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Assessment of Stigma and Related Factors in Involuntary Movement Disorders

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Original Research Article

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Abstract: Stigma can be seen as an attitude, located at the individual level, based on ignorance, prejudice and fear of a particular group. It is a societal issue and resolution lies with the population at large, rather than those individuals experiencing symptoms of mental distress. One of the methods for indirect measurement of stigma is by self-esteem. This Cross sectional study was conducted on patients with involuntary movements, categorized on basis of etiology, into involuntary movements due to psychotropic medication and involuntary movements due to neurological disorders. After consent, socio-demographic data was obtained. Semi structured stigma questionnaire was used to assess stigma, Derriford appearance scale, Rosenberg self-esteem, Abnormal involuntary movement scale were administered for all the patients to find out other related factors. The patients with involuntary movements were discriminated, faced criticism, avoided social situations and public places, and with low self-esteem had problems with their appearance. Both Groups faced same amount of stigma. Stigma strongly correlated with severity of involuntary movements.
Keywords: Stigma, Rosenberg, socio-demographic, ignorance, neurological disorders.

INTRODUCTION

Many studies have documented stigma associated with a wide variety of chronic health conditions in the past few decades, particularly in mental health, epilepsy, leprosy, HIV/AIDS and other chronic, disabling conditions. Stigma can be seen as an attitude, located at the individual level, based on ignorance, prejudice and fear of a particular group [1]. Despite this knowledge and the far-reaching consequences of stigma, comparatively little progress has been made in systematically addressing stigma, and the often resulting discrimination, in public health programs[2].

AIM OF THE STUDY

To study stigma associated with patients affected with involuntary movement disorders

Objectives

- To study stigma in patients having involuntary movement disorders.
- To assess the distress, difficulties experienced in living and self-esteem in patients with involuntary movement disorders.
- To compare stigma association with illness related variables.
- Null Hypothesis: No stigma associated in patients with involuntary movement disorders

DATA SOURCE

Present study conducted in department of psychiatry, Institute of mental health, Hyderabad, a tertiary care psychiatric facility. This 600 bedded hospital under Osmania general hospital-Hyderabad.

Type of patient

Patients with involuntary movements.

Type of study

Cross sectional study

INCLUSION CRITERIA

- Those who are willing to give informed consent.
- Either the involuntary movements should be related to usage of psychotropic medication or

they should be part of involuntary movement disorders.
- Age above 18 years.

EXCLUSION CRITERIA:
- Those who are not willing to give consent.
- Patients with diagnosis of dementia.
- Patients with Psychogenic involuntary movements, Mental retardation, Involuntary movements due to substance use and Patients with active mental illness

Sample size
Total sample size of the study is 60

STATISTICAL METHODS

Descriptive statistics were done for all the continuous demographic and clinical variables and for assessment of stigma and need assessments and frequencies (percentage) were used for all categorical parameters.Quantitative statistics were done to assess significance across the groups**.** Spearman rho correlation test was used to assess the relationship between the stigma and socio-demographic, clinical variables. Statistical analysis was done using SPSS22.0 version

Tools
- Semi Structured Intake Proforma.
- Rosenberg Self Esteem Scale.
- Derriford Self Appearance Scale (Das 24).
- Abnormal Involuntary Movement Scale (Aims).

RESULTS
- 60 patients with involuntary movements divided into two groups.
- Group 1-patients with involuntary movements developed due to psychotropic medication.
- Group 2- patients with involuntary movements developed due to neurological disorders, not due to psychotropic medication usage.
- Each group consists of 30 patients with involuntary movements which are matched in sex with patients taken in each Group consists of 15 male and 15 female patients with involuntary movements

Table-1: Sociodemographic data across 2 groups

VARIABLE	GROUP 1 N (%)	GROUP 2 N (%)	TEST(CHI SQUARE)	SIGNIFICANCE
1) SOCIOECONOMIC STATUS :				
LOWER	6 (20.0)	10 (33.3)	1.94	0.38
MIDDLE	23 (76.7)	18 (60.0)		
UPPER	1 (3.3)	2 (6.7)		
2) EDUCATION :				
ILLITERATE	11 (36.7)	13 (43.3)	2.60	0.63
PRIMARY	8 (26.7)	9 (30.0)		
HIGH SCHOOL	6 (20.0)	5 (16.7)		
INTERMEDIATE	5 (16.7)	2 (6.7)		
GRADUATE AND ABOVE	0 (0.0)	1 (3.3)		
3) OCCUPATION :				
UNSKILLED	4 (13.3)	5 (16.7)	1.37	0.72
SEMISKILLED	11 (36.7)	14 (46.7)		
SKILLED	7 (23.3)	4 (13.3)		
UNEMPLOYED	8 (26.7)	7 (23.3)		
4) RESIDENCE :				
RURAL	16 (53.3)	15 (50.0)	0.49	0.79
SEMI URBAN	10 (33.3)	9 (30.0)		
URBAN	4 (13.3)	6 (20.0)		
5) MARITAL STATUS :				
UNMARRIED	6 (20.0)	2 (6.7)	2.86	0.41
MARRIED AND LIVING TOGETHER	19 (63.3)	23 (76.7)		
SEPARATED OR DIVORCED	4(13.3)	1(10.0)		

DIAGNOSIS

Patients from Group 1 having diagnoses of Schizophrenia (53%, N=16) , Bipolar affective disorder (BPAD ~ 33%, N=10) and Psychosis NOS (13%, N=4). Group 2 having cases of Parkinson`s disease (PD ~ 50%, N=15), others (20%, N=6), Tourette`s disease (10%, N=3), Cerebrovascular accident (CVA ~10%, N=3), Huntington's disease (HD ~ 7%, N=2) and Rheumatic disease (RD ~3%, N=1).

Table-2:Type of involuntary movement

GROUPS	TREMOR	AKATHISIA	DYSTONIA	T D	CHOREA	ATHETOSIS	TICS	CHI SQUARE	P VALUE
GROUP 1	12 (40.0)	4 (13.3)	9 (30.0)	5 (16.7)	0 (0.0)	0 (0.0)	0 (0.0)	24.0	0.001**
GROUP 2	15 (50.0)	0 (0.0)	1 (3.3)	2 (6.7)	6 (20.0)	2 (6.7)	4 (13.3)		
Total N (%)	27 (45.0)	4 (6.7)	10 (16.7)	7 (11.7)	6 (10.0)	2 (3.3)	4 (6.7)		

Tremor consists of major involuntary movement in Group 1 and 2 (40 and 50%, N=12 and 15 respectively), with overall of 45%(N=27).

In Group 1 other involuntary movements were Dystonia (30%, N=9),Tardive dyskinesia (~17%, N=5) and Akathisia (~13%, N=4). In Group 2 Chorea (20%, N=6),Tics (~13%, N=4), Athetosis (~7%, N=2), Tardive dyskinesia (~7%, N=2) and Dystonia (~3%, N=1).There is significant statistical difference between two Groups (p value 0.001) as per type involuntary movements were concerned.

Table-3:Duration of involuntary movements

ITEM	GROUPS	MEAN (S.D.)	MEDIAN	CHI SQUARE	P VALUE
Duration of involuntary movements in days	GROUP 1	80.0 (148.2)	30.0	-2.31	0.03*
	GROUP 2	156.2 (103.6)	135.0		

Mean duration of involuntary movements in days is in group 1 and group 2 were 80 and 156.which shows significantly high in group 2 with statistical significance between two groups as per duration of involuntary movements were concerned (p value ~0.025).

STIGMA

Table-4:Do you agree that there is stigma?

GROUPS	Yes N (%)	No N (%)	Chi Square value	P Value
GROUP 1	30 (100)	0 (0.0)	4.29	0.04*
GROUP 2	26 (86.7)	4 (13.3)		

Severity of stigma on scale of 1 to 10

Patients rating of severity of stigma on a likert scale of 1 to. Most patients from both the groups (~ 42%) rated stigma as 6. There was no statistical significant difference among the groups (p value 0.17).

Table-5:Situations where more stigmatized?

GROUPS	Public places N (%)	Home N (%)	Both N (%)	Chi Square value	P Value
GROUP 1	17 (56.7)	0 (0.0)	13 (43.3)	3.09	0.21
GROUP 2	11 (36.7)	1 (3.3)	18 (60.0)		

As shown in Table, both groups stigmatized highly at public places, at both home and public places compared to at home only. But no statistical significant difference (p value 0.21) was found.

Table-6:Comparision of stigma and coping

GROUPS	Always N (%)	Sometimes N (%)	Never N (%)	Chi Square value	P Value
1. WORRIED ABOUT TREATED LESS?					
GROUP 1	9 (30.0)	20 (66.7)	1 (3.3)		
GROUP 2	5 (16.7)	21 (70.0)	4 (13.3)	3.00	0.23
2. TREATED FAIRLY AT YOUR WORK PLACE?					
GROUP 1	3 (10.0)	20 (66.7)	7 (23.3)		
GROUP 2	5 (16.7)	22 (73.3)	3 (10.0)	2.20	0.33
3. HEARD ANY NEGATIVE COMMENTS?					
GROUP 1	0 (0.0)	25 (83.3)	5 (16.7)		
GROUP 2	1 (3.3)	25 (83.3)	4 (13.3)	1.10	0.57
4. AVOIDED PUBLIC AND SOCIAL INTERACTIONS?					
GROUP 1	5(16.7)	25(83.3)	0(0.0)		
GROUP 2	5(16.7)	21(70.0)	4(13.3)	4.35	0.11
5. KNOWLEDGE ABOUT ILLNESS WILL HELP IN REDUCING STIGMA?					
GROUP 1	8(26.7)	22(73.0)	0(0.0)		
GROUP 2	6(23.1)	20(76.9)	0(0.0)	0.10	0.76
6. MEDICATION TO REDUCE MOVEMENTS WILL REDUCE STIGMA?					
GROUP 1	25(83.3)	5(16.7)	0(0.0)		
GROUP 2	17(65.4)	8(30.8)	1(3.8)	2.95	0.23
7. SUPPORT FROM FAMILY AND FRIENDS WILL REDUCE STIGMA?					
GROUP 1	13(43.3)	17(56.7)	0(0.0)		
GROUP 2	1(3.8)	25(96.2)	0(0.0)	11.60	0.001**

Table-7:Comparision of components of aims in group 1 & 2

	Group	Mean (S.D.)	Chi square	P value
Facial and oral movements	GROUP 1	7.93 (4.30)		
	GROUP 2	4.30 (4.00)	3.40	0.001**
Extremity movements	GROUP 1	1.70 (2.23)		
	GROUP 2	1.50 (1.93)	3.72	0.71
Trunk movements	GROUP 1	1.30 (1.44)		
	GROUP 2	0.83 (1.32)	1.31	0.20
Global judgements	GROUP 1	8.30 (1.71)		
	GROUP 2	8.27 (2.18)	0.07	0.95
AIMS total score	GROUP 1	19.43 (5.88)		
	GROUP 2	15.00 (5.23)	3.10	0.005**

High mean AIMS total score in Group 1 compared to Group 2 with statistically highly significant (p value 0.003).

Table-8:Spearman rho correlations of 5 dimensions

		AIMS score	DAS score	RSES score	Severity of stigma	Duration of movement
AIMS score	r	1.000	.438**	-.364**	.421**	-.514**
	p	.	.001	.004	.001	.001
DAS score	r	.438**	1.000	-.792**	.681**	-.465**
	p	.001	.	.001	.001	.001
RSES score	r	-.364**	-.792**	1.000	-.714**	.488**
	p	.004	.001	.	.001	.001
Severity of stigma	r	.421**	.681**	-.714**	1.000	-.488**
	p	.001	.001	.001	.	.001
Duration of movement	r	-.514**	-.465**	.488**	-.488**	1.000
	p	.001	.001	.001	.001	.

AIMS scores have strong positive linear relationship with scores of DAS and severity of stigma with p value 0.001 for all. But has negative linear relationship with RSES scores (p=0.004) and duration of involuntary movement (p= 0.001).DAS scores has strong positive linear relationship with scores of AIMS and severity of stigma .Negative linear relationship with scores of RSES and duration of involuntary movement with p value 0.001 for all scores.

RSES scores has strong positive linear relationship with duration of involuntary movement (0.49). Negative linear relationship with scores of AIMS (p=0.004), DAS and severity of stigma with p value 0.001 for all other scores.

Duration of involuntary movement has strong positive linear relationship with scores RSES. Negative linear relationship with scores of AIMS, DAS and severity of stigma with p value of 0.001 for all.

Severity of stigma has strong positive linear relationship with scores AIMS and DAS. Negative linear relationship with scores RSES and Duration of involuntary movement with p value of 0.001 for all items.

DISCUSSION

- Most of patients with involuntary movements belong to middle class socio-economic status, were illiterates or had primary school education, were semi-skilled workers by occupation and were mostly hailing from rural areas.
- High proportion of patients (70%, N=42) from both the Groups were married and were living with their spouse.
- Patients from Group 1 having diagnoses in percentages are Schizophrenia (53%, N=16), Bipolar affective disorder (BPAD ~ 33%, N=10) and Psychosis NOS (13%, N=4).
- Patients from Group 2 having diagnoses in percentages are Parkinson`s disease (PD ~ 50%, N=15), followed by others (20%, N=6), Tourette`s disease (10%, N=3), Cerebrovascular accident (CVA ~10%, N=3), Huntington's disease (HD ~ 7%, N=2) and Rheumatic disease (RD ~3%, N=1).
- Tremor consists of major involuntary movement in Group 1 and 2 (40 and 50%, N=12 and15 respectively), with overall of 45% (N=27). Patients in Group 1 having involuntary movements other than tremor were Dystonia (30%, N=9), Tardive Dyskinesia (~17%, N=5) and Akathisia (~13%, N=4). Patients in Group 2 having Chorea (20%, N=6), Tics (~13%, N=4), Athetosis (~7%, N=2).
- Duration of involuntary movements was higher in Group 2 compared to Group 1.
- Majority of patients 93% (N=56) agreed that there was stigma to involuntary movements and 77% (N=46) rated severity of stigma on a scale of 1 to 10 as scores between 5 to 7, and there was no difference between two Groups .
- About 52% (N=31) stigmatized at both home and public places, and about 47% (N=28) stigmatized only at public place.
- About 67% in Group 1 and 70% in Group 2 worried about that they were sometimes treated less.
- About 67% in Group 1 and 73% in Group 2 patients said that they were not treated fairly sometimes at their work place.
- 83% in both Groups heard negative comments sometimes about involuntary movements or persons with involuntary movements.
- About 83% in Group 1 and about 70% - Group 2 at least sometimes avoided public and social interactions.
- About 73% in Group1 and 79% in Group 2 said that sometimes knowledge about illness will help in reducing stigma.
- About 83% in Group 1 and 65% Group 2 felt that medication to reduce involuntary movements will always reduce stigma.
- About 43% in Group 1 accepted that support from family and friends will always reduce stigma as a coping, but only ~4% accepted that support from family and friends will always reduce stigma, with statistically significant difference between two Groups, suggesting that patients in Group1, who had involuntary movements due to psychotropic medication along with mental disorders seeking more support from family and friends.
- All above findings were in this study were correlating with other studies, among them were study of Social stigmatization in patients with cranial and cervical dystonia by Rinnerthaler M *et al.* [3]**,** study of Chorea and Stigma in Huntington's Disease by LaVonne Goodman M.D [4]**,** study by Davies *et al.* [5], Sandor *et al.* [6]**,** Schrag *et al.* [7]**,** Moore *et al.* [8]

ROSENBERG SELF ESTEEM SCALE

- In this study mean scores in Rosenberg self-esteem scale in both Groups were 13.00, scores less than 15 suggestive of that patients with involuntary movements of two Groups were with low self-esteem because of their involuntary movements, but no significant difference between two Groups.

- The study findings were correlating with study of Social stigmatization in patients with cranial and cervical dystonia by Rinnerthaler M *et al.* [3]**.**

DERRIFORD APPEARANCE SCALE

- In present study shown that mean Derriford appearance scale score of Group 1 is 61 and Group 2 is 57. High scores in both suggestive of having problem with self-consciousness about appearance regarding their involuntary movements. Both Groups fall into moderate problem category in scale of 0 to 96. But there was no significant difference between two Groups regarding appearance.
- These study findings were correlates with studies by Ruetsch , Viala, Bardou, Martin P, Vacheron MN (2005)[9].

ABNORMAL INVOLUNTARY MOVEMENT SCALE

In the present study mean Abnormal involuntary movement scale scores of Group 1 and 2 are 19.4 and 15.0. Patients of both Groups had severity of involuntary movements in mild category; however mean score was high in Group 1 than Group 2 with highly significant difference between both Groups. Thus involuntary movements were severe in patients with involuntary movements due to psychotropic medication, mainly due to acute psychotropic induced involuntary movements like dystonia; akathisia and tremor were severe in intensity. And also mean score of facial and oral movements in AIMS is high in group 1 (7.93) than group 2 (4.30) which is highly significant. This was mainly due involuntary movements in group 1 like Dystonia affects predominantly facial and oral areas.

AIMS scores has strong positive linear relationship with scores of severity of stigma, as with increasing AIMS scores also increases scores of DAS and increases severity of stigma. But has negative linear relationship with RSES and duration of involuntary movement, so with increasing AIMS scores RSES scores decreases, AIMS scores were high in patients who were having less duration of involuntary movements. With increasing severity of involuntary movements patients were with more psychological disturbances, problems about their appearance and low self-esteem.

The study findings were in concordance with study by Davis *et al.* [5] where they found that with increasing severity of involuntary movements there was more stigmatization. Also correlates with study by Schrag [7] where more severe motor complications occur also correlates with stigma levels. This also supported by Rinnerthaler M *et al***.** [3] that patients were rated as less accountable for their actions, less likeable, less trustworthy, less attractive, less self-confident, more odd and different, more reserved, and more piteous

Severity of stigma has strong positive linear relationship with scores AIMS, DAS. Negative linear relationships are noted with scores RSES and Duration of involuntary movement. Where severity of stigma to involuntary movements was high ,patients have been with psychological problems, severity of involuntary movements were more, had problems with their appearance, they were dependant, their functioning less and they get problems to adjust to work and social situations.

This study findings were correlating with studies by Link & Phelan [10]**,** Weiss & Ramakrishna [11] that stigma has indirect but strongly negative implications for public health efforts to combat the diseases concerned. Both personal effects and negative public health impact are surprisingly similar for a wide range of chronic stigmatized conditions.

CONCLUSION

- The patients with involuntary movements were discriminated, faced criticism, avoided social situations and public places, with low self-esteem, had problems with their appearance.
- There was no difference among the two Groups regarding stigma ,both Groups faced same amount of stigma but patients of involuntary movements due to psychotropic medication (Group 1) seeking more support from family and friends.
- Both groups scored less in Rosenberg self-esteem scale which was suggestive of low self-esteem in both the Groups.
- In Derriford appearance scale, Group 1 scored 61 and Group 2 also scored high which suggested that both the groups had problem with self-consciousness about appearance.
- In Abnormal involuntary movement scale, patients of both Groups had severity of involuntary movements in mild category, however score was high in Group 1 than Group 2 and score of facial and oral movements in AIMS is high in Group 1 than Group 2.

Severity of involuntary movements associated with severe stigma, psychological disturbances, and problems about their appearance and low self-esteem.

LIMITATIONS OF THE STUDY

- Small sample size.
- This was a cross sectional study

- There was no standardization for stigma questionnaire.

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