

# I'm Not the Gingerbread Man! Exploring the Experiences of College Students Diagnosed with ADHD

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## Abstract

*This study explored how undergraduate students diagnosed with AD/HD remain in college. Using a qualitative research design from a grounded theory perspective, the researchers captured the personal stories of 10 college students from two universities similar in location, size, and liberal arts tradition. The findings included themes related to attitudes about their diagnosis, adapting to college, and recommendations for students, college personnel, and parents.*

*"They have this fit mold, like this cut gingerbread mold, and here's me. I am Santa Claus and they want Gingerbread Man, and I don't fit in the Gingerbread Man cut out because I'm different."*

According to researchers, fewer students with a self-reported disability matriculate and graduate from college than students who do not report a disability. In 1999, Horn and Berkold reported that out of a "nationally representative" sample of 21,000 undergraduates, only 6% self-reported a disability (p. 59). Of those, approximately 63% enrolled in a two or four-year, public or private college or university compared with 72% of students who did not report a disability. Horn and Berkold (1999a) analyzed data during the 1995-1996 academic year collected by four different surveys "conducted by the National Center for Education Statistics" (p. 59). Included in the data were self-reports of disabilities by the national sample. Disabilities were summarized by the following six categories: (a) visual impairment, (b) hearing impairment, (c) speech impairment, (d) orthopedic impairment, (e) learning disability, and (f) other disability or impairment. Additionally, Horn and Berkold found that

of students without a disability, approximately 64% had obtained a credential or were still enrolled in college during 1994, compared with only 52% of students with a disability. Furthermore, students with disabilities were more likely to matriculate to a two-year institution whereas students reporting no disabilities attended a four-year college or university.

There is multitude of reasons why many students diagnosed with a disability do not succeed in college. "When students were ranked according to how qualified they were for admission to a 4-year college, students with disabilities were much less likely to be even minimally qualified" (Horn & Berkold, 1999a, p. 61). For example, in the area of specific learning disabilities 45.1% were considered to be in the low quartile, 50.7% were in the middle quartile, and 4.2% were in the high quartile (Horn & Berkold, 1999b). Overall, students with disabilities were more likely "to have taken remedial mathematics and English courses in high school, less likely to have taken advanced placement courses, had lower high school GPA's, and had lower high average SAT entrance exam scores" (Horn & Berkold, 1999a, p. 61).

Students with disabilities have self-reported insufficient academic preparation for college level work (Hurst & Smerdon, 2000), including difficulty with English (Bramer, 1994); lower vocabulary, reading, arithmetic scores (Fisher, 1998); and spelling scores (Barkley, 1998). Particularly problematic symptoms include the inability to remain attentive for a long period of time, reflect before taking action, and plan (Teeter, 1998). According to research conducted by Henderson (1999), students with disabilities, in general, self-report lower perceptions of ability than students without disabilities in a variety of areas, including: (a) cooperativeness, (b) intellectual self-confidence, (c) emotional health, (d) overall academic ability, (e) writing ability, (f) mathematical ability, and (g) drive to achieve. Interesting, Henderson found that students with disabilities self-report a more positive perception of their artistic and creative ability than peers who do not have a disability.

More specific to AD/HD (attention deficit/hyperactivity disorder), in a 15-year follow-up to their Montreal Children's Hospital study, Weiss and Hechtman (1993) found that of students diagnosed with AD/HD only 5% graduated from college compared with 42% of students without AD/HD in the control group. In 1962-1965, Weiss and Hechtman analyzed the efficacy of certain medications on behavior and intellectual functioning of 104 hyperactive children. At the time of the study, the children were ages 6 to 12 years old. The control group consisted of 45 non-disabled subjects. For the 15-year follow-up, Weiss and Hechtman evaluated 61 of the original sample with a control group of 41 subjects. Along with the data on college graduation, the authors found that at least 66% of the follow-up sample complained of at least one symptom of the syndrome compared with only 7% in the control group. Additionally, a significant number in the experimental group complained that they continued to have feelings of restlessness even as adults.

Therefore, there is evidence to suggest that students diagnosed with AD/HD are placed at greater risk for academic impairment and underachievement than their peers without AD/HD (Heiligenstein, Guenther, Levy, Savino, & Fulwiler, 1999; Teeter, 1998). The primary obstacle in choosing to attend college for adults diagnosed with AD/HD may be related to low self-esteem. Thus, researchers have discovered over the past decade that low self-esteem is one consequence of AD/HD that leads to depression, and feelings of inferiority and isolation (Bramer, 1994; Green & Chee, 1998; Slomkowski, Klein, & Mannuzza, 1995). Among adults who do matriculate, many find that they are not prepared to succeed in academically.

Researchers postulate that some of these students come to higher education with symptoms of AD/HD, but without a diagnosis. These students manage to complete secondary education by using teacher, peer, and family support structures (Barkley, 1998; Malakpa, 1997). However, once they enter the world of advanced scholarship and learning, they discover that the old support structures are either not available or are no longer sufficient (Hechtman, Weiss, Perlman, & Amsel, 1984).

Fisher (1998) found that adults with more positive outcomes were not symptom-free, but they managed their symptoms more efficiently. In this connection self-awareness of one's intellectual and academic functioning is important. Barkley (1998) found young adults diagnosed with AD/HD before college were far more likely to have attended college (68%) because they were more self aware of their needs and more knowledgeable about what to do if they needed help. According to Teeter (1998), these students were well adapted for the transition because they "have developed a set of study strategies, work closely with faculty and/or academic advisors, receive psychological or emotional support from parents and/or therapists, have a tenacious approach to meeting challenges, and have a support group of friends" (p. 307).

Farrell (2003) reported that AD/HD has "increased steeply in years, as more children have been diagnosed with the disorder" (p. 1). While many are being diagnosed as children, a percentage of young people experience the symptoms of AD/HD without the knowledge of medication and support well into adulthood, and just at the point of college matriculation (Teeter, 1998).

The consequences of this situation are problematic for higher education faculty and staff. First, as mentioned, is the missed opportunity of these adults to benefit from years of learning to adapt to their disability prior to entering the world of advanced learning (Fisher & Beckley, 1999). Second, depending on the timing of the diagnosis, it is possible that these adults are struggling with the emotional overlays of the AD/HD diagnosis at the same moment that they are having to manage the transition into college (Teeter). Finally, it is reasonable to deduce that if these individuals maneuvered secondary education without a diagnosis, they may slip through the diagnosis cracks altogether, missing the chance for much-needed help in college (Ingram, Hechtman, & Morgenstern, 1999).

With students diagnosed with AD/HD entering college in increasing numbers and students being responsible for self-identification, increasing attrition looms large unless colleges and universities are prepared to meet the challenge of retaining this potentially vulnerable student population (Denckla, 1993; Silver, 2000). Universities and colleges are not required by law to reduce stan-

dards for admission or graduation, or to waive course requirements that are deemed necessary for a degree. Institutions are, however, required to not discriminate against an individual based on a disability (Katz, 2003). Even though under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act, individuals with disabilities are guaranteed certain protections and rights to equal access to programs and services, it is up to students to present documentation that their disability “substantially” limits a major life activity such as learning.

There is a multitude of hurdles embedded in this one unique challenge. For example, how does an institution identify those who have not been diagnosed? Once the student is identified, how do faculty and staff accommodate the student’s needs while maintaining the academic integrity of the course, program of study, and institution? What about students who are never identified? How do they influence the productivity of the classroom and the culture of the institution? Worse yet, how does the missed opportunity for support influence the students’ success? Some of the best answers to these important questions may come directly from those students diagnosed with AD/HD.

The more that is known about the influence of AD/HD symptoms on the college experience of students with AD/HD, the better prepared faculty and administrators can be to fight the battle of challenging recruiting and increasing attrition. The extant literature offers a wealth of research findings about the AD/HD diagnosis and experiences of those living with the disability (Atkins, 1996; Barkley, 1998; Silver, 2000; Weiss, 1992; Weiss, Hechtman, & Weiss, 1999). Research reports about college students diagnosed with AD/HD are minimal, but increasing (Heiligenstein et al., 1999; Quinn, 1994; Willis, Hoben, & Myette, 1995). More research is needed to update what is currently known about AD/HD and the American college student (Bramer, 1994; Eaton & Wyland, 1996; Heiligenstein et al., 1999; Willis, et al., 1995).

Research relating the stories of college students attending a variety of postsecondary institutions helps to inform future policymaking for this vulnerable population and the development of valid strategies to help these students succeed. The intent of this study was to explore how undergraduate students diagnosed with AD/HD who matriculated into a public and private university remain in college.

## Method

The defining construct of this study was the ability of students to remain in college. Because this research did not investigate the typical quantitative variables associated with collegiate success, such as grade point-average, class attendance, and so on, the ability “to succeed” could not be the defining construct. Therefore, the researchers chose a construct that could best operationalize the existence of students with AD/HD in the collegiate experience. By using “remain” as the defining construct in the intent of study, the researchers acknowledged that the focus of this study was not to explore success mechanisms designed by students with AD/HD, but to discover which mechanisms students use to simply exist in an environment of advanced learning.

Furthermore, whereas the study included two research sites, comparison of student beliefs between the two sites was not the purpose. Instead, the two campuses were used as a multi-site strategy to enhance the external validity of the study (Merriam, 1998). To fully understand the phenomenon, the researchers explored student attitudes about their diagnosis, experiences with education, strategies used to remain in an educational environment, and important support structures for that survival. Specifically, using a qualitative research design from a grounded theory perspective, the researchers captured the personal stories of 10 college students from two universities similar in location, size, and liberal arts tradition located in southwestern Arkansas. The research conversations took place during the 2001-2002 academic year.

### *Qualitative Methodology*

Qualitative research is an inductive process that encourages the use of exploration and investigation to generate hypotheses and theoretical constructs (Ary, Jacobs, & Razavieh 2002; Merriam, 2002a). Researchers with an interest in qualitative inquiry encourage a world view of a socially constructed reality informed by human interaction (Denzin & Lincoln 2000). The intent of the qualitative study, therefore, is to use the individual voice to explain an unobservable phenomenon, typically built around a defining construct that is not easily operationalized. Qualitative research embodies a variety of exploration traditions (Creswell, 1998), each of them informing the researcher’s use of data collection, analysis, and reporting techniques, and each proposing a slightly different perspective on reality. The grounded theory approach is but one of the many philosophical perspectives or traditions that guide qualitative research (Glaser & Strauss, 1967).

With the grounded theory approach, researchers make no assumptions or suppositions about the phenomenon, or intent of study, a priori. Grounded theorists develop research questions based on personal experiences with a phenomenon and design a study to fully explore that phenomenon. "The intent of a grounded theory study is to generate or discover a theory, an abstract analytical schema of a phenomenon, that relates to a particular situation" (Creswell, 1998, p. 56). Once data are collected, the grounded theorist typically uses some variation of the constant comparison approach to analyze the data and design a theoretical framework for explaining the phenomenon a posteriori (Strauss & Corbin, 1998).

Even though qualitative findings are not generalizable from the sample to a larger target population, grounded theorists are still interested in making inferences from the voices heard to the theory constructed (Creswell, 1998; Strauss & Corbin, 1990). This transition from qualitative data to abstract theory requires the same scientific process and attention as the quantitative movement from sample to population. Grounded theorists must design studies that are internally and externally valid in order to make appropriate inferences to constructed theory (Merriam, 1998). Whereas the concept of validity is more familiar to quantitative researchers, the term is equally important to grounded theorist only from a different perspective (Lewis & Ritchie, 2003).

As with quantitative research, internal validity for qualitative research involves the process of ensuring that the research design is truly investigating that which it is purported to investigate (Lewis & Ritchie, 2003, Miles & Huberman, 1994), or the congruency between the research findings with reality (Merriam, 2002b). Likewise, for both quantitative and qualitative researchers external validity is the process of improving the applicability of the findings to other groups or other settings. The concepts are the same, but the questions asked and the processes followed are different. Qualitative researchers design studies using strategies of internal validation to ensure that the research design is truly exploring the stated intent of study. These strategies include (a) triangulation, (b) member checks allowing participants to review research findings, (c) long-term observation, and (d) peer review or audit (Merriam). Because the focus of grounded theory is the development of a theoretical framework explaining the stated phenomenon, it is imperative that the research design internally validate against that phenomenon.

Additionally, qualitative researchers incorporate techniques to strengthen the external validation of the findings to ensure that inferences made from the data collected to the theory constructed are appropriate and ex-

planatory. Such techniques as providing rich, thick description of the research method and findings to enhance the transparency of the process and using a multi site design improve the external validity of the study (Merriam, 1998). Finally, qualitative researchers employ an auditing process of the entire study from start to finish, validating research findings (Merriam).

Finally, positivists and grounded theorists share the concept of reliability. In both philosophical arenas, reliability refers to the ability to replicate the findings of the study or, in other words, the consistency of research results (Miles & Huberman, 1994, Merriam, 2002b). Qualitative researchers ensure reliability by reporting research in a manner that makes the research process transparent (Ary et al., 2002), using a systematic data analysis method, and linking the interpretation of findings with data collected (Lewis & Ritchie, 2003). Most important, however, reliability in qualitative studies is linked to the quality of the sample. Because qualitative studies are inductive in nature and the explorations of an unobservable phenomenon, researchers rely on purposive sampling techniques to 'purposively select' participants in the study that can best explain the phenomenon (Ary et al.). This purposive process is a critical link between the phenomenon and the reliability of the findings.

### *Sample*

An important first step toward identifying a reliable sample is to develop a set of sampling criteria that informs a systematic selection of study volunteers. The sampling criteria included students (a) diagnosed with AD/HD as their primary disability, (b) who provided documentation to the Office of Disability Support at one of the two participating Arkansas institutions, (c) currently enrolled in a public or private, four-year college in southwestern Arkansas, (d) currently enrolled in undergraduate courses, and (e) between the ages of 18 and 24 years old.

The researcher worked with the Director of the Office of Disability Support (DSS) at both institutions to recruit volunteers for the study. The researcher asked the DSS coordinators to select only those students with a diagnosis of AD/HD. Both coordinators indicated that they had names of students on file for whom a diagnostician had diagnosed only AD/HD. Each coordinator pulled the files of those students for the researcher to use as the sampling frame.

Only students with a single diagnosis of AD/HD were included in the subject pool. Even with this attempt at homogeneity, the possibility existed that students participating in the study had symptoms of other disabilities such as a learning disability (Teeter, 1998). This possi-

bility was a limitation to the reliability of the study, interfering with the consistency of the findings due to the probable existence of multiple symptoms. A total of 14 students with a single diagnosis of AD/HD attended the public institution from which 2 participated in the main study. A total of 25 students diagnosed with AD/HD attended the private institution. Of these, 10 participated in the study (3 students participated in the pilot study and 7 participated in the main study).

The two institutions chosen for this study were located in the same town in southwestern Arkansas. The population of the town was approximately 10,900 people in 2001. Both institutions had a stated liberal arts mission and tradition. The private religious university enrolled approximately 1,800 students in the 2001/2002 academic year. The private university offered undergraduate degrees only, with a stated mission of preparing students for leadership and service. The public secular university enrolled approximately 3,500 students. Its mission was to foster exemplary undergraduate degrees in the arts and sciences and undergraduate and graduate degrees in teacher education and business administration.

The students in the study represented a broad range of disciplines including music education, mass communication, biology, psychology, business, nursing, Spanish, theology, and physical education. Of the 10 students who participated in the main study, three were white females and seven were white males. Two students were diagnosed by a doctor when they were 6 to 9 years old. Three students received their diagnosis during their adolescence. Five students received their diagnosis while attending college. All students indicated that a psychiatrist, psychologist, neurologist, or a specialist in AD/HD had performed the diagnosis. Some of the students indicated that they suffered severe symptoms, while others stated and exhibited less notable manifestations of AD/HD. The actual classification of each participant's AD/HD was not accessible.

### *Pilot Study*

A pilot study to test the data collection and analysis protocol, the interview script, and the researcher's interview skill was conducted. The researcher chose the private university for the pilot study due to the larger number of students with documented AD/HD at that university. Three students participated in the pilot interviews.

Based on the pilot study, the researcher made minor changes to the cover letter, interviewing techniques, and the interview script. Related to the cover letter, the researcher discovered that students recruited for the pilot study were more likely to volunteer if they talked with their disability support coordinator and received reassur-

ances from that coordinator about the nature of the study. Therefore, the cover letter for the main study was revised to include wording that encouraged students to have such a conversation. The pilot study sessions also helped the researcher practice important interviewing skills related to using appropriate probes to ensure that students engaged in focused conversations (Krueger & Casey, 2000) and managing a research conversation to guarantee that all comments were clearly captured on the audio-tape. Finally, the researcher revised, and added, main questions on the interview script to enhance student conversation congruent with the intent of the study. These lessons informed changes made to the main study to improve the internal reliability of the resulting theoretical framework (Merriam, 1998).

### *Main Study*

*Recruiting volunteers.* In an attempt to protect the privacy of students registered with the disability support center at each university, the researcher and director of each center agreed that all initial communication with students would be channeled through the center. Therefore, the researcher provided both directors with a letter to mail to students with documented AD/HD on each campus. The letter included information about the (a) purpose of the research, (b) data collection method, (c) informed consent process, and (d) protection of student anonymity. The directors also attached a letter that encouraged students to participate in the study with instructions to call the researcher to volunteer. A total of four letters were sent by the disability support centers at the private university over a period of two months to the remaining 17 students diagnosed with AD/HD. Three letters were separately mailed over three months to 14 students at the public university. At the completion of the recruitment phase, eight students from the private institution and two students from the public institution volunteered to participate in the research conversations.

When preparing for the student interviews, the researcher either called students or sent them a letter at least twice before each interview to remind them of their appointment. If the student did not attend the interview, the researcher called the student to reschedule. Even with this strategy, the researcher experienced several problems in recruiting volunteers. Students diagnosed with AD/HD who attended the chosen public and private university were reluctant to participate in the study due to time constraints, scheduling problems, and concerns about confidentiality. In some cases, those who did volunteer frequently forgot interview appointments or dropped out of the study. Consequently, the researcher was forced to break protocol on several occasions to recruit volunteers by using member recommendations.

The researcher verified the status of the recommended participant with the DSS coordinator at each college before contacting the new participant. Since the protocol was designed to ensure a valid representation of the entire phenomenon by the voices heard, this break from the protocol was an important limitation to the internal and external validity of the study by injecting opinions from those recruited through a convenience sampling instead of purposive sampling process.

*Data collection.* The researcher conducted one personal interview with each of the 10 volunteers. All of the interviews took place in a secluded area of a restaurant away from campus in an effort to protect student confidentiality. The incentive for participation was a free meal during the interview. At the beginning of the interview, the researcher explained the purpose of the study, discussed the confidentiality process, and asked the volunteer to sign an informed consent form. Additionally, the researcher notified the volunteer that the session would be tape-recorded and asked for permission to do so.

With introductions completed, the researcher used an interview script that included eleven main questions designed to stimulate conversation with the student. Probes were used as needed to elicit in-depth conversation or to enhance clarity of a student's response (Krueger & Casey, 2000). Of the 11 main questions, six were designed based on extant literature about college students diagnosed with AD/HD and their experiences on a university campus (see Table 1).

The remaining five questions were developed after the pilot study and were a result of the lessons learned from the pilot (see Table 2). All of the questions were intended to provide the researcher with important information explaining the stated phenomenon.

*Data analysis.* Due to the recruiting problem, the researcher did not have the luxury of pre-determined interview appointments allowing for time to code each transcript after an interview. Therefore, the researcher used a research log to note important themes emerging from each interview. The researcher reviewed notes in the log

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Table 1

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*Main Study Questions Including Pilot Study Information*

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1. Tell me about your diagnosis.
    - a. When were you diagnosed?
    - b. Why did you get assessed?
    - c. How did you react when you heard you had AD/HD?
    - d. How did your parents react?
    - e. Do your parents ever get frustrated with you? Why? How do you feel about that?
    - f. How do you feel about having AD/HD now?
    - g. Do you feel your symptoms have changed from when you first found out to today? In what way?
    - h. What do you think about medication?
  2. If you could thank someone for encouraging you to go to college, who would it be, and why?
  3. Describe how your family reacted when you decided to go to college. Describe how they act now.
  4. Imagine someone came up to you and asked you to write a book about succeeding in college. What would you write about in the academic section? What would you write about in the chapter dealing with academic accommodations and faculty cooperation? What would you recommend for families? What would you recommend to faculty or administrators reading your book?
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*Main Study Questions Including Pilot Study Information*

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5. If someone asked you to explain why you needed accommodations, what would you say to them?
6. Let's say an instructor or administrator questioned your request for accommodations. How would you or have you advocated for yourself?
7. If a friend you knew had AD/HD and was deciding to either attend a community college, private college or public university their first year after graduation, what would you tell them and why?
  - a. How did you decide on attending this institution?
  - b. What do you see in your future adventures?
8. How would you describe the peer response on this campus toward students with AD/HD?
  - a. How do they react about you getting accommodations?
  - b. What are their attitudes like toward you? Do they make fun of you? Do they believe you should be in college?
  - c. Have you ever had a peer ask you for medicine?
9. Now that you have been in college for a while and have experienced getting to know the faculty and administrators, if the president came up to you today and said he was going to let you give out an award for the best academic instructor, and the most student oriented administrator, what traits would you look for in an instructor? What traits would you look for in an administrator?
10. If you could change something (academically or emotionally) about how this university helps those who have AD/HD, what would it be and why?
11. If you could give this institution a gold star on helping you through college, what would it be in and why?

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and listened to the tape-recording of all previous interviews. This strategy was employed to prepare the researcher for the next interview and remind him of data contradictions that required further exploration in the next interview.

After all interviews were completed, the researcher began the data analysis phase using the grounded theory approach of Strauss and Corbin (1998). In the first step, the researcher open coded each transcript, writing memo statements about the open codes in the research log. Second, the researcher input the transcripts and open-code data into NUD\*IST Software for Qualitative Data Analysis (Version 5) to begin the axial coding process. Third, two internal auditors verified the open coding process. The auditors simultaneously open coded three transcripts. Once the researcher and auditors completed coding, they met to compare codes and negotiate differences. This process ensured the internal validity of the final reporting of the phenomenon (Merriam, 1998). Even though the auditors and researcher compared coding categories, the purpose of the audit was not to arrive at a consensus

on a set of categories, but to ensure the validity of the interpretation *process*.

The researcher created the axial codes by hand. Using the open-coded hard copies produced by the computer program, the researcher linked categories based on the characteristics and range of the open codes to form a more precise phenomenon. A theoretical framework was created using the axial codes. This framework changed as the researcher grounded the resulting theory in the experiences of the volunteers.

In the fourth step of the data analysis, the researcher engaged in selective coding to refine the resulting theory. The researcher reviewed the theoretical framework for density throughout the coding process by examining the properties and dimensions of the themes. In the fifth step of data analysis, the researcher re-examined those areas considered special codes, because of rarity, by reviewing the data to ensure that information from other cases was not overlooked. The researcher reported any extraneous cases in the final theory to improve validity and explanatory power.

Table 2

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*Questions Added to Main Study Based on Pilot Study Information*

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1. Tell me about your diagnosis.
  - a. When were you diagnosed?
  - b. Why did you get assessed?
  - c. How did you react when you heard you had AD/HD?
  - d. How did your parents react?
  - e. Do your parents ever get frustrated with you? Why? How do you feel about that?
  - f. How do you feel about having AD/HD now?
  - g. Do you feel your symptoms have changed from when you first found out to today? In what way?
  - h. What do you think about medication?
2. Let's say an instructor or administrator questioned your request for accommodations. How would you or have you advocated for yourself?
3. How did you decide on attending this institution?
4. What do you see in your future adventures?
5. How would you describe the peer response on this campus toward students with AD/HD?
  - a. How do they react about you getting accommodations?
  - b. What are their attitudes like toward you? Do they make fun of you? Do they believe you should be in college?
  - c. Have you ever had a peer ask you for medicine?

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With the framework explaining the phenomenon completed, the researcher engaged in the final step of the data analysis process by attempting a member check of the theory to enhance validity. Unfortunately, the members asked to participate in the member check never responded. Therefore, the researcher engaged in a final audit using an external auditor to review the entire research process from recruitment to data analysis in both the pilot and main study. The purpose of this external audit was to ensure the generalizability from the voices heard to the theory developed.

## **Results**

The researcher identified four constructs explaining the phenomenon. Each construct explored student attitudes about (a) life with AD/HD, (b) adolescence with AD/HD, (c) college and AD/HD, and (d) advice for students, college personnel, and parents.

### *Life with AD/HD*

This first construct merged themes related to learning to live with AD/HD symptoms. In the themes melded into this construct, students spoke of their emotions around their diagnosis, strategies used to manage their



medication, and the consequences of their disability. Some students discussed the positives of an AD/HD diagnosis. These individuals viewed their disability as a gift that gave them the insight to embrace diversity. For the most part, however, the students talked of the burden of AD/HD and the daily hurdles they had to jump to keep their young lives from spinning out of control. To some students, the AD/HD diagnosis was a relief,

*It made me realize that it wasn't just me being rude, interrupting. Or it wasn't me not wanting to grow up and quit talking. That doesn't excuse that I shouldn't work on it, but at least I have a name [for] it.*

The students also talked about their parents' reactions to the diagnosis. Some students reported that their parents did not believe the diagnosis. As one student stated, "He's offended almost that I have ADD ... my dad's like- 'You don't have ADD. You got a 3.9 GPA in high school. You're a Dean's List student in college.'" Other students told of parents who appeared relieved with the diagnosis providing their child with valuable support.

Students listed a variety of medication they took to control their AD/HD symptoms, including Ritalin, Adderal, and an anti-depressant. Some students indicated that they were using a natural remedy coupled with trying to control their diet to manage their disorder. Regardless of the medication used, the timing for taking their medication was critically important. According to one student, taking his or her medication,

*... Just depends on what activity I'm doing. I mean, if it's something I have a lot of autonomy, and I'm not going to be disrupting anybody, I won't ever take a Ritalin. If I've got to sit still through anything; I'm taking a Ritalin. Just cause I can't get comfortable.*

Whereas students recognized the value of AD/HD medication, they also understood that the medication did not, and could not, cure their disorder. One student stated that even though her grades improved while taking the medication, "I still talk up a storm. So [my AD/HD] really hasn't changed in that respect."

When the researcher asked students to explain what it was like to have AD/HD symptoms, one student commented,

*ADD does not describe me, it is me ....it's not just two or three things about me. It's like an octopus cause it has tentacles into every single aspect of me ...I'm ADD. It affect[s] everything.*

Although most students stated that some of their symptoms had improved, the students lived with continuing challenges. "I will never out grow it, but I think I've just learned to compensate better ...I'm not as obnoxious

[as I was before]." Some students felt their symptoms were increasing in frequency because at college they were not receiving the same one-on-one help they enjoyed in high school or while living at home. One student talked about the link between his symptoms and depression, "I was struggling with my ADD. And the ADD brought me into depression last semester because I was so focused on studies ..."

Some of the symptoms these students discussed included a lack of ability to generalize information, being inattentive and impulsive, having a bad memory and slow processing speed, and difficulties in reading and math. One student discussed how difficult it was to comprehend the written word, "You can read a question five times and still nothing goes through your mind." Another student discussed her inability to focus on studying. "I [would] have to go do that [sic] homework. [And I would be] 'There's a spot on the floor. How did that get there? I bet it was coke or maybe it was Kool-Aid.'" I mean, seriously."

Students talked about their definitions of different AD/HD symptoms, such as impulsivity and processing speed. For example, one student described impulsivity as "[The ability to] do many things at once. Just not complete." Another student said, "I change the subject just because I get bored with what you're saying and [I] start thinking about what I'm going to say. I'm really bad about interrupting ..." Some characterized themselves as fragmented thinkers who had to always think about what they were about to say before jumping into the conversation. For some students, one troubling symptom was a poor memory. "I still have a lot of trouble with certain things. I will get halfway through a sentence and completely forget what I was saying. I mean, [my friends will] remind me and [it] still won't come to me."

While many students expressed negative views of having AD/HD, some noted that AD/HD could have some positive attributes. One student said her sensitivity towards others was positive because, "I can ... put myself in other people's shoes." Another student believed that everyone should have AD/HD. "I like to think of ADD as something people need, that everybody needs, I think, something in their life that helps them find their weaknesses."

Based on the qualitative data in this study, it is reasonable to posit that the process of living with AD/HD was a challenge for these college students. Specifically, the AD/HD diagnosis influenced their thinking about self, interrupted the flow of their daily lives due to thoughts about managing their symptoms, and interfered in their self assessment of important life skills such as memory, attention span, and information processing. For these

students, AD/HD also positively “intruded” in their thinking about others, making them more sensitive to diversity and issues of difference. It can be argued, however, that even this positive intrusion may divert their attention from the task of staying in college.

#### *Adolescence with AD/HD*

Even though the researcher did not ask a question about adolescence, almost all students talked about experiences from their adolescent years that had shaped their attitude about their disability. For many those lived experiences revolved around their parents’ attitudes concerning the diagnosis. “Like they’d always get mad at me because I couldn’t never [*sic*] pay attention ... They’d sit down and try to explain something and I just could not pay attention. I tried and I really couldn’t [do it].”

Additionally, students talked about the negative attitudes of some high school teachers. One student reminisced about a time when his teacher tried to get him extended time on exams. “It was a struggle with a lot of teachers because a lot of them didn’t believe in ADD. Their like-‘Oh, you’re just using that as an excuse.’” Students also shared feelings of isolation while working in the school’s resource room.

*I didn’t like [the resource room] because I felt like I was being secluded. They would remove me from the classroom and put me into a smaller classroom. I didn’t like it because then everybody was like “Where’s she going?” and then I have to say “I [am] going to resource.” And then people would be like “What’s wrong with you?,” you know?*

As the Life with AD/HD construct explained the intrusive nature of AD/HD on participants’ thinking about self, this construct informs the intent of this study through the examination of the students’ thoughts about the reaction of others to their symptoms. The fear of being treated differently by parents and teachers, being misunderstood, and isolation from peers during their pre-collegiate experience may help to explain the phenomenon of their collegiate experience. Thus, it is reasonable to suggest that these students carried those fears from high school to college, once again, diverting their attention from the demands of college. Because of the research design, all students interviewed were registered with the Office of Disability Support on their campus and were receiving support from that office. But what about those students diagnosed with AD/HD who were not registered? Is it possible that these fears kept them from approaching the support they needed? Did that fear intrude on their ability to seek help?

#### *College and AD/HD*

During adolescence, for many students, their parents’ encouragement heavily influenced their decision to attend college. As one student stated,

*[My parents] told me I wasn’t going to sit at home and be a bum for a year ... I wanted to do college and they thought I could. My dad ... gave me ... the confidence to go through it.*

The students talked about the challenge of adapting to the advanced learning required in college. “It’s been tough and it’s tougher with ADD and [to] make the grades, to pay attention, regurgitate all that stuff back out. It really is pretty tough.” Connecting the college experience with their diagnosis, these students also talked about confidentiality and disclosure. Some students willingly shared their AD/HD diagnosis with their peers; others were more discrete.

The researcher asked participants to describe how they study given their individual symptoms and to make recommendations to students who are thinking about entering college. They stated that each person has to find their own study method. According to one student,

*I just try and take good notes and try [to] pay attention in class. And then I go to my room and look over the notes and everything. And then like after I memorize it, I like to go and bounce it off someone else.*

Another student commented,

*I was [doing] a lot of math. I was just constantly working problems till you get [*sic*] the hang of it. But some of the classes that you read a lot and recite definitions, I [made] note cards ... I’ll write them out on a note card and do one side and do the other just like flash cards. I’ll just do that until I get them all right.*

Most of all, students indicated that learning to self-accommodate and approaching professors for help were vital to remaining in college. One of the self-accommodation strategies shared by many students was to enroll in fewer classes. “I can’t take more than 12 hours and do what I love. I love to learn, and I love what I’m studying.” A student described his ability to organize by explaining, “I’m a Post-It notes person. I’ve got notes everywhere. I’ve got a calendar. I just tried [*sic*] to keep well organized.” “Plugging my ears help[s] tremendously” for a test or for study purposes, said another student. “I think that really helped me to be able to concentrate on the question [asked].”

Some of the accommodations students asked for included extended time to complete writing assignments

and take exams, having a note-taker in class, and using a tutor. According to one male student, tutoring was an important strategy to ensure academic success. In selecting that all-important tutor, he had one pivotal criterion, "... I [sic] got to have somebody who's able to tutor without getting mad at me. That's sometimes a chore."

In order to receive accommodations at the college level, a letter must be delivered to the instructor informing him or her of the type of accommodation needed. Students shared a dislike of personally submitting an accommodation letter to professors. These students talked about unpleasant previous experiences when submitting their letter, ranging from negative verbal feedback from a professor to a student perception of body language that communicated disapproval.

The students preferred to have the letter mailed to professors ensuring peer confidentiality. As one student stated,

*One time I even got [my accommodation letter] out before class and three different people passed it around, and I was like, "Excuse me. Hello. That's mine". Yeah, they're [sic] like, "Ooh, what's this? Ooh, I need to get me one of these forms. Then I'll be a good student." I just felt like really small that day.*

Some students decided not to ask for accommodations for different reasons. One student asserted, "My philosophy is that the world is not going to make all these accommodations just for me. And I best deal with [it] while I can learn to deal with [it] ..."

In addition to problems with the accommodation letter, some students argued that too many professors were not sympathetic to their disability. One student felt that professors pressured them to conform to a "mold" of the perfect student.

*They have this fit mold, like this cut gingerbread mold, and here's me. I am Santa Claus and they want a Gingerbread Man, and I don't fit in the Gingerbread Man cut out because I'm different. And they're like, "Well I'm sorry. That's just the way it is."*

On the other hand, many students had had several positive experiences with professors. One student told of a professor who allowed him to come to another class to take his exam.

*Like I had a class at 10 o'clock, and I had a class at 11 o'clock, and so whenever I had to ... take [a] test [in his class] ... he would let me come at his 1 o'clock class because I could take the test in enough extended time.*

Peer attitude also affected how college students with AD/HD felt about their disability. A student discussed

times when peers would openly disclose her disability to other students,

"Especially, if it's like out in public and people can hear that don't know. That hurts. I just like-I want to tuck my head in my shell and crawl away and be like a turtle, you know?"

Students also discussed their attitudes about the effort they put forth just to remain in college. One student revealed his strategy as follows "Just keep encouraging, saying you can do it. I think one of the biggest things that ADD affects [is] confidence." Another student stated that someone with AD/HD must have the desire to do well in college in order to succeed.

*Yeah. It's got to be a real desire . . . I know a lot of students here on campus kind of read the book. Kind of take the test and kind of do it. Kind of get a B, and no problem. And they get out of college, and it wasn't anything. Someone with ADD has to be very deliberate.*

Whereas the two previous constructs explain the connection between AD/HD and the college experience, this construct provides information on the strategies the students used to remain in college, including the importance of parental support, peer encouragement, and self-accommodation. Evidence provided in this construct suggests that the students who volunteered for this study were sensitive to the demands of college and to their own challenges related to those demands and the symptoms of AD/HD. They self-accommodated by learning study methods congruent with their symptoms, attempting to find the correct number of credits to take each semester, and staying organized. In addition, these students, who were registered with the Office of Disability Support, learned to accommodate by asking for help with note-taking or tutoring. Still, even with support, they talked of the challenges of managing the accommodation letter process by notifying each professor at the beginning of each new semester. The reaction of the professor, both positive and negative had left an indelible imprint on the minds and hearts of these students about their academic value.

#### *Advice for Students, College Personnel, and Parents*

Throughout the interview sessions, students shared their thoughts about the support structures they needed to remain in college. The majority of students interviewed stated that if they could give a gold star to their institution for helping them in their journey, they would give it to the Disability Support Center. One student disclosed he liked the way they tried to help keep in touch with him. Students felt appreciated and understood when Disability Support directors made sure they had useful ac-

commodations, helped them learn how to prioritize and study, and called specialists to get more information on how to help them. Additionally, students shared tales about faculty members who had walked the extra mile to help students succeed.

These students also made suggestions for matriculating students with AD/HD, the Disability Support Center, professors, administrators, and family. One student advised high school students with AD/HD,

*[To] learn how to study before you get [to college]. Take harder high school classes ... My freshman year I didn't do all that super which is common for college students, but if you're already struggling, it blows people out of the water.*

For those students who knew they had AD/HD before entering college, a student suggested "...to go ahead when they're sending out applications to look into the disability programs and see what's out there. See if that might help them make a better choice which college to attend." While attending college, the participants in these research conversations talked of the need for support group sessions with other students diagnosed with AD/HD so they could talk to someone else "... cause we would all understand one another."

Every student recommended that professors, administrators, and other students receive disability training. "Yeah, let them know what it's like. Like, give them a scenario and let them, you know, put them in our shoes. And let them know how we feel." For those who might refuse the training one student suggested, "I guess if you don't understand it, you don't believe you need to read up on it. And if you don't, you sure don't need to be teaching somebody with it."

Participants had specific recommendations for professors. For example, one student recommended, "Just be patient. Cause we're not trying to be a smart-ass or anything if we're not getting it, but we ask you over and over ... just to make sure that we got it. Go slow." Another student recommended that professors try a variety of testing alternatives to allow students with disabilities options for demonstrating competency. One student said, "I'd rather apply it. Like ... do a presentation and get up there and talk..."

Students also had advice for administrators, as well as parents. One student encouraged college administrators to search for alternatives to the traditional entrance exam, eliminating the one-size-fits-all method of evaluating student merit. As one student stated,

*I had them before, the ACT and the SAT. I made a 1000 on the SAT, which really is barely enough to get into this school. I came here and I've been on the President's List the last three years.*

For parents, students talked about the importance of providing children with disabilities a supportive environment with a continuous flow of positive reinforcement. "It makes a big difference when [positive reinforcement] comes from your parents."

For these students, college survival was a formula of recognizing their unique challenges due to the symptoms of AD/HD, coupling that recognition with strategies for remaining in college, and searching for support structures that make the extra effort bearable. These students diagnosed with AD/HD offered advice for retention that is solid advice for any college student, including finding support structures, working with caring and compassionate faculty members, learning how to study, and preparing for college in high school. Interesting, in all of their uniqueness the students may have found the norm.

## Discussion

It is reasonable to assume that adults with AD/HD try to live normal lives. A part of this normalcy is to attend college and receive specialized training in an occupation of one's choice. However, many of these individuals never obtain the initial degree they set out to get due to their varied needs in a restricted higher education setting (Bramer, 1994). Those who do continue with collegiate studies learn to pour themselves into the perfect college student mold created by a culture that does not accept deviation from the norm. Understanding the ability of these students to fit, or not fit, in that mold may be the first step toward understanding how they remain in college.

The students talked about professors who were willing to provide the necessary accommodations. They discussed the unique situations that they dealt with in efforts to obtain academic accommodations from their professors because of their disability. For these students, college life was more than just getting up and attending class. For some, it was discovering they had a disability and deciding what they were going to do about it in terms of confidentiality, medication, and how to overcome to "become" (Fisher & Beckley, 1999).

Themes interwoven throughout these students' experiences included those emotional feelings related to the unwillingness of people to understand them, participating in an environment laden with judgment or prejudice, and dealing with feelings of frustration with self (Bramer, 1994; Green & Chee, 1998; Slomkowski et al., 1995) and with others as a result of that prejudice. McCune (2001) reported similar findings of students feeling a stigma when they self-identified their disability to their institution. Some students related this emotional response to feeling

like a student of color and the exclusion it brought in terms of being admitted into college. Congruent with research findings reported in the literature, these students talked about the importance of support networks on campus and beyond in giving them caring and compassionate guidance, and their concerns about the diminished nature of that support once they left high school for college (Hechtman et al., 1984 Malakpa, 1997).

The very definition of AD/HD, for these students, was formed by unknowing or uncaring high school teachers and peers who simply labeled students with AD/HD as “lazy.” These very labels influenced concepts of self-esteem and self-worth. Congruent with the extant literature postulating the low self-esteem of students diagnosed with AD/HD (Green & Chee, 1998), these students talked of situations that made them feel “like really small” or wanting “to tuck my head in my shell and crawl away and be like a turtle.”

The students in this study expressed concerns about an uninspiring college environment in terms of the internal college support structure that specifically dealt with accommodations, acceptance into the college life, and peer groups. Acceptance into college was a chore in itself because of the “student mold” created by administration and college faculty, and their unwillingness to look outside this segregating box. This opinion of an “undue burden” was also found by Williams and Ceci (1999), who asked professors their opinions about accommodating students with disabilities. Some professors felt that accommodating students with disabilities penalized those without disabilities. Many students in this study sensed that professors wished they could simply stuff the “disabled” into the “normal” box making them conform to the ideals of the perfect student, a perception that left many with feelings of inadequacy and weakened self-confidence.

Several of the students not only dealt with low self-esteem, but also faced taunting demons of self-doubt. Similar findings were reported by Dooling-Litfin and Rosen (1997), who compared 86 self-identified students with AD/HD and 477 randomly selected volunteers with no history of childhood AD/HD. The authors suggested “there is something affecting the self-esteem of people who were identified AD/HD as children, and this effect appears stable even among the most successful group of the AD/HD population” (p. 79). Just as Henderson (1999) and Atkins (1996) found, the participants in this study talked of their self-doubts related to the very skills needed to stay in college. For some, these skills included a poor memory, inability to integrate information, and the inability to stay on task. For others, memory was not the problem. Instead, they struggled with the ability to comprehend or relate concepts. Conversely, as with

Henderson’s research, these students shared positive perceptions concerning their disability related to an enhanced understanding of others and an appreciation for diversity. Unfortunately, in the larger view of their self-worth, the positives were not enough to outweigh the negatives.

The theoretical framework constructed through the stories of the 10 college students in this study included constructs that helped to explain the phenomenon of students managing AD/HD symptoms while remaining in college. Six hypotheses were generated from the emergent constructs. First, AD/HD was a formidable presence in the lives of these college students that infiltrated every experience, to include the collegiate experience. At a moment in time when all students are learning survival strategies, students living with the symptoms of AD/HD were forced to develop those strategies within the suffocating embrace of their symptoms.

Second, the fear of reliving past experiences of being misunderstood and isolated from peers informed perceptions about the college experience and the people involved in that experience. Because of these pre-determined fears, the students’ perceptions may be slightly skewed, placing their interaction with support services, faculty, peers, and even knowledge in a different light compared with other students.

Third, these students, who were registered with the Office of Disability Support on their campus, were sensitive to the demands of college, aware of the challenges they faced, and cognizant of the strategies they must develop to learn to exist in college. This hypothesis, then, begs the “chicken-versus-egg” question. Were the students in this study aware of these demands and challenges because of their interaction with disability support? Or did these already aware students realize the need to seek the help of disability support? The answer to that question may help to further define “remaining in college” for all college students experiencing the symptoms of AD/HD.

Fourth, the drive to achieve along with the need for self-encouragement and motivation was an important strategy used by these students to continue their existence in college.

Fifth, there was evidence to support the hypothesis that for college students diagnosed with AD/HD the accommodation letter process was a trying experience that, coupled with the fear of isolation, may explain why some do not seek the help they so desperately need.

And, finally, the survival strategies used by these students were very similar to those needed by all students, finding support structures, working with caring and compassionate faculty, learning how to study, and preparing for college while in high school.

## Recommendations for Practice

The most important recommendation linking this research to practice is the development of training programs for college administrators, faculty, and students to help them understand the lived experiences of students with AD/HD. Students with disabilities want significant others to know about their disability, to understand their frustration, and to appreciate their daily struggle. These students recommended training sessions that teach the facts, eliminate the fiction, and open the mind of others to a reality with multiple and interlocking “molds.”

Such a training session might include role play, presentations by individuals with AD/HD, and reading the stories of those struggling to succeed. Disability support administrators could offer mini-workshops at varying times and locations congruent with faculty, staff, and student schedules. Possible topics include college students with AD/HD and their first-year experience; the positive and negative experiences these students perceive while they attend college; student attitude about the AD/HD diagnosis; and what can be done to make college careers for these students more successful. Additionally, these students want training sessions for others that emphasize issues related to confidentiality.

Other training ideas gleaned from the qualitative data include training for students diagnosed with AD/HD related to (a) their rights under disability law, (b) appropriate study techniques congruent with their disability, (c) learning to self-advocate and self-accommodate when necessary, (d) understanding their learning style and the strengths of that style, and (e) the services provided by their institution to support students with AD/HD. In addition, the researcher recommends that directors of disability support programs should send surveys to instructors, administrators, and students to ascertain what their needs are in terms of disability information allowing administrators to design valid training programs.

## Conclusion

The voices of the 10 students participating in this study tell the story of the highs and lows of living with AD/HD and navigating turbulent adolescent years while managing the symptoms of AD/HD. The stories shared irrefutably link AD/HD symptoms with college success or failure and the drive to achieve. At least for these students during this moment in time, AD/HD is a formidable presence in their ability to reach their full potential. It prevents the “normal” gravitational pull that keeps all aspects of their young lives spinning around them just as the planets move around the sun. For students who do

not struggle with the symptoms of AD/HD, the gravitational pull is an invisible force with the planets moving in some logical fashion at a controllable speed. Students with AD/HD, on the other hand, are constantly aware of the chaos moving around, above, below, and beyond. They are always sensitive to the need to manage the pull to prevent their universe from spinning out of control.

The energy that it takes to keep the pull manageable and lives livable is exhausting for these students. Whereas students without a disability expend their energy managing the highs and lows of adolescence, functioning within the new reality of college life and college expectations, and pushing the envelope of success, the students in this study must divide their energy, constantly fearing academic and social foes. For these students to remain in college, faculty and staff must, first, appreciate the energy drain of living with AD/HD and, second, develop strategies that help these students plug that drain.

In the cookie-cutter world of the Gingerbread Man, students diagnosed with AD/HD are Santa Claus supporting their emotional baggage while trying to manipulate an unforgiving academic chimney. Students diagnosed with a disability believe they are more artistic and creative than their peers who do not have a disability. Students diagnosed with AD/HD believe they are more sensitive to others because they understand the challenges of a one cookie-cutter world. Students believe that, given just one chance, they can unpack their emotional baggage and make a small difference in the world. Perhaps these are just the competencies needed in contemporary society. Perhaps it is time to change the cookie-cutter.

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