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# Relationship between Psychological Problems and Quality of Life among Leprosy Patients

Mona M. Barakat[1], Hanan, N. Zaki[2]

[1]Psychiatric and Mental Health Nursing. Faculty of Nursing. Benha University, Egypt.
e-mail: Lovegana120@yahoo.com
[2]Psychiatric and Mental Health Nursing. Faculty of Nursing. Benha University, Egypt.
e-mail: hanan_nasef2000@ yahoo.com

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## ABSTRACT

***Context:*** Depression and anxiety are most prevalent in patients with leprosy, impacting patients' quality of life.
***Aim:*** This study aimed to assess psychological problems and quality of life among leprosy patients and investigate the relationship between psychological problems and quality of life among leprosy patients.
***Methods:*** A Descriptive correlational design was utilized to fulfill the aim of this study. The study was conducted at the Dermatology & Leprosy clinic in Benha City, Kaluobia Governorate, which is affiliated with the Ministry of Health. A descriptive study among 100 leprosy patients was recruited consecutively from dermatology and leprosy outpatient. Three tools were used to achieve the aim of this study. A structured Interviewing schedule, the World Health Organization Quality of Life (WHOQOL)-BREF Questionnaire, and Depression Anxiety Stress Scales (DASS).
***Results:*** The majority of the studied patients had a low level of quality of life; also, two-thirds had a moderate level of depression, and about two-thirds of them had a severe level of anxiety, while the majority of them had a moderate level of stress; also, more than half of them had a severe level of total DASS. Also, a statistically significant negative correlation between the total quality of life and total DASS among the studied patient with leprosy at p-value =<0.05.
***Conclusion:*** leprosy patients have a low level of quality of life and have a high prevalence of psychological problems present with moderate to severe levels of total depression, anxiety, and stress, which impact their quality of life. The study recommended that continuous counseling and health education for leprosy patients avoid or minimize the psychological problems and improve their quality of life. Psycho-educational program to improve psychological wellbeing and quality of life of leprosy patients.

***Keywords:*** Psychological problems, quality of life, leprosy patients

## 1. Introduction

Leprosy is a chronic granulomatous disease caused by *Mycobacterium leprae* that predominantly affects the skin and peripheral nerves, resulting in neuropathy and associated long-term consequences deformities and disabilities. Leprosy is known to occur at all ages ranging from early infancy to very old age. Leprosy is curable, and early treatment averts most disabilities *(WHO, 2018).* More than 200 thousand new cases of leprosy are added *(Naaz, Mohanty, Bansal, Kumar, & Gupta, 2017)*. In Egypt, Leprosy was eliminated as a significant public health problem in 1994. The WHO target of decreasing the disease prevalence to less than one case per 10,000 populations achieved on the national level. Almost 60% of new cases detected each year in Egypt originate from only six governorates, mainly located south of the country *(Amer & Mansour, 2014).*

The current Global Leprosy Strategy, 2016-2020, accelerating towards a leprosy-free world, is innovative as it gives, in addition to a solid medical component, increased visibility and weight to the human and social aspects affecting leprosy control *(World Health Organization "WHO," 2016).* Approximately 6% of new cases reported annually are children under 15 years of age. Thus, leprosy is still a concern in Egypt as well as many countries. However, some governorates focal points where the rate is still high *(World Health Organization "WHO," 2019; Schreuder, Noto, & Richardus, 2016).*

Leprosy is one of the most stigmatized diseases known today *(Sermrittirong & Van-Brakel, (2014).* Leprosy is striking fear in society as a mutilating, disfiguring, contagious, and incurable disease. Leprosy has been a highly stigmatizing disease in Egypt for centuries because it causes physical disfigurement *(Sharma, Joshi, & Kumar, 2017).* The stigma surrounding leprosy can be a significant burden and affects many dimensions of a person's quality of life and mental health *(Noordende, Brakel, Banstola, & Dhakal, 2016).*

Leprosy patients sometimes delay seeking proper care until they develop physical deformities. These physical deformities can result in unemployment, comorbidities like depression, anxiety, and worsening of their condition, including permanent disability, which can intensify the stigma. Furthermore, the quality of life declines rapidly. The concept of quality of life denotes the impact that an illness or injury has on a person's wellbeing. It includes physical and psychological health, social relationships, and a person's interaction with the environment *(Santos et al.,*

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[2]*Corresponding author: Hanan Nasef Zaki*

*2016).* Many studies have shown that leprosy and its stigma have a prevailing effect on a patient's social life, affecting marriage, employment, mental health, interpersonal relationships, leisure activities, and attendance at social and religious functions *(Kumari, Wickramasinghe, & Madhavi, 2017; Geetha, Dhanalakshmi, & Judie, 2015).*

Most studies found depressive disorders to be the most common psychiatry comorbidity followed by anxiety disorders. Anxiety disorder the most common psychiatric disorder. Up to 70% of patients were found to have depressive disorders in some studies, while anxiety disorders present in up to 28% of leprosy patients. There is also evidence of schizophrenia and other psychotic disorder in this population *(Eyanoer, 2018; Mahendra et al., 2018).* Anxiety and depression are increasing among people with leprosy, and it may lead to decreased social participation and impaired the quality of patient's life *(Ramasamy, Panneerselvam, Govindharaj, Kumar, & Nayak, 2018).*

The disease can affect a patient's manners for the rest of their life. The high rate of suicidal attempts highlights the patients' concept of psychological disorder due to leprosy. Grief appears to be the first and most general reaction that leprosy sufferers show after a diagnosis of leprosy. In some cases, the morbidity becomes chronic, and psychiatric disorders are indicated *(Sharma et al., 2017).* Segregation and deprivation of the usual privileges of home environments lead to anxiety. They seem to have weak egos and lack independence in feeling, thinking, and action. Problems that leprosy patients feel include shame, lowering their self-esteem, dependency, and even aggressiveness. These difficulties could also extend to their families and caregivers who need more support *(Dako-Gyeke, 2018; Lee, Lee, & Ko, 2015).*

Despite significant improvements in leprosy treatment since the introduction of multidrug therapy (MDT) 3 decades ago, the global incidence remains high, and patients often have long-term complications *(White & Franco-Paredes, 2015).* Nurses view the patients as one unit as a biological, psychological, social, and spiritual being when giving holistic care. To see the human as a unique individual and continually considering the person as one unit is not always easy to put into practice. Practical and medical skills one learns by experience but learning to see patients in other dimensions, psychological, social, and spiritual, requires experience and closer contact with the patient. The nurse has the role of health educator and deals with education regarding health promotion, prevention, treatment, and rehabilitation for leprosy patients. Nursing leprosy patients require professional mental, physical, and psychological care and disease treatment for improving the quality of care, which impacts the quality of their life *(Love & Asabea, 2014).*

Generally, despite efforts by the Egyptian government to decrease the incidence of leprosy and increase treatment accessibility, the psychological and social rehabilitation of leprosy patients living in communities has not been adequately addressed. The psychological status and QOL of leprosy patients living in the community tend to be lower than in the general population due to prevailing poor attitudes of society towards leprosy and aggravated by disability caused by leprosy *(Adhikari, Shrestha, Kaehler, Raut, & Chapman, 2013; Kaehler, Adhikari, Raut, Marahatta, & Chapman 2015; Marahatta et al., 2018).* Leprosy negatively impacts patients' physical and social functioning, which may, in turn, influence their psychological status *(Savassi, Bogutchi, Lima, & Modena, 2014; Leite & Caldeira, 2015).* The psychological health of patientsaffected with leprosy is affected by several economic and social factors and intimately connected with QOL *(Stevelink, Van-Brakel, & Augustine, 2011).*

Leprosy continues to be a serious public healthproblem in the developing world, as in Egypt. It is primarily because leprosy is a medical problem with grave social overtones since permanent and progressive disability and consequent psychological problems as depression and anxiety are a recognized sequela of untreated leprosy. Hence,leprosy does not affect the patient alone but also their families and the community at large. So, this study was conducted to assess psychological problems and quality of life among leprosy patients.

## 2. Significance of the study

Leprosy is a medico-social problem with a decline in its medical form due to effective treatment (MDT). However, its social aspect in terms of stigmatization, disability, deformities, loss of self-respect, loss of self-esteem, ostracizing of affected ones, and misconception of the disease by the community have well identified as a significant threat which effect on psychological status and quality of life among leprosy patients.

The actual causes for choosing this topic confined to a social one: The Egyptian people know about this disease is very infectious, leading to people are afraid of lepers approaching, shaking their hands, sitting behind them, and eating from their food which impacts psychological status and quality of life. So, leprosy patients isolating in the leprosy colony Abu Zaabal in Qalyoubiya, 40 km north of Cairo. So, the researchers wanted to shed light on this problem.

## 3. Aim of the study

This study aimed to assess psychological problems and quality of life among leprosy patients and investigate the relationship between psychological problems and quality of life among leprosy patients. This aim achieved through the following research questions:

- What are the levels of psychological problems among leprosy patients?
- What is the level of quality of life among leprosy patients?
- What is the relationship between psychological problems and quality of life among leprosy patients?

### 3.1. Operational definitions

*Psychological problems*

Psychological problems are operationally defined as scores on Depression Anxiety Stress Scales*,* based on three subscales of anxiety (DASS- A), depression (DASS-D), and stress (DASS-S), developed by *Lovibond and Lovibond (1995)*.

*Quality of life*

Quality of life is operationally defined as scores on the World Health Organization Quality of Life (WHOQOL)-BREF Questionnaire, classifying four domains, developed and validated by *Skevington et al. (2004).*

## 4. Subjects & Methods

### *4.1. Research design*

A descriptive correlational design was employed to describe the levels of psychological problems and quality of life among leprosy patients and measure the relationship between those variables.

### *4.2. Research setting*

The study was conducted at the Dermatology and Leprosy clinic in Benha City, Kaluobia Governorate, which is affiliated with the Ministry of Health. This setting was mainly chosen because the flow rate of patients with leprosy is satisfactory for the study.

### *4.3. Subjects*

Based on the confidence interval (CI) of 95%, and at power analysis, 80%, the sample size ranged from 80-100, so that the sample size was 100 patients based on the number of the recurring patient last year. A convenience sample of 100 leprosy patients was recruited consecutively from dermatology and leprosy outpatient according to the following: *Inclusion criteria:* Patient's diagnosis with leprosy, and patients willing to participate in the study. *Exclusion criteria:* Patients who suffered from psychiatric, neurological, and organic diseases were also excluded as they may directly affect the mental status of an individual.

### *4.4. Tools of the study*

Three tools were utilized for collecting data.

### 4.4.1. Structured Interviewing Questionnaire

It designed by the researchers after reviewing related literature consisted of two parts:

The first part: Socio-demographic data, which includes (Age, sex, marital status, educational level, occupation, residence, cohabitation, and income).

The second part: Clinical data, which includes (Duration of illness, number of injuries, have you any problems associated as deformity, site and time of developing appearance deformity, chronic illness, the family supported, and family history of disease).

### 4.4.2. The World Health Organization Quality of Life (WHOQOL)-BREF Questionnaire

Quality of life was assessed by using the WHOQOL-BREF tool. This scale was developed by *Skevington Lotfy, O'Connell, and WHOQOL Group (2004)*. WHOQOL-BRIEF is a self-report questionnaire that contains 26 items and classifies four domains:

- The physical domain contains seven items for Q (3, 4, 10, 15, 16, 17, 18), like the statement" Do you have enough energy for everyday life?"
- The psychological domain contains six items for Q (5, 6, 7, 11, 19, 26), like the statement "Are you able to accept your bodily appearance?"
- The social relations domain contains three items for Q (2o, 21, 22), like the statement "How satisfied are you with your personal relationships?"
- The environmental domain contains eight items for Q (8, 9, 12, 13, 14, 23, 24, 25), like the statement "How safe do you feel in your daily life?" Also, items one and two overall measure quality of life and general health" How would you rate your quality of life?"

It is a five-point Likert scale from one to five. Reverse three negatively phrased items (Q3, Q4, and Q26) (1=5) (2=4) (3=3) (4=2) (5=1). This reverse transforms negatively framed questions into positively framed questions. The responses were analyzed from a Likert scale, distributed an intensity scale (nothing extremely), capacity (nothing completely), frequency (never-always), and evaluation (very satisfied, very bad, or very good).

*Scoring system*

- More than 75% was considered high QOL.
- 50-75% was considered moderate QOL.
- Less than 50% was considered low QOL.

### 4.4.3. Depression Anxiety Stress Scales (DASS)

Depression, Anxiety, and Stress Scales developed *Lovibond and Lovibond (1995).* The DASS consists of 21 items, is a self-report screening tool that measures the frequency of behaviors or intensity of feelings based on three subscales of anxiety (DASS-A), depression (DASS-D), and stress (DASS-S). A DASS total score was computed from the three subscale scores of items rated on a four-point scale (i.e., from 0 = "Did not apply to me" to 3 = "Applied to me very much or most of the time"). The total equals 63 points. The higher the score, the worst the DASS.

*Scoring system for DASS*

- 0-21 normal level of DAS.
- 22- 30 mild level of DAS.
- 31-47 moderate level of DAS.
- 48-63 severe level of DAS.

### *4.5. Procedures*

The operational design for this study included the preparatory phase, validity, and reliability of the tools, ethical considerations, pilot study, and fieldwork. The preparatory phase included reviewing the relevant literature to develop and validate data collection instruments. Content validity was done to assure that the utilized tools measure what it was supposed to measure. Tools developed by the researchers were examined by a panel of five experts of psychiatric nursing to determine whether the included items clearly and adequately cover the domain of content addressed. Test-retest was repeated to the same sample of leprosy patients on two occasions and then compares the scores. The Cronbach's coefficient alpha of Quality of Life (WHOQOL)-BREF Questionnaire is 0.92 for the total score, while Depression Anxiety Stress Scales is 0.94.

Official permission was obtained from the hospital authorities in the identified setting to collect the necessary data, and patient consent was obtained to participate in the study. Approvals of patients were obtained before data collection and after explaining the purpose of the study. Anonymity was assured as the filled questionnaire sheets were given a code number (not by names). The leprosy patients ensured that the questionnaire sheet will be used only for the study and will discard at the end of the study. The study maneuvers do not entail any harmful effects on participation. The patients who participated in the study were informed about having the right to withdraw at any time without giving any reason.

A pilot study conducted on10% of the studied subjects, (10) leprosy patients who added to the whole studied sample. The purpose of the pilot study was to ascertain the clarity, applicability, relevance, and content validity of the tools, testing the feasibility of the study process, estimate the time needed to complete the sheet, and the necessary changes were undertaken. The pilot study found that (1) The tools were clear and applicable (2) the Tools were relevant and valid. (3) No problem was interfering with the process of data collection. (4) The tools were made ready for use.

The actual fieldwork was carried out from the beginning of August 2018 to the end of November 2018. The study setting was visited two times/week, starting from 9 Am to 12 Pm. At the beginning of the interview, the researcher greeted the patients, introduced herself to each patient, explained the purpose of the study, took oral consent to participate in the study, filled structured interviewing questionnaire sheet. Then each patient was asked to fill (WHOQOL)-BREF Questionnaire and Depression Anxiety Stress Scales DASS.

### *4.6. Data analysis*

The results were statistically analyzed by using SPSS version 22. Numerical data expressed as mean ± SD, and range. Qualitative data expressed as frequency and percentage. Relations between different variables were tested using Friedman's test, t-student. Pearson's Correlation analysis was used to show the strength and direction of the association between two quantitative variables. P-value <0.05 is considered significant.

## 5. Results

Table 1 shows that the frequency distribution of study patients regarding socio-demographic characteristics. It saw that less than half (43.0%) of the sample were in the age group of 40-<50 years old with mean age 40.24±9.82, and more than half of the sample (59.0%) were females. Also, more than three-quarters (79.0%) were married. This table also shows that more than one-third (35.0%) of the sample had cannot read and write. More than half (51.0%) were unemployed, more than half (72.0%) their residence in urban, while the highest percentage of the sample (48.0%) their monthly income enough, and most of the sample (84.0%) cohabitation with the family.

Table 2 displays the clinical data of the studied patients. It shows that more than one-third (37.0%) of the sample had less than five years of duration of illness. Also, about two-thirds (63.0%) and less than one-third (28.0%) of the sample had one injury to two injuries from the disease, respectively. This table also shows that near to three quarters (71.0%) of the sample have problems associated with a physical disability (deformity), while more than half (59.2%) and more than one third (39.4%) of the sample their deformity in his legs and his arms respectively. Also, near to half (49.3%) develop the appearance of deformity during treatment, and the majority (91.0%) have no chronic illness, while the majority of the sample (72.0%) have family support. Also, the majority of the sample (90.0%) have no family history of the disease.

Figure 1 shows that the frequency distribution of studied patients regarding the level of quality of life. More than half of the studied patients (59.0 %) had a moderate level of the physical domain. Also, about two thirds (64.0) of them had a low level of the psychological domain; also, nearly half of the studied patients (46.0%) had a moderate level of the social domain, and the majority (85.0%) had a low level of the environmental domain. In contrast, most of the studied sample had a low quality of life (72.0%).

Figure 2 illustrates the percentage distribution of studied patients regarding the total of depression, anxiety, and stress. Two-thirds of the studied patients (65.0%) had a moderate level of depression, and about two-thirds of them (65.0%) had a severe level of anxiety. In comparison, most of the studied patients (73.0%) had a moderate level of stress.

Figure 3 portrays that the frequency distribution of studied patients regarding the total level of DASS. There is more than half of the studied patients (59.0%) had a severe level of total depression, anxiety, and stress.

Table 3 shows the correlation between the total quality of life and total depression, anxiety, and stress of the studied patients. The result shows no statistically significant correlation between the total quality of life and total depression among leprosy patients. The present study also shows a negative correlation but not statistically significant between the total quality of life and total anxiety (as p =.531, which exceed 0.05), and negative correlation but not statistically significant between the total quality of life and total stress (as p =0.352 which exceed 0.05) that could not reach the significant level.

Figure 4 illustrates the correlation between the total quality of life and the total DASS scale of the studied patients. This figure reveals that statistically significant negative correlation between the total quality of life and total DASS among the studied patient with leprosy at p-value =<0.05.

Table 4 reveals a correlation between the total quality of life and clinical data of the studied patients. There is a statistically significant negative correlation between the total quality of life and the duration of illness of the studied patients. There is also a statistically significant negative correlation between the total quality of life and the number of injuries of the studied patients at p-value =<0.05.

Table 5 illustrates the relationship between total quality of life and deformity among the studied patients. There is a statistically significant relationship between total quality of life and the studied patients with and without deformity at p-value = <0.05.

Table 6 shows the relationship between the total DAS scale and deformity among the studied patients. There is no statistically significant relationship between total DASS and the studied patients with and without deformity at p-value = >0.05.

Table 7 reveals the relationship between total quality of life and socio-demographic characteristics of the studied patients. There is no statistically significant relationship between total quality of life and socio-demographic characteristics of the studied patients at p-value = >0.05.

**Table (1): Frequency and percentage distribution of studied patients regarding their socio-demographic characteristics (n=100).**

| Socio-demographic characteristics | No. | % |
|---|---|---|
| **Age (years)** | | |
| 20 < 30 | 17 | 17.0 |
| 30 < 40 | 23 | 23.0 |
| 40 < 50 | 43 | 43.0 |
| ≥ 50 | 17 | 17.0 |
| Mean ± SD | 40.24±9.82 | |
| **Gender** | | |
| Male | 41 | 41.0 |
| Female | 59 | 59.0 |
| **Marital status.** | | |
| Single | 9 | 9.0 |
| Married | 79 | 79.0 |
| Divorced | 2 | 2.0 |
| Widow | 10 | 10.0 |
| **Educational level** | | |
| Cannot read and write | 35 | 35.0 |
| Basic learning | 32 | 32.0 |
| Secondary learning | 28 | 28.0 |
| University learning | 5 | 5.0 |
| **Occupation** | | |
| Employment | 19 | 19.0 |
| Free work | 30 | 30.0 |
| Unemployment | 51 | 51.0 |
| **Residence** | | |
| Urban | 72 | 72.0 |
| Rural | 28 | 28.0 |
| **Income** | | |
| Not enough | 40 | 40.0 |
| Enough | 48 | 48.0 |
| Enough and save | 12 | 12.0 |
| **Cohabitation** | | |
| Alone | 4 | 4.0 |
| With family | 84 | 84.0 |
| With relatives | 12 | 12.0 |

**Table (2): Frequency distribution of the studied patients regarding clinical data (n=100).**

| Clinical data | No. | % |
|---|---|---|
| **Duration of illness (years)** | | |
| less than five years | 37 | 37.0 |
| 5- less than10 years | 32 | 32.0 |
| Ten years to more | 31 | 31.0 |
| **The number of injuries** | | |
| One injury | 63 | 63.0 |
| Two injuries | 28 | 28.0 |
| Three injuries | 9 | 9.0 |
| **Have you any problems associated with a physical disability (deformity)** | | |
| Yes | 71 | 71.0 |
| No | 29 | 29.0 |
| **If yes, where the site (n=71)** | | |
| Arms | 28 | 39.4 |
| Legs | 42 | 59.2 |
| Ears | 1 | 1.4 |
| **Time of developing appearance deformity (n=71)** | | |
| Before the first visit to the hospital | 33 | 46.5 |
| During treatment | 35 | 49.3 |
| After treatment | 3 | 4.2 |
| **Chronic illness** | | |
| Yes | 9 | 9.0 |
| No | 91 | 91.0 |
| **Family supported** | | |
| Yes | 72 | 72.0 |
| No | 28 | 28.0 |
| **Family history of the disease** | | |
| Yes | 10 | 10.0 |
| No | 90 | 90.0 |

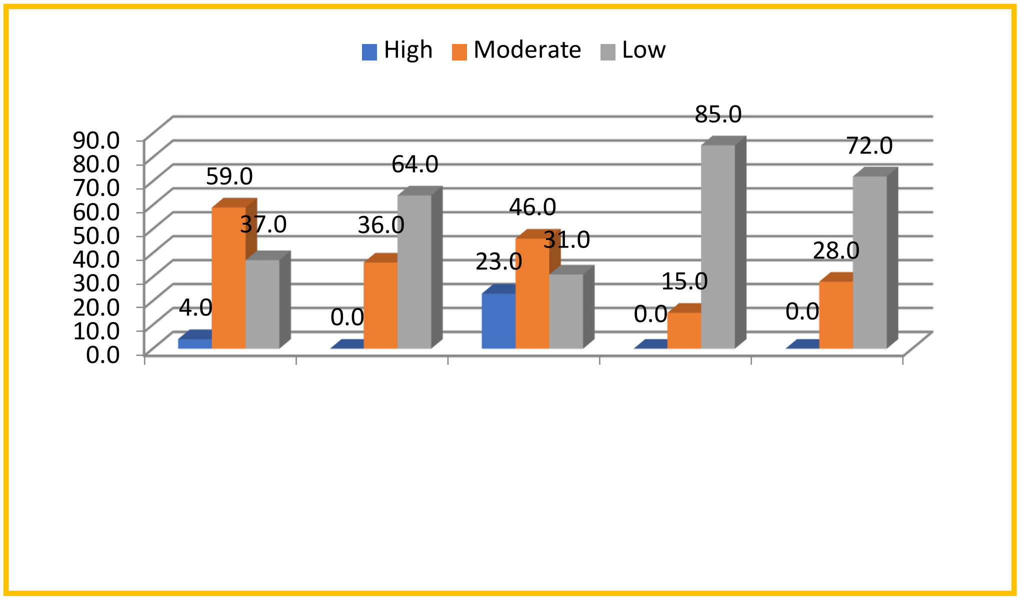

**Figure (1): Percentage distribution of studied patients regarding total level of quality of life (n=100).**

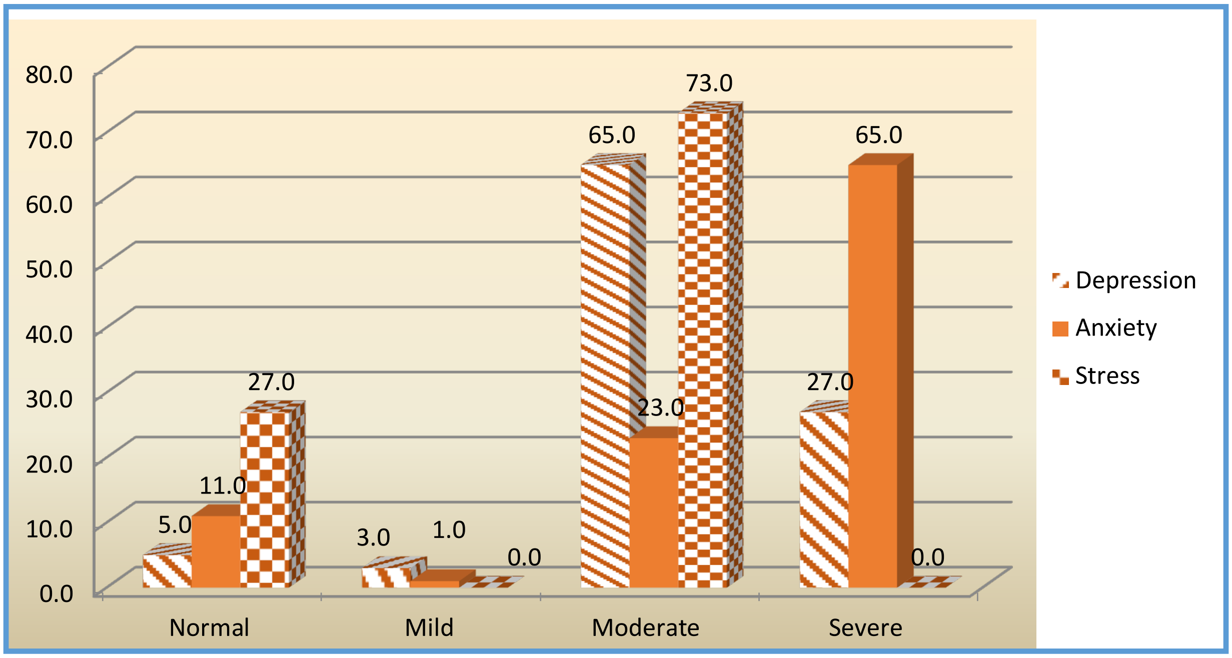

**Figure (2): Percentage distribution of studied patients regarding total levels of depression, anxiety, and stress subscales (n=100).**

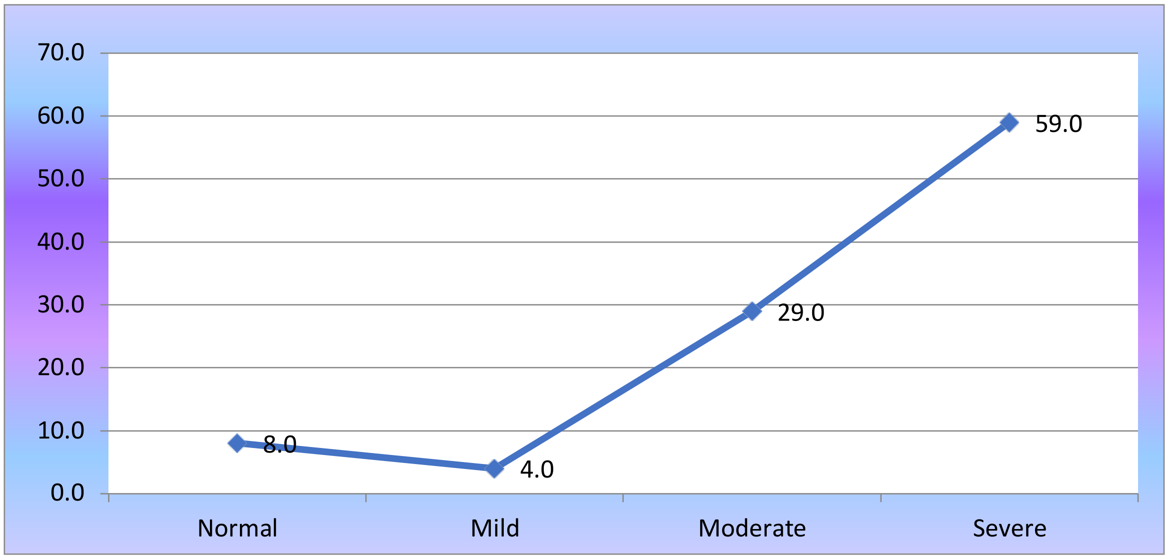

**Figure (3): Percentage distribution of studied patients regarding total levels of DASS (n=100).**

**Table (3): Correlation between total quality of life and total depression, anxiety, and stress of the studied patients (n=100).**

| Scales | | Total quality of life |
|---|---|---|
| **Total depression** | **r** | 0.009 |
| | **P-value** | 0.926 |
| **Total anxiety** | **r** | -0.063 |
| | **P-value** | 0.531 |
| **Total stress** | **r** | -0.094 |
| | **P-value** | 0.352 |

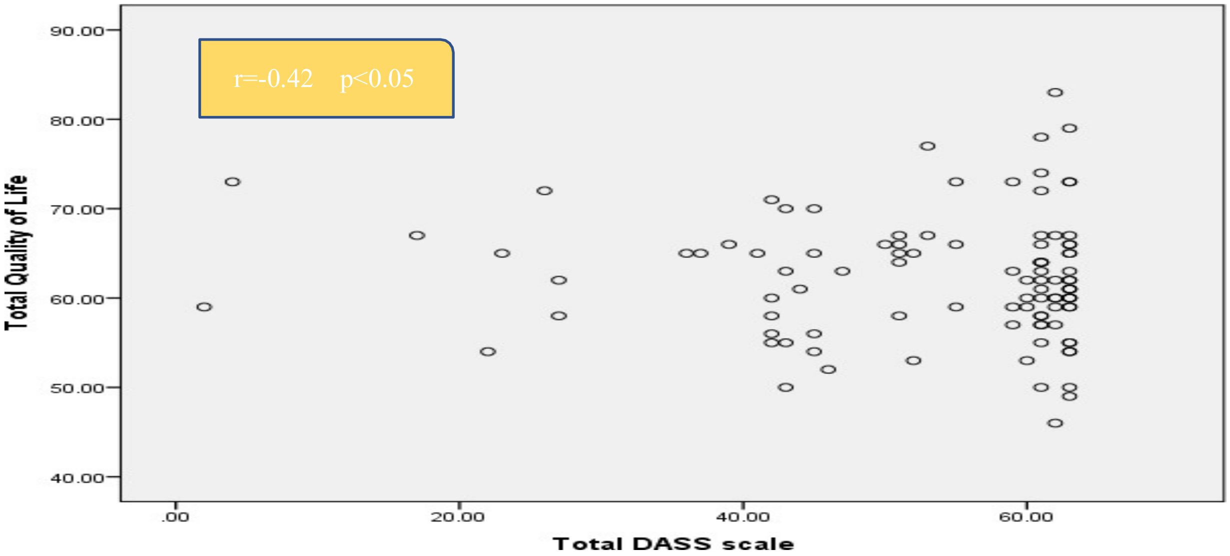

**Figure (4): Correlation between total quality of life and total DASS scale of the studied patients (n=100).**

**Table (4): correlation between total quality of life and clinical data of the studied patients (n=100).**

| Clinical data | Total quality of life | |
|---|---|---|
| | r | P-value |
| **Duration of illness** | -0.21 | 0.03 |
| **Number of injuries** | -0.26 | 0.009 |

**Table (5): Relationship between the total quality of life and deformity among the studied patients (n=100).**

| Total quality of life | Patients with deformity (n=71) | | Patients without deformity (n=29) | | $X^2$ | p-value |
|---|---|---|---|---|---|---|
| | n | % | n | % | | |
| **Low** | 56 | 78.9 | 16 | 55.2 | 5.73 | 0.017 |
| **Moderate** | 15 | 21.1 | 13 | 44.8 | | |

**Table (6): Relationship between total DASS and deformity among the studied patients (n=100).**

| Total DASS | Patients with deformity(n=71) | | Patients without deformity (n=29) | | $X^2$ | p-value |
|---|---|---|---|---|---|---|
| | n | % | n | % | | |
| **Normal** | 8 | 11.3 | 0 | 0.0 | 5.64 | 0.13 |
| **Mild** | 4 | 5.6 | 0 | 0.0 | | |
| **Moderate** | 20 | 28.2 | 9 | 31.0 | | |
| **Sever** | 39 | 54.9 | 20 | 69.0 | | |

**Table (7): Relationship between the total quality of life and socio-demographic characteristics of the studied patients (n=100).**

| Socio-demographic characteristics | Total quality of life | | | | $X^2$ | p-value |
|---|---|---|---|---|---|---|
| | With deformity (n=72) | | No deformity (n=28) | | | |
| | n | % | n | % | | |
| **Age (years)** | | | | | | |
| 20 < 30 | 9 | 12.5 | 8 | 28.6 | | |
| 30 < 40 | 16 | 22.2 | 7 | 25.0 | 4.51 | 0.21 |
| 40 < 50 | 33 | 45.8 | 10 | 35.7 | | |
| ≥ 50 | 14 | 19.4 | 3 | 10.7 | | |
| **Gender** | | | | | | |
| Male | 27 | 37.5 | 14 | 50.0 | 1.3 | 0.25 |
| Female | 45 | 62.5 | 14 | 50.0 | | |
| **Marital status** | | | | | | |
| Single | 5 | 6.9 | 4 | 14.3 | 2.08 | 0.55 |
| Married | 58 | 80.6 | 21 | 75.0 | | |
| Divorced | 1 | 1.4 | 1 | 3.6 | | |
| Widow | 8 | 11.1 | 2 | 7.1 | | |
| **Educational level.** | | | | | | |
| Cannot read and write | 24 | 33.3 | 11 | 39.3 | 0.82 | 0.84 |
| Basic learning | 24 | 33.3 | 8 | 28.6 | | |
| Secondary learning | 21 | 29.2 | 7 | 25.0 | | |
| University learning | 3 | 4.2 | 2 | 7.1 | | |
| **Occupation** | | | | | | |
| Employment | 13 | 18.1 | 6 | 21.4 | 0.15 | 0.92 |
| Free work | 22 | 30.6 | 8 | 28.6 | | |
| Unemployed | 37 | 51.4 | 14 | 50.0 | | |
| **Residence** | | | | | | |
| Urban | 55 | 76.4 | 17 | 60.7 | 2.45 | 0.11 |
| Rural | 17 | 23.6 | 11 | 39.3 | | |
| **Income** | | | | | | |
| Not enough | 25 | 34.7 | 15 | 53.6 | 3.06 | 0.21 |
| Enough | 38 | 52.8 | 10 | 35.7 | | |
| Enough and save | 9 | 12.5 | 3 | 10.7 | | |

## 6. Discussion

Interestingly, Egypt is one of the most ancient places where leprosy was observed *(El Meniawy, Essam, & Khaled, 2018)*; the oldest recorded leprous case was from Dakhleh Oasis *(El-Gendy, El-Gohary, Shohdy, & Ragab, 2016)*. Leprosy is a chronic infectious disease caused by Mycobacterium leprae. Worldwide, more than 200 thousand new cases of leprosy added, although the World Health Organization set a goal to stop this disease by 2020 *(World Health Organization "WHO" 2018)*. Leprosy patients are forced to be segregated from or leave their families and are therefore considered exiles from their societies. With lack of knowledge about leprosy and its disability in society causes patients to experience negative stigma, which also makes them hesitant to go to the treatment that eventually can lead to a vicious circle *(Asampong, Dako–Gyeke, & Oduro, 2018)*.

Both the debilitating effects and disfigurements of leprosy, society tends to stigmatize negatively those suffering from leprosy. The impact of negative stigma on society causes depression, anxiety, social isolation, and problems in the workplace that cause difficulty in a patient's daily life. Leprosy is not merely a physical disease; it also produces psychological and social problems and physical disabilities. Leprosy and leprosy-related disabilities may predispose people to develop psychological, economic, and social problems that might adversely affect life quality *(Naaz et al., 2017)*.

The present study illustrates that the socio-demographic profile of the leprosy patients, less than half of the sample were in the age group of 40 < 50 years old with a mean age of 40.24±9.82. This result agrees with a study carried out by *Onyeonoro et al. (2016),* who found that the average mean age of study patients was 40.2±19.6 years. This result disagrees with *(Leite & Caldeira, 2015),* who founded that his studied patients were between 66-75 years. In the same line with *(Govindharaj et al., 2018)*, this result showed that the studied patients were in the age group of 20 to 40 years.

Concerning the gender of the studied patients, more than half were females, suggesting a higher incidence among females than males. This study agrees with a study carried by *Kumari et al. (2017),* who founded that more than half of the patients were females. On the other hand, This result disagrees with studies carried by *Geetha et al. (2015); Shumet, Demissie, and Bekele (2015),* their results showed that most of the sample were males.

Concerning marital status, the present study reveals that more than three-quarters were married. This finding may be due to the Egyptian culture of early marriage females. The result agreed with *Lee et al. (2015); Girma, Bobosha, Hailu, and Negera (2018),* who found that less than half of the samples were married patients. On the other side, this result disagrees with *Shokre and Souilm (2018),* who stated that most of the sample were unmarried. The difference between the two studies mightbe a cultural difference.

Regarding the educational level, the present study shows that more than one-third of the studied patients could not read and write. This result agrees with *Xiong et al. (2019),* who stated that most participants could not read and write. This result disagreement with *Govindharaj et al. (2018)* showed that more than half of his sample were literate. The result of the present study disagrees with Pérez- *Hernández et al. (2017)*. Their result illustrated that the most frequent level of education of the sample was a primary school. The same side with *Peters et al. (2017)* found that most of the sample finished elementary school.

Regarding occupation, the present study results prove that more than half of the sample was unemployed. This result agrees with *Shokre and Souilm (2018),* who stated that more than half were unemployed. In the same line, the results consistent with *Eyanoer (2018),* who founded that more than three-quarters of the sample was unemployed. On the other hand, the result disagreed with *Leite and Caldeira (2015),* who stated thatmost of the sample were retired or pensioners. Also, *Ramasamy et al. (2018)* showed that nearly to one- third of the study sample were farmers.

Regarding residence, nearly three-quarters of the sample were residing in an urban area. The present study agrees with *Hemavathy and Nagarathnamma (2018)* founded that majority of the subjects from an urban locality. This result disagreement with a study carried by *Mahendra et al. (2018),* who founded that most patients belong to rural. The present study also shows that nearly half of the sample their monthly income enough. This finding may be due to community support for these patients. This result disagreed with *Reis et al. (2013); Azad-uz-zaman, Hossain, Boiragee, and Parvin (2016);* who founded that income lower or equal to the minimum wage among the studied patients.

The present study illustrates the clinical data of the studied patients concerning the duration of illness. The result illustrated that less than half of the studied patients had less than five years. This finding may be due to most patients delayed in visiting a doctor that leads to prolonging their duration of illness. It may be related to the incubation period of leprosy is long. The result agrees with a study carried by *Govindharaj et al. (2018),* who showed thatmore than half of their study sample their disease duration was more than three years. This result disagrees with *Arora (2016),* who founded that more than two-thirds of the patients have leprosy related disabilities for more thanten years.

The present study shows that more than two-thirds of the studied patients have problems associated with physical disabilities (deformity). This finding may be due to delayed seeking treatment that leads to visible deformity among leprosy patients. *Nayak, Satheesh, and Shashidhar (2017)* explained that nerve damage is the most characteristic feature of the disease and is also the cause of most of the disability that the patient suffers. This result agrees with *Arora (2016),* who stated that more than two-thirds of the sample suffering from a leprosy-related disability. This result also agreed with *Dessoki, Soltan, and Ezzat (2018),* who found that physical deformity was present in the patients.

Concerning to site of deformity among the patients. More than half and more than one-third of the studied patients their deformity in their legs and arms, respectively. This result supported with *Sarkar, Dasgupta, and Dutt (2012)* found that feet were the commonly involved site of disability, followed by hands. On the other side, the result disagreed with studies done in North India that found a claw hand to be the most common deformity *(Chhabra, Grover, Singal, Bhattacharya, & Kaur, 2015).*

The present study shows that about half of the studied patients develop the appearance of deformity during treatment. This finding may be due to delay in diagnosis and delay in providing proper care for the disease. This result was consistent with *Patil and Sherkhane (2016),* who founded that nearly half of patients had already developed disability by diagnosis. This result disagreement with a study carried by *Arora (2016),* who founded that about two-thirds of the sample was found to have a leprosy-related disability before the first visit to the hospital.

Concerning the presence of family support or not, the present study showed that most of the sample have family support. This finding may be due to the Egyptian culture about supporting family members during the disease period. This result disagrees with a study by *Damte, Berhe, and Hiwot (2011),* who stated that the total leprosy patients do not support the family.

The present study shows that most of the studied patients have no family history of the disease. This result disagreed with *Dessoki et al. (2018),* who stated that most of the studied patients have a family history of leprosy disease. The result also did not come with *Yamaguchi, Poudel, and Jimba (2013),* who founded that more than half of the adolescents had one parent with a history of leprosy, and less than half of them had two parents with a history of leprosy. Leprosy occurring in families is a well-established fact because the spread of leprosy is predominantly through nasal droplets and close contact among family members living in the same environment, which is conducive for the spread of leprosy, especially if one member is borderline lepromatous or lepromatous leprosy type, smear-positive “open case."

The present study illustrates the frequency distribution of studied patients regarding the total quality of life. The majority of the studied patients had a low level of total (QoL). This finding may be due to factorsthat potentially contribute to the deteriorated QoL in leprosy patients. This finding may be due to late diagnosis, reactions, disability, prejudice, and stigma. The quality of life of such persons declines rapidly. Other causes listed by *Lusli et al. (2015)* stigma toward persons affected by leprosy and their families have also adversely affected their quality of life due to their mobility, interpersonal relationships, marriage, employment, leisure, and social activities.

This result consistent with *El-Refaei, Daifalla, Kasem, and Bayomy (2018); Brouwers, Van Brakel, and Cornielje (2011); Umoh and Effiong (2015); & Geetha et al. (2015),* who stated that the leprosy patients showed lower QoL scores in all domains physical, psychological, social, and environmental domain of life of the victims than the general population. The result is consistent with *Yap, Kiung, and Yap (2016); Dinesh and Logaraj (2016),* who observed that the person affected with leprosy disability has a poor quality of life. The result was inconsistent with *Eyanoer (2018),* who founded that fifty-seven percent of leprosy patients do not disrupt their qualityof life.

The current study observed that the physical domain had a moderate level regarding their QOL. This finding may be due to patients with leprosy reactions tending to have more severe physical impairment in the physical domain. This domain consists of pain and discomfort, dependency on medication or treatment, energy and fatigue, sleep and rest, mobility, daily activities, and work capacity. Professional activities and leisure were the worst affected. Those with a physical disability tend to have more impairment in their quality of life *(Costa et al., 2012; & Santo et al., 2015)*. The presence of pain affects physical and emotional wellbeing; leads to social isolation, relationship and psychological problems, and an inability towork *(Reis et al., 2013)*. This result also agreed with a study showing that leprosy individuals had low quality of life scores in the physical health domain *(Savassi et al., 2014)*.

In the current study, the result reveals that a low level of psychological domain regarding their QoL. This finding may be due to physical disabilities caused by the disease that may result in enormous psychological consequences and more possibility of worsening QoL. Low scores in psychological domains may be because neurological pain affects specific items of these domains. The presence of pain was associated with anxiety, depression, poor quality of sleep, and a reduced capacity to perform daily and occupational activities, and it also impairs participation in social activities. Leprosy and leprosy-related disabilities may predispose people to develop psychological, economic, and social problems which adversely affect QoL *(Proto, Machado-Filho, Rehder, Paixão, & Angelucci, 2010)*. This result consistent with a study by *Mankar, Joshi, Velankar, Mhatre, and Nalgundwar (2011);* the studies revealed that the overall the QoL of leprosy patients was lower in the psychological domain.

The present study also shows that nearly to half of the studied patients had a moderate level of social domain regarding their QoL. This finding may be attributed to the presence of community support adopted for leprosy patients' rehabilitation and family support for these patients. This result disagreement with *Savassi et al. (2014),* who founded that a higher score was in the social domain.

The result shows that most of the studied patients had a low level of environmental domain regardingtheir QoL. This finding may be due to social stigma and discrimination, financial resources, dissatisfaction with accessibility to health services, and dissatisfaction with transport" participation in and recreation opportunities were the most affected in the environmental domain among leprosy patients *(Peters et al., 2013)*. People affected by leprosy sometimes become isolated because of a fear of infecting others or because of internalized feelings of being less worthy. As a result, people affected by leprosy might lose their job or their customers or may decide to resign or close their business *(Peters et al., 2014)*. This result disagrees with *El-Refaei et al. (2018);* hisfinding of the study shows a better score in theenvironmental domain.

The present study results illustrate that two-thirds of the studied patients had a moderate level of depression. This finding may be related to that leprosypatients may arise as a complication or a consequence of primary skin disease, in reaction to disfigurement, perceived social stigma or undesirable changes in lifestyle and living conditions, divorce, high rates of unemployment, and displacement from their areas of residence. The present study findings evidence this finding that more than half of the studied patients were unemployed.

This result consistent with *Lepra's (2017)* studies that showed that more than half the people affected by leprosy would face depression. The result agreed with *Ibikunle, Onwuakagba, Okongwu, and Madu (2019);* the results showed that most participants were severely depressed. The result was inconsistent with *Dessoki et al. (2018),* who founded that less than half of the studied patients had a low level of depressive symptoms.

The present study shows that about two-thirds of the studied patients had a severe level of anxiety. This finding may be due to common reactions after knowing their diseases were anxiety and hopelessness. Also, the visibility of skin lesions causes embarrassment, sadness, shame, and anxiety. Leprosy patients often suffer from painful physicaland mental symptoms. This suffering reflected on their reluctance and delay in seeking hospitalization, and it generates great anxiety. This result is consistent with *Shoar etal. (2016),* who stated that anxiety symptoms among leprosy patients increased from admission to more extended hospital stay. On the same side, the result consistent with *Dessoki et al. (2018),* who stated thatabout half of the patients had anxiety symptoms.

The present study results reveal that most of the studied patients had a moderate level of stress. This finding may be due to the assumption of leprosy that is an incurable, hereditary, cursed, and impure disease that causes patients angry, disappointed even being introverted and leads them to treatment adherence; this factor can cause patients to suffer from psychological problems such as depression, anxiety, and stress. The result was consistent with *Noordende, Brakel, Banstola, and Dhakal, (2016),* who stated that leprosy patient suffers from emotional problems as emotional stress.

The present study shows that more than half of the studied patients had a severe level of total depression, anxiety, and stress. This result may be due to the negative stigma on society that causes psychological problems like depression, anxiety, and stress. This result concurs with the result of a study in India, which revealed that less than half of the patients exhibited psychological distress like depression, anxiety, and stress. This result is consistent with previous literature by *Eyanoer (2018),* who stated that leprosy patients face problems in many aspects such as social, economic, cultural, and national security. Both the debilitating effects and disfigurements of leprosy, society tends to stigmatize negatively those suffering from leprosy.

The result shows no statistically significant correlation between the total quality of life and total depression among leprosy patients. This result consistent with *Ibikunle et al. (2019),* who stated that there was no statistically significant correlation between the total level of depression and total quality of life. The present study shows negative but not statistically significant between the total quality of life and total anxiety (at p =.531, which exceed 0.05), and statistically negative correlation but not statistically significant ( at p=0.352), which exceed 0.05 between the total quality of life and total stress at p-value =<0.05 that could not reach the significant level.

The present study reveals a statistically significant negative correlation between the total quality of life and total DASS among the studied patient with leprosy. This finding may be due to psychological distress, including depression, stress, and other anxiety-related states, which have beenrelated to lower QoL. This result is consistent with *Bektas and Demir (2016),* who found increasing anxiety anddepression, leading to decreased quality of life.

The result reveals a statistically significant negative relationship between total quality of life and the duration of illness of the studied patients. The result also shows a statistically significant negative relationship between total quality of life and the number of injuries of the studied patients. This result was consistent with a study by *Dessoki et al. (2018),* who found a statistically significant negative correlation between the total quality of life and duration of illness and the number of injuries of the studied patients.

The present study illustrates a statistically significant relationship between total quality of life and the studied patients with and without deformity. This finding may be due to disability and leprosy are the two most stigmatized terms instilled in the mind of people and society in a more significant way. When these two strike someone together, it will fetch a very series impact on their quality of life and lowers the morale of the affected person. The result is consistent with *Govindharaj et al. (2018),* who found a highly significant difference seen among leprosy-affected persons with a disability and without a disability in all four domains. The persons with a disability had a lower quality of life than persons without a disability. In the same line, *Dinesh and Logaraj (2016)* observed that the person affected with leprosy disability has a poor life quality.

The study finding shows no statistically significant relationship between total DAS and the studied patients with and without deformity. *Dessoki et al. (2018);* his finding showed that there was no statistically significant difference between deformity and Beck Anxiety and Depression Inventory scores. On the other side result inconsistent with *Reis et al. (2014)* his results showed a higher prevalence of psychological distress in leprosy patients with higher disability levels, further patients with psychological distress had the lowest quality of life.

The present study shows no statistically significant relationship between total quality of life and socio-demographic characteristics among leprosy-affected persons with disability and without disability at p-value =>0.05. This result is consistent with *Geetha et al. (2015),* who found no significant relationship between leprosy patients' total quality of life and their socio-demographic variable.

## 7. Conclusion

Hence, it could conclude that patients with leprosy disease have a low level of quality of life, a low level of the psychological and environmental domain, and a moderate psychological and physical domain level. A significantly high prevalence of psychological problems presents with a severe level of total depression, anxiety, and stress, which impact the quality of life of leprosy patients. A statistically significant negative correlation between the total quality of life and total DASS among the studied patient with leprosy at p-value =<0.05.

## 8. Recommendations

The present study emphasizes the need for:

- Continuous counseling and health education for persons affected with leprosy to avoid or minimize the psychological problems and improve their quality of life.
- Psycho-educational program to improve psychological wellbeing and quality of life of leprosy patients.
- Promote community integration of leprosy patients by addressing all forms of discrimination and stigma.
- Psychological rehabilitation of people with leprosy deficits to improve quality of life.
- Develop a strategy for leprosy patients, increase the number of skilled specialists and develop programs highlighting the importance of research in leprosy to reduce its complications.

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