

Psychosocial Problems in Epilepsy

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Summary

Psychosocial aspects of epilepsy have been subject of increasing interest. Limitations on the study of this subject are, frequently, related to the methodology applied. Methods and measures needed to be universally adapted to different cultures. The WPSI has been applied to epileptics from different countries with psychosocial problems. The efforts from different groups, applying these techniques, translating tests and adapting them to different cultures may be the best way to define the methodology and to find out the best strategy to prevent or treat the psychosocial problems.

Keywords: Epilepsy; Psychosocial Aspects; WPSI

Resumo

Os problemas psicossociais têm uma grande importância em epilepsia mas têm recebido pouca atenção. Uma das razões para esta falha têm sido as dificuldades de adequada taxonomia. Na nossa opinião testes ou baterias de testes devem ser usados para despistar as alterações e permitirem uma efectiva comparação dos problemas psicossociais através das diferentes culturas. O WPSI é um teste que tem sido utilizado e que revela a importância das relações psicossociais e tem sido usado em estudos dos problemas psicossociais da epilepsia nos diferentes países. Espera-se que os esforços para o desenvolvimento de um modo de classificação internacional dos problemas psicossociais da epilepsia permitam melhorar os métodos de tratamento e de prevenção.

Dodrill CB and Batzel LW. Psychosocial Problems in Epilepsy. *Bolt. Epileps.* 1992; 1: 22-27

Introduction

Psychosocial problems in epilepsy are often as important as the crises or seizures themselves. However, in contrast to the very significant amount of time that has been spent on reducing the frequency of seizures in people with epilepsy, relatively little effort has been expended on dealing with the practical consequences of psychosocial concerns including difficulties in relating with others, vocational problems, financial limitations, difficulties accepting seizures, the needs for taking medication consistently, related emotional concerns, etc. The intent of this chapter is emphasize the importance of such problems, to summarize what is known in several important areas, and to make suggestions about what can be done in the future to improve psychosocial adjustment in epilepsy.

One major reason for the lack of scientific advancement in psychosocial adjustment in epilepsy is the fact that there is no universally accepted list of areas appropriately

included as "psychosocial". That is, there is no classification system of psychosocial problems in epilepsy. The importance of this omission may not be readily apparent until it is recalled that if there were no classification system of epileptic seizures, it is unlikely that medical treatment for epilepsy would be systematic and efficiently directed. Drugs would tend to be given at random, and little progress would be made towards stopping seizures. Thus, in reviewing psychosocial aspects of epilepsy, we need at least some type of tentative framework to guide us, even if that framework has limitations.

Levin et al. (1988), in a fairly recent review of the literature on psychosocial problems in epilepsy, faced the same problem, and they chose to resolve this difficulty by using the framework for psychosocial difficulties set up by the Washington Psychosocial Seizure Inventory (WPSI)¹. There are advantages to this approach, especially since the WPSI was designed to cover a full range of psychosocial problems in epilepsy. However, we have not chosen to follow exactly the same outline because the purpose of this chapter are somewhat different than that of a general review paper. In particular, in this paper we wish to emphasize a comparison of psychosocial adjustment across groups of people with epilepsy, and especially cross-culturally. In so

* The preparation of this chapter was supported by NIH grants NS 17111 and NS 24823 awarded by the National Institute of Neurological Disorders and Stroke, PHS/DHHS, USA.

doing, we will focus upon those studies which utilized the WPSI because it permits a comparison between groups both within a country and between countries.

We will begin with a discussion of several important issues in the assessment of psychosocial problems in epilepsy and will go on to review what is known in several important psychosocial areas.

Methods of Psychosocial Assessment

There are two general procedures which professionals have used to evaluate psychosocial problems in epilepsy. The first of these is rating. The rating systems which have been accomplished vary remarkably in approach and sophistication. Typically, they are rather informal with no attempts at all towards external validation and with few efforts towards the establishment of reliability or consistency of measurement, either across raters or over time. In addition, ratings are routinely accomplished for purposes which may be specific for the particular studies in which they are used. In the uncommon circumstance that the rating procedures used appear similar in more than one study, it appears that the ways in which the ratings were made probably varied significantly. Thus, it is unlikely that they are truly comparable. This is especially true for investigations completed in different countries. Given all of these factors, we have chosen not to cover studies based upon ratings in our review.

The second general method of assessment of psychosocial problems in epilepsy is to utilize tests or inventories. Properly used, these assessment procedures meet a number of the objections just mentioned with respect to ratings. They are, of course, not without problems, especially when used cross-culturally. This is true for linguistic reasons, sampling differences, and other factors discussed below. One of the greatest problems with tests and inventories is that until the publication of the WPSI in 1980, none existed which were explicitly directed towards the evaluation of psychosocial problems in epilepsy. Perhaps the most commonly used measure of adjustment in epilepsy prior to the WPSI has been the Minnesota Multiphasic Personality Inventory². While the value of this inventory in evaluating psychiatric and emotional difficulties with many patient groups has been established, there is nothing in this inventory which deals directly with the social implications of epilepsy. Furthermore, the MMPI was developed in a psychiatric hospital situation and norms do not exist for people with epilepsy.

For reasons such as those indicated above, the WPSI was developed specifically to evaluate psychosocial concerns in adults with epilepsy. While space will not be taken to detail the procedures used in the development of this inventory since they are elsewhere presented¹, it should be noted that a premium was placed upon objectivity and upon establishing a firm empirical basis for the use of each item in every scale. In particular, the placement of items on scales based upon subjective perceptions of item content

was rejected. Likewise, a factor analytic approach was rejected because of the subjectivity involved in establishing the statistical criteria for factor determination and because of the subjectivity involved in naming the factors which is routinely done based upon an armchair review of item content. Instead, items were placed on scales only when each item had demonstrated its ability to replicate the judgments of trained professionals with respect to adequacy of psychosocial functioning in the area in question. The results was an inventory which to a considerable degree replicates the judgements of professionals in identifying the absolute and relative psychosocial problems in the patients to whom it is given. Using this technique, problems in each of the following areas are evaluated:

Family Background. Problems are identified in one's family of origin which may result in later psychosocial difficulties.

Emotional Adjustment. General emotional concerns (depression, anxiety, personal insecurity, etc.) are evaluated without any effort being made to subdivide the area.

Interpersonal Problems. A person's ability to effectively relate to other in a variety of contexts is assessed.

Vocational Adjustment. An appraisal of the effects of the seizure disorder on this important area is undertaken here.

Financial Status. This is an especially important area since many persons with epilepsy are unemployed.

Adjustment to Seizures. The response of the person to their seizures is sought out including feelings of embarrassment, resentment, etc.

Medicine and Medical Management. Assessed here are reactions to the attending physician and acceptance of the need to take medication chronically.

Overall Psychosocial Functioning. This provides an index of the person's overall adjustment psychosocially.

In addition to the above eight clinical scales, three validity scales (Lie, Rare Items, Number Blank) are part of the WPSI. The adult inventory has been translated into 14 languages beyond English (Portuguese, Spanish, French (continental and Canadian), Italian, German, Dutch, Finnish, Danish, Czech, Polish, Hungarian, Tamil, Chinese, Japanese) and about 40 papers have been published on its application to various psychosocial problems in epilepsy. An adolescent form of this test has been developed as well³.

With the same empirical emphasis, the WPSI profile which was developed to convey the results of the WPSI was also based upon empirical considerations. Utilizing multiple regression, scales were placed upon the profile directly dependent upon their relationship with professional ratings of adequacy of adjustment. Higher scores indicate poorer adjustment, with four areas of profile elevation identified to aid in interpretation. These are indicated on the right of the profile, and have the following approximate meanings: **Area 1** — No problems; **Area 2** — Possible/slight difficulties; **Area 3** — Definite problems; **Area 4** — Severe/major problems.

The approach used in the development of the WPSI

and WPSI profile is by no means perfect, but it has been the best that we have been able to find in evaluating psychosocial problems in epilepsy. We will now utilize this method in comparing psychosocial concerns in epilepsy across groups.

Type and Extent of Psychosocial Problems in the USA

Before attempting to undertake a comparison of psychosocial problems in epilepsy on an international basis, it is worthwhile to comparatively summarize the findings from a number of places within a single country in which psychosocial evaluation has been conducted. As the WPSI was developed in the United States, it is not surprising that there are more studies published from this country than from any other single country. The first effort to do a multi-site comparison study with the WPSI was published in 1984⁴. The study summarized WPSI results on 315 adults with epilepsy which were tested at five different places across the United States. Samples from Denver, Miami, Seattle and Spokane ranged from 45 to 100 persons and all consisted of individuals who were seeking assistance either psychosocially or medically from specialized epilepsy centers or epilepsy societies. Although they differed from one another in geographical location, biodata variable, and seizure history variables, their average WPSI scores were completely indistinguishable from one another. Their average profile is well represented by the Seattle sample of 100 persons which is shown in Figure 1. Since much of the profile is in Area 3, it is clear that the type of person in these four samples had a number of psychosocial concerns including those which are emotional, interpersonal, vocational, and financial in nature as well as some difficulties in dealing with their seizures.

Washington Psychosocial Seizure Inventory

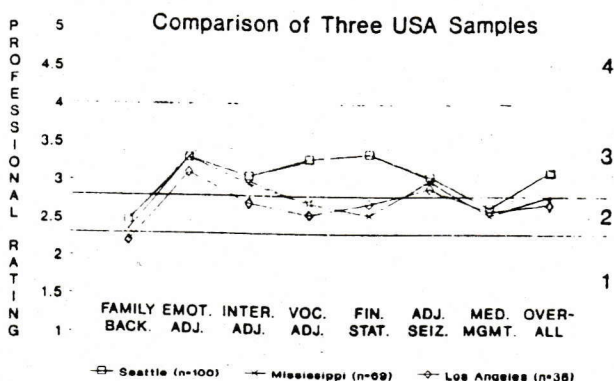


Fig. 1. Average WPSI profiles for samples of patients from three places in the United States (Seattle, Mississippi, Los Angeles).

Only the fifth sample differed in any significant way from the other four. Collected in Mississippi, it was actually a multi-state sample which consisted of 69 persons who were patients of private neurologists and had not necessarily requested assistance beyond routine medical care (40%), or who were members of various epilepsy societies (40%), or who had responded to an article in the National Spokesman, the national newspaper of the Epilepsy Foundation of America. These patients had complex partial seizures. This sample as a whole reported fewer financial problems and fewer vocational difficulties than the other four samples, and they reported a few less problems in their family backgrounds (Figure 1). These differences appear related to the fact that a significant portion of these persons were patients who were either employed (or had close relatives who were employed) so that they could pay for private medical care. Clearly, community-based samples are needed which would appropriately represent the many persons with epilepsy who are presumably functioning reasonably well within the community.

One step in this direction is the work of Helgeson et al. (1990) who sampled patients with epilepsy at a health maintenance organization in the Los Angeles area⁵. While interested primarily in the effects of an epilepsy education program upon psychosocial change, when the pre-treatment scores are combined for their control and experimental groups, an average profile is obtained which is presented in Figure 1. This group is in many respects similar to the Mississippi group with overall adjustment about the same, even though emotional and interpersonal adjustment were perhaps slightly better. It was clear, however, that the Los Angeles group was better adjusted than the Seattle group, and the average profiles in fact do not overlap (Figure 1). This underscores the importance of different sampling procedures.

One paper has been published which does attempt a truly community-based sample with the WPSI. This investigation⁶ began with 235 individuals who had active seizures 5 years previously. This was an unbiased sample from the community of Rochester, Minnesota, USA, even though it is a rather strictly Caucasian, semi-affluent community with above average education for the USA as a whole (average of 13.7 years of formal education). Also, all persons with intelligence estimates less than 70 were eliminated from the sample. Thus, while a community-based sample was obtained, it is not clear that this sample is representative of the USA as a whole. Three subsamples were identified: Group A — persons who had not had any seizures in the last 12 months and who had not been on medication during this period of time ($n = 25$); Group B — persons who were on medication during the last 12 months but who had no seizures ($n = 49$); and Group C — persons who both were on medications during the last 12 months and had at least one seizure during that time ($n = 37$). The average WPSI profiles for the three groups are presented in Figure 2.

Washington Psychosocial Seizure Inventory

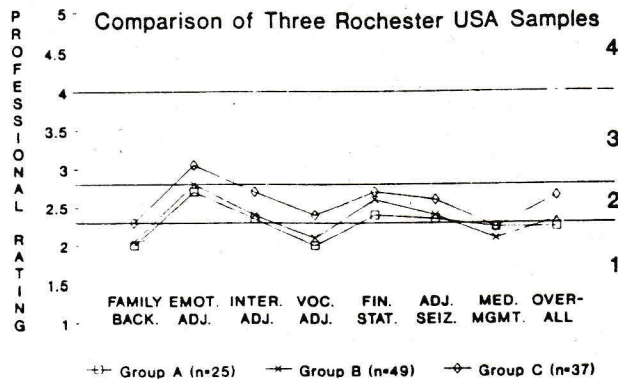


Fig. 2. Average WPSI profiles for three samples of patients from Rochester, Minnesota, USA (Group A — no seizures or antiepileptic drugs in the last year; Group B — no seizures in the last year, but antiepileptic drugs were taken; Group C — both seizures and antiepileptic drugs in the last year).

The study Trostle et al. (1989) provides us with valuable information⁶. It is clear that degree of psychosocial problems increases as one goes from Group A to Group C. However, it is obvious that the greatest difference is between Group B and Group C. That is, having an active seizure disorder rather than merely taking medications is associated with increased psychosocial difficulties, perhaps for a number of different reasons. The people in Group A had typically not had seizures for a number of years and it is questionable as to whether they should have been included in the study at all. Likewise, the people in Group B did not have active seizures and some of them probably had not had attacks in several years. Indeed, an average of 6.2 years had elapsed since the last seizure for all patients in this study (all three groups taken together). Nevertheless, because the patients in Group B continued to take medications for seizures, one could reasonably argue that they were appropriately diagnosed as suffering from epilepsy. When Group C is compared with the Mississippi and Los Angeles samples in Figure 1, it appears that it is slightly better adjusted. This is probably due to differences in sampling, in educational level, in the elimination of retarded subjects, employment status (it is not clear that any of the Rochester sample was unemployed), and perhaps to other factors as well.

We became interested in how much difference in psychosocial adjustment might be associated with a variable such as years of education, but our perusal of literature in the area revealed no direct information. Therefore, we

searched our own data base and found 511 adults (aged 16 and older) with confirmed epilepsy (primary seizure diagnoses: complex partial, 266; generalized tonic-clonic, 82; simple partial, 51; absence, 45; atonic, tonic, clonic, 14; combinations of these, 50; unclassified, 3). Average age at onset of seizures was 14.28 years ($SD = 10.78$), and an average of 1.89 antiepileptic drugs ($SD = .83$) were taken at the time of testing. Probable etiology of the seizures disorder was unknown in 284 cases and known in 227 (traumatic, 93; infectious, 48; birth-related, 24; neoplastic, 16; vascular, 9; combinations of these, 37). All but 25 were Caucasian (black, 11; native American, 7; Asian, 6; Latino, 1). These 265 females and 246 males averaged 29.09 years of age ($SD = 9.85$) and 11.71 years of formal education ($SD = 2.68$). We found that 176 persons had less than 12 years of education, 189 had exactly 12 (equivalent to completion of high school or a secondary school diploma in the USA), 91 had completed at least one full year of college but had not completed at least a bachelor's degree and a few completing more advanced university work (16-20 years).

The average WPSI profiles for each of the four education groups is presented in Figure 3. It is clear that persons with less education had more psychosocial problems, and that the university educated group had the fewest difficulties. This was especially apparent with respect to Vocational Adjustment and Financial Status with statistically significant differences demonstrated at the $p < .001$ level using one way analysis of variance. Other differences were also evident, and it is clear that educational level is a variable which needs to be considered when studies such as that of Trostle et al. (1989) are interpreted⁶.

Washington Psychosocial Seizure Inventory

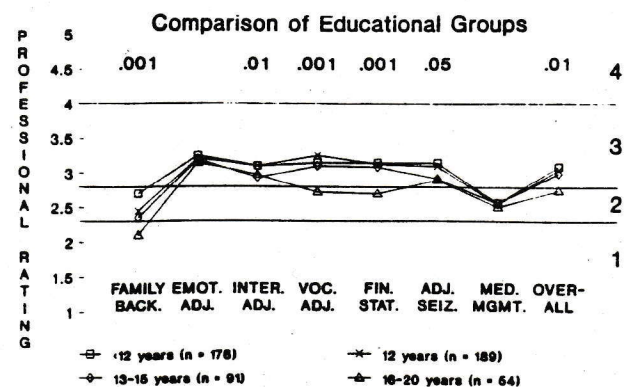


Figure 3. Average WPSI profiles for patients from Seattle divided according to number of years of formal education.

Overall, the degree of psychosocial problems found within a given culture is no doubt related to a number of factors and among these are type of sampling procedures utilized, socioeconomic status, educational level, severity

of seizure disorder, and underlying impairment of brain functions. At the present time, work is needed which would help to identify persons *in advance* who are susceptible to the development of psychosocial problems so that programs of prevention can be set up. This would be a far more desirable circumstance than the current all too common procedure of attempting to resolve difficulties after they have become chronic and resistant to change.

International Evaluation of Psychosocial Problems

An international comparison of psychosocial problems in epilepsy would facilitate communication among professionals in various countries and would promote the exchange of information on psychosocial assessment and intervention. It would also help to pave the way for the establishment of an international classification system of psychosocial problems in epilepsy. Difficulties in making cross-cultural comparisons are immediately evident, however. A method of common assessment of psychosocial problems is required, but the best way to do this is not necessarily clear. The lack of such a method has unquestionably contributed to limited investigation in the area, and in fact very few cross-cultural comparisons were made prior to the development of the WPSI. Even with the international use of this inventory, however, difficulties in translation are inevitable, and there is no guarantee that exactly the same meaning is conveyed, even with careful attention to linguistic matters. Furthermore, although the same meaning may be conveyed, there is no certainty that patients in various cultures will interpret the items in an identical manner, the various psychosocial areas evaluated may have differential importance, and even test-taking attitudes such as the degree of openness or honesty also vary across cultures. While these factors and others are definite problems, a number of efforts have now been reported to compare psychosocial adjustment cross-culturally, a few of which will be summarized here. In order to facilitate international communication, we will once again focus on studies utilizing the WPSI.

In the largest multi-cultural study reported to date⁶, patients were administered the WPSI in Canada ($n = 100$), Finland ($n = 84$), German Democratic Republic ($n = 100$), and the United States ($n = 127$). The samples from Canada, Finland, and the United States were all from epilepsy centers whereas that from the German Democratic Republic was from a clinic of neuropsychiatry. All four groups appeared to have received specialized medical assistance for their seizure disorders. In other respects they also appeared to be reasonably similar, although equivalence could not be established because of known or potential differences across the cultures. Analysis of the data on the WPSI revealed three different types of findings of interest.

First, while the profiles were parallel to one another in many respects, it was clear that the more similar the culture to the United States where the WPSI was devel-

oped, the higher the average profile (greater numbers of psychosocial problems reported). Most similar in elevation to the United States profile was that of Canada with Finland being next and the German Democratic Republic showing the least similarity. The interpretation of these findings is uncertain since it could not be determined if people with epilepsy in some cultures merely had fewer problems, if the WPSI became less and less effective in measuring problems as cultural dissimilarity increased, or if there was another source of response bias (such as a tendency to minimize problems) which may have been responsible.

Second, certain features of the WPSI profiles could be related to particular characteristics of the cultures. For example, socialized medicine and work support were perhaps best developed in Finland and the German Democratic Republic, and least well in the United States. This may be related to the fact that most vocational and financial problems were reported in the United States, and the fewest in Finland and the German Democratic Republic.

Third, it is clear that willingness to admit to various types of psychosocial problems varies markedly across cultures. If patients admit to few problems and have high scores on a scale such as the Lie Scale of the WPSI, then are they merely attempting to cover up difficulties or might they in fact have fewer problems? A discussion of this problem has already been presented^{6,7}, but in some cultures, this is an especially difficult for which clear answers are lacking.

Investigations in a number of other countries have been completed in the last few years, and the results from four of these will be briefly summarized here. Bere and Flanagan (1987) studied 94 adults with epilepsy in Australia drawn from a rehabilitation center and from the membership of an epilepsy association⁸. Of these, 50 had idiopathic epilepsy, and 44 had post-traumatic epilepsy and the average WPSI scores of both groups were considered together. Preiss, et al. (1989)⁹ randomly selected 100 ambulatory adults with epilepsy from a clinic for paroxysmal diseases in Prague, Czechoslovakia and administered the Czech version of the WPSI. There were 55 men and 45 women in this sample. Loiseau et al. (1988)¹⁰ administered the French version of the WPSI to 11 adults with difficulty to manage seizures in Bordeaux, France. These patients were entering an experimental drug trial with stiripentol, and the data reported here were obtained on the pre-existing drug regimen prior to the administration of stiripentol. Curral (1989) administered the Portuguese version of the WPSI to a mixed group of 40 adults with partial and/or generalized epilepsy in or near Porto, Portugal¹¹. The groups was a mixture of urban and rural persons, of whom 26 were on antiepileptic monotherapy and 14 on polytherapy.

The average WPSI profiles for the four groups just described are presented in Figure 4. The profile patterns are remarkably similar. The only score which is greatly different on any scale from the others is better adjustment with respect to Medicine and Medical Management for the

French sample. These were very carefully selected patients who were to undergo an important drug trial, and it is likely that they were selected in part because of excellent rapport with their physicians, and also because of demonstrated ability to take medication faithfully. These are the areas evaluated by this scale. It is also noted that the geographically close French and Portuguese patients reported similar and increased problems in Adjustments to Seizures. The other scores were quite similar, and the possibility is raised commonalities around the world.

Washington Psychosocial Seizure Inventory

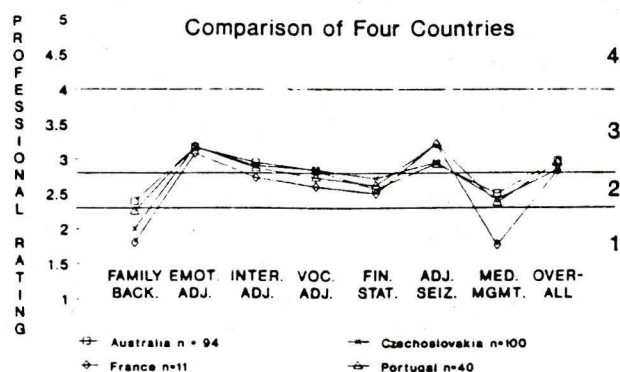


Figure 4. Average WPSI profiles for samples of patients from Australia, Czechoslovakia, France and Portugal.

Conclusions

Psychosocial problems are of great importance in epilepsy, but they have received less attention by the professionals than they deserve. At least one reason for this is the lack of an adequate taxonomy for these difficulties. In our opinion, tests or inventories have broader uses than ratings, and despite their limitations, they are more likely to permit an effective comparison of psychosocial problems within and across cultures. The WPSI is one such inventory, and it has been relied upon in this chapter to illustrate important psychosocial issues and to provide comparative information about psychosocial problems in epilepsy from several countries. It is hoped that current efforts will lead to additional foundational knowledge which will permit the development of an international classification system of psychosocial problems in epilepsy, and which will also result in improved methods of both treatment and prevention.

Acknowledges

The preparation of this chapter was supported by NIH grants NS 17111 and NS 24823 awarded by the

National Institute of Neurological Disorders and Stroke, PHS/DHHS, USA. The WPSI was developed with assistance of a grant from the Epilepsy Foundation of America. Address reprint request to Carl B. Dodrill, Ph. D., Regional Epilepsy Center (ZA-50), Harborview Medical Center, 325 Ninth Avenue, Seattle, WA 98104, USA.

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