

# Youth Perceptions of Attention-Deficit/Hyperactivity Disorder and Barriers to Treatment

Canadian Journal of School Psychology  
28(2) 193–218  
© 2013 SAGE Publications  
Reprints and permissions:  
sagepub.com/journalsPermissions.nav  
DOI: 10.1177/0829573513491232  
cjs.sagepub.com



Lindsey Walker-Noack<sup>1</sup>, Penny Corkum<sup>2</sup>, Nezihe Elik<sup>1</sup>,  
and Isabel Fearon<sup>3</sup>

## Abstract

The purpose of this study was to gain information about how youth with ADHD perceive this disorder and the barriers to treatment. Six focus groups were conducted in three locations within Nova Scotia (two of each: elementary school students, middle school students, high school students). Qualitative data was collected from 25 youth (aged 10 to 21) diagnosed with ADHD. Data analysis conducted through *Ethnograph* software revealed several themes: (a) participants did not perceive ADHD in a positive light; (b) youth recognized the need for intervention and identified school supports as particularly important; (c) youth reported both benefits and negative effects of pharmacological and psychosocial interventions; and (d) youth with ADHD perceived that the general public is misinformed about ADHD, which contributes to social stigma and stereotyping. The results have implications for school psychologists, who are in an ideal position to help demystify ADHD and to facilitate the collaboration between the youth, parents, and teachers.

## Résumé

Cette étude avait pour but de recueillir de l'information sur la manière dont les jeunes souffrant du trouble de déficit de l'attention avec hyperactivité (TDAH) perçoivent ce désordre, de même que sur les obstacles au traitement. Six groupes de discussion ont été menés, regroupant des élèves de trois endroits en Nouvelle-Écosse (deux groupes de chacun des niveaux suivants, soit primaire, intermédiaire et secondaire). Des données qualitatives ont été recueillies auprès de 25 jeunes (de 10 à

<sup>1</sup>Mount Saint Vincent University, Halifax, NS, Canada

<sup>2</sup>Dalhousie University, Halifax, NS, Canada

<sup>3</sup>IWK Health Centre, Halifax, NS, Canada

## Corresponding Author:

Penny Corkum, Department of Psychology and Neuroscience, Dalhousie University, Halifax, NS, B3H 4J1, Canada.

Email: penny.corkum@dal.ca

21 ans) ayant reçu un diagnostic de TDAH. L'analyse des données, à l'aide du logiciel *Ethnograph*, a permis de dégager plusieurs thèmes : (1) les participants n'ont pas une perception positive du TDAH; (2) les jeunes reconnaissent la nécessité d'intervenir, soulignant tout particulièrement l'importance du soutien des écoles; (3) les jeunes rapportent tant les bienfaits que les effets négatifs de la médication et des interventions psychosociales et enfin, (4) les jeunes atteints du TDAH estiment que le grand public est mal informé au sujet de ce trouble, ce qui contribue à la stigmatisation sociale et à la persistance des stéréotypes. Les résultats interpellent particulièrement les psychologues en milieu scolaire, qui sont les mieux placés pour aider à démystifier le TDAH et à favoriser la collaboration entre les jeunes, les parents et les enseignants.

### Keywords

ADHD, youth, treatment, barriers, stigma

Attention-Deficit/Hyperactivity Disorder (ADHD) is one of the most common mental health disorders of childhood. The core symptoms of this disorder often contribute to negative consequences for youth, including academic underachievement, poor child–parent relations, peer rejection, and social and adaptive impairments (Chronis, Jones, & Raggi, 2006). To enhance the prognosis for youth with ADHD, pharmacological (e.g., psychostimulants) and psychosocial (e.g., behavior modification) interventions are generally prescribed to alleviate the core symptoms, which include inattention and/or hyperactivity/impulsivity. Such treatments have been studied extensively and are empirically supported for the treatment of ADHD (Chronis et al., 2006; Pelham, Wheeler, & Chronis, 1998); however, overall treatment adherence is not optimal, indicating that nonadherence is a major barrier to the effective treatment of ADHD.

The World Health Organization (2003) reports that adherence in developed countries averages only 50% for most diseases and disorders. Nonadherence rates to prescribed treatments for ADHD are estimated to be between 20% to 65% (Swanson, 2003). Research examining treatment nonadherence has found several factors that are related to treatment nonadherence. Specifically, several studies have demonstrated that incomplete or misguided parental knowledge and negative treatment attitudes are related to nonadherence (Bennett, Power, Rostain, & Carr, 1996; Corkum, Rimer, & Schachar, 1999; Monastra, 2005). Ibrahim (2002) found that family characteristics, such as family dysfunction and negative familial medication experiences have been linked to treatment nonadherence. Several studies show that demographic variables, such as ethnicity, gender, and socioeconomic status may be indirectly linked to nonadherence (Arnold et al., 2003; Power, Russell, Soffer, Blom-Hoffman, & Grim, 2002). For example, Arcia, Fernandez & Jaquez (2004) found that cultural beliefs may impact a family's decision to commence or adhere to treatment. Bussing, Koro-Ljungberg, Gary, Mason, & Garvan (2005) reported that girls with ADHD are less likely to receive treatment than boys, and African American families were less likely to seek help from

medical professionals than Caucasian families. In addition, a positive relationship was indicated between socioeconomic status and adherence (Power et al., 2002). The relationship between symptomology and adherence was indicated through Charach, Ickowicz, & Schachar's (2004) study which found that more severe symptoms at baseline were related to a greater treatment response and lower attrition, while Swanson (2003) postulated that poor self-regulation and distractibility can contribute to medication nonadherence. Comorbid mental health disorders such as Oppositional Defiant Disorder (ODD) were linked to an increased likelihood of attrition and drop-out rates (Thiruchelvam, Charach, & Schachar, 2001). Child factors related to nonadherence were identified as low intelligence and antisocial behavior (Power et al., 2002). Treatment infeasibility, unpleasant medication side effects (Kendall, Hatton, Beckett, & Leo, 2003; Power et al., 2002; Travell & Visser, 2006), and negative social stigma of receiving treatment (Stine, 1994; Swanson, 2003) have also been linked to nonadherence. Past research has identified a relationship between the above factors and nonadherence via parent interviews, surveys, and national statistical data; however, only a handful of studies have focused on youth perceptions of treatment as contributing to the ADHD treatment nonadherence research base.

To date, few published research studies exist on youth perceptions of ADHD and treatment (Sciberras, Efron, & Iser, 2011). Together, these studies have generated six key findings. First, youth have awareness that core ADHD symptoms contribute to a negative impact at school and home (Kendall et al., 2003; Raskind, Margalit, & Higgins, 2006; Singh, 2007; Travell & Visser, 2006). Second, youth with ADHD tend to describe their disorder in terms of consequences (e.g., being "bad") rather than symptoms of the disorder (Kendall et al., 2003). Third, research suggests that youth want to be involved in the process of their diagnosis and treatment, as studies report that youth have a desire to be given a choice regarding treatment (Brook & Boaz, 2005; Travell & Visser, 2006). Fourth, youth hold both positive and negative attitudes about medications, with common benefits including improved concentration, behavior, academics, and decreased hyperactivity, and common disadvantages including medication side effects, negative psychological feelings, and social embarrassment (Baxley, Turner, & Greenwold, 1978; Bowen, Fenton, & Rappaport, 1990; Kendall et al., 2003; Singh, 2007; Singh et al., 2010; Sleator et al., 1982; Travell & Visser, 2006). Fifth, past research indicates that there may be poor agreement between youth and parent perceptions with regard to specific reasons for taking medications (Bowen et al., 1990) and identifying the benefits and adverse effects of medication (Bowen, Fenton, & Rappaport, 1990; Efron et al., 1998). Finally, children in some studies appeared to discuss their ADHD as part of their personal identity (Raskind et al., 2006; Singh, 2007). The above research has laid the groundwork for studying youth perceptions of ADHD and treatment; however, this literature base is neither complete, nor comprehensive. Specifically, there are gaps of varying extents with respect to youth perceptions of positive aspects of ADHD, behavioral and academic interventions, and youth perceptions of public attitudes about ADHD.

Research is beginning to demonstrate that an increasingly important element of an individual's "ADHD experience" is the stigma that is attached to the diagnosis. Despite

societal access to information about mental health, Martin, Pescosolido, Olafsdottir, & McLeod (2007) found that one in five adults are unwilling to have children with mental health disorders in the vicinity of their home or children and that the behaviors associated with ADHD increased preference for social distance. Coleman, Walker, Lee, Friesen, and Squire's (2009) study found that nearly one in four peers blame the child for his/her disorder, and that children with mental health diagnoses hold stigmatizing beliefs about their own conditions. Wiener et al. (2012) found that children with ADHD reported their problematic behaviors as stigmatizing more often than typically developing peers, and perceive higher levels of stigmatization in relation to their parents, teachers, and peers. Harris, Milich, Corbitt, Hoover, and Brady (1992) found that typically developing children's impressions and behavior toward a child with ADHD was negatively impacted simply by providing preliminary negative information about the behavior of the child with ADHD. Additional results suggested that the child with ADHD experienced several negative effects as a result of these interactions with peers. Various studies have set out to investigate parent perceptions of the stigma attached to youth with ADHD. These studies revealed parent reports of feeling stigmatized for having a child with ADHD, a need to invest time and resources into managing the stigma attached to their children (Koro-Ljungberg & Bussing, 2009; Singh, 2004), and concern for their child's low self-esteem as a result of the stigma attached to ADHD (dosReis, Barksdale, Sherman, Maloney, & Charach, 2010). There appears to be an absence of a core research base with regard to youth experiences of stigma (Hinshaw, 2005). Pescosolido (2007) suggested that the stigma attached to youth mental health disorders cannot be inferred from similar studies with adults, and Hinshaw (2004) urged researchers to use open-ended questions within research methodologies to help facilitate a dialogue between the research community and those affected by mental health disorders.

Due to reported high levels of nonadherence and the limited research base of youth perceptions of the ADHD experience, treatment, and stigma, the current study examines youth perceptions of the ADHD experience and barriers to treatment. Given the relatively early stage of inquiry on this topic, qualitative research methods are critical for identifying and describing youth perceptions of ADHD and treatment barriers. This qualitative information may open the door for future researchers to investigate whether quantitative relationships exist between youth perceptions and treatment barriers. The current study is a qualitative phenomenological research design in which the investigators collected data from youth participants via several focus groups in order to better understand youth perceptions of ADHD, treatment, and stigma through their firsthand experiences. The main research questions of this study were developed to better understand youth's perceptions of ADHD, treatment, and social attitudes about ADHD: (a) What do youth perceive as beneficial aspects and general difficulties due to ADHD? (b) Which supports are viewed as helpful in coping with the negative aspects of ADHD? (c) What do youth perceive as treatments for ADHD, and what are the positive and negative aspects of such treatments? (d) What are youth perceptions of public attitudes about ADHD, and what knowledge do they believe should be acquired by the public to assist youth with ADHD and to reduce stigma?

## Method

### Participants

Twenty-five youth (15 male, 10 female) attending elementary, middle, and high schools in three areas of Nova Scotia participated in one of six focus groups. Participants ranged in ages from 10 to 21 ( $M = 14.32$ ,  $SD = 2.68$ ) and were attending Grades 4 to 12 ( $M = 7.96$ ,  $SD = 2.28$ ). Of the six focus groups, two groups consisted of elementary students, two groups of middle school students, and two groups of high school students. The number of participants in each focus group ranged from two to five.

### Participant Characteristics

All participants had a diagnosis of ADHD as reported by their parents. ADHD subtypes, as reported by parents, were as follows: 52% ( $n = 13$ ) Inattentive type, 20% ( $n = 5$ ) Combined type, 8% ( $n = 2$ ) Hyperactive/Impulsive type, 8% ( $n = 2$ ) ADHD Not Otherwise Specified, and 12% ( $n = 3$ ) parents were unsure of subtype. Additional diagnoses (e.g., Learning Disabilities, Anxiety, etc.) were present in 44% ( $n = 11$ ) of participants, and 76% ( $n = 19$ ) were taking medication for ADHD. Of those participants taking medications, 53% ( $n = 10$ ) were prescribed Concerta, 16% ( $n = 3$ ) were prescribed Biphentin, 16% ( $n = 3$ ) were prescribed Strattera, 10% ( $n = 2$ ) were prescribed Dexedrine, and 5% ( $n = 1$ ) were prescribed Adderall. In terms of family composition, 88% ( $n = 22$ ) of participants came from two-parent families and 12% ( $n = 3$ ) from single-parent families. The number of children in the families ranged from one to three ( $M = 1.80$ ,  $SD = 0.57$ ). Social status was computed using Hollingshead's (1975) four factor index of social status. Computed scores showed that families fell within the following categories: 8% ( $n = 2$ ) within "machine operators and semiskilled workers," 12% ( $n = 3$ ) within "skilled craftsmen, clerical, and sales workers," 68% ( $n = 17$ ) within "medium business, minor professional and technical workers," and 12% ( $n = 3$ ) within "major business and professionals."

### Measures

*Background Information Questionnaire.* This author-developed questionnaire was completed by parents for the purpose of collecting demographic and diagnostic information. Information collected included birth date, family composition, parent/guardian occupation, child's history of psychological disorders (e.g., ADHD, anxiety), and medication use (e.g., stimulants, antidepressants).

*Structured Discussion Guide*<sup>1</sup>. The focus group discussion guide was constructed by the authors and utilized to structure discussions with youth participants. The discussion guide included five discussion topics, as well as pre-identified prompts in the case that participants were unable to progress through the discussion. Prompts were given by the facilitators and included rephrasing questions when participants did not understand

or suggesting alternative contexts (e.g., school, home, and community) when discussions were at a lull. Discussion questions and prompts were not modified between focus groups regardless of age, but rather were designed to be appropriate across all age groups.

The first three discussion questions were directed at obtaining youth perceptions of ADHD: (a) "What are the good things about ADHD?" (b) "What is hard about having ADHD?" and (c) "What are things that kids with ADHD need help with?" The next discussion question was directed at obtaining information about treatments for ADHD and their barriers: (d) "What are things that can help ADHD?" After answering this question, participants were asked to identify the pros and cons of medication, behavioral, and academic interventions. The final topic was aimed at understanding youth's perceptions of public beliefs about ADHD: (e) "What do other people think and what should they know about ADHD?" These topic questions are not to be confused with our research questions as presented above; rather, these were the specific questions asked to the participants during the focus groups, which helped the authors to answer the research questions.

## **Procedure**

Ethics approval was granted from the university and local hospital. Participants were recruited through flyer distribution in a range of settings (e.g., doctors' offices, mail), as well as direct contact with participants who participated in past studies within our research laboratory. Parents who expressed interest were given information about the study via telephone. At that time, parents were asked about the nature of their child's diagnosis. If the child met inclusion criteria, a date and location of a focus group was provided. Inclusion for participation was that the child: (a) had been diagnosed with ADHD by a mental health professional as reported by their parent, and (b) was attending Grades 4 to 12. The lower grade limit was set to Grade 4, as research regarding child demystification groups had found that children younger than this typically have difficulty articulating their thoughts about ADHD (MacKay & Corkum, 2006).

Prior to the commencement of the focus groups, parents of all participants were asked to read and sign an informed consent form and complete the Background Information Questionnaire. Youth participants of all ages were given information about the process of the focus group and were asked to give their assent to participate. Once information was collected, parents were told that they were free to leave and return at the end of the group. All focus groups were conducted by the first and second authors. All focus groups were audio-recorded and later transcribed. The focus group structure was based on Morgan and Krieger's (1997) work. Each focus group began with an ice-breaker activity to build rapport and increase comfort of participants prior to the discussion. Next, the facilitator explained the nature of the discussion and rules of participating (e.g., talk one at a time, no right or wrong answers). The discussion was structured to include discussion of five topics and each topic was introduced via Microsoft PowerPoint®. The discussion was led by

the first author, and the second author assisted with the discussion and took notes on each PowerPoint slide, allowing participants to review their statements. The duration of focus groups was 90 to 120 minutes, and following the session, participants were provided with snacks, an age-appropriate ADHD information package, and a gift certificate of CAD\$5 value.

## Analyses

The Background Information Questionnaire was analyzed using descriptive statistics in the Statistical Package for the Social Sciences, Version 15.0 (SPSS 15.0). Focus group content was recorded to audio-tape and transcribed verbatim. Each transcript was reviewed and specific statements (e.g., answers to questions, statements made during discussions) from all participants were subsequently marked for themes by hand. Themes were coded to numbers for later analysis. Statements were excluded if they were specific only to the person expressing it (e.g., all other participants disagreed), if it was not specific to ADHD (e.g., grievance about school in general), and if it consisted of one word with no elaboration (e.g., “yes”).

Statements were first coded into topic themes, major themes, and subthemes by the first author. Subsequently, the second author made suggestions, and both investigators agreed on the final inclusion of themes. Topic themes refer to the specific topics discussed and questions asked by the facilitator during the focus groups. Major themes are the overarching themes that emerged from a combination of subthemes (e.g., ADHD symptoms). Subthemes denote the coding of similar or meaningful statements made by focus group participants. Finally, a content analysis of the transcripts was conducted using the *Ethnograph* computer software program. Similar statements from each discussion question were grouped into subthemes and recoded by numbers. Subthemes eventually developed into major themes under each topic area.

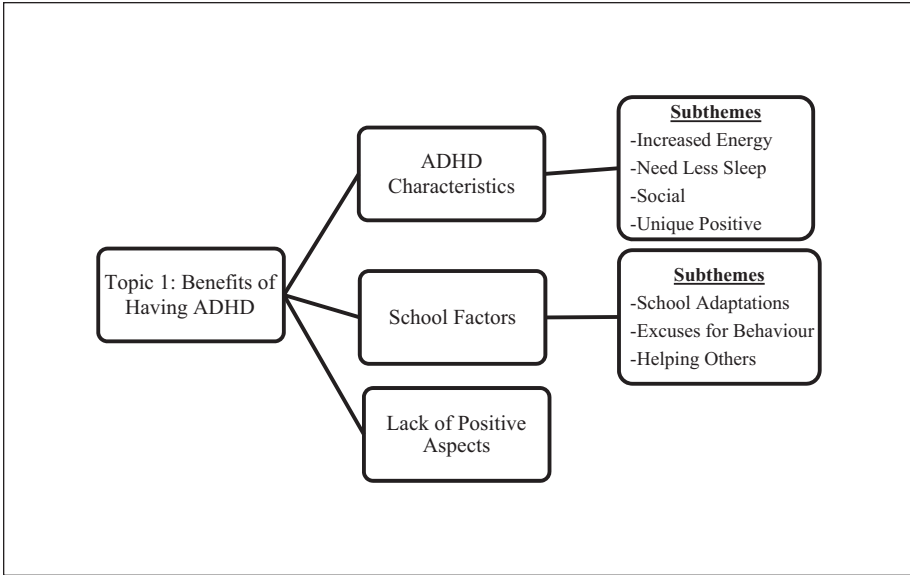
## Results

### *Qualitative Data Analysis of Focus Groups*

Of the five topics discussed, a total of 18 major themes (range: 3-5 themes in each topic) and 61 subthemes (range: 7-19 for each topic) emerged. Major themes are discussed under each topic area, and subthemes are discussed under a description of each major theme.

**Topic 1: Benefits of Having ADHD.** The major themes within this topic reflected participants' experiences in relation to benefits of having ADHD. Overall, this topic was most difficult for participants to discuss, and many participants appeared not to have previously considered the positives of having ADHD. Three major themes emerged: (a) ADHD characteristics, (b) school factors, and (c) lack of positive aspects of ADHD.





**Figure 1.** Topic 1.

(1) *ADHD characteristics.* Statements reflected that some benefits were due to ADHD symptoms and related characteristics: increased energy (18 statements), needing less sleep (seven statements), being outgoing and social (five statements), and uniqueness in a positive way (three statements). Participants reported that ADHD is associated with having more energy, which was beneficial in physical education and extracurricular activities. Some participants reported needing less sleep than the average person their age to function throughout the day: “. . . No matter how much sleep I get . . . I always have enough energy for the day” (middle school). In addition, adolescent participants reported that having ADHD made them more outgoing in social situations: “We are always the life of the party . . . we’re cool; we know how to have fun!” Participants in some groups reported that ADHD made them unique in positive ways such as being creative and the ability to complete some tasks. For example, an elementary school participant reported: “I’m not like the same as somebody else . . . some things I can do better than anybody else.”

(2) *School factors.* Statements that reflected benefits in the school context generated three subthemes: helpful school adaptations (14 statements), making excuses for behavior (five statements), and helping others due to preexisting knowledge about ADHD (three statements). Adolescent participants identified benefits with regard to school adaptations, while younger participants reported benefits to be escaping punishment for unacceptable classroom behaviors by blaming ADHD. In addition, participants reported having more knowledge about ADHD, which allowed them to help other students with ADHD. For example, a middle school participant reported, “If you



have ADHD, you'll like know a lot about it so you could actually help other kids with ADHD with stuff they don't know."

(3) *Lack of positive aspects.* Although participants had difficulty discussing the benefits of ADHD, a few explicitly stated that no positives exist (three statements). For example, a high school participant stated that such benefits were unrelated to ADHD and were instead related to one's personality: "Well realistically, I don't think that there's any benefit to having ADHD . . . people can personally be more energetic and more artsy, and it doesn't have anything to do with ADHD."

*Topic 2: Difficulties Due to ADHD.* Participants were asked to discuss difficulties due to ADHD. This topic was discussed with ease as compared to the first topic. Three major themes emerged: (a) difficulties due to characteristics and features associated with ADHD, (b) school difficulties, and (c) home difficulties.

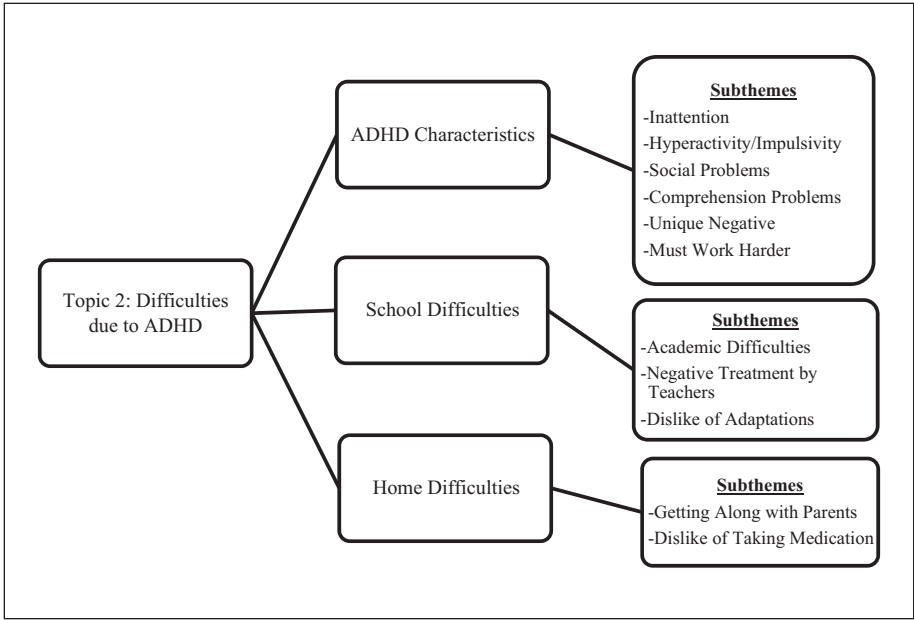


Figure 2. Topic 2.

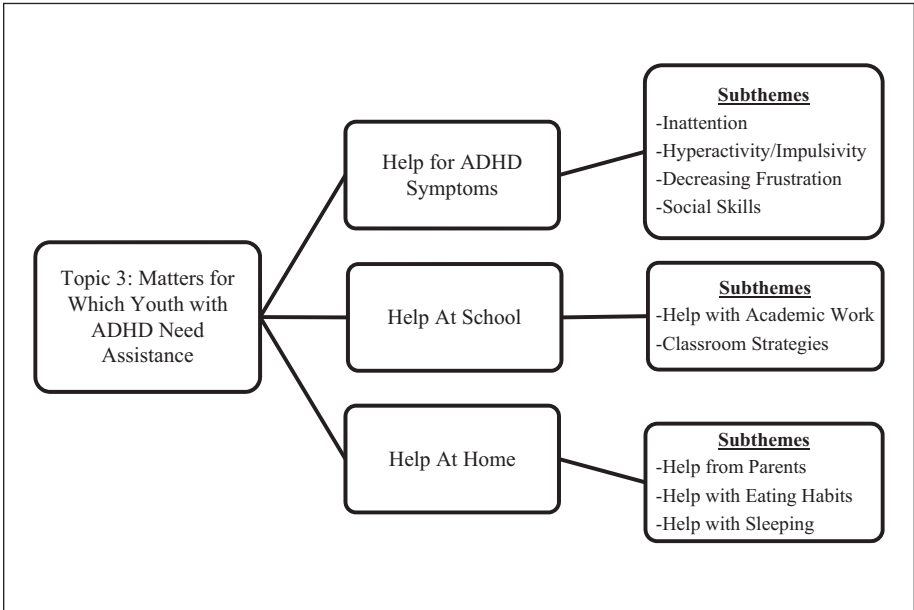
(1) *ADHD characteristics.* Participants discussed negative experiences across a number of contexts due to core symptoms and associated features of ADHD. Subthemes included: difficulties due to inattention (24 statements), difficulties due to hyperactivity and impulsivity (13 statements), social problems (13 statements),

comprehension problems (five statements), uniqueness in a negative way (two statements), and having to working harder to be successful (two statements). Participants made several statements regarding difficulties experienced due to core ADHD symptoms (i.e., inattention, hyperactivity, and impulsivity). Inattentive symptoms were characterized by difficulty focusing, listening attentively to others, concentrating and filtering distractions, and forgetting. In terms of hyperactivity and impulsivity, participants reported difficulties sitting for long periods of time, being too talkative, and controlling behavior: "I get distracted and I can't really stay in one spot that long." Negative unique characteristics were reported in one elementary group. One participant reported that he felt and acted different from other people, which lead to social difficulties. Participants attributed several social problems to ADHD (e.g., fighting with friends, being the subject of teasing, being impatient, acquiring a bad reputation, and difficulty getting along with others). One elementary school participant described the social difficulties he experienced: "What's hard about ADHD is that a lot of people don't like you . . . people teasing you about you being a freak." Difficulties with comprehension, understanding facts, and difficulties with school work and homework were also reported. Some participants reported that they had to work twice as hard as their peers in order to complete school work and that assignments and homework were often lengthy tasks.

(2) *School difficulties.* Three subthemes emerged regarding school difficulties: academic difficulties (nine statements), negative treatment from teachers (five statements), and dislike of adaptations (four statements). Participants reported difficulties with homework, a variety of academic subjects, and experiencing scrutiny from their teachers. For example, a middle school participant reported, "Well, at my school, since I have ADHD, like whenever I start to do like good and that . . . like I behave somewhat good, the teachers always try and find like the one little thing I do wrong because they know that I'm going to like mess up sometimes." Although participants reported school adaptations to be a benefit under topic one, adaptations were discussed in terms of disadvantages in response to the second question. Disadvantages of adaptations included receiving more teacher help, teasing about adaptations, and leaving fun classroom activities to go to the Learning Centre/Resource Room. For example, an elementary school participant stated, ". . . when there's something fun that we're doing in class that I find really fun and then I have to leave for the Learning Centre."

(3) *Home difficulties.* Two subthemes that relate difficulties in the home context emerged: getting along with parents (four statements) and dislike of taking medications (four statements). Older participants stated that taking medication is a hassle. Difficulties getting along with parents, difficulty meeting parents' expectations, and being denied permission to do certain activities because of ADHD were brought up in all age groupings. For example, an elementary school participant reported, "Because I have ADHD, my mom usually doesn't let me do certain things that my sister can do."

**Topic 3: Matters for Which Youth With ADHD Need Assistance.** This topic was introduced to determine youth’s perceptions of specific difficulties for which they need assistance. Three major themes emerged and included: (a) help for ADHD symptoms, (b) help at school, and (c) help at home.



**Figure 3.** Topic 3.

(1) *Help for ADHD symptoms.* A review of statements indicated that participants required support for symptoms and characteristics associated with ADHD: support for inattentive (26 statements) and hyperactive/impulsive (17 statements) symptoms, decreasing frustration (six statements), and social skills (four statements). All groups reported needing help with inattention (e.g., staying focused, listening, staying on topic, filtering distractions, staying organized, time management, and remembering). Hyperactivity and impulsivity were also identified as areas that youth with ADHD need help with. Groups reported needing assistance with being still, being quieter, “keeping things together,” controlling behavior, decision making, and thinking before acting. One high school participant reported: “Judgement, like making good judgements about situations, like we don’t think as clearly as other people do, like we make stupid decisions.” In addition, participants reported needing help with calming and relaxing when frustrated. Older participants identified social skills and situations (e.g., making friends, teasing, being included, etc.) as areas requiring support. For example, a middle school participant reported how difficulty focusing in social situations can lead to frustration:

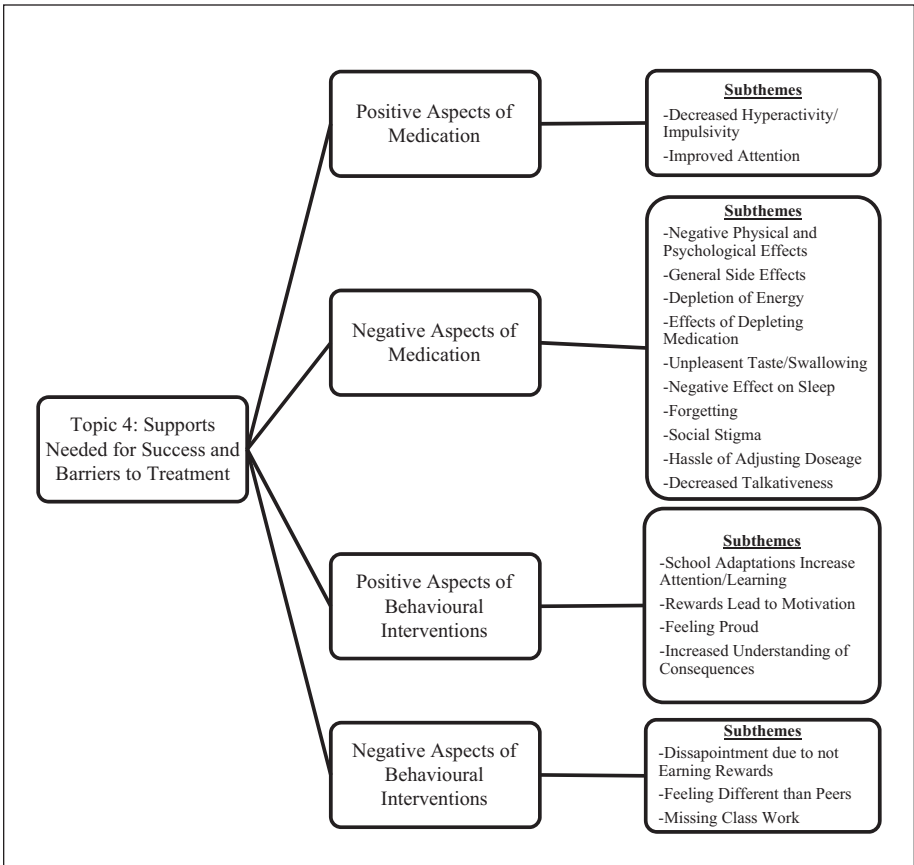
"When you have friends sometimes, a lot of them talk at the same time and then it's hard to listen to everybody and then you get frustrated and you . . . it's hard."

(2) *Help at school.* Statements generated two subthemes regarding help in the school context: help with academic work (16 statements) and classroom strategies (five statements). Participants in all six focus groups made statements regarding academic work as an area that students with ADHD need help with (e.g., homework, academic subjects, class work, getting assignments in on time, reading and writing). Participants also provided suggestions of how teachers could assist students with ADHD, such as having smaller classes, giving less homework and fewer assignments, and providing additional opportunities to release energy. One high school participant noted that moving around can help decrease hyperactivity in the classroom: "I think that they should just let us run around more."

(3) *Help at home.* The following subthemes were developed through discussions of assistance required in the home context: help from parents (four statements), help with eating habits (three statements), and help with sleeping (two statements). Help from parents included remembering, chores, and getting along. Help with eating habits included reduction of sugar and amount of food intake. Participants also made statements about sleep, related to a busy mind at night. For example, an elementary participant reported that adults had increased pressure, which affected his sleep: "One thing I don't like about ADHD is . . . two people trying to tell you what to do at the same time and not getting enough sleep by too much pressure."

*Topic 4: Supports Needed for Success and Barriers to Treatment.* This question was introduced to the discussion to determine participants' experience with pharmacological and psychosocial interventions, as well as to understand perceptions of successful supports for managing the symptoms and features associated with ADHD. Several supports were identified, as well as suggestions of what parents, teachers, and youth can do to reduce difficulties that are experienced due to ADHD. All six focus groups included statements about medication and school adaptations as supports for ADHD. Statements regarding school adaptations included reducing school work, making assignments and projects more interesting, allowing for movement-breaks, individual support, additional time to work on assignments, and checking for understanding during classes. Only two focus groups identified behavioral interventions (e.g., reinforcement) as a means of helping youth with ADHD, and when asked, many participants expressed that rewards and reinforcement were unhelpful for managing symptoms. Other identified supports included extracurricular activities (e.g., sports, building), organizational strategies (e.g., use of daily planner, making lists), and relaxation strategies (e.g., yoga, participating in enjoyable activities). In addition, participants identified strategies that youth with ADHD can practice (e.g., coping strategies and practicing academic work) and reported that parents could learn more about ADHD, help with homework, and try to better

understand their child. In the second part of discussion under this topic, participants were asked to discuss positive and negative aspects of the interventions they identified.



**Figure 4.** Topic 4.

(1) *Positive aspects of medication.* Participants in all six groups identified several ADHD symptoms that were reduced due to medication use. Subthemes included: decreased hyperactivity and impulsivity (18 statements) and improvements in attention (17 statements). These participants reported that medication aids with the core symptoms of hyperactivity and impulsivity, and group discussions indicated that medication had a calming effect and helped to reduce urges to move around, fidget, and leave assigned seats to explore the classroom, while helping to control impulsive behavior (e.g., hitting) and follow rules. For example, a middle school participant stated, “It helps you from not hitting people. Like when I didn’t take medication one time, I got suspended from school for a week because I hit somebody.” In terms of reducing

inattentive symptoms, these participants also reported that medications increased their ability to focus, concentrate, listen attentively, and to apply themselves to school work.

(2) *Negative aspects of medication.* The youth's comments indicated that the negative aspects of medications significantly outweighed the positive. Participants' discussions clustered into 10 subthemes; negative physiological and psychological effects (13 statements), general side effects (e.g., mood swings, depression/suicide,<sup>2</sup> drowsiness; 12 statements), depletion of energy (11 statements), effects of depleting medication (six statements), unpleasant taste and difficulty swallowing pills (eight statements), negative effect on sleep (four statements), forgetting to take medication (four statements), social stigma (two statements), hassle of adjusting dosage (two statements), and decreased ability to be talkative (two statements).

Participants in all focus groups reported that medication had a negative effect on appetite. Specifically, there was consensus regarding little desire to eat throughout the day and increased desire to eat junk-food late at night. Several participants reported losing a significant amount of weight when taking medication for ADHD. For example, a high school participant reported, "For me . . . with the medication that I have, when I started taking it, immediately one of the things I noticed was that I dropped weight like melting wax." Regarding general side effects, participants in all six groups reported that medications caused symptoms of drowsiness, nausea, headaches, mood swings, effects on short-term memory, and withdrawal. Younger participants described mood swings and how medications made them "feel different," while older groups reported concern about side-effects as outlined by pharmaceutical companies (e.g., depression) and negative physical sensations (e.g., heart palpitations, migraines). For example, a high school participant reported: ". . . When I was on Concerta, I'd miss like one day, and it would literally be like going cold turkey off of hard drugs . . . Like going through withdrawal and everything. Like headaches, feeling nauseous, and just . . . it was gross."

Participants reported that medication depleted their energy, which in turn affected school performance. Performance also seemed to be affected in everyday functioning; for example, a high school participant stated, ". . . They [medication] made me feel like a zombie. Not only are you not hyper, you just don't have the energy to do anything other than your basic functions." Statements indicated that depleting medication had negative psychological and physiological effects. Statements reflected extreme changes in hyperactivity throughout the day, feelings of "going crazy," and extreme tiredness by the end of the school day. Participants also discussed the hassle of trying numerous medications before finding the right type and dosage. Taste and swallowing pills were negative aspects discussed by younger participants and appeared to be difficult for youth when beginning medication as a young child. All age groups reported negative effects on sleep (e.g., difficulty falling asleep and taking longer to fall asleep after taking medication too late during the day). Participants also reported getting into trouble at school and home for forgetting to take their medication. Although many participants stated that medication had a positive effect on hyperactivity, adolescents reported that medication decreased their ability to be talkative, which had a negative

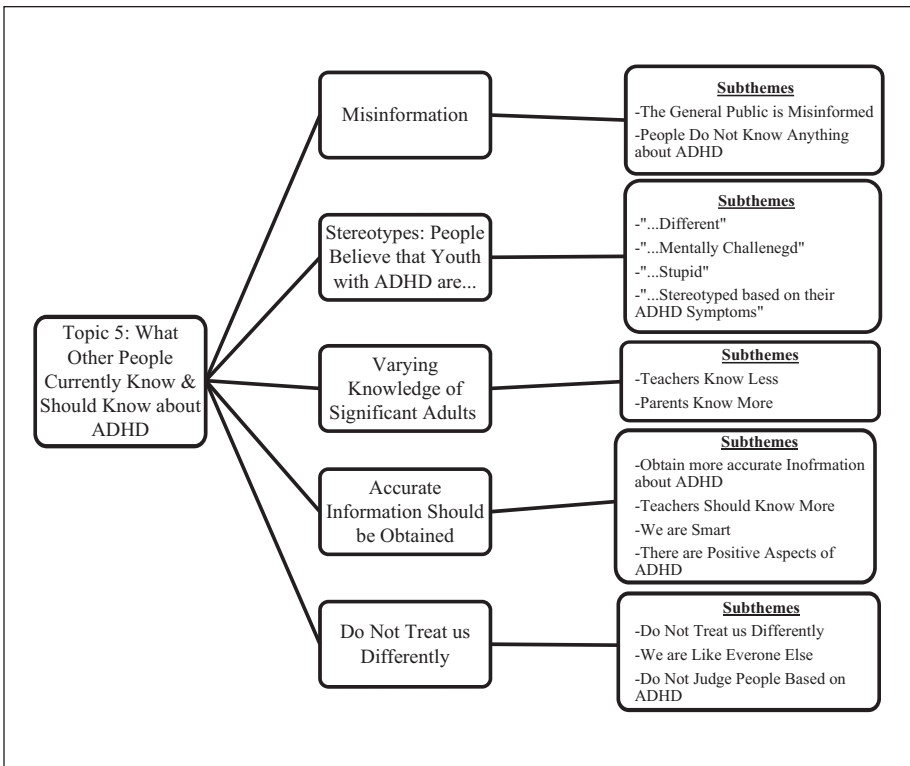
effect on their classroom participation and social abilities. One high school participant said, “. . . Honestly, I find that I fare out better socially when I don’t take it because I am more outgoing . . .” Reports also indicated that social stigma is attached to taking medications. For example, an elementary participant reported, “. . . It’s kind of embarrassing when you have your friends come over and they see them [pills] sitting on the table and they’re wondering what that’s for and then . . . they ask me what it’s for and I just tell them . . . I had a cold, or I’m sick . . .”

(3) *Positive aspects of behavioral interventions.* Four subthemes emerged during discussion of the positive aspects of behavioral interventions: school adaptations increase attention, understanding, and learning (13 statements); obtaining rewards leads to motivation (12 statements); feeling proud of obtaining rewards (three statements); and an increased understanding of consequences (three statements). Participants reported that one-on-one support from the classroom teacher, organizational strategies, and curriculum adaptations were most helpful. For example, one high school participant reported that adaptations allowed her to enjoy academics: “Ever since I’ve come here, for example, I’ve done a lot better in things like reading, and I actually enjoy it.” Regarding behavioral reinforcement programs, most adolescent participants stated that such programs were unhelpful in higher grades, but that rewards somewhat increased motivation to complete work and behave appropriately in earlier grades. Younger participants reported that rewards were motivating to behave appropriately. Statements also indicated that gaining rewards and succeeding led to proud feelings. Participants reported that reward programs and behavioral charts enabled them to see their progress and understand the consequences of their actions.

(4) *Negative aspects of behavioral interventions.* Three subthemes emerged during discussion of the positive aspects of behavioral interventions: disappointment when rewards are not received (eight statements), feeling different from peers (five statements), and missing class work (two statements). The feeling of disappointment emerged during discussions with younger participants. Disappointment was reported for not doing as well as peers on a behavioral program, feeling left out, and feeling bad about oneself for not succeeding on a reinforcement program. A middle school student reported disappointment after working hard and not being rewarded: “Sometimes when I work really hard . . .and she [teacher] promises us something and it doesn’t happen and you get disappointed because you worked so hard just to get the thing you wanted.” Older participants stated that school adaptations and extra help could lead to peer teasing and misconceptions. Additional negative feelings included: feeling as if they were being treated differently by teachers, insecurity, and feeling different from peers. Participants in all groups agreed that school adaptations were most helpful; however, most participants did not agree with being taken out of fun classes to go to the Learning Centre. An important negative aspect of school adaptations was reported by just one middle school participant: that there is “only one person” to help a number of students, and students with ADHD could not always receive the help they required due to lack of resources.



**Topic 5: What Other People Currently Know and Should Know About ADHD.** The purpose of the final topic was to learn about participants' perceptions of societal beliefs about ADHD to gain a preliminary understanding of how this may affect self-perceptions. This topic was addressed by asking participants what other people believe about ADHD and what other people should know about ADHD in order to reduce stigma and increase public understanding of the disorder. Five major themes emerged. Three major themes related to the beliefs of others: (a) misinformation, (b) stereotypes based on ADHD symptoms, (c) varying knowledge of significant adults (e.g., parents and teachers). Two themes related to what others should know: (d) people should have accurate information about ADHD, and (e) youth with ADHD should not be treated differently.



**Figure 5.** Topic 5.

(1) **Misinformation.** Participants' statements generated two subthemes: that the general public is misinformed about ADHD (15 statements) and that other people do not know anything about ADHD (13 statements), and both were perceived as contributing to inaccurate perceptions of youth with ADHD. All participants reported that the general public is misinformed about ADHD, and statements reflected that such youth are

perceived as “bad,” that ADHD is perceived as a learning disability, and that if someone (e.g., on the street) was asked what ADHD is, their answer would likely be wrong. Other statements reflected that people think negatively of ADHD youth, believe that they are going to fail, and their peer group would believe that ADHD youth do not deserve to be in the same classroom as youth without ADHD. For example, a middle school participant stated the following: “Well, I find like a lot of people, like they really don’t understand what ADHD is. They think it’s some kind of thing that makes you really stupid and . . . they think it’s a mental handicap or something, but it’s nothing like that at all.” Participants in all groups reported that most people in the general public do not know what ADHD is. Statements that comprised this subtheme reflected beliefs that most people do not know what the acronym “ADHD” stands for and that most people would not know anything about ADHD unless an immediate family member had the disorder.

(2) *Stereotypes based on ADHD characteristics.* Participants voiced that other people think that youth with ADHD are: different from the rest of the public (eight statements), mentally challenged (seven statements), and “stupid” (five statements). In addition, participants reported that youth with ADHD are stereotyped based on the core symptoms of their disorder (nine statements). Participants’ statements reflected that youth with ADHD are perceived solely by the core symptoms of the disorder. All groups included discussion that youth with ADHD are perceived as unable to learn, listen, sit still, and are “always hyper.” For example, an elementary school participant reported, “[They would think that] we’re like, challenged, like have a really, really hard time learning.” A middle school participant reported, “Maybe other people would think that . . . they’re better than you, so . . . they shouldn’t be in the same classroom as you.” Participants in all age groups reported that people think that youth with ADHD are different from the general public. Statements comprising this subtheme included public beliefs that there is “something wrong” with ADHD youth, that they are “weird,” “freaks,” and that people in the general public probably think that they are superior to youth with ADHD. Statements reflected perceptions that ADHD is probably viewed as a mental challenge, which was reflected by statements that people think that youth with ADHD are “crazy,” “mentally handicapped,” and that ADHD is associated with Autism. In addition, statements from participants in high school groups indicated that people in the general public think that youth with ADHD are “dumber than most people” and “stupid.” This major theme is an extension of the *Misinformation* theme, as statements were expressed with regard to stereotypes and attitudes that are formed based on inaccurate information obtained by the general public.

(3) *Varying knowledge of significant adults.* Statements indicated that youth perceive that teachers know less (eight statements) and parents know more (four statements). When asked what teachers know about ADHD, participants responded that most teachers do not understand ADHD or how to teach students with ADHD. Statements reflected that teachers are uninformed about ADHD and forget that

certain students have ADHD. It was also reported that teachers do not like students with ADHD and might believe that such students are incapable of completing school work. For example, a high school student felt neglected by her teachers: "... my teachers sort of shoved me off to the side and forgot that I was there so they didn't have to put the extra time into helping me." In terms of parental knowledge of ADHD, participants stated that parents who have children with ADHD probably know a lot about the disorder. This belief was supported by statements reflecting that parents have more experience after raising a child with ADHD and associated disorders.

(4) *Accurate information to be obtained.* Participants' statements indicated that people should obtain accurate information about ADHD (24 statements), that teachers should know more about ADHD to better service students (nine statements), that people should know that youth with ADHD are smart (eight statements), and people should know that there can be good things about having ADHD (three statements). All participants wanted the public to have more accurate information about ADHD. Statements reflected that people should know that youth with ADHD are "not autistic," that they have "a lot of energy," that ADHD is a lifelong disorder that cannot be cured, that it is common, that it is a real problem, and that both males and females have ADHD. Statements also reflected how youth with ADHD differ from one another. For example, a high school participant reported, "It [ADHD] comes in more than one form ... and there's all different ways it can manifest in a person."

Participants also wanted the general public to know what ADHD is, that students with ADHD learn differently, and that students with ADHD are not "slacking off." For example, an elementary school student reported that "What people should know is that we're the same as everybody else, but our brain is just wired differently." Participants in all age groups had suggestions for teachers, such as altering negative beliefs about ADHD and gaining more information about teaching students with ADHD in order to improve student success. A middle school participant wanted teachers to "Teach us the way we learn." Participants in all groups reported that the public should know that they are smart and that successful historical figures had ADHD (e.g., Bob Dylan, Albert Einstein). Younger participants discussed how people should know that there are benefits to having ADHD.

(5) *Do not treat us differently.* Statements that developed under this major theme reflected: that people should not treat individuals with ADHD differently from those without ADHD (nine statements), that the public should know that youth with ADHD are similar to everyone else (seven statements), and that the public should not judge people based on ADHD (two statements). Participants in all age groups wanted people to know that ADHD does not make a person exceptionally different from other students, but rather, youth with ADHD just need more help than others. Participants also said that all people are different in their own way, and ADHD does not make people "weird" or "crazy." Youth with ADHD wanted people to follow the golden rule: "Treat others the way you would want to be treated."

## Discussion

The purpose of this study was to examine youth perceptions of ADHD, treatment, and stigma in order to further understand the “ADHD experience” as well as an explanation for the high rates of treatment nonadherence within this population. Four research questions were posed at the outset of this study, and four main findings emerged from the data.

First, youth with ADHD view their disorder more negatively than positively, as evidenced by the fact that participants in all age groups had more difficulty discussing the benefits of ADHD (55 total statements), as compared to the difficulties they experience (85 total statements). This finding supports the existing research that youth with ADHD have a mostly negative view of their disorder and experience several difficulties due to ADHD (Kendall, Hatton, Beckett, & Leo, 2003; Travell & Visser, 2006); however our findings would suggest that youth have a more complex view of their disorder. Many participants appeared perplexed to be asked about the benefits of having ADHD, but when given time to reflect, were able to identify some positives. This finding contributes to the existing literature base, as the benefits of having ADHD have not been specifically addressed in prior research. This new information speaks to the importance of encouraging youth to reflect on the potential positive attributes of this diagnosis.

Second, youth with ADHD were aware of their need for assistance and appeared to have an understanding of specific treatments and supports that are required for their success. Participants were aware that they required assistance with the core symptoms of ADHD and academic difficulties, and were able to articulate several strategies to support them. Interestingly, there was an overwhelming response with regard to interventions to assist youth within the school context. Previous research has suggested that youth have a desire to be included in the process of determining their treatment regimen (Travell & Visser, 2006). Our findings would suggest that the youth are an integral part of the team to consult during the treatment process in both home and school settings.

One of the more major findings yielded from this study is that youth perceive medication to be superior to behavioral treatments with regard to the effectiveness of treating the core ADHD symptoms despite having more negative than positive experiences with medications. Several studies have found that youth with medication experience express concern about the side-effects of medication (Bowen et al., 1990; Kendall et al., 2003; Singh, 2007; Singh et al., 2010; Travell & Visser, 2006), while there is insufficient evidence on the youth's perception of behavioral treatments and associated barriers. Our results indicated that there were mostly supporting statements for behavioral programs in elementary groups when compared to older participants. Our findings also identify youth perceptions regarding barriers of behavioral programs (e.g., decreasing novelty of rewards, peer awareness, incorrect teacher implementation) and academic supports (e.g., lack of resources and missing regular class time).

Another major finding was in relation to the overwhelming number of statements that the general public is misinformed and hold stereotypic attitudes about ADHD, that

youth feel mistreated, and request that the public modify their existing negative attitudes about youth with ADHD. The fact that these children have an understanding that people think that they are “bad,” “stupid,” and unable to learn speaks to the need for improved education and training for teachers, peers, parents, and the general public overall. This finding is supported by results of several studies that suggest that there is a strong negative stigma attached to ADHD (Martin et al., 2007; Coleman et al., 2009; Harris et al., 1992; Koro-Ljungberg & Bussing, 2009; Bussing, Koro-Ljungberg, Gary, Mason, & Garvan, 2009; Singh, 2004; dosReis et al., 2010; Mukolo & Heflinger, 2011); however, our study gives a specific voice to youth with ADHD regarding the feelings and experiences they have in response to living with a stigmatized disorder.

It is also important to point out that some major and subthemes were linked across topics. For example, *ADHD Characteristics* and *School Factors* were identified across the first three topics as major themes of discussion. Other links are evident throughout our research that identifies the convoluted nature of the youth's perception of the ADHD experience. For example, *More Energy* was a subtheme identified under the *Good Things About ADHD* topic, while *No Energy* was identified as a subtheme under the major theme of *Negative Aspects of Medication*. We can see here that an identified positive aspect about ADHD is perceived to be suppressed by one of the leading prescribed treatments for ADHD. This point also illustrates our findings that youth perceive negative experiences with ADHD treatments. Together, our findings suggest that the youth's perception of ADHD and/or treatment may itself be a barrier to treatment adherence. In reexamining the research on treatment adherence, we can see a theory developing that there are several indicators for treatment nonadherence (e.g., family history, specific child, and family characteristics, etc.), and we propose adding the youth's perception to this growing list.

### *Implications for the School Psychologist*

The above findings have a number of implications for the school psychologist, who is often responsible for diagnosing ADHD, planning school-based interventions, and consulting with parents and educators. The finding that youth have a complex view of their disorder, which appears to be more negative than positive, speaks to the importance of demystifying youth about ADHD at the time of diagnosis, as well as providing age-appropriate education at life transition stages (e.g., adolescence, transition from middle school to high school, etc.). The attributions made about the behaviors demonstrated by youth with ADHD should also be considered given that Kaidar, Wiener, and Tannock (2003) found that children with ADHD view their problematic behavior as being more stable across situations and less controllable. Like these authors (Kaidar et al., 2003), we also recommend that children with ADHD are provided with education that provides a balanced view about the positive and negative aspects of having ADHD.

School psychologists may also consider including the youth as an important consultant while determining appropriate school-based interventions. This implication is supported by our findings that youth appear to be aware of their difficulties and

need for assistance and have a general understanding of beneficial interventions, as well as with Travell and Visser's (2006) finding that youth desired to be involved in the process of their diagnosis and treatment. When making recommendations to parents and educators regarding appropriate school based interventions and behavioral strategies, the youth may be more apt to participate as a contributing member of the treatment planning team, in comparison to being a recipient of the interventions.

Another important role of the school psychologist will be addressing the stigma that is experienced by youth with ADHD. Our study, along with several others has identified that the stigma attached to the ADHD diagnosis and associated behaviors is real, can be emotionally trying, and can have negative consequences for youth with ADHD. Hinshaw (2005) reported that, unfortunately, increased knowledge alone does not necessarily transform attitudes, and that the stigma of mental disorders must be addressed at multiple levels within society (e.g., public policy, general health care reform, media, etc.). At the school level, the psychologist may assist with stigma reduction by educating the family on the appropriate Education Act legislation, connecting families with advocacy programs and support groups, recommending empirically supported interventions, providing counseling sessions to promote appropriate coping strategies (Hinshaw, 2005), and continuing to provide appropriate ADHD education to school personnel and students. Such support from the school psychologist may assist in reducing stigma beliefs held by peers and teachers, as well as providing the family with appropriate resources and coping mechanisms for handling the ramifications of stigma.

The above suggestions may lead to more positive treatment outcomes, thus increasing adherence to treatment. The importance of a partnership between the youth, parent, and teacher is implied by the above findings and implications, and the school psychologist is ideally situated to form this alliance by having a working relationship with all parties. Like Sciberras and colleagues (2011), we believe that a critical component of an ADHD treatment program is to engage youth in terms of understanding their experience of having ADHD.

### *Methodological Issues*

The findings of this study should be interpreted in consideration of the study limitations. Findings of the current study may not be generalizable to the entire population of children with ADHD, as participants were primarily Caucasian and residing in Nova Scotia. These results may not generalize to youth of diverse backgrounds, as perceptions of ADHD and treatment barriers may be influenced by demographic factors. The focus group dynamic also contributes to a limitation of this study, as each group contained participants that were vocal to varying degrees, potentially allowing for more vocal participants' perceptions to be more salient in the research findings than the opinions of their quieter counterparts. Another methodological limitation of this study includes the researchers' reliance on parent report of an ADHD diagnosis rather than administration of evidence-based assessment of ADHD. However, the main point of the study was to have youth with ADHD who had life experiences with

this disorder. In addition, the themes generated from qualitative data reflect the interpretation of the researchers. Although the researchers attempted to present results through the participants' meanings of statements, like all qualitative research, a degree of subjectivity is inherent in the overall findings.

### **Future Directions**

Future research may focus on translating the above findings into specific barriers by developing a questionnaire. This would allow youth perceptions of treatment barriers to be measured through quantitative analysis to determine whether statistical relationships exist between perceptions of treatment and levels of adherence. It would also be interesting to determine whether youth perceptions of ADHD and treatment differ by age and/or gender. In addition, future research may focus on determining whether increased education about ADHD and treatment are related to more positive self-perceptions and more positive attitudes toward ADHD.

Other topics of study that emerge from this data include determining whether the inclusion or exclusion of youth throughout the process of diagnosis and/or treatment contributes to treatment efficacy and adherence. In addition, the small literature base regarding stigmatizing experiences on youth with ADHD appears to be at the early stages of inquiry and may be considered an important factor in the overall ADHD experience and treatment adherence. The existing literature base and our findings appear to have merely scratched the surface of this topic and as such require more development.

### **Conclusion**

The current study set out to answer a number of research questions pertaining to youth's perceptions of ADHD and treatment barriers. Our findings add to the literature by identifying that youth have a complex, rather than just negativistic, view of ADHD, youth have realistic and complicated perceptions of treatment, and strong perceptions of public stigmatization. Youth's comments spoke to their desire to strike a balance between receiving the help they need and yet being treated similarly to their peers. Furthermore, this research indicates that the youth's perception of ADHD and treatment may itself be defined as a barrier to treatment adherence. Findings of the current study have implications for mental health professionals providing service to youth with ADHD, families, and educators. Further identification of treatment barriers and increased education about ADHD and treatment may allow youth, parents, educators, and the general public to have more positive opinions about individuals with ADHD and treatment options, thereby increasing chances of treatment adherence and thus, improving the overall academic and personal success of youth with ADHD.

### **Acknowledgment**

We would like to thank all the youth and their parents who participated in this study, as well as the following people who helped with this study: Melissa McGonnell, Fiona Davidson, Kait Sullivan, Tamara Libfeld, and Pamela Blotnicky.



## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was partially supported by a grant from Social Sciences and Humanities Research Council of Canada (820-2005-1024).

## Notes

1. This guide is available from the corresponding author, Penny Corkum, upon request: penny.corkum@dal.ca
2. Statements regarding depression and suicide were not made based on a first-person experience, but rather related to participants' statements of reading about the possible side-effects of their medications.

## References

- Arcia, E., Fernandez, M. C., & Jaquez, M. (2004). Latina mothers' stances on stimulant medication: Complexity, conflict, and compromise. *Journal of Developmental and Behavioural Pediatrics*, 25, 311-317.
- Arnold, L. E., Elliot, M., Sachs, L., Bird, H., Kraemer, H. C., Wells, K. C., & Wigal, T. (2003). Effects of ethnicity on treatment attendance, stimulant response/dose, and 14-month outcome in ADHD. *Journal of Consulting & Clinical Psychology*, 71, 713-727. doi:10.1037/0022-006X.71.4.713
- Baxley, G. B., Turner, P. F., & Greenwold, W. E. (1978). Hyperactive children's attitudes concerning drug treatment. *Journal of Pediatric Psychology*, 3, 172-176. doi:10.1093/jpepsy/3.4.172
- Bennett, D. S., Power, T. J., Rostain, A. L., & Carr, D. E. (1996). Parent acceptability and feasibility of ADHD interventions: Assessment, correlates, and predictive validity. *Journal of Pediatric Psychology*, 21, 643-657. doi:10.1093/jpepsy/21.5.643
- Bowen, J., Fenton, T., & Rappaport, L. (1990). Stimulant medication and attention deficit/ hyperactivity disorder: The child's perspective. *American Journal of Diseases of Children*, 145, 291-295. Retrieved from <http://archpedi.jamanetwork.com/article.aspx?articleid=515582>
- Brook, U., & Boaz, M. (2005). Attention-deficit/hyperactivity disorder and learning disabilities: Adolescents' perspective. *Patient Education and Counseling*, 58, 187-191. doi: 10.1016/j.pcc.2004.08.011
- Bussing, R., Koro-Ljungberg, M. E., Gary, F., Mason, D. M., & Garvan, C. W. (2005). Exploring help-seeking for ADHD symptoms: A mixed methods approach. *Harvard Rev Psychiatry*, 13(2), 85-101.
- Charach, A., Ickowicz, A., & Schachar, R. (2004). Stimulant treatment over five years: Adherence, effectiveness, and adverse effects. *Journal of the American Academy of Child and Adolescent Psychiatry*, 43, 559-567. doi:10.1097/00004583-200405000-00009
- Chronis, A. M., Jones, H. A., & Raggi, V. L. (2006). Evidence-based psychosocial treatments for children and adolescents with attention-deficit/hyperactivity disorder. *Clinical Psychology Review*, 26, 486-502. doi:10.1016/j.cpr.2006.01.002

- Coleman, D., Walker, J. S., Lee, J., Friesen, B. J., & Squire, P. N. (2009). Children's beliefs about causes of childhood depression and ADHD: A study of stigmatization. *Psychiatric Services, 60*, 950-957. doi:10.1176/appi.ps.60.7.950
- Corkum, P., Rimer, P., & Schachar, R. (1999). Parental knowledge of attention-deficit hyperactivity disorder and opinions of treatment options: Impact on enrollment and adherence to a 12-month treatment trial. *Canadian Journal of Psychiatry, 44*, 1043-1048. Retrieved from <http://web.ebscohost.com/ehost/pdfviewer/pdfviewer?sid=112c5c6e-0e39-48e3-85db-eee3b464aa21%40sessionmgr15&vid=7&hid=14>
- dosReis, S., Barksdale, C. L., Sherman, A., Maloney, K., & Charach, A. (2010). Stigmatizing experiences of parents of children with a new diagnosis of ADHD. *Psychiatric Services, 61*, 811-816. doi:10.1176/appi.ps.61.8.811
- Efron, D., Jarman, F. C., & Barker, M. J. (1998). Child and parent perceptions of stimulant medication treatment in attention deficit hyperactivity disorder. *Journal of Pediatric Child Health, 34*, 288-292. doi:10.1046/j.1440-1754.1998.00224x
- Harris, M. J., Milich, R., Corbitt, E. M., Hoover, D. W., & Brady, M. (1992). Self-fulfilling effects of stigmatizing information on children's social interactions. *Journal of Personality and Social Psychology, 63*, 41-50. doi:10.1037/0022-3514.63.1.41
- Hinshaw, S. P. (2004). Parental mental disorder and children's functioning: Silence and communication, stigma and resilience. *Journal of Clinical Child and Adolescent Psychology, 33*, 400-411. doi:10.1207/s15374424jccp3302\_22
- Hinshaw, S. P. (2005). The stigmatization of mental illness in children and parents: Developmental issues, family concerns, and research needs. *Journal of Child Psychology and Psychiatry, 46*, 714-734. doi:10.1111/j.1469-7610.2005.01456.x
- Hollingshead, A. B. (1975). *Four factor index of social status*. New Haven, CT: Yale University Press. Retrieved from [http://www.yale.edu/sociology/faculty/docs/hollingshead\\_socStat-4factor.pdf](http://www.yale.edu/sociology/faculty/docs/hollingshead_socStat-4factor.pdf)
- Ibrahim, E. S. (2002). Rates of adherence to pharmacological treatment among children and adolescents with attention deficit hyperactivity disorder. *Human Psychopharmacology, 17*, 225-231. doi:10.1002/hup.406
- Kaidar, I., Wiener, J., & Tannock, R. (2003). The attributions of children with attention deficit/hyperactivity disorder for their problem behaviors. *Journal of Attention Disorders, 6*(3), 99-109. doi:10.1177/108705470300600302
- Kendall, J., Hatton, D., Beckett, A., & Leo, M. (2003). Children's accounts of attention deficit/hyperactivity disorder. *Advances in Nursing Science, 26*, 114-130. Retrieved from [http://journals.lww.com/advancesinnursingscience/Abstract/2003/04000/Children\\_s\\_Accounts\\_of.4.aspx](http://journals.lww.com/advancesinnursingscience/Abstract/2003/04000/Children_s_Accounts_of.4.aspx)
- Koro-Ljungberg, M., & Bussing, R. (2009). The management of courtesy stigma in them lives of families of teenagers with ADHD. *Journal of Family Issues, 30*, 1175-1200. doi:10.1177/0192513X09333707
- MacKay, L., & Corkum, P. (2006). Evaluation of a demystification workshop for children with ADHD. *Journal of Developmental and Physical Disabilities, 18*, 319-332. doi:10.1007/s10882-006-9019-3
- Martin, J. K., Pescosolido, B. A., Olafsdottir, S., & McLeod, J. D. (2007). The construction of fear: Americans' preferences for social distance from children and adolescents with mental health problems. *Journal of Health and Social Behaviour, 48*, 50-67. doi:10.1177/002214650704800104
- Monastra, V. J. (2005). Overcoming the barriers to effective treatment for attention deficit/hyperactivity disorder: A neuro-educational approach. *International Journal of Psychophysiology, 58*, 71-80. doi:10.1016/j.ijpsycho.2005.03.010

- Morgan, D. L., & Krieger, R. A. (1997). *The focus group kit*. Thousand Oaks, CA: SAGE.
- Mukolo, A., & Heflinger, C. (2011). Factors associated with attributions about child health conditions and social distance preference. *Community Mental Health Journal*, 47, 286-299. doi:10.1007/s10597-010-9325-1
- Pelham, W. E., Wheeler, T., & Chronis, A. (1998). Empirically supported psychosocial treatments for attention deficit hyperactivity disorder. *Journal of Clinical Child Psychology*, 27, 190-205. doi:10.1207/s15374424jccp2702\_6
- Pescosolido, B. A. (2007). Culture, children, and mental health treatment: Special section on the National Stigma Study—Children. *Psychiatric Services*, 50, 611-612. doi:10.1176/appi.ps.58.5.611
- Power, T. J., Russell, H. F., Soffer, S. L., Blom-Hoffman, J., & Grim, S. M. (2002). Role of parent training in the effective management of attention deficit/hyperactivity disorder. *Disease Management and Health Outcomes*, 10, 117-126. doi:1173-8790/02/0002-0117
- Raskind, M., Margalit, M. H., & Higgins, E. L. (2006). My LD: Children's voices on the Internet. *Learning Disability Quarterly*, 29, 253-268.
- Sciberras, E., Efron, D., & Iser, A. (2011). The child's experience of ADHD. *Journal of Attention Disorders*, 15, 321-327. doi:10.1177/1087054710361671
- Singh, I. (2004). Doing their jobs: Mothering with Ritalin in a culture of mother-blame. *Social Sciences & Medicine*, 59, 1193-1205.
- Singh, I. (2007). Clinical implications of ethical concepts: moral self-understandings in children taking methylphenidate for ADHD. *Clinical Child Psychology & Psychiatry*, 12 (2), 167-182.
- Singh, I., Kendall, T., Taylor, C., Mears, A., Hollis, C., Batty, M., & Keenan, S. (2010). Young people's experience of ADHD and stimulant medication: A qualitative study for the NICE guideline. *Child and Adolescent Mental Health*, 15(4), 186-192.
- Sleator, E. K., Ullman, R. K., & von Neumann, A. (1982). How do hyperactive children feel about taking stimulants and will they tell the doctor? *Clinical Pediatrics*, 21, 474-479. doi:10.1177/000992288202100805
- Stine, J. J. (1994). Psychosocial and psychodynamic issues affecting nonadherence with psychostimulant treatment. *Journal of Child and Adolescent Psychopharmacology*, 4, 75-86. doi:10.1089/cap.1994.4.75
- Swanson, J. (2003). Compliance with stimulants for attention-deficit/hyperactivity disorder: Issues and approaches for improvement. *CNS Drugs*, 17(2), 117-131. doi:10.2165/00023210-200317020-00004
- Thiruchelvam, D., Charach, A., & Schachar, R. J. (2001). Moderators and mediators of long-term adherence to stimulant treatment in children with ADHD. *Journal of the American Academy of Child and Adolescent Psychiatry*, 40, 922-927.
- Travell, C., & Visser, J. (2006). "ADHD does bad stuff to you": Young people's and parents' experiences and perceptions of attention deficit hyperactivity disorder (ADHD). *Emotional and Behavioural Difficulties*, 11, 205-216. doi:10.1080/13632750600833924
- Wiener, J., Malone, M., Varma, A., Markel, C., Biondic, D., Tannock, R., & Humphries, T. (2012). Children's perceptions of their ADHD symptoms: Positive illusions, attributions, and stigma. *Canadian Journal of School Psychology*, 27, 201-217.
- World Health Organization. (2003). *Adherence to long-term therapies: Evidence for action*. Retrieved from [http://www.who.int/chp/knowledge/publications/adherence\\_full\\_report.pdf](http://www.who.int/chp/knowledge/publications/adherence_full_report.pdf)

## Author Biographies

**Lindsey Walker-Noack** is a school psychologist (Can. Reg.) with the Halifax Regional School Board. Her work within the school setting focuses on assessment of learning disabilities and

other mental health disorders, as well as assessment and intervention for school-aged youth with behavioral difficulties.

**Penny Corkum** is an associate professor of Clinical Psychology at Dalhousie University. She also helped to establish and currently manages an inter-institutional ADHD Clinic in Truro, NS. Her research and clinical work is in the area of ADHD and pediatric sleep, with a specific focus on developing and evaluating interventions.

**Nezihe Elik** is a psychologist at the Developmental Pediatrics and Rehabilitation Program, McMaster Children's Hospital, and an assistant professor (Part-Time) at the Department of Psychiatry and Behavioral Neurosciences, McMaster University, Hamilton, Ontario. Her research focuses on interventions for children with ADHD, and her clinical work is on assessment and treatment of young children with cognitive, behavioral, and social-emotional difficulties, and children and adolescents with intellectual disabilities.

**Isabel Fearon** is a psychologist with the Child and Family Day Treatment Service at the IWK Health Centre in Halifax, NS. Her clinical and research interests are focused on children with disruptive behavior disorders, assessment and treatment of child mental health disorders, as well as program development and evaluation.