

Dermatology Life Quality Index and Social Stigma among Patients of Hansen's Disease

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Received : 18.09.2020

Accepted : 06.07.2021

The chronic nature of Hansen's disease causes long term physical and social effects on the lives of patients and their families. Religious, cultural, and social beliefs about Hansen's transformation and disability lead to the stigma that has a major effect on patients' lives. The quality of life of a person affected with leprosy/Hansen's disease (PAL) declines rapidly. The present study aims to evaluate the Quality of Life (QOL) and measure various aspects of stigma in Hansen's disease. This study aims to evaluate the Dermatology Life Quality Index (DLQI) and Evaluation of Social status in patients of Hansen's disease (PAL) using the Stigma Assessment and Reduction of Impact (SARI) scale in patients presenting to the outpatient department. This Prospective, Observational study of 2 months duration involved PAL attending the Dermatology outdoor department. QOL and Social Status of PAL in society were assessed by the Dermatology Life Quality Index (DLQI) and Stigma Assessment and Reduction of Impact (SARI) Questionnaire, respectively. SARI scale is developed to measure various aspects of the stigma of PAL. Findings indicated that out of 35 PAL, 43% (15) had an extremely large impact on their quality of life followed by 37.3% (13) had a very large impact on their quality of life, followed by 14.1% (5) having a moderate impact and 5.6% (2) had no effect at all on their quality of life. According to SARI scale mean score for Internalized Stigma was 3.86 ± 3.28 suggesting that Internalized stigma was more prominent, followed by Disclosure Stigma (mean score = 2.49 ± 3.10) which was next followed by Experienced stigma (mean score = 1.26 ± 2.63) and finally Anticipated Stigma (0.66 ± 1.69). The total means score for all four domains was 8.26. According to the Pearson's correlation value, there was a negative correlation between the quality of life and impact on social stigma in our study. ($R = -0.265$). Based on the findings, it was concluded that stigma and associated psychosocial problems appear to be common in Hansen's disease that significantly affect the quality of life (QOL) of Hansen's disease patients.

Keywords : Hansen's Disease, Stigma, Quality of Life, QOL, SARI Scale

Introduction

Hansen's disease is a chronic infectious communi-

cable disease caused by *Mycobacterium leprae*, which poses a great risk of permanent physical

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disability. Hansen's disease creates a serious public health concern due to its impact on the wellbeing of affected people. People affected with Hansen's diseases are often stigmatised. Health-related stigma can have a serious effect on the affected person and their family members (Dadun et al 2017 a & b).

The attribute as the source of discreditation is the classic definition of stigma by Goffman (Goffman 1963). Once stigma is established, social stigma manifests in a myriad of conceptually distinct stigma-related processes. Stereotyping, prejudice and discrimination are the major foundations of social stigma. Structural inequalities at laws, policies, religions and other institution structures are constructed in ways that reflect the rights, freedom and resources of the stigmatised person and that prevent stigmatised groups from fully participating in society and perpetuate social stigma.

Stigma-related stress is an experience of for stigmatised groups and individuals that exists as acute and chronic discrimination, expectations of rejection, management and concealment of stigma and internalised stigma, which ranges from very distal to the self and perpetuated by outside social sources. Social stress makes an individual to adopt changes intra-personally, interpersonally or in his or her environment. Generally, stigma-related stress is a negative force in the lives of stigmatised groups and individuals and can result in a number of negative mental health, physical health, performance and relational outcomes (Frost 2011).

Hansen's disease and its visible deformities contribute to intense social stigma and social discrimination of the patients (Tiway et al 2011). Hansen's disease not only affects patient's economies but also creates psychosocial burdens in the community. Hansen's disease and its stigma have a major effect on a patient's life affecting

marriage, interpersonal relationships, employment and social interactions (van Brakel et al 2014). Deprivation of social amenities and facilities in the community and the status of the lower livelihood affect their quality of life. Such patients are marginalised in their community, and deprived of citizenship and individual rights (Sermrittirong et al 2015). In some cultures, the word leprosy is used as a curse word in their conversation. Hansen's disease patients were forced to leave homes; some were admitted to asylums or sanatoriums. Large numbers of PAL beg on the places of worship (Raju & Kopparty 1995).

Hansen's disease has been seen as the epitome of stigmatisation. The quality of life of such affected individual's declines rapidly.

DLQI most frequently used method for evaluating the quality of life for patients with different skin conditions was created by Andrew Y Finlay and Gul Karim Khan (Finlay & Khan 1994). DLQI consists of 10 questions covering the following topics: symptoms, embarrassment, shopping and home care, clothes, social and leisure, sport, work or study, close relationships, sex, treatment, and each question refer to the impact of skin diseases on the patient's life over the previous week. A comprehensive, reliable and valid stigma measurement tool, Stigma Assessment and Reduction of Impact (SARI) project, was developed by van Brakel (Dudan 2017 a). This scale is useful to identify target areas of the high level of stigma and to increase insight into which type of stigma is most prevalent. SARI questionnaire can measure the various dimensions of Hansen's disease stigma quantitatively. It consists of total 21 questions for measuring four domain of social stigma; Experienced stigma (8 items), Internalised stigma (6 items), Perceived stigma (4 items) and Disclosure concerns (4 items) and scored on the Likert scale (always, often, rarely, sometimes

and don't know).

As per World Health Organization (WHO 2019) 202256, new cases of Hansen's disease were reported in 2019. Every year, over 200,000 such cases are detected globally, and India accounts for more than half of these. Global leprosy (Hansen's disease) strategy 2021-2030 has a long term vision of zero leprosy: zero infection and disease, zero disability, zero stigma and discrimination (WHO 2019).

The present study aims at evaluating the quality of life and assess the type of stigma by using the Dermatology Life Quality Index (DLQI) and Stigma Assessment and Reduction of Impact (SARI), respectively.

Material and Methods

This prospective observational study has used the following inclusion and exclusion criteria :

Inclusion Criteria

- Patients who are willing to give their informed consent

- All diagnosed leprosy patients attending Dermatology OPD and agreeing to answer questions related to their Quality of life

Exclusion Criteria

- Patients who are not willing to give their informed consent
- Patients age <18 years

Methodology

A total of thirty-five confirmed cases of Hansen's disease, on treatment or released after treatment were enrolled in the present study. The study was done at a tertiary care teaching hospital. The data collection was done after the Institutional Review Board approval. Written Informed Consent was taken from all the patients in their vernacular language. The aims and objectives of the study were explained to all the subjects. The information was recorded and kept secret from each other. Demographic data like name, age & sex, along with details of clinical examination which included the deformities recorded as per case

Annexure 1 : Dermatology Life Quality Index (DLQI) Score

1. Over the last week, how **itchy, sore, painful** or **stinging** has your skin been?
2. Over the last week, how embarrassed or self-conscious have you been because of your skin?
3. Over the last week, how much has your Skin interfered with you going **shopping** or looking after your **home** or **garden**?
4. Over the last week, how much has your Skin influenced the **clothes** you wear?
5. Over the last week, how much has your Skin affected any **social** or **leisure** activities?
6. Over the last week, how much has your skin made it difficult for you to do any **sport**?
7. Over the last week, has your skin prevented you from **working** or **studying**?
If No, over the last week how much has your skin been a problem at **work** or **studying**?
8. Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?
9. Over the last week, how much has your skin caused any **sexual difficulties**?
10. Over the last week, how much of a problem has the **treatment** for your skin been, for example by making your home messy, or by taking up time?

record form. This data was collected for the duration of 2 months from June-July 2019 (ICMR Reference ID 2019-05422).

The present study used two validated questionnaires, Dermatology Life Quality Index (DLQI) and Stigma Assessment and Reduction of Impact (SARI) - to analyse the psychosocial impact and the effect on professional life due to the skin disease. Questionnaires of both tools were simple for the patient to comprehend and were self-explanatory.

Quality of Life was assessed by the Dermatology Life Quality Index (DLQI) (Annexure 1). It is a simple 10 question validated questionnaire that examines the effect of the skin problem on the patient's social and work life in the past one week (Finlay & Khan 1994). The questionnaire was available in three vernacular languages; Hindi, Gujarati & English. It was self-explanatory and handed to the patient for filling.

The Social Stigma of the patient was assessed by the Stigma Assessment and Reduction of Impact (SARI) Questionnaire (Annexure 2). This questionnaire included 21 questions for measuring four domains of social stigma; experienced stigma (7 items), internalised stigma (6 items), anticipated or perceived stigma (4 items) and disclosure concerns (4 items) and scored in the Likert scale (always, often, rarely, sometimes and don't know). The first question asks whether something has occurred to them. The response options are: 1) 'no', 2) 'yes', 3) 'don't know, and 4) 'not relevant. If the answer is 'yes', a second question is asked about the frequency of occurrence. The response options are: 1) 'always/often' (score 3), 2) 'sometimes' (score 2), and 3) 'rarely/once' (score 1). The minimum total score is 0, and the maximum total score is 66. It interprets more the score the stigma felt by the patient is more (Dadun et al 2017 a).

Annexure 2 : Application of SARI scale

SARI Stigma Scale v.1.1 (based on the Berger HIV stigma scale)		No	Yes	Don't know	Not Relevant	Always / Often	Sometimes	Rarely / once	Score
		Experienced stigma							
1a	Do some people who know you have (had) leprosy keep more distance from you?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
2a	Do people you care about stop contacting you after learning you have (had) leprosy?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
3a	Did you lose friends by telling them you have (had) leprosy?	0		0	0				
b	(If yes) How often has this happened?					3	2	1	
4a	Do people avoid touching you once they know you have (had) leprosy?	0		0	0				

b	<i>(If yes) How often has this happened?</i>				3	2	1
5a	Have people physically backed away from you when they learn you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often has this happened?</i>				3	2	1
6a	Do people seem afraid of you once they learn you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often has this happened?</i>				3	2	1
7a	Do you feel set apart and isolated from the community since learning you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often has this happened?</i>				3	2	1
Subtotal							
Disclosure concerns							
8a	Are you careful who you tell that you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often are you careful?</i>				3	2	1
9a	Do you feel the need to hide your leprosy?	0	0	0			
b	<i>(If yes) How often do you feel the need to hide your status?</i>				3	2	1
10a	Do you believe telling someone you have (had) leprosy is risky?	0	0	0			
b	<i>(If yes) How often do you believe it is risky?</i>				3	2	1
11a	Do you worry that people may judge you when they hear you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often do you worry about this?</i>				3	2	1
Subtotal							
Internalised stigma							
12a	Do you feel guilty because you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often has this happened?</i>				3	2	1
13a	Do you feel you are not as good a person as others because you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often has this happened?</i>				3	2	1
14a	Are you embarrassed that you have (had) leprosy?	0	0	0			
b	<i>(If yes) How often has this happened?</i>				3	2	1
15a	Does having (had) leprosy make you feel unclean?	0	0	0			
b	<i>(If yes) How often has this happened?</i>				3	2	1

16a	Do you regret having told some people that you have (had) leprosy?	0	0	0	
b	(If yes) How often has this happened?				3 2 1
17a	Does having (had) leprosy make you feel that you are a bad person?	0	0	0	
b	(If yes) How often has this happened?				3 2 1
Subtotal					
Anticipated stigma					
18a	Do people affected by leprosy lose their jobs when their employers find out?	0	0	0	
b	(If yes) How often does this happen?				3 2 1
19a	Are people affected by leprosy treated like a public nuisance?	0	0	0	
b	(If yes) How often does this happen?				3 2 1
20a	Do most people think that a person affected by leprosy is disgusting?	0	0	0	
b	(If yes) How often does this happen?				3 2 1
21a	Do most people feel uncomfortable around someone affected by leprosy?	0	0	0	
b	(If yes) How often does this happen?				3 2 1
Subtotal					
Total score					

The analysis was carried out by using SPSS23. Correlation between QOL and Social Stigma was estimated using Pearson's correlation coefficient.

Results

Profile of Respondents

A total of 35 PAL visiting the dermatology department who fulfilled the inclusion criteria were enrolled in present study. The mean age of PAL in our study was 41.2 ± 15.38 years. The highest number of these PAL belonged to age group of 21-30 years (9 PAL). 83% of male predominance was seen. In present study 65.71% PAL belong to lower socio-economical status. (Kuppuswamy 1981) Out of the total 35 patients 63% (22 PAL) were married, 26% (9 PAL) were single and 11% (4 PAL) were divorced.

Types of Hansen's Disease

Out of 35 PAL 63% (22 PAL) were suffering from lepromatous leprosy, 26% (9 PAL) were suffering from borderline lepromatous leprosy, 11% (4 PAL) were suffering from borderline lepromatous leprosy. In our study, we have also observed Grade 2 deformities in 25(71.42%) of PALs.

Duration of Illness

Out of the total 35, 6 PAL were suffering from the disease for less than 6 months. 23 PAL were suffering from the disease from 6 months to 2 years, 5 were suffering from the disease from 2.5 years to 4 years, and only 1 PAL was suffering the disease for more than 4 years.

Quality of Life Assessment

Out of the 35 PAL in our study, 43% (15 PAL) had an

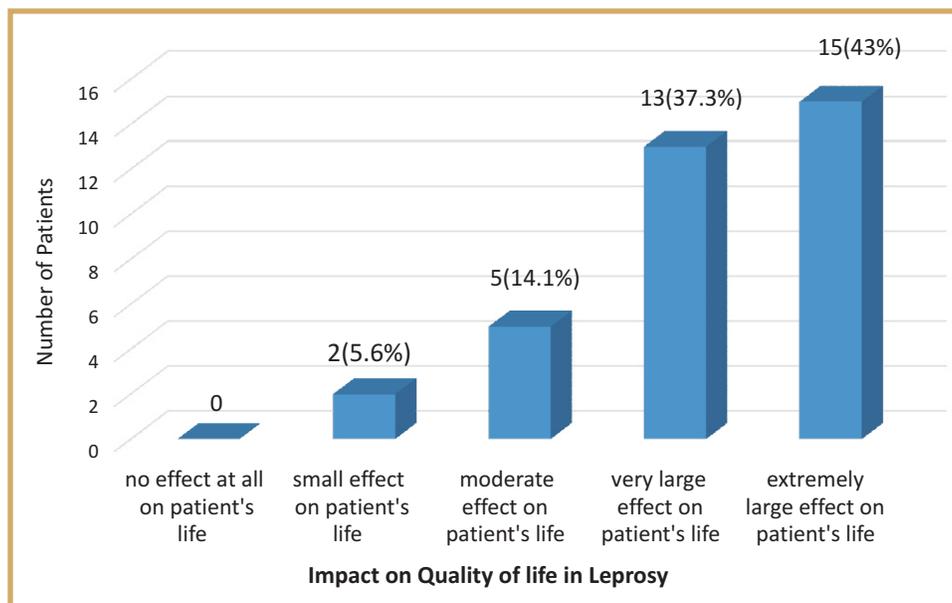


Fig. 1 : Quality of life according to DLQI Score (N=35)

Table 1 : Internalised Stigma

	NO	YES
Do you feel guilty because you have (had) leprosy?	(45.71%)16	(54.28%)19
Do you feel you are not as good a person as others because you have (had) leprosy?	(74.28%)26	(25.71%)9
Are you embarrassed that you have (had) leprosy?	(60%)21	(40%)14
Does having (had) leprosy make you feel unclean?	(60%)21	(40%)14
Do you feel set apart and isolated from the community since learning you have (had) leprosy?	(88.57%)31	(11.42%)4
Does having (had) leprosy make you feel that you are a bad person	(80%)28	(20%)7

Table 2 : Disclosure Stigma

	NO	YES
Are you careful who you tell that you have (had) leprosy?	(60%)21	(40%)14
Do you feel the need to hide your leprosy status?	(88.57%)31	(11.42%)4
Do you believe telling someone you have (had) leprosy is risky?	(74.28%)26	(25.71%)9
Do you worry that people may judge you when they hear you have (had) leprosy?	(74.28%)26	(25.71%)9

Table 3 : Experienced Stigma

	NO	YES
Do some people who know you have (had) leprosy keep more distance from you?	(85.71%)30	(14.28%)5
Do people you care about stop contacting you after learning you have (had) leprosy?	(85.71%)30	(14.28%)5
Did you lose friends by telling them you have (had) leprosy?	(100%)35	0
Do people avoid touching you once they know you have (had) leprosy?	(85.71%)30	(14.28%)5
Do people have physically back away from you when they learn you have (had) leprosy?	(94.28%)33	(5.71%)2
Do people seem afraid of you once they learn you have (had) leprosy?	(94.28%)33	(5.71%)2
Do you feel set apart and isolated from the community since learning you have (had) leprosy?	(97.14%)34	(2.85%)1

Table 4 : Anticipated Stigma

	NO	YES
Do people affected by leprosy lose their jobs when their employers find out?	(88.57%)31	(11.42%)4
Are people affected by leprosy treated like a public nuisance?	(97.14%)34	(2.85%)1
Do people think that a person affected by leprosy is disgusting?	(94.28%)33	(5.71%)2
Do people feel uncomfortable around someone affected by leprosy?	(85.71%)30	(14.28%)5

Table 5 : Mean DLQI with Gender and type of leprosy

Gender and Type of Leprosy		DLQI Score	
		Mean	SD
Gender	Male	18.65	7.87
	Female	18.29	7.68
Disease	borderline lepromatous	23.75	7.08
	borderline tuberculoid	21.33	4.06
	Lepromatous	16.63	8.63

Table 6 : Spearman's Rho Correlation

			Total Stigma Score
Spearman's rho p	Total DLQI	Correlation Coefficient	-.272
			Sig. (2-tailed)
			.113

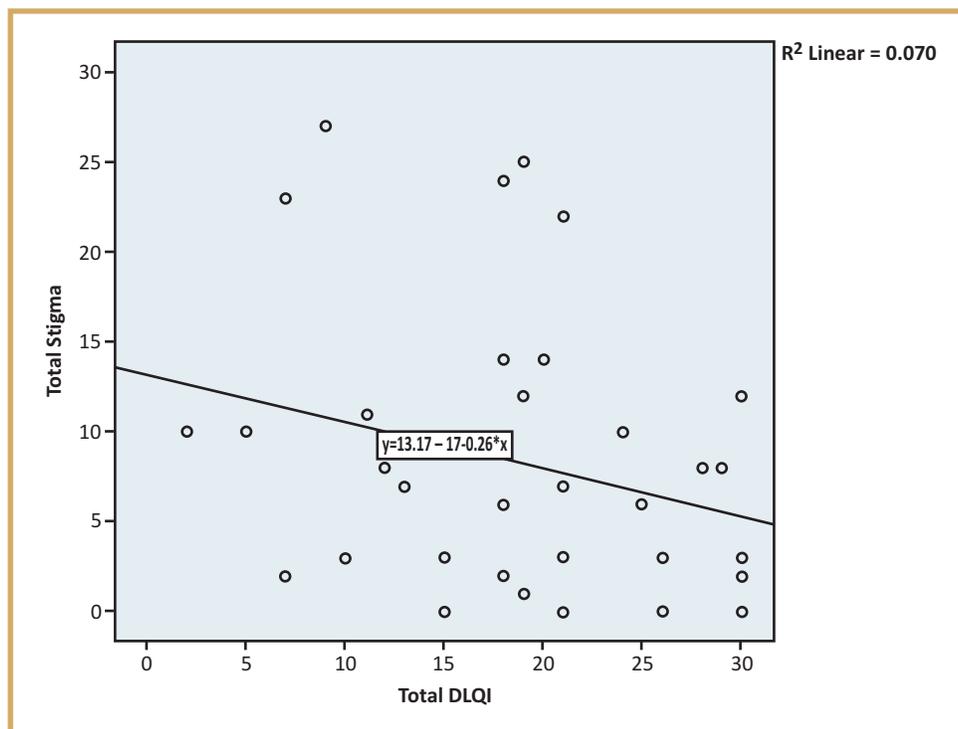


Fig. 2 : Correlation between QOL and Impact on Social Stigma

extremely large impact on their quality of life, followed by 37.3% (13 PAL) who had a very large impact on their quality of life, followed by 14.1% (5 PAL) had a moderate impact on their quality of life, followed by 5.6% (2 PAL) having no effect at all on their quality of life. (Fig. 1)

Social Stigma Assessment According to SARI scale

According to SARI scale mean score for Internalized Stigma was 3.86 ± 3.28 (Table 1), which suggests that internalised stigma was maximum, followed by Disclosure Stigma (mean score = 2.49 ± 3.10) (Table 2), next followed by Experienced stigma (mean score = 1.26 ± 2.63) (Table 3) followed by Anticipated Stigma (0.66 ± 1.69) (Table 4).

DLQI Scores in Relation to Gender and Type of Leprosy

Findings of DLQI scores in relation to gender and type of leprosy are summarized in Table 5. While gender had negligible relationship with these scores, the type of leprosy appeared to have marginal effect.

Correlation between Quality of life (QOL) and Social Stigma

There was a negative correlation between the quality of life and impact on social stigma in our study according to Spearman's Rho correlation value. ($\rho = -0.272$) as shown in Table 6 and Fig. 2. This suggests that QoL degraded with increasing impact on social stigma.

Discussion

Hansen's disease is known to have the potential to cause permanent and progressive physical disability creates a serious public health concern due to its impact on the wellbeing of PALs. Visible deformities and disabilities with religious, cultural and social beliefs about Hansen's disease impact the social stigma and discrimination against some person affected with Hansen's disease.

Social stigma and discrimination are important factors that cause social exclusion of people affected with Hansen's disease from the community and cause deprivation of their citizenship and individual rights. Fear of acceptance by society and lack of understanding of the cause of the disease has led to a great impact on the person's quality of life. QoL includes domains that are related to physical, mental, emotional, social functioning, and the social context in which people live (Yadav 2011). Comprehensive understanding of these aspects is essential to estimate the impact of leprosy on QoL.

Leprosy related social stigma and discrimination are the crucial factors that cause social exclusion of leprosy-affected people from the community and cause deprivation of their social and individual rights despite all the progress on treatment, prevention of disabilities, and mass awareness programs to minimize the exclusion and stigmatization against Hansen's disease affected people. Our study found that a significantly large number (19/35, 54.28%) of people felt guilty for their leprosy status. Similarly, 14 (40%) PALs reported feeling embarrassed that they have (had) leprosy. Many PAL, 14 (40%) still feel careful and concerned while disclosing that they have leprosy. Although, our study findings also suggest that a sizeable proportion of PAL have broader acceptance in their family and social surroundings and self-awareness about their condition. 21 (60%) PAL reported no feeling of

being unclean, and 31 (88.57%) had no sense of being set apart or isolated in their social and community life. A large number 31 (88.57%) doesn't feel the need to hide their illness, and not a single PAL lost a close friend due to his leprosy positive status. However, a few aspects such as gender, age, and area of residence still play a vital role in the experience of stigma and treatment-seeking behaviour. In the present study, 29 (83%) male PAL came out to seek treatment compared to lower proportion of female PALs; these findings are consistent with the previous research. Singh et al (2009) reported 3:1 male predominance in Hansen's disease in other parts of India. Gender issues have been considered important by others also in leprosy-affected communities (Dijkstra et al 2017). It is also known that women are disproportionately affected by the consequences of leprosy-related stigma. In another study female PAL feared disease more than males (Voorend et al 2011).

The manifestations of stigma and the psychological and socioeconomic impacts have been shown to have a significant effect on the quality of life (QoL) of PAL. In the present study, 43% (15 PAL) had a significant impact on their quality of life, followed by 37.3% (13 PAL) had a very large impact on their quality of life, followed by 14.1% (5 PAL) had a moderate effect on their quality of life whereas 5.6% (2 PAL) did not affect at all on their quality of life. (Fig. 1). These findings are consistent with the previous studies (Mankar et al 2011, Govindharaj et al 2018).

The stigma is mainly due to the deformity and disfigurement seen among the Hansen's disease patients. In our study, we also observed visible deformities in 25 (71.42%) PAL. People with Hansen's disease with more visible deformities faced more stigma than those with less visible deformities (Boku et al 2010). Persons with leprosy-related disabilities reported a lower

quality of life than those without disabilities (Joseph & Rao 1999). However, the impact of disabilities can be reduced by timely voluntary disclosures as done by most of the participants of our study.

A person stigmatised by Hansen's disease may internalise the negative attitudes (Stevellink et al 2012) and feelings, maladaptive behaviour, identity transformation and stereotype. In the present study internalized stigma was most dominant which was followed by disclosure stigma, experienced stigma and anticipated stigma in this order. Stigma can result in discontinuation of treatment, delayed presentation of symptoms, and refusal of proper treatment that significantly impacts the health of the person affected with Hansen's disease. Livingston & Boyd (2010) defined such attitude and feeling as internalised or self-stigma, which is perhaps the universal form of Hansen's stigma that impacts mental wellbeing, social participation, and quality of life, similar to the stigma experienced in the form of discrimination (Stevellink et al 2012).

Sources of stigmatisation and disease condition of the affected person are two major aspects of stigma assessment (Weiss 2008). Sources of stigmatisation may be community persons or health workers but may also be discriminatory laws, policies, or practices. These aspects need due attention.

Persons affected by Hansen's disease have multiple feelings of fear, anxiety and sorrow when first diagnosed. The psychological impact of the diagnosis 'leprosy' can be severe and may lead to depression and even suicide or attempted suicide, as documented by many investigators (Tsutsumi et al 2007). Relationships with a marital partner, friends, and neighbours can also be disturbed, leading the affected person to loneliness and isolation (Lusli et al 2015). Present study

shows self stigma may be much more serious problem rather than real stigma at community level. Socio-behavioural studies with adequate sample size need to focus on positive and negative influences.

Conclusion

The present study shows that Internalized stigma is the most widespread form of stigma among persons affected by leprosy, followed by Disclosure Stigma, Experienced stigma and Anticipated Stigma. The present study also concludes that QoL in PALs degrades with an increased impact on social stigma in persons affected with Hansen's disease.

Social Stigma leads to a huge range of adverse effects on the quality of life of a person affected with Hansen's disease. Implementation of Various interventions will be essential for addressing or preventing the negative impact of social stigma, with goal of improving the mental wellbeing and social participation of person affected with Hansen's disease.

Acknowledgement

This work was carried out as a part of an ICMR STS project (Reference ID 2019-05422) of AR Changhulani. Support and opportunity from ICMR is gratefully acknowledged.

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How to cite this article : Chaudhary RG, Changhulani AR, Malhotra SD et al (2021). Dermatology Life Quality Index and Social Stigma among Patients of Hansen's Disease. *Indian J Lepr.* **93**: 349-360.