosy (e.g. nurse, doctor, social worker)
Context	Adult in Health Service/Community	Neonatal Paediatric Mental disorder
Language	English (*min. Abstract)	Full text without Abstract on English
Date range	≥ 2007- 2017	< 2007

2.2 Inclusion and Exclusion Criteria

Departing from the qualitative evidence then set inclusion and exclusion criteria that focus on qualitative method approach as needed which includes specificity in qualitative research or research mixed methods. In the mixed method, research uses only part of the qualitative approach that exists and depends on the decryption of qualitative methodology and excerpts from the support participants in the study. Eligible studies that describe life experiences directly related to leprosy. Language eligibility criteria with minimal abstract language criteria using English. Publications considered tracing from 2007-2017 and under 2007 are excluded. Further inclusion group criteria are groups with adult category participants and are not limited to gender. Neonatal, children and mental disorders are excluded

2.3 Search Strategy

A systematic search of electronic databases begins on September 12, 2017, by determining the feasibility of repeated confirmation on *professional scientist*. This study was conducted in accordance with the guidelines Critical Appraisal Skills Programme (CASP) which relates to the qualitative assessment of the evidence. The first step: we search the electronic database Scopus, Medline, ProQuest, Elsevier, Science Direct, CINAHL, JSTOR, Sage Journal, Wiley Online Library, Springer Link, EBSCO Host, and Oxford Academic Journal to identify key articles and identify keywords by adjusting the main concepts: 1. People with leprosy, 2. Life experience 3. Qualitative Study. Our keywords search for both quotes and full articles, including title, abstract, text, and references information. The second step, translating keywords in English to search relevant articles in electronic databases. The third step, do a filter using CASP to determine the article that overpass for further review according to the topic. The complete search strategy is limited to the last 11 years between 2007 and 2017.

2.4 Study Selection

Three levels of screening are used to remove duplicate titles, abstracts, and citations. First, 3 reviewers (YD, TS, and EF) filter all data that relevance based on the contents of the articles. The second level, the full text of all articles retained after first-degree screening is appraisal independent of relevance by three reviewers. Consensus meetings were held to ensure eligibility after several quality

assessment review options are completed before data extraction.

2.5 Quality Appraisal

Quality assessment of articles to be review using the Critical Appraisal Skills Program (CASP) special qualitative study tool. There are 10 different questions that consider the results of qualitative studies, the validity of studies, and usability (Critical Appraisal Skills Program, 2013). CASP helps reviewers to systematically check whether a study meets the criteria in the 10 questions by choosing "yes", "no" or "not now" from each question. Each document is rated independently by 3 reviewers (YD, TS, and EF). The existing assessments are combined with other reviewers in one file and if there is any disagreement among the dining reviewers it will be completed in the next discussion phase. The allocation of scores on a scale of 10 for each reviewed article is based on how many "yes" answers in the scores and yes scores above 7 or more refers to excellent article quality. The purpose of this quality assessment is not to distinguish between qualities but in a systematic process and standardized processes can provide high-quality reviews based on existing topics.

2.6 Data Extraction

The reviewed data are continued to see the expression of the experience of people with leprosy in living their daily lives. Each study has been read at least 3 times before data extraction to ensure a thorough understanding of the content. The following steps:

- 1) Identify studies using relevant databases by using additional characteristics of keyword studies: authors, publication year, study design, study types and sample characteristics
- 2) Use the terms of inclusion and exclusion criteria to filter the study and narrow the focus
- 3) Independently extract data on research characteristics (reference details, population, determination, objectives or study objectives, methodologies, methods of data collection and analysis)
- 4) The reported findings include major themes and subthemes, including author descriptions and labels, and all illustrated excerpts

Data extraction protocol in the final stages by collecting data extraction results from 3 reviewers (YD, TS, and EF) to compare data extraction and discuss if there is a difference. The differences appear in the review together by using the full article.

3 RESULTS

A search strategy is performed by generating a total of 393 citations, which remove 257 duplicates. 216 existing literature is removed during first screening because the title and / or abstract is not in accordance with specified eligibility criteria. 51 full article of second stage screening of the 12 articles obtained is maintained for review. Three additional articles are obtained from the reference screening stage and thus the final series includes 15 articles about the experience of people with leprosy.

3.1 Quality Appraisal

The assessment of the quality of this study using the Critical Appraisal Skills Program, the quality of the 15 articles scored very well, with scores equal to or higher than 7 (scale 10). In the existing research meet some of the requirements of the CASP tool.

3.2 Study Characteristics

A number of 15 studies reviewed in 2007-2017 were conducted in 12 countries: Indonesia, Brasil, India, Uganda, South Korea, Iran, Pakistan, Nepal, Nigeria, Malaysia, Japan and Ghana. Qualitative research methods include phenomenology, FGD, retrospective, narrative descriptive, explanatory model, qualitative on mixed methods. There is no limit on gender aspect, education, marital status, economy, etc.

3.3 Result of Synthesis

The literature search identifies 15 journals describing individual experiences with leprosy. Finally, 8 findings of the main theme of the synthesis results are done in summarized in Appendix 3: Understanding of Leprosy, Experience of Physic, Experience of Health, Experience of Psychology, Experience of Stigma, Experience of Social, Experience of Economic, and Experience of Activity.

3.4 Understanding of Leprosy

Lack of education and some participants never experience of formal education of their understanding of leprosy is a disease of God. Leprosy disease because of heredity and easily transmitted to the surroundings. Diseases due to curses and dirty words Diseases of the skin, joints, nerves and eyes (Ebenso et al., 2007; Schuller et al., 2010; Van'T Noordende, 2016). Argues that leprosy causes deformity and disability. Leprosy can heal and nothing more than

skin diseases.(Singh et al., 2013). Starting from allergies, minor injuries but if not treated will become more severe (Susanto et al., 2017)

The participant's opinion, leprosy is a different type of leprosy and is associated with diabetes. Assume that leprosy is exactly the same as diabetes mellitus and leprosy is transmitted by couples who have diabetes (Peters et al., 2013; Charles-Damte, 2016) Transmission of leprosy is considered by individuals because by air, handshakes, eating together, touching, descendants, breastfeeding, and using things used by people with leprosy (Peters et al., 2013).

3.5 Experience of Physic

Individuals with leprosy report that they have painful experiences with symptoms before treatment, symptoms after treatment of dark skin, skin rashes, physical deformities and disabilities (Peters et al., 2013; Lusli et al., 2015). The presence of body image disturbances and symptoms that arise from diseases such as the onset of nodules, lost toes, hand contractures, eyebrow loss, and certain progressive symptoms and complications that result from prolonged physical and prolong illness (Singh, 2012; Yang, 2014). While the aggravating factors of the disease are when not continuing treatment or after giving birth (Raphael et al., 2017)

People with leprosy hide the disease because of most of the damage, and disability to the body so that the need for tools to help the function of the missing limb (Adhikari, 2013). Physical disability and physical contractures caused by leprosy reactions that occur in more than 50% of patients with leprosy MB. The MDT consumes effects on weight gain, hair loss, acne, swollen face, and diabetes (Sillo et al., 2016). People with leprosy in their body parts leave behind the residual form of disability or scar (Dako-Gyeke et al., 2017). The reactions of leprosy include loss of taste sensation, injury, deformity, and disability (Yirga, 2016). Individuals find it difficult to meet sexual needs due to constrained disabilities (Van'T Noordende et al., 2016). Working hard becomes A problem (Schuller et al., 2010), add with the problem of deformity they experience because of the growing issue of leprosy itself (Charles-Damte, 2016). Conduct self-care during illness and do exercises to reduce disability and further nerve damage (Susanto et al, 2017)

3.6 Experience of Health

Professional Health workers do not provide clear information related to leprosy to patients Some health workers simply convey that the disease is a common

skin disease whose treatment is free of charge (Peters *et al.*, 2013). Access to health services has little difficulty or obstacles, they have difficulty in terms of payment, and sometimes get a rejection from health workers (Dako-Gyeke *et al.*, 2017). Intensive treatment provides such as medication management and rehabilitation management (Yang, 2014). Giving MDT consume gives side effects that make hair fall out, and unwell (Sillo *et al.*, 2016). The aggravating factor of the disease is when not continuing treatment. Individuals say that those who stop for 1 month at the time of treatment experience loss of fingers (Raphael *et al.*, 2017)

The ability of self-care during illness and doing exercises to reduce disability and further nerve damage with self-care group approach (Susanto, *et al.* 2017). The majority of cases, the group suggested traditional treatment with a massage using herbal oils and creams. Treatment at home and away from health facilities (Abedi *et al.*, 2013; Singh *et al.*, 2013). Selection of alternative medicine, spiritual and traditional, and participants joined in self-care group. Counselling about the use of personal protective equipment preventive efforts to avoid accidents caused by loss sensation in the fingers (Yirga, 2016). Health aspects experienced never get attention so that treatment is lived alone without sufficient attention (Van'T Noordende *et al.*, 2016). Women with disabilities have serious problems in obtaining health services, due to long distances and poor road access and inability to use vehicles (Schuller *et al.*, 2010; Charles-Damte, 2016)

3.7 Experience of Psychology

The disease is a great impact on emotions, feelings of shame, denial, anxiety, depression, sadness, feel unloved so they are inferior (Charles-Damte, 2016; Yirga, 2016; Dako-Gyeke *et al.*, 2017). Thus, feelings of shame and being quiet when meeting with people who are not known so that the impact on psychological conditions, feel ashamed if living with family (Schuller *et al.*, 2010).

Fear and worried of the patient on the transmission of infection caused by perception and stigma that arise (Sillo *et al.*, 2016; Van'T Noordende *et al.*, 2016). They also feel dirty and hide from people around by confining themselves at home. All participants said they felt pessimistic, lacking motivation, they did not know what to do next (Lusli *et al.*, 2015). The presence of fear is expressed with concern and tries to distance, and fears when expelled, restricted, and rejected from society (Adhikari *et al.*, 2013). The interaction between self-isolation and isolation by the community makes people with leprosy feel shy and quiet in the same

time and some family members also do the same to the individual (Peters *et al.*, 2013).

Unlike psychosocial, some people consider the hospital as a quiet and safe place because of the persecution they live during the community (Raphael *et al.*, 2017) Feelings of comfort is felt and felt the same as others, by gaining a friendly experience of nursing services and other patients. Patient satisfaction because not required must cover the defect suffered. And the existence of Conflict and hatred with previous family members so that arises feelings of guilt about the pain that must be experienced by his family. Because of blame, both parents because of illness suffer during this time (Yang, 2014)

During participating in self-care forums, discussing the issues or problems felt related to leprosy, sometimes something entertaining can reduce stress (Susanto *et al.*, 2017) After these diseases are treated, they feel the power that comes from their spiritual beliefs, so that respondents feel able to deal with various situations and conditions that exist (Peters *et al.*, 2013).

3.8 Experience of Stigma

The experience of stigma in people with leprosy who have disabilities affects negative effects on their emotions, thoughts, behaviours, and relationships. Many individuals with leprosy get experiences related to stigma and discrimination while interacting with others. Some people including family, friends and the neighbourhood begin to ignore them since they learned they had the disease (Dako-Gyeke *et al.*, 2017). The phenomenon of stigma is the most common and frequent context (Lusli *et al.*, 2015).

Individuals with leprosy conceal illness suffering from family, neighbours, and friends to avoid discrimination and environmental stigma around (Peters *et al.*, 2013; Sillo *et al.*, 2016). The reason for the low self-esteem is because of fear of discrimination and separation from around. People hate leprosy for fear of transmission of this disease so that individuals with leprosy move to seek support (Adhikari *et al.*, 2013; Yirga, 2016). Public opinion and label that leprosy is worst (Singh *et al.*, 2013; Charles-Damte, 2016). sometimes the family members who initiate the stigma are present in the form of not wanting them to be in the community, some people avoid, and the reluctance of a partner in sexual intercourse (Ebenso *et al.*, 2007; Van'T Noordende *et al.*, 2016).

Lack of knowledge of the disease so that causes the separation to make by the family for fear of contracting leprosy such as separating cutlery, separating clothes they wear, and their beds. A

difficulty getting married because people think that leprosy is a hereditary disease (Schuller *et al.*, 2010)

In contrast to the existing studies in hospitals that show that feeling safe while in the hospital because the community feels the persecution (Raphael *et al.*, 2017). Therefore, there are no rules that restrict the patient to cover the defect suffered and the absence of stigma that exists because the community majority has the same fate as each other (Yang, 2014).

3.9 Experience of Social

When knowing suffering from leprosy, individuals with feelings lose the meaning of support from their families and often lose the respect of the community and lost self-esteem. Some patient patients feel that their family does not support, makes sense of solitude and causes big problems and is not appreciated by the (Abedi *et al.*, 2013; Adhikari *et al.*, 2013). The presence of barriers between existing communities and the simultaneous rejection they feel due to skin rashes, physical deformity, and visual impairment. After suffering from restriction leprosy or intercourse, the rejection and verbal violence from family, friends, society and the environment become disturbed (Ebenso *et al.*, 2007; Sillo *et al.*, 2016; Van'T Noordende *et al.*, 2016; Dako-Gyeke *et al.*, 2017). In everyday social life is aware of the stigma that comes when they try to build social relationships. People affected by leprosy mention that their social relationships are often limited to the medical context, ie with patients and health professionals (Lusli *et al.*, 2015). Not involved in social activities and divorced by a healthy partner and difficulty in finding a life partner (Schuller *et al.*, 2010; Yirga, 2016).

Individuals say after their husbands know that the wife has leprosy, the husband then divorces her. Another participant said that his wife refuses to sex with her leprous husband. While other participants got expelled from school, even some of them feel the persecution from the community (Raphael *et al.*, 2017). Another participant reported that she was married after she suffered from leprosy. Feel treated well when there are social gathering activities, and get the attention of the community (Raphael *et al.*, 2017) Contrary to the attitude of the in-laws who tend to always support. Public relations are less good because of knowing the illness in suffering (Charles-Damte, 2016)

Join in self-care group of individuals with leprosy get support from family during treatment and can return to work after recovery process (Susanto *et al.*, 2017). Hospice care Experiencing a long and permanent separation from the family, due to isolation at the hospital and getting a new family (Yang, 2014). Interact with the family through

discussions about the problems experienced (Singh *et al.*, 2013)

3.10 Experience of Economic

Most of the people with leprosy experience financial-related concerns encountered plus problems such as discrimination, isolation and restrictions due to disability that will arise that makes the economy burdened. (Adhikari, 2013; Charles-Damte, 2016; Lusli *et al.*, 2015). Stigma and Disability affect the difficulty of job search, resulting in the inability to provide income and just be a caretaker at home (Schuller *et al.*, 2010; Sillo *et al.*, 2016). They are rejection in communities with food-related jobs where community group leaders believe that leprosy can infect through feeding or drinking (Peters *et al.*, 2013). The impact of leprosy on productivity and educational problems that exacerbate in obtaining employment leading to poverty (Dako-Gyeke *et al.*, 2017; Yirga, 2016). Economic burdens caused by poverty, poor lives, and feelings of burden coupled with high financing, they lose their jobs and thus have no income. One participant says that no one wants to accept people with leprosy to work so they have no job, no income, and feel disappointed (Abedi, 2013).

In addition to the financial burden that must be obtained when undergoing treatment process for health insurance into the hospital as well as a lot of time is wasted because of the long treatment period (Raphael *et al.*, 2017; Singh *et al.*, 2013). Compliance with treatment results in a good recovery process and is re-employed after the recovery process (Susanto *et al.*, 2017). Some participants receive social empowerment-related empowerment that the financial improvements gain after obtaining socio-economic rehabilitation both from local service through microcredit and skills upgrading (Ebenso *et al.*, 2007)

3.11 Experience of Activity

Experience of active individuals with leprosy. Activity and productivity decreases due to disability (Yirga, 2016). The disability that makes the tough job becomes a problem. Not involving people with leprosy participating in an event and being treated differently than healthy people (Schuller *et al.*, 2010). Proteases are needed to walk on people with leprosy who have disabilities (Adhikari *et al.*, 2013). Sexual activity is disturbed by the disability they have so that their partners are reluctant to contact and the side effects of steroid drug (Sillo *et al.*, 2016).

Missing a jobs make routine work activities that are now much different, some are dropping out of school because of having long-term vision problems

cause grief and low motivation for social activities (Peters *et al.*, 2013; Van'T Noordende *et al.*, 2016; Dako-Gyeke *et al.*, 2017). Sometimes individuals get a good situation to use their capabilities. Participants demonstrated a strong desire to meet their needs such as getting food, medicine, and work. The rest of the people with disabilities have the power to try to access to work or in the development of their business (Lusli *et al.*, 2015)

A participant married after he suffered leprosy. Being treated during social gatherings, and getting the attention of the community (Raphael *et al.*, 2017).

The scope of hospital Sorok for example, the obstacles experienced in life in the community, the anticipation of vasectomy for married, forced abortion during pregnancy occurs, and the importance of having religion to continue the life of the community (Yang, 2014). Associated with activities include: Home activities take care of themselves during illness and do exercises to reduce disability and further nerve damage (Susanto *et al.*, 2017); Ability activity that is able to do renovation of house (Ebenso *et al.*, 2007); Discuss with family-related problems perceived (Singh *et al.*, 2013)

Table 3: Quality appraisal of studies with CASP tools.

No	Title, Authors, & Time	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Were the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	score
1	Peters et al., 2013	√	√	√	√	√	-	√	√	√	√	9
2	Abedi, 2013	√	√	√	√	√	-	-	√	√	√	8
3	Lusli et al., 2015	√	√	√	√	√	√	-	√	√	√	9
4	Yang, 2014	√	√	√	√	√	-	√	√	√	√	9
5	Raphael et al., 2017	√	√	√	√	√	√	√	√	√	√	10
6	Adhikari, 2013	√	√	√	√	√	√	-	√	√	√	9
7	Schuller et al., 2010	√	√	√	√	√	-	-	√	√	√	8
8	Susanto et al., 2017	√	√	√	√	√	√	-	√	√	√	9
9	Dako-Gyeke et al., 2017	√	√	√	√	√	-	-	√	√	√	8
10	Sillo et al., 2016	√	√	√	√	√	-	√	√	√	√	9

11	Ebens o et al., 2007	√	√	√	√	√	-	-	√	√	√	8
12	Van'T Noord ende et al., 2016	√	√	√	√	√	√	√	-	√	√	9
13	Yirga, 2016	√	√	√	√	√	√	√	√	√	√	10
14	Singh et al, 2013	√	√	√	√	√	-	-	√	√	√	8
15	Charle s- Damte , 2016	√	√	√	√	√	√	√	√	√	√	10

Table 4: Summary of studies and study results.

No	Title, Authors, & Time	Design	Main Result
1	The Meaning of Leprosy and Everyday Experiences: An Exploration In Cirebon, Indonesia. (Peters et al., 2013)	Qualitative	Giving Meaning to Leprosy, etiologi, seeking care: Perspective on Diagnosis and Treatment, Understanding Healing and Cure, Impact of living with cure
2	An Exploration of Health, Family, and economic Experience of Leprosy Patient, Iran. (Abedi, Javadi, & Naji, 2013)	Qualitative	physic, health, family and Economic.
3	Dealing with Stigma: Experiences of Persons Affected by Disabilities and Leprosy. (Lusli et al., 2015)	Qualitative	Stigma, impact on emotions, impact on thoughts, impact on Behaviour, and impact on Relationship
4	Life Experience of Korean Patients with Hansen's Disease in Sorok Island Hospital. (Yang, 2014)	Qualitative	Bad disease approaching as fate, family breakup and far from the village, new life in Sorok Island Hospital, treatment of Hansen's Disease and disability, life in the disease community, comfort and hope
5	The Lived Experience of Patients with Leprosy at Kaganda Hospital, Uganda. (Raphael et al., 2017)	Qualitative	Living with physical disability, living with social dilemmas, living with economic hardships, relative social acceptance, and living in harmony with self and God
6	Stigma in Leprosy: A Qualitative Study of Leprosy Affected Patients At Green Pastures Hospital, Western Region of Nepal. (Adhikari, 2013)	Mixed Method: Quantiative & Qualitative	Concleanment and disclosure Self stee, shame, and from others Perceptions of the diease effects Marriage and leprosy Experience with leprosy
7	The Way Women Experience Disabilities and Especially Disability Related to Leprosy in Rural Areas in South Sulawesi, Indonesia. (Schuller et al., 2010)	Mixed Method: quantitative & qualitative	work Social Activity Acceptance in community Self stigma
8	The Experiences of People affected by Leprosy Who Participated in Self-Care Groups in The Community: A Qualitative Study in Indonesia. (Susanto, Dewi, & Rahmawati, 2017)	Qualitative	Self-perceived condition Adherence to treatment Ability to do self-care The kind of help and services received Acceptance and support for leprosy patients
9	Stigmatisation and Discrimination: Experiences of People Affected by	Qualitative	Link between Lack of Knowledge/Myths about Leprosy and Stigma Access to Health Services

	Leprosy in Southern Ghana. (Dako-Gyeke, Asampong, & Oduro, 2017)		Access to Employment Contentment with the Leprosarium
10	A Temporal and Sociocultural Exploration of the Stigma Experiences of Leprosy Patients in Brazil. (Sillo et al., 2016)	Qualitative	stigma changing attitude towards and leprosy discrimination by the government discrimination by the family member discrimination by the work place complication of leprosy
11	Impact Of Socio-Economic Rehabilitation On Leprosy Stigma In Northern Nigeria: Findings Of A Retrospective Study (Ebenso et al., 2007)	Qualitative Retrospective	Stigma: knowledge, beliefs and attitudes. Overall changes in participants' lives following their experience of SER. Impact of SER on participation in life situations. Changing community attitude toward SER participants. Suggestions for improving SER service delivery
12	The Impact on Leprosy on Marital Relationships and Sexual Health Among Married Women in Eastern Nepal. (Van'T Noordende, T., Van Brakel, Banstola, & Dhakal, 2016)	Mixed Methods	Additional Information Concerning Leprosy-Affected Women Results Regarding Marriage, Sexual Relationships, and Sex Education Applicable to All Women Factors Affecting the Marital Relationship of Women Factors Affecting the Sexual Relationship of Married Women in Nepal
13	Exploring the Challenges of Rural People affected by Leprosy to Reintegrate within Their Community of Origin and Their Coping Mechanisms: A Study in ALERT Center, Addis Ababa. (Yirga, 2016)	Qualitative	biological challenge psychological challenge social challenge economic challenge The coping mechanisms
14	The Health Seeking Behavior of Leprosy Patients (Singh, Sinha, Banerjee, & Jaswal, 2013)	Qualitative:an explanatory model	Perseption treatment
15	The Lived Experiences of Women Living in a Leprosy Colony in Hyderabad, India: A Phenomenological Study. (Charles-Damte, 2016)	Qualitative	Who i am, relationship, leprosy, social issue, life in the colony

Table 5: Synthesised findings.

No	Title, Authors, & Time	About Leprosy	Physic Experience	Health Experience	Psychology Experience	Stigma Experience	Social Experience	Economic Experience	Activity Experience
1	Peters et al., 2013	√	√	√	√	√		√	√
2	Abedi, 2013			√			√	√	
3	Lusli et al., 2015		√		√	√	√	√	√
4	Yang, 2014		√	√	√	√	√		√
5	Raphael et al., 2017 Uganda		√	√	√	√	√	√	√
6	Adhikari, 2013		√		√	√	√	√	√

7	Schuller et al., 2010	√	√	√	√	√	√	√	√
8	Susanto et al., 2017	√	√	√	√	√	√	√	√
9	Dako-Gyeke et al., 2017		√	√	√	√	√	√	√
10	Sillo et al., 2016		√	√	√	√	√	√	√
11	Ebenso et al., 2007	√		√		√	√	√	√
12	Van'T Noordende et al., 2016	√	√	√	√	√	√		√
13	Yirga, 2016		√	√	√	√	√	√	√
14	Singh et al., 2013	√	√	√	√	√	√	√	√
15	Charles-Damte, 2016	√	√	√	√	√	√	√	

4 DISCUSSION

This systematic review study shows the life experiences of people living with leprosy living their daily lives. All based on study and research included in the review. This study is needed to improve the quality of services offered by health professionals. Critical appraisal applied to the study highlights the limitations of existing literature methodologies, particularly the lack of reference to theoretical saturation and the lack of detail surrounding the minor themes of each study. The present study provides important clear data from the analysis and confidence of the results obtained, especially in minor themes (codes). The complexity of individual life experiences with leprosy provides a different perspective, requiring an approach through a more thorough assessment not only in how to solve leprosy from the point of view of treatment. It needs a more thorough and deep assessment, then in understanding needed a good understanding between health workers with people with leprosy so that not only physical but also able to answer other problems. The synthesis of evidence can identify all the objectives of the review identifying the importance of individual understanding of leprosy, what happens from the physical aspect, the fulfilment of the health, the psychological dynamics experienced, the stigma dynamics that occur, the relationships and social roles, economic demands, and daily activities that is lived. (Ebenso *et al.*, 2007; Schuller *et al.*, 2010;

Peters *et al.*, 2013; Singh *et al.*, 2013; Charles-Damte, 2016; Van'T Noordende *et al.*, 2016; Susanto, et al, 2017).

4.1 Implication for Practice

Reviews conducted to focus on understanding and experience from the aspect side of the life experience of individuals with leprosy. The existing study makes it clear that in the lives of people with leprosy from the above results from understanding to other aspects. Understanding leprosy-related individuals should be more emphasized as to whether leprosy is actually, what constraints arise, major problems that often occur, the process of treatment, drug side effects, disability, self-view and society, difficulty in the move and also touch on the economic aspect (Charles-Damte, 2016; Lusli et al., 2015; Peters et al., 2013). It is important for health workers to be able to conduct early assessments on things outside the objective point of view. For example by assessing the emotional, psychosocial status, etc. So that the provision of individual services with leprosy can be accommodated well and not generalize and do not forget to provide the correct understanding and justification of the wrong perception when finding individuals with leprosy thoughts that are not appropriate

4.2 Strengths and Limitations

It should be acknowledged that in conducting a general literature review there is no scope for in-depth analysis of the data collected so consideration is necessary on a number of limitations when synthesizing the studies found. First, all studies are meta-aggregated, often found differences in interpreting experience and interpretation of study results. This can happen at any time during a synthesis of qualitative data on aggregate from various sources (Sandelowski, Barroso and Voils, 2007). Minimizing potential errors, the guidelines used in this study using the systematic review methodology of The Joanna Briggs Institute in 2014 include screening on multiple data extraction quotes and reporting findings that are considered to be non-credible. The research team also has expertise in reviewing the life experiences of leprosy patients, the individual life dynamics with leprosy, and qualitative methodologies. Secondly, it is possible that our search strategy failed to identify all related literature because we chose to make a narrow search including keywords that are explicitly relevant to the topic. Third, Analysis is focused on a particular concept and has a certain theoretical orientation. Consequently, some of the uniqueness of the article is missed in the analysis. Further consideration of political and environmental factors is limited to recent data.

5 CONCLUSIONS

This systematic review of various qualitative studies from various countries that provide a collection from an informed perspective on the life experiences of individuals with leprosy in living their daily lives during leprosy. Individual life experiences with leprosy provide information that is so diverse and has some similarities around the world. Individuals with leprosy are faced with various problems arising from leprosy both in the community and in the hospital. Diverse experiences of forming individuals with leprosy have diverse perspectives and attitudes in placing themselves in the environment. The uniqueness of each individual with leprosy imaged that every human being has different uniqueness and problem. This review extends and deepens our understanding of individual experiences with leprosy thus providing implications for field practice in dealing with individuals with leprosy in different ways. The current results provide a clear illustration of the current knowledge base and identify where some of the elements of understanding are well supported by the literature and elsewhere. This information may be useful to guide further research.

It is important that clinicians consider the interventions to be given, use them to support and improve patient-focused care and improve the well-being of patients with leprosy.

REFERENCES

- Abedi, H., Javadi, A. and Naji, S. (2013) 'An exploration of health, family and economic experiences of leprosy patients, Iran', *Pakistan Journal of Biological Sciences*, pp. 927–932. doi: 10.3923/pjbs.2013.927.932.
- Adhikari, B. *et al.* (2013) 'Stigma in leprosy: a qualitative study of leprosy-affected patients at green pastures hospital, western region of Nepal', *J Health Res*, 27(5), pp. 295–300. Available at: <http://www.jhr.cphs.chula.ac.th>.
- Bhat, R. M. and Prakash, C. (2012) 'Leprosy: An overview of pathophysiology', *Interdisciplinary Perspectives on Infectious Diseases*, 2012. doi: 10.1155/2012/181089.
- Van Brakel, W. H. (2006) 'Measuring health-related stigma—a literature review.', *Psychology, health & medicine*, 11(3), pp. 307–334. doi: 10.1080/13548500600595160.
- Van Brakel, W. H. *et al.* (2012) 'Disability in people affected by leprosy: the role of impairment, activity, social participation, stigma and discrimination.', *Global health action*, 5, pp. 1–11. doi: 10.3402/gha.v5i0.18394.
- Brandtsma, J. W. and Van Brakel, W. H. (2003) 'WHO disability grading: operational definitions.', *Leprosy review*, 74(4), pp. 366–73. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/14750582>.
- Charles-Damte, M. (2016) *The Lived Experiences of Women Living in a Leprosy Colony in Hyderabad, India: A Phenomenological Study* Marjorie Charles-Damte A Dissertation Submitted to the Faculty of The Chicago School of Professional Psychology In Partial Fulfillment of the Require, ProQuest. Faculty of The Chicago School of Professional Psychology.
- Chingu, D., Duncan, M. and Amosun, S. (2013) 'The quality of life of people with leprosy-related residual impairment and disability in Malawi—is there a difference between people living in a leprosarium and those re-integrated into their communities?', *Leprosy Review*, 84(4), pp. 292–301. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/24745128>.
- Costa, M. D. *et al.* (2012) 'Assessment of quality of life of patients with leprosy reactional states treated in a dermatology reference center.', *Anais brasileiros de dermatologia*, 87(1), pp. 26–35. doi: S0365-05962012000100003 [pii].
- Critical Appraisal Skills Program (2013) 'CASP: 10 questions to help you make sense of qualitative research', *Dept. of General Practice, University of Glasgow*, 1303(2017), pp. 1–6. doi: 10.1111/j.1600-0447.1980.tb10232.x.
- Dako-Gyeke, M., Asampong, E. and Oduro, R. (2017) 'Stigmatisation and discrimination: Experiences of

- people affected by leprosy in Southern Ghana', *Lepr Rev*, 88, pp. 58–74.
- Debats, D. L. (1996) 'Meaning in life: Clinical relevance and predictive power', *British Journal of Clinical Psychology*, 35(4), pp. 500–516. doi: 10.1111/j.2044-8260.1996.tb01207.x.
- Del'arco, R. *et al.* (2016) 'The Association Between Neuropathic Pain and Disability Grades in Leprosy', *Lepr Rev*, 87, pp. 53–59.
- Dijkstra, J. I. R., Brakel, W. I. M. H. V. A. N. and Elteren, M. V. A. N. (2017) 'Gender and leprosy-related stigma in endemic areas : A systematic review', pp. 419–440.
- Ebenso, B. *et al.* (2007) 'Impact of Socio-Economic Rehabilitation On Leprosy Stigma In Northern Nigeria : Findings of A Retrospective Study', *Asia Pacific Disability Rehabilitation Journal*, 18(2), pp. 98–119.
- Elamin, A. a, Stehr, M. and Singh, M. (2012) 'Lipid Droplets and Mycobacterium leprae Infection.', *Journal of pathogens*, 2012, p. 4. doi: 10.1155/2012/361374.
- Heijnders, M. L. (2004) 'The Dynamics of Stigma in Leprosy', *International Journal of Leprosy and Other Mycobacterial Diseases*, 72(4), p. 437. doi: 10.1489/1544-581X(2004)72<437:TDOSIL>2.0.CO;2.
- Lusli, M. *et al.* (2015) 'Dealing with stigma: Experiences of persons affected by disabilities and leprosy', *BioMed Research International*, 2015. doi: 10.1155/2015/261329.
- Lusli, M. *et al.* (2016) 'The Impact of a Rights-Based Counselling Intervention to Reduce Stigma in People Affected by Leprosy in Indonesia', *PLoS Neglected Tropical Diseases*, 10(12), pp. 1–25. doi: 10.1371/journal.pntd.0005088.
- MA, H. *et al.* (2012) 'A profile of patients treated at a national leprosy outpatient referral clinic in Rio de Janeiro, Brazil, 1986–2007', *Rev Panam Salud Publica*, 31, pp. 485–491. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/22858815>.
- Mace, C. R. *et al.* (2014) 'Translating the Link between Social Identity and Health Behavior into Effective Health Communication Strategies: An Experimental Application Using Anti-Smoking Advertisements', *NIH Public Access*, 29(10), pp. 1057–1066. doi: 10.1021/ja303183z.Aqueous.
- Peters, R. M. H. *et al.* (2013) 'The meaning of leprosy and everyday experiences: An exploration in Cirebon, Indonesia', *Journal of Tropical Medicine*, 2013. doi: 10.1155/2013/507034.
- Price, V. G. (2017) 'Factors preventing early case detection for women affected by leprosy: a review of the literature', *Global Health Action*. Taylor & Francis, 10(sup2), p. 1360550. doi: 10.1080/16549716.2017.1360550.
- Rafferty, J. (2005) 'Curing the stigma of leprosy', *Lepr Lev*, 76(2), pp. 119–126. Available at: <https://www.lepra.org.uk/platforms/lepra/files/lr/June05/150523.pdf>.
- Raphael, B. M. *et al.* (2017) 'The Lived Experience of Patients with Leprosy at Kagando', *Public Health International*, 2(2), pp. 67–74. doi: 10.11648/j.ph.20170202.12.
- Reeder, G. D. and Pryor, J. B. (2008) 'Dual Psychological Processes Underlying Public Stigma and the Implications for Reducing Stigma', *Mens Sana Monogr*, 6(1), pp. 175–186. doi: 10.4103/0973-1229.36546.
- Rodrigues, C. & L. N. (2011) 'Leprosy now; epidemiology, progress, challenges and research gaps', *The lancet infectious diseases*, 11(6), pp. 464–470. doi: 10.1016/S1473-3099(11)70006-8.
- Sandelowski, M., Barroso, J. and Voils, C. I. (2007) 'Using qualitative metasummary to synthesize qualitative and quantitative descriptive findings', *Research in Nursing and Health*, 30(1), pp. 99–111. doi: 10.1002/nur.20176.
- Santos, V. S. *et al.* (2015) 'Functional Activity Limitation and Quality of Life of Leprosy Cases in an Endemic Area in Northeastern Brazil.', *PLoS neglected tropical diseases*, 9(7), p. e0003900. doi: 10.1371/journal.pntd.0003900.
- Santos, V. S. *et al.* (2016) 'Pain and quality of life in leprosy patients in an endemic area of Northeast Brazil: a cross-sectional study', *Infectious Diseases of Poverty*. Infectious Diseases of Poverty, 5(1), p. 18. doi: 10.1186/s40249-016-0113-1.
- Schuller, I. *et al.* (2010) 'The way women experience disabilities and especially disabilities related to leprosy in rural areas in South Sulawesi, Indonesia', *Asia Pacific Disability Rehabilitation Journal*, 21(1), pp. 60–70.
- Sillo, S. *et al.* (2016) 'A temporal and sociocultural exploration of the stigma experiences of leprosy patients in Brazil', *Lepr Rev*, 87, pp. 378–395.
- Singh, G. (2012) 'Psychosocial aspects of Hansen's disease (leprosy)', *Indian Dermatology Online Journal*, 3(3), p. 166. doi: 10.4103/2229-5178.101811.
- Singh, S. *et al.* (2013) 'The Health-Seeking Behavior of Leprosy Patients: An explanatory model', *Health, Culture and Society*, 4(1), pp. 52–65. doi: 10.5195/HCS.2013.105.
- Stevellink, S., Van Brakel, W. and Augustine, V. (2011) 'Stigma and social participation in Southern India: differences and commonalities among persons affected by leprosy and persons living with HIV/ AIDS', *Psychol Health Med*, 16(6), pp. 695–707. doi: 10.1080/13548506.2011.555945.
- Susanto, T., Dewi, E. I. and Rahmawati, I. (2017) 'The experiences of people affected by leprosy who participated in self-care groups in the community : A qualitative study in Indonesia', *Lepr Rev*, 88, pp. 543–553. Available at: <https://www.lepra.org.uk/platforms/lepra/files/lr/Dec17/Lep543-553.pdf>.
- Taipel, H. (1978) *Social categorization, social identity, and social comparisons*. London: Academic Press.
- The Joanna Briggs Institute (2014) *Joanna Briggs Institute Reviewers' Manual 2014 Edition*. 2014th edn. Adelaide: The Joanna Briggs Institute. Available at: joannabriggs.org/assets/docs/sumari/reviewersmanual-2014.pdf.

- Turner, J. (1999) *Some current issues in research on social identity and self-categorization theories*. Edited by D. B. Ellemers N, Spears R. Oxford: Blackwell Publishers.
- Van'T Noordende *et al.* (2016) 'The impact of leprosy on marital relationships and sexual health among married women in eastern Nepal', *Journal of Tropical Medicine*, 2016. doi: 10.1155/2016/4230235.
- Weiss, M. G. (2008) 'Stigma and the social burden of neglected tropical diseases', *PLoS Neglected Tropical Diseases*, 2(5). doi: 10.1371/journal.pntd.0000237.
- WHO (2001) *International Classification of Functioning, Disability and Health (ICF)*, World Health Organization. Available at: www.who.int/classifications/icf/en/ (Accessed: 21 January 2018).
- WHO (2012) *Global leprosy situation, 2012*, *Weekly Epidemiological Record*. Available at: http://www.who.int/lep/resources/who_wer8734/en/ (Accessed: 27 October 2017).
- Wilder-Smith, E. and Van Brakel, W. H. (2008) 'Nerve damage in leprosy and its management', *Nat Clin Pract Neurol*, 4(12), pp. 656–663. doi: 10.1038/ncpneuro0941.
- World Health Organization (2017) 'Global leprosy update, 2016: accelerating reduction of disease burden', in *Weekly epidemiological record*. World Health Organization, pp. 501–520. Available at: <http://apps.who.int/iris/bitstream/10665/258841/1/WE R9235.pdf?ua=1>.
- Yang, Y. K. (2014) 'Life Experiences of Korean Patients with Hansen's Disease in Sorok Island Hospital', *Journal of Korean Academy of Nursing*, 44(6), p. 639. doi: 10.4040/jkan.2014.44.6.639.
- Yirga, M. (2016) *Exploring the challenges of rural people affected by leprosy to reintegrate within their community of origin and their coping mechanisms: A Study in ALERT Center, Addis Ababa*. Addis Ababa University School of Graduate Studies. Available at: <http://etd.aau.edu.et/bitstream/123456789/10087/1/11.Melese Yirga.pdf>