Living with a Hidden Handicap - a Qualitative Study of Coping Strategies in Chronic Epilepsy.

Caisa Hofgren, John Eric Chaplin, Eva Norlin - Bagge, Sven G. Carlsson* and Kristina Malmgren
Institute of Clinical Neuroscience, Dept. of Neurology, Sahlgrenska University Hospital, and *Dept of Psychology, Göteborg University, Sweden.

Hofgren, C., Chaplin, J. E., Norlin-Bagge, E., Carlsson, S.G., & Malmgren, K. Living with a hidden handicap – a qualitative study of coping strategies in chronic epilepsy. Göteborg Psychological Reports, 1998, 28, No. 8. Semistructured interviews were conducted with 28 persons who had been operated because of pharmaco-resistant epilepsy, in order to describe their perceived illness-related demands and coping strategies. A qualitative method was used to analyse the interviews. From the interview data it was possible to describe the demands that patients experienced in connection with epilepsy. These concerned three main areas: the medical symptoms of epilepsy, the perceived own understanding of epilepsy and the social reactions to the disorder. A large number of coping strategies were described and categorised into a taxonomy. A total of fifteen categories of coping were identified and characterised as problem-focused or emotion-focused. Patients showed an overall problem-focused coping approach and the most reported strategy was “campaign against”, which was referred to by 27 of the 28 interviewees. The most common of the emotion-focused strategies was “deny oneself”, mentioned by 19 of the 28 interviewees. Most interviewees used a wide range of strategies and often alternated between different strategies.

Keywords: Pharmaco-resistant epilepsy, epilepsy surgery, psychosocial problems, handicap, coping strategies.

Introduction

Epilepsy is a condition with recurring unprovoked seizures often resulting in a temporary impairment of consciousness which may be
associated with physiological, behavioural or cognitive reactions. Between the seizures most individuals are neurologically unaffected but may be affected by the psychological and social consequences of having epilepsy. It is well recognised that the medical manifestations of epilepsy are only part of the individual experience of epilepsy. Epilepsy is also associated with a broad range of psychosocial problems which are related both to factual limitations and to perceived stigmatisation. These problems vary in nature with the individual and the level of impairment. Studies indicate that people with epilepsy have lower self esteem (Dodrill, Batzel et al. 1980; Collings 1990). Other signs of psychological distress include high rates of depression (Robertson and Trimble 1983), anxiety (Dowds, McCluggage et al. 1983; Betts 1988; Gumnit 1991), suicide (Barraclough 1981; Upton and Thompson 1992), lower rates of marriage (Levin, Banks et al. 1988) and greater degree of unemployment and underemployment (Chaplin, Floyd et al. 1993) than the population at large. For some individuals the psychosocial effects of epilepsy may have a greater impact upon the individual than the seizures themselves (Wright 1976; Thompson and Oxley 1993).

Successful seizure control can be achieved in the majority of patients with antiepileptic medication. The psychosocial consequences of epilepsy for the individual may be lessened by successful medical treatment (Jacoby 1995). However, even where seizure control is complete the individual may still experience psychosocial problems associated with ‘having epilepsy’ (Jacoby 1995). This reflects the fact that adjustment to a chronic condition is not merely a function of the severity of the disorder (Charmaz 1983). There are mediating factors of a psychological and social nature which determine an individual’s reaction.

For some patients with pharmaco-resistant epilepsy, surgery is a valuable treatment option. Irrespective of seizure outcome patients may experience problems in dealing with their changed circumstances or re-establishing their role in life in relation to others. Living without seizures and the consequent life changes may be as problematic as learning to live with unfulfilled expectations of epilepsy surgery (Ferguson and Rayport 1965).

The concept of coping has been the focus of much interest in research concerning how people adapt to stressful life events. According to Lazarus and Folkman (Lazarus 1991) there are two main types of coping, problem-focused and emotion-focused. However, although coping responses have been shown to be important in the mediation of psychological effects of a chronic illness (Hallberg and Carlsson 1991) there have been few studies examining the relationship between epilepsy and coping (Scambler and Hopkins 1986; Scambler and Hopkins 1990; Upton and Thompson 1992). In the study by Upton and Thompson, an adapted version (Felton, Revenson et al. 1984) of the ‘Ways of Coping Checklist’ (Folkman and Lazarus 1980) was used. The authors concluded that coping affects emotional adjustment to epilepsy and that certain strategies are more efficacious than others. However, they also noted that coping is not always a conscious or deliberate response. This is essentially a similar conclusion to that of Scambler and Hopkins (Scambler and Hopkins 1986).
who looked at the specific case of coping with the stigma of epilepsy (the hidden distress model) via qualitative research methods. The present study aimed at exploring the nature of coping in epilepsy by using a qualitative and non-directive approach. Through a qualitative method it would be possible to grasp the complexity and the process aspects of how coping strategies are used in relation to adjustment to the psychosocial demands of epilepsy. The purpose was to explore how people with a history of chronic epilepsy handle their situation after epilepsy surgery and to describe the coping patterns identified in order to get a better understanding of the psychological impact of epilepsy.

**Patients and Methods**

*The study population*

The study is part of a broad follow-up of patients who have undergone epilepsy surgery at Sahlgrenska University Hospital. The epilepsy surgery program started in 1987 and the present study concerns the first thirty-three patients, operated between 1987 and 1990. Three of these patients were not asked to participate in the study, two because they lived too far away and the third because of a chronic psychosis due to which he was not considered able to take part in an interview session.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Patient Data (N=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>Age at interview (years)</td>
<td>36.7</td>
</tr>
<tr>
<td>Duration of epilepsy (years)</td>
<td>20.1</td>
</tr>
<tr>
<td>Interval epilepsy surgery – interviews (years)</td>
<td>3.5</td>
</tr>
<tr>
<td>Males/females</td>
<td>11/17</td>
</tr>
<tr>
<td>Marital status at time of the interview</td>
<td>N</td>
</tr>
<tr>
<td>Living with spouse</td>
<td>17</td>
</tr>
<tr>
<td>Living alone</td>
<td>8</td>
</tr>
<tr>
<td>Living with parents</td>
<td>3</td>
</tr>
<tr>
<td>Sources of financial support at time of the interview</td>
<td>N</td>
</tr>
<tr>
<td>Working full time/part time</td>
<td>20</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td>Sick leave or disability pension</td>
<td>6</td>
</tr>
</tbody>
</table>
The remaining thirty patients were approached by a letter explaining the nature of the study and informed consent to be interviewed was obtained from twenty-eight patients.

The patients’ mean monthly seizure frequency before the operation was 22.5 (range 1 – 151) The type of operation was temporal lobe resection in 26 cases and frontal lobe resection in two cases. At the time of the interview 12 patients (42.9%) had been seizure free for an average of 3.2 years (range 1 – 5.1 years) while the remaining 16 patients (57.1%) still had recurring seizures.

**Interview procedure**

A semi-structured interview schedule was developed broadly based on the topic areas of the Epilepsy Psycho-Social Effects Scale (EPSES). The topic areas of the EPSES were derived from in-depth interviews of people with chronic and newly-diagnosed epilepsy who were encouraged to talk about the problems they experienced with epilepsy (Chaplin, Yepez-Lasso et al. 1990; Chaplin, Floyd et al. 1993). The interview structure in the present study varied depending on the issues of greatest importance to the interviewee, however certain main problem areas were covered in each interview. These were the individuals'

- attitudes to epilepsy
- experience of seizures
- outlook on self
- perception of the view and attitude of others to epilepsy
- employment situation
- leisure time activities
- perception of cognitive problems

The respondents were given the opportunity to express their feelings, attitudes and views concerning how they ‘lived with epilepsy’. The problem areas were used as guidance for the interviewer and where responses where not forthcoming, open ended questions were formulated. Interviewees were asked to give a description of how they experienced the problem areas and to communicate their thoughts and actions considering the significant difficulties they experienced and how they tried to solve the problems.

The interviews were conducted by two of the co-authors (CH and EN-B). They lasted between one and two hours and were tape recorded in their full length with the exception of one interview where written notes were taken. The taped interviews were transcribed verbatim.
Content analysis of the interview data

Table 2
Examples of Experiences and Reactions to Epilepsy. Content Analysis of Interview Data

<table>
<thead>
<tr>
<th>Core quality</th>
<th>Dimensions of experience</th>
<th>Behavioural/cognitive actions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shame</td>
<td>“it's a feeling that has been learnt”</td>
<td>“don't know what to do”</td>
</tr>
<tr>
<td></td>
<td>“to myself and others”</td>
<td>“pretend I’m asleep”</td>
</tr>
<tr>
<td>Responsibility</td>
<td>“everybody can have this”</td>
<td>“you don’t think it can happen to you”</td>
</tr>
<tr>
<td></td>
<td>“you cannot help it”</td>
<td>“I spoke about it”</td>
</tr>
<tr>
<td></td>
<td>“not being ashamed”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“nothing to be hypocritical about”</td>
<td></td>
</tr>
</tbody>
</table>

The approach taken to the interview analysis was qualitative and phenomenological. The interpretation was systematically based on interview content according to the grounded theory approach (Glaser and Strauss 1967). The respondents were encouraged to talk about their subjective experience of epilepsy and their emotional or cognitive reactions to that subjective reality (Giorgi 1995). All statements were numbered for future reference. The methodology used for content analysis of the interview data was an adaptation of the open coding system described by Glaser and Strauss (Glaser and Strauss 1967) and included the following steps:

1) Different important aspects of the experiences and reactions to epilepsy were identified in the data by the first author (CH) (see examples in table 2, column 2).

2) The core quality of the experiences and reactions were then identified and grouped under headings (see examples in table 2, column 1).

3) Core examples of the respondents' behavioural or cognitive actions/coping strategies in relation to the earlier described main problem areas were identified for each interview transcript. These core examples were written in full and collected in the form of a summary for each interview (see examples in table 2, column 3).

4) The summaries of the interviews were analysed in random order to determine the characteristics of the actions/coping strategies taken, i.e. those examples revealing major characteristic similarities were grouped together to form a taxonomy of coping strategies. This taxonomy was then applied to the next randomly selected interview transcript and evaluated.
for its adequacy to describe the data. Where the taxonomy was found to be inadequate new categories were added or core actions were grouped differently. This process was continued until no new categories emerged. This technique has similarities to the constant comparative method (Glaser and Strauss 1967; Strauss and Corbin 1990).

5) The taxonomy was then applied to all 28 interviews and each interview transcript was evaluated on the basis of the complete taxonomy.

6) Eighteen of the 28 interview summaries were analysed by a second investigator (JE C) and this analysis was compared to the initial analysis. Where differences in analysis emerged these were discussed and resolved.

Results

Problem areas

From the analysis of the interview data a great deal of variation in the descriptions of the problem areas emerged. Some major themes were evident from the data and are presented below. Attitudes to epilepsy were in some cases dominated by a marked non-acceptance, but in other cases the diagnosis appeared to be a fairly well-integrated part of life. Many of the interviewees gave very elaborate descriptions of how they experienced the manifestations of their epilepsy. The arbitrary nature of the disease and the great amount of disappointment after having had a seizure were clearly expressed. One of the interviewees said that he always believed the most recent seizure to be the last and he experienced an enormous disappointment and sadness after each new attack. The medical symptoms and circumstances of epilepsy were domains that seemed to continue to puzzle the individual. Though there were expressions of a negative self-image and even of self-destructive tendencies, there were also abundant examples of confidence and acceptance. The feeling of insecurity was however often present.

Perceptions of the reactions of other people to epilepsy emerged as another problem area. Several interviewees demonstrated some difficulties dealing with the reactions of other people. Almost all declared that they had sometimes met a negative attitude or lack of understanding from other people. A number of interviewees had the experience of being harassed at school because of epilepsy, which they said had had a strong negative impact on their lives. When discussing their employment situation and leisure time activities, the attitudes of others often emerged as the greatest problem. Some individuals felt restricted at work because they couldn’t take part in certain tasks, due to the risks involved or because they did not have a driving licence. There were also a number of interviewees who felt they were excluded from employment because of the disease.
Cognitive problems were commonly reported in the interviews. Mostly the complaints concerned memory problems, but a few interviewees experienced speech difficulties or attentional difficulties. Feelings of fatigue or of being easily exhausted were also frequently reported.

**Categorising the problem descriptions**

The given data structure was in the form of demands placed on the individual (the problems of dealing with epilepsy) and the actions taken in dealing with those demands (the coping strategies). Although the focus was to identify a taxonomy of coping strategies used by people with epilepsy following surgical treatment, characteristics of the demand side of the structure also emerged. Three major themes appeared which helped to characterise the coping strategies.

1) **Perception of medical symptoms.**  
Respondents' descriptions of having to deal with the seizure itself and with the cognitive limitations related to the condition and to side effects of the medication.

2) **Perception of one's own reactions to epilepsy.**  
Respondents' descriptions of having to deal with their own reactions to having epilepsy, their loss of self-esteem and belief in themselves.

3) **Perceptions of others' reactions to epilepsy.**  
Respondents' descriptions of having to deal with reactions and limitations from their surroundings, including both other people (family, friends and strangers) and the social and working environment (e.g. employment and driving regulations).

**Categorising the coping strategies**

Following the completion of the analysis procedure a final taxonomy of strategies was constructed from the interview statements. Fifteen main strategies were identified, listed in Table 3.

The possibility of using Lazarus’ (Lazarus 1991) concept of emotion-focused and problem-focused coping as a dichotomy was explored and is illustrated in Table 4.
Table 3
Taxonomy of Coping Strategies

1. Being active/struggling for normality
2. Knowledge-seeking
3. Making practical adaptations
4. Looking for alternative treatments
5. Looking for psychological support
6. Campaigning against/being open about epilepsy
7. Resignation
8. Day-dreaming
9. Deny oneself/withdraw
10. Finding a meaning to life
11. Pretending everything is all right/putting up a brave face
12. Rationalisation
13. Hoping
14. Concealing the epilepsy
15. Indifference

Table 4
Main Types of Coping

<table>
<thead>
<tr>
<th>Emotion-focused strategies</th>
<th>Problem-focused strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resignation</td>
<td>Being active/struggling for normality</td>
</tr>
<tr>
<td>Daydreaming</td>
<td>Knowledge-seeking</td>
</tr>
<tr>
<td>Deny oneself/withdraw</td>
<td>Making practical adaptations</td>
</tr>
<tr>
<td>Finding a meaning to life</td>
<td>Looking for alternative treatments</td>
</tr>
<tr>
<td>Pretending everything is all right/putting up a brave face</td>
<td>Looking for psychological support</td>
</tr>
<tr>
<td>Rationalisation</td>
<td>Campaigning against/being open about epilepsy</td>
</tr>
<tr>
<td>Hoping</td>
<td></td>
</tr>
<tr>
<td>Concealing the epilepsy</td>
<td></td>
</tr>
<tr>
<td>Indifference</td>
<td></td>
</tr>
</tbody>
</table>

A taxonomy of coping strategies

Coping is generally not a consciously defined activity. Therefore “coping strategies” were often poorly formulated and changed in character depending upon a number of different variables. The taxonomy described below is therefore a description of the most prominent strategies. Where possible the categories will be illustrated with quotes from the data.
Being active/struggling for normality. Statements within this category generally indicated an acceptance of the diagnosis, but the patients also clearly demonstrated that they found it important to "be like everybody else" and they made attempts to obtain a "normal life". Interviewees would attempt to stop the epilepsy from interfering with their lifestyle. This can be seen in the interviewees’ descriptions of how their family did not make exceptions for them. However, some individuals took the standpoint of "normality" to a degree approaching denial. Example statements from the interviews include: "My point of view is that you have to live your life even if you have a handicap. You cannot be totally isolated because of it..." or "Many people said that how could I dare to go bicycling, but I have been cycling all these years and I find it very difficult, yes, difficult to give up cycling. And like I say, what will happen will happen anyway".

Interviewees also made a point of the importance not to have a fixation on the seizures or "make a fuss" of them. This can be said to refer to a more "active" aspect of acceptance, that is, that the patient is aware of the fact that he or she has a chronic disease and has this under consideration when decisions are made in daily life and that the person does not intend to "give in" because of the disease. Strategies of this type were sometimes used by the individual as a way of handling a single attack, by diminishing its importance and more generally by thinking that having seizures did not create too much trouble in their lives.

Knowledge-seeking. Some strategies were used to gain more knowledge and understanding of epilepsy in general. Interviewees learnt a great deal about their own attacks, their type of epilepsy and about treatment alternatives. Interviewees gave examples of trying to find explanations of why seizures occurred and what the seizures looked like, to the extent of wanting to see their own videotaped attacks. They expressed the need for receiving reliable information. Example statements from the interviews include: "I had a need to know what I had been doing and I always asked after the seizure: What have I done? What was the attack like?" or: "Both my husband and I read about it because we wanted to know... what the different causes could be, about the course and the treatment and everything".

Making practical adaptations. The interviewees described a large number of practical arrangements and adaptations. They consistently reported how they made changes in their living as well as in their personal adaptations, trying to deal with their epilepsy. Examples from the interviews are: "...so I take notes every day if there has been some special incident. So when I don’t remember what it was I can go back ... I have tried to learn not to be under stress". "If I felt a seizure was about to occur, I would lay down..." "I didn’t want to have a seat in the middle of a cinema or theatre house."

Looking for alternative methods. This category is based on one interview: trying to find help and treatment from outside the ordinary health care system, such as homeopathy or acupuncture. Example from the interview: "I believe there should be many alternatives ways offered in order to get help. I have been making use of acupuncture, zone therapy,
and homeopathy. With this and through taking vitamins and minerals, I have been able to feel that I'm well."

Looking for psychological support. Collected into this category are strategies which describe the active seeking of support from others. One most often turned to the family, but sometimes to work mates or to an organisation. The local Epilepsy associations were essential supportgivers. The respondents described the support both in terms of its psychological quality and in terms of practical help. An important aspect is to be fully accepted as a person with epilepsy. For instance some individuals rely on a family member, most often the spouse, to provide information on epilepsy. Some patients described an ambition to work through the experience of having epilepsy, that is to talk to others with the same diagnosis or to a person considered to have some insight, as this meant an opportunity to share the experience. Statements from the interviews include: "Then I thought it was important to tell my new friends..., about it, it is important to tell people..." "It's important to have someone to talk to about this, someone outside the family because it's very tough for the family". "I had work mates, whom I felt I had confidence in and to whom I could talk, and that is important..."

Campaigning against/being open about epilepsy. This category consists of statements in which there was a description of fighting against the disorder and of not "giving in" to it. The dominating strategy here was to be open and outspoken about the epilepsy. Example statements from the interviews include: "I have told this to the people that I found I had to tell it to..." "But I have done the kind of things... that maybe not everybody has done, I have travelled a lot and that went very well, in spite of having epilepsy". Statements here also indicated a need to challenge some of the consequences that were perceived to restrict normal living. Expressions include: "... if it happens that you have a seizure and for instance fall into the water or something like that. The most important thing then is actually to go back into the boat the day after so that you don't become afraid."

Resignation. A different way of coping with the above mentioned aspects were declarations expressing an air of discouragement and despair demonstrating some of the hopelessness that may follow from the burden of having a chronic disease. However, these expressions could most often be said to indicate the patience with which people are able to endure this kind of problem in their everyday life. There were expressions like: "There are a lot of things you would like to do, but you can't". There were some interviewees who described ways to cope with their epilepsy by leaving the responsibility for their lives to other people or to the health care system. In some cases an underlying anger was apparent, but the feelings were completely repressed or expressed in terms of frustration.

Daydreaming. Some interviewees indulged in the daydream of not having epilepsy at all or a longing for the possibility of being more safe and independent, i.e. that the fear of having a seizure would not always be present. In this context respondents were aware of the prognosis, but there was a need for relief, represented by drifting away from reality. An
example from the interview: "...sometimes you can think of how wonderful it would be not to feel this anxiety."

Deny oneself/withdraw. Some interviewees denied themselves the opportunity to participate in certain activities. There were also many examples of social withdrawal, most often as a result of a conscious reflection. According to the data this type of strategy was often the result of problems earlier experienced in the relationships with others because of the epilepsy or because of the attitude held by the family or significant others earlier in life. There was a tendency to generalise from this aspect to many other domains in life. Statements in this category include: ‘I don’t know how you can get to know anybody, I know nothing about that because I have not made friends with other people since I was a child’ or: ‘I wouldn’t want to meet an epileptic person on the whole. That’s probably why I don’t think that other people want to be with me.’

Finding a meaning to life. Included within this strategy are efforts made to maintain a positive outlook. Examples from this type of strategy were given by interviewees who said that they had, in some cases, re-evaluated certain aspects of life and that the experience of having epilepsy had resulted in a better understanding of the suffering of others. There was also reference to feelings of growing personal maturity. Interviewees made statements like: "... it's like all this has brought something very positive with it,... you put a value to things in a different way". or: "You have to try to have a positive outlook...” A few interviewees said that they had turned to religion to help them find meaning in their lives.

Pretending everything is all right/putting up a brave face. Interviewees referring to this type of strategy were trying to diminish their own problems as compared to others. They also believed that their lives could have been much worse. Other examples of this strategy are when the interviewees try to protect significant others by reassuring them that they are feeling well. Statements from the interviews include. ‘I didn’t say anything to my mother. ...I hoped I wouldn’t have to. I wanted to spare her, so to say”... ‘I also know that there are others who are worse off...

Rationalisation. Interviewees gave some examples of rationalisation in thinking and behaviour especially in consideration of interpersonal relationships. Such rationalisations where based on the way they perceived the attitude of others to them as being a person with epilepsy. Thus, the strategy was often used in social interactions. One interviewee described how complex his relations to others were, since he had once been hassled in school because of his epilepsy. He often rejected others, but also expressed that he very much wanted to get closer to others.

Hoping. This is a strategy which involves less fantasy than daydreaming. The hope is based on some reality and therefore should be classified as different from daydreaming. For example a person may hope that a new medication will be available in the future or that the advance of medical science will bring new forms of treatment. Some individuals expected to achieve things, such as driving a car, and had a realistic expectation that they could be seizure free for long enough to gain a licence. The belief in a better future often appeared in the interviews.
Examples of statements from the interviews include: "Things happen all the time. And today I'm still thinking and hoping for something to happen in the future, so that I can get a little better. For now you will have to live with this. But you don't want to throw away the hope, you want to keep hoping. Hoping for a new medicine or other treatment."

Concealing the epilepsy. There were deliberate efforts made by interviewees to conceal or hide their disorder. For example they would choose not to talk about their epilepsy to others or they would give various explanations as reasons for seizures. Other interviewees hid the fact that they took medication. Example statements from the interviews include: 'I had to bluff when I was at the shipyard and say that I felt dizzy. Then I kept it secret, that was the mistake I made, so to say. I didn't say anything from the beginning, because I had heard that I could get fired and everything" or: 'I didn't talk about my epilepsy, not in the beginning" (when applying for a job).

Indifference. This strategy includes both descriptions of denying having epilepsy and of an indifferent attitude to the occurrence of seizures or to having epilepsy. Examples of statements from the interviews include: "Then I'm such a person, I believe, I don't go around thinking very much, instead I accept things the way they are. That's why I haven't found this to be so troublesome either, but looked upon it as it is". "I have been having this for 20 years now so I'm quite used to it. I don't care so much nowadays if I have it."

Ranking of strategies. From the data it is was possible to identify the frequency with which each coping strategy had been used and the strategies were ranked according to this (see table 5) The respondents often mentioned the use of several coping strategies, the range was between 3 and 11. The most common strategies could be classified within the category of 'campaign against' which could be applied to 27 of the 28 interviewees’ descriptions. It is also notable that problem-focused strategies were identified more frequently than emotion-focused strategies.

If the interviewees are divided into subgroups related to the outcome of surgery (seizure free or not seizure free), no differences are found among the four problem-focused strategies "campaign against", "making practical adaptations", "being active/struggling for normality" and "looking for psychological support" (Cf. table 5 which shows that these strategies were used by a vast majority of the patients). However, when considering the strategies with an emotion-focused direction interviewees who were not seizure free gave examples of using the strategies "daydreaming" and "finding a meaning to life" more frequently than those who had became seizure free. Otherwise there were no main differences in the descriptions of how respondents tried to handle their situation with epilepsy.
Table 5

*Rank Order of Coping Strategies N = 28*

<table>
<thead>
<tr>
<th>Coping Strategy</th>
<th>Nr of respondents</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campaigning against</td>
<td>27</td>
<td>96.4</td>
</tr>
<tr>
<td>Making practical adaptations</td>
<td>24</td>
<td>85.7</td>
</tr>
<tr>
<td>Being active/struggling for normality</td>
<td>21</td>
<td>75.0</td>
</tr>
<tr>
<td>Deny oneself/withdraw</td>
<td>19</td>
<td>67.9</td>
</tr>
<tr>
<td>Looking for psychological support</td>
<td>18</td>
<td>64.3</td>
</tr>
<tr>
<td>Resignation</td>
<td>16</td>
<td>57.1</td>
</tr>
<tr>
<td>Pretending everything is all right</td>
<td>16</td>
<td>57.1</td>
</tr>
<tr>
<td>Knowledge-seeking</td>
<td>13</td>
<td>46.4</td>
</tr>
<tr>
<td>Concealing the epilepsy</td>
<td>9</td>
<td>32.1</td>
</tr>
<tr>
<td>Finding a meaning to life</td>
<td>9</td>
<td>32.1</td>
</tr>
<tr>
<td>rationalisation</td>
<td>5</td>
<td>17.9</td>
</tr>
<tr>
<td>Day-dreaming</td>
<td>4</td>
<td>14.3</td>
</tr>
<tr>
<td>Hoping</td>
<td>3</td>
<td>10.7</td>
</tr>
<tr>
<td>Indifference</td>
<td>3</td>
<td>10.7</td>
</tr>
<tr>
<td>Looking for alternative methods</td>
<td>1</td>
<td>3.6</td>
</tr>
</tbody>
</table>

**Discussion**

The aim of this study was to identify the coping strategies people with epilepsy apply to the problems they encounter in living with epilepsy, in the interviews often referred to as a "hidden handicap". Three basic problem areas emerged from the data that the individual has to deal with in relation to living with epilepsy. These are: dealing with the medical symptoms of epilepsy; dealing with the personal reactions to epilepsy and dealing with the reactions of the surroundings. Fifteen specific coping strategies employed to deal with these problem areas were identified.

A number or the strategies were considered to have the quality of emotion-focused coping as defined by Lazarus (Lazarus 1991). These strategies involve how an individual interprets the situation with seizures and their consequences. Strategies sometimes had a passive value (e.g. resignation) and sometimes indicated the possibility of a positive change (e.g. hoping). Other strategies used could clearly be referred to as problem oriented, as when an individual was looking for social support or tried to alter their life style (e.g. making practical adaptations). As these latter strategies were directed towards the experienced demands and were aimed at promoting positive changes they are referred to as problem solving strategies. It is not possible to assign a definite positive or negative quality to any of these coping types; passive resignation may be the most adaptive strategy in the face of an overwhelming situation, and actively challenging the environment may ultimately result in being classified as awkward or difficult.
Lazarus and Folkman (Lazarus and Folkman 1984) defined coping as "cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person". In the past a major issue within the literature on coping and stress has been whether the individual’s response choice is dependent upon the given situation (process argument) or upon the characteristics of the individual (trait argument) (Lazarus 1993a; Lazarus 1993b). It is clear from our data that the coping response is dependent both upon the individual and upon the situation and that the choice is not stable. It has also been argued in the literature that flexibility in the choice of coping strategies is linked to better adjustment and greater extent of well-being (Lester, Smart et al. 1994). In our study a larger number of coping strategies seems to be more related to a larger number of diverse problems perceived by the individual.

The patients interviewed did not tend to use any 'global' strategy nor did they appear to invariably use the same cluster of strategies when confronted with problems. In every situation where the individual must confront a 'problem' with epilepsy a choice is made as to which response (coping strategy) will allow the individual to avoid or improve their situation for the future. Also apparent from the interviews is that individuals do not have an overall understanding of the actions they are taking nor the range of strategies they use. The patient can be said to have a 'tool box' of strategies. These strategies can be both active and passive. Some are tried and tested and tend to be selected first in order to solve any problem, others are less familiar, and still others are not in the 'tool box'. The choice of strategies may be guided by either emotion-focused or problem-focused interpretations of the situation. Any two given situations, which from an objective viewpoint would appear similar, are not necessarily treated as the same even by the individual. Both passive and active coping strategies may be applied to what appears to be similar problems.

One of the choices a person with a "hidden" handicap is facing is whether to be open about the problem or to keep it secret, concealing it from others. There are of course many situations where it may not be beneficial to tell others about the problem, but it may also be expected that the secret will turn out to be a burden for the individual and the strategy itself will become a handicap. The extent to which the epilepsy is hidden will be a factor in determining the choice of strategy.

Some strategies seem to be more commonly used than others. The most commonly identified problem-focused strategy was that of 'campaign against'. This indicates that even people with a long history of epilepsy do not merely accept the limitations posed by epilepsy. The second most commonly identified strategy was the struggle to 'be normal' by which they meant that they would not allow epilepsy to interfere with important goals in their lives. There were some patients who could be said to still challenge the diagnosis and its consequences, and they were determined not to "give in" to the disorder. Another interesting finding was that the patients who had been seizure free for several years following surgery, essentially still employed the same coping strategies as those who had
seizures. There may of course be several reasons for this. One interpretation is that people who have had epilepsy for more than half of their lives have 'grown up' with the disease and with the need to cope with the situation. Probably the patients had not left the diagnosis of epilepsy behind even though they had been seizure free for several years at the time of the interview.

At the same time, the most commonly used emotion-focused strategy was identified as 'deny oneself/withdraw', which contrasted to 'campaign against' because it means that the person has deliberately chosen not to fulfil some goals. They may for instance have decided not to have children because of the epilepsy. Surprisingly the analysis of the interview data revealed that these two apparently contradictory strategies were in several cases employed by the same individual. Contradictory strategies were identified in several of the responses of the patients. Coping is usually seen as belonging to our conscious cognitive repertoire, but the impression from the interview data is that the patients used the strategies without being aware of their potential or if one strategy would be more successful than another. They did not give a logical explanation in terms of experienced effectiveness of the strategy of choice, which implies that they do not have a conscious understanding of which strategies they are actually using. Where respondents sought to explain their choice of strategy they usually made reference to expressions of basic values concerning how to behave in life. Therefore it would appear that patients would benefit greatly from being aware of the huge variety of coping strategies, and how to benefit from them. We suggest this is a fruitful avenue for rehabilitation in people with chronic epilepsy. There are also implications that supporting the network of the person, encouraging the individual to take part in social activities and providing relevant information to the patient and the family will be interventions of great importance.

References


