A descriptive study to assess the general wellbeing and psychological distress of leprosy patients in selected leprosy centre at Indira Gandhi Medical College and Hospital, Shimla (H.P.) India.

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ABSTRACT

Throughout its history, leprosy has been feared and misunderstood. For long time leprosy was thought to be a hereditary disease, a curse, or a punishment from God. Before and even after the discovery of its biological cause, leprosy patients were stigmatized and shunned. For example, in Europe during the Middle Ages, leprosy sufferers had to wear special clothing, ring bells to warn others that they were close, and even walk on a particular side of the road, depending on the direction of the wind. Problem statement: A Descriptive Study to Assess the General Wellbeing & Psychological Distress of Leprosy Patients in Selected Leprosy Centre, I.G.M.C.Shimla, (H.P). Objectives: The objectives of this study were to assess the general well being of the leprosy patients, to assess the psychological distress of leprosy patients, to find the association between general well being and psychological distress with their selected demographic variables. Materials and methods: A Quantitative approach and non-experimental descriptive design was adopted to accomplish the main objectives of the study. The study was conducted in leprosy center, I.G.M.C.Shimla. The target population of the study was all leprosy patients of leprosy center, I.G.M.C.Shimla. The total sample size was 100 leprosy patients selected by convenient sampling technique, The tool was constructed to assess the general well being & psychological distress of leprosy patients. Analysis and interpretation: Most of the patients (78%) had some well-being risks. The majority of the patients (71%) had moderate psychological distress. The highest general well being was in the physical domain and the least well being was in social domain among leprosy patients. Conclusion: Type of family, duration of suffering from illness, had significant association with the general well-being and psychological distress.

Keywords: *Descriptive, Assess, General Well Being, Psychological Distress*

1. INTRODUCTION

Throughout its history, leprosy has been feared and misunderstood. For a long time leprosy was thought to be a hereditary disease, a curse, or a punishment from God. Before and even after the discovery of its biological cause, leprosy patients were stigmatized and shunned. For example, in Europe during the middle Ages, leprosy sufferers had to wear special clothing, ring bells to warn others that they were close, and even walk on a particular side of the road, depending on the direction of the wind. Even in modern times, leprosy treatment has often occurred in separate hospitals and live-in colonies called leprosarium's because of the stigma of the disease. Leprosy has been so prevalent in various areas as certain times throughout history that is has inspired art work and influenced other cultural practices (Litchfield, AAOHN, 2010).

1.1 Statement of the Problem

A Descriptive Study to Assess the General Wellbeing and Psychological Distress of Leprosy Patients in Selected Leprosy Centre at Indira Gandhi Medical College and Hospital Shimla (H.P.)

1.2 Objectives

- To assess the general wellbeing of the leprosy patients.
- To assess the psychological distress among the leprosy patients.
- To find the association between general wellbeing and psychological distress with there selected demographic variables.

2. METHODS AND MATERIALS

2.1 Research Approach
A Quantitative approach was adopted to accomplish the objectives of the study that is to assess the general wellbeing and psychological distress of leprosy patients.

2.2 Research Design
Non experimental descriptive design was adopted to accomplish the main objectives of study.

2.3 Setting of Study
The present study was conducted in leprosy centre. The rationale for selecting these setting for the study was the geographical proximity and availability of data.

2.4 Population
The target population of study was all leprosy patients of leprosy centre.

2.5 Sample and Sampling Technique
100 leprosy patients will be selected by convenient sampling technique, the subjects who will be available in leprosy centre at time of data collection wills taken as sample.

2.6 Development of the Tool
The tool was constructed to assess the general wellbeing & psychological distress of leprosy patients. The tool was developed after extensive review of literature, experts' opinion and researcher's own experience in clinical area as well as in teaching institution.

Positive Statements were	Negative statements were
1,2,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17, 18,19,20,21,22,23,24,26,27,28,29,30,31,32, 33,34,35,36,37,38,39,40,42,43 44,45,47,48,49, 50.	25, 41, 46

Scoring: Each item was given score accordingly

Positive items:		Negative items:	
Outstanding wellbeing =	1	Outstanding wellbeing =	4
Good wellbeing =	2	Good wellbeing =	3
Some wellbeing =	3	Some wellbeing risk =	2
Serious and unnecessary risk=	4	Serious and unnecessary risk=1	
Maximum Score = 200		Minimum Score = 50	

Criteria measure for each domain
Outstanding wellbeing =   > 161
Good wellbeing   =   124-161
Some wellbeing risk   =   87-124
Serious and unnecessary risk =   < 87

Criteria measure for each domain
Outstanding wellbeing   => 34 ,Good wellbeing = 34-26
Some wellbeing risk =   < 26- 18, Serious and unnecessary risk =   < 18

Section C: Three point rating scale to assess the psychological distress of leprosy patients. It consisted of total 40 items.

Scoring: Each item was given score accordingly:
Always = 3, Sometimes= 2,   Never   = 1
Maximum Score = 120,   Minimum Score =   40

Criteria measure < 67 =   Mild psychological distress**,** 67-94=   Moderate psychological distress > 94 =   Severe psychological distress

Tryout: Tryout of tool was done for clarity and feasibility of conducting the study. necessary modifications were made after tryout.

Content Validity: It was determined by experts 'opinion, the tool was given to experts from the field of psychiatry, experts of psychiatry and mental health nursing from various nursing and medical colleges. Certain additions, deletions and refinement of items were done after the suggestions of experts.

Reliability of Tool: Reliability of three point rating scale was determined by split half method, using Spearman brown's formula. The value of r was found to be 0.838. Hence tool was considered reliable.

Ethical Considerations: Approval was taken from the ethical and research committee of the institution. Permission was taken from head of selected leprosy centre. Before data collection. Written informed consent was taken from individual subject before administering the tool.

Pilot Study: Pilot study was conducted in the month of February 2017 on 10 leprosy patients of selected leprosy centre. Analysis and interpretation of data collected in pilot study was done in accordance to objectives and feasibility was assessed.

Data Collection Procedure: Data collection procedure will carry out in the month of March 2017.Written permission was taken from the incharge of selected leprosy centre. Before data collection researcher will introduced she, explained the purpose of study, clarified queries and took consent from individual subject.

Difficulties faced by researchers: Problems faced were**:** Some time subjects got irritated because of their condition, so they avoided to interact: Difficulty in seeking permission from the institution.

3. PLAN FOR ANALYSIS
Analysis and interpretation of data was done according to the objectives using descriptive and inferential statistics. The level of significance at p level 0.05 was chosen.

4. ANALYSES AND INTERPRETATION OF DATA
The collected data was tabulated and analyzed using descriptive and inferential statistics under following headings:

Table 1: Distribution of Selected Socio Demographic Variables

Socio Demographic Variables		N=100	
		Frequency(f)	Percentage(%)
Age (in years)	20-40	7	7%
	40-60	51	51%
	60-80	42	42%
	Any Other	0	0%
Gender	Male	44	44%
	Female	56	56%
Educational Status	Illiterate	99	99%
	Primary	1	1%
	Middle	0	0%
	Matric	0	0%
	Higher Secondary	0	0%
	Graduation and above	0	0%
Occupation	Unemployed	100	100%
	Private Service	0	0%
	Self Employed	0	0%
	Govt. Services	0	0%
Marital Status	Unmarried	0	0%
	Married	94	94%
	Widow	0	0%
	Divorced	6	6%
	Separated	0	0%
Religion	Hindu	100	100%
	Muslim	0	0%
	Sikh	0	0%
	Christian	0	0%
Monthly Family income	Rs. < 3,000	100	100%
	Rs. 3,001- 4,000	0	0%
	Rs. 4,001- 5,000	0	0%
	Above Rs.-5,000	0	0%
Residential Place	Urban	100	100%
	Rural	0	0%
Type of Family	Nuclear	38	38%
	Joint	62	62%
Duration of your suffering with leprosy	20-30	13	13%
	31-40	20	20%
	41-50	67	67%

Table 2: Criteria Measure Of Wellbeing Score

Category Score	Frequency	Percentage
Outstanding wellbeing(>161)	0	0%
Good wellbeing(124-161)	9	9%
Some Wellbeing Risks(87-124)	78	78%
Serious and Unnecessary Risks(<87)	13	13%

Maximum Score=200 Minimum Score =50

Table 3: Descriptive statistics of general wellbeing of leprosy patients. N=100

Descriptive Statistics	Mean	SD	Median	Maximum	Minimum	Range
Wellbeing Score	101.48	13.86	100.00	145	80	65

Maximum= 200 Minimum= 50

Table 4: Descriptive statistics of Area wise analysis of general wellbeing score of leprosy patients

Descriptive Statistics	Physical Health	Social Health	Emotional Health	Spiritual Health	Intellectual Health	Overall
Mean	28.40	15.96	21.13	18.32	17.67	101.48
S.D.	4.723	4.007	2.565	4.886	3.461	13.863
Median	28	15	21	17	16.5	100
Maximum	40	30	27	36	29	145
Minimum	19	10	16	10	12	80
Number	100	100	100	100	100	100

Table 5: Item wise analysis of general wellbeing score of leprosy patients (refer Figure 4.19)

	Area	Itemwise Analysis	4 %(f)	3 %(f)	2 %(f)	1 %(f)
General Welllbeing	**Physical Health**	Qno.1	15	6	6	73
		Qno.2	80	20	0	0
		Qno.3	81	15	4	0
		Qno.4	90	7	1	2
		Qno.5	35	13	2	50
		Qno.6	10	32	7	51
		Qno.7	44	29	1	26
		Qno.8	49	34	8	9
		Qno.9	80	16	1	3
		Qno.10	4	0	2	94
	Social Health	Qno.11	12	61	5	22
		Qno.12	8	7	9	76
		Qno.13	61	12	8	19
		Qno.14	8	2	6	84
		Qno.15	2	0	1	97
		Qno.16	0	10	1	89
		Qno.17	5	1	8	86
		Qno.18	11	2	0	87
		Qno.19	5	1	4	90
		Qno.20	1	10	3	86
	Emotional Health	Qno.21	65	26	2	7
		Qno.22	15	14	3	68
		Qno.23	6	58	4	32
		Qno.24	1	76	7	16
		Qno.25	0	30	3	67
		Qno.26	27	58	3	12
		Qno.27	2	28	1	69
		Qno.28	5	43	8	44
		Qno.29	4	6	1	89
		Qno.30	4	7	2	87
	Spiritual Health	Qno.31	0	2	5	93
		Qno.32	29	40	4	27
		Qno.33	12	66	11	11
		Qno.34	57	19	3	21
		Qno.35	2	17	3	78
		Qno.36	2	8	5	85
		Qno.37	6	11	1	82
		Qno.38	2	4	4	90
		Qno.39	14	11	2	73

		Qno.40	6	24	0	70
		Qno.41	10	78	8	4
		Qno.42	2	25	14	59
		Qno.43	1	10	2	87
		Qno.44	0	8	10	82
	Intellectual Health	Qno.45	4	9	6	81
		Qno.46	0	78	13	9
		Qno.47	0	15	13	72
		Qno.48	7	39	2	52
		Qno.49	7	8	4	81
		Qno.50	1	26	7	66

Table 6: Frequency and percentage of psychological distress score of leprosy patients

Criteria Measure of Psychological Distress Score		
Category Score	Frequency	Percentage
Severe(>94)	29	29%
Moderate(67-94)	71	71%
Mild(0-67)	0	0%

Maximum Score=120 Minimum Score=40

Table 7: Descriptive statistics of psychological distress score of leprosy patients, N=100

Descriptive Statistics	Mean	SD	Median	Maximum	Minimum	Range
Psychological Distress Score	92.72	4.207	93.00	103	83	20

Maximum= 120 Minimum= 40

Table 8: Item wise analysis of psychological distress score of leprosy patients (refer Figure 4.24)

	Areas	Itemwise Analysis	Always %(f)	Sometimes %(f)	Never %(f)
Psychological Distress Score	**Section-C**	Qno.1	52	47	1
		Qno.2	59	39	2
		Qno.3	14	82	4
		Qno.4	18	78	4
		Qno.5	34	62	4
		Qno.6	11	89	0
		Qno.7	10	88	2
		Qno.8	43	57	0
		Qno.9	75	23	2
		Qno.10	75	19	6
		Qno.11	19	80	1
		Qno.12	18	80	2
		Qno.13	12	86	2
		Qno.14	36	64	0
		Qno.15	66	32	2
		Qno.16	12	83	5
		Qno.17	39	61	0
		Qno.18	74	22	4
		Qno.19	54	38	8
		Qno.20	24	76	0
		Qno.21	54	44	2
		Qno.22	77	16	7
		Qno.23	47	47	6
		Qno.24	52	46	2
		Qno.25	14	86	0
		Qno.26	15	79	6
		Qno.27	39	55	6
		Qno.28	18	82	0
		Qno.29	43	57	0
		Qno.30	60	38	2
		Qno.31	58	40	2
		Qno.32	12	74	14
		Qno.33	13	85	2
		Qno.34	49	49	2
		Qno.35	63	37	0
		Qno.36	26	70	4
		Qno.37	18	82	0

	Qno.38	20	76	4
	Qno.39	8	55	37
	Qno.40	2	84	14

Table 9: Association between the general wellbeing of leprosy patients in selected leprosy centre with their selected Socio Demographic Variables

Demographic Variables		Levels (N=100)				Association with WELLBEING Score				
Variable	Opts	Outstanding wellbeing	Good wellbeing	Some Wellbeing Risks	Serious and Unnecessary Risks	Chi Test	P Value	df	Table Value	Result
Age (in years)	20-40		0	7	0	3.208	0.524	4	9.488	Not Significant
	40-60		4	41	6					
	60-80		5	30	7					
	Any Other		0	0	0					
Gender	Male		4	38	2	5.026	0.081	2	5.991	Not Significant
	Female		5	40	11					
Educational Status	Illiterate		9	77	13	0.285	0.867	2	5.991	Not Significant
	Primary		0	1	0					
	Middle		0	0	0					
	Matric		0	0	0					
	Higher Secondary		0	0	0					
	Graduation and above		0	0	0					
Occupation	Unemployed		9	78	13	NA				
	Private Service		0	0	0					
	Self Employed		0	0	0					
	Govt. Services		0	0	0					
Marital Status	Unmarried		0	0	0	1.800	0.407	2	5.991	Not Significant
	Married		9	72	13					
	Widow		0	0	0					
	Divorced		0	6	0					
	Separated		0	0	0					
Religion	Hindu		9	78	13	NA				
	Muslim		0	0	0					
	Sikh		0	0	0					
	Christian		0	0	0					
Monthly Family income	Rs. < 3,000		9	78	13	NA				
	Rs. 3,001-4,000		0	0	0					
	Rs. 4,001-5,000		0	0	0					
	Above Rs.-5,000		0	0	0					
Residential Place	Urban		9	78	13	NA				
	Rural		0	0	0					
Type of Family	Nuclear		4	34	0	9.161	0.010	2	5.991	Significant
	Joint		5	44	13					
Duration of your suffering with leprosy	20-30		0	13	0	13.892	0.008	4	9.488	Significant
	31-40		0	20	0					
	41-50		9	45	13					
Duration of stay in leprosy centre	20-30		0	3	0	7.051	0.133	4	9.488	Not Significant
	31-40		0	17	0					
	41-50		9	58	13					

Table 10: Association between the psychological distress of leprosy patients in selected leprosy centre . Their selected Socio Demographic Variables.

Demographic Variables		Levels(N=100)			Association with PSYCHOLOGICAL DISTRESS Score				
Variable	Opts	Severe	Moderate	Mild	Chi Test	P Value	df	Table Value	Result
Age (in years)	20-40	0	7		3.246	0.197	2	5.991	Not Significant
	40-60	15	36						
	60-80	14	28						
	Any Other	0	0						
Gender	Male	12	32		0.114	0.736	1	3.841	Not Significant
	Female	17	39						
Educational Status	Illiterate	29	70		0.413	0.521	1	3.841	Not Significant
	Primary	0	1						
	Middle	0	0						
	Matric	0	0						
	Higher Secondary	0	0						
	Graduation and above	0	0						
Occupation	Unemployed	29	71		NA				
	Private Service	0	0						
	Self Employed	0	0						
	Govt. Services	0	0						
Marital Status	Unmarried	0	0		2.607	0.106	1	3.841	Not Significant
	Married	29	65						
	Widow	0	0						
	Divorced	0	6						
	Separated	0	0						
Religion	Hindu	29	71		NA				
	Muslim	0	0						
	Sikh	0	0						
	Christian	0	0						
Monthly Family income	Rs. < 3,000	29	71		NA				
	Rs. 3,001-4,000	0	0						
	Rs. 4,001-5,000	0	0						
	Above Rs.-5,000	0	0						
Residential Place	Urban	29	71		NA				
	Rural	0	0						
Type of Family	Nuclear	6	32		5.195	0.023	1	3.841	Significant
	Joint	23	39						
Duration of your suffering with leprosy	20-30	0	13		8.346	0.015	2	5.991	Significant
	31-40	4	16						
	41-50	25	42						
Duration of stay in leprosy centre	20-30	0	3		1.669	0.434	2	5.991	Not Significant
	31-40	4	13						
	41-50	25	55						

4.1 Summary of Major findings
Majority of patients were in age group of 40-60 years (51%), were females (56%) were illiterate (99%) and (94%) married. Majority (62%) were living in joint family. All the subjects (100%) were Hindu, unemployed, having monthly income < 3000Rs and were from urban area. On the basis of total mean general wellbeing score it can inferred that general wellbeing of leprosy patients was some wellbeing risk.

5. DISCUSSION
First objective of present study was to assess the general wellbeing among leprosy patients. Study results revealed that none had outstanding wellbeing, 9% had good wellbeing.78 % had some wellbeing risk and 13% had serious and unnecessary risk wellbeing. The mean score of general wellbeing was101.48,

6. SUMMARY AND RECOMMENDATIONS
The present study was conducted to assess the general wellbeing and psychological distress among leprosy patients in selected leprosy centre. Conceptual framework was developed based on Roy adaptation model (1964) Convenient sampling technique was used for selection of samples. Pilot study was conducted during the month of February 2017 on 10 subjects in leprosy centre.

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