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

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1. Introduction

Neither seizure-related variables nor psychopathology fully explains the reduction in health-related quality of life reported by people with epilepsy (PWE) [1]. Several studies suggest that an individual's coping resources are an important determinant of their resilience to seizures [2–4]. Interest in coping dates back to early psychoanalytic theory, but has intensified since the 1960s [5], especially with the work of Lazarus [6–8], Billings and Moos [9,10], and Krohne [11].

Coping with a chronic disorder such as epilepsy is a complex process involving largely conscious coping behaviors, coping cognitions, and contextual or situational factors [12]. It is recognized that there are interactive relationships between coping strategies or processes, personality traits, and an individual's environment [13]. Coping is now thought to occur at different “levels.” On the one hand, it is affected by general dispositional features of the individual (i.e., engagement vs disengagement). On the other hand, coping behavior is determined by specific situations (“I turned to work to take my mind off the way things were going at home”).

In practical terms, the phenomenon of “coping” has been divided into a range of coping strategies, which have been characterized and measured using different assessment tools. Typically, researchers have allocated a range of coping strategies to a smaller number of dispositional coping preferences. One important division that has been suggested is that between problem-focused approaches (aiming to resolve or change the problem causing distress) and emotion-focused coping (attempting to change one’s feelings about the problem) [7]. Others have proposed a more general distinction between engaging and disengaging ways of coping [13]. One prominent form of disengagement has been called avoidance-oriented coping [5,14]. A third approach (based on factor analysis of questionnaire data) has distinguished between “positive” ways of coping (including planful problem solving, seeking social support, and accepting responsibility) and “negative” ways of coping (including escape avoidance, distancing, and confrontational coping) [15]. Although it is recognized that in some situations “negative” coping styles can be associated with less maladaptive outcomes (escape/avoidance can be an effective way of dealing with incurable illness, as it can alleviate psychological stress) [16], the preferred use of “negative” coping styles has been found to be associated with poor treatment outcomes in PWE [17,18]. In fact, comorbid anxiety or depression has been shown to be more closely linked to “negative” coping than to seizure-related variables [15]. In contrast, the use of “positive” coping styles (including learned resourcefulness and planful problem solving) is usually associated with lower levels of anxiety and depression in PWE [3,4,19]. Importantly, previous studies have demonstrated that PWE can be trained to adopt more problem-focused coping styles and that this is associated with improvements in functioning and quality of life [20]. Given that coping with epilepsy therefore

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appears to have clinical relevance, it is important that clinicians recognize their patients’ coping behavior and take their coping resources into account when they make and communicate treatment decisions.

Many of the previous studies of coping in PWE have significant limitations. First, there is no clear consensus about how coping styles should be operationalized, or even whether coping behavior can be categorized. This has led to the use of different scales, some of which do not meet acceptable psychometric standards [13]. Moreover, it is now widely accepted that coping is a variable phenomenon: faced with the same problem, individuals are likely to use different coping strategies at different stages of their disorder [8]. The same individual may use contrasting ways of coping if faced with two different (but similar) problems at the same time. Despite this, coping measures usually ask about a limited period (e.g., the last week) and encourage respondents to self-report how they have coped with specific situations (which may not be related to seizures).

For these reasons we wanted to study coping behavior in relation to seizures more directly by observing how PWE interact with a neurologist when they discuss their disorder. We used an approach inspired by two complementary interactional and linguistic analytic methods: Discursive Psychology and Conversation Analysis. The main focus of these methods is not the topical level (talking about coping), but the interactional and linguistic analysis of communication behavior. Unlike other qualitative approaches (such as Grounded Theory and Interpretative Phenomenological Analysis), these methods do not employ “coding and counting” to derive insights into the interactants’ thinking [21]. Instead, microanalytic approaches attribute meaning to the communication resources that interactants choose to employ as they talk to each other. Over the last 40 years, researchers using microanalytic linguistic and interactional analysis have shown that communication is not merely an exchange of factual details and that interactional resources are not chosen randomly, but that particular methods convey particular meanings and are used to implement specific social activities [22–24].

In the analysis of illness narratives, interactional and linguistic features using microanalytic methods can yield compelling insights into the psychological underpinnings of behaviors and subjective symptoms [25,26]. Previous sociolinguistic research has demonstrated that conversations between doctors and patients are not limited to talk about symptoms or treatments, and how microanalytic examination of the methods speakers use to tackle additional issues can provide a deeper understanding of their communication [27,28]. For instance, patients who consult a doctor face the challenge of presenting their concerns as “doctorable,” that is, as a legitimate health problem calling for discussion with a health professional. Patients commonly do this by reporting how they have been coping with their health problem themselves before deciding to see a doctor [29,30]. Presenting one’s concerns about a problem and looking for medical help is thus not a neutral activity but one for which patients feel accountable.

In this pilot study we explore whether microanalytic linguistic and interactional analysis can be used to observe and describe coping behavior in first encounters between PWE and a neurologist, and whether this form of analysis may enhance our understanding of how well PWE cope with their condition.

2. Methodology

2.1. Patients and interview method

Our study is based on the verbatim transcripts of video recordings of 30-minute clinical encounters between nine PWE and a neurologist (M.R.) they were meeting for the first time. They had been referred to the Royal Hallamshire Hospital, Sheffield, UK, for video/EEG monitoring to confirm the diagnosis of epilepsy (see Table 1 for demographic details). All final diagnoses were supported by video/EEG recordings of typical seizures. Patients were asked to complete the Hospital Anxiety and Depression Scale (HADS) immediately after the interview [31]. Patients were included in this study only if they did not have intellectual impairments making them unable to give their own informed consent or communication difficulties necessitating the presence of an interpreter or the use of communication aids.

The semistructured interviews were originally conducted for a study investigating the discriminating value of a range of linguistic features in the differential diagnosis of epileptic and nonepileptic seizures [32]. For a summary of the interview procedure, see Table 2. One important feature of these interactions is that the interviewer pursued a nondirective style of questioning which left patients free to choose how to deal with the given topic. The opening question did not mention epilepsy; the subsequent questions about different seizures (first/last/worst) gave PWE different response options. PWE were given the opportunity to talk about what they (rather than the doctor) deemed most relevant. Importantly for the present study, this questioning did not introduce the topic of coping, unless this was brought up by the patients themselves.

2.2. Analytic method

The data were examined using a microanalytic approach focusing on interactional and linguistic resources inspired by Discursive

Table 1
Patients: demographic and clinical details.

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Sex</th>
<th>Age</th>
<th>Duration of seizure disorder (years)</th>
<th>Video/EEG-confirmed diagnosis</th>
<th>HADS score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carl</td>
<td>M</td>
<td>50</td>
<td>31</td>
<td>ICE* with absences and GTCS</td>
<td>3</td>
</tr>
<tr>
<td>David</td>
<td>M</td>
<td>32</td>
<td>1</td>
<td>FE with SPS, CPS, GTCS</td>
<td>8</td>
</tr>
<tr>
<td>Henry</td>
<td>M</td>
<td>50</td>
<td>28</td>
<td>FE with SPS, CPS, GTCS</td>
<td>4</td>
</tr>
<tr>
<td>Jack</td>
<td>M</td>
<td>67</td>
<td>32</td>
<td>FE with SPS, CPS, GTCS</td>
<td>8</td>
</tr>
<tr>
<td>Ken</td>
<td>M</td>
<td>34</td>
<td>5</td>
<td>FE with CPS, GTCS</td>
<td>6</td>
</tr>
<tr>
<td>Pamela</td>
<td>F</td>
<td>43</td>
<td>31</td>
<td>FE with CPS; additional nonepileptic seizures</td>
<td>5</td>
</tr>
<tr>
<td>Peter</td>
<td>M</td>
<td>30</td>
<td>20</td>
<td>FE with CPS, GTCS</td>
<td>–</td>
</tr>
<tr>
<td>Samantha</td>
<td>F</td>
<td>45</td>
<td>27</td>
<td>FE with SPS, CPS, GTCS</td>
<td>–</td>
</tr>
<tr>
<td>Sandra</td>
<td>F</td>
<td>41</td>
<td>38</td>
<td>FE with CPS</td>
<td>6</td>
</tr>
</tbody>
</table>

* ICE, idiopathic generalized epilepsy; FE, focal epilepsy; SPS, simple partial seizures; CPS, complex partial seizures; GTCS, generalized tonic–clonic seizures; HADS, Hospital Anxiety and Depression Scale (0–7 = normal; 8–10 = borderline; ≥11 = clinically relevant).
Psychology (DP) and Conversation Analysis (CA). In line with these methods, we did not interpret people’s talk as a direct route to cognitive processes, but as a form of social action designed for a particular interactional context. We considered the acknowledgement of this context and its effect on interactional behavior key to gaining a full understanding of people’s utterances. DP focuses particularly on how psychological motives and intentions are negotiated in interaction [33]. CA focuses on the linguistic or conversational methods speakers use to attain specific interactional aims. CA is based on the close examination of transcripts including apparently redundant aspects of talk, such as silences, inbreaths, and overlaps [23]. The analysis is not based on preconceived categories, but on the sense the participants make of the interaction as it unfolds [22,34]. To allow close linguistic analysis, the transcripts contained information about minute details of talk including silences (which were timed), overlapping talk, interruptions, and cutoffs (self-interruptions) in line with CA conventions [35]. For the sake of clarity the extracts included here have been simplified. Names have been replaced by pseudonyms.

2.3. Analytic approach

In line with established practice in CA and DP, all analyses were carried out by a single linguist (C.M.) experienced in the use of microanalytic linguistic and interactional methods. The transcripts were approached in several distinct steps. First, we identified explicit narratives about or implicit reference to coping. Second, we identified the distinctive linguistic strategies associated with these narratives and the description of particular coping methods. Third (and most importantly), we identified and described conversational and linguistic features (i.e., types of communication behavior) that directly display coping behaviors at any point during the observed encounters.

3. Results

3.1. Patients

None of the patients included in this study had elevated depression scores on the HADS (median = 2.5, range = 1–7). HADS anxiety scores were normal in five and borderline high in three (median = 6, range = 3–9). One patient (Peter) failed to complete the HADS, but explicitly displayed evidence of depression and anxiety during the interview and was referred for an urgent psychiatric assessment after the encounter.

3.2. Topical/narrative analysis

3.2.1. PWE present themselves as coping well

The topic of “coping” was initiated by many patients, although it was not specifically addressed by the doctor’s questions. While acknowledging the seriousness of their disorder, eight of the nine PWE produced narratives in which they portrayed themselves as coping particularly well with the disorder, and as being successful in leading a “normal” life. This theme most often emerged at the beginning and end of the interviews, that is, at those places where the interview schedule left PWE with the greatest degree of freedom of topic choice. Our findings suggest that most PWE are keen to portray themselves as “copers” by expressing their determination to deal with the disorder (Samantha: “whether I like it or not I’m sorta facing it head on”) and by showing the doctor how they handle their seizures in everyday life. For instance, Sandra responds to the last question in the interview (“What do you enjoy doing?”) by reporting that she does many different things and that “it [epilepsy] don’t really stop me doing anything,” thereby stating explicitly that epilepsy does not affect her life at all. She corroborates this statement through her subsequent narrative about going swimming and the description of how she deals with the risk of seizures on those occasions (the lifeguard knows about her epilepsy and is “fine” about it). PWE may also provide examples of how members of their social networks (family, friends, colleagues) treat their attacks as something “normal” and nothing to worry about. In some of these narratives, the introduction of a third person can appear quite defensive, as if a witness was indeed needed to support the point made by the PWE. For instance, Sandra states that her family does not even notice the seizures any longer and act as if “it’s not happening.” Narratives of this type reinforce the idea that the PWE has managed to integrate epilepsy into his or her life and show that the disorder is not particularly disruptive, even in the judgement of others. As such, these narratives function as a “normalization device” (i.e., to communicate to the doctor that epilepsy has become a part of normal life).

3.2.2. Coping as a learning process

Four of nine PWE differentiated between the early phases of their illness—when they were not aware of what was going on—and their present situation, in which they know what to do when they have the seizures. Capably reacting to seizures may involve attempts to stop or delay them (Ken: “I tend to (0.75) sit’n (1.7) not block it out, I try to concentrate, (.) erm (3.3) it’s (1.3) I try and s (0.4) I s (.) I try and stop meself from (.) having a tonic clonic”), to ensure one’s safety during the seizure (Samantha, “we don’t really need an ambulance man so long as I’m .hh in a safe place”), or to maintain one’s social role. Jack, for instance, described leaving a meeting when he noticed that he was having a seizure. Coping is presented not only as something that has been learned, but also as a process of continuous adjustment of behaviors and habits to avoid or control the seizures, for instance, by avoiding different activities that might trigger the attacks.

Having learned to cope with their seizures, PWE presented themselves as knowledgeable about their condition. They volunteered illness theories (see Example 1 in Appendix), which were frequently in explicit contrast with medical explanations they had received (see Example 2). They could also display their willingness to take responsibility for their condition and make their own medical choices. Samantha, for instance, declared that she would undergo a hysterectomy if she could be assured that it would stop her seizures.

3.2.3. Topicalizing “control”

The topic of “control” over the seizures, as well as over other aspects of their life, was very much in evidence in these narratives. It
was featured in eight of nine encounters. “Control” appeared as an integral aspect of coping with epilepsy. The importance of this theme was supported by a number of observations. This topic is always initiated by the PWE (Samantha: “I never let it sorta... get in my way it was just a niggling little thing... initially”); it tended to recur during the opening phase of the interview (David: “I kind of stop these... and I’d be able to (1.2) really calm meself down... (0.6) and like (.) concentrate; and then I have to look up in the air... (0.75) just focus and just stop”), and was often reiterated and topological in different narratives during the rest of the encounters.

3.3.1. Control as an interactional resource

One important indirect way of communicating “control” over seizures involved PWE minimizing the severity of their seizures or distancing themselves from the possibility of seizure-related risks. Six of nine PWE displayed this communication behavior using one of several narrative moves. PWE could compare their current condition with more serious health problems they had in the past. They might contrast their present situation with that before they understood their seizures better or their seizures improved. They could also volunteer narratives about other PWE they know or have heard about, whose situation was worse than their own. Carl, for example, mentioned an acquaintance who had so many tonic–clonic seizures that he had to be accompanied by a carer, was taken to hospital, and eventually died because of his seizures.

3.3.2. Distancing from more severe epilepsy

One important indirect way of communicating “control” over seizures involved PWE minimizing the severity of their seizures or distancing themselves from the possibility of seizure-related risks. Six of nine PWE displayed this communication behavior using one of several narrative moves. PWE could compare their current condition with more serious health problems they had in the past. They might contrast their present situation with that before they understood their seizures better or their seizures improved. They could also volunteer narratives about other PWE they know or have heard about, whose situation was worse than their own. Carl, for example, mentioned an acquaintance who had so many tonic–clonic seizures that he had to be accompanied by a carer, was taken to hospital, and eventually died because of his seizures.

3.3.3. Linguistic and interactional analysis

3.3.3.1. Control as an interactional resource

The control that PWE seemed keen to exert over their condition was also evident in their interactional behavior: most PWE took active control of the interview from the very beginning. Six of nine participants volunteered seizure descriptions before the doctor had actually asked about seizures (see Example 2), three further patients did so with minimal prompting. One patient (Jack) explicitly clarified his role in the interview by making a meta-interactional enquiry (“It’s okay to go ahead and speak?”). PWE might also detail the process of discovery of their disorder without prompting. Samantha, for instance, described that for years she ignored the symptoms and did not think that they could be related to a condition like epilepsy.

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3.3.5. Topicalizing distress

The topical analysis of the interaction with one of the nine patients yielded a strikingly different result. Peter made his distress about epilepsy clear throughout the interview. He immediately and explicitly asked for help. Unlike the other PWE, his talk focused mostly on how hard it was for him to cope with his seizure disorder. He demonstrated his lack of control over his life (and his seizures) by crying for most of the interview. At one point he expressed suicidal ideation. However, despite his despair and the link he made between his emotional state and his epilepsy, Peter was quite clear that he was not particularly concerned about the seizures themselves: when asked explicitly about this, he denied that the seizures themselves were upsetting. What he could not cope with was his isolation (“I’m by myself... there’s nobody there who can help me.”) and the victimization which he attributed to having epilepsy (“People call me like spasso.”).

3.3.6. Summary of topical observations

Our analysis at the topical level reveals a degree of ambivalence toward (living with) epilepsy. Predominantly, patients seem keen to present themselves as actively engaging and “coping” with their disorder. Less prominently, epilepsy (at least if present in others or at the beginning of the disorder) is presented as a rather disturbing and dangerous condition.

3.3.7. Linguistic and interactional analysis

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The control that PWE seemed keen to exert over their condition was also evident in their interactional behavior: most PWE took active control of the interview from the very beginning. Six of nine participants volunteered seizure descriptions before the doctor had actually asked about seizures (see Example 2), three further patients did so with minimal prompting. One patient (Jack) explicitly clarified his role in the interview by making a meta-interactional enquiry (“It’s okay to go ahead and speak?”). PWE might also detail the process of discovery of their disorder without prompting. Samantha, for instance, described that for years she ignored the symptoms and did not think that they could be related to a condition like epilepsy.

This interactional behavior contrasts with that typically shown by patients with nonepileptic seizures who are more likely to force the doctor to take charge of the encounter by adopting a very passive role in similar clinical encounters [36,37].

PWE presented themselves as capable witnesses of their condition by producing seizure narratives including objective/factual accounts of their seizures (i.e. what actually happened) and descriptions of their subjective experience (i.e., what they felt or thought was happening during the seizures) (Example 1). The factual descriptions might be quite graphic and were sometimes supported by witnesses’ accounts and direct reported speech or thought (e.g., Example 1, lines 2, 3). When replying to the doctor’s specific prompts to talk about seizures (first, last, worst seizure), most patients showed strong alignment and cooperation with the interviewer’s interactional purposes, suggesting that ( unlike patients with nonepileptic seizures) [36,37], they did not find it difficult to focus on particular seizure episodes.

Occasionally, PWE also exerted control over the interaction with the doctor by expressing strong misalignments with him which were not only displayed at a topical level but were also communicated by the linguistic structures they employed. This was evident when the doctor went back to matters that had already been discussed or proposed, albeit implicitly, explanations or ideas with which the PWE disagreed (see Example 3). Sandra, for instance, repeatedly avoided a clear response to the interviewer’s inquiry about her worst seizure, implicitly denying she ever had a particularly bad seizure. Instead of answering the doctor’s inquiry, she tried to shift the focus to less threatening matters. When asked directly by the doctor about anxiety, she did not just answer by saying “No I don’t worry,” but chose to exclaim “Oh no....” This “oh” is highly significant, because it emphasizes the of-courseness, the almost self-evident truth of what’s being claimed, through treating the question as inappropriate [38]. She then uses formulation effort (self-repair, upgrade) to try and convince the doctor about how little the seizures bother her (see Example 3). The fact that seizures were actually quite problematic for this patient was indicated by narratives offered elsewhere in the interview and by her use of nonverbal communication resources. Throughout the interview Sandra maintained an extremely controlled posture. She persistently hid the arm that is most affected in the attacks under her blanket.

3.3.7.2. Microanalytic features suggesting epilepsy constitutes a challenge

The interactional devices discussed so far indicate that most PWE included in this study were keen to present themselves to the neurologist as resourceful individuals who take an active stance toward their seizures and handle their disorder well. However, closer examination of the transcripts revealed additional findings that suggest that some individuals may not be coping as well with their problem as they are trying to convey. First, it was very notable how prominently and with how much formulation effort (hesitations, self-repairs/self-corrections, reformulations, use of metaphors and meta-linguistic comments) most PWE discuss their seizures (see Example 4). The time and effort expended on the description of seizure symptoms seems at odds with the more explicit statements that the seizures are nothing (much) to worry about, especially when one considers that the interview schedule did not include a question asking PWE precisely to describe their symptoms during the seizures. The interpretation that the seizures are a more frightening experience than overtly admitted is supported by the metaphors PWE use when they talk about their seizures. Five of the nine PWE preferred metaphors that describe the seizures as an external (and somewhat threatening) entity that does things to them (and which they cannot control). The PWE were depicted as the victim of their seizures in some of these conceptualizations (see Table 3 for examples).
3.3.3. Avoiding talk about seizure symptoms

Although most PWE showed a readiness to describe subjective seizure experiences in great detail, some avoided focusing on potentially frightening seizure symptoms by the persistent use of medical jargon (such as “tonic–clonic seizures”), despite prompting to talk about their seizure experience. A more subtle form of distancing from seizure experiences could be demonstrated by resistance to the use of more explicit labels such as “seizure,” “fit,” “blackout,” or “attack.” This could take the form of an unusual use of pronouns (before “seizure” or an equivalent noun was first mentioned; see Example 5). Alternatively, PWE might use self-coined terminology (such as “reactions”; see Example 2, line 12). PWE could also pause immediately before saying seizure or employ discourse markers such as “you know” through which they explicitly avoid naming the problem. We have previously documented that these observations are much more common in patients with nonepileptic seizures [39], but they were also noted in three of the nine PWE discussed here.

3.3.4. Distancing from seizure experiences

PWE could also distance themselves from more threatening seizure symptoms by switching to the use of impersonal verbal forms (“you”) while describing their own seizure experience. This was particularly striking when they gave a subjective description (i.e., by using the pronoun I), then suspended the utterance, reformulating it using the impersonal verbal form you (Ken: “... stops at before I (0.25) before you pass out”).

3.3.5. Summary of linguistic/interactional observations

The linguistic and interactional analysis of these clinical interviews reveals that PWE use a range of conversational methods that implicitly support the “control” theme that characterized so many of the participants’ narratives. This concordance of topical and linguistic or interactional means of communication is not surprising [34,40]. However, closer inspection of the linguistic tools and interactional moves employed by PWE reveals some findings that are at odds with the speakers’ assertions that they are coping well and that their lives are “normal” despite the seizures.

4. Discussion

4.1. Main findings

Our topical, linguistic, and interactional analysis of first encounters between PWE and a neurologist yields discordant findings. The predominant finding at the more superficial topical level is that the PWE in this sample are keen to communicate that they are in control of their disorder. Eight of nine do not explicitly describe epilepsy as a particularly troublesome issue in their lives. This is particularly evident in those PWE who readily focus on their seizure symptoms without specific prompting in the opening phase of the interview. However, closer inspection of the data and the analysis of linguistic and interactional features points in a somewhat different direction: despite their unsolicited “normalization” attempts, it emerges that epilepsy actually is quite problematic for most of these PWE. Features such as the formulation effort associated with the description of seizures or the avoidance of talk about seizure symptoms and even the use of labels for the seizures communicate a degree of anxiety about seizures and their consequences. These contrasting features are present in all patients, although to variable extents.

Some of the features discussed here may communicate both themes simultaneously. For instance, we have suggested that the immediate focus on the seizures in the opening phase, the reiteration of seizure talk in the last phase of the interview when the doctor asks about what they enjoy doing, and the display of formulation effort in relation to the attacks are an implicit display of control or mastery over the seizures. At the same time, early and somewhat excessive talk about seizure symptoms seems at odds with the explicit suggestion that everything is “normal” and that the seizures do not represent a significant problem. In fact, in these respects, the interactional behavior of PWE resembles that of patients with panic attacks [41,42]. Patients with panic disorder have been found to detail and volunteer their anxiety symptoms very quickly when they talk to a doctor. If their seizure disorder was not a major problem, as most PWE are trying to convey in these interviews, they might not be expected to maintain such a clear focus on the seizures, especially when answering the first and last questions of the interview. It would also be unexpected for patients to volunteer a much greater number of seizure accounts than directly requested by the interviewer or to recomplete and elaborate particular seizure narratives. The sometimes laboriously described instance of the most minute details of the seizures offers further indication that seizures constitute a more significant experience than explicitly stated, especially when one considers how difficult it appears to be for PWE to share these experiences intersubjectively [43].

The contrast between the readily apparent message that the PWE is coping well with her or his disorder and the more subtle linguistic and interactional indicators suggesting that the seizures are actually rather frightening becomes particularly clear in some interactions. Samantha, for instance, displays topical, interactional, and linguistic features indicating that she is in control of the seizures and explicitly discusses how little the seizures interfere with her life. Then, in stark contrast with her previous talk, she declares: “... if someone could sort of... (0.75) gi’ give me umm... an indication that by having a hysterectomy or something and getting rid of my ovaries or something... I’d indeed put myself through that.”

At first sight it may be difficult to understand how PWE can communicate two very different concepts of their experience of living with seizures at the same time. One possible explanation is that they have more conscious control over the topical level of their communication with the doctor (e.g., the way they construct their narratives or the information they choose to include) than over its linguistic and interactional aspects. Given that all participants in this study were admitted to the hospital because they continued to experience seizures despite antiepileptic drug treatment, we suggest that the analysis of their talk at this less conscious, deeper level comes closer to their actual feelings about their seizures. In fact, one might conclude that these PWE discuss the themes of “control” and “normality” so prominently, because they experience their seizure disorder as a threat to their sense of identity and normality.

We should point out that our findings are closely connected to the methodology used. Previous sociolinguistic research has demonstrated that the systematic analysis of talk at different levels can yield a complex and at times apparently inconsistent understanding of patients’ illness experience and communication [25,26]. A study examining talk between women with breast cancer for instance examined the role of statements reflecting “positive thinking” (such as “you have to be positive”). It showed that rather than reflecting a
positive attitude toward coping with cancer, such statements were often the final part of a particularly painful self-disclosure that allowed other women to respond to the speaker [28]. Obviously, our findings are likely to be influenced by the nature and setting of the interviews. Jack's clarification of his role in the interview (“It's okay to go ahead and speak?”) is a particularly explicit indication that the participants were aware of the doctor's unexpected passivity. In the same way as it has been suggested that patients' apparent rejection of emotional etiological factors for chronic fatigue syndrome could be an artifact of the interaction between doctors and patients in the clinic [26], it could be argued that the prominence of the “control” and “normality” themes had something to do with the facts that these were first encounters between PWE and a neurologist and that the doctor did not direct the conversation more clearly. Although the doctor did not ask much, silence—the absence of uptake by the doctor—is, of course, an interactional device that is likely to have influenced the course of these conversations [24,40,44]. However, our experience with patients with nonepileptic seizures interviewed in the same manner shows that the preferred topic of the patients' elaboration is not a direct consequence of the interview setting or structure: whereas “control” and “normality” predominated in the encounters involving PWE, patients with nonepileptic seizures were much more likely to discuss the consequences and unpredictability of seizures in their lives, coming across as people in urgent need of help from the doctor [36,37].

4.2. Limitations

Our study has a number of important drawbacks. First, our observations are based on a small number of patients. This study was intended as a pilot. It was our intention to explore whether microanalytic linguistic and interactional analysis could be used to observe and describe behavior. We did not intend to describe interactional manifestations of coping in a representative sample of PWE. In fact, our patient group could not be considered representative of PWE in general: all patients had medically refractory seizure disorders with frequent epileptic seizures. All but one patient had focal epilepsies. Furthermore, the interviews were conducted in a rather unusual clinical setting, which may have influenced patients' communication behavior (during inpatient evaluation with video/EEG monitoring). We interviewed patients on only one occasion. We may have obtained different results if we had been able to analyze follow-up interviews. What is more, we cannot offer any external validation of our observations: it would be desirable for future studies to demonstrate correlations between interactional displays of coping, coping behavior in “real life,” and clinical outcomes. It would also be of great interest to observe how PWE cope with interactional challenges in clinical encounters when other people (such as friends and family members) are present.

5. Conclusions

Despite these drawbacks, this study illustrates that the more detailed linguistic inspection of transcripts of conversations between patients and clinicians can enhance our understanding of patients' thoughts and feelings about illness. This study demonstrates what focused sociolinguistic analysis can add to more conventional coping assessment tools such as questionnaires. Our results go some way to show why difficulties with coping and closely associated emotional disorders (especially anxiety and depression) are often overlooked in epilepsy clinics [45,46]. Given that PWE do not appear keen to display these problems, clinicians need to be particularly perceptive if they want to identify them. Our findings suggest that this means not only registering what patients say, but also paying attention to how they talk.

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Appendix A. Transcripts and analyses

Example 1: Samantha

Transcript

(Elicited seizure episode—first seizure)

1 S: umm .hh and I'd maybe (0.2) sort of fall asleep
2 watching TV and I'd wake up thinking oh god
3 I'm gonna be sick y'know .hh I'd just wake up
4 thinking .hh I need a wee I'm gonna be sick
5 and I were having a recurring dream that's
6 what I thought (0.5) that's what I thought it was
7 hh umm y'know and I'd sort of wake up .hh and then
8 I might go to sleep and it might happen again .hh an'
9 (0.25) I really thought there were something in
10 my subconscious that wanted to come out

Analysis

S. provides a factual/objective description (lines 1–4); followed by a subjective seizure account, (lines 5, 6) and personal illness theory (lines 9, 10).

Example 2: David

Transcript

(Open phase)

1 I: i wonder whether you could (0.2) tell me what
2 your expecTAtions were from (0.25) coming here
3 this week;
4 (0.75)
5 I: what you were hoping to get out of it?
6 (0.5)
7 D: h expectations? (0.75) erm .h (1.3) find out (0.25) why
8 (1.5) i get these (0.25) reactions;
9 I: mh,
10 D: ((smacks lips)) (0.25) and (0.50) i've had encephalitis
11 eighteen months ago, (0.50) and ever since (0.2) then
12 0.50) i've BEEN havin (0.25) a reaction (1.3) we
13 0.50) cos its with my chin they thought was
14 EPILEPSY; (0.75) er: (1.2) some of 'em MUST be,
15 0.6) i think are (0.50) some of 'em (-) i don't
16 think ARE cause i can stop 'em meSELF;

Analysis

D. responds almost immediately to the opening question (lines 7, 8); gives background information (lines 10, 11); use of self-coined terminology (line 12, “reactions”); describes his seizures (line 13); differentiates between different types of seizures (lines 14–16); and offers his own illness theory (in explicit contrast to the doctor's diagnosis) (lines 13–16).

Example 3: Sandra

Transcript

(Open phase). The patient has just told the doctor that seizures are more frequent when she gets anxious.
1 I: you say it’s more when you when you get more anxious (0.5)
more anxious about anything in particular about the seizures or-
3 (0.5)
4 S: ‘oh NO! I don’t worry about (0.2) DON’T really worry about
5 that because uh’ (0.2) I’m sort of used to em- (.75) (ge) after
6 so many years just (1.3) you get used to em (0.2) being there.

Analysis
I. suggests that the seizures may be a cause of anxiety. Not only
does S. deny this assumption, but her response is designed to dis-
play strong misalignment with the doctor: S. responds with some
delay (0.5-s silence in line 3) and prefaces the denial with “oh,” a
discourse marker displaying strong misalignment with the
assumptions carried by the question [38]. Further the denial is
marked by higher pitch (indicated by “’”), marked stress (indicated
by the capital letters), and animated intonation (indicated by the
exclamation mark). S. uses a reformulation (“I don’t worry about
(0.2) DON’T really worry about...”) and emphasizes the second
“DON’T” to upgrade the initial statement and produce an extreme
case formulation, reinforcing her claim that she does not worry
about her seizures [44].

Example 4: David

Transcript
(Open phase—symptomatology of the seizures)

1 D: mh, (0.75) you get pain, when it goes into a BIG
2 one: (0.5) (it=se or do ge- he-) i can get a headache
3 (0.25) from it; (1.0) (‘smacks lips) and .
4 this one i=ts not (0.25) i say a pain, but it=ts not
5 a LASTing pain, (0.25) it=ll- or a- (0.25) well it=ts a
6 f: a FEElin; (0.5) like (0.2) it=ts not a (0.6)
7 <<p> er er> (0.25) it=ts like a (0.5) (‘smacks lips)
8 you know (0.25) you kind=a you know it=ts (th)a-(h)appening;

Analysis
D. provides a description of the pain he feels during the sei-
zures. His talk is characterized by various pauses, hesitations,
self-repairs, restarts and reformulations (see especially lines 2, 5–
7).

Example 5: Samantha

Transcript
(Open phase). The patient responds to the first question:

1 I: can I ask you what your expect;ATion was when youhhh
2 <<p> came > (in here this week,)>
3 S: ‘hmm ((‘smacks lips) ‘ummm well=I was rather
4 hoping (_) to get to the BO:tton of it ideally
5 in the long term I’d like=I’d like to
6 <<laughter voice> BE CUR:ED> of it, ummmm
7 ((‘smacks lips)). ‘hmm uh=and=l=I understand that
8 they’ve (FOUND scarr:ing) on my=on my brain

Analysis
The patient responds to the question by referring to her disor-
der or seizures using the pronoun “it,” lines 4–6, thereby avoiding
the use of a clear labels such as “seizure,” “attack,” or “epilepsy.”
S’s use of the pronoun implies that she expects the doctor to know
what she is talking about.

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