

# College Students and Multiple Sclerosis: Navigating the College Experience

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## Abstract

The number of children and adolescents diagnosed with multiple sclerosis (MS) is on the rise, increasing the importance of understanding how to support college students living with the disease. Based on the results of two studies, this paper aims to identify challenges facing college students with MS, as well as possible resources and strategies for helping college students with MS have a successful college experience. The first study explored parents' concerns about their child managing college and MS. The second study examined perspectives of college students with MS on challenges, coping strategies, and supports while attending college and living with a chronic illness. Findings from both studies are used to make recommendations for assisting college students with MS as they strive to meet their educational goals.

*Keywords: multiple sclerosis, college students, college accommodations, student disability services*

College students today face a wide variety of challenges and opportunities as they navigate the college experience. Living with a chronic illness or disability can create additional challenges to reaching one's educational goals. Multiple sclerosis (MS) is an example of a chronic illness that may make college life more difficult. MS is the most common disease of the central nervous system in young adults (National Multiple Sclerosis Society [NMSS], 2015) and there are a growing number of adolescents being diagnosed with this disease (Thannhauser, 2014). As the number of young adults with MS increases, so does the need for understanding how to best support college students with MS.

MS was once believed to be a condition that primarily affected middle-aged females. However, increasing diagnosis of MS in children and adolescents led to the formation of the International Pediatric Multiple Sclerosis Study Group (IPMSSG) in 2002 (IPMSSG, 2018). In 2006, six pediatric MS centers of excellence were opened in the United States to address the growing population of children and adolescents with MS. Currently there are 13 pediatric centers of excellence throughout the U.S. (NMSS, 2015). Today, we know that MS has the potential to impact individuals primarily between 15 and 60 years of age, with one male being diagnosed per every two females (Mayo Clinic, 2017). Rates of MS diagnosis across all age groups are

on the rise due to increased access to magnetic resonance imaging (MRI), as well as better understanding of the disease (Benito-León, 2011).

According to the National Institutes of Health (2015), approximately 250,000 to 350,000 individuals in the United States are currently living with MS, with approximately 200 new cases diagnosed each week. Organizations such as the National Multiple Sclerosis Society (2015) report an increase in the number of individuals living with a diagnosis of MS have increased from 123,000 in 1980 to 400,000 in 2012. According to the Multiple Sclerosis International Federation (2016), approximately 2.3 million individuals were diagnosed with MS worldwide in 2013. This is an increase of 9.8% in comparison to the number of cases in 2008. Approximately 5% of those diagnosed internationally with MS are children, with estimates ranging from 8,000 to 10,000 children under 18 years old currently living with MS in the United States (NMSS, 2015). As with adult MS, rates of diagnosis of pediatric MS are increasing (Chitnis et al., 2011). While estimates of the number of college students with MS have not yet been reported, the increasing rates of pediatric and young adult diagnosis of MS suggest it is likely the number of college students with MS is on the rise as well. Therefore, it is becoming more important to understand the specific needs of college students with MS.

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Multiple sclerosis (MS) is an immune-mediated disease that causes an individual's immune system to attack his or her own central nervous system. Myelin, the protective coating that covers each nerve fiber, is gradually damaged, resulting in scar tissue. As the myelin is compromised, the nerve impulses that are attempting to travel from the brain, spinal cord, and optic nerves are derailed or lost, affecting individuals in a wide variety of ways (NMSS, 2015). Often referred to as a "snowflake" disorder, MS impacts each person differently, depending on the severity and location of lesions on their brain (Banwell et al., 2016). Estimated prevalence rates for common symptoms of MS include 75-81% of individuals experience fatigue (Braley & Chervin, 2010; Kister, 2013), 70% loss of balance/dizziness (Marrie, Cutter, & Tyry, 2012), 65% numbness (Ford et al., 2012), 50% depression (Siegert & Abernethy, 2005), 50% mobility issues (Goldenberg, 2012), 50% cognitive dysfunction (National Institute of Neurological Disorders and Stroke, 2018), and 45% vision problems (Nicolaie, van Houwelingen, & Putter, 2015).

An additional challenge of MS is the unpredictable nature of this disease. For most impacted by MS, problems may appear and disappear, as individuals experience relapses or flares (Rumrill & Roessler, 2015). The continual management of these various symptoms of MS contributes to the complexity of juggling health issues while simultaneously navigating typical college responsibilities and opportunities.

A common issue facing college students with disabilities or health concerns centers on the differences between managing their needs at the high school level as compared to the college setting (Daly-Cano, Vaccaro, & Newman, 2015). For example, entering college students will need to identify their health status, register with disability services, self-monitor their health status, and discuss accommodations for optimal success in the college setting (Helm et al., 2009). A parent or guardian that has served as their advocate in the educational setting has most likely accompanied the majority of youth impacted by MS throughout their K-12 career. As students with MS enter college, the responsibility to advocate for resources and accommodations becomes their own (Daly-Cano et al., 2015). In addition, college students are taking over responsibility for more of the medical management of their MS. This process may be particularly challenging for students with MS, as they may be pioneers at their community college or university, paving the way for other students with MS.

College students with disabilities face the challenge of not only managing their disability; they also have the responsibilities related to handling all the in-

formation regarding meeting their individual needs. One issue centers on deciding if they should disclose their disability to others. More specifically, students must decide whom they will tell, how much to share, and when to disclose this information (Trammell, 2009). Kranke, Jackson, Taylor, Anderson-Fye, and Floersch (2013) found that students with non-apparent or hidden disabilities consider three different issues when making the decision to share their disability and request accommodations in the college setting. These factors include the stigma often related to disabilities, the stability of their specific disability, and the worry that their condition will limit skills to achieve academic success. Some college students may decline college accommodations because they are not willing to disclose their disability status due to concerns about what may happen as a result. As Trammell (2009) stated, "Disclosure should lead to accommodation, but it can lead to discrimination, as well." (p. 23). Sniatecki, Perry, and Snell (2015) studied faculty attitudes towards students with disabilities, as well as their level of knowledge and awareness of student disability policies and procedures. Students with hidden disabilities such as mental health issues or learning disabilities were viewed more negatively by faculty members than students with physical disabilities. Additionally, some faculty members reported the belief that offering accommodations may provide an unfair advantage to some college students and compromise academic integrity.

While some challenges facing college students with MS may be visible such as mobility issues, other symptoms may not be outwardly visible to others such as fatigue, depression, vision problems, dizziness, or numbness. Mullins and Preyde (2013) interviewed college students with hidden disabilities. They found that the academic needs of the students with hidden disabilities were met through classroom accommodations, including note takers and text-to-speech capabilities to assist with reading assignments. However, students described several organizational and social obstacles they faced in the college setting, including faculty members' and other students' limited and inaccurate knowledge or experience regarding hidden disabilities. In addition, due to the nature of their disability as not necessarily noticeable to others, the validity of their disability diagnosis was often questioned by others, including doubt that particular supports were even necessary for the college student to be successful.

A common challenge for the typical college student centers on getting adequate sleep (Gaultney, 2010). Some researchers have found that sleep deprivation is a problem facing the majority of college

students, as almost 75% of college students reported problems of sleep disturbances and challenges falling asleep (Buboltz, Brown, & Soper, 2001). Others have stated over 60% have been categorized as poor-quality sleepers (Lund, Reider, Whiting & Prichard, 2010). Eighty-one percent of college students reported getting 6-7 hours of sleep every night or less (Araújo et al., 2013), which does not meet the National Sleep Foundation guidelines of 7-9 hours of sleep each night for young adults aged 18-25 years (Hirshkowitz et al., 2015).

College students with MS face the challenge of managing common sleep issues in the typical college population, as well as considerable fatigue that often accompanies an MS diagnosis (NMSS, 2015). Approximately 75% of all individuals with MS describe high levels of fatigue, as well as reporting fatigue as a symptom that concerns them the most, even more than pain and impairments to physical abilities (Bralley & Chervin, 2010).

As more young adults are diagnosed with MS and enter higher education, it becomes increasingly important to understand their needs, and best strategies for supporting college students with MS. Using the results of two studies, this paper examines the following questions:

1. What challenges does MS add to lives of college students?
2. What strategies and resources are most helpful for assisting college students with MS in meeting their educational goals?

In the first study, parents share their concerns about their children with MS navigating the college experience and provide suggestions for assisting students with MS in reaching their education goals. The second study reports on the experiences and perspectives of college students with MS specifically examining aspects of college life MS makes more challenging, coping strategies used to manage the college experience, and perspectives of the usefulness of support resources. Findings from both studies are used to make recommendations for assisting college students with MS as they strive to meet their educational goals.

### Method

This article reports on the results of two studies aimed at gaining a better understanding of the experiences and needs of college students with MS. Study 1 examines parents' perspectives on the educational experiences and needs of their children with an MS diagnosis. Study 2 is a pilot study reporting on col-

lege students' experiences navigating postsecondary education while managing their MS. Results of both studies are used to provide recommendations for supporting college students with MS.

### Study 1

**Participants.** This study includes a subset of participants from a larger study of 42 parents of children with MS examining the impact of pediatric MS on children and families. The insights of 30 mothers and one father of children with MS including three parents of children who have graduated with either a two- or four-year degree, nine parents whose children were currently attending college, four parents of children who were planning to start college in the next few months, three parents of children who started college but dropped out, and 12 parents of children with MS who brought up higher education as an issue of hope or concern for their child during the larger study are included. Parents discussed the experiences of seven male and 24 female children with MS ranging in age from 11 to 33 years ( $M = 17.6$ ) years who had received a diagnosis of MS between five and 19 years of age ( $M = 13.9$ ) and had an MS diagnosis for one to 17 years ( $M = 3.3$ ).

**Procedure.** Information about the study was sent to several professional organizations and support groups serving families of children MS, who then forwarded the information to potential participants. Interested parents responded to an online demographic survey and provided their contact information. The researchers then contacted potential participants to arrange a phone interview. Semi-structured phone interviews were completed by one or jointly with both of the first two authors. Interviews asked parents about their child's and family's experience through the diagnosis process, impact of the disease on the child's family, school, and social life, and parents' hopes and concerns for their child's future. Parents were also asked to identify unmet needs and provide suggestions for professionals working with adolescents with MS in the medical field, schools, and community, as well as advice for parents receiving a recent diagnosis of MS for their child. All interviews were recorded and transcribed verbatim. The results of this study focus on parents' discussions of past, present, and future education related issues.

**Data analysis.** The first two authors read all 42 interview transcripts highlighting all references to higher education in the past, present, or future. Thirty one participants discussed higher education and were included in this study. The first and second authors began the process of coding the data by independently reading all comments related to education and mak-

ing note of initial observations through the process of memoing (Creswell & Poth, 2018). Both authors then re-read the transcripts and developed summary statements (Creswell & Poth, 2018). The second author then used the memos and summary statements to identify issues emerging from data. The first author reviewed the initially identified issues and both researchers worked together to reach consensus on emerging issues and identify common themes connecting these issues.

## Study 2

**Participants.** Information about the study was sent to several professional organizations working with people with MS and to the directors of departments serving students with disabilities at numerous college and universities in the Midwest, who then forwarded the information to potential participants. Twenty-two college students with MS completed the survey online via SurveyMonkey. Demographic information for the participants is provided in Table 1.

**Measures.** Based on existing research on common issues facing college students, coping strategies used by college students, and challenges of living with MS, a questionnaire was developed examining the topics listed below. The questionnaire was piloted by five individuals with MS who provided feedback on the initial survey. The final survey incorporated content and wording feedback from the pilot group.

**Disclosure of MS diagnosis.** Participants were first asked the amount of time between receiving a diagnosis of MS and sharing this information with family members and close friends. They were then asked if they had shared their diagnosis more publicly, and if so, how long after the initial diagnosis did they begin sharing more publicly.

**Added challenge of MS on college life.** Participants were provided a list of 13 common aspects of college life. For each that was applicable, they rated how much they believed MS impacted that aspect of their lives from 1 (*not challenging*) to 5 (*very challenging*). Participants were then asked to discuss any additional challenges they faced at college.

**Coping strategies.** Participants were provided a list of 11 common coping strategies for college students and asked to select all they used to cope with college life. For each strategy selected, they rated the perceived effectiveness of the strategy for coping from 1 (*not effective*) to 5 (*very effective*). Participants could also list other coping strategies not included on the survey.

**Support resources.** Participants were then provided a list of seven resources that might be available to assist them with managing MS and college.

Participants indicated whether or not each resource was available to them and if they used the resource. If they used the resource, they rated the usefulness from 1 (*not useful*) to 5 (*very useful*). For the same resources, participants rated how useful they believed each resource could be if it were available and used. Participants were provided the opportunity to list additional resources they used or thought would be beneficial that were not included on the original list.

## Results

### Study 1

**Themes and issues.** Examining the data for information that could provide insights on how to support and promote academic success for college students with MS, eight issues emerged from parents' discussions of their children's past educational experiences and concerns for their children's future. These eight issues were combined into four broader themes that are presented below.

**Theme 1: Increased understanding of MS by educators is needed.** Parents repeatedly reported that the general public, including educators, know little about MS. People particularly are unaware that children and adolescents can have MS, leading to questions about the accuracy of the diagnosis. Parents felt increased understanding of MS by educators would lead to more willingness to develop and utilize accommodations that would aid in the academic success of their children.

**Issue: Lack of understanding of MS decreased support by educators.** Many parents reported negative experiences with school personnel during their child's K-12 education. Parents shared their concerns regarding limited awareness of educational professionals that MS was even a possibility for students. In particular, several shared that children with MS often do not fit the stereotypical image of an individual utilizing a wheelchair after an MS diagnosis. The often invisible nature of MS symptoms led to their child not receiving the supports they needed to succeed academically while managing MS. As one parent shared,

For teachers...it's not always obvious that someone has MS and that they are experiencing whatever, fatigue or depression or numb feet or feeling like their brain's not working as fast as it should be. All these things are invisible and so, professionals like teachers should be increasing their awareness to provide empathy for students like that.

Another parent of an adolescent, who did not regularly show outward signs of the disease, discussed a situation where the school was aware of the diagnosis and a plan to go directly to the nurse if symptoms began at school was in place. This adolescent experienced a humiliating scenario that also resulted in delayed medical treatment, and ultimately the family's decision to send their daughter to a different high school.

She had gone to her science teacher and told her, 'I need to go the nurse,' that she was having slurred speech. She [the teacher] called the resource officer instead...they took her to the principal's office, and called in her guidance counselor and with the resource officer, interrogated her for two hours before they called the nurse.

*Issue: Understanding of MS was associated with more effective accommodations.* Several parents identified educators who worked diligently to provide accommodations that would benefit their child. In particular, educators who had knowledge about or experience with MS (e.g., had a relative with the disease) were reported to have greater understanding, empathy, and willingness to help students be academically successful.

One parent discussed how a vice principal, whose husband had MS, became a strong advocate for her child. She was willing to use creative interventions to assist the child to be successful. The parent provided several examples of how the vice principal helped create and implement accommodations that enhanced her high schooler's academic success. For example, relapses frequently led to days of missed school for the student. So the vice principal developed the following plan:

The teachers had a GoPro that would get transferred to each classroom. They would wear that in the classroom, basically around their neck, so that it was mostly trained on their face rather than the entire classroom, for privacy. Then [student] could Skype in and she'd see the teacher, and he'd turn it around to show the board when he was doing board work. She could then participate in the conversations, and participate in the class. If she was having severe spasticity she would just send an email.

**Theme 2: Medical needs.** There currently is no cure for MS; however, treatments to keep the disease from worsening are widely used. Parents expressed concerns over their child's medical needs being met while at college. The two most frequently discussed

concerns were over day-to-day medications and access to appropriate medical care when needed.

*Issue: Day-to-day management of MS.* Maintenance treatment options for young adults with MS include a variety of medications with administration ranging from daily oral medications taken one to two times daily; injectable prescriptions administered once a day, every other day, or three times per week; or intravenous (IV) medication received at intervals ranging from once every month to once every six months (Costello, Halper, Kalb, Skutnik, & Rapp, 2017). When facing a relapse, some individuals may require an IV for one to five days completed either as an outpatient or inpatient depending on the severity of the relapse (Narulo, Hopkins, & Banwell, 2015). As adolescents move into adulthood, they become responsible for their own day-to-day disease management. This transition raised concerns for parents.

A parent of one young man who planned to start college in several months, approximately 3 ½ hours away from home reported:

We do his injections, and I guess as we get ready to transition to college, I have to figure out- he is going to have to learn to do them, and we are going to have to figure out how to overnight-ship his medicine, . . . His medicine is supposed to be refrigerated, and I don't want him to feel weird about his little dorm fridge having medicine in it, you know, but I guess we'll figure all that out.

*Issue: Medical care near college.* Several parents discussed changing their child's physicians to professionals closer to where they would be attending college. For example, one parent reported:

So I decided I was going to switch [child's] neurologist from [location a], and now she's going to [location b] and that center. That's in [city], and she's going to be going to college close to there. So I thought, that makes sense.

Another parent felt access to a good medical facility should be part of the child's decision when choosing where he would attend college. "I'm [parent] like, 'first year you're home, but when you do decide to go, please pick metropolitan so I know you're at a decent hospital.'"

*Issue: Relapses.* In addition to day-to-day management of MS, parents reported concerns about the impact of unpredictable relapses on their child's education. Several parents discussed previous negative impacts of relapses on their child's academics. One parent said:

She had her second flare in October, which knocked her out of that semester. She went back and worked to catch up. The second year she went back but she lived at home. She made it about a semester and a half and had to leave because she had another flare. She went out on medical leave and wasn't able to come back. After three months they retracted the scholarship.

**Theme 3: Meeting college demands.** Parents expressed concerns over their child's ability to navigate the demands of college and MS.

*Issue: Balance.* A frequent concern was balancing the symptoms and unpredictability of MS and college as exemplified by one parent who stated, "I think for him it's giving him the psychological tools to navigate college, family, and work as safely as possible for him. It's going to be tough." Some parents were confident in their child's ability to succeed, however that might require slowing down a bit. The parent of a daughter in her third year of college who has had some struggles with meeting the demands of college and of MS reported, "She's doing better with that mentality, realizing that I can still get there, it's just going to take me a little longer."

*Academic supports.* Several parents discussed the types of accommodations their children received at their college or university. Parents generally appreciated the support student disability services were providing for their child. For example, one parent discussed accommodations provided through disability services:

The college was very good about it. You want your books on your computer; they put Dragon Naturally Speaking on her laptop for her for free. You can have a scribe. You can take your tests in the library in a quiet room.

Parents of two students noted positive experiences with faculty. One of these parents said, "He got lucky because his professors, he told them what his condition is. His professors were kind enough to help him, give him extra days, sending in the homework assignments or whatever he needed."

**Theme 4: Future employment.** Parents frequently expressed concern about the long-term impact on their child's ability to hold a full-time job. For example, one parent had the following to say about her daughter:

She's very academically inclined and I don't want her to lose that as she's even moving into college. I think that she is special academically, so do the

teachers, and you wonder, because of the MS, I don't think that, even her neurologist, I think she can still do whatever she wants to do, if we can't get the pain minimized, then I wonder, will she be able to hold a job?

Another parent said:

I'm thinking- we're going to put him through school, and he got in an architecture program, so he should come out and do well, I didn't want to stop him from doing anything he wants to do, but I do worry about his job if he has episodes down the road.

Other parents believed MS had to be consideration for future career choice, as exemplified by one parent:

I want her to get out of high school and go to college and do what she wants to do, but at the same time she has to think about just because her mind wants to do it, it has to be something that her body can do too. Just trying to pick a career that will be accommodating to a possible MS flare-up.

Another parent stated:

She wanted to be a vet tech, but because she has immune suppression, she's been told by certain vet tech schools that that's not possible, so she's rethinking what she can do, and she's also thinking about: "What can I do if I won't be able to walk"?

## Study 2

This pilot study provides an initial look at the experiences of college students with MS. Descriptive statistics of the survey items are discussed. The small sample size limits the ability to examine correlations between variables; however, the results provide initial insights into the experiences of students with MS in the college setting and provides direction for future research.

**Disclosure of MS status.** Participants told some of the people closest to them about their diagnosis immediately ( $n = 19$ ) or within a year of diagnosis ( $n = 3$ ). Participants varied on if and when they shared the information more publicly with only three participants sharing their MS status publicly immediately, three shared more publicly within six months of diagnosis, another three between six months and one year of diagnosis, one between one and two years following diagnosis, one between two and

three years after diagnosis, five have not yet shared publicly, and another six have not shared and do not intend to share publicly.

**Challenges.** Participants identified and rated aspects of college life they believed were made more difficult by MS. Getting enough sleep/rest, managing work and class schedules, health needs/medications, school work, and helping others understand MS were rated as the most challenging aspects of living with MS while in college. Table 2 includes the number of participants reporting MS impacting each area of life and the mean level of additional challenge they believe MS imposed.

Participants were provided the opportunity to briefly expand on challenges. Fifteen participants provided written comments about challenges. Six comments expanded on challenges included on the survey. Two additional comments discussed the intersection of the disease and school; for example, one participant wrote “when having symptom flares and dealing with how to do school work during these periods.” Two others dealt with support resources including not knowing how to get support or feeling support was inadequate:

Push-back from professors on my accommodations, falling behind on work, being so exhausted I only have energy for either attending classes or doing homework, feeling unsupported, constantly and repeatedly having to explain myself, I have a professor that triggers anxiety attacks, accommodations are also inadequate-- we have to essentially negotiate our accommodations with our professors.

Two participants discussed challenges from others not understanding MS. One participant reported:

I have dealt with a lot of ableism from faculty and students. For example, I use a handicap parking space, and I often will be confronted or receive disgusted looks for doing so. It's hard to get people to understand invisible auto-immune diseases.

The other wrote:

Publicly dealing with the side effects of MS drugs when people don't know your diagnosis. For example, on Tecfidera, severe flushing is a side effect - and can more or less strike at any time - so that introduces some complications to socially navigate if people don't know what you're going through.

Additional comments include dealing with keeping health insurance, not being able to keep up with everyone else, and taking care of a pet.

**Coping strategies.** Table 3 summarizes the results on coping strategies participants reported using and the rated effectiveness of each. Sleep, listening to music, communicating with friends and families, exercising, and watching television or movies were the most frequently used coping strategies, as well as those rated as most effective. Participants added additional coping strategies including hobbies such as painting, drawing, swimming, and writing poetry, prayer, meditation, counseling, and using medical marijuana. One participant identified what he or she perceived as a negative coping strategy, “a less healthy coping mechanism is drinking, which I am trying to cut back on,” and an additional participant noted she was not coping well stating, “honestly ‘coping’ seems generous for how I’m doing. I’m going on my second medical-leave and my GPA is probably below a 2.5.”

**Support resources.** Participants reported using an average of three out of seven support services included on the survey with two participants reporting they did not utilize any of the listed support services, seven participants used one or two services, nine used three or four services, and five used five or more services. The most frequently used campus resources included student disability services, campus health services, counseling services, and resources to educate others about MS, with each of these resources being used by half or more of the participants. Of those, student disability services and counseling services were rated as the most helpful resources by those utilizing these services. Face-to-face support groups for college students with MS was reported to be used by only three participants, however it was rated as the most helpful resource. Not all resources were available at all colleges, and even when available, not all participants chose to use them. Participants were asked to rate what they believe the usefulness of each resource would be if it was available and used. Students with MS rated student disabilities services as likely to be the most useful support resource, followed by a face-to-face MS support group for college students, counseling services, resources to share with others to help them understand MS, and an online support group for college students with MS. Table 4 includes the number of participants using each of the seven college resources included on the survey, the mean reported usefulness of each resource by those utilizing, and the perceived usefulness of each resource by all participants, if it was available and used.

## Discussion

With rates of diagnosis of MS in children and adolescents on the rise (Thannhauser, 2014), more students with MS will likely enroll in higher education; as a result, understanding how to successfully assist college students with meeting their education goals becomes increasingly important. Results of the two studies discussed in this paper provide information useful for thinking about strategies that might assist college students with MS.

College students with MS rated getting enough sleep/rest as the number one challenge of negotiating college life with MS. This concern was echoed by parents who were worried about the ability of their child to manage the demands of college and MS. While time management (Misra & Mckean, 2000) and getting enough sleep can be a challenge for all college students (Gaultney, 2010), fatigue frequently experienced by individuals with MS significantly amplifies this challenge. Those advising and working with students with MS might keep this in mind when helping students with MS plan their course schedules. For students with MS where fatigue is a major symptom, discussing strategies that might increase the opportunity for students to get the added rest needed to combat fatigue such as taking fewer credits, scheduling classes to allow needed breaks, or considering online options may help students with MS better balance college and managing MS.

In addition, parents expressed concerns over the impact of MS on their child's future career. Some parents reported MS should be a consideration in the career paths their children select. While the impact MS on individuals varies significantly, it might be beneficial for academic advisors to talk with students about their individual symptoms and how different professions may be easier or more difficult to negotiate given their particular situation. College students were not asked about the impact of MS on their future careers. Future research should further examine college students' perspectives on the impact of MS on their career choice.

A primary concern expressed by parents and the third biggest challenge noted by college students, was meeting their medical needs while attending college. To help ease these concerns and to help assure the medical needs of students with MS are met, university health services and student disability services could provide a contact list of local professionals who are available to assist with MS-related medical needs. Working with students on a plan to meet their day-to-day medical needs, as well as a strategy to deal with relapses if they occur while at school, could assist

students with MS in remaining healthy, increasing their odds of academic success.

College students with medical needs or disabilities face challenges deciding if and with whom to share information about their disability. In order to receive accommodations that could help their success, they need to share at least some information about their condition with university staff and their professors. While the majority of college students had shared their diagnosis with close family and friends, results were more mixed with regards to sharing their diagnosis more publicly. Almost half of the participants had not yet shared their diagnosis more publicly, and more than half of those reported that they never intended to share their diagnosis publicly. While participants were not asked why they might not disclose, previous research finds college students are often concerned about the impact of revealing their disability on the way they are perceived by others (Kranke et al., 2013; Trammell, 2009). At least some research suggests there may be good reasons for the reluctance of some college students with disabilities to disclose their disability status. For example, Trammel reviewed research on the impact of disclosure of a disability to university faculty, noting results suggest that disclosure can sometimes do more harm than good by leading to stigmatization and discrimination.

Some of the negative perception may be due to lack of understanding of students' specific conditions (Rao, 2004). Both parents of children with MS and college students with MS report that additional education would be useful for supporting students with MS. Parents reported greater support, resulting in more successful K-12 educational outcomes for their children with MS, when educators had a better understanding of the disease. College students with MS identified resources that help others understand MS as a useful form of support. The results of the two studies presented here, suggest that providing instructors with basic information about MS might help faculty to better understand the challenges and needs of students with MS, which could increase their receptiveness to making reasonable accommodations. Additionally, if students felt university personnel had a better understanding of MS, some might be more willing to share information about their disease helping them to get additional support that could help them be more successful. Finally, there is evidence to suggest many faculty are interested in learning more about effectively working with students with different disabilities, however getting faculty to take the time to attend training workshops is often difficult (Sniatecki et al., 2015).

One possible strategy to increase faculty understanding and support of students with MS might be developing a one-page handout briefly explaining MS and common symptoms of the disease that, if students chose to, they could provide to instructors along with their accommodation letters. Such information might provide some context and rationale for the accommodations the student is requesting, potentially increasing faculty members' willingness to assist the student in reasonable ways. Providing space for students to personalize the information by noting how they are specifically impacted by MS, if a student so chose, might further aid in faculties' understanding of the needs of individual students. Overall, a greater understanding of the disease by faculty has the potential to improve support of students with MS by decreasing stigma, increasing support for the requested accommodations, and possibly contributing to faculty willingness to further develop creative strategies to assist these students. Since students differ in if and how much they want to disclose about their disabilities, it is important to emphasize that it be each individual student's choice whether or not to share information sheets or details about how they are impacted by MS. Future research evaluating the usefulness of such resources could help determine whether this strategy is viewed as beneficial by students and faculty, and if it impacts educational outcomes.

Another strategy to help faculty understand not only MS, but also a wide range of other disabilities that may impact the students they work with, might be to develop a database with information sheets similar to discussed in the previous paragraph. While physically handing faculty an information sheet so they do not have to search out the information themselves is likely to be valuable, providing a webpage with easy to access information about a wide variety of health and disability issues may further support faculty as they work to best support students' academic success.

Evaluating the effectiveness of approaches like those discussed above is an important next step in working to support students with MS, as well as students with a wide range of disabilities. Pilot testing a variety of different strategies for training faculty to determine what methods are most preferred, utilized, and lead to the greatest support for students with disabilities would be valuable for all students with disabilities.

### **Limitations**

The research presented here is a preliminary look at potential challenges as well as possible strategies to help college students with MS successfully reach their higher educational goals. Both studies reported

in this paper relied on self-selected samples through snowball recruitment methods; therefore are not representative of all children or college students with MS. The sample size of study 2 was particularly small for a quantitative study further, limiting generalizability; however, it does provide some initial insights and a starting point for future research. Parents' reports of children's experiences and their concerns for their children's success in college may or may not be similar to children's concerns and experiences themselves. The survey completed by college students, although based on existing research, likely did not capture all the challenges and coping strategies used by college students with MS. Furthermore, the survey measured college students' perceptions of the usefulness of various support services; however, it did not assess how much each resource may or may not have contributed to academic success or a positive overall college experience for students.

The work presented in this paper could be expanded by interviewing college students with MS as they prepare to attend college and throughout their college career. Open-ended questions that allow college students to describe in their own words their expectations, challenges, and supports that helped them navigate various aspects of the college experience, could provide additional insights that would be valuable for identifying strategies that are most effective at supporting students with MS successfully earn their desired degrees.

As we continue to work to assist college students with a wide range of disabilities in meeting their higher education goals, understanding how different conditions impact students' success can help tailor recommendations for individual students. The goal of the studies discussed in this paper was to provide preliminary insights that might be useful for improving educational outcomes for college students with MS. However, by examining the experiences and supports for students with MS, we also provide ideas for strategies that might be generalized to other conditions.

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Table 1

*Participant Demographics*

Gender	
Female	20
Male	1
Not specified	1
Age	
18-20	6
21-23	8
24-26	1
27-29	4
31-33	2
36-38	1
Degree Sought	
Associate	1
Bachelor's	16
Master's	1
Doctoral	3
Other	1
Current Credit Hours	
Six or fewer	5
7 to 12	6
13 to 18	10
19 or more	1
Living Arrangement	
At home with parents	6
On campus housing	2
Off campus	14
Time Since Diagnosed with MS	
Less than 1 year	5
1 to 2 years	5
3 to 4 years	5
5 to 6 years	1
7 to 8	4
15 years or more	2

Table 2

*Mean Score on Perceived Challenge MS adds to Common Aspects of College Life*

Aspect of College Life	n	Challenge Added by MS Mean Score
Getting enough sleep/rest	21	3.89
Managing work and class schedules	21	3.58
Health needs/medication	22	3.47
Exams/Tests/Homework	21	3.32
Helping others understand MS	21	3.00
Dating	19	2.94
Socializing and meeting new people	21	2.89
Living in residence hall	8	2.88
Personal care (cooking, cleaning, laundry)	21	2.84
Maintaining friendships	19	2.78
Living with roommates	11	2.73
Communicating with professors	21	2.42
Communicating with classmates	21	2.32
Accessible transportation to class	19	2.00

Table 3

*Use and Mean Perceived Effectiveness of Common Coping Strategies*

Coping Strategy	Number of Participants Using	Mean Rated Effectiveness
Sleeping	15	3.86
Listening to music	13	3.79
Spending time/communicating with family	11	3.65
Spending time/communicating with friends from college	10	3.06
Spending time/communicating with friends from home	9	3.56
Exercising	9	3.25
Watching television/movies	9	3.00
Playing video games	8	3.00
Reading	6	3.00
Social networking	7	2.13
Eating	5	2.32

Table 4

*Number of Participants Using and Perceived Usefulness of Campus Support Resources*

Resource	Number of Participants Using	Mean Rated Usefulness by Those Using	Perceived Usefulness of Resource if Available and Used ( <i>n</i> =22)
MS support group for college students face-to-face	3	4.00	3.50
Student disability services	13	3.92	3.73
Counseling services	11	3.10	3.23
Resources to share with others to educate about MS	11	2.91	2.91
MS support group for college students online	4	2.00	3.05
Campus health services	14	2.34	2.64
Career services	9	2.40	2.32