Attachment 6.

Education of Students with the Chronic Illness Disability of

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

(ME/CFS.

Attachment 6

Morris, D. (2001), peer-reviewed abstract ‘Education, Equity and Cognitive Dysfunction Dilemmas,’ paper presented at The Third Sydney International Clinical and Scientific Meeting, 'The Medical Practitioners' Challenge' at Manly Pacific Parkroyal, Sydney, Australia, held 1-2 December, 2001 for Researchers and Clinicians. Sydney, convened by Alison Hunter Memorial Foundation. CME points awarded.

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Education, Equity and Cognitive Dysfunction Dilemmas.

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Objective:

To raise awareness of medical practitioners to the full implications of their medical certification of disability assessment and long term disability for chronic and complex illnesses. This includes awareness of the need for full understanding and cognisance of the implications of all symptoms of ME/CFS and the far reaching impact of the same.

Abstract:

This paper addresses the issue of the Cognitive Dysfunction of ME/CFS affecting education and educational outcomes for students and also how the present system leaves vulnerable medical practitioners, disability officers, academics and teachers under the Federal Disability Discrimination Act, 1992.

The doctoral research is ‘The lived experience of ME/CFS: a study in human rights and equity in tertiary education’. It has forty participants from twenty-four of the thirty nine Australian universities and eight TAFE/OTEN institutions. All states and territories of Australia are represented. All participants, without being asked, drew attention to the adverse impact of the cognitive dysfunction of ME/CFS on their academic experiences. The research reveals that no attention has been given to making appropriate accommodations for this symptom. The present situation is that the only symptom of ME/CFS which is being accommodated in tertiary education is fatigue.

The DDA (1992), especially Section 6, Indirect Discrimination, allows for all persons to have equity accommodations commensurate with their disability. Further it is not a legal defence to say that a person did not know of their responsibilities under this act. Currently, medical practitioners and disability liaison officers (often allied health workers), who are not trained educators, are forced to make assessments outside their areas of expertise on educational outcomes. Trained educators, capable of assessing the impact are not involved in the making of recommendations for accommodation. This is the equity and cognitive dysfunction dilemma in education.

1. Introduction

The doctoral research is to ascertain the lived experience of a group of students in tertiary (post-secondary) education in Australia who have the chronic illness of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and assess their experiences from the perspective of human rights, equity and quality of life. There seems to be a chasm between the medical knowledge of a condition, and how it impinges on academic progress. The complexity of the medical symptoms, and their far-reaching impact on the ME/CFS student, has meant that there has been many complaints amongst tertiary ME/CFS students that their needs for suitable accommodations for cognitive dysfunction are not being met.

The research methodology employed is critical ethnography (1). This is exploratory research and, as the first research conducted in a research field, it is not possible to commence with a research hypothesis. Further questionnaires and surveys are not appropriate for data gathering in a new research area.

2. The Research Participants.

Forty Australian students with ME/CFS from all states and territories of Australia, representing twenty-four Australian universities and eight TAFE/OTEN colleges were accessed for their lived educational stories. Participants were recruited through personal electronic mails and also a general mailing to an Australian internet ME/CFS listserv. Additionally letters were written to the members of the South Australian ME/CFS Student Telephone Support network list. Snowballing also occurred where students and non-students contacted persons whom they perceived could be likely participants. The state ME/CFS Societies were not accessed nor were the Disability Liaison Officers of the Australian universities.

The participants had to meet the criteria of having been enrolled at an Australian tertiary institution (post-secondary schooling) post 1994, and whose medical illness complied with the Ramsay 1988 research definition (2) (with the additional six month criteria of the Fukuda *et al.* (3) research definition for ME/CFS). As Ramsay is a stricter definition than Fukuda, all participants also met the CDC Fukuda criteria.

All persons who met these qualifying criteria were accepted into the study. The gender breakdown was twenty-nine females, and eleven males which approximates to the gender composition of ME/CFS as found by Jason (4). The ages of the participants ranged from nineteen to sixty-two years. The duration of ME/CFS was from nine months to twenty-five years with a mean duration of eight years.

3. Data Collection.

Computer electronic mail access was not a qualifying criterion, and ordinary mail was accepted, so as not to limit this research to those persons with computers. It was apparent that the use of electronic mail as the medium of research gathering was popular with the research participants with only five persons sending their stories through the post (5). A participant wrote, when returning her consent form and initial questionnaire,

> I am looking forward to writing down my experiences, I am so glad you are doing this research, it gives so many of us a voice. Most of the time no one wants to know. (Nola)

4. Historical background

With the advent of the new name for ME, coined in 1988 by the Centers for Disease Control, USA, the focus changed away from the encephalitic features of ME, to emphasis on the less serious, but statistically more common symptom of fatigue (6). In the public perceptions thereafter ME was thought to be merely chronic fatigue (7). The encephalitic features have been ignored or relegated to a secondary position (8). The present situation is that the only symptom of ME/CFS which is being accommodated in tertiary education is fatigue (9).

The cognitive problems of ME/CFS typically include poor concentration and short-term memory, word-finding difficulty, and inability to cope with multiple stimuli and then there is fragile retrieval (10,11,12,13,14,15,16,17). Ramsay (16) says that the person with ME/CFS is dogged by persistent profound fatigue accompanied by a medley of symptoms such as headache, attacks of giddiness, muscle weakness, blurred vision and/or diplopia (double vision) and a general sense of ‘feeling awful’. Further physical problems may also intrude on persons with the condition, such as the symptom of hyperacusis (16). There may also be heightened environmental chemical sensitivity (18).

> Many report difficulty in saying the right word and are conscious of the fact that they continue to say the wrong one, for example ‘cold’ when they mean ‘hot’. Others find that they start a sentence but cannot complete it, while some others have difficulty comprehending the written or spoken word (2).

Bastein (10, p.454) found almost a decade ago that:

> The patient sample had the following neuropsychological impairments: word finding problems; subtle problems with receptive and expressive aphasia, including intermittent dysnomias; decreased concentration; distractability, problems in recall, verbal more than visual, including remote memory disturbance; dyscalculia …; both gross and fine motor problems; spatial-perceptual dysfunction, including losing their way while driving; some abstract reasoning disturbance, primarily non-verbal; decreased visual discrimination; and problems in sequencing.

According to Preston (19) brainwaves, without warning, may change from beta (thinking) to delta and theta waves, (associated with sleep and pre-sleep states in healthy people) as sudden inexplicable “power drains” during cognitive challenge. Others, such as DeMerleir, De Becker, Peterson, Nicolson, W. Behan, McGregor, Casse, Robinson, Kilburn, Komaroff (20) have drawn attention to their own research findings in the areas of biochemistry, microbiology, immunology, pathology, physiology and other medical disciplines impacting on neurocognitive dysfunction.

5. Participant stories

Thirty five participants wrote their personal story of experiences as a tertiary student with ME/CFS. The participants were not directed on what they had to write, and comments were not sought about the cognitive dysfunction: yet every story , without exception, mentioned their difficulties in this area, and the lack of understanding and accommodation which they received, and which in turn affected their academic achievements and was deleterious to their health (21). The research reveals that no attention has been given to making appropriate accommodations for this symptom.

> This was the most prominent problem for me - the cognitive dysfunction, brain fog etc. As a tertiary student, you obviously are expected to have some level of intelligence and be able to ‘think on your feet’ which is near impossible with brain fog. How does one portray this to the rest of the young, fit and healthy class, who are wondering why you are stumbling to spit out a coherent sentence, especially when they know that yesterday you

> could throw out thoughtful, witty comments along with the best of them. (Vicki)

More time has to be spent in encoding new information, yet on the day of an examination there can be no assurance that this information will be able to be retrieved and utilised, as mental fatigue will mean that the brain has apparently shut down (22,23,24). ME/CFS students colloquially call their cognitive dysfunction ‘Brain Fog’. ‘Brain Fog’ occurring during an examination would mean there would be great difficulties in continuing the assessment. ‘Brain Fog’ has a variable duration, often lasting into the next day. Most students, when ‘Brain Fog’ sets in, call it a day, and know that it is no use to try and persist with the examination. In fact, they find that paradoxically that trying to persist will mean that they are only exacerbating the problem - as they are faced with no other alternative but to hand in their paper and depart the examination room: additional time does not allow for this phenomena (25,26). And likely, many academics and teachers, who have organised the extra time for the ME/CFS student are left puzzling as to why the ungrateful student left the examination early without completing the paper.

> At the time I found it hard to concentrate, sit for very long [so] I requested another means of assessment or allowances for my illness. The exam was to be three hours. My grades were good I thought they would think I had valid grounds. I told the [examination] officer that I was quite sick with CFS, and had a Dr’s certificate and needed some changes made. She told me that she understood CFS but then went on to tell me that I could do the exam in stages but would not be able to be let out of the room. I then informed her that after a short time I may have to lie down and it would take me a long time to recover enough to start again…. I felt that she would understand the level of my disability at the time. She told me that I would have to lie in the corner, that was the only thing she could do. There was no way I could lie in front of around 150 males and females adult student and sleep to recover on the carpet floor. I would have had to stay there for days then! I decided that I would attend the exam and then do what I could and leave. I left 1 1/2 hours early and did not get the grade I would have if I had been well or by another assessment method. I didn't know about a misadventure or request for illness and I had lost faith in the system to help me so I didn't ask any further at the time. (Kathryn)

Unfortunately, this experience of Kathryn was not an isolated occurrence and stories with similar content were collected from all states of Australia.

> My brain had had a good rest now… it seemed OK. But when I tried to introduce it to this (to me) massive amount of new information it was supposed to deal with - it collapsed and completely shut down. I struggled to

> get through the readings for the subject, to take in the concepts, but I just couldn't retain anything. I found it fascinating and was desperate to learn. But even though I went over and over and over everything, my brain just couldn't take it in. My memory was still far from normal and by stressing it in this way I made it far worse than it had ever been before. (Rosemary)
>
> The strange things about exams, once you've got CFS, is that the longer you have to prepare for them and the harder you work, the sicker you get and the worse you do. So while other students are checking timetables and saying 'Oh good, three weeks till such and such,' you're thinking 'Oh no, what a disaster, three weeks to prepare!' On several occasions I asked (and was allowed) to do an exam as soon as lectures finished, sparing myself weeks of illness and ending up with a better result. (Marlene)
>
> But my brain shut down and I lost short term memory. While at Uni I forgot where I was and what I was doing on my way to the library. I wondered, jokingly and not yet in panic, if I had developed amnesia. I tried the standard test- what is my name - and couldn't think of it. My reasoning was curiously impaired, and I finally worked out how to get home from my limited memory access. The next day I was fine. (Barry)

These are only a few of the many extracts from the participant stories which could have been presented here. It is immediately obvious that these difficulties, which are being experienced by the ME/CFS students, have a uniqueness about them: the interrelatedness of ME/CFS with cognitive dysfunction and physical incapacity, and the physical and mental requirements of assessment. (Further participant comments in the endnote).

6. Disability Legislation

How can this dilemma of academic assessment requirements be achieved, whilst also extending equity and equal opportunity to the ME/CFS students? This problem becomes even more acute when the present legislation is taken into account. The *Disability Discrimination Act* (27), is the Australian standard for assessing disability discrimination and in education sections 6 and 22 are particularly applicable. Section 22 is written to explain direct discrimination in the field of education and there is good compliance with the requirements of this section of the Act (27a). The *Disability Discrimination Act* (27b), Section 6 states:

> **Indirect disability discrimination**
> For the purposes of this Act, a person ("discriminator") discriminates against another person ("aggrieved person") on the ground of a disability of the aggrieved person if the discriminator requires the aggrieved person to comply with a requirement or condition:
> *(a)* with which a substantially higher proportion of persons without the disability comply or are unable to comply; and

> *(b)* which is not reasonable having regard to the circumstances of the case;
> and
> with which the aggrieved person does not or is not able to comply

Indirect Discrimination occurs when 'normal' students are able to comply with a regulation/situation, whereas the student with the disability cannot due to the nature of their impairment.

7. Findings

The research found that there were profound difficulties experienced by all forty participants with cognitive dysfunction. These findings are consistent with the research findings of those who have used the CDC Fukuda definitions (28,29,30,31,32,33), and others using this same definition).

Analysis revealed that generally Australian tertiary institutions are aware of the provisions of Section 22 of the Disability Discrimination Act 1992 which is specifically for education (27a). Evidence of apparent infringements of the Disability Discrimination Act 1992 emerged from the research stories particularly in relation to Section 6, which deals with Indirect Discrimination (27b). There were also infringements of the *Students with Disabilities: Code of Practice for Australian Tertiary Institutions,* (34) by the institutions although having inclusive policies in place. The institutions had limited perceptions of disability which meant they focussed on accommodations for those students with visible disabilities (eg. students with visual impairment, hearing impairment and who utilised wheelchairs for mobility), where as invisible disabilities, such as chronic illness, were overlooked. There was also evidence of the medical model of disability emerging which places the participant in the victim role, and affects quality of life, human rights and equity issues.

8. Discussion

The persons with whom the students with ME/CFS have to deal with to obtain accommodations are persons who are trained in diverse areas of health, such a speech therapy, occupational therapy, nursing, welfare work, etc. Students may also have to deal with the faculty officer who has been given the task of finding accommodations for students with a disability. The accommodations are not designed to fit the students disability, but rather how the student may be made to fit in with the requirements of the institutions.

The present system means that the student with ME/CFS has to obtain a medical certificate to obtain disability accommodations within their tertiary institution. As ME/CFS is not accepted as a long term disability this means that, in most institutions, there has to be certification for each examination or accommodation (35). The institution says that they make the accommodations which are recommended by the student's medical practitioner. The institutions have their guidelines (36) which they use to make accommodations for ME/CFS which are based on traditional precedent and also on their suppositions of what they think constitutes the medical condition of Chronic Fatigue Syndrome.

The medical practitioner, who is requested over and over again to provide certification, will usually name the diagnosed condition of their patient, but is unable to provide details of how this condition will affect the learning outcomes of their patient in an educational setting. If a medical practitioner were to do so they would be making education assessments outside of their area of medical expertise. Hence it is neither professional, nor even unethical, for a medical practitioner to attempt to try and assess learning outcomes for the myriad of tertiary courses. The medical practitioner will write the certificate stating that their patient has 'Chronic Fatigue Syndrome', and maybe, because of their patients prompting, request additional time for their patient to allow for rest periods (as allowed by the tertiary institution precedence procedures to supposedly accommodate Chronic Fatigue Syndrome). The tertiary institution will then implement their preconceived stereotype program which has never been examined for appropriateness nor based on research findings. Extra time is the usual accommodation which is offered to ME/CFS students, but it is obvious that this accommodation falls far short of being adequate, and may in itself, even constitute indirect discrimination, as many students could find that the extra time allowed (making the examination of longer duration) has actually worsened their physical condition. And another question is also raised - how much extra time needs to be allowed to achieve equity? The student's cognitive dysfunction has been ignored and no accommodations have been made.

The question must be asked, should the ME/CFS student with cognitive dysfunction even be sitting examinations? Given the medical condition symptomatology, it is questionable as to whether examinations are an appropriate form of assessment at all (37). Certainly the provision of allowing extra time is not an appropriate accommodation for all students with ME/CFS. No-one can take away from the students with ME/CFS the symptoms of this condition which affects them, but there needs to be a thorough investigation of appropriate accommodation and assessment procedures (38,39).

8. Conclusion

It is apparent that ME/CFS students are being seriously disadvantaged, both academically and also with the effects on their physical health, when being placed in the same category as other students with chronic illnesses, or being placed along side students with writing difficulties, who need additional time. In fact, the very use of examinations as a means of assessment must be called into question.

Medical practitioners are not able to write certificates for their ME/CFS tertiary students patients which make specific learning assessments to ensure equity accommodations, as it is outside of their area of medical expertise. And the persons in the tertiary institutions are not trained to be able to assess the learning outcomes for ME/CFS tertiary students. Currently, medical practitioners and disability liaison officers (often with paramedical backgrounds), who are not trained educators, are forced to make assessments outside their areas of expertise on educational outcomes.

This results in the current situation where ME/CFS students are not receiving the appropriate accommodations to which they are entitled under the Federal Disability Discrimination Act (27). Further the act does not allow for the 'discriminator' to plead that they did not understand they were discriminating (40). The present system would seem to leave medical practitioners, disability officers, academics and teachers vulnerable under the Federal Disability Discrimination Act, 1992.

9. Dilemmas

- Who can assess the educational learning outcomes of the cognitive dysfunction of ME/CFS subject by subject?
- Who is responsible for equity?
- What can be done?

These are the present dilemmas, dilemmas of a flawed system which is incapable of making the appropriate accommodations which the Disability Discrimination Act (27), especially Section 6 expects and sets out. Many students could even challenge this lack of equity. And if legally challenged where will the fault be found to lie - in the system, or in the persons implementing the system? There is the likelihood of a test case in this area and the findings will be interesting. This is the equity and cognitive dysfunction dilemma in education.

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Endnote:

Short term memory recall for terminology was a difficulty, but the excruciating myalgia pain was very severe. … I ceased writing for half an hour. I did the remaining questions in severe pain and headache - pain in my hand, arm shoulder, and neck, not only in the muscles, but also in the nerves like a drill, which was most distracting… I struggled to write - my hand was numb and had pins and needles, and frozen in a cramp holding the pen. …I could have cried with the pain. …The last question I was too tired to think, too pained … , so I jotted some points down. The pain was akin to medieval torture! PS. I got HD! (Elizabeth)

The exam variations I have arranged thus far have included double time and a 1 hour rest break, which was intended to be either short rest periods or a longer rest if I needed to lie down. Nevertheless, I have had invigilators who refuse to let me out of the room, and it is very difficult to lie down in a small, crowded, stuffy room - on the floor - and call it rest. (Tammie).

My memory and concentration became very poor, and although I have some native talent for dealing with things on the fly, when my brain fogged too much I just lost it completely. The first time I recall this happening was in Honours, and I managed to just focus on the issue and ignore everything else (including the fact that my vision had tunnelled and I couldn't really see the room). (Barry).

My one remaining subject, in second-year [subject name] had an mid-semester exam …, which I think was worth 10%. It was a one-hour exam to be held in our last lecture. I was having massive concentration and memory problems and I knew I wouldn't be able to perform normally on this exam, so I sought to be given extra time - I applied for this through the Faculty office and they granted it to me. However when I arrived at the exam, the people running it did not have a clue who I was and in fact there was no provision for me to have extra time. (Rosemary)

Extra time is essential, but if you take too much, you are so exhausted by the end that you can't function properly anyway. Going down hill as you slog through the paper happens regardless. I discovered this when I once looked at a computer programming paper I'd done and found simple arithmetic errors peppering what would have been the last half hour. I'd used the right method but ended up with nonsense because I'd calculated 3 X 2 = 4, or some such nonsense. I also noticed that in the time left at the end I'd 'checked' the paper and changed several things to incorrect answers. From then on I never checked an exam paper, even if I had time left. By the time I'd gone through it once I felt so ill that any changes were bound to be for the worse. (Marlene).

The nature of CFS means that attendance to many lectures is not possible, nor is the compulsory attendance to tutorials. Despite requests for lectures to be taped, this has always been refused. Missing more than 3 tutorials per semester automatically leads to the loss of 15% of my final mark and the preclusion from sitting Supplementary Exams (which may be necessary due to poor health on the day of the exam). There is no

> concession for the fact that having CFS makes it virtually impossible to meet this compulsory requirement. Medical certificates are accepted only if obtained on the day of illness, which is rather difficult when my GP is a 20 minute drive away and I can't get off the couch! (Tammie)

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