Patients and Relatives' Perspectives about Electroconvulsive Therapy (ECT) In Khartoum, Sudan

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ABSTRAK

Kekurangan ilmu pengetahuan dan sikap acuh tidak acuh terhadap keperluan rawatan terapi elektrokonvulsif (ECT) mempengaruhi rawatan psikiatri dari segi morbiditi dan mortaliti. Terdapat sedikit kajian sistematik yang dilaporkan mendalami bidang ini. Kajian ini bertujuan untuk menilai pengetahuan, sikap dan kepatuhan dalam penggunaan ECT dari perspekstif pesakit dan ahli keluarga iaitu di Khartoum, Sudan. Kajian ini merupakan kajian pemerhatian berdasarkan hospital di mana 103 pesakit psikiatri dan ahli keluarga yang mendapatkan rawatan di Hospital Psikiatri Taha Basher and Eltigani Elmahi, Sudan pada 2016. Keduadua pesakit dan ahli keluarga ditemubual tentang pengetahuan dan sikap terhadap penggunaan ECT. Peratus skor dikira berdasarkan jawapan positif dengan mengira min daripada jawapan. Semua data dikira melalui soal-selidik secara 'pre-designed' dan seterusnya dianalisa secara statistik. Lelaki diwakili seramai 61 jaitu 59.2% di mana kumpulan pesakit adalah di antara 16-30 tahun. Skor keseluruhan terhadap penggunaan ECT pada para pesakit dan ahli keluarga adalah sebanyak 54.9%, dan 59.4%, masing-masing. Penerimaan penggunaan ECT sebagai perawatan dipersetujui sebanyak 43.7% oleh para pesakit dan melebihi 70% pesakit dan ahli keluarga percaya bahawa dengan memberi ECT untuk perawatan kes psikiatri. Para pakar psikiatri merupakan sumber utama informasi dilaporkan oleh pesakit (73.8%) dan ahli keluarga (67%). Para ahli keluarga yang terdiri dari lelaki menunjukkan sikap cenderung untuk mencadangkan perawatan ECT (p=0.004). Para pesakit dan ahli keluarga melaporkan pengetahuan dan sikap yang sederhana atau baik terhadap penggunaan ECT.

Kata kunci: elektrokonvulsif, perspekstif, pengetahuan

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ABSTRACT

Lack of knowledge and inappropriate attitude towards electroconvulsive therapy (ECT) treatment may affect the outcome of psychiatric's morbidity and mortality. However, less systematic studies have been done on this area. This study aimed to assess the patients' and relatives' perspectives, i.e. knowledge, attitude and compliance on ECT in Khartoum State, Sudan. This was an observational hospital-based study conducted among 103 psychiatric patients and their relatives respectively who visited the Taha Basher and Eltigani Elmahi psychiatric hospitals during 2016. Both the patients and their relative inquired about different criteria of knowledge and attitude towards ECT. The percentage of score was calculated based on their positive answers by selecting the most appropriate answer or by calculating the mean of many positive answers. All the data were collected through a pre-designed questionnaire, and further analyzed statistically. Male was represented 61 (59.2%) and the commonest age group of patients was 16-30 years. The overall score of knowledge towards ECT among patients and their relative was 54.9% and 59.4%, respectively. Acceptance on the use of ECT were agreed by 43.7% of patients and more than 70% of patients and their relatives believed giving ECT for emergency psychiatric cases. Psychiatrist was the most frequent source of information reported by both patients (73.8%) and relatives (67%). Male relatives showed significantly higher attitude of recommending ECT treatment (p=0.004) for other patients. Patients and their relatives were reported to have moderate and better knowledge and attitude towards the use of ECT, respectively.

Keywords: electroconvulsive therapy, knowledge, perspective

INTRODUCTION

Electroconvulsive therapy (ECT) is a physical therapy uses a small electrical current to yield a generalized cerebral epileptic effect or seizure under the influence of general anesthesia. ECT treatment is mainly indicated largely to alleviate severe depression. ECT is also recommended for patients with other psychiatric conditions, comprising of serious suicidal intent, bipolar disorder, schizophrenia, catatonia and schizoaffective disorder (Fink 2001).

ECT is one of the physical therapies

that has been used and has persisted Despite controversies until now. encircling its use, it still remains as one of the most efficacious interventions for many severe mental disorders (Dowman et al. 2005). Public stigma has been attached to the use of ECT (Dowman et al. 2005). Studies that have appraised the knowledge and attitude of patients with mental illness and who have received ECT and their relatives. had suggested that they were mostly gratified with their knowledge (Bauer et al. 2007). Attitudes have become more clear following the experience from

the therapy (Kellner 2013). Besides, the relatives who have been a part of the practice of ECT administrations were usually well informed and have more optimistic attitude toward ECT, than those who on no occasion had such involvement on ECT.

About 100,000 people in The United States and over one million worldwide receive ECT annually (Lisanby 2007). This number is clearly not well known and despite years of social, political, and judicial attacks and shortfalls, or poor acceptance by the public, ECT is still has role to play in the mainstay of psychiatry treatment. More studies focusing on the knowledge and attitude of the patients and their families would enlighten about the practice of ECT. Hence, the present study attempted to investigate the patients and relatives' perspectives (knowledge, attitudes and compliance) on ECT in Khartoum State, Sudan in 2016.

During the psychiatric practice at the psychiatric hospitals and clinics in Sudan, the treating team commonly receives an obvious negative reaction as the ECT was being offered/advised. It used to be a domain of argument, hesitancy and negotiation, which might reach to a degree of refusal and discontinuation of the treatment plan. This hesitant behavior was noted among patients who were receiving ECT for the first time, as well as among the group of patients who had previously or repeatedly received ECT.

It is hypothesized that people were lacking sound of knowledge and appropriate attitude towards ECT. Therefore, there is a need for thoroughly scientific evaluation in which could provide a baseline information about the overall perception on this, specifically in Sudan. This study tries to demonstrate the level of knowledge and attitude towards ECT which influences the patients and their relatives's decision toward ECT. By identifying the concept of ECT, it might ultimately come in favor of patients' health, relative's satisfaction and the overall community health and welfare.

This study aimed to assess the patients and relatives' perspectives (knowledge, attitude and compliance) on ECT in Khartoum State, Sudan in 2016. In specifically, we were interested in determining the knowledge, attitude and compliance of the patients and their relatives care givers toward ECT. Besides, this study also focuses to identify cues/factors that negatively affect the attitude towards ECT among the patients and relatives. Moreover, the acceptance of ECT among the patient and their relatives post-ECT sessions as well as the source of information about ECT were as well evaluated during this study.

MATERIALS AND METHODS

This was an observational descriptive cross-sectional hospital-based study. This study was conducted in two main public psychiatric hospitals in Khartoum state, Sudan: (i) Taha Basher psychiatric hospital and (ii) Eltigani Elmahi psychiatric hospital. Total bed capacity is 164 beds in total which receiving patients from all Sudan as well as receiving patients as emergencies and as outpatients for follow-up.

applied This study simple randomised technique by selecting the patient until a targeted sample size was achieved. Any patients (participants) who attend those hospitals to receive ECT and their relatives were recruited to the study. The inclusion criteria were: being Sudanese nationality, clinically stable at the time of assessment, all patients who attend the ECT and have completed the prescribed sessions and recovered. The relatives of the patients were required to be more than 18 years old, who have a decision authority in the ECT treatment for patients, and they were free from any major physical or psychiatric illnesses, as well as living with the patients and keenly involved in their treatment.

The exclusion criteria were: including patients with acute disturbance (acute intoxication with alcohol or drugs, acutely psychotic, organic brain disorder or mental retardation), patients less than 18 years, relatives with psychiatric or physical illness, which can affect the information concerning the patient's illness (e.g. Alzheimer dementia and illnesses related to memory deficit or confusion). The list of variables investigated during the study were including socio-demographic variables (sex, age, education), history of ECT, sessions number, knowledge (source of information) and attitude (comfort ability, acceptability to the procedure of the ECT).

The sample size was calculated based on the Variables of equation: $n=Z2PQ/d^2$; n= sample size, z=the normal standard deviation (e.g. 1.96 for 95% confidence level); p=the

rate of ECT in El-Tigani Al-Mahi and Taha Bashar Hospital (4% & 3%, respectively) (Estimated according to rate of attendance at 2 psychiatric Hospitals in Khartoum); q=the frequency of nonoccurrence of an event (1-P = 0.96 & 0.97, respectively);d=precision 0.05. The sample size was calculated based on the 13052 patients who attended El-Tigani Al-Mahi Psychiatric hospital during sixmonth period prior to the research in 2016, and 472 patients who received ECT during this study period.

Therefore, the sample size for patients from Eltigani Elmahi hospital was 59 patients (n=0.04 0.96 x (1.96)2(0.05)2).The sample size calculated for Taha Basher Psychiatric hospital was 44 patients which was calculated based on the total number of the attendee for the previous six months prior to the research in 2016 which was 9355 patients and the total 2016 of the patients who received ECT during this study period which was 230 per period, (n=0.03 0.97 x (1.96)2(0.05)2). Accordingly, sample size of the two hospitals was 103 patients and 103 relatives.

The data was collected by selfquestionnaires with administered close-ended questions under the direct observation of the researcher. This process was divided into two phases. The phase 1 of the study involved framing of the questionnaire. The items included in the questionnaire were drawn from two sources: (i) Freeman Kendell questionnaires and and scales that assess attitudes of diverse populations towards ECT. These guestionnaires were translated to the

Arabic language and then later it was adapted to the local language (Pretest questionnaire was applied before the final modification). (ii) Clinical experience of three psychiatrists based on the detailed interviews with both the patients and their relatives who were advised to receive ECT. The phase 2 involved administration of the questionnaire (interview questionnaire) to the study population.

Statistical Package for the Social Sciences (SPSS, vers. 17) was used for the statistical analysis. The researcher followed the subsequent steps during the construction of the study tool: reviewing of the previous studies about this topic in order to take advantage of them in the preparation of the data-collection tool (questionnaire), two parts had been included on the questionnaire. Based on the earlier studies, the items in the questionnaire were divided into two sections: Section I: It included background data of the participants of the study (i.e. personal data related to demographic characteristics): Section II: It included all variables relevant to the ECT.

The researcher adopted to quintet Likert scale (Likert Scale) for the evaluation and scoring of the data. Each degree "Likert" scale quintet weighted as follows: agree (3), don't know, and (2), don't agree (1). The questionnaire was evaluated through a pilot study by assessing its reliability and validity. The knowledge and attitude were evaluated and scored as follows: (i) Good (having a score > 70%), (ii) average (having a score 50-69%) and (iii) poor (having a score < 50%).

The study was approved by the

research and Ethical Committee of the Sudan Medical Specialization Board. Permission was taken from the Ministry of Health, Khartoum state. Taha Basher, Eltigani Elmahi. Written informed consent was obtained from all the participants.

RESULTS

The current study involved 206 participants in which 103 patients were diagnosed clinically with different psychiatric illnesses and 103 relatives were attended the ECT sessions with the patients in the two public psychiatric hospitals (Eltigani Elmahi and Taha Baasher Psychiatric Hospitals). Socio-Demographic characteristics of ECT patients and their relatives were shown in Table 1.

Overall Score of Knowledge

The overall score of knowledge towards ECT for both the patients and relatives were 54.9% and 59.4%, respectively. Meanwhile, the patients' and relatives' positive attitude scores were 59.1% and 70.7%, respectively. The patients' have knowledge about the site of electric shock in body (97.1%), requiring investigations ECT session (94.2%), concept towards ECT (77.9%), the side effects of ECT (72.8%) and number of weekly sessions scored (71.8%). Besides, they have been least scored with regard to necessity of patient's consent (26.2%) and the length of sessions (1%).

Knowledge towards the Concept of the ECT

Age group (yrs.)	Patients		Relatives	
	Frequency	Percent		
Age group (yrs.)				
18-30	55	53.4	28	27.2
31-45	34	33.0	50	48.5
46-60	11	10.7	20	19.4
>60	3	2.9	5	4.9
Educational level				
Male	61	59.2	65	63.1
Female	42	40.8	38	36.9
Educational level				
Uneducated	13	12.6	22	21.4
Khalwa	5	4.9	8	7.8
Primary school	33	32.0	31	30.1
Secondary school	33	32.0	25	24.3
University level	19	18.4	16	15.5
Postgraduate	0	0.0	1	1.0
Occupation				
Employee	33	32	19	18.4
Housewife	22	21.4	20	194
Students	16	15.5	31	30.1
Idle	15	14.6	6	5.8
Daily workers	7	6.8	13	12.6
Retired	5	4.9	2	1.9
Merchants	3	2.9	1	2.9
Free business	2	1.9	10	9.7
Monthly household inc	come			
Less than 100	17	16.5	14	13.6
1000-2500	78	75.7	79	76.7
3000-4500	7	6.8	9	8.7
5000-6500	1	1.0	1	1.0
Residence				
Rural	44	42.7	41	39.8
Urban	59	57.3	62	60.2

Table 1: Characteristics of the ECT patients and their relatives at the psychiatric Hospital in Khartoum

The knowledge about the concept of ECT was assessed and scored based on the percentage of positive answers. The patients scored 90.3% and 88.3% on knowledge regarding the treatment given extra electrical power and cure using the electricity, respectively. Besides, they also scored 48.5% on the knowledge about continuity of therapeutic effect of electric shock temporary. The relatives have scored 96.1% and 95.1% on the knowledge of the cure using the electricity and regarding considering ECT as a punishment meant for irritable and violent patients, respectively.

The patients and relatives scored 74.8% and 78.6% regarding the inquiry about whether they consider electric shock can be given during psychiatric emergency cases, respectively. In regard to the possibility of giving shock to pregnant women, they have scored 4.9% and 3.9%, respectively. Denying the negative impact of ECT on treating the psychiatric patients by patients and relatives were reported to score 92.2% and 94.2%, respectively.

The patients showed positive response regarding inquiry about frequent development epilepsy by ECT treatment (94.2%), danger of death during the session (92.2%) and permanent damage to the brain cells (90.3%). Moreover, the relatives had scored 99.02%, 90.3% and 96.1% on the same criteria, respectively. Patients inquiring about the high risk of ECT, considering ECT as harsh way procedure and considering ECT as an illegal method of treatment showed a positive knowledge score of 94.2%, 95.1% and 92.3%, respectively.

Among co-patients, the positive score of knowledge towards the existence of risk ECT therapy, considering ECT as inhumane procedure, outdated, harsh method of treatment and the worst treatment options was 97.1, 97.1%, 97.4% 97.1% and 97.1%, respectively.

The source of knowledge about ECT among patients, psychiatrist, and personal experience for ECT, experience of ECT from friends or relatives and general oral information were reported with a score of 75.7%, 73.8%, 3.9% and 26.2%, respectively. Among the co-patients, specialized scientific publications, doctors in other specialties, personal experience for ECT and experience of ECT from friends or relatives were reported scoring by 83.5%, 67%, 67% and 35%, respectively.

There was no significant association (p=0.198) on the cross-tabulation between the use of anesthetic materials during an electric shock and the gender. However, males (56.2%) showed higher knowledge as compared to the females (43.8%). Moreover, knowledge about the investigation also showed no significant association with the age (p=0.697). Cross-tabulation between the need to take the patient's permission before electroconvulsive therapy and gender revealed a significant association (p=0.05). Male relatives showed significantly higher attitude of recommending ECT treatment for other patients (p=0.004).

DISCUSSION

The current advancement, enables ECT by using electric currents, given

in a controlled setting to achieve the most benefit with the possible risks. The approach to ECT is still attached to stigma in many communities, including public and health providers, although it is much safer to be practiced in recent days. The current study attempted to assess the patients and relatives' perspectives about electroconvulsive therapy at Taha Basher and Eltigani Elmahi psychiatric hospitals.

Perception of patients towards the ECT was assessed by estimating the level of knowledge and attitude in which they showed moderate knowledge and attitude towards ECT (54.9% and 59.1%, respectively).

They showed higher knowledge regarding the elements on routinely done: site of electric shock in body (97.1%), investigations required before ECT session (94.2%), mean of carrying ECT session (90.3%), weekly and total number of sessions (71.8% and 66%, respectively). But their knowledge was poor regarding basic criteria of knowledge towards ECT: therapeutic effect of ECT (27.8%), indications for ECT (42.3%) and health provider who is entrusted ECT (28.2%). Their least knowledge was found regarding length of sessions (device conduction) which was identified by only one patient (1.0%). This might suggest that, patients have insufficient knowledge towards all the aspects of ECT procedure; they were more knowledgeable towards what they have experienced (e.g. number of sessions, the need for investigations prior to the procedure and the type of machine and current used) but have ignored knowledge on indications, therapeutic effects, length of sessions and health provider who was entrusted ECT. This is in accordance with the previous study (Rajagopal et al. 2012). This study has also indicated areas in which the practice of ECT can be improvised in order to enhance the satisfaction among patients and relatives (Rajagopal et al. 2012). The same study also reported similar findings showing that, fewer patients had knowledge about the more rigorous aspects of the procedure, the consent process, mechanism, usual reasons for treatments/indications and side effects.

These findings were also compatible with the dominant trends in the literature, which proposes that the patients who receive ECT regularly know little about what it precisely comprises these intervention for (Rajagopal et al. 2012). Few studies from India had earlier reported that a high proportion of patients (>65%) had adequate knowledge of ECT (Chavan et al. 2006). However, on closer scrutiny, the percentage of patients with full understanding of the treatment, predominantly about the placement of electrodes, period of electrical stimulus or fits, adverse effects and indications, were normally much lower (6-17%) in these studies. These factors have affected the overall attitude towards the ECT acceptance. The main source of information about ECT among patients was the psychiatrists' explanation prior to the procedure (75.7%), followed by patients' own experience reaching to the same level (73.8%). At the same time, patients as public tend to gain their knowledge verbally from their community (experience of friends and

relatives and from public.

Relatives rely on patient's personal experience as one of their main sources of information (67%). Besides, they also have reported other different sources, including specialised scientific publications (83.5%) and doctors in other specialties (67%). Many cues or indications that expected to pose negative effect on the attitude towards ECT were mostly being reflected in the outcome of the treatment. It is shown that, therapeutic effects can create such scenario, following a poor knowledge towards the indications of ECT. Moreover, mass media (TV, magazine), social media (the Internet, Facebook), health providers rather than the psychiatrists play a diminished role in raising the awareness/ public awareness on ECT. In addition, low socio-economic status (e.g. lowincome and limited education) was super added to the previous cues/ indications.

The negative role of media and community had been discussed in previous literature; Dan et al. (2014) found that, patients obtained information, mostly from media (44%), doctors (23%), and from personal experiences (13%). On the other hand, relatives obtained information almost equally from media (26%), doctors (27%), and experience of friends or relatives (28%).

Payne and Prudic (2009) in New York had discussed about passive attitude of other clinicians towards ECT, in which they claimed to routinely hear responses from other clinicians such as "Oh, do they still do that?" and "I thought that was outlawed." Besides, Andrews and Hasking (2004) hypothesised that the life-threatening nature of ECT descriptions in the media, and the arts exerts an egregious effect on the public opinions. Besides, Payne and Prudic (2009) also reported that, an educational campaign regarding ECT intended at both the medical community and the lay public could help to offset its negative image; however, such campaign has never been implemented.

Mostly, knowledge and attitude of relatives impact the patient's response to the treatment. In current study, relatives showed slightly better knowledge and attitude compared to the patients (59.4% and 70.7%, respectively). Together with the patients, the relatives able to gain high knowledge about elements routinely done: site of electric shock in body (99%), investigations required before ECT session (96.1%), mean of carrying ECT session (89.3%) and weekly and total number of sessions (85.4% for each). Besides, they had fair knowledge (68.3%) as they were inquired about some aspects on ECT conception (e.g. temporary effect of ECT, the procedure is cure using electricity). On the other hand, they showed moderate knowledge towards therapeutic effects of ECT (50.2%) and showed poor knowledge towards side effects of ECT (29.1%).

In similar to the current study, Dan et al. (2014) also showed that, relatives were somewhat better informed and more positive about ECT than the patients. However, Chavan et al. (2006) reported a similar level of knowledge and attitude between both the patients and relatives (56.2% and 57.3%, respectively).

Most of the item on knowledge about elements routinely done in the current study were slightly higher but with few differences compared to the previous finding (Rajagopal et al. 2012). The latter study has reviewed that, knowledge about the number of sessions per week and total courses were 84.4% and 64.9%, respectively. Moreover, their knowledge about the investigations, mean of carrying ECT sessions and site of electrode score were 74.03%, 49.4% and 87%, respectively. The same study reported similar level of knowledge about the concept and side effects of ECT (70.1% and 57.1%). but they showed higher knowledge towards the therapeutic effect of ECT (94.8%). Relatives were having poor knowledge regarding identifying the length of session, indications for ECT and necessity of patients' consent with the score of 8.7%, 43.7% and 35%, respectively.

In the study by Rajagopal et al. (2012), the relatives showed more knowledge towards length of session (55.8%) and necessity of consenting the patients (64.3%). Besides, knowledge regarding indication of ECT showed controversial results in which the score was high in identifying that ECT is used to treat acute psychiatric conditions not responding to drugs (81.8%) but showed a diminished knowledge in the possibility of using ECT in pregnant women, i.e. 6.5% (Dan et al. 2014).

A total of 31% of female gender showed a significantly higher agreement for consenting patients prior to ECT procedures compared to the males, i.e. 23%. Meanwhile a total of 49.2% male showed a significantly higher refusal for obtaining permission from patients compared to the females (26.2%), at p=0.05. Recommending ECT for other patients was found significantly more preferred by males compared to the females (p=0.004, 86.2% vs. 57.9%, respectively).

CONCLUSION

were reported to have Patients moderate knowledge and attitude towards ECT, while their relatives showed better knowledge and attitude compared to the patients. In regards to the indications of ECT, both patients and relatives had a good knowledge regarding giving ECT to psychiatric emergency cases. In addition, the latter group also had good knowledge on giving ECT for delayed cases. Meanwhile, they both showed poor knowledge about giving ECT for nonresponsive cases, older persons and pregnant women. ECT was more frequently, recommended as a line of treatment for other patients by relatives compared to the patients. The information about ECT was mostly assessed from psychiatrists, while the mass media was diminished.

RECOMMENDATION

Even though ECT was long back introduced in Sudan, it still has not reached the updated international guidelines and requirements. According to the current findings, accessibility of ECT as an essential line of treatment in other states of Sudan could decrease the burden of patients, relatives and health centres in Khartoum. Raising the knowledge and positive attitude of the communities towards ECT in specific areas (effectiveness of treatment, areas of providing the service) could lead to a better treatment outcome. Medical professionals in psychiatric field and other specialties should impart proper information about the ECT in order to increase the acceptance rate of this treatment among the patients and relatives. Besides, more efforts should also be taken by the representative of mass media (TV, the Internet, social media) to educate the patients with psychiatric disorders and their relatives about ECT. This can be accomplished by organizing educational TV programs and seminars, leaflets and articles in magazines.

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