Conversational displays of coping resources in clinical encounters between patients with epilepsy and neurologists: a pilot study

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Lay description
The degree to which epileptic seizures cause a person with epilepsy (PWE) to be disabled is not only explained by the severity or frequency of their seizures but also by their ability to live with them. The ability to deal with adversity is determined by a number of factors including the range of coping methods which the PWE has at their disposal. Some methods are helpful (because they reduce the impact of a problem) others less so. Unhelpful (or “negative”) ways of coping are associated with poor seizure treatment outcomes.

Different ways of coping are usually measured with self-report questionnaires. However, these questionnaires may produce a biased picture because people may find it difficult to judge their preferred coping styles objectively. For this reason, in this study we used Discourse Analysis in order to investigate nine interviews of PWE with their neurologist in order to detect direct references to coping with epilepsy (as narratives about it) but also linguistic and interactional features of the talk which may show how people are coping with their seizures. Our analysis was based on a close study of transcripts of the conversations between PWE and a neurologist.

Topical analysis – We started our analysis by looking at those parts of the transcripts which referred to the topic of coping directly. We found that all patients discussed this topic although the doctor had not specifically asked about it. PWE seemed keen to show that they were in control of their illness and able to lead a normal life. They did this by telling the doctor brief stories about how well they or the people they lived with handled their seizures. Some patients admitted that they had struggled with their seizures initially but that they were coping very well now. Several patients show how easy it is for them to cope with their seizures by talking about the difference between their own seizures and those of other with much more serious forms of epilepsy.

Interactional and linguistic analysis - When we looked more closely at how people talk about their epilepsy, a different picture emerged. Even those PWE who had said that they can lead a normal life despite their epilepsy showed by how they spoke of their seizure disorders that they were more concerned than they were happy to tell the doctor directly. Given that many claimed that epilepsy was no significant problem for them, it was surprising how often and how precisely some PWE described their seizures. Some kept coming back to different seizure experiences although the doctor had not specifically asked them to do so. Others avoided seizure descriptions, using technical terms for seizures, although the doctor asked them to talk of their experiences rather than just using medical labels. Some kept using pronouns instead of naming their seizures (they used words such as “they”, “them”, “it”). Several used metaphors for their seizures which described seizures as attacking the person from the outside or doing things to the person which they could not control or stop.
In summary, the closer analysis of how PWE talk suggests that they were more concerned about their epilepsy and found it harder to cope with it than they said directly to the doctor. It is possible that this observation is explained by the fact that patients feel the need to portray themselves as capable, strong individuals when they talk to a neurologist. This means that doctors have to learn to listen out much better for the more subtle signals patients send out which indicate that they are distressed by their seizures and need more help.

**Full report**

In chronic disorders, there seems to be a close relationship between coping and health-related quality of life. Coping with a chronic disorder such as epilepsy is a complex process involving both conscious coping behaviours, coping cognitions and contextual or situational factors. Co-morbid anxiety and/or depression in people with epilepsy (PWE) have been shown to be more closely linked to ‘negative’ ways of coping (such as escape, avoidance, distancing, confrontive coping). Moreover, it has been demonstrated that PWE can be trained to adopt more effective coping style for dealing with their illness.

In view of the clinical relevance of coping resources, it is important for doctors to be aware of their patients’ coping resources and to take coping styles into account when they make and communicate treatment decisions.

The questionnaires which are used to assess preferred coping styles may be biased because of their self-report format: subjects may not be fully aware of the psychological and affective problems they have in relation to a problem (as epilepsy), or they may try to portray an image of themselves which does not reflect reality. For these reasons, we decided to observe coping more directly by analysing how people with epilepsy (PWE) interact with their doctors and by describing the linguistic and interactional resources they use in these interviews. 

**Methods** - We analysed nine semi-structured interviews in which PWE talk to with their neurologist. We used Conversation Analysis and Discursive Psychology, two complimentary methodologies which have proven particularly effective in the analysis of doctor-patient interaction and can yield insights into the psychological underpinnings of behaviours and subjective symptoms. We analysed the narratives initiated by PWE in the interview which were related to coping as well as the linguistic and interactional features characterizing their talk. 

Narrative/topical analysis – Overwhelmingly (8/9 cases), PWE portrayed themselves as ‘copers’ by demonstrating their determination to deal with their illness. They offered narratives in which they showed how they were in control of their seizures and their lives, and how they could lead a normal life, although some acknowledged that epilepsy was a problem, especially at the beginning of the illness. These narratives are told from a subjective point of view and mainly report how PWE deal with their seizures, as well as how they succeed in integrating epilepsy in their lives. Coping is presented as a learning process and as a process of continuous adjustment of behaviours and habits in order to avoid or control the seizures. These subjective narratives are corroborated by reports about how people from their social networks (members of the family, friends, colleagues, etc.) react to them having seizures. All these narratives are used as ‘normalisation’ devices through which PWE
prove to the doctor that epilepsy is not particularly disruptive and it is part of their ‘normal’ life. A less significant number of narratives suggest that epilepsy can be frightening. This is evident, for instance, in narratives about acquaintances who have much more disabling forms of epilepsy or when they talk about the onset of the illness (when they did not know they had epilepsy and could not control it).

*Linguistic and interactional analysis* – The ambivalence found in the analysis of narratives is also present in interactional and linguistic features. All PWE take control of the interview from the very beginning by focusing on the illness and describing the seizures or, as it happens in one specific case, by explicitly describing the emotional problems related to it. The control over the interview is also evident when PWE avoid responding to specific questions which they find threatening: these are usually those which link epilepsy with emotional troubles. Even some aspects of their interactional behaviour therefore allow the PWE to display that they are in control and that epilepsy is not a problem, there are also features in their talk which seem to be at odds with this. Firstly, the descriptions of the seizures and the symptoms are characterized by extensive formulation effort (hesitations, self-corrections, reformulations, etc.), which would be unexpected if the seizures were not significant enough to warrant this effort. Secondly, seizures are frequently described through metaphors: in some of these conceptualise seizures as a fight or something which acts on patients over which they have no control. Thirdly, PWE may persistently use medical jargon (as “tonic-clonic seizures”), thereby avoiding a subjective description of the attacks. These and other linguistic and interactional features, suggest that PWE are not as much in control as they are trying to convey. Their seizures appear to be a more significant problem than they are keen to admit. This interpretation is not only supported by the observations that all patients who participated in this research had refractory epilepsy and had been admitted to hospital for video-EEG observation to allow their neurologist to optimise their seizure treatment. The HADS scores of the participants were also in keeping with this interpretation. Although none of the eight patients who completed the HADS had elevated depression scores, three were borderline for anxiety. The patient who did not complete his HADS score had to be referred for urgent psychiatric advice because he was acutely suicidal.

In sum, the communication behaviour of PWE seems to highlight two concurrent and contrasting aspects of coping with epilepsy. PWE try to portray themselves as being in control of their illness and treat their epilepsy as not being particularly problematic. It should be noted that this aspect emerges from that level of interaction which is easier to control by speakers whether consciously or not: i.e. offering topics and designing their narratives as they wish. However, the analysis of the interactional and linguistic features of the exchange which are not so easy to control and of which speakers are usually not consciously aware, hint at more significant emotional and adjustment problems to living with epilepsy in this patient group.