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The occupational and quality of life consequences of chronic fatigue syndrome/myalgic encephalomyelitis in young people

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Abstract

Introduction—Chronic fatigue syndrome, termed myalgic encephalomyelitis in the United Kingdom (CFS/ME), is a debilitating condition involving severe exhaustion, cognitive difficulties, educational and vocational losses, and disruption of social activities and relationships. CFS/ME may affect volition (that is, value, interest and sense of competence).

Purpose—To test Model of Human Occupation (MOHO) concepts by comparing young people with and without CFS/ME in terms of occupational participation, volition and health-related quality of life during infection and over time.

Method—Three hundred and one people (12–18 years old) diagnosed with glandular fever were evaluated at the time of acute infection (baseline). Six months following diagnosis, 39 of them met the criteria for CFS/ME. A further 39 who recovered were randomly selected and matched to CFS/ME participants. Both groups were re-evaluated at 12 months and 24 months. The *Occupational Self Assessment* and the *Child General Health Questionnaire* were used to compare occupational participation.

Results—Those with CFS/ME reported lower levels of perceived competency, more difficulties with physical functioning and poorer general health status than those who recovered.

Conclusion—Those with CFS/ME report lower perceived competency, and compromises in physical functioning, school performance, social activities, emotional functioning and general health. This supports the MOHO assertion that impairments affect volition and quality of life.

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Introduction

Young people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) experience overwhelming fatigue for at least 6 months and a range of additional symptoms, including cognitive impairment, ongoing sore throat, tender glands, aching muscles, joint pain, headaches, unrefreshing sleep and fatigue after exercise (Afari and Buchwald 2003, Garralda and Rangel 2004, Jason et al 2006, Turnbull et al 2007). CFS/ME is more prevalent among girls (Rimes et al 2007) and it occurs in approximately 0.2% of young people (Jordan et al 2006). To date, the literature has shown that CFS/ME disrupts participation in the academic, social and functional activities of young people and adults (Hughes 2009). For example, the severity of fatigue and associated symptoms of CFS/ME cause frequent absences from school (Smith et al 2003, Garralda and Rangel 2004, Richards et al 2005). One study in the United Kingdom identified CFS/ME as the most common cause of prolonged medical leave from school among young people (Dowsett and Colby 1997). One-third of young people with CFS/ME report severe restrictions of all activities and marked drops in school performance; some miss up to 80 days in a 6-month period (Smith et al 1991). One study (Krilov et al 1998) found that only 14% of young people with CFS/ME attended school regularly and another found that 55% reported a decline in academic performance since illness onset (Carter et al 1995).

Along with limitations in important academic areas, young people with CFS/ME have difficulty in functioning and participating in social and family events. Carter et al (1995) found that 80% of young people showed a major reduction in their extracurricular activities at school. Garralda and Rangel (2004) found that the functional impairments of young people with CFS/ME were higher than for those with cystic fibrosis and juvenile rheumatoid arthritis. Additionally, these investigators found that young people with CFS/ME experienced occupational impairments, including absence from school, loss of contact from their peer groups and marked inactivity (Garralda and Rangel 2004). They stopped socialising with friends and their family relationships became strained. Similarly, Richards et al (2005) explored functional impairment in 30 young people with CFS/ME and 30 young people with irritable bowel disorder. Those with CFS/ME showed a high level of difficulty relating to and performing activities with parents and peers (Richards et al 2005).

Absence from school for long periods of time and missed peer and social activities not only disrupt a child's learning but may also perpetuate feelings of limited self-efficacy, loss of control and decreased self-confidence (Smith et al 2003). Garralda and Rangel (2004) found that children with CFS/ME appear to lose confidence over time in their ability to perform educationally and socially. Limited participation in important developmental activities (for example, school, social and family) may increase anxiety and contribute to fears related to a wide range of performance areas. All of these limitations and fears may be associated with decreased feelings of competence at a critical time in an adolescent's life.

According to the Model of Human Occupation (MOHO) (Kielhofner 2008), when an illness interferes with a person's perceived competence, it is said to interrupt volition. Volition is manifest in the thoughts and feelings that an individual has about himself or herself as an actor in the world (Kielhofner 2008). These thoughts and feelings occur as the individual anticipates, chooses, experiences and evaluates what he or she does (Kielhofner 2008). Moreover, they pertain to how one assigns values, finds interest and feels competent in everyday occupations (that is, work, play and self-care activities). According to MOHO, impairments not only affect the ability to perform but also can have profound effects on volition which, in turn, can compromise quality of life (Kielhofner 2008). To test this MOHO-based assertion, the authors examined the extent to which young people who developed CFS/ME viewed and valued their performance (Perceived Competency and

Values) as compared with fully recovered controls. Additionally, they examined whether young people with CFS/ME would rate themselves as having a lower functioning and health-related quality of life as compared with their fully recovered peers. The findings from prior studies of quality of life in CFS/ME are largely retrospective and occupational participation has never been examined in an adolescent CFS/ME sample. There is a dearth of research in the area of CFS/ME that is occupation focused and focused upon young people.

The central objective was to compare young people who did and did not recover from glandular fever, in terms of occupational participation and health-related quality of life during infection and 6 months, 12 months and 24 months following infection. It was hypothesized that young people with CFS/ME would demonstrate more limitations in their perceived competence for daily life activities but equivalent value for daily life activities, as compared with controls at all time points. In terms of quality of life, it was hypothesised that young people with CFS/ME would demonstrate more limitations than controls at all time points.

Method

Design

This was a prospective case-control cohort study that involved comparing measures of occupational participation and functioning in young people who did and did not recover from glandular fever over a 2-year period. This 2-year period included four evaluation time points: (1) initial diagnosis with glandular fever (baseline); (2) 6 months following initial diagnosis; (3) 12 months following initial diagnosis; and (4) 24 months following initial diagnosis. Upon diagnosis with glandular fever, the young people were enrolled in the study and administered a baseline evaluation. Six months following the initial diagnosis with glandular fever, participants were then re-evaluated and classified as either recovered (controls) or non-recovered (CFS/ME). CFS/ME participants and controls were then compared in terms of occupational participation and functioning at all four evaluation time points (that is, at baseline and at 6-month, 12-month and 24-month follow-ups).

The study was approved by the institutional review boards of the Children’s Memorial Hospital and the University of Illinois at Chicago.

Participants

A total of 301 young people diagnosed with glandular fever was enrolled. The young people were referred to the study by school nurses, emergency rooms and the virology laboratory of the Children’s Memorial Hospital and through paediatric and family practices, including the Paediatric Practice Research Group, a referral network of the Children’s Memorial Hospital. Six months following their initial diagnosis, all participants underwent a telephone screening interview to determine their recovery status. Those who screened positive for possible CFS/ME and a group of participants who recovered underwent complete physical and psychiatric examinations with laboratory work, intensive medical history interviewing and a review of past-year medical records. Following this evaluation, 39 of the non-recovered young people met paediatric case criteria for CFS/ME (Jason et al 2006).

The Jason et al (2006) definition of CFS/ME in young people shares some similarities with guidelines that are in use within the United Kingdom (Turnbull et al 2007). However, because this study was conducted within the United States, the Jason et al (2006) criteria, which are based on the international research guidelines for classifying CFS (Fukuda et al 1994), were applied. For additional information about diagnosing CFS/ME in young people,

readers in the United Kingdom are referred to the National Institute for Health and Clinical Excellence guidelines (Turnbull et al 2007).

Thirty-nine screened negative controls who had fully recovered from glandular fever at the 6-month time point were randomly selected from the remaining pool of participants and matched one to one with the CFS/ME participants in terms of gender and Tanner stage. Tanner stage is a means of staging young people in terms of their development during puberty. It is based on the degree to which secondary sex characteristics, such as pubic hair, have emerged, and the extent to which genitalia in boys and breasts in girls have developed. The authors elected to match participants according to Tanner stage, rather than age, because CFS/ME has been hypothesised to involve the endocrine system, and Tanner stage offers a more accurate means of eliminating hormonal differences that may contribute to symptomatology at various stages of development.

Procedures

The original diagnosis of glandular fever was confirmed by a review of laboratory and clinical records and by additional laboratory testing within the authors' own facility, when necessary. Upon enrolment and during active infection, all participants took part in an extensive in-person interview and assessment battery, which included measures of occupational participation and quality of life at baseline. Classification as being either recovered or not recovered from glandular fever was based on results from a telephone screening interview, which occurred 6 months after the initial diagnosis.

Screened positive participants and a group of screened negative controls were invited to the Children's Memorial Hospital for a more comprehensive evaluation, which included complete physical and psychiatric examinations and additional laboratory work. At that time, the participants were also administered the same in-person interview and assessment battery that they received at baseline. A provisional diagnosis of CFS/ME was made by the examining physician and the final classification as having CFS/ ME (Jason et al 2006) was determined through a blind panel of independent chart reviewers following the clinical evaluations.

The 39 participants with CFS/ME and matched controls were invited for re-evaluation at the 12-month and 24-month follow-up time points. Both re-evaluations involved the same assessment battery and laboratory work that was administered at the other time points. Thirty-six of the 39 diagnosed as having CFS / ME underwent a reevaluation at 12 months (3 were lost to attrition); 11 had recovered and 3 were reclassified as having an alternative medical or psychiatric explanation for their symptoms that disqualified them from being classified as CFS/ ME (that is, CF-explained), leaving 22 participants classified as CFS / ME (7% of the original sample, all female) and their 22 matched controls.

At the 24-month follow-up, 3 more participants with CFS/ME were lost to attrition. Six had recovered and 2 were reclassified as CF-explained (that is, having developed an exclusionary medical or psychiatric diagnosis). One participant who did not meet severity criteria for CFS/ME at 12 months developed more severe symptoms again at 24 months and was reclassified as having CFS/ME at that time. Additionally, one participant, who was originally classified as CFS/ME at 6 months, had an explanation for her enduring symptoms at the 12-month time point (pregnancy and miscarriage), but no longer had this explanation at 24 months and was again classified as CFS/ME. This left 13 participants (all female, 4% of the original sample) with CFS/ME and their 13 matched controls 24 months after initial infection. Additional information about how participants matriculated through this study and further detail about the way in which this sample was characterised may be found in Katz et al (2009).

Measures

Chronic Fatigue Syndrome Screening Questionnaire—The *Chronic Fatigue Syndrome Screening Questionnaire* (Jason et al 1997) was used to assess sociodemographic characteristics and to evaluate the presence versus absence of CFS/ME symptoms. The questionnaire assessed interviewees' sociodemographic characteristics and supported preliminary classification into screened positive (nonrecovered /possible CFS / ME) versus screened negative (recovered/control) groups. Basic demographic data included age, ethnicity, socioeconomic status, marital status and gender. The revised scoring rules for Hollingshead's (1975) original scale for classifying parental education and income, developed and validated by Wasser (1991), were used to characterise participants' families in terms of socioeconomic status. This screening scale has demonstrated high discriminant validity and excellent test-retest and interrater reliability (Jason et al 1997).

Occupational Self Assessment—The Occupational Self Assessment (OSA) is a client-centred measure of occupational participation (Baron et al 2006). It is a 21-item self-rating scale designed to capture individuals' perceptions of how illness and disability affect their occupations. Based on MOHO (Kielhofner 1995, 2002, 2008), this scale provides information about people's values and perceptions of their own performance (competency). It measures what an individual views as important (values) and how well the individual believes he or she is doing when performing the activity (perceived competency).

The OSA allows clients to rate their own competence in 21 areas of performance and participation and, on a separate scale, to assign value to those same areas. A score is derived by adding up the ratings made on the OSA (Version 2.2) items for Values (importance of occupations) and Perceived Competency (the young people's view of their performance). For Values, numerical scores of 1, 2, 3 and 4 are assigned to the ordinal qualifiers, 'Not so important, Important, More important, and Most important', respectively. For Perceived Competency, young people rate their performance on daily occupations as 'A lot of problem, Some difficulty, Well, and Extremely well'; these responses too are coded from 1 to 4, respectively.

Kielhofner et al (2009) examined the psychometric properties of the OSA using this numerical scale and found that the ratings categorised participants accurately and discriminated well. Using Rasch analysis, Kielhofner et al (2009) reported good validity and sensitivity in measuring values and perceived competency. Young people that show increased competency experience a positive sense of self and an ability to control actions in their environment. This leads to additional performance and self-confidence. Children with disability who have low performance competence may not be motivated to participate in occupations. In a recent population-based study, the OSA demonstrated adequate construct validity, sensitivity and stability over time in young people with and without CFS/ME (Taylor et al, in press).

Child Health Questionnaire—The *Child Health Questionnaire* (CHQ – CF87) (Landgraf et al 1996) is a measure of health-related quality of life with well established psychometric properties. This measure was designed for young people of 10 years or older and comprises scales that are specifically developed for this age range. For this study, the following areas of healthrelated quality of life were assessed: physical functioning, physical role functioning (that is, limitations in schoolwork and activities with friends), emotional functioning, behavioural problems and general health.

Data analysis

Chi-square tests and independent samples t-tests were used to compare the CFS/ME participants with their matched controls in terms of sociodemographic characteristics. Comparisons of occupational competency, values and quality of life were made using independent samples t-tests. Means and standard deviations were provided for all continuous variables and frequencies and percentage values were provided for all categorical variables. To reduce the risk of Type I error emanating from multiple comparisons, statistical significance was set conservatively at $p<0.01$.

Results

Sociodemographic characteristics of the sample

There were no significant differences in gender, family socioeconomic status, body mass index, age and work and /or study status between the CFS /ME participants and the one-to-one matched controls. Descriptive statistics are presented in Table 1.

Hypothesis I: Occupational participation (competence and values)

Independent samples t-tests revealed that young people with CFS/ME demonstrated significantly lower perceived competence scores at baseline ($t[76] = 2.99$) and at the 6-month ($t[76] = 3.71$) and 12-month ($t[40] = 3.16$) follow-up time points when compared with their matched controls. There were no significant differences between the CFS/ME participants and the controls in perceived competence at the 24-month time point.

In terms of value for occupation, there were no significant differences between the young people with CFS/ME and their matched controls at any of the time points. Means and standard deviations are presented in Table 2.

Hypothesis II: Health-related quality of life

At baseline (during acute glandular fever infection), there were no significant differences in physical functioning (according to scores on the CHQ – CF87) between young people who later developed CFS/ME and their matched controls. However, there were significant differences between the two groups at 6 months ($t[76] = 6.85$), 12 months ($t[40] = 3.76$) and 24 months ($t[24] = 3.00$) following the initial infection. Young people with CFS /ME reported more difficulties with physical functioning than their healthy peers.

With respect to physical roles, such as schoolwork and activities with friends, there were no significant differences at baseline between young people who later developed CFS/ME and their matched controls. The two groups did differ significantly at the 6-month ($t[76] = 4.62$), 12-month ($t[40] = 4.03$) and 24-month ($t[24] = 3.73$) time points. Those with CFS/ME exhibited more limitations related to schoolwork and activities with friends.

In reference to emotional functioning, young people that later developed CFS/ME and their matched controls did not differ significantly at baseline. They did differ significantly at the 6-month ($t[76] = 3.66$) and 12-month ($t[40] = 3.03$) time points. Young people who developed CFS/ME demonstrated more difficulty with emotional functioning than the fully recovered matched controls. These differences were no longer significant at the 24-month time point. Developing CFS/ME following glandular fever infection did not appear to affect behavioural functioning. The two groups did not differ significantly at any of the time points. Conversely, the two groups differed at all of the time points in terms of their perceptions of their own health (general health). Young people who developed CFS/ME reported significantly poorer general health than their fully recovered peers at baseline (t[76]

= 4.35) and at the 6-month (t[76] = 7.35), 12-month (t[40] = 4.26) and 24-month (t[24] = 3.23) time points (see Table 3 for means and standard deviations).

Discussion

Before this study, little was known regarding the extent to which CFS/ME interfered with occupational participation and quality of life among young people. A prospective investigation was conducted of young people who contracted glandular fever and either recovered or did not recover within a 2-year period. During the acute stage of glandular fever, the young people who would later develop CFS/ME perceived themselves as having lower levels of competency in everyday occupations and as having a poorer general health status than those who would experience a normal recovery from glandular fever. There were no significant differences in the extent to which the two groups valued participating in everyday occupations as important aspects of their lives. This finding suggests that, although the young people with CFS/ME perceived various occupations as being highly important, they reported significant deficits in their ability actually to perform those occupations in a way that made them feel competent and effective. The differences in reported occupational competency between the two groups persisted for the first year following glandular fever but began to attenuate during the second year after infection as other limitations decreased and fewer young people remained ill. Thus, it appears that limitations in perceived competency at occupation may be related to actual impairment level and diagnostic status. Recovery rates, attrition and a lack of statistical power at the 24-month time point also contributed to the observed decrease in significant differences between the two groups of young people.

The differences in health-related quality of life that were observed between the two groups of young people at baseline became even more pervasive over time. During the 2 years following glandular fever, the young people with CFS/ME were significantly more limited in terms of their physical functioning, school performance, activities with peers and their overall general health.

Additionally, the emotional functioning of the young people with CFS/ME suffered as a result of not recovering from glandular fever, particularly at the 6-month and 12- month time points when a majority of the young people remained ill and their symptoms were at their peak. However, difficulties with emotional functioning appeared to decrease by the 24-month time point. Interestingly, the experience of developing CFS/ME did not appear to be significantly associated with any behavioural difficulties that the young people might have had.

As with all studies, this study carries certain limitations, which restrict the extent to which these findings may be interpreted and viewed as generalisable to all settings. First, for this report the participants' self-reported competency and quality-of-life ratings were not corroborated with observational and functional capacity measures. Therefore, it is possible that additional variables contributed partly to any differences that were observed between the two groups. Secondly, there may have been some risk for Type II error in this study. The sample size was reduced at the 12-month and 24-month time points due to a combination of young people recovering from CFS/ME or changing diagnostic categories and due to some minimal attrition. Some of the statistical trends toward differences in competency and quality-of-life ratings, particularly at the 24-month time point, may have been statistically significant had a larger sample been tested.

Conclusion

This study provided evidence in support of the Model of Human Occupation assertion that impairments not only affect the ability to perform but also have an impact on volition and quality of life (Kielhofner 2008). Although they appear to value occupations as much as their peers, young people that develop CFS/ ME following infection perceive themselves as less competent in performing those occupations. Additionally, they experience marked compromises in terms of their quality of life in a number of areas, including physical functioning, school performance and activities with peers, emotional functioning and general health. These findings suggest that occupationfocused rehabilitation programmes that address not only the functional limitations but also the volitional consequences of chronic fatigue are indicated for this population. Ashby et al (2006) have developed a consistent approach within the United Kingdom that emphasises collaboration and addresses both the functional and the psychological aspects of CFS/ME in young people. Additionally, Taylor and colleagues describe an approach to rehabilitation that specifically emphasises volition and is based on the Model of Human Occupation (Taylor and Kielhofner 2003, Taylor et al 2003).

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Key findings

- Young people that develop CFS/ME following infection believe themselves to be less competent in performing everyday occupations as compared with their recovered peers.
- Additionally, they report decreased quality of life.

What the study has added

This study supports the need for occupation-focused rehabilitation programmes that focus on changing young people's attitudes about their own performance, supporting their re-engagement in personally relevant occupations and assisting them in accommodating to their functional limitations so that they can experience improved quality of life.

Table 1

Descriptive data on sociodemographic characteristics of participants with CFS/ME and the matched controls

	Comparison groups	
	CFS group (n = 39)	**Matched controls (n = 39)**
	Frequency (%)	**Frequency (%)**
School/work activity		
Full-time students, not working	24 (61.54)	21 (53.85)
Full-time students, part-time work	14 (35.90)	18 (46.15)
Part-time students, not working	1 (2.56)	0 (0)
Gender		
Female	35 (89.74)	35 (89.74)
Male	4 (10.25)	4 (10.25)
Ethnicity		
African American	3 (7.7)	1 (2.56)
Caucasian	34 (87.18)	36 (92.31)
Multi-raced	2 (5.13)	1 (2.56)
Others (not Latin American)	0 (0)	0 (0)
	Mean (SD)	**Mean (SD)**
Age (years)	16.08 (1.40)	16.31 (1.32)
Body mass index	22.10 (3.497)	21.37 (3.009)
Family socioeconomic status (SES) score	59.41 (23.78)	64.69 (22.49)

SD = standard deviation. Ethnicity was not known for one matched control.

Table 2

Occupational participation in young people with CFS/ME and matched controls at baseline (infection) and 6-month, 12-month and 24-month follow-ups

	Comparison groups	
	CFS group (n = 39)	Matched controls (n = 39)
	Mean (SD)	Mean (SD)
Competence at occupations		
Baseline (infection)*	54.50 (5.68)	58.38 (5.78)
6-month follow-up*	54.95 (6.35)	61.32 (8.53)
12-month follow-up*	54.05 (7.07)	62.15 (9.25)
24-month follow-up	56.93 (9.79)	62.47 (11.14)
Value for occupations		
Baseline (infection)	52.39 (4.69)	55.24 (6.75)
6-month follow-up	52.20 (5.19)	54.42 (6.82)
12-month follow-up	53.07 (6.79)	55.65 (4.60)
24-month follow-up	53.43 (9.65)	55.93 (5.10)

SD = standard deviation.

*Indicates a statistically significant difference at $p \leq 0.01$.

Note: Due to a combination of attrition and recovery in the CFS/ME group, at the 12-month time point the sample size was reduced to 22 in each group. At the 24-month time point, the sample size was reduced to 13 in each group.

Table 3

Health-related quality of life in young people with CFS/ME and matched controls at baseline (infection) and 6-month, 12-month and 24-month follow-ups

	Comparison groups	
	CFS group (n = 39)	Matched controls (n = 39)
	Mean (SD)	Mean (SD)
Physical functioning		
Baseline (infection)	66.04 (23.29)	75.02 (20.74)
6-month follow-up*	78.54 (16.33)	97.80 (6.51)
12-month follow-up*	73.43 (20.08)	96.88 (7.01)
24-month follow-up*	77.21 (23.71)	97.44 (5.32)
Role physical (schoolwork and activities with friends)		
Baseline (infection)	54.70 (33.56)	63.53 (31.32)
6-month follow-up*	75.73 (27.08)	96.87 (8.81)
12-month follow-up*	67.25 (24.98)	94.44 (16.71)
24-month follow-up*	70.94 (22.92)	96.58 (9.50)
Emotional functioning (role emotional)		
Baseline (infection)	69.80 (33.72)	83.19 (27.44)
6-month follow-up*	77.21 (28.72)	95.73 (13.15)
12-month follow-up*	65.36 (31.64)	92.98 (21.34)
24-month follow-up	79.49 (23.06)	97.44 (5.32)
Behavioural functioning (role behavioural)		
Baseline (infection)	74.64 (31.42)	90.88 (22.64)
6-month follow-up	89.74 (22.71)	99.43 (2.48)
12-month follow-up	80.12 (31.55)	96.97 (9.81)
24-month follow-up	86.32 (25.32)	97.44 (9.25)
General health		
Baseline (infection)*	52.71 (18.43)	69.15 (14.77)
6-month follow-up*	46.63 (17.08)	70.58 (11.03)
12-month follow-up*	46.49 (16.01)	69.74 (17.59)
24-month follow-up*	43.01 (21.46)	66.54 (15.13)

SD = standard deviation.

*Indicates a statistically significant difference at p≤0.01.

Note: Due to a combination of attrition and recovery in the CFS/ME group, at the 12-month time point, the sample size was reduced to 22 in each group. At the 24-month time point, the sample size was reduced to 13 in each group.