

Adherence to ADHD medication during the transition to college: Experiences, needs, and challenges

by

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Abstract

Self-management of chronic illness is an abrupt challenge for adolescents as they transition into adulthood. This struggle is most evident when they move away to college and no longer have instrumental support for disease management from their parents. Adolescents with Attention-Deficit Hyperactivity Disorder (ADHD) may be at an even greater risk for poor self-management and medication adherence, as skills essential to these health behaviors are inherently impaired in these individuals. Despite knowing that self-management during transition to adulthood is particularly difficult for adolescents with chronic illness, little is known about how these individuals manage chronic conditions on their own. Therefore, the current study seeks to explore the medication self-management experiences of adolescents with ADHD on the cusp of transition to young adulthood. Participants will be college freshmen with ADHD prescribed daily medication for their condition. Individual focus interviews will be conducted using a semi-structured interview script. Several measures related to ADHD medication management will also be completed. Data will be analyzed via directed content analysis and descriptive statistics. The knowledge obtained from these interviews will assist in developing future interventions for college freshmen with ADHD.

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Adherence to ADHD medication during the transition to college: Experiences, needs, and challenges

Non-adherence to medical regimens in adolescents with chronic illness populations is estimated to be around 75% (Rapoff, 2009). This high percentage is quite alarming, as the consequences of non-adherence can be severe. Non-adherence has been found to be associated with negative outcomes such as worse disease symptoms, increased impairment, emotional problems, higher healthcare costs, hospitalization, and sometimes death (DiMatteo, Giordani, Lepper, & Croghan, 2002; Hommel, Denson, & Baldassano, 2011; Sokol, McGuigan, Verbrugge, & Epstein, 2005). Because adolescence is the period in which lifelong health behaviors become established (Holmbeck, 2002), it is imperative that we identify the challenges adolescents experience in adhering to their medical treatment.

Several developmental factors may contribute to high rates of non-adherence among adolescents with chronic conditions. Parent-child conflict tends to increase during adolescence, due to adolescents' desires for increased autonomy being at odds with the need for continued parental oversight (Laursen, 1995; Smetana, Yau, & Hanson, 1991; Steinberg, 1988). The presence of a chronic condition then provides an additional layer of complexity as parents may be reluctant to grant autonomy to adolescents with chronic, potentially life threatening illnesses (Rianthavorn & Ettener, 2005). The demands of the adolescents' illness requires them to comply with both parental and medical authority. This doubling of authority, at a time where independence is normally granted, can lead adolescents to willfully defy established rules (Rianthavorn & Ettener, 2005). Adolescents may sabotage their medical treatments (e.g. miss a medication dose) as a way to rebel and to express their dislike of medical dependency (Rianthavorn & Ettener, 2005). They may also neglect their medical regimen to avoid feeling

different from their peers (La Greca & Schuman, 1995). Relatedly, social demands can greatly impact adherence by creating barriers to the development of friendships and romantic relationships (La Greca & Schuman, 1995; Rosina, Crisp, & Steinbeck, 2003). Unfortunately, adolescents' inability to foresee the long-term negative implications of non-adherence can reinforce this risky behavior pattern (Shaw, 2001).

Adherence in Adolescents with ADHD

To date, the majority of the research literature on adherence in adolescent populations has focused on those with chronic medical conditions such as cancer, HIV, diabetes, and asthma (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Bender, 2006; Butow, Palmer, Goodenough, Lockett, & King, 2010; Murphy et al., 2005). Less is known, however, about adherence among adolescents with conditions that are considered more psychiatric in nature, such as Attention-Deficit Hyperactivity Disorder (ADHD). ADHD is one of the most common chronic illnesses among adolescents and young adults. According to the most recent National Study on College Student Health (2014), approximately 8% of adolescents report having ADHD, a disorder characterized by symptoms of inattention, hyperactivity, and impulsivity (American Psychiatric Association, 2013). Similar to other chronic illnesses, successful management of ADHD requires high rates of adherence to medical treatment, specifically daily prescriptions of stimulant medication such as methylphenidate and dextroamphetamine salts, although it is important to note that combined treatment (e.g., medication and behavioral therapy) is effective as well (American Academy of Pediatrics, 2001; MTA Cooperative Group, 1999).

Adhering to a daily medication regimen may be challenging for adolescents with ADHD in several ways. First, the skills essential for medication taking (e.g. organization, sustained attention, memory, limited distractibility, problem solving) are inherently impaired in these

individuals (Barkley, 1997; Dodson, 2008; Marije Boonstra, Oosterlaan, Sergeant, & Buitelaar, 2005). Issues with memory can lead to frequent occurrences of adolescents forgetting to take their medication at the prescribed times. Also, a lack of organization and sustained attention may limit their abilities to engage in health behaviors that require preparation and diligence (e.g. refilling a medicine before it runs out, scheduling an annual check-up with a doctor). Second, the stigma of receiving treatment for ADHD may negatively influence their choice to adhere. Peers may believe individuals are using their ADHD diagnosis as an excuse for not trying or a chance to seek stimulant drugs (Brinkman et al., 2011). Thus, several risk factors (i.e., developmental factors, cognitive impairments, peer relationships) may make it challenging for an adolescent with ADHD to adhere to prescribed treatment.

ADHD Management during the Transition to Young Adulthood

Difficulties adhering to medical treatment due to factors associated with adolescence and ADHD may be further amplified as adolescents transition into young adulthood. The transition from high school to college, for example, is a challenging time for many young adults and poses unique challenges for adolescents with ADHD. Compared to the adolescent years, the college years are characterized by increased autonomy and risk taking, reduced parental supervision, and less daily structure (Arnett, 2000; Fromme, Corbin, & Kruse, 2008; Morgan, 2012). With regard to increased freedom, adolescents are more likely to engage in risky behaviors such as heavy drinking, marijuana use, sex with multiple partners, and reckless driving (Bina, Graziano, & Bonino, 2006; Fromme et al., 2008). Risk taking appears to escalate in college due to young adults' faulty perceptions of invincibility (Shaw, 2001). Since they are no longer under the watchful eye of their parents, the college environment is conducive to risky behaviors such as providing easy access to alcohol and drugs (Fromme et al., 2008). These factors are a dangerous

combination that can contribute to poor adherence in adolescents with chronic illness. This is not surprising, given that volitional non-adherence is another risky health behavior that adolescents with chronic illness may engage in, due to their inability to foresee the long-term repercussions of poor adherence on their health status (Bender, 2006; Shaw, 2001). Because adolescents tend to be present-focused, they have a harder time appreciating how current behaviors, such as non-adherence, may negatively impact their health years down the road.

Changes in parental supervision also may impact adherence. Whereas increased parental supervision over medical care is associated with better adherence, parental involvement in care decreases as adolescents age and approach adulthood (Ellis et al., 2007; Modi, Marciel, Slater, Drotar, & Quittner, 2008). Additionally, young adults quickly discover their newfound freedom comes with more responsibilities than they had anticipated (Morgan, 2012). Youth with ADHD tend to have even more responsibilities than their healthy counterparts, as they are now expected to manage medical tasks previously managed by their parents (e.g., medication taking, managing medical appointments, obtaining refills) in addition to learning how to master other life skills associated with becoming a functioning adult (e.g., laundry, meal planning, managing finances).

With regard to reduced daily structure, it is not uncommon for college students to pull “all-nighters” to cram for exams, stay out until the early morning hours socializing, and eat and sleep at atypical times. In the most recent National Study on College Student Health (2014), approximately 43% of college students reported feeling tired and sleepy three to five days of the week. This lack of sleep is clearly impairing their daily functioning as almost 41% reported it as being at least more than a little problem (National Study on College Student Health, 2014). With the lack of parental oversight previously received in high school, young adults in college are no longer obligated to follow curfews, eat at scheduled meal-times, nor balance studying and

socializing activities. As adherence to medical treatment is positively associated with structure and routine (Fiese, Wamboldt, & Anbar, 2005), these erratic behaviors can make adherence particularly challenging. Thus, it appears that numerous factors coalesce into a “perfect storm” for non-adherence during the transition to young adulthood for adolescents with ADHD. This can have many harmful consequences.

Consequences of Poorly Managed ADHD

Adherence to prescribed medication minimizes the negative impact of ADHD on both short-term and long-term academic, social, and vocational functioning (Greenhill et al., 2007; Multimodal Treatment of ADHD Study Cooperative Group, 1999). Non-adherent individuals tend to experience greater overall ADHD symptom severity, thus leading to lower levels of global functioning (Brinkman et al., 2011; M.T.A.C.G., 1999; Safren, Duran, Yovel, Perlman, & Sprich, 2007). Non-adherent adolescents with ADHD report poor academic adjustment, lower grades, less productivity and study skills, decreased focus, sloppier handwriting, little creativity, and reduced career decision making self-efficacy (Brinkman et al., 2011; Heiligenstein, Guenther, Levy, Savino, & Fulwiler, 1999; Norwalk, Norvilitis, MacLean, 2009; Weyandt & DuPaul, 2006). Adolescents also report impaired communication and listening skills and increased impulsivity, causing them to become less conscientious of their social interactions with others (Brinkman et al., 2011; Shaw-Zirt, Popali-Lehane, Chaplin, & Bergman, 2005). Long-term consequences of poorly managed ADHD include a decreased likelihood of obtaining a college degree, difficulties in achieving career milestones, high job turnover rate, lower work-performance ratings, greater tendencies towards anti-social behavior, and an increased risk of incarceration and adult criminal activity (Goodman, 2007). Given the many negative and

potentially life altering consequences of poorly managed ADHD, it is critical for adolescents with this condition to have their symptoms properly controlled.

It is important to note that many of the previously mentioned consequences of poorly managed ADHD are preventable with proper care and adherence to medical treatment, although it should be stated that accommodations and other behavioral strategies are also critical in addressing aspects of ADHD impairment. In order to optimize the outcomes of individuals with ADHD, we need to better understand the experiences and challenges faced by adolescents as they transition to college and independent adulthood. To our knowledge, no studies have examined disease management and adherence in adolescents with ADHD as they transition to young adulthood. This is surprising given that youth with ADHD comprise a significant portion of the college student population compared to other disability categories (Weyandt & DuPaul, 2006). In addition, academic performance during college is critical for long-term outcomes such as employment and career achievement (Tan, 1991). The current study moves the research literature forward by exploring the experiences of adolescents with ADHD on the cusp of transition to young adulthood. Although this study is primarily focused on medication self-management, it also briefly taps into non-medication related management such as obtaining academic accommodations. Through the use of qualitative interviews, we identify common themes in facilitators and barriers to medication self-management during this critical developmental period. Due to the limited research on adherence in students with ADHD transitioning to college, the current study is exploratory in nature and thus has no a priori hypotheses. Information obtained through this qualitative exploration is presented for the purposes of guiding future quantitative research as well as the development of intervention

programs to facilitate medication adherence during this critical developmental period for adolescents with ADHD.

Method

Participants

Participants were 10 freshmen with ADHD at a large, public southeastern university who were: (1) full-time freshman in his or her second semester, (2) living independently (not at home with parents), (3) diagnosed with ADHD, (4) taking medication for ADHD (prescribed oral daily dosing), and (5) ages 21 or younger. These criteria were established to capture those students most likely to be managing ADHD medication independently for the first time. The study was conducted in the spring semester so that participants had sufficient time in the fall semester to experience the transition period. Because we were primarily interested in experiences adhering to ADHD medication alone, students with other conditions (psychiatric, developmental, or medical) that would confound their ability to speak exclusively about ADHD were excluded. This included individuals with comorbid conditions involving a daily treatment regimen in addition to their diagnosis of ADHD (e.g. diabetes, inflammatory bowel disease) that could possibly interfere with their ability to talk specifically about ADHD self-management.

Procedure

Participants were recruited via fliers distributed around the college campus and via an email sent to all students registered with the school's disability office. After determining study eligibility, individuals were scheduled for a 1-2 hour in-person interview at the study site. Eligible students under the age of 19 were required to obtain parental consent before participating per state law regarding the age of majority. Consent forms were either sent to the

students' parents by their request or given to the students to share with their parents. Signed consents/assents were obtained prior to participation in study procedures.

As part of their involvement in the study, participants took part in a 1-2 hour-long interview and completed several pen-and-paper questionnaires. All study procedures were conducted in a private clinic room located in the university's Psychological Services Center. Interviews were conducted until data saturation occurred. Data were considered saturated when no additional information was learned from subsequent interviews (Guest, Bunce, & Johnson, 2006). This is a commonly accepted method for determining sample size in qualitative research. Participants were compensated \$25 for their time and efforts.

Measures

Qualitative Interview

Development of measure and theoretical underpinnings. A semi-structured interview was developed for this study by the lead investigators (W.N.G., S.S., J.K.) based on their expertise in adherence to medical treatment, models of health behavior, and ADHD.

Development of the interview was guided by the Health Belief Model (HBM), a well-known theory developed in the 1950's to understand why individuals choose to either engage or not engage in particular health behaviors (e.g. exercise, smoking, adhering to medical regimens) (Rosenstock, 1974; Strecher, Champion, & Rosenstock, 1997). This model has been well-received in the literature and continues to be one of the most popular theories used to inform health behavior (Painter, Borba, Hynes, Mays, & Glanz, 2008). Refer to Table 1 for a reference on how the Health Belief Model constructs were used to develop the questions in the interview.

The HBM is composed of six primary constructs. They are the following: (Rosenstock, 1974; Strecher et al., 1997).

1. Perceived Susceptibility: a person's acceptance of his or her medical condition, and his or her subjective perceptions of vulnerability to developing the illness.
2. Perceived Severity: the person's evaluation of the medical and social consequences of having the disease as well as not receiving treatment. This also encompasses a person's assessment of school, work, and social impairments that either having the disease or not receiving treatment causes.
3. Perceived Benefits: the person's evaluation of the particular benefits that would ensue if a health action was taken as well as his or her beliefs in the feasibility and efficaciousness of the health action.
4. Perceived Barriers: impediments and obstacles that interfere with the health behavior (e.g. negative side effects, inconvenience, financial costs). Individuals will frequently engage in a cost-benefit analysis where the patient weighs the pros and cons of the health action. The amount of perceived barriers has consistently appeared as the most powerful predictor of adherence (Janz & Becker, 1984).
5. Cues to Action: stimuli to trigger the health behavior. They are categorized as either internal (e.g. symptoms, pain) or external (e.g. prompting by others, media, an event) (Janz & Becker, 1984; Rosenstock, 1974).
6. Self-Efficacy: person's confidence in his or her ability to successfully execute the health behaviors in order to receive the desired outcomes (Bandura, 1977; Rosenstock, Strecher, & Becker, 1988).

According to the HBM, individuals are more likely to engage in a health behavior when they: 1) are more accepting of their medical condition, 2) perceive their illness to be threatening with potentially serious consequences, 3) believe the health action is effective, 4) experience less

barriers and more cues to action, and 5) are more confident in their abilities to engage in the specific health behavior (Janz & Becker, 1984).

Completed measure. Based on the expertise of the interview designers, a twenty-question interview was developed (See Appendix A for a complete copy of the interview). The resulting interview assesses students' self-management of ADHD during their transition period from supervision to independence at college, with a particular emphasis on assessing facets of the HBM (e.g., perceived barriers, cues to action) to understand why students choose to either engage or not engage in certain health behaviors related to their ADHD. Since ADHD is primarily managed via medication, a discrete health behavior that has a lot of research literature, this study primarily focused on adherence to prescribed medication. However, given that the MTA Cooperative Group (1999) discusses more comprehensive behavioral approaches to ADHD management, opportunities were incorporated in the interview to assess how students were engaging in these strategies. Therefore, health behaviors were defined broadly to include all aspects of ADHD management including medication taking and associated tasks (e.g., obtaining refills), obtaining needed academic supports, and non-medication-related ADHD management strategies (e.g., study skills).

Administration of Measures

Interview. The one-on-one focus interviews were conducted by research personnel who either had a M.S. or Ph.D. in clinical psychology, along with several years of experience in clinical interviewing. All participants were reminded of the purpose of the interview and the importance of honest and detailed answers. Interviewers emphasized the conversation was not a test, alluding that there were no right or wrong answers. Participants were encouraged to ask for clarification if they did not understand the phrasing of any question.

The focus interview facilitators used a semi-structured interview script to guide the discussion of issues related to managing ADHD in college. This included soliciting information about the facilitators and barriers regarding ADHD management and the impact of transitioning from medical supervision to independence. All focus interviews followed the same scripted format with identical questions. The facilitator did not deviate from the script unless clarification of answers was needed. The interviews were video and audio recorded for the purpose of data transcription and analysis as well as preventing data loss due to possible equipment failure.

Demographic questionnaire. All participants completed a demographic questionnaire specifically created for this study (See Appendix B). The questionnaire gathered basic demographics (e.g. ethnicity, age) and more specific information tailored to the study (e.g. age of ADHD diagnosis, prescribed ADHD medications).

ADHD Management Questionnaire. All participants completed an ADHD Management Questionnaire that was developed for this study (See Appendix C). The first part included questions regarding participants' ADHD treatments and control of symptoms before coming to college (e.g. level of parental involvement, level of control of ADHD symptoms, and number of days medication is not taken). Participants responded using a 10-point Likert scale, with 0 indicating low levels of treatment/symptoms and 10 indicating high levels. A second part of this measure asked the same questions as the first; however, the questions were directed to participants' ADHD treatments and control of symptoms after coming to college. An additional three questions regarding all facets of adherence were included in the second part of the questionnaire (e.g. exact number of pills, at the correct times instructed, exact number of times). Adherence questions were presented in a multiple choice format ranging from 'never' to 'always.'

Adolescent Medication Barriers Scale (AMBS). The Adolescent Medication Barriers Scale assesses perceived barriers to medication taking in adolescents with chronic conditions (Simons & Blount, 2007). A total of 17 items comprise the scale ($\alpha = .86$). For each item, adolescents are presented with a specific barrier to medication taking (e.g., I believe that this medicine has too many side effects) and asked to rate how much they agree that they experience that barrier using one of five response options: strongly disagree, disagree, not sure, agree, strongly agree (See Appendix D). The AMBS demonstrates good construct validity. Higher AMBS scores were associated with more frequent and intense side effects, low adolescent and parent knowledge, and separated families with high conflict (Simons & Blount, 2007).

Statistical and Thematic Analyses

Quantitative data from the questionnaires were analyzed with descriptive statistics. Interviews were transcribed, verbatim, by trained undergraduate research assistants. Each interview was triple checked for accuracy by other research assistants who did not create the original transcription.

Because extensive literature exists on the HBM, a directed approach to content analysis was used to code the data (Hsieh & Shannon, 2005). Directed content analysis is a structured approach in which the primary constructs and previous literature of a theory guide the creation of the codebook (Hsieh & Shannon, 2005). The goal of our directed content analysis was to conceptually extend the theoretical framework behind the HBM when examining ADHD self-management in freshmen (Hsieh & Shannon, 2005). In order to reach this goal, the key concepts of the HBM were identified as the initial coding categories, and each code was operationalized in a codebook. All transcripts were coded according to a codebook developed by the first author based on the HBM. As the HBM was not designed to be specific to one chronic illness, health

behavior, or developmental period, it was not expected that codes derived from this model would be all-inclusive with regard to data coding and analysis. As such, new codes were allowed to develop as they existed in the data.

All transcripts were coded by three independent coders, all of which were graduate students with Bachelor's and/or Master's degrees in Psychology who underwent formal training in qualitative coding with the lead investigator. Each coder received training on the codebook prior to beginning. The training included reviewing the definition of each code and discussing possible examples of data that would match each code. Throughout coding, the principal investigator and coders periodically met to clarify questions and to add new codes if needed. After coding was complete, all coders met to discuss their coding. Discrepancies in coding were solved via consensus vote

Themes were identified based off the frequency in which certain codes displaying commonalities arose in the transcripts. Thus, a theme was defined as a frequently occurring idea that emphasized a particular pattern in the coded data (Hsieh & Shannon, 2005). This theoretically-guided, yet flexible approach to data analysis allowed for a comprehensive understanding of the information obtained and subsequent identification of themes. Based on group discussion and code frequency data, themes were identified by the group. Therefore, the interrater reliability for thematic codes was 100%.

Results

Participant Characteristics

Participant demographics are presented in Table 2. As seen in Table 2, 70% of participants were male, and the average age was 19 years old.

Parental Involvement in ADHD Care

On a scale ranging from 0-10, with 0 indicating not at all involved and 10 indicating completely involved, the average level of parental involvement in ADHD care prior to moving away to college was rated to be 6.80 ± 3.04 . This significantly decreased to 2.80 ± 3.46 following the move to college, $t(9) = 3.686, p = .005$.

Control of ADHD Symptoms

On a scale ranging from 0-10, with 0 indicating not at all controlled and 10 indicating completely controlled, average participant rated control of ADHD symptoms prior to moving away to college was 6.10 ± 2.73 . This did not change following the move to college ($M = 6.40, SD = 1.78$), $t(9) = -.25, p = .80$. When asked to rate their confidence in their ability to successfully manage their ADHD symptoms using a 0 (not at all confident) to 10 (complete confidence) scale, participants reported moderate confidence ($M = 6.70, SD = 2.16$).

Adherence

On a scale ranging from 1-5, with 1 indicating never and 5 indicating always, participant rated mean adherence was 4.10 ± 0.57 for taking the exact number of pills, 3.40 ± 0.97 for taking the pills at the times instructed, and 3.70 ± 0.82 for taking the pills for the exact number of times per day that they were instructed. When asked how many days they have missed taking their medication in the last week, participants reported no difference in the amount of missed days pre-college ($M = 3.00, SD = 1.16$) compared to the amount of days after moving to college ($M = 3.50, SD = 1.90$), $t(9) = -.83, p = .43$.

Barriers to Medication Taking

All participants endorsed at least one barrier to adherence. The most common barriers to adherence reported (endorsed as agree or strongly agree on the AMBS) were “personally don’t feel like taking the medicine” ($n = 9$), “find it hard to stick to a fixed medication schedule” ($n = 8$),

and “it is difficult to make it to the pharmacy to pick up prescription before the medicine runs out” ($n= 6$).

ADHD Transition Concerns

Five major themes emerged regarding the transition and medication self-management experiences of young adults with ADHD from supervised adolescence to independent young adulthood: 1) Transitions to independence are often abrupt, and many adolescents lack medication self-management skills, 2) Disease beliefs, perceived academic demands, and medication side-effects result in high levels of volitional non-adherence, 3) Poor self-management has serious negative implications on school performance, 4) Pressure from peers to share medication is frequent, and it can negatively affect social functioning and adherence, and 5) Social support is greatly needed. Each theme is discussed below, with representative quotes included within the text as well as in Table 3.

Theme 1. Transitions to independence are often abrupt, and many adolescents lack medication self-management skills ($n=7$).

The majority of participants reported that their parents were highly involved in their medical care before coming to college. Parents refilled prescriptions, scheduled doctor appointments, and provided medication reminders. When asked about the level of parental involvement in his ADHD care, one student noted, “She (Mom) would remind me to come up at a certain time and get my medication. She would always go to the doctor and grab it for me. Um, so I really just had to worry about going, taking it, and it was – kind of like a baby-feeding schedule. Still easy for me.” However, as the participants transitioned to college, the responsibilities abruptly shifted from parent to child. The students stated they were now the ones primarily in charge of their own ADHD treatment. One participant commented on his decrease in

parental support, “They’re just like, okay, well you just go the medical center, and we’ll pay for it, but you can get it yourself. You can pick it up yourself. It’s just on you now. You’re in college.”

Because many of the participants became accustomed to immense parental supervision over their medical care, the abrupt transition to independence was a challenging experience and many lacked the skills necessary to manage their ADHD independently. Comments such as “it was a pain,” “smack in the face,” and “kind of a shell shock” were common. As one participant noted, “It was really hard. Um, I couldn’t, the first couple of months I got my prescription, it uh, I got my prescription at home in August, so I came here and once that ran out it took me two months to get it refilled just because it was I didn’t know the process. I didn’t know what to do and so then I just was like I’ll get around to it eventually and then never really did.”

On top of their unfamiliarity, the immediate decline of parental support along with their newfound independence hindered the relative ease with which they transitioned. When discussing his challenges, one participant commented, “It’s been hard for the past two semesters cause I went from being like handed the medicine to you have the entire world and campus to yourself. You can do whatever you want. Your parents aren’t here anymore.” This increase in freedom forced them to prioritize their responsibilities, and for many, the balance between friends, medication, schoolwork, and self-care was extremely overwhelming.

Although most participants reported an abrupt transition from parent supervised ADHD care to independent self-management, three participants did not provide support for this theme. These participants differed from others in that they had low parental involvement in medical care prior to moving to college either due to living away from home (i.e., attended a boarding school) or assuming primary responsibility for their ADHD care while still in high school..

Theme 2. Disease beliefs, perceived academic demands, and medication side-effects result in high levels of volitional non-adherence (n=10).

Purposeful, or volitional, non-adherence was common among students interviewed. This was primarily due to inaccurate beliefs about ADHD and when medication is necessary, or the desire to avoid medication side-effects. Regarding disease beliefs, many students expressed the belief that they would/should “outgrow” ADHD and that medication should no longer be necessary. Many believed that extra self-discipline and structure would be enough to manage ADHD symptoms and purposefully skipped medication dosages or took less than prescribed to try to “wean” themselves. As one participant stated, “I obviously need to get off of this at some time in my life. So that’s why I initially tried, I was like okay, I’m out of medicine. Let me try to do it myself.”

In addition to inaccurate disease beliefs, participants also held inaccurate beliefs about when medication was necessary. This led them to alter their medication schedules and dosages based on perceptions of academic demands instead of the doctor’s prescriptive orders. These alterations included taking medication in the evening for study/homework time but relying on their own abilities to focus while in class and purposefully skipping medicine on lighter academic load days (e.g., only one class). As stated by one participant: “I mean sometimes I’m just, okay well it’s just one class today. I don’t need it, which is Tuesday/Thursday, so...And, then I’ll have those days where I feel like I can conquer the world so I am going to try without it today.” Skipping medications on “light” days allowed participants to stockpile medication for perceived critical periods. As one participant commented, “If finals are coming up. That’s a game changer.” Almost all of the participants reported expending a greater effort to ensure that

their medication was taken when they had large assignments or impending exams compared to more lax weeks where minimal schoolwork was due.

Side-effects were another common reason for non-adherence. Many students reported skipping medication to avoid its negative impact on their sleep, appetite, mood, or social functioning. One participant stated: “I don’t feel like myself. I don’t feel comfortable going to hang out with my friends afterwards. I really don’t. I feel awkward. And, I don’t feel like I get along with them when I have taken my medicine.” Students also chose to avoid taking medication on the weekends for safety reasons. If they had plans on consuming alcohol at a social gathering or party, they would skip their morning doses of medication, even when they had classes to attend. Mixing alcohol with their medication was a huge concern, stemming from doctor’s recommendations as well as past experiences.

Theme 3. Poor self-management has serious negative implications on school performance (n=9).

The perceived severity of poor self-management on school performance was high among all participants. Many looked back on their first semester with regret and acknowledged the role their ADHD management played in poor academic outcomes. If they decided to take ‘medication vacations,’ negative outcomes would immediately follow. Reflecting on a past medication vacation, one participant stated “I stopped going to class, which was kind of weird. I just couldn’t wake myself up in the morning, like, okay you can get out of bed. Enough to like take notes, and I fell asleep in class a lot more and I don’t know, I should’ve gone sooner cause my grades kinda went down.”

In addition to skipping class more often, participants who struggled with adhering to their ADHD medication also reported difficulty staying “on task” to study and complete assignments.

As one participant noted, “Because I don't know when I don't take my medicine I just, I'm not really doing a lot of school as much school work as I should be doing. Like when I'm writing a paper um, yeah actually I the last paper I wrote I forgot to get my prescription refilled, and um I was sitting there writing and writing and I would zone out for five minutes and write another sentence and zone out for five minutes and it's just harder to remember what I was thinking to write and stuff like that.”

Collectively, skipping class and not being able to remain focused on academics resulted in poor grades. When asked to describe the outcomes of poor medication taking, one participant summed it up perfectly, “My grades just suffer. It's a lot harder to, like, accomplish the things I want to accomplish.”

Theme 4. Pressure from peers to share medication is frequent, and it can negatively affect social functioning and adherence (n=9).

Almost every participant mentioned medication sharing in their interview, even though they were not specifically asked about this behavior. Many of them reported experiencing uncomfortable levels of pressure to share or sell their medication, particularly from friends and members of their own sorority/fraternity. Because of this, many students described the decision to sell or not sell as a complicated dilemma. If they did not sell, they might lose significant friendships or be flagged as the “uncool” fraternity brother/sorority sister. However if they did share their medication, this would have a significant negative impact on their daily functioning. When a participant was asked why he chose to resist this pressure, he stated, “With the refill times, I can't necessarily spare all that many. I need it on a daily basis. I can't just be like, yeah, sure, have some of mine and I'll suffer for a week.”

Although the majority recognized the costs and dangers of sharing their ADHD medication, some participants reported succumbing to pressure and distributing their medication to close friends. One participant stated, “To be honest, there were some times whenever my friends would be like, ‘Look, I’ve got this really big test. I need to stay up.’ And, I’d be like, ‘You know, I’ve never really sold it.’ But, I actually just give it to them. Just be like, ‘Look, this is obviously just a one-time thing. I don’t do this a lot.’”

As critical exam periods approached, pressure to share or sell medication intensified. One participant commented on the going rate of one pill during finals, “Yeah, one guy, he was so desperate to get something for like that night. He’s like ‘I’ll give you twenty dollars for one pill.’” Thus, pressure to share medication came in the form of peer pressure and financial incentives.

Theme 5. Social support is greatly needed (n=8).

Many students reported that having ADHD can be an isolating experience and expressed the desire to connect with other, more experienced peers with ADHD. Because the college experience is very new to incoming freshmen, many of them perceived great benefits from meeting with an experienced upperclassman diagnosed with ADHD who could offer advice on how to master college with ADHD. Several participants reported the desire to have peer mentors who could provide resources that they have found to be beneficial, as well as give tips on how to schedule classes and what professors to take. More importantly, they wanted a supportive friend who could easily empathize with the challenges of being a college student with ADHD such as the pressure to share medication.

The majority of participants also wished that they could have an academic coach or counselor who specialized in working with students diagnosed with ADHD. They expressed that

with the help of a counselor, they could become more confident in managing their disorder on their own. As one participant noted, “I do need like a little help or like someone to check in every once in a while. Like, ‘hey how are you doing?’ Like, ‘how are your grades doing? Are you taking your medicine? Do you feel confident about this semester?’” Although there are specific academic counselors for their individual majors, many of them felt as if these counselors were inconsiderate of their ADHD being an influential factor that can affect their academics. Some noted that a counselor who is specialized to work with students diagnosed with ADHD may also be a reliable resource where students can bring their concerns and stressors to discuss. As a trained mental health professional, the counselor could teach coping skills and behavioral strategies to manage their ADHD symptoms, as well as provide resources that past students have found to be helpful on campus.

Non-medication related management

Although not the major focus of the study, non-medication related management strategies were inquired about in addition to medication taking. Specifically, we wanted to know the extent to which students were registered for academic accommodations. Surprisingly, only 4 participants were registered for academic accommodations with the Office of Accessibility. Common reasons for this low number of registered participants were the following: lack of awareness about the office and the available accommodations, feeling ashamed to receive extra academic assistance, ADHD illness stigma, and believing that their ADHD was not severe enough to receive accommodations.

When asked why he had not registered with the Office of Accessibility, one participant described the embarrassment related to seeking help, ““Going to the Office of Accessibility is kind of like saying I can’t do it on my own, and I need help. And, you know, there’s always that

voice in the back of your head – like knuckle up and take care of yourself – you don’t need to be babied and stuff like that.” In addition, other students believed that the Office of Accessibility was only for students with severe disabilities (e.g., being in a wheelchair). Therefore, they did not consider ADHD to be a qualified diagnosis for receiving accommodations. One participant explained, “Like the Office of Accessibility is for people that have a case where they really can’t take care of themselves. I don’t think my condition was severe enough to register for it.”

Discussion

By conducting focus interviews with college students, we were able to gain a more detailed understanding of the transition experience from supervised adolescence to independent young adulthood. We were also able to recognize why students choose to either engage or not engage in particular health behaviors related to their ADHD. Specifically, 1) abrupt transitions in self-management, 2) volitional non-adherence due to poor ADHD education, misperceptions of academic demands, and side-effects, and 3) ADHD-stigma, help-seeking, and social support all contributed to students’ experiences. In line with this, each contributing factor is discussed below, along with suggestions for how to optimize outcomes for students with ADHD transitioning to college.

Abrupt Transition of ADHD Management and Suggestions for Improvement

Due to the abrupt removal of parental involvement, the transition to independence was extremely challenging for young adults with ADHD. Many students lacked the necessary critical self-management skills needed for a successful transition to college. With no formal plan for transition prior to their arrival at college and few opportunities to practice self-management skills (e.g., refilling a medication, reminding one’s self to take medication), the transition was

overwhelming. For many, transitioning to college was the first time they ever attempted to self-manage their ADHD independently.

Learning self-management skills in the context of other major life changes (e.g., moving away from home, higher academic demands, less structured living situation) likely made it more difficult for students to effectively manage ADHD. Further, it appears that many adolescents were abruptly given responsibility for their ADHD care and not given the opportunity to develop mastery of the skills necessary to manage their ADHD prior to having to do it on their own.

The difficulties experienced by students managing ADHD speak to the need to transfer responsibility for ADHD management prior to moving away to college. Suggestions to better facilitate transition of ADHD management from parent to adolescent are discussed below as well as briefly summarized in Table 4. In order to address the abrupt transfer of medical responsibilities from parent to adolescent, behavioral skills training, a highly effective procedure consisting of four steps (i.e., instruction, modeling, rehearsal, and feedback), should be utilized by parents to progressively teach new self-management skills to their adolescents (Miltenberger, 2011). Applying this four-step approach to medication taking, parents should describe the rationale and importance of adherence and then model good medication-taking behaviors such as using medication reminder alarms and tying medication-taking with everyday activities (e.g., setting the pill out each morning with breakfast, placing the medication bottle by the toothbrush holder). Adolescents should then be afforded multiple opportunities to rehearse/practice managing their medical care under the supervision of their parents. Doing this while under the supervision of the parent provides adolescents with the opportunity to practice their new skills in a safe, supportive setting that also provides the opportunity for corrective feedback should the adolescent experience difficulty learning the skill. Once the adolescent has demonstrated mastery

of one skill, the parent can then move toward teaching another important skill (e.g., scheduling doctor appointments, ordering refills). As self-management skills gradually develop over time, it is important to begin teaching self-management skills early in adolescence so that youth are comfortable managing ADHD on their own before they move away to college. By gradually guiding the adolescents and setting developmentally-appropriate guidelines, it is expected that young adults with ADHD will feel much more prepared to manage their medical care independently once they transition to college. Table 5 provides a summary of developmentally appropriate guidelines for adolescents and young adults with ADHD that has been adapted from the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition's (NASPGHAN) transition checklist for individuals with inflammatory bowel disease.

Volitional Non-adherence and Suggestions for Improvement

ADHD misinformation.

In addition to the abrupt nature of transition, young adults' intentional choices to skip their medication also contributed to non-adherence. Volitional non-adherence was high due to inaccurate disease beliefs about ADHD, misperceptions of academic demands, and side effects. Many young adults felt that their ADHD symptoms would not persist past adolescence, leading them to neglect their regimens in hopes of weaning themselves off the medication. To address these inaccurate disease beliefs, improved ADHD education is needed for this population. Generally, the bulk of disease education from medical providers occurs upfront upon diagnosis unless patients request more information periodically (Pratt, Seligmann, & Reader, 1957). Unfortunately, many are diagnosed with ADHD at a fairly young age (American Psychiatric Association, 2013), decreasing the likelihood that they will understand and retain the information. Although disease information should be tailored to meet the cognitive capacity of

the patient, it should not be exclusively given upon time of diagnosis as its relevance will differ for various developmental and life changes. Therefore, adolescents who will be transitioning to college should receive information about the chronicity of ADHD as well as the importance of remaining faithful to their ADHD regimen. Additional disease information is necessary as adolescents transition to young adulthood (e.g., starting college, entering the work force) in order to reduce the likelihood of them engaging in risky health behaviors. Specific resources tailored towards ADHD education can be found on the Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD) and the American Academy of Pediatrics' websites.

Misperceptions of academic demands and ADHD medication use.

Volitional non-adherence was not only impacted by inaccurate disease beliefs but also by misperceptions of academic demands. Young adults with ADHD chose to neglect their medical regimens on slow academic weeks as opposed to heavy weeks full of impending exams and projects. This phenomenon of becoming more faithful to one's regimen when exams are approaching shares similarities with white-coat compliance, a theory that suggests patients' adherence levels increase due to looming doctor appointments (Feldman, Camacho, Krejci-Manwaring, Carroll, & Balkrishnan, 2007). Although some believed this tactic was efficacious for academic success, others learned the detriments of poor adherence on their "off-weeks," often at a time when it was too late to reverse their mistakes. To address these academic misperceptions, medical guidance should be provided prior to the transition to college regarding the importance of the consistency of medication taking, regardless of the amount of academic demands. Also, because adherence appears to be higher around check-up points (e.g., doctor's appointment, final exams) (Feldman et al., 2007), it seems that young adults with ADHD would

benefit initially from being held accountable for consistent medication taking whether that be through a buddy-system or a counselor.

Medication side-effects.

Lastly, volitional non-adherence was impacted by side effects. The most common reported side effects in young adults with ADHD were loss of appetite, inability to fall asleep, and negative changes to personality. Previous research has demonstrated that side effects are one of the most consistent reasons patients choose to not adhere to treatment across various disease populations (Ammassari et al., 2001; Horne & Weinman, 2002; Lambert et al., 2004). Some side effects of medications are unavoidable while others can be eluded. Therefore, a careful distinction needs to be drawn between unavoidable, but tolerable, side effects versus those that are intolerable. In response to side effects, it is essential that young adults develop self-advocacy skills so that they can communicate to their medical providers when they are experiencing intolerable side-effects. By communicating their experiences with particular medications to doctors, it increases the likelihood that the doctor will trial a new medication for the patient to avoid volitional non-adherence.

ADHD-related Stigma, Help-seeking, and Social Support

Not only did young adults with ADHD purposefully neglect their medical regimens for various reasons, but they also intentionally chose to not seek help or obtain appropriate accommodations for their illness. Many of them reported that asking for help and utilizing accommodations was associated with a negative stigma of weakness. Hence, it appears that illness stigma played a large role in interfering with help-seeking behavior, which is consistent with findings in previous literature (Eisenberg, Downs, Golberstein, & Zivin, 2009). To address this issue, campus initiatives should focus on ADHD stigma reduction, such as reporting the high

percentage of college students affected by this illness on posters around campus. Social norm-based interventions have successfully been used in the past for other illness populations to alter individual health-related attitudes and behaviors and to correct misperceptions about others' views on help-seeking and illness (Wechsler et al., 2003). In addition to social norm-based interventions, clearing up misconceptions about accommodations would help reduce the stigma surrounding help-seeking behaviors. For example, students with ADHD would benefit from an explanation that obtaining accommodations does not give them an unfair advantage over their peers but rather "levels the playing field." It is also important to emphasize to individuals with ADHD that the reasons for their accommodation needs are kept private within the Office of Accessibility. Obtaining accommodations does not label a student with ADHD as "disabled" for all to see, which seems to be a huge concern among this population.

To combat the stressors associated with the independent self-management of ADHD, most young adults strongly endorsed the need for social support during this rough transition process. Many participants reported a desire to have a peer network that would match them as incoming freshmen with older students with ADHD. A peer network would not only serve the purpose of additional social support, but it is also an excellent reminder to students that they are not alone in their diagnosis of ADHD. Knowing that there are other students on campus who are struggling with the same issues related to ADHD would help bolster social connectedness in this population while decreasing the isolation that many of them reported. Previous literature has demonstrated remarkably positive outcomes for peer mentoring and support programs in adolescents with various chronic illnesses (e.g., spina bifida, diabetes, cerebral palsy, epilepsy) such as learning new skills (e.g., self-management, coping), increased emotional understanding, enlarging the perspective of what is normal, and providing opportunities to extend help to others

(Kyngäs, 2004; Olsson, Boyce, Toumbourou, & Sawyer, 2005; Stewart, Barnfather, Magill-Evans, Ray, & Letourneau, 2011). Other social benefits include enhanced social identity through group approval and a reduced sense of isolation (Olsson, Boyce, Toumbourou, & Sawyer, 2005).

Study Strengths and Limitations

These results should be considered in light of the strengths and weaknesses associated with this study. As previously mentioned, this was the first study conducted to understand the self-management experiences in students with ADHD as they transition from adolescence to young adulthood. Thus, information obtained from this study is considered to be a novel contribution to the research literature. The use of consistent methodology across participants via a semi-structured interview allowed us to identify commonalities across participants. The use of theory and expert opinion to guide the development of our semi-structured interview as well as the analysis and interpretation of our qualitative data is another strength. Theme consensus across all coders was also emphasized during the analysis of data, thereby increasing the reliability of our analyses. In addition, our findings demonstrate ecological validity as we captured the young adults' transition experiences as they were going through the process of transitioning to independence (e.g., first semester of college to second semester).

Several limitations exist in this current study. As with many studies, selection bias is a possibility. Recruitment occurred during a limited time period until a sufficient number of participants were obtained. The students with ADHD who volunteered to participate may be more likely to seek support in times of need compared to the students with ADHD who did not respond to emails or fliers. Therefore, it is possible that the students in our study may have reported experiences with self-managing ADHD that are qualitatively different from other

college students with ADHD. Secondly, because our study was only conducted at one site, it is possible that the results may not generalize to other college populations across the United States. Thirdly, we measured participant's perceptions of self-management and adherence was not measured objectively. Previous literature demonstrates that participants tend to overestimate their adherence (Waterhouse, Calzone, Mele, & Brenner, 1993). Thus, it is possible that participants may have minimized their difficulties with adherence due to social desirability. However, given that the non-evaluative nature of the interview was emphasized and participants reported high levels of non-adherence, underreporting of non-adherence may not have been a concern. In the future, objective measures such as electronic monitoring caps or pill counts should be used to give more accurate readings of adherence.

Finally, it is important to note that this study was originally designed to have a focus group interview format with multiple participants at a time. However, due to suboptimal recruitment and scheduling difficulties, the format was changed to individual interviews. This decision was supported by both past research and the university's Office of Accessibility who raised concerns about illness-related stigma potentially impacting students' willingness to participate in a group setting. When the interview format was changed from group to individual, an increase in recruitment was noted. Given the amount of stigma reported by our participants and the impact of interview format on study recruitment, future work with students with ADHD should consider recruitment strategies and study designs that will minimize barriers to participation, such as stigma. Research from other highly stigmatized chronic illness populations may provide insight on how to increase recruitment of young adults with ADHD. For example, in a study examining the barriers to adolescents' with HIV participation in prevention research, the following suggestions were compiled to help combat stigma and increase recruitment: use

recruiters that the youth will feel comfortable with, rely on the youth's social network to assist with recruitment, and utilize Internet-based recruitment strategies (DiClemente, McDermott Sales, & Borke, 2011).

Future Directions

With regard to future research directions, systematic measurements of adherence over time and reports of academic outcomes of students with ADHD are needed to understand the causal relationships between adherence and academic performance. In order to address the transition challenges experienced by young adults, workshops need to be created that teach parents how to provide guidance on self-management skills in a developmentally appropriate fashion for adolescents as they transition to young adulthood. While some of this information is available in a generic format (e.g., <http://www.gottransition.org>, <http://hscj.ufl.edu/JaxHATS/>), data from our interviews suggest the need to develop a resource that is specific to the needs of families with ADHD, hence the creation of Table 4. This is desirable in helping to reduce the burden and shock on young adults with ADHD as they move to college and become responsible for their own medical needs. Young adults with ADHD would also greatly benefit from both parental and medical advice prior to starting college on issues that are contributing to poor adherence (e.g., inaccurate disease beliefs, misperceptions of academic demands, and side effects). In addition, the development of a program that helps connect students with ADHD with the supports they need (e.g., academic and social) is needed. Interventions that seek to promote self-advocacy in young adults with ADHD would also be helpful in increasing their knowledge of ADHD, their abilities to communicate their medical needs, and their willingness to pursue appropriate academic accommodations for ADHD. Adopting a comprehensive approach that targets the educational and behavioral needs of

adolescents with ADHD transitioning to college will better prepare them for the challenges of this new setting and hopefully optimize their social, emotional, and academic outcomes.

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Table 1.

Construction of semi-structured interview using the Health Belief Model

Constructs of the Health Belief Model	Representative Questions
Perceived Susceptibility	<ul style="list-style-type: none"> • “Because you are participating in this interview, you are obviously a college freshman with ADHD. Briefly, tell me how old you were when you were diagnosed.”
Perceived Severity	<ul style="list-style-type: none"> • “What do you think would happen if you didn’t take your medication?”
Perceived Benefits	<ul style="list-style-type: none"> • “What benefits do you get from taking your medication?”
Perceived Barriers	<ul style="list-style-type: none"> • “What causes you to miss medication doses?” • “What challenges have you experienced in managing your ADHD here at Auburn?”
Cues to Action	<ul style="list-style-type: none"> • “What helps you remember to take your medications?” • “Are there times when you are better at taking your medications than others?”
Self-Efficacy	<ul style="list-style-type: none"> • “How confident are you in your ability to manage your ADHD?” • “Why? What would help you be more confident?”

Table 2.

Participant Demographics

	Mean +/- SD or %
Age	19 +/- 0.47
Gender (male)	70%
Ethnicity	
Caucasian	80%
African American	20%
Age at diagnosis	15.70 +/- 3.50
Prescribed medication (extended release formula)	50%
Adderall	40%
Vyvanse	40%
Concerta	10%
Focalin	10%
Number of times a day instructed to take medication (one pill each morning)	70%

Table 3.

Concerns surrounding ADHD Transition

Themes	Quotes
<p>Theme 1. Transitions to independence are often abrupt, and many adolescents lack self-management skills (n=7).</p>	<p>“And now I’m like trying to take care of this all on my own just for me like just to take care of my own self I’m like wow, like it’s I didn’t realize like how much it is to deal with life with ADHD.”</p> <p>“And I guess then just coming to college and just being a college student I realized that I guess that I have a lot more responsibility and I wasn't prepared for that responsibility. So it was kinda like a false sense of security like you can do this, and then I really like couldn't.”</p> <p>“I expected it to be a breeze. Because in high school I was just in like these easy classes and was like eh whatever, like it doesn't really matter I'm just you know, chugging along doing my thing at like an average level or whatever, and then you get here and I'm like lower tier student like struggling to keep up but like I had no idea I would have to register it like as a disability, like...”</p>
<p>Theme 2. Disease beliefs, perceived academic demands, and medication side-effects result in high levels of volitional non-adherence (n=10).</p>	<p>“But uh if I ever have a relaxing week, I'll just like kinda like look at my watch and be like, ‘Oh, I haven't taken my medication all day.’ So depending on how the week is.”</p> <p>“I’m dead against all types of ADHD medication because of the social anxiety I feel from it.”</p> <p>“The negative side effects would be good to add. Well one, just never being hungry or not having an appetite. And then the other big one would probably be the lack of sleep it can cause.”</p>

“I get headaches, um I’m grumpy. People hate being around me when I’m on my medicine, like my friends are like, ‘You must be on your meds today.’”

Theme 3. Poor self-management has serious negative implications on school performance (n=9).

“When I’m not on my medication like I will not want to sit down and do homework at all because I know if I sit down, I’m going to be like, ‘Man, I’ve been sitting forever.’ I would fail. Miserably fail.”

“I probably would drop out of engineering.”

Theme 4. Pressure from peers to share medication affects social functioning and adherence (n=9).

“So, they all want some and are like, ‘hey, can you sell me some Vyvanse,’ and I say no and no, this is mine, I need it for my studies. And I guess people don’t always accept that. They’re like, ‘But it’s just one pill dude, like can you help me out?’”

“A lot of kids are always trying to buy my Vyvanse. Always. They know you are ADHD or have ADHD, or even just have a prescription, then they just kind of annoy you repetitively.”

“But I mean if I’m at the library and I like have mine with me and my friend who is like also hyper distracted, like whatever, then I mean like I’ll give her one, but it’s like it’d be different if she was saying she was gonna like go get high off =Vyvanse= or whatever, you know? Yeah like if they’re, like if you’re my friend then sure but like if I don’t know you then I’m not gonna sell you my medicine, that’s weird.”

Theme 5. Social support is greatly needed (n=8).

“Some kind of counseling where if you are struggling with anything that, I guess, if you- you could be registered, and you know you have ADD and just come and talk to the counselor and it’s like what, you know, ‘What are you having problems with?’ ‘I’m having trouble...managing my time. I’m having trouble getting myself to do my schoolwork.’ Just anything as long as you could be honest with them.”

“Um, the learning communities. Felt like well maybe like if there are more like there’s like a, not to like put people down, but like solely like a learning

community for people with ADHD or something like that. Then, we could help each other out and just try to help each other stay focused.”

“There's usually a list of kids that come through in freshmen year like, and they would start a Facebook group called, 'Auburn Freshmen 2014' or 'Auburn Graduating class of 2018' or stuff like that, so if someone from the Office of Accessibility were to go on there and be like 'Hey, um, if you ever have any questions or anything with ADHD, contact this number we can get you paired up with a buddy.’”

Non-medication related management: obtaining accommodations (n=6).

“I just I wanted I always wanna try and do it on my own, and sometimes, I'll try and then end up in the situation where it's too late to get help, but I usually just try to get it done on my own, without help. Yeah, I just if I don't, if I can't do it myself, it's hard for me to ask for help.”

“I just I wanted I always wanna try and do it on my own, and sometimes, I'll try and then end up in the situation where it's too late to get help, but I usually just try to get it done on my own, without help. Yeah, I just if I don't, if I can't do it myself, it's hard for me to ask for help.”

“I don't know. I guess it just, if there wasn't like a negative connotation people would be a lot more open. There would be a lot more resources that people could get help.”

Table 4.

Suggestions to Improve Transition

Challenges to Target	Suggestions
1. The abrupt nature of transition and the removal of parental involvement.	<p>Start the transition process early.</p> <p>Parents should utilize behavioral skills training (i.e., instruction, modeling, rehearsal, feedback) to teach their child self-management skills.</p> <p>Provide corrective feedback so that the adolescent is fully prepared to manage his/her medical care on his/her own.</p> <p>Set developmentally appropriate guidelines and progressively transfer medical responsibilities to the adolescent.</p>
2. Inaccurate disease beliefs	<p>Encourage the adolescent to discuss ADHD specific disease information with his/her medical provider before moving to college. If the adolescent believes he/she will outgrow ADHD, encourage him/her to have this discussion with his/her doctor.</p>
3. Misperceptions of academic demands and when medication is necessary	<p>Encourage the adolescent to discuss the importance of consistency in medication taking, regardless of amount of academic demands, with his/her medical provider before leaving for college. The adolescent can create a list of questions related to his/her medication regimens to ask the doctor so he/she is fully prepared to properly handle his/her medication taking responsibilities.</p> <p>Warn the adolescent of the negative consequences of not adhering to medical treatment (e.g., low grades, reduced productivity) while emphasizing the benefits (e.g., increased focus).</p>
4. Side effects	<p>Promote self-advocacy in adolescents and afford them plenty of opportunities to communicate their medical needs and their responses to medication to their doctors.</p> <p>Encourage the adolescent to evaluate his/her side effects and distinguish between the unavoidable tolerable versus intolerable side effects.</p>
5. Illness stigma	<p>Campus initiatives and other college organizations should focus on reducing the stigma of ADHD and other illnesses by promoting awareness across campus via posters, lectures, and events. For example, try to normalize the processes of obtaining accommodations by showing the statistics of college students who are eligible to receive them.</p>

6. Lack of social support

- Create peer networks on college campuses so that young adults with ADHD are given the opportunity to connect with others diagnosed with the same illness. Provide a hierarchical structure so upperclassmen can provide tips to freshmen on how to handle the challenges of having ADHD while in college.
Utilize on-line support groups for further assistance.
Colleges can also provide specific academic/mental health counselors for students with ADHD.
-

Table 5.

Developmentally-appropriate transition guidelines for adolescents and young adults with ADHD

Age and Developmental Period	Guidelines for Patient
<p>12-14 (Early Adolescence):</p> <p>New knowledge and responsibilities</p>	<p>I can describe my ADHD condition.</p> <p>I can name my medications and the amount/times I take them.</p> <p>I can describe the common side effects of my medications.</p> <p>I know my doctors' names and his/her roles.</p> <p>I can answer at least one question during my doctor appointment.</p> <p>I can manage my medical tasks while at school.</p> <p>I can call my doctor's office to make or change an appointment.</p> <p>I can describe how my ADHD affects me on a daily basis.</p>
<p>14-17 (Mid Adolescence)</p> <p>Building knowledge and practicing independence</p>	<p>I know my medical history.</p> <p>I know if I need to transfer to an adult psychiatrist.</p> <p>I reorder my medications and call my doctor for refills.</p> <p>I answer many questions during a health care visit.</p> <p>I spend most of my time alone with the doctor during my health care visit.</p> <p>I understand the risk of medical non-adherence.</p> <p>I understand the impact of drugs and alcohol on my condition.</p>
<p>17+ (Late Adolescence)</p> <p>Taking charge</p>	<p>I can describe what medications I should not take because they might interact with the medications I am taking for my ADHD.</p> <p>I am alone with the doctor or choose who is with me during a doctor visit.</p> <p>I can tell someone what new legal rights and responsibilities I gained when I turned 18.</p> <p>I manage all my medical tasks outside the home (e.g., school, work).</p> <p>I know how to get more information about ADHD.</p> <p>I can book my own appointments, refill prescriptions, and contact my medical team.</p>

I can tell someone how long I can be covered under my parents' health insurance plan and what I need to do to maintain coverage for the next 2 years.

I carry insurance information (card) with me in my wallet/purse/backpack.

APPENDICES

Appendix A: Focus Interview Script (Page 49-50)

Appendix B: Demographic Information (Page 51)

Appendix C: ADHD Management Questionnaire (Page 52-53)

Appendix D: Adolescent Medication Barriers Scale (Page 54-55)

APPENDIX A

Focus Interview Script:

I. Introduction

a. Welcome

“Welcome and thank you for coming to this interview. You have been invited to participate because your point of view is very important to us. We greatly appreciate your contribution to this project. This interview is not a test. There are no right or wrong answers. We are simply interested in what you think and feel about the issues we will ask you about.”

b. Statement of purpose of the interview

“The purpose of this interview is to learn about your experiences managing ADHD treatment and symptoms throughout your freshman year.”

c. Guidelines to follow during the interview

“There are a couple guidelines I would like to ask you to follow during the interview. First, because we have limited time together, I may need to stop you and move on to our next questions. Second, when talking, please try not to reveal any personally identifying information about yourself, such as your name. What questions do you have about this? ...Okay, let’s get started.”

II. Warm Up

a. Set the Tone & Set participant at ease

“Because you are participating in this interview, you are obviously a college freshman with ADHD. Briefly, tell me how old you were when you were diagnosed and how you heard about the study.”

III. Establish easy and nonthreatening questions

a. Initial questions should be general and less threatening

- *“Great. Now that we know where you are from, let’s move on to the main part of the interview. To start, what are you currently doing to manage your ADHD?”*

IV. Establish more difficult questions

a. The more difficult or personal questions should be determined

- *“Prior to starting school at Auburn, how involved were your parents in your ADHD management?”*
- *“How involved are your parents now?”*
 1. *“What do you handle vs. them?”*
- *“What has the transition to managing your ADHD independently been like?”*
 1. *“Was there anything that surprised you or that you weren’t expecting?”*
- *“What did you do in order to prepare for this transition?”*
- *“What challenges have you experienced in managing your ADHD here at Auburn?”*
- *“What benefits do you get from taking your medication?”*
- *“What do you think would happen if you didn’t take your medication?”*
- *“What helps you remember to take your medications?”*
- *“What causes you to miss medication doses?”*

- *“Are there times when you are better at taking your medications than others?”*
- *“How have your social experiences affected your ADHD management?”*
 1. *“To what extent have you disclosed having ADHD to others?”*
- *“How confident are you in your ability to manage your ADHD?”*
 1. *“Why? What would help you be more confident?”*
- *“Looking back on your freshman year, what resources do you wish you would have had to help you manage your ADHD?”*

V. Wrap-up

- a. Identify and organize the major themes from the participant's responses
 - *“Unfortunately, we are close to being out of time. Once discussions like these get started, they move at a fast pace and there is less time to express your points of view than we would like. Let me attempt to summarize the key ideas I have heard. One key ideas is that ...”*
 - *“Second, ...”*
 - *“And Third, ...”*
 - *“What would you like to add to my summary?”*
- b. Ensure that any conversational points not completed are mentioned
 - *“There were several topics that we touched on that we were unable to completely discuss during this interview. (briefly summarize these issues). It's unfortunate that we were unable to spend more time discussing it but I did want to acknowledge them as important issues.”*

VI. Participant check

- a. Determine how participant perceives selected issues
 - *“Let me close by checking with you on a few issues. At this point, I'm not looking for further discussion, just a general idea of how you feel a particular way. Again, please let me know your opinion. First, do you feel that having ADHD has affected your freshman experience?”*
 - *“Second, do you feel that transitioning to college has created new challenges for you in managing your ADHD?”*

VII. Closing statements

- a. Request anonymity of information and answer any remaining questions
 - *“As we come to a close, I would like to remind you that the audio and videotape of this session will be transcribed. You will be assigned a false name for the purpose of transcript and data analysis so that you will remain anonymous. Are there any questions I can answer?”*
- b. Express thanks
 - *“Thank you for your contribution to this project. This was a very informative interview and your open and honest responses will be an enormous asset to our work. Again, we very much appreciate your involvement.”*

Appendix B

**DEMOGRAPHIC INFORMATION
Teens/Young Adults**

Your Ethnic Background:

Black White Bi-racial
 Hispanic Asian Other

Please select your identified sex:

Male
 Female

What is **your** age in years? _____

Marital Status:

Single Divorced Other
 Married Remarried
 Separated Widowed

What age (years) were you diagnosed with ADHD? _____

Please list the medication(s) you are prescribed for your ADHD:

Is your prescribed medication an extended release formula?

Yes No Not sure

How often, or at what times of day if applicable, are you instructed to take the above medication(s)? Examples: 1 pill once a day in the morning (or at a specific time such as at 7 am); 1 pill in the morning and one in the afternoon (and specific times, if applicable).

Appendix C

ADHD Management Questionnaire

Part One: Your ADHD Treatments and Control BEFORE Coming to College

The following questions ask you to rate situations as they were prior to college. In answering this question, please think about the year prior to you starting your freshman year at Auburn.

1. **How involved WERE your parents in your ADHD care prior to moving away to college?** When answering, please consider their involvement in all aspects of care including getting or purchasing medication refills, reminding you to take your medication, and scheduling appointments. Please circle one number below using a scale of 0 to 10, with 0 being “not at all involved” and 10 being “completely involved.”

0 1 2 3 4 5 6 7 8 9 10

2. On a scale of 0 to 10, with 0 being “not at all controlled” and 10 being “completely controlled”, **how well controlled would you rate your ADHD symptoms prior to moving away to college?** (circle one below)

0 1 2 3 4 5 6 7 8 9 10

3. Sometimes it can be a hard to remember to take all of your medicines. On an average week, how many days would you typically **miss** taking your ADHD medicine(s) as recommended?

0 1 2 3 4 5 6 7

Part Two: Your ADHD Treatments and Control AFTER Coming to College

Now that you are away at college, please think about the following situations and rate them in terms of how you are currently doing.

4. **Currently, how involved are your parents in your ADHD care?** When answering, please consider their involvement in all aspects of care including getting or purchasing medication refills, reminding you to take your medication, and scheduling appointments. Please circle one number below using a scale of 0 to 10, with 0 being “not at all involved” and 10 being “completely involved.”

0 1 2 3 4 5 6 7 8 9 10

5. On a scale of 0 to 10, with 0 being “not at all controlled” and 10 being “completely controlled”, **how well controlled would you rate your CURRENT ADHD symptoms?** (Circle one number below)

0 1 2 3 4 5 6 7 8 9 10

6. On a scale of 0 to 10, with 0 being “not at all confident” and 10 being “completely confident”, **how confident are you in your ability to manage your ADHD symptoms?** (Circle one number below)

0 1 2 3 4 5 6 7 8 9 10

7. How often do you take the **exact number of pills** you were instructed to take?

a. Never b. Rarely c. Sometimes d. Usually e. Always

8. How often do you take the pills **at the times** you were instructed to?

a. Never b. Rarely c. Sometimes d. Usually e. Always

9. How often do you take the pills for the **exact number of times** per day that you were instructed?

a. Never b. Rarely c. Sometimes d. Usually e. Always

10. Sometimes it can be a hard to remember to take all of your medicines. Over the past week, or last 7 days, how many days have you **missed** taking your ADHD medicine(s) as recommended?

0 1 2 3 4 5 6 7

Appendix D

AMBS

Name/ID _____ Date _____

Taking medication daily for life is a difficult task. We would like to find ways to make this process easier for you. Listed below are several reasons that teens have told us make it difficult for them to take their medications on schedule every day. Please read each statement carefully. Check the box to the right that reflects how much you agree or disagree with each statement.

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
1. I believe that the medicine is hard to swallow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I believe that I have too many pills to take	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I don't like how the medicine tastes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I believe this medicine has too many side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I don't want to take the medicine at school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel that it gets in the way of my activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I am forgetful and I don't remember to take the medication every time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I am not very organized about when and how to take the medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I do not want other people to notice me taking the medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I sometimes just don't feel like taking the medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I find it hard to stick to a fixed medication schedule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I don't like what the medication does to my appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I am tired of taking medicine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I am tired of living with a medical condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Sometimes I don't realize when I run out of pills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I get confused about how the medicine should be taken (with or without food, with or without water, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Sometimes it's hard to make it to the pharmacy to pick up the prescription before the medicine runs out

Is there anything else that we did not mention that makes it hard for you to take your medication on schedule everyday?

♥ 2007 Laura Simons, Ph.D. To obtain copies or psychometric data for this measure contact: LauraESimons@gmail.com