Assessment of Mental Well-Being and Quality of Life in the Context of Disability in Leprosy Patients

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India accounts for 60% of new leprosy cases worldwide. The prevalence of poor psychological well-being and poor quality of life among leprosy disabled patients varies from 25 to 53%. It is a prospective, exploratory, cross-sectional study of 35 leprosy disabled patients visiting dermatology OPD with the use of WEMWBS and WHOQOL-BREF scales. Grade 1 deformity was noted in 9/35 (25.7%), and grade 2 deformity was seen in 26 /35 (74.3%). Good psychological well-being was found in 19/35 (54.3%) and 17/35 (48.6%) had a poor quality of life. A significant association was found between age and quality of life (p=0.047). The degree of disability directly affected the quality of life (p < 0.05), and factors such as education and employment played a role in the prevention of disability (p < 0.05). The higher the degree of disability, the poorer the quality of life and psychological well-being. Age, employment, and educational status affect quality of life as well as psychological well-being of leprosy patients. Social and psychological support should be available to all affected individuals, as it can help in their rehabilitation. Early diagnosis and treatment can prevent deformity, improve mental well-being, and enhance quality of life. There is need to carry out such studies with adequate sample size, appropriate profiles of disease, different socio-cultural and geographical settings.

Keywords : Disability, Leprosy, Mental Well-Being, Psychological Support, Quality of Life

Introduction

Leprosy is a contagious disease caused by *Mycobacterium leprae*. If treated early, it can prevent development of deformities. Leprosy patients often feel excluded from social events and this diminishes their mental and social health (Rafferty 2005).

Among the 22 global priority countries, Brazil and India have the highest prevalence of the disease (Rao & Suneetha 2018). India accounts for 60% of new cases worldwide (Rao & Suneetha 2018). In India, there are 132 new leprosy cases with grade 2 disability rate per 10000 people according to WHO report (WHO 2021). In Indonesia it was found that 47.7% of leprosy patients had a poor quality of life while 59.4% had a disability score of 2 and a poor quality of life (Utama et al 2017) . In Southern Nepal, it was shown that the prevalence of poor psychological well-being in people with other skin diseases was only 9.3%, while it was 28% in leprosy patients (Odds ratio (OR) = 6.02) (van Dorst et al 2020). A study in

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Kashmir reported that grade 2 disabilities were almost twice as common as other disabilities, the incidence of grade 2 disabilities was 25.56% (Rather et al 2022). A similar observation was made in Bangalore (Raghavendra et al 2017) where 74% of children had grade 2 disabilities, a study in Kenya also observed the same to be true (Ong'ang'o et al 2022). Das et al (2020) found that women had a lower quality of life than men due to being economically poor, which limits access to health care. In Egypt it was found that out of the four domains of the WHO Quality-of-Life (WHOQOL-BREF) psychological domain had the lowest scores on most variables, which could be due to neuropathic pain affecting certain domains (Barakat & Zaki 2019). Pai et al (2022) had similar findings but Santos et al (2015) showed lower scores in the physical and environmental domains. A study from West Bengal reported that significant differences were found in all four domains of quality of life (Govindraj et al 2018). This may indicate that leprosy primarily affects the underprivileged and marginalized. Family income and quality of life were found to be significantly related. In Bangladesh, 53% of leprosy patients suffered moderate-to-severe depression, while 44% had mild depression (Bow-Bertrand et al 2019). The reasons for poor mental health were associated with high levels of disability, low education and poor socioeconomic status (Das et al 2020, Govindhraj et al 2018). In our tertiary care institution, we conducted this cross-sectional study on leprosy patients with deformities (Grade 1 and 2). We sought to assess the influence of leprosy on patients' mental health and quality of life of the affected individuals.

Materials and Methods

Our study was a prospective, exploratory, cross-sectional study conducted over two months. Leprosy patients attending the dermatology outpatient department of a tertiary care hospital in Dakshina Kannada district of Karnataka participated in the study. Patients diagnosed with leprosy (grade 1 and grade 2 deformities) and above 18 years of age who consented to participate in the study were included. Those who were not willing to participate or not willing to fill the questionnaires (WHOQOL-BREF and WEMWBS) were excluded. Thirty-five individuals who met the above inclusion and exclusion criteria were studied.

After ethical approval, the selected patients were informed about the study and its conduct. Before participating in the study, patients were provided informed consent. A paper-based questionnaire was used for the survey, with questions in Kannada, English, or Malayalam as some of the patients hailed from the neighbouring state of Kerala.

The degree of disability was determined using the World Health Organization leprosy classification system (Brandsma & van Brakel 2003). Physical disability in leprosy is defined by WHO in three categories:

Grade 0-no disability (no anaesthesia) and no visible damage or deformity to eyes, hands, or feet.

Grade 1-loss of protective sensitivity of eyes, hands, or feet, but no visible damage or deformity.

Grade 2-presence of deformity or visible damage to eyes, hands, or feet.

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) was used to measure mental well-being (Tennant et al 2007). The WEMWBS contains 14 items related to positive attributes of mental well-being. Responses range from 1 (never) to 5 (always), giving a total score between 0 and 70.

The WHO Quality-of-Life BREF Scale (WHOQOL-BREF) was used to assess participants' quality of

life (WHO 1997). It includes 26 questions, 2 of which are general. The remaining 24 questions are classified as physical (B3, B4, B10, B15, B16, B17, and B18), psychological (B5, B6, B7, B11, B19, and B26), social relationships (B20, B21, and B22), and environment (B8, B9, B12, B13, B14,

Table 1 : Characteristics of domains of QOL and WEMWBS.

Time Period	N	Minimum	Maximum	Mean	Std. Deviation	Median
Domain 1	35	9	34	20.37	6.431	19.00
Domain 2	35	8	29	17.83	5.533	18.00
Domain 3	35	3	15	8.71	2.945	8.00
Domain4	35	16	34	23.23	4.977	22.00
QOL	35	46	103	69.60	17.203	68.00
WEMWBS	35	18	70	44.43	13.870	42.00

Table 2 : Frequency of demographic variables, disability grading, QOL and WEMWBS.

		Frequency	Column N%
WHO disability grading	1	9	25.7%
	2	26	74.3%
QOL	Poor	17	48.6%
	Good	18	51.4%
AGE	< 30 years	3	8.6%
	30 - 49 years	7	20.0%
	50 - 69 years	10	28.6%
	> 69 years	15	42.9%
WEMWBS	Poor	16	45.7%
	Good	19	54.3%
GENDER	Male	21	60.0%
	Female	14	40.0%
MARITAL STATUS	Single/Unmarried	11	31.4%
	Married	24	68.6%
EDUCATION	Primary school	26	74.3%
	High school	9	25.7%
WORKING	Unemployed	25	71.4%
	Full time	5	14.3%
	Part time	3	8.6%
	Retired	2	5.7%
TYPE	Multibacillary (MB)	32	91.4%
	Paucibacillary (PB)	3	8.6%

B23, 24 and 25). Each question can be scored out of 5 (1= not at all, 2 = a little, 3 = moderately, 4 = mostly, and 5 = completely). The raw scores range from 7 to 35, 6 to 30, 3 to 15, and 8 to 40 for each dimension, with higher scores indicating higher quality of life.

Results

The characteristics of the four domains of quality of life (QOL) and WEMWBS, such as mean, standard deviation, and median, are depicted in Table 1. The 35 participants were categorized into good and poor groups using the median of WHOQOL-BREF and WEMWBS scores. A median of greater than or equal to 68 was good QOL, and a value of less than 68 was considered to be poor QOL. In the WEMWBS, a median of greater than or equal to 42 was considered to indicate good psychological well-being and a median of less than 42 was considered to indicate poor psychological well-being.

Table 2 shows that of the 35 participants, nine participants (25.7%) had a disability of grade 1, and 26 participants (74.3%) had a disability of grade 2. There were 42.9% over 69 years old.

Table 3 : Variables in comparison with QOL.

		QOL						p value
		Poor			**Good**			
		Count	Row N%	Column	Count	Row N%	Column	
WHO disability grading	1	1	11.1%	5.9%	8	88.9%	44.4%	0.009
	2	16	61.5%	94.1%	10	38.5%	55.6%	
WEMWBS	Poor	15	93.8%	88.2%	1	6.3%	5.6%	0.000
	Good	2	10.5%	11.8%	17	89.5%	94.4%	
AGE	< 30 years	0	0.0%	0.0%	3	100.0%	16.7%	0.047
	30 - 49 years	2	28.6%	11.8%	5	71.4%	27.8%	
	50 - 69 years	4	40.0%	23.5%	6	60.0%	33.3%	
	> 69 years	11	73.3%	64.7%	4	26.7%	22.2%	
GENDER	Male	8	38.1%	47.1%	13	61.9%	72.2%	0.129
	Female	9	64.3%	52.9%	5	35.7%	27.8%	
MARITAL STATUS	Single	6	54.5%	35.3%	5	45.5%	27.8%	0.632
	Married	11	45.8%	64.7%	13	54.2%	72.2%	
EDUCA-TION	Primary school	15	57.7%	88.2%	11	42.3%	61.1%	0.067
	High school	2	22.2%	11.8%	7	77.8%	38.9%	
WORKING	Unemployed	16	64.0%	94.1%	9	36.0%	50.0%	0.026
	Full time	0	0.0%	0.0%	5	100.0%	27.8%	
	Part time	1	33.3%	5.9%	2	66.7%	11.1%	
	Retired	0	0.0%	0.0%	2	100.0%	11.1%	
TYPE	Multibacillary	16	50.0%	94.1%	16	50.0%	88.9%	0.581
	Paucibacillary	1	33.3%	5.9%	2	66.67%	11.1%	

Table 4 : Variables in comparison with WHO disability grading.

		WHO disability grading						p value
		1			**2**			
		Count	**Row N%**	**Column**	**Count**	**Row N%**	**Column**	
WEMWBS	Poor	1	6.3%	11.1%	15	93.8%	57.7%	0.016
	Good	8	42.1%	88.9%	11	57.9%	42.3%	
AGE	< 30 years	3	100.0%	33.3%	0	0.0%	0.0%	0.007
	30 -49 years	3	42.9%	33.3%	4	57.1%	15.4%	
	50 -69 years	1	10.0%	11.1%	9	90.0%	34.6%	
	> 69 years	2	13.3%	22.2%	13	86.7%	50.0%	
GENDER	Male	5	23.8%	55.6%	16	76.2%	61.5%	0.752
	Female	4	28.6%	44.4%	10	71.4%	38.5%	
MARITAL STATUS	Single	3	27.3%	33.3%	8	72.7%	30.8%	0.886
	Married	6	25.0%	66.7%	18	75.0%	69.2%	
EDUCATION	Primary school	4	15.4%	44.4%	22	84.6%	84.6%	0.017
	High school	5	55.6%	55.6%	4	44.4%	15.4%	
WORKING	Unemployed	4	16.0%	44.4%	21	84.0%	80.8%	0.001
	Full time	5	100.0%	55.6%	0	0.0%	0.0%	
	Part time	0	0.0%	0.0%	3	100.0%	11.5%	
	Retired	0	0.0%	0.0%	2	100.0%	7.7%	
TYPE	Multibacillary	7	21.9%	77.8%	25	78.1%	96.2%	0.090
	Paucibacillary	2	66.67%	22.2%	1	33.3%	3.8%	

In this group 74.3% had completed elementary school and 25.7% had completed secondary school. Seventy-one percent (25) of the subjects were unemployed. Seventeen of the participants (48.6%) had poor quality of life, while 18 (51.4%) had good quality of life. Poor psychological well-being was found in 16 (45.7%), and 19 (54.3%) had good psychological well-being.

Table 3 shows that out of the 9 participants with a grade 1 disability, one person (11.1%) had a poor quality of life and eight (88.9%) had a good quality of life. Among the 26 individuals with a grade 2 disability, 16 (61.5%) had a poor quality of life and 10 (38.5%) had a good quality of life. A statistically significant correlation between the degree of disability and the participants quality of life (p =0.009).

The correlation between psychological well-being (WEMWBS) and quality of life showed that out of the 16 participants with poor psychological well-being, 15 individuals (93.8%) had a poor quality of life, and one individual (6.3%) had a good quality of life. Out of the 19 individuals with good psychological well-being, two individuals (10.5%) had poor quality of life and 17 individuals (89.5%) had a good quality of life.

Demographic details such as age showed that all three individuals under the age of 30 had a good quality of life, while participants aged older

than 69 years, 11 people (73.3%) had a poor quality of life. There was a significant relationship between the increasing age of the participants and diminishing quality of life (p=0.047).

Out of the 25 unemployed individuals, 16 (64%) had a poor quality of life and nine (36%) had a good quality of life. Five individuals (100%) with full-time employment had a good quality of life. There was a significant relationship between the type of job and quality of life of the participants(p=0.026).

Table 4 shows 16 participants with poor psychological well-being, one person (6.3%) had a disability level 1, and 15 people (93.8%) had a disability level 2. Of the 19 individuals with good mental well-being, eight individuals (42.1%) had

a grade 1 disability, and 11 individuals (57.9%) had a grade 2 disability. The results show that there was a significant relationship between the level of disability and quality of life of the participants(p=0.016).

Demographic details such as age showed that three people (100%) under the age of 30 had a grade 1 disability. Among participants older than 69, two people (13.3%) had a grade 1 disability and 13 (86.7%) had a grade 2 disability. Table 4 shows there was a significant relationship between the participant's age and degree of disability (p = 0.007). Of the 26 individuals with primary education, 22 individuals (84.6%) had a grade 2 disability and 5 individuals (55.6%) with higher education had a grade 1 disability

Table 5 : Variables in comparison with WEMWBS.

		WEMWBS						p value
		POOR			**GOOD**			
		Count	Row N%	Column	Count	Row N%	Column	
AGE	<30 years	0	0.0%	0.0%	3	100.0%	15.8%	0.198
	30-49 years	2	28.6%	12.5%	5	71.4%	26.3%	
	50-69 years	5	50.0%	31.3%	5	50.0%	26.3%	
	>69 years	9	60.0%	56.3%	6	40.0%	31.6%	
GENDER	Male	7	33.3%	43.8%	14	66.7%	73.7%	0.072
	Female	9	64.3%	56.3%	5	35.7%	26.3%	
MARITAL STATUS	Single	5	45.5%	31.3%	6	54.5%	31.6%	0.983
	Married	11	45.8%	68.8%	13	54.2%	68.4%	
EDUCATION	Primary school	14	53.8%	87.5%	12	46.2%	63.2%	0.101
	High school	2	22.2%	12.5%	7	77.8%	36.8%	
WORKING	Unemployed	15	60.0%	93.8%	10	40.0%	52.6%	0.053
	Full time	0	0.0%	0.0%	5	100.0%	26.3%	
	Part time	1	33.3%	6.3%	2	66.7%	10.5%	
	Retired	0	0.0%	0.0%	2	100.0%	10.5%	
TYPE	Multibacillary	15	46.9%	93.8%	17	53.1%	89.5%	0.653
	Paucibacillary	1	33.3%	6.3%	2	66.7%	10.5%	

p value found using chi square /Fisher's exact test

Table 6 : Correlation between the variables.

		Domain 2	Domain 3	Domain 4	QOL	WHO disability grading	WEM-WBS
Domain 1	Pearson Correlation	.742	.483	.737	.908	-.543	.868
	p	0.000	0.003	0.000	0.000	0.001	0.000
Domain 2	Pearson Correlation		.464	.641	.864	-.546	.800
	p		0.005	0.000	0.000	0.001	0.000
Domain 3	Pearson Correlation			.746	.716	-.416	.604
	p			0.000	0.000	0.013	0.000
Domain 4	Pearson Correlation				.899	-.719	.795
	p				0.000	0.000	0.000
QOL	Pearson correlation					-.658	.915
	P					0.000	0.000
WHO disability grading	Pearson correlation						-.575
	P						0.000

(p=0.017). Out of the 25 unemployed individuals, 21 individuals (84%) had a grade 2 disability and all the individuals with full-time employment had a grade 1 disability. The two retired participants (100%) had a grade 2 disability. There was a significant relationship between the type of employment and the participants' level of disability (p=0.001).

The other demographic variables, such as gender, marital status, and type of leprosy, showed no significant correlation with the degree of disability (p > 0.05).

Table 5 shows the relationship between psychological well-being (WEMWBS) and demographic variables like age, gender, marital status, education, occupation, and leprosy. It shows no significant link between psychological well-being and the demographic variables of the participants (p > 0.05).

p value found using chi square /Fisher's exact test

Table 6 shows a significant correlation between Domain 1, Domain 2, Domain 3, Domain 4, Quality of Life, WHO, and WEMWBS. The p-value for all correlations is < 0.05, so all variables have a significant relationship.

Discussion

In our study, most participants had grade 2 disabilities: 26/35 participants (74.3%), and 9/35 (25.7%) had grade 1 disabilities. Similar observations on disabilities were made in Kashmir by Rather et al (2022) and in Bangalore by Raghavendra et al (2017). Additionally, we discovered that younger age groups had lower disability scores, while the elderly had a higher disability score. The longer the disease remains undiagnosed and untreated the higher the likelihood of deformity. Out of the 26 individuals, 15.4% had grade 2 disability and had a high school diploma, while 84.6% had an elementary school diploma. Individuals with higher levels of education had fewer deformities than those

with lower levels of education. Knowledge about leprosy, or even just knowing about it, can prevent people from developing disabilities.

Self-care is one of the most important approaches to treating leprosy and an essential step in preventing disability (Das et al 2020). People with disabilities need to take good care of their anaesthetic hands and feet and avoid activities that could worsen their condition. To reduce the risk of injury, physiotherapy to the affected body parts and modification to lifestyle is necessary. Warm water, soap and lubrication with oil is required to compensate for the moisture they lose when they sweat. These measures are a necessary substitute for the loss of normal function.

The results showed that 25 of the 35 participants were unemployed. An interview with them revealed that most of them had to quit their jobs due to impairment. Some even said they lost their jobs because the workers feared disease would spread to them. If even one family member stops working, it plunges the rest of the family into poverty. This affects the quality of life and mental health of the individuals involved, as they often rely on the help of their families or caregivers to perform their day-to-day activities. Leprosy is a complicated disease that affects a person's body, social life, and mental health. The result of this study shows that 94.1% of people with poor quality of life had a disability level of 2, and only 5.9% had a disability level of 1. This shows us that the level of disability greatly affects the quality of life of leprosy patients. People with a disability level of 2 cannot perform even the simplest activities. This significantly worsens their quality of life and sense of individuality. Most people with leprosy have paralytic deformities like clawed hands, foot deformities, and facial paralysis. Additionally, they frequently have anaesthetic deformities like ulcers. Anaesthetic

deformities occur after injuries to body parts that often go unnoticed and affect the performance of routine activities that are considered superficial (Raghvendra et al 2017).

Demographics such as age and quality of life show that 64.7% of those with poor quality of life are over 69 years old, while 0% are younger. This is consistent with the results of a study by Pai et al (2022) which found that quality of life scores decreased with age and that older patients had lower scores than younger patients in all four domains, with the psychological domain being the most affected. This is likely related to the fact that the disease causes more anxiety and fear, making it difficult to enjoy life. Similar research was carried out in eastern India by Das et al (2020) did not show any conclusive link between aging and quality of life. Our study showed no significant association between gender and quality of life. This is in contrast to Das et al (2020) which found that women's quality of life was worse than men's, but more men are affected by the disease than women (Das et al 2020). Similar findings were made in a study in Kenya of 98 leprosy patients, which found that women are not as financially independent as men in their community, limiting their access to health care and other essential services (Ong'ang'o et al 2022).

In our study, the small sample size could explain insignificant association between gender and quality of life. The results showed that 94.1% of those with a poor quality of life were unemployed leprosy patients. Work plays a role in a person's quality of life by providing self-confidence and a sense of self-sufficiency.

WHO states that a person's quality of life depends on how they see their place in life and their goals, expectations, principles, and care for others. It also depends on their culture and beliefs. Many studies have already shown that

a person's socioeconomic status in turn affects their quality of life (Govindhraj et al 2018, Das et al 2020, Utama et al 2020). People with low family income perform worse in a variety of domains, according to Govindharaj et al (2018). People with leprosy who belong to a low socio-economic group are less likely to get treatment because they must choose between treatment or basic daily necessities. It has also been shown that they often risk their health and the health of their families because of financial constraints.

The WHOQOL-BREF consists of four physical, psychological, social, and environmental domains. In this study, the social domain scored the lowest on most variables. This could be due to the fact that the stigma attached to the disease makes sufferers feel isolated from social interactions at home and in the community. Diagnosis and treatment alone do not promise a good quality of life for those affected. It is important to destigmatize the disease and educate the family about it.

Self-confidence is critical for successful self-care (Darlong 2021). Adhering to self-care practices and maintaining healthy behaviours are critical. Social support is essential to the success and maintenance of self-care practices (Darlong 2021). Not only family members but also friends, medical professionals, and the community as a whole can provide social support. They can provide support by reinforcing positive thoughts about the disease and its treatment. More information about the illness and its dissemination through social media can help with this.

The environment domain was rated lowest after the social domain, which could be because the Indian public knows less about leprosy and a non-disability-friendly environment. Patients with leprosy say that because of the constant burden of the disease, they have less time to do fun things or relax. This is consistent with the Brazilian study by Santos et al (2015), in which leprosy patients scored lower in the physical and environmental domains, but contrasts with an Egyptian study which 64% had a low psychological domain (Barakat & Zaki 2019). The degree of disability is a big part of how people with leprosy feel about themselves (WEMWBS). Most people with disabilities in grade 1 (88.9%) had good psychological well-being, but more people with disabilities in grade 2 had poor psychological well-being. This suggests that people's psychological well-being worsens as disability increases. van Dorst et al (2020) in Nepal showed that the incidence of poor psychological well-being was significantly higher in the leprosy affected group than in the reference group and that leprosy patients were six times more likely to develop poor psychological well-being than the reference group (van Dorst et al 2020). In addition, leprosy patients were more likely to be depressed and self-harm. In this study, the low psychological well-being of those with leprosy may be due to the fact that their disease makes it difficult for them to do everyday things, which can make them feel more stressed. Leprosy patients with disfigurements have a difficult time in society, mainly because the disease has a bad reputation.

This study directly links psychological well-being to a person's quality of life. Psychological well-being includes various areas such as relationships, work and more. Family plays a vital role in maintaining good psychological well-being. When the attitudes and behaviours of family members and the community are poor, it negatively affects the psychological well-being of the leprosy patient. There is also a cumulative development of self-stigma that exacerbates psychological distress. Anxiety, depression, and suicidal thoughts are common problems leprosy patients face (van Dorst et al 2020). Leprosy

treatment rarely includes psychological services, but they should be considered.

Conclusions and way forward

Our study found that age, occupation, and education affect quality of life and psychological well-being of leprosy patients. Social support also contributes to the patient's well-being. Psychological support should be available to all affected people, as it can help improve their situation. Early diagnosis and treatment, as well as services to help people get back on their feet after the disease has caused significant damage, are essential. However, these findings should not be generalized unless these are confirmed with well-designed studies in significant number of leprosy affected persons with different types of disabilities from different socio-economic and socio-cultural backgrounds. Such studies and eventually meta-analysis of findings of different studies will be important for taking decisions at public health level.

Acknowledgment

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