

Invisible Chronic Illness in Female College Students

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Abstract

This study examined how female students negotiate the experience of college while living with an invisible chronic illness. Four research questions were explored. Quantitative data, through the use of online surveys, were collected from 105 female students living with a chronic illness enrolled at a medium-sized university in the Southwestern U.S. Results indicated that the majority of participants view their illness as a serious condition that has impacted their life. The majority of respondents reported that they feel capable of completing college, obtaining a job, and view themselves as a person of worth; however, nearly all respondents reported they have avoided social situations in college because of their chronic illness. The majority of participants indicated they accept their chronic illness diagnosis and about half reported that they engage in healthy coping behaviors. We discuss implications of the findings for administrators and disability support services and suggest additional research.

Keywords: chronic illness, disability, higher education, females

Chronic illnesses such as multiple sclerosis, lupus, endometriosis, fibromyalgia, and many more have the potential to disrupt an individual's sense of self, construction of self, and role performance, especially while attending college (Dennison et al., 2011; Werner et al., 2004). More importantly, many of the symptoms of chronic illnesses follow a relapsing-remitting pattern and are not always easily apparent to others. Some hidden symptoms and less visible symptoms of chronic illnesses include chronic pain, fatigue, inflammation, bowel and bladder disturbances, and limitations in mobility, just to name a few (Vassilev et al., 2014). Unfortunately, stigma often derives from issues of legitimacy related to the visibility of chronic disease symptoms because the symptoms might not be discernible to others (Green et al., 2005). When symptoms cannot be seen, relatives, friends, employers, and colleagues are unlikely to understand the seriousness of the illness and how it impacts the life of the person. Even worse, once individuals finally decide to disclose their chronic illness to those outside of their family, they are often not believed by others (Vickers, 2017), and some individuals have reported that others have accused them of faking or making up their illness to avoid obligations or gain special ad-

vantages (Green, et al., 2005). Lack of disclosure and efforts to conceal their disability status often result in increased anxiety within this population, which can, in turn, exacerbate chronic illness symptoms (Adams & Proctor, 2010; Livneh et al., 2001; Vickers, 2017).

The process of psychosocial adjustment to college as a female with a hidden chronic illness involves many factors such as stigma management, disclosure, coping strategies, social support, and identity reconstruction (Davis, 2006). Women, more often than men, face stigma, shame, blame, and credibility issues when disclosing their invisible chronic illness within various institutions (Werner et al., 2004). This study examines how female students in higher education negotiate the experience of college while living with a hidden chronic illness. More specifically, this study provides knowledge and insight about a unique population and the way this population navigates and experiences the reality of living with a hidden chronic illness while attending college.

Four research questions are explored in this study: How do female students feel about their chronic illness in general? How has the identity of female students living with an invisible chronic illness been impacted by attending college? How do fe-

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male students with an invisible chronic illness adjust to college and cope with their chronic illness? How do female college students with an invisible chronic illness perceive the effectiveness of accommodations provided by individual instructors, Disability Support Services (DSS), and the university overall? Data, using self-report surveys, were collected from female college students located at a medium-sized (approximately 16,000 students) state university in the Southwestern U.S. who are living with a hidden chronic illness. The survey used in this study collected data concerning each respondent's attitudes and perceptions toward their experiences and identity as a female college student living with a hidden chronic illness, as well as their attitudes towards feeling included in day-to-day college life, whether or not they perceive that they have equal access to programs at their university, and their attitudes and perceptions towards social acceptance.

Related Literature

Hidden Chronic Illness in Higher Education

Students with chronic health problems are entering universities at numbers higher than ever before, and they face a number of unique challenges in the university (Korbel et al., 2011; Peña, 2014; Wodka & Barakat, 2006). Royster and Marshall (2008) contend that "the nation's colleges and universities have yet to recognize the significance of this development and its implications for traditional faculty-student relationships, student support services, and the strict time structures that frame college life" (p. 120). Additionally, numerous studies have found that increases in stress contribute to increases in chronic illness symptoms and severity, as well as impaired immune system functioning (Matheny et al., 2005; Rawson et al., 1994; Vassilev et al., 2014). Transitioning to college includes many stressors. However, students with a chronic illness often face additional challenges during college, which might include attending numerous medical appointments, ongoing illness management, exacerbation of illness symptoms, and issues related to autonomy, all of which contribute to problems of attrition (Adams & Proctor, 2010; Moore, 2012; Wodka & Barakat, 2007). It is unsettling, to say the least, that many students, despite exhibiting outstanding academic abilities, end up with an academic history of incompletes, withdrawals, and failing grades because the structure of higher education has fallen short in providing an accessible environment for students with chronic illness (Royster & Marshall, 2008).

Due to the ableistic structure of higher education, students with chronic illness can be a source of frustration for instructors (Evans et al., 2017). This frustration partly comes from the fact that instructors are often faced with students of varying learning needs coupled with limited resources (Evans et al. 2017). Even though "students with disabilities must identify their own needs before colleges and universities will provide accommodations" (Adams & Proctor, 2010, p. 177), it is common for students with a chronic illness not to self-identify as having a disability because they do not view their chronic illness as a disability (Royster & Marshall, 2008). Additionally, due to the unpredictability of chronic illness symptoms, accommodations are unique to each student and require continuous adaptation, adjustment, negotiation, and arrangement in order to appropriately meet the needs of students with a chronic illness (Royster & Marshall, 2008). Adams and Proctor (2010) discovered that students who experienced a high degree of self-advocacy skills were found to be more successful in adapting to college life, which highlights the importance of self-advocacy skills for this population within higher education settings. However, the reality is that students with a chronic illness often lack self-advocacy skills, as well as the knowledge of how to address their chronic illness needs in a higher education environment (Royster & Marshall, 2008).

Women Living with Chronic Illness

Women are known to be affected by invisible chronic illness at higher rates than men (Åsbring & Närvänen, 2002; Werth et al., 2018). Women with invisible chronic illness constantly face judgment and questioning about whether or not their illness is legitimate or imaginary (Repetto et al., 2012.) In addition, women are repeatedly given a psychiatric label, which is now the modern form of female hysteria (Werner et al., 2004; Vickers, 1997). Research has indicated that women face stigma, shame, blame, and credibility issues when disclosing their invisible chronic illness within various institutions (Werner et al., 2004). Important to note, Clark pointed out in 2006 that women of color with invisible disabilities and chronic illnesses in higher education have yet to be studied. In most of the research on this topic, the majority of participants have been middle-class white women (Clark, 2006). This is troubling because African American women are affected by Lupus at higher rates than any other female ethnic group (Rosales and Person, 2003).

Women in patriarchal society are often viewed as "caretaker" and not "cared for" (Mintz, 2007). "In a culture that privileges only the white, male 'able'

body as the 'neutral' and normative self, disability is both an emphatically particular embodied reality and a trope for disenfranchisement" (Mintz, 2007, p. 39). The study of disabilities has examined how some individuals with disabilities reclaim, redefine, and/or reframe their identity outside of the dominant paradigm of ableism (Clark, 2006). "What one understands of disability, femaleness, and identity is continually being unraveled and unwoven" (Mintz, 2007, p. 44). For those living with a chronic illness that is episodic or progressive in nature, identity and the ability to self-identify as disabled may need to be reworked repeatedly as symptoms emerge (Mintz, 2007; Davis, 2006).

Separation, as a component of felt stigma, occurs when individuals encounter numerous negative reactions from others which can result in depression and negative perceptions of the self (Evans et al., 2017; Green et al., 2005). Green et al. (2005) revealed that individuals with disabilities report losing their own sense of worth, sense of identity, and sense of being a whole person, all of which can lead to social isolation. "If the self we see reflected in the eyes of others is devalued, there is little incentive for social interaction" (Green et al. 2005, p. 210). Individuals with an invisible chronic illness actively attempt to manage felt stigma, either through rejection of a disabled identity or by embracing a disabled identity (Evans et al. 2017). For example, Riddell and Weedon (2014) found that some individuals with disabilities are beginning to embrace the political category of disability by lessening the negative image of disability and by focusing on ability and difference rather than disability and normalcy that comes from socially constructed environments.

Chronic Illness as a Continual Disruptive Event

As a founder in the field of chronic illness, Bury (1982) noted that constantly changing symptoms and life circumstances require constant adjustments on behalf of the person with a chronic illness and as such, the process of adjustment will be ongoing and changing. Additionally, there are disruptions in the everyday taken-for-granted assumptions in the individual's plans for the future and a newly, ever-present, casted shadow of anxiety and uncertainty. Bury contended that these disruptions are crucial for sociologists to understand because they are powerful enough that "a fundamental re-thinking of the person's biography and self-concept is involved" (p. 169). Indeed, Bury's work on the chronic illness experience "suggests that the assault on identity for many people when they are unable to perform as usual can be profound" (Dyck & Jongbloed, 2000, p. 342).

The British Social Model of Disability

The British Social Model of Disability provides a perspective that is helpful to institutional organizations in understanding individuals with disabilities as well as individuals with invisible chronic illness. Invisible chronic illnesses meet criteria for disability defined by the United Nations, which suggests that a disabled persons' ability to carry out daily living activities results in multiple hindrances to their financial and social circumstances (Jung, 2002); thus, the Social Model of Disability is an appropriate perspective to use in current understandings of invisible chronic illness. The Social Model of Disability posits that social structures fail to properly accommodate disabled individuals, which leads to oppressing this population (Clark, 2006; Olkin, 2002). Society largely views health and illness as a responsibility of the individual which should be managed through proper lifestyle choices (Vickers, 2017). Olkin (2002) outlines the importance for wider society to utilize this model and warns that it is imperative that society adopts the social model or else persons with disabilities will continue to be disadvantaged.

Structural conditions, such as the fact that higher education has been restructured to align more with a neoliberal agenda, has resulted in a system that values product over people (Jung, 2002). Current declines in economic conditions have resulted in a decline in the amount of funding and resources in disability services (Riddell & Weedon, 2014). By ignoring structural factors that oppress, separate, and hinder individuals with disabilities by fully participating in society, the focus remains on the individual as being defective (Clark, 2006).

Invisibility

Visibility of chronic illness poses unique challenges for students whose impairments are not readily visible when compared to students with visible impairments (Clark, 2006). Research should distinguish between the two because students with hidden or less visible impairments are likely to have vastly different experiences in higher education settings than students with impairments that are easily seen by others (Green, et al., 2005). People with invisible disabilities do not report experiencing pity and awkwardness in social interactions, but instead report higher levels of blame and separation due to misunderstandings and stigmas resulting in a variety of individual outcomes (Martz, 2003). Once a negative label from society is placed upon an individual, it is likely that the individual will experience additional hindrances that will interfere with their complete integration and acceptance into society, as well as interfere with the achievement

of the individuals' personal goals, such as acquiring a college degree (Seo & Chen, 2009).

The choice to conceal or disclose their disability status depends on weighing the costs and benefits of self-disclosing (Riddell & Weedon, 2014). A positive aspect of disclosing their disability status within the university is that the university can usually ensure students receive accommodations (Adams & Proctor, 2010; Vickers, 1997). Despite the advantages of disclosing their disability status, students often choose to hide their status and aim to pass as normal in an attempt to avoid stigma and discrimination (Åsbring & Närvänen, 2002; Moore, 2012; Riddell & Weedon, 2014; Vickers, 1997). There might be little motivation to disclose a chronic illness if others will not believe the illness or if the illness is highly stigmatized. Indeed, students report experiencing suspicion and lack of confidence from instructors after choosing to disclose their status (Riddell & Weedon, 2014) and choosing to disclose can be described as "damned if you do, damned if you don't" (Moore, 2012, p. 208).

Often, in terms of deadline extensions and disability related absence accommodations, Disability Support Services offices leave these decisions up to the discretion of the instructor. Many students with a hidden chronic illness report being told by professors that they could not receive disability-related accommodations because this would not be fair to the other students (Jung, 2002). Due to strict attendance policies, cumulative absences will eventually force students to self-disclose their invisible chronic illness. Additionally, some illnesses may lead others to doubt a legitimate need for accommodations that may require frequent absences from class during acute episodes or exacerbations. Furthermore, students may then be reluctant to self-identify and request accommodations from faculty who may not see any obvious impairment" (Korbel et al., 2011, p. 19). Students might also be reluctant to disclose for fear of discrimination and fear that future employment prospects within the field of their studies will be impacted (Riddell & Weedon, 2014). For some individuals, choosing not to disclose is the most rational choice in a situation (Matthews, 2009).

It is important to note that one of the authors of this study is a current female college student living with hidden invisible illnesses. The author entered college with major depressive disorder, generalized anxiety disorder, and post-traumatic stress disorder. However, in the course of her college experience, she began to experience physical symptoms that first led to a misdiagnosis of multiple sclerosis then later to a diagnosis of fibromyalgia. The author approaches this research using her own personal experience

while also recognizing that no two individual experiences are ever the same.

Data and Methods

Quantitative data, using self-report surveys, were collected from female college students living with a hidden chronic illness who were located at a state university in the Southwestern U.S. This study was approved as exempt by the university's Institutional Review Board.

The online survey collected demographic information about the participants, which included each participant's age, race, sex, ethnicity, socioeconomic status, marital status, and the number of years the participant has attended college. The sample includes both undergraduate and graduate female students who were, at the time of the study, enrolled at the university. A recruitment email was sent to all registered students at the university (at the time approximately 15,500 students), which included a full description of the study, as well as a URL link that students could click if they chose to complete the voluntary online anonymous survey. After the recruitment process was complete, participants had a one-month period to complete the survey. A total of 118 responses were obtained. After examination of the responses, the incomplete surveys were discarded, leaving 105 completed surveys, which were chosen for analysis.

The survey used in this study collected data concerning each respondent's (a) attitudes toward and perceptions of their experiences and identity as a female college student living with a hidden chronic illness, (b) attitudes toward feeling included in day-to-day college life, (c) whether or not they perceive that they have equal access to programs at their University, and (d) their attitudes and perceptions towards social acceptance. Each item used a five-point Likert scale format. The survey used in this study contains a total of 72 questions and was pilot tested with a panel of three individuals before distribution. These three individuals were current or former graduate students who are living with a chronic illness. Items were revised for clarity as needed based on a review of the pilot test. A substantial number of the items came from previously validated instruments. Specifically, 24 of the 72 items came from previously validated instruments.

To measure participants' coping and adjustment strategies, survey items 1-5 and 21 were drawn from COPE, which is a questionnaire developed to assess the different ways individuals respond to and manage stress (Carver et al., 1989). Additionally, items 8-9, 33, 35-36, which pertain to self-management of

chronic illness, were drawn from The Chronic Illness Resources Survey (Glasgow et al., 2000). In order to examine the impact chronic illness has on the identity of each participant, survey items 10-20 and 24 were taken from the Revised Illness Perception Questionnaire (Moss-Morris et al., 2002) and items 26 and 29 were taken from Rosenberg's (1965) Self-Esteem Scale. The remaining items were created for the purposes of this survey.

Data analysis was completed with SPSS 25. Frequency distributions and contingency tables were used to examine trends and patterns in the responses and to address the research questions. To ensure accurate interpretations of the data, participants who had not registered with DSS (76 cases) were excluded from the data analysis that involved questions about DSS services. Additionally, participants who had not requested accommodations from individual instructors (58 cases) were also excluded from the data analysis concerning instructor accommodations.

Results

The most frequently reported chronic illnesses, depicted in Table 1, were chronic migraines (24.8%), asthma (18.1%), and irritable bowel syndrome (17.1%), which is similar to the general population (Beatty, 2018). General demographic information on the participants can be found in Table 2. Table 3 shows that a total of 39% of participants reported that their illness was progressive, 26.7% indicated that their illness was not progressive, and 34.3% were not sure. At the time the survey was completed, 85.7% of participants indicated that their chronic illness does follow a relapsing-remitting pattern. The length of time participants had been diagnosed with their chronic illness or illnesses varied, with 29.5% responding that they had been diagnosed for less than 1 to 3 years and 22.9% responding that they had been diagnosed for four to seven years.

This study also examined the relationship between age and whether participants believe that they are capable of completing college and holding down a job. As shown in Table 4, while the sample is skewed toward younger years, the majority agreed or strongly agreed that they have adapted to college. Somers D showed (.013; $p > .05$) no statistically significant relationship between age and the perception of ability to complete college and hold a job. Given the skew of the sample, it is harder to draw firm conclusions about the relationship between age and adaptation to college. Additionally, we examined the relationship between time since diagnosis and respondents' belief that they are capable of completing college and

holding a job, as shown in Table 5. The findings indicate that those who have had their diagnosis for the longest periods of time tend to agree that they have adapted the best to college and seem more likely to strongly agree (4-7 years and more than 12 years). However, Somers D indicated (-.08; $p > .05$) no statistically significant relationship between the number of years since diagnoses and belief in capability of completing college and holding a job.

Research Question 1

Survey results that pertain to the first research question are summarized in Table 6. This question asked how female students feel about their chronic illness in general. The vast majority of participants viewed their chronic illness as a serious condition (67.7% agreed or strongly agreed) and the vast majority also reported that their chronic illness has had a strong impact on their life (92.7%). Additionally, the results also indicate that the majority of participants have faced serious financial consequences because of their illness (68.5%). Respondents reported that their illness has had other negative effects on them as well, including depression (53.3%), anger (52.3%), fear (50.4%), and anxiety (72.4%). In terms of accepting their chronic illness, most had come to some degree of acceptance of their condition, with 68.6% of survey participants agreeing or strongly agreeing with the statement, "I accept my illness diagnosis and that it can't be changed," and 75.3% agreed or strongly agreed with the statement, "I am used to the idea that I have a chronic illness." Taken together, the findings for this question suggest that most female college students living with an invisible chronic illness view and accept that their illness is a serious condition that has negatively impacted their finances and emotional well-being.

Research Question 2

Research Question 2 asked how the identity of the respondents as persons with an invisible chronic illness has been impacted by attending college. The findings in Table 7 indicate that close to a third (31.4 %) of the respondents reported that they have spent a moderate or large amount of time grieving the person they were before their illness. Nearly two thirds (64.8%) of participants reported that they either agreed or strongly agreed that they often view their body as a barrier, which is known to impact one's identity.

For the purposes of this study, identity is defined as the set of meanings associated with the self (Burke & Stets, 2000). Disability identity is defined as both an individual and social phenomenon, which is known to change based on the context of the sociocultural

Table 1*Most Commonly Reported Types of Chronic Illness(es) of Participants*

Type of Chronic Illness	N	Percentage
Chronic Migraines	25	23.8
Asthma	19	18.1
IBS	17	16.2
Endometriosis	16	15.2
Fibromyalgia	16	15.2
Hashimoto's Thyroiditis	15	14.3
Arthritis	13	12.4
Chronic Fatigue Syndrome	10	9.5
Diabetes	8	7.6
Rheumatoid Arthritis	8	7.6
Ulcerative Colitis	7	6.7
Unknown Differing Diagnosis	7	6.7
Cancer	7	6.7
Mold Sensitivity	4	3.8
Crohn's	4	3.8
PCOS	4	3.8
Celiac	4	3.8
Complex Regional Pain Syndrome	4	3.8
Multiple Sclerosis	3	2.9
Hypoglycemia	3	2.9
Lyme Disease	3	2.9

Note. N=105.

Table 2*Characteristics of Participants*

Item	N	Percentage
Age Group		
17-21	22	20.9
22-26	34	32.4
27-31	10	9.5
32-36	14	13.3
37-41	8	7.6
42-51	10	9.5
52-66	4	3.8
67+	3	2.9
Ethnicity		
White	75	71.4
Hispanic or Latino	15	14.3
African American	10	9.5
American Indian or Alaska Native	4	3.8
Asian	1	1.0
Type of Employment		
Full time	34	32.4
Part time	39	37.1
Unemployed	32	30.5
Length of time as a student at this university		
1-2 semesters	42	40.0
3 semesters to 1.5 years	28	26.7
2-3.5 years	23	22.0
4-5 years	8	7.6
6+ years	4	3.8
Highest Level of Education		
High school or GED	30	28.6
Associates Degree	24	22.9
Bachelor's Degree	36	34.3
Master's Degree	14	13.3
Doctoral Degree	1	1.0

Note. N=105.

Table 3*Information About Participants' Illness*

Item	N	Percentage
Years diagnosed with illness		
1-3 years	31	29.5
4-7 years	24	22.9
8-11 years	19	18.1
12+ years	31	29.5
Is your chronic illness progressive?		
Yes	41	39.0
No	28	26.7
I don't know	36	34.3
Does your illness follow a relapsing-remitting pattern?		
Yes	90	85.7
No	13	12.4
I don't know	2	1.9

Note. N=105.

Table 4*Age and Self-Reported Level of Adaptation to College*

I am Capable of Completing College and Holding a Job						
Age	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Total
	(N) %	(N) %	(N) %	(N) %	(N) %	(N) %
17-21	(1) 4.5	(2) 9.1	(2) 9.1	(6) 27.3	(11) 50.0	(22) 21
22-26		(8) 23.5	(4) 11.8	(6) 17.7	(16) 47.1	(34) 32.4
27-31	(1) 10.00	(1) 10.00	(1) 10.00	(3) 30.0	(4) 40.0	(10) 9.5
32-36		(1) 7.1	(1) 7.1	(8) 57.1	(4) 28.6	(14) 13.3
37-41		(2) 25.0		(4) 50.0	(2) 25.0	(8) 7.6
42-46		(1) 16.7		(1) 16.7	(4) 66.7	(6) 5.7
47 -51		(1) 25.0		(1) 25.0	(1) 25.0	(4) 3.8
52-56	(1) 25.0			(1) 25.0	(2) 50.0	(4) 3.8
57-61					(1) 100.0	(1) .95
62-66		(1) 100.0				(1) 100.0
67+	(1) 33.0	(1) 33.0	(1) 33.0			(3) 2.9

Note. $N = 105$; Somers $D (-.081; p=.364)$.

Table 5*Length of Time Since Diagnosis and Adaptation to College*

Years Since Diagnosis	I am Capable of Completing College and Holding a Job					Total
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	
	(N) %	(N) %	(N) %	(N) %	(N) %	
1-3 years	(1) 3.2	(5) 16.1	(6) 19.3	(9) 29.0	(10) 32.2	(31) 29.5
4-7 years	(1) 4.16	(4) 16.7	(2) 8.3	(5) 20.8	(12) 50.0	(24) 22.9
8-11 years	(1) 5.3	(3) 15.8		(9) 47.4	(6) 31.6	(19) 18.0
12 + years	(1) 3.2	(5) 16.1	(1) 3.2	(7) 22.6	(17) 54.8	(31) 29.5

Note. N=105; Somers D (.115; p=.182).

Table 6*How Participants Feel About Their Chronic Illness*

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
	(N) %	(N) %	(N) %	(N) %	(N) %
My illness is a serious condition	(28) 26.7	(43) 41	(23) 21.9	(8) 7.6	(3) 2.9
My illness has major consequences on my life	(41) 39	(50) 47.6	(7) 6.7	(6) 5.7	(1) 1
My Illness does not have much effect on my life		(4) 3.8	(4) 3.8	(45) 42.9	(52) 49.5
My illness has caused serious financial consequences	(39) 37.1	(33) 31.4	(13) 12.4	(17) 16.2	(3) 2.9
I get depressed when I think about my illness	(23) 21.9	(33) 31.4	(22) 21	(19) 18.1	(8) 7.6
My illness makes me feel angry	(16) 15.2	(39) 37.1	(19) 18.1	(20) 19	(11) 10.5
My illness makes me feel afraid	(18) 17.1	(35) 33.3	(19) 18.1	(22) 21	(11) 10.5
Having this illness makes me feel anxious	(30) 28.6	(46) 43.8	(17) 16.2	(12) 11.4	(4) 3.8
I accept my illness diagnosis and that it can't be changed	(26) 24.8	(46) 43.8	(17) 16.2	(12) 11.4	(4) 3.8
I am used to the idea that I have a chronic illness	(32) 30.5	(47) 44.8	(9) 8.6	(15) 14.3	(2) 1.9
Sometimes when I think about my illness, I say to myself 'this isn't real'	(5) 4.8	(28) 26.7	(10) 9.5	(30) 28.6	(32) 30.5
There is very little that can be done to improve my illness	(21) 20	(37) 35.2	(23) 21.9	(17) 16.2	(7) 6.7

Note. N=105.

Table 7*How Has College Impacted Their Identity*

	A lot	Medium Amount	Little bit	Not at all	
	(N) %	(N) %	(N) %	(N) %	(N) %
I spend time grieving the person I was before the onset of my illness	(12) 11.4	(24) 22.9	(30) 28.6	(39) 37.1	
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
	(N) %	(N) %	(N) %	(N) %	(N) %
I often view my body as a barrier	(28) 26.7	(40) 38.1	(23) 21.9	(13) 12.4	(1) 1.0
I have felt judged by others regarding the legitimacy of my symptoms	(55) 52.4	(30) 28.6	(8) 7.6	(9) 8.6	(3) 2.9
My illness strongly affects the way others see me	(7) 6.7	(25) 23.8	(20) 19	(28) 26.7	(25) 23.8
Despite my illness, I feel just as capable as the next person of completing college and holding a job	(45) 42.9	(30) 28.6	(9) 8.6	(17) 16.2	(4) 3.8
I feel that I am a person of worth on an equal plane with others	(49) 46.7	(36) 34.3	(13) 12.4	(6) 5.7	(1) 1.0
There have been occasions when I have avoided social situations because of my illness	(43) 41.0	(51) 48.6	(3) 2.9	(8) 7.6	
Even though I have a chronic illness, it has not affected my ability to sustain close relationships	(23) 21.9	(36) 34.3	(10) 9.5	(27) 25.7	(9) 8.6

Note. N=105.

environment and how that environment defines disability (Evans et al., 2017). Also known to impact identity is the way others view a person in terms of their chronic illness, in which others' perceived feelings become internalized (Evans, 2017). The process of identity development is fundamentally a social process in which "identities are formed through mirroring, modeling, and recognition through available identity resources" (Forber-Pratt et al., 2017, p. 198). According to social identity theory, "people prefer to see themselves in a positive light, which implies that there will be a general search for positive distinctiveness in their perceptions of and dealings with other groups" (Brown, 2020, p. 5). A key finding is that 81% of respondents agreed or strongly agreed that they have felt judged by others regarding the legitimacy of the symptoms caused by their chronic illness. However, in a seeming contradiction, when asked to respond to the statement "My illness strongly affects the way others see me," just over half (50.5%) disagreed or strongly disagreed with this statement.

The vast majority of participants (89.6%) agreed or strongly agreed that there have been occasions when they have avoided social situations because of their chronic illness. However, it is important to note that avoiding social situations on occasion because of a chronic illness does not necessarily mean that living with a chronic illness prevents one from sustaining close relationships with others. In fact, over half (56.2%) of the participants agreed or strongly agreed that their chronic illness has not affected their ability to sustain close relationships. The ability to sustain close relationships has the potential to impact one's identity. Taken together, the findings in Table 7 suggest that having a chronic illness profoundly affects, in a number of ways, one's identity and construction of self.

Research Question 3

The third research question asked how female students with an invisible chronic illness adjust to and cope with their chronic illness in the new context of college. Findings are reported in Table 8, which shows that participants reported using a number of strategies to adjust to college and to cope with their chronic illness. Only a small percentage (7.6%) reported self-medicating with drugs or alcohol as a way of coping and instead, respondents (54.3%) were much more likely to report seeking out support and someone to talk to about how they felt. The results in Table 8 also indicate that time management is an important consideration for students with a chronic illness. Almost three fourths (74.3%) of respondents agreed or strongly agreed with the statement, "I manage my time by planning ahead and prioritizing activities ac-

ording to limited energy and phases of fatigue" and over half (55.2%) indicated that they either spend "quite a bit" or "a great deal" of time arranging their schedule so that they could more easily do the things they need to get done in daily life because of their illness. Taken together, the findings here suggest that the majority of the respondents living with an invisible chronic illness engage in a number of adaptive coping strategies such as time management, and seeking social support while attending college.

Research Question 4

Research Question 4 asked how female college students with an invisible chronic illness perceive the effectiveness of accommodations provided by individual instructors, DSS, and the university overall. Results for this question, presented in Table 9, reveal that about a quarter of respondents (24.7%) disclosed their illness to instructors only if necessary. In fact, 18.1% of survey respondents reported that they have felt they have had to disclose their chronic illness to instructors when they were not comfortable doing so. In terms of comfort with the process of disclosing to instructors, a significant percentage (43.8) reported discomfort. Over half (56.2%) of the survey respondents reported that they had not received accommodations from instructors for their chronic illness. Of the participants who have received accommodations from instructors (43.8% of the sample), 58.7% agreed or strongly agreed that the accommodations they received were appropriate, 56.5% agreed or strongly agreed that the accommodations were adequate, and 77.1% of respondents indicated that they had never been denied an accommodation from an instructor.

Over two thirds (67.3%) of respondents had not registered with DSS. Of those respondents who had registered with DSS, only about 40% (41.2%) felt that the process to register with DSS at this university was easy. These respondents were also asked to evaluate how knowledgeable the DSS office was concerning chronic illnesses. Over half (52.9%) took a neutral position, neither agreeing or disagreeing, while 7.6% either agreed or strongly agreed that the DSS office is knowledgeable of chronic illness and 8.6% disagreed or strongly disagreed. Almost half of the respondents (47.1%) were neutral concerning the adequacy of their accommodations provided by DSS. Almost a third (32.3%) agreed that accommodations received from DSS were appropriate, while 10.5% either agreed or strongly agreed and 5.7% either disagreed or strongly disagreed that DSS accommodations were appropriate.

Table 9 indicates that a large majority of the participants reported feeling valued as a student at this

Table 8*How Participants Adjust to College and Cope with Their Illness*

	A lot	Medium	Little bit	Not at all	
	(N) %	(N) %	(N) %	(N) %	(N) %
I use alcohol or drugs to make myself feel better	(2) 1.9	(6) 5.7	(21) 20.0	(76) 72.4	
I drink alcohol or take drugs in order to think about my illness less	(1) 1.0	(4) 3.8	(9) 8.6	(91) 86.7	
When I need support, I talk to someone about how I feel	(11) 10.5	(46) 43.8	(26) 24.8	(22) 21.0	
	A great deal	Quite a bit	Moderate amount	A little	Not at all
	(N) %	(N) %	(N) %	(N) %	(N) %
To what extent have you arranged your schedule so that you could more easily do the things you need to get done in daily life because of your illness	(29) 27.6	(29) 27.6	(24) 22.9	(18) 17.1	(5) 4.8
To what extent have you thought about or reviewed how you were doing in accomplishing your disease management goals	(25) 23.8	(26) 24.8	(22) 21.0	(27) 25.7	(5) 4.8
	2X week	1X week	2X month	1X month	Bi-monthly
I spend ___ amount of time attending doctors' appointments related to my chronic illness	(2) 1.9	(8) 7.6	(18) 17.1	(26) 24.8	(51) 48.6
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I try to see my illness in a positive light	(18) 17.1	(39) 37.1	(28) 26.7	(13) 12.4	(7) 6.7
I learn to live with my chronic illness	(39) 37.1	(55) 52.4	(8) 7.6	(2) 1.9	(1) 1.0
I manage my time by planning ahead and prioritizing activities according to limited energy and phases of fatigue	(34) 32.4	(44) 41.9	(15) 14.3	(6) 5.7	(6) 5.7

Note. N=105.

Table 9*Perceived Effectiveness of Accommodations*

	Always	A lot of the time	Moderate amount	A little	Not at all
	(N) %	(N) %	(N) %	(N) %	(N) %
This university has rules or policies that make it easier for me to manage my illness	(7) 6.7	(16) 15.2	(31) 29.5	(21) 20.0	(30) 28.6
I've had a flexible school schedule so that I could adjust to meet my needs	(13) 13.3	(32) 30.5	(19) 18.1	(21) 20.0	(19) 18.1
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
I feel valued as a student.	(24) 22.9	(56) 53.3	(16) 15.2	(5) 4.8	(4) 3.8
I have felt pressured to take online courses because of my illness	(37) 35.2	(26) 24.8	(22) 21.0	(10) 9.5	(10) 9.5
My illness prevents me from being involved in campus activities	(13) 12.4	(21) 20.0	(32) 30.5	(26) 24.8	(13) 12.4
Having my illness makes it more difficult for me to make friends in college	(8) 7.6	(21) 20.0	(19) 18.1	(28) 26.7	(29) 26.6
I engage in efforts to hide my illness	(25) 23.8	(34) 32.4	(14) 13.3	(25) 23.8	(7) 6.7
The accommodations I have received from instructors have been appropriate	(8) 7.6	(19) 18.1	(75) 71.4	(1) 1.0	(1) 1.0
The accommodations I have received from instructors have been adequate	(7) 6.7	(19) 18.1	(74) 70.4	(3) 2.9	(2) 1.9
The accommodations I have received from DSS have been appropriate	(5) 4.8	(6) 5.7	(88) 83.8	(1) 1.0	(5) 4.8
The accommodations I have received from DSS have been adequate	(6) 5.7	(6) 5.7	(86) 81.9		(7) 6.7
My instructors are knowledgeable of chronic illness issues and disability-support accommodations	(10) 9.5	(24) 22.9	(50) 47.6	(11) 10.5	(10) 9.5
The DSS office is knowledgeable on chronic illnesses.	(5) 4.8	(3) 2.9	(88) 83.4	(7) 6.7	(2) 1.9
	Frequently	On Occasion	Twice	Once	Never
Have you ever been denied an accommodation from an instructor?.	(4) 3.8	(4) 3.8	(4) 3.8	(16) 15.2	(77) 73.3

Note. N=105.

university. However, nearly half (48.6%) reported that university rules or policies have not made it easier for them to manage their illness. Respondents were also asked about their ability to create a flexible school schedule that they could adjust to meet their needs. The largest single percentage (43.8%) reported that they always or a lot of the time had flexibility to do so. Over half (56.2%) of participants reported that they engage in concealment strategies.

The three most common symptoms that participants listed as posing the biggest challenge to their success at this university included fatigue (76.2%), headaches (44.5%), and gastrointestinal issues (42.9%). Over half (60%) agreed or strongly agreed that they had felt pressure to take online courses as opposed to face-to-face courses because of their chronic illness, while just over half (51.5%) reported that their illness did not negatively impact their attendance. The two most commonly listed accommodations that are the most important to their success at this university were absence accommodations (55.2%) and extended time to complete assignments (31.4%). Taken together, the findings from this question suggest that most female students who are living with an invisible chronic illness will disclose their illness to instructors only when absolutely necessary. Fatigue was reported as the symptom that poses the biggest challenge to the success of students with chronic illness. Additionally, female students living with an invisible chronic illness at this university often considered requiring medical documentation a barrier to receiving accommodations, and that their most needed accommodation was absence accommodations.

Discussion

It is clear that the majority of female students surveyed feel that their chronic illness is a serious condition that has profoundly impacted their life. While the majority have come to terms with accepting their illness, large numbers of respondents reported that they continue to experience significant emotional effects, including anxiety, depression, anger, and fear. This finding is consistent with other research, which has also suggested that anxiety is prevalent amongst the chronically ill population (Adams & Proctor, 2010; Livneh, Martz, & Wilson, 2001; Vickers, 2017). Nearly all of the participants indicated that they have avoided social situations because of their chronic illness. Avoiding potential stigma in social situations could partially explain this finding because the vast majority of respondents reported having felt that others often misunderstand their illness and questioned the legitimacy of their illness symptoms (Goffman,

1963). The finding of participants viewing their body as a barrier and spending a significant amount of time grieving the person they were before their illness onset indicates that having a chronic illness while attending college has the potential to profoundly impact one's identity and construction of self. An encouraging finding was that despite their perceptions of being misunderstood and judged by others, most respondents were still able to maintain (a) a sense of themselves as capable of functioning effectively in the world and (b) positive feelings about themselves, both of which are consistent with social identity theory's contention that "people prefer to see themselves in a positive light" (Brown, 2020, p. 5).

Coping strategies of participants revolved around time management, self-acceptance, reframing how they think about their illness, and seeking support from others. Time management was found to be important to the vast majority of participants due to fatigue and limited energy caused by their chronic illness. Significantly, over three quarters of participants listed fatigue as the symptom that poses the biggest challenge to their success at this university, which extends prior knowledge on the hidden chronic illness experience (Moore, 2012). The findings also indicate that the majority of respondents disclosed their illness to instructors only if necessary and a small percentage of respondents indicated that instructors have been unwilling to provide accommodations in the past. It was not surprising that more than any other accommodation, absence accommodations were reported by participants to be the most important to their success at this university. This might also partially explain the finding that around 60% of the survey participants reported that they have felt pressured to take online courses due to their illness.

This study is consistent with previous research that finds that requiring medical documentation of a disability is a barrier to receiving accommodations (Riddell & Weedon, 2014); almost a quarter of participants listed medical documentation as a barrier that they have experienced to receiving accommodations. Most students did not perceive being negatively judged by their peers for absences or lack of participation, however almost a quarter indicated that they had perceived negative judgement from their instructors due to their chronic illness. A new finding that should not be taken lightly was that students with a hidden chronic illness have actually received entire letter reductions in their grades due to compulsory attendance policies

Implications

The findings in this study suggest the need for universities to review their policies that disadvantage students with hidden chronic illnesses. Universities should take into consideration how policies disadvantage students with invisible illnesses by using the British Social Model of Disability, which can help shed light on the struggles faced by students living with an invisible chronic illness. According to this model, when social structures, such as university departments and offices, fail to properly accommodate individuals with hidden chronic illnesses, they further contribute to oppressing and disadvantaging this population (Clark, 2006; Evans, 2017). The findings in this study suggest that public universities should focus not only on ADA compliance, but also on inclusion of all marginalized students, which includes students with hidden illness.

The data in this study imply that higher education needs to find ways to encourage disclosure among students and faculty. Students with chronic illnesses may perceive that disclosure may be stigmatizing and would not necessarily lead to improved outcomes for them. The situation with disclosure may be complicated by gender specific issues such as aspects of traditional gender role socialization that may discourage women from stepping forward and disclosing their illness. In addition, racial or ethnic issues may impact the willingness and comfort of female students in disclosing their disability status.

The findings suggest a continued need for theory development that effectively develops and elaborates a more detailed understanding of the experiences of college females who are coping with a potentially stigmatizing chronic illness while also navigating the experience of higher education in an institutional setting that may lack the flexibility to effectively accommodate their needs. Additionally, a more fully developed theoretical understanding should incorporate an understanding of the intersectional effects of race, ethnicity, and gender.

Encouraging disclosure means raising disability awareness and fostering positive attitudes towards disability. Fostering an environment that provides students with invisible chronic illnesses to meet other students in similar situations can provide “a sense of validation of your physical condition, of your emotional feelings and perhaps some relief from isolation” (Moore, 2012, p. 206). Instructors can provide better accommodations to students when they are aware of a student’s hidden impairments; thus, our findings suggest that educational institutions need to find ways to foster an environment that encourages students to disclose their hidden impairments (Matthews, 2009).

Disability services offices can play a role in fostering greater faculty awareness of disability issues so that faculty are better informed and can therefore be more easily enlisted as advocates for students with hidden disabilities in need of accommodations.

A number of colleges and universities have programs in place that may be helpful for disability offices to consider implementing. Marist College in Poughkeepsie, New York has a specific program in their disability support office that helps to prepare students to discuss their accommodation needs with professors (Understood For All Inc, 2020). The University of Michigan’s disability support office created “Campus Mind Works,” which is an online resource where students who are diagnosed with an ongoing mental health disorder can get information about managing their illness as well as how to get the most out of their college experience (University of Michigan, 2020). Additionally, the University of Michigan’s disability support office has a separate and specific registration process for students with chronic health conditions.

The findings in this study suggest that university policies regarding absences should be examined and revised when it is determined that these policies may be disadvantaging students with hidden chronic illness. The finding that a small percentage of participants have experienced reductions in their grades as a result of missing class due to their chronic illness should not be taken lightly. This finding was compounded by the fact that more than any other accommodation, absence accommodations were reported by participants to be the most important to their success as students. The findings in this study suggest that it may be challenging for students with hidden chronic illnesses to succeed in environments that implement compulsory attendance policies. Colleges and universities should review and revise policies of this nature that are a hindrance to students with hidden chronic illness. Additionally, the finding that over a quarter of participants listed medical documentation as a barrier to receiving accommodations means that this needs to be addressed by DSS offices as well.

Limitations and Future Research

It is crucial that future research continues to further explore obstacles and barriers faced by female college students who are living with an invisible chronic illness. Future research should also continue to examine how this population adjusts and copes with their illness, and propose potential policy solutions within colleges and universities.

Because African American women comprised only 9.5% of this study’s sample, this study does

not capture the chronic illness experience of African American women attending college. The heterogeneity of the factors mentioned above in this sample washes out between group differences, which can cause us to overlook important aspects of different individuals' experiences. For example, given that African American women are affected by Lupus at higher rates than any other female ethnic group, research regarding the chronic illness experience of African American college women is needed and necessary (Rosales & Person, 2003).

Additionally, because quantitative studies often fail to fully capture true depictions of the invisible chronic illness experience, authentic narratives of those living with invisible chronic illness while attending college are crucial to a complete understanding of such lived experiences (Moore, 2012). Detached, removed third parties have conducted most of the current research on this topic, which highlights the need for more research in this area to use an auto-ethnographic process to better capture the chronic illness experience (Green et al., 2005; Moore, 2012; Pena, 2014). Additionally, a participatory action approach may be helpful to researchers. Due to all participants being from the same geographical location, results cannot be generalized to all female college students living with a hidden chronic illness. Another limitation of this study is that the survey relied on the honesty and accuracy of the participants' responses.

The finding that 60% of the survey participants reported that they have felt pressured to take online courses due to their illness warrants further investigation. As noted, a significant percentage of the respondents reported that they had not registered with DSS. One possible reason for this finding is that students may not realize that they qualify for accommodations through DSS because of their chronic illness. Another possibility is that students are fearful of discrimination and potential stigma that comes with registering with DSS, as this study revealed that fear of discrimination and stigma was prevalent among respondents who were living with an invisible illness. The finding that 81% of the participants either agreed or strongly agreed that they have felt judged by others regarding the legitimacy of their illness symptoms, as well as the fact that over half of the participants engage in "concealment strategies" (Goffman, 1963, p. 87), reaffirms that living with an invisible illness is often extremely stigmatizing.

The majority of respondents reported having felt that others often misunderstand their illness, question the legitimacy of their illness symptoms, that they have avoided social situations because of their illness. They often view their body as a barrier, and they

spend a significant amount of time grieving the person they were before their illness onset, all of which indicate that having a chronic illness while attending college has the potential to profoundly impact one's sense of identity and construction of self. At the same time, a reassuring finding in this study reveals that in spite of the struggles faced by respondents, most were still able to maintain a sense of themselves as capable of functioning effectively in the world with positive feelings about themselves as well as utilize healthy coping skills.

Additional research is warranted to investigate how the identity of a person with a chronic illness changes and adjusts throughout the life experience. Constantly fluctuating and progressing symptoms of chronic illness require continual adjustments on behalf of the person, which means that the process of adjustment will be ongoing and changing (Bury, 1982; Mintz, 2007). Disruptions in the everyday taken-for-granted assumptions in the individual's plans for the future that so often characterize chronic illness cast a shadow of anxiety and uncertainty for the college student living with an invisible illness (Riddell & Weedon, 2014). Understanding how invisible chronic illness impacts the lives of female college students should be important to universities because this population is increasing, but it should also be important to scholars because much can be learned about day-to-day situations by analyzing situations and circumstances that are "radically disturbed" (Bury, 1982, p. 169; Moore, 2012).

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