

International Comparison of Psychosocial Problems in Adults with Epilepsy

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Psychosocial problems in epilepsy have been documented for a number of years, but an objective comparison of the types and extents of such problems in various cultures has not been accomplished. Undoubtedly, one major reason for this pertains to the difficulty in objectively specifying what psychosocial problems exist, and in being able to do this in a way which is at least reasonably consistent in different cultures. This chapter describes such a comparison in two North American countries, one Scandinavian country, and one European country, and summarizes a special session at the Fourteenth Epilepsy International Symposium.

SUBJECTS

All individuals evaluated for this investigation were adults (age 16 and over) with confirmed seizure disorders. Basic biographical and seizure history information from each of the four samples is given in Table 1. The group from the United States consisted of 127 people who constituted a representative sample of the outpatient clinic of the Regional Epilepsy Center, University of Washington School of Medicine, Seattle, Washington. This is a center specializing in difficult to manage seizure problems. The Canadian sample consisted of 32 inpatients and 68 outpatients who were seen at a regional Epilepsy Unit of University Hospital, London, Ontario, Canada. The system of medical care in Canada makes it likely that this group included many routine cases as well as more difficult to manage seizure problems. Sixty-nine of the adults in the Finnish sample were outpatients at the Pitäjänmäki Epilepsy Research Center in Helsinki, and fifteen

TABLE 1. *Biographical and seizure history data on epileptic patients from four countries*

Variable	Country			
	USA	Canada	Finland	GDR
No. of patients	127	100	84	100
Average age (yrs)	29.2	29.4	33.2	35.8
Sex				
Males	67	45	37	65
Females	60	55	47	35
Seizure type				
Partial	89	68	33	57
Generalized	28	32	67	34
Unclassified or mixed	10	0	0	9
Average age at onset of epilepsy (yrs)	13.7	15.1	15.6	19.3

were outpatients of the Tampere University Hospital in Tampere. Only patients who could read were included in the sample. Seventy-five percent were employed. With respect to education, 47% had received vocational training, and 6% had received university education. Finally, the German sample consisted of 100 outpatients with chronic epileptic disorders who had been known to the Nervenlinik am Friedenshof for some 10 to 15 years. A random selection of individuals attending the clinic was included in the sample.

A review of the above information and the data presented in Table 1 reveals certain similarities. The age of the patients was fairly similar, those in the German sample being the oldest. For seizure diagnosis, the partial epilepsies were better represented than generalized seizure disorders in most cases. Perhaps most important, it is clear that in the majority of cases, the people evaluated in each country had long-standing seizure problems. Cultural differences made the extent of education in the four samples difficult to evaluate, but no marked differences were observed among the groups.

METHODS

In order to accomplish our stated goal, it was necessary to use an objective method for the identification of psychosocial problems in epilepsy which could be applied to the various countries. It was recognized that any single method might not be equally effective in all countries, and that it might produce results that are not fully comparable because of cultural differences. A search was therefore made for the best available method. Instead of using some type of interview procedure, which undoubtedly would vary markedly from one setting to the next, it was finally decided to use an objective test or inventory. The inventory selected was the Washington Psychosocial Seizure Inventory (WPSI, Dodrill et al. 1980) because it

had been designed specifically to identify psychosocial problems in people with epilepsy. This inventory was developed through an empirical item-by-item anchoring procedure by which inventory items were placed in scales according to demonstrated relationships, with professional judgments of adequacy of functioning in the areas in question. The eight areas evaluated by the WPSI are as follows: Family Background, Emotional Adjustment, Interpersonal Adjustment, Vocational Adjustment, Financial Status, Adjustment to Seizures, Medicine and Medical Management, and Overall Psychosocial Functioning. The inventory also includes three validity scales (Number of Unanswered Items, Lie Scale, Rare Items Scale) to help identify invalid profiles. The standard English version was used in the United States and Canada, the Finnish translation (by I. and U. Tacke) in Finland, and the German translation (by T. Naumann) in the German Democratic Republic.

RESULTS

The results of the study are given in Fig. 1 where mean or average profiles are presented for each of the four groups. The results may be interpreted with respect to the elevations on the profile with higher scores indicating more difficulties. Areas of profile elevation [1, 2, 3, 4] are indicated on the far right. Area 1 is typically associated with no psychosocial problems and areas 2, 3, and 4 are associated with questionable, definite, and severe problems, respectively. The sample from the United States consistently had the highest scores, and the sample from the German Democratic Republic consistently had the lowest scores. Intermediate scores were obtained by the samples from Canada and Finland, and whereas there was some overlap in scores, in general it was observed that the Finnish sample tended to have lower scores than the Canadian sample. The general trends are particularly evident on the Overall Psychosocial Functioning Scale. Although space does not permit reporting of the detailed statistical analyses that were conducted, it should be noted that by means of one-way analysis of variance, statistically significant differences were found on each of the scales at the 0.01 level or greater, indicating that there were differences among groups on each of the psychosocial variables.

One major finding of the study was that there were substantially different numbers of individuals in the groups who had high Lie Scale scores (scores of 4 or more) as established in the original validation of the inventory (1). The numbers (and percentages) of individuals falling outside the normal range were as follows: United States, 26 (20%), Canada, 35 (35%), Finland, 25 (30%), and German Democratic Republic, 63 (63%). Respective average scores were 2.0, 2.8, 2.5, and 4.3. The significance of this will be discussed later. However, it should be noted that when individuals with high Lie Scale scores were eliminated, the profiles from all countries became more elevated and the gap between the countries became slightly reduced.

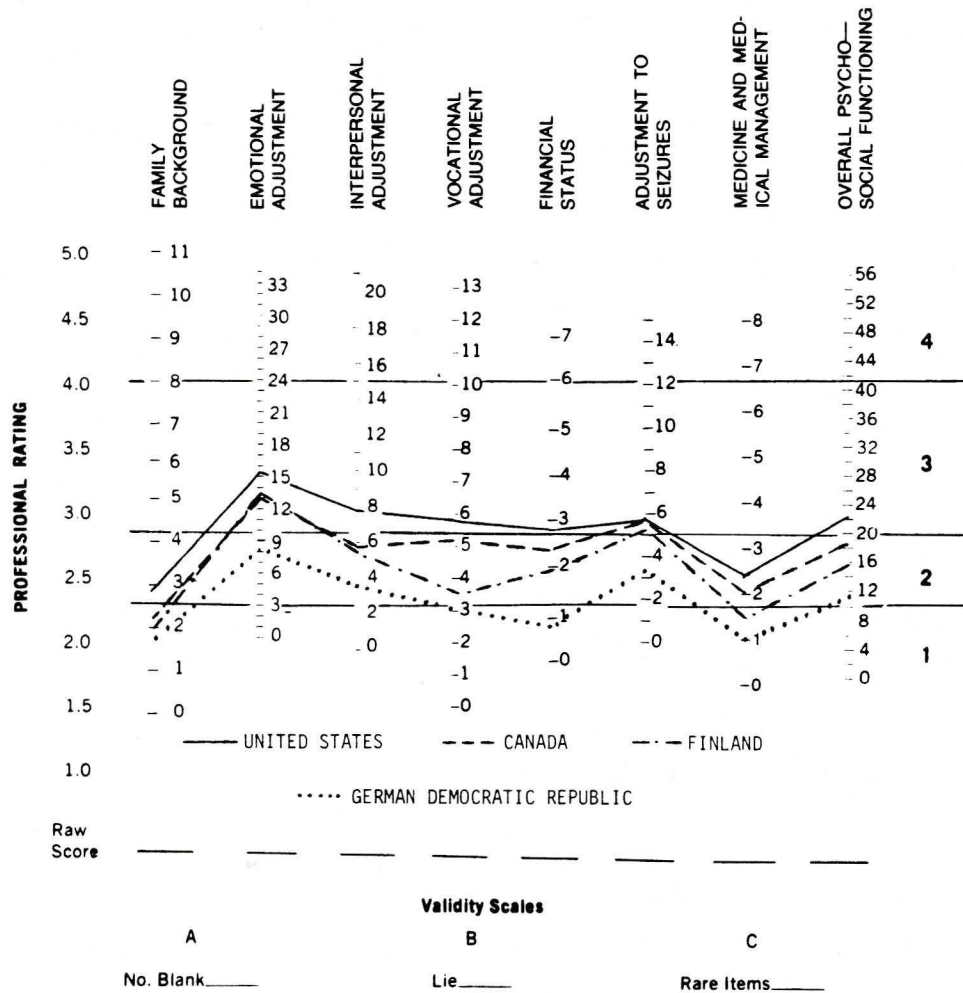


FIG. 1. Average WPSI profiles for groups of adults with epilepsy from four countries.

DISCUSSION

Many findings from this investigation deserve comment. First, despite the fact that statistical differences were demonstrated on each of the WPSI scales, many of the differences among the countries demonstrated in Fig. 1 appear to be differences in profile elevation rather than profile configuration. For example, the highest profile point for each group was on the Emotional Adjustment Scale. Thus, for each group, emotional factors were at the

forefront, and this was true even though the extent of such problems varied in the groups. Patients from the four cultures reported depression, tension and anxiety, and similar problems. The lowest point on the profile for each group was also the same for each group, namely, the Family Background Scale. When each group was evaluated individually, and the relative extent of difficulties within each group was compared, in *all* instances fewer problems were reported with respect to family relationships than in connection with any other area. Thus, the greatest and least problem areas appear to be the same in the four samples, at least as identified by the WPSI. Finally, it was noted that in only one instance did the lines from two countries cross. In general, the lines are quite parallel to one another. It therefore appears clear that the differences in the groups do not consist primarily of differences in types of problems reported, but rather in the degree to which they were reported.

One should consider several hypotheses in attempting to account for differences in the profile elevations of the four groups. First, it may be that the WPSI is most sensitive to psychosocial problems of individuals residing in the United States, where it was developed. When cultures become increasingly dissimilar socially, economically, and politically, the WPSI may become increasingly insensitive to psychosocial problems. Thus, the Canadian profile is closest in elevation to the United States, the profile from Finland is next closest, and that from the German Democratic Republic is farthest.

A second hypothesis to account for the differences in profile elevation, deals with the substantial differences in scores on the Lie Scale among the groups. Higher lie scores were associated with lower profiles. It is likely that there are cultural differences which are important and which have an effect on profile elevation. In the German group, a second administration of the WPSI to people with high scores after explaining the purpose of the study resulted in lower scores, but higher profiles.

A third hypothesis to help explain the differences among the four groups, is that there are actual differences in psychosocial problems among the patient groups in the various countries. For example, in the area of finances, it is clear that the United States has the least well-developed program of socialized medicine, and individuals in the United States report more financial problems than in any other country. It also seems likely that unemployment or fear of unemployment may be more important to patients where there are greater financial concerns. Thus, the differences on the Vocational Adjustment and Financial Status Scales were particularly noteworthy (Fig. 1). Relatively more important, in such countries as Finland and the German Democratic Republic, are difficulties in dealing with seizures. We conclude that whereas many of the differences in the groups might relate to factors producing differences in profile elevation, there are some differences in profile configuration which are of interest and may reflect actual differences among the cultures.

A fourth hypothesis which might account for some of the differences among the groups pertains to sampling of patients. Easy to manage patients might report fewer psychosocial problems than more difficult, chronic cases. It may be that there was a greater proportion of difficult to manage cases in the United States sample than in any other sample, and this may help to account for the fact that the United States profile was generally higher than the other profiles. It is also possible that there were differences among the samples with respect to such variables as seizure type, but the psychosocial significance of such differences is uncertain.

In addition to the four hypotheses given as possible reasons for differences among the groups, there may well be other cultural differences and factors of significance which are difficult to identify. In view of all these variables, it is perhaps remarkable there were as many similarities in profile configuration as there were. It may therefore be that there are some parallels in the types of psychosocial problems reported even in diverse cultures. However, caution must be exercised in coming to final conclusions based on the data in this study. One should bear in mind that the inventory utilized was developed in the United States, and originally only for people in that country. The items used in the inventory are sometimes difficult to accurately translate, and some item content may not be appropriate in other countries. Problems in translation were observed in several instances in this study, and they may have had a slight effect upon the German and Finnish findings. Thus, a reformulation and restandardization of the WPSI may ultimately be required in countries where the predominant language is not English.

The data from this study suggest that there are similarities in the psychosocial problems experienced by people with epilepsy in various cultures. This appears reasonable in view of the fact that seizures are generally similar in most countries, and they may produce similar stresses. However, any conclusions drawn at this time must be tentative, and further research will be required to determine the reasons for cross-cultural similarities and differences in the psychosocial problems of people with epilepsy.

ACKNOWLEDGMENTS

The research reported in this paper was supported in part by NIH grant 17277 and by NIH contracts NO-NS-0-2281 and NO1-NS-2-2341, awarded by the National Institute of Neurological and Communicative Disorders and Stroke, PHS/DHHS, United States. The special assistance of M. Kasparick and B. Michalowski are acknowledged for the completion of the study in the German Democratic Republic. Similar expression of gratitude is offered to W. T. Blume, J. P. Girvin, and M. Del Campo for assistance in complet-

ing the Canadian study, and to R. Lehtovaara for assistance in completing the study in Finland.

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