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Stigma and self-esteem in patients of bronchial asthma

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Abstract

Asthma is a debilitating chronic disease that renders individuals physically as well as mentally sick. The perception of stigmatization further leads to inappropriate control of asthma resulting in a bidirectional relationship. A prospective, cross-sectional study was conducted in a tertiary care centre of semi urban area of north India during 2021-2022. Three hundred cases of bronchial asthma and 50 healthy controls were enrolled. The asthma control test (ACT) was used to evaluate the control of asthma. Stigma and self-esteem were measured with the use of 28 item self-stigma scale, Rosenberg self-esteem scale, and stigma-related social problem scale (SPSS). The impact of

sociodemographic and clinical profiles on stigma and self-esteem was evaluated. Correlation of different scales with each other was done along with. The mean age of asthmatic patients was 47.41 ± 15.507 years with 56% being females; 49.3% of patients were well controlled and 36.3% were partly controlled. Positive subscales of 28 item self-stigma scale, Rosenberg self-esteem scale and SSPS showed statistically significant differences between cases and controls ($p < 0.001$). ACT significantly correlated with 28 item self-stigma scale, Rosenberg self-esteem scale and SSPS, and all three stigma and self-esteem scales correlated significantly with each other. Stigma and low self-esteem were found to be significantly higher in asthmatic patients than healthy controls. This needs to be addressed on priority as it can contribute to poor mental health and poor asthma outcomes.

Key words: asthma, stigma, self-esteem.

Introduction

Asthma is a heterogeneous disease, usually characterised by chronic airway inflammation. It is defined by the history of respiratory symptoms such as wheeze, shortness of breath, chest tightness and cough, that vary over time and in intensity, together with variable expiratory airflow limitation [1]. It is a debilitating chronic disease that renders individuals physically and mentally sick [2].

Stigma is “an attribute that is deeply discrediting”, that reduces someone “from a whole and usual person to a tainted, discounted one” [3]. Diagnosis-related stigma manifests as denial and hiding the diagnosis of asthma. Treatment-related stigma is most commonly attributed to the use of inhalers. Patients describe “embarrassment of taking inhalers” which reduces their ability to adhere to adequate inhaler technique. Thus, higher stigma in asthma patients and their lack of confidence in self-management plans regarding underuse/overuse of inhalers in an acute attack is an area to be worked upon [4]. This whole concept of perception of stigmatization leads to inappropriate symptom control especially in public gatherings and workplaces, as a result making asthma difficult to manage by health professionals.

Scarce data on the measurement of stigma and self-esteem by use of discrete tools is available from the Indian subcontinent. Hence a study was planned to assess the stigma and self-esteem in patients of bronchial asthma and correlate it with socio-demographic and clinical profile.

Material and Methods

It was a cross-sectional study conducted in a tertiary care centre in semi urban area of north India during 2021-2022. The study included 300 patients of bronchial asthma diagnosed as per GINA 2020 guidelines [1], who presented to the outpatient Department of Pulmonary Medicine, Government Medical College Patiala, Punjab, India. 50 healthy individuals were taken as controls.

Exclusion criteria

Patients <18 years of age, those already diagnosed with psychiatric illnesses and/or taking associated medications, patients with hearing, speech impairments and/or cognitive disability, congestive heart failure/ stroke/ pulmonary tuberculosis/ chronic obstructive pulmonary disease (COPD)/ community-acquired pneumonia (CAP)/ any malignancy were excluded from the study.

Assessment parameters

After informed consent, baseline assessment was done using the following instruments:

- i) Socio-demographic Performa: A specially constructed structured Performa was used to record the relevant data.
- ii) Asthma control test (ACT): Control of asthma was judged by using ACT. It is a tool used to assess limitations of activity, shortness of breath, night-time symptoms, need for rescue medicine and patient's overall rating in asthma control over the last 4 weeks [5].
- iii) 28 item self-stigma scale: It was used as a standardised instrument to measure the self-stigma. It is a brief scale that assesses patients on 3 domains i.e., Disclosure, discrimination and positive aspects. Each response was recorded on a Likert scale [6].
- iv) Rosenberg's self-esteem scale: It is a self-reported instrument for evaluating individual self-esteem. It consists of 10 questions regarding self-esteem and their response is marked on a Likert scale [7]. Patients were also classified as having High/ Normal/ Low self-esteem based on their scores >25/ 15-25/ <15, respectively.
- v) Stigma-related social problem scale (SSPS): It includes items on a broad range of social activities. The responses are aggregated into 2 domains i.e., distress (10

items) and avoidance (10 items). Items responses are finally aggregated into summated scale scores. It was used to measure distress and social avoidance due to their ailments [8]. Patients were classified as having very mild/ mild/ moderate/ severe impairment based on their scores <20 / 20-39 / 40-59 / >60, respectively.

Statistical analysis

The normality of quantitative data was checked by measures of Kolmogorov Smirnov tests of normality. Our variables were non-normally distributed (skewed) and were represented as mean \pm SD; and median and interquartile range. Comparisons for the two groups were made by the Mann-Whitney U test. When we had more than two Groups (age groups, education) comparisons of values of skewed data were made with the Kruskal-Wallis test followed by the Mann-Whitney test. Categorical variables were reported as counts and percentages. Group comparisons were made with the Chi-Square test if all expected cell frequencies were more than 5, and Fisher's Exact test when expected cell frequencies were less than 5. Spearman correlation coefficient was calculated to see the relation between variables. A p-value < 0.05 was considered significant. Analysis was conducted using IBM SPSS STATISTICS (version 22.0). The study was approved by the institutional Ethics Committee.

Results

A total of 300 asthmatic patients and 50 healthy controls meeting the inclusion and exclusion criteria were included in the study. The mean age of patients was 47.41 ± 15.507 years and that of controls was 44.32 ± 17.198 years. Both groups were matched concerning age, marital status, demography, educational status, body mass index (BMI) and addiction (Table 1).

The time since diagnosis of asthma for many patients was 1 month to 1 year (40.7%), as depicted in Table 2. Seasonal variation was the most common triggering factor. Most of the patients (73.3%) did not report any co-morbidity. In asthmatics, 39% were using metered dose inhalers (MDI) and 21% were using dry powder inhalers (DPI). 99.3% were never hospitalised for any acute exacerbation in the last 1 year (Table 2). According to ACT, 49.3% of cases were well controlled, 36.3% were partly controlled and 14.3% had uncontrolled asthma (Table 3). Table 3 also shows the number of patients of each subclass according to Rosenberg self-esteem scale and SSPS.

The mean values of 28 item self-stigma scale, Rosenberg self-esteem scale and SSPS in cases were significantly poorer than controls ($p < 0.001$) (Table 4).

Further, on studying the effect of socio-demographic factors on ACT, stigma and self-esteem related scales (28 item self-stigma scale, Rosenberg self-esteem scale and SSPS), it was seen that females had a higher stigma as measured by 28 item self-stigma scale. It was also seen that patients who were widowed, had poorer asthma control as measured by the ACT (Table 5).

A correlation matrix was applied to deduce the relationship of ACT and Stigma and self-esteem related scales (28 item self-stigma scale, Rosenberg self-esteem scale and SSPS) with each other (Table 6). ACT, 28 item self-stigma scale and SSPS showed significant positive correlation with each other. Rosenberg self-esteem scale showed a significant negative correlation with all scales.

Discussion:

In our study, the mean age of asthmatics was 47.41 ± 15.507 years. This is in concordance with the available literature [9-11]. Gender distribution with female preponderance and distribution of patients with respect to demography, education and occupation in our study was similar to the available literature [9-14]. Distribution of patients as per marital status was similar to a few studies [9,15], but was different from a study done by Cheng *et al.* in which only 23.2% were married [16]. 31.7% of our cases were obese. Our results are similar to previous studies [10,17,18]. There is a strong positive association between obesity and asthma in adult Indian women [19]. Obesity causes significant changes to normal lung physiology in adults. Studies in the past have shown that obese people are at increased risk of developing asthma. Obese asthmatics have more symptoms and have more frequent and severe exacerbations, reduced response to several asthma medications, and decreased quality of life [20,21].

The cases and controls were matched with respect to age, marital status, demography, educational status, BMI and history of addiction. Patients were recruited from a single tertiary care centre which was located in semi-urban area and caters to patients coming from the surrounding vicinity. This could be the possible reason for slight differences in the socio-demographics of our participants.

Only 27.7% of our patients had long-standing asthma (>5 years). The majority of our patients (73.7%) did not suffer from any comorbidity. Our results were similar to the

available literature [22,23]. 34.7% of patients in our study were either not taking any inhalational therapy or were taking oral medications/injectables. Similar to the available literature, 39% of patients were using MDI [10,24-27]. Since all the patients in our study were enrolled from the routine outpatient department (OPD). 86% of patients had no emergency visits in the past 1 year. The history of hospitalization in the past one year was given by only 1 patient.

Assessment of asthma control by ACT showed 49.3% of patients to be well controlled, rest being partly controlled or uncontrolled. This is in concordance with the literature available [28]. Since our study recruited patients from OPD, well controlled asthma to the extent of 49.3% could be explained, However, partly controlled/ uncontrolled asthma may be attributed to incorrect inhalational techniques, frequent use of reliever medications without the use of controllers and irregular follow-up [29].

Although asthma has not been described as a psychosocial condition until recently, emotional and nervous stress is known to trigger asthma symptoms [30]. It has been commonly seen that comorbid psychiatric conditions are infrequently recognised in routine clinical practices in asthmatics. They are even less frequently treated [31-33]. Psychosocial distress in patients of asthma with the use of discrete tools has been explored only to a limited extent in the past. Few studies on detailed psychiatric assessment have shown the diagnosis of anxiety and major depressive disorder (MDD) to be frequent in asthmatics [34]. Isolated case reports on experiences of patients living with asthma have shown feelings of discrimination, separation, guilt and devaluation. Patients have felt that life has been unfair towards them [6].

Our evaluation of stigma by use of the 28-item self-stigma scale and SSPS and evaluation of self-esteem by use of the Rosenberg self-esteem scale showed that asthmatics had significantly poorer scores on both stigma related scales and significantly lower self-esteem than controls. Similar results were obtained by Ahmad *et al.* and Seigel *et al.* [10,35]. Higher stigma and poor self-esteem in asthmatics can be explained by chronicity of the disease, limitation of routine activities and avoidance of participation in community activities [36]. Myths about “dependence on inhalers” prevail by and large in the society, with poor social support extended by their fellows [37]. Patients also report being “looked upon” and “discriminated” in education and at work. Reluctance to use inhalers in public and at workplaces further contributes to poor symptom control. This vicious cycle of stigma, self-esteem and asthma control contributes to increased morbidity and reduced quality of life in the asthmatics [36].

Our study thus gauged the magnitude of stigma and self-esteem in patients with asthma. Asthma and its association with stigma have been known for decades but had been rarely measured from the Indian subcontinent with the use of discrete psychological assessment tools. Our findings could be reflecting just the tip of an iceberg. We also need to explore if this sub-group of asthmatics, with higher stigma and lesser self-esteem, is more vulnerable to developing psychiatric illness over a period of time.

Except for gender, which affected the results of 28-item self-stigma scale, it was seen that scores of all other scales were unaffected by any socio-demographic variable. Female asthmatics, forming a major proportion of our cases, experienced higher stigma than males possibly due to more patriarchal customs and beliefs in our country. Similar results were obtained in other studies [10,38,39].

A correlation matrix was applied to deduce the relationship of ACT, Stigma and self-esteem related scales (28 item self-stigma scale, Rosenberg self-esteem scale and SSPS) with each other. It is derived from our study and is understandable that patients with poor control of asthma (as measured by ACT) have higher stigma and lower self-esteem (as measured by stigma and self-esteem related scales, $p < 0.001$). In addition, when the subgroups of patients classified as per ACT (as well controlled/ partly controlled/ uncontrolled asthma) were compared with subgroups of patients as per Rosenberg self-esteem scale (as high/normal/ low self-esteem), the results were highly significant ($p < 0.001$). 40.5% of patients with well controlled asthma had high self-esteem. However, only 26.6% of partly controlled and 16.3% of uncontrolled asthmatics had high self-esteem. Similarly, when the subgroups of patients classified as per ACT (as well controlled/ partly controlled/ uncontrolled asthma) were compared with subgroups of patients as per SPSS (as very mild/mild/ moderate/ severe impairment), the results were again highly significant ($p < 0.001$). 91.2% of well controlled asthmatics had mild impairment. However, 77.1% of partly controlled and 39.5% of uncontrolled asthmatics had mild impairment. Level of symptom control thus highly correlated with the stigma and self-esteem scales. Kozyrskyj *et al.* also showed that stigma and self-esteem are affected by the severity of asthma [40]. Vice versa, we, support the fact that psychopathology may play a role in the management of asthma [41]. The correlation of stigma and self-esteem scales with each other shows interdependence amongst them, and a conclusion that these can be used interchangeably, with preference of one over the other, as per personal choices,

training and ease of administration by the clinicians in routine OPD practice for screening purposes.

Our study also highlights the fact that the proportion of patients with poor control of asthma should be specially evaluated for estimation of stigma and self-esteem, as they are the vulnerable group. These patients need to be separately encouraged, counselled and assured and their psychosocial concerns addressed on priority before they develop psychiatric illnesses. In the past, appropriate management has shown to reduce psychological distress drastically [42]. Our results should be of special interest to clinicians, researchers and policymakers and can be used to tailor education and behavioural interventions at the global level.

Limitations

The study was conducted at a single centre. Thus, might not be replicative of varied populations worldwide. Since the patients were not followed up, improvement/deterioration in stigma and self-esteem or development of psychiatric illness in due course of time, is not available. Recall bias cannot be ruled out in our study, as patient's responses to the questionnaires might have affected the original results.

Conclusions

There is an urgent need to evaluate stigma and self-esteem in patients of bronchial asthma, particularly in those with poorer disease control, by use of easy-to-administer screening tools in our routine OPDs, in addition to medical management and it should become a standard of care, in the years to come.

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Table 1. Demographic distribution of cases and controls.

Variable	Category	Cases, n (%)	Controls, n (%)	p value
Mean age		47.41 ± 15.507	44.32 ± 17.198	0.199
Gender	Male	132 (44.0%)	40 (80.0%)	<0.001**
	Female	168 (56.0%)	10 (20.0%)	
Marital status	Married	258 (86%)	43 (86%)	0.766
	Unmarried	39 (13%)	7 (14%)	
	Widow	3 (1%)	0 (0%)	
Demography	Urban	117 (39.0%)	21 (42.0%)	0.688
	Rural	183 (61.0%)	29 (58.0%)	
Highest completed education level	Uneducated	76 (25.3%)	11 (22.0%)	0.386
	Primary school	55 (18.3%)	15 (30.0%)	
	Secondary School	115 (38.3%)	16 (32.0%)	
	Graduate	41 (13.7%)	7 (14.0%)	
	Post-graduate	13 (4.3%)	1 (2.0%)	
Occupation	Government job	18 (6.0%)	4 (8.0%)	<0.001**
	Housewife	98 (32.7%)	9 (18.0%)	
	Labourer	49 (16.3%)	16 (32.0%)	
	Private job	34 (11.3%)	16 (32.0%)	
	Retired	15 (5.0%)	1 (2.0%)	
	Self employed	69 (23.0%)	0 (0.0%)	
	Student	16 (5.3%)	3 (6.0%)	
	Unemployed	1 (0.3%)	1 (2.0%)	
Income per month (Rupees)	Nil	117 (39.0%)	13 (26.0%)	0.023*
	1000-5000	18 (6.0%)	0 (0.0%)	
	5001-10000	60 (20.0%)	8 (16.0%)	
	10001-15000	32 (10.7%)	6 (12.0%)	
	15001-20000	34 (11.3%)	12 (24.0%)	
	=/>20001	39 (13.0%)	11 (22.0%)	
BMI	Under weight	34 (11.3%)	6 (12.0%)	0.104
	Normal	81 (27.0%)	22 (44.0%)	
	Over weight	57 (19.0%)	6 (12.0%)	
	Obese 1	95 (31.7%)	14 (28.0%)	
	Obese 2	33 (11.0%)	2 (4.0%)	
History of any addiction	No	286 (95.3%)	46 (92.0%)	0.323
	Yes	14 (4.7%)	4 (8.0%)	

n, sample size; BMI, Body mass index; *significant at 0.05 level (2-tailed); **significant at 0.01 level (2-tailed).

Table 2. Disease related variables in cases (n=300).

Variable	Category	n (%)
Time since diagnosis	<1 month	5 (1.7%)
	1 month - 1 years	122 (40.7%)
	1 year - 5 years	90 (30.0%)
	> 5 years	83 (27.7%)
	Total	300 (100.0%)
Triggering factors	Dust	103 (34.3%)
	Harvesting	28 (9.3%)
	Others	2 (0.7%)
	Seasonal variation	167 (55.7%)
	Total	300 (100.0%)
Co-morbidity	No	220 (73.3%)
	Yes	80 (26.7%)
Type of treatment	MDI	117 (39.0%)
	DPI	63 (21.0%)
	Nebulization	16 (5.3%)
	Nil/Oral/Injectables	104 (34.7%)
Regularity of treatment	Irregular	120 (40.0%)
	Regular	180 (60.0%)
Emergency visits	nil	258 (86.0%)
	1	34 (11.3%)
	2	5 (1.7%)
	3	2 (0.7%)
	≥4	1 (0.3%)
Hospitalizations	≥1	2 (0.7%)
	-	298 (99.3%)

n, sample size; MDI, metered dose inhaler; DPI, dry powdered inhaler.

Table 3. Classification of cases according to ACT, Rosenberg self-esteem scale and SSPS in cases (n=300).

		Cases, n (%)
ACT score	0	148 (49.3%)
	1	52 (17.3%)
	2	57 (19.0%)
	3	22 (7.3%)
	4	21 (7.0%)
ACT classification	Well controlled	148 (49.3%)
	Partly controlled	109 (36.4%)
	Uncontrolled	43 (14.3%)
Rosenberg self-esteem scale	High self-esteem	96 (32.0%)
	Normal	146 (48.7%)
	Low self-esteem	58 (19.3%)
SSPS	Very mild impairment	1 (0.3%)
	Mild impairment	236 (78.7%)
	Moderate impairment	59 (19.7%)
	Severe impairment	4 (1.3%)

n, sample size; ACT, asthma control test; SSPS, stigma-related social problem scale.

Table 4. Comparison of stigma and self-esteem related scales in cases (n=300) versus controls (n=50).

Scale	Domain	Cases (mean \pmSD)	Controls (mean \pmSD)	p- value
28 item self-stigma scale	Discrimination subscale	13.24 \pm 12.983	7.30 \pm 4.687	0.187
	Disclosure subscale	12.23 \pm 12.237	6.00 \pm 3.807	0.079
	Positive subscale	7.25 \pm 2.311	9.06 \pm 1.695	<0.001**
	Total score	32.72 \pm 24.992	22.36 \pm 7.979	0.879
Rosenberg self-esteem scale		22.18 \pm 5.690	25.54 \pm 2.393	<0.001**
SSPS		29.93 \pm 10.995	23.62 \pm 3.386	<0.001**

SSPS, stigma-related social problem scale; **significant at 0.01 level (2-tailed).

Table 5. Correlation of ACT and Stigma and self-esteem related scales (28 item self-stigma scale, Rosenberg self-esteem scale and SSPS) with sociodemographic variables and with each other in cases (n=300) .

	ACT (p-value)	28 item self-stigma scale (p-value)	Rosenberg self-esteem scale (p-value)	SSPS (p-value)
Correlation with sociodemographic variables				
Age group	0.182	0.536	0.069	0.327
Gender	0.651	0.005**	0.170	0.132
Marital status	0.040*	0.785	0.889	0.067
Rural/urban	0.910	0.398	0.630	0.220
BMI	0.339	0.167	0.093	0.686
Income	0.702	0.191	0.366	0.370
Education	0.714	0.787	0.520	0.632
Comorbidity	0.451	0.697	0.282	0.145
Correlation with each other				
	ACT (p-value)	28 item self-stigma scale (p-value)	Rosenberg self-esteem scale (p-value)	SSPS (p-value)
ACT	1.000	0.349**	-0.310**	0.342**
28 item self-stigma scale	0.349**	1.000	-0.583**	0.546**
Rosenberg self-esteem scale	-0.310**	-0.583**	1.000	-0.646**
SSPS	0.342**	0.546**	-0.646**	1.000

ACT, asthma control test; SSPS, stigma-related social problem scale; BMI, body mass index; *significant at 0.05 level (2-tailed); **significant at 0.01 level (2-tailed).