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Objective Assessment of Psychosocial Problems in Epilepsy and Its Relevance to Employment

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INTRODUCTION

As one of the world's foremost epileptologist has said, "There is practically no epileptic patient who is not confronted with some type of psychosocial problem..." (1, p.74) In one study (2), fewer than one of four individuals with seizure disorders were free of intellectual problems, neurological handicaps, and behavioral problems. The reasons for these concerns are not difficult to find and include brain damage, social stigma, problems in accepting the seizure disorder itself, discrimination with respect to employment, etc. So important are these problems that it is almost certainly true that the majority of us at this conference have been repeatedly struck by the great significance of psychosocial difficulties with respect to adjustment in life and it is likely also that many of us have concluded that these difficulties are at least as significant as the effects of seizures themselves upon adjustment, and perhaps more so.

Despite the importance that we might attribute to psychosocial concerns, it is remarkable to note that the evaluation of these difficulties is usually done subjectively. Furthermore, the objective tests and inventories, such as the Minnesota Multiphasic Personality Inventory (MMPI) that have sometimes been employed in the evaluation of psychosocial problems in epilepsy have routinely been developed with other patient populations and are therefore not geared to identify the particular psychosocial difficulties often seen with seizure disorders. Equally important, some of these testing devices interpret certain manifestations of seizures as psychiatric problems and therefore can be quite misleading. Thus, despite the frequency and importance of psychosocial problems, apparently no one has developed, specifically for epilepsy, a complete test or inventory having a series of scales which would permit a comprehensive, objective, and systematic assessment of psychosocial problems. The purpose of the paper today is to present such an inventory and furthermore to show how it can be useful in a clinical context and in a research context. The specific problem that will be discussed is that of employment and the potency of psychosocial variables with respect to employment will be demonstrated and will be compared with the potency of other variables specifically including seizure type, seizure frequency, and extent of neuropsychological

impairment.

THE WASHINGTON PSYCHOSOCIAL SEIZURE INVENTORY (WPSI)

Our preliminary work in psychosocial problems in epilepsy consumed several years during which we identified the areas that we wished to study and during which also we began to construct the WPSI. Details on the development of the WPSI are presented elsewhere (3). Briefly, 132 items printed on both sides of a single sheet of paper were constructed, each of which is answered "Yes" or "No" according to self-perceived usual feelings and actions of the patient. The 7 clinical areas that we identified will now be described, each of which was ultimately evaluated by a series of items which correlated well with professional judgments of adequacy of functioning in the area in question.

Family Background

The intention here was to identify problems in the home in which one grew up which might have an impact on functioning in later life. The areas evaluated included relationships with parents, teachers, and peers. Sample items from the scale that was ultimately developed included, "Did you feel secure in the home in which you grew up?", "As a child, did you have trouble making friends?", and "Were you well accepted by your school teachers?"

Emotional Adjustment

A general assessment of emotional problems was very important but an overall indicator was desired since it was not within the scope of the WPSI to provide detailed evaluations of a variety of emotional difficulties such as might be found with the MMPI. The latter inventory could be given when emotional concerns were in evidence on the WPSI. Our experience suggested that the problems of depression, tension, anxiety, worry, inability to think clearly, over-sensitivity, poor self-image, general dissatisfaction with life, and non-specific somatic concerns were among those most commonly seen with people having seizures. These problems are therefore most strongly represented although more serious psychotic thought patterns were also covered to some degree. Sample items included, "Are you generally free from depression?", "Are you often tense and anxious?", "Are you usually able to think clearly?", and "Do you often wish you were dead?"

Interpersonal Adjustment

We were convinced of the importance of interpersonal adjustment in the total wellbeing of the person with seizures and felt it important to evaluate general comfort in social situations. Ability to meet others, extent of friendships, sufficiency in number of social contacts, and ability to deal with the opposite sex were examined. Sample questions included, "Do you have trouble meeting people?", "Do you enjoy social gatherings?", "Do you have trouble expressing your opinions to others?" and "Do you feel at ease around people of the opposite sex?"

Vocational Adjustment

This appears to be an especially important part of adjustment for the adult with seizures. An evaluation of the interaction of the seizure disorder itself in obtaining and maintaining employment appeared to be central to assessment in this area since seizures are often cited as the reason for unemployment. Sample of questions included, "Have you ever lost a job because of your seizures?", "Are you satisfied with your employment situation?", "Do you need vocational counseling?", and "Is transportation a problem?" The questions do not ask if the person is actually employed. The relevance of such questions to actual employment status will nevertheless be demonstrated later in this paper. Furthermore, they are relevant even when it is very difficult to relate seizure type or seizure frequency to degree of employment.

Financial Status

An evaluation of financial status and self-perceived financial security seemed especially important with individuals who are often dependent upon others for basic support. A small group of items ultimately passed all criteria and included, "Do you have sufficient money for basic needs?", "Do you feel financially secure?", "Can you afford your present living arrangement?", and "Do you have enough money to pay your bills?"

Adjustment to Seizures

Many people with epilepsy are resentful and embarrassed about their seizure disorder, find themselves ill at ease because of possible seizures, feel that they are less worthwhile, and believe that they are less accepted by others because of the seizures. Questions were therefore devised which tapped each of these areas and which included, "Do you feel resentful that you have seizures?", "Are you comfortable going out despite possible seizures?", and "Do you have trouble accepting your seizure problem?"

Medicine and Medical Management

Overall psychosocial adjustment may be significantly affected by a person's perception of the treating physician, acceptance of the need to take medications, and belief in the adequacy of the treatment. The questions tapping this area included, "Do you like your doctor?", "Do you feel your doctor really cares about you as a person?", "Do you feel your seizures are being controlled as well as they can be?", and "Do you frequently have trouble remembering to take your medications?"

Overall Psychosocial Functioning

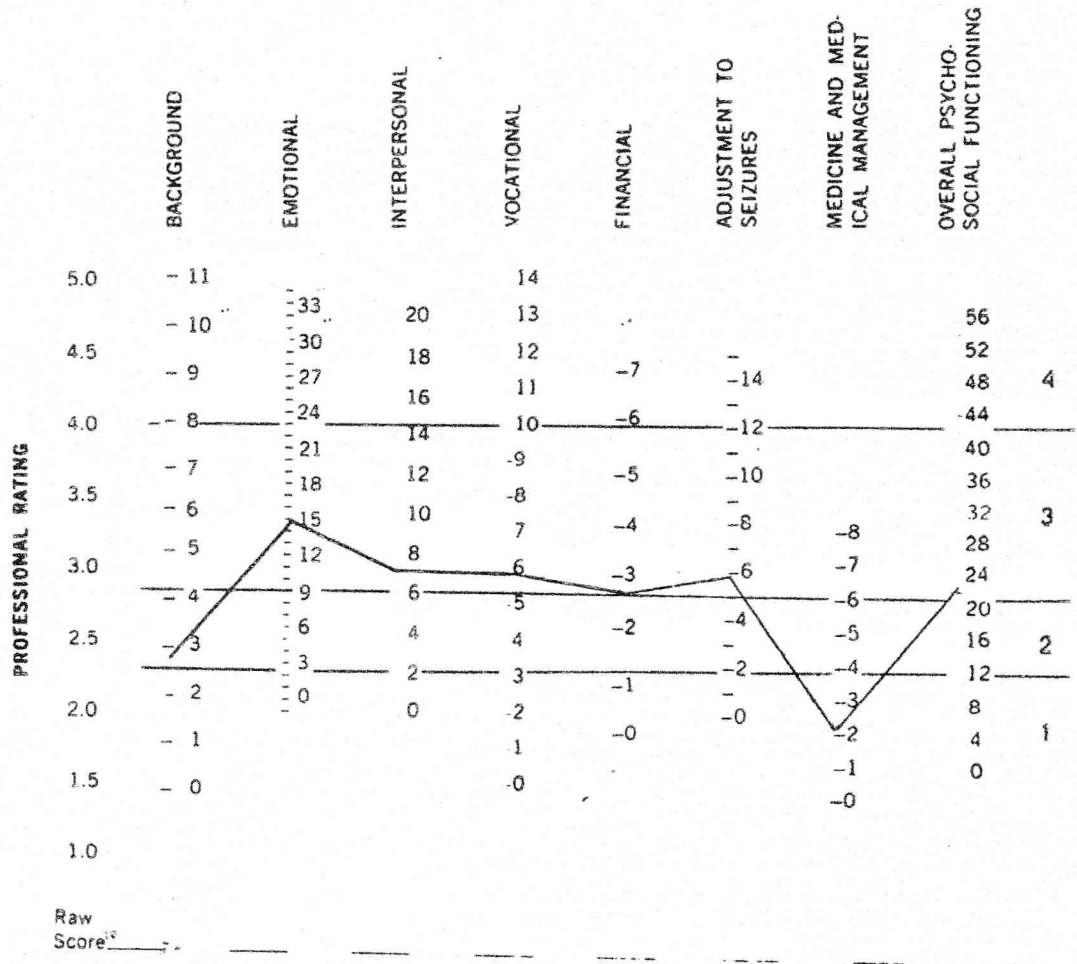
We felt it would be important to obtain an index of the extent overall which a person seemed able to adapt to demands of life. The items that ultimately went into this scale were those which correlated best with judgment of overall functioning, regardless

of the scale in which they appeared and they included an especially strong representation from the Emotional Adjustment Scale.

It is important to stress that all items were placed in the various scales on a strictly empirical basis with a procedure very similar to that which was used in the development of the MMPI. A total of 127 epileptics were extensively evaluated by a social worker or psychologist and difficulties were sought out in each psychosocial area of interest. Ratings were made during interviews without any knowledge of the patient's responses to the WPSI. The ratings for each area were then correlated with every item in the WPSI and an item was placed in one and only one of the first seven scales (excluding Overall Psychosocial Adjustment) providing that by the point-biserial correlation technique the correlation was statistically significant at the .01 level or better. The item was placed in the scale with which it correlated most, regardless of the content of the item. Interrater reliability was established as were reliability and validity of the WPSI scales themselves. A complete description of this study including the crossvalidation phase is found elsewhere (3). With the scales empirically derived as described above, each patient could be scored for the number of items on each scale which were in the direction suggestive of difficulties. Although the scores that resulted were sufficient for research purposes, we were interested in presenting the information in a way that would be meaningful clinically. We therefore developed the profile which is presented on the next page. I should remark that in developing this profile we were unable to use a normal group as a criterion since it is of course not possible to ask a normal person, "How do you feel about your seizure problem?" Furthermore, we found that standard scores such as percentiles were not an effective index of problems within our epileptic sample since the extent of problems varies greatly from one area to the next. For example, emotional and interpersonal problems are extremely common in our group, but few appear with respect to medical management and in fact our patients usually report a fondness for their physicians (those that do not have probably gone elsewhere). Therefore, the profile was constructed with the professional ratings used as criterion and placement of raw scores was made by simple linear regression techniques with higher professional ratings and higher scale scores corresponding to more problems. Finally, it was possible to identify areas of profile elevation as follows: Area 1 -- No significant problems; Area 2 -- Possible problems but of limited significance; Area 3 -- Unquestioned difficulties with definite adjustmental significance; and Area 4 -- Severe problems with striking impacts. With these facts in mind, the line plotted on the profile of Figure 1 (which represents the 127 individuals used in the original study) demonstrates that our patients have definite emotional, interpersonal, vocational, and financial problems as well as difficulties in accepting their seizure disorders. It should also be remarked that various patterns of profile elevation have proved to be of importance clinically and that they have pointed both to different types of difficulties and to different suggestions with respect to remediation.

WASHINGTON PSYCHOSOCIAL SEIZURE INVENTORY

Profile Form



Validity Scales

A
No. Blank 0-13

B
Lie 0-3

C
Rare Items 0-5

RESEARCH WITH THE WPSI

I wish now to briefly refer to two research studies that we have done with the WPSI and then to present a third one in a more detailed fashion as this has not appeared elsewhere in print. In the first investigation (4), we were interested in relating the WPSI to vocational status and in comparing its ability to identify people with chronic unemployment problems with that of the more standard indices of unemployment including extent of education, intelligence, and neuropsychological impairment. Intelligence was assessed by the Wechsler Adult Intelligence Scale and neuropsychological impairment was evaluated by the Neuropsychological Battery for Epilepsy (5). We used a total of 58 adult epileptics from our facility who could be clearly classified as Employed (at least 20 hours per week in competitive employment for the last six months), Underemployed (sheltered workshop placement or competitive work less than 20 hours per week), and Unemployed (less than 5 hours per week of employment of any type). The results demonstrated that the WPSI Vocational Adjustment Scale and overall neuropsychological impairment were both more related to employment status than any of the other indicators. It was also noted that these two sets of measures were the only ones which were devised specifically for work with epilepsy and the possibility was considered that they might be more sensitive than general indicators of intelligence and emotional status to disabling conditions.

In the second study (6), 100 adult epileptics were divided into four levels of functioning according to standard indicators of intelligence (Wechsler Adult Intelligence Scale), neuropsychological impairment (Neuropsychological Battery for Epilepsy), emotional adjustment (MMPI average profile elevation), and psychosocial functioning (WPSI Overall Scale). When the patients were divided according to intelligence and neuropsychological impairment, the extent of systematic fluctuation in emotional adjustment and psychosocial functioning was assessed, and vice versa. Results showed that emotional status and intelligence were unrelated, that there was only a slight relationship between intelligence and psychosocial functioning (decreased intelligence was associated with greater psychosocial problems), that emotional adjustment was moderately related to neuropsychological impairment (greater problems in each going together), that psychosocial functioning was moderately related with intelligence, and that the most consistent relationships were to be found between neuropsychological impairment and psychosocial functioning. Thus, increased psychosocial problems were associated with increased difficulties in brain functions and vice versa, but these findings would not have been apparent using only the more general indicators.

Finally, we were interested in extending the vocational studies summarized above to the question of which variables are most important in unemployment and we therefore examined in more detail the seizure information, neuropsychological data, and WPSI scores on the 58 people in the employment study. The seizure-related variables

that appeared to have the greatest promise were seizure type and seizure frequency. The neuropsychological variable of greatest promise was the percentage of scores outside normal limits on the 16 specialized neuropsychological tests which form the Neuropsychological Battery for Epilepsy. The psychosocial variable of greatest promise was the WPSI Overall Psychosocial Functioning Scale. For all analyses, individuals were classified as employed (underemployed or fully employed) or unemployed.

Using the international classifications scheme (7), the variable of seizure type was first considered and a table presenting frequencies of employment and unemployment for each seizure type was prepared. Essentially every seizure type had an employment rate of approximately 50% except for elementary partial seizures where the rate was approximately 25%. The small differences across the seizure types were not statistically significant ($\chi^2 = 2.76$). Thus, at least among this patient group, seizure type is not related to employment status.

Evaluation was then made by relating employment with the presence or absence of seizures in the past 60 days. Groups were set up which had no seizures, seizures (but no major motor attacks), and seizures including major motor attacks. For each grouping of these seizures approximately 50% of the people were employed so that no statistically significant difference emerged ($\chi^2 = 0.75$). This is consistent with other data from our Epilepsy Center which point to very few seizure-related losses of jobs and it is also consistent with previous work (8).

Individuals were then classified as showing neuropsychological impairment or not showing impairment by criteria previously published (5). By these criteria, 0 to 40% of the tests outside normal limits is in the normal range whereas 41 to 100% is in the range of impaired brain functions. A statistically significant difference emerged ($\chi^2 = 8.29$, $p < .01$) and it was noted that 69% of individuals classified as showing no neuropsychological impairment were employed whereas exactly the same percentage who demonstrated such impairment were unemployed. Thus, impairment in brain functions as demonstrated by neuropsychological tests is reliably related to employment status but there are still 30% of the individuals for whom the test results are not perfectly consistent.

The patients were then classified according to their scores on the Vocational Adjustment Scale of the WPSI. Scores of 0 to 5 (areas 1 and 2 on the profile) were taken to suggest no problems whereas scores of 6 and more were suggestive of difficulties. Once again, a statistically significant difference was found across the patients with respect to employment status ($\chi^2 = 9.88$, $p < .01$). Seventy percent of individuals with scores in the no problem range were employed whereas some 71% of individuals scoring in the problem area were unemployed. Thus, this variable was also much related to vocational status even though it is not possible to tell from the WPSI Vocational Scale whether or not a person is employed.

Patients were finally classified according to whether they simultaneously demonstrated neuropsychological and psychosocial problems using the criteria already identified. When one considers all three employment levels, a highly statistically significant difference is found and the data is presented in Table 1. To summarize, if problems in either the psychosocial nor the neuropsychological areas are identified, there is an employment rate of 87% in this chronic epileptic population whereas if there is problems in one area but not the other the employment rate is 48% and if there are problems in both area, the employment rate is 20%.

TABLE 1

FREQUENCIES OF DIFFERING LEVELS OF EMPLOYMENT AS
RELATED TO NEUROPSYCHOLOGICAL AND TO PSYCHOSOCIAL PROBLEMS

NEUROPSYCHOLOGICAL AND PSYCHOSOCIAL PROBLEMS	FREQUENCIES OF		
	FULL EMPLOYMENT	UNDER- EMPLOYMENT	UN- EMPLOYMENT
NEITHER PRESENT	12 (80%)	1 (7%)	2 (13%)
ONLY ONE PRESENT	6 (26%)	5 (22%)	12 (52%)
BOTH PRESENT	2 (10%)	2 (10%)	16 (80%)

$$\chi^2 = 22.17 \text{ (p} < .001\text{)}$$

The data from this study clearly demonstrate that neuropsychological and psychosocial variables are important correlates of employment status in adults with epilepsy. It seems likely that at least in this patient group they are more potent than any seizure-related variable. It may of course be that in other groups of epileptics where seizures come much less frequently than with this group, they would have greater significance. This however has not yet been demonstrated and it is difficult to believe that psychosocial problems would prove to be inconsequential even when seizures are less frequent. When one considers the data that has been presented, it is somewhat disconcerting to note that the vast majority of resources dedicated to assist people with difficult seizure problems are directed toward seizure control when it may be that it is the psychosocial and neuropsychological variables which need the greatest portion of the attention. Admittedly, neuropsychological and psychosocial problems can emerge secondary to deterioration following multiple attacks, and seizure control is therefore to be strongly encouraged. However, it may also be true that one must go beyond the question of seizure control to the very important psychosocial variables before we can hope to deal with the full range of problems which epilepsy presents. It is therefore very gratifying to me to be a part of this workshop and it is my hope

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