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Patterns of Psychosocial Problems in Chronic Epilepsy

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Psychosocial problems in epilepsy are common and of major importance, but they tend to be poorly defined and conceptualized. Patterns of psychosocial difficulties are rarely specified, and practically never on the basis of objective criteria. In this study, an attempt was made to identify both the absolute and relative extent of psychosocial difficulties in a group of individuals with difficult-to-manage seizure problems.

SUBJECTS

A total of 294 adults (age 16 and over) with confirmed epilepsy were identified. All were patients at our regional epilepsy program, which is a specialized treatment facility in the state of Washington. The sample was considered to be reasonably representative of our patient group. However, the sample tended to include people who had more severe seizure disorders, and possibly also more severe psychosocial problems. There were 139 males and 155 females. They averaged 28.62 years of age (SD = 9.52) and 12.28 years of education (SD = 2.41). With respect to primary seizure type, approximately 57% had complex partial seizures, 10% had elementary partial seizures, and 33% had generalized seizures of one type or another. Age at onset of seizure disorder averaged 14.15 years, and in approximately 53% of the cases, factors in the history had been identified that were believed to be etiologically related to the seizure disorders.

METHODS

In order to accomplish our stated goal, it was necessary to select an objective method for the identification of psychosocial difficulties in epilepsy. Such a method would need to be a reasonably comprehensive one which would touch on the major

psychosocial problems known to occur among people having epilepsy, but it would also have to be reliable and relatively easy to obtain. The procedure that was ultimately selected was the administration of the Washington Psychosocial Seizure Inventory (WPSI) (1). This inventory evaluates both the relative and the absolute extents of difficulties in the following psychosocial areas: Family Background, Emotional Adjustment, Interpersonal Adjustment, Vocational Adjustment, Financial Status, Adjustment to Seizures, Medicine and Medical Management, and Overall Psychosocial Functioning. This 132-item inventory is typically administered in either written or tape-recorded form over approximately 20 minutes, and can be scored by handscoring stencils in about two minutes.

The WPSI renders a profile for each individual, and clinical work has provided for the establishment of four regions of profile elevation: (1) no significant problems; (2) possible problems, but of limited significance; (3) distinct difficulties with definite adjustmental significance; and (4) severe problems with a striking impact upon adjustment. Thus, at least within the limitations of the inventory, it is possible to identify the degree of problems and to compare the relative extents of difficulties across the various areas assessed. The inventories were scored in the standard manner, and profiles were drawn for each patient. Prior to beginning the study, all patients were eliminated who had profiles which were considered invalid according to published criteria (1). The data were then compiled so that both the absolute and relative ranks of psychosocial problems in the group could be identified.

RESULTS

The results of the study will first be examined with respect to the absolute extent of psychosocial problems, as revealed on each of the scales. Second, the relative extent of difficulties will be evaluated.

Table 1 presents information concerning exactly how many individuals fell in each range of profile elevation for each scale. As can be seen by looking down each of the columns across the WPSI scales, the number of people falling into each

TABLE 1. *Frequencies of ranges in profile elevation for 294 adults*

WPSI scale	Ranges of profile elevation				Percent of persons in problem area
	1	2	3	4	
Family Background	142	73	67	12	27
Emotional Adjustment	5	39	200	50	85
Interpersonal Adjustment	50	86	133	25	54
Vocational Adjustment	68	56	132	38	58
Financial Status	93	19	108	74	62
Adjustment to Seizures	35	117	124	18	48
Medicine and Medical Management	219	63	12	0	4
Overall Psychosocial Functioning	38	87	149	20	57

area of profile elevation varies substantially. In the first column, for example, the scores vary from as low as five to as high as 219, a greater than 40-fold difference. Equally striking discrepancies are noted in the other columns. These discrepancies make it evident that psychosocial problems in epilepsy are not randomly distributed. The final column in this table summarizes the percentages of individuals in the third and fourth profile areas, which are the areas clinically associated with psychosocial problems. Again, a very marked fluctuation from one area to the next is observed, with emotional and financial problems at the forefront but with difficulties pertaining to interpersonal and vocational adjustment close behind. With respect to Overall Psychosocial Functioning, significant problems were found in almost 57% of the subjects. It was of interest to observe that in only 8% of the subjects was there no score in one of the problem areas (profile areas 3 and 4). Furthermore, in some two-thirds of the cases, there were definite problems in three or more psychosocial areas. Thus, there is no question that this group demonstrates many psychosocial and social concerns.

The results were then compiled with respect to the two high points on the profile. These high points would represent the greatest areas of psychosocial concern, and Table 2 presents the results. This table demonstrates that when the extents of psychosocial problems are compared with one another, emotional and financial concerns are most frequently identified as the greatest difficulties, although problems pertaining to job placement are nearly as great. However, when the next-to-highest peak points are also considered and are added together with the highest points, problems in emotional adjustment clearly emerged as the most prevalent. In fact, among the seven basic scales (not including Overall Psychosocial Functioning), the following combinations were seen most frequently: Emotional Adjustment, Interpersonal Adjustment (15% of all cases); Emotional Adjustment, Vocational Adjustment (13%); Emotional Adjustment, Financial Status (16%); Emotional Adjustment, Adjustment to Seizures (13%); and Vocational Adjustment, Financial Status (12%). Thus, the vast majority of individuals with epilepsy display only a handful of patterns of major psychosocial problems.

TABLE 2. *Highest WPSI scales with 294 adult epileptics*

	Percentage of time in which scale is		
WPSI scale	Highest	Second highest	One of the two highest
Family Background	5	7	14
Emotional Adjustment	26	36	62
Interpersonal Adjustment	12	15	26
Vocational Adjustment	21	14	34
Financial Status	26	15	40
Adjustment to Seizures	10	14	24
Medicine and Medical Management	0	0	0

DISCUSSION

The data presented above amply demonstrate that, at least with respect to our subject population, psychosocial problems in epilepsy by no means appear randomly. Emotional problems are most commonly seen, and we have noted that these difficulties most frequently include neurotic or neurotic-like concerns pertaining to anxiety, depression, tendencies to worry, somatic concerns, and a poor self-image. However, with high frequency, emotional concerns, combined with others, create a total constellation of problems which we believe is quite different from one person to the next. For example, individuals with financial difficulties, in combination with depression, tension, and anxiety, are different from individuals who demonstrate difficulties in getting along with others, in addition to their emotional problems. In the case of the former, some financial counseling may help to alleviate many of the difficulties, and perhaps substantial change could be effected even by such a simple procedure as placement on public assistance rolls. In the latter case, however, a much longer course of psychotherapy may well be indicated. Such therapy may be required before progress in other areas, such as vocational adjustment, can occur.

Worthy of at least some comment are the difficulties that were very rarely found. Even when strictest confidence was assured, our patients rarely reported difficulties with their physicians, and thus the problems identified here relative to the other concerns were minimal. It is likely, of course, that this is, at least in part, a product of self-selection, since patients who are unhappy with their doctors tend to go to others. Putting aside this one point, which produces results that are probably artifactual in nature, it was also noted that problems with respect to family background were relatively rarely observed; furthermore, they rarely occurred in combination with difficulties in interpersonal relations, vocational adjustment, and acceptance of seizures. Other infrequently observed combinations pertained to interpersonal adjustment and adjustment to seizures, as well as to interpersonal adjustment and vocational adjustment. None of these combinations occurred more often than three percent of the time, and are in marked contrast to the series of two-point combinations occurring 12% of the time or more (identified at the end of the last section). The rare two-point combinations provide further evidence that psychosocial difficulties in epilepsy follow patterns which can be identified.

CONCLUSIONS

This study presents the results of an evaluation of the psychosocial problems of a group of patients with difficult-to-manage seizure disorders. Among the patients evaluated, emotional difficulties were at the forefront, but financial problems, concerns with employment, and problems related to interpersonal relationships were not far behind. When patterns of psychosocial difficulties were sought, it was discovered that a few different patterns encompassed the outstanding problems demonstrated by the majority of patients.

The results of this study argue against a general therapeutic approach in dealing with psychosocial problems in epilepsy. Unless the psychosocial problems are objectively specified in each case, and unless appropriate therapeutic intervention is identified, one should not expect vast changes with a very general approach. It may be that progress in dealing with psychosocial problems in epilepsy has been prevented in substantial part because the nature of such difficulties has never really been known nor objectively specified. Although inventories such as the WPSI unquestionably have their limitations, their reliability and validity have been demonstrated (1), and they represent a start toward an objective approach to psychosocial difficulties. If further strides can be made along these same lines, it seems likely that such steps will provide a basis for change in this very important and difficult area.

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REFERENCE

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