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THE HEARTBREAK OF PSORIASIS: IMPACT ON QUALITY OF LIFE

Dermatology

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ABSTRACT

Chronic disfiguring nature of psoriasis results in a significant psychological impact on the patient. "Heartbreak of Psoriasis" is a phrase commonly used to refer to the emotional distress in addition to the physical stress of the disease. The aim of the current study was to identify the variables affecting the quality of life (QoL) and correlating them with clinical severity of psoriasis. In a hospital based cross-sectional study, 70 patients of psoriasis diagnosed clinically, were studied. The extent of disease severity and the health-related quality of life were assessed using PASI and psoriasis disability index (PDI) respectively, the latter was suitably modified and a version in the local language, Hindi, was also provided. The clinical PASI scores correlated significantly with the extent of impact of psoriasis on physical disability, along with individual aspects of PDI (except work/school – related activities and personal relationships). We also noticed a decreasing trend in mean PDI as the age increased. The hindi PDI is an acceptable, reliable and valid measure of psychological distress in these patients. The study provides compelling data to improve physician's awareness regarding the clinical variables affecting patient's QoL and thus adopting a more holistic approach including psychological measures.

KEYWORDS

Psoriasis, Quality of life (QoL), PASI, Heartbreak, Psoriasis Disability Index (PDI)

INTRODUCTION

I am silvery, scaly. Puddles of flakes form wherever I rest my flesh… Lusty, though we are loathsome to love … the name of the disease, spiritually speaking, is Humiliation.

John Updike, "From the journal of a Leper"(Updike, 1982)

The definition of psoriasis as "a common, chronic, disfiguring, inflammatory condition of the skin"(Griffith, Camp, & Barker, 2004) does not significantly consider the psychological impact of the disease. "Heartbreak of Psoriasis" is a phrase commonly used to refer to the emotional distress in addition to the physical stress of the disease.

Psoriasis is a serious condition strongly affecting the way a person sees him and the way he is seen by others. It has tremendous economic and financial ramifications. Psoriasis has a significant negative impact on patients health related quality of life. Psoriasis patients often experience difficulties like maladaptive coping responses, problems in body image, self-esteem, and self-concept and also have feelings of stigma, shame and embarrassment regarding their appearance. This is often accompanied by a perception of being evaluated by others based on their disfigurement. Individuals with psoriasis commonly engage in coping strategies to avoid unwanted and unpleasant social consequences. However, most of these strategies fail to improve patients' QoL. Discussing their skin condition, covering their lesions, and avoiding contact with people are significantly associated with negative impact on life.(Gupta & Gupta, 1998)

The anguish expressed by many psoriasis patients has been explored extensively in western literature over many decades. The Psoriasis Disability Index (PDI) was one of the attempts to quantify the impact of psoriasis on patients' lives and is the most commonly used disease-specific instrument for this purpose. Surprisingly, very few Indian studies have looked into the psychological aspects of this chronic disfiguring disease. The reliability and validity of the PDI have been evaluated using different languages and in different psoriasis populations.

The present study was thus designed to identify the clinical variables affecting the QoL, correlating them with clinical severity of psoriasis and to formally validate the Hindi version of PDI in Indian patients with psoriasis.

METHODS

A hospital based, prospective study involving 70 patients of clinically diagnosed psoriasis, was conducted in a tertiary care hospital in Uttar Pradesh. The study was conducted between January 2016 and April 2017 (16 months).

After explaining purpose and contents of the study to subjects, written informed consent was obtained from each. A detailed history with special emphasis on psoriasis including age at onset, total duration, duration of present episode, remitting and relapsing factors, history of joint and nail involvement along with family history was recorded on a pre-designed case record form. Dermatological examination including morphological type of psoriasis, associated nail and scalp involvement and Psoriasis Area Severity Index (PASI) was calculated for all patients.

CALCULATION OF PASI

The body was divided into 4 sections (head (H) (10% of a person's skin); arms (A) (20%); trunk (T) (30%); legs (L) (40%)). For each section, the percent of area of skin involved was estimated and then transformed into a grade from 0 to 6.

0% of involved area, grade: 0
< 10% of involved area, grade: 1
10-29% of involved area, grade: 2
30-49% of involved area, grade: 3
50-69% of involved area, grade: 4
70-89% of involved area, grade: 5
90-100% of involved area, grade: 6

Within each area, three clinical signs estimated the severity: erythema (redness), induration (thickness) and desquamation (scaling). Severity parameters were measured on a scale of 0 to 4, from none to maximum. Hence, the final formula for calculating PASI score is as follows:

$$PASI = 0.1(Eh + Ih + Dh)A + 0.2(Eu + Iu + Du)A + 0.3(Et + It + Dt)A + 0.4(El + Il + Dl)A$$

The score can vary from 0 to 72. In our study:
PASI<7 was graded as MILD;
7-12 was graded as MODERATE
>12 was graded as SEVERE(He et al., 2012)

QUALITY OF LIFE ASSESSMENT

All participants were asked to fill out a multidimensional Quality of Life assessment questionnaire comprising the psoriasis disability index (PDI)(Finlay & Coles, 1995; Finlay & Kelly, 1987) according to

their own feelings and opinions. Both Hindi and English versions of the questionnaire were included in the materials. Those who had difficulties in completing questionnaires by themselves were helped, but every answer was solely based on participant's own response.

Psoriasis disability Index

The Psoriasis Disability Index questionnaire is designed for use in adults, i.e. patients over the age of 16. It is self-explanatory and can be handed to the patient who is asked to fill it in without the need for a detailed explanation. It is usually completed in three or four minutes.(Finlay & Kelly, 1987) There are two possible alternative formats of the PDI. One uses visual analogue scales for each answer, the other uses tick box choices for each answer.

Scoring (Visual Analogue Scale)

The scoring of each question is answered on a graded scale from 0 – 6. If a question is left unanswered the score taken is 0. The PDI is calculated by summing the score of each of the fifteen questions resulting in a maximum of 90 and a minimum of 0. The higher the score, the more quality of life is impaired. The PDI can also be expressed as a percentage of the maximum possible score of 90.(Finlay & Coles, 1995; Finlay, Khan, Luscombe, & Salek, 1990)

Scoring (Tick-box method)

The scoring of each question is answered on a series of 4 answers; not at all (scores 0), a little (scores 1), a lot (scores 2), very much (scores 3). If a question is left unanswered the score taken is 0. The PDI is calculated by summing the score of each of the 15 questions resulting in a maximum of 45 and a minimum of 0. The higher the score, the more quality of life is impaired. The PDI can also be expressed as a percentage of the maximum possible score of 45.(Finlay & Coles, 1995; Finlay et al., 1990)

The PDI can be analysed under five headings as shown in table 1.(Finlay & Coles, 1995; Lewis & Finlay, 2005)

TABLE – 1 PSORIASIS DISABILITY INDEX

Section	Questions	VAS	Tick-Box
Daily Activities	Questions 1, 2, 3, 4 and 5	Score max 30	15
Work or School or alternative questions	Question 6, 7 and 8	Score max 18	9
Personal relationships	Questions 9 and 10	Score max 12	6
Leisure	Questions 11, 12, 13 and 14	Score max 24	12
Treatment	Question 15	Score max 6	3

We used a modified version of the original PDI (1990 version) questionnaire to suit the local population. The original PDI is a 15-item standardized questionnaire to yield a total score (range: 0–45) with higher score indicating greater limitations experienced because of psoriasis. We have added two questions - "how much was the work in kitchen affected?" (Only for patients committed to kitchen activities) and "how much financial burden did you (patient) experience due to the treatment of psoriasis?" - under the subdivisions of 'work or school' (alternative questions if not at work or school) and treatment-related questions respectively. These questions were relevant in our cultural setting. The resulting score, thus, ranged from 0 to 48 (or 0 to 51) instead of 0 to 45.(Rakhesh, D'Souza, & Sahai, 2008)

For comparison with previous studies, we also expressed the total score as percentage. As in the original questionnaire, all the questions related to events took into account the preceding 4 weeks.

RESULTS

We enrolled 70 psoriasis cases for the study of which, 46 (65.7%) were males and 24 (34.3%) were females. We did not find any significant difference in the mean total PDI between males and females. (T score = 1.116, p = 0.268)

CORRELATION OF DESCRIPTIVE CHARACTERISTICS WITH PDI

We observed a negative correlation of age of onset with Total PDI (r =- 0.168; p=0.017). Thus, patients with earlier age of onset of psoriasis were associated with worse physical disability scores than those with late onset of psoriasis. Total disease duration and duration of current episode had no significant impact on the mean PDI (p = 0.511 & 0.082, respectively). A positive correlation was also seen of the Body Surface Area involved with Total PDI, with a highly significant p value (r = 0.450; p < 0.001). (Table 2)

TABLE – 2 PEARSON'S CORRELATION TO EVALUATE THE RELATION BETWEEN DESCRIPTIVE CHARACTERISTIC AND PDI SCORES (TOTAL)

Score	r - value	p - value
Age of onset with PDI	- 0.168	0.017
Total disease duration with PDI	0.081	0.511
Duration of current episode with PDI	0.213	0.082
Body surface area (BSA) with PDI	0.450*	< 0.001**

On comparing the mean total PDI of patients in different age groups, we observed the highest mean PDI in patients of age group 21 – 30 years. We also noticed a decreasing trend in mean PDI as the age increased. (Table 3)

TABLE – 3 PDI IN DIFFERENT AGE GROUPS

Age in years	No of Patients	Mean PDI
<20	5	19.6
21-30	12	26.4
31-40	23	15.7
41-50	18	18
51-60	7	17.7
61-70	4	11.5
>71	1	22

CORRELATION BETWEEN PASI AND PDI

A highly significant correlation was found between PASI and total PDI (r = 0.424; p <0.001). There was a significant correlation of the PASI score with all subdivisions of PDI except work/school-related activities and personal relationships. The correlation was highly significant for daily activity subdivision (r = 0.446; p <0.001). (Table4)

TABLE – 4 PEARSON'S CORRELATION TO EVALUATE RELATION BETWEEN PASI SCORES AND PDI SCORES (TOTALAND SUBDIVISIONS)

	r-value	p-value
Daily activity	0.446	<0.001*
Work / School	0.158	0.204
Personal Relationships	0.21	0.09
Leisure	0.293	0.017
Treatment	0.351	0.004
Total - PDI	0.424	<0.001*

On comparing with the different groups of patients based upon clinical severity of patient, we observed a higher mean PDI in patients of severe psoriasis as compared to moderate or mild groups. These results have been displayed in table 5.

TABLE – 5 CORRELATION OF SEVERITY GROUPS OF PASI WITH PDI

	PASI	PDI	R value	P value
Mild (n = 6)	4.73	16	0.686	0.002
Moderate (n = 20)	9.7	16.4	0.545	0.006
Severe (n = 44)	22.94	21.4	0.327	0.019

PDI – THE RESPONSE PATTERN

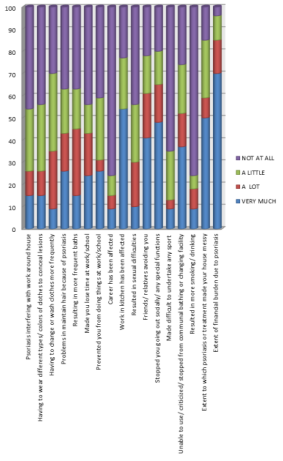
The percentage of patients ticking each response and the overall pattern of response in the PDI is given in Table 6 and Figure 1, respectively.

TABLE – 6 DISTRIBUTION OF RESPONSE TO EACH OF THE ITEMS OF PDI

Q. No	PDI (relate to last four weeks	RESPONSE			
		VERY MUCH (%)	A LOT (%)	A LITTLE (%)	NOT AT ALL (%)
1	Psoriasis interfering with work around house	15	11	28	46
2	Having to wear different types/ colors of clothes to conceal lesions	15	11	30	44
3	Having to change or wash clothes more frequently	9	26	35	30

4	Problems in maintain hair because of psoriasis	26	17	20	37
5	Resulting in more frequent baths	15	30	18	37
6	Made you lose time at work/school	24	19	13	44
7	Prevented you from doing things at work/school	26	5	28	41
8	Career has been affected	9	6	9	76
9	Work in kitchen has been affected	54	0	23	23
10	Resulted in sexual difficulties	10	20	26	44
11	Friends/ relatives avoiding you	41	20	17	22
12	Stopped you going out socially/ any special functions	48	17	15	20
13	Made difficult to undertake any sport	9	4	22	65
14	Unable to use/ criticized/ stopped from communal bathing or changing facility	37	15	22	26
15	Resulted in more smoking/ drinking	9	9	6	76
16	Extent to which psoriasis or treatment made your house messy	50	9	26	15
17	Extent of financial burden due to psoriasis	70	15	11	4

Figure1: DISTRIBUTION OF RESPONSE TO EACH OF THE ITEMS OF PDI



"VERY MUCH" and "NOT AT ALL" response

We observed that questions relating to work in kitchen and financial burden to the patient got the maximum response by patients as being affected very much by psoriasis. The minimum affect or "not at all" response was seen maximum in questions relating to career being affected and increased smoking/drinking due to psoriasis. These results have been displayed in table 7 and 8.

TABLE – 7 RESPONSE "VERY MUCH"

Q. No	Question	No	%
9.	Work in kitchen has been affected (n =24)	13	54
12.	Stopped you going out socially/ any special functions (n = 70)	34	48
16.	Extent to which psoriasis or treatment made your house messy (n = 66)	33	50
17.	Extent of financial burden due to psoriasis (n = 66)	46	70

TABLE – 8 RESPONSE "NOT AT ALL"

Q. No	Question	No.	%
1.	Psoriasis interfering with work around house (n = 65)	30	46
8.	Career has been affected (n = 50)	38	76
13.	Made difficult to undertake any sport (n = 40)	26	65
15.	Resulted in more smoking/ drinking (n = 66)	50	76

DISCUSSION

Psoriasis can have a profound impact on a patient's quality of life. And though psoriasis generally does not affect survival, it certainly has a number of major negative effects on patients, demonstrable by the significant detriment to quality of life. Sufferers are also most likely to feel self-conscious, be disturbed / inconvenienced by the shedding of the skin, live in a constant fear of relapse, and avoid social interactions. Very few Indian studies have examined this aspect of Indian patients of psoriasis.

DESCRIPTIVE FEATURES

Correlation with age

In our study, we observed a negative correlation of the age of onset of Psoriasis with total PDI (r =-0.168; p=0.017). Thus, patients with an earlier onset of the disease were associated with worse scores than those with late onset. Ginsburg et al, in her study of stigmatization found that being older at onset of psoriasis protects people against anticipating rejection, feeling sensitive to opinion of others, feeling guilt and shame, and secretiveness.(Ginsburg & Link, 1993) Our study is in concordance with this finding. Pakran et al also made similar observations of having a higher mean PDI score in patients with earlier onset of psoriasis (r = -0.29, P = 0.03). (Pakran, Nandakumar, & Riyaz, 2011) Disease duration had no significant impact on the mean PDI.

We observed the highest mean PDI to be in patients of age group 21 – 30 years. Also, a decreasing trend in mean PDI as the age increased was noted. This observation could be due to the chronicity of the disease, which enables the patient to cope up with the disease as the age advances and hence causing a lower impact on the quality of life with increasing age.

Correlation with Body Surface Area

An important observation in our study was that there was significant positive correlation in the total PDI with the area of Body Surface involved in psoriasis (r =0450, p <0.001). This finding suggests that the surface area involvement has a great impact on the psychosocial well being of a patient. This is also supported by the fact that patients with exposed parts of the body involved often felt the need to cover that area by wearing full sleaves shirts and full length pants (as told by 4 patients while filling the daily activities sub-division of PDI). Despite a thorough search of literature, we could not find any study which has attempted to correlate the BSA with PDI score.

CORRELATION OF PASI WITH PDI

Correlation with Total PDI

The clinical severity measurement correlated significantly with overall physically disability (PDI) in our study (p <0.001). Our findings were in concordance with those of other investigators like Rakhesh(Rakhesh et al., 2008), Pakran(Pakran et al., 2011), and Zehui He(He et al., 2012), who also found highly significant correlation between PASI scores and PDI scores. Fortune et al(Fortune, Main, O'Sullivan, & Griffiths, 1997), however, did not find any significant correlation between PASI and PDI scores. On closer examination of Fortune's study(Fortune et al., 1997), we noted that most of his patients had low clinical severity (mean PASI = 8.8) as compared to our study (mean PASI = 16.6). Hence the extensive involvement in most of our patient's causing physical disability and imposing limitations on their life styles, explains the highly significant correlation between PASI and PDI in this study, similar to the findings in other studies, which had higher mean PASI values. This is in contrast to Fortune's(Fortune et al., 1997) study, where patients had milder disease so as not to interfere with their lifestyles.

Correlation with Subclasses

We also observed significant correlation of the PASI score with all subdivisions of PDI, except work/school – related activities and personal relationships, which failed to correlate with PASI scores. Finlay, in an earlier study, had found the PASI score to significantly correlate with all aspects of PDI.(Finlay & Kelly, 1987) The absence of any significant correlation between the clinical severity and work/school - related activities, points towards the fact that most of our subjects belonged to lower socio-economic class. The disease severity would not interfere with their necessity to work and earn a living for

themselves as well as for their dependents. The lack of significant correlation between PASI and personal relationships can be justified by the strong family values and emotional bonds shared by the patients and their family members, which is an integral part of the Indian culture.

Correlation of Clinical Severity with PDI

According to the PASI score assessed by us, there were 6 patients (8.6%) with PASI <7, 20 patients (28.6%) with PASI 7–12, and 44 patients (62.8%) with PASI ≥ 12. Therefore, the subjects were divided into three "severity" groups: mild, moderate, and severe. The PDI score showed significant difference among the three groups (Kruskal-Wallis test$\chi 2$=76.30, P < 0.001) and increased with the increasing severity of psoriasis. This confirms our earlier finding that more extensive involvement of psoriasis is associated with greater disability with a higher PDI score. Thus PDI is a reliable instrument for people with psoriasis to assess the disabilities and limitations related to life styles.

ANALYSIS OF PATTERN OF RESPONSE IN PDI QUESTIONNAIRE

Analysis of the PDI questionnaire on the basis of percentage of response for each aspect of disability [Figure 1] showed that questions related to treatment –related difficulties scored the highest, and questions related to career being affected and leisure activities scored the least. Our findings are in concordance with the findings in study by Rakhesh et al.(Rakhesh et al., 2008) In their study, the mean sub-scores of daily activities and treatment sections were greater than those of the other 3 sections. Even in study by Pakran et al, the response pattern showed how the financial burden and treatment related problems adversely affect the quality of life in their patients.(Pakran et al., 2011)

Almost 85% of the patients in our study responded with "very much" or "a lot" to the question relating to extent of financial burden due to psoriasis. We included this question in the study in the original second version of PDI, due to its relevance in our cultural setting. This finding can be explained by the fact that most patients belong to the lower socio-economic group in the study, who have to bear the cost of medicines on their own contributing to a great financial burden. Similarly we had also included another question in our study relating to work in kitchen being affected. More than 50% of female patients with psoriasis responded with "very much" to this question. This as explained by a few patients was due to their concern of skin scales falling into the food they prepare, which might spoil its taste and quality. In our study, some of the patients had problems with question 10 due to cultural difference & shame of talking about sexual relationships in a religious country such as India.

The question relating to patients "going out socially/ any special functions" also got maximum response with "very much", due to patients being very ashamed of the visibility of their lesions and also supported by their attempt to keep the skin fully covered in order to hide their lesions.

Kent in his study suggested that 3 items, viz., "problems around the house/garden," "difficulties with patients' partners or close friends," and "effect on career prospects," be dropped from the questionnaire as they were not psoriasis specific.(Kent & Al-Abadie, 1993) We partially agree with his findings, especially on the last aspect, as that was the question pertaining to the least reported problems in our psoriasis patients too. The other questions, which got a maximum "not at all" response, were those relating to "sports activity" and "increased smoking and drinking". This can be explained by the fact that in our study group with the age group beyond 18 years, sports activities are not routinely undertaken unless for professional purpose.

To conclude, the Hindi version of PDI is a reliable and valid instrument and can be used to assess patient-reported impact of psoriasis. It is expected to help improve the QOL assessment of Indian patients with psoriasis because until now there have been few instruments to measure psoriasis-specific QOL in India.

DECLARATIONS

Funding: NIL
Conflict of interest: None declared
Ethical approval: YES

Image 1: CLASSICAL PSORIATIC PLAQUE

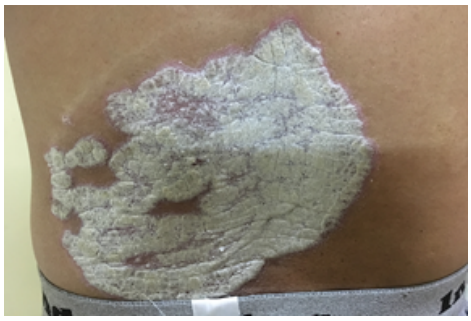


Image 2 & 3: CHRONIC PLAQUE PSORIASIS (EXTENSOR SURFACE)

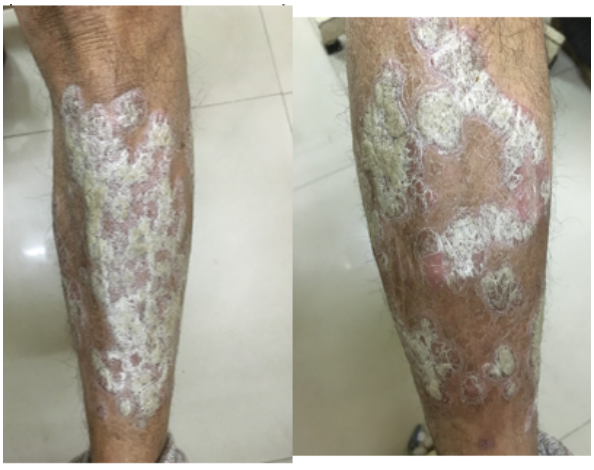
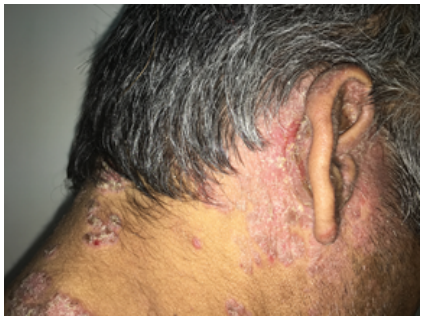


Image 4: SCALP PSORIASIS



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