

Psychosocial Evaluation of Epileptic Patients with Washington Psychosocial Seizure Inventory

Epilepsili Hastaların Psikososyal Açıdan WPSI (Washington Psychosocial Seizure Inventory) ile Değerlendirilmesi

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Purpose: Psychosocial problems associated with an illness do not receive adequate interest in developing countries. This study was designed to provide data on, and to draw attention to, psychosocial aspects of epilepsy in Turkey.

Patients and Methods: The Washington Psychosocial Seizure Inventory (WPSI) was administered to 51 adult epileptic outpatients (28 males, 23 females; mean age 29.3±8.1 years). Seizures were classified according to the proposal of ILAE. Disturbances in several areas of psychosocial functioning were evaluated and results were compared with those of other countries.

Results: The highest scores indicating definite psychosocial problems were obtained from overall psychosocial functioning, emotional adjustment, and interpersonal adjustment scales. Comparison with other countries showed a similar profile with higher peaks in Chile and lower peaks in developed countries.

Conclusions: In order to enhance patients' compliance to treatment and improve their psychosocial adjustment, rehabilitation efforts designed for Turkish epileptic patients should consider the results obtained from WPSI.

Key Words: Adaptation, psychological; developing countries; epilepsy/psychology/ rehabilitation; personality inventory; psychometrics; psychological tests; quality of life; Turkey.

Amaç: Gelişmekte olan ülkelerde hastalıklara eşlik eden psikososyal sorunlara ne yazık ki gereği kadar ilgi gösterilmemektedir. Bu çalışmada epilepsili hastaların psikososyal açıdan ele alınması ve bu konuya dikkat çekilmesi amaçlanmıştır.

Hastalar ve Yöntemler: Poliklinikte izlenen 51 erişkin epilepsili hastaya (28 erkek, 23 kadın, yaş ort. 29.3+8.1) Washington Psychosocial Seizure Inventory (WPSI) uygulandı. Hastaların nöbetleri ILAE önerilerine göre sınıflandırıldı; psikososyal işlevler açısından değişik alanlardaki bozukluklar değerlendirildi ve sonuçlar diğer ülkelerle karşılaştırıldı.

Bulgular: Ciddi psikososyal sorunların göstergesi olarak yorumlanan yüksek puanlar, genel psikososyal işlevlerden, emosyonel ve kişilerarası uyum ile ilgili bölümlerden elde edildi. Diğer ülkeler içinde, sadece Şili'nin daha yüksek puanlar ile aynı alanlarda yüksek çıkışlar yaptığı; gelişmiş ülkelerde ise daha düşük sapmalar gösteren bir profil olduğu gözlemlendi.

Sonuç: Hastaların tedaviye uyumunu ve psikososyal uyumlarını artırmak için WPSI gibi yöntemlerin rehberliğinde rehabilitasyon çalışmalarının yapılması yaşam kalitesinin artması açısından önem taşımaktadır.

Anahtar Sözcükler: Adaptasyon, psikolojik; gelişmekte olan ülkeler; epilepsi/psikoloji/rehabilitasyon; kişilik envanteri; psikometri; psikolojik testler; yaşam kalitesi; Türkiye.

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Quality of life (QOL) is a construct that includes an individual's well-being and daily functioning. It is defined as "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns."⁽¹⁾ The least understood and most neglected aspects of epilepsy are the social, psychological and behavioral problems that are as debilitating as the seizures themselves. Being stigmatized may also be the center of concern for the patient and the family.^(2,3) Due to considerable shortcomings of health care systems in developing countries, it is not easy to treat an epileptic patient without a governmental social support.

There is no standard definition of a psychosocial problem, nor is there any agreement on which grounds psychosocial problems exist. One of the definitions for QOL in epilepsy is: "QOL in people with epilepsy is an individual's perception of the impact of their condition and its treatment. It reflects the discrepancy between the person's actual and desired physical and psychological health, level of independence, and social relationships."⁽⁴⁾ This unclear situation is more complicated by the difficulty in dealing with QOL in an objective and reliable manner.

There are many different instruments to evaluate QOL. Among these is the Washington Psychosocial Seizure Inventory (WPSI), which is widely used in assessing objective indices of adaptation and functioning of epileptic patients. Dodrill et al.⁽⁵⁾ identified eight general areas of psychosocial concern in epileptic patients: (i) family background, (ii) emotional adjustment, (iii) interpersonal adjustment, (iv) vocational adjustment, (v) financial status, (vi) adjustment to seizures, (vii) medicine and medical management, and (viii) overall psychosocial functioning. The Washington Psychosocial Seizure Inventory has been translated into many languages and, thus, has found application in various countries.⁽⁶⁻⁸⁾ Reports from developing countries, however, are limited.

This study was designed to provide data to gain a better insight into psychosocial aspects of epilepsy in Turkey and to draw attention to these neglected aspects of epilepsy, with a comparison of results with those of other countries.

MATERIALS AND METHODS

Patients

The study group was randomly selected from patients who had had seizures for at least six months and were followed and treated by the

Epilepsy Outpatient Clinic of Bakırköy State Hospital for Psychiatric and Neurological Diseases. After a preliminary interview in which study objectives were explained and informed consent was obtained, 51 patients were administered the WPSI.

Exclusion criteria included illiteracy, a diagnosis of a psychotic disorder according to DSM IV criteria,⁽⁹⁾ and the presence of a physical handicap. A diagnosis of epilepsy was based on clinical and laboratory findings. Seizures were classified according to the guidelines set forth by the International League against Epilepsy.⁽¹⁰⁾

Our hospital is situated in the most populated city of Turkey, providing specialist psychiatric and neurologic services for the inhabitants of Istanbul and western region of Turkey, most of whom migrated from rural areas of the country. Thus, the study group was comprised of a heterogeneous population in terms of sociocultural and economical background

Methods

The Washington Psychosocial Seizure Inventory was translated from English into Turkish and vice versa; it was then reviewed and validated by a bilingual panel. The WPSI includes 132 items pertaining to diverse areas of psychological and social relevance, to which subjects are expected to give either affirmative or negative responses. It consists of the following eight clinical scales including family background (FB), emotional adjustment (EA), interpersonal adjustment (IA), vocational adjustment (VA), financial status (FS), adjustment to seizures (AS), medicine and med-

TABLE 1
Characteristics of Patients (n=51)

Sex (n)	Female	23
	Male	28
Mean age (years)		29.3±8.1
Mean education (years)		7.61±3.6
Educational status (years)	5-8	38
	8 +	13
Mean seizure duration (years)		9.5±7.5
Seizure-free (< 1 year)		17
Uncontrolled seizures (n)		34
Annual income (USD)	<3000	28
	>3000	23
Type of seizures (n)	Partial	29
	Generalised	22

ical management (MM), and overall psychosocial functioning (OPF) and three validity scales: blanks of unanswered items, lie and false answers, and rare items. Scale scores are classified within four areas from 1 to 4 showing the severity of psychosocial difficulties as no, possible, definite, and severe problems, respectively.⁽¹¹⁾

Data Analysis

Data were analysed by computer. Means (and SD) for all scales were computed. Inventories with >3 points in the lie scale were separately analysed and compared statistically. Patients were also evaluated with regard to age, financial status, education and seizure duration.

RESULTS

Of the study group, 23 patients (45%) were females and 28 patients (55%) were males. Mean age was 29.3±8.1 years. The characteristics of the study group are shown in Table 1.

Mean scores (and SD) obtained from WPSI scales are shown in Table 2. The mean score for the total sample in all cases, except for FB and MM scales, was consistent with level 3, showing definite psychosocial problems. Distribution of peak scores in descending order was as follows: FS, EA, IA, AS, VA, and OPF. Mean scores of all WPSI scales from six diverse countries are shown in Table 3.

Subjects with valid lie scale scores of ≤3 (n=17) were separately analysed (Fig. 1) and compared with 34 patients whose lie scores were not valid within the range of 4 and higher. Patients with valid answers had mean scores slightly higher except for FB, which was the same for both; how-

TABLE 2
Mean (n=51) and Valid (n=17) Scores
in WPSI Scales

WPSI scale	All scores	Valid scores
Family background (FB)	3.00±2.3	3.00±2.65
Emotional adjustment (EA)	13.90±6.5	18.35±6.31
Interpersonal adjustment (IA)	8.18±4.9	9.82±5.19
Vocational adjustment (VA)	5.53±2.8	6.29±3.08
Financial status (FS)	3.84±2.1	4.29±1.35
Adjustment to seizures (AS)	5.94±3.0	6.35±3.90
Medicine & medical management (MM)	1.92±1.6	2.53±1.94
Overall psycho-social functioning (OPF)	21.35±10.3	26.76±9.63
Blanks	1.59±2.9	1.35±2.74
Lie	4.19±1.9	2.06±1.03
Rare items	3.15±2.2	2.65±1.50

ever, the severity scales remained the same at every field (Fig. 1).

Patients were also evaluated with regard to the duration and frequency of seizures. The mean duration of seizures was 9.5±7.5 years; the frequency of seizures fell within the range of 8 per month and 4 per year in 34 patients (66%).

In addition, a comparison was made between patients with complete remission for at least a year and those with uncontrolled seizures despite adequate dose and duration of antiepileptic medication. Higher scores were found in the latter group as expected (Fig. 2).

A comparison with respect to annual income of more than 3000 USD and less than 3000 USD

TABLE 3
Mean Scores in WPSI Scales from Six Countries (All Patients)

	Turkey	Canada	Finland	GDR	USA	Chile
Family background	3.00±2.3	2.29±2.46	2.04±2.19	1.64±2.10	2.72±2.3	3.6±2.6
Emotional adjustment	13.90±6.5	13.08±7.46	11.7±7.07	8.20±6.16	14.95±8.21	16.3±7.2
Interpersonal adjustment	8.18±4.9	5.80±4.80	5.39±4.47	3.22±3.46	7.30±5.49	10.1±5.3
Vocational adjustment	5.53±2.8	5.20±3.49	3.48±2.77	3.01±2.43	5.77±3.59	7.1±3.1
Financial status	3.84±2.1	2.29±2.15	1.94±2.12	0.83±1.23	2.82±2.41	4.9±1.8
Adjustment to seizures	5.94±3.0	5.75±3.64	5.44±3.56	3.32±3.11	5.91±4.16	7.5±3.7
Medicine, medical management	1.92±1.6	1.96±1.54	1.38±1.49	1.03±1.46	2.30±1.79	2.8±1.9
Overall psycho-social functioning	21.30±10.3	18.80±11.3	15.12±9.60	11.12±8.59	22.5±13.1	2.8±1.9
Blanks	1.59±2.9	2.84±2.12	2.54±2.09	4.34±2.46	2.04±1.86	0.3±0.9
Lie	4.19±1.9	2.84±2.12	2.54±2.09	4.34±2.46	2.04±1.89	3.4±2.0
Rare items	3.15±2.2	1.62±2.16	1.33±1.13	2.87±1.64	2.16±1.43	4.0±2.7

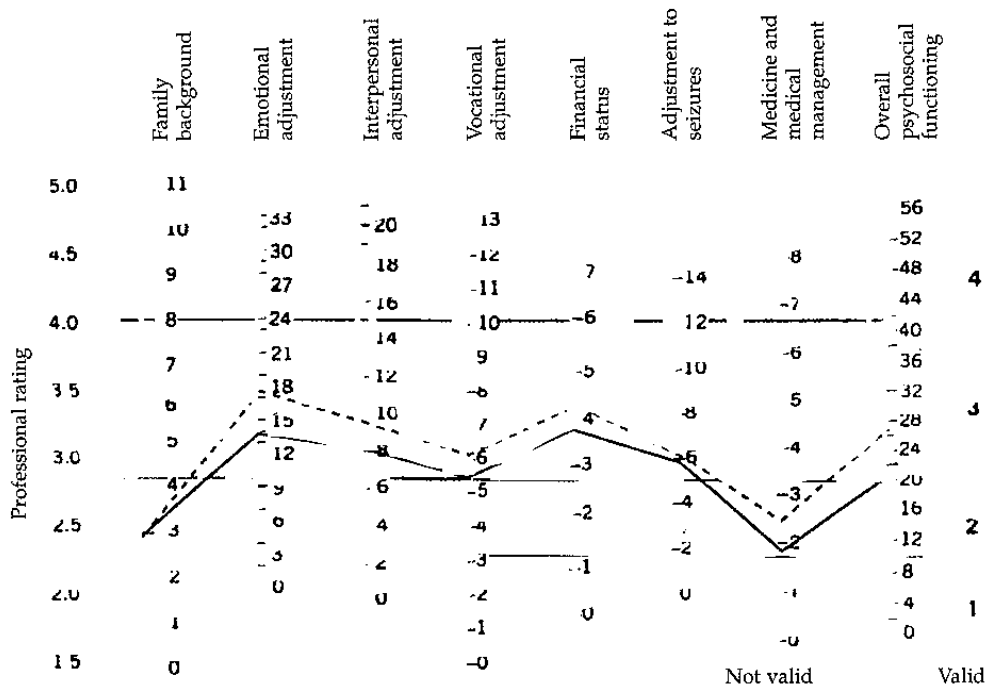


FIGURE 1

Average WPSI profile for Turkish patients.

revealed a notable peak at IA in the former and at FS in the latter groups (Fig. 3).

Patients with an educational status of eight years or longer (high school and university degree) exhibited lower scores at FS and VA (Fig. 4).

Overall analyses showed that none of the patients fell into the severity scale 4, with FB and

MM exhibiting the lowest scores in every analysis.

Finally, results from previous reports of patients with valid lie scale scores were derived^[7] and plotted in the profile sheet, along with our findings (Fig. 5). Our study showed the second highest scores after those of Chile, while the for-

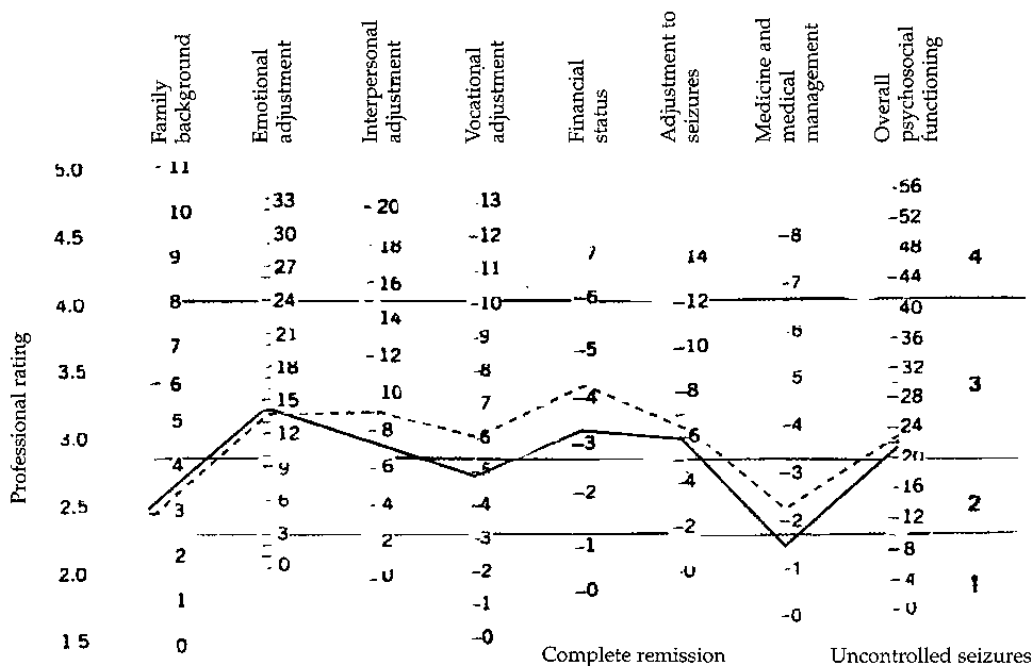


FIGURE 2

Profile results with regard to seizure control.

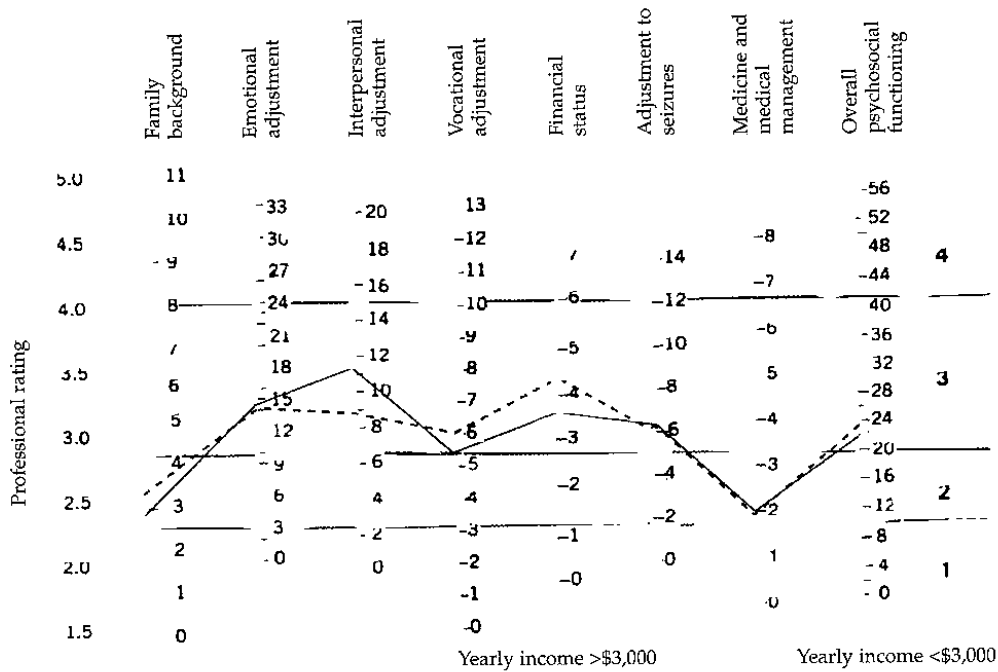


FIGURE 3
Profile results with regard to yearly income.

mer German Democratic Republic had the lowest scores.

DISCUSSION

Since QOL per se is a subjective phenomenon, its assessment lies inevitably on relative and subjective variables. A variety of factors can play a role

in the onset and development of psychological and social problems in epileptic patients.^[12] Studies across Europe show that coping both with the side effects of the treatment and the psychosocial consequences of epilepsy is mentioned among the most difficult aspects in dealing with seizures, as well as social prejudices,^[2,13] varying

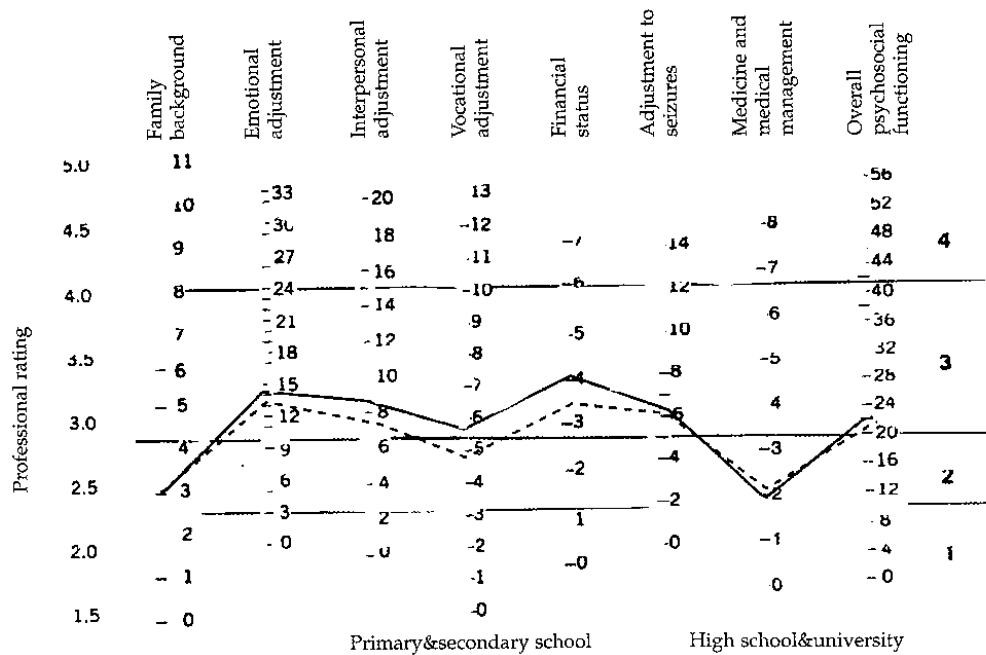


FIGURE 4
Profile results with regard to educational status.

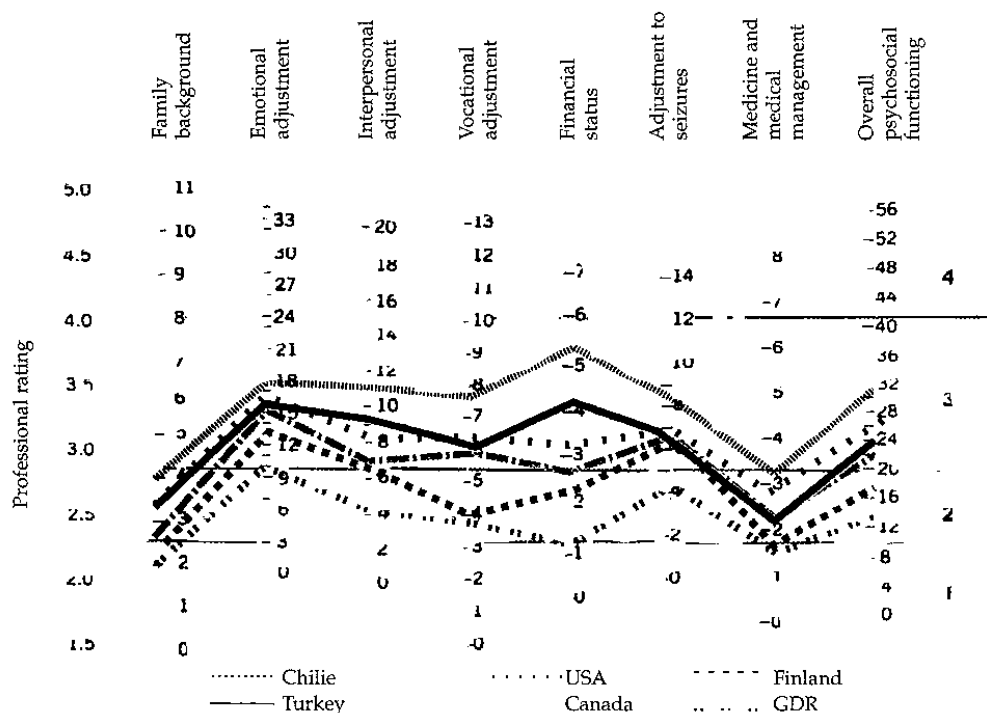


FIGURE 5

Comparison of the mean scores of six countries.

from one country to another. Cultural, social and linguistic differences may also account for this diversity. There may be some other subtle influences, one of which is the compulsory military service, in Turkey, for all men who attain 20 years of age, with some exceptions. Among them, epilepsy is one of the medically accepted excuses, bringing about considerable consequences for man living in rural and urban areas. In rural areas it is a matter of honor for a young man to do his military service, otherwise, in some cases he may not receive adequate respect from his neighborhood even to get married. In urban areas, however, there might be men who are reluctant to do their military services for various reasons. Therefore, the scores are subject to changes if questions regarding this subject are included.

Our high lie scale average obtained may result from various reasons: Many individuals may have a tendency to conceal their problems. Another reason may be some linguistic difficulties in understanding the context; however, the authors feel that the text of the inventory has been adequately translated and cross-checked. Lastly, although the inventory was administered only to patients who declared unequivocal consent, there may still remain some unwillingness on the part of the subjects. Nevertheless, the abovementioned reasons do not seem to exert significant influence

on the overall results. Moreover, comparison of patients with and without valid answers did not show a marked difference in terms of severity scales.

Comparison of our patients' profiles with regard to their income, education status, and seizure frequency showed that the higher the patient's socioeconomic status is, the lower are the severity scale scores, suggesting a favorable influence on the enhanced coping skills of the patients.

An overall analysis of figures from six different countries having diverse sociocultural and economic background showed that developed countries (Canada, Finland, former German Democratic Republic, and USA) shared a similar profile with lower peaks, while developing countries (Chile and Turkey) had higher severity scales, with Chile being succeeded by Turkey.

On the other hand, remarkable differences were found between these countries at VA and FS categories, with the former having fewer problems than the latter. It is also obvious that financial and vocational difficulties may well influence all other fields including EA, IA, and OPS.

Interestingly, VA scores were not as high as FS scores in our patient population. What this may reflect is that a satisfactory level of employment

cannot generate a sufficient level of income. Similarly, investigation of the levels of education and employment status showed that most of the patients are employed in jobs that lag behind their educational status. On the other hand, unemployment rate was higher than that of the country average which is approximately 11%.

Our MM scores suggest fewer problems in this area, reflecting good relations between physicians and patients, in spite of the presence of a wide variety of problems in medical services. This may partly be due to the authoritarian status assigned to physicians among Turkish population, and to the patients' hesitation in criticizing medical issues in front of their physicians.

In conclusion, our study provides instrumental data in a group of epileptic patients in Turkey on the assessment of quality of life in different parameters such as adjustment to seizures, emotional and vocational adjustment, and medical management. In developing countries like Turkey, medical management is often given more importance than other matters such as the quality of life by either the patients, their family members, and the physicians, since seizures (or the illness itself) are considered a priority target in dealing with epilepsy.

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