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An Exploration of Quality of Life among Ontario Postsecondary Students Living with the Chronic Illness Ehlers-Danlos Syndrome

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An Exploration of Quality of Life among Ontario Postsecondary Students Living with the Chronic Illness Ehlers-Danlos Syndrome

Abstract

Ehlers-Danlos Syndrome (EDS) is a connective tissue disorder that results in negative health events. It also holds potential for periodic or permanent disability and psychosocial stress. While a diagnosis of EDS can occur at any age, the psychosocial effects of an EDS diagnosis can be especially challenging when symptoms present during postsecondary education. This qualitative study examined the psychosocial effects of EDS on the quality of life of Ontario postsecondary students (*n*=11). After a brief online eligibility survey, one-to-one semi-structured interviews were conducted. Thematic analysis of interview data revealed that emotional factors such as anxiety and depression, faculty and peer attitudes including issues of judgment and stigmatization, and feelings of frustration affect the quality of life of postsecondary students living with EDS.

Le syndrome d'Ehlers-Danlos est une maladie qui affecte les tissus conjonctifs et qui cause de gros problèmes de santé. Elle peut également causer des incapacités périodiques ou permanentes et du stress psychologique. Le diagnostic de syndrome d'Ehlers-Danlos peut survenir à n'importe quel âge, toutefois les effets psychosociaux du diagnostic de cette maladie peuvent être particulièrement difficiles quand les symptômes sont présents parmi les étudiants universitaires. Cette étude qualitative a examiné les effets psychosociaux de cette maladie sur la qualité de vie des étudiants universitaires de l'Ontario (*n*=11). Après une brève enquête d'admissibilité en ligne, des entrevues individuelles semi-structurées ont été menées. Les données de l'analyse thématique des entrevues ont révélé que les facteurs émotionnels tels que l'anxiété et la dépression, les attitudes des professeurs et des autres étudiants, ainsi que les questions de jugement et de stigmatisation et les sentiments de frustration, affectent la qualité de vie des étudiants universitaires qui sont atteints du syndrome d'Ehler-Danlos.

Keywords

chronic illness, Ehlers-Danlos Syndrome, quality of life, postsecondary education, Ontario; maladie chronique, , syndrome d'Ehler-Danlos qualité de vie, enseignement post-secondaire, Ontario

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The experience of postsecondary education is regarded by some to be the best time of a person's life. It is a time to study areas of special interest, grow as an individual, and enjoy the unique extracurricular and social activities of college and university life. While this representation of post-secondary education applies to many students, for those who live with largely invisible chronic illness, frequently, this is not the case. Ehlers-Danlos Syndrome (EDS) is one such illness, and those who live with it and attend postsecondary education are likely to experience a quality of life that is markedly different from that of their peers.

In the qualitative study recounted here, the researchers explored the perspectives of Ontario postsecondary students who live with EDS. The study garnered insights into the quality of life of these students and highlights the need for dedicated supports for students who live with chronic illness, instructor training, and peer support.

Literature Review

Ehlers-Danlos Syndrome

EDS is an incurable connective tissue disorder that negatively impacts collagen production. Collagen affects approximately 80% of all human systems including skin, organs, joints, and the nervous and circulatory systems (Ehlers-Danlos National Foundation (EDNF), 2009). EDS manifests in multiple ways: the most common types are classical, hypermobility, and vascular. Hypermobility, fragile skin, and easy bruising are characteristics of all types of EDS while vascular EDS can result in aneurysm, dissection, and spontaneous organ rupture, and often precludes an average lifespan. As a result, EDS generates diverse negative health events including periodic or permanent disability (Boston Children's Hospital, 2014; U.S. National Library of Medicine, 2014).

EDS has a prevalence of 1 in 5,000 (U.S. National Library of Medicine, 2014). As of 2014, Ontario's total population was known to be 13.7 million people (Statistics Canada, 2014), so there were approximately 2,700 people living with EDS in Ontario in 2014. Many people with EDS become symptomatic in their early twenties (Adib et al., 2005; EDNF, 2009), right around the time when they are considering or are enrolled in postsecondary education. Daily dislocations and subluxations 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). Because many students with this disorder are unable to participate normally in physical activities including regular classroom and social activities, their physical, social, and emotional development can be negatively affected (Adib et al., 2005).

EDS is a relatively invisible chronic illness. Disabling fatigue, pain, and stress generated by the incontinence of symptoms are invisible attributes of EDS that result in a poor health-related quality of life (Fikree et al., 2016; Krahe et al., 2017; Pacey et al., 2015). Because outward physical signs of limitations in ability are not always present, professors, peers, friends, and significant others have no basis for altering their expectations regarding the functional capacity of those with EDS (Falvo, 2014). As individuals with EDS cannot consistently meet expectations set by themselves and by others, they may experience feelings of uncertainty, incapability, and inadequacy (Falvo, 2014).

EDS, Wellbeing, and Quality of Life

Although many young people cope well with the emotional aspects of having a chronic illness, some are likely to have lower levels of emotional wellbeing than their healthy peers (Herts et al., 2014; Yeo & Sawyer, 2005). Emotional wellbeing becomes further problematic when, in the context of attending school, the limitations of this illness coincide with the time needed to prepare assignments, meet deadlines, and take tests and exams (University of Manitoba, 2014). These frustrations can trigger negative thoughts and self-perceptions. Chronic illness is also 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, or being unable, incapable, or not good enough frequently result from the physical symptoms. These feelings are often exhausting and have significant and longstanding emotional effects (Falvo, 2014).

The invisibility of EDS may also lead to stigmatization derived from a lack of understanding of the effects of EDS (Berglund et al., 1999). Stigma can overshadow the many positive characteristics of individuals with EDS and affect their willingness to accept or divulge information about their health condition (Falvo, 2014). Due to scarring and the use of adaptive equipment by the person with EDS, perceptions of body image may also add to stigmatization (Berglund et al., 1999). These differences in appearance and health can elicit negative comments and perceptions when people with EDS use the accommodations to which they are entitled such as an accessible parking permit. Stigmatization is further accentuated when healthy individuals view those with chronic illnesses like EDS as conditions rather than as individuals (Smart, 2012). Stigmatization may affect the ability of an individual with EDS to engage in the activities of daily living (e.g., shopping, making dinner) and social activities (e.g., attending school or a party). If individuals are unable to participate in such activities, their self-esteem and quality of life may be negatively affected.

Quality of life (QoL) is defined as “the product of the interaction between an individual’s personality and the continuous episodes of life events. The life events occur within a multi-dimensional set of domains, namely, liberty, knowledge, economics, health, safety, social relationships, spirituality, environment, and recreation” (Hajiran, 2006, p. 33). While QoL varies from person to person, individuals with EDS may define it based on their medical conditions. For example, students with EDS may define QoL not merely on whether they will attend a postsecondary institution, but on whether they will be physically capable of attending on-campus classes or participating in the extracurricular activities that are integral to their idea of a full postsecondary experience. For other students with EDS, a meaningful QoL could mean effectively balancing medical appointments with online classes or part-time study.

Theoretical Considerations

Critical theory conceptually supports QoL. QoL, as it pertains to the psychosocial and academic experiences of postsecondary students with EDS, critically challenges many of the institutional structures within contemporary higher education. According to Maddock (1999), critical theory represents a “critical, progressive orientation in education which aims at least at the amelioration of social conditions” (p. 43). For critical theorists, the development of a critical lens is both the goal of education and a tool that must be used by educational institutions to reflect on their perpetuation of power disparities and social injustices (McKernan, 2013).

Critical theory is of particular significance to our study since it is rooted in the needs and experiences of less advantaged populations (Rexhepi & Torres, 2011). Even with critical theory's focus on less advantaged populations, there is little discussion in the critical educational theory literature pertaining to students with chronic illnesses or disabilities. As Erevelles (2009) asserts:

> The fact that critical theorists of education have not recognized disabled people as critical agents does not in any way imply that disabled people have passively waited around for this recognition. Conscious of their experiences of social, economic, and political subjugation, disabled scholars and activists have struggled to claim space, voice, and power to disrupt the normative ideals of the social world that has historically ignored them. (p. 71)

In this study, it was anticipated that many of the participants—namely, postsecondary students living with EDS—would share similar struggles with "claiming space" during their school experiences (Erevelles, 2009). Even though critical theory may not encompass all issues for postsecondary students with EDS in Ontario, it is appropriate for this study, especially when it is combined with a quality of life conceptual framework.

The purpose of this study was to explore how EDS affects the quality of life of Ontario postsecondary students living with EDS. Postsecondary studies can be stressful, especially for students negotiating chronic illness and its implications on QoL (Jung, 2002). Understanding the student perspective of what it is like to participate in a postsecondary program will provide greater insight into the QoL of postsecondary students with EDS and yield important insights for educators.

The following three overarching questions guided this exploratory study:

1. What are the psychosocial experiences of Ontario postsecondary students who live with EDS?
2. What are the academic experiences of Ontario postsecondary students who live with EDS?
3. How do the psychosocial and academic experiences of Ontario postsecondary students who live with EDS affect their quality of life?

Method

Research Design

An exploratory qualitative case study approach comprised the research design. Qualitative approaches are particularly useful when examining issues of health given that they reflect individuals' and groups' subjective experiences of health, disease, and, in this case, postsecondary education when a chronic health challenge is involved (Fossey et al., 2002). Qualitative research also lends itself to the development of new knowledge in poorly understood or complex health areas such as EDS.

In this study, health was conceptualized as a determinant of educational attainment while the case study methodology enabled the researchers "to explore individuals or organizations, simple through complex interventions, relationships, communities, or programs" (Yin, 2003) and supported "the deconstruction and the subsequent reconstruction of various phenomena" (Baxter

& Jack, 2008). This approach also supported understanding of the psychosocial and academic impacts of EDS on postsecondary students since a variety of lens and data sources were used.

Participants

Following ethical approval, participants were purposively recruited through online support groups for persons living with EDS in Ontario. Recruitment involved posting a description of the study, an invitation to participate in the study, and a link to an eligibility questionnaire. The purpose of the eligibility questionnaire was two-fold: (a) to ensure that potential participants met all eligibility criteria, and (b) to obtain relevant demographic information (Table 1). To be eligible for the study, participants were required to be enrolled either full-time or part-time in postsecondary studies at an Ontario college or university and have a diagnosis of EDS. Respondents who did not meet these criteria were excluded from the study. Age was not an inclusion criterion because it was expected that the students would vary in age owing to their health, family, and life circumstances. Sixteen individuals responded to the eligibility questionnaire; eleven responded to the request for an interview. Table 1 provides an overview of the 11 participants, the nature of their postsecondary institutions, and how they studied.

Table 1
Overview of Participants

Gender	Current Age (years)	College or University	Enrolment Status	Mode of Delivery
Female	36-40	University	Part time	Mixed or blended delivery
Female	41-45	University	Part time	Mixed or blended delivery
Female	18-25	University	Other	In person (face to face)
Female	31-35	University	Full time	Online
Female	18-25	College	Full time	Mixed or blended delivery
Female	26-30	University	Part time	Mixed or blended delivery
Male	31-35	University	Full time	In person (face to face)
Female	18-25	University	Part time	Mixed or blended delivery
Female	18-25	College	Full time	In person (face to face)
Female	18-25	University	Full time	In person (face to face)
Female	26-30	University	Part time	In person (face to face)

Data Collection

The data for this study were collected using open-ended semi-structured interviews conducted via web conferencing (Britten, 1995). The eight interview questions were developed prior to the interviews and were presented in the same order to all participants (see the Appendix). The interview questions were developed collaboratively by the members of the research team and were created based on the chronic illness and EDS literature. It should be noted that although a standardized interview format was used, all interview questions were presented in an open-ended context which enabled the participants to respond in whatever manner they felt was most appropriate. Written informed consent was obtained by emailing all participants an information and consent form that the participants signed, scanned, and returned via email prior to participating in an interview.

Prior to beginning the interview, each participant was provided with a verbal description of the purpose of the study and the interview process as well as an opportunity to withdraw. The principal investigator conducted interviews with the eligible participants via web conferencing (i.e., Skype). Each interview was recorded for later transcription. The interviews ranged in length from 15 to 60 minutes.

Data Analysis

Each participant was assigned a pseudonym and a colour code to distiguish his or her unique interview responses on a master form. All interview recordings were then transcribed verbatim by the principal investigator. Close attention was paid to capturing important elements such as the participant’s rate of speech and expressed emotion. The principal investigator organized the transcripts by question on a master interview guide to simplify coding and thematic analysis (Creswell, 2003; Miles et al., 2014) and conducted a combination of descriptive and process coding during first cycle coding and preliminary analysis (Creswell, 2003; Saldaña, 2009). A second cycle of coding and analysis was used to identify emergent themes for each participant (Miles et al., 2014) which were then compared across participants (Fossey et al., 2002). This process of analysis was used until no new categories or themes were identified. The research team used peer debriefing during the analysis process (Creswell, 2003). Specifically, the prinicpal investigator communicated regularly with the other two team members about various aspects of the analysis, including new categories and subcategories that were emerging and any difficulties that presented. When differences of opinion were encountered, diaglogue was used to arrive at a consensus by the members of the research team.

Results

Four primary themes emerged including the following: (a) illness as social detriment, (b) an emotional rollercoaster, (c) academic roadblocks, and (d) critical supports. Each of these themes and related sub-themes as well as select examples and quotations are provided. All names have been changed to protect the participants’ identities.

Theme 1: Illness as Social Detriment

Social relationships refer to the students' interactions with friends, family, peers, and others in society both in the academic sphere and in non-academic social spheres. Based on the participant interviews, these interactions were detrimentally affected by their illness. The theme of illness as social detriment includes four sub-themes: invisibility, unpredictability, reluctance to form relationships, and stigmatization.

Invisibility

All participants indicated that lack of awareness of both EDS and invisible illness by their peers, professors, and staff in their academic institutions affected them socially. As an example, Hilary remarked that she had difficulty conveying the impacts of EDS to peers and others at her school. She explained that "it's not as easy as saying, like, as easy as saying I have diabetes and everyone knows what that is. You have to explain exactly what EDS is and how it affects you." Other participants, including Alexa, opted not to disclose their EDS to their school friends to avoid judgments.

Since EDS is an invisible illness, students can present as able-bodied unless they wear obvious adaptive and supportive equipment or use mobility devices. Jane noted her frustration with invisibility and exclusion due to her EDS this way:

> When people did ask you to go out to the campus pub or something, if you're having a bad day and can't go or something they get frustrated with you because you can't go out and they think that you're just kind of avoiding them for the sake of avoiding them 'cause if you look normal, you must be normal type of deal.

Unpredictability

Several participants emphasized the unpredictability of EDS and the implications of this unpredictability on their social experiences at school. Ten out of eleven participants indicated that it was emotionally and socially difficult to commit to social and academic activities because they would often have to back out due to their EDS. Five participants indicated that they were worried about letting people down. Group work was a notable challenge, as Amber explained:

> I really, really do not like the idea of doing group projects just because, um, I don't like the thought of someone counting on me and then me not being able to do it because I'm sick or something. Um, and same with my professors.

Overall, the participants indicated that the unpredictability of EDS resulted in stress and anxiety about breaking plans at the last minute, working at a slower place, and inability to fully commit to social events and course projects. Four of the participants indicated that choosing not to make plans was a viable protection strategy against anxiety, stress, and judgement by others.

Reluctance to Form Relationships

Reluctance to form relationships was the most frequently occurring socially-related sub-theme. Nine participants referred to this idea a total of 21 times. One participant had vascular EDS, the most serious form of EDS. Steven described his reluctance to form relationships as a result of his diagnosis this way:

> Well, Type IV [vascular EDS]…we feel very differently about this disease and it literally puts us on a stopwatch and, uh, more than likely most of us have, you know, ten years left of life and I think that changes your perspective…. It's not going to affect you very socially if you're like "aww, I've got this problem" but I don't want to make a lifelong friend that I'm going to lose in a quick time. That's a whole different story.

Not all participants recounted highly negative inter-personal experiences. For some, finding the right peer group provided a good distraction from the issues and pain associated with EDS. Lindsay commented how "this semester I have found some incredible people who I love hanging out with and going out with. They make my pain and fatigue disappear and allow me to feel normal again." At the same time, the participants reported how the mindsets and actions of others could damage self-esteem and motivation. Hilary summarized the difficulty inherent in being a postsecondary student with a chronic illness/disability in the following passage:

> Uh, it's actually challenging because you don't want to be looked at as different. You don't want to, like saying you have a disability is like hard if you think about it. There's such stigma and there's such negative connotations that go with a disabled person that people see just from lack of education or just lack of people having the attractions [sic] of people with a disability. That creates like a stigma around myself, which sometimes you don't feel like explaining.

The students indicated that they were not only wary of how peers perceived them. They were equally worried about judgments and stigmatization by their professors. Freya explained her inner dialogue regarding approaching professors to discuss accommodations in the following passage:

> I don't go into it [the conversations] enthusiastic necessarily because I'm like I've got to talk to the prof and now every time they look at me they'll be like, oh, there's that person. At least that's how I feel. I think that they're looking at me like that, you know? Like I'm looking for a hand out or something. So it's definitely changed the experience, I think.

The participants also reported that requesting academic accommodations included a social component. Many participants worried about how they were perceived by their peers when they used the accommodations to which they were entitled. Many, like Hilary, thought that their peers might perceive such accommodations an unfair advantage over the general population. Hilary explained how she has had to leave class to write exams and tests because of her EDS and how her peers questioned her departures and accommodations:

> So, students always assume different reasons why they think that you get extra things and why it's easier for you but in realistic [sic], it's not done so that I have an easier time, it's so that I'm on a normal playing field, which I don't think people understand.

All but one participant felt that lack of understanding of EDS negatively influenced their social relationships and experiences which then affected their emotional stability and academic success.

Stigmatization

A recurrent sub-theme raised by the study participants was the social impact of feeling judged or stigmatized by others. Hilary summarized this difficulty in the following statement:

> Uh, it's actually challenging because you don't want to be looked at as different. You don't want to, like saying you have a disability is like hard if you think about it. There's such stigma and there's such negative connotations that go with a disabled person that people see just from lack of education or just lack of people having the attractions [sic] of people with a disability. That creates like a stigma around myself, which sometimes you don't feel like explaining.

Other participants identified how they were wary of how others perceived them. Jane talked about her interactions with the consultants at her school's disability services office. She explained that her original experiences were positive and attributed this to the fact that they had firsthand experiences with disabilities. Once she switched consultants, the experience changed. Jane explained how she "found that the last [consultant] was a male and he didn't have a disability and he kind of interpreted what I was saying as I wanted extra help because I was lazy more so than actually needing the help."

Theme 2: An Emotional Rollercoaster

The idea of an emotional rollercoaster headed in a downward direction was reported by the participants and included experiences of anxiety and depression, self-doubt, and a sense of running out of time. Anxiety and depression were raised by five of the eleven participants. The participants identified several causes of anxiety and depression including managing difficult social situations and being away from home, support systems, and medical teams. Marie described her anxiety this way:

> I noticed I developed a lot more anxiety when I was doing postsecondary education because there's not as much support, my parents weren't there and my friends and all that kind of stuff. And just feeling inadequate because I wasn't making it to class and feeling different and not really understanding why.

Freya explained her constant battle with self-doubt and her studies:

> I know the average student doesn't care, oh I slept in today, I missed class, whatever. For me, if I miss class, it's like, can I even do this? I start questioning the whole thing again, you know, like if I missed today, what about next week?

Two participants with complex diagnoses indicated that running out of time was a factor with significant emotional consequences. Steven, diagnosed with vascular EDS, explained his relationship with time this way:

> I’m Type IV [Vascular EDS], um, I’ve already survived a few almost death type of things, um, and my life expectancy isn’t more than five or six years so I’ve considered my post-graduate work to be a kind of semi-retirement and, uh, the people that I work with kind of understand that, um, so it changes into the fact that they kind of sense that I have urgency to get things done and not just as a normal student but because there is an actual time clock. That’s probably the biggest issue. Time.

Freya, facing a possible Multiple Sclerosis diagnosis in addition to EDS, expressed similar sentiments about time:

> Time is a barrier for sure because, for me, probably, well, I probably also have MS [Multiple Sclerosis], I’ve not been diagnosed but MS runs in my family and my EDS kind of manifests a lot like MS, like the relapse remitting style so I can go for four or five years out in the world… no problem and then I hit a wall that’s so incredibly horrible…. I have this internal pressure of, I have to get things done in chunks, while I’m good.

Theme 3: Academic Roadblocks

A strong fear of the unknown was identified as an underlying factor affecting the participants’ experiences of the academic realities of going to school. Jane explained how a fear of the unknown affected her school experience:

> You’re hesitant to register because if you pay all the money, if you commit to something, I don’t like backing out. So if halfway through you’ve already paid all your money, you’ve already done that much work to all of a sudden have to pull out and do nothing and have to lose all that money, it’s, it can get aggravating because you don’t want to work that hard to get nothing in the end of it.

Jane further explained that she needs to take the chance that she will be able to complete the semester every time she registers. Amber expressed a similar sentiment about the unknown:

> Um, I have always liked planning things and knowing exactly how things are going to happen and with EDS, all that just went out the window. My plan to, you know, finish a university degree in four years is now going on eight so, um, yeah, it just sucks.

Participants repeatedly identified flexibility as an important adaptive coping strategy. Nine participants described considerable frustration with their educational experiences. Frustrating events ranged from interpersonal misunderstandings to administrative mix-ups to unforeseen medical events that interfered with attending classes. Genevieve outlined her frustration with her institution regarding a mishap involving an accommodation for a distance education exam:

> I think, I was really disappointed about how they handled the whole thing [losing an exam]. I think what's hard is because it was such a, because it happened twice, the first time you think it could just be an honest mistake and you hope that people are going to take whatever steps to make sure this kind of thing doesn't happen…. I think it's because, um, I happen to be a student who didn't fit the mold in terms of how they normally administer those exams. I think that's why there was this major error in this program.

The participants often spoke about the uncertainty associated with EDS. Freya explained that "with EDS, we're different and…on some days it can be great and then the next day, it's like, I can't even sit up. I can't get out of bed, I absolutely cannot leave my house." Steven corroborated Freya's statement in the following way:

> Some days are really bad and some days I can't get out of bed and that's not because I'm carrying the weight of depression or anything, like I physically cannot move so that's going to affect your school. There's just no other way around it.

As noted earlier, the participants agreed that the uncertainty of EDS symptoms affects their ability to participate successfully in group assignments. Participants worried that peers would perceive them as skipping class because of their frequent absences from school.

Two participants indicated they had been publicly embarrassed by their professors which, in turn, affected them emotionally. Marie described how a professor "called her out" in front of the entire class based on a medical need:

> My professor said in the opening speech that you weren't allowed to go to the washroom during the class, which it's only an hour and a half but that was the end of the world for me… and for half an hour I was almost crying and I had a urinary tract infection because of tethered cord and I needed to go to the bathroom…. The professor was like, if you leave don't ever come back. That just terrified me because I was really young and no one ever told me what was wrong with me.

Marie explained that incidents like this increased her reluctance to return to class for fear of a repeat of the embarrassing incident. Alexa described a private conflict with a professor that also affected her emotionally:

> There is one professor and I tried to talk to her about it [EDS] and she pretty much just said it sucks to be me and that it's not her problem pretty much and that there's no reason for her to accommodate me… I was very upset, like I sat in the hall and cried for 15 minutes.

Like Marie, Alexa was worried about returning to her class after the above incident for fear of similar future occurrences. Freya expressed that professors do not always realize how difficult it can be to disclose an EDS diagnosis and ask for help. She stated, "I find it embarrassing, like really embarrassing. I'm not someone who typically likes to ask for help and I'm, as I'm sure you've noticed with Ehlers-Danlos, you have to ask for help a lot sometimes."

Theme 4: Essential Supports

Supports emerged as a distinct theme in the participants' remarks. Many of the participants indicated that various support systems had helped them to overcome their anxieties and achieve emotional stability. Table 2 presents the supports that, according to the students, helped the students address their limitations and overcome the obstacles of their educational lives. Often, these obstacles existed on a daily basis.

For Jane, a daily obstacle was the amount of pressure that she placed on herself to succeed:

> I can't go into it putting half of my effort in so I do find that I go in getting not necessarily depressed in the sense that I need medication or anything but I do know that I put a lot on my own shoulders in order to try completing it so it does make me more stressed out and more agitated, I guess.

Table 2

Participant-described Supports and Relevant Domains

Support (as described by participants)	Domain
Friends	Psychosocial
Online Support Groups	Psychosocial, Medical, Academic
Face-to-face support groups	Psychosocial, Medical
Medical Teams	Medical
Psychologists	Psychosocial, Medical
Medication	Medical
Family/Spouses	Psychosocial, Medical, Academic
Motivational Quotes	Psychosocial
Internal/Personal Motivation	Psychosocial, Academic
Disability services/accommodation	Medical, Academic
Advocates	Medical, Academic

Steven spoke highly of his support system as a means of helping him to overcome academic and psychosocial obstacles. He explained:

> Um, and emotionally it's a rollercoaster, it's, Grad School is really hard on your emotions and when you add in this extra layer of complexity, um, I'm glad I have a support system because there's no other, there just would be no other way.

When asked to suggest what might be helpful to know as a means of supporting future postsecondary students with EDS, nearly every participant emphasized the importance of finding a support group or network to help the person through the difficult times.

Most of the participants indicated the professor is an important factor in academic success. Only one participant who was a distance education student expressed indifference towards faculty support as a means of facilitating academic achievement. Many of the participants gave examples of how their academic success improved when they felt valued and supported by professors. Jane explained this idea:

> If they [professors] understand what I'm going through and acknowledge it and try to help me out, I strive in their class because I feel comfortable with them, I feel comfortable asking them for other extensions or to meet with me one-on-one to go over lectures that I missed, but if I'm not comfortable with them, if I feel like they overlook me in the sense that I'm just skipping classes, then I do get frustrated with them and it does impact my marks.

According to the participants, students who feel supported by professors seem to be more likely to seek the accommodations that will help them succeed. Conversely, negative experiences with professors can deter students from seeking further supports. Alexa recounted an unsupportive experience when she decided to disclose her EDS to her professor for the first time:

> I was opening up to her and explaining to her, to her how I felt and the issues I had, um, and reasons for being five minutes late for class which generally is not a big deal but for her it was and she just kicked me out of class and said "you just lost five per cent."

While students with EDS may choose not to participate in a social engagement due to health reasons, their peers might not understand the rationale for choosing to stay home or for non-participation. At the same time, the need for supportive and understanding friends is essential. Marie outlined a scenario in which her friends helped her to enjoy an evening out despite her health issues:

> So, I was vomiting all night and had this huge party to go to and they all sat with me while I was vomiting and finally at 10:00 I stopped vomiting and we shoved all these plastic bags in our purses and we went and I got sick in the cab and I got sick when we got there and as soon as I got home but all I wanted to do was just be a part of it that night and that was a really good story for me.

Marie explained that it is sometimes more important for her to feel part of a social situation than to worry about her health challenges. In Marie's case, her friends served as her support system and helped to allay many of her anxieties about transitioning to and enjoying the social aspects of postsecondary education.

Discussion

In this study, the participants identified how engagement in meaningful social interactions and positive emotional exchanges with peers and instructors were important to their postsecondary experiences. Stated another way, as students living with EDS, their QoL was affected by the nature of their interactions and exchanges. Unfortunately, many of these experiences were negative in character.

Additionally, the participants indicated that it was difficult to establish or maintain the friendships that typically develop during the postsecondary years because of their chronic illness and the assumptions held by peers. They also noted increased feelings of stress and anxiety related to their EDS and attributed these emotions to social situations and the realities of managing a complex medical condition in a postsecondary setting.

EDS likewise affected the participants academically. Nine out of eleven participants in this study noted feelings of frustration regarding their studies. This frustration appears to stem, as

Genevieve explained, “from not fitting the mold” of other students who do not have chronic illnesses. Course-based activities involving group work were especially stressful for participants.

These findings align with the literature that emphasizes that students with chronic illnesses struggle with a lack of faculty and peer awareness, overcoming negative peer attitudes, and difficulty attending classes (Asprey & Nash, 2006; Hutcheon & Wolbring, 2012; Jackson, 2013; Jung, 2003). How these challenges are mitigated impacts the student’s QoL and overall educational experience.

The findings further suggest that participants’ psychosocial experiences were often externally motivated, meaning that the students tended to focus on the expectations and perceptions of others. The prevalence of the participants’ concern regarding the perceptions of their peers is evidence of this finding. Having difficulty maintaining meaningful relationships, feeling pressure to educate peers and professors about EDS on a constant basis, and having to manage unpredictable health situations in the school setting contributed to the participants’ psychosocial experiences. Managing health conditions such as EDS can result in stress and psychological turmoil, as the person is constantly required to adjust to changing lifestyles and abilities (Falvo, 2014). In all, EDS appears to have a substantial impact on the psychosocial experiences of postsecondary students who live with this illness. These negative psychosocial experiences, in turn, detract from social relationships, sense of identity, and overall QoL.

The literature on chronic illness in education demonstrates that the attitudes of peers and educators can dramatically affect the academic success of students with chronic illnesses (Jackson, 2013; Rao, 2004; Sachs & Schreuer, 2011). In this study, participants explained that, when peers and professors acknowledged their EDS, they felt comfortable advocating for themselves and seeking accommodations. In contrast, when some of the participants felt judged or stigmatized, they were not inclined to seek supports or engage in peer relationships. It appears that students with EDS are more likely to enjoy positive psychosocial and academic experiences when they feel that their medical, social, and academic concerns are legitimized. Conversely, they are less likely to thrive in their studies if they are subjected to judgment, stigmatization, and frustration, all of which ultimately detract from QoL.

Few students in this study reported programs or services on campus which support students with chronic illnesses. This finding aligns with the literature which indicates that programs for students with static disabilities exist while programs serving students with highly variable chronic illnesses such as EDS do not (Côte & Levine, 2002; Herts et al., 2014; Jackson, 2013; Stephens & Norris-Baker, 1984). With increased access to chronic illness-related supports and services including mentorship and peer support, postsecondary students with EDS may identify as engaged members of the campus community, a circumstance, which ultimately enhances QoL (Korbel et al., 2011).

Strengths and Limitations

Although this study is small in scope, the findings contribute to future work on the issue of learning in the postsecondary environment when students live with chronic illness. Based on a careful search of the literature, this study appears to be unique in its examination of the social, emotional, and educational aspects of EDS among postsecondary students. Finally, the implications of this study for postsecondary education may be transferable to contexts involving other chronic illnesses and, thus, hold benefit for a wider audience than the Ontario EDS population.

The study is not without limitations. First, it was restricted to postsecondary students with EDS in Ontario. A larger population that would garner the perspectives of students from other provinces and territories should be considered in future studies. Further, the study focused solely on students' perspectives. A study exploring professor and institutional perspectives on instructing and supporting postsecondary students who have disclosed that they have a chronic illness would be valuable. While the participants disclosed their status as full- or part-time students and how they learned such as in face-to-face classrooms, blended learning contexts, or fully online settings, these areas were not investigated in the interviews. Also, the possible differences between the experiences of students enrolled in colleges versus universities were not examined and represent other areas for study. Finally, this study recruited participants through online support groups. It is documented in the literature that females access support groups more often than males, which may account for only one male participant in this study (Barker 2008; Krizek et al., 1999).

Conclusion

This study focused on chronic illness in the form of EDS and how students who live with EDS experienced their postsecondary education. Participants indicated that EDS affected them emotionally, socially, and academically, and that their health and academic experiences contributed to their social and emotional wellbeing and overall quality of life. Due to the nature of this study and its contribution to a considerable gap in the literature regarding EDS and the postsecondary student population, the study provides a useful starting point for future studies on chronic illness in postsecondary education. It also offers insight into the need for greater education of professors and staff in disability centres in relation to their work with students. It further identifies the need for education within the student population itself. While this need comes with certain complexities, professors do have a role to play in ensuring that all students are treated compassionately and respectfully. Such modelling will, in likelihood, lead to learning about appropriate interactions and treatment of others on the part of the broader student community.

Important strides have been made in legislating inclusive accommodation policies for persons with disabilities in postsecondary education and in other contexts involving the activities of daily life. Regrettably, as evidenced in the literature and in this study, comparable progress has not been made for the case of people with chronic or invisible illnesses such as EDS. Lack of awareness and understanding of the similarities and differences between disabilities and chronic illnesses may contribute to this situation. Continued study of the psychosocial and academic impacts of chronic illnesses such as EDS and the accommodations required to mitigate barriers to achieving a postsecondary education as well as implementation of recommendations derived from such studies are critical to shifting the student experience to a more positive context than presently exists.

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Appendix

Semi-Structured Interview Guide

1) How do you feel your EDS influences your interpersonal (e.g., peer, teacher) interactions when you are at school?

2) Describe any accommodations or special allowances you receive as a result of your EDS. Can you share your experiences with your university disability services, if applicable?

3) How do your professors accommodate your chronic illness? In what ways do their efforts impact you socially, emotionally, and/or academically?

4) Can you share some examples of how EDS may affect your ability to enjoy a postsecondary student experience including your friendships, social life, performance in your courses?

5) What barriers (if any) to meeting your academic goals have you experienced because of your EDS?

6) Can you tell me how managing your EDS during your postsecondary education has affected you emotionally? What supports have you found to be helpful? What other supports would you recommend?

7) What suggestions do you have so that other and/or future postsecondary students with EDS have the best possible educational experience?

8) Is there anything else that we haven’t already talked about that you’d like to add?