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Collett, Tracey

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Making sense of M.E./C.F.S - embodied experience, non legitimate illness, and the moral career

Tracey Collett

Abstract

The condition known as Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) is an illness of unknown aetiology. In the absence of any organic proof of its existence, the prevailing UK view is that it is a form of atypical depression or a somatic disorder. ME/CFS is said by sufferers to affect physical and cognitive functioning and last for years. However, many argue that because ME/CFS is seen as a psychological illness their complaints of 'being really ill' are not taken seriously.

Based on a mixed method study of 266 persons with ME/CFS, this paper explores how individuals experience a chronic condition when their ideas about illness clash with the ideas of others. First, drawing on the findings of a quality of life study and 45 interviews, the "lived" or "embodied" experience of ME/CFS is explored. Second, the paper examines the social course of ME/CFS, in terms of the pathways that sufferers take through their illness as they seek to understand their symptoms, reconstruct order and maintain control of their disrupted lives.

It is argued that sufferers of ME/CFS undergo a form of suffering and exclusion which is the consequence of 1) frequent disbelief and misunderstanding about the condition; 2) uncertainty as to the aetiology and trajectory of the illness and 3) the denial access to any form of social support. This form of suffering is experienced alongside the experience of substantial physical impairment. In addition to drawing attention to the marked disadvantage experienced by sufferers of ME/CFS, this paper highlights the moral dimension of the illness career and the ways in which individuals make sense of their conditions in the context of cultural non-legitimation.

Keywords: Chronic Fatigue Syndrome, ME, Quality of Life, Illness Career

1. Introduction

Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) is understood to be an illness characterised by relapsing chronic fatigue that is not the result of ongoing exertion and is not substantially relieved by rest (Fukada, 1994). In addition to fatigue, which is said to affect both physical and cognitive functioning, the majority of patients report chronic, persistent bodily pain and a host of fluctuating, concurrent symptoms. Recent reports suggest that ME/CFS can last for many years, the condition is reported to affect individuals of all ages world-wide and it is estimated that ME/CFS affects 150 000 individuals in the UK (Jason et al. 1997).

Despite general acceptance that ME/CFS exists, its aetiology and management have been the focus of intense medical debate. This debate has arisen because conventional medical tests have shown little evidence of pathological illness in patients. The debate centres on whether the condition is a psychological illness or whether it is a disease. Advocates of the psychological view base their hypotheses on the finding that many ME/CFS patients fulfil the diagnostic criteria for conditions such as atypical depression, personality somatisation and perception or effort disorder (see for example Swanick et al. 1995, Surawy et al. 1995, Wesseley, 1992, 1999). They maintain that organic factors may precipitate the symptoms of ME/CFS but behavioural factors perpetuate them. In contrast, those supporting a physiological aetiology maintain that psychological symptoms are the outcome of the disease rather than the cause, that psychological studies are biased and that if funding were made available it would be possible to show that the condition is the result of either a virus or chemical poisoning (see for example, Dowsett, 1990, Bruno, 1994, Behan, 1996).

The official view of ME/CFS tends to support the psychological paradigm. Following a 1996 report undertaken by the Royal Colleges of Physicians, Psychiatrists and Practitioners, medics are advised that there is little evidence to support physical theories and that psychological factors play an important role in perpetuating the condition. The Royal Colleges Report and two subsequent publications advocate a bio-psycho-social approach to treatment and recommend the use of cognitive behavioural therapy to readjust the motivational balances of patients. However, despite the popularity of the psychological paradigm, medics within the field of virology, neurology and toxicology continue to search for a physical aetiology.

In the preoccupation with the search for a cause, there has been little research in the UK into the impact of ME/CFS on the daily lives of sufferers. Nonetheless, newspaper articles and support group magazines paint a bleak picture of disablement and stigmatisation. As such, sufferers report that ME/CFS causes almost complete incapacity, however it is often regarded socially as 'malingering' or 'hypochondriasis'. The experience of ME/CFS, as reported by sufferers, suggests that when medical and lay ideas about illness clash, the process of making sense of and understanding bodily change is profoundly obstructed.

Within the sociology of health and illness the importance of being able to make sense of illness is a major theme. Writers such as Bury, (1982), Frank (1995) and Leder (1990) have demonstrated that chronic illness forces us to face fundamental existential, moral and psychological issues that overshadow the whole of our lives and call into question our individuality, competence, identity and life projects. Charmaz (1984) speaks of "the loss of self", whereas Kleinman (1988) likens the onset of chronic illness to finding oneself in an unfamiliar landscape without a map to navigate. In short, it is maintained that within the context of chronic illness we are forced to revise our personal identity and life history in terms of the illness (see for example Williams, 1984). Whilst on the one hand deeply personal, this process cannot be divorced from the cultural context within which it takes place (Early, 1984, Garro, 1994, Good and Good, 1994, Bury, 1992). The aim of the study presented here was to consider how or whether individuals are able to make sense of illness when their claims to being ill are dismissed and what the outcome of not being able to make sense of illness might be. The objectives were to first, explore the embodied experience of ME/CFS and second, investigate the social course of ME/CFS as sufferers seek to make sense of their symptoms, reconstruct order and maintain control of their lives.

2. Methods

A. Research design, ethics and sample selection

The research incorporated both questionnaires and in-depth interviews. Having gained ethical approval and after several pilot studies, persons with ME/CFS were recruited via ME support groups in Plymouth, Cornwall, Gloucester, Cheshire and London. Copies of the questionnaire were included in each groups' quarterly newsletter alongside a stamped addressed envelope and an article explaining the nature of the research. 500 questionnaires were sent out in total and 306 were returned. The criteria for inclusion in the final questionnaire sample was that individuals had been diagnosed with ME or CFS by a GP or another NHS consultant. Those individuals diagnosed with illnesses in addition to ME/CFS were excluded. The final sample size for the questionnaires was 266. The sample comprised of 52 males and 208 females with a mean age of 45 (range, 16 – 70). The interview sample (N = 45) were recruited from the Devon and Cornwall support groups. The respondents were 23 males and 22 males who had become ill between the ages of 16 and 70.

B. The questionnaire

The embodied experience of ME/CFS was explored via the questionnaires through the use of the quality of life scale, the SF – 36 (Ware et al. 1993). The SF – 36 is a generic health survey that has been developed for use in many countries and utilised in numerous studies. Within the SF – 36, quality of life is measured in terms of 8 dimensions. These are physical functioning (PF), role limitations due to physical problems (RP), role limitations due to emotional problems (RE), social functioning (SF), bodily pain (BP), vitality (V), mental health (MH) and general health perceptions (GHP). Physical functioning is measured by asking questions such as "how far does your health limit you in moderate activities such as lifting and carrying groceries, walking a mile, climbing stairs". Role limitations caused by physical problems are measured by questions such as "during the past 4 weeks how far have you had to cut down on your regular daily activities because of your health". Role limitations due to emotional problems are measured by questions such as "how far have you cut down on your regular daily activities because of your emotional problems". Social functioning is measured by questions such as "during the past 4 weeks how far has your health interfered with your normal social activities such as visiting family or friends, neighbours or groups". Vitality is measured by asking respondents to give an indication of how tired or worn out they have been over the last 4 months and bodily pain is measured by asking "how much pain interfered with your normal work during the last 4 weeks". Mental health is measured by asking about whether patients have felt nervous.

C. Analysis of the questionnaire data

The data from the CFS questionnaires was entered onto an SPSS spread sheet. The SF – 36 scoring algorithms were calculated and the mean scores for the ME/CFS sufferers were compared with the published mean scores for normal population (Jenkinson, 1999) and for persons with low back pain (Rothwell et al. 1997), multiple sclerosis (Garrat et al, 1993) and chronic depression (CASG, 1999).

D. The Interviews

The face to face interviews lasted for up to one hour and took place in the respondents' homes. The respondents were simply asked to tell the interviewer 'how it all started'. From then on, a conversation ensued relating to the embodied experience of ME/CFS and the process of being ill.

E. Analysis of the interview data

The data from the interviews was transcribed and entered into the qualitative data analysis package NUDIST*. It was then subjected to rigorous content analysis (Marshall and Rossman, 1989).

4. The findings

A. The Embodied Experience of ME/CFS

All of the interview respondents reported suffering from severe chronic fatigue. Fatigue was described as affecting physical and cognitive functioning. In describing the experience of fatigue the metaphor of a leaky battery was often used. Like a battery, it was argued that the body with ME/CFS can store a finite amount of energy. Once used up the body requires hours, days or weeks of rest in order to "recharge".

In addition to the experience of constant fatigue 80% of the interview group reported experiencing acute bodily pain. The respondents used the words "tremendous", "massive", "absolutely crazy", "exhausting" and "horrible" to describe its intensity. Whilst the pain appeared to affect different areas of the respondents' bodies, all those who reported pain claimed that it was always present and persisted despite treatment. Above and beyond the symptoms of fatigue and pain the respondents reported periods of disturbed sleep, "brain fog", emotional instability, memory loss, problems with hearing and balance, allergies, speech disturbance, feeling extremes of hot and cold, problems with co ordination, heart palpitations and digestive problems.

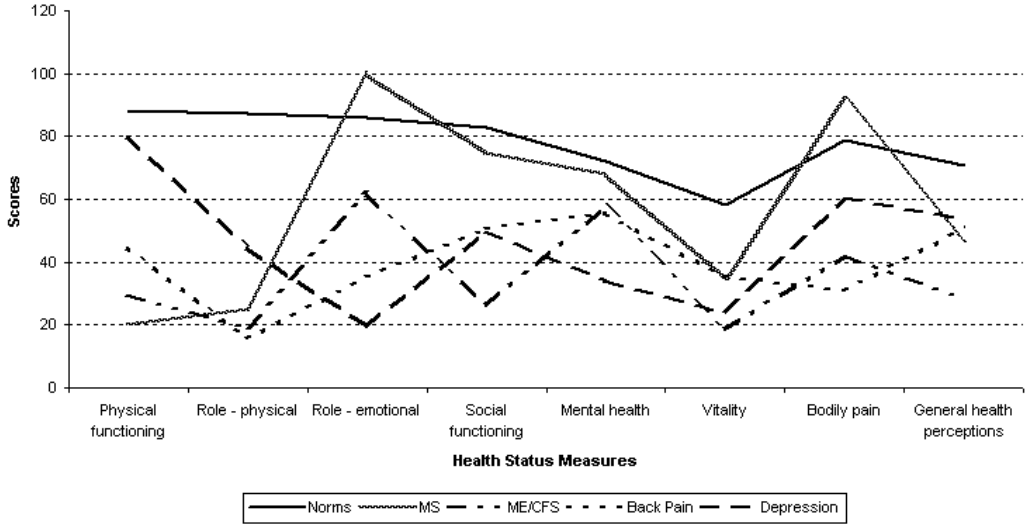
For the interview respondents, the body with ME/CFS dominated everyday life. This is bought into focus by contrasting the quality of life of sufferers with the quality of life of the healthy population and persons with other illnesses. Figure 1 below shows the levels of impairment reported by individuals for each dimension of the quality of life as measured by the SF – 36. The scoring of the SF-36 is such that the lower the score, the worse the quality of life. Charted on the graph are the mean average scores for each dimension for the ME/CFS questionnaire group alongside the published mean scores for the healthy population, and groups of individuals with MS, low back pain, epilepsy, diabetes and depression.

Figure 1 indicates that for the ME/CFS sufferer, physical health and social functioning are the most severely affected, whereas mental health is less affected. Figure 1 further shows that in terms of physical health, in comparison to healthy males and healthy females, the ME/CFS group has only 25% of the capacity for physical functioning and 25% of the capacity for role physical. Further, the ME/CFS group have 50% more bodily pain than the healthy males and females and only 30% of the normal quota of vitality. Indeed, it appears that in terms of physical health ME/CFS sufferers have levels of impairment as severe, if not worse, than sufferers of multiple sclerosis and worse than sufferers of low back pain, diabetes, epilepsy and depression. Similarly, in terms of social functioning, the graph indicates that ME/CFS sufferers have 25% of the capacity for 'getting out' that healthy individuals have. Moreover, the ME/CFS group, show markedly more impairment in terms of social functioning than the ms group, the low back pain group, the diabetes group, the epilepsy group and the depression group.

In comparison, mental functioning appears to be affected, but to a much lesser extent. For example, the ME/CFS group have, on average, 50% lower functioning than the healthy males and females. In addition, the respondents have 65% of the capacity for 'role emotional' that the healthy males and females. Moreover, general mental functioning is higher in the ME/CFS group than it is in depression and low back pain and much closer to the mental health of the other illness groups.

The salience of these findings is illustrated by the interview data. For example, the amount of energy that an individual has at any one time was said to enable an individual to do a minor activity such as "walking 100 yards", "putting the shopping away", "reading a letter" or "watching half an hour of television". Indeed, the fatigue in ME/CFS was so severe that all of the respondents reported being barely able to look after themselves, let alone go out to work or socialise. All of those interviewed were virtually housebound and confined for the best part of their daily lives to either the bed or the settee. The impact on the respondents of ME/CFS was such that many spoke of being imprisoned by their bodies and of feeling as if life had "just stopped in its tracks".

Figure 1. The SF– 36 Scores for ME/CFS and the Disease Comparison Groups



B. The social course of ME/CFS

In addition to examining the impact of ME/CFS on the body and everyday functioning, the second objective of this study was to explore the social course of illness or the pathways through illness that sufferers take as they seek to make sense of the symptoms, reconstruct order and maintain control. The findings relating to this aspect of the study are shown below.

B (I). Making sense of the symptoms of ME/CFS

During the pre-diagnosis stage of ME/CFS many of the respondents defined their symptoms as "trivial" and carried on with everyday life. Surprisingly, despite feeling increasingly unable to cope, the respondents spent on average, two years trying to continue as normal and many took on extra activities, such as going to the gym, in order to try and regain fitness. The majority of the respondents eventually reconsidered the meaning of their symptoms when they were unable to carry on any longer. Importantly 20% of the respondents only "gave up the struggle" when they were forced to:

> I struggled on for so long I can't remember ... feeling so ill and I was getting to the office at 8 0 clock in the morning and feeling so ill, so drained. I carried on for 18 months I wasn't the sort of person to stop work for illness but as I carried on it got worse. I just got worse and worse and then one day I collapsed (Kevin, aged 51, ME/CFS 10 years)

The above finding indicates that on entry into the medical system many sufferers of ME/CFS are already severely incapacitated by their symptoms. Indeed, many of the respondents stated that because of their poor condition they expected that illness would be detected immediately and they would be given access to treatments and advice. Contrary to this however, the first visit to the GP marked the beginning of a long phase of testing for illness. Typically tests would be taken and the results would show no sign of disease, sufferers would then be sent to consultant after consultant yet no illness was

detected. The experience of the medical merry go round (Robinson,1988) is described by Richard who said:

> I went back to the doctors. Nothing progressed from there – more blood tests – more nothing ... and I'm back and forth and back and forth and having another load of tests and every time I think "Oh great, this should finalise it. I can get back to square one, I can get back to racing" but the tests came back and there was nothing there (Richard, aged 19, ME/CFS 6 years)

Within the questionnaire sample the average phase of testing for illness was 2 years (range: 2 months – 8 years).

During the phase of testing for illness the respondents were without a diagnosis. The implications of this were far reaching. In the first instance GPs and consultants, exasperated with the situation, began to put the condition down to "the aches and pains of everyday life". The continued insistence by sufferers that there was "something really wrong" was perceived as either malingering or a form or hypochondrias. The typical reaction of GPs is illustrated by Pip below:

> (The doctor) told me it was virtually all in my mind, he saw about 14 women a year with my complaint. All I needed to do was to go for all the things I really wanted to do but felt I couldn't at the time even though they would make me ill I would be better in 6 months (Pip, aged 40, ME/CFS 10 years)

Secondly others, for example friends, family and work colleagues tended to take the same view as the GP, as David states:

> My whole family doubted me. Everyone doubted me. On top of the massive symptoms I was having it was horrible (David, aged 30, ME/CFS 6 years)

In all, the consequence of severe incapacity, no diagnosis and disbelief and blame for illness was said to exacerbate the losses already bought about by ME/CFS and lead to a deep sense of confusion and social isolation:

> It became a big void of emptiness because previously I had been fighting to find out what was wrong and what to do etc etc. Suddenly you're in a void you haven't got a name for it, how then do you get it over to family and friends, because it sounds like you're inventing something and where do you go from here. It's a world without an end as if you don't know whether this is for life or just for tomorrow. You're on your own Buster with this kind of thing. It's like stepping out of an aircraft that's flown away and you've stepped into a total void ... nothing (Wendy, aged 54, ME/CFS 21 years)

> I wished for brain tumour, I was disappointed when they said I didn't have one, I desperately wanted people to acknowledge that I was in a really bad way (Tina, 25, ME/CFS, 4 years)

As a result of finding themselves undiagnosed, some of the respondents began to consider that their condition was, after all, 'in the mind'. Eventually, however, all of the respondents pursued a medical diagnosis (many travelled miles and paid vast amounts of money to be diagnosed by a medical consultant) and were, after many more tests, told that they were suffering from ME or CFS.

B (II). Reconstructing order

On receiving a diagnosis all of respondents expressed immense relief because they could begin to reconstruct their lives. As Jane states:

> I came away from the doctors, it seems stupid and I've spoke to other people since and I came away happy, because he made me feel as if it wasn't in my mind ... (I said to my husband) "they've diagnosed it, I have got an illness. Now I can try and build my life" (Jane, aged 54, ME/CFS 6 years)

However, despite succeeding in gaining an official diagnosis, the usual avenues of support available to persons with chronic illness remained blocked. Indeed, the integrity of the respondents continued to be questioned by GPs many of whom were said to have blamed their patients for time wasting and to have been reluctant to give any advice with regards to the aetiology and management of the condition:

> My first GP ... he sent me to a psychiatrist, he asked me about my sex life, whether I liked the opposite sex – it was as if he was saying I had ME because I was homosexual. The whole attitude at the doctor's surgery was horrible, when I got upset with them they saw it as a sign of instability ... I asked a locum whether aloe vera might help and he said "you've either got skin problems of you are a woman (Dan, aged 26, ME/CFS 6 years)

In addition, friends, colleagues and family members often continued to treat sufferers' claims to be 'really ill' with scepticism, as did disability officers, whose job it was to assess the eligibility of the sufferer for financial support.

The findings presented thus far raise the question of how, give the general context of dismissal and lack of medical advice about ME/CFS, sufferers make sense of their conditions? How do they answer questions such as why me? what will happen to me now? (Bury, 1992). In response to their situations, the respondents drew eventually on alternative discourses of ME/CFS. Available from ME/CFS support groups and complementary therapists, these discourses tended to suggest that ME/CFS is caused by external agents such as a virus or organophosphate poisoning. They were often contextualised by the respondents within their own biographies and thus helped reconstruct order by providing what was seen as a plausible explanation for the condition. For example Kevin states:

> I used timber treatments. That was the start of it (Kev, aged 51, ME/CFS 10 years)

Further, the alternative discourses of ME/CFS acted to protect the moral integrity of the sufferer by providing a rationale that stated that 'others' react the way they do because they are simply uneducated about the reality of ME/CFS and have a 'limited understanding' of it. Despite being able to justify ME/CFS to themselves however, the findings suggest that sufferers fail to change the views of others.

Further to seeking explanations for their condition, in the absence of much advice from their GPs, the respondents sought information and advice about ME/CFS from other sources such as complementary therapists, spiritual healers, books and websites. However, many of these sources were said to produce a confusing and endless stream of advice for treating the symptoms of ME/CFS which was often conflicting, expensive and ineffective. As a result, the majority of the respondents chose to rely mainly of themselves for the management of their illness, consulting "ME/CFS friendly" GPs only when the need arose for treatments such as painkillers or sedatives.

B (III). Maintaining control

Despite the use of management strategies such as "pacing", for the majority of the respondents, accepting ME/CFS as part of their everyday lives was part of a personal, ongoing daily struggle. Indeed, the respondents in this study can be said to have reached a stage of 'barely tolerating illness'. That sufferers do not fully accept their ME/CFS appears to be due to the unrelenting demands that the condition makes on the body and social action. These demands are compounded by the fact that due to the non-acceptance of the severity of the condition, many sufferers do not obtain the financial assistance necessary for help with daily chores. Because of this, sufferers are unable to use their limited energy to engage in activities that reaffirm the self and life in general. Instead, they are compelled to use the time available to them, to try and ensure that the very basic conditions for existence are met. For many, this situation is one of perpetual chaos as they see their previous standards of living fall away and worry about the future. An illustration of this is provided in the following quotes. Adrienne lived alone but had a supportive network of friends through her local ME Association. She was also able to afford help in the home:

> I don't have a dull time ... there are lots of reasons for being, like going to the sea, seeing the birds and the flowers – what's real the sea crashing on the rocks or a bank balance? You've always got a role to play in life and personal worth. People say why pay all that money to have a home help, it means I don't have to keep struggling and I

> can do things that are important I can keep my sense of place in the world. (Adrienne, aged 54, ME/CFS 21 years).

On the other hand, Jane, like the majority of the respondents states:

> I desperately need total rest as I am acutely ill ie someone to do the washing, gardening, look after the kids. Everything has gone to rack and ruin. My husband can only do so much work and run our sons around, we all desperately need a family holiday as the pressure from my illness falls on the whole family. Some relief from the financial pressure caused by my loss of job and prospects would help dramatically (Jane, aged 42, ME/CFS 2 years)

4. Conclusion

This study has examined the explored the experience of illness and the social course of ME/CFS as sufferers seek to come to terms with and make sense of their condition. It has shown that in ME/CFS, on average, physical functioning is impaired to the point where individuals are housebound for the best part of their daily lives, let alone able to work or socialise. Indeed functional capacity in ME/CFS appears to be as severe if not worse that it is in sufferers of multiple sclerosis and worse than it is for sufferers of low back pain, epilepsy, diabetes and depression. Further, in terms of social functioning persons with ME/CFS have only 25% of the capacity for getting out' than the healthy population. Many sufferers spoke of their lives as "having stopped" or "as if a door has just closed on life and there is nothing on the other side". Respondents frequently referred to the terminal boredom of spending everyday confined to the settee "watching the world go by" and many had tried to commit suicide "because of the hideousness of the condition".

In addition to illustrating the impact of ME/CFS on the body and everyday life, this study shows that the suffering experienced by sufferers is compounded by the fact that it is a contested illness. In the context of "cultural non-legitimation", sufferers experience significant marginalisation. This is the result of first, frequent moral judgements about the nature of their condition and consequently, denial to much social support and uncertainty as to the aetiology and trajectory of illness. Despite, the obstacles put in the pathways of making sense of their conditions however, the study shows that individuals with ME/CFS can and do go some way towards reorienting themselves after the onset of illness. This is due to the availability of explanations for and advice about the condition that exist beyond the biomedical view of ME/CFS. Such explanations are used within the illness narratives of sufferers to reconstruct their personal life histories, serve to explain illness and provide a rationale for having it. Whilst this may be the case, due to the continued lack of social support, particularly financial support, it appears that many individuals with ME/CFS never fully reconcile their illness into their lives.

The case of ME/CFS tends to have much in common with the literature on the experience of back pain (Vranken, 1989), Rheumatoid arthritis (Locker, 1983) and Chronic Obstructive Airways Disorder (Williams, 1994). All of which are illnesses whose symptoms are either invisible or associated with 'the aches and pains of everyday life. In addition, the experience of ME/CFS may be similar to the experience of persons with other conditions that are contested (for example, Gulf war syndrome, organophosphate poisoning, repetitive strain injury and multiple chemical sensitivity). The advantage of studying the experience of persons with what might be termed the non legitimate illnesses is that first a particular form of suffering is made visible and second, the social and cultural construction of illness becomes apparent. Finally, it is possible to witness how, within such a context, suffering persons' actively attempt to reconstruct their worlds.

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Address for correspondence: Dr. Tracey Collett, Department of Sociology, University of Plymouth, 8, Portland Villas, Drake Circus, Plymouth, Devon, UK. PL4 8AA. Email: T.Collett@Plymouth.ac.uk

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