

Introduction

- The Centers for Disease Control (CDC) defines chronic disease as a condition that lasts 1 or more years, requires ongoing medical attention and/or limits activities of daily living.
- One in four students in the US, ages 6-19, lives with a chronic disease (CDC, 2019).
- Studies have shown that college students with chronic illness find it difficult to succeed in traditional degree programs due to disruption caused by relapses and unpredictable waxing and waning symptoms.
- College students who are 18 to 22 years of age, are transitioning from childhood/adolescence to adulthood.
- Living with a chronic illness can challenge the transition when there is a lack of support and shifts in wellness.

Purpose

The purpose of this project is to describe the meaning of the lived experience of college students with a chronic illness.

Sample

Study participants were students living with a chronic illness

- Age range 18-22
- N=4 (Female, n=3; Male, n=1)
- Not born with a chronic illness
- Have had experience in a college level environment
- Able to speak and understand English
- Lives in the Chicagoland area

Methods/Procedures

Design: Cross-sectional, descriptive qualitative design

Recruitment: Social networking; chain sampling technique

Data Collection: In-depth interviews using semi-structured interview guide with open-ended questions

Analysis

- Interviews were transcribed verbatim
- Coding was done after reading through the transcripts
- Repeating ideas were put into categories, themes, and subthemes



Findings

Stressors

Participants describe multiple stressors related to:

Balancing academics and illness:

“I would just be in pain and it really affected me mentally because I had to just try to balance school, and (my extra-curricular responsibilities), and not being able to do those things impacted my ability to focus on school and spending time with friends, and it kind of impacted my college experience.”

Social Exclusion:

“For my friends, I didn’t really know how to tell them. I can’t always do the same stuff they do and that was a bad thing my freshman year.”

Unpredictability of Illness:

“For me I still have it now, so they still don’t know if it’s going to go away or if it’s going to stay, so there’s a lot of uncertainty.”

Feelings of Guilt and Burdensome:

“I shouldn’t feel bad, but I still feel bad. I can’t control when I have a low blood sugar, but it almost feels like I’m walking in and the professor almost kind of doubts as if I really have a low blood sugar”

Lack of support:

“I don’t think that many professors are that understanding about issues with students with chronic illness.”

Self Advocacy

All participants shared the importance of self-reliance and necessity to advocate for themselves in order to manage their academic performance and manage their chronic illness in an academic environment.

“I had to navigate how I could feel good enough and still be in the major to still feel good just because I have this chronic illness and it’s not gonna change that”

Support

Participants describe the importance of social support to help them cope with stress and it came from a variety of sources:

“I made a lot more friends that I think are more understanding and I feel I can talk to them about it.”

Participants expressed the loss of support from family members when they came to college:

“My mom is a really big support for me and not having her around was very different”

University policies are vital to protect and support students with chronic illness:

“If I didn’t have those and professors who were not legally binded to give me those accommodations then I wouldn’t consider myself as having that much support.”

Discussion

Conclusion:

- In this sample, themes that describe the experiences of college students living with a chronic illness include perceived stresses, self advocacy and support.
- Participants indicate that they have stress about managing school and illness in college, balancing a social life, feeling guilt and having stress about the future and chronic illness management.
- Self- Advocacy can be seen when students are trying to manage their illness and make academic accommodations.
- Support systems were found amongst families and peers
- Issues of support arise when talking about campus support, the students often felt guilty or unsupported by their campus and professors
- Participants feel empowerment and self-advocacy skills are necessary in order to balance chronic illness and academics.

Implications:

- Universities should include faculty and staff development about students’ chronic illness and potential accommodations needed.
- Universities should provide a workshop surrounding social emotional learning for staff faculty and students to encourage empathy and inclusivity.
- Offer support groups on campus for students who have chronic illness.
- Students need to be informed about 504 and eligibility prior to college or within the first semester to provide adequate learning environment
- Continue to empower college students with chronic illness and actively listen to their concerns.

Future Research

- Larger sample size
- Exploring the experience of college professors who interact with college students recently diagnosed with chronic illness.
- Exploring the lives of college students with a chronic illness who also face financial pressures.
- Exploring the experience of a full-time college student diagnosed with a chronic illness within the last year.
- A longitudinal study that follows students living with a chronic illness from beginning to high school to end of college.

Acknowledgements

- Special thank you to Dr. Jorgia Connor for guiding me through the research process.
- This project is dedicated to my peers who are living with a chronic illness and were lovely enough to share their experiences for this project.
- And lastly, I would like to thank my parents, Bernadette and John Anichini, for supporting my research endeavors.

