

Knowing 'ME' Knowing You: The Discursive Negotiation of Contested Illness within a Family

Doug Crix, Jacqui Stedmon, Cordet Smart and Rudi Dallos*

University of Plymouth

Abstract

Although CFS/ME (Chronic Fatigue Syndrome/Myalgic Encephalomyelitis) has been heavily researched and contested, there is a distinct absence of studies which consider the relationship between the illness and family process. This is a striking omission given the centrality of the family to the proximal management of the illness. This study used a discourse analytic methodology to consider how talk about illness is locally negotiated by a family in the context of a single family interview. The individual in the family who had been diagnosed with CFS/ME was a sixteen year-old adolescent girl who had experienced symptoms for 18 months. Our findings suggested that family discourses about CFS/ME were polarized around the issue of intentionality. Two family members deemed the illness to represent 'genuine illness' and two regarded the illness to be intentionally used for advantage. These illness accounts were considered as both constitutive-off and constituted-by family conflict. We consider the implications of these findings in developing clinical formulations of the illness and in determining how best to support recovery.

Keywords: CFS/ME; Family; Discourse analysis

Introduction

Inevitably the human condition confronts us all with experiences of ill health and sickness. A critical task we face at times of ill health is to make sense of our bodily experiences and negotiate the effects of illness on our physical capabilities and our social relationships.

For some health concerns dominant bio-medical accounts are available labeling symptom clusters with diagnoses and offering technologies to assist in recovery. Ill health that cannot clearly be located within a medical explanatory framework is frequently highly contested, resulting in public battles for recognition and better understanding [1,2]. These diagnostic disputes present us with a possibility of viewing the social tensions surrounding culturally prominent discourses of medicine and health [1]. Kleinman and Kleinman (1985) [3] emphasize the dialectic relationship between illness and social practices, a relationship which is mediated by the social meanings and legitimacies afforded to the symptoms within local systems of power. In this study we consider the social tensions surrounding the contested diagnosis of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) in adolescence and how these are managed by one family. Specifically we are concerned with the ways in which claims of expertise and knowledge of the illness are negotiated by the family and how differing constructions of the illness position family members.

The terms CFS and ME are diagnostic terms used to describe clusters of symptoms characterized primarily by severe and disabling fatigue, substantial impairment in short-term memory and concentration, unrefreshing sleep, and musculoskeletal pain [4,5]. Although a wealth of published literature investigates how adults describe their experiences of CFS/ME, few studies have considered the experiences of younger people with the illness. It is clear from the literature that has been published, that the symptoms are associated with severe impairment in daily functioning and general wellbeing amongst children and young people [6-11].

Studies employing questionnaire-based measures have compared the impact of CFS/ME on lifestyle with other pediatric disorders sharing similar central illness features [6,8,10]. These studies propose that CFS/ME is associated with lower school attendance, higher levels of emotional disturbance and greater impairment to social life than the

matched disorders. It is suggested that the impairment associated with CFS/ME is difficult to account for from a purely patho-physiological perspective (i.e., the physical limitation arising from the symptoms does not predict the associated functional impairment). Furthermore one study suggested that Junior Idiopathic Arthritis, which does not have a clearly defined etiology or treatment pathway, is not associated with comparable levels of distress to CFS/ME. The authors conclude that the higher level of distress is also unlikely to be accounted for by the absence of a known cause or treatment for the condition [7]. The experience of delegitimation has however consistently been reported as central to the experience of the illness, and may be relevant in an attempt to understand the increased functional and emotional impairment associated with the condition. The perception of negative social evaluation and disbelief of illness symptoms has been linked with emotional distress, social isolation, school absenteeism and increased family conflict [9,11,12].

A recent review of qualitative studies [13] highlighted the experience of delegitimation as central to adults' experiences of the illness. The entrenched controversies and conflicts surrounding the condition may be conceptualized through dichotomous positions which characterize the illness as real or unreal, medical or psychiatric, mind or body, and practitioner defined or patient defined [14]. A growing body of discourse analytic literature has become interested in the ways in which individuals with CFS/ME adopt a position in relation to these dichotomies in order to manage accountability and blame. Discursive psychological approaches attend to the ways in which talk about illness structures illness identity (subjectivity) and illness experience, and accomplishes interactional (intersubjective)

*Corresponding author: Rudi Dallos, Department of Clinical Psychology, 5050 Rolle Building, Plymouth University, Plymouth PL4 8 AA, United Kingdom, E-Mail: R.Dallos@Plymouth.ac.uk

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tasks. Within this framework illness accounts cannot simply be seen as statements reflecting fixed internal beliefs, but rather as accounts situated within interactions legitimating particular versions of the self or illness and actively undermining others [15].

In clinical consultations a micro political struggle has been described between physicians and sufferers in which the true nature of the illness is contested [16]. Physicians may attempt to introduce psychiatric explanations for the symptoms, and patients conversely stress the absence of mood disturbance at onset and highlight the physicality of the illness experience [16]. Psychiatric labels may be resisted because they are felt to imply that the illness may be "all in the mind", due to a failure of reasoning, motivated by secondary gains or faked in order to manipulate others [15,17-20]. Through talk individuals construct themselves as having had healthy pre-illness identities and emphasise the 'genuineness' of their symptoms in contrast to others who may be 'jumping on the ME bandwagon' [20]. The illness is constructed as physical in nature, severe and enigmatic [18]. Sufferers attend to potentially negative evaluations in interactions with physicians (e.g. that they may be unmotivated to recover), through describing themselves as active in seeking a resolution [18].

Interestingly no studies have attempted to consider how these processes might be relevant to the experiences of families. Families will be perhaps the most significant and most immediate context in which individuals with CFS/ME interact. Two qualitative studies have explicitly suggested the importance of support and understanding in family relationships for individuals with CFS/ME [21]. A child's chronic illness is generally accompanied by a radical adjustment in family dynamics. All families must negotiate changes in family member's roles and identities following the onset of the physical symptoms [22]. There is evidence that many parents of children with CFS/ME give up their work to care for their ill child, siblings receive less parental attention and care, and family activities are restricted [12,23]. Family functioning in turn is strongly related to the course and outcome of chronic illness [24]. This may be particularly important where the ill individual is an adolescent because of the associated developmental process for the sick child. This includes intellectual development, changes in the physical size and structure of the body, hormonal changes, emotional challenges and the development of a social identity and sexual relationships [25].

The reciprocal relationship between disease/illness and family patterns was popularly theorised by Minuchin [26]. His conceptualization of "psychosomatic families" emphasized the importance of family relationship patterns to the expression of physical illness. He suggested particular family patterns of relating, such as enmeshment, over-protectiveness, triangulation and poor conflict resolution, may exacerbate illness symptoms and behaviors consequently reinforcing problematic family patterns. More recently this model has been re-conceptualized as a bio behavioural model [27,28] with an emphasis on patterns of responsively at both an individual level (bio behavioural reactivity) and a family systemic level (interpersonal responsively). This model attempts to account for a rapidly increasing evidence base which suggests that the expression of physical illness in a pediatric population and patterns of family relating are closely linked.

The present study therefore considers the family as central to the experience of CFS/ME in adolescents. To our knowledge no other studies have been published used discursive methodologies to consider how families talk about contested illnesses. However, Gale [29] has described the use of a discursive/conversational analysis to explore the joint construction of meanings in the conversational processes

in family therapy. Talk, in this sense is not a neutral medium for conveying beliefs about the illness but rather a form of social action whereby differing constructions of the illness are actively negotiated by the family. We postulate that family members' illness constructions are likely to be constituted by local social and medical constructions of the illness, the media, the internet, stories of friends and family and 'folk models' of illness causation and cure [30]. The particular versions of illness constructed and subjugated will invariably reflect the particular interests of the individual in relation to the illness and the management of blame and accountability [15].

The present study

The present study considers how talk about CFS/ME functions in a single family in the local context of a family interview which prompted the family to speak about their experiences of the illness. We were particularly interested in how the family negotiates talk around the diagnosis given the presence of multiple conflicting discourses surrounding the illness.

This process of negotiation is hugely significant clinically because of the centrality of the family to recovery and the presence of similar discursive dilemmas in the consulting room. A secondary aim of the study was therefore to consider the implications of our research for clinical work with families. We were particularly interested in how discourses surrounding the illness might be helpfully approached by clinicians so that constructive dialogues may emerge in clinical consultations with families.

Method

Design

This study considers how members of one family define and understand a contested diagnosis through talk-in-interaction. The setting for the interaction was a family interview about the illness and its effects on family life. The family were given general questions about their experiences with CFS/ME and invited to discuss them with each other. Although recently there has been a progression in research toward exploring discourse through naturally occurring conversation [29,31] family interviews offer distinct benefits for this research. They afford the possibility of concentrating on a specified topic of interest so that the way in which family members introduce and manage broader social discourse on illness may be considered. It is also notable that clinical settings frequently involve a similar format to the family interview, where the family is asked to respond to a series of questions, this may allow our data to accord more strongly with the type of information which may be encountered clinically.

A single-case design offers the opportunity to examine in depth the way that discourses of health and illness are played-out in a family context. A traditional positivist stance to research may consider a single case design to be a major constraint of the study. The absence of multiple family interactions may be seen to limit the possibility of aggregating data and making generalisable claims. Discourse analysis challenges this notion by suggesting that the kinds of data which are aggregated in social science research (e.g. the surveying of attitudes) frequently miss the complexity of socio-cultural phenomena. Instead discourse analytic researchers claim that an in depth analysis of a fragment of data can be far more helpful in revealing properties of the broader picture through focussing on social-cultural-moral phenomena in everyday interaction [32]. In accordance with this, we are interested in examining in depth how particular versions of the illness are constructed by family members, how these positions are

constituted-by broader socio-cultural resources and the upshot of these accounts for relationships within the family. We can reasonably expect some of the patterns that emerge in this family's interaction around CFS/ME will be found in other families interactions surrounding similar illnesses.

Participants

Recruitment took place at a Paediatric Department of a Regional General Hospital. Paediatricians at the department were asked by the researcher to invite any families on their caseload where an adolescent suffered with CFS/ME. The participating family was the first family to respond to this request. The family consisted of an adolescent girl 'Rose' (16 who was diagnosed with CFS/ME), her mother 'Mary' (41), sister 'Lucy' (14) and the sister's friend 'Emma' (14). Although Emma was not a family member, the family described her as 'part of the family' because she was round at the family house most days. The family dog 'Cliff' (a small puppy) was also brought to the meeting, for the duration of the interview he was held by 'Rose'. Rose's father Paul no longer lived with the family following a divorce approximately a year ago.

Rose had experienced the symptoms of CFS/ME for 1-2 years. At the time of our interview she rated her symptoms at 70% on the Functional Abilities Scale [33], which indicates 'moderate disability.' This level of functioning corresponds to mild symptoms at rest, which worsen to severe symptoms upon physical or mental exertion. She described her social life as very restricted and had not been able to attend her final year at school. When the symptoms were at their worst she rated her ability as 0% on the Functional Abilities Scale, which describes very severe disability. This level of functioning corresponds to being bedbound, extreme sensitivity to light, touch and sound, and difficulty with eating and talking.

Procedure

The family interview took place at a university venue, and was video recorded so that non-verbal aspects of communication could be analyzed in addition to the verbal material. The family was prompted by five open-ended questions to discuss the illness, its effects on family life and the roles of family members and professionals in responding to the symptoms. The questions were deliberately selected to cover broad topic areas about the illness and how the family organizes itself in relationship to the illness. They were offered to the family using a flip-chart board. This was done in order to mitigate the effect of eye-gaze in selecting particular family members to answer the question.

Having completed the analysis of the data, the clinical implications of the results were considered with the secondary researcher (J.S.) who has considerable experience working in a paediatric context with families of children with a variety of diagnoses, both established and contested. This meeting informed the clinical orientation of the discussion section and attempted to ground the study in the broader context of therapeutic and psycho-therapeutic literature.

Method of analysis

The primary topic of interest was how talk about CFS/ME was accomplished by family members and what actions were performed through the use of particular discursive practices. In approaching this task it was relevant to consider in detail the sequential production of utterances, how particular kinds of discourse emerged in (or were constrained by) family members' while talking about the illness, and the ways in which inter-subjective difference and mutuality were accomplished through talk. The particular versions of CFS/ME

produced in the family interview were perceived to relate dialectically to broader socio-cultural constructs and practices surrounding health and illness.

Previous discourse analytic studies on CFS/ME have suggested that discursive psychology offers an important way of understanding how and why particular accounts of the illness are constructed by sufferers [15,17,18]. In these studies speakers are of interest as 'social actors' [34] who produce particular accounts as situated accomplishments in order to account for the self and manage blame. The present study considers all family members as social actors, with talk about the illness actively positioning them in relationship each other and the illness.

Our approach to analysis drew upon conversation analytic and discourse /critical discourse analytic procedures articulated by Wooffitt [35] as well as the discursive psychological approach of Wetherell et al. [36]. It rests on the assumption that talk is socially oriented, and that the language produced by family members is consequently a social action rather than a neutral means of conveying the true nature of things (e.g. thoughts and beliefs). Conversation analytic approaches were employed through a close focus on the linguistic and paralinguistic features of talk and the way that the interaction was managed between participants. The labeling of linguistic features of talk and rhetorical devices used by participants (e.g. active voicing) draws heavily upon conversation analytic traditions. In keeping with discursive psychological approaches we were interested in how stake and accountability was managed by participants, and how identity was produced in interaction. We also attempted to consider family interaction in more systemic terms through noticing how discursive positions adopted by family members served to create particular kinds of relationships between family members.

Analytic process

The verbal content of the video recordings were initially transcribed orthographically. Transcripts were repeatedly read and re-read by the primary author, whilst considering the research question "how does talk about CFS/ME function in this family". It was clear at this stage that competing constructions of the illness were being negotiated by family members. The researchers consequently focused on the points of the family interview where competing constructions were most visible and considered the ways in which these constructions were constituted and how they appeared to function within the conversation.

Analysis

The family interview invited family members to consider a series of questions about the family's experiences of CFS/ME and about the roles of the family and health professionals in the illness. In responding to these prompts two opposing constructions of CFS/ME emerged in the family's talk about the illness. One construction scripted the symptoms as representing 'genuine illness', and was oriented toward reinforcing the credibility of the symptoms and managing blame and accountability. The other scripted symptoms as intentionally being used for an advantage, with symptoms disappearing in the advent of a sufficiently motivating reason.

Our analysis of the interaction considers the way that the two constructions are built up by family members and how these versions function to position members in relation to the illness and each other. These may be summarised as 1) The construction of a 'genuine illness' account 2) The construction of the illness as 'intentionally used for advantage' 3) The negotiation of Lucy's 'intentional' account of the

illness 4) The positioning of Paul through his construction of CFS/ME as 'intentional'.

The construction of a 'genuine illness' account

The initial two extracts consider the use of physical and psychological discourses in order to support a 'genuine illness' account of the symptoms and manage accountability and blame. Within the family the 'genuine illness' account is primarily co-constructed by Rose and her mother Mary.

The first extract has been taken from the beginning of the family interview where the family members are invited to speak about CFS/ME for the first time.

EXTRACT 1 – Psychological stress discourse used to account for the development of the illness

Researcher: ...So the first question is (researcher reads out question on the flipchart) what have y' (.) been your experiences with the symptoms, when did they start, and what has happened since? (sits down)

38 (2.0)

Mary: .hhpffffffffff[ffffffffff]

40 Rose: (gestures to mother) he asked about your experiences

41 Mary: ok (.) [well it it's it]=

42 Rose [° don't be mean°] eheh

43 Mary: =it all blurs into one a little bit (looks at interviewer and gestures circle with arms)

44 Lucy: hmmmhuh (laughs)

45 Mary: Because we've as a family we've been going through a very difficult time for a long time um (.) with their dad and (.) marriage problems and break up and (nods)(.) Grandma dying. Grandma died May (.) May of last year wasn't it? And that was probably the beginning, >one of the triggers that actually triggered off Rose's ME< (.)

49 Rose: °and I was getting bullied really ba:ad°

50 Mary: You were getting bullied at school (.) um (.) you got ill as well, you got a viral illness and hh (1.8) you just sort of turned from being >really a<strong (3.7) healthy person, to into someone who couldn't do anything didn't you?

53 Rose: yeah em

The interactive sequence following the prompting question is clearly tentative, indicating that the production of a particular illness account requires careful negotiation by the family. Rose gestures to her mother to offer an account of her experiences (line 40), but then quickly and quietly interjects with "don't be mean" (line 42). This interjection suggests Rose is aware of the presence of an alternative construction of the illness which depicts her in more negative terms. Through her utterance she seems to be attempting to foreclose Mary from constructing an identity-threatening account of the illness.

The illness model that is developed by Mary (lines 45-48) suggests that it was the result of the cumulative effect of emotional stress on the family. This psychological account is particularly significant given the apparently biomedical construct of 'symptoms' implied by the question. Rose aligns herself with Mary's account and expands on the stress-based formulation of the illness by making her experiences of

being bullied relevant (line 49). This expansion potentially serves two further functions for Rose. Firstly, it emphasizes the severe nature of the stress, thereby legitimating illness as a reasonable consequence. Secondly, the event she identifies is a stressor exclusive to her, therefore accounting for why she may have developed illness and other family members did not.

Another feature of the account which is apparent is that Rose's response to the stressors is never developed. We do not hear for example, how Rose felt following her parent's divorce, or how she coped (or struggled to cope) with her Grandmother's death. This omission seems to serve an important function in managing Rose's accountability in responding to stress through omitting her agency. Instead a contrast structure is provided (lines 50-53) to illustrate the change from a strong healthy person to "someone who couldn't do anything." Kemp's [37] ethnographic studies of agency in discourses of distress are of relevance to an interpretation of this sequence. He suggests that Euro-American idealised (healthy) discourses of self-control and independence may be latent in accounts of emotional distress and illness. For this reason speakers represent themselves as passive in the face of external circumstances and reposition their agency as actively attempting to recover control and restore personal agency. As a result of this, talk about emotional distress may be associated with narrative incoherence and low levels of narrativity because the production of a narrative requires agency to 'drive the story forward' (Kemp) [37].

EXTRACT 2 – The negotiation of CFS/ME's status as a genuine physical illness

72 Mary: ...There's no (.) °as far as I know - there's no specific test they do and they say ↑'yes you have got ME because of that' - it's a:

74 Rose: but I did have loads and loads of symptoms

Mary: ↓an exclusion of everything

76 Rose: yeah

Mary: do you want a list of what all the symptoms are? (.) Have been? (laughs)

78 Researcher: (hesitant) I I guess so yeah.

Mary: heh:h (laughing) what what you do it, cos you were living with it

80 Rose: uh pins and needles like constantly throughout my whole body, like all around my heart and my eyes

82 Researcher: (gently nodding) mmm.

83 Rose: And constantly feeling dizzy, and like passing out >a lot of the time<, um I didn't have any temperature control whatsoever, um like my feet um the rest of my body would be absolutely freezing, but I'd feel hot (.) um I know it sounds silly but I used to have well I for like a wee a lot (laughs) >I don't know if that's a symptom but< um just...

87 Mary: terrible [pain

Rose: [absolute pain everywhere, and just lots of really really painful stuff.

89 Mary: mood-swings,

Rose: yeah,

91 Mary: unable to sleep

Rose: well I can't sleep

93 Mary: ↑well

Rose: and when I do get to sleep I sleep forever.

In extract 2 the medical status of CFS/ME as a physical illness is actively negotiated between Mary and Rose. The extract follows Mary's description of the presence of "crazy symptoms" which had been "very frightening". Mary introduces diagnosis as having helped them to legitimate these enigmatic symptoms; however she also suggests that there are no specific tests that identify the illness and that CFS/ME is a diagnosis of exclusion (line's 72 and 75). Rose's response "but I did have loads and loads of symptoms" (line 74) seems to indicate that she regards the absence of a diagnostic test as a threat to the credibility of the diagnosis. The list of symptoms provided by Rose (lines 80-81 and 83-86), and subsequently co-constructed between Rose and Mary (lines 87 to 94) acts to counter this threat. This medical organization of the discourse provides 'hard evidence' for the physical reality of the illness and indicates that the effects of the illness are extensive and pervasive. Furthermore the use of adverbs such as; "absolute", "constantly", and "really" assert extreme case formulation of the illness asserting its seriousness [38]

A further characteristic of the interaction is the way that ontological threat to the illness is managed between Mary and Rose. The threat posed by the absence of a diagnostic test indicated by Rose (line 74) is quickly responded to by Mary who invites the production of a list of symptoms (line 77). Mary's laughter at this point in the interactive sequence (lines 77 and 79) does not appear to be inviting intimacy, affiliation or alignment, but rather it seems to indicate a 'delicate interaction slot' [39] Later in the interaction, Rose introduces a symptom which Rose is not sure is associated with CFS/ME (line 85). This potentially undermines the status of the list of symptoms as indicating a bona fide illness, it is consequently repaired by Mary who introduces the strong medical symptom of "terrible pain" (line 87).

The construction of the illness as 'intentionally used for advantage'

The question 'What impact has CFS/ME had on the family' is used by the family as an opportunity to introduce the alternative construction of the illness which is put forward by Lucy. Extract 3 occurs after a brief family exchange in which Lucy (Rose's sister) asks for the question to be clarified.

EXTRACT 3- Lucy's competing account is introduced

178 Mary: What effects has it had (.) on the family?

179 Lucy: Um it makes me annoyed because (.) it just does. (makes eye contact with Rose) You do my head in <uhmuhmuhmfff>

181 Emma: One day she's happy [and]

Lucy: [yeah]

183 Emma: the other day she's like sad.

184 Lucy: Like one second she's really happy and then really moody and then like being horrible to all my friends so I don't want to invite anyone o:ver ever (.) (makes eye contact with Rose) cos she'll sh'salways horrible

187 (3.7) (Lucy nods and makes eye contact with the researcher, then stops nodding and turns to Rose re-establishing eye contact)

189 Rose: and what about me being (gestures inverted commas with fingers) "lazy" as you call it?

191 Lucy: oh

Rose: and that

193 (.)

194 Lucy: Yeah well (.) some days you're like 'arh:h I can't move' and if Ryan calls you're like ↑"oh I'm going to see Ryan"

196 Mary: Ryan's the boyfriend

Rose: 'I'm not always [like that

198 Lucy: yeah you are (Mary coughs) so she's, if there's something to do with Ryan ↑"oh I'm better now"

The construct of "mood-swings" is used by Lucy to introduce an alternative account of Rose's behavior: one which allows a less sympathetic version of Rose's identity to be scripted whilst not directly challenging the 'genuine illness' narrative. This is discursively achieved through the use of an extreme case formulation, in which Rose being 'really horrible' prevents Lucy from engaging in the normal activity of inviting friends over (lines 185-186). As Lucy develops her account she makes eye contact with Rose and with the researcher (lines 179, 185, 187. Stivers [40] suggest that eye contact may be used by participants in order to "mobilize a response." In this instance Lucy appears to be inviting a response from Rose or the researcher in order to allow her to elaborate and justify her negative identity construction. Through not responding Rose actively prevents the troubling identity issue from being developed. Instead she invites Lucy to defend her description of her as "lazy" (line 189).

Rose's request that Lucy justify her use of the word "lazy" appears somewhat disjunctive from the preceding conversation on mood-swings. A shared assumption implicit in both constructs however appears to be the intentionality behind Rose's behaviors and implicitly that accountability lies with Rose and not with the illness. The construct "laziness" is therefore easier for Rose to defend than "mood swings" as it is more closely related to the construction of CFS/ME. This may allow her to have more confidence that Mary will help her manage accountability of the illness and reject the negative construction particularly in the local context of a family interview about the illness.

Lucy develops a clear formulation of the illness which is rhetorical to the dominant construction of the illness in the family interview (Lines 193-194 and 197-198). She uses a discursive strategy called 'active voicing' to add authenticity and bring to life her reformulation by speaking from the point of view of Rose [41] The statement "arh:h I can't move" which might be construed as a sign of severe illness becomes "oh I'm better now" when a sufficient motivator arrives. In this way the credibility of Rose's symptoms as indicating 'genuine illness' is directly undermined and Rose is positioned as someone who has agency but is just 'lazy'.

The negotiation of conflicting accounts

By positioning Rose as someone who has agency and who uses the illness to her advantage, Lucy makes an epistemological claim which threatens the 'genuine illness' construct and holds Rose accountable. The following extract considers the ways in which this problematic assertion is managed by Mary to reassert the existence of a real illness.

EXTRACT 4- Mary's management of competing accounts of CFS/ME

197 Lucy: ... if there's something to do with Ryan ↑"oh I'm better now"

198 Mary: so she feels she uses it as an excuse sometimes and uh

Lucy: yes

200 Mary: and you feel annoyed that you have to do work sometimes she doesn't have to do so much uh yes so that's struggles that's caused a few problems hasn't it? (.) and then also because Rose's always been a hard, quite hard worker at doing things, and I sometimes find myself getting frustrated because I'm obviously on my own now and there's jobs that need doing in the house, sort of that need two people and I find myself getting frustrated sometimes that she's there, and she used to be very strong and capable and can't do it because she has a lot of back pain and everything and she=

207 Rose: =I can't even stand up for more than [five minutes to do up my shoes].

208 Mary: [some days she can do some days she can do things and other days she just can't do it and so um I have to be careful not to get (.) um cross and angry and I also sometimes because she can't do something I don't expect Lucy to do it either, and so i end up doing everything and getting a bit worn out.

212 Rose: °Yeah she [shouts at us

Mary: [because I actually used to have ME myself (.) um and then I get=

214 Lucy: = does that mean I'll get it?

Mary: no not necessarily at all.

216 Lucy: good

Mary manages Lucy's claims primarily through downgrading their status to something that she feels sometimes (line 198). In doing so she is able to introduce an alternative account for why Lucy is sceptical of the illness (lines 200-201). This account uses a completely different interpretative repertoire of sibling rivalry to imply that Lucy is sometimes jealous that Rose doesn't have to do as much work. Mary seems to be aware that this formulation is potentially problematic for both Rose and Lucy. She therefore constructs a positive account of Rose's pre-illness character as someone who has "always been a hard, quite a hard worker" (line 202) and aligns herself with the position she had scripted for Lucy (line 203) (i.e. someone who struggles with having to do work.)

Mary also uses the interactive sequence to reinstate the legitimacy of the illness which has been called into question by Lucy's account. By announcing that she had previously suffered from CFS/ME, Mary authenticates her 'category entitlement' [42] to speak with authority about the illness. Her lived experience of the illness substantiates the genuine status of the illness and inoculates against further challenge. This effect is presumably reinforced by Mary's status as the girls' mother. A further consequence of this device is that it aligns Rose and Mary through joint membership of the CFS/ME category. Lucy's question 'does that mean I'll get it' (line 214) reflects her positioning outside this category.

The positioning of Paul through his construction of CFS/ME

Although Paul (Rose's father) was not present at the family interview, his account of the illness was introduced by Mary on two occasions (extract 5 and extract 6).

EXTRACT 5 – Paul's construction of CFS/ME is linked with the marital break-up

217 Mary: an:nd um (2.0) so tha' so that's. It's I wouldn't say it's.

It made the break up um of things a lot harder, because Dad just didn't - her Dad just doesn't recognize it at all or understand it=

219 Rose: =he just called me a lazy failure constantly

220 Mary: yeah he his sister has been has told her to snap out of it and thinks' it's all made up. He did the same to me when i had it (Lucy stands up and gets pen from Mary's bag and starts drawing on shoe) um he doesn't understand it all thinks it's all in your head and you just have to snap out of it (.) And so um (Rose coughs) I (1.8) it it helped me realize that it was really time to go when Rose developed it it was it was it was ↑ that's not the reason but it was that kind of helped push Ok this has got to happened sooner rather than later. Cos their relationship was:s totally=

227 Rose: =the second he came in the room I would have a panic attack and pass [out every night]

Mary: [yeah it was um]

Rose: which was not nice

230 Mary: so that has had, it's had a big impact,

EXTRACT 6 – Paul is positioned as not understanding CFS/ME

349 Mary: It would be nice if Dad understood wouldn't it? (2.0)

Rose: mm

351 Mary: I think it would be:e (.) ah:h (.) it would be a lot easier if he:e were to:o (.) get it and actually understand it really (Rose coughs) and not [think it's a big excuse]

353 Rose: [or like at least try to understand it]

354 M: yeah

On both occasions the account of CFS/ME which Paul is construed to take up is ostensibly similar to Lucy's with the illness being scripted as under Rose's intentional control. Paul's supposed account of the illness is however managed quite differently from Lucy's. As someone who doesn't "get", "recognize" or "understand" the illness (extract 5, line 218; extract 6, lines 349 & 351), his position is established as one of ignorance. In contrast to Lucy he is actively positioned as culpable for not trying to understand it (extract 6, lines 353-354).

Paul's unreasoned and thus unreasonable position is worked up with recourse to an obsolete folk-psychological construction of mental illness based on a Cartesian dualism of the body and mind. He is therefore presented as believing that the illness is "all in the mind" and that Rose should just "snap out of it" (extract 5, lines 222-223). Mary suggests that the upshot of this state of affairs was that she recognized that she could not reason with Paul and she was able to realize "it was time to go" (extract 5, line 223) In doing so she shifts the topic of conversation from the illness to her marital relationship. Her account of Paul's approach to the illness serves to illustrate how unreasonable he can be and therefore works to manage her own accountability for the marital break-up.

The alignment between Rose and Mary's accounts is once again present in these interactive sequences. Rose's alignment with Mary's negative formulation of Paul is made through her suggestion that he doesn't even try to understand her illness (extract 6, line 353). She also explicitly links his presence with the expression of her physical symptoms (extract 5, line 219). The link between the illness and Rose's conflictual relationship with Paul is also made by Mary in at the outset

of the family interview, where it is the first stressor that she links with the development of the illness (extract one, line 46).

Discussion

Our analysis suggested that the fault-lines upon which opposing constructions of CFS/ME were produced did not correspond to a purely psychological-physical division as is commonly represented in the literature. Instead the family's constructions of the illness were organized around the issue of agency and intentionality.

The two opposing discursive constructions of CFS/ME produced by the family reflected a split in the family narrative surrounding the illness. Mary and Rose were closely aligned through an account which scripted Rose's illness as genuine and as a consequence of external events (i.e. physical illness and psychological stress). Paul (as he was depicted in the family interview) and Lucy were also aligned, albeit implicitly, through their skepticism that the symptoms of illness were outside of Rose's control. Both versions of the illness were worked up rhetorically in order to counter each other. Mary and Rose's account therefore attempted to undermine any possibility that Rose may have any motive to remain ill. Lucy and Paul's account rhetorically argued that Rose did have agency and that she was intentionally using the symptoms to her advantage.

The emergence of these opposing positions in the family may be contextualized within theoretical constructions of 'self-hood' proposed by Kemp [37]. He suggests that conceptualizations of the self are culturally bound by a modernist dualism. On the one hand the self is construed as a passive 'body-object' constrained and determined by forces outside of its control. On the other hand the self is construed as an autonomous centre of consciousness, with agency and power. These positions are strikingly similar to the two discursively constructed versions of Rose's selfhood with regard to the illness. Mary and Rose's account of the illness positioned Rose as passively determined by psychological and biological forces outside of her control. Conversely Lucy and Paul's account positioned Rose as self-determining and autonomous.

The family's accounts of illness served to actively position family members in relation to one another, these positions also seemed to be indicative of more enduring patterns of relating within the family. Of particular importance to constructions of CFS/ME was the conflict in Mary and Paul's marital relationship. Mary's narrative of marital disharmony seemed to be entangled with her own discursive construction of Rose's "CFS/ME". The implication of this was that Mary's construction of the illness was in-part contingent on her conflictual relationship with Paul. The development of competing accounts of the illness was therefore constitutive-off and constituted-by marital conflict. In the family interview Mary's account of Paul's approach to the illness scripted him as insensitive to Rose's suffering and fixed in his opinion. This account consequently also functioned to manage Mary's accountability for the marital break-down, and explain why "it was time to leave."

The family configuration which emerged in the family's discourse around CFS/ME closely resembled the systemic construct of triangulation. Minuchin's original conceptualization of triangulation suggested that family or marital conflict may be diverted through a focus on an ill child [26]. In her revision of this model Wood [27] proposed a form of triangulation which occurs when parents openly hold conflicting ideas about whether to nurture an ill child or expect them to assume responsibility for their own wellbeing. She suggests

that this may result in a coalition between the child and one parent against the other parent (and consequently a stressful relationship with the other parent).

Our analysis suggested that in the case of a contested illness these processes may be mediated through different discursive constructions of the illness (e.g. as intentionally used for advantageous genuine illness). Alignment in Mary and Rose's accounts of CFS/ME appeared to represent a coalition against Paul's account of the illness and potentially his role in the marital break-up. Lucy's discursive construction of the illness, which also contested the legitimacy of the illness, appeared to be aligned with Paul's although this seemed to remain unacknowledged by the family.

The family processes which existed alongside the illness seemed to create difficulties for all family members but particularly perhaps for Rose and Lucy. Lucy's position was problematic because of her need to manage divided parental loyalties. Although her opposing account was carefully managed by Mary (in order not to distance her from the immediate family unit) this was at the expense of the legitimacy of her construction of the illness and perhaps her relationship with Paul. Rose's position was difficult because the rhetorical construction of the illness appeared to be caught up in the marital conflict. Any improvement in Rose's symptoms through changes in mood may have been interpreted as evidence that she was 'faking' the illnesses. Consequentially Rose may felt that in order to prove the legitimacy of the illness that she needed to renounce her own agency. A further effect of the entanglement of the illness with the marital conflict may have been the difficulty for Rose in being able to resolve her conflictual relationship with Paul without disturbing her alignment with Mary.

Clinical Implications

One of the initial aims of the study was to consider how discourses surrounding the illness may be helpfully approached by clinicians so that constructive dialogues can emerge in clinical consultations with families. Our findings confirmed the importance of considering the whole family's relevance to the construction of the illness. In the present study, family members' constructions of the illness appeared to be bound up in family processes rather than being the result of family members simply contesting/aligning with external discourses about the illness.

The family processes that we hypothesized as being relevant to this family had implications for the kinds of interventions that may be most helpful. Specifically we felt that a primary aim for any intervention would be to enable a less polarized conceptualization of the illness to emerge in the family discourse. This would enable Rose to be both responsible for her own physical and psychological wellbeing (i.e., have agency) and be sensitively responded to as someone who has been affected by external events (physical ill health and psychosocial stress). It is possible that 'evidence-based' interventions such as CBT with their explicit focus on 'graded exercise' may have helped Rose through offering a legitimate way that Rose can have agency in her own recovery whilst being sensitive to the psychosocial stressors affecting her. Alternatively a systemic focus on family conflict may have enabled the relationship between marital conflict and the illness to be disentangled. This would have allowed less polarized perspectives on the illness to be taken up by Mary and Paul, and for Rose and Lucy's relationship with Paul (and each other) to be repaired.

Another significant clinical implication of the study was the apparent utility of a focus on micro-processes of talk-in-interaction. We considered this narrow gaze to be helpful both in formulating the

family processes which were relevant to the maintenance of the illness and in considering the helpfulness of different clinical approaches to intervention.

References

1. Brown P (1995) Naming and Framing: The Social Construction of Diagnosis and Illness. *J Health Soc Behav* 14: 4-52.
2. Swoboda DA (2006) The social construction of contested illness legitimacy: a grounded theory analysis. *Qualitative Research in Psychology* 3: 233-251.
3. Kleinman A, Kleinman J (1985) Somatisation: the interconnections in Chinese society among culture, depressive experiences, and the meaning of pain. *Culture and Depression: Studies in the Anthropology and Cross-cultural Psychiatry of Affect and Disorder*. University of California Press, Berkeley.
4. Fukuda K, Straus SE, Hickie I, Sharpe MC, Dobbins JG, et al. (1994) The Chronic Fatigue Syndrome: A Comprehensive Approach to Its Definition and Study. *Ann Intern Med* 121: 953-959.
5. Sharpe M (2005) Psychiatric diagnosis and chronic fatigue syndrome: Controversies and conflicts. *Journal of Mental Health* 14: 269-276.
6. Garralda ME, Rangel L (2004) Impairment and coping in children and adolescents with chronic fatigue syndrome: a comparative study with other pediatric disorders. *J Child Psychol Psychiatry* 45: 543-552.
7. Rangel L, Garralda ME, Hall A, Woodham S (2003) Psychiatric adjustment in chronic fatigue syndrome of childhood and in juvenile idiopathic arthritis. *Psychol Med* 33: 289-297.
8. Richards J, Chaplin R, Starkey C, Turk J (2005) Illness Beliefs in Chronic Fatigue Syndrome: A Study Involving Affected Adolescents and their Parents. *Child and Adolescent Mental Health* 11: 198-203.
9. Roche J, Tucker S (2003) Extending the Social Exclusion Debate: An Exploration of the Family Lives of Young Carers and Young People with ME. *Childhood* 10: 439-456.
10. Smith MS, Martin-Herz SP, Womack WM, Marsigan JL (2003) Comparative Study of Anxiety, Depression, Somatization, Functional Disability, and Illness Attribution in Adolescents with Chronic Fatigue or Migraine. *Paediatrics* 111: e376-e381.
11. Tucker S, Tatum C (2000) Speaking Up An Examination of the Experiences of Children and Young People with ME. Association of Youth with ME, Milton Keynes, UK.
12. Van Hoof ELS, De Becker PJ, Lapp C, De Meirleir KL (2009) How do adolescents with chronic fatigue syndrome perceive their social environment? A quantitative study. *Bulletin of the IACFS/ME* 17: 16-31.
13. Larun L, Malterud K (2007) Identity and coping experiences in Chronic Fatigue Syndrome: A synthesis of qualitative studies. *Patient Educ Couns* 69: 20-28.
14. Travers MK (2006) From Violation to Reconstruction: The Process of Self-Renewal Associated with Chronic Fatigue Syndrome. University of Sydney.
15. Horton-Salway M (2001) Narrative Identities and the Management of Personal Accountability in Talk about ME: A Discursive Psychology Approach to Illness Narrative. *J Health Psychol* 6: 247-259.
16. Banks J, Prior L (2001) Doing things with illness: The micro politics of the CFS clinic. *Soc Sci Med* 52: 11-23.
17. Guise J, Widdicombe S, McKinlay A (2007) 'What is it like to have ME?': the discursive construction of ME in computer-mediated communication and face-to-face interaction. *Health (London)* 11: 87-108.
18. Guise J, McVittie C, McKinlay A (2009) A discourse analytic study of ME/CFS (Chronic Fatigue Syndrome) sufferers' experiences of interactions with doctors. *J Health Psychol* 15: 426-435.
19. Horton-Salway M (2004) The local production of knowledge: Disease labels, identities and category entitlements in ME support group talk. *Health (London)* 8: 351-371.
20. Horton-Salway M (2007) The ME Bandwagon and other labels: Constructing the genuine case in talk about a controversial illness. *Br J Soc Psychol* 46: 895-914.
21. Whitehead LC (2006) Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Soc Sci Med* 62: 2236-2245.
22. Newby NM (2006) Chronic Illness and the family life-cycle. *J Adv Nurs* 23: 786-791.
23. Jackson EL (1999) The effects on siblings in families with a child with chronic fatigue syndrome. *J Child Health Care* 3: 27-32.
24. Crane DR, Marshall ES (2006) *Handbook of Families and Health: Interdisciplinary Perspectives*. Sage Publications, California.
25. Jones JF, Nisenbaum R, Solomon L, Reyes M, Reeves WC (2004) Chronic fatigue syndrome and other fatiguing illnesses in adolescents: a population-based study. *J Adolesc Health* 35: 34-40.
26. Minuchin S, Baker L, Rosman BL, Liebman R, Milman L, et al. (1975) A conceptual model of psychosomatic illness in children. *Family organization and family therapy. Arch Gen Psychiatry* 32: 1031-1038.
27. Wood BL (1993) Beyond the "psychosomatic family": a biobehavioral family model of pediatric illness. *Fam Process* 32: 261-278.
28. Wood BL (1999) Relationship matters. *Families, Systems & Health*, 17: 145-147.
29. Gale J (2010) Discursive Analysis: A research approach for studying moment-to-moment construction of meaning in systemic practice. *Human Systems* 21: 176-208.
30. Gwyn R (2002) *Communicating Health and Illness*. Sage Publications, London.
31. Potter J, Hepburn A (2004) *Understanding research methods for social policy and practice*. The Policy Press, London.
32. O'Byrne R, Hansen S, Rapley M (2008) "If a girl doesn't say 'no'...": young men, rape and claims of 'insufficient knowledge'. *Journal of Community & Applied Social Psychology* 18: 168-193.
33. Moss J (2005) Development of a functional ability scale for children and young people with myalgic encephalopathy (ME)/chronic fatigue syndrome (CFS). *J Child Health Care* 9: 20-30.
34. Wetherell M, Taylor S, Yates S (2001b) *Discourse as Data: A Guide to Analysis*. Sage Publications, London.
35. Wooffitt R (2005) *Conversation analysis and discourse analysis: A comparative and critical introduction*. Sage Publications, London.
36. Wetherell M, Taylor S, Yates S (2001a) *Discourse Theory and Practice: A Reader*. Sage Publications, London.
37. Kemp M (2003) Hearts and minds: Agency and discourse on distress. *Anthropology & Medicine* 10: 187-205.
38. Pomerantz A (1986) Extreme case formulations: A way of legitimizing claims. *Human Studies* 9: 219-229.
39. Haakana M (2002) Laughter in medical interaction: From quantification to analysis, and back. *Journal of Sociolinguistics* 6: 207-235.
40. Stivers T (2010) An overview of the question-response system in American English conversation. *Journal of Pragmatics* 42: 2772-2781.
41. Wooffitt R (1992) *Telling Tales of the Unexpected: Accounts of paranormal experiences*. Hemel Hempstead, Harvester Wheatsheaf.
42. Potter J, Wetherell M (1989) Fragmented ideologies: Accounts of educational failure and positive discrimination. *Interdisciplinary Journal for the Study of Discourse* 9: 175-190.