Dental care of the homebound patient with myalgic encephalomyelitis/chronic fatigue syndrome

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Abstract
Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a disabling condition affecting millions of adults and children worldwide. Despite the development of multiple criteria sets for defining this disorder, agreement on the core symptoms and other implications of ME/CFS point to the importance of understanding their role in oral health care. Overall, care for the homebound and bedbound population with ME/CFS issues has been under-addressed in the literature to date and there has been little consideration of the oral health needs of this population. Evaluation, diagnosis and treatment of dental concerns may be hindered by many of the diverse symptoms of ME/CFS. The present paper utilizes the International Consensus Criteria (ICC) in discussing treatment considerations for the most severely affected patients with ME/CFS, both in oral evaluation and active care. While no specific dental pathology is linked to ME/CFS, proper care for the patient so affected must take into account the disorder’s symptoms and severity.

Introduction
Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is an umbrella term for a chronic, complex disease with multiple and varying symptoms. The syndrome as presently named was described in 1988 [1]; however, reports of illnesses with similar presentations had been published decades earlier [2]. While the most glaring feature of ME/CFS is severe and limiting muscular fatigability, the syndrome will often present with numerous other chronic and recurring symptoms.

Up to 2.5 million Americans suffer with ME/CFS. Despite this high number, many researchers believe that a significant number of cases remain undiagnosed, thus dramatically increasing the disease prevalence. At present, there is no diagnostic test demonstrating adequate sensitivity and specificity, nor is there a treatment for ME/CFS patients. Among diagnosed cases, approximately 25 percent of patients are homebound, and many of these are bedbound [3].

To date, there is disagreement on whether to use the term “myalgic encephalomyelitis”, “chronic fatigue syndrome” or a hybrid of the two terms when referring to this disorder. This confusion has led to concerns in both research and clinical care of patients affected by these symptoms. In attempts to clarify this matter, multiple definitions and criteria sets have been forwarded [4]. Among the most commonly employed of these include the Holmes criteria (1988) [5] and
London criteria (2014) [6] which are no longer in use, as well as the widely quoted and inclusionary Fukuda criteria (1994) [7].

The myalgic encephalomyelitis international consensus criteria (ME-ICC) [8] was introduced in 2011; it advocates for the use of the single term ME in relating to this disorder and seeks to address both the research and medical care. Another criteria set [9] was introduced in 2015 by the Institute of Medicine (IOM) for use in the United States and proposed but did not adopt the use of the term “systemic exertion intolerance disease” (SEID) to replace ME, CFS and ME/CFS.

This paper will use the term “ME/CFS”, reflecting its scope and overall acceptance by the medical community. At the same time, discussion of the concerns that interfere with dental evaluation and care will utilize the ME-ICC criteria. Patients meet this criteria if they present with at least one symptom from four distinct categories: postexertional neuroimmune exhaustion, neurological impairment, immune/gastrointestinal/genitourinary impairment and energy metabolism/ion transport impairment.

Dental caries and periodontal disease are the two primary dental disease entities of the oral cavity [10], affecting persons both ambulatory and homebound. While a major concern for those not able to travel to a dental office for care is access to needed treatment, there are numerous other issues affecting these patients, particularly those with ME/CFS. This paper will focus on the symptoms of ME/CFS affecting the oral environment and discuss both the challenges and approaches to their care.

**The challenges of ME/CFS**

There are two primary concerns confronting the dentist attempting to provide care for the person with ME/CFS. The first relates to the diagnosis of pain and evaluation of the chief complaint, while the second relates to the provision of treatment to address these concerns. These issues, while of concern to the ME/CFS population as a whole, are exacerbated in those who are more severely affected and who may be bedbound and/or homebound.

**Assessing oral complaints**

Although death is seldom a result of oral disease, the impact of untreated pathology is significant. It is believed that several billion people suffer from odontogenic and other oral diseases. Many of these individuals report pain [11]. For the individual with ME/CFS, oral pain can be severely debilitating. The physical and psychological toll of pain will often manifest in exacerbations of fatigue and further decrease that patient’s functional level.
Oral complaints are often vague and difficult to diagnose. In many instances, their etiologies may be multifactorial. The list of differential diagnoses for even the most straightforward-appearing symptoms is extensive. Sources of oral pain may include odontogenic, periodontal, mucosal, neuromuscular and osseous structures. Etiologies also vary, with possibilities including bacterial, viral and traumatic causes. The diagnosis of odontogenic pain will often be elusive, as the sensory nerve fibers from the pulp of multiple teeth may converge into the same region of the trigeminal nucleus.

Diagnosis of oral pain involves obtaining a thorough understanding of the patient’s chief complaint and presenting symptoms, followed by clinical observation and examination and the performance of any appropriate diagnostic testing and radiographic evaluation. The patient with ME/CFS will often present difficulties in each of these steps in diagnosis.

Eliciting the chief complaint:
The chief complaint is the patient’s primary reason for the dental visit. Prior to examination, the dentist will orally review the patient’s symptoms and obtain a thorough medical history. This oral interview will provide important detail regarding numerous aspects of pain or discomfort, including duration, severity, characteristics, triggers and ameliorating factors. The medical history is a critical part of this review, and will allow the dentist to factor into the care plan any medications, food and drug allergies and concerns impacting on treatment.

Patients with ME/CFS will frequently present with cognitive dysfunction, often referred to as “brain fog”. With up to 85% of patients experiencing some degree of cognitive impairment [12], these neurocognitive deficits are most prominent in concentration, reaction time and information processing [13]. Confusion, memory problems, poor word-finding ability and mental fatigue will all contribute to difficulty in the patient adequately expressing the chief complaint and expanding upon it to provide needed detail [14]. In addition, cognitive dysfunction concerns will similarly interfere with a review of the medical history and complicate the obtaining of informed consent necessary for examination and treatment.

In addressing the chief complaint of a patient with ME/CFS, the practitioner must evaluate the extent and nature of the cognitive challenges presented. For the homebound and bedbound patient, these challenges may be extensive [15]. If patients are unable to adequately present their medical history or elucidate the chief complaint, they may designate a family member or other individual to assist in transmitting this information. This individual may similarly be involved in the consent process and assist the patient in understanding and applying information that they may be given during the care visit. Memory loss concerns may be best addressed by providing straightforward, uncomplicated printed literature to supplement conversations or demonstrations regarding procedures and home care.
Memory loss, exertional dyslexia and difficulties in information processing may hinder the arrival at an accurate diagnosis. It is imperative that the practitioner utilize all possible objective means to obtain information, including thorough physical examination, radiographs and other appropriate diagnostic tests.

Headache may mimic other pain of myofacial origin and may be confused with TMJ-related symptoms. Thorough questioning, examination and the use of imaging studies is essential. Other muscular pain, often noninflammatory and potentially radiating, may also cloud diagnosis. Commonly noted in patients with myofacial pain [16], headache is a common feature of both ME/CFS and depression [17]; studies indicate a strong bi-directional relationship between these two neuro-immune disorders [18]. While the dentist evaluating the cause of reported pain may suspect depression as a cofactor, research has shown that ME/CFS can be clearly differentiated from depression [19].

**Clinical evaluation:**

Thorough extraoral and intraoral examination of the patient presenting with dental or other orofacial concerns is essential to clarification of the chief complaint and determining an accurate diagnosis. Due to increased fatigability resulting from ME/CFS, bed bound or homebound patients may exhibit decreased stamina, limiting their ability to withstand a prolonged examination. Post-exertional neuroimmune exhaustion (PENE), otherwise referred to as post-exertional malaise, a cardinal feature of ME/CFS [8], is responsible for an increase in fatigue that may occur immediately, or that may be delayed by several hours or days following activity. This fatigued state may often be extended up to or beyond 24 hours [20]. The eleven-item Chalder Fatigue Scale [21] or other fatigue questionnaires [22] may be utilized to determine the extent, nature and characteristics of both physical and mental fatigue in the individual patient. If the patient presents with significant fatigue, examination may best be deferred if possible. To decrease post-exertional recovery time, the patient should be advised to rest prior to the provision of dental care.

The extraoral examination focuses on non-orofacial aspects of the patient that may impact diagnosis and clinical care. Several symptoms consistent with those seen in ME/CFS are also noted in routine dental interactions. Patients with ME/CFS are significantly more likely to experience depression and anxiety [23], which has been linked to patients becoming more sensitive to gastric acid [24]; stress and exhaustion may also contribute to the creation of physiological changes that could increase the effects of gastric reflux [25]. Gastroesophageal reflux disease (GERD) is commonly noted in dental patients, evidenced by a smooth, glass-like appearance of the lingual aspect of the anterior dentition and characteristic pitting of the cusp tips of posterior teeth. Concomitant symptoms of GERD, also noted in ME/CFS [26], include heartburn, nausea and patient complaint of a lump in the throat. In evaluating the patient with
ME/CFS, an investigation into the presence of GERD-like symptoms may influence the choice of dental restorative materials used and consideration for referral to a gastroenterologist.

Patients with ME/CFS may exhibit other gastrointestinal symptoms [27], including either anorexia or increased appetite, coinciding with marked weight fluctuation. An understanding of eating and weight patterns is integral to dental diagnosis and treatment planning. In patients with limited verbal ability, including those who might have ME/CFS-related issues with cognition, the dentist must recognize that such dietary symptoms are often nonodontogenic in origin. Any potential organic cause of weight fluctuation must be ruled out and referral to a nutritionist should be made. Numerous clinical studies of dietary modifications and nutraceuticals have been published examining their role in ME/CFS pathogenesis, outcome and treatment of symptoms. Although these have not been conclusive, investigation in this direction should be undertaken.

Dental patients with ME/CFS may complain of sinusitis and on examination may exhibit tender lymph nodes. Given the presumed role of viral and/or bacterial infection in ME/CFS initiation or modulation [28], it would not be surprising to note these findings during clinical evaluation. The dentist must recognize the potential for infection in these patients and, if an orofacial etiology of the infection is not identified, refer the patient for appropriate medical evaluation.

ME/CFS and autistic spectrum disorder:
Autistic spectrum disorder (ASD) is a neurodevelopmental condition with effects on communication, behavior and socialization, currently believed to affect approximately 1 in 54 children in the U.S. alone [29]. ASD affects primarily males and is often diagnosed by age three, while ME/CFS demonstrates a preponderance for middle-aged females. It would appear that these two disorders are easily differentiated, however there are situations in which a patient might be dually diagnosed with both ASD and ME/CFS or in which a diagnosis may be difficult to ascertain. Genetic and viral factors have been implicated as possible causes for these two conditions, leading numerous researchers to investigate potential links between ME/CFS and ASD as well as other developmental disorders [30]. Clinically, both ASD and ME/CFS may present with similar symptoms and share some behavioral characteristics.

Exertional fatigue, cognitive dysfunction (“brain fog”) and memory issues are hallmark traits of ME/CFS and are commonly noted in ASD. In attempting to diagnose ASD, care should be taken to rule out concomitant ME/CFS. Similarly, consideration of a diagnosis of ASD is appropriate for those patients undergoing evaluation for ME/CFS.

As noted, characterizing the chief complaint in the dental patient with ME/CFS may prove challenging. Many of these patients will also present with exaggerated responses to pain and to stimulation with other noxious stimuli, similar responses to those seen in many individuals on the autism spectrum. Other sensory concerns noted on dental presentation in both patient groups
include modification or sensitivity to taste and smell [31]. These responses may complicate diagnoses relying on subjective patient reporting, specifically where such diagnosis is reliant on assessment of pain character, duration, intensity and triggers.

**Providing dental treatment**

In addition to difficulties in ascertaining details of the medical history and the chief complaint, the dentist will also find challenge in providing dental treatment to the patient with ME/CFS, particularly those who are bedbound or homebound. These patients will present with heightened exacerbations of this disorder, above and beyond those patients who are able to seek in-office care.

Many of the concerns noted above will significantly interfere with the provision of dental care to this patient population. Post-exertional malaise will often limit the patient’s tolerance to undergo dental treatment. The more severely affected patient will also experience debilitating pain that may not only cloud the differential diagnosis for oral pain but that may limit the patient’s ability to tolerate any oral care, including at-home oral hygiene procedures. This may result in delaying needed care and in the worsening of oral conditions. Treatment planning should prioritize those oral needs that are most likely to destabilize and that are least elective in nature. Consideration should be given to deferring multi-step dental procedures where possible, substituting those with procedures that can be accomplished in fewer visits. Particularly with those patients who demonstrate evidence of immunocompromised status, attention should be paid to early elimination of conditions causing or potentially leading to infection and pain.

A prominent feature of ME/CFS is orthostatic intolerance (OI) [32]. The presence of OI with lightheadedness and dizziness as often seen in this population [33] will lead to many of these patients remaining homebound or even bedbound. The 2003 Canadian Consensus Criteria includes other related findings, including ataxia, poor balance and muscle weakness [34]. Intraoperatively, care should be taken to avoid rapid postural changes. In addition to assuring that the patient does not fall during or after treatment, the dentist must consider the increased possibility that patients presenting with OI may suffer from falls at other times, damaging oral appliances, the dentition or oral soft tissues. As such, removable dentures, retainers and ceramic fixed prostheses may be contraindicated based on the patient’s inability to ambulate safely.

During treatment, individuals with ME/CFS may develop pain in the temporomandibular joint (TMJ) region due to muscular fatigue. Intraoperatively, the use of a mouth prop to support the jaw will decrease stress on the musculature and reduce joint pain. The patient should also be allowed frequent breaks during the appointment as needed.

Respiratory symptoms frequently noted in persons with ME/CFS include exertional dyspnea and difficulty breathing as well as fatigue of chest wall musculature [8]. The patient’s ability to
breathe comfortably and effectively is critical in the provision of dental care. Most dental procedures involve the introduction of water and particulate dental materials into the oral cavity, in addition to the presence of the patient’s own saliva. To provide access and help maintain a dry field, the patient will also often be asked to maintain an open-mouthed posture. Given the respiratory symptoms noted, in addition to generalized fatigue, many individuals will find this challenging. Dental care should be planned to limit the duration of each appointment, using faster-setting and moisture-tolerant materials when possible. During the procedure, patients may find it easier to breathe and maintain opening if the head is semi-elevated rather than laid flat.

While there is no specific treatment for ME/CFS, many individuals are taking medications for control of pain, fatigue, disordered sleep and comorbid depression [35]. Among these are pharmacological agents with the potential to produce significant oral adverse effects. In particular, gabapentin, duloxetine, beta blocking agents, SSRIs and tricyclic antidepressants increase the risk for the development of xerostomia. Midodrine, an alpha-1 agonist used to treat symptoms of OI [36], has been linked to increased risk of stomatitis. Patients with ME/CFS often exhibit sensitivity to medications and may have exaggerated responses to sedatives. Clonazepam is often used by those with ME/CFS as a sleep aid; its concurrent use with other sedative medications or known respiratory depressants should be approached with caution.

Of particular interest to those providing dental care to the population of individuals with ME/CFS is the exaggerated sensitivity to exertion and increased adrenaline flow these patients report. An increase in adrenaline level has been linked to PENE and OI [37]. Epinephrine should be used sparingly in treating dental patients with ME/CFS and other alternatives should be considered where possible.

As noted previously, the mouth of the homebound or bedbound patient with ME/CFS may suffer from neglect as dental care appointments are deferred. Effort should be made to stress the importance of oral home care, encouraging both proper and frequent tooth brushing and flossing. Antibacterial oral rinses should be encouraged and a swish-and-expectorate regimen of oral rinsing after food or drink ingestion should be instituted to remove oral food debris. If poor oral hygiene is present and persists, consideration should be given towards prescribing a caries-preventive 5000ppm fluoride dentifrice [38] and twice daily mouth rinsing with 0.12% chlorhexidine solution [39]. In some cases, patients may not be able to perform at-home oral self-care without assistance. In these instances, the caregiver should be instructed in proper techniques and the importance of daily upkeep should be stressed. Dental recall examinations should be scheduled on a more frequent basis than for those without ME/CFS, with appointments scheduled every three to four months.

**Discussion**
The symptoms of ME/CFS can significantly complicate the provision of routine dental care to this complex patient population. Due to disabling fatigue and muscle pain, even ambulatory individuals will often defer or completely avoid dental appointments and procedures. For those who are homebound or bedbound, resources available to them to obtain dental care are even more limited. Although there are dentists who will provide some mobile dental services to at-home populations, their availability varies widely by region. This limited ability to address oral health needs often results in worsening of periodontal, dental and overall oral conditions. In turn, the development of pain and infection will exacerbate ME/CFS symptoms, leading to further patient decline.

Although many of the more severely compromised individuals with ME/CFS will be cared for at home or in hospital-based dental facilities, the majority of those seeking dental treatment will be seen in the private practice office setting. In addressing the needs of these patients, the dental office must recognize the significant impact of the patients’ disability on their scheduling and keeping appointments. Dental treatment plans should reflect these issues, avoiding lengthy, complex and multi-visit procedures. Triage of oral health needs to prioritize those conditions that may lead to pain and/or infection is essential to this population.

Many patients presenting for dental care will be wheelchair-dependent. Dental practices should be compliant with the Americans with Disabilities Act (ADA) guidelines relating to office accommodation to persons with disabilities. Title III regulations, originally published in 1991, delineate comprehensive obligations of public and commercial facilities towards these patients [40]. While building codes apply to new construction and renovations only, the dentist should consider ways in which to assure a secure, more comfortable and efficient patient experience.

Appropriate care for the dental patient with ME/CFS involves an understanding and appreciation of the diverse and limiting symptoms with which these patients present. Similar to those on the autistic spectrum, these patients will often present with sensory sensitivities that must be addressed. Some, such as an aversion to bright lights and loud sounds [41], may be alleviated by simple in-office modifications such as lowering the lights and maintaining a quiet operatory. In many cases, the more severely affected patients may require headphones or darkened glasses or an eye mask to limit painful sensory stimulation. Other sensory issues, such as modification to sense of taste or smell, will require reevaluation of diagnostic criteria for oral concerns, particularly in the presence of brain fog.

While there are many individuals who have been diagnosed with ME/CFS, research indicates that the true number of those so affected is in actuality considerably higher. In addition to recognizing the role of ME/CFS symptoms in the evaluation and treatment of oral health care issues, the dentist should similarly be aware of these symptoms and, if present, consider discussion with the patient’s primary care physician or other appropriate members of the health
care team. Many patients experience frustration in suffering from symptoms of ME/CFS without obtaining a diagnosis or care plan. The dentist, particularly if there is a long history of care for that individual, may be the first health care provider to recognize the hallmark signs of this disorder and recommend further evaluation.

**Conclusions**

ME/CFS has numerous debilitating symptoms beyond its cardinal features of chronic fatigue and post-exertional malaise. The more severely affected patient will often be homebound or even bedbound and prove a significant challenge to the dental team and to those caregivers providing at-home oral care. An understanding of the role of the symptoms of ME/CFS in the care of dental patients so affected is critical to the overall management of this complex population. As oral disease will often result in pain and infection, maintenance of oral health should be a significant component in any overall care plan for these individuals. Effective communication with both the patient and any caregivers is essential to this plan. Dentists should be aware of their role as members of an interdisciplinary health care team, and their input should be sought out by the broader medical care community involved in the care of these patients.

**References**


