Published in final edited form as:

Acad Pediatr. 2012 January ; 12(1): 53–61. doi:10.1016/j.acap.2011.10.003.

In their own words: Adolescent views on ADHD and their evolving role managing medication

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Abstract

Objective—Up to 90% of adolescents with ADHD remain functionally impaired, yet less than half continue to take medication. The objective of this study was to gain a detailed understanding of how adolescents with ADHD contribute to medication treatment decisions.

Methods—44 adolescents with ADHD aged 13 to 18 years old participated in 1 of 7 focus groups. An experienced facilitator used a semi-structured focus group guide to prompt discussion which was audio-recorded and transcribed verbatim. We coded transcripts using an inductive approach. Thematic saturation was reached after the seventh focus group.

Results—Adolescents assumed increased responsibility for managing medication as they matured and developed insight into the functional impact of ADHD and medication on their lives. Insights were often formed by contrasting time spent on and off medication. ADHD impacted functioning in the following domains: academics, social interactions and relationships, creativity, and driving skills. Select domains were relevant for some adolescents but not others. Adolescents described different roles that they played in managing medication as well as strategies they employed to exert autonomy over medication use. Side effects were common and contributed to negative feelings toward medication. Some adolescents had begun to use medication selectively. Many expressed uncertainty about future use of medication.

Conclusions—Adolescents assume an increasing role in managing medication for ADHD. Well-structured and coordinated trials stopping medication and measuring outcomes relevant to adolescents, parents, teachers, doctors, and/or other stakeholders may help ensure a developmentally appropriate transition from family to self-management of ADHD.

Key Terms

Adolescent; ADHD; Self-Management; Decision-Making; Transition

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Potential Conflicts of Interest: None of the authors have a conflict of interest to report. Eli Lilly and Company had no role in design, conduct, data analysis/interpretation, or manuscript preparation. The sponsor reviewed and approved the manuscript for submission without revision.

INTRODUCTION

The American Academy of Pediatrics (AAP) recommends that primary care providers educate children about ADHD in a developmentally appropriate manner and involve them (as well as parents and teachers) when specifying target outcomes, selecting treatment strategies, and monitoring progress toward goals.¹ As with any chronic health condition, it is expected that a child's role in this process will increase as they mature.² Child efforts to exert greater control over medication management can lead to conflicts with their parents and/or clinicians. For children with ADHD, many dislike taking medication due to lack of perceived need for or improvement from medication, experience of social stigma and/or side effects.^{3–11} Indeed, many adolescents argue with their parents, refuse to take medication, and/or covertly dispose of medication.^{4,9} Given that up to 90% of adolescents with ADHD remain functionally impaired,¹² it seems likely that many could benefit from medication.¹³ Yet less than half of adolescents with ADHD continue to take medication.¹⁴

The objective of this study was to gain a detailed understanding of how adolescents with ADHD contribute to medication treatment decisions. This information is needed to help guide clinician and family efforts to optimize management of ADHD. We used qualitative research methods because they are often useful in exploring complex, multi-faceted issues that may not be readily elicited by more direct, close-ended quantitative survey methods. The methods were used to better understand how adolescents contribute to ADHD medication treatment decision-making and not to test specific hypotheses.^{15–17}

METHODS

Sample

Adolescents were eligible to participate in one of seven focus groups if they had been diagnosed with ADHD, were between the ages of 13 and 18 years, and had been seen for ADHD in the past 2 years at 1 of 10 community-based pediatric practices in the Cincinnati/Northern Kentucky region. Adolescents (n=1,694) were identified through a billing database. Recruitment was stratified by sex and age (13–15 and 16–18 years). We randomly sampled an equal number from each stratum. This procedure enhanced sample variability by ensuring that boys and girls at a full range of ages would have an equal opportunity to participate. The parents of 283 adolescents received a letter from their child's doctor inviting them to participate in the study. This number was chosen to ensure an adequate sample of participants. Only one child per family was eligible to participate (no siblings). Of 283 parents, 16 indicated via a returned postcard that they did not want to be contacted. The remaining families received a follow-up telephone call, but 83 families could not be reached. Of those contacted by telephone (n=184), 63% expressed interest in participating. Subsequently, these eligible and interested adolescents were scheduled to participate based on their availability to attend focus groups. The Cincinnati Children's Hospital Medical Center (CCHMC) Institutional Review Board reviewed and approved this study. Adolescents provided assent and parents provided written consent prior to participation.

Data Collection

During recruitment, each parent answered a brief telephone screening questionnaire to confirm study eligibility. The questionnaire asked about the diagnosis and treatment of their adolescent with ADHD. To describe the sample, parents also reported their adolescent's race/ethnicity using investigator-defined categories. Focus group sessions, which included adolescents from all age and sex strata, were held at CCHMC, located in urban Cincinnati as well as 3 CCHMC-affiliated suburban locations during afternoon and evening hours in order to increase participation rates and enhance sample variability. The focus groups averaged

1.5 hours in duration and were audio-taped. Each adolescent was reimbursed \$50 for their time and travel expenses.

Focus groups were led by one of the investigators (*S.N.S.*), an experienced focus group facilitator. The prompting questions used in the focus groups were developed during group meetings with all investigators and informed by the extant literature (Table 1). Broad, open-ended questions were followed by more specific, probing questions to clarify the participants' responses and to explore the context of the responses. The semi-structured questions and focus group format allowed the participants to elaborate on their experiences and initiate discussions about issues that might not have been anticipated by the research team. The questions were designed to explore adolescent involvement in making decisions about continued use of ADHD medications including factors that influence decisions and practical aspects of medication taking. Questions also explored adolescent perceptions of the impact of ADHD on creativity and driving skills. The focus group guide was pre-tested with the target population to ensure the questions were easy to understand and elicited substantive discussion about the research topic. Research team members observed the session to identify opportunities to clarify the wording of questions and/or to augment with new questions worthy of inclusion. Participants were asked at the end of the session if there were any other related questions not discussed that they thought should be included in future groups. The research team met to debrief and modify the focus group guide to incorporate feedback from the team and the participants. Subsequently, the question guide was modified slightly in an iterative process as the focus groups progressed to accommodate new issues that were raised by adolescents. During the last few groups, the investigators reached a consensus that focus group discussions yielded no additional information about the impact of ADHD on adolescent's lives and insight about medication treatment decisions. This determination was based on concurrent data analysis, as described below. As thematic saturation had been reached,¹⁸ recruitment of participants for the focus groups was suspended with 44 of the 184 eligible and interested adolescents having participated in the study.

Data Analysis

Each focus group session was transcribed verbatim and entered in a computerized transcript database. "Comments" were defined as any uninterrupted utterance in response to a question and each comment was assigned a unique identification number in the database. We used an inductive approach to coding whereby the research team allowed ideas and patterns of ideas to emerge from the transcripts without any pre-conceived constructs.¹⁸ Following each focus group, each of the 4 investigators, trained in 4 different (academic) disciplines (*W.B.B.*, *S.N.S.*, *A.R.Z.*, *M.O.V.*), first read the transcripts independently and identified repeating ideas or patterns of ideas as themes. Collaboratively, the investigators labeled themes and constructed initial codes. During the second stage, the research team conducted focused coding, whereby the major and minor themes and their properties were described, categorized, and organized into a codebook. Each reader then independently coded participants' comments utilizing the codebook which was revised as coding progressed. Regular group meetings were held to discuss the codes assigned to comments for each transcript and to arrive at consensus. This collaborative, reflective process allowed for the expression and discussion of multiple perspectives and prevented the personal or disciplinary biases of a single researcher from excessively influencing the findings.^{15,19,20} A total of 477 unique supporting comments corroborated 4 major and 21 minor themes. Using the transcript database, the investigators generated a list of all verbatim quotations supporting each of the themes and together selected the most representative comments for presentation here (n=86).

RESULTS

A total of 44 adolescents participated in 1 of 7 focus groups. The mean age of participants was 15.1 years (standard deviation [SD] = 1.6), and 41% were 16 years of age or older. Parent-reported race of participants was predominantly Caucasian (68.2%) and African American (25%), which is similar to the Cincinnati/Northern Kentucky general population. Consistent with the purposeful sampling method, a similar number of males (n = 24) and females (n = 20) participated. On average, adolescents had been diagnosed with ADHD 8.7 years (SD = 3.3) prior to focus group participation. Nearly all children (97%) had tried medication for ADHD, and based on adolescent reports during the focus group, 68% continued to take medication for ADHD.

The major and minor themes and representative verbatim quotations are presented in Tables 2, 3, 4 and Table in the text.

Major Theme 1: Meaning of ADHD

Adolescents used a variety of terms to describe the meaning of ADHD in their lives. For many, ADHD was defined in behavioral terms (minor theme 1a):

“To me it’s always meant that I was hyperactive and couldn’t pay attention when people are talking to me.”

“...I used to feel so unfocused. It was like watching everybody else in a play. I sort of felt kind of cut-off.”

“I do think I am different because I notice a difference in my behavior and the way I think and the way I do things, but it’s not bad the way I do things. I kind of like the way I do things.”

Others defined ADHD using more abstract terms and concepts (minor theme 1b):

“It’s just a different way of processing thoughts.”

“Every human being has their own mental quirks, and it’s not always ADHD and it’s not always a mental illness or disease. Sometimes it’s just something funny that makes us different.”

For some, ADHD held no personal meaning as they denied that they had ADHD (minor theme 1c):

“I don’t know. I don’t feel that I have it. Sometimes I deny having it because don’t feel it is necessary or whatever.”

“I don’t think I got it. If I want to do my work, I will do it.”

Major Theme 2: Appraisal of Functional Impact of ADHD and Medication

The functional impact of ADHD and medication on multiple facets of adolescent lives was discussed in depth. Adolescents were able to assess and describe these impacts by contrasting their experiences with and without medication. Such contrasts were possible for many adolescents as medication use had been inconsistent and/or they were not currently taking medication. The key domains of functioning were: school, social interactions and relationships, personality, creativity, and driving. Select domains were relevant for some adolescents but not others. Comments in the left column of Table 2 are from teens who perceived problems from ADHD and/or benefit from the use of medication. Comments in the right column are from teens who did not perceive problems from ADHD and/or benefit from the use of medication. The relative frequency of contrasting teen comments presented is representative of the underlying distribution of responses in the raw data.

Minor Theme 2a: Impact at School

Most of the adolescents recalled that medication was recommended by teachers and/or physicians in order to achieve academic success. Most of these adolescents observed improvement in their performance at school while taking medication, though some did not report noticing a difference on or off medication (Table 2, minor theme 2a). Among those who reported academic improvement, most cited an enhanced ability to focus on schoolwork and achieve favorable outcomes.

Minor Theme 2b: Social Impact, 2c: Impact on Personality

The importance of peer influence and social acceptance was a prominent theme as adolescents discussed their perceptions of the impact of ADHD and medication use on their social lives (Table 2, minor theme 2b) and personality (Table 2, minor them 2c). Some identified specific improvements in their social interactions when taking medication while others felt that medication had a negative impact on their social lives and/or personality. Some described feeling “*like a robot*” only interested in completing school work. Others felt medication took away a feeling of exuberance that was part of their identity. As a result, these adolescents and, in some cases, their peers did not like who they were when they took medication. Peer assessment of the impact of medication was influential with some adolescents.

Minor Theme 2d: Impact of Stigma; 2e: Creativity

Many of the participants reported sharing their diagnosis with friends and that for some “*having ADHD wasn’t a big deal*.” However, stigma was still manifest in various forms and did impact them (Table 2, minor theme 2d). Most of the stigma was felt at school, and was related to social acceptance by peers. Adolescents also expressed a variety of views on how ADHD and/or medication impacted their creativity (Table 2, minor theme 2e). Insights were mixed as adolescents discussed ADHD’s impact on their writing, artistic, and computer gaming skills. Several student-athletes reflected on ADHD medication’s effect on their skills on the playing field with both positive and negative effects noted.

Minor Theme 2f: Driving Skills

We presented participants with information about driving risks associated with ADHD. Few of the ≥ 16 year old adolescents were aware that they were at increased risk for automobile accidents compared to adolescents without ADHD or that medication had been shown to improve performance in driving simulators. Subsequently, some questioned the validity of these findings. Adolescents commented on the perceived impact of ADHD and medication on their driving skills (Table 2, minor theme 2f). Among the small minority of drivers who reported past citations and/or collisions, all denied that ADHD was a factor in the incident (e.g. “*It was not my fault*.”).

Minor Theme 2g: Medication Side Effects

Participants commented on the consequences of medication side effects (e.g. appetite suppression and resultant weight loss, delay in sleep onset, irritability, etc.) and their experiences with changing dosages and/or medications. Many adolescents cited their experiences with side effects as a major reason they disliked medication and wanted to discontinue use. Participant comments from this subtheme were common ($n = 38$), but they did not shed new light on the experience.^{4,11} Therefore, we chose to exclude these verbatim quotations from Table 2.

Major Theme 3: Involvement in Discussions and Decision-Making

Adolescents described involvement in discussions and decision-making with their parents and doctor that increased over time (Table 3). Teens describe being a silent bystander at the time of diagnosis (Table 3, subtheme 3a). Subsequently, some become ambivalent reporters (Table 3, subtheme 3b) and others more active reporters of symptoms and side effects during doctor visits and at home (Table 3, subtheme 3c). Some teens described having a role, along with their parents, in deciding which dosage was best for them (Table 3, subtheme 3d). While some teens seemed to be content with their level of involvement (Table 3, subtheme 3e), it was clear that others didn't feel listened to by their parents or doctor because medication was continued despite their vocal protests (Table 3, subtheme 3f).

Teenagers described parental involvement in medication taking that ranged from providing direct supervision, to reminders, to providing no supervision (Table 3, subtheme 3g). Many adolescents acknowledged that forgetting to take their medication was an issue (e.g. *"Sometimes I forget and sometimes I don't."*). Some adolescents exerted autonomy over medication decisions through covert medication disposal (e.g. throwing away medication when parents weren't looking) (Table 3, minor theme 3h) and overt trials on and off medication (e.g. convincing parent to let them stop taking medication for some period of time) (Table 3, minor theme 3i). Many teens reported that as they became more independent in decision-making regarding medications, they tested efficacy or continued efficacy of the medication. Some experimented over the summer months so they did not have to jeopardize their schoolwork.

Major Theme 4: Full Autonomy

As adolescents assumed increasing independence over management of medication for ADHD, choices became more deliberate (Table 4). Some adolescents began to use medication selectively depending on perceived need to complete daily tasks (e.g. tests, team sports) (Table 4, minor theme 4a). Some who had stopped taking medication questioned whether they should resume. Many adolescents expressed doubt and uncertainty about their future use of medication (Table 4, minor theme 4b). In group discussions, adolescents who viewed academic success as the primary purpose of ADHD medications, perceived little utility in continuing medication once school was finished. Uncertainty was also fueled by the trade-offs of taking ADHD medication recognized by adolescents (Table 4, minor theme 4c).

DISCUSSION

Based on self-reported data, adolescents assumed increased responsibility for managing medication as they matured and developed insight into the functional impact of ADHD and medication on their lives. Insights were often formed by contrasting time spent on and off medication. Select domains of functioning were relevant for some adolescents but not others. Adolescents described different roles that they played in managing medication as well as strategies they employed to exert autonomy over medication use. Peer feedback influenced appraisals of medication for some teens. Some adolescents had begun to use medication selectively. Many expressed uncertainty about future use of medication.

ADHD puts adolescents at risk for impaired functioning in multiple domains (e.g. academics,²¹ peer relationships,²¹ family relationships,²² driving²³). Our analysis of adolescent comments demonstrates that the key domains of functioning impacted by ADHD were: school, social interactions and relationships, creativity, and driving skills. Select domains were relevant for some teens but not others. This highlights the need to tailor target outcomes and management strategies for the individual teen as recommended by the AAP¹

and other authors.^{24,25} Interventions are needed to help adolescents, parents, and clinicians to negotiate shared goals and treatment plans as well as to monitor progress toward those goals. Goals that are S.M.A.R.T. (i.e. specific, measureable, attainable, relevant, and time-bound) may be more likely to lead to improvement.²⁶ While our study was not designed to determine the accuracy of teen appraisal of impairment, there is strong evidence that children with ADHD have unrealistically high self-views of skills and competence compared to children without ADHD.²⁷ Differences of opinion on functional impairments may be a source of conflict between teens and their parents. Interventions that result in accurate self-appraisals may help teenagers to more effectively manage their ADHD.

Many adolescents described their involvement in discussions and decision-making with their parents and doctors as inadequate. Why might this be? Despite their lobbying efforts, medication is continued. Parents likely know their teen's opinion but limit their share in decision-making due to worry that he/she lives in the moment and doesn't prioritize outcomes that are important in the long run. Parents likely fear that their teen will 'ruin their life' by missing opportunities that he/she will come to value later (when it's too late). Based on teen perceptions, some parents and doctors are more successful than others in involving them in a meaningful way in management decisions. Medication use becomes a battle of attrition for parents and teens unable find common ground.

Normal adolescent development is characterized by the pursuit of independence. For teens with a chronic health condition, efforts to exert control over daily life often include aspects of medication management.² Selective use of ADHD medication described by adolescents in this study mirrors that reported by college students.¹¹ Whether selective use of ADHD medication constitutes effective self-management or misuse of a prescribed prescription medication is debatable, but awareness of selective use is important for physicians and parents so that medication can be a continued topic of discussion given the chronic nature of ADHD. Our previous work with parents of children/adolescents with ADHD revealed that trials on and off medication to determine the continued need for medication were common and rarely coordinated by a physician.²⁸ In the current study, adolescents reported similar trials stopping medication. This phenomenon may represent a continuation of the medication usage pattern demonstrated by their parents, curiosity on the part of adolescent patients, or an act of rebellion from teens who feel their voice is not respected by their parents and/or doctor. Regardless, adolescents and their parents may benefit from trials that are more highly structured. The American Academy of Child and Adolescent Psychiatry,²⁹ authors of the Multimodal Treatment Study of ADHD in Children,³⁰ and others^{31,32} have recommended that physicians coordinate trials stopping medication as follows: 1) consider annually when stable and doing well, 2) best when there are few transitions or demands (e.g. mid-school year), 3) avoid at beginning of any school year, especially at the start of junior/senior high school, 4) try discontinuing medications for 2 to 4 weeks with close monitoring of target outcomes. Structured trials stopping medication have the potential to be a powerful tool to foster productive partnerships between adolescents, parents, and physicians. Such trials can empower teens by legitimizing their preferred option of discontinuing medication, giving them more of a voice in discussions with their parents and doctors. Well-structured trials can also reassure parents by operationalizing a measurement system to detect early struggles before they become crises (e.g. school failure, delinquency, etc.). Use of S.M.A.R.T. goals, discussed previously, may accelerate what adolescents, parents, and doctors learn from trials discontinuing medication. Future studies should test whether physician-directed trials of medication discontinuation can identify children/adolescents with ADHD who continue to suffer from functional impairments in a timely manner and avert undesirable outcomes.

Many adolescents in our study and previous studies dislike taking medication for ADHD due to side effects, lack of perceived need for or improvement from medication, and/or social stigma.³⁻¹¹ It is striking that despite the advent of extended-release medications that eliminate the need for a daily visit to the school nurse's office, these teenagers reported stigma in the school setting as a result of comments or actions of other students and/or their teachers. In addition, social networks and peer acceptance were influential. Positive and negative feedback from peers, some of which was directly solicited, weighed heavily with some adolescents as they appraised the utility of medication. This finding is in contrast to a study by Knipp et al. that reported teens with ADHD did not perceive that their friends noticed a difference when they were on or off medication.¹⁰ This may be due to the fact that the previous study included only adolescents currently taking medication whereas one-third of adolescents in our study were no longer using medication.

Very few of the adolescents ≥ 16 years old in our study were aware of driving risks associated with ADHD or that medication can improve driving performance in teens with ADHD.³³ Moreover, many adolescents remained skeptical about their personal risk after being presented with this information. The AAP policy statement entitled "The Teen Driver" has highlighted the need for prevention through office-based counseling and other efforts.³⁴ Future studies should examine how adolescents with ADHD process risk information when making decisions about medication use.

This study has several limitations. Information was elicited in focus groups comprised of adolescents who were mainly White or African-American, which was reflective of the region's racial composition and therefore may not reflect the views of other racial/ethnic groups of teenagers in other regions. Also, the group setting may have inhibited some adolescents from electing to participate in the study. Adolescents who did participate may have been influenced by comments made by others in their group and biased our findings toward consensus view or opposite views.

The strength of qualitative research is that it allows us to gain a deeper understanding of a phenomenon in the words of those who are affected by an experience.¹⁵ In this case, what was not well understood was how adolescents with ADHD view the disorder and contribute to medication treatment decisions. Using focus groups and a semi-structured question guide, we probed, in-depth, the perspectives of a group of adolescents living with ADHD. Interpretations of the teens' statements were made by consensus of a multi-disciplinary team of researchers with varying perspectives. Together, the authors describe how teens contribute to ADHD medication treatment decisions. While efforts were taken to generate a sample with variation in age, gender, race, and urban-suburban residence, this study was not meant to produce any conclusion about the phenomenon under study that could be generalized to all adolescents with ADHD. Opportunities exist for quantitative investigations to test the implied hypotheses about relationships between variables identified that influenced adolescents in our study.¹⁵

CONCLUSION

Adolescents assume an increasing role in managing medication for ADHD, but may benefit from support. Time on/off medication informed perceptions of ADHD and medication. Well-structured and coordinated trials stopping medication and measuring outcomes relevant to adolescents, parents, teachers, doctors, and/or other stakeholders may help ensure a developmentally appropriate transition from family to self-management of ADHD. Studies are needed to determine the efficacy of such interventions and guide their implementation in clinical practice.

WHAT'S NEW

Select functional domains were relevant for some adolescents but not others, highlighting the need for negotiation of shared treatment goals that are measureable. Structured trials stopping medication are described which may help clinicians support the transition from family to self-management.

Acknowledgments

The authors have no conflicts of interest to report. Conduct of the study was funded by Eli Lilly and Company. The sponsor reviewed and approved the manuscript for submission without revision. The sponsor had no role in design, conduct, data analysis/interpretation, or manuscript preparation. Dr. Brinkman is supported by a Mentored Patient-Oriented Research Career Development Award from the National Institute of Mental Health (K23 MH083027). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Mental Health or the National Institutes of Health. We acknowledge the community-based practices that recruited participants for this study and David Schonfeld, MD who assisted with development of the focus group guide.

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Table 1**Semi-Structured Focus Group Guide**

1.	Some families find choosing whether or not to take medicine for ADD or ADHD a difficult decision. Tell me about a time when your family re-visited this decision.
2.	What was important when deciding whether or not to continue medicine?
3.	How did you convey your wishes?
4.	How did your parents and doctor take your wishes into account?
5.	Should kids or teens be asked to help decide whether to use medicine? If so, at what age?
6.	In some families, parents remind teens to take their medicine or they give them their medicine and watch them take it. In other families, kids are more in charge of taking their medicine. What is it like in your family?
7.	Ask of those kids who are in charge of taking their medicine: Describe what it was like when your parents had a greater role in making sure you took your medicine. Tell me some reasons why you gained more responsibility. What was the change like for you? Would you like more responsibility than you already have? Would you like more help remembering to take it? Do your parents ever question whether you've taken your medicine? When does this happen?
8.	How do you think that things will change when you get older and move out of your parents' house, get your own place or move away for school?
9.	There have been studies that show drivers who are not taking ADHD medications are at increased risk for serious accidents. Have you ever heard about this before? Have you ever discussed this with your parents or doctor? If so, did this influence decisions to start or continue medicine? How? If no, are you surprised by this? Will this impact decisions about driving or taking medicine?
10.	Did you or your parents have concerns that you would rely on medicine to help you focus or control your behavior? If so, how did that affect decisions that were made?
11.	Some kids with ADHD say that they feel more creative when they are not on medicine. Do you agree or disagree with that comment? If agree: Did this affect/influence any of the decisions that were made about taking medication for you?
12.	Thinking back over your experience with ADD/ADHD treatment, can you think of anything that could have been changed that would have made treatment of ADD or ADHD a better experience for you?
13.	Let's say that you were meeting some kids who were just diagnosed with ADD/ADHD. Is there anything you would want to tell them about treating their ADD/ADHD? Would you have any advice about taking medication?
14.	This concludes the series of questions I have for you to answer. Is there anything else that you would like to discuss that you think is important to add to this research study? Anything that you think that we have missed about the decision process for adolescents with ADD/ADHD and their families?

Table 2**Major Theme 2: Appraisal of Functional Impact of ADHD and/or Medication**

Minor Theme	Comments from teens who perceived problems from ADHD and/or benefit from the use of medication	Comments from teens who did not perceive problems from ADHD and/or benefit from the use of medication
2a. Impact at School	<p>“For me, there’s a big difference grade wise [on/off medicine].”</p> <p>“It does help me with math, I can do everything faster.”</p> <p>“Sometimes I forget to take [medication] and I will just be so unfocused that I don’t even know what the heck is going on in the classroom.”</p> <p>“My handwriting is sloppier when I don’t take my medicine.”</p> <p>“My [sister] calls me ADHD freak...I always tell her that it is better than me being a loser and not taking [medicine] and failing everything, because my sister is the dropout. I told her that I didn’t want to be like her”</p>	<p>“I could tell [teachers] couldn’t even tell when I was on medication or not because days that I took it they would say; ‘Did you take it?’ They would think that I didn’t take it.”</p> <p>“I don’t see how it can make you get better grades, being on medicine. I used to be bad but I got good grades, but my behavior was bad not my grades.”</p>
2b. Social Impact	<p>“Some [of my friends] like me more with the medicine than they do without it. They think I act really, really dumb and don’t think before I act... I share with them [whether taken medication that day] because I want to see if they like me more with medicine or without medicine.”</p> <p>“[Medicine] helps me to actually pay attention more to other people and listen to what’s going on with them because I know that I would want somebody to listen to me. My communication skills have gotten sharper.”</p> <p>“When I am off the medicine I feel like a complete moron for being so talkative.”</p> <p>“You don’t think before you say something. I might say something that hurts somebody.”</p>	<p>“I’ve had a lot of people tell me they don’t like me when I am on my medicine because they think I am way too mellow.”</p> <p>“It’s more fun without medicine--- people laugh at your jokes.”</p> <p>“When I used to go to elementary [school], [classmates] used to notice. I come in, don’t say anything to nobody, do my work. They say, ‘He must be on that medicine’.”</p> <p>“I am just kind of a social person, so it doesn’t matter whether I’m on the medicine or not.”</p> <p>“In some ways, [the medicine] worked too good but it killed your social life.”</p>
2c. Impact on personality		<p>“I don’t really have a different personality when I am on or off [medicine].”</p> <p>“[Medicine] made me different. It made me all calm and quiet and stuff and I don’t like that. I like to be wild.”</p> <p>“I am much more energetic, not hyper, just energetic and I just have more fun on weekends or when I don’t take [medicine].”</p> <p>“When you’re off the medicine that is the only time you can really be you.”</p>
2d. Impact of Stigma	<p>“It doesn’t affect me until people start making fun of other people who have ADD or ADHD. They talk about it</p>	<p>“It doesn’t seem like a big deal anymore. People don’t judge you for having [ADHD].”</p>

Minor Theme	Comments from teens who perceived problems from ADHD and/or benefit from the use of medication	Comments from teens who did not perceive problems from ADHD and/or benefit from the use of medication
	like it's a horrible thing and they make fun of it on the bus and at school."	
	"You got ADHD? I really don't want to get to know you."	
	"In 6 th grade the teacher would ask me, 'Did you take your medicine?' in front of the whole class. Embarrass me and stuff."	
	"Some of the older people in my general familyas well as older teachers...think that medication is a copout and just a scapegoat for me not trying."	
	"I think [teacher] thinks that since I have ADHD, I am like a troublemaker...she said; 'I am watching you.'"	
	"When I was in junior high, you didn't want to tell everybody that you went to other classes to get your tests read because it was something that was looked down upon."	
2e. Impact on Creativity	"I feel more creative on the medicine. When you are actually able to focus on something, like drawings, it comes out just beautiful."	"I don't think [medicine] affects my creativity at all. On it or off it."
		"[Medicine] heightens your focus but I think it also lowers your creative capacity."
		"...I really do kind of like having ADD because it gives me some strengths too, some extreme strengths. I am a really great artist and a great writer and I even had some things published so I like it. For me, I think it's defined as advanced daydreaming."
2f. Impact on Driving Skills	"I never get behind the wheel unless I am medicated because I could get sidetracked too quickly."	"I can't really tell a difference how I drive without [medicine]. I've been in an accident...that was not my fault. I don't think it [medicine] affects me at all how I drive."
	"I had to drive here and I didn't take medication today so I just got distracted more. There seems to be more distractions than there would be when I am on [medicine]."	"...got my first ticket about 2 weeks after I got my license." (was not taking medicine and parents didn't discuss meds after ticket)
	"I forgot my medicine one morning and we are driving to school. Every car that passes I get distracted by it and I could barely pay attention to the road." (mom told him to take medicine the next day before driving)	"I am extremely attentive. It's just I am so fixed in I will actually sing with music without actually realizing it. I got hit within a week of having a car, but that doesn't mean I am not a good driver or a lesser driver. It wasn't my fault. Things happen."

Abbreviations: ADD = attention deficit disorder, ADHD = attention-deficit/hyperactivity disorder.

Table 3**Major Theme 3: Involvement in Discussions and Decision-Making**

Minor Theme	
3a. Silent Bystander	<p>"I didn't say nothing to the doctor. Mom was just doing all the talking. He was like, 'Yeah, we need to put her on medication.'"</p> <p>"I usually don't talk [during doctor visits]. I don't think [my doctor] really cares at all about what I'm saying. He makes decisions anyway. If I tell him I really don't want to be on medicine, he says, 'Well, you are gonna stay on it because you need to stay on it.' Then I think about it and I don't really care because it does help me at school."</p>
3b. Ambivalent Reporter	<p>"[During doctor visits] I don't know what they're thinking. I just sit there and doodle. If they talk to me I will multi-task and answer."</p> <p>"They kept on asking me stuff but I didn't know how to answer it...the questions.....questions like "Do you think you can go without the medicine?"</p>
3c. Active Reporter of Symptoms and Side Effects	<p>"It hurts my stomach when I take it. I don't like taking it. [My doctor] said I need to eat with it but I never eat in the morning."</p> <p>"When I was younger, I didn't have a whole lot of say-so in what was going on [at doctor's visits]. It was just, 'Take your medicine.' As I got older, they started talking to me more and asking me if I was having a hard time focusing or if I was doing better, things like that. It got better as I got older."</p>
3d. Contributor to Dosage Adjustments	<p>"It was me and my mom and my doctor. We tried to agree on what would make sense and tried different things until it worked."</p> <p>"The doctor can certainly help but in the end, it has to be a family-centered choice just to decide where [the dosage] needs to be."</p>
3e. Gaining a Voice	<p>"I just have more decisions. It's more up to me that it was before."</p> <p>"I had to talk to my parents for a while and they finally said OK [to stopping medication]. They are thinking about putting me back on it [after two years off] so I can focus in class. I think I should get back on it too."</p> <p>"I really didn't like Adderall that much anyway and so I was just like, 'Let's try that one my aunt recommended.' I asked about it and [my doctor] said 'Yes'. So we tried that and I have been on that ever since."</p> <p>"I didn't when I was really little, but I started asking about it whenever my doctor recommends a new medicine, I will ask about side effects."</p>
3f. Vocal Protester Not Given a Vote	<p>"I don't want to take it now. I just don't like it. They won't let me stop."</p> <p>"My mom didn't listen to me at all. I had to take it."</p>
3g. Parent Supervision of Medication Taking	<p>"My mom watches me take it."</p> <p>"My mom leaves it out every day when I get up."</p> <p>"My mom trusts me to take it. I do it on my own."</p>
3h. Covert Medication Disposal	<p>"At one point I wanted to see if it was all mental or if it was actually the medicine. So for a week, I emptied the capsules in the bathroom. I was horrible that week."</p> <p>"I even hid medicine sometimes but eventually my mom found out and she was very angry at me and I have to take the medicine now."</p>
3i. Overt Trials On and Off	<p>"When I went off, I wanted to see if I could just be OK without [medicine]."</p>

Minor Theme	
Medication	<p>My golf game went to hell.”</p> <p>“I stopped taking [medicine] on my own (at age 15). I decided I wasn’t going to take it anymore. I didn’t feel that I needed it. I would go off it during the summer and I felt fine without it, so I just never started taking it again. At first, [my parents] were mad because I just refused to take it and then they finally gave in I guess.”</p> <p>“I am the one that suggested I [should] get back on Concerta [because] right now I don’t do nothing in class---failing, F, F, F in everything.”</p>

Table 4**Major Theme 4: Full Autonomy**

Minor Theme	
4a. Selective use of medicine	<p>“There is a time to take your medicine, there are times not to, and there are times to change your medicine and times not to.”</p> <p>“The medication is just a tool to help you do what is required of you.”</p> <p>“I am at the point now where I take it on test days, when I know I need to concentrate more than other days.”</p> <p>“Just depends on what is coming up. If it was near the end (school year) and your tests were just easy, I just wouldn’t need to take it and I just stopped taking it and save it for next month.”</p> <p>“Usually over the summer I will kind of lean away from it because I want to have fun and not focus too much. Summer is not about focusing. Quite the opposite.”</p> <p>“It depends what I am doing. I am a three sport athlete, wrestling, football and a goalie in soccer. It depends on which sport...football it’s more of the angry stuff and the Concerta. When it comes to wrestling, it’s the Ritalin cuz it cuts the weight and gives you more energy. Then when it comes to soccer, it’s just the Adderall cuz it gives you pressure...ability to go out and get it.”</p>
4b. Future Medicine Use	<p>“I think about it all the time. I don’t know when I’ll stop taking it. I don’t want to be taking it when I get older and I don’t want to go through college having to take medicine.”</p> <p>“Well I really don’t want to take medicine that much, but I kind of need it too. I don’t want to take it my whole life so I want to eventually kind of train myself out of it...just taking pills your whole life is depressing.”</p> <p>“In college, if I don’t really have a hard time concentrating in my classes, I probably won’t take it. It will save money. But if I am still staring out the window, looking at spots on the wall, then I probably will take it.”</p> <p>“I think that when I get to college the medicine will be more of a focusing tool. Like on days that I don’t have class, I may take a small dose of Ritalin but I probably won’t take. Basically, I just use it as a tool to help me focus and not make a fool of myself.”</p> <p>“Even if I have to take it the rest of my life, it’s gonna help me.”</p> <p>“I just don’t think I will need it for a job. I think I would be more focused than at school [where] I am with a bunch of friends...”</p>
4c. Trade Offs	<p>“I say it was a good and bad experience. [My mom] liked that I was doing good in school but at the same time, at home she didn’t like the way I was acting. I wasn’t myself.”</p> <p>“I was just able to focus more, but [medication] has its defects. You are tired, you are sleepy, you get headaches and all of that. But overall the good outweighs the bad.”</p> <p>“I have more fun without it, but I get better grades.”</p>