Title: Individuals' Experience of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis:
an Interpretative Phenomenological Analysis

Running Title: Experience of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis

Authors: **Megan A Arroll**, Department of Psychology, University of Surrey, Guildford,
Surrey, GU2 7XH (Author for correspondence)

Victoria Senior, Department of Psychology, University of Surrey, Guildford, Surrey,
GU2 7XH

ABSTRACT

Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) is a condition of unknown aetiology that consists of symptoms such as fatigue, muscle and joint pain, gastric problems and a range of neurological disturbances. Due to the fact that these symptoms are complaints that most individuals will experience to a varying degree, it seems pertinent to investigate the processes by which those with CFS/ME conceptualise their symptoms and the experience of reaching a diagnosis. Participants were recruited from local CFS/ME support groups. Eight semi-structured telephone interviews were conducted and transcribed and the verbatim transcriptions were analysed according to Interpretative Phenomenological Analysis. Six distinct themes were uncovered that illustrated the participants' experience and perception of their symptoms. These included symptomatology and illness course, interference with daily and working life, frequency of symptoms, external information, diagnosis and treatment. The findings were discussed in terms of internal and external cues related to symptom perception and the discovery that the possession of a diagnosis did not necessarily signify the end of the journey.

KEY WORDS: Chronic Fatigue Syndrome; Interpretative Phenomenological Analysis; symptom perception; illness experience

INTRODUCTION

Chronic Fatigue Syndrome (CFS), also known as Myalgic Encephalomyelitis (ME), is a condition of unknown aetiology, which is highly heterogeneous and has had a controversial history, producing conflicting findings not only relating to its cause but also with regard to its course and prognosis (Jason et al., 2001; Jason, Fennell, & Taylor, 2003). The symptoms experienced are highly variable and are complaints also reported by people who do not have a diagnosis of CFS/ME. These can include severe cognitive impairments (e.g. problems with attention, problem-solving, concentration, memory and verbal communication) and debilitating physical difficulties brought about by fatigue, muscle and joint pain, and gastric problems, amongst others.

The label 'Chronic Fatigue Syndrome' was first proposed by Holmes et al. (1988) of the Centers for Disease Control (CDC). This name was recommended to replace that of a number of terms that implied a causal pathology (e.g. 'Myalgic Encephalomyelitis', 'Post-Viral Fatigue Syndrome' and 'chronic Epstein-Barr virus syndrome'), as there was a lack of correlation between biological markers and symptomatology. Hence, this new label reflected the prime clinical characteristic of the condition without alluding to an underlying physical aetiology and, in turn, the definition was based upon signs and symptoms of the patient group. However, many individuals use the term Myalgic Encephalomyelitis (indicating muscle pain and inflammation of the brain), a fact that is reflected by the titles of the two largest charitable organisations in the UK, the ME Association and Action for ME. However, discussion of the nomenclature of this

controversial illness is outside the scope of this article (please see Hyde (2003) for a discussion of this topic).

The original CDC case definition has been revised and, presently, there are two widely used guidelines: the Oxford criteria (Sharpe et al., 1991) and the Centers for Disease Control (CDC) criteria (Fukuda et al., 1994). Both these definitions have the prerequisite of at least six months' severe fatigue, with the CDC insisting that the fatigue be of new and definite onset, not the result of ongoing exertion, not alleviated by rest and meeting four out of eight minor symptom complaints. In addition, underlying organic and psychiatric conditions that may explain the fatigue must be excluded before a diagnosis of CFS/ME can be made.

Characteristics of CFS/ME include persistent mental and physical fatigue accompanied by a range of neurological, autonomic, neuroendocrine, immune and sleep difficulties (Carruthers et al., 2003). In turn, these manifestations produce a range of functional limitations including severe cognitive impairments (e.g. problems with attention, problem-solving, concentration, memory and verbal communication) and debilitating physical difficulties such as problems with general mobility and self-care, shopping, food-preparation and housekeeping (Taylor & Kielhofner, 2005). These impairments are often acute and enduring, impacting upon an individual's personal, occupational and social lives. Therefore, as CFS/ME has such a wide-ranging influence on individual's lives, investigating this condition within the patients' phenomenological experience will provide depth and detail to our present understanding of CFS/ME.

As the symptoms that indicate CFS/ME are physical sensations that most people will experience at some point in their lives (e.g. muscle pain, digestive problems, fatigue) the process that leads individuals to perceive their symptoms as a sign of an underlying illness or disease may be important in understanding how CFS/ME develops. In particular, what factors and events allow individuals to evaluate their bodily signs as CFS/ME? Can these occurrences shed new light onto the nature of the disorder?

In the wider health psychology literature, experimental studies show at best modest average correlations between symptom reports and actual somatic change (Pennebaker, 1982). However, this is not to say that the experience of bodily sensations is fallacious; rather the perception of symptoms is a subjective evaluation of internal activity. Therefore other factors, namely psychological and external or social influences, may be important when investigating symptom perception. One such factor that may influence how symptoms are perceived relate to their specific attributes. For instance, symptoms that represent a viral causation were positively related to self-care, as opposed to the utilisation of professional treatment (Bishop, 1987), implying that viral illnesses are perceived as less serious than other conditions. Also, a perceived physical aetiology, as opposed to psychological causation, was associated with seeking professional attention, again implying a greater significance to one's health status.

As the characteristics of a condition have been shown to relate to individuals' evaluation of their ill health, the cues that influence how individuals define particular diseases may

also play a part in how an illness is perceived. Interpretation of symptoms can be aided by the existence of a well-defined prototype for a given illness (Bishop & Converse, 1986). For instance, the change in shape and growth of a mole would be seen by most people as a clear indication of skin cancer, whereas intermittent chest pain could be evaluated as a sign of angina or simply a case of indigestion. With regard to CFS/ME, where there is not a clear-cut prototype, the process by which individuals first of all define their illness and subsequently attach personal meaning may differ from that of a disease with a well-defined prototype.

To investigate the process by which individuals conceptualise their bodily signs and sensations as consistent with the label CFS/ME, a methodology that permits individuals to convey their own journeys would seem advantageous. Previous qualitative research in the area of CFS/ME has focused on participants' beliefs about the cause of their illness and symptomatology (Clements, Sharpe, Simkin, & Borrill, 1997; Ray et al., 1998), coping behaviours (Ware, 1999) and life changes due to the condition (Tuck & Wallace, 2000; Asbring & Naervaenen, 2002). However, the factors that influence how individuals with CFS/ME perceive their symptoms have not been investigated from a phenomenological epistemology, therefore this will be the framework of the present study.

METHOD

Participants

Initial contact was made with two South East of England CFS/ME support groups via group listings held by the ME Association. Following a series of discussions with the committee members of the support groups, agreement was obtained to place an advertisement in their quarterly newsletters. Ten individuals subsequently contacted the primary researcher, either directly or via the committee members, indicating willingness to partake in the study. Of these ten participants, three were male and the remaining seven female. However, two of the ten interviews were discarded due to poor recording quality. The remaining sample consisted of two male and six female participants with ages ranging from 35 to 67 (average age 55.5, SD = 9.4). The average length of time the participants had been living with CFS/ME was 21.4 years (SD = 16.3) although this varied widely from 6 to 53 years.

The Interview

A number of participants expressed concerns about committing to a face-to-face interview, such as poor health on the day and the anxiety that may result in cancelling. Therefore, the interviews were scheduled on convenient dates and times with the request from the researcher to cancel or reschedule at any time before or during the interview. In addition, some participants stated that their symptoms could be aggravated by the introduction of new chemicals to their homes (one participant reported a chemical

sensitivity so severe that she could not speak at length to anyone who wore make-up) and thus the decision was taken to conduct the interviews via telephone.

An information pack including an information sheet and consent form was posted to each participant. The interviews were semi-structured and consisted of a range of open-ended questions, including prompts that allowed further elaboration of the topic under discussion. If it was deemed that the participants had adequately answered questions remaining on the schedule, these were omitted from the interview. The structure of the interview schedule complied with a funnelling approach (Guba & Lincoln, 1981), whereby a general question regarding the participants' experience of CFS/ME was posed at the outset, with more specific lines of enquiry following. The broad question of 'Can you please describe to me how you became ill with CFS/ME?' was posed to commence the interview. Additional topics included in the interview schedule were the cause of CFS/ME, the effect on one's life, the process of diagnosis and advice that one would give another individual who believed that he/she might be suffering from CFS/ME. The duration of the interviews was between 26 and 90 minutes, with an average interview lasting 40.8 minutes (SD = 20.6). The eight good-quality recordings were transcribed verbatim. Pseudonyms were created for each participant to ensure their anonymity and full permission was obtained to use verbatim quotations in the final write-up of the study.

Analysis

Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003) was employed to analyse the data (please see Brocki & Wearden (2006) for a recent systematic review

of the use of IPA in health psychology). This qualitative tool has theoretical groundings in approaches such as phenomenology (Giorgi, 1995) and symbolic interactionism (Denzin, 1995). For this reason IPA posits that of fundamental importance to the researcher are the meanings that people ascribe to events, because meanings occur and are interpreted in and as a consequence of social interaction. Hence, IPA accepts that the interaction between the respondents' accounts and the interpretative framework of the researcher is highly influential to the analytic process. An assumption of IPA is that the thoughts of an individual's interview narrative are not transparent, but that these statements should be taken at face value, with the understanding that the researcher's interpretations and conclusions are crucial (Smith, 1996).

The goal of IPA is therefore to investigate respondents' perceptions of their social world by maintaining as far as possible an insider's view of the phenomenon that is being explored (Smith, 1996). Thus, IPA is not interested in producing an objective record of an object or event, but is concerned with individuals' personal accounts, i.e. the way in which they behave or think of that object or event. As such, IPA was deemed to be an appropriate analytical tool in the context of the present aim, that is, to take into account individuals' (with CFS/ME) experience of their illness.

The process of IPA is case-by-case analysis followed by comparison across cases. This method consists of a number of stages. To begin with, one transcript was read thoroughly and repeatedly, which permitted the researcher to become familiar with the account, as each additional reading tended to evoke new insights. Initial coding then entailed noting

down anything of interest, interpretations and making summaries of ideas. From this stage recurrent themes were extracted, with key words or phrases that captured the essence of the content acting as codes. This procedure was then repeated for each transcript. At this point the researcher attempted to identify repeated patterns emerging in the subsequent transcripts whilst still allowing additional topics to be identified (Smith & Osborn, 2003). The next stage involved looking for thematic connections, both within and across transcripts. These themes were then clustered and developed into a consolidated list of master or superordinate themes. The transcripts were reread to ensure that the themes and sub-themes could be undoubtedly recognised in the verbatim transcripts. Finally, transcript quotations were noted for each theme and a file created.

FINDINGS

The point where individuals perceive their - often numerous and disparate - bodily sensations as indicative of CFS/ME is influenced by a number factors. In the present study, symptomatology and illness course, interference with daily and working life, frequency of symptoms, external information, diagnosis and treatment each played a part in the recognition of individuals' symptoms as CFS/ME.

CFS/ME Symptomatology and illness course

The participants listed numerous symptoms consistent with those previously observed in individuals with CFS/ME. Persistent or relapsing fatigue of at least six months' duration is the primary criterion of the two most widely used case definitions for

CFS/ME. However, the term ‘fatigue’ does not adequately capture the participants’ experience.

The big thing, the thing that really spoils your life is what I call a lack of stamina. I don’t like this concept of chronic fatigue, I’m not tired all the time, sometimes I’m not tired at all, if I do nothing I often feel pretty well, as soon as I start doing something it tires me too quickly. (Gerald, 63, illness duration 39 years)

Gerald’s fatigue is not a continuous phenomenon, but is reliant upon his activity levels, and so is more post-exertional in character. This is an important distinction when trying to understand the illness, as individuals with CFS/ME can often appear relatively well and it is not until they go over their energy limits that their symptoms begin.

I feel all right just at the minute, I’ll keep going but then forgetting you’re already more or less at zero and then by keeping on going, you’re taking yourself into the red as it were rather than leaving enough balance to get home or to cook or whatever it is you need to do next. (Sarah, 55, illness duration 7 years)

Sarah describes a process whereby she must calculate how much of her energy a particular task will demand and whether it is possible to do more than the necessities. If this evaluative process is not adhered to, and the available energy is spent, symptoms will occur. It is unknown whether people without CFS also conceptualise energy levels as a finite resource that can be depleted. This experience also appears to be rather different to common conceptualisations of fatigue and is quite unlike the perception of constant lethargy that is associated with CFS/ME. Not all of the participants were aware of the triggers for their symptoms, however, and spoke of the unpredictable nature of symptom onset:

I’ll wake up and I’ll feel really rotten. I’ll get up and have breakfast and still feel rotten, I then think I’ll go back to bed so I’ll go back to bed for an hour or two and I’ll perhaps feel a

bit better, get up, poodle round a bit, take things very easy, don't go out and I can never predict whether this sort of thing is going to happen. (Gerald, 63, illness duration 39 years)

Similarly, Emma commented that her CFS/ME was 'really weird, it just seems to change a lot' and Sue mentioned that 'you feel you're getting better and then you think, uh oh'. This seemingly irregular course of the illness was not only present in day-to-day life for the participants, but also for longer periods with similarly unpredictable remission of symptoms, as Mary found:

I did have periods of relapse and remission, I had periods where I'd be really bad or I couldn't even tell you because I was too ill to pay attention like say six weeks and then at a certain hour of a certain day I would just get a bit better and I'd be middling for a while, a few more weeks and then it would start all over again and I was just never able to make rhyme or reason out of what caused it. (Mary, 56, illness duration 10 years)

Although the interviewees stated the fatigue (or related construct) was the predominate symptom of their illness, this was by no means the only symptom present. The participants listed a range of symptoms including pain (muscle, joint and head), gastrointestinal problems, cognitive difficulties and sleep impairments. Again these are all consistent with previous, quantitative findings. However, the course of these symptoms altered over time with no apparent reason. This extent of symptoms was extremely distressing for the individuals to deal with, as Deborah details:

I couldn't actually explain of course how many things were going wrong all at the same time so for me it was just a wilderness and completely drowning in symptoms. (Deborah, 53, illness duration 53 years)

The powerful imagery apparent from Deborah's accounts may intimate that she felt unsafe within her own body. The concept of being lost, i.e. not knowing where to go or how to arrive back at a place of security, illustrates the confusion and helplessness her

illness produced. Again, as with the concept of fatigue, this magnitude of foreign bodily sensations is qualitatively distinct from a representation of CFS/ME as solely causing tiredness.

It is apparent from these personal histories that the symptoms experienced were severe, distressing and disruptive to the individuals' lives. However, these descriptions are only the starting point in the interviewees' stories. Perhaps what is more revealing is the process, or journey, by which these individuals came to view their symptoms as indicative of CFS/ME.

Am I really ill? Interference with daily and working life

In day-to-day life, ill health is not unusual. Many people suffer from common colds, allergies and a range of chronic illnesses without major disruption to their lives. From the participants' accounts, it was the unusual nature of the disruption or interference with everyday life that led them to evaluate their symptoms.

I'm sure I had the symptoms then for other things beforehand but I didn't actually think about it really because although it did incapacitate me to a certain extent, I was still able to do things, I was able to work and able to get out and about. So yeah, I mean people in their life don't always concentrate on the fact that they're ill, I never used to think in terms of being ill, it was just some sort of weakness from getting a bit older (laughs) and you don't realise that you are ill. (Peter, 56, illness duration 20 years)

Peter's cognitive processes changed from thinking in terms of the natural course of life (aging) to considering his bodily signs in terms of a pathology. Without this interference in his work, Peter would not have begun on the path towards understanding his symptoms

as a specific disease entity. This crossover from health status to that of illness was accompanied by numerous changes in the participants' lives, affecting their interpersonal and occupational roles. For example, Mary was forced to downgrade her working role:

I just couldn't do anything that I used to be able to do with the same strength, I was still trying to be at work and I began doing things I'd never done before in the NHS like trying to get other people to do things for me, 'Would you just run to x-rays' while I sit here on my bum because I just didn't have the energy to do it and at the hospital they could tell something was wrong with me, I don't know what they thought. I also couldn't remember things by the way which was very embarrassing and they invited me to change my job to a less responsible one, instead of being in charge of a whole ward I was put in Out-Patients and I opted to work part-time and that was easier and I carried on like that a bit longer until I got referred to a Consultant who then in turn diagnosed my illness and wrote me off work, bless him, and I've never been back. (Mary, 56, illness duration 10 years)

For some, it was not solely the physical symptoms that led to a disruption in previous activity, but appeared to be an interaction with emotional triggers:

I was at college at the time which I found very hard work and stressful and then my mother ended up with having an operation for cancer and I was just under so much stress that I didn't feel well and I wondered if I just needed a rest. But it just got worse and worse, I was exhausted, not feeling well, just not coping, I mean my brain didn't work at all, I couldn't write my essays, it was just beyond me so I had to give up college. (Lucy, 58, illness duration 16 years)

The disturbance in the individuals' daily lives led them to question their symptoms and rather than rationalising their ill health as due to age or stress, they began the quest for an identifiable illness to give meaning to their experiences.

What's wrong with me? Frequency of symptoms and the search for the cause

Although the interference with daily life was indeed difficult for the participants and led them on the quest to understand the cause of their infirmity, this occurrence alone was not sufficient to denote CFS/ME. Therefore the next phase in the assessment of symptoms was concerned with the exploration or checking of symptoms against known disease types such as common colds and viral infections. However, this seemingly straightforward process was hampered by the unusual frequency of these symptoms.

I had a tingling and the sort of thing you expect to get better after a couple of days and I waited and it just wouldn't go away so I'd get better for a few days and then it would just come on me again. I'd go to work in the morning and feel okay, by lunchtime my throat would be getting sore and by the time I would go home at night I'd start aching and I'd start running a fever, so it was just like a very, very common sort of viral infection which just kept repeating, repeating and wouldn't go away. I went to see my GP and had a couple of courses of antibiotics and I just could not get it to go away. (Caroline, 57, illness duration 15 years)

As can be seen from Caroline's experience, the very nature of the illness led her to believe her symptoms were associated with a relatively innocuous and brief pathology. However, the insistence of these symptoms brought about a query in her mind as to whether they were a sign of a common infection or perhaps something more serious. Thus, Caroline compared her bodily signs with a known disorder (viral infection) and although the constituent components of the illness appeared to match the characteristics of this condition, the persistence of the symptoms did not.

External factors were also questioned in the search for an explanation. For instance, in looking for an unusual or distinctive occurrence in her recent history that might shed light

onto the development of her symptoms, Sarah rationalised her initial illness in terms consistent with her environment:

Well I suppose when I first became ill I wasn't sure it was ME and I was overseas so my story might be a little bit different, you know you can get tropical things out there, other infections which maybe would be not so common here. So I think I had gut problems initially but of course in the less developed countries there are those things around, parasites and other bits of stuff so I think my weak area for a while had been the gut which of course doesn't give you much energy and it's sore so I suppose for a while I thought that was the main issue and it may have been to begin with. (Sarah, 55, illness duration 7 years)

Another anomalous quality of the participants' experiences related to the initial recovery after an acute phase of ill health. However, residual complaints persisted and, again, it was the persistence of these symptoms rather than the symptom per se that directed the evaluative process.

Well I recovered very rapidly but you do when you're young and vibrant (laughs) but I just never felt quite right and I had all sorts of symptoms that I'd never had before. In fact the muscle pains in my legs were very pronounced, I'd only ever experienced these sort of muscle pains when I've had flu, proper flu, I don't just mean a cold, I mean a flu when you're in bed for a week. So I knew about these muscle pains which feel like the beginning of cramp but I had these quite severely and something which I have observed over the years is I have always had a sore throat, I have a sore throat 24 hours a day, 365 days a year. Now I live with it, it's so persistent I hardly notice it. (Gerald, 63, illness duration 39 years)

The search for meaning through previous knowledge of illness and environmental cues gave the participants some understanding of their experience, but this was not sufficient to resolve the nature of their illness. As symptoms persevered, the journey continued.

Signposts: Information and the path towards a diagnosis

Through the wilderness of ambiguous bodily signs and severe ill health, the participants not only used internal cues such as the frequency of their disturbances, but also external information to provide lay theories of understanding. For example, although Lucy initially attempted to normalise her symptoms by rationalising them as general complaints caused by stress, when an outsider recognised her symptoms as consistent with CFS/ME, and her husband obtained what was deemed as relevant knowledge, her perception of her illness altered:

One of the women that I was at college with, she was very concerned of course that I wasn't well, I was in my third year at college and we'd got quite friendly and it was her that said to me 'I think you've got ME' because she had one of her friends had ME and it was her that said it's very similar and I know my husband was away for a weekend, this was after I had to leave college, he was away for the weekend and when he came back, he'd been in a bookshop and he threw the book at me and he said 'This is what you've got' and it was a book about ME. I mean he'd read through it and he'd said 'That's you' so then I started reading a bit more about it and I think I got in touch with the M. E. Association and what have you, that was when I thought yes this is ME. (Lucy, 58, illness duration 16 years)

This novel information provided by a third party and corroborated by a significant other shed new insight into Lucy's experience. However, additional information was not enough on its own for all the interviewees to come to the conclusion that their condition was CFS/ME. Yet again, due to the nature of the symptomatology, Caroline found it difficult to accept that her poor health was other than a virus, as this appeared more consistent with her knowledge and experience:

I think at one point one of the Inspectors at work said to me 'You could have ME' but all I knew about ME was that it was an illness where you felt tired all the time and I didn't actually feel tired, I was working hard, I worked all my appointments, I was swimming, I

was very fit and what it seemed to me was I had a virus. (Caroline, 57, illness duration 15 years)

Conversely, this subsequent information also led participants to evaluate their experience retrospectively. Rather than question whether she was suffering from CFS/ME, Sarah attempted to equate her previous experience with the additional knowledge, thus creating personal understanding of her ambiguous and distressing symptoms.

I got a sore throat and I asked for help with the doctor for the sore throat and he gave me Septrin and that did not help, in fact at that point I was extremely ill and I wonder if that was really the last straw on top of everything else and I hadn't thought of it very specifically until I read McIntyre's book on ME and she said there are some cases where Septrin initiates ME and really I was quite shocked when I read that and I thought I wonder if that's really what happened with me. (Sarah, 55, illness duration 7 years)

With this new template for comparison, the interviewees were able to conceptualise their experience in terms of CFS/ME. Media representations of CFS/ME as a condition which occurred in a certain type of person, probably accompanied by an associated representation that those affected were overstating their symptoms, could slow identification of the disease label.

I'd read a headline in the newspaper, something about Yuppie flu and I remember thinking as I read it I don't even have time to read that article, those Yuppies, I don't know what's wrong with them! Boy am I ill! They should know what illness is like! (Laughs) I didn't realise it was the same illness that we all had. (Mary, 56, illness duration 10 years)

This new information from external sources presented the possibility that their ill health may be due to a condition known as CFS/ME. In some cases this was accepted, although others still had difficulty in associating this illness with their own experience. This may be due to the attributes of CFS/ME; although the condition does have diagnostic criteria,

it is still an illness of unknown aetiology and at best is defined as a cluster of symptoms. Therefore this discovery was not yet the end of the journey.

Light at the end of the tunnel? The struggle for a diagnosis

Once the individuals had a label for their illness experience, the process of seeking a diagnosis commenced. The interviewees sought professional counsel as to whether the condition known as CFS/ME was the correct term for their poor health. However, this process proved to be somewhat problematic.

I had actually seen my own GP who said to me ‘You’ve got post viral...’ what’s it called, post viral syndrome and I’d never heard of that, I’d never heard of that, I said ‘Well I don’t know if it’s post viral but it’s viral (*laughs*), I’m infectious’ ... I remember at one point saying to the locum, I said ‘What happens if the virus doesn’t get better?’ he said ‘Oh you don’t get viruses like that!’ (*laughs*). (Caroline, 57, illness duration 15 years)

As can be seen in Caroline’s account, the uncertain aetiology of the illness had an impact of the diagnostic process. Many names have been used for the condition in recent history, including Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, Post-Viral Fatigue Syndrome and the Chronic Fatigue and Immune Dysfunction Syndrome, which reflects the lack of understanding of its cause. Due to this uncertainty, and in a similar vein, Lucy’s doctor could not supply her with a definitive response:

When I went back in to get the results, they did say to me did I think it was cancer and I thought no I never even thought it was cancer, I said ‘Is it ME? Could it be ME?’ and it was ‘Well we don’t know what to do with it, we don’t call it ME’ and that was it. (Lucy, 58, illness duration 16 years)

The first step towards reaching a diagnosis of CFS/ME requires the exclusion of all possible causes of the presenting symptomatology. If after the physical examination and

routine tests no active disease process can be found, the practitioner must use their experience and knowledge to conclude that the patient is suffering from CFS/ME. As Emma describes, her GP explored some possible causes of her symptoms:

I went to the doctors a couple of times during that period, I think the first time, even though it was February, we said could it be hay-fever, I think I had a test for glandular fever that came up as negative and they didn't really say anything, they didn't know what to say.

(Emma, 35, illness duration 6 years)

Thus, Emma's doctor followed this route by excluding glandular fever but did not provide a diagnosis or further advice. Subsequently, Emma returned to her GP with additional symptoms in the hope of finding the source of her ill health.

I went back to my GP and I said 'I've got earache, can you look at my ears?' and I explained all these other symptoms, I said 'In the mornings I just feel too tired to get up and go to work' and she said 'Oh I think maybe you've got depression' (laughs) and I said 'Well what about the earache?' It was strange, so I didn't get any kind of help there.

(Emma, 35, illness duration 6 years)

As Emma did not receive satisfactory assistance she consulted another GP who then referred her to a specialist and was later provided with a diagnosis. This course of action not only lengthened the period between initial symptom occurrence and treatment but also caused Emma a great deal of confusion and frustration at a time when her health was already poor; a fact she felt exacerbated her symptoms. Hence the search for a diagnosis was often a lengthy ordeal with numerous unfruitful meetings, which often led to difficult relationships between the participants and their care providers. The lengthy course led Emma to state that 'I haven't seen a single doctor or Consultant who seemed to have got their head round the idea of ME'; similarly Deborah commented: 'no GPs have been very understanding of ME, I've never come across a GP that understood'. However, Gerald

did not report these arduous and exasperating experiences, although he understood that they were common and had a theory as to why this should be the state of affairs:

My doctor was very understanding, I'd been very lucky with him but then you see I'm tall, I'm male, I'm articulate and I advise ME sufferers not to be short, female and inarticulate, doctors treat them with disdain. (Gerald, 63, illness duration 39 years)

Although this statement is one individual's opinion, the present accounts do support it. The female interviewees in this study reported more problems with gaining a diagnosis and recall being treated with disdain and as if they were an annoying irritation. One situation that Deborah experienced nearly ended in physical violence due to the way in which she felt she had been treated by a medical practitioner:

So yeah basically it was a nightmare and also the final days with that particular GP, my last GP, my son nearly hit the GP for trying to intimidate me, my son actually nearly punched the GP, so it was pretty horrendous and my son was only 16 at the time and the doctor was a great big, fat alcoholic and I was a bit nervous because I'm very small and I thought all hell would break loose but we left there and I never went back. (Deborah, 53, illness duration 53 years)

The narratives clearly illustrate that this portion of the participants' quests was fraught and engendered little relief not only from physical symptoms but also from the confusion and disorientation that their illness generated. Bearing in mind that a diagnosis should bring some clarity to an individual's situation, the occurrences reported here reflect the continuing confusion from all parties surrounding CFS/ME. Therefore, the path towards a diagnosis of CFS/ME may not have delivered the resolution that had been hoped for.

Where do I go from here? Finding effective treatment for CFS/ME

Following on from the process of gaining a diagnosis for their illness experience, the participants looked to their medical practitioners for treatment options. But, yet again, this was not a straightforward progression.

The doctor said I suggest you stop work and rest and pace yourself, he didn't use the word 'pace' but take it easy. He recommended meditation which at the time I was still so speedy, so running on my adrenaline that I went to the course but I didn't practice it as much as I could have or should have if you see what I mean, he wanted me to do it maybe twice a day. Other than that he didn't suggest anything else, everything that I did for myself I found out about it for myself if you see what I mean. (Mary, 56, illness duration 10 years)

As Mary declared, her doctor's suggestion of meditation came at a point in her illness where she did not feel able to follow it. This deficiency in conventional treatment, apart from anti-depressants (which resulted in symptom aggravation in all but one of the participants), coupled with limited guidance, led the interviewees to search for self-treatment methods.

There are so many different things that people will tell you, if you don't understand what the illness is, you'll find that you'll read it in the paper saying that this is the way to go about it, changing diet and changing this, that and the other (laughs), you change various bits and parts of your life but there were 1001 things that you get in terms of advice and trying to work out what are the two or three things that might be very useful. It takes a long time to sort all that out ...I mean when I was first ill, it was colonic irrigation and all that lot (laughs) and all that sort of thing and that was very fashionable in those days, not that I ever did but it could have been a way forward for me. (Peter 56, illness duration 20 years)

This situation left individuals to their own devices, in some cases at great expense, and often led to frustration, disempowerment and ultimately, in the worst scenarios, deterioration in health status. When considering that diagnosis and subsequent treatment

should bring relief and restoration of physical condition, the narratives examined here exhibit harrowing and enduring experiences. Even in the case of Deborah, who eventually found a compassionate doctor, advice was limited:

The doctor said 'Believe me, I know what's wrong with you, you don't need to do anything at all, you just go home and put your feet up, that's it, end of story because you're signed off for the rest of your life' and that was that really. Even he didn't realise at the time how bad some of my symptoms were and it even took him... adding it up between them it took actually about eight years to actually cover all the ground that needed to be covered and I'm still not convinced that everything is being... that I couldn't do more. (Deborah, 53, illness duration 53 years)

Deborah's lack of conviction that her illness could not be treated more effectively exemplifies the further journey that the participants had to embark upon, which led Gerald to question whether his underlying condition had indeed been correctly diagnosed or if separate physical difficulties could account for his symptoms:

I had something wrong with me which was nothing at all to do with the ME, I wondered whether once they put these problems right, all my other problems would go away. Of course they didn't. (Gerald, 63, illness duration 39 years)

This hope that his symptoms would be alleviated through treatment for an unrelated condition exemplifies the lack of effective care he received. His reaction when his symptoms did not cease, 'of course they didn't', suggests that he has lost faith in the possibility of a return to good health. This conflict between the desire for a cure and the reality of continued ill health indicates that diagnosis and treatment may not have, in itself, represented a conclusion for the interviewees. Therefore, the participants' personal journeys with CFS/ME have not reached the final curtain.

DISCUSSION

This paper has presented a quest, in the form of personal histories, for a rationalization of physical signs and subsequent diagnosis of these symptoms. From the initial experience of bodily sensations, through the disruption these symptoms imposed on individuals' lives, which led, in turn, to the evaluation of symptoms in terms of known diseases. When the known disease entities proved inadequate explanations of symptomatology, external information shed new light onto personal experience. However, a diagnosis of CFS/ME was not the end of the journey and, in fact, may have only been the beginning in the search for treatment and restoration of health status.

The symptomatological findings in this study were in accordance with previous studies. Similar to previous research by Hart and Grace (2000), one of the participants was reluctant to discuss fatigue, *per se*, but rather conceptualised the notion as a lack of something more concrete, in this case stamina. Furthermore, as in the Cohn (1999) study, the participants described their predominate symptom in terms of energy levels, where an individual is allocated a set amount and any expenditure that exceeds this amount will result in ill health. Equally, the description of CFS/ME symptomatology as fluctuating in nature (Ware, 1999) was also apparent in the present study.

The journey from the initial experience of symptoms to the discovery of an illness label that could account for these symptoms was aided by a number of factors. As Zola (1973) suggested, the interference in daily life that the symptoms caused to each individual initially highlighted the need to evaluate these disturbances. However, as the symptoms

that define CFS/ME are common within a healthy population, it was not the symptoms themselves that concerned the interviewees, but rather the frequency of bodily disturbance (Radley, 1994). This incidence of symptomatology prompted the interviewees to question whether their complaints were 'everyday' occurrences or a sign of a more serious underlying disorder.

However, this factor in itself was not sufficient to indicate a CFS/ME pathology. It was not until an outside party provided a suitable prototype for CFS/ME that many of the individuals in this study conceptualised their ill health as being caused by CFS/ME. Yet this signpost on the path towards personal understanding was not the end of the story. Numerous participants still had a struggle for recognition of their condition. Furthermore, even with a positive clinical diagnosis of CFS/ME the journey was not at an end. As this condition is of unknown aetiology, treatment options consist of symptom reduction and psychological intervention, rather than cure. Therefore, the quest for a diagnosis may only be the first chapter of a much longer chronicle.

The participants in this study had CFS/ME for many years (in some cases decades) and, hence, were recalling experience retrospectively, therefore future research may want to look at individuals at different points in their condition. For instance, individuals who have recently received a diagnosis of CFS/ME may recall dissimilar experiences to those who have had that label for a lengthy period of time. This issue of transferability, or how findings apply to similar contexts from which they have arisen (Henwood & Pigeon, 1992), should be considered due to the heterogeneous nature of the CFS/ME population

and the fluctuating course of the condition. Those who participated were well enough to do so, which may have not been the case at other periods of their illness. In the same vein, the most severely affected proportion of CFS/ME sufferers could not take part in the present study due to their ill health. This group of individuals, who are often house- and bed-bound, are often excluded in research and may experience differing patterns in their quest for understanding their illness. Further studies investigating the personal stories of those with CFS/ME may want to address this issue.

As the underlying cause of CFS/ME is still unknown, the present findings shed light onto the process whereby individuals identify their bodily experience with CFS/ME. There is the suggestion that early diagnosis of this disorder leads to a better prognosis (Carruthers et al., 2003), therefore these findings can be used by health psychologists to develop strategies for prompt syndrome recognition. Of particular interest is the ‘signpost’ theme: if patients are provided with information in primary care settings they may be able to evaluate their symptoms in terms of CFS/ME. This increased knowledge may aid individuals and their medical practitioners in assessing the ambiguous signs and symptoms that are associated with CFS/ME.

The present study has opened a window into the world of CFS/ME. By using a method of investigation that does not constrain the findings to be interpreted in terms of pre-set hypotheses, this study has highlighted the lived experience and meaning-making of those with CFS/ME. The findings should enlighten the researcher and/or practitioner to the process by which individuals recognise their symptomatology as being consistent with

CFS/ME. This greater understanding can only be of benefit to all parties in what is still an uncertain and contentious disorder.

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