Reviewing the Impact of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome on Daily Functioning Using a Holistic Model: It’s Implication on Intervention

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Abstract

This review examines the disruption to individual’s life quality by recognizing the symptoms of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and their impact on a person’s occupational performance. The Canadian Model of Occupational Performance and Engagement (CMOP-E) provides a holistic theoretical framework to analyze the impact of ME/CFS on occupational performance and assists in the identification of non-pharmacological interventions. Discussion on the importance of engagement to persons’ health and well-being is reviewed and barriers to participation are highlighted. The CMOP-E framework is recognized as a useful tool in the assessment and treatment for individual’s with ME/CFS. This paper illustrates how occupational therapy practice applies the CMOP-E to help persons with ME/CFS participate actively in daily living tasks and improve function. Additionally, the CMOP-E framework, which is widely adopted in occupational therapy practice, can be applied in multidisciplinary rehabilitative treatments to improve patients’ health and quality of life. The review also proposes some recommendations/guidelines for designing treatment interventions for ME/CFS.

Introduction

Myalgic Encephalomyelitis, more commonly known as Chronic Fatigue Syndrome (ME/CFS), is a debilitating condition characterized by intrusive fatigue exacerbated by physical or cognitive exertion. This kind of fatigue does not improve with rest and is presented along with a cluster of other various cognitive and physical symptoms. Post-exertional malaise, impaired concentration and memory, and unrefreshing sleep are characteristics of this illness [1,2]. In an overview of the Canadian Consensus Document on ME/CFS, Carruthers and van de Sande [3] provide a clinical case definition, describing the disorder as an “acquired organic, pathophysiological, multisystemic illness” emphasizing the connection between activity and fatigue. However, some of the works from Fukuda et al., [1] have shown that diagnostic tests or pathognomonic signs of ME/CFS are not well validated. There have been numerous reports discussing the confusion of evidence on the aetiology of ME/CFS [4]. In particular, the symptoms of ME/CFS have been classified in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorder (DSM-IV) as somatic symptoms disorders [5], indicating the importance of using a biopsychosocial approach to prevent over-sight on the severity of the condition and warrant repeated medical referrals to address patients’ psychosocial symptoms [6]. Overall, these reports demonstrate evidence of the physiological and biochemical abnormalities in patients with ME/CFS and suggest that the symptoms of ME/CFS are resulted from the underlying biological and physiological mechanisms of ME/CFS. The commonalities between these abnormalities are debilitating fatigue that is not recovered with rest, lightheadedness, sore-throats, muscle pain, tender glands and headache.

The illness affects all ages, races and socio-economic groups. It has a significant impact on the individual’s lives, their families and caregivers. According to Friedberg et al., [7], at least one million Americans have been diagnosed with ME/CFS. The disorder most commonly occurs between the ages of 20 and 50 though children and adolescents have been affected. There are approximately 42% of the adult population in the United States affected by ME/CFS and approximately 70% of them are female [7]. In children it appears equal number of boys and girls are affected [7]. In Canada, 411,500 people have been diagnosed with ME/CFS, which is almost 4 times more common than Multiple Sclerosis [8]. The illness also has serious effects on a person's ability to perform their pre-morbid roles. Reduction in a person's ability to carry out activities of daily living may result in a lower sense of competence and poor quality of life [9]. Despite the multitude of information available, there continues to be barriers to diagnosis, assessment and intervention for individual’s afflicted with ME/CFS. These barriers ultimately impede the rehabilitation plan and occupational adaptation and in some cases recovery from the illness. This review will examine and discuss different aspects of functional deficits and their most updated treatment strategies for people with ME/CFS using the Canadian Model of Occupational Performance and Engagement (CMOP-E) framework. The review will also propose potential intervention strategies to facilitate daily performance and improve quality of life of these individual’s.

ME/CFS: A CMOP-E Perspective

The impact of ME/CFS on a person’s daily living can be analyzed using the Canadian Model of Occupational Performance...
and-Engagement (CMOP-E) which is a holistic rehabilitation model for promoting function and successful occupation [10]. CMOP-E considers occupational performance in three areas of daily function, namely self-care, leisure and productivity [10]. These three occupational performance areas are supported by several performance components, namely affective, physical and cognitive components and influenced by many environmental factors such as social, cultural, institutional and physical environments [10]. Using this framework, human occupation of a person afflicted with ME/CFS can be understood by how the person performs their needed occupational tasks based on his/her intact performance components, e.g., having adequate cognitive abilities and actively engaging in their environment. Occupation is the “vehicle that enables acting on the environment” [11]. ME/CFS may be severe enough to interfere with a person’s occupational performance. The ability of individuals to perform their self-care, leisure and productivity may be drastically reduced by accompanying fatigue, pain, cognitive problems and other multi-systemic symptoms.

The CMOP-E framework is an encompassing approach, which recognizes treatment at the individual level and the importance of providing environmental supports to facilitate successful occupational engagement and promote optimal function. Recognition of individual’s ME/CFS experience and knowledge and involving the person in identifying interventions supports a client-centred approach, which is the foundation of occupational therapy practice [12]. According to the framework, individual’s successful function is based on the interplay between the person, environment and occupation. Hence, incorporating the person’s values and experience, the therapist’s clinical skills and experience, and evidence-based research will provide a holistic approach to care for individuals with ME/CFS.

**Consideration of Performance Components under the CMOP-E**

The person is at the centre of this model which is made up of three performance components: affective, physical and cognitive. Spirituality is at the core of the person, which acknowledges that meaningful occupation is determined by the person and that spirituality is expressed in human occupation [11]. When an individual with ME/CFS attempts to act upon their environment without optimal supports, dysfunction may occur. Barriers in the environment will impact their performance and may prevent successful engagement. Without successful engagement, individual’s may have difficulty expressing themselves, disrupting their sense of competence.

**Affective**

Emotional, mental and physical fatigue resulting from the effects of ME/CFS is accompanied by biological and psychosocial problems [13]. Memory problems, difficulties with concentration and sleep problems are often resulted from depressive moods, stress and/or emotional triggers, which contribute to a diminished ability to participate in occupation [14]. For example, a person may have difficulty with relationships, social activities and/or experience educational and vocational losses. Attree et al., [13] discussed how prospective memory affects the daily lives of people with ME/CFS. Remembering to pass a message to a friend or turn off the stove after cooking a meal or take medication may be disrupted by cognitive failures. Multiple or detailed tasks may increase the individual’s fatigue and result in poorer performance, this in turn affects the individual’s view of their self.

Lopez et al., [15] tested a group-based intervention called Cognitive Behavioural Stress Management (CBSM). This intervention addressed the individual’s stress, quality of life and symptoms of ME/CFS. Recognizing that stress may further dysregulate the immune system, the CBSM incorporates relaxation techniques, cognitive restructuring and interpersonal skills such as assertiveness and anger management. Group participation may also improve perceptions of social support. In the past, findings have indicated that CBSM reduce the symptoms of ME/CFS and improve individual’s quality of life [15]. Practical life skills that aid the person in developing self-regulation skills can be taught and practiced when the individual’s are engaged in occupation. Skills that contribute to successful engagement may improve the person’s perceived quality of life and ultimately the person’s affect. In addition, Attree et al., [13] suggestion of management programs that focus on factors such as self-efficacy is in line with the CMOP-E framework. Identifying rehabilitation assessment tools and interventions that address the person’s belief in their ability to participate in meaningful occupation may improve the life quality of individuals with ME/CFS.

**Physical**

Physical symptoms of ME/CFS include post-exertional malaise, headaches, sore-throats, tender lymph nodes and generalized pain [7]. In addition to overwhelming fatigue, the implications of these physical symptoms drastically reduce an individual’s ability to participate in daily activities. The legitimacy of these physical symptom reports by people with ME/CFS have been scrutinized by the medical model resulting in improper diagnosis, treatment and recommendation for people with ME/CFS. These prominent features of ME/CFS have been found to impair individual’s participation in activity and their ability to maintain previous roles [16].

Review of the literature indicates that commonly recommended interventions to address the physical symptoms such as Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) have mixed results. There are discrepancies between patient reports of the effectiveness of GET and Randomized Control Trials (RCT) evidence supporting the efficacy of GET. For example, some studies have found a moderate improvement with GET and CBT using quality of life measures [17,18]. However, self-report measures showed that individuals who participated in GET perceived themselves as worse [17,18]. Some patients have described clinical encounters when receiving CBT and GET as “harmful”, stating a feeling of being ‘pushed’ to exercise and feeling blamed when the recommendations are not working. In addition, individuals with ME/CFS reported that the effectiveness of CBT and GET often contradict with the National Institute for Clinical Excellence (NICE) guideline [19] which recommends the need for psychological therapy and physical activity [8].

Other interventions that are more accepted by individuals with ME/CFS include adaptive pacing therapy which teaches them to stay in within their “energy envelope” [18]. A rehabilitation management tool that teaches clients to self-monitor and self-regulate their energy expenditures is described by Jason et al., [18]. This provides an alternative approach to the more commonly prescribed treatments and may be more suitable for individuals with ME/CFS. Since the energy level of people with ME/CFS can fluctuate on a given day, it is more important to provide interventions that teach individuals with
ME/CFS to self-monitor and self-regulate their energy. Studies have demonstrated that teaching a person with ME/CFS to stay within their "energy envelope", pace activities and manage symptoms can remarkably improve their quality of life [20]. However, it is important to note that while the energy envelope theory and adaptive pacing therapy seem beneficial, some findings were not supportive of these techniques. For example, White et al., [17] found that adaptive pacing did not show more effective outcome than standard medical treatments, and others have reviewed mixed findings for patients with ME/CFS applying the pacing techniques [21-23]. Some reports also commented that research supporting the envelope theory was weak and that energy conservation techniques, e.g., asking patients to stay within their energy envelop, might lead to reduced level of activity or function or even negatively promote a state of "staying in an envelope of ill health" [19,21,23,24].

The energy envelope approach is a rehabilitation method that originally appeared in 1997 for teaching individuals with ME/CFS to assess their perceived available energy to aid in avoiding overexertion [18]. It proposes that individual's with ME/CFS who overexert themselves cut back on activity to prevent relapses. When conserving energy they are able to regain tolerances to activity over the long-term [18]. By using client-centred tools such as teaching self-regulation and self-monitoring within a context meaningful to the individuals, these individuals would be able to sustain their mental and physical functioning while minimizing relapses and reducing symptom severity. The CMOP-E framework embraces the concepts of these techniques because the therapeutic process focuses on having patients to identify their treatment goals and encourages patients to actively participate in daily activities. For example, the CMOP-E can be used for people with ME/CFS to identify areas of deficits in occupational performance, e.g., what activities are important to him/her and what tasks that he/she would like to complete, and then monitor his/her energy expenditure to prevent set-backs and take reasonable steps towards completing his/her goal(s). Hence, using the CMOP-E, therapists encourage patients to engage in activity by enabling individuals affected with this illness to prioritize what is meaningful to them. However, given the inconclusive evidence of these techniques, i.e., adaptive pacing and staying within energy envelope, the application of these techniques remains cautious and patients who use these techniques should be continuously monitored to determine effectiveness or identify adverse effects.

Cognitive

Individuals with ME/CFS have cognitive difficulties including difficulties with memory, information processing speed, sustained and/or divided attention [25]. According to Komaroff and Buchwald [26] and Grafman [27] as cited in Shanks et al., [25], 85-95% of people with ME/CFS have cognitive problems which affect daily functioning. In addition, physical exertion can result in reduced cognitive function and debilitating malaise [28]. The "overload phenomena" brought on by the persons' hypersensitivity to environmental stimuli, e.g., odors, temperature extremes and noise, causes worsening of cognitive and other symptoms. This worsening of symptoms can result in what has been described as a "crash". The person with ME/CFS is immobilized by physical and/or mental exhaustion and the recovery process from these periods is slow [29].

The multitude of symptoms experienced by a person with ME/CFS demands the need for a comprehensive client-centred rehabilitation plan. In a large randomized research trial, the effectiveness of four treatments for individuals with ME/CFS was tested [17]. They compared treatment outcomes on patients who received Specialist Medical Care (SMC) alone or with Adaptive Pacing Therapy (APT), Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET). Findings from this study supported CBT and GET as a reliable form of therapy for individuals with ME/CFS. The trial did not support APT for ME/CFS. Since some individuals with ME/CFS have reported these therapies as being non-effective, there is a need for qualitative research including narratives or description of experiences from individuals with ME/CFS.

In the CMOP-E model, meaningful occupation is defined by the client [10]. Tools to assess the person's function and participation in interventions that are deemed important by the client may be necessary for developing a meaningful treatment program. Meaningful occupation may increase individuals' participation and/or compliance with the treatment plan.

Consideration of Environmental Factors under the CMOP-E

Providing appropriate environmental supports to reduce barriers is an important step to consider when treating a person with ME/ CFS. Without external supports, these individuals will come across multiple barriers when attempting to engage in their environment. Environmental barriers will disrupt performance. The CMOP-E framework that guides rehabilitation by recognizing interventions that treat performance components (the components discussed in the previous section) are only one part of the rehabilitation plan. The CMOP-E framework recognizes environmental factors, such as social, cultural, institutional and physical environments, as one of the most important intervention areas especially for chronic conditions like ME/CFS. Addressing meaningful occupation and providing environmental supports may facilitate successful engagement and optimal performance [10].

Social

Therapeutic intervention that promotes supportive environments will facilitate occupational engagement, which is at the core of individuals' health and well-being [11]. As an element of the environment, social supports have been recognized as a significant source of help for individuals with ME/CFS. Jason et al. [18] assessed the services needs of individuals with ME/CFS and found that a volunteer caregiving system to provide assistance with errands and chores was preferred. The data collected helped to determine if volunteer "buddies" would aid in helping individuals to stay within their "energy envelope" instead of expending more energy than they had available. The same study also found that emotional support and assistance with daily needs was a high priority need preferred by individuals with ME/CFS [18]. The participants in the study were able to avoid setbacks and increase tolerances to activity by avoiding over exertion. This study indicated that rehabilitation programs should be tailored to the individuals needs.

Staying within the individuals "energy envelope" is a client-centred approach to managing ME/CFS, which emphasizes that maintaining energy levels may improve clients' perceived energy and thereby increase their capacity to engage in more activity. Goudsmit et al., [30] proposed that pacing could stabilize ME/CFS and help avoid post-exertional malaise. If the person with ME/CFS is performing at their maximal functional level, then pacing can be incorporated into
a multi-disciplinary rehabilitation program tailored for the person. This strategy differs from GET, which emphasizes maintaining and increasing activity despite symptoms.

Participants in a study completed by de Carvalho Leite et al. [31] further emphasized the need for social supports to improve quality of life and alleviate the impact of the illness. They described the need for client-centred care from health and social services. Illness management, social and financial supports were expressed needs. Barriers to these supports stemmed from social, cultural, organizational and professional norms. Since quality of life influences a person's functional status and their ability to engage in their environment, health and social programs, which support social inclusion such as work roles, leisure participation and performance and self-care are necessary supports for illness management and a person's overall well-being.

Cultural

Cultural norms and role expectations can influence the ability of individuals with ME/CFS to engage in their environment. A person's age, gender, ethnic background and financial status can make participation in certain occupations difficult and inequities in treatment may occur [31], de Carvalho Leite's study reported that people from minority ethnic backgrounds had difficulty accessing health care and social supports. The participants reported that they experienced stigmatization when attempting to access health services. Also, individuals of different cultural backgrounds may delay seeking healthcare services because of perceptions of the healthcare system. Instead of accessing traditional health care, these individuals may choose alternative therapies, prayer or spiritual healing [32].

Taylor et al., [9] state that ME/CFS symptoms can make it extremely difficult or impossible for the persons with this illness to perform activities of daily living. Therefore, maintaining daily routines and meeting role expectations can be significantly impaired in individuals with ME/CFS. The fluctuation of the symptoms makes it difficult for individuals to predict their abilities and be reliable for others. Significant losses in social life, family, school and work roles may result from impairments. Sustained attention, concentration and physical activity are particularly difficult and can result in increased symptoms, which disrupts individuals' ability to perform previous roles. Pacing and energy conservation strategies may assist with helping individuals with ME/CFS maximize their role functioning.

Institutional

Structural or system barriers can prevent individuals from accessing health care. Lack of a referral system and health care providers' insensitivity to people's needs were reported as system barriers, resulting in low healthcare utilization rate among individuals with ME/CFS [33]. Economic resources and cost of healthcare might be reasons why some individuals with ME/CFS do not seek health care services [33]. Individuals without health insurance reported they did not utilize health care services and attempted to self-diagnosis and treat [33]. Apart from this, parents of children with ME/CFS often report pediatricians' lack of knowledge and uncertainty of making a diagnosis. Some studies have shown that parents did not understand the referral process or how to get practical support [34]. Late diagnosis and poor management can lead to further disadvantage for individuals with ME/CFS. The majority of medical practitioners view illness from a biomedical model [35]. This model often leads to barriers in diagnosis and management of the illness. In a cross-sectional study conducted by Comiskey and Larkan [36], individuals with ME/CFS reported waiting approximately 3.7 years from symptom onset to diagnosis. Past studies also found that wrong diagnosis and inappropriate medical management are the reasons why individuals with ME/CFS have not been properly diagnosed and treated [33]. A holistic model to understand the bio-psychosocial aspects of ME/CFS may be necessary to address the barriers to early diagnosis and illness management.

Physical

Accessibility including lack of transportation to get to appointments, too short of appointments or difficulty getting timely appointments is physical constraints that have interfered individuals ability to utilize health care services [35]. In addition, environmental barriers in the person's environment may limit the individual with ME/CFS from engaging in occupation or making occupational adaptations [9]. Buildings and facilities that are designed for the able-bodied are barriers to accessing health-care for those who have limited ambulation. In addition, sports facilities, recreation complexes and shopping centers may present many difficulties for individuals with ME/CFS. For example, many individuals with ME/CFS have sensory challenges i.e., multiple chemical sensitivity. Temperature extremes, bright lights, noise and synthetic chemicals pose challenges to these individuals by increasing their symptoms [28]. As a result, they may limit their exposure to these environments resulting in reduced participation in social and leisure activities and a sense of isolation. Physical environmental adaptations that support mobility, energy conservation and reduced exposure to environmental stimuli that triggers the person's symptoms will aid in occupational adaptation and ultimately facilitate successful engagement in their environment.

Implication for intervention

The CMOP-E was used as a comprehensive framework to discuss individuals with ME/CFS and its impact on occupational performance. Themes repeatedly identified through various literature reviews are the need for early and proper diagnosis, client-centred care and social and environmental supports. Focusing on the individual in the rehabilitation plan is only one part of a successful intervention plan. There is a need for rehabilitation therapists to participate in the rehabilitation management program for individuals with ME/CFS to aid in developing environmental supports to maintain function and to facilitate successful engagement. Interventions for ME/CFS can be provided at an individual level, but must also extend to the environmental level. Physical, environmental, cognitive and emotional supports are paramount for maintaining function or sustaining roles. The need for occupational therapists and other professionals to understand the variable nature of this illness and its impact on occupational performance is necessary for proper diagnosis, creating assessment tools and providing holistic interventions.

Treatment Recommendations for People with ME/CFS

Multi-disciplinary and interdisciplinary management of ME/CFS is paramount for individuals living with this condition. Therapists can provide client-centred care and facilitate environmental and emotional/social supports for their clients: Below are some guidelines extrapolated from this review for intervention planning and treatment of individuals with ME/CFS.
Professional and peer-facilitated programs are necessary to improve quality of life by enabling individuals to engage more successfully in occupation. These programs may include professional education, lifestyle management skills, mutual support and health-care client collaboration. For example, the therapist may educate the clients on the nature of the illness and the clients may wish to participate in defining their illness and describing their experience of the illness. Lifestyle management suggestions or recommendations can be made and clients can share their suggestions, encouraging group engagement while simultaneously enabling them to participate in health decision making and emphasizing empowerment. These programs provide social benefits and encourage goal attainment which has been found to be one of the only significant predictors of quality of life improvement [37].

Knowledge base in environmental modifications, body awareness and exercise programs are important for empowering individuals with ME/CFS. Facilitation in home adaptations, proper body biomechanics and pacing/energy conservation strategies are essential factors in achieving a positive outcome [38]. Providing education on equipment and teaching lifting, pushing and pulling techniques, proper body biomechanics and alternate methods of completing activities to conserve energy may empower individuals to increase their functional abilities and sustain occupational roles. In addition, graded exercise groups including strengthening and stretching programs can increase a person's ability to become more functional [39].

Using Cognitive Therapy (COG) to enable individuals with ME/CFS to learn to balance between activity, rest and leisure may be useful. This may lead to healthier social relationships, reduce stress and alleviate maladaptive cognitions. For example, the therapist may wish to teach relaxation techniques, self-regulation skills and pacing skills that will ultimately influence nervous system dysregulation and improve the immune system.

Functional evaluations in the home and work site evaluations for those who continue to be employed is important for identifying occupational barriers such as environmental, personal and task-related barriers. Therapists should assess individuals' ability in engaging in occupation and evaluate how the person's surroundings, habits and behaviours and performance skills may contribute or hinder successful engagement. Therapist may also recommend work accommodations by collaborating with the client and employer and providing education, recommending adaptive equipment or modifications in the home or workplace to reduce symptoms of ME/CFS and facilitate successful engagement.

**Limitations to Current Practice and Research**

The majority of research for ME/CFS has focused on the benefits of CBT and GET, which has been disputed by many individuals with ME/CFS. The "energy envelope" theory incorporates strategies by teaching individuals to pace their daily activities and be responsible for self-regulating and self-monitoring their energy expenditures. However, there have been much inconsistency in the literature regarding the use of these techniques especially the adaptive pacing and the energy envelops concepts. Therefore, application of these techniques should be closely monitored and patients should be given feedback throughout the treatment process. Therapists using the CMOP-E framework have a distinct advantage in working with individuals with ME/CFS as they use a holistic approach to help client manage the disease, which includes evaluation of the client's current functional status in the home and/or outside the home, education on the impact of the illness, training clients in energy conservation techniques, recommendations for adaptive aids in the home and work modifications for individual to resume paid employment. Nevertheless, empirical evidence regarding the use of the CMOP-E for this population is still lacking and further research is needed to develop standardized programs.

**Future Research**

Development of future multidimensional assessment tools and interventions used by healthcare professionals may be determined by listening and learning from the individuals with ME/CFS. Symptoms of the illness need to be understood in a broader perspective including the effects of the illness on the person's functional ability and their ability to engage in occupation in their environment. Rehabilitation practitioners, like occupational therapists, may consider investigating the treatment outcome of application of the CMOP-E using both quantitative and qualitative research methodologies in large scale studies. Quantitative approaches would allow practitioners to have a better understanding on the magnitude of symptom reduction when patients perform activities that they considered meaningful. Qualitative approaches would allow more in-depth analysis of patients' feeling especially on psychosocial impacts. Other research may include case studies and interrupted time series studies as well as development of standardized tools based on the person's pre and post morbidity functional status. Overall, research should emphasize both self-reported physical symptoms and client-centred treatment methods for improving quality of life of individuals experiencing ME/CFS.

**Conclusion**

Individuals with ME/CFS lives are affected daily by symptoms of this illness. Their ability to engage in meaningful occupation may be drastically reduced by affective, physical and cognitive difficulties. The CMOP-E is an occupational therapy framework used throughout this review to discuss the impact ME/CFS on a person's occupational performance. A discussion of how the illness affects a person and their occupational performance while considering the context of the environment is provided. Common themes for treatment and management of ME/CFS were identified and treatment recommendations are outlined to guide therapists in providing a client-centred rehabilitation plan, which incorporates the dynamic interaction of the person, occupation and environment. By treating not only the individuals' symptoms of ME/CFS but rather the person's occupational performance within the context of their environment, therapists can provide a unique, holistic and occupation focused treatment plan.

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