# The development of a pre-visit educational video to encourage family communication during adolescent ADHD visits

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**ABSTRACT**

Youth with attention deficit/hyperactivity disorder (ADHD) and their parents have questions for their healthcare providers about ADHD but they do not ask them. The purpose of this study was to explore the acceptability of and valued content for educational videos to be used as an intervention to engage families during adolescent ADHD visits. We held separate focus groups with teens with ADHD, their parents, and providers. Based on focus group information we identified six key themes: 1) Talking to your doctor about your ADHD; 2) Controlling ADHD without medication; 3) ADHD medications; 4) ADHD and school; 5) ADHD and your relationships; and 6) Helping your parents understand ADHD. Each theme includes three key messages to educate families and demonstrate how teens can address these topics with their parents and provider. Our patient-centered approach obtained input to develop educational videos that aim to improve communication between families and providers about ADHD.

**INTRODUCTION**

Attention deficit/hyperactivity disorder (ADHD) is a prevalent mental health condition that affects an estimated 11% of school-aged children in the United States (Visser et al., 2014). The number of children diagnosed with ADHD and subsequently the number of children taking ADHD medications continues to increase annually (Visser et al., 2014). Youth with ADHD are more likely to have a poorer quality-of-life, impaired peer relationships, and a reduced life expectancy compared to those without ADHD (Barkley & Fischer, 2019; Dewey et al., 2018).

The Institute of Medicine recommends that patients and their families be engaged and included in decision making during medical visits, but limited data exist examining pediatric patient and parent participation during ADHD visits (Institute of Medicine, 2001). Previous investigations have found that adolescents and their parents are typically not included in decision making during pediatric ADHD visits (Brinkman et al., 2011). A previous study by Sleath and colleagues (2014) found that during pediatric

ADHD primary care visits, pediatric patients and their parents do not ask their providers questions about ADHD and providers do not ask for their input. Specifically, providers included adolescent input in the ADHD regimen in 3% of visits and parent input in 4.5% of visits (Sleath et al., 2014). Additionally, in an observational study of children with ADHD, only one adolescent and three parents asked their provider a question about ADHD (N=67, Sleath et al., 2014). This is important given that another study found that youth with ADHD had an average of 8 questions about their condition and its treatment that they wanted to ask their provider (Sleath et al., 2017). These findings suggest that pediatric patients and their families have questions about ADHD that they are not asking during their visits.

Investigations into why pediatric patients and their parents are not engaged in their medical visits found barriers among all parties (i.e., pediatric patients, parents, and healthcare providers). Boland and colleagues (2019) found that although intention to use shared decision making (SDM) was high amongst providers, less than half reported using SDM after receiving training on how to do so. Health care providers most commonly identified insufficient time as the barrier to participating in shared decision making (Boland et al., 2019). However, Brinkman et al found that use of decision-making aids improved shared decision making and did not significantly extend visit time (2013). Frequently identified barriers by parents of adolescents with any disease include a perceived lack of medication options, concerns about alternative options, and cost (Boland et al., 2019). Pediatric patients across all disease states frequently identify that feeling disempowered or intimidated stopped them from participating in visits (Boland et al., 2019).

Previous studies demonstrate that pre-visit interventions such as educational videos are effective at improving communication during medical visits and are well received by patients (Sleath et al., 2018; Stribling et al., 2016; Trinh et al., 2014). However, few studies have investigated the utility of educational videos for improving provider communication between both pediatric patients and parents. Recently, a study in youth with asthma found that use of a pre-visit video/question prompt list intervention improved

youth question-asking and provider education during visits (Sleath et al., 2018). The current study describes creation of a pre-visit video that encourages *both* the adolescent and parent to actively ask questions during ADHD primary care visits.

Widespread use of mobile devices and social media make videos a favorable mechanism to encourage families to be more engaged and involved in discussions around ADHD management. Youth are more likely to engage with digital mental health interventions if they are easily accessible, simple to use, and age-appropriate (Liverpool et al., 2020). Therefore, the objective of this study was to create a set of brief educational videos that adolescents and their parents will watch prior to adolescent ADHD visits to encourage both the adolescent and parent to actively participate in medical visits. The videos will be included as part of an intervention that will be evaluated in a randomized controlled trial to investigate their effectiveness at improving communication about ADHD during primary care visits.

## METHODS

### Initial Focus Groups

We conducted six focus groups with a convenience sample of adolescents, their parents, and providers. Adolescents and their parents were recruited from two rural North Carolina pediatric primary care clinics that the research team worked with previously (Sleath et al., 2016). Clinic staff distributed fliers to eligible families who then called a designated research team member if they were interested in participating. The clinic staff verified the ADHD diagnosis in the medical record and referred eligible patients for the study. Inclusion criteria for pediatric patients were: 11 to 17 years of age, able to read and speak English, had a diagnosis for ADHD, and saw a provider at a clinic participating in the study. Since the team previously conducted a similar study in youth with asthma at these sites, patients who participated in the previous study were excluded from participating in this study. Inclusion criteria for parents were: at least 18 years of age, able to read and speak English, and status as legal guardian of the pediatric patient. Inclusion criterion for providers was to be a practicing provider at one of the two

participating clinics. This research was approved by the University of North Carolina Institutional Review Board (Study 19-1409).

All participants provided informed written consent or written assent, as appropriate. We held two focus groups with adolescents and two focus groups with their parents. Adolescent and parent focus groups were held simultaneously at the same location to make participation more convenient for the families. Parent and adolescent focus groups were held separately in separate rooms. Two focus groups were held with providers. Each provider focus group was conducted at a pediatric clinic during lunchtime. These providers worked at pediatric clinics and provided care to adolescents with ADHD.

Adolescents, parents, and providers completed anonymous written surveys that collected their age, race, gender, and ethnicity. Parents were also asked how many years of education they had completed. Providers were asked what type of provider they were (physician, physician's assistant, nurse practitioner, or other), how many years they have practiced, and what their opinions were on how much they thought an adolescent's and a parent's preferences should be taken into account when they are treating the child's ADHD.

All focus groups were audio-recorded and then transcribed into a written transcript with identifiers removed. All focus group participants were asked questions about 1) What they thought of the idea of having a pre-visit educational video, 2) What challenges exist to communicating about ADHD, 3) What we should include in the video to encourage communication between families and providers about ADHD, 4) What topics they would emphasize most in the video, and 5) What type of video would be best (for example, animated versus live actors) and how long it should be. Providers and parents received $50 for participating in focus groups and adolescents received $25.

<u>Analysis of Initial Focus Group Data</u>

The research team used a coding process that was utilized in a prior study (Sleath et al., 2016). Six individuals on the research team analyzed the focus group transcripts independently. Individuals identified four themes from the focus groups that they believed were most important to include in the educational ADHD video and sent them to the project manager. The project manager tabulated the results and presented them at a team meeting. The most commonly identified themes were discussed, and the six most important themes were identified through group discussion and mutual agreement.

Following the identification of six themes to highlight in the educational video, each research member generated three messages that could be included to capture each theme. Team members reported these messages to the project manager who tabulated the results. The research team then met and reached consensus on which messages to include in the video for each theme.

Video Script Drafting and Feedback

Educational video scripts were written for each of the six key themes. The video scripts were written by two team members using FinalDraft Version 11.0 script writing software. The lead team member for the video script drafting was an expert in developing simple and concise materials to educate and communicate healthcare related messages to patients. The scripts were then reviewed by the team, including adolescents with ADHD and their parents as well as three consultants with expertise in ADHD. Adjustments were made to the scripts based on feedback.

Follow-up Feedback on the Initial Version of the Video

A sample version of an educational video was developed using puppets rather than actors due to COVID-19. Each research team member was asked to provide feedback on the video. A youth advisory board was established to provide feedback on video creation. Youth with chronic medical conditions were recruited through school nurses and clinics to serve on the board as student representatives. The group met together

via Zoom, watched the video together and suggested improvements. The videos were adjusted based on feedback from the groups.

## RESULTS

### Initial Focus Groups

Demographic Data

Twelve adolescents participated in the two focus groups. Seventy-five percent were male. Eight percent were Hispanic or Latino, 42% were Native American, 33% were African American, 8% were Pacific Islander, 25% were White, and 8% selected "other" for race. Participants were able to select multiple races. The adolescents ranged from 11 to 16 years of age. Seventy-five percent of participants were 11 to 14 years old and 25% were 15 to 16 years old.

Thirteen parents participated in two focus groups. Eight percent were male. Fifty-four percent were Native American, 31% were African American, and 15% were White. The parent participants were between 30 to 70 years of age, with the most parents between the ages of 35 to 39 (N=3). Seventy-six percent of parents had less than 12 years of education, 23% had 12 years of education, and 63% had more than 12 years of education.

Fourteen providers participated in two focus groups. Forty-three percent were male. Thirty-six percent were Native American, 7% were Asian, and 57% were White. Sixty-four percent were physician assistants, 7% were nurse practitioners, and 29% were physicians. Twenty-one percent had practiced as a healthcare provider for less than 5 years, 29% 5-10 years, 21% 10-20 years, and 29% for greater than 20 years.

Educational video format suggestions

Parents, providers, and adolescents all endorsed that they liked the idea of watching an educational video before their visit. Youth suggested that the video should show examples of teens interacting with their doctor at the doctor's office. Regarding speaking with their doctor, one adolescent stated the video should show "how do you approach it and how do you tell them what you've got to tell them." Adolescents also suggested the video include a doctor explaining ADHD, animations, or a trivia game. Providers emphasized that the video should include an individual such as an athlete or someone the teens look up to and that the teen characters in the video should be representative of youth with ADHD. All groups said that the video should be no longer than five minutes to maintain the adolescent's attention.

Focus group video content suggestions

The research team identified six themes to be included in the educational videos:1) Talking to your doctor about your ADHD, 2) Controlling ADHD without medication, 3) ADHD medications, 4) ADHD and school, 5) ADHD and your relationships, and 6) Helping your parents understand ADHD. Each theme was selected to encourage families to ask more questions during their medical visits about these areas. The six themes and their key messages are illustrated in Table 1.

Talking to your doctor about ADHD

Parents, providers, and teens all brought up the importance of teens talking openly with their doctor about their ADHD. One youth stated, "Don't be nervous when you ask the questions because he is here to listen." Providers emphasized the importance of families asking questions. As one provider said, "Unless you ask, you won't get the answers that you're looking for." Providers stated that patients need to let their doctor know when they are having side effects or if their medications are not working. The parent or guardian leaving the room for a portion of the visit was also suggested. Parents were supportive of this idea, as illustrated by one parent who said, "a lot of kids would talk to the doctor, but they won't talk to him if I'm in the room." All parents stated that they had never been asked to step out of the room during any appointments.

Controlling ADHD without medication

Another theme that appeared in all focus groups was ways to control ADHD without medications. Youth shared tips that they felt were helpful. One adolescent stated, “Listen to music while you work, it helps you stay focused.” When adolescents were asked what has helped them the most to make their ADHD better, the most common response was eating. Specifically, they shared that eating regular meals even in the absence of an appetite helped prevent unwanted side effects from medications. Parents and providers also discussed the importance of eating breakfast and snacks at times when the teen does have an appetite, such as a in the morning prior to taking medication. Playing sports and exercising was also discussed by all groups.

ADHD Medications

ADHD medication side effects were a major theme that was brought up in all focus groups. One youth stated, “The medicine affects your appetite, and if you don’t eat, it gives you headaches because you haven't ate all day.” In addition to appetite suppression, providers discussed the impact of medications on mood. One stated, “I’ve heard them say they don’t feel like themselves.” Providers also discussed the importance of patients being open about how their medication is impacting them, whether negatively or positively. Parents discussed the challenge of ensuring adherence to medications. One parent said, “they get tired of taking their medications.” Some parents shared they trusted their child to take their medication independently, while others discussed counting their child’s pills and closely monitoring behavior to determine if the medication was taken. One parent stated, “but the side effects of the medication, she started hiding the medications or pretending like she took them, and she didn’t.” Additional side effects including jitteriness, insomnia, and mood changes were also discussed. All groups agreed that medications help adolescents in school and can improve focus and grades.

ADHD and School

Parents, providers, and adolescents all brought up challenges with ADHD at school. Parents especially emphasized the impact of bullying and aggressive behavior at school. One parent said, “If they know you have any kind of problems, they bully you.” Another parent shared that she had moved her child to homeschooling due to bullying. Adolescents also discussed their responses to being picked on at school. As one teen said, “Without your medicine, like, people just say something, and you get mad. On your medicine, it’s like you just give them a warning.” Providers emphasized the importance of both adolescents and parents communicating with the school and teachers. One provider stated, “The one that a lot of kids I feel like they should ask and don’t are things in a school setting - when can I get additional time to complete a test? I’ve had quite a few that don’t know they can get help in school.”

ADHD and your relationships

All groups discussed the impact of ADHD on relationships. The topic of stigma and feeling different was particularly emphasized. One teen explained how it can be hard for others to understand, stating “You can take your medicine and then you’ll feel better, but they don’t know how it is, and they can’t really get your mood and how you’re feeling.” Providers shared that they felt the stigma of taking medications for ADHD made it hard for adolescents to follow their treatment plans. As one provider stated, “They think something is wrong with them - so they don’t take their meds.” Parents particularly emphasized the importance of youth feeling as if they are not different or alone. One parent explained the impact of her child’s ADHD on friendships saying, “She’s concerned about what her friends think - you know, her friends recognize when she’s on certain medications.” Another parent stated, “Your child’s not abnormal from any other child; that your child is still a normal child even with ADHD.”

Helping your parents understand ADHD

Parents, providers, and adolescents all emphasized the importance of communicating openly about ADHD. Providers explained that poor family communication can lead to poor management of ADHD. One provider said, “The parents will say they won’t; they’re refusing to take their medicine, and the kid’s

like, well my stomach is hurting every day. There's no communication." Providers also talked about the importance of parents understanding how medications can impact their child's behavior. For example, one provider stated, "Irritability in the afternoons; it's not the child, or it's not the medicine; it's the medicine wearing off. Some people don't realize that." Parents emphasized the importance of adolescents being open about their ADHD and that parents must be willing to listen. One parent described the challenges of communicating about ADHD stating, "some things that he experiences he doesn't tell me, and sometimes I don't know how to find out what's really going on with him." Another shared advice for how to better communicate with adolescents saying "Just listen to the child. Really listen because in between their talking you'll get them to tell."

**Follow-up Youth Advisory Board Meetings for Feedback on the Initial Version of the Video**

Demographic Data

Eleven adolescents participated in two advisory board group meetings. Thirty-six percent were male. Eighty-one percent were White and 18% were African American. The adolescents ranged from 13 to 17 years of age. Seventy-two percent of participants were 16 to 17 years old and 27% were 13 to 15 years old. Forty-five percent of the adolescents had a diagnosis of ADHD.

Advisory Board Feedback on the Initial Video

The adolescents all stated that the video information was informative and covered appropriate content. Additionally, they emphasized that they felt the video voices and length were appropriate. The major change recommended by members was to remove the puppets and use animations to better cater to the target age range. In response to the feedback provided, we replaced the video puppets with animation.

**DISCUSSION**

Through focus groups with providers, parents, and adolescents we identified six themes that the participants felt were important to help families communicate more effectively with each other and their

providers to improve ADHD management. We used these themes to create educational videos that aim to educate parents and teens about ADHD and demonstrate ways to better communicate about its management. After watching the videos, we hope that families will better understand ADHD and feel comfortable asking their provider more questions during visits in order to better manage ADHD symptoms and medication side effects. Prior work in ADHD found that better treatment adherence was associated with improved academic performance and that patients taking medication for treatment were less likely to develop additional related mood disorders (Boland et al., 2020). Therefore, ensuring families communicate with their provider to optimize treatment is important.

Key messages all groups thought should be emphasized in the educational videos were that adolescents should not feel nervous or embarrassed talking to the doctor and to be open about their struggles. All groups acknowledged that many teens find it challenging to talk about the impact of ADHD on their lives in areas such as mood, relationships, and physical side effects. The video provides examples of how youth might conduct these conversations. Both adolescents and parents agreed it may be helpful to have time alone with the provider, suggesting that more effective communication amongst all parties (adolescents, parents, and providers) is necessary. Another major theme was ADHD's impact on relationships. Adolescents explained that it can be hard for others to understand what it's like to have ADHD. Future work should explore effective ways to share this experience. Parents particularly emphasized the importance of teens knowing that they are not alone, abnormal, or different. Providers shared that the stigma around ADHD often leads patients to stop taking their medications. The focus group input echoes previous examinations of the stigma of ADHD in youth. Martin et al (2007) found that approximately 1 in 5 adults preferred that their family avoid interacting with youth with ADHD. Pescosolido et al (2008) found that only 38.4% of people consider pediatric ADHD a very serious problem (compared to 83.5% for pediatric depression), despite its documented impact on numerous outcomes and quality of life. Future work should explore the impacts of increased discussion of ADHD on stigma.

Side effects of ADHD medications (particularly stimulants) are common and well documented. Khajehpiri et al (2014) found that amongst a group of children with ADHD taking stimulant medications, 100% of children had at least 1 side effect during a 6-month period. Although the impact of side effects is established, little is known about how families and youth feel communicating about these side effects and the outcomes of doing so. All focus groups discussed that medication efficacy and side effects need to be talked about more frequently and openly. Providers, parents, and adolescents all emphasized the importance of discussing if medications are helping or causing bothersome side effects so that the provider can adjust or change the medication as needed. Providers specifically emphasized that patients should alert providers to problematic side effects promptly rather than waiting several months until their next scheduled visit.

Strengths of our study include a multi-stakeholder perspective (adolescents, parents, providers) and inclusion of expert opinion as well as adolescent and parent feedback to modify scripts. This study also has limitations. We acknowledge the possibility of selection bias. It is possible that only the most motivated families with ADHD participated. Additionally, the use of a convenience sample could influence the trustworthiness of the data. Lastly, we included only pediatric primary care physicians, whose opinions may differ from other types of providers. Even with these limitations, our study used a patient-centered research approach to obtain insightful input from providers, parents, and adolescents to determine the themes for an educational video intended to encourage family engagement during adolescent ADHD visits.

If families are more educated about ADHD and more engaged discussing questions and concerns during visits, youth with ADHD may have better outcomes. Consistent with our asthma intervention, the video developed here will be used as part of an intervention in a randomized controlled trial (RCT) examining the intervention's effectiveness at improving communication between patient, parent, and provider during ADHD primary care visits (Sleath, 2016). If the subsequent RCT demonstrates that the intervention is

effective in increasing question-asking, self-efficacy and shared decision-making, then it could lead to better outcomes such as medication treatment adherence and nonmedication management strategies as well as long-term health outcomes. Additionally, if results demonstrate the intervention improves communication and patient outcomes, it could be disseminated with ease to other practice sites and serve as a model to be applied to other disease states.

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**TABLE 1. Video themes and key messages for the educational video.**

| Video Theme | Key Messages |
|---|---|
| Talking to your doctor about ADHD | Do not feel nervous or embarrassed about talking to your doctor, it's important that the doctor knows your struggles.<br>If you are on medications, let the doctor know how it's affecting you and if the dose needs to be adjusted.<br>Have a list of questions ahead of time to ask your doctor about your ADHD. |
| Controlling ADHD without medications | Regular food and hydration can help control the up and down energy levels.<br>Exercise can help improve ADHD, try to do it when you can.<br>Improve concentration by removing distractions and trying focusing techniques such as yoga or meditation. |
| ADHD Medications | Ask your doctor why medications are important for ADHD. Medications can help many teenagers with ADHD stay focused.<br>Some medications may have side effects and adjusting dose or switching to a different medicine may help you find the most effective one for you. Tell your doctor if you have side effects.<br>Taking your medications at a different time may help with side effects. |
| ADHD and School | Tell your teacher how you are feeling.<br>Don't let kids picking on you get to you.<br>Your school may be able to provide some accommodations. Talk with your parents, teachers and counselors about a 504 plan. |
| ADHD and your relationships | Remember that you are not alone.<br>Some teens grow out of ADHD and some continue to take medications when they are older.<br>Taking time away from screens and using techniques can help you focus and make ADHD better. |
| Helping your parents understand ADHD | Remember that It can be difficult for others to understand what it's like to have ADHD, so be open with your parents about your day.<br>Tell your parents if you are having side effects or problems with your medications.<br>See if there are support groups or a therapist can help foster the conversation between the teen and parent. |

**REPORT ADDENDUM**

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Compliance with Ethical Standards

Prior to the focus groups, all participants received a consent form describing the purpose and details of the study. Adolescent participants received assent forms that described the study in an appropriate way for their age and reading level. Additionally, parents completed parental consent forms for all pediatric patients participating. Consent forms were locked in a secure cabinet. All interaction involving human participants was conducted per the University of North Carolina IRB standards. The accepted IRB Number for this study is 19-1409.

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Conflicts of Interest

The authors have no conflicts of interest to disclose.