

Self-concept's dimensions in persons with epilepsy: implications for psychosocial development

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SUMMARY

Living with epilepsy means to face many challenges related to the physical, social and psychological dimensions of this condition. In an attempt to understand the impact of epilepsy for self and identity problems, we compared the self-esteem of adults with epilepsy (N=80) with a group of asthmatics (N=80) and a group of healthy adults (N=80). The subjects were administered the Self-Perception Profile for Adults, developed by Messer & Harter, 1986, which assesses self-judgments in specific life domains and also global self-esteem. We also conducted a semi-structured interview to examine the impact of epilepsy and of fits on the daily psychological well being of patients as well as specific needs for professional help. The results showed that when compared with the asthmatic and the healthy, epileptics perceived themselves less competent and adequate in intellectual achievements and in social accomplishments, in other words, personal attributes which cross valued social roles in areas like education, work and relationships. Also, interviews revealed that epileptics felt stigmatized and non accepted by the community members, need more specific information about their condition and would like to have professional support to overcome better some of their psychosocial problems.

Introduction

The psychological aspects of epilepsy (E) have been recently emphasized as one of the most relevant factors of E and consequently of the quality of life of persons with E as well as with their treatment. The aim of the present work is to study the relevance of epilepsy for self and identity problems in order to organize adequate medical and psychological approaches. In order to achieve this goal, first we applied the methodology developed by Harter, (1), to compare the self-esteem of epileptics, asthmatics (this population has been selected because these patients are also suffering from a chronic disease characterized by episodes) and healthy people; second, we developed a semi-structured interview to obtain information about fits, communication skills concerning the disease, causal attributions and needs for professional help.

Patients and methods

Subjects

Two-hundred and forty subjects divided in three groups of eighty persons (epileptics, asthmatics and healthy) were studied. The epileptic patients' characteristics were also the base for the selection of the two other groups. All of them were adults (15 to 50 years), with a minimum of primary school level of education, absence of any other serious physical or psychological handicap, and leading a regular family, social and professional life. The

general characteristics of the sample are shown in Table 1.

Measures

Subjects were administered: (a) the *Adult Self-Perception Profile* (ASPP), developed by Messer and Harter (2) which assesses 12 specific domains of self-esteem distinguished by adults (1): *sociability, job competence, nurturance, athletic abilities, physical appearance, adequate provider, morality, household management, intimate relationships, intelligence, sense of humor and global self-esteem.*; (b) a *semi-structured interview* developed for the purpose of this study with questions related to social and family life, information needs, communication and negotiation skills concerning the condition, causal attributions to epilepsy, specific feelings, thoughts and behaviours around fits and needs for professional help.

Procedure

Subjects were tested individually and the same version of ASPP was administered to epileptics, asthmatics and healthy. The portuguese version of ASPP was evaluated, in terms of internal consistency and construct validity, for each group and for all the sample (3). Both epileptics and asthmatics were interviewed individually.

Statistical Analysis

ANOVA procedures (one-way and multiple analysis of variance) for identification of between and within subject differences were conducted for self-esteem results. Qualitative analyses of the epileptics' interviews were also conducted.

Results

The results concerning the self-esteem are shown in Table 2 and refer to the application of ASPP. Between-subject differences were found for: (a) *Intelligence* - epileptics felt less able than healthy

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Table 1 - Characteristics of the sample

	Epileptics (N=80) %	Asthmatics (N=80) %	Healthy (N=80) %	Total (N=240) %
Sex				
female	47.5	57.5	55.0	53.3
male	52.5	42.5	45.0	46.7
Age (years)				
15-22	41.3	33.8	38.8	37.9
23-35	42.5	40.0	47.5	43.2
36-50	16.3	26.3	13.8	18.8
Civil status				
single	53.8	46.3	60.0	53.3
married	46.3	52.5	37.5	45.4
widowed	-	1.3	-	0.4
divorced	-	-	2.5	0.8
Education (years)				
≤ 9	68.8	70.0	32.5	57.1
10-12	16.3	18.8	41.3	25.5
≥ 13	15.0	11.3	26.3	17.5
Occupational status				
high qualified workers	12.5	8.8	20.0	13.7
qualified	20.0	18.8	25.0	21.3
semi & non qualified w.	38.8	38.8	33.8	37.1
non labour force	28.8	33.8	21.3	28.0
Onset of disorder				
≤ 10 (years)	28.8	47.5	-	38.2
11-16	41.3	12.5	-	26.9
≥ 17	30.0	40.0	-	35.0
Actual fits				
presence	58.7	62.5	-	60.6
absence	41.3	37.5	-	39.4
Medication				
yes	90.0	68.8	-	79.4
no	10.0	31.3	-	20.6
Type of seizure				
tonic-clonic	35.0	-	-	-
simple partial	1.2	-	-	-
complex partial	16.2	-	-	-
partial sec. generalized	12.5	-	-	-
myoclonic	7.5	-	-	-
more than one of these types	27.4	-	-	-

people and the same occurred with asthmatics, when compared with the healthy ones; (b) *Athletic Abilities* - asthmatics felt less competent than the healthy ones; (c) *Morality* - epileptics and asthmatics felt less adequate than the healthy people.

Within-subjects differences analysis were also conducted, as a function of sex, age, civil status, education, occupational status, seizure type, onset of disorder, medication, fits and residence (urban=65%, rural=35%). The results showed significant differences for: (a) *Athletic Abilities* (sex & age) - males scored higher than females ($p < .02$) and the youngest group scored higher than the oldest one ($p < .01$); each of these factors was associated with sport activities and interactions

between the variables were found not be significant at the 5% level. (b) *Morality* (onset of seizures & education) - the more educated epileptics scored higher than the less educated ones ($p < .05$) and persons who had the first fit around or after 17 years old scored higher than those who had the first fit around or before 10 years of age ($p < .05$); each of these factors was closely associated with *Morality* and interactions between them were not found to be significant at the 5% level. (c) *Intimate Relationships* onset of seizures & civil status) - persons with epilepsy since or after 17 years old scored higher than those who had the first fit around 10 ($p < .05$) and married epileptics scored higher than single ones ($p < .05$) each of these variables became of relatively little importance in

Table 2 - Self-esteem of epileptics, healthy and asthmatics

Subscales	Epileptics		Normals		Asihmatics		F ratio
	Mean	St. Dev.	Mean	St. Dev.	Mean	St. Dev.	
Sociability	11.7	2.85	12.4	2.80	12.0	2.60	1.102
Job Competence	11.8	2.10	12.0	4.42	11.6	2.22	.710
Nurturance	12.4	2.36	12.0	2.13	12.3	2.05	.555
Athletic Abilities	9.5	2.69	10.1	2.93	8.7	2.48	5.331*
Physical Appearance	11.6	2.58	11.8	2.44	11.5	2.32	.275
Adequate Provider	11.9	2.39	12.2	2.00	11.9	2.04	.519
Morality	11.7	2.57	12.6	2.32	11.5	2.35	4.594**
Household Management	11.6	2.80	11.6	3.28	11.5	2.90	.014
Intimate Relationships	10.7	2.61	11.0	2.90	10.7	2.57	1.010
Intelligence	10.4	2.30	11.6	2.26	10.5	2.16	7.813*
Sense of Humor	10.9	2.97	11.6	2.57	11.2	2.44	1.320
Global Self-Worth	16.4	4.21	17.4	3.85	16.9	3.69	1.400

Note: df = degrees of freedom * p < .01 ** p < .05 df = 2

the determination of Intimate Relationships once the other was taken into account, which reflects the close association between age at onset of seizures and civil status. (d) *Job Competence* (civil status) - married epileptics scored higher than the single ones (p < .05). (e) *Sociability* (actual presence of fits) - epileptics with fits scored lower than those who do not have fits (at least during the last year) (p < .05).

The answers of epileptics to the interview showed that: (a) The majority of patients felt uncomfortable when speaking about their E (embarrasement, avoidment, confusion, sadness, emptiness, fear of rejection by others) and almost all of them chose only the closest family members and the intimate partners to self-disclosure. (b) In most of the cases patients felt stigmatized by the disorder and were concerned with other people's discovery of their disease; they also considered that others' lack of information and misconceptions about the causes of the disease were the base for the mentioned discrimination attitudes. (c) Half of the patients wished to know more about their condition, specifically, to share experiences and feelings with other epileptics, to know how to ask for adequate help from others and to know more about the cronicity of the condition, while others mentioned they prefer to be in ignorance, since knowledge means to be counscious of their condition and consequently to become anxious, afraid, confused, strange and depressed. (d) In general, patients did not attribute to epilepsy their positive or negative life events. (e) The majority of epileptics evidenced the need for professional help mainly to overcome problems related to sociability, intimate relationships, work and family relationships.

Discussion

The results showed that epileptics felt less competent or adequate in intellectual abilities and social accomplishments. Since these are personal attributes necessary for several social valued roles in our society (i.e.: going to school, getting a job, getting married, being a father/mother) they can have considerable impact on an overall sense of epileptics self-esteem. Moreover, a sense of inferiority in these areas, as a result of medical condition, can originate negative affects which can regulate low levels of achievement motivation (on school, work, relationships) and undesirable

patterns of social behaviour such as isolation and withdrawal. Finnaly it is important to note that although these patients lead a quite fulfilling life comparing with asthmatics and healthy persons, they present low levels of self-esteem in specific areas of life and misconceptions about their condition, which must be taken into account. Accordingly, programs to enhance or reevaluate self-esteem, specially in these domains, need to be carried out. The specific domain approach adopted makes it possible to individualize psychological interventions, according to special areas of concern of epileptics and thus to be more effective in the treatment of these patients. We also consider that this population can be an important group of reference to further the study of the psychosocial development of epileptics as well as their personal coping styles concerning E.

References

- Harter S
Processes underlying the construction, maintenance and enhancement of the self-concept in children.
In: J. Suls, G.A. Greenwald (Eds), *Psychological Perspectives on Self*, vol. 3, chap. 6, 1986
- Messer B, and Harter S.
Manual for the Adult Self-Perception Profile.
University of Denver, 1986
- Taveira MC, Martins da Silva A, Mena Matos P, et al.
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