

Coping with refractory epilepsy

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We investigated the coping behaviour and its correlation with demographic and illness-related data, depression, locus of control and psychosocial adaptation in 40 patients with intractable epilepsy with primarily or secondarily generalized tonic-clonic seizures. Three standardized self-reporting questionnaires were applied, which are the Freiburg Questionnaire of Coping with Illness (FKV), the von Zerssen Depression Scale (D-S), and the IPC-questionnaire measuring generalized locus of control beliefs; the Social Interview Schedule (SIS), a semi-structured interview, was used to measure the psychosocial adaptation. Active, problem-focused and compliance strategies were predominantly used and regarded as most helpful. Hence, the epileptic patients use similar coping patterns reported in patients with other non life-threatening chronic diseases. The level of depression was moderate and in the range of other chronic somatic diseases. The use of coping patterns, which are regarded as maladaptive, was correlated with distinct depression, a small degree of internal locus of control beliefs and poor psychosocial adaptation. These results indicate the possibility to improve psychosocial adjustment by supporting effective strategies.

Key words: epilepsy; coping; depression; psychosocial adjustment; adults; neurology.

INTRODUCTION

Patients with medically intractable epilepsy may suffer from a variety of problems. These include the effects of the disorder itself (uncontrolled seizures, increasing memory disturbances), the therapy (need to take medications regularly, side effects of medication), and psychosocial aspects like restriction in vocational and recreational activities, stigmatization or altered perception of control^{1–7}. Beside these factors, the use of coping strategies has also been identified as having an influential effect on the psychosocial adjustment of these patients^{8,9}. Coping strategies are generally defined as the 'efforts, both action orientated and intra-psychoic to manage (i.e. master, tolerate, reduce, minimize) environmental and internal demands and conflicts among them, which can tax or exceed a person's resources'¹⁰. The main emphasis of the current coping research lies no longer on the factors which cause illness, but rather on the patient's resources and efforts which can support and restore psychosocial adjustment and health. This point of view is part of a change of paradigm from pathogenetic to salutogenetic conception¹¹ and aims at

understanding emotional, cognitive and behavioural efforts of patients dealing with an illness. This approach also contains an assessment of the effectiveness of coping strategies, providing the possibility to reduce ineffective and to support efficacious coping strategies by psychological intervention.

This study aims to investigate the use of coping strategies in people with chronic, uncontrolled epilepsy, and to explore the relationship between these coping strategies and demographic, illness-related, and psychosocial variables. The specificity and effectiveness of coping strategies have been studied in particular.

MATERIALS AND METHODS

Subjects

Subjects were obtained from an inpatient epilepsy unit in a rural area in Germany. Criteria for inclusion were that the person was 18 years of age or older, had medically uncontrolled epilepsy of at least 3 years duration with antiepileptic drug therapy and an average of one or

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more seizures per month during the preceding year including generalized tonic–clonic seizures. The seizure frequency had to be reliably documented during this year. Exclusion criteria were an inability to understand the directions or content of the sampling procedures, or serious co-morbidity. During the period of investigation, a total of 40 patients met these criteria and were included in the study.

Measures

Basic demographic and medical details were collected in all subjects. The acquired epilepsy variables included frequency of seizures, type of seizures, age at onset, duration of epilepsy, and, if defined, epilepsy syndrome. According to the average seizure frequency, the patients were divided into four groups: (1) one seizure/month, (2) two to four seizures/month, (3) five to 20 seizures/month, and (4) more than 20 seizures/month. Finally, the subjects were requested to complete three self-rating questionnaires and to answer one semi-structured interview.

Coping

The 35-item Freiburg Questionnaire of Coping with Illness (FKV-LIS)¹² measures current coping strategies with chronic diseases. Subjects rated their use of each coping strategy on a five-point, strongly-agree, strongly-disagree continuum. The five standard scales comprised 23 of the 35 items: depressive coping (F1), active and problem-focused coping (F2), distraction and self-affirmation (F3), religiousness and search for meaning (F4) and dissimulation and wishful thinking (F5). Additionally, two integrating scales were established on the basis of the assumed effectiveness of the coping strategies. They were categorized as ‘effective coping’ (F-EC) and ‘ineffective coping’ (F-UC)¹³. All scales range from one to five.

State depression

The Depression Scale of von Zerssen¹⁴ was employed. The 16 items are on a four-point, agree–disagree scale (0–3) and scores summed to provide an index of current depression, ranging from zero to 48.

Locus of control beliefs

The IPC questionnaire¹⁵ measures generalized locus of control beliefs providing a six-point scale (1–6) for each of the 24 questions. The three standard scales characterize internal locus of control (I-scale), other powerful locus of control (P-scale) and chance locus of control (C-scale) and range from eight to 48 each.

Psychosocial adaptation

The SIS (Social Interview Schedule)¹⁶ is a semi-structured interview that was used to assess the patient’s perception of his/her psychosocial situation during the four weeks before admittance to the hospital. The patient’s statements concerning partnership, family, economic and occupational situation, social contacts and leisure activities were rated on a four-point scale (1–4) by the investigator. High scores corresponded to a poor psychosocial adaptation. The items were integrated in two dimensions, ‘Social Management’ (M), and ‘Satisfaction’ (S), ranging also from one to four (sum of scores divided by number of items).

Analysis

The data collected were analysed using SPSS (Statistical Package for the Social Sciences, Version 4). The statistical analysis included calculation of mean values, standard deviations, Spearman rank correlation coefficients, *t*-tests, chi-squared tests and a covariance analysis with ‘age’ and ‘duration of illness’ as covariants.

RESULTS

The sample comprised 40 patients; 21 (52.5%) were male and 19 (47.5%) female. Patients ranged in age from 20 to 54 years, with a mean of 36.6 (± 10.1) years; 19 (47.5%) patients were married, 12 (30.0%) unmarried, six (15%) divorced and three (7.5%) widowed. The majority (72.5%) lived together with a partner or other persons in a household, 11 patients (27.5%) lived alone. Years in full-time education ranged from 8 to 19 years with a mean of 9.9 (± 2.3) years. Most of the patients (31; 77.5%) were unemployed or retired, nine (22.5%) were employed. Twenty-three patients (57.5%) were considered as having complex partial seizures and secondary generalized tonic–clonic seizures, four (10%) simple partial seizures and secondary generalized tonic–clonic seizures. The remaining patients were described as having primary generalized tonic–clonic seizures (6; 15%) or non-classified generalized tonic–clonic seizures (7; 17.5%). The age of onset ranged from 1 to 46 years with a mean of 20.2 (± 11.9) years. The mean duration of the epilepsy was 16.5 (± 9.4). Eleven patients (27.5%) had an average seizure frequency of one seizure per month, 13 (32.5%) had two to four seizures per month, 12 (30.0%) had five to 20 seizures per month and four (10%) had more than 20 seizures per month (Table 1).

Table 1: Patient group details.

Sex	
Males	21 (52.2%)
Females	19 (47.5%)
Age (years)	
Range	20–54
Mean	36.6
SD	10.1
Age of onset (years)	
Range	1–46
Mean	20.2
SD	11.9
Duration of epilepsy (years)	
Range	3–40
Mean	16.6
SD	9.4
Seizure frequency (stage)	
(1) 1/month	11 (27.5%)
(2) 2–4/month	13 (32.5%)
(3) 5–20/month	12 (30%)
(4) > 20/month	4 (10.0%)
Seizure type	
Primarily generalized	6 (15%)
Secondarily generalized	27 (67.5%)
Unclassified	7 (17.5%)

Table 2: Rank ordering and means of FKV scales.

FKV scales	No. of items	Mean (SD)
(F2) Active and problem-focused coping	5	3.3 (3.3)
(F3) Distraction and self-affirmation	5	3.3 (3.0)
(F-EC) Effective coping	19	3.0 (7.4)
(F4) Religiousness and search for meaning	5	2.6 (3.7)
(F1) Depressive coping	5	2.4 (3.8)
(F5) Dissimulation and wishful thinking	3	2.3 (2.7)
(F-UC) Ineffective coping	11	2.2 (6.7)

The mean depression state score was 13.3 (± 9.6) with a range from one to 43. This represents a moderately high depression, comparable with scores found in other chronic diseases¹⁴. The coping items with the highest ratings were ‘deciding to fight against the illness’ (mean 4.13), ‘following the doctor’s advice to the point’ (mean 4.05) and ‘placing trust in the doctors’ (mean 3.65). The most helpful coping strategies were considered to be ‘deciding to fight against the illness’, ‘seeking information about illness and treatment’ and ‘encouraging oneself’. Active and compliance-orientated strategies dominated also at the scale level. ‘Active and problem-focused coping’ and ‘distraction and self-affirmation’ had distinctly higher ratings than the other three standard scales. Hence, the integrating scale ‘effective coping’ showed a higher rating than ‘ineffective coping’. Rank ordering and means of the FKV scales are shown in Table 2.

Correlations between coping strategies, demographic and epilepsy variables

Epilepsy variables were found to be largely independent of sociodemographic data. Women were sign-

Table 3: Correlations of coping strategies with demographic and epilepsy variables.

	F1	F2	F3	F4	F5	F-EC	F-UC
Age	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.	n.s.
Duration of epilepsy	n.s.	—*	n.s.	n.s.	n.s.	—**	n.s.
Seizure frequency	—*	—**	n.s.	n.s.	n.s.	—**	n.s.
Depression	—***	n.s.	n.s.	—*	—**	n.s.	—***

* $P < 0.05$, ** $P < 0.01$ and *** $P < 0.001$.

ificantly older at onset of epilepsy than were men ($P < 0.05$), but beyond this there were no other significant gender differences in the demographic or illness-related variables. Depression state showed a significant correlation with seizure frequency ($r = 0.31$; $P < 0.05$). The coping strategies proved to be independent from age or other demographic data with the exception that women had higher levels of active, problem-focused coping than men ($P < 0.01$). A long duration of the epilepsy ($r = -0.32$; $P < 0.05$) and frequent seizures ($r = -0.39$; $P < 0.01$) were associated with low levels of active coping. Low levels of effective coping ($r = -0.42$; $P < 0.01$) and the use of depressive coping ($r = 0.33$; $P < 0.05$) were also related to a high seizure frequency, but not to the duration of the illness. As expected, depression state was highly significantly correlated with depressive coping ($r = 0.76$; $P < 0.001$), and furthermore, with the coping strategies dissimulating/wishful thinking ($r = 0.45$; $P < 0.01$) and religiousness/search for meaning ($r = 0.35$; $P < 0.05$) (Table 3).

Locus of control beliefs and psychosocial adaptation

The I-scale of the IPC-questionnaire, representing internality, had a higher ranking (mean 31.5 (± 6.4)) than the scales characterizing external locus of control beliefs (C-scale 27.7 (± 5.0); P-scale 26.5 (± 4.7)). The locus of control beliefs were not correlated with demographic data or illness-related variables such as seizure frequency or duration of the epilepsy. The P-scale, representing powerful others control beliefs, was correlated with the coping modes religiousness/search for meaning ($r = 0.59$; $P < 0.01$), dissimulation/wishful thinking ($r = 0.61$; $P < 0.01$), depressive coping ($r = 0.46$; $P < 0.05$), and the integrating scale ineffective coping ($r = 0.54$; $P < 0.05$).

The mean values for the SIS dimensions satisfaction (2.43 ± 0.5) and social management (1.93 ± 0.5), characterizing the psychosocial adaptation, were in the range of other chronic diseases¹⁶. Demographic data and the duration of the disease were not related to the psychosocial adaptation, but a high frequency of seizures

Table 4: Correlations of psychosocial adaption with other variables.

	Seizure frequency	Depression	F1	F-UC	IPC
SIS-S	—*	—*	n.s.	—*	n.s.
SIS-M	—*	—**	—*	—*	—**

* $P \leq 0.05$ and ** $P \leq 0.01$.

was connected with lower levels of social management ($r = 0.33$; $P < 0.05$) and satisfaction ($r = 0.31$; $P < 0.05$). High levels of depression were related both to an unfavourable satisfaction ($r = 0.32$; $P < 0.05$) and social management ($r = 0.47$; $P < 0.01$). Ineffective and depressive coping strategies were correlated with a poorer social management ($r = 0.35$; $P < 0.05$ and $r = 0.38$; $P < 0.05$, respectively), and ineffective coping was also correlated with lower levels of satisfaction ($r = 0.36$; $P < 0.05$). Finally, chance locus of control beliefs were associated with an unfavourable social management ($r = -0.63$; $P < 0.01$) and the correlation between satisfaction and social management was highly significant ($r = 0.63$; $P < 0.001$) (Table 4).

DISCUSSION

This study shows that patients with chronic epilepsy use predominantly active, problem-focused and compliance-related coping strategies. Furthermore, the patients considered these strategies as most helpful for psychosocial adjustment to the illness. Depressive and denial strategies were less frequently used and were associated with higher levels of depression and a poorer psychosocial adjustment.

The tendency for epileptic patients to use coping patterns which are considered to be associated with a favourable adjustment to the illness is confirmed by other studies. Upton and Thompson explored coping strategies and psychological adjustment in 137 people with intractable epilepsy⁹. In their study, the use of the coping strategy 'cognitive restructuring' was associated with a better psychological adjustment, which was defined as high levels of acceptance of the illness, and low levels of depression, anxiety, and social avoidance. In contrast, the use of the strategies 'self blame', and particularly 'wish-fulfilling fantasies' was correlated with a poor psychological adjustment. Snyder investigated 107 patients who had had epilepsy for 1 year or longer⁸. Two coping strategies (problem-orientated and affective-orientated) and their relation to epilepsy-specific stressors, trait anxiety, and perception of health were investigated. Problem-orientated coping strategies were more often used than affective-orientated strategies. The former were more often found in patients who perceived their health as good, and less frequently in patients with high trait anxiety scores.

A comparative study investigating patients with gynaecologic cancer, diabetes and epilepsy with the same measure (Zürcher questionnaire of coping with illness (ZKV)) found predominant similarities between the subgroups with high levels of imperturbability relating to the illness, particularly in the epileptic patients¹⁸.

Although chronic epilepsy may be considered as an illness which is associated with specific stressors (e.g. uncertainty about the occurrence of seizures, loss of control during seizures), there are currently no indications for a specific coping pattern in epileptic patients. Hence, epileptic patients use the same coping strategies as found in patients with other chronic, non-rapidly progressive and non life-threatening diseases^{19,20}.

Furthermore, the levels of depression, control orientations and psychosocial adjustment revealed no epilepsy-specific features and were comparable with other chronic neurological and non-neurological diseases. With respect to social management, we found no evidence of social isolation or ostracization as reported in previous studies^{6,21}.

Not only a high seizure frequency, but also the use of coping strategies which were considered as ineffective were correlated with high levels of depression and poor psychosocial adjustment. This may be judged as a further indication for the maladaptivity of these coping strategies.

As this is a cross-sectional correlational study, however, no statements about directions of causality can be conclusively made. Furthermore, the cross-sectional design does not take the process-character of coping into consideration, which is emphasized in the transaction model by Lazarus and Folkman²². An additional methodological flaw in this study is the problem of confundation, which was particularly relevant to the investigation of psychological features. Stressors, coping strategies and adaption criteria may be difficult to differentiate. As an example, depression could be regarded as a symptom of the epilepsy (stressor), as a maladaptive coping strategy or as a consequence of a poor psychological adaption. Finally, the relatively small sample size and the selection of the sample from inpatients of a Neurological Hospital limit the conclusions which can be drawn from this study.

CONCLUSIONS

Several results from this study may have practical implications for health professionals dealing with epileptic patients. Firstly, the correlations between high seizure frequency and both high levels of depression state and a poor psychosocial adjustment suggest that the most important aim of the therapy is optimal seizure control.

Secondly, this study has demonstrated that the use of different coping strategies is associated with different levels of emotional adjustment. It is evident that certain strategies were related to good and others to poor adjustment. Hence, psychological interventions which can convert ineffective coping strategies into efficacious strategies may prove beneficial for the patients. The primary goal should be to enhance the active and rational coping strategies. The patient's trust in the doctor and his medical advice, and the receipt of information about the illness are among the most important coping strategies in epileptic patients. If this is taken into consideration in the interaction with the epilepsy patient, the cooperation between physician and patient, and the compliance of the patient, could be improved.

ACKNOWLEDGEMENTS

The authors would like to thank the staff of the Neurologische Klinik Hephata (Director: Professor Dr Maier-Ewert, Schwalmstadt-Treysa, Germany) for their help with data acquisition and P. Zoefel, Hochschulrechenzentrum, University of Marburg, Germany, for his advice regarding the statistical analysis.

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