

# The College Experience for Students With Chronic Illness: Implications for Academic Advising

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*A purposive sample (2 males, 3 females) of students (aged 18–29 years) with chronic illness completed standardized measures and a semi-structured interview. Content analysis of the interview data revealed two themes: stress exacerbating symptoms of illness and a desire for a support group on campus. Viewed through the theory of emerging adulthood, participants' social support data suggest that some college students with chronic illness are challenged by the developmental tasks of this life stage due to their health issues. Male students with chronic illnesses may be at a higher risk than females for college adjustment problems. The growing population of those with a diagnosis can benefit from developmental advising that includes validation of their particular challenges and appropriate intervention.*

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More than 20 years ago, Byrd (1995) addressed the changes in the demographic characteristics of the undergraduate student body, which diverge from those of the relatively homogeneous undergraduate cohorts of previous generations, and asserted that “as the student population continues to diversify, every campus finds itself with more people that the original system was not designed to accommodate” (p. 2). Since the time of Byrd’s call for advisors to attend to “how a student’s demographic characteristics might affect the classroom experience and the matriculation path through the university” (p. 2), the number of students with chronic illness joining the undergraduate population has increased. More recently, Kennedy and Ishler (2008) pointed out the changing profile of the undergraduate population and included students with disabilities in their list of notable demographic changes. Students with chronic illness constitute a part of this growing group of undergraduates who require special accommodations.

## Students with Chronic Illness

Wodka and Barakat (2007) noted that young people with chronic illness comprise a growing population. In this paper, we describe some of the challenges experienced by this unique cohort of college students. We refer to Perrin, Bloom, and Gortmaker’s (2007) definition of a chronic illness as “a health condition that lasts  $\geq 12$  months or at time of diagnosis is likely to have a duration of  $\geq 12$  months” (p. 2755). Typical conditions prevalent among the undergraduate population at our institution, Monmouth University, include chronic lyme disease, Crohn’s disease, sickle cell anemia, and diabetes. Chronic illnesses usually require long-term treatments, and the consequences of taking medications and the disease symptoms can be more severe than those for students with acute illnesses (e.g., bronchitis or influenza) (Shelley & Pakenham, 2004). Daily treatment makes up a major component in the management of many chronic conditions (Smith, Taylor, Newbould, & Keady, 2008), often with a regimen requiring administration of medications (some by injection) at various times throughout the day, which can complicate a student’s academic schedule. Perrin et al. (2007) suggested that increasing rates of childhood chronic conditions naturally lead to the higher numbers seen during adulthood; they also indicate health-related reductions in educational opportunities for young adults.

## Emerging Adulthood as a Lens for College Student Development

To better understand the growing population of undergraduates with chronic illness, we use this phenomenological study into the consequences of their health issues in terms of discomfort in the classroom, means of progression through the curriculum toward degree completion, and lived experience. Although we focus on traditional-aged college students, we include students in the full emerging adulthood range of 18 to 29 years old in our look at student development because, based on our observations, many individuals with chronic illness progress more slowly through

college than do their peers in good health. Consistent with an approach to the practice of advising that is both developmental and holistic, as discussed by Hagen and Jordan (2008), we use Arnett's (2000) theory of emerging adulthood to describe the normative developmental issues of traditional-aged undergraduates and explore the issues that might be more complicated for students with chronic illness.

Arnett (2000) described emerging adulthood as a unique developmental period in current cultures that delay typical transitions into the status of adult, such as marriage and financial independence. During this time, a young person typically feels neither like an adolescent nor an adult. Exploring and clarifying a sense of self and gaining independence are central developmental tasks during this stage of life, but a chronic illness may hinder accomplishment of emerging adults' developmental tasks and prevent the personal growth expected during the college years. For example, people with a chronic illness often become dependent upon a particular family member who continually offers help (Martire & Schulz, 2007), and dependence on family members for help with health issues may conflict with the goal of increasing independence and normative transfer of emotional dependence from parents to peers.

Youniss and Smollar (1985) suggested that starting in the adolescent years young people shift emotional investment from family to friends, and Arnett (2010, p. 211) posited that normatively "friends provide a bridge between the close attachments young people have to their family members and the close attachment they will eventually have to a romantic partner." According to McGillin's (2003) study of the transition to college, resilient students, particularly males, generally list peers (as opposed to parents) as primary sources of support. Thus, in the present study, we examine the size and composition of the social support systems of students with chronic illnesses and their satisfaction with them.

### **Invisibility of Chronic Illnesses**

In addition to concerns with academic progression and related issues, we explore students' feelings about the invisibility of their conditions. Although some chronic illnesses exhibit physical manifestations, acquaintances often are unaware of another's chronic illness, and as a result, students may continually need to explain their condition (Shapiro, 2002) to others, including

their professors and advisors. Women with chronic illness generally express ambivalence about disclosing their disabilities, and Jung (2002) described the scrutiny that such disclosure entails. Some chronic illnesses engender sympathy toward the student; however, those relatively unknown by those unaffected or poorly understood by medical professionals may inspire criticism (Shapiro, 2002), encouraging students to refrain from disclosing their condition even if such a strategy hinders their educational opportunities.

Christian and D'Auria (1997) noted that some choose to keep silent about a chronic illness as a coping mechanism used to maintain a sense of normalcy. Often college students with chronic illnesses view college attendance as a beginning of a new life and hope to leave behind any stigma associated with their atypical situations. As St. Louis (2009) explained, aspirations for a fresh start may reflect a willingness to overcome challenges, however as they attempt to escape from their illness by not talking about it, students with chronic illness may deprive themselves of the support from disabilities services personnel that could enhance their likelihood of successfully completing the degree.

Our study expands on a qualitative pilot study conducted by St. Louis (2009), who explored the experiences of female students with chronic illness at the medium, private university where we conducted our investigation. St. Louis (2009) noted that some students with chronic illness were unaware of the accommodations available through disability services, highlighting the need for advisors to share information about available support and increase their own awareness of this growing group of students with special needs.

In the current qualitative study, our small, purposive sample (Creswell, 2007) included both male and female participants. Fossey, Harvey, McDermott, and Davidson (2002) asserted that qualitative methodologies are particularly useful for gaining insight into how subgroups with a common medical problem experience their lives. The semi-structured interviews provided an opportunity for participants to describe their experiences as students with a chronic illness and the responses of their professors to their need for accommodations. The *Student Adaptation to College Questionnaire* (SACQ) (Baker & Siryk, 1989) allows for the comparison of college management of challenges undertaken by students with chronic illness and those without such

a diagnosis. The information may help advisors clarify the ways to facilitate the personal growth and progress toward a degree of students with unique issues related to their health situations. Specifically, it offers insight imperative for advisors working within a developmental framework that “focuses on the needs of the student in determining how the advising interaction shall transpire” (Hagen & Jordan, 2008, p. 25).

## Method

### Participants

A purposive sample (per Cresswell, 2007) of 5 participants (2 male, 3 female, age range of 18 to 29 years,  $M = 21.2$  years) was recruited from a private university with approximately 4,000 undergraduates. The Disability Services Department notified students registered with it via e-mail about the opportunity for participation. The sample included 2 first-year students and 1 sophomore, junior, and senior. Two participants received credit in a psychology class for research participation. Chosen participants, who each have a chronic illness, were using disability services at the time of the study or had used them in the semester prior to participation. The selection of this purposive sample is consistent with the criteria delineated by Merriam (2002) who explained that participants should be exemplars of the specific population of interest and that the criteria for their selection should be transparent. The Institutional Review Board of the university reviewed and accepted the procedure, and all participants were treated according to American Psychological Association (APA) ethical guidelines (APA, 2002).

### Measures and Procedure

The study measures included a demographics questionnaire to describe the participants. We also employed the SACQ (Baker & Siryk, 1989), the *Short Form Social Support Questionnaire* (SSQ6) (Sarason, 1983), and a semi-structured interview. Participants filled out a sheet of typical demographic questions on gender, age, current year in college, annual income, and ethnicity.

**Student Adaptation to College Questionnaire.** The SACQ (Baker & Siryk, 1989) features 67 self-report items on 4 subscales that measure academic, personal-emotional, and social adjustment to college as well as attachment to the institution. All subscales of the measurement were found internally consistent in several independent studies (Baker & Siryk, 1989) with Cronbach's  $\alpha$

values greater than .80 and valid as demonstrated through significant correlations between the SACQ subscales and relevant measures such as academic motivation, depression, grade-point average, and involvement in social activities. In this study, we examine the scales for social-adjustment, personal-emotional adjustment, and academic adjustment.

**Short Form Social Support Questionnaire.** The SSQ6 (Sarason, 1983) consists of six items used to assess social support in various contexts. Participants write the names of nine or fewer people from whom they receive social support in each context. They also rate their satisfaction level with the support from the people on their lists on a 6-point Likert scale, with 6 being *very satisfied* and 1 being *very dissatisfied*. Internal consistency for this measure has been demonstrated with Chronbach's  $\alpha$  values greater than .90 as well as a good test-retest reliability (Sarason, 1983). Two scores are obtained from this instrument: Scale A measures the number of support figures available to the respondent across all contexts, and Scale B (which is not correlated with Scale A) measures the respondents' satisfaction with the support they receive. The identities of social support providers can be analyzed to determine whether they are appropriate for the developmental stage of the respondent.

**Semi-structured interviews.** We conducted the semi-structured interviews after the participants finished responding to the paper-and-pencil measures. Before asking the scripted questions, we reminded participants that they would be audio recorded, for transcription purposes only, as had been indicated on their informed consent forms. We obtained qualitative data (see Appendix) to provide rich data in the students' own voices (as per Polkinghorne, 2005). One of us, serving as the interviewer, quickly established rapport with all of the participants by disclosing her diagnosis with chronic illness. The remainder of the interviews followed participant responses to the questions.

All students participated individually. They completed their questionnaires and answered the interview questions in private.

## Results

### Social Support

**The magnitude and nature of social support network.** According to SSQ6 Scale A, participants listed from 16 to 47 people as support, demonstrating the variability that exists within the sample. The student with the fewest people in his social support network listed his mother first for all six

contexts. He listed his physician second, his father third, and acknowledged one peer, the same individual, for three of the six contexts.

The other male participant reported the largest network. He first listed a friend, then his wife as the most supportive people and added many other friends. He also noted his mother for four of the contexts, but she was listed as the fifth most important in the groups.

The females in the sample showed less variability in the size (23 to 29 persons) of their support networks across the six contexts. However, the participant with 29 support persons tried to acknowledge as many as 54 people, as she reported her whole sorority as one of her sources of support. However, she did not list any family members in her network. The other two women listed both parents prominently in their networks, with both parents frequently in the first and second position across contexts.

**Satisfaction with the social support network.** For SSQ6 Scale B (Sarason, 1983), respondents' satisfaction with their social support was relatively independent of the size of their networks. Two participants (one male and one female) responded with the highest level of satisfaction across all six contexts.

All three of the others responded with a score of 5 out of 6 or *fairly satisfied* for the item regarding support "to console you when you are very upset." In general, though, the respondents indicated that they were at least fairly satisfied with the support they received in all six contexts.

**Interview insights.** Participants' responses to the semi-structured interviews were transcribed verbatim. The transcripts were subjected to an inductive content analysis designed to reveal recurring themes across participants, consistent with data analysis conducted within a phenomenological framework (Berg, 2007). To demonstrate the quality of the study and the objectivity of the coding that was focused on identifying the manifest content (Berg, 2007) of the interviews, the transcripts were also content analyzed by an independent auditor who was not involved in the study. The two major themes we and the external auditor identified are reported here. Other experiences that were mentioned by the students that help describe their challenges and offer insight into areas for intervention by advisors were also noted. Following the suggestions of Merriam (2002, p. 31), we offer the "rich, thick descriptions" in the words of the participants.

The first recurring theme illustrates the way stress contributed to participants' symptoms. P2 shared:

Stress is really bad. I've had a hard time managing my stress. That's actually what caused my flare-up last semester. Umm, end of fall semester last year, the day after finals I was in the hospital for 2 weeks over Christmas and New Year's Eve. It was awful. I didn't even know I was sick, that's how stressed out I was. And I had hundreds upon hundreds of ulcers in my whole digestive tract, and I didn't have any pain, 'cause I was so worried about all the stress, and my doctor said it was the worst she has ever seen in her career. And I thought I was fine! I was actually supposed to leave for Florida Christmas night and I was like, "I have to go, I have to go," and she was like, "You're going to be here for a while."

Participant P1 shared that

even though I've been healthy for a year, it [stress] still makes me exhausted. It's like little things too, like tests, projects, mid-terms, papers, finals. They just make me very tired and like it makes some of my joint pain come out sometimes. And my back pain. Pain and exhaustion and I have to go to the doctor, and the hospital. For pain.

P5 described the actual physical result of stress for her illness: "If I am more stressed out, my blood sugar tends to be higher. Umm, I am pretty good with, like papers and homework assignments, and stuff. It's usually finals and stuff that gets me stressed."

In the second emergent theme, participants expressed desires to attend a support group for their specific illness or for those with various illnesses. One participant (P1), who attended an existing Lyme disease support group in place on campus, stated:

It is very helpful. I've made great friends. Yeah, it's [the Lyme support group] been very helpful, I feel like other people need some place to talk about a chronic illness instead of like not talking about it with anyone but their parents. They need someone on campus; they can't just keep going home.

All of the remaining participants expressed their desire to belong to a chronic illness support group on campus; for example, P2 said,

Yeah, cause I'm the type of person where, this is like a huge accomplishment for me that I've done all this, and that I've travelled, with my Crohn's disease—it has never held me back, so I'm the type of person that wants to be an advocate for it and anyone that needs help. I'm more than happy to help anyone, ya know? Even if it's not Crohn's disease it can be anything. Actually my doctor's office holds through all the Merri-dian hospitals a support group for Crohn's disease and I go there and I talk to parents and kids that are younger than me. So I'm always willing to be an advocate, so that would definitely be something I'd be interested in.

P4 said,

I don't know of any support groups on campus. I mean I guess, it probably wouldn't hurt. I would actually like to join one. I think it would be good for me to do. I don't really have friends, especially here at [college] and by the time I am done with class, I am pretty tired and just want to go home. But, I am interested in a support group that maybe I could join.

P5 stated, "I think that [a support group on campus] would be cool. I used to go to one at home, but not here on campus."

In addition to dialogue related to the two recurring themes, participants offered other contexts for their experiences. Most participants mentioned that professors were generally understanding of the participants' medical issues. For example, P5 stated, "I am registered at Disabilities Services and I had them fill out all the stuff in case something happens, like a flare-up."

P4 said,

I only really go to them [professors] if I have a problem. I utilize Disabilities Services to take my exams, but I don't really talk to my professors about my situation. I don't really talk to anyone. I come to campus for two classes, then I go home. I don't really like to hang around.

One discrepant case, P1 described that

I only had a few teachers who gave me a hard time. Yeah, and they were like "you're always sick; you're always tired; why do you always look tired?" I'm sorry. I can't help it, and yeah, I had an English professor who really didn't understand. We got into an argument about me being tired. She made me sit in front of the class to keep an eye on me, like in the front row to make sure I wasn't falling asleep. And she told me I was yawning too much and she asked me if she was boring me, when she knew about everything. She told me I needed to get more sleep and that I needed to take care of myself.

### Adjustment to College

We scored the participants' questionnaires according to the *SACQ Manual* (Baker, & Syrik, 1989), which contains separate norms for male and female students. The full-scale college adjustment scores ranged from the 24th percentile to the 86th percentile. Both males gave low scores on the scales (24th and 34th percentiles), whereas the females' scores (ranging from 79th to 86th percentile) indicate good adjustment to college.

Both of the males scored below the median on the Social Adjustment scale, with one participant far below the norm (8th percentile); the other male participant's score fell into the 46th percentile. Conversely, all 3 females generated scores above the median in social adjustment: from the 66th to the 79th percentile.

The Personal-Emotional Adjustment scale scores for the 2 males were low: the 12th and 16th percentiles. Conversely, the females' scores varied widely on this scale, with two ratings falling below the median (31st and 42nd percentiles) and one above it (82nd percentile).

Academic Adjustment scores ranged from the 27th to the 82nd percentile. Whereas the lowest score came from one of the males (27th percentile), the other low score (31st percentile) came from one of the female students. The lowest of the scores above the median (54th percentile) was from the other male, and the other 2 female participants scored at the 62nd and 82nd percentiles.

## Discussion

This phenomenological study features an initial exploration of the experiences of emerging adults with chronic illness attending college. The growing number of students with chronic conditions (Perrin et al., 2007; Wodka & Barakat, 2007) present unique needs, and the conviction that these students need a voice in the literature motivated us to make this first step in publishing research about them. The invisibility (Shapiro, 2002) of their situation needs to be explained to advisors and other college personnel. Because their experiences with chronic illness cannot be separated from the personal growth issues germane to their developmental status, we restricted our examination to emerging adults. Although many of the issues regarding intervention and accommodations to facilitate progress of college students with chronic illness are not age specific, the central personal development issues of traditional-aged college students (Arnett, 2000; Youniss & Smollar, 1985)—gaining independence from their parents and developing an adult identity—are intricately tied to the challenges of managing life as a person with chronic illness.

Experiences with chronic illness during college adds to the existing stress of students and limits their access to conventional stress-relief and socialization methods normative in the undergraduate population. For example, specific dietary, medication, and rest regimens affect the ability of students to stay up late, when their peers often socialize. According to Kennedy and Ishler (2008), alcohol consumption is a normative behavior for students, whether of legal age or not, and that undergraduates report drinking to purposefully facilitate social interaction; however, the nature of some illnesses or the medication used to control it prohibit safe social drinking. As a result, faced with the conflict between desire to be part of the undergraduate culture and the need to follow a strict medical regimen, emerging adults with chronic illness struggle to negotiate the campus climate. By understanding the degree to which a chronic illness influences students' ability to thrive in a college environment, advisors learn the best means of helping students to adjust, establish strong support networks, and achieve their life goals.

The descriptive data we examine from two standardized measures and a semi-structured interview all converge into an image of a group, which shows some variability, who generally experience challenges in their social adjustment

to college and their progress in normative emerging-adulthood developmental tasks. The participants included parents and physicians as members of their close social-support groups. The interview data fills in the picture of students who may need help connecting with peers on campus. Advisors can point to the student with chronic illness who belongs to a sorority as a good model for suggestions on coping; students with chronic illness may benefit from joining clubs or groups of interest, other than those that address issues related to their illness, to develop peer relationships.

This sample of students expressed interest in participating in an on-campus social support group for those with chronic illnesses, even if they already attended a support group in the community. People living with a chronic illness and struggling with negative relational impacts of their condition desperately want to be heard and understood; they want their experiences validated (Docherty & McColl, 2003).

Within the population of college students with chronic illness, males may experience college adjustment problems to a greater extent than females. With smaller and fewer age-appropriate social-support systems than enjoyed by females, males experience more personal-emotional distress. Male students in the general population are less likely to seek help (e.g., Munir, Pryce, Haslam, Leka, & Griffiths, 2006; Pleck, 1995; Stapley & Nye, 2007), thus advisors may need to extend specific outreach to males with chronic illness.

Advisors provide the critical link between the student with special needs and the other constituencies on campus (Harding, 2008). Within their advising role, they provide referrals and information crucial for facilitating the progress of those with chronic illness. However, while Kennedy and Ishler (2008, p. 130) emphasized the need for advisor awareness of all possible sources of support or services available to advisees with special needs, they also cautioned advisors that "some students with disabilities may not want to be identified, and their privacy must be respected." Thus, advisors must tread carefully and create an atmosphere where they develop rapport with advisees such that their students feel comfortable sharing information regarding chronic illness or other needs for special services.

The first step in the process is consistent with Harding's (2008) call for advisors to spend more time in relationship building in the initial meetings with an advisee. Time spent getting to know the

advisee as an individual including not only his or her values and goals, but individual special circumstances, will allow the advisor to facilitate the student's progress through the curriculum and with personal growth.

Most of the advisors who responded to a national survey reported that students eligible for accommodations did not register with a disabilities office until they experienced academic problems (Preece, Roberts, Beecher, Rash, Shwalb, & Martinelli, 2007). The advisor needs to ask in an open manner about any issues in the advisee's life that may require special consideration in planning her or his progress through the major. Recognizing that some students feel reluctant to disclose disability information, advisors need to reiterate the query about accommodations in all advising sessions so that the advisee in need reaches a point of comfort in sharing information important to achieving success.

Advisors knowledgeable about common issues for students with chronic illness can readily discuss scheduling needs, just like those considered for athletes, to accommodate advisees based upon their medical regimens, needs for rest, or recurring appointments with health care professionals. They might also need to discuss the maximum number of credits for which students should enroll based on their current health status. The advisor and advisee should candidly factor the likelihood of missing classes into decisions about class schedules; for example, absences from classes that meet once a week may create different consequences for the student than missing a class that meets twice per week. Likewise, students need to consider when they would be most likely to successfully complete lab courses.

Now that many institutions offer hybrid and online courses, advisors should explore student preferences for this type of delivery, determining for example, whether the student needs training with the technology used. The move toward increased distance learning may be a boon to those with medical issues, especially those who find traveling to campus on a specific schedule daunting.

Advisors interested in reaching advisees with chronic illness need to ask about the best ways of meeting or communicating. Do in-person meetings create stress in either arranging or attending them? Would the advisee prefer to correspond by e-mail? Phone? Being careful about only disclosing information that the students want to share, advisors can intervene with faculty members.

Some of the participants of this study shared situations indicating that students with chronic illness may want advisors to advocate for them when professors do not understand the ways their illness affects their classroom performance or the impact of stress created by mid-term and final examination periods, for example, on their symptoms. Some faculty members simply lack awareness about the ways stress-induced exacerbation of symptoms can hinder students diligently trying to keep up with their course schedules.

In this study, we explored the experiences of students in a medium-sized private university, and we encourage others to conduct a similar study at other types of institutions. Research is needed on the knowledge of faculty members and advisors about chronic illness and their own attitudes toward providing accommodations to students with invisible conditions. Additional investigations on the student decision-making process on disclosure of the chronic illness could inform techniques for diplomatically and legally eliciting information about special needs in early advisor-advisee interactions.

Overall, we contend that more awareness is needed regarding the challenges faced by undergraduates with chronic illness. Advisors can play a pivotal role in facilitating students' adjustment to college, personal growth, and academic success through their individual advising relationships, their referrals, and as a resource for other college personnel about this population with special needs.

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#### Authors' Notes

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**Appendix.** Semi-structured interview script

Before we get started, I wanted to share with you a little about myself, and why I am choosing to do research that involves chronic illness. First, my name is Katie and I am a senior psychology major here. I am interested in chronic illness and how it affects emerging adult college students because I am dealing with the same issue. I am currently being treated rather aggressively for chronic Lyme disease. I have had this since I was just out of high school. Unfortunately, I had some setbacks into my undergrad course work that involved heart attacks, inability to actually get out of bed, and general Lyme flare-ups. This has caused me personally to have to take semesters off, limit my course work, and adapt myself to my illness. Although it has taken me significantly longer than my classmates, I will be graduating in May at 29 years old, something I was told I would never be able to accomplish. That is just a little about me, now if I can hear your story:

Please remember that this is strictly confidential, and I am audio-recording strictly for transcription purposes only.

Please tell me a little about yourself, and your chronic illness, if you don't mind.

How old were you at the time you were diagnosed?

Could you understand what that meant? If so, explain.

How has being a college student and having a chronic illness affected your life?

(probing follow-up—Have you struggled with maintaining course work?)

Are your professors aware of your situation, and how have they dealt with you personally?

(probing—are they understanding? do they give you extra help? etc.)

Can you explain how stress may or may not influence you or your ability to complete assigned tasks?

(probing—do you get more stressed out during finals or for an upcoming project? How so, and what are the consequences of stress?)

What is your experience with life here at Monmouth and dealing with a chronic illness?

(probing— do you find you have support if you need it? Do you utilize that support?)

How has the fact that you are continuing your education and dealing with a chronic illness affected you? Are you afraid you won't succeed because of this? Please explain.

Do you feel it has affected your relationships with other students?

Is there anything else you would like to share with me that we haven't already talked about?