

## Quality of Life among Leprosy Patients

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### ABSTRACT

Leprosy is an infectious disease caused by *Mycobacterium Leprae*, an acid-fast, rod-shaped bacillus. The disease mainly affects the skin, the peripheral nerves, the mucosa of the upper respiratory tract, and the eyes. Leprosy is curable and treatment in the early stages can prevent disability (WHO, 2022). Nerve damage is the main cause of the disabilities or impairments seen among Leprosy Patients. *Mycobacterium Leprae* causes inflammation of the nerves and damages the nerves that supply blood to the hands, feet, and eyes. A descriptive cross-sectional study was carried out in Lalgadh Leprosy Hospital, Dhanusha-10, Lalgadh. 100 Leprosy patient were included in the study through a random sampling method. A standard questionnaire was used to collect data regarding the Quality of life among Leprosy Patients. Data was collected after receiving an ethical approval letter. Data was analyzed and interpreted using SPSS version 16. The study revealed that 25.01 of the respondents had a better Quality of life in the environmental domain than physical, social relationship, and psychological domains.

**Keywords:** Leprosy, Quality of Life

### I. INTRODUCTION

#### 1.1 Background of the Study

Quality of life as an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns (World Health organization, 2019). Assessment of one's quality of life is measured using three dimensions: life satisfaction (cognitive appreciation), affect (a person's feelings or emotional states which can be both positive and negative, typically measured with reference to a particular point in time) and eudemonics (a sense of having meaning and purpose in life or better

psychological functioning) (OECD Guidelines, 2013). [1] Leprosy is an infectious disease caused by *Mycobacterium Leprae*, an acid-fast, rod-shaped bacillus. The disease mainly affects the skin, the peripheral nerves, mucosa of the upper respiratory tract, and the eyes. Leprosy is curable and treatment in the early stages can prevent disability (WHO, 2022). Nerve damage is the main cause of the disabilities or impairment's seen among Leprosy Patients. *Mycobacterium Leprae* causes inflammation of the nerves and damages the nerves that supply blood in the hands, feet and eyes. All the complications of leprosy like paralysis, blindness, iritis, hair loss, infertility, kidney failure, muscle weakness, disfiguration of face and erectile dysfunction and infertility in men, etc. occur because of nerve damage (The Leprosy Mission International, 2022). According to National Manual for Leprosy Elimination, a Paucibacillary (PB) patient must complete 6 monthly doses of Multidrug Therapy (MDT) within 9 months and a Multibacillary (MB) patient must complete 12 monthly doses of MDT within 18 months (Chalise et al., 2005)[2]. There were 202 to 256 new leprosy cases registered globally in 2019. Of them, 14 893 were children below 14 years and the new case detection rate among child population was recorded at 7.9 per million child population based on 178 to 371 cases at the end of 2019, the prevalence corresponds to 22.9 per million populations (Leprosy Hansen's Disease, 2021). Routine activities to control Leprosy effectively in Nepal started from 1960 onwards. A survey conducted in 1960 with the support from WHO, estimated 1,00,000 cases of leprosy in the country. In 1966, a leprosy control program using Dapsone monotherapy was started as a pilot project in Nepal. The project gradually expanded as a vertical program and remained so till 1987 when it was integrated into general health services (Leprosy



Control and Disability Management Programme, 2021)[3]. Quality of life is compromised among Leprosy patients, due to damage in the physical and psychological domains. The physical domains have direct control in patients' work and daily activities while the physiological domain represents the way patients see themselves and relates to interactional aspects in the environment they live. The assessment of Quality of life is a relevant process because it aims at strengthening the quality of care provided and expanding public policies related to the Quality of life of leprosy patients and their families (Barcelos et al., 2020). Leprosy patients are stigmatized in the Nepalese Society mainly those with visual deformities. The family members of leprosy affected patients also experienced limitation and restriction in their social life. Although presence of intensive rehabilitation of psychological and socioeconomic support networks of leprosy affected people and their families is increasing but all these individuals have to deal with a poor quality of life and ongoing struggle against leprosy stigma (Yamaguchi et al., 2013)[4].

### 1.2 Rationale of the Study

Leprosy remains a disease of concern in many countries of Africa, Southeast Asia and the Americas where more than 200000 new cases, including around 25000 infections in children, are being diagnosed every year (Smith et al., 2015)[5]The number of leprosy patients is increasing in Nepal even after declaration of elimination in 2010. The prevalence of leprosy was found to be 0.77/10,000 population in 2010 and 0.99/10,000 in 2018 but at present, the registered prevalence has remained below the elimination level with the national registered prevalence is 0.73/10,000 in 2021. Leprosy has been demonstrated to have an impact on Health-related Quality of life and the mental health status of affected individuals. The self-esteem as well as physical and emotional well-being of leprosy patients and their families are likely to be affected. Quality of Life of Leprosy affected people is

affected by the physical, psychological and environmental domain, it is necessary to investigate and improve Health related Quality of Life of Leprosy Patient (Yamaguchi et al., 2013)[6].

### 1.3 Significance of the Study

The study will help to find out the quality of life among leprosy patients. Its findings might be helpful for other researchers in future for reference. This study might be useful in conduction of large-scale comparative studies in coming days. The findings and analysis of this study will be beneficial for the whole nursing profession and health care providers. This study will be helpful to fulfill researcher's academic requirement and build their capacities to work in related research topics.

**1.4 Research Questions** What is the Quality of Life among Leprosy Patients of Lalgadh Leprosy Hospital, Dhanusha, Lalgadh?

### 1.5 Research Objectives

#### General Objective

To assess the Quality of Life among Leprosy Patients of Lalgadh Leprosy Hospital, Dhanusha-10 Lalgadh.

#### Specific Objective

To assess the Domain of Quality of Life among Leprosy Patients of Lalgadh Leprosy Hospital, Dhanusha- 10 Lalgadh.

### 1.6 Research Variables

#### 1.6.1 Dependent Variable

Quality of Life among Leprosy Patients

#### 1.6.2 Independent Variables

Age, Gender, Religion, Educational Status, Marital Status, Family History, Family Type, Disability, Duration of Leprosy Diagnosed

### 1.7 Conceptual Framework

The conceptual Framework is the thinking process that is developed by the researcher. It is a whole picture of frame of study that provides a clear concept or information to the reader.

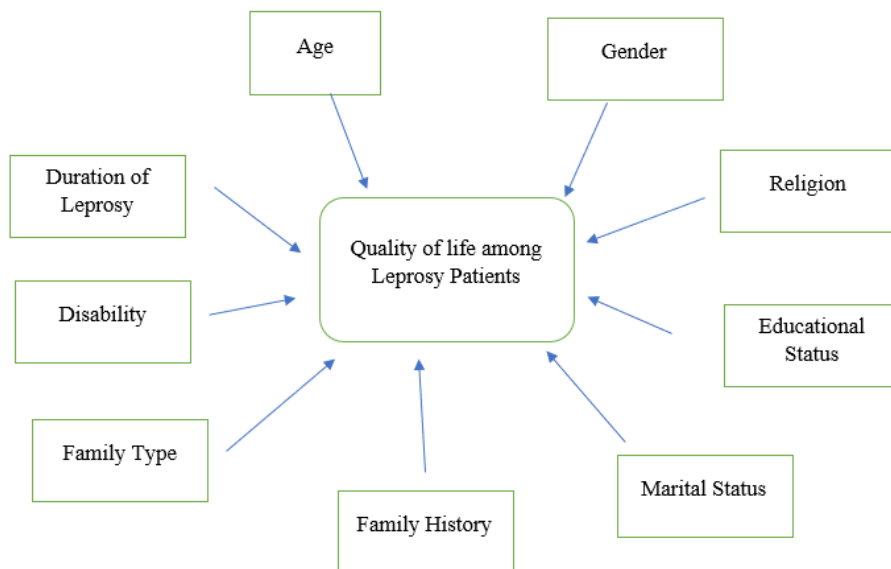


Figure 1: Conceptual Framework on Quality of Life among Leprosy Patients

### 1.8 Operational Definition

**Quality of life:** In my study, it refers to the level of satisfaction with life and health-related factors, experience with the environment, social, physical and psychological among leprosy-affected patients.

**Leprosy Patients:** These refers to the individuals who are under-diagnosed for leprosy and leprosy-affected disabled peoples visiting the in-patient and out-patient department of Lalgadh Leprosy Hospital.

### 1.9 Limitations of the Study

The study will be done only in one leprosy hospital that's why it is difficult to generalize in all population of Nepal.

A literature review summarizes that the impact on Quality of Life among leprosy-affected patients is significantly different depending upon the physical, psychological, and environmental domains. In conclusion, there is a need for early detection and management of leprosy to prevent deformities and disabilities which might improve the quality of life of persons affected by Leprosy.

## II. RESEARCH METHODOLOGY

### 2.1 Design of the study

Types of study which simply characterize the prevalence of the quality of health outcome among leprosy affected patients over a define period of time.

### 2.2 Study Population

The study of the population was in Leprosy Patients of In-patient department and people visiting out-patient department of Lalgadh Leprosy Hospital.

### 2.3 Study Area

The study was conducted in Lalgadh Leprosy Hospital, Lalgadh Dhanusha.

Lalgadh Leprosy Hospital was established in 14 Kartik 2053 B.S under Nepal Leprosy Trust. During the establishment it was 50 bedded now it has upgraded to 100 bedded. Lalgadh Leprosy Hospital has an annual patient-flow over 1,100 new leprosy patients and over 12,000 total leprosy consultation.

### 2.4 Sampling Technique

Purposive Sampling refers to a group of non-probability sampling techniques in which units are selected because they have characteristics that was needed in research sample.

### 2.5 Sample Size

The sample size was calculated using the formula:

$$n = \frac{z^2 \times p \times q}{e^2}$$

Where, n= sample size

$$z = 1.96$$

$$p(\text{prevalence}) = 34.21\% \text{ (Das et al., 2020).}$$

$$q = 1 - p$$

e= maximum estimated error accepted (5%)

$$n = \frac{z^2 \times p \times q}{e^2} = (1.96)^2 \times 0.3421 \times 0.8684$$

$$(0.05)^2 = 456$$

But due to time constraint, the sample size was taken only 100.

### 2.6 Eligibility Criteria

Both Male and Female Leprosy Patient of IPD and OPD of Lalgadh Leprosy Hospital was included.

### 2.7 Research Instrument

A standard questionnaire (WHOQOL-BREF) was used to access Quality of Life of Leprosy Patient. The questionnaire was cover with 4 domains: Physical Health, Psychological Status, Social Relationships, Environment.[8]

### 2.9 Data Collection Plan

Firstly, Formal permission was taken from Lalgadh Leprosy Hospital.

Before giving questionnaire, informed consent was taken from Hospital and Patients by explaining all the matters related to study and objective.

Data was collected by face to face interview.

### 2.10 Ethical Consideration

During the study all ethical consideration was assured and precaution was taken to ensure the safety and rights of all the participants. [9]

Formal permission was taken from the concerned authority.

Privacy, confidentiality, and anonymity of participants were highly assured.

Nobody was forced to participate in this study all the respondent had their own choice.

No discrimination was made according to caste and religion.

### 2.11 Data Analysis Plan

After the collection of data, all collected data will be reviewed and checked for completeness, consistency, and accuracy. All the collected data was organized, edited, coded, classified, and tabulated. The data was entered into SPSS (Statistical Package for Social Studies) for further analysis. The data was analyzed by descriptive methods such as percentage, frequency, mean, median, and standard deviations. The analyzed data was represented in the form of a table.

It deals with cross-sectional descriptive analysis and interpretation of data obtained from the patients of Lalgadh Leprosy Hospital, Dhanusha, Lalgadh regarding their Quality of life. The data collected has been analyzed considering the research questions and objectives of the study, through numerical order. The results were analyzed through Statistical Package for Social Science (SPSS). The data has been taken from primary source. The final findings are presented as below.

## III. SOCIO-DEMOGRAPHIC CHARACTERISTICS

Below, shows that regarding the age among 100 respondents, highest percent 41% belong to age group above 60 years and lowest percent 28% belong to age group 20-39 years. With regards to gender, 73% were male and 27% were female. Regarding marital status, 4% were unmarried and 96% were married. Concerning educational level, highest percent 58% were illiterate and lowest percent 3% were higher level (more than 12). Regarding family type, highest percent 65% were lived in joint family and lowest percent 1% were lived in extended family. With regards to religion, the highest percentage 92% was Hinduism and the lowest percentage 1% was Buddhist.

Table 1

Socio-Demographic Characteristics		n=100
CHARACTERISTICS	FREQUENCY	PERCENTAGE
<b>Age group</b>		
20-39 years	28	28.0
40-59 years	31	31.0
Above 60	41	41.0
<b>Mean± standard deviation 51±1.64</b>		
<b>Gender</b>		
Male	73	73.0
Female	27	27.0
<b>Marital status</b>		
Unmarried	4	4.0

Married	96	96.0
<b>Education</b>		
Illiterate	58	58.0
Basic (1-8)	22	22.0
Secondary (9-12)	17	17.0
Higher (more than 12)	3	3.0
<b>Family type</b>		
Nuclear	34	34.0
Joint	65	65.0
Extended	1	1.0
<b>Religion</b>		
Hinduism	92	92.0
Buddhist	1	1.0
Muslims	7	7.0

### 3.1 Respondents Information on Effect of Leprosy

With regards to family history, the highest percent 89% had no family history and the lowest percent 11% had a family history of leprosy. The table further shows that the highest duration of diagnosis 69% belongs to 1-10 years and the lowest 3% belongs to 41-50 years. Concerning disability, the highest percent 79% were able to perform, and

the lowest 21% need assistance.[10] The table also shows that self-consciousness was present among very little among 54%. With regards, more than half of respondents 53% claimed that little social or leisure activities were skin affected over last weeks. Regarding skin prevented activities highest percent 54% shows that there was no effect over the last week. Table also shows that 47% of respondent claimed there was no skin created problems with partner, friends or relatives over the last week.

Table 2

CHARACTERSTICS	FREQUENCY	PERCENTAGE
n=100		
<b>Family History of Leprosy</b>		
Yes	11	11.0
No	89	89.0
<b>Duration of Diagnosis</b>		
1-10 years	69	69.0
11-20 years	16	16.0
21-30 years	9	9.0
31-40 years	3	3.0
41-50 years	3	3.0
<b>Disability</b>		
Able to perform	79	79.0
Need assistance	21	21.0
<b>Embarrassed or self-conscious about your skin</b>		
Not at all	32	32.0
A little	54	54.0
A lot	10	10.0
Very much	4	4.0
<b>Skin affected any social or leisure activities</b>		
Not at all	33	33.0
A little	53	53.0
A lot	10	10.0
Very much	4	4.0
<b>Skin prevented you from working or studying</b>		
No	54	54.0
Yes	46	46.0

**Skin created problems with your partner or your close friends or relatives**

Not relevant	1	1.0
Not at all	47	47.0
A little	35	35.0
A lot	13	13.0
Very much	4	4.0

**3.2 Quality of life of Physical Health**

With regards to satisfied with health, 40% respondent had answered they are very much satisfied with their health.

Regarding any medical treatment needed in daily life, 64% had answered moderate amount is needed in their daily life. Regarding enough energy, 38% respondents had answered they have a little energy for their everyday life. Regarding the ability to get around, 44% of respondents had

answered that they have good ability to move around. Regarding satisfied with sleep, 43% of respondents had answered they are satisfied with their sleep. Regarding ability to perform their daily activities, 55% respondents were satisfied with their ability. With regards to capacity for work, 45% of respondents were satisfied with their capacity for work.

**Table 3**  
 Respondents Quality of Life of Physical Domain (Items 3,4,10,15,16,17,18), n=100

Physical Domain	Frequency Percentage				
	Not at all	A little	A moderate amount	Very much	An extreme amount
Satisfied with health	1 (1.0%)	28 (28.0%)	31 (31.0%)	40 (40.0%)	-
Need any medical treatment	1 (1.0%)	14 (14.0%)	64 (64.0%)	19 (19.0%)	2 (2.0)
Have enough energy	<b>Not at all</b>	<b>A little</b>	<b>Moderately</b>	<b>Mostly</b>	<b>Completely</b>
	6 (6.0%)	38 (38.0%)	21 (21.0%)	18 (18.0%)	17 (17.0)
Able to get around	<b>Very much</b>	<b>Poor</b>	<b>Neither poor nor good</b>	<b>Good</b>	<b>Very Good</b>
	2 (2.0%)	19 (19.0%)	9 (9.0%)	44 (44.0%)	26 (26.0)
	<b>Very Dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither Satisfied nor Dissatisfied</b>	<b>Satisfied</b>	<b>Very Satisfied</b>
Satisfied with your sleep	2 (2.0%)	12 (12.0%)	19 (19.0%)	43 (43.0%)	24 (24.0)
Ability to perform daily living activities	1 (1.0%)	15 (15.0%)	27 (27.0%)	55 (55.0%)	2 (2.0)
Capacity for work	2 (2.0%)	26 (26.0%)	23 (23.0%)	45 (45.0)	4 (4.0)

**3.3 Quality of life of Psychological Domain**

Regarding enjoying life, 40% respondents had answered they enjoy their life very much. Regarding their life to be meaningful, 48% respondents had answered not at all. Regarding able to concentrate, 38% respondents had answered they

are very much able to concentrate. With regards to accept their bodily appearance, 41% respondents had answered moderate to accept their bodily appearance. With regards to satisfied with yourself, 55% respondents were satisfied. Regarding negative

feelings, 33% respondents had answered very often for their negative feelings.[11]

**Table 4**  
 Respondents Quality of Life of Psychological Domain (Items 5,6,7,11,19,26), n= 100

Psychological Domain	Frequency Percentage				
	Not at all	A Little	A moderate	Very Much	An extreme amount
Enjoy life	3 (3.0%)	29 (29.0%)	28 (28.0%)	40 (40.0%)	-
Feel your life to be meaningful	3 (3.0%)	30 (30.0%)	48 (48.0%)	19 (19.0%)	-
Able to concentrate	8 (8.0%)	26 (26.0%)	28 (28.0%)	38 (38.0%)	-
Accept your bodily appearance	3 (3.0%)	20 (20.0%)	41 (41.0%)	25 (25.0%)	11(11.0%)
Satisfied with yourself	<b>Very Dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither Satisfied nor Dissatisfied</b>	<b>Satisfied</b>	<b>Very Satisfied</b>
	2 (2.0%)	14 (14.0%)	26 (26.0%)	55 (55.0%)	3 (3.0%)
Negative feelings	<b>Never</b>	<b>Seldom</b>	<b>Quite Often</b>	<b>Very Often</b>	<b>Always</b>
	16 (16.0%)	26 (26.0%)	23 (23.0%)	33 (33.0%)	2 (2.0%)

### 3.4 Quality of life of Social Relationship

Regarding satisfied with their personal relationships, 65% respondents were satisfied with their personal relationships.

Regarding their sex life, 52% respondents had answered they were satisfied with their sex life. With regards to support that they get from their friends, 54% respondents had answered they were satisfied with their friends.

**Table 5**  
 Respondents Quality of Life of Social Relationship (Items 20,21,22), n=100

Social Relationship	Frequency Percentage				
	Very Dissatisfied	Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
Satisfied with personal relationships.	1 (1.0%)	12 (12.0%)	19 (19.0%)	65 (65.0%)	3 (3.0%)
Satisfied with sex life.	2 (2.0%)	15 (15.0%)	29 (29.0%)	52 (55.0%)	2 (2.0%)
Satisfied with the support you get from your friends.	8 (8.0%)	24 (24.0%)	11 (11.0%)	54 (54.0%)	3 (3.0%)

### 3.5 Quality of life of Environmental Domain

With regards to feel safe in their daily life, 64% respondents had answered they feel safe in their daily life. Regarding healthy of their physical environment, 60% respondents had answered in moderate amount they are healthy in their physical environment. Regarding money, 43% respondents had answered they don't have enough money to meet their needs. With regards to information, 34% respondents had answered they get a little bit

information which is needed in their day-to-day life. Regarding opportunity for leisure activities, 39% respondents had answered they have moderate amount of opportunity for their leisure activities. With regards to conditions of their living place, 54% respondents were satisfied with their living place. Regarding health services, 60% respondents were satisfied with their health services. Regarding transport, 71% respondents were satisfied with their transportation.

**Table 6**

Respondents of Quality of Life of Environmental Domain  
 (Items, 8,9,12,13,14,23,24,25)

n=100

Environmental Domain	Frequency Percentage				
	Not at all	A little	A moderate	Very Much	Extremely
Feel safe in your daily life.	2 (2.0%)	9 (9.0%)	22 (22.0%)	64 (64.0%)	3 (3.0%)
Physical environment.	2 (2.0%)	23 (23.0%)	60 (60.0%)	16 (16.0%)	-
Enough money.	43 (43.0%)	36 (36.0%)	10 (10.0%)	7 (7.0%)	4 (4.0%)
Get available information in your day-to-day life.	8 (8.0%)	34 (34.0%)	27 (27.0%)	27 (27.0%)	4 (4.0%)
Opportunity for leisure activities.	6 (6.0%)	31 (31.0)	39 (39.0%)	22 (22.0%)	2 (2.0%)
	<b>Very Dissatisfied</b>	<b>Dissatisfied</b>	<b>Neither Satisfied nor Dissatisfied</b>	<b>Satisfied</b>	<b>Very Satisfied</b>
Satisfied with living place.	3 (3.0%)	11 (11.0%)	11 (11.0%)	54 (54.0%)	3 (3.0%)
Satisfied with health services.	3 (3.0%)	11 (11.0%)	21 (21.0%)	60 (60.0%)	5 (5.0%)
Satisfied with transport.	2 (2.0%)	8 (8.0%)	18 (18.0%)	71 (71.0%)	1 (1.0%)

### 3.6 Mean of each domain of Quality of Life

Shows that less than half of the respondents (25.01) has good quality of life in

environment domain rather than physical, psychological and social domain.



**Table 7**

Mean of Each Domain of Quality of Life  
 n=100

DOMAIN	MEAN	STANDARD DEVIATION
Physical (3, 4, 10, 15, 16, 17, 18)	23.32	4.052
Psychological (5, 6, 7, 11, 19, 26)	18.27	3.29
Social Relationship (20, 21, 22)	10.14	1.853
Environment (8, 9, 12, 13, 14, 23, 24, 25)	25.01	3.945

#### IV. DISCUSSION

This chapter related the findings in a logical and rational way for the problem area and research question within the framework of the theory structured established in chapter one. This is concerned with summary of the findings of the study, conclusion and recommendation.

##### 4.1 Major Findings and Discussion

This is the study of Quality of Life among Leprosy Patients of Lalgadh Leprosy Hospital, Dhanusha. The study is based on primary data. Non-probability, purposive sampling method was adopted for data collection. The number of sample is 100. Standard questionnaire was prepared to obtain necessary data and information. The collected data were thus thoroughly analyzed on the basis of objective of the study.

##### Regarding the socio-demographic data

Concerning the demographic characteristics of the present study, it revealed that the mean age of respondents was 51.38. Most of the respondents belongs to the age group of 60 years and above which is similar to the study done by Dr. Nagla, Dr. Abdel, Dr. Gehad, 2021 that shows the mean age of the respondents was 51.79 and more than half of the respondents belong to the age group 40-60.

##### Regarding the Quality of life among leprosy patients

In the present study, with relation to the quality of life among leprosy patients, study represents that the respondents had good quality of life in environmental, Physical and Psychological

domain than Social Relationship domain which is similar to the study done in Sri Lanka (Nadeeja et al., 2015) revealed that with regards to four domains of quality of life, the area of environment, Physical and Psychological are less affected. Results of present study is found to be contrary to the study done in Brazil (Graziele et al., 2021) which revealed that the highest mean of quality of life was observed in psychological domain (16.28) and lowest in the environmental domain (13.86).

#### V. CONCLUSION

This present study is a small-scale descriptive study which was conducted to assess quality of life among leprosy patients of Lalgadh leprosy Hospital, Dhanusha. 100 respondents were taken through purposive sampling technique and data was collected using structured questionnaire. Ethical consideration was followed throughout the study and data was analyzed, interpreted and presented in tables. Majority of respondents were male and were between the age group of above 60 years. Most of the respondent belong to Hinduism religion and most of them had no any family history of leprosy. Regarding duration most of the respondents belong to 1-10 years and more than one third of respondent had no major disability. While talking about the quality of life among leprosy patients, the study revealed that out of four domains, environmental domain has highest mean of quality of life which shows that majority of respondents were satisfied regarding their

environmental domain rather than physical social and psychological domain.

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