

Quality of Life, Mental Health, and Perceived Stigma among Leprosy Patients

Amira Abdellatef Abo Kersh¹, Ghada M. Abd Khalik¹, Fatma M. El-Esawy¹ and Eman M. Abd el- sattar²

¹Dermatology, Venerology and Andrology Department, Faculty of Medicine, Benha University, Benha, Egypt

²Family Medicine Department, Faculty of Medicine, Zagazig University, Zagazig, Egypt

E-mail: amiraabdellatef73@gmail.com

Abstract

Background: Leprosy is a chronic, infectious, granulomatous illness that has the ability to injure the nervous system, making the patient physically disabled and even deformed. Complex issues may be caused by leprosy, a chronic illness. Problems with mental health, social life, finances, culture, safety, and even national security are all aspects of leprosy. The purpose of this study is to identify socio-demographic determinants, perceived stigma, and other variables that contribute to leprosy patients' quality of life and mental health. In conclusion, the quality of life for those living with leprosy is quite low. Environmental, physical, psychological, and social aspects of quality of life are all adversely impacted by leprosy. A number of mental health issues, including sadness, worry, and stress, manifest in leprosy patients. mental health declines in tandem with the severity of physical disabilities. Among those living with leprosy, there is a significant prevalence of stigma.

Key words: Leprosy, mental health, stigma, and quality of life

1. Hey there

Mycobacterium leprae (*M. leprae*) is the causative agent of leprosy, also known as Hansen's disease. The obligatory intracellular bacillus *Mycobacterium leprae* is acid-fast, gram-positive, and shows tropism for skin phagocytes and peripheral nerve Schwann cells [1].

Leprosy may damage a person's quality of life (QoL) because to its effects on the skin and peripheral nerves, which in turn induce physical incapacities and

2. Leprosy

Leprosy has a long history that goes back thousands of years. Around 1550 B.C., an Egyptian papyrus record detailed it. Around 600 B.C., an illness similar to leprosy is described in Indian literature. Common belief is that Alexander the Great's troops returned from India with leprosy in tow. There was no cure or understanding of the disease's biological basis back then. Leprosy victims therefore had disabling skin issues that frightened onlookers. [4].

Public health

Countries in the Southeast Asian (SEAR) and African (AFR) regions have the best rates of new case detection. Among the 127 nations that reported in 2020, the top three for new cases (>10,000) were Indonesia, India, and Brazil [1]. With a prevalence rate that dropped from 0.17 per 10,000 in 2010 to 0.075 per 10,000 in 2016, Egypt has achieved the WHO goal of eliminating leprosy at the national level. However, there are still some areas that have not yet achieved elimination; between 300 and 900 new cases/year have been reported in Egypt. [5].

The Origins of Leprosy

Mycobacterium leprae (*M. leprae*) is the causative agent of leprosy, a long-term bacterial illness. *Bacillus leprae* is an obligate intracellular bacterium that is acid-fast, gram-positive, and has a preference for skin phagocytes and peripheral nerve Schwann cells [1]. Many nations where leprosy is prevalent have yet to fully investigate *Mycobacterium lepromatosis*, despite its recognition as an additional causative agent. It has also been observed that both species may cause

abnormalities that have significant social, emotional, and psychological consequences [2].

For a long time, leprosy was the most stigmatizing disease in the world. For those living with the condition, stigma is an ongoing and serious issue, and it also makes it difficult to execute effective public health measures. As a result, leprosy policy has rightfully prioritized reducing stigma [3].

infections. Due to a ~9% divergence in whole-genome sequencing, *M. lepromatosis* is now recognized as a separate species, despite the fact that its similarities first led researchers to believe it was a novel strain of *M. leprae* [6].

Things that might put you at risk: In close proximity to people who have lepromatous or multibacillary leprosy, Being around armadillos, Hereditary susceptibility, immunosuppression, or immunodeficiency [7].

Differentiating leprosy types:

The Ridley-Jopling grouping system:

The whole spectrum of the clinical characteristic is addressed. A weak immune response with an increased number of multibacillary cells follows a strong one with a low number of tuberculoid organisms. In general, this categorization is established based on neurologic, cutaneous, and biopsy results. Because of this, doctors can predict with some degree of certainty the kind of immunological response that will be generated. The acid-fast bacilli found in the dermis are likewise associated with the aforementioned results. There are many types of lepromatous leprosy, including tuberculoid (TT), borderline tuberculoid (BT), mid-borderline (BB), lepromatous leprosy (LL), and indeterminate (I) [8].

The World Health Organization's System of Classification:

For situations where there would be little clinical or laboratory evidence, a different categorization profile was created. The quantity of lesions is the foundation of this system. Paucibacillary (PB) leprosy

is defined as the presence of five or fewer skin lesions in the absence of visible bacilli on skin smears. Whereas, a single lesion PB is used when just one lesion is seen. In multibacillary leprosy (MB)[8], a positive skin smear test indicates the presence of six or more lesions.

Standard of Living

The World Health Organization (WHO) states that quality of life (QoL) is an individual's view of their place in life in relation to their aspirations, expectations, worries, and objectives within the framework of their own cultural and value-based systems [9].

From a mental health standpoint, quality of life encompasses not just how happy a person is with their surroundings, but also how content they are with their bodily and mental health, as well as their social interactions [10].

Leprosy and other crippling skin disorders have a devastating effect on quality of life. Because leprosy is a chronic illness with noticeable dermatological symptoms that don't go away no matter how long a person takes to cure it, it has a devastating impact on the social life and self-esteem of those who suffer from it. Patients' physical and mental health suffer, and they become socially isolated as a result, which has a detrimental impact on their quality of life (QoL)[11].

Several factors may influence the quality of life (QoL) associated with leprosy. These include the time it takes for the illness to start and how long it lasts, as well as social and clinical characteristics such the kind of leprosy, responses, nerve involvement, disability grade, deformity, and systemic involvement. Because of the social stigma and physical disfigurement it causes, leprosy is the most stigmatized illness. Physical deformities and limitations result from the disease's sneaky development, responses, and postponed treatment. Patients with these impairments may face social stigmatization, which may cause them to withdraw from society. This, in turn, can have negative effects on their interpersonal relationships, marriage, job, and social life, all of which contribute to a decline in quality of life [12].

Leprosy patients often have a variety of disabilities, including but not limited to: diminished sensitivity, muscular weakness, ulceration, abnormalities of the hands and feet, and trouble shutting their eyelids [13]. People with leprosy may have a worse quality of life because their disabilities limit their ability to do productive tasks on a daily basis [14].

Improved service delivery to leprosy patients and the extension of comprehensive treatment are both possible outcomes of a deeper knowledge of patients' quality of life (QoL) [15].

3. Mental Health

According "A state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively

and fruitfully, and is able to make a contribution to his or her community" [16] is what the World Health Organization (WHO) calls mental health. The chronicity, impairments, and cosmetic deformities of leprosy are well-known to generate secondary psychological repercussions for sufferers [17].

The following symptoms are associated with psychological discomfort in leprosy patients:

Affective: it's marked by unpleasant emotional symptoms including being fearful, dissatisfied, and mourning over the sickness that's now afflicting one, lacking confidence, feeling humiliated, and fearing social exclusion.

Disturbing thoughts are a hallmark of cognitive symptoms, which might include an inability to cope with the condition or find solutions to difficulties, a gloomy outlook on life's prospects, and even suicidal thoughts.

In the conative disorder, indicators of maladaptive behavior include a lack of openness and an avoidance of situations requiring intense social interaction.

On the physical level, leprosy causes a number of unpleasant physiological symptoms, such as an innate sense of weakness that makes it difficult to cope with everyday challenges.

Leprosy sufferers' mental health may be worsened by a number of circumstances, including:

Specific kind of leprosy Psychological discomfort is more common in patients with multi bacillary leprosy, according to certain studies, compared to those with pauci bacillary type. Patients with MB leprosy type are needed to take pharmacological therapy for 12 months and engage in more intense self-care compared to those with PB type. This might be because MB leprosy type disability episodes are more comprehensive and simpler to manage.

There was a highly significant correlation between the level of disability experienced by leprosy patients and mental health problems, particularly level 2 disability, when compared to leprosy patients experiencing only level 1 disability or no disability at all.

Understanding leprosy: patients' ignorance about the disease has a significant impact on their faith in their treatment and the stigma that develops throughout the course of a leprosy patient's life. Not only may patients absorb stigma from their surroundings, but they can also internalize it (self-stigma). Leprosy patients often suffer from mental health issues as a result of inaccurate information and misconceptions regarding the disease [18].

As a long-overlooked facet of leprosy work, the detrimental effects on mental health are all the more reason why social assistance is so important for adjusting to life with leprosy and improving mental wellness. Critical interventions for people's mental health include family or peer counseling, individual or group treatment, building social support networks, champions, economic empowerment, and resilience building [19].

Stigma

Stigma has taken on many different meanings over the years. The Greek origin of the term stigma suggests a connection to a pointed object. In subsequent centuries, it came to mean the visible markings—scars or burns—that declared a someone to be a slave, traitor, or crime. A person is stigmatized when they are unfairly judged based on their perceived differences from the general population [20].

One of the obstacles to leprosy control is stigma. There are three types of stigma that people with leprosy may face: internalized stigma, perceived stigma, and enacted stigma. When people are insulted directly, it is known as enacted stigma (discrimination). Stigma in the shape of prejudice and bad emotions about what other people will do to oneself is known as expected stigma or perceived stigma. A person experiences internalized stigma, also known as self-stigma, when they start to believe the negative things that other people say and think about them. As a result of societal shame, leprosy sufferers may experience depression. Feelings of worry and despair are exacerbated because these people have a hard time embracing their impairment [21].

The psychological and social health of the stigmatized individual is impacted. Feelings of humiliation or terror might trigger anxious thoughts and sadness. Reduced social engagement or even social isolation may ensue from the resulting anxiety and despair. People with mental health issues may be less likely to seek medical treatment when they are afraid others will judge them negatively [22].

When people are aware of the unfavorable attitudes and behaviors associated with a certain disease, it is called perceived stigmatization. Some forms of stigmatization are more obvious than others; for example, being asked to leave a public location. Other forms are more subtle, such as staring or avoiding eye contact [23].

There is a significant amount of felt stigma among those living with leprosy. This is because disease management efforts put so much emphasis on lowering disease burdens that they neglect the important part of altering community attitudes regarding the illness via ongoing education and communication. In addition to societal issues like stigma, the fact that these individuals are chronically poor and lack access to healthcare makes them susceptible to infectious illnesses like leprosy.[24].

It will be challenging to eradicate leprosy as a public health hazard and the prevalence may even grow if the stigma surrounding the disease is not removed. Consequently, public health must take the lead in addressing this illness by devising a plan to stem the tide of new cases and combat the associated stigma. These aimed to 1) increase community-wide early case detection; 2) enhance leprosy services, including rehabilitation programs that integrate with basic health care and referrals; 3) disseminate information or run media campaigns to change people's perception of

leprosy as a curable disease; 4) eliminate stigma by raising awareness of the disease; 5) empower survivors in all areas of life and encourage their active participation in leprosy control; 6) restore self-esteem; and 7) create programs to prevent disabilities or permanent damage [25].

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