nature of the illness (Jason et al., 2004; Ramsay, 1988b). However, there are patients and researchers who maintain that ME and CFS are two different illnesses and oppose simply changing the name of CFS to ME (Twisk, 2014).

Partly in response to the concerns that have been expressed about CFS and to a lesser extent ME, particularly by patients, the committee was asked to recommend whether new terminology for ME/CFS should be adopted, a request that is addressed in Chapter 7. As noted in Chapter 1, the committee uses the umbrella term “ME/CFS” to refer to ME and CFS throughout this report.

**BURDEN OF ME/CFS**

My personal experience of having ME/CFS feels like permanently having the flu, a hangover, and jet lag while being continually electrocuted (which means that pain plays at least as much of a role in my condition as fatigue).  

As noted in Chapter 1, ME/CFS affects between 836,000 and 2.5 million people in the United States (Jason et al., 1999, 2006a; Reynolds et al., 2004). It affects more women than men, and although many seeking care for ME/CFS are Caucasian, the illness may be more common in minority groups (Jason et al., 1999, 2009, 2011; Reyes et al., 2003). The average age of onset is 33, although ME/CFS may begin as early as age 10 and as late as age 77 (NIH, 2011). Symptoms can persist for years, and most patients never regain their premorbid level of health or functioning (Nisenbaum et al., 2000; Reyes et al., 2003; Reynolds et al., 2004). The duration of ME/CFS and the potentially debilitating consequences of symptoms can be an enormous burden for patients, their caregivers, the health care system, and society.

**Disability and Impairment**

Several ME/CFS symptoms—including fatigue, cognitive dysfunction, pain, sleep disturbance, post-exertional malaise, and secondary depression or anxiety—may contribute to impairment or disability (Andersen et al., 2004; Tiersky et al., 2001). Patients with ME/CFS have been found to be more functionally impaired than those with other disabling illnesses, including type 2 diabetes mellitus, congestive heart failure, hypertension, depression, multiple sclerosis, and end-stage renal disease (Jason and Richman,
Symptoms can be severe enough to preclude patients from completing everyday tasks, and 25-29 percent of patients report being house- or bedbound by their symptoms. Many patients feel unable to meet their family responsibilities and report having to reduce their social activities (NIH, 2011). However, these data include only patients who were counted in clinics or research studies and may underrepresent the extent of the problem by excluding those who are undiagnosed or unable to access health care (Wiborg et al., 2010). More information on disability in ME/CFS can be found in Appendix C.

Health Care Costs and Utilization

Patients with ME/CFS spend considerably more on health care than the general medical patient population (Twemlow et al., 1997). They also see more physicians and visit their health care providers more often relative to the general medical patient population (Thanawala and Taylor, 2007; Twemlow et al., 1997). Many patients report barriers to accessing health care as well, including the nature of their illness and financial considerations (Lin et al., 2009; Thanawala and Taylor, 2007).

Household Income

ME/CFS symptoms often are so debilitating that patients are unable to work or attend school full-time (Crawley et al., 2011; Solomon et al., 2003; Taylor and Kielhofner, 2005; Twemlow et al., 1997). A review of 15 studies conducted between 1966 and 2004 showed that unemployment rates among those with the disorder ranged from 35 to 69 percent in 13 of these studies (Taylor and Kielhofner, 2005). ME/CFS was found to account for $8,554 in lost household earnings, 19 percent of which was attributable to lower educational attainment (Lin et al., 2011). Another study, conducted among ME/CFS patients in Kansas, found that ME/CFS resulted in reduced household and labor force productivity that caused individual income losses of approximately $20,000 annually (Taylor and Kielhofner, 2005). Reductions in employment and productivity per hour resulted in a 37 percent reduction in household productivity and a 54 percent reduction in labor force productivity (Reynolds et al., 2004).

Economic Costs

As noted, ME/CFS often lasts for many years, and beyond lost income, inflicts substantial economic costs at both the individual and the societal level. In one study, annual direct medical costs per ME/CFS patient ranged from $2,342 in a community-based sample (previously undiagnosed) to
$8,675 in a tertiary sample (already diagnosed) (Jason et al., 2008). Another study found that individuals with ME/CFS incurred $3,286 in annual direct medical costs (Lin et al., 2011). The direct and indirect economic costs of ME/CFS to society are estimated to be approximately over $18 to $24 billion annually (Jason et al., 2008).

REFERENCES


