Research Journal of
Medical Sciences

Research Article
doi: 10.36478/makrjms.2024.8.475.479

A Comparative Study of the Quality of Life, Knowledge, Attitude and Belief about Leprosy Disease among Leprosy Patients and Community Members

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Key Words
Leprosy, quality of life, knowledge, attitude, beliefs, stigma, community awareness

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Received: 19 June 2024
Accepted: 26 July 2024
Published: 30 July 2024

Citation: Saurabh Krishna Misra, Ravi Ranjan Singh, Hariom K. Singh and Richa Dokania, 2024. A Comparative Study of the Quality of Life, Knowledge, Attitude and Belief about Leprosy Disease among Leprosy Patients and Community Members . Res. J. Med. Sci., 18: 475-479, doi: 10.36478/makrjms.2024.8.475.479

Abstract

Leprosy is a chronic infectious disease that primarily affects the skin, peripheral nerves, mucosa of the upper respiratory tract and eyes. Despite significant advancements in treatment, stigma and discrimination against leprosy patients persist. This study aims to compare the quality of life, knowledge, attitude and beliefs about leprosy among leprosy patients and community members in the Delhi NCR region. A cross-sectional study was conducted from July 2020 to April 2022 involving 110 participants, including 55 leprosy patients and 55 community members. Data were collected using structured questionnaires assessing quality of life (WHOQOL-BREF), knowledge, attitude and beliefs about leprosy. Statistical analysis was performed using SPSS software, with descriptive statistics and inferential analysis (Chi-square test and t-test) to compare the two groups. The mean quality of life score for leprosy patients was significantly lower (mean=50.2, SD = 10.5) compared to community members (mean=72.4, SD=8.7) ($p<0.001$). Knowledge about leprosy was higher among community members, with an average score of 78% correct answers compared to 62% among leprosy patients ($p<0.01$). Attitudes toward leprosy were more positive among community members (mean attitude score=7.8, SD=1.2) compared to leprosy patients (mean attitude score=6.1, SD=1.5) ($p<0.05$). Beliefs about leprosy, including misconceptions about transmission and treatment, were more prevalent among leprosy patients. The study highlights significant disparities in quality of life, knowledge, attitude, and beliefs about leprosy between leprosy patients and community members. There is a critical need for targeted educational interventions to address misconceptions and improve the quality of life for leprosy patients. Enhancing community awareness and reducing stigma can contribute to better health outcomes and social integration for individuals affected by leprosy.

INTRODUCTION

Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by the bacterium Mycobacterium leprae. It primarily affects the skin, peripheral nerves, mucosa of the upper respiratory tract and eyes[1]. Despite significant advancements in treatment and the availability of effective multi-drug therapy (MDT), leprosy remains a public health concern in many parts of the world, including India[2]. India accounts for a significant proportion of the global leprosy burden, with new cases being reported annually[3]. The disease not only affects the physical health of individuals but also has profound social and psychological impacts due to the stigma and discrimination associated with it[4]. Leprosy patients often face social exclusion, which adversely affects their quality of life[5]. Understanding the knowledge, attitude and beliefs of both leprosy patients and community members is crucial for developing effective interventions to combat stigma and improve the overall quality of life for those affected by the disease. Previous studies have shown that misconceptions about leprosy transmission and treatment persist among the general population and even among leprosy patients[6,7]. These misconceptions contribute to the stigma and discrimination faced by patients, hindering their social integration and access to healthcare services[8]. Furthermore, the quality of life of leprosy patients is often compromised due to the physical and psychological impacts of the disease[9].

This study aims to compare the quality of life, knowledge, attitude, and beliefs about leprosy among leprosy patients and community members in the Delhi NCR region. By identifying the disparities in these areas, the study seeks to highlight the need for targeted educational interventions and policy measures to address misconceptions, reduce stigma, and improve the quality of life for leprosy patients.

MATERIALS AND METHODS

Study Design: A cross-sectional study was conducted to compare the quality of life, knowledge, attitude and beliefs about leprosy among leprosy patients and community members in the Delhi NCR region. The study was carried out from July 2020 to April 2022.

Study Population: The study sample consisted of 110 participants, divided into two groups: 55 leprosy patients and 55 community members. Leprosy patients were recruited from leprosy clinics and treatment centers in the Delhi NCR region. Community members were selected from the general population living in the same area, ensuring they had no history of leprosy.

Inclusion and Exclusion Criteria

Inclusion Criteria:

- Leprosy patients who had been diagnosed and were undergoing treatment.
- Community members aged 18 years and above, residing in Delhi NCR.
- Participants who provided informed consent.

Exclusion Criteria:

- Individuals with cognitive impairments that could hinder their ability to respond to the questionnaire.
- Community members with a history of leprosy or other chronic infectious diseases.

Data Collection: Data were collected using structured questionnaires administered through face-to-face interviews. The questionnaire comprised four sections: demographic information, quality of life assessment, knowledge about leprosy and attitudes and beliefs towards leprosy.

Quality of Life Assessment: The World Health Organization Quality of Life-BREF (WHOQOL-BREF) questionnaire was used to assess the quality of life. It consists of 26 items covering four domains: physical health, psychological health, social relationships and environment.

Knowledge about Leprosy: A knowledge questionnaire was developed, consisting of 20 multiple-choice questions covering the etiology, transmission, symptoms, and treatment of leprosy. Each correct answer was awarded one point, with a maximum possible score of 20.

Attitudes and Beliefs towards Leprosy: Attitudes were assessed using a 10-item Likert scale questionnaire, where responses ranged from strongly agree to strongly disagree. Beliefs were evaluated through open-ended questions about common misconceptions regarding leprosy.

Statistical Analysis: Data were analyzed using SPSS software version 25.0. Descriptive statistics, including means, standard deviations and frequencies, were calculated for demographic variables and questionnaire scores. Comparative analyses between leprosy patients and community members were performed using Chi-square tests for categorical variables and independent t-tests for continuous variables. A $p<0.05$ was considered statistically significant.

RESULTS AND DISCUSSIONS

Demographic Characteristics: The demographic characteristics of the study participants are

Table 1: Demographic Characteristics of Study Participants

Characteristic	Leprosy Patients (n = 55)	Community Members (n = 55)	p-value
Mean Age (years) 42.6 (SD = 11.3)	40.4 (SD = 10.7)		0.32
Gender (Male/Female)	30/25	28/27	0.45
Educational Level (%)			
No Formal Education	20%	5%	0.02*
Primary Education	40%	35%	0.65
Secondary Education	30%	40%	0.35
Higher Education 10%	10%	20%	0.15

* p < 0.05 indicates statistically significant difference.

Table 2: Quality of Life Scores (WHOQOL-BREF)

Domain	Leprosy Patients (mean ± SD)	Community Members (mean ± SD)	p-value
Physical Health	48.3 ± 11.2	70.5 ± 9.3	<0.001*
Psychological Health	49.5 ± 10.8	73.1 ± 8.5	<0.001*
Social Relationships	51.0 ± 9.7	74.0 ± 7.8	<0.001*
Environment	51.9 ± 10.3	71.8 ± 8.2	<0.001*
Overall Quality of Life	50.2 ± 10.5	72.4 ± 8.7	<0.001*

* p < 0.05 indicates statistically significant difference.

Table 3: Knowledge about Leprosy

Group	Mean Score ± SD	p-value
Leprosy Patients	12.4 ± 3.1	
Community Members	15.6 ± 2.4	<0.01*

* p < 0.05 indicates statistically significant difference.

Table 4: Attitudes towards Leprosy (Likert Scale Scores)

Group	Mean Score ± SD	p-value
Leprosy Patients	6.1 ± 1.5	
Community Members	7.8 ± 1.2	<0.05*

* p < 0.05 indicates statistically significant difference.

summarized in Table 1. The mean age of leprosy patients was 42.6 years (SD=11.3) and for community members, it was 40.4 years (SD=10.7). There was no significant difference in gender distribution between the two groups (p=0.45).

Quality of Life: The quality of life scores, assessed using the WHOQOL-BREF questionnaire, are presented in Table 2. Leprosy patients had significantly lower overall quality of life scores compared to community members (mean=50.2, SD=10.5 vs. mean=72.4, SD=8.7, p<0.001).

Knowledge about Leprosy: Knowledge scores about leprosy are shown in Table 3. Community members scored higher on the knowledge questionnaire compared to leprosy patients (mean=15.6, SD=2.4 vs. mean=12.4, SD=3.1, p<0.01).

Attitudes towards Leprosy: The attitudes towards leprosy were assessed using a Likert scale and the results are presented in Table 4. Community members had more positive attitudes towards leprosy than leprosy patients (mean attitude score=7.8, SD=1.2 vs. mean attitude score=6.1, SD=1.5, p<0.05).

Beliefs about Leprosy: Beliefs about leprosy, including misconceptions, were more prevalent among leprosy patients. Common misconceptions included beliefs about the hereditary nature of the disease and its incurability. These misconceptions were significantly higher among leprosy patients compared to community members (p<0.05).

These findings underscore the significant differences in quality of life, knowledge, attitudes and beliefs about leprosy between leprosy patients and community members, highlighting areas for targeted educational interventions and stigma reduction efforts.

This study aimed to compare the quality of life, knowledge, attitude and beliefs about leprosy between leprosy patients and community members in the Delhi NCR region. The findings reveal significant disparities in these areas, underscoring the need for targeted interventions to address the challenges faced by leprosy patients.

The results indicated that leprosy patients have a significantly lower quality of life compared to community members across all domains assessed by the WHOQOL-BREF questionnaire. This aligns with previous studies that have documented the detrimental impact of leprosy on patients' physical, psychological, and social well-being[1,2]. The stigma associated with leprosy exacerbates these issues, leading to social isolation and reduced opportunities for economic and social participation[3]. Addressing these quality of life issues requires comprehensive rehabilitation programs that not only focus on medical treatment but also on social and psychological support. The study found that community members had higher knowledge scores about leprosy compared to leprosy patients. This discrepancy may be due to limited access to information and educational resources among leprosy patients[4]. Enhancing knowledge about leprosy is crucial as it directly influences attitudes and beliefs, which in turn affect how patients are treated within their communities. Public health campaigns and educational programs tailored to both patients and the general population can help bridge this knowledge gap and dispel myths surrounding the disease[5]. Community members exhibited more positive attitudes towards leprosy than leprosy patients. This finding is consistent with other studies that have reported negative self-perceptions and internalized stigma among leprosy patients[6]. Negative attitudes and self-stigma can lead to delayed health-seeking behavior, poor treatment adherence and further deterioration of the patient's condition[7-9]. Interventions aimed at reducing stigma and promoting positive attitudes are essential. These can include community-based awareness programs and support groups for patients to share experiences and foster mutual support. The study highlighted that misconceptions about leprosy, such as beliefs in its hereditary nature and incurability, were more prevalent among leprosy patients. Such misconceptions contribute to the stigma and discrimination that patients face[10-13]. Addressing these erroneous beliefs is critical for improving the social acceptance of leprosy patients. Health education initiatives should focus on providing accurate information about the transmission, treatment, and curability of leprosy to both patients and the broader community[14,15]. The findings of this study have several implications for public health policy and practice. Firstly, there is a need for integrated health education programs that target both leprosy patients and the general community to improve knowledge and reduce stigma. Secondly, interventions should be designed to enhance the quality of life of leprosy patients through comprehensive rehabilitation services that include psychosocial support. Finally, policies should focus on creating an inclusive environment for leprosy patients, promoting their social and economic integration.

This study has some limitations. The cross-sectional design limits the ability to draw causal inferences. Additionally, the sample size was relatively small and confined to the Delhi NCR region, which may limit the generalizability of the findings. Future research should

consider longitudinal studies with larger and more diverse populations to further validate these findings.

CONCLUSION

In conclusion, this study underscores the significant disparities in quality of life, knowledge, attitudes and beliefs about leprosy between leprosy patients and community members. Addressing these disparities requires targeted educational interventions, stigma reduction efforts and comprehensive support services for leprosy patients. Such measures are essential to improve the health outcomes and social integration of individuals affected by leprosy.

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