



## **Full Length Research Article**

### **STIGMA ASSOCIATED WITH ELECTROCONVULSIVE THERAPY AMONG PATIENTS WHO RECEIVED ECT**

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#### **ABSTRACT**

The purpose of this study was to assess the stigma associated with ECT among patients at Department of Psychiatry, Christian Medical College, Vellore. A sample of 50 was selected using consecutive sampling technique. Data were collected by interviewing the subjects with Stigma assessment scale. The mean age of patient was 30.42 years Majority of the population still holds ECT as a stigmatizing treatment option. The findings of the study demonstrate the need for adequate psycho education to the subjects in reducing stigma and could be utilized in clinical areas by nurses in improving the effective evidence based care to patients undergoing ECT.

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#### **INTRODUCTION**

Mental illness stigma is a matter of great concern to mental health advocates. Negative responses to people who have been identified as having a mental illness are seen as a major obstacle to recovery, limiting opportunities and undermining self-esteem (Fink & Tasman, 1992). Electroconvulsive therapy (ECT) remains one of the most controversial treatments for psychological disorders and continues to be the subject of impassioned debate among various fractions of society, within both the professional and lay communities (Townsend, 2007). Stigma leads to negative stereotyping and to discriminatory behaviour towards people who underwent ECT. The world celebrated 73 years of ECT recently. Whilst ECT has stood the test of time for more than seven decades, stigma remains one of the main issues that need to be addressed. Though an effective treatment, it is often misunderstood and maligned not only by the lay public but by psychiatrists as well. The stigma of ECT didn't just happen "It came about because of the way it was administered in the past." (Hageseth, 2006). When patients mention that they have had ECT, they are often viewed as a "two-headed" freak (Kivler, 1999). The language used to describe the ECT is often clothed in ridicule. The term "shock therapy" conjure up the image of pain which further stigmatizes this treatment (Stuart, 2001).

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Why should a therapy that has a proven effectiveness, remain cloaked in stigma? (Kivler, 1999). The controversy that exists over the relevance of ECT in contemporary psychiatric care often excludes the opinion of patients. Optimizing ECT service delivery must include the perspectives and input of service users. Whatever the causes, self report and experimental analogs are no substitute for information about real life experiences. To truly understand and appreciate what stigma is and how it affects people who underwent ECT, we have to hear from the ones who face that stigma on a daily basis. They can best inform us- from their own personal experience and in their own words – what stigma is, what it does, and how it is conveyed. There is a paucity of studies in India that assess the patient's and primary care giver's perception of stigma associated with ECT. Given that ECT is a commonly used treatment modality in the country, this study addresses an important issue.

#### **MATERIALS AND METHODS**

Descriptive design was employed for the study. Study participants were the patients who were recruited from the Department of Psychiatry, Christian Medical College, Vellore. A sample of 50 consecutive patients were selected for the study. Data were collected from patients using Consumer Experiences of Stigma Questionnaire (CESQ) which was modified by the investigator for the study. This scale (Wahl,

1999 & Dickerson *et al.*, 2002) has two sections covering the stigma(9items) and discrimination(12items) experiences. A five point Likert scale was used. Each item has an option for entering 'does not apply' for individuals for whom the question is not relevant.

## OBSERVATIONS AND RESULTS

The descriptive analysis of the socio-demographic and clinical variables revealed that the mean age of patients was 30.42 years. Majority (60.0%) of the patients were males.

Majority of patients were from a rural background and were single. Majority of the study participants were undergoing ECT for a diagnosis of schizophrenia; the majority had been having an illness for more than two years. Nearly half (52%) of the patients had their ECT during the last 6-12 months.

**Stigma Section:** Responses to the stigma items of the CESQ are found in Table 1. The majority of the patients reported experiencing stigma related to ECT in some way or the other. Many patients were concerned about others perceiving them negatively as a result of having undergone ECT.

**Table 1. Stigma related to ECT among patients assessed with the Consumer experience of Stigma Questionnaire (CESQ)**

Sl no:	Stigma items	Never n (%)	Seldom n(%)	Some times n(%)	Often n(%)	Very often n(%)
1	Have you worried that others will view you unfavourably because you have received or receiving Electro convulsive therapy?	15 (30%)	13 (26%)	8 (16%)	10 (20%)	4 (8%)
2	Have you been in situations where you heard others say unfavourable or offensive things about persons receiving Electro convulsive therapy?	20 (40%)	17 (34%)	6 (12%)	7 (14%)	0
3	Have you seen or read things in the mass media (eg: television, movies, books) about persons receiving Electroconvulsive therapy which you found hurtful or offensive?	17 (34%)	17 (34%)	12 (24%)	3 (6%)	1 (2%)
4	Have you avoided telling others outside of your immediate family that you have received or receiving Electro convulsive therapy?	7 (14%)	7 (14%)	9 (18%)	15 (30%)	12 (24%)
5	Have you been treated as less competent by others when they learned you had received or receiving Electro convulsive therapy?	7 (14%)	22 (44%)	11 (22%)	10 (20%)	0
6	Have you been shunned or avoided by others when they learned that you had received or receiving Electro convulsive therapy?	12 (24%)	17 (34%)	12 (24%)	9 (18%)	0
7	Have you been advised to lower your expectations in life because you had received or receiving Electro convulsive therapy?	11 (22%)	26 (52%)	11 (22%)	2 (4%)	0
8	Have you been treated fairly by others who knew you received or receiving Electro convulsive therapy?	6 (12%)	25 (50%)	16 (32%)	3 (6%)	0
9	Were friends understanding and supportive after learning that you received or receiving Electro convulsive therapy?	6 (12%)	15 (30%)	17 (34%)	10 (20%)	2 (4%)

\* Not all respondents answered all questions; therefore the number of responses does not total 50 and the percentages do not total to 100 percent.

**Table 2. Discrimination related to ECT among patients assessed with the Consumer experience of Stigma Questionnaire (CESQ)**

Sl no:	Discriminationitems	NEVER n (%)	SELDO M n (%)	SOME TIMES n (%)	OFTEN n (%)	VERY OFTEN n (%)
10	Have you been turned down for a job for which you were qualified when it was learned that you had received or receiving Electro convulsive therapy? *	15 (30%)	5 (10%)	4 (8%)	7 (14%)	3 (6%)
11	Have you been denied Electro convulsive therapy because your finances was insufficient for you to pay the cost of treatment?	34 (68%)	14 (28%)	2 (4%)	0	0
12	Have you had difficulty renting an apartment or finding other housing when your psychiatric disorder and Electro convulsive therapy was known? *	19 (38%)	3 (6%)	1 (2%)	0	0
13	Have you been denied educational opportunities (for eg: acceptance into schools for education programs) when it was learned that you had received or receiving Electro convulsive therapy?*	11 (22%)	5 (10%)	5 (10%)	4 (8%)	7 (14%)
14	Have you been excluded from volunteer or social activities outside the mental health field when it was known that you had received or receiving Electro convulsive therapy?	27 (54%)	20 (40%)	3 (6%)	0	0
15	Have you been excluded from volunteer or social activities within the mental health field when it was known that you had received or receiving Electro convulsive therapy?	25 (50%)	17 (34%)	8 (16%)	0	0
16	Have co-workers or supervisors at work were supportive and accommodating when they learned you had received or receiving Electro convulsive therapy? *	5 (10%)	16 (32%)	15 (30%)	5 (10%)	2 (4%)
17	Have you been turned down for health insurance coverage/financial assistance on the basis of your mental health treatment history?	38 (76%)	9 (18%)	3 (6%)	0	0
18	Have you been denied a passport, driver's license, ration card or other kinds of permits when it was learned you had received or receiving Electro convulsive therapy? *	36 (72%)	4 (8%)	0	0	0
19	Have you had the fact that you received or receiving Electro convulsive therapy used against you in legal proceedings (such as child custody or divorce disputes)?	48 (96%)	1 (2%)	0	1 (2%)	0
20	Have you been treated with kindness and sympathy by law officers, police men etc when they learned that you had received or receiving Electro convulsive therapy? *	23 (46%)	17 (34%)	2 (4%)	0	0
21	Have you avoided indicating on written applications (for jobs, licenses, housing, school, etc) that you had received or receiving Electro convulsive therapy for fear that information would be used against you? *	24 (48%)	5 (10%)	8 (16%)	0	4 (8%)

\* Not all respondents answered all questions; therefore the number of responses does not total 50 and the percentages do not total to 100 percent.

Most individuals reported having avoided telling others about having undergone ECT. Several felt that they had been treated unfairly as a result of others knowing that they have had ECT.

**Discrimination Section:** Participants' responses to the discrimination items of the CESQ are provided in Table 2. There was a relatively low frequency of reported experiences of actual discrimination in other areas such as having been turned down for volunteer activities, denied health insurance or passport, ration card or driver's license because of having received ECT. About 14 % reported of having being denied educational opportunities because of received ECT.

## DISCUSSION

The majority of the patients reported experiencing stigma related to ECT in some way or the other. Many patients were concerned about others perceiving them negatively as a result of having undergone ECT. Most individuals reported having avoided telling others about having undergone ECT. Several felt that they had been treated unfairly as a result of others knowing that they have had ECT. These findings suggest that feelings of alienation and devaluation by others are wide spread among persons in the sample. The results are consistent with the extent of negative attitudes that has been documented among the general public toward persons with serious mental illness (Nunnally, 1961; Rabkin, 1974). Similar responses to these items were found in the results of Dickerson (2002) on stigma related to mental illness. About half of the respondents endorsed having supportive and understanding friends in contrast to the findings of Roeloff *et al.*, (2003) who reported stigma related to mental illness to significantly affect friendships. Only a few respondents reported that they had been advised to lower their expectations in life because of having received Electro convulsive therapy.

While these findings are encouraging, it could also be related to the following factors:

- Those who experience significant stigma may have dropped out of treatment and therefore been unavailable for the study.
- Many patients may have become accustomed to the stigma and may not presently perceive it as a major problem.
- Schizophrenia with its chronic course, affective blunting and cognitive deficits may dull the patient's responses.

Also of interest were the responses to the item about accounts of ECT in the media. Some respondents in the current sample indicated that they found media accounts 'offensive' or 'hurtful' at least sometimes. Such a reaction could be due to any of many news reports or fictional stories involving mental illness and ECT. However few respondents made reference to recent news coverage of violent acts committed by persons with mental illness. Similar findings were reported by study done by Euba & Crugel (2009) in which negative depictions of ECT may contribute to the stigma of mental illness, by marginalizing this treatment and therefore those severely ill patients who receive it. Fear of being discriminated against was prevalent among many respondents while actual discriminatory experiences secondary to having received ECT were reported by many in the areas of employment and education. These findings are similar to those of Roeloff *et al.*,

(2003) who identified significant effects of stigma related to mental illness on employment. A lack of support from work colleagues was also reported by several individuals.

There was a relatively low frequency of reported experiences of actual discrimination in other areas such as having been turned down for volunteer activities, denied health insurance or passport, ration card or driver's license because of having received ECT. While other studies on stigma related to mental illness have indicated the existence of such problems, (Farina, 1998; Corrigan & Penn, 1999), the present sample consists of people mostly from a low socioeconomic background where these issues are less relevant. Given the lack of a social security net in our country, most patients' financial needs were met by their family members. Thus most responses mention that treatment was not denied because of lack of financial support from other insurances or agencies. Similarly, very few of the respondents indicated that they had problems in obtaining a house for rent because of their treatment history; this reflects the support provided by family. Many respondents reported not being treated with kindness and sympathy by law enforcement officials. These responses may reflect the adversarial interaction with law enforcement officials that subjects may have had in the process of illness or involuntary hospitalization. A similar pattern of responses to this item was found in the results of the National Alliance for the Mentally ill (NAMI) sample (1999). A small percent of patients mentioned that they would avoid writing in application forms about having been given ECT, suggesting their concerns about stigma.

## Limitations

- Given the complex nature of stigma, it is possible that the tools that were used in this study have only looked at certain issues and may not have fully captured all of the relevant aspects of stigma and discrimination related to ECT.
- Patient's response may vary on occasions because of people's tendency to give socially desirable response.
- It is possible that there is a subgroup of patients and care givers who felt extremely stigmatized because of received ECT and therefore did not return for follow-up to the hospital and is not part of the sample studied.

## Conclusions

A detailed understanding of the patient's perspectives of stigma related to ECT helps in understanding and managing patients with mental illness. The majority of the population still holds ECT as a stigmatizing treatment option. Education is an essential part of care and an effective method for improving the knowledge about the effectiveness of ECT and reducing the stigma related to it. These results could be utilized in clinical areas by nurses in improving the effective evidence based care to patients undergoing ECT.

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