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A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences
of interactions with doctors

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Abstract

The aetiology, symptoms, diagnosis and treatment of ME/CFS are controversial. Doctors and sufferers often have opposing perspectives, leading to problematic clinical interactions. We use discourse analysis to explore ME/CFS sufferers' descriptions of interactions with medical professionals taken from an asynchronous online sufferers' support group. Participants described themselves as experiencing limited medical care and attention but restricted criticisms to pragmatic or ancillary matters that were better grounded as "legitimate" than controversial areas. Participants also described themselves as active in seeking a resolution to their problems. They thus attended to possible negative attributions of being "complaining" or unmotivated to seek recovery.

Keywords

doctor-patient; discourse analysis; email interviewing; ME/CFS; support group

The phrase "Chronic Fatigue Syndrome" (CFS) refers to a condition in which sufferers complain of recurrent and unexplained fatigue. As a consequence, people who have CFS, otherwise known as Myalgic Encephalomyelitis (ME), describe themselves as facing a variety of impairments in daily functioning. The prevalence of ME/CFS has been reported as ranging from 0.1% to 2.6% of the population, depending on the criteria employed (Cairns & Hotopf, 2005). Other researchers have suggested that prevalence lies within the mid-range of these values, with 110,000 and 150,000 people being affected *per annum* in the UK (Cooper, 1997; Levine, 1997).

The study of ME/CFS is a complex matter, because some clinicians have expressed reservations about the physical status of this condition. Furthermore, there is disagreement between some clinicians and their patients regarding the extent to which ME/CFS has underlying somatic causes. Indeed, this dissent as to the nature and cause of ME/CFS extends to the illness label itself; clinicians have adopted CFS as the appropriate term, whereas sufferers prefer to describe it as ME (Prins, van der Meer, & Bleijenberg, 2006).

In the study of ME/CFS, factors ranging from immunological issues and neuroendocrinology to psychiatric complaints have all been examined. However, to date, no specific aetiology has been agreed (Afari & Buchwald, 2003). As a consequence, there is no unambiguous diagnostic medical test for this condition. Rather, diagnosis of ME/CFS is made on the basis of reported symptoms. These symptoms, which differ in nature and intensity between sufferers, might include reports of persisting or relapsing fatigue lasting 6 months or more, sore throat, tender lymph nodes, joint and muscle pain, headaches, post-exertion malaise, sleep disorder and impaired memory or concentration (Fukuda *et al.*, 1994; Holmes *et al.*, 1988; Schluederberg *et al.*, 1992). However, the medical account of the illness has been challenged by patient organisations such as the ME/CFS Alliance (Banks & Prior, 2001) in favour of their own experience-based explanations (for brief summaries of these controversies, see (Horton-Salway, 2001; Tucker, 2004).

There is a particular difficulty in this area: where doctors are presented with patients whose symptoms do not appear to have a well-defined organic cause, they might tend to downplay the importance of that illness. Indeed, where patients complain of medically unexplained symptoms, they

sometimes report that interactions with doctors are hostile or unsympathetic. Studies of ME/CFS patients have shown that they report most dissatisfaction in cases where the doctor has displayed scepticism about their condition (Page & Wessely, 2003). Such difficulties tend to determine the nature of doctor-patient interactions. Either the doctor and patient restrict their discussion to a limited range of symptoms, or there is a breakdown in the clinical relationship. In these latter cases, patients often turn instead to the help and guidance offered by patient-support groups (Stanley, Salmon, & Peters, 2002).

The contested nature of ME/CFS has also generated interest from qualitative researchers interested in the effects of this uncertainty. Three issues in particular have been pursued:

- (i) variability in the meaning and construction of ME/CFS;
- (ii) the warranting of knowledge claims about ME/CFS;
- (iii) dealing with the implication that sufferers might have a psychological rather than physical illness.

In relation to the first issue, (Bülow & Hydén, 2003) identified at least three “interpretative frameworks” that were used often simultaneously by patients, nurses and physicians in the context of a patient school. These included biomedical, biopsychosocial and non-medical or everyday explanations of the illness. Banks and Prior (2001) noted the use of similar accounts of the illness in their study of medical consultations. Their concern, however, was more specifically with the conflict between lay (biomedical) versus professional (biopsychosocial) accounts than with the frameworks themselves. They argued that consultations can become almost a political contest as different parties seek to define the “true” nature of the disorder.

Horton-Salway, however, questioned the implied distinction between lay and expert knowledge, because it rests on the assumption that there are discrete and identifiable forms of knowledge. She argued that “it should be the local production of expertise and experience and the legitimacy of related claims that is the focus of interest” (2001: 354). Thus, Horton-Salway’s analysis focused on the second issue, that is, how the clinical psychologist and sufferers establish their respective entitlements to make authoritative claims about ME/CFS. She showed that they do so in part by making relevant their membership of particular categories (as, respectively, expert in psychological intervention and as sufferers with a wealth of experience). She showed how expertise and experience were treated as forms

of knowledge that added credibility to a speaker's account, or undermined others' accounts of the condition. Similarly Tucker (2004) examined how sufferers constructed ME/CFS as a knowable, legitimate illness by drawing a contrast between a specialist doctor who can produce a correct diagnosis and "ordinary" GPs (General Practitioners) who lack knowledge of, and therefore the ability to recognize, ME/CFS in sufferers.

Other work has examined how participants employ conversational strategies such as the use of medical terms and corroborative evidence (Horton-Salway, 2001; Tucker, 2004; Bülow & Hydén, 2003) to establish the factual status of their claims that ME/CFS is a physical and therefore legitimate illness. In addition, Bülow and Hydén (Bülow, 2004; Bülow & Hydén, 2003) show how sufferers deal with the problem of legitimacy by co-constructing consensual views (e.g. in support groups) against which personal experience is compared. In this way, group experience is used to validate individuals' experiences.

The third issue concerns the inferential consequences of the questioned legitimacy of ME/CFS, and in particular the idea that it is primarily psychological, being related to depression, anxiety and psychiatric illness (Banks & Prior, 2001; Horton-Salway, 2004), and therefore not really a physical illness (Banks & Prior, 2001). For example, it might be inferred that sufferers are simply malingering (Horton-Salway, 2001), or they might be stigmatised because it is more socially acceptable to suffer physical illness (Tucker, 2004). All of these assumptions have negative implications for the kind of person one is taken to be, and they therefore constitute a threat to identity. This third strand of work has therefore focused on how sufferers deal with these problematic inferences. Some of these identity problems are dealt with through establishing the legitimacy and veracity of ME/CFS as a recognizable condition. However, sufferers might also produce attributions for the onset of the illness (e.g. contracting a viral illness), which simultaneously attend to their accountability for having it (Tucker, 2004; Horton-Salway, 2001). They also address negative identities directly, for example by constructing themselves as previously very active, thereby deflecting the possible inference that they are lazy or depressed (Horton-Salway, 2001). Finally, Banks and Prior show how physicians might be sensitive to these problems and deal with them by "by-pass[ing] psychological language" (Banks & Prior, 2001) and using instead the vocabulary of brain

chemicals (such as serotonin), which in turn opens the possibility of prescribing anti-depressants without talk of depression.

So, previous qualitative studies have revealed some of the ways in which the talk of clinicians and sufferers is sensitive to a number of interactional and inferential issues. However, it is noteworthy that most of this research has been conducted in face-to-face settings such as interviews (Horton-Salway, 2001; Tucker, 2004), support group meetings (Horton-Salway, 2004) or clinical settings (Bülow, 2004; Bülow & Hydén, 2003). In particular, few previous qualitative studies in the area of ME/CFS have focused on other forms of communication, especially those forms that are mediated by computer-based systems such as the internet.

This is an important omission, because internet communication is increasingly providing a useful domain for interactions and support among those who are chronically ill (Hardey, 1999; Nettleton & Burrows, 2003), or who have incapacitating physical or speech difficulties (Bowker & Tuffin, 2004). One of the reasons for this is that internet-based support groups do not involve the same constraints of time and availability that are associated with face-to-face support groups. This is important, because evidence suggests that inconvenient location and time are common reasons for individuals dropping out of ME/CFS support groups of this sort (Friedberg, Leung, & Quick, 2005). Moreover, just as the internet offers opportunities for patients, it also presents valuable opportunities to the researcher. Internet-based support groups do not face patients with the same constraints as face-to-face groups and thus offers researchers the possibility of recruiting from a wider range of potential participants. Furthermore, because internet-based research offers participants the opportunity to respond where and when they feel most comfortable and rested, and to break off and resume the research interaction as necessary, ME/CFS participants might be more likely to engage in such research than in research conducted within face-to-face settings. This is especially true of asynchronous forms of computer-mediated communication such as email-based support groups.

At this stage, it is worthwhile pointing out that computer-mediated communication reflects properties which are similar to spoken communication. Yates (Yates, 2001) found that the range of vocabulary used in such communication resembled oral vocabulary rather than written communication in terms of the more limited variance in words used. Fernback (Fernback, 2003) also concluded that computer-mediated

communication is a site of oral culture, although one that undoubtedly possesses print characteristics. Other work has addressed the functional properties of computer-mediated communication. For example, Antaki and colleagues (Antaki, Ardévol, Núñez, & Vayreda, 2005) and Lamerichs and Molder (Lamerichs & Molder, 2003) show how internet users, like participants in conversation, attend to issues of accountability in postings. With particular regard to ME/CFS, Guise and colleagues (Guise, Widdicombe, & McKinlay, 2007) found that sufferers using internet forums constructed accounts of their experiences in ways that closely resembled those found in face-to-face focus groups. This is not, of course, to say that communication found in forums such as internet-based support groups will be identical to, or completely representative of, that found in everyday conversation; rather that previous research in this area shows that a similar range of concerns and issues arise for those involved.

Moreover, previous findings suggest that internet-based sources provide particular advantages for the researcher in being suited to the collection of data on sensitive topics. In this respect, the anonymity offered by the internet allows individuals to express themselves and to negotiate identities in ways that are less available to them in other contexts. For example, Giles (Giles, 2006) in studying pro-anorexia websites, found that users commonly negotiated meanings of health and illness that were somewhat different and less constrained than those that might be expected in conventional medical encounters. In the case of the present study therefore, the possibilities made available by communications in internet-based data offered potential insights into aspects of the highly sensitive elements of their experiences. Given the sensitivity commonly found in interactional encounters between medical practitioners and patients in relation to this contested condition, internet-based sources provide one means for sufferers to discuss freely these perhaps most problematic aspects of their experiences.

Method

Data and participants

A total of 38 sufferers took part in this study. Data were collected from an internet-based ME/CFS support group. Initially, a message was sent to the group's email list inviting group members to participate in the research by responding to a series of open-ended questions. Those group members who chose to then provided responses to the research questions posed. These responses were available for other members to read and comment on. To this extent, discussion among group members was asynchronous

(i.e. not “real time”). Different group members responded to different research questions, with individual members responding to as many or as few questions as he or she opted to do. Data are quoted with spelling and punctuation features as they appeared in the original message.

The research was approved by the University of Edinburgh Department of Psychology Ethics Committee. The research process was carried out in accordance with the ethical recommendations outlined in the British Psychological Society’s Code of conduct and ethics (BPS, 2006). In particular, the Society’s four key ethical principles, respect, competence, responsibility and integrity, were adhered to throughout the research process. This involves the researcher in: respecting individual differences which arise, among other sources, out of disability; respecting confidentiality; ensuring that participants are given ample opportunity to understand the nature and purpose of the study and restricting observations to those occasions where participants could reasonably expect what they say and do to be observable by others; ensuring that participants understand their absolute right to withdraw from the study at any time; attending to the general interests of participants and giving due consideration to the research as it will be viewed by the participants; being honest and accurate in interactions. In order to meet these criteria, all respondents were given assurances of confidentiality and contact details in case they wished to withdraw at a later stage (none did). All personal and place names represented in the resultant data were changed.

The research questions that were emailed to the group members were open, general, non-directive and related to their illness. This analysis focuses on the responses in which participants described their interaction with health professionals, orienting in particular to the question “how do you feel about the way medical people treat you?” Six group members responded to this question.

Analytic procedure

Our methods are rooted in the theoretical assumptions that language has a social function and is a medium of social action (McKinlay & McVittie, 2008). Analysis therefore focuses on the ways in which descriptions of participants’ experiences are constructed, and on the functional relevance of those constructions within the local context. The form of discursive analysis selected here draws on insights from conversation analysis (Sacks, 1995) and discursive psychology (Edwards, 1997; Potter & Hepburn, 2003). The focus of discursive psychology is on the ways in which participants’ psychological concerns

and categorizations are bound up with interactional matters, and on the ways in which speakers in their discourse construct agency and accountability. For example, descriptions that are carefully designed to allow inferences to be drawn from them are potentially observable in written as well as verbal communication.

With this in mind, the analytic process was as follows. First, the six responses received were examined to identify recurrent patterns in the data. Somewhat surprisingly, only one of the six responses constructed the participant's experience in unqualified negative terms. In the other five cases, participants formulated their responses in relatively positive terms. These responses were therefore selected for further analysis. (The negative case is not analyzed here, but is discussed further below.) Next, these broadly identified positive constructions were subjected to a fine-grained analysis in which every detail of what is written is treated as potentially significant because it was written in that particular way and in that particular local context (Edwards, 1997). To this extent, the analysis was guided by the emphasis of discursive psychology on the action-orientation of language and on the way in which discourse is designed to accomplish particular effects (McKinlay & McVittie, 2008). In the analysis that follows, we examine in detail three of the five 'positive' responses to identify how participants' experiences of interactions with medical professionals are constructed and warranted, and the actions that are accomplished through these constructions.

Results

In the first extract, the discussion group contributor provides a description of his experience with a pair of medical professionals in response to the question "how do you feel about the way medical people treat you?" which was previously posted by the researcher onto the discussion board.

extract 1: Gordon.

1 I've been wondering what I
2 could reply to this. My GP*
3 seems to be sympathetic. He
4 certainly fills in the insurance
5 review forms for me without
6 question. My consultant (Dr G)
7 took my condition seriously and
8 prescribed amytrip, which helped
9 me a lot. He seemed very
10 interested in any information I
11 gleaned off the internet. My
12 only complaint is that he
13 refused to try out any treatment
14 that had not already been fully
15 vindicated by trials. So no
16 chance of trying out vit B12
17 injections, or ampligen, or
18 anything else. He is just s**t
19 scared of being sued. So I am
20 not holding my breath for any
21 treatment, as I know it takes
22 years for any trials to
23 complete.

* General Practitioner

Gordon's immediate orientation to the question is that it is one that requires a considered response. The effect of this is to set up the description that he subsequently provides as being otherwise hearable as problematic. These potential problems become evident in his descriptions of contact with two medical professionals, namely his GP and his consultant.

In referring to his GP, Gordon offers a qualified description of him as appearing to be "sympathetic". This description is juxtaposed with a description of the actions that the GP has carried out, namely that he has filled in forms as required without question. It is, however, noteworthy here that no mention is made of medical treatment or of care, the actions that normally would be expected of a medical practitioner. Gordon's description of his consultant, in contrast, does specify actions that the consultant took, based on his medical expertise. However, although Gordon goes on to indicate that the consultant displays appropriate levels of interest in what he has to say, the issue of relative expertise remains in question. It is noteworthy here that Gordon describes information about his condition as coming from him, and as being derived through a particular process, gleaning, which indicates the exhaustive and careful nature of the way in which he conducted his search for information. Gordon goes on to complain that his consultant refuses to try other relevant forms of clinical treatment, which he enumerates through a three-part listing at lines 16 to 18. Although Gordon sets out grounds on which the consultant's decision might be taken to be based, he also provides an alternative explanation that centres on the consultant's fear of the legal consequences of trying out these alternative treatments. Having described his consultant as offering only limited forms of treatment, Gordon goes on to provide an upshot in which he describes himself as being unlikely to benefit from any treatment in the immediate future.

The overall effect of this response is that although Gordon describes his GP and consultant as seeming sympathetic and interested, he makes no mention of receiving medical treatment from his GP and the possibility of receiving what he views as appropriate treatment from his consultant is explicitly ruled out. The ordinary expectation of interacting with health professionals would be that an individual would receive treatment deemed appropriate to the condition in question. Lack of such treatment consequently would be regarded as a complainable matter. Yet in this response, Gordon explicitly restricts his complaint to one specific aspect of his ongoing interactions with health professionals. It is this

restricted scope of the complaint as described that might be taken to be problematic, a problem that is signalled by Gordon's initial response to the question in lines 1-2.

The second extract is a response to the same question from a different discussion board contributor.

extract 2: Lesley.

1 I am very lucky in having a
2 sympathetic GP who does believe
3 in ME, and he is reasonably
4 willing for me to have any
5 treatments I have heard of that
6 can be tried within the UK
7 system. He did make a mistake
8 writing to support me for my
9 DLA* tribunal and said I could
10 walk 50 yards when it is
11 actually only about 15. He did
12 write another letter correcting
13 his mistake, and I got it in the
14 end. However I do wish he would
15 suggest a follow-up
16 visit/appointment in say 6
17 months or even a year's time, as
18 I wouldn't then feel totally
19 written off as currently I never
20 see him unless I initiate an
21 appointment, which I rarely do.
22 I know there is nothing he can
23 do, but it makes a psychological
24 difference to feel there is a
25 follow-up. I used to see him far
26 more often when I was working
27 and needed sick notes

* Disability Living Allowance

At the start of her discussion group contribution, Lesley offers a description of herself and her situation in relation to her GP. She describes these in positive terms, by evaluating herself as “very lucky” which is associated with particular attributes of her GP, that he is sympathetic and does believe in ME. One inference that might be available from this description is that her GP would display medical expertise in proposing treatment for this condition. Later in the extract, however, at lines 22-23, Lesley undermines this possible inference in stating that she knows that there is nothing her GP can do. This statement indicates the possibility that her GP cannot provide relevant expertise in the treatment of her condition. A second potential inference from her description of her GP as believing in ME is that the GP would display care and concern for a patient with this condition. However, at lines 14-27, Lesley also undermines this possible inference by stating that her contact with her GP is infrequent and arises only at her instigation, in contrast to her previous experience when working. The consequence of this is that she does not receive the psychological support that might be expected and feels “totally written off”.

Given that Lesley’s claim to be lucky does not rest on the clinical expertise of her GP, nor on medical care and attention, the remainder of her contribution is taken up in proposing other grounds for this claim. The first part of these grounds is found at lines 3-14, where Lesley describes her own initiatives in relation to her condition and the GP’s responses to these. One of these initiatives relates to treatment. Lesley proposes that the responsibility for identifying potential treatments lies with her in “hearing of them” as potentially being available. The second initiative relates to the financial consequences of living with ME in leading to potential eligibility for Disability Living Allowance.

The GP is described as being supportive in both of these instances, although only to a qualified extent. Lesley presents the GP’s position on treatments she has heard of as being “reasonably willing”, suggesting less than wholehearted acceptance of her suggestions. She then describes her GP’s actions of writing a letter as supporting her in her attempts to qualify for Disability Living Allowance. However, she describes his actions as being initially flawed in incorrectly describing her physical capacities, an error that might have led to a negative determination of her application. Moreover, this error relates to a clinical observation that a GP might reasonably be expected to carry out successfully. Her eventual success in qualifying for this allowance is described as only arising after her GP writes an additional letter to correct his own mistake.

The second part of Lesley's warrant for the claim to be "lucky" is produced at lines 28-37, where she describes her interactions with a different medical professional:

extract 3: Lesley.

28 The BAMS* doc was polite and
29 seemed sympathetic at the time,
30 but he wrote that the clinical
31 findings didn't co-relate with
32 such a profound loss of mobility
33 so I didn't get DLA till after a
34 tribunal. I was pleased to note
35 that this has been highlighted
36 as a common problem recently in
37 Hansard

*BAMS: Benefits Agency Medical
Service

Lesley characterises this episode in terms of a contrast between the doctor's apparently positive stance and the nature and outcome of his actions. Although, like her own GP, the BAMS doctor wrote a letter on her behalf, in this case the doctor's letter did not support her description of her condition and this led to an initial refusal by the relevant governmental agency of her claim for financial support. The doctor's lack of support, and the consequent negative outcome, are presented by Lesley as incorrect in that his description of her condition was subsequently overturned by an appropriate tribunal. Moreover, this lack of professional support is presented as being problematic not just for Lesley, but for many other people with ME for whom such lack of support is a "common problem". The status of this latter consensual claim is strengthened by Lesley's reference to Hansard, the authoritative written account of official parliamentary transactions within the UK Houses of Parliament.

Lesley's status as being "lucky" in respect of her current health care arrangements is, then, established in part through a contrast with other clinical encounters in which she experienced a lack of support which is depicted as both problematic and common to those with ME.

In the subsequent part of her discussion group contribution, Lesley provides a third element of her warrant for the claim to be "lucky". Here, she introduces a further evaluative contrast (lines 38-75) between her own case and that of her sister-in-law.

extract 4: Lesley.

38 My sister-in-law who also has
39 ME in [city name] has had far
40 worse treatment and when she
41 moved house had to go through
42 no less than 9 GPs before she
43 found one who was sympathetic
44 to ME. She also had a horrendous
45 time with an ENT* consultant she
46 was referred to when she had bad
47 earache for several months.

48 Below is what I wrote to the
49 list about the consultant's
50 letter recently in case you
51 missed it. He wrote to her GP
52 who also did not believe in ME
53 and wrote in her referral letter
54 to the consultant 'she claims
55 to have ME'. My sister-in-law
56 asked for copies of the
57 correspondence as she made a
58 complaint, and has only just
59 sent me a copy recently. I asked
60 if I could copy it to the list
61 as I thought you would be
62 interested, tho it happened a
63 year ago, to see the sort of
64 thing we can be up against :-(.
65 I was appalled to see this in
66 writing from a consultant to a
67 GP.

[copy of letter from consultant omitted]

68 My sister-in-law complained to
69 the BMC** and they have
70 reprimanded him for not taking
71 her views into consideration,
72 but that is just a slapped wrist
73 I presume. Also she has now
74 thank goodness got an ME
75 friendly GP.

* Ear, Nose and Throat

** British Medical Council

In this section of her contribution, Lesley describes the interactions of a fellow ME sufferer, her sister-in-law, with medical professionals. Lesley describes her sister-in-law as encountering on “no less than 9” occasions the problems seen as common in the earlier part of her account. The sister-in-law’s difficulties in interacting with the medical professionals are, moreover, exacerbated with the description of her further interactions with a consultant specialist in ear, nose and throat complaints. At lines 51-55, both of these professionals are described as discounting her sister-in-law’s description of her condition and as making this disbelief explicit in the ongoing communication between them.

Her sister-in-law’s interactions with both her doctor and her consultant are negatively evaluated on two bases: they are far worse than Lesley’s own experiences and they are described in extreme terms as both horrendous and appalling. As was the case in her earlier description of her own experiences, Lesley here grounds her negative evaluation by making references, at lines 68-73, to an external authority, in this case the British Medical Council, to which her sister-in-law complained about her treatment by the medical consultant involved. The outcome of this complaint, in the form of a reprimand for the consultant, is presented as vindicating her sister-in-law’s claims and, by inference, Lesley’s own negative evaluation.

One interesting feature of Lesley’s use of extreme negative formulations in evaluating her sister-in-law’s experience is that it is similar in some respects to the way in which extreme case formulations are deployed in everyday conversational contexts. Edwards (Edwards, 2000) has argued that extreme case formulations might display an affiliative stance among speakers in local conversational contexts. In the present instance, Lesley’s extremely negative assessments of her sister-in-law’s experiences might similarly indicate a design feature that displays affiliation with other members of the discussion group. This affiliative stance is made more explicit at lines 63-64, where Lesley aligns herself with her fellow ME sufferers through her reference to shared experiences of problems in interacting with medical professionals. The negative status of this shared experience is given emphasis through Lesley’s use of a “frowning face” emoticon.

Lesley's initial claim to be "very lucky" therefore provides an inferential context for subsequent descriptions of her own negative experiences and those of other ME sufferers. By providing negative evaluations of her own prior experiences and those of others, she is able to establish that her current situation, which she describes as one in which she feels "totally written off" is nevertheless, by contrast, a relatively positive one.

In establishing that her current situation is relatively positive, Lesley relies in part on two contrasts. The first is a contrast between her experiences at different times. The second is a contrast between her case and that of another person, her sister-in-law, whose experiences are evaluated in highly negative terms. In other cases, respondents to the discussion board utilised similar contrasts in evaluating some of their own experiences as highly negative.

extract 5: Dave.

1 My experience with medical
2 people has been varied. The GP
3 at my local practice who
4 diagnosed me did so quite
5 quickly and took the time to
6 explain about the different
7 types of fatigue illnesses. I
8 began to suffer the ME symptoms
9 after contracting a severe
10 throat infection. At first I was
11 diagnosed as suffering from
12 Post Viral Fatigue and the GP
13 explained how it was not
14 uncommon to suffer this after a
15 viral illness and that it
16 generally clears up after a few

17 months. I did not recover and in
18 fact became more ill, at this
19 point he told me about CFS. I
20 should point out that very early
21 in my illness I had a series of
22 blood tests and was referred to
23 a consultant who performed
24 various heart and sleep tests,
25 everything was found to be
26 normal. I was prescribed Epogam
27 (evening primrose oil) within a
28 few weeks of becoming ill and
29 also various anti depressants
30 (Seroxat, Lustral Diophemene?)
31 all the AD's* made my symptoms
32 worse and I was immediately
33 taken off them. I don't see my
34 GP very often but I go along
35 every few month just to let him
36 know I'm still alive and still
37 ill. On my last visit I asked
38 for a referral to Dr N at
39 [city name] and he is looking
40 into this for me. I think I have
41 been fortunate in seeing this
42 particular doctor when I first
43 became ill, I have on occasion
44 had the misfortune to visit
45 three of his colleagues all of

46 whom seem to have the opinion
47 that this illness is
48 psychological. One of these
49 doctors told me "you don't want
50 to have an illness without a
51 cure" when I asked if I had ME,
52 as if I had chosen to be ill
53 with this. Another one kept
54 asking if I was depressed and
55 kept insisting on writing me a
56 prescription for AD's, I stood
57 my ground with him and told him
58 in no uncertain terms that I was
59 not depressed and did not
60 want his prescription. The
61 third one never spoke to me I
62 sat there waiting for him to
63 speak and he said nothing, I'd
64 only gone for some Epogam so
65 asked him for it, he wrote out
66 the prescription, handed it to
67 me and pointed at the door. I
68 was so shocked I just walked
69 out. To finally answer your
70 question I feel very let down by
71 the majority of the medical
72 people I have come into contact
73 with and have heard about
74 through other people. I could

75 rant and rage about these people

76 but on this occasion, I'll leave

77 that to others.

* Anti-depressants

At the start of his contribution, Dave sets the scene for varying descriptions of his experiences. He begins by characterising his interactions with his GP in relatively positive terms. Unlike Lesley's description in Extract 2, Dave's description here at lines 2-24 suggests both medical expertise and care and concern, in that the diagnosis was provided quite quickly, the GP "took the time" to provide explanations in the course of the interaction, and the GP carried out tests and made referrals to other, more specialized, medical professionals.

One inference available from this description of Dave's early interactions with his GP would be that he would have received treatment that successfully dealt with his condition. As the contribution continues, however, it becomes evident that this has not happened. He describes, at lines 7-19 how his condition has progressed over time and that far from recovering, he has become "more ill". At lines 19-33, Dave describes the tests that were performed as not identifying any particular health problem and the treatment that he received as making his symptoms worse rather than better prior to these being discontinued. Moreover, just as Lesley describes her current interactions with her GP as ones which she is required to initiate and which do not involve successful clinical outcomes, so Dave describes his current contact with his GP as sporadic and as merely serving to inform the GP of his continuing ill-health.

However, like Lesley, Dave describes himself as being fortunate in terms of the treatment he has had from his GP (lines 40-43). And once again, the warrant for this claim is made out by setting out a contrast between those experiences that are evaluated relatively positively, and other experiences that are evaluated, at line 44, in more negative terms.

At lines 48-69, Dave provides descriptions of a variety of interactions with his GP's colleagues that highlight the unsatisfactory nature of his experiences. In contrast to his descriptions of his own GP's treatment, Dave describes these interactions as lacking either appropriate medical treatment or due care and concern for his condition. The first doctor is described as casting doubt on the legitimacy of Dave's

condition and as suggesting that Dave himself might have some responsibility for it continuing. He describes his interaction with the second doctor as comprising a contest between the GP and himself as to the nature of his illness and the appropriate treatment for it. The extent of this contest is given emphasis by Dave's description of himself as standing his ground during these interactions. Although these are accounts of unsatisfactory clinical interactions, they do incorporate descriptions of interaction between Dave and his doctors. However, Dave goes on to describe his third encounter as being in effect a non-interaction between the medical practitioner and himself. The extreme nature of this is emphasised through Dave's three-part list formulation at lines 65-67, and by his reference to his own mental state of shock at line 68.

The upshot of Dave's contrasting descriptions of his experiences comes at lines 69-77. Here, his description of negative experiences, although hearably bad in itself, is presented as being a moderate account of these interactions. Dave states that he could describe these interactions in somewhat more extreme ways but does not do so on the basis that the extent of the difficulties will already be known to others who have ME.

The range of descriptions of his interactions with medical professionals thus goes to warrant Dave's claim at lines 40-42 that he has been "fortunate" in seeing a particular GP. Notwithstanding that his encounters with this professional have not produced any successful outcome in treating his condition or in providing ongoing care and concern, these encounters are presented as being far preferable to the alternatives that are on offer and about which Dave can also speak from personal experience.

It is noteworthy that, in their descriptions of positive experiences, neither Gordon nor Lesley nor Dave describes an expectation of receiving any particular treatment for their condition. Rather, in making out these positive evaluations, each portrays their GPs as dealing with their illness in ways that are sensitive to their concerns. Lesley and Dave contrast this with other circumstances in which medical professionals display a lack of belief in the status of ME as a recognisable medical condition in its own right and which thus display insensitivity to their descriptions of illness.

Discussion

In the preceding analysis, we see that the participants' contributions to the discussion group orient to their actions with medical professionals in three ways. First, insofar as participants complain

about aspects of these interactions, they do so in ways that are limited to specific aspects of their treatment. Second, it is noteworthy that the participants describe themselves as being fortunate in the experiences that they have had with medical professionals. Last, each of these descriptions functions to present the participant as taking an active role in the management and potential treatment of his or her condition. We now consider each of these in turn.

Let us begin by examining the complaints that the participants do make. Commonly, two things patients might expect from medical practitioners are medical expertise, and care and concern for their condition. In the extracts reported here, the contributors to this discussion group describe in detail the variety of ways in which these expectations are not currently met. In a wide range of circumstances, having expectations that are not met is treatable as complainable. However, the participants do not complain of this state of affairs and restrict their complaints to pragmatic or ancillary matters.

One possible explanation as to why participants might describe their experiences in this way lies in the potential interactional difficulties that might arise if they were to complain more widely about their treatment by medical professionals. In particular, were participants to complain about lack of medical expertise or lack of care they could face the potential problem of being characterized as 'moaners' or 'whingers'. Previous research does indicate that speakers can forestall potential difficulties of this sort through the use of 'legitimate complainables' (Pomerantz, 1986). This type of formulation presents the complaint as arising out of the objective features of the object complained about, rather than arising from the subjective interests of the complainer. Indeed, complaints which are expressed in this fashion are less likely to be viewed in a negative light. (Edwards, 2005). However, in the present case, for participants to construct such a complaint as a 'legitimate complainable' would involve expressing their complaints in a manner which located the focus of the complaint in objective properties of their medical condition and of the expertise, or care and concern that was lacking. But this would be to face participants with a highly sensitive issue, given the controversial nature of ME/CFS as an illness, and the absence of any recognized medical intervention. Formulating a complaint as a 'legitimate complainable' therefore reflects the difficulties commonly faced by ME/CFS sufferers in negotiating acceptance of their condition. The solution for participants is to leave uncomplained of matters that might well be 'legitimate complainables' in relation to interactions with medical professionals in other circumstances, such as cases where well-

recognized treatment regimens exist. Doing so does not necessarily render these aspects of experiences reasonable; it does, however, function to ward off possible attributions of negative complaining, and so to construct participants as reasonable and tolerant individuals.

Moreover, the participants here attend to any negative inferences available about them as individuals in a second way, namely by describing themselves as fortunate. By attributing to themselves the property of good fortune, they present a version of themselves as particular sorts of people. Rather than being portrayed as individuals who are overwhelmed by their situation, these narratives present a version of the participants as people who “count their blessings”. In this respect, the participants’ discussion board contributions resemble episodes of naturally-occurring spoken discourse. As Jefferson (Jefferson, 1984) has shown, the telling of troubles in everyday talk is sometimes designed to show that the trouble-teller is not overwhelmed by the difficulties being described. Jefferson suggests that the inclusion in a troubles-telling account of laughter, for example, allows the speaker to display that he or she is able to “rise above” the problems being described. In the present case, descriptions of being fortunate similarly suggest that the participants are able to cope with what are recognisably difficult aspects of experience.

It is here that the function of the third key element of the participants’ descriptions becomes particularly noteworthy. They present themselves not only as able to cope, but, further, as actively engaged in seeking resolution of the problems they face. So, for example, in extract 2, Lesley positions herself as an active agent in relation to her condition and in identifying potential treatments. In contrast, her GP is positioned as a passive actor who merely complies with Lesley’s initiatives by being responsive to her suggestions about treatment, by offering written support for her actions in pursuit of financial support, and by correcting his mistakes when necessary. Descriptions of activities such as these orient to potential negative attributes associated with the condition of ME/CFS in particular. A common characterization of people who suffer from this condition is that, far from suffering from a serious illness, they lack ordinary or everyday levels of self-motivation, and do not make sufficient effort to recover. By embedding within their narratives of medical interactions descriptions of themselves as active agents in seeking out information and treatment, the participants here are able to undermine potential attributions of this sort.

We have seen, then, that much of the discussion board contributors' discussions are concerned with attending to issues of illness and identities. It is noteworthy that in the context of the support group, the participants not only constructed particular identities for ME sufferers but also challenged other competing versions. We noted earlier that one respondent to the question posed provided an unqualified negative account of her experiences. That response failed to warrant the respondent's complaints as being legitimately complainable or to construct the individual as being in any way fortunate. The posting of this response led to an exchange between several group members (not reproduced here for reasons of brevity) in which other group members challenged the proposed identity. On such occasions, members of the group in effect policed the identities available for ME sufferers and the inferences available for how their experiences should be understood. In working up versions of themselves as uncomplaining, fortunate and active people, and undermining competing versions, the participants orient to the negative inferences that are commonly drawn about individuals who suffer from ME/CFS. Their descriptions at the same time build up particular versions of what should be viewed as desirable medical practice in relation to this condition, and of the medical professionals involved. It should be noted that, within these descriptions, evaluations of good and bad practice are based not on clinical expertise but rather on willingness to attend to pragmatic matters, and to refrain from making psychological assessments. Interactions that are positively evaluated are those in which clinicians do not contest the existence or nature of ME/CFS as proposed by sufferers. Research suggests that two-thirds of ME/CFS patients are dissatisfied with the level of care they received from their doctors. They are also dissatisfied with the nature of the interactions which they have with those doctors (Prins et al., 2006). It is suggested (Stanley et al., 2002) that GPs should avoid either denying or acquiescing with patients' descriptions of their condition. In so doing, they are more likely to be viewed as neither rejecting patients nor colluding with the conditions as described but, rather, as encouraging patients to be more active in addressing their own symptoms. Interactions in which GPs take up positions such as these are more likely to mirror sufferers' own negotiations of identity, and to be viewed as sensitive to their concerns. In encounters with medical professionals, clinical expertise, or lack thereof, is taken to be of relatively minor importance; it is the insensitivity to their carefully-worked constructions of identity that ME/CFS sufferers treat most negatively in such contexts.

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