Perspectives of College Students on their Childhood ADHD

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Abstract:
Purpose: To determine what successful young adults perceive was helpful to them when they were struggling with their attention-deficit hyperactivity disorder (ADHD) symptoms as children.
Study Design and Methods: Sixteen young adult college students with a history of ADHD participated in semi-structured interviews that asked them which people and what strategies they had found most helpful to them during their childhood. Data were analyzed using content analysis.
Results: The most helpful people were parents and teachers; the most helpful strategies were caring behaviors and active teaching/learning strategies. Participants remembered helpful people as "giving me strategies to help me keep my mind focused on something; keep me involved, keep me interested."
Clinical Implications: Children with ADHD need the support of caring adults who use active teaching strategies. Nurses working with children and adolescents in any setting can educate parents about the best ways to help children with ADHD succeed, using some of the results of this research.
Keywords: Adolescents; Attention-deficit hyperactivity disorder; ADHD; Child

Article:

Attention-deficit/hyperactivity disorder (ADHD) is a common behavior disorder characterized by inattention and/or hyperactivity and impulsivity, which interferes with functioning in all areas of a person's life (American Psychiatric Association [APA], 2000). In 2008, the latest year for which national statistics are available, approximately 5 million children in the United States between the ages of 3 and 17 were diagnosed with ADHD (Centers for Disease Control and Prevention [CDC], 2009); this is about 8% of all children in this age range. ADHD can contribute to school problems including poor performance on tests, failure to complete assignments, careless work habits, and poor writing (Wolraich et al., 2005), and can also lead to psychopathology in adulthood including addictive problems, antisocial personality disorder, anxiety disorders, and depression (Biederman et al., 2006; Fischer, Barkley, Smallish, & Fletcher, 2002; Forsman, Larsson, Andershed, & Lichtenstein, 2007). ADHD has been associated with substance use, family problems, early parenthood, and social impairment (Barkley, 2004; Barkley, Fischer, Smallish, & Fletcher, 2006; Wolraich et al.).

Studies have examined children with ADHD from many perspectives, including common comorbidities and treatment strategies (for a review, see Wolraich et al., 2005). Knipp (2006), however, suggests that more studies are needed to examine the perceptions of those actually living with the disorder, and Hughes (2007a) suggests that it is important to talk with those directly affected by ADHD to learn how to design interventions to help them cope and improve their outcomes. Few studies have asked young adults with ADHD what was helpful to them as they struggled with their disorder in childhood, although it is possible that asking those who have successfully negotiated ADHD could provide important information for the design of interventions for children with the disorder. Therefore, this study explored persons and strategies that college-enrolled young adults with a history of ADHD perceived were most and least helpful to their management of ADHD during childhood.

Method

Design and Sample

The authors used a qualitative method to collect data in individual interviews with college-enrolled young adults who had had ADHD since childhood. Participants were recruited from a disability services office of a large university in the southeastern United States. The staff invited young adult college students who had had ADHD since childhood to participate. Students who were interested signed a phone call form indicating their willingness to be contacted about the study. Potential participants were then screened by phone by an author. If a potential participant reported that he or she had been diagnosed with ADHD by a healthcare provider during childhood, an interview was scheduled. The university's Institutional Review Board approved the study.
A convenience sample of 16 participants was included (age range 18–25 years; 13 were female and 3 male). Twelve were non-Hispanic whites, two were non-Hispanic blacks, one was Hispanic, and one was of Asian-Indian descent. Participants' academic majors varied widely across schools and departments at the university; none were nursing students. All participants reported receiving treatment for ADHD symptoms. Most (n = 12) reported receiving medication as the only treatment, but 3 reported receiving a combination of medication and therapy, and 1 reported receiving therapy only. During the interviews, some of the participants reported they had symptoms of ADHD throughout childhood, but that their official diagnoses of ADHD had come during high school or beyond.

Data Collection

After the authors obtained informed consent and basic demographic information, a semi-structured interview guide was used to direct the discussion. Interview questions included "What strategies were most/least helpful to you in helping you manage ADHD-type behaviors during childhood? Who were the persons who were most/least helpful to you? What did these persons do to help you manage your ADHD-type behaviors?" Follow-up questions were used to clarify meanings. The interviews were held in a private space in a public building to maintain confidentiality. Participants received $20 at the end of the interview. Each participant was interviewed once, for 30 minutes to 1 hour, and audiotaped individual interviews were transcribed verbatim.

Data Analysis

Data were analyzed using the content analysis method described by Patton (1990). First, the authors individually immersed themselves in the data by reading and rereading the transcripts. Notes were made in the margins of the interview texts on questions regarding people who were the most and least helpful, what these people did that was most and least helpful, and what settings were most difficult. The researchers then categorized the data using concepts that came from participants' words. These categories were discussed among the researchers to determine the final categories. This analytical step was meant to verify the categories. The transcripts were then re-read to ensure the categories were complete and representative of the participants' experience.

Findings

Who Were the Helpful People in Their Lives?

Participants said that before being diagnosed with ADHD, they had a sense that something was wrong; they hoped others would recognize their struggles and help them. These feelings were revealed in statements such as "I knew there was something wrong; why am I like this?" and "Can't anyone see I'm struggling?" The sense of struggling with ADHD symptoms was pervasive in the interviews, but the struggle was made easier by people who were available to participants and provided help in a positive way. Helpful people were identified as those who were affirming, accepted participants as they were, and did not focus on their problems but, rather, found creative ways to help them learn and adapt. This was reflected in statements such as

> "They studied with me, and called the stuff out to me, particularly for a test, and them answering the questions helped me. You telling me and me asking the question helps me learn, this was a way of studying I didn't have to feel bad about, because I was asking someone else the questions."

Participants remembered helpful people as "giving me strategies to help me keep my mind focused on something; keep me involved, keep me interested." Individual attention was an important aspect of the help they

received, as reflected in comments like “having the special attention and having the option of one on one time.” For example, “they spent personal time with me.” Helpful people were supportive and patient, they “re-taught things I didn’t understand,” “answered my questions,” “worked with, not against me, ” and “advocated for me. ”

Parents

Most participants (14) identified parents as helpful to them as they struggled with ADHD symptoms during their childhood. Parents who were helpful were those who were firm and supportive, and who provided a structured environment to enhance the child’s productivity. One participant reported that her mother was helpful in the following way: “My mom really, she kept on top of me to make sure I came home from school and had a snack and did my homework, then went out and played with my friends.” Another added, “My dad was really caring...he was really strict, but he was very caring and supportive....”

Active teaching and learning strategies and acting as an advocate were also important parental behaviors noted by participants. One remembered: “Certain types of card games that worked at times ... that took thought, but were very creative and allowed me to keep my mind going.” Another said, “If I had a problem with a teacher, she [mother] was on the phone that afternoon... She went to bat for me many times.”

Teachers

School was by far the most challenging setting for participants as they struggled with their ADHD behaviors. Teachers were the second most commonly identified helpful persons identified by participants (n = 13, with some participants identifying more than one helpful person). Like parents, teachers who were helpful were patient and caring and they used active teaching and learning strategies. One participant described how teachers were helpful: “My teachers in high school were very, very helpful and they understood that I needed extra time. They were willing to stay after school and let me do my stuff. I had a resource teacher also for one of my periods for class and we did study skills — That’s where I learned how to do my note cards.”

Other teacher behaviors that participants identified as helpful included availability, caring behaviors, tough love, patience, willingness to explain things, motivating, and teaching these study participants organization techniques.

Helpful teachers explained concepts carefully and slowly, demonstrating that they cared. One student said, She would sit down with me and be like “This is what you need to work on, this is why.” Willingness to take time with participants was often mentioned and seemed to reflect a special kind of caring. Because children and adolescents with ADHD often have difficulty grasping concepts and assimilating information, teachers’ willingness to spend extra time was especially useful and appreciated by participants.

Helpful teachers were tenacious; they did not retreat or withdraw from participants with ADHD because of their challenging behaviors but were willing to give extra attention, and this extra attention took extra time on the part of the teacher. One participant said, “The special ed teacher in my high school was really helpful because she was always checking up on me... reminding me that I did have all these opportunities available...so she helped out a lot, with just sort of being there and I think just the way she came about it.”

Helpful teachers encouraged their struggling students. They did not wait for the student to have a successful product but gave kudos for efforts expended in the process. One student said, “I remember one day I got really frustrated ‘cause I couldn’t do it and she gave me hug and said, ‘it’s frustrating, but you’re getting it ... and it’s okay.”

Although helpful teachers were identified as nice and friendly, they often took a tough love approach. They set expectations and goals and then set limits for the students to help them achieve their goals. One participant reported that his teachers were: “Very kind, very patient... oddly militant, but not in a bad way. You know, they told me something to do, and they weren’t going to budge on it.”

Teachers who were identified as helpful used active teaching and learning strategies. They changed strategies regularly and were not afraid to abandon a strategy when it did not work for a particular student. Participants perceived learning as fun when active teaching and learning strategies were used. One participant said, "Yeah, she would come and get me and [say], 'Okay, let's try it this way and let's add this and it's still not quite working, so let's put in this thing over here...we would play and it never seemed like work." One participant reported, "Like when we were studying geography and stuff, we'd actually bring clay in and make things. Stuff like that, very hands on so that you could be interested in something that was boring."

Patience was extremely important to these students' learning. The college-aged students recognized their challenging childhood behaviors and knew that they were taxing for others, and they valued the teachers who had persevered with them: "Patience ... I required a lot of patience."

Finally, helpful teachers manifested good behaviors themselves, role modeling them and setting the expectation that their students would also possess these. One participant said, "My 5th grade teacher ... was very organized and she made us be organized too.... We walked through the whole thing...Her teaching me those organization skills was fantastic."

What Characteristics Did Helpful Others Exhibit?

Although study participants most often identified parents and teachers as the persons who had been helpful to them, they also spoke of siblings and extended family members (e.g., grandparents and a cousin), a coach, counselor/psychologist, and a boyfriend. Characteristics of these individuals included being (1) caring, (2) firm, (3) understanding, (4) supportive, (5) patient, (6) a good listener, (7) compassionate, (8) kind and positive with feedback during interactions, (9) accepting of them as persons, and (10) in tune with their struggles. One participant described how her school counselor was helpful. The counselor helped her recognize "I'm not on anyone's given time schedule because I can get caught up with trying to do too much with my ADHD than I can handle."

Although some participants referred to a traditional view of caring by others, others recognized that they were not the easiest children to manage, and they reported that they had valued and responded to a tough but caring approach. "A lot of teachers cared about me as an individual. I wasn't the easiest kid ... Teachers who helped me always cared about me and they always told my parents what was going on and if I was screwing up." One participant described a person [teacher] who used kind firmness, saying, "You know, she pushed me like a coach. Insisted I make good grades and (said), 'you can do it' and 'Yeah, when it comes time for homework, it's time for homework!'" Overpermissiveness was not helpful. In looking back over their lives and the struggles they had faced, they said they valued a kind but firm approach to help them achieve their goals.

Persons who were firm but not dogmatic and inflexible were helpful. One participant said, "They [teachers] were understanding. If I needed more time, they gave me extra time on tests and stuff." Another participant described how teachers could be understanding, saying, "All in all - teach, but don't make them [children] feel bad about it. Because it's so easy for ADHD children to feel bad about themselves and who they are."

Being supportive was another important characteristic. Participants did not expect parents or others to ameliorate their ADHD symptoms, but they expected and appreciated listening and support. Support, patience, and active listening were described as helpful. For example, "To listen ... That would be the number one thing to have, patience... Like I know I talk around the bush and it sometimes takes me a little bit longer to get to the actual point." Another participant said, "Listening, I think the listening to me and not just saying, 'she's lazy or doesn't care about her score,' cause I do care...." It was important to these participants that they not be negatively labeled and that their ADHD-type behaviors not be interpreted as character flaws.

Participants identified compassion as another important characteristic. One participant said, "When I say compassionate, I mean compassionate about embracing a different type of life, a different type of mindset and having an open mind to the fact that I don't think like they think." Another reported that her teacher could "see

who I am on the inside and what I care about, that I do want to do well and reach my potential." One participant said of a teacher: "He knew that I was struggling and the fact that he knew... kind of stood out to me."

What About Characteristics of Unhelpful People?

Participants described an almost daily struggle with their ADHD symptoms, and some behaviors of others that did not help their struggle, or worse, intensified the struggle and contributed to their feeling that they were alone in their battle with their ADHD symptoms. Participants reported a profound sense of aloneness when others failed to notice or take action to help them. One said, "They made me feel alone." Participants reported that they understood that something was wrong with them, but they did not understand what, and they needed a knowledgeable and compassionate person to help them. They did not always receive the help they sought. The lack of awareness or action on the part of adults was reflected in statements like "They should have known" and "They didn't understand." Some adults either were completely unaware of the struggles of these children or ignored them. One participant reported, "They would get mad at me" and "They disregarded my feelings" and "They told my mother I was a problem child, that I was stupid." One participant remembered thinking, "Can't anyone see I'm struggling?"

Coach/Teachers

Specific groups of adults were identified by participants as sometimes behaving in unhelpful ways. More than one student identified a sports coach as a person who contributed to feelings that others did not understand her. One participant said that through his remarks, a coach implied to the student that she had complete control over her symptoms. The coach got upset and snapped, "Did you not pay attention!?" Hurtful comments by teachers and others were vividly remembered by participants. One participant relayed an experience that had happened many years earlier: "The teacher spanked me for misbehaving; she said I was stupid."

Some participants thought that teachers should have recognized their ADHD symptoms earlier. Others made comments that reflected teachers' lack of knowledge about the nature and symptoms of the disorder, like "They should have helped me or cared." Participants believed that some teachers did not care about them and disregarded their feelings: "They yelled," "scolded," "got frustrated" and made "strangulation gestures," or they "did not adapt to my needs." Often participants believed that they were doing the best they could, and they were frustrated when no positive reinforcement was given.

Parents

In some cases behaviors of parents were identified as being unhelpful to these study participants as they struggled with their ADHD symptoms. More than one participant reported that their parent did not recognize that a problem existed. For example, one participant reported that her parent discounted her troubling symptoms "...the classic-just get over it. And my mom thought my behaviors were just a part of being a child."

A number of behaviors were identified by our study participants as being unhelpful to them as they navigated the challenges of having ADHD. Certainly having symptoms ignored or relegated to something that would be outgrown was a commonly reported unhelpful behavior. Participants found it unhelpful when others would get mad at them secondary to their ADHD-type behaviors. Others talked about how unhelpful it was when their special needs were not addressed. Several participants verbalized the recognition that they often needed extra time to get things done, extra explanations to understand something, and often extra help. They reported that these extras were often requisite to their mastery of something. "Don't assume that the child can do anything, generally there are a lot of assumptions made that the child at 6 or 7 years old can so this or do that. Someone with ADHD, you've got to get in and do it step by step by step. And you've got to teach them to slow down and spend time with them." Another reported "Like if I don't understand something and when I ask them for some help they don't want to explain it to me anymore. They will expect you to get it right the first time."

Participants reported that at times they were "yelled at" and this was perceived as particularly unhelpful. Another challenging behavior exhibited by others was ridicule. Persons with ADHD feel bad enough about their behaviors, and when others laughed at them, this increased their own bad feelings.

Clinical Implications

Nurses can use the information in this study to approach pediatric and adolescent patients with ADHD in a different way. Because these college-aged students explained that caring, active teaching/learning strategies were the most useful behaviors for them, nurses should adopt these approaches when teaching children about their health. Hughes (2007b) suggests that when persons working with children with ADHD do not view ADHD as a biopsychosocial problem, their approaches to these children can be harmful. The behaviors our participants reported as helpful were being firm but kind; this reflected empathy with the child's struggle. These behaviors are the antithesis of blaming the child for problems, and thus are consistent with a biopsychosocial view of ADHD.

Collett and Gimpel (2004) found that children with ADHD tended to have a negative attributional style; that is, these children tended not to attribute positive events in their lives to their own behaviors. The behaviors and characteristics that participants in our study identified as most helpful tended to be positive types of parenting and communicating. If nurses can help parents to understand these issues, they may be influential in helping children with ADHD to overcome their tendency toward a negative attributional style. More research in this area is needed, however.

Limitations of this study include the small sample size and the preponderance of female participants in our sample. The study participants was recruited from a university disability services office, which likely meant that they were receiving services. The experience of college students receiving services might be different from college students who are not receiving services. Moreover, young adults who are in college may be different from young adults who are not in college.

Future research is needed with samples of young adults who are not receiving disability services, young adults who are not in college, young men, young adults who are from minority populations, and those suffering from comorbid chronic health conditions. Boys are diagnosed with ADHD at more than twice the rate of girls, and those whose health is fair or poor have more than twice the likelihood of being diagnosed with ADHD as those in good health (CDC, 2009).

Timely identification and intervention for these children should be stressed to teachers and parents so that they can provide or help access needed support (Dang, Warrington, Tung, Baker, & Pan, 2007). Failure to identify and provide appropriate early interventions can result in undesirable outcomes, including future psychopathology (Greenhill, Posner, Vaughan, & Kratochvil, 2008). Two interventions that have been identifi ed as effective for children with this disorder include parent training to help parents learn to manage their child and classroom interventions that teachers can implement (Pelham, Wheeler, & Chronis, 1998). Among these strategies include things such as token economies and the use of time out (Pelham et al.). Nurses can help with early identification of children with ADHD by encouraging parents of children with symptoms suspect of an ADHD diagnosis to access a multi-method, multidisciplinary assessment by experts in this complex disorder. Nurses can also help parents respond better to children with this diagnosis by helping parents understand that using positive parenting techniques, by being a strong advocate for his or her child and helping the child access needed resources, and by using active teaching/learning strategies with their child can help a child have improved outcomes. School nurses can help teachers understand the biopsychosocial nature of ADHD, the importance of early intervention, and the importance of using active teaching/learning strategies with these children. These nursing interventions with parents and teachers can increase the potential for positive results in a child's home life, school performance and behavior, and success in the community.

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