

Brown, Sarah and Cox, Diane (1999) Supporting pupils with chronic fatigue syndrome. *Educational Psychology in Practice*, 15 (3). pp. 183-189.

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Supporting Pupils with Chronic Fatigue Syndrome

Sarah Brown and Diane L. Cox

Summary

Following concern about how to support pupils with Chronic Fatigue Syndrome (CFS), the first author (an educational psychologist) attended a two-day course run by Havering Hospitals Trust Chronic Fatigue Syndrome Diagnostic and Management Service. This article seeks to describe the approach used, and investigate the ways in which EPs can work with pupils, while supporting and liaising with the medical team.

Introduction

Why would an educational psychologist (EP) choose to write about Chronic Fatigue Syndrome? During my first year working as an EP, I have met two pupils, both of secondary age, who have a diagnosis of Chronic Fatigue Syndrome. Although only two cases, they caused me considerable concern as I thought that I did not have sufficient knowledge to help these pupils, or their schools. I was also being asked questions by the special educational needs co-ordinators (SENCOs) involved – such as, should we get a Statement of special educational needs, should we disapply him or her from the Standardised Attainment Tests, isn't he or she just refusing school?

Within LEA structures, as with any groups of people, there is often considerable scepticism about the existence of CFS, and the type of help which should be given to pupils with this illness. Unsure of my role, I attended a two-day course run by the CFS team based within the Essex Centre for Neurological Sciences at Oldchurch Hospital (within the Havering Hospitals NHS Trust). This article is based largely on what I learned at this course, and is co-authored by a (then) member of the team. It examines how the role of EP can fit in with the structure of treatment offered by the team.

Havering Hospitals NHS Trust, Chronic Fatigue Syndrome Diagnostic and Management Service

The CFS team consists of a consultant neurologist, a head occupational therapist (at the time) who has joint-authored this paper, three senior occupational therapists, a senior physiotherapist, two part-time counsellors, an administrator and a link person from the National Centre for ME (myalgic encephalomyelitis). The team have access to six inpatient beds but see most individuals on an outpatient basis. The team work within a client-centred approach (Canadian Association of Occupational Therapists, 1991), using the principles of cognitive behaviour therapy and graded activity (Deale et al, 1997), and report that 82 per cent of patients had a perceived increase in level of ability six months after treatment (Cox and Findley, 1998). This is one of the first such teams in the country, and is currently engaged in taking referrals and in training professionals from across the UK.

Chronic fatigue syndrome

CFS is popularly known as ME (myalgic encephalomyelitis). Myalgia means muscle pain; encephalomyelitis means inflammation of the brain. Because not every person with the illness has one or both of these, the term Chronic Fatigue Syndrome (Fukuda et al, 1994) is seen as a better descriptor, and is now increasingly used by professionals in the field. To fulfil this definition, a person must have fatigue which is both mental and physical, and must be acquired (that is, the onset is recognisable and new). Fatigue is seen as an inability to *sustain* output for activities, rather than a 'weakness' which prohibits the ability to generate any output at all.

Prevalence

It is difficult to know the prevalence of CFS, as many cases may go undiagnosed. Latest figures indicate the prevalence to be between 0.5 per cent and 1.5 per cent of the general population (Pawlikowska et al, 1994; Vercoulen et al, 1996). Dowsett and Colby (1997), in a study in six LEAs, found that CFS is 'the single biggest cause (51 per cent) of long-term sickness absence in children', with the second biggest cause of absence being leukaemia and cancer. In a review of three studies on the prevalence of CFS, Dobbins et al (1997) concluded that CFS is most common in the adult population but that it is uncommon among children ages 3–11 years. This would indicate that among the school population, we are most likely to find CFS in adolescents. The Royal Colleges' report (1996) states, 'CFS in children is a complex issue' and 'does occur in children and adolescents' (p 29). However, this report gives no indication of the age range and notes that there is no firm information currently on prevalence in children and adolescents.

Diagnosis

Historically, many chronic illnesses have been difficult to define. Specific causative agents are often unknown and diagnostic laboratory tests frequently have poor sensitivity and specificity (Holmes et al, 1998; Holmes, 1991). Owing to these problems, case definitions have been developed through consensus of expert committees for such illnesses as rheumatoid arthritis, and various psychiatric diseases (Holmes, 1991). Due to the unknown aetiology of the illness, specific definition and diagnostic criteria for CFS were essential to increase understanding, aid study of the illness, and to determine subgroups (Holmes, 1991; Fukuda et al, 1994). Laboratory tests concerning CFS have been shown to contribute little to its assessment, diagnosis and treatment due to insufficient sensitivity and explicitness (Valdini et al, 1989; Vercoulen et al, 1994; Bates et al, 1995). Fulfilment of a specific set of criteria would also ensure that other diagnosis such as fibromyalgia were not missed (Goldenberg et al, 1990). Therefore, to obtain a diagnosis of CFS from the team at Haverling Hospitals, a person must fulfil the Centre for Disease Control criteria. This definition was developed by Fukuda et al (1994) and updated from Holmes et al (1988), and requires a person to experience at least four out of the following eight symptoms:

- cognitive difficulties (eg poor short-term memory and concentration span)

- myalgia (muscle pain)
- swelling of the lymph glands
- headache
- multi-joint pain
- unrefreshing sleep
- sore throat
- post exertion fatigue.

Symptoms must have been experienced for longer than six months. Fatigue must be substantial and intrude on activities of daily living, other causes must be excluded, and the fatigue must have the quality of 'central fatigue', that is, due to some dysfunction of the nervous system. Fatigue may be experienced directly after an activity, but can also be delayed, perhaps for up to two to three days. In addition, those with CFS experience prolonged recovery times when they become fatigued. This leads to the characteristic 'peaks and troughs', with bursts of activity (perhaps only short) followed by overwhelming fatigue and a long recovery time.

This disease can affect anyone, but Findley (1998) has noted the following common groups who appear to be over-represented in the population of those with the disease: backpackers, teachers, secondary-school pupils, those trying to hold down competitive careers, busy homemakers and health professionals. Certain people may have a predisposition to the disease. It has been found to run in some families, be seen in people with asthma, eczema, hayfever, allergies or irritable bowel syndrome, be seen in some people with a prior history of depression, and be linked to some other metabolic or genetic disorders (Findley, 1998). Stress is reported by the CFS team to be a significant factor in the onset of CFS, with patients often being able to identify a stressful time as the start of their difficulties. Evans et al (1997) comment that 'it may be that more chronic stress ... is associated with more serious impairment of immune responding, which may have implications for a person's physical health' (p 307).

Recovery is not described by the team as a total absence of symptoms but as the person's ability to manage CFS, and to carry out activities for daily living, productivity and leisure within that management.

Intervention

Cognitive Behaviour Therapy (CBT) is a relatively recent addition to psychological intervention. It appears to fill the gap between purely behavioural methods and dynamic psychotherapies, being directly

concerned with faulty thoughts and feelings (Enright, 1997). CBT is based on the theory that inaccurate, unhelpful beliefs, ineffective coping behaviour, negative mood states, social problems, and the pathophysiological processes all interact to perpetuate illness (Sharpe et al, 1997). The efficacy of CBT has been shown in the treatment of other disorders such as anxiety disorder, obsessional-compulsive disorder, panic disorder and agoraphobia, schizophrenia and depression (Andrews, 1996). The application of CBT to many conditions other than depression was based on the premise that cognitive and behavioural factors are relevant to all human experience. Its use now ranges from depression to chronic pain (Enright, 1997).

Over the last 10 years, a theory of CFS has developed which proposes that certain factors and events precipitate, trigger, and perpetuate the illness (Wessely et al, 1989; Butler et al, 1991; Surawy et al, 1995). This theory attempts to explain how certain life stresses may precipitate CFS in pre-disposed persons, and how cognitive, behavioural, physiological and social factors then interact to perpetuate the illness (Surawy et al, 1995). With any long-term illness, it can be very difficult to retain a positive outlook in the face of prolonged disability, restriction of everyday life, and absence of a ready cure. Thus, feelings associated with CFS such as frustration, anger, irritability, anxiety, demoralisation, and profound change in mood, could impair recovery.

The CFS team in Havering Hospitals, therefore, use cognitive behaviour therapy techniques within a client-centred approach to treatment (Cox, 1998). This approach involves teaching skills for the self-management of behaviour. It was developed from Bandura's (1977) ideas that people may need to be taught the skills for producing appropriate behaviours. It also concerns restructuring of cognitions about a person's illness and their views of themselves in their situation (Beaver, 1996). Studies have shown the effectiveness of such an approach in CFS (Sharpe et al, 1996; Deale et al, 1997). The Havering Hospitals treatment follows two strands, as follows:

Physical symptoms

The first strand involves drug treatment for physical symptoms. Such symptoms may include pain, disturbed sleep pattern, and bowel disorders. Sleep disturbance and pain is often treated with antidepressants, such as Amitriptyline and Trimipramine. These drugs are also

commonly prescribed for depression but dosages in this treatment are different. This is an important area for shared understanding, as misunderstandings about why these drugs are used, and following misperceptions about the diagnosis, can lead to delay in treatment (Findley, 1998).

Education and management programme

The second strand involves the patient in an active role. As the programme developed it was apparent that it fell within the Canadian Occupational Performance Model guidelines for client-centred practice (CAOT, 1991), although at the time it was developed this model was unknown. The client-centred approach encourages patients to direct their own therapy, to accept personal responsibility and to make decisions. The therapist acts as a facilitator, offering opportunities and education, enabling patients to explore thoughts and feelings in a safe therapeutic environment (CAOT, 1991; Cox and Findley, 1998). The main emphasis of the CFS Havering Hospitals programme is on dealing with problems identified by the patient, using activities that are meaningful to the individual. The aim following intervention is for the patient to have an increase in their level of ability, reduced symptoms, and a positive change in thinking style and management of the illness (Cox, 1999). The full details of the programme have been discussed elsewhere (Cox, 1998; Cox, 1999).

The programme, therefore, is tailored to individual needs, and aimed at assisting the person to manage their symptoms to a degree where 'normal' living is possible. Patients are asked to analyse their daily activities, from waking to sleeping. Following this, the individual is asked to sort the activities they carry out in terms of the amount of energy they require; either low, medium or high. A programme is developed by the occupational therapist and patient, which builds in rest periods and a balance of activities during the day (Cox, 1998; Cox and Findley, 1998). Assuming this level of activity can be maintained over a period of time, activity levels may be increased by up to 15–20 per cent at a time.

In addition to the development of such a daily programme, patients are supported by the occupational therapists and counsellors on the team in re-conceptualising their illness and understanding how they can play a part in their own recovery. Techniques such as 'scaling' are used, with which EPs will be familiar in the use of Solution-Focused Brief Therapy (George et al, 1990).

The role of the EP

The relevance of this knowledge to the role of an EP has become clear. The over-representation of secondary-school pupils and teachers in the group of people with CFS (Estridge, 1998) means that we are all likely to meet CFS in the course of our work.

Attitudes

Perhaps the most important set of attitudes to examine is one's own. The CFS team emphasise that a patient's distress must be accepted as genuine, and if one cannot do this, then there is no point working with an individual. When working with young people, or indeed adults, it will be important for the EP to be seen to believe in the difficulties that person is experiencing. In a sense it does not matter whether one believes in CFS or not, as long as one is able to work with the individual in their particular situation. Higgins and Siner (1996) suggest that it is crucial to be open-minded, and to respond to the individual rather than their illness. This acceptance of the person conforms to Roger's (1977) description of genuine-ness, unconditional positive regard, and empathic understanding, are mainstays of EP practice.

The attitudes of professionals working with young people, and in particular, those of school staff, are also important. As Dowsett and Colby (1997) point out, many members of school staff will have direct experience of someone with CFS, whether in the school or home environment, and therefore will have developed firm views on the subject. EPs are in a position to share their knowledge. This may involve colleagues in the LEA beyond those immediately within schools. For example, Wallace (1997) referred to the need for home tutors to have a good understanding of CFS, suggesting that 'the lack of expertise among home tutors is worrying because ME can affect the brain even more than the body' (p 3).

The interaction between home and school, clearly, is one which can promote or inhibit success in most areas. The attitude of parents will affect the management of CFS by a young person. It is not only the attitudes of parents who 'don't believe' that can be negative. Parents who accept the symptoms and feelings of their child as genuine can become over-protective. For adolescents, the move back towards dependence may cause anxiety and conflict, as their relationship with parents may appear to be regressing. In addition, parents and other members of the family may experience their own stress and

feelings of resentment, since CFS disrupts and inconveniences normal family life. Siblings may find it difficult to accept the high levels of attention being received by one member of the family. Potentially, EPs are in a position to work with families, by reinforcing the principles of the management programme, and providing support to the family in allowing the young person with CFS some independence. Some EPs may be in a position to enter into more direct work with families in exploring attitudes and feelings. Others may need to facilitate access to the appropriate local agencies.

Finally, the attitudes of the person who is ill are important. For young people, whose condition may have been provoked by high levels of stress around the time of onset of puberty, change of school, peer pressures and exam pressures, the ability to express and understand their own feelings may be an area of considerable difficulty. The use of cognitive behaviour therapy by the CFS team will have begun this process of enabling young people to understand and express feelings, and EPs have expertise to offer in further supporting this process. The use of techniques in personal construct psychology (Ravenette, 1997) may enable the EP to facilitate a young person to gain an understanding of their perceptions of themselves and their illness.

The stress of illness may lead to other difficulties. Elander and Midance (1997) state that 'many chronic childhood illnesses are associated with increased behaviour problems and greater difficulties in coping and adjustment in affected children' (p 211), and suggest that children's perceptions of their illness probably play a greater part in predicting adjustment than physical aspects of the condition. An investigation of perceptions may help in averting these kinds of problems, or in dealing with them when they arise.

Therapeutic interventions

Many EPs do not see themselves as counsellors, nor do they spend a great deal of time in this role. However, an understanding of the kinds of emotions that may be associated with an illness like CFS will be useful. Counsellors on the CFS team describe a range of emotions that may be apparent: sadness, guilt, loneliness, jealousy, annoyance, anger, isolation, boredom, humiliation, depression, anxiety, and feeling overwhelmed. In addition, some sufferers describe a feeling of bereavement (Campling, 1996) for the loss of the person that they used to be, and for the loss of friends, interests and so on.

Whether EPs take a direct part in counselling activities, or simply share understanding with those involved with the young person, an acceptance of a range of perhaps unpredictable emotions, and an understanding of how they link with the illness will be important. In addition, the ability to model a tolerance of a painful emotional state, and contain negative feelings such as frustration and anger over the illness, may enable the young person to do this him or herself (Greenhalgh, 1994).

Assessment

EPs may be asked to carry out assessments prior to the start of home tuition, or re-entry into school. The principles of the management programme apply, and so assessment should take place over time, or include breaks. EP assessment may also provide an overview of the types of activity which are more difficult or easier for the young person; for example, they may find short-term retention of facts difficult, or activities with a defined beginning and ending easier.

Liaison with, and support of treatment

EPs may feel pushed by the school and/or the LEA to get the pupil back into school as fast as possible, no matter what. However, if it is accepted that the type of treatment offered is valid and successful, then it requires support. This means resisting the temptation to move too quickly, and accepting that the increase of activity will take time. EPs may be in a position to recommend that home tuition is in place, within the pupil's programme, and that this remains in place for a substantial period of time, albeit with short bursts of tuition. Similarly, when a pupil is able to return to school, a slow, carefully graded reintegration programme will be important, and liaison with agencies involved will be useful (Markovitch, 1997). Colby (1994) stresses that pushing a child beyond his or her limitations at this stage will be counter-productive, as the resulting stress will lead to a relapse. The Royal Colleges' report (1996) suggested that the involvement of parents in the treatment process is essential, particularly in view of a gradual planned reintegration to school. The report goes on to say that medical practitioners should be mindful of their statutory duties relating to the School Attendance Act and the Children Act (p 31).

Alongside this slow, gradual programme it is useful to consider the purpose of any education programme being delivered. In learning, the importance for pupils

of understanding the relevance and meaning of work set, and its aims, has been well established. Is it, therefore, useful for home tutors or schools to deliver tiny parts of different subjects, or to focus on one topic? It is easily forgotten that GCSEs do not have to be taken in Year 11 but that if necessary, a pupil could work towards one GCSE over two years, and tackle others at college later. Encouraging the use of reinforcement materials may also help; for example, the use of audio- and video-taped books or television education programmes which supplement the scheme of work being followed.

When a pupil re-enters the school environment, or starts to attend on a reduced timetable, EPs should be able to advise schools on the usefulness or otherwise of a Statement of special educational need. It will be valuable to encourage school staff to take time to reflect on the individual pupil's situation, and to collaborate in finding strategies to assist the pupil. It may be that extra adult support is needed, for example, to supervise rest breaks, or provide indoor supervision at breaktimes. The EP may also provide advice on suitable approaches to the curriculum, and on access to special arrangements for tests, SATs and external examinations.

School refusal

An important issue to raise in this context, concerns school refusal. Colleagues may ask how one can tell whether a child is genuinely ill or simply refusing school. Franklin (1997) notes three main differences: a school refuser has an erratic pattern of non-attendance, joins in with peer activities at weekends and does not want to be in school. A CFS sufferer has prolonged periods of absence, there is no change at weekends, and wants to get back to school. EPs are not able to make a 'diagnosis'. However, a CFS diagnosis from the Havering team is based on evidence over time, and a set of defining criteria. It is unlikely that a pupil with no underlying problems would be able to meet these but the possibility of a child with CFS developing anxieties or phobias about school would be understandable, following long-term absences.

Conclusion

This article has set out to explain the diagnosis and treatment of CFS by the dedicated team at Havering Hospitals, and to examine how an EP may contribute to supporting young people with CFS. EPs are in a position to examine and influence the attitudes of

those involved with the pupil, to share knowledge about the condition and its possible treatment, to liaise with school, family and professionals, to advise on approaches to teaching and learning, and perhaps above all, to listen to the pupil concerned.

Although CFS team in Havering Hospitals is one of the first in the country, there are likely to be individual practitioners working in this way, and it is hoped that more teams will begin to appear around the country. It is not yet possible to fully understand CFS, but an understanding of the approach of the CFS team and a willingness to support young people in this way is a step in the right direction.

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Further reading

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Follow-up references

Canadian Assoc. of Occupational Therapists
Ottawa
Ontario
Canada.

The National ME Centre
DSC
Harold Wood Hospital
Gubbins Lane
Romford RM3 0BE
Tel: 01708 378050
e-mail: nmecent@aol.com

Sarah Brown is an educational psychologist in Kent. Her address for correspondence is: Educational Psychology Service, Joynes House, 1-4 New Road, Gravesend, Kent DA11 0AT. Diane Cox was the head occupational therapist and co-ordinator of the Chronic Fatigue Syndrome Service for Havering Hospitals NHS Trust. She now holds the post of senior lecturer in occupational therapy, Professions Allied to Medicine. Her address for correspondence is: South Bank University, 103 Borough Road, Southwark, London SE1 0AA.

This article was submitted in July 1998 and accepted after revision in February 1999.