# PSYCHOSOCIAL ASPECTS OF EPILEPSY[1]

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## SUMMARY

Advances have recently been made in studying psychosocial dimensions of epilepsy. This article reviews the different approaches used to study social and psychological dimensions of epilepsy and outlines the major psychosocial issues for persons with epilepsy. Presenting and underlying problems are conceptualized as ranging from 'inner' to 'outer' in terms of whether the problem relates to the person's knowledge of and reactions to self, to family and friends and to institutions of education and employment. Particular attention is paid to the importance of investigating aspects as self-worth, causal attributions, self-efficacy and identity development processes as complement to currently prevailling research issues. The article concludes with research issues, social and educational policy suggestions that emphasize the need of planning and organizing more adequate professional services for persons with epilepsy.

Key-Words: Epilepsy, psychosocial aspects, social dimensions.

## INTRODUCTION

Recently, there has been an increasing interest in the study of the psychosocial as-

pects of epilepsy (Danesi, 1984; Danesi, Odusote, Roberts, Adu, 1984; Levin, Banks, Berg, 1988), in both sociological and psychological components (cf. Danesi, 1984; Danesi et al, 1984). Much of that work was based on accidental clinical observations and pointed towards the existence of negative social attitudes, stereotypes, stigmatization and of social discrimination against the epileptic, in areas such as educa-

tion, work and interpersonal relationships. Social and psychological problems of persons with epilepsy seemed to have, in many cases, more painful effects than the seizures themselves (Kramer, Beier, Wittman, 1985) and the change of social beliefs and attitudes regarding epilepsy may contribute in a significant manner to the effectiveness of intervention programs, emphasizing the need to study them in a more systematic approach (Caveness, Merritt, Gallup, 1974; Diehl, 1975). Nevertheless, studies in this area are very scarce, when compared to those developed in the area of pharmacology.

Even though an exaggerated focus on this problem may produce iatrogenical effects of discrimination regarding epileptics (Fraser, 1978; Lehtovaara, 1983; Risch, 1978; Ryan, Kemper, Emlen, 1980), the analysis of those stigmas may contribute to more adequate medical interventions and psychological approaches (Awaritefe, Longe, Awaritefe, 1985).

In this paper different approaches used to study the psychosocial aspects of epilepsy are reviewed and the main social phenomena and psychological problems are outlined.

## SOCIAL ASPECTS OF EPILEPSY

During the past twenty years many public opinion surveys emerged which saught to evaluate the social attitudes regarding epilepsy and the psychosocial problems the epileptic face. The studies were carried out in Poland (Zielinski, 1974), the United States of America (Caveness et al., 1980; La Martina, 1989, Finland (Jivanainen, Uutela, Vilkkumaa, 1980), Netherlands (Commission for the Control of Epilepsy and its Consequences, 1977, in Thorbecke, 1987), Italy (Canger, Cornaggia, 1985) and in the Fede-

ral Republic of Germany (Thorbecke, 1985, 1987) and tried to evaluate the knowledge and causes of epilepsy as well as the epileptic's acceptance. The results of those surveys are presented in Table 1.

There is evidence to conclude that beliefs and attitudes regarding epilepsy are related to background culture and education and despite however the efforts accomplished in several countries, negative attitudes towards epileptics and lack of knowledge about the fundamental aspects of the disease persist (Awaritefe et al., 1985; Canger, Cornaggia, 1987; Gallhofer, 1984; Jivainainen et al., 1980; LaMartina, 1989; Thorbecke, 1987). In less developed countries, for instance, heriditibility, witchcraft, contagiousness and brain damage are the main perceived causes of epilepsy which highlights a general ignorance concerning the causes of the disease (cf. Table 1). Yet, positive attitudes towards epileptics can be found more frequently in younger and more literate public.

The studies demonstrated also that questions such as the individual's behaviour in real situations, the aknowledgement of the disease's symptoms and opinions on the treatment's outcomes as well as on the inheritance of epilepsy should receive more attention from research (Thorbecke, 1987). In fact, various of the cross-sectional studies referred were based on Caveness interview (Caveness et al., 1974) which meanwhile has been considered insufficient to establish the range of attitudes regarding epileptics (Rader, Ritter, Schwibbe, 1986).

The use and development of other methodological instruments made it possible to identify other dimensions of the problem. For example, the "Osgood's Semantic Differential" (Osgood, Suci, Tannenbaum,

### TABLE 1
### Social attitudes towards epilepsy

| QUESTIONS | COUNTRIES | Poland | U.S.A. | | Netherlands | Finland | Italy | | F.R.G. |
|---|---|---|---|---|---|---|---|---|---|
| | | 1974 | 1979 | 1987 | 1980 | 1980 | 1983 | 1985 | 1984 |
| | | % | % | | % | % | % | | % |
| 1. Have you ever heard or read about the disease called "epilepsy"? | Yes | 95 | 95 | 92 | 89 | 95 | 73 | 73 | 83 |
| | No | 5 | 5 | 8 | 11 | 5 | 27 | 23 | 17 |
| | No opinion | - | - | - | - | - | - | - | - |
| 2. Did you ever known anyone who had epilepsy? | Yes | 57 | 63 | - | - | 49 | 44 | 61 | 33 |
| | No | 38 | 32 | | - | 51 | 29 | 39 | 59 |
| | Not familiar | 5 | 5 | - | - | - | 27 | - | 8 |
| | No opinion | - | - | - | - | - | - | - | - |
| 3. Have you ever seen anyone who was having a seizure? | Yes | 77 | 59 | - | - | 45 | 38 | 52 | 32 |
| | No | 33 | 36 | - | - | 55 | 35 | 48 | 60 |
| | Not familiar | - | 5 | - | - | - | - | - | 7 |
| | No opinion | - | - | - | - | - | 27 | - | 1 |
| 4. Do you think epilepsy is a form of insanity? | Yes | - | 3 | 16 | 15 | - | 5 | 8 | 25 |
| | No | - | 92 | 80 | 66 | - | 58 | 79 | 73 |
| | Not familiar | - | 5 | - | 19 | - | 37 | - | - |
| | No opinion | - | - | 4 | - | - | - | 13 | 2 |
| 5. Would you object to having any of your children in school or at play associated with persons who sometimes had seizures? | Yes | - | 6 | | - | 19 | - | 11 | 23 |
| | No | - | 89 | | - | - | - | 80 | 77 |
| | Not familiar | - | 5 | | - | 81 | - | - | - |
| | No opinion | - | - | | - | - | - | 9 | - |
| 6. Do you think epileptics should be employed in jobs like other people? | Yes | - | 79 | | 83 | - | 51 | 70 | 80 |
| | No | - | 9 | | 10 | - | 11 | 15 | 18 |
| | Not familiar | - | 5 | | - | - | - | - | - |
| | No opinion | - | 7 | | 7 | - | 38 | 15 | 2 |
| 7. Would you object to having any of your children married with an individual with occasional seizures? | Objection | 51 | 18 | | - | - | - | - | 30 |
| | No objection | 35 | 68 | | - | - | - | - | 28 |
| | Don't know | 14 | 14 | | - | - | - | - | 42 |
| | No opinion | - | - | | - | - | - | - | - |
| 8. What do you think is the cause of epilepsy? | Brain disease | - | - | 19 | - | - | - | 10 | - |
| | N.S. disease | - | - | 12 | - | - | - | 28 | - |
| | Heredity | - | - | 11 | - | - | - | 11 | - |
| | Birth defect | - | - | 2 | - | - | - | 10 | - |
| | Other diseases | - | - | 5 | - | - | - | 1 | - |
| | Do not know | - | - | 49 | - | - | - | 16 | - |
| | Not familiar with epilepsy | - | - | - | - | - | - | 27 | - |
| 9. Do tou think epilepsy is a curable illness? | Yes | - | - | - | - | - | - | 37 | - |
| | No | - | - | - | - | - | - | 31 | - |
| | No opinion | - | - | - | - | - | - | 32 | - |

1957) and the "Behavioural Differential of Triandis" (Triandis, 1971) were recently used to identify and compare up to what point the public would socialize with epileptics and "cured" psychotics (Awaritefe et al., 1985). Another example is the case of the "Attitudes Towards Persons with Epilepsy Scale" (ATPE), developed by Antonak and Rankin (1982), a scale designed to evaluate five types of important factors to the social integration of epileptics: (a) attitudes regarding educational and social integration, (b) attitudes regarding employment, (c) negative attitudes regarding sexual behaviour, (d) open discrimination and, (e) passive tolerance.

In short, we may conclude that public attitudes surveys may constitute important sources of information concerning the complexity of the stereotypes and beliefs regarding the epileptic's behaviour. These stereotypes and beliefs are related to the way like epileptics cope with their epilepsy (Rader et al., 1986) and thus, they can offer useful information to the planning of interventions that aim to change attitudes and contribute to decrease its negative effects on the patients.

## EPILEPTICS PERCEPTIONS OF EPILEPSY

Recently, taking into account the public attitudes toward epilepsy, research focused on patients evaluation of their own condition (Danesi, 1984; Ryan et al., 1980; Beran, Read, 1980). Ryan et al., analysed the extent to which epileptics feel stigmatized by the disorder and observed that, in the U.S.A., the majority of the patients didn't feel so. On the other hand, studies carried out in less developed countries like Nigeria (Danesi,

1984) and Ethiopia (Giel, 1968) found that a great number of patients felt stigmatized by their disease and were unwilling to be identified by the public as epileptics. These results are similar to those of public surveys carried out in the same countries: while in the U.S.A. public attitudes have been becoming more and more posi-tive, due mainly to better public education, in Nigeria (Dada, Odekuu, 1966) and in Ethiopia (Giel, 1968), epilepsy is still per-ceived as a contagious disease and as a form of insanity which let us assume that perhaps epileptics' perception work as a reflexion of public opinion.

The evaluation of psychological and social difficulties among the epileptics has taken place in a subjective manner or through inadequate measures, sometimes developed and standardized among non-epileptic populations. The most common example is the use of the "Minnesota Multiphasic Personality Inventory" (MMPI) (Dahlstrom, Welsh, Dahlstrom, 1972), developed within a psychiatric context, to evaluate psychiatric aspects associated with epilepsy (Bear, Fedio, 1977; Matthews, Klove, 1986; Hermann, Schwartz, Whitman, Karnes, 1980). The instrument does not cover important psychosocial areas and includes items which may be interpreted as psychopathology, which really are phenomena associated to seizures disorders (Dodrill, Batzel, Queisser, Temkin, 1980). In addition, lack of definition of psychosocial problems, desagreement between authors and the difficulties in studying these aspects in an objective, reliable manner (Dodrill, 1983; Dodrill, Breyer, Diamond, Dubinsky, Geary, 1984; Dodrill et al., 1980), associated to inherent difficulties to classify the epileptic patient in terms of epilepsy itself, are some other methodological limitations in research.

In this context, Dodrill et al. developed a "complete test or inventory having several scales, which permits in a comprehensive, systematic and objective way the assessment of psychosocial problems" -- the "Washington Psychosocial Seizure Inventory" (WPSI) (Dodrill et al., 1980). The inventory consists of a total of 132 forced choice items and tries to identify gobal psychosocial difficulties among the epileptics in eight interrelated areas, according to the self-perceived usual feelings and actions of the individual: (a) family background, (b) emotional adjustment, (c) interpersonal adjustment, (d) vocational adjustment, (e) financial status, (f) adjustment to seizures, (g) medicine and medical management and (h) overall psychosocial functioning.

Several have been the studies developed with the WPSI which has been referred to as an useful measure to study the psychosocial problems of adult epileptics, offering a framework for the definition of problematic areas and enabling the comparison of different populations in cross-sectional studies (Batzel, Dodrill, Fraser, 1978; Dodrill, 1983) as well as the evaluation of progresses in longitudinal ones (Tan, 1983). More recently, the psychosocial dimensions of the WPSI have served as parameters to categorize and discuss the psychosocial problems of epilepsy (Levin et al., 1988).

Developments in methodology reflect a movement from a social to an individual emphasis of the study of phychosocial aspects of epilepsy. Recently, there is a larger concern with the cognitive representations of the patients of their condition and it is recognized that special attention should be paid to their ability to cope with the disease, in different areas of life. Therefore, we assume that the complexity of psychological and

social attitudes towards epilepsy suggest the importance of focusing research and intervention both on individual and environment elements -- the focus should be on the process of transactions between the epileptic and particular environments. The immediate physical, social and psychological context within which those transactions are constructed -- the situation, as well as how the developing person constructs or makes meaning of that situation are important dimensions of the process Brofenbrenner, 1986). Thus, the change of epileptics' life style should embody intentional educative actions among this specific population and also among their families and friends as well as interventions in other particular environments where epileptics live.

Self-Help-Groups and Self-Help-Organizations (also known as Self-Patient-Organizations) may play a preponderant role in these type of interventions. Self-Help Groups are small groups of voluntary people with a common problem in which professional aid cooperate only in special occasions and not full time. They are generally organized on a democratic collaboration of their elements and have as main goals promote exchanges of experiences concerning the disease and its consequences and to provide a better adjustment of the patients' needs in areas like social relations, public education and medical management. In Europe, there are several Self-Help-Groups in Finland, Netherlands, Italy (which can count on a national Self-Help-Organization), England, Switzerland, Belgium, West Germany, France and Austria.

Self-Help or Patient-Organizations are organizations of persons with a common disease in which the professional aid generally cooperate as a counselor and ocasio-

nally as a director (Vonk-Herwegh, 1988). In the U.S.A., besides these groups, there are 135 other types of organizations, some of which are autonomous, others members of the Epilepsy Foundation of America (Shaw, 1983).

The problems of interaction between epileptics and society and within the patients theirselves are not yet solved. Thus, it is important to continue, in different countries, the study of attitudinal and psychological dinensions associated with epilepsy to contribute to a deeper and more comprehensive analysis of this specific goup.

## 'SYCHOSOCIAL PROBLEMS OF 'PILEPSY

The study of psychosocial aspects of pilepsy puts in evidence the impact of the 'isorder on individual's life style. The sychosocial problems of epilepsy will be onceptualized by the authors in terms of hether the problem relates to the person's nowledge of and reactions to self, to family nd friends and to institutions of education nd employment.

### 'lf-relationship

Research on emotional adjustment of the ileptics highlights the relationship between specific factors of emotional disturnce (emotional and behavioural difficul-s, psychiatric and personality problems) d epilepsy. Despite some controversy nerated around contradictory results, there some consensus regarding the epileptic's ndency towards psychopathology and notional maladjustment (cf. Levin et al., '88).

Among the different complaints of the tients with seizures are depression, ten-

sion and anxiety, incapacity to think clearly as well as unspecific somatic troubles, hipersensitivity, low self-esteem, general insatisfaction with life and also difficulties in dealing with the seizures (Dodrill et al., 1980).

Dodrill, Beier, Kasparick, Tack & Tan (1984) compared studies carried out with adult epileptics in Canada, Finland, German Democratic Republic and in the United States of America and concluded that emotional concerns (inferiority feelings, negative reactions to the environment and progressive isolation) and difficulties in dealing with seizures (threat of a possible fit, fear that others will discover their epilepsy and resentfullness concerning seizures) were the most critical psychosocial issues, when compared with questions related to family background and medical management. In countries with better health policies and vocational rehabilitation programs, vocational and financial problems were bearly referred. Similar conclusions were found in another study recently carried out in the German Federal Republic (Kramer et al., 1985). Despite the existence of psychosocial problems common to epileptics of different cultures, it is necessary to analyse deeply possible differences in the degree and nature of those problems in order to develop more adequate research and interventions in this area.

Based on such studies, Tan (1986) compared epileptics, neurological cronical patients with multiple sclerosis and, a control group. A qualitative analysis of the nature of the emotional problems enabled to verify that, due to social stigmas, only epileptics were concerned with other people's discovery of their disease, which evidences the need for specific psychological and psychosocial interventions on these patients.

Other studies seek to analyze the prevalence of psychiatric symptomatology (e.g.:

psychosis, hysteria, anxiety and depression) and the prevalence of such symptoms in specific types of epilepsy (e.g.: in left temporal lobe epilepsy). Others, study the association between epilepsy and various personality traits and disorders, as for example: viscosity, hiposexuality, variability and unpredictability, lack of control, overemphasis on religious and philosofical concerns, hypergraphia, rigidness nonadapted presentation and dependency (cf. Levin et al., 1988).

The main question — whether an epileptic personality exists or not — still prevails. There is however, with few exceptions (Fenton, 1981; Hermann, Reil, 1981), major agreement regarding the possible personality pattern as a result of psychological stress, life-style restriction, adverse family environment and less as a result of the epileptic seizures.

Several researchers devoted their attention to violence and agressive behaviours and some studies empirically proved the direct association between agressive behaviours and epilepsy (Bear, Freeman, Greenberg, 1984; Blumer, Benson, 1982; Elliot, 1976; Sherwin, 1982; Whitman, Coleman, Berg, King, Desai, 1980). They stated, with other authors' opposition (Hermann et al., 1980; Pincus, 1980; Stevens, Herman, 1981), that agressive behaviour during seizures is stereotyped, simple, unsustained and non-intentional (Delgado-Escueta, Mattson, King et al., 1981).

Suicide rates were also studied and they are higher in the epileptic population than in general population (Levin et al., 1988). These results point towards the presence of low self-esteem, of negative affects and of depressive states which have been, on many occasions, associated with seizures.

The relationship between self-esteem and affect has deserved particular attention

in psychology. Althought there is some controversy whether the depreciative attitudes towards one's self (low self-esteem) are a symptom of depression, in general, low self-esteem appear associated to depressive affects. Recent studies carried out among non epileptic adolescents also reported an association between depressive affects, low self-esteem and suicidal ideas (Harter, 1988). Recently, Harter (1987) considered that relations between the perceived competence and the importance of success in certains areas of life, the insatisfaction with physical appearance and, the lack social support may be accompanied by low self-worth. In other words, depression may occur connected to negative attitudes regarding one's-self or as a reaction to loss or to lack of social support which consequently has different implications on research and intervention. The deepening of these aspects with epileptics would permit a better understanding of the epileptics relation with themselves as well as to decide the type of intervention which fits this type of problems and individuals more adequatly.

### Communication and Relationship with Others

There are few studies on the quality of epileptics' interpersonal relationships and the majority approaches this area in an adjustment perspective and not so much in a developmental perspective. In these studies, interpersonal adjustment is understood to be the person's ability to relate to others in an adequate form. Comfort in social situations, capacity to establish a reasonable number of social contacts, to have intimate friendships and to relate with the opposite sex are described as being important factors in the definition of this construct (Dodrill et al., 1980).

Research focused on family problems of interpersonal nature and on problems with

colleagues during childhood which may result in future psychosocial difficulties and, very specially, on problems of sexual adjustment and marriage (Baumer et al., 1981; cf. Levin et al., 1988; Shaw, 1983).

The relationship patterns in families with an epileptic member (cf. Ferrari et al., 1983) as well as their effects on the epileptic Baumer, David, Valentine, Roberts, Hugnes, 1981; cf. Commission, 1977; Lechtenberg, 1985; Ozuna, 1979) demonstrate the existence of different types of reactions and specific familiar behaviours, ranging from overprotection, guilt, fear(e.g.: that the child vould die during a seizure), panic, shock, age, confusion, embarassment, sadness, anxiety, depression and avoidment and, still, chaviours of ostracism, intolerance, overegligence, lack of collaboration in medical eatment, jealousy of brothers, changes in unily activities and low expectation levels garding the epileptic children. Generally, ie degree of stress experienced by the faily seems to be related with the way its ements cope with epilepsy. It is mostly the izures that contribute to such an environent (Dunlap, Hollinsworth, 1977). On the her hand, family reactions and attitudes fluence the way the epileptic perceives, es with and handles his/her disease, and ith the quality of his/her relationships. Ritie (1981) observed that epileptic children esent low involvment in the family inte-ction, when compared to non epileptic ildren. Various studies demonstrated, on : other hand, that feelings of guilt and of ssimulation are easily identified and also ose of withdrawal, denial, dependency and low self-esteem (cf. Levin et al., 1988). rthermore, expectations of the significant ters have an impact on the personal valorition of the epileptic and particularly the

supportive social attitudes may be a predictive reference point of the epileptics' self-esteem.

Self-esteem development may be promoted in different periods of existence by particular sources of social support (Harter, 1987, 1988). In childhood and adolescence, the influence of family support is so important as that of school colleagues, of friends and of teachers, because they constitute objective public sources of reinforcement and social support, perceived by the individuals as being necessary for self validation. Generally, they contribute to the individual's cognitive evaluation of his condition and for the resources to cope with it and further to the way the patient selects adaptative behaviours (Moss, 1966, in Jesus, 1988). In adulthood, however, the most important dimensions seem to be sociability, intimate relationships and the capacity to care for most significant others (Harter, 1988).

The studies concerning epileptics' interpersonal development should take into account life-cycle changes of the relationship' nature and contribute to a better understanding of this group's process of interpersonal relationship.

Other aspects that may be taken into account are *autonomy, interdependence* and *cooperation*, which are involved in the way the person directs the process of relationship with others, aspects recently studied in psychology (Selman, 1980; Soares, Campos, 1986). In the epilepsy literature, these aspects are not object of a systematic study. On several occasions, however, *autonomy* and *independence* are referred to and discussed. Max (1980), for example, refers that, when the epileptic seeks any attempt towards autonomy from his overprotective family by taking on social, sexual and occu-

pational initiatives, a serie of environment reactions emerge which seek to maintain the epileptic's role of diseased. Thus, the epileptics frequently feel ambivalent regarding their family dependence and their attempt of autonomy (Max, 1980).

*Cooperation* is another aspect of the relationship and is intimately related to the notion of independence. Cooperation deals with the capacity to participate with others in a project, which is a fundamental aspect of more intimate relations such as marriage. Lower rates of marriage have been reported among the epileptics, being though a phenomenon more common among men than women (cf. Batzel, Dodrill, 1984). Dansky, Andermann & Andermann (1980) concluded that the percentages are lower mostly when epilepsy occurs before the age of 20. This, according to the authors, suggests that sex role expectations and perceived abilities of marriage may be of importance in the decision to marry. Epilepsy may also be relevant, since it may disturb or prevent sexual relationships. The sexual behaviour seems to be inferior and to present more disturbance on the epileptics when compared with non-epileptic population (Max, 1980; Lechtenberg, 1984; Fenwick, Toone, Wheeler, Nanfee et al., 1985).

Batzel et Dodrill (1984) found that epileptics that never married and lived in dependent settings presented lower achievement in ability tests, when compared with those that never married and lived independently. This, according to the authors, is due to the fact that the first may have no one to turn to for solving of everiday problems.

Other interpersonal issues referred in the literature are isolation and withdrawal (cf. Lewin et al., 1988) which by turn are related to marriage and sexual behaviour. Once

again fear, anxiety, as well as other people's attitudes, namely of the family (Arangio, 1980; Ritchie, 1981), contribute to the behaviours of avoidance and withdrawal (Laaksonen, 1983). Hospitalization may also interefere with the opportunities of social interaction and equally contribute to social isolation (Lechtenberg, 1985). In the same way, low self-esteem may reinforce this pattern and reduce the possibilities of learning to interact in an adequate manner (Ozuna, 1979; Woodward, 1982). On some occasions this points towards the conclusion that the mental or personality disturbances are the main cause of the problems in this area, although there is no empirical evidence for this idea.

Bandura's theory of self-efficacy (1977, 1986 a, b), a psychological cognitive behavioural perspective, may contribute to analyse self-efficacy perceptions of the epileptics, in the area of interpersonal relationships.

Bandura postulates that the lack of efficacy perceived by the individual in coping with potentially aversive events may originate not only fear expectations but also avoiding behaviours. People that perceive themselves as inefficient under potential threats (which is the case of the epileptic seizures, that challenge the normal course of life) face such situations with anxiety, conjecture and avoid them. They may consider that their unsucsessful efforts evoke adverse reactions on the others and give up from already begined interactions when they don't know how to cope with unpredictable situations. The feeling of inefficacy may involve perceptions of loss of total control, abandonment and inability to make decisions which are some of the more common complaints among epileptics

(Dodrill et al., 1980). In this theory, there's an attempt to evaluate what the people believe they can accomplish under various circumstances, independently of the skills they posess or of the competences the task requires. Underlying is the idea that the human accomplishments are partially determined by self-esteem judgements, in other words, by the beliefs on 'how' and 'up to what point' I am able to use my competences correctly when I confront myself with realities in continuos changing, many of which contain ambiguous, unpredictable and anxious elements (which is the case of some of epileptics' life situations).

The epileptics seem unfit to overcome conditionalisms determined by potential sources of social support and relationships, proving themself unable and defensive. It would be important to study self-efficacy perceptions in the epileptics and how such judgements influence behaviour and development. On the other hand, interventions toward the self-efficacy of these patients may contribute to adequate their personal theories of success which are important to behaviour change.

Since studies emphasize the epileptics' difficulties and seizures compared with the importance that has been given to their general and specific potentialities and abilities (Fraser, 1978; Lehtovaara, 1983; Risch, 1978) the support to such difficulties has been conceived almost exclusively in a remediative and crisis perspective. Meanwhile research on relationships, in psychology, demonstrated that the interpersonal development process does not occur naturally nor does it emerge unilaterally: it is a process of construction in the individual's interaction with others and implies confronting new experiences, experiencing new roles and learning new behaviours (Soares, Campos, 1986). The support to relationship difficulties should be a systematic, intentional and educational intervention and should not be limited to the seizures moments or to seizures prevention. It is also meant to promote and optimize epileptics' autonomy and responsability when interacting with others, by: (a) developing adequate conceptions concerning relations with other persons or social situations which in turn are decisive of social behaviour and adaptation (Schantz, 1983), (b) becoming more able of evaluating and monitoring weaknesses and potentialities in relationships and, (c) becoming more able of setting goals and developing adequate skills (Campos, 1976; Soares, Campos, 1986; Nelson-Jones, 1986; Sprinthall, Collins, 1984).

*Relationship with Educational and Employment Institutions*

Vocational issues assume a central role in the literature regarding to psychosocial aspects associated to epilepsy. Among other problems, issues related to frequency and control of seizures and stress in achievement activities are referred as main problems (Fraser, Smith, 1982).

Research gives special attention to employment issues and seeks to evaluate the epileptics' perception of their job status such as job loss due to seizures and actual needs of vocacional counseling. Others analyze the personality caracteristics that may predict sucess or insucess in vocational area such as inteligence, the psychological and personality functioning, age, income and the neuropsychiatric functioning (cf. Levin et al., 1988).

There is agreement that unemployment and underemployment caracterize many of the carrer status of adult epileptics (Broughton, Broughton, Guberman, Roberts, 1984; Dodrill, 1983; Fraser, 1980; Masland, 1983; Schneider, Conrad, 1983). The difficulties reported among the epileptics are situated mainly on the level of job-looking and job-maintaining (cf. Lewin et al., 1988; Wohrl, 1988) and, according to some authors, (Freeman, Gayle, 1978; Fukishima, 1978) they appear many times associated to seizures. Furthermore, even the epileptics which had complete vocational training designed to facilitate the integration into working life, presented difficulties in seeking and mainly in maintaining their jobs (Wohrl, 1988).

The effects of situational factors such as the complexity of occupational tasks and relationships' atmosphere at work may be at the base of the problems of occupational satisfaction and of commitment of epileptics regarding the organization. In turn, these issues may have a strong impact on absenteeism and on job changing (DeCotiis, Summers, 1978; Hachman, Oldham, 1975). Another aspect referred to in the literature is early retirement (Wohrl, 1988). Rish (1978) and Dodrill (1983) considered that vocational counseling may constitute an important source to these problems.

Rodin, Rennick, Denerll & Lin (1972) suggested that persons with epilepsy learn to expect failure and are conditioned to be less competitive. Recently, research from attributional perspective, which have received relevant attention within the area of social and applied psychology, emphasized that ascriptions of failure to stable (uncontrollable) causes (e.g.: seizures) decrease subsequent expectancies of sucess, whereas attributions of failure to internal causes (e.g.: lack of effort) maximize negative self-esteem related affects following the outcomesFosterling, 1989). In contrast, sucess attributed to variable factors (e.g.: luck) are maximized when internal factors attributions are made.

It is therefore possible that the epileptics attribute their lack of sucess to seizures, in this and in other areas of life, which may produce expectancies of future failures. Even when faced with successes, they may attribute them to chance and, consequently, changes in behaviour have lower probability to occur.

These issues have evident pratical implications to the individuals at risk (with a history of negative results) since, as consequence, avoidment and withdrawal response patterns may occur and epileptics may show reluctancy in getting involved in appropriate instrumental activities. It is then necessary to evaluate beliefs systems that mediate the epileptics' behaviour and consequently conceive and develop, in a more systematic way, interventions for its adequation.

Bad employment prospects leads the epileptic to meet generally dependent on other people, in the finantial point of view. This problem has served as theme in the literature but has not originated a systematic study. Generally, the epileptics receive state pensions or depend on the family to finantially manage their life (cf. Levin et al., 1988). Recently, Earl (1986) suggested that family therapy fosters the epileptics' finantial management coping skills.

The future tendencies of educacional and occupational worlds are not good prospects to persons with epilepsy: skills levels required for occupational success will increase, the content and complexity of jobs is being modified by technological change, average higher levels of education will be re-

quired for jobs success (Hoyt, 1988). It is also known that jobs which demand medium level competences will be less represented in the jobs of the future and that a more reduced number of workers without occupational qualifications will have access to jobs. On the other hand, the great need for workers to possess basic academic skills, problem solving skills and interpersonal skills and, also, general employability skills (e.g.: critical thinking precision and systems thinking skills) highlights the need of occupational actualization.

In minority populations such as the epileptics, the social bias and the stereotypes regarding the disease limit the opportunity of their vocational development. In general, epileptics are badly represented in the higher levels of training and in certain occupational fields and levels. Scambler and Hopkins (1980) verified, for example, that 21 out of 40 epileptics did not reveal their illness at work and, 43% considered that their careers has been inhibited by the stygma of epilepsy. The psychological pressures in this area may lead to rejection and to feelings of inferiority as well as to a weak occupational integration.

The global adjustment of the epileptics may be promoted if the vocational issues came to be object of study and treatment. Some empirical evidence in this area suggest that, in non-epileptic populations, the support to these problems contributes to promote self-esteem, self-discipline and social contacts (Boy, 1987).

It also seems evident that it is necessary to help persons with epilepsy to cope with other important vocational issues such as the elaboration and implementation of carrer projects, the problems of adjustment to the world of work and of preparation of retirement.

Institutional policies and practices should be changing to foster current educational and employment conditions for persons with epilepsy. Epileptics seem to be less favoured by the educational system and even more poorly by the occupational system than the non-epileptics and so will have to deal, in the future, with serious working difficulties. Education may constitute a priority and a more valid mean than others to reduce the social obliquity of this group which will imply an open educational system regarding acess and success, the existence of compensatory programs and of an adequate vocational training. Also, educacional actions should reflect the emphasis toward preparing persons for work in a generic sense instead of preparing persons for specific types of jobs (Hoyt, 1988).

## CONCLUSIONS AND IMPLICATIONS FOR INTERVENTION

We have reviewed and critiqued some areas of epilepsy psychosocial research that are relevant to an understanding of the impact of the disorder on the individual's lifestyle.

The value of social support and professional aid in providing assistance to self, environment and culture mix problems that affect persons with epilepsy were emphasized. Consequently, the authors suggested the importance to researchers and clinicians to consider the characteristics of the objective environment and of how epileptics translate the consequences of support into meaningful contexts. Further knowledge in this area should require a corresponding openess to different disciplines and methods of study, if the fullest depiction of the psychosocial dimensions of epilepsy is to be achieved. In this sense, the authors outlined some of the

contributions that psychology can offer to the study and intervention on this area.

Early interventions designed to help epileptics to develop supportive relationships within the family and in close social settings should be developed since they may have long term impact on epileptics' life style. Also, it is therefore important to study, in a more systematic approach, the lived, perceived and felt meanings epileptics give to their lives and whether thay accept an optimistic or a pessimistic estimate of their health and the consequences of these processes on afective, behavioural and cognitive dimensions of their personal development.

In short, the study of cultural and social educational life contexts of epileptics may contribute to the understanding of their identify formation and to answer questions such as: up to what point do epileptics experience more serious discontinuities in their identity development (due to seizures occurence and to psychosocial features of their disorder) than other populations? Up to what point do those discontinuities affect their health and life-style?

In countries in which there is no systematic study on psychosocial issues of epilepsy, despite efforts developed by epilepsy institutions, the development of systematic studies on the emotional, interpersonal and achievement issues of epileptics would permit the planning and the organization of professional services adequate to their cultural and educational background. This is why some efforts are been done by research groups in Portugal concerning the problems of epileptic's identity and their relationship with social environment. This work, bringing together experiences from from psychological and medical staff, is now under analysis and the results will be soon expected.

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