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Original Research Article

A clinical study to assess disability and stigma associated with psoriasis

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ABSTRACT

Background: Psoriasis relatively common, chronic, inflammatory and hyper-proliferative skin disease that affects 1.4% to 2.0 % of the population. Pateints with psoriasis have to face severe problems with stigmatization, discrimination and negative attitudes in general among the public, and often bear the brunt of public rejection.
Methods: A cross-sectional observational study was carried out on psoriasis patients attending dermatology outpatient department of Era's Lucknow medical college and hospital between November 2018 and November 2020. Patients with pustular psoriasis, mycosis fungoides, pityriasis rubra pilaris, and other severe medical conditions like heart failure, liver cirrhosis were excluded from the study.
Results: Present study included 170 (aged 16 to 76 years; mean age 37.74±13.70 years; 62.4% males) clinically diagnosed patients of Psoriasis. P-score was observed with increase in Body Surface area, maximum for cases with BSA ≥25%. There was a strong positive significant linear correlation between stigmatization scores and disability scores ($r=0.746$; $p<0.001$), thus indicating that with increase in p scores there was a significant increase in PDI scores and vice versa.
Conclusions: Present study showed that feeling of stigmatization and disability was highly prevalent in psoriasis patients. It was seen that stigmatization and disability showed a strong correlation. The findings of study showed that there is need to create awareness regarding psoriasis as a non-communicable disease in order to increase the acceptance of psoriasis patients in society and to reduce their stigmatization.

Keywords: Participation scale, Psoriasis disability index, Psoriasis area severity index

INTRODUCTION

Psoriasis is classically defined as a chronic inflammatory condition of the skin presenting with scaly, erythematous plaques on the body's various surfaces. It is relatively common, chronic, inflammatory and hyper-proliferative skin disease that affects 1.4 % to 2.0% of the population and comprises 2.6% of skin related visits to primary care physicians, or between 0.3% and 1.6% of all visits to family physicians. There are more than 125 million people, or nearly three percent of the world's population including men, women, and children even newborn babies, who endure the symptoms of Psoriasis.

It is a non-contagious, immune-mediated, genetic disease that appears on the skin and/or involving the joints. Although traditionally psoriasis has been considered a dermatologic disease, contemporary medical literature is accumulating to support the assertion that psoriasis is actually a multisystem disease.

As a systemic, inflammatory autoimmune disease, Psoriasis is also connected with an elevated risk for other serious, chronic and/or life-threatening conditions, including cardiovascular disease, diabetes, stroke and cancer. As many as 30 percent of people with psoriasis will be diagnosed with psoriatic arthritis, a specific form

of arthritis that is painful and debilitating and causes joint damage.

It is estimated that at least 10 percent of psoriasis sufferers have a severe form which causes disability and exclusion from a normal life. Many tolerate constant pain from cracking and bleeding lesions and bear the humiliation and dis-comfort of continually flaking skin.

Although there are numerous treatments for psoriasis, many still face a very poor quality of life because the treatments do not work, work poorly, are too expensive, or are not available to them. Especially in developing countries, people with psoriasis have to face severe problems with stigmatization, discrimination and negative attitudes in general among the public, and often bear the brunt of public rejection. Many people with psoriasis isolate themselves because of such a deep sense of shame, embarrassment and low self-esteem.[3]

The growing sense of disability and stigmatization is responsible for a high degree of psychological distress and depression in psoriatic patients. Stigmatization, humiliation, rejection and other social difficulties are quite common in the life of patients with psoriasis and may exacerbate negative emotions, maladaptive thought processes (example- defectiveness), unfavourable self-perceptions (example- lowered self-esteem and negative body image), and negative be-haviour patterns (example-excessive social avoidance). These negative attributes influence the employment capacity, career prospects and earning potential of psoriasis on patients. As a result, coping with psoriasis is as much about coping with underlying psychological processes as it is about dealing with the physical side of the disease.

The extent of stigmatization among psoriatic patients has a direct influence on their quality of life and degree of disability. Although, a number of studies have found association between stigmatization and disability among psoriasis patients.[11] However, most of them are from western countries and there is lack of contemporary literature from India addressing the issue. Hence, the present study was carried out to assess the stigma and disability among patients with psoriasis and to find out whether there is any correlation of severity of psoriasis with stigma and disability among psoriasis patients.

METHODS

Study settings

Study was conducted in the OPD of Department of Dermatology, Era's Lucknow Medical College and Hospital, Luck-now after getting approval from the medical ethics. It was a Cross-sectional observational study which was conducted from Oct-2018 to Oct-2020 on clinically diagnosed cases of Psoriasis visiting the OPD where included.

A total of 170 patients were included in the study defining our inclusion and exclusion criteria.

A detailed dermatological and clinical history was noted for every case followed by a thorough general and physical examination. All the patients were subjected to:

Disability was assessed by PDI in patients with psoriasis. PDI is a 15-item scale with scores ranging from 0 to 3 for each items, thus the maximum score could be 45, indicating total disability while score 0 indicates no disability. For the purpose of present study, we converted the scores into percentile scores and quantified the level of disability as follows:

<25% disability- percentile scores 0-25 (minimal), 25-50% disability- percentile scores 25-50 (mild), 50-75% disability- percentile scores 50-75 (moderate), >75% disability- percentile scores >75 (severe).

Stigma associated with psoriasis was studied using p scale. Severity of psoriasis was assessed using PASI score.

Patients were classified as: Mild Psoriasis (PASI <5), Moderate Psoriasis (PASI 5-10), Severe Psoriasis (PASI >10).

PDI questionnaire and p scale were self filled by patients. In case of illiterate patients, questions were asked orally to fill questionnaire. P score <12 was considered as no restriction, 13-32 as moderate, 33-52 as severe and 53-90 as extreme restriction respectively[23].

Routine investigations like skin biopsy and blood profile was done in all the cases.

Statistical tools employed

The statistical analysis was done using Statistical Package for Social Sciences (SPSS) Version 21.0 statistical Analysis Software.

RESULTS

Present study included a total of 170 clinically diagnosed patients of Psoriasis fulfilling the inclusion criteria and giving consent (aged 16 to 76 years, mean age-37.74±13.70 years, 62.4%males)

Following tables show the key findings in the study:

Table 1 shows only 41 (24.1%) patients had involvement of single site. Among single site involvements, involvement of scalp was most common (7.1%) followed by upper limb (6.5%), lower limbs (4.1%), palms (3.5%), trunk (2.4%) and soles (0.6%) respectively.

Table 1: Distribution of study population according to site.

Site	No. of cases	Percentage
UL, LL, Trunk	36	21.2
UL, LL	28	16.5
Scalp, UL, LL, Trunk	25	14.7
Palm and soles	18	10.6
Scalp	12	7.1
UL	11	6.5
LL	7	4.1
Palms	6	3.5
Trunk	4	2.4
Scalp, UL	4	2.4
UL, Trunk	4	2.4
All sites	4	2.4
LL, Trunk	3	1.8
Palms, soles, UL, LL	3	1.8
Scalp, LL	3	1.8
Palms, soles, scalp	1	0.6
Soles	1	0.6

Table 2: Distribution of study population according to PASI.

PASI	No. of cases	Percentage
≤5 (Mild)	35	20.6
5.1-12 (Moderate)	37	21.8
12.1-20 (Severe)	37	21.8
>20 (Very severe)	61	35.9

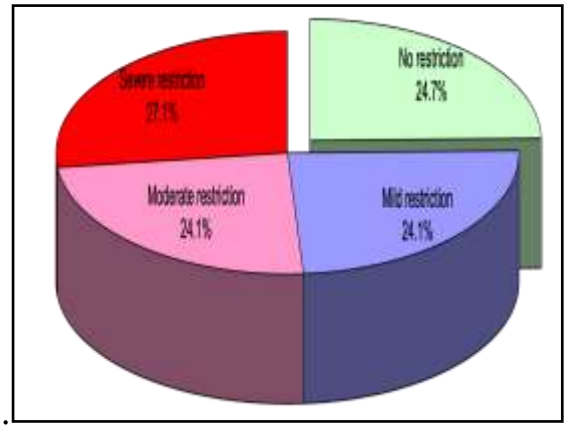

Figure 1: Distribution of cases according to level of stigmatization

A total of 129 (75.9%) had involvement of multiple sites. Among these, combined involvement of upper limb, lower limb and trunk was most common (n=36; 21.2%) followed by upper limb and lower limb (n=28; 16.5%), scalp, upper limb, lower limb and trunk (n=25; 14.7%) and palm and soles (n=18; 10.6%). A total of 4 (2.4%) cases had involvement of all sites. Among less common combinations were scalp and upper limb (n=4; 2.4%), upper limb, trunk (n=4; 2.4%), lower limb and trunk (n=3; 1.8%), palms, soles, upper limb and lower limbs (n=3; 1.8%), scalp and lower limb (n=3; 1.8%) and palms, soles and scalp (n=1; 0.6%) respectively.

Table 2 shows majority of the patients (57.7%) had severe to very severe PASI score (12.1-20 and >20). Only 20.6% had mild (≤5 PASI) and 21.8% had moderate (5.1-12.0 PASI) level of severity. Range of PASI in study population was 0.4-72, mean PASI was 18.44±14.68.

Figure 1 based on quartiles of p scale of patients enrolled in the study, patients in first quartile (24.7%) were classified as no restriction, 24.1% patients in second quartile were classified as mild restriction, 24.1% patients in third quartile were classified as Moderate restriction and 27.1% patients in fourth quartile were classified as Severe restriction.

Table 3 shows item wise response to Psoriasis disability index.

Table 4 shows only 11.8% patients had >75% disability, 22.9% 50-75% disability. Majority of the patients had ≤50% disability (65.3%), 30.0% patients had ≤25% disability.

Table 5 shows significant difference in P score (level of stigmatization) of cases having Psoriasis at different sites was observed. P-score was maximum in cases with Psoriasis at all sites (71.00±26.87) followed by at Scalp, UL, LL, trunk (45.96±17.23), palms, soles, upper limb, lower limb (44.33±3.79), upper limb, lower limb, trunk (36.06±18.09) and scalp, upper limb (34.25±27.40) while minimum p score was observed for cases having psoriasis at Soles (4.00) followed by at palms (10.33±4.59), Palms, soles (12.50±8.123), Scalp (15.25±14.10) and palms, soles, scalp (17.00).

Table 6 shows a significant association of p score with body surface area.

Figure 2 shows A subsequent increment in p score (level of stigmatization) was observed with increase in PASI severity. Patients with mild PASI had minimum p score (10.57±8.46) followed by those with moderate PASI (18.51±11.66), maximum p score was observed for cases with very severe PASI (45.93±17.06) followed by severe PASI (28.78±15.34). Above association was found to be significant.

Table 7 shows the level of disability was maximum among cases with very severe PASI (27.07±9.69) followed by having Severe PASI (18.27±8.55), Moderate PASI (13.43±7.50), minimum level of disability was observed among cases with Mild PASI (10.34±8.71). Association of PASI and level of disability was found to be significant statistically.

Table 3: Itemwise response to PDI (% respondents).

S. no.	Item	Very much	A lot	Little	Not at all
1	Psoriasis interfering with work around hours	5	8	5	82
2	Having to wear different types of clothes to conceal lesions	12	14	14	60
3	Having to change or wash clothes more frequently	37	20	18	25
4	Problem in maintaining hair because of psoriasis	25	30	15	30
5	Resulting in more frequent baths	18	15	22	45
6a	Made you lose time at work/ school	35	12	13	40
7a	Prevented you from doing things at work/school	28	20	17	35
8a	Career has been affected	22	10	18	50
6b	Stopped you from carrying out your normal activities	18	28	14	40
7b	Attend the way you do your normal daily activities	40	25	20	15
8b	Work in kitchen has been affected	54	12	22	12
9	Resulted in sexual difficulties	10	13	10	67
10	Created problems with family members/friends	12	10	6	72
11	Stopped you going out socially/ any special function	65	20	10	5
12	Made difficult to undertaken any sport	5	5	10	80
13	Unable to use/ critized/ stopped from communal bathing or changing facility	20	3	2	75
14	Resulted in more smoking/ drinking	15	10	15	60
15	Extent to which psoriasis or treatment made your house messy	70	15	10	5

Table 4: Distribution of cases according to disability (PDI).

S. no.	Characteristic	No. of cases	Percentage
1	≤25% Disability	51	30.0
2	25-50% Disability	60	35.3
3	50-75% Disability	39	22.9
4	>75% Disability	20	11.8

Table 5: Association of level of stigmatization (P-score) with site of involvement.

S. no.	Site	No. of cases	Mean P score	S.D.	Min.	Max.
1	UL, LL, Trunk	36	36.06	18.09	0	74
2	UL, LL	28	24.54	15.53	1	63
3	Scalp, UL, LL, Trunk	25	45.96	17.23	11	72
4	Palm and soles	18	12.50	8.12	3	30
5	Scalp	12	15.25	14.10	1	48
6	UL	11	18.73	6.47	11	33
7	LL	7	25.29	17.86	0	50
8	Palms	6	10.33	4.59	2	16
9	Trunk	4	25.75	19.47	8	45
10	Scalp, UL	4	34.25	27.40	0	65
11	UL, Trunk	4	26.50	8.81	17	37
12	All sites	4	71.00	26.87	33	90
13	LL, Trunk	3	29.00	12.77	15	40
14	Palms, soles, UL, LL	3	44.33	3.79	40	47
15	Scalp, LL	3	21.33	19.86	7	44
16	Palms, soles, scalp	1	17.00	.	17	17
17	Soles	1	4.00	.	4	4

F=5.744 (ANOVA); p<0.001

Table 6: Association of level of stigmatization (P-score) with body surface area.

S. no.	Body Surface Area	No. of cases	Mean P score	S.D.	Min.	Max.
1	<10%	68	13.37	9.78	0	50
2	10-25%	55	30.67	13.53	7	63
3	>25%	47	49.49	17.40	11	90

F=100.892 (ANOVA); p<0.001

Table 7: Association of level of disability (PDI score) with PASI severity.

S. no.	PASI Severity	No. of cases	Mean PDI score	S.D.	Min.	Max.
1	Mild (≤5)	35	10.34	8.71	3	45
2	Moderate (5.1-12)	37	13.43	7.50	2	32
3	Severe (12.1-20)	37	18.27	8.55	2	40
4	Very severe (>20)	61	27.07	9.69	6	45

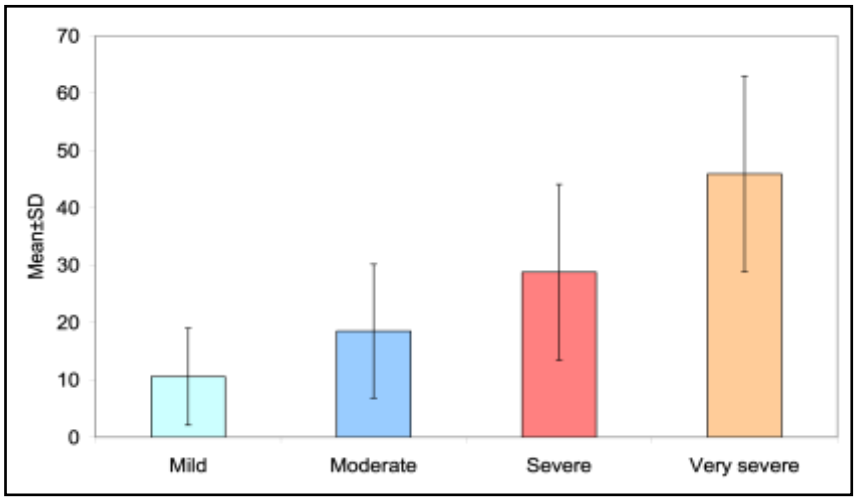

Figure 2: Association of level of stigmatization (P-score) with PASI severity.

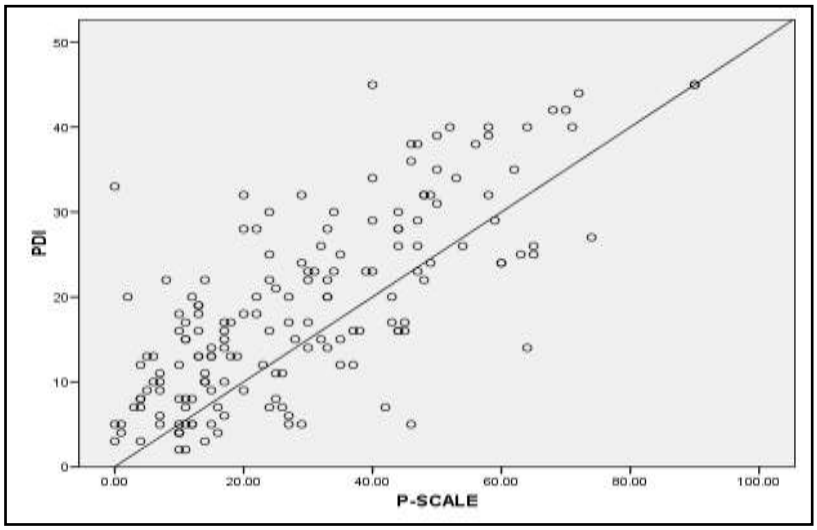

Figure 3: Correlation of level of disability (PDI) and stigmatization (P-scale).

(Figure 3) shows a strong positive significant linear correlation between stigmatization scores and disability scores (r=0.746; p<0.001), thus indicating that with increase in p scores there was a significant increase in PDI scores and vice versa.

DISCUSSION

Psoriasis is a disease marked by presence of scaly dry patches which are cause of pain, discomfort and distress. Psoriasis is reported to be viewed with disgust, fear, and aversion in society resulting in a social stigma which can subsequently be responsible to feelings of shame and anxiety in the affected patients.[22] The social stigmatization of psoriasis acts as a barrier in normal functioning of the affected patients and has a detrimental effect on the social life of the patient. Adversely affected social life of the patients affects the routine functioning of the patient. Patients try to avoid socializing, they avoid going to places where a large number of people gather, leading to a feeling of disability.

Keeping in view the social and psychological impact of psoriasis on patient life, the present study was planned to assess the disability and stigma associated with psoriasis and to find out the factors that determine it.

Stigmatization of psoriasis patients has been an issue of interest for the dermatologists as well as psychologists. In the recent years, a number of studies on stigmatization of psoriasis patients with diversified profile have been conducted with a variable age and gender profile. Ghorbanibirgani et al conducted their study on a small sample of 15 psoriasis patients aged between 18 and 58 years with dominance of females (60.0%).[24] Łakuta et al conducted their study on 148 psoriasis patients with mean age 34.6 years and dominance of females (70.3%).[25] The age and gender profile of pa-tients in present study was similar to that reported by Kashyap et al who conducted their study in 125 psoriasis patients with mean age 39.92 years, of which 78 (62.4%) were males.[26] Dimitrov et al too conducted their study in a male-dominated psoriasis patient population (60.2%) who had a mean age of 36.6 years.[27]

In present study, we found moderate to severe restriction of social participation in 24.1% and 27.1% patients. Only 24.1% patients did not experience any restriction. Thus, we can say that more than three-fourth (75.9%) patients expe-rienced some kind of stigmatization. Compared to present study, Pichaimuthu et al reported some kind of stigmatiza-tion in 28% of psoriasis patients and reported severe stigmatization in only 2.7% of patients.[28]

As far as disability is concerned, in present study we used Psoriasis Disability Index (PDI) for measurement of disabil-ity. It is a scale that has 15-items covering five domains, viz., daily activities, employment, personal relationships, lei-sure time, and treatment effects.

In present study, using PDI, we found disability upto 25% in 30% of patients, 25-50% disability in 35.3%, 50-75% dis-ability in 22.9% and >75% disability in 11.8% patients. In fact, more than one third (34.7%) patients had >50% disability. In present study, we quantified the level of disability using PDI on the basis of conversion of PDI scores to a 100-point scale. None of the previous studies have done it so far.

The findings in present study underscore the reality that psoriasis is a disease that attracts social stigma which tends to affect the quality of life of psoriasis patients. It is high time to create awareness regarding psoriasis and to provide social as well as psychological support to psoriasis patients in order to make their life more comfortable and to give them an opportunity to live life at par with any other citizen. Further studies to unravel the driving factors behind this stigmatization are recommended to find out the dark areas where the awareness campaigns should be targeted.

Limitations

Being a single centred study the enrolled patients in my study belonged mostly to rural area in the western Uttar Pradesh thus the results can't be generalised.

CONCLUSION

The present study was conducted to assess the disability and stigma associated with psoriasis. A total of 170 clinically diagnosed cases of Psoriasis were enrolled in the study. Age of patients enrolled in the study ranged from 16 to 76 years, mean age was 37.74±13.70 years. Majority of the patients were male (62.4%), had plaque type of psoriasis (91.8%). In majority of the patients effect of psoriasis was observed on multiple sites. Most common affected site were upper limb (68.2%) and lower limb (62.9%) followed by trunk (44.1%), scalp (26.5%), palms (20.0%) and soles (15.3%). Majority of the patients had affected >10% of body surface area (60.0%), had Severe to very severe psoriasis area and severity index (PASI). Range of duration of psoriasis was 1 month to 25 years, mean duration was 4.48±4.95 years. Prevalence of <25%, 25-50%, 50-75% and >75% disability was 30%, 35.3%, 22.9% and 11.8% respectively. Based on p scores quartile distribution, a total of 42 (24.7%) patients had no stigmatization, 41 (24.1%) had mild stigmatization, 41 (24.1%) had moderate stigmatization and 46 (27.1%) had severe stigmatization. No significant association of age was observed with severity of stigmatization and severity of disability. Level of stigmatization of both the genders was comparable while level of disability was significantly higher among males as compared to females. Cases with Erythroderma type of Psoriasis had significantly higher level of stigmatization and disability. Level of stigmatization and level of disability were found to be associated with site of Psoriasis. Higher the affected body surface area, higher the level of stigmatization and level of disability. Level of disability and stigmatization were associated with PASI severity. Duration of psoriasis did not show significant association with levels of disability and stigmatization. A moderate level of linear correlation between level of disability and level of stigmatization was observed. There was a high level of

stigmatization and disability in psoriasis patients which was dependent on patient sex, site of lesion, type, extent, and severity of psoriasis.

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