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EPILEPTIC PATIENTS' & THEIR RELATIVES' PERSPECTIVES OF EPILEPSY

BY

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Abstract

Epilepsy is usually associated with mystery, prejudican and hostility. It is presented with different psychosocial implications that affect patient's prognosis.

This study attempts to determine epileptic patients' and their relatives' perspectives of epilepsy.

The main results yielded by this study are that patients feel less stigmatized than their relatives, relatives tried other means than medical treatment and that epileptics in general are still believed to be possessed. Study also revealed some of the native practices during seizure.

Introduction

Prejudice and hostility, toward persons with epilepsy are commonly encountered reactions in the community. These reactions stem from the fact that epilepsy is one of the diseases associated with mystery, ignorance and misinformation. In addition, epilepsy was known as the "sacred or Holy disease" (Shaheen and Rackawy, 1965).

Epileptic patients were believed to be affected by the Devil and were treated with special religious rituals (Okasha, 1980). These beliefs have affected patients and their relatives reaction towards the disease and the treatment methods. In addition special social and psychological problems are encountered by epileptic patients which in turn affect patient's prognosis.

Several studies have been carried out on the psychosocial implications of epilepsy (Hauck, 1972; Rodin, 1972; Remschmidth, 1973; Juul and Jensen, 1974; Danesi, 1982), others emphasised the psychosocial problems presented by adult epileptic patients across the same country Dodrill et al.(1984), and cross culturally, Dordill et al. (1984). Several investigators studied the community attitudes toward epilepsy ,Vinson(1975), Caveness and Allup, (1980). Along the same line, few researchers devoted their work to the evaluation of how patients see their own condition,Ryan et al.(1980), Beran and Read (1980), Danesi (1984).

The present study aims at determining how epileptic patients and their relatives see their own condition, their views and beliefs about epilepsy as well as their perceived views of others towards persons with epilepsy.

Material and Methods

- This study was carried out at the neurological out patient departments of the Main University Hospital and Ras El Tin Hospital.
- The total sample consisted of 100 subjects
  - 50 epileptic patients.
  - 50 accompanying relatives.
- The instrument for this study was a questionnaire developed by the researchers after a thorough review of the literature. It is composed of two main parts. The first part deals with personal and social data. The second part elicits information related to the subjects view about their own conditions, views and believes about epilepsy as well as their perceived views of others towards a person with epilepsy.
- Every patient and/or relative was interviewed individually. The time of the interview extended to around one hour for each interviewed.

- The period of data collection was six months.

Results

- As regards the patients' and relatives primary search for treatment, 60% of patients went to general practitioner and 10% went to neurologist. The rest of the sample went to healers or they did not do any thing after the initial seisure.In relation to relatives figure were 70 and 10 respectively. Table I. No significant difference between patients and their relatives was found in this respect.
- As for the secondary search for treatment line, the patients and their family follow three main lines of treatment. Medical treatment (70-48%), religious practices (12-16%) and traditional practices (18-36%).
  These traditional practices include magic with craft, Zaar, Talisman's services and endogenous beliefs. There was a significant difference between patients and relatives responses as regards medical treatment and use of traditional practices only.(Table II)
- As regards the relatives opinions about causes of epilepsy in general and related to their patients' about half of the sample said that they do not know the cause of epilepsy in general, while the figure was only 26% in relation to their own patients.
  Also 30% think that fever is a cause of epilepsy. Comparison between causes of epilepsy related to their patients and those in general no significant difference was found. (Table III).
  Table IV shows relatives management of their patients during fits. It appears that 56% do nothing to their patients during the fit. Only 2% consider safety measures, and 24% try native measures. In relation to relatives feelings towards their patients, 26% have mixed feeling, 38% of the relatives sympathize with their patients and 2% are afraid from the patient Table V.
  Patients' and relatives beliefs in relation to leading a normal life are shown in table VI. It is apparent that 56% of patients think they can marry and lead a normal life. While 44% of the relatives think that their patient cannot get married.
  Also 60% of patients think they can have children

Table (I) Patients' & Relatives' primary search for treatment line.

Items	Patients		Relative		Z
	No	%	No	%	
General practitioner	33	66	35	70	-0.617
Neurologist	3	10	5	10	zero
Healers (Zaar holy persons, witches)	4	8	8	16	-1.11
Do not do anything	8	16	2	4	1.56
Total	50	100	50	100	

Table (II) Patients' & Relatives secondary search for treatment line.

Treatment line	Patients		Relatives		Z
	No	%	No	%	
Medical treatment	35	70	24	48	2.29*
Religious practices	6	12	8	16	0.5
Traditional practices(Zaar).	9	18	18	36	1.96

Table (III) Relatives opinion about causes of epilepsy in general and related to their patients'.

Causes of epilepsy	In General		In Relation to their patients		Z
	No	%	No	%	
Head injury	3	6	9	18	0.25
Fever	15	30	14	28	0.2
Psychological factor	5	10	12	24	1.75
Touch of devil	6	12	2	4	1.15
Do not know	21	42	13	26	1.52

Table (IV) Relative management of their patients during fits.

Management	No	%
Oral medicine	2	4
Safety measures	1	2
Religious practices	3	6
Native	12	24
Cold compresses	1	2
Amonia	3	6
Nothing	28	56

Table (V) Relatives' feelings toward their patients.

Relative feelings	No	%
Sympathize with the patient	19	38
Over protecting the patient	8	16
Sad & depressed feeling	6	12
Fear from patient	3	6
no identified feeling	1	2
Mixed feelings.	13	26

Table (IV) Relative and patients beliefs in relation to leading a normal life.

Belief item	Patients		Relatives		X^2 Result
	No	%	No	%	
Can marry:Yes	28	56	22	44	4.6*
No	7	14	17	34	
Can have children:Yes	30	60	20	40	6.16*
No	7	14	17	34	
Can work: Yes	30	60	13	26	13.8*
No	13	26	28	56	
Can proceed Yes	28	56	40	80	4.6*
in education: No	12	24	5	10	

while the figure was only 40% for their relatives. Difference between patients and relatives answers as regards leading a normal life was found to be highly significant. In relation to being able to marry (X^2-46), have children (X^2-616), can work (X^2-13.8) and proceed in education (X^2-4.6).

Discussion

The results of the study provide a number of findings of interest. Perhaps the most remarkable of these is that patients with epilepsy do not feel universally stigmatized by the disorder while the reverse is found among their relatives. In general patients' views about epilepsy are more positive than their relatives. The previous results suggest that patients more than their studied relatives, feel at ease to talk about their condition, accept to be identified by neighbours and teachers as epileptics and feel they are treated normally by others. In addition more than half of the patients believe that they can have a normal life. In other words they can marry, have children, work and the disorder would not affect their education. The same finding was reported by Dodrill (1983).

Moreover observation by Ryan et al. (1980), suggests that in the U.S. persons with epilepsy do not feel stigmatized in contrast to Danesi's,(1984) results which reveal that in Nigeria most epileptic patients feel stigmatised and are unwilling to be identified by the public as epileptics.

Of interest is that most patients were satisfied with their line of medical treatment and do not try other methods. The same findings were reported by Danesi, (1984) who mentioned that 2/3 of his sample preferred medical treatment while only one third would combine medical treatment with "native medicine" or "spiritual healing methods". On the other hand a larger percent of relatives tried other methods of treatment for their epileptic patients. Among these some tried religious means while the others tried native practices, magic - witchcraft talisman's services. Also they practiced some endogenous beliefs as wrapping him in black sheet, covering him with pig's blood.

Among those using native practices a large percent

mentioned the "zaar" as a way of treatment. This reflects the general belief that epileptics are "possessed" and this is a means to get rid of such "Possession".

Moreover, during a fit relatives practices are far from the medical line of treatments thus while around half of the relatives do not approach the patient at all other practices vary from forcing oral medication to reading verses of the Koraan to saying the call for prayer in his ear or drawing a cross on his forehead with liquid blue.

It was also astonishing to find that some relatives try cold compresses during the fit. This may be due to the general belief that epilepsy is the result of high fever. It was worth nothing that only one relative would look for the patient's safety during the fit.

Also a small percent of the relatives stated that they would try to awaken their patient by using ammonia, this is related probably to the fact that epilepsy is associated with loss of consciousness and the previously mentioned method is the one well known for patients to regain consciousness. These results reflect the cultural view of epilepsy and that the most urgent and immediate need is to stop the fit by all means with little concern about the patient himself or his safety.

Relatives' reactions and feelings towards their epileptic patients were mostly negative and inadequate. This is understandable as culturally reaction to "sick people" is usually negative and varies from sympathy to over protection on one hand, to anxiety, fear and rejection on the other.

In spite of the fact that studied patients were chronic yet fear was an expressed feeling among some relatives. This may be due to the fact that epilepsy is culturally considered a mental illness, or a sign of possession. It may also be due to the fact that mass media represents epilepsy and convulsions in a frightening way and with destructive consequences. Epilepsy also represents loss of control and as such is fear provoking.

Patients were initially treated by general practitioner. This might reflect a belief that at the start of illness epilepsy is an illness like any other. The percent of those that went to a specialist was comparatively high and might be attributed to the difference in level of education of the studied sample. This may also explain -the fact that one fifth of the sample tried native healers before any medical treatment. The same findings were reported by Danesi, 1984 who claimed that the widespread wrong attitudes toward epileptic patients are much less among educated Nigerians but still prevailing among illiterates.
In the United States the public attitudes toward epilepsy has been steadily improving over the years and this has been attributed to better education (Caveness and Gallup, 1980).

It is worth nothing that the differences found between relatives and patients in relation to the initial treatment and to trying other treatment methods can be attributed to several factors. Thus patients at the start of treatment might have not been aware that they were treated for this particular condition. In addition relatives might have attempted to treat their own patients by traditional means or others without the patients knowledge. Another reason might be that patient's might have been very young at the onset of the disease and could not remember their initial treatment.

An indication of the prevailing attitude towards epilepsy is the discrepencis in the findings related to the studied sample answers to the causes of epilepsy as a general condition and the cause of their own patients' illness. Thus while around fifty percent of the relatives claimed that they do not know the causes of epilepsy, most of them stated different causes for their patient's condition. This is an indication of the over use of the defense mechanism of rationalization to overcome the anxieties faced by the relatives in relation to their patient's illness.

It was interesting to find out that 12% of the relative sample believed that epilepsy results from the touch of the devil. However when they were asked about

the reasons behind their patient's illness none of them mentioned this cause. This may denote that they do not want to admit that their relative is touched by the devil as this may be due to social reasons, and they are afraid to be stigmatized.

These findings are in accord with those of many studies in different African countries. Thus in Nigeria epilepsy was regarded as a sign of visitation by the devil and epileptics were believed to be possessed (Dada and Odekal, 1966).

In general,epileptics were regarded as "spiritual" holy person (Collomb et al., 1968). In Ethiopia epilepsy was regarded as a dreadful disease (Giel, 1968).

We conclude that patients and their relatives are faced with psychosocial and emotional problems. The pattern of these problems differed substantially from patients to their relatives. Such findings would have implications not only for understanding the problem facing epileptic patients, but also for initiating further research and developing affective program of remediation.

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- مبادىء الأمراض النفسية ـ د. عمر شاهين، د. يحيى الرخاوى ـ مكتبة النصر الحديثة ١٩٦٥ ـ ص ١٠.
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وجهة نظر مرضى الصرع وأقربائهم فى مرض الصرع

« مـــوجـــز »

اقترنت النظرة لمرض الصرع بالغموض والإجحاف والعداء. وقد انعكس ذلك على مختلف الجوانب النفسية والاجتماعية لهؤلاء المرضى مؤثراً على المآل المرضى. وترمى هذه الدراسة إلى وصف تلك النظرة.

وأهم ما انتهت إليه نتائج هذه الدراسة أن مرضى الصرع يعانون من الوصمة الاجتماعية بصورة أقل من أقربائهم وأنهم ما زالوا يعتقدون أنهم خاضعون لروح شريرة أو متخبطون بمس من الشيطان وأن الأقرباء قد سلكوا طرقاً علاجية غير العلاج الطبى وأوضحت الدراسة اللجوء لبعض الممارسات «البلدية» أثناء النوبات الصرعية.

ABSTRAIT

Les perspectives de l'épilepsis chez les épileptiques et leurs parentés

L'épilepsie est associées habituellement avec le mystère, le préjudice et l'hostilité. Elle présente des implications psychosociales différentes qui ont une influence sur le pronostic de la maladie. L'étude essaye de determiner les perspectives de l'epilepsie chez les epileptiques et leurs parentés. Les principaux résultats obtenus sont que les patients sentent moins stigmatisé que leurs parentés; ceux-ci essayent autres moyens que le traitement médical. Pourtant, les épileptiques sont considérés généralement être posséder. L'étude montre aussi quelques natives coutumes présentes durant la crise épileptique.