

# The Academic and Psychosocial Impacts of Ehlers-Danlos Syndrome on Postsecondary Students: An Integrative Review of the Literature

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## Abstract

Ehlers-Danlos Syndrome (EDS) is a complex, often invisible, connective tissue disorder that has arguably profound psychosocial and academic impact on postsecondary students. It is an underdiagnosed and misunderstood condition that is the focus of little research, particularly within the social sciences. Several factors influence the academic experiences of postsecondary students with EDS, including institutional issues, faculty attitudes, accommodations, school attendance, and technology use. Psychosocially, adjusting to new or changing diagnoses, dealing with the stigmas and misperceptions of others, and the ongoing identity formation of youth are major factors for students. Since there is a notable shortfall in academic literature with the specific focus of EDS in postsecondary education, this review draws from the peripheral fields of chronic illness and disability studies for support.

*Keywords: Ehlers-Danlos Syndrome, chronic illness, post-secondary, psychosocial, academic barriers*

Ehlers-Danlos Syndrome (EDS) is a connective tissue disorder where the body does not produce proper collagen (Ehlers-Danlos National Foundation [EDNF], 2009). Collagen is effectively the “glue” that holds the body together, and it directly affects approximately 80% of human systems, including skin, organs, joints, and the nervous and circulatory systems (EDNF, 2009). There are multiple manifestations of EDS; the most common are the classical, hypermobility, and vascular types. The vascular form of EDS can result in spontaneous organ rupture and often precludes an average lifespan. The diagnosis rate of the different types of EDS is presently unknown. However, according to the EDNF (2015), the prevalence of EDS is estimated to be about one in 2,500 to one in 5,000. Using these incidence rates, the EDS population in Ontario, Canada, for example, can be estimated to be approximately 2,700, given a population of 13.7 million people (Statistics Canada, 2014). Vascular EDS is estimated to have a prevalence of approximately one in 250,000 (EDNF, 2015).

EDS is not a new disease. In 1901, Edward Ehlers, a Danish dermatologist, recognized the con-

dition when he published details of a patient with lax joints, hyper-extensible skin, and inclination to bruising (Parapia & Jackson, 2008). In 1908, Henri-Alexandre Danlos, a French physician, suggested that skin fragility and vascularity were cardinal features of this syndrome (Parapia & Jackson, 2008). The classification of EDS began in the late 1960s when it was defined according to nine subcategories (Parapia & Jackson, 2008) that have since been revised to six main types (EDNF, 2015).

Many people with this disorder become symptomatic as young adults (Adib, Davies, Grahame, Woo & Murray, 2005; EDNF, 2009), right around the time that they are considering or are enrolled in postsecondary education. Daily dislocations cause many problems for students with EDS in the school setting (Tinkle, 2010). Furthermore, low muscle tone and delayed fine and gross motor skills cause individuals with EDS to appear clumsy and uncoordinated (Adib et al., 2005). Many students with this disorder are unable to participate normally in physical and regular classroom activities. This circumstance negatively affects their physical and psychosocial development.

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Currently, there is limited research on EDS. Of the research that does exist, little of it focuses on educational accommodations and modifications that can help students with their academic and psychosocial development. Instead, the focus is clinical issues and, thus, serves medical professionals rather than students, educators, and support workers (e.g., Adib et al., 2005; Castori et al., 2012; Milhorat, Bolognese, Nishikawa, McDonnell & Francomano, 2007; Savasta, Merli, Ruggieri, Bianchi & Sparta, 2011). No studies have been found in which the relationship between EDS, emotional and social development, identity formation, and academic achievement are examined. As such, there remains a large gap in the body of knowledge about this disease and the postsecondary student experience. Moreover, because EDS and its co-morbidities are under-recognized in the general population, there is a systemic lack of awareness of the accommodations required for students with this condition. Even in the broader context of chronic illness and postsecondary education, there are few resources. In short, students with chronic illnesses, such as EDS, are an under-studied, under-represented population in the postsecondary environment.

This literature review builds around two overarching interconnected themes: academic considerations and psychosocial considerations. Within these themes, specific subcategories are explored. They include institutional issues, faculty attitudes, accommodations, school attendance, technology, and stigmas and (mis)perceptions relating to chronic illness. Before relevant literature in these areas is explored, essential terminology is explained and a number of key ideas drawn from Federal and Provincial legislation are offered as important context. The grounding theoretical framework is also presented in advance of the literature itself.

### **A Note on Terminology Use**

The terms chronic illness and disability are not interchangeable nor are the concepts mutually exclusive. The United Nations (2007) used the term disability to apply to all persons with disabilities including those who have long-term physical, mental, intellectual, or sensory impairments, which, in interaction with various attitudinal and environmental barriers, hinder the person's full and effective participation in society on an equal basis with others. The term chronic illness is less formally defined. Larson (2006) defined chronic illness as "an ongoing medical condition with a spectrum of social, economic, and

behavioural complications which require meaningful and professional involvement" (p. 5). The consensus is that a chronic illness is a medical condition, disease, or injury that has lasted more than three to six months and has caused an individual to significantly alter his or her day-to-day activities (Repetto et al., 2012). Decreased endurance, mobility, or cognitive functioning results in a limitation of the individual's ability to continue his or her usual lifestyle (Wide-man-Johnston, 2015). An individual with chronic illness is never cured.

Because there is no specific literature on the psychosocial and academic development of postsecondary students with EDS and limited literature on the topic of chronic illnesses and postsecondary education, the literature of disability studies was considered in this review. Furthermore, as the rights of individuals with chronic illness are governed by the same legislation as disabilities, many of the examples cited within the disability studies literature can be applied to people with chronic illnesses as well. While EDS is a chronic illness by definition, many of its symptoms result in temporary or long-term disablement; thus, within the body of the paper the terms chronic illness and disability are both used. As further context to the review, as appropriate, the ideas presented within the aforementioned sub-sections will focus on issues and barriers with recommendations and strategies outlined in a Summary section.

### **Legislation**

In Canada, Section 15(1) of the Charter of Rights and Freedoms (1982) stated the following:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental and physical disability.

Notably absent from the above statement is mention of geography. Hence, accommodations for persons with disabilities enrolled in postsecondary institutions varies according to where the student lives. Additionally, the Charter is quite broad and, therefore, open to interpretation when accommodations for persons with disabilities are developed and regulated (Black, 2004). Further, health status and chronic illness are not mentioned specifically in this legislation, thus generating questions about how they should be

addressed and accommodated. By comparison, in the United States of America, the passing of Section 504 of the Rehabilitation Act of 1973 allowed, for the first time, many people with severe limitations to enter higher education (Stephens & Norris-Baker, 1984).

At the provincial level, in Ontario, important strides have been made that mandate accommodation of persons with disabilities. In 2001, the Ontarians with Disabilities Act was passed. It requires the government and wider public sector including colleges, universities, hospitals, and school boards to develop accessibility plans (Ministry of Community and Social Services, 2013). In 2005, the Government of Ontario passed the Accessibility for Ontarians with Disabilities Act; the aim of this act is to make Ontario barrier free for individuals with disabilities (Mullins & Preyde, 2012). Additionally, according to the Ontario Human Rights Commission, service providers must take the needs of persons with disabilities into account and remove all existing barriers to services like education.

### **Models for the Conceptualization of Disability, Illness, and Health: Biopsychosocial Model**

The biopsychosocial model of disability, illness, and health grounds the examination of the academic and psychosocial considerations required for students with chronic illnesses including EDS. The biopsychosocial model suggests a complex interaction of biological, psychological, and social factors that play a significant role in an individual's ability to function (Falvo, 2014). Conceptualizing chronic illness and disability as health conditions that affect functional capacity allows for increased understanding of individual experiences of such health conditions. The World Health Organization (WHO, 2014) accepted the biopsychosocial model as the dominant approach to understanding disability and health. The WHO acknowledges that all persons may experience elements of disability over the course of a lifetime through changes in health or environment and the impact of the disability/health condition on the functioning of an individual. Just as people vary in relation to their functional capacity, people vary in their personal resources, access to social supports, and abilities to cope (Falvo, 2014). Through the application of the biopsychosocial approach, an understanding of disability and health that incorporates all aspects of an individual's life experience will be obtained.

### **Academic Considerations**

For the purposes of this review, the term academic considerations is used to refer to logistical concerns that affect learning within the postsecondary educational setting. These concerns include but are not limited to institutional issues, faculty attitudes, accommodations, school absence, and technology.

**Institutional issues.** Recent research indicates that more than half of Americans experience at least one chronic illness (Goodwin & Morgan, 2012). Despite the challenges that persons with chronic illnesses face, they can be highly productive members of the academic community. The key to their success lies in institutional policies and practices that ensure equity and support productivity. In a 2005 postsecondary report entitled "Ontario: A Leader in Learning," the following directives were set out:

Require institutions to reach out to students with disabilities at their schools and in their communities to ease the transition to postsecondary education. Provide funding for enhanced academic and career counseling on campus. Allow for the evolution of centres of research and service excellence and distribute funding to institutions for supports and services on the basis of the size of a given institution's population of students with disabilities. (Higher Education Quality Council of Ontario, 2013, p. 1)

Each of the above touches on a major facet of the issue of access to postsecondary education for persons with disabilities and/or chronic illness. According to Jung (2003), in postsecondary education, accessibility refers to "the institution's legal obligation to create genuine learning opportunities for people with disabilities to participate in all aspects of university life" (p. 92). The duty to accommodate requires the institution to take an active part in modifying practices, facilities, and/or services that prevent the inclusion and participation of students with disabilities who are otherwise qualified to attend school. In addition to bigger picture issues such as inadequate funding to reach out to students with chronic illness and make systemic and structural changes, other more subtle barriers also hinder the full participation of students with chronic illnesses. Some of these barriers include a lack of faculty and peer awareness; lack of participation in academic and non-academic discourse; and financial, time, and other resource constraints (Hutcheon & Wolbring, 2012). Each of these barriers is problemat-

ic since they lead to diminished postsecondary school experiences and negative effects on students' beliefs, identities, and self-concept.

**Faculty attitudes.** According to Jackson (2013), educators may be uncomfortable dealing with students with chronic illness because they lack knowledge and understanding of specific conditions. In the case of a chronic illness, the faculty member must feel adequately prepared to help the student. Faculty attitudes and responses can dramatically affect the academic success of students with chronic illness. How open faculty is to learning about different medical conditions and modifications and accommodations that support their students with such illness is particularly important. Faculty who are positive and approachable help students with chronic illnesses to feel secure and included in their learning environments. Too often, there is a level of skepticism about chronic illness on the part of faculty that students need to overcome in addition to their other challenges.

Perceptions of negative attitudes by faculty may prevent students with chronic illnesses like EDS from disclosing their health situations, using self-advocacy skills, and requesting accommodations (Rao, 2004; Sachs & Schreuer, 2011). In a survey conducted by Sachs and Schreuer (2011), 50% of students with disabilities indicated that faculty members understood their needs but only 25% of faculty members were willing to help accommodate them. In an effort to capture the faculty perspective, Bruder and Mogro-Wilson (2014) examined faculty awareness and attitudes towards students with disabilities. While their study was limited to one university and to disabilities in general, their study consisted of 2,056 faculty and graduate students. Despite the fact that half of the faculty reported having a student with a disability in at least one of their classes, faculty members still reported feelings of pity, awkwardness, embarrassment, and admiration for students with disabilities. Within the classroom the majority of faculty members provided accommodations to students with disabilities. However, 7% of the faculty viewed the provision of accommodations as inconvenient, disruptive, and caused feelings of unfairness in other students. Furthermore, 59% of the faculty were uncertain as whether students with disabilities were being fairly treated by the university, with 18% stating that the university was doing a poor job including students with disabilities in social organizations and co-curricular activities. Other findings indicate that faculty may be reluctant to provide certain accommodations for fear of lowering academic standards (Barzandeh, 2005).

**Accommodations.** People with chronic illnesses represent a significant proportion of the population of persons with disabilities (Jung, 2003). Most students with chronic illnesses like EDS depend on disability policies and supports in order to access the same postsecondary educational opportunities as their non-disabled peers (University of Manitoba, 2014). For some, making higher education more accessible and including previously excluded groups in the classroom are perceived as disruptive and even threatening to the existing institutional order of the university (Hutcheon & Wolbring, 2012; Jung, 2003). Students who receive academic accommodation as a result of a chronic illness may also be the target of resentment on the part of their peers because accommodations may be seen as unfair despite the fact that, in reality, accommodations correct inequitable outcomes of social arrangements (Jung, 2003).

Students with chronic illnesses, like EDS, experience unique issues that often require specific and targeted educational accommodations. In a study comparing young adults with childhood onset of chronic illness with their healthy peers, those with chronic illness experienced lower rates of high school graduation, college attendance, college graduation, and employment (Maslow, Haydon, McRee, Ford, & Halpern, 2011). Better educational accommodations in secondary school and an increased emphasis on the transition to postsecondary education for students with chronic illnesses might encourage students requiring accommodations to enroll in postsecondary degree or diploma programs and experience success (Haas & Fosse, 2008). In Ontario, transition planning for students moving from secondary school to postsecondary education is part of a student's Individual Education Plan (IEP) (Ontario Ministry of Education [OME], 2002). If the student does not have an IEP, he or she will likely not have a transition plan in place prior to graduation from secondary school.

While students with EDS have needs similar to those of students with disabilities, they also have unique challenges and issues that may require deviation from the standard academic accommodations typically provided in the postsecondary institutional setting (Korbel, Lucia, Wenzel, & Anderson, 2011). Often students do not realize that they are allowed to advocate for themselves and ask for different accommodations if the ones in place are ineffective (Kurth & Mellard, 2006). Kurth & Mellard examined how postsecondary students with disabilities perceived the accommodations available at 15 community and technical colleges in California, Minnesota and Kansas.



Their findings suggest that the accommodations offered to postsecondary students who have disabilities are often ineffective and inappropriate because the accommodations focus on the disability rather than on the students' contextual and functional needs. For example, a common accommodation offered to students is writing tests and examinations in an alternative location. While this accommodation meets the academic needs of a student, the student may feel isolated from classmates. Thus, accommodations must be examined to ensure that they are meeting both academic needs as well as the student's personal needs. The postsecondary students in Kurth and Mellard's study also stated that independence was one of the most important factors when selecting an accommodation. While adaptive technology (e.g., computers, tablets, voice-to-text, text-to-voice) provides academic independence, accommodations were not provided to ensure that the participants were able to maintain independence in terms of transportation, extracurricular activities, housing, and accessible facilities. Overall, Kurth and Mellard conclude that while postsecondary institutions are meeting their legal obligations a greater focus must be given to the entire context of student life by incorporating system wide universal design concepts.

At the postsecondary level, it is the responsibility of the student to self-advocate to ensure his or her needs are being appropriately met. While many services are often available within institutions, the student must still advocate for him or herself in order to receive appropriate accommodations. Additionally, while students generally have the opportunity to select accommodations from a list of possibilities, it is their responsibility to work with faculty and disability service professionals to tailor them to their circumstances (Kurth & Mellard, 2006). Further, faculty have different interpretations of accommodations. Thus, students must communicate with their instructors to ensure that their needs are being met while the integrity of the postsecondary institution is still maintained (Korbel et al., 2011). Faculty need to recognize that no two days will be the same for students with chronic illnesses and that some of the most helpful accommodations are discretion, understanding, and adaptability.

A further challenge affecting student success is a pedagogical one. Faculty often lack the knowledge and experience to prepare materials, classes, and courses for students with chronic illness. One way of designing lessons and classroom activities to ac-

commodate multiple student needs is the practice of Universal Design (UD). UD is a philosophy and set of principles that relate to the structuring of teaching and course design (Davies, Schelly & Spooner, 2013). While primary and secondary school environments have adopted some of the practices of UD, postsecondary institutions have been slower in adopting this design. This slow uptake may be due to the fact that faculty rarely have formal teacher training. Hence, unless institutions offer specific UD workshops, it is unlikely that faculty will have experience in designing courses using its principles (Dallas, Upton, & Sprong, 2014). Incorporating UD into higher education requires an institutional shift from the individualized nature of accommodation to training opportunities for faculty in the use of UD.

Perhaps there has been a lack of emphasis on training faculty to work with students and colleagues with chronic illnesses and disabilities because people with disabilities/chronic illnesses comprise a small minority of the overall postsecondary population. Barnes (1999) noted the following:

The current presentation of disability in universities fosters the notion that disability is an individual or family 'problem'; that the disabled voice is absent from the curriculum; that disabled people are objectified as a result; that there is a lack of critical analysis and that this is due to the absence of disabled scholars and researchers within universities. (p. 567)

Although Barnes' remarks are a valuable commentary, it is also possible that there is a presence of disabled scholars and researchers in the academy who choose not to disclose their disabilities or chronic illnesses. Making a systemic change, like institutional implementation of UD, could help all students since individual learning needs and styles are recognized and valued in the UD context. Furthermore, accommodations would likely not need to be individually sought to the degree they presently are.

**School attendance.** A student with chronic illness may be absent from class due to appointments or hospitalizations. As a result they will miss valuable learning time and risk falling behind in their studies. Students with a chronic illness are absent, on average, ten days per academic year compared to a three-day absence for those who do not have chronic conditions (Jackson, 2013). This higher rate of absenteeism contributes to lower levels of academic achievement

which can negatively affect success in receiving and retaining bursaries and scholarships. Financial stress, health stress, social isolation, and slower maturation are all negative outcomes of prolonged absence (Martinez & Ercikan, 2009; Maslow, Haydon, McRee & Halpern, 2012). As health declines, so too does academic achievement and school attendance (Haas & Fosse, 2008).

**Technology.** As noted previously, students with chronic illness tend to be absent from school more frequently than their healthy peers. According to Jackson (2013), there is high value when faculty and institutions support the learning of chronically ill students during periods of absence. By continuing to complete course requirements at home, the student will be aware of what is being covered in class and be better prepared when he or she does return to school. Another possible solution to allay concerns about absence is enabling students who are unable to physically attend class to interact with their peers and the course material through various new technologies (e.g., podcasting lectures, discussion forums, Skype sessions, webinars). Increasing opportunities for distance and online education are being offered through Canadian postsecondary institutions (Ontario Ministry of Training, Colleges and Universities, 2015). Wilkie (2011) asserted that the impacts and implications of chronic illness on students deny them the normal social interactions of school. In these cases, technology-mediated education may be a viable option for facilitating learning and socializing. Web cams, voice and video streaming, along with other technologies including asynchronous course methods, can help students who are in hospital or recovering at home to stay engaged in their coursework (Jackson, 2013). While there are ethical factors such as gaining consent from all other students to appear on video, technology has emerged as an important means of providing engagement and socializing opportunities for the EDS student at home. These newer forms of technology provide wonderful flexibility and new opportunities for people who were previously marginalized, limited, and prevented from seeking educational experiences through alternative models (Black, 2004).

## **Psychosocial Considerations**

For the purposes of this review, the social and emotional impacts of chronic illness on postsecondary students will be examined under the broad category of “psychosocial considerations.” Social and emotional considerations are, arguably, linked in the case of EDS in an academic environment. Health conditions can trigger significant change, resulting in stress associated with psychological turmoil and physical imbalance as individuals adjust to lifestyle changes, loss of control, pain and discomfort, and potential alterations in status, independence, and financial stability (Falvo, 2014). Given that EDS is chronic, painful, and potentially disabling, it follows that it may include some degree of psychosocial impairment (Lumley, Jordan, Rubenstein, Tsipouras & Evans, 1994).

Many people with EDS experience co-morbidities like dysautonomia, a disorder of the autonomic nervous system function that can be local or generalized, acute, or chronic (National Institute of Neurological Disorders and Stroke, 2013). One of the effects of this co-morbidity is orthostatic intolerance (Mayo Clinic, 2009), which affects recreation and social development. Students with EDS and various co-morbidities may find it harder to participate in common postsecondary social settings including going to the gym and going out with their peers. Socialization is important since studies show that students with friends and social supports recover more quickly from illnesses and are healthier overall than those who are isolated from peers and classmates (Ryan, 2001; Wentzel, Barry, & Caldwell, 2004). This finding suggests how substantive the effect of EDS and related conditions is on daily functioning and how important accommodations and a normalized social context are.

In addition to the physical aspects of EDS that affect an individual’s social and emotional wellbeing, how individuals view their conditions, causes, and implications greatly affects their social interactions (Falvo, 2014). The diagnostic process for EDS is a significant predictor of reaction as well; reactions of grief, fear and anxiety, anger, depression, and guilt are common following diagnosis (Smart, 2012). The lack of obvious disease in relatively high functioning of people with EDS may lead physicians to suggest psychiatric diagnoses rather than physical or medical ones (Lumley et al., 1994). When these reactions are experienced simultaneously, they can affect the emotional state of a student pursuing a postsecondary education. Positive social interaction and interpersonal support can help students with chronic illness to offset some of

this emotional turmoil. Conversely, health conditions can lead to a change in social status whereby students with chronic illnesses may find themselves in a socially devalued role (Falvo, 2014). Social isolation can easily precipitate an emotional spiral.

Although many young people cope well with the emotional aspects of having a chronic illness, many chronically ill young people are likely to have a lower level of emotional wellbeing than their healthy peers (Herts, Wallis, & Maslow, 2014; Yeo & Sawyer, 2005). This circumstance makes sense given the various physical symptoms of chronic illnesses, including the following:

- Fatigue and limited physical endurance due to the drain of energy on the person's body or the presence of chronic pain;
- Fluctuating capacity to participate in daily activities due to exacerbations and remission of the disease itself;
- Difficulty concentrating due to emotional factors, medication side effects, or pain;
- Difficulty with mobility due to inflamed joints, limited nerve function, or decreased strength;
- Periods of diminished productivity throughout the day; and
- Frequent absence from class. (University of Manitoba, 2014, pp. 23-24)

Chronic illness is particularly frustrating when students feel well enough to complete their studies most of the time. It becomes additionally problematic when the limitations of their illness coincide with the time needed for preparing assignments, meeting deadlines, and/or taking exams. These frustrations can trigger negative thoughts and self-perceptions. Chronic illnesses, like EDS, can be a barrier to self-confidence and a sense of self-efficacy since it is associated with the risk of failure (Cunningham & Wodrich, 2006). Feelings of uncertainty, being unable, incapable, or not good enough result from challenging and unpredictable physical symptoms. They are often exhausting and have significant and longstanding emotional impacts (Falvo, 2014).

Another important psychosocial consideration is the invisibility of EDS. Matthews (1994) defined invisible disability as "one that is hidden so as not to be immediately noticed by an observer except under unusual circumstances or by disclosure from the disabled person or other outside source" (p. 7). Having a chronic illness that is not visible leads to different

set of psychosocial implications than a visible disability or illness does. Because there are no apparent outward physical signs to indicate limitations, others have no basis on which to alter their expectations regarding the functional capacity of the individual (Falvo, 2014). In this situation, there is often a need to "prove" the validity of the illness because it is not immediately visible to others. Many individuals with invisible illnesses and disabilities have remarked that "you get tired of defending yourself all the time" (Smart, 2012).

Conversely, with an invisible illness or disability, the individual has the ability to fully control his or her identity since there is no visible "evidence" of disability (Olney & Brockelman, n.d.). In a study conducted by Olney and Brockelman, students with visible disabilities appeared to have integrated disability into their identities to a greater degree than those who had invisible disabilities. The researchers also discovered that, if students with disabilities felt that faculty viewed them as competent, they would be more likely to disclose their disabilities than otherwise. The politics of visibility has significant psychosocial impacts on postsecondary educational accommodations as well as relationships with faculty, peers, and the involved students themselves.

**Stigmas and (mis)perceptions.** Another dominant theme in the literature pertains to how students with chronic illnesses are perceived by their peers and faculty. Stigma is related to what society considers to be deviations from the norm (Falvo, 2014). Often, healthy individuals view those with chronic illnesses as their conditions rather than as individuals (Smart, 2012). For the most part, stigmatization occurs because of a lack of understanding about the condition. Unfortunately, the power of stigma can overshadow the positive characteristics of individuals with chronic illnesses like EDS; it can impact self-perceptions and the person's willingness to accept or divulge the health condition (Falvo, 2014). One of the most significant causes of misperceptions about students with EDS is the symptom of easy bruisability which is often misconstrued as abuse. An altered body image because of scarring and the use of adaptive equipment (e.g., braces and mobility aids) may add to feelings of stigmatization (Berglund, Nordstrom, & Lutzen, 1999).

Stigmatization is a characteristic of postsecondary life and is particularly prevalent in cases of invisible illnesses or disabilities. People with invisible illnesses or disabilities often receive negative comments about their disability. Comments can range from belittling

comments about the severity of their issues to comments that suggest that people with disabilities are bad, unstable, or incapable. In an effort to avoid stigma, individuals with chronic illnesses may deny, minimize, or ignore their condition and/or management plans (Falvo, 2014). Invisible illnesses, like EDS, can be very difficult interpersonally because the person with EDS appears to be healthy when he or she, in actuality, is not (Vash & Crewe, 2004). This difference in appearance and health often elicits negative comments and perceptions from others such as when people with invisible illnesses or disabilities use the accommodations to which they are entitled (e.g., an accessible parking permit). There is likewise the perception that people with disabilities or illnesses do not belong in a college or university setting. Chronically ill students and students with disabilities may be seen to unnecessarily drain or waste scarce educational resources, especially when there is fierce competition for funding and enrolment (Jung, 2002; Hutcheon & Wolbring, 2012). Having access to normal life and social activities including attending school, gaining meaningful employment, and maintaining contact with peers are essential for boosting self-esteem and improving quality of life.

### **Recommendations for Practice**

In this review, the psychosocial and academic impacts of EDS on post secondary students were examined. Institutional issues, faculty attitudes, accommodations, school attendance, and technology use comprised the most significant academic issues for postsecondary students with EDS. Psychosocially, experiences with stigmas and misperceptions were found to be the most prevalent themes.

Based on the reviewed literature, several recommendations for improvement to the postsecondary experience for students with EDS more generally have been identified. They include:

- Increasing faculty knowledge through training opportunities to help alleviate some of the worry and uncertainty associated with teaching students with EDS. Increased training related to chronic illness, such as EDS, in postsecondary education may also help faculty understand the need to accommodate students with such illnesses. In cases of highly variable illnesses, like EDS, an orientation course or workshop on chronic illness in general that

provides fundamental information about how to manage the health problems associated with the illness can be beneficial (Obeng & James, 2010). In the case of EDS, the training should address the fact that certain activities like repetitive motions and daily activities (e.g., carrying heavy books, note taking, standing or shifting positions in class, etc.) may cause damage to joints or fragile tissues (Snuggs, 2013) and put the student at risk for injury.

- Encouraging disability service educators to work collaboratively with faculty and students to develop supportive environments. This way, faculty learn to understand the need for student accommodation as well as the process of developing reasonable accommodations that do not compromise the academic integrity of the institution. Disability services need to ensure appropriate treatment of the students using their services by faculty and other professionals within the institution.
- Allowing students with EDS access to accommodations, such as those outlined by the University of Manitoba (2014), encourages full participation in the postsecondary academic environment. Suggested accommodations include having note-takers, having professors provide hard-copies of session materials, private and confidential conferencing with professors, permitting the use of computers,, home access to library/resources,, permitting the recording of lectures,, tutoring services, flexibility with deadlines, extra time on exams and tests, writing exams in a separate space, and flexibility with attendance penalties.
- In addition to these more standard accommodations, institutions must consider accommodations that are outside of the norm, including such things as permitting students to lie down as needed, to shift positions or stand up in class, and to use varying adaptive/assistive devices (e.g., canes, wheelchairs, neckbraces) without a requirement for disclosure.
- Advertising available supports and services to students with chronic illnesses, like EDS including access to leadership and mentorship opportunities on campus. Supports and services must address all aspects of campus life (e.g., transportation, housing, extracurricular and social activities) and not just the academic components.



- Considering enhanced funding and scholarship opportunities as well as academic and career counseling for students with chronic illnesses as per the Higher Education Quality Council of Ontario (2013) recommendations.
- Utilizing technology-mediated education where appropriate (e.g., podcasting lectures, discussion forums, Skype, etc.) to assist students with EDS and other chronic illnesses in full academic participation despite potential absences.

### Summary

Currently, chronic illness is not specifically addressed in Canada's provincial and federal legislation that ensures rights of access for persons with disabilities. Students with chronic illnesses depend on disability policies in order to access the same educational opportunities as their healthy peers, which means that they must often identify themselves as having a disability rather than an illness. Furthermore, not all people with EDS or other chronic illnesses experience physical disabilities. Hence, it is possible that students who have never considered themselves persons with disabilities before enrolling in postsecondary education must self-identify as a person with a disability in order to access the programs and services they need to ensure academic and psychosocial success.

Since there is an underwhelming amount of existing literature on EDS in postsecondary students, literature from chronic illness and disability studies were consulted. It is assumed that the postsecondary experience for students with EDS is similar to the postsecondary experience of students with other chronic illnesses and disabilities. Much of the literature and discussion relating to accommodations is both generalizable and transferable between groups. Thus, the psychosocial and academic impacts of EDS on postsecondary students requires further consideration.

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