

# Students with Anxiety Disorders: Self-Advocacy, Daily Life Activities, and Meaningfulness of the College Experience

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## Abstract

Students with disabilities are attending college in increasing numbers (Kim & Lee, 2016); consequently, academic, disability, and counseling resources directed toward full participation in the college experience are strained. To access support resources, college students must assume the responsibility of disclosing their disability and seek assistance without help from parents or teachers (Evans et al., 2017; McCarthy, 2007). Seeking assistance requires knowledge of resources and effective communication skills. Communication, especially the ability to advocate for self, is an essential, yet often a challenging skill for the student with a disability (Daly-Cano et al., 2015). Self-advocacy requires conveying needs and wants to achieve academic success and engagement in the college environment (Stodden et al., 2003). The purpose of this qualitative phenomenological descriptive inquiry was twofold: to understand how college students with an anxiety disorder perceive self-advocacy and second, to understand how self-advocacy influences their daily life activities related to the college experience. The results revealed that although self-advocacy was difficult to learn and master, students recognized the value of self-advocating. As students learned to self-advocate, they experienced more success responding to challenges. Further, students identified the most daunting daily life activities to navigate within the college environment as health management, education participation, communication management, social participation, and sleep participation. Study participants included a criterion purposive sampling of 10 college students. Eight students identified as female and two identified as male. The students ranged in age from 19-31 years old. They were diagnosed with an anxiety disorder, had disclosed their disability, and were registered with disability services.

*Keywords: self-advocacy, anxiety, college student, daily life activities, students with disabilities*

As students transition to college, they experience challenges including unfamiliar academic workloads, new daily life activities and personal responsibilities, and changing relationships (Traino et al., 2019). The transition for students with mental health disabilities may be even more concerning as they struggle to self-advocate for their academic rights (Kreider et al., 2015). According to the National Center on Education Statistics (NCES) and the National Council on Disability (NCD), the number of students with physical and mental health disabilities enrolling in college with the desire to obtain a degree continues to increase (Kim & Lee, 2016). National data reflect that approximately 19% of college students report having a disability (The Postsecondary National Policy Institute, 2018). Regarding a mental health diagnosis, onset typically occurs prior to age 25 (Alonso et al., 2018;

Hartrey et al., 2017; Schindler & Kientz, 2013) when some individuals are attending college and away from traditional support systems (Hartrey et al., 2017). Parent and teacher support, in the form of advocacy, is expected in elementary and secondary education, but in college, advocacy is the student's responsibility (Evans et al., 2017; McCarthy, 2007). The influential elements of self-advocacy aligned with this study include understanding oneself and one's rights, being able to communicate with others, and taking initiative (Daly-Cano et al., 2015). Lacking experiences to self-advocate, many students are simply unprepared to do so. Because students are unprepared to self-advocate, they often do not know where to turn for help on a college campus, thus impacting many aspects of their college experience (Hong, 2015; Johnson & Irving, 2008).

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Standard support for students with mental health disabilities on a college campus includes obtaining accommodations through disability services, seeking clinical management through a university or college counseling center, or a combination of both. Often, accommodations primarily focus on learning and academics, and the students' daily life activities are disregarded (Myers et al., 2013). This narrow focus can result in obstacles to full participation in campus life for the student with a mental health disability (Robbins et al., 2018). Overcoming these obstacles requires some degree of self-advocacy.

Self-advocacy is an important skill for individuals as they approach adulthood (Roberts et al., 2016). Understanding and advocating for disability rights are significant for the college student with a mental health disability as they navigate accommodations and daily life activities within the college environment. Focusing on students with anxiety disorders, this inquiry sought to understand perceptions of self-advocacy for the college student with an anxiety disorder, and to understand how self-advocacy influences daily life activities.

## Literature Review

### Disability Law and Mental Health

Disability law addresses the civil and legal rights of individuals with disabilities. These rights safeguard against discrimination in employment, housing, access to public services, and education. Passed in 1990, the Americans with Disabilities Act (ADA) is an all-inclusive act that ensures individuals with disabilities have the same opportunities as Americans without disabilities (U.S. Department of Justice Civil Rights Division, n.d.). A second essential act is the Rehabilitation Act of 1973. This Act states that a qualified individual with a disability shall not be excluded from programs receiving federal financial assistance, which includes colleges and universities (29 U.S.C. § 701). Thus, students with documented disabilities have both a civil and legal right to access education. Disability status is fluid and may vary in duration and timing, affect a variety of systems within the body, be stable, episodic, chronic or temporary and affect most people at some time in their lives (Evans et al., 2017). Compliance with disability law includes providing accommodations that facilitate learning or participation.

Recent data trends reveal the continual increase of college students with diagnosed mental health disabilities (Lipson et al., 2019). Three of five students report experiencing the feeling of "overwhelming anxiety" (Roy, 2018, p. 10). Although anxiety is

common for college students, it may be considered an anxiety disorder when experienced consistently (American Psychiatric Association, 2013). Anxiety involves emotions of worry and fear which may be an irrational response to a particular event (American Psychiatric Association, 2013). Anxiety disorders commonly disrupt student roles (Alonso et al., 2018) and affect identity perceptions (Vaccaro et al., 2015). Students with disabilities experience fluctuations in self-perceptions of identity through their interactions with others in the classroom and on campus. Thus, when a student's identity is impacted, participation in daily life activities, education, health management, and social activities becomes challenging (Kreider et al., 2015).

### Student Identity and Accommodations

Higher education institutions must comply with disability law. It is essential that students with disabilities understand their legal rights in education. Navigating the college experience requires having the ability to seek and advocate for resources, resulting in accommodations for identified and approved needs. Many students, however, have limited knowledge of the process and may even forgo accommodations (Kreider et al., 2015; Prince, 2015) due to:

- lack of self-advocacy skills (Hong, 2015)
- stigma, attitudes of unfairness, and cynicism from professors and peers as accommodations are used (Kreider et al., 2015)
- discrimination or fear of being treated differently from "normal" peers, being viewed as incapable of completing the coursework (Hong, 2015)
- social isolation from peers or being labeled as a "disabled person" when using accommodations (Hong, 2015, p. 220)
- lack of awareness of how to access or navigate disability services (Hong, 2015)
- desire for a sense of belonging (Vaccaro et al., 2015)
- desire for success without assistance (Kreider et al., 2015)

When students do not have adequate self-advocacy skills and choose not to pursue accommodations, academic performance and daily life activities become challenging (Fleming et al., 2018; Krieder et al., 2015).

### Daily Life Activities/Occupations

Daily life activities, also referred to as "occupations," within the methods and procedures of this

study include nine categories: activities of daily living (ADLs), instrumental activities of daily living (IADLs), health management, rest and sleep, education, work, play, leisure, and social participation (American Occupational Therapy Association, 2014). Expanding on the definition of daily life activities, they are “central to a person’s health, identity, and sense of competence and have particular meaning and value to that client” (p. S7). Some common examples of occupations for the college student include laundering clothes, cleaning their living space in a residence hall, accessing food sources on campus or grocery shopping, managing their time, managing their money, attending classes, seeking health care, or joining an organization. In brief, daily life activities include “things people need to, want to and are expected to do” (World Federation of Occupational Therapists, 2012, para. 2).

These daily life activities contribute to a well-balanced and fully functional lifestyle. Students with disabilities are particularly vulnerable to disrupted daily life activities within the college environment (Schindler, 2019) and may encounter challenges when struggling with adequate self-advocacy skills (McCarthy, 2007). Conversely, accommodating academic, domestic, and social aspects can result in a meaningful college experience (Spencer et al., 2018). When students with a mental health disability understand disability rights, issues of identity, the accommodation process, participation in daily life activities, and the significance of self-advocacy skills, they are better able to facilitate a meaningful college experience.

### **Statement of Significance**

In terms of seeking accommodations in college, parents and teachers, as discussed above, are no longer responsible for advocating on behalf of students (Evans et al., 2017; McCarthy, 2007). Instead, students who decide to seek accommodations must disclose their disabilities to a disability service professional on campus (Hsiao et al., 2018). According to McCarthy, (2007) “for students with disabilities, self-advocacy is not preferred; it is essential” (p. 16). However, for many students, self-disclosure and self-advocacy present barriers (Hong, 2015; Kreider et al., 2015). Many students with mental health disabilities, in particular, struggle with self-advocacy when attempting to secure their academic rights (Kreider et al., 2015).

In addition to requiring academic support in the form of accommodations, students with mental health disabilities struggle with their identities as individuals with a disability, and struggle with how to navigate their daily life activities within the new college

environment. Campus life involves an intricate interplay of personal and environmental factors which influence daily life activities (Lahav et al., 2016). These factors extend beyond the classroom, contributing to identity and belonging in the college environment which is especially important for college students with disabilities (Vaccaro et al., 2015).

Students have access to campus services such as the disability service office or counseling center, but both require the student to initiate and self-advocate (Evans et al., 2017; McCarthy, 2007). Even if the student is able to self-advocate, and request services, disability service professionals and campus counselors are often overwhelmed as the number of individuals seeking services increases yearly (Prince, 2015; Wesley, 2019). Research indicates that universities must provide more thorough support to students with mental health disabilities (Francis et al., 2018). According to Myers et al. (2013), “An institution’s mission should not only be to follow the letter of the law but also to embrace and demonstrate the spirit of the law through how students are treated on a daily basis” (p. 31). Colleges and universities need additional programming and services to support these students (Evans et al., 2017) beyond what the law requires. Many studies discuss self-advocacy skills for college students with disabilities, however, there is a gap in addressing how self-advocacy impacts daily life activities for college students with anxiety disorders.

## **Project Description**

### **Study Background**

The researcher, an occupational therapist, utilized the Ecology of Human Performance (EHP) framework, which is a guiding framework within the occupational therapy profession that takes a holistic perspective and interdisciplinary approach. EHP considers the person, context, task, and performance. In this study, students (the person) are interconnected with their contexts which include age, developmental stage, life cycle, health status, and the physical, social, and cultural aspects of their environments (Dunn et al., 1994; Dunn et al., 2003). The framework assimilates a phenomenological and physical perspective when analyzing the person and context relationship (Dunn et al., 1994). Tasks are behaviors that allow an individual to achieve person-centered goals, which additionally contribute to their roles and daily life activities/occupations (Dunn et al., 2003). Finally, performance is the student’s ability “to engage in tasks” within their preferred context (p. 227).

This framework supports an interdisciplinary approach (Dunn et al., 2003), which is important

as we attempt to address the needs of students with mental health disabilities in higher education and create a team of allies to provide additional support. This study focused on exploring the perceptions of self-advocacy for students with anxiety disorders as related to their participation in meaningful daily life activities/occupations associated with their college experience.

- The primary research question was: What are the perceptions of self-advocacy for college students with anxiety disorders?
- The second research question was: How does self-advocacy impact occupational engagement as related to the student's college experience?

## Methods and Procedures

### *Study Design*

The researcher chose a qualitative phenomenological approach to uncover exploratory and descriptive knowledge (Crookes & Davies, 2004) and to understand the essence of each student's lived experience, including what and how they experience the phenomenon (Creswell, 2013; Crookes & Davies, 2004; Cypress, 2018). EHP, the theoretical framework, supports this comprehensive perspective by providing a holistic view of the person, context, task, and performance of each student (Dunn et al., 2003). Study participants, higher education students with anxiety disorders, chose to participate based on criterion sampling. All students who participated completed a Research Study Consent Form. The university's institutional review board approved the IRB protocol.

### *Recruitment Strategy and Participants*

The university director of disability services contacted 156 students with documented and disclosed anxiety disorders. All students received an electronic mailing which included a brief message introducing the study with an attached recruitment letter. Student information was not shared with the researcher or other potential participants. Minors or those who had not disclosed an anxiety disorder to disability services were the only individuals excluded from this study. The researcher did not have contact with any students until after they read the recruitment materials and chose to contact the researcher. Of the 156 students who received the study recruitment materials, 12 contacted the researcher via email or text message and 10 of those chose to participate. The study cohort consisted of eight participants who identified as female and two participants who identified as male. The age range was 19-31 years old.

### *Data Collection*

Prior to beginning each interview, per phenomenological suggestion, the researcher shared the motivation for this study with the students (Creswell, 2013). They completed a consent form, a HIPAA form, and were given the opportunity to ask any questions pertaining to the nature of the study. The researcher completed individual meetings in private office space and audio recorded interviews to ensure fidelity upon transcription. Each interview lasted approximately 90 minutes.

The two data collection strategies included semi-structured, open-ended interview questions pertaining to student perceptions of self-advocacy and the Occupational Profile Template. An explanation of each strategy follows.

**Self-Advocacy Questions.** The researcher independently developed the open-ended questions for this study based on common themes and concepts pertaining to self-advocacy cited in referenced literature. A panel of doctoral educated professionals reviewed the questions including the director of disability services and two faculty in the occupational science/occupational therapy department (see Table 1).

**The Occupational Profile Template.** An occupational therapist possesses unique expertise in daily life activities (occupations) and, therefore, may use the Occupational Profile Template as a tool for better understanding the student's viewpoint and history (American Occupational Therapy Association, 2017). The Occupational Profile Template is a tool to help determine the student's priorities, goals, and interests, which in turn helps the student identify meaningful daily life activities that can be impacted by self-advocacy skills. The researcher modified the first question of the occupational profile to make it more pertinent for the study participants. Page numbers listed on the Occupational Profile Template correlate to the definitions in the *Occupational Therapy Practice Framework: Domain and Process*, 3rd Edition (OTPF) (American Occupational Therapy Association, 2014). According to the OTPF, occupation is considered the "daily life activities in which people engage;" the framework identifies an extensive list of these daily life activities (p. S6). All students were provided definitions from the OTPF to promote consistency among responses.

### *Analysis*

The researcher audio-recorded each participant interview, transcribed all questions, and to assure accuracy, performed a second review of each interview and transcription. In phenomenological research, the researcher expects the phenomenon to emerge with-

out predetermined expectations (Cypress, 2018). The researcher used open coding to highlight recurring or distinct themes and identify significant participant quotes to aid in explanation of the theme. From each data set, the researcher drew conclusions about the students' perceptions of self-advocacy and how it influences their engagement with the college experience. The researcher assigned participants an ID number and pseudonym to ensure anonymity and reduce identifiers and coded audio recordings and transcripts with an ID number linked to participant names and contact numbers. Audio recordings were transcribed and uploaded to a secure server with password protection. The researcher kept coded transcripts, data, and the master key separate from contact information in a locked cabinet in the Occupational Science/Occupational Therapy department.

## Findings

The researcher organized the outcomes of this study into two categories based on data collection strategies. Initial findings include the themes that developed from semi-structured self-advocacy questions (see Table 2). Next, the researcher uncovered five distinct daily life activities based on the Occupational Profile Template (see Table 3).

## Outcomes

### *Self-Advocacy Questions*

All participants answered semi-structured interview questions pertaining to self-advocacy to address the first research question: *What are the perceptions of self-advocacy for students with anxiety disorders in higher education?* The themes that emerged included interpretations of self-advocacy, associated feelings with self-advocacy and anxiety, the value of self-advocacy, personal experiences, and the journey toward self-advocacy (see Figure 1).

### *Interpretation*

First, it was essential for the researcher to discern each student's interpretation of self-advocacy. Each student's life story included understanding, articulating, and practicing self-advocacy to varying degrees, and students explained different self-advocacy definitions during the interview process. Students defined self-advocacy as speaking up and/or standing up for oneself, taking initiative and action, and getting what one needs. Self-advocating is also a way to acknowledge one's weaknesses and share what is unique to that individual. One student named Lucy defined self-advocacy as "working so that you have a voice and your needs are met." The age of onset and diag-

nosis varied for each student; therefore, self-advocacy materialized during different stages. For example, a student named Kate discussed how she learned to self-advocate in college, whereas some students were still learning.

### *Feelings*

All participants sufficiently articulated the meaning of self-advocacy; however, feelings about self-advocacy differed. Two students revealed positive feelings linked to self-advocating as Kenneth stated, "it feels ok." Erin was currently confident about self-advocating, but in the past, she kept to herself and did not self-advocate. According to Erin, a lack of self-advocacy "hurt me in the long run." To accomplish preferred tasks and goals, Erin learned that self-advocacy was an essential skill. Most students associated negative feelings with self-advocating, including feeling anxious, scared, uncertain, embarrassed, frustrated, disrespected, and angry. Anger and disrespect loomed when students felt wrongfully challenged about their anxiety disorder and/or their academic accommodations. For example, in reference to accommodations, Kelly said, "I went through a lot to get this and it is really disrespectful and inappropriate for you to challenge me even though I'm your student or I am young." Kelly expressed strong feelings associated with perceptions surrounding her accommodations.

Not only does the thought of self-advocating generate both positive and negative feelings, but the student must navigate and manage the symptoms of anxiety as well. Anxiety manifested both physically and emotionally for the students interviewed. Physical symptoms included stomach pain, fatigue, feeling like nerves are exposed, shortness of breath, and increased heart rate. When discussing anxiety symptoms, Kelly stated, "It just kind of seeps out of me in every way that it can." The symptoms of anxiety can be so debilitating that students have difficulty getting out of bed to attend class or take an exam. In terms of emotional symptoms, Henry reported that he does "not feel mentally present" when experiencing anxiety. Kate is impacted socially when her anxiety is heightened and stated, "I might be more difficult to hang around because I'm in my own head." Thoughts of failure tended to consume her.

### *Value*

As indicated in the interviews, most students associated negative feelings with the thought of self-advocating. Despite the overwhelming negativity, all students believed self-advocacy to be an important and essential skill to their development and success.

**Table 1***Supporting Literature for Self-Advocacy Questions*

Self-Advocacy question developed based on supporting literature	Supporting Literature – guiding the development of self-advocacy questions
What does the term self-advocacy mean to you?	Understanding one’s rights, communicating with others, and taking initiative, (Daly-Cano et al., 2015).
How do you feel when you know you need to advocate for yourself (self-advocate) within the college environment?	Mental/Emotional Struggles, (Hong, 2015).
How do you experience your anxiety? When thinking about your anxiety disorder, talk about why self-advocacy may or may not be important.	Self-advocacy improves college experience, (Vaccaro et al., 2015).  Self-advocacy is essential, (McCarthy, 2007).  Importance of self-advocacy, (Daly-Cano et al., 2015).
During your lifetime, describe a situation in which you needed to self-advocate.	Faculty Perceptions, (Hong, 2015).
When requesting or discussing accommodations, describe your interactions with individuals you classify as authority figures.	Learning to self-advocate, (Daly-Cano et al., 2015).
If you have spoken to your peers about your accommodations, describe your interactions with them once they know you are receiving accommodations.	Navigating the college experience, (Kreider et al., 2015).  Experiences with faculty, staff, and peers, (Evans et al., 2017).
Describe your support systems prior to entering college.	Quality of Support Services, (Hong, 2015).
Describe your support systems as a college student.	Family Support, (Francis et al., 2018).
As a college student, how do you educate others about your anxiety disorder?	Supportive relationships and belonging, (Vaccaro et al., 2015).  Advocacy is a journey, (McCarthy, 2007).  Family support, (Daly-Cano et al., 2015).

*Note.* The researcher developed self-advocacy questions based on common and reoccurring themes in recent literature as noted in Table 1.

**Table 2***Process of Identifying Themes for Self-Advocacy Questions*

Self-Advocacy question from which theme was derived	Significant Participant quotes which illustrate the definition and theme	Emerging themes
What does the term self-advocacy mean to you?	“Working to have representation or understanding of whatever you are going through. Working so that you have a voice and your needs are met.” (4)	Interpretation
How do you feel when you know you need to advocate for yourself (self-advocate) within the college environment?	“If I need to self-advocate because someone is not believing me or following my accommodations, that makes me angry because they were so hard to get.” (1)	Feelings
How do you experience your anxiety?	“Anxious. Very anxious and frustrated a lot. I know I need to do it, but it is still hard. I don’t know how people are going to think of me or how they are going to react or if I’ll even accomplish anything.” (8)	
When thinking about your anxiety disorder, talk about why self-advocacy may or may not be important.	“If you don’t advocate for yourself, you’re not going to heal and if you don’t advocate for yourself, you may not even believe that you need help.” (10)	Value
During your lifetime, describe a situation in which you needed to self-advocate.	“Talking with teachers and doctors and explaining what I need.” (1)	Personal Experiences
When requesting or discussing accommodations, describe your interactions with individuals you classify as authority figures.	“Advocating for yourself to yourself.” (10)	
If you have spoken to your peers about your accommodations, describe your interactions with them once they know you are receiving accommodations.		
Describe your support systems prior to entering college.	“To be a self-advocate is hard if you don’t have a lot of support from other people. The reason I was able to be a self-advocate is that I felt supported by most of my peers, mom, and psychologist. Without that support, I don’t know if I would be as vocal or feel as confident.” (9)	Journey Guided by Support
Describe your support systems as a college student.		
As a college student, how do you educate others about your anxiety disorder?		

*Note.* The researcher derived self-advocacy themes from participant answers to the self-advocacy questions. The number after each significant participant quote correlates to the assigned participant number in Table 4.

**Table 3***Challenging Daily Life Activities for Students with Anxiety Disorders as Impacted by Self-Advocacy*

Foundational Themes as Identified in <i>Occupational Therapy Practice Framework, 3rd Edition</i>	Definition from <i>Occupational Therapy Practice Framework, 3rd Edition</i>	Significant Participant quotes which best illustrate the definition and theme
Health Management	<p>Health Management and Maintenance:</p> <p>“Developing, managing, and maintaining routines for health and wellness promotion, such as physical fitness, nutrition, decreased health risk behaviors, and medication routines” (OTPF, 2014, p. S19).</p>	<p>“It’s a complicated process getting diagnosis overall.” “It took a while to get to a good point.” (7)</p> <p>“It’s hard to find the right medications and dose.” (3)</p>
Education Participation	<p>Formal Education Participation:</p> <p>“Participating in academic, nonacademic, and vocational educational activities” (OTPF, 2014, p. S20).</p>	<p>“Under normal circumstances, I’m pretty productive, but once I get to the point where I’m so overwhelmed, I can’t do anything, and I don’t know where to start.” (8)</p>
Social Participation	<p>Social Participation:</p> <p>“The interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends; involvement in a subset of activities that involve social situations with others and that support social interdependence” (OTPF, 2014, p. S21).</p>	<p>“Being so concerned about what others think of me hinders a lot and dictates a lot of what I do.” (8)</p> <p>“Social is always an issue.” “Junior year - really aching for social experiences.” (5)</p>
Sleep Participation	<p>Sleep Preparation &amp; Sleep Participation:</p> <p>“Engaging in routines that prepare the self for a comfortable rest...Preparing the physical environment for periods of unconsciousness...”</p> <p>“Taking care of personal needs for sleep, such as ceasing activities to ensure onset of sleep, napping, and dreaming; sustaining a sleep state without disruption; and performing nighttime care...” (OTPF, 2014, p. S20).</p>	<p>“Sometimes I have a hard time falling asleep and I usually can’t stay asleep.” “I have had a lot of issues with sleep in my life.” (1)</p>



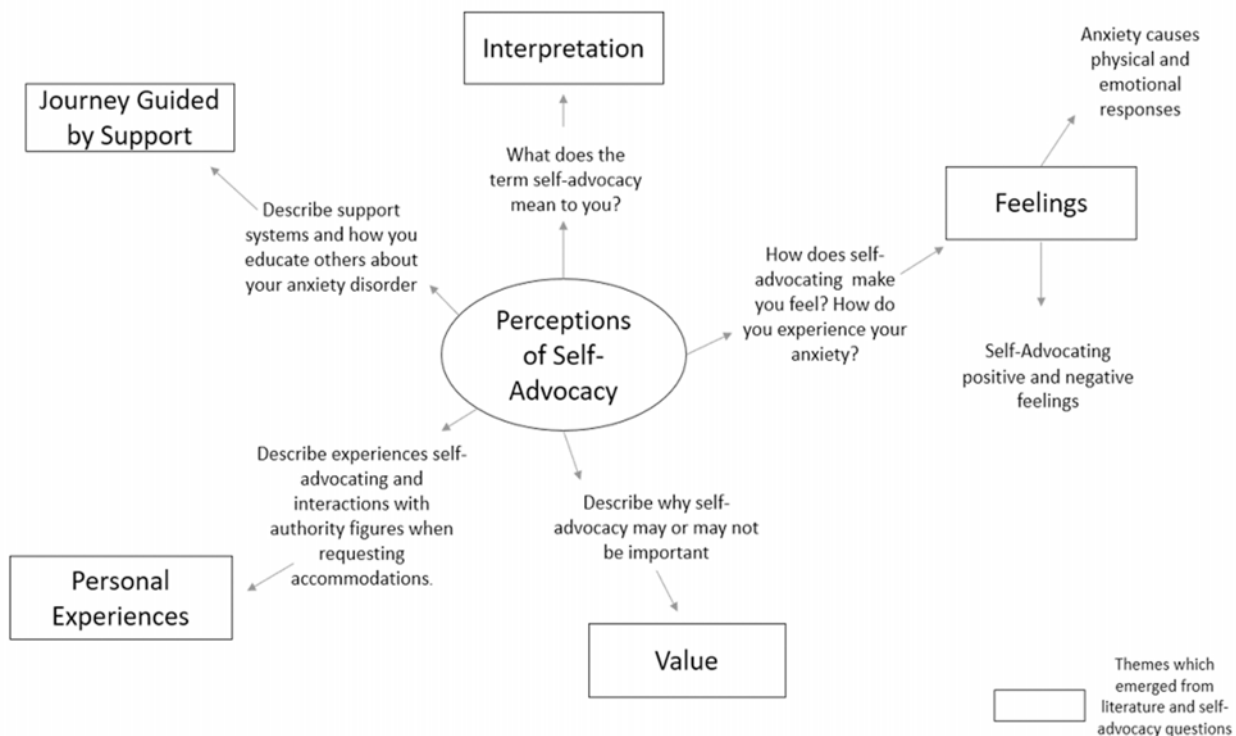
(Table 3 Continued)

Communication Management	<p>Communication Management:</p> <p>“Sending, receiving, and interpreting information using a variety of systems and equipment, including writing tools, telephones, keyboards, audiovisual recorders, computers or tablets, communication boards, call lights, emergency systems, Braille writers, telecommunication devices for deaf people, augmentative communication systems, and personal digital assistants” (OTPF, 2014, p. S19).</p>	<p>“I feel like social media is not productive unless I’m using it to learn more or laugh at.” “I don’t like scrolling and looking at what people are doing. I feel like that makes me feel worse about myself.” (10)</p>
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Note. Conducting the Occupational Profile Template and providing participants with definitions from the OTPF (AOTA, 2014) led to these five themes. The five daily life activities/occupations listed in Table 3 were impacted by self-advocacy and were the most challenging for students in this study.

Figure 1

Conceptual Diagram Illustrating the Themes Pertaining to the Students’ Perceptions of Self-Advocacy



Note. At the core is the first research question, “what are the perceptions of self-advocacy for students with anxiety disorders?”

Students recognized the value of self-advocating as one described self-advocacy as a way to promote growth and healing. While they perceived the value, students reiterated that it was difficult to self-advocate and that self-advocacy is a learned skill. Carrie stated, “It is so hard to advocate for yourself as someone with anxiety because it is so anxiety provoking.” Yet, students learned that anxiety increases if they do not advocate for themselves. It is important to consider that anxiety is an invisible disability that makes self-advocacy imperative. According to Lucy, “If you don’t speak up about it, no one is going to know it is there or that it exists.” Due to the nature of this invisible disability, students struggled with others understanding or believing their needs.

### *Personal Experiences*

Each student shared personal experiences of having to self-advocate in the college environment. Initial experiences included disclosing feelings, concerns, or disabilities to teachers, doctors, and disability service professionals. These early experiences were often a critical juncture in understanding one’s needs. As students obtained diagnoses and began to figure out their disability, they were able to begin educating others and eventually self-advocate. According to Kate, “Going to disability services and saying something was wrong was self-advocacy.” Kelly discussed how she talked with her teachers about her needs and didn’t mind explaining her necessary accommodations. Other students had mixed feelings about the student-professor relationship. Some trusted professors and were willing to engage in disability related conversations while others felt it was unnecessary for professors to understand the disability or why they needed accommodations. Tara stated, “It’s not my obligation to explain my disorders to other people. The people that already need to know about it, know about it.” Likewise, Rachel did not openly discuss her needs, but said, “Sometimes I do wish I could talk about it so people could understand why I do or don’t do certain things.”

Students were more guarded and selective when deciding with which peers to share their disability related experiences. Kelly stated, “I never tell people if I don’t feel comfortable. I would never do that to myself.” She was cautious when determining whom she could trust. According to Kelly, “With peers, I never come right out and say it if I don’t feel a need to.” Students often had a select group of friends to whom they felt safe disclosing, but did not openly discuss their disability with a larger population.

### *Journey Guided by Support*

Students were at different places in their self-advocacy journeys and required a great deal of support from others. Without support, most students felt they would not find success with the college experience. All students reported using parents as significant support systems with the mother being relied on the most. According to Kate, “Mom has still remained a really important support system for me.” Students relied on friends for support, but also recognized the importance of not burdening peers with disability related concerns. Lucy made one close friend in her dorm and commented, “I don’t know how she has stepped into this role, but we have grown closer and have been each other’s person to talk to about our struggles.” Additionally, students depended on therapists and counselors for support while navigating anxiety disorders. When these students felt supported, they were better able to self-advocate.

Not only did students with anxiety disorders require human support, but they also needed support in the form of academic accommodations. All students in this study relied on academic accommodations provided through disability services. According to Erin, “It’s leveling the playing field because it takes me a longer time to process and comprehend things than somebody who does not require accommodations.” Students articulated that accommodations allowed for everyone to have equal opportunities.

Students encountered discrimination when peers and faculty exhibited negative behaviors in relation to accommodations. Shannon provided an example of peer negativity when a classmate announced, “I wish I could have accommodations so I could have extra time—that’s not fair.” These types of statements were upsetting to students, including Shannon, who described the time-consuming process of obtaining accommodations. Other students shared how peers thought accommodations provided them an advantage or that they were “hacking the system.” In terms of faculty, students tried to limit their interactions and preferred to email testing forms to avoid conversations or confrontation. Since their disabilities were primarily invisible, students felt that others were more apt to question the validity of their disabilities and accommodations.

Student interviews revealed thoughtful and complex perceptions of self-advocacy, and each student’s self-advocacy journey included multiple layers. As students reflected on their life histories, discussions about self-advocacy continued.

### ***The Occupational Profile Template***

Students shared life stories while answering questions from the Occupational Profile Template in order to address the second research question: how does self-advocacy impact occupational engagement as related to the student's college experience? This process allowed students to discover occupational successes and barriers within the college environment. The most challenging daily life activities that were impacted by self-advocacy were: health management, education participation, social participation, sleep participation, and communication management (see Figure 2).

### ***Health Management***

It was not easy for students with anxiety disorders to take the initial step to disclose health concerns to parents, teachers, or medical professionals, but acknowledging the need for help was an important step in their self-advocacy journey. This essential, yet difficult, first step required students to speak up about how they were feeling and functioning within their environments. According to Tara, it was a "complicated process getting the diagnosis." Students were often misdiagnosed initially and then received additional diagnoses over time. Among study participants, there was a high level of comorbidities, including anxiety disorders, attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), post-traumatic stress disorder (PTSD), depression, bipolar disorder, eating disorder, and autism spectrum disorder (ASD). Each individual experienced anxiety differently. Often, it was difficult to know which diagnosis was impacting which activity or task (see Table 4).

Besides obtaining a diagnosis, receiving the correct medication and/or dosage often required multiple visits with the physician. Erin stated that it was "hard to find the right medications and doses." Returning to physicians required students to self-advocate for their health and well-being. Kelly stated, "I know for a fact I could not be where I am now without my medication." Most students reported that medication was a critical component in their ability to function.

### ***Education Participation***

When students with anxiety disorders are struggling academically, they have the option to self-advocate and disclose their disabilities to disability service professionals and receive accommodations. All students in this study received academic accommodations; nevertheless, most expressed difficulties with participation in education. Kelly stated, "education is the main concern and always has been. It's very difficult being a student with all of the disorders I have."

Educational difficulties included trouble maintaining focus in class or with assignments, studying, completing coursework, becoming overwhelmed with assignments, and taking exams. According to Lucy, "My anxiety, as well as some other factors, can make school work very hard." Many students reported increased anxiety surrounding academics. Rachel stated, "Under normal circumstances, I'm pretty productive, but once I get to the point where I'm so overwhelmed, I can't do anything, and I don't know where to start."

### ***Social Participation***

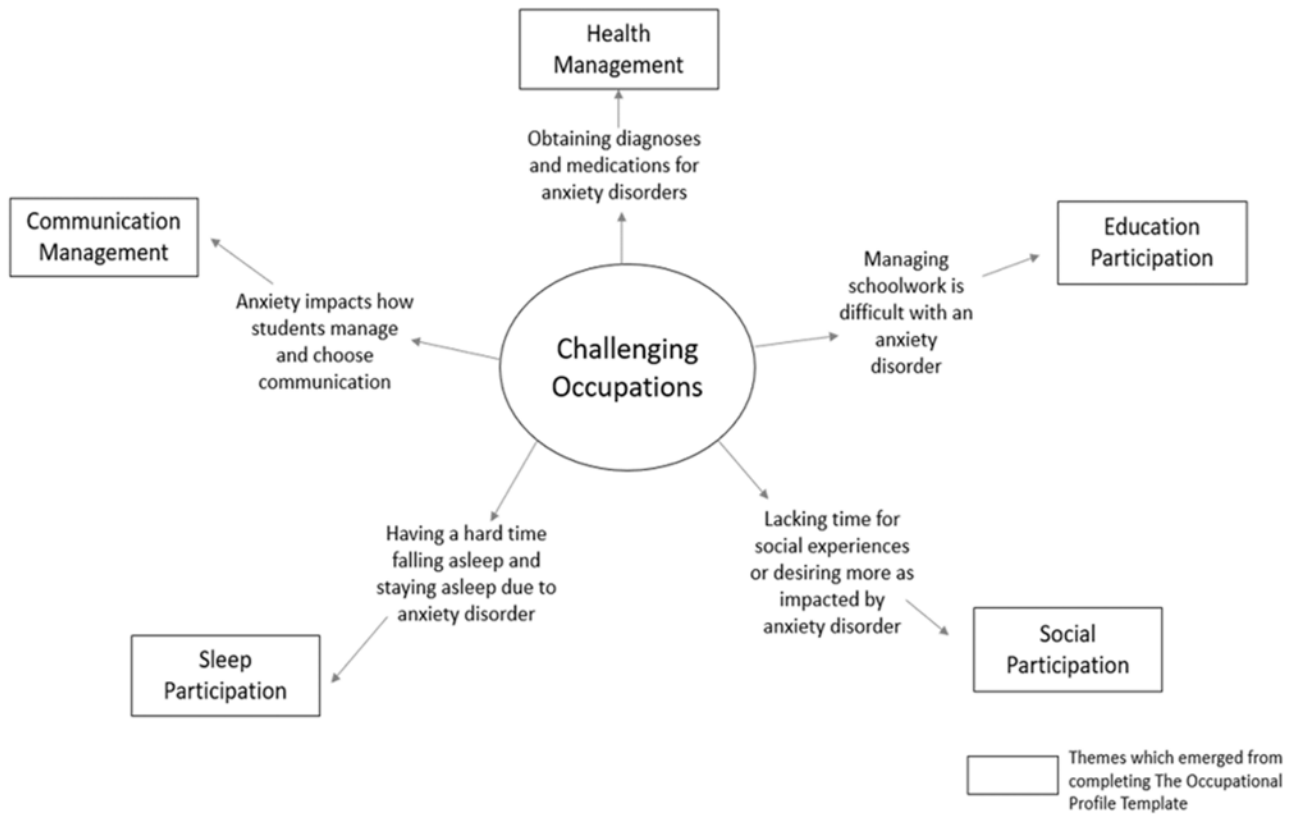
An anxiety disorder can negatively impact a college student's social participation. Social concerns included fitting in or belonging, meeting and talking to new people, and finding the time to socialize especially when academic burdens were so great. Some students chose down time over socialization especially when exhausted and overwhelmed by academic demands. Shannon advocated for her social needs by taking the time to "calm down, relax and do nothing." While it was necessary for Shannon to decrease social experiences, other students desired additional opportunities. Henry expressed frustration with social participation as it had always been an issue. He described how he was "really aching for social experiences." Additionally, Rachel desired to be "more comfortable around others" as she was often concerned about what others thought of her. Students in this study had varying degrees of social participation, impacted by multiple diagnoses and the ability to self-advocate.

### ***Sleep Participation***

Falling asleep or sustaining sleep without disruption was a common theme for students in this study. Sleep participation has been a struggle for most students throughout their life and many have relied on supports. Students self-advocated when they acknowledged sleep difficulties and sought assistance. Supports included weighted blankets, melatonin, guided meditation, and altering the lights and sounds of their sleep environments. Kelly, Erin, Lucy, and Rachel all reported using weighted blankets as valuable additions to their sleep routine. According to Kelly, the blanket "helps with panic attacks, anxiety attacks, if I just can't fall asleep, or if I'm stressed... and I can't put a finger on it. I'll put it on, and I feel so much better. I feel relief right away." Other students excelled at creating boundaries and had strict routines associated with sleep. Kate was careful to not let anything ruin her sleep schedule. By advocating for sleep needs, some students' daily life activities were limited including education participation, social participation, and communication management.

**Figure 2**

*Conceptual Diagram to Illustrate the Themes of Challenging Daily Life Activities/Occupations*



*Note.* Conceptual diagram illustrating how themes pertaining to the second research question, “How does self-advocacy impact occupational engagement as related to the student’s college experience?”

**Table 4***Participant De-Identified Demographics: Age, Gender, and Diagnosis*

Assigned number & pseudonym	Age/Gender	Diagnosis	Age of diagnosis and/or onset of anxiety
1 – Kelly	19/F	Anxiety ADHD OCD Dysthymia	Onset: 6th grade Diagnosis: Sophomore in high school
2 – Kenneth	31/M	Anxiety Panic Disorder	Diagnosis: 27 years old but felt anxiety earlier
3 – Erin	21/F	Anxiety ADHD Depression Excoriation OCD Panic Disorder Trichotillomania	Diagnosis: 15 years old but felt like she was struggling for a long time before
4 – Lucy	19/F	Anxiety ADD Depression	Diagnosis: Sophomore in high school
5 – Henry	23/M	Anxiety Depression Pervasive Developmental Disorder	Diagnosis: Freshman in high school
6 – Shannon	22/F	Anxiety Heart Arrhythmia OCD Panic Attacks	Diagnosis: Freshman year in college but had symptoms since kindergarten
7 – Tara	21/F	Anxiety ADHD Depression	Diagnosis: 16 years old
8 – Rachel	19/F	Anxiety Depression Eating Disorder Social Anxiety	Onset: 7th grade Diagnosis: Senior year of high school
9 – Kate	21/F	Anxiety PTSD	Diagnosis: Freshman year of college but always felt anxious
10 – Carrie	22/F	Anxiety Depression Panic Disorder Bipolar Type 1	Onset: 12 years old Diagnosis: 17 years

*Note.* The study participant was assigned a number and pseudonym. The age, gender, diagnosis and onset were self-reported by study participants.

### ***Communication Management***

When discussing communication management, students focused on the virtual world and included both positive and negative aspects of communication. The positive elements they identified included emailing, texting, and videotelephony (video chat, Facetime, etc.). The benefits of email and text as opposed to face-to-face communication included the opportunity to process information and provide a well-thought-out response. Some students worried about saying the wrong thing, offending, or hurting others' feelings. Additionally, students preferred communicating with professors about accommodations over email. They wished to avoid confrontation or to avoid being challenged about their accommodations. Students in this study were also very connected to family members, and videotelephony allowed them to stay in close contact with family and friends at any time. Kate stated, "It's wonderful to be able to contact parents via text or Facetime. I rely on that a lot throughout the week." Many students checked in daily with family members.

Students identified social media as the primary negative aspect of virtual communication. Using social media could be overwhelming and difficult to manage. Students reported that having to monitor excess information about another individual's life was distracting, a waste of time, and anxiety inducing. According to Carrie, "I feel like social media is not productive. I don't like scrolling and looking at what people are doing. I feel like that makes me feel worse about myself." Students reported that when they distanced themselves from social media or took breaks, they felt more present.

The students in this study shared sincere stories about life as a college student with an anxiety disorder. As the stories unfolded, it became evident that self-advocacy had an influence on students' daily life activities. Some students were able to self-advocate in their daily life activities while others were in the early learning stages of self-advocacy. The ability to self-advocate had an overarching effect on their college experience.

### **Discussion**

As the population of students with disabilities who attend a college or university continues to increase, additional resources are vital to support these individuals. Students agreed to participate in this study for a variety of reasons, but the primary motivator was a desire to contribute to the greater good for the sake of improving the college environment for future students with mental health disabilities, and

specifically anxiety disorders. The present study uncovered students' perceptions of self-advocacy and self-advocacy's relationship to daily life activities. All participants openly shared stories about their experiences as individuals with anxiety disorders. The researcher used open-ended self-advocacy questions and the Occupational Profile Template to form a comprehensive understanding of the students. The data collection strategies allowed the researcher to discern student successes and barriers within the college environment. Additionally, EHP, the chosen framework, guided the study and was reflected in the holistic student narratives. Interdependent person/context relationship influences how the students are able to perform by engaging in tasks, which impacts the college experience. The remainder of this section discusses the themes gleaned from the open-ended self-advocacy questions and the Occupational Profile Template.

### ***Self-Advocacy Questions***

As discussed earlier, self-advocacy is a learned skill which is not easy for many college students. According to Daly-Cano et al., (2015) "In learning a skill such as self-advocacy, it is important to acknowledge that many students will not use this skill without deliberate and repeated instruction" (p. 222). Numerous factors impacted students' abilities to self-advocate and influenced where they positioned themselves in this journey. Students in this study did not participate in formal instruction. They developed self-advocacy skills with support and instruction from parents and teachers and by experiencing failures and successes throughout the process.

All study participants unanimously affirmed that self-advocacy was an important and essential skill to acquire and maintain. Student interpretations of self-advocacy mirrored definitions from the literature. Although students were able to interpret and recognize the value of self-advocacy, it was burdensome for most. The thought of self-advocating mainly elicited negative feelings. Students explained experiences regulating physical and emotional feelings linked with anxiety in addition to the negative feelings associated with self-advocating. Student diagnoses and personal experiences were unique to each individual; therefore, each participant was at a different phase in their self-advocacy journey.

### ***Occupational Profile Template***

The data from the Occupational Profile Template reflected five significant daily life activities/occupations which students considered challenging. Students with anxiety disorders certainly experienced

success; however, the daily life activities which students found problematic within the college environment further informed this study. The five daily life activities included health management, education participation, social participation, sleep participation, and communication management.

Health management includes obtaining correct diagnoses and correct medications. In order to receive an initial diagnosis and/or medication, the student needed to self-advocate by seeking help. Most continued discussions with parents, teachers, and professionals to alter diagnoses and medications. Some students continued to uncover new diagnoses and changed medications. Self-advocacy is and will be required throughout students' lives as they manage their health.

Education participation is difficult; the educational experience can be overwhelming for a variety of reasons including accomplishing academic requirements and the self-advocacy needed to accomplish desired tasks. However, students are more accustomed to advocating for their academic needs as opposed to other occupational needs. All students in this study received academic accommodations through disability services. Disclosing a diagnosis was one more steppingstone in the student's self-advocacy journey as opposed to those who had not registered with disability services. Most students preferred, simply, the responsibility to disclose to disability services; however, students are expected to go one step further and discuss accommodations with professors. Students often avoided face to face contact with professors and sent accommodation letters or testing requests via email. Even though students received academic accommodations, they continued to struggle with completing assignments and exams and maintaining focus.

Some students were satisfied with social participation, yet most students found socialization to be complicated. Obstacles to socializing occurred for multiple reasons. For example, the symptoms associated with anxiety disorders disrupted student's opportunities for peer interaction. Physical and emotional symptoms of anxiety required students to take frequent breaks from academics and activities and to remove themselves from social situations. The literature stated that students with disabilities commonly choose social acceptance over academic success when accommodations contribute to being socially isolated from peers or being labeled as a person with a disability (Hong, 2015). However, in this study, students chose sleep or education related daily life activities over social participation out of necessity. Making these difficult decisions required self-advocacy.

While students desired socialization, the practicality of getting adequate rest and completing academic requirements outweighed social participation.

Most students reported struggling with sleep at some point in their lives. Students self-advocated when they prioritized sleep and chose to seek out supports to encourage successful sleep participation. As discussed, four students used weighted blankets to facilitate calm and restful sleep experiences. Students preferred natural remedies such as meditation, white noise and altering the lighting, over prescription sleep medications.

Some students found communication management positive, while others found it a struggle. The virtual world provided a considerable amount of communication, and students had mixed feelings about that. Students generally preferred emailing and texting over face-to-face communication as it allowed additional time to process and formulate suitable responses; they also preferred videotelephony for communicating with close friends and family members. Students in this study relied heavily on frequent family support, overwhelmingly from mothers, and this was best achieved through texting and videotelephony whenever necessary. Interestingly, most students found social media to be an unfavorable and ineffective form of communication. Often, social media elicited negative feelings. Students benefited from self-advocacy when choosing the most appropriate form of communication and when recognizing the need to make changes or take breaks from the virtual world.

### **Limitations**

While this research provided an abundance of data for present and future studies, limitations do exist. One limitation is that due to criterion sampling, the findings could not necessarily be generalized to a larger population of all college students with anxiety disorders. A second limitation is the lack of diversity among participants: as 8 of the 10 students identified as female, all ranged in age from 19-31, and all attended a private, religiously affiliated university in the Midwest. A third limitation was the time parameters of this study; follow up with students could provide additional insights into the study's efficacy.

### **Implications**

The results of this study offer a variety of opportunities for future research and programming for disability support professionals and an interdisciplinary team. Both the current data and literature suggest that students will benefit from self-advocacy programming as it is a learned skill and not intuitive for most students.

Considering the challenges students with anxiety disorders face communicating with professors and peers, instruction from a practitioner on how to self-advocate may help decrease barriers. Programming for students may be best implemented through a collaborative and interdisciplinary approach. The interdisciplinary team may include individuals from disability services, occupational therapy, counseling, the health center, residence life, and the dean of students office.

An interdisciplinary team would add valuable insights to assist with the surge of students with disabilities and already stressed resources. When considering self-advocacy programming, the team can help students realize how to best manage their daily life activities in college, especially education participation and communication, to foster more positive and productive academic relationships.

Further, the current study helped reinforce that learning how to self-advocate is difficult, it produces positive and negative feelings, and students with anxiety disorders must also manage the physical and emotional symptoms associated with their anxiety disorder. An interdisciplinary team is well suited to create holistic self-advocacy programming to address the skills and feelings surrounding self-advocacy and to recognize how symptoms of anxiety impact daily life activities within the college environment. While this study focused on anxiety disorders, evidence in the literature suggests that a wide variety of students with disabilities struggle with self-advocacy; therefore, this programming may serve a larger and more inclusive population.

Beneficial strategies may include focus groups or peer groups to discuss student concerns and needs and role-play activities and instruction based on self-advocacy development. Self-advocacy programming may also be offered as a recommended workshop prior to beginning course work at the college or university. Additionally, an interdisciplinary team can benefit students by participating in college or university panels that target student health and wellness, campus life, and navigating academics. Panels may include disability support professionals, an occupational therapy practitioner, campus counselors, practitioners from student health, and administrators from residence life and the dean of students office. The team would provide a holistic perspective and diverse expertise that targets the daily life activity barriers discussed in this research.

Next, an interdisciplinary team can work together to utilize the guiding framework of this study, the Ecology of Human Performance (EHP), to its full extent by incorporating the five intervention approaches when working with students with disabilities in

higher education. After completing student interviews, follow-up meetings with each student would be beneficial to discuss interview results and implement a student-centered intervention plan. The EHP intervention approaches address the person, context, and task in order to enhance the student's skills, accommodate the environment, prevent problems from occurring, and proactively look for ways to improve performance within the context for all individuals (Dunn et al., 1994).

The interdisciplinary team may work with the student to develop strategies for turning daily life activity barriers experienced in college into successes. A few examples include the following:

- Role-playing with the student to practice self-advocacy with professor-student interactions regarding accommodations
- Develop groups to explore the feelings associated with self-advocating and the impact on participation in daily life activities
- Assisting with health concerns related to symptoms of anxiety and comorbidities
- Developing academic strategies to promote efficient study practices
- Assessing residence halls, classrooms, cafeterias, and other campus buildings to determine the best access and the most comfortable experiences
- Assisting with daily scheduling to help students enhance social experiences and sleep
- Creating peer groups to practice communication management and socialization

The above examples offer flexible opportunities for individual and group interventions and may occur with one or more members of the interdisciplinary team.

Another consideration is that all students in this study discussed the importance of parents as support systems while navigating the college environment. Based on this study, students relied heavily on parental support. Parent perspectives may provide additional insight into the student's ability to self-advocate and participate within the college environment. Additionally, an interdisciplinary team may create workshops and materials on how parents can support their student during this transition and new phase of life. A transitional workshop could be offered simultaneously with the student self-advocacy workshop prior to beginning their initial coursework.



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