I Have Always Felt Different: The Experience of Attention-Deficit/Hyperactivity Disorder in Childhood

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Childhood attention-deficit/hyperactivity disorder (ADHD) is one of the most important psychiatric problems of our time. This study examined the experience of childhood ADHD within the contexts that are most significant to this age group—home, school, and friendships. The sample included 16 college-enrolled young adults (ages 18–25) with a self-reported history of ADHD. Participants revealed feelings of difference, misunderstanding, and struggle in all areas of their lives (home, school, and friendships). Nurses can use these findings to improve the care and long-term outcomes of children diagnosed with ADHD.

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Attention-deficit/hyperactivity disorder (ADHD) is a behavior disorder characterized by a “persistent pattern of inattention and/or hyperactivity—impulsivity that is more frequently displayed and more severe than is typically observed in individuals at a comparable level of development” (American Psychiatric Association, 2000, p. 85). According to the Centers for Disease Control and Prevention (CDC) (2005), in 2003, nearly 8% of school-aged children were reported to have ADHD; it affects 50% of patients treated at child and adolescent psychiatric clinics, making it one of the most important psychiatric disorders of our time (Department of Health and Human Services, CDC, 2005).

There is an abundance of literature on the epidemiology, etiology, and clinical management of ADHD, but far less has been written on psychosocial interventions to help children and families struggling with ADHD (Pelham, Wheeler, & Chronis, 1998; Szatmari, 1992; Weisz & Hawley, 1998), and even less is known about individuals’ experience of ADHD. The little research that has been done on the ADHD experience was conducted with children and adolescents (Bitar, 2004; Kendall, Hatton, Beckett, & Leo, 2003; Krueger & Kendall, 2001). However, Jones and Foreland (2003) have suggested that children may be poor interpreters of their experiences of ADHD. Rabiner (n.d.) noted that adults could accurately describe their ADHD symptoms during childhood. However, although few studies have explored adults with ADHD (Cottrell & Langzettel, 2005) or parents’ experiences of having a child with ADHD (Perry, Hatton, & Kendall, 2005), no published studies that examined ADHD from the perspective of young adults who had the disorder as children and adolescents have been found (Children and Adults with Attention Deficit/Hyperactivity Disorder [CHADD], 2006).

This article reports findings from a phenomenological study of childhood ADHD as recalled by college-enrolled young adults. The study was part of a larger study designed to identify the strategies and individuals young adults remembered as
most helpful to them in managing their ADHD during childhood.

METHODS

Setting and Sample

Participants were recruited from an office of disability services in a southeastern university. The researchers met with the disability services staff to explain the study and seek permission to recruit participants. The disability services staff agreed to assist the researchers by explaining the study to students who met the study criteria. After students were told about the study by the disability services staff, those who were interested in participating signed an interest list. The investigators regularly checked the list and contacted interested students via telephone. Before their inclusion in the study, potential participants were screened for ADHD by one of the investigators, who asked callers if they had been diagnosed with ADHD by a health care professional. The study was approved by the university’s institutional review board, and written informed consent was obtained from all participants. Individuals were compensated US $20 to participate. Names and references to places have been changed in this report to protect participants’ identities.

The sample included 16 college-enrolled young adults (ages 18–25) with a self-reported history of ADHD. Three participants were male, and 13 were female. Of the 16 students, 2 were non-Hispanic Black, 1 was of Asian-Indian descent, 1 was Hispanic, and the remainder were non-Hispanic Whites. Five participants reported being diagnosed by a psychiatrist, 8 by a psychologist, and 2 by a primary care physician; 1 could not recall who made the diagnosis. All participants reported receiving treatment for ADHD; 12 received medication only, 1 received therapy only, and 3 received both medication and therapy. Thirteen participants lived with both parents; 2 lived with parents who had divorced or remarried, and 1 did not specify.

Data Collection

The study used an existential phenomenological approach in the tradition of Husserl (1913/1931) and Merleau-Ponty (1962), as described by Thomas and Pollio (2002). According to Pollio, Henley, and Thompson (1997), to illuminate human experience, the researcher must seek a “rigorous description of human life as it is lived and reflected upon in all of its first-person concreteness, urgency, and ambiguity. For existential phenomenology, the world is to be lived and described, not explained” (p. 5). To obtain a rich description of the lived experience, a dialogue must occur, where

one member of the dialogic pair, normally called the investigator, assumes a respectful position vis-à-vis the real expert, the subject, or more appropriately, the coresearcher. In this way, the path toward understanding emerges from the common respect and concern of two people committed to exploring the life world of one of them (Pollio et al., 1997, p. 29).

In this study, phenomenological interviews were used to obtain descriptions of the lived experience of childhood ADHD in the contexts of home, school, and friendships—contexts that are important to the full understanding of childhood ADHD (Barkley, 1990; Krueger & Kendall, 2001; Leung, Robson, Fagan, & Lim, 1994).

The nondirective individual interviews were conducted by two of the coinvestigators; one was a doctorally prepared, experienced qualitative researcher and a board-certified psychiatric and mental health nurse; the other was a master’s-prepared, trained research assistant and second-degree nursing student (with baccalaureate and master’s degrees in health sciences). Interview training for the research assistant consisted of didactic material, observation of two interviews conducted by an experienced researcher, and critique and discussion after some of the research assistant’s interviews. Both interviewers were Caucasian women—one was middle-aged and the other one was slightly younger.

Consistent with the procedure outlined by Thomas and Pollio (2002), the opening interview questions were crafted as broadly as possible: “Tell me a story about having ADHD at home,” “Tell me a story about having ADHD at school,” and “Tell me a story about having ADHD when interacting with friends.” Follow-up probes such as “Tell me more about that” were used to clarify descriptions. Interviews were neither highly structured nor standardized. The interviews were conducted between October 2005 and February 2006 and were audio taped and transcribed verbatim. They took place in private rooms in the campus library to assure participant confidentiality. Interview length had an average of 1 hour.

Data Analysis

Data were analyzed using the method described by Thomas and Pollio (2002). The researchers analyzed each transcript for meaning units.
In existential phenomenological methodology, the “criterion for validity becomes whether a reader... would be able to see textual evidence supporting the interpretation, and whether the goal of providing a first-person understanding was attained” (Pollio et al., 1997, p. 53). In the final research report or article, the researchers must provide for the reader enough verbatim data (participants’ words) to support the interpretation. In other words, “validity is not determined by the degree of correspondence between the description and reality but by whether convincing evidence has been marshaled in favor of the aptness of the description” (Pollio et al., 1997, p. 53).

Evidential support, according to Pollio et al. (1997), includes examination of methodological and experiential concerns. Methodological concerns include rigor and appropriateness. These concerns were attended to through adherence to the research method and plan, use of an interpretive research group, and a documented data analysis audit trail. Experiential concerns include plausibility and illumination. Plausibility is the degree to which the evidence presented is convincing and credible. Illumination addresses the following question, “does the interpretation provide insight to the reader or evaluator?” (Pollio et al., 1997).

**FINDINGS**

According to existential phenomenology, every experience has a figure that stands out and a ground that is the context of the experience. In this study, the ground of the experience of ADHD was loneliness and isolation. As noted by one participant, “Can’t anyone see I’m struggling?” Against the backdrop of this struggle, the figural theme of the experience of ADHD at home was “dealing with getting along (with my parents)”; the figural themes of the experience of ADHD at school were “I missed a lot of stuff,” “I was different,” and “I learned to manage”; the figural themes in the experience of ADHD in friendships were “I was different” and “I was misunderstood.”

**Home**

Participants’ experience of having ADHD within the context of home was expressed in the theme “dealing with getting along (with my parents).”

**Dealing With Getting Along (With My Parents)**

Getting along with parents was central to these young adults’ childhood experiences of ADHD. In their view, children with ADHD have more trouble than others. One participant noted: “It is also coming of age, every kid goes through this, and getting to know yourself and not being afraid of who you are... so, it’s rough on anyone, but it tends to be a little rougher on people with special needs.” In describing the impact of their ADHD on family life, participants recalled individual frustration, verbal arguments with parents and siblings, and, in the words of one participant, “mass chaos fights.”

Fighting with parents was often caused by the failure of the child or the adolescent to perform chores within the expected time frame. Because of their distractibility and hyperactivity, participants said that they had difficulty completing tasks, causing problems with their parents. Parents’ encouragement to do various household chores (such as laundry, vacuuming, and “keeping my room clean”) often resulted in verbal altercations. One participant recalled,

> Doing chores and stuff at home, I always had a problem getting things done. I never really finished anything. I always started things and then I’d go off and watch TV. I got distracted very easily doing chores. I don’t know if it was voluntary distraction... but we definitely fought a lot about getting chores done.

Another participant said,

> I like to read the newspaper at home on the weekends with my mom there. Sometimes I get so focused on the newspaper or what I’m doing that I don’t want to do what my parents have asked me to do, like the vacuuming or the laundry. ’Cause they want it to be done, they expect it to be done and if I haven’t done it, then I have a problem... Doing things for my parents and being aware of what needs to be done around the house, that’s the only times it really gets to me or hurts me.
Other participants perceived misunderstanding and lack of patience from their parents. One recalled,

Quit nagging me, quit bugging me. And it would be just, “Clean your room, can you please pick up this, can you get your laundry out of the dryer, we’ve got to leave in 30 minutes, are you getting ready, come on, come on, get out of bed.” And I would just be like, “Leave me alone!”

Another participant said, “I tend to be hyperactive. I had trouble having a relationship with my mom. Dealing with getting along with them. That was a major thing... now it’s getting a little better.” Again, “It was hard ‘cause sometimes my parents and I would struggle. We’d have arguments.”

Although participants had trouble getting along with their parents, many perceived their parents as supportive. Participants also had a degree of sympathy or understanding for how their behavior affected their parents. For example, one said, “I’m forgetful. And she’d get home from a hard day at work and I’d bug the crap out of her. She’d tell me to do something and I’d forget it.”

The support participants experienced from parents helped balance some of the negative effects of ADHD, such as poor academic performance and low self-esteem. As one participant recalled,

My dad just loves me. I can remember every Sunday morning getting ready for church. I would walk in his room, this was when I was little, and he would whistle at me... so, like, maybe helping me with the school stuff wasn’t his thing, but he made me feel like the most beautiful girl in the world, and for someone with ADHD, that’s huge because your self-concept is a lot of times deflated due to your academic success and not understanding some other things. That was huge.

Another participant described crying with her mother after she shared how ADHD affected her:

Mom was really supportive... I remember just breaking down and crying. She was on the floor, cleaning the bathroom floor on her hands and knees. And she was like, “Kerri, I did not know any of this. I’m so sorry.” And, she just held me and I just cried and cried. And she said, “You are not different. You are beautiful and sweet.” And she went about affirming me and who I really am. [She said] “I’m so sorry, I had no idea you felt like that.” I mean, it didn’t take away the problem, but it affirmed me, that she cared... No matter how much I went to school and felt like... nobody liked me or nobody this or that, when I went home, I knew it wasn’t fake. And it was a good place. There, I was loved; I fit in and I was fine.

Participants also described mothers who made sure that they did their homework and who provided consequences if they did not do so.

Persistent, supportive parents were conveyed by this participant:

My parents did provide support... with homework; making sure I was on top of things. It kind of got to the point where it was nagging, but that’s how they got the actual answer from me. They had to play 20 questions. I wasn’t trying to withhold information; it just took 20 questions to get the full description. You couldn’t ask, “what do you have for homework?” It was like, “do you have any homework?” “Yes.” “What is it?” “Math.” “What’s it on?” “This stuff.” “Do you have English homework?” “Yes.”... They had to go through a much larger spectrum of questions just to get the answer to, “Do you have any homework?” Otherwise they wouldn’t know what it was that needed to be done. And they wouldn’t know whether or not I was done so “you can go watch TV,” or “you can go play.” That was incredibly helpful.

Mothers made special accommodations and helped participants by using strategies such as flash cards, colored film through which to read, books on tape, cognitive games, and motivational tools; they helped participants organize and prioritize their time, and they proofread papers, reviewed math problems, and assisted with reading. As participants got older, mothers provided less direction to get them accustomed to being a little more self-directed.

School

Participants’ experiences of having ADHD within the context of school was expressed in three figural themes: “I was different,” “I missed a lot of stuff,” and “I learned how to manage.”

I Was Different

Children with ADHD felt different from others in school. School taxed their fragile self-esteem by providing numerous situations that proved to them they were different: School was a place where they were expected to sit still, pay attention, and grasp concepts quickly, all of which were difficult for them. They realized even as young children (some talked about experiences as early as first grade) that they did not learn as easily as “regular” or “normal” kids do. Once participants were diagnosed with ADHD and began treatment, other differences became apparent. Although treatment may have improved their ability to focus in a classroom, the knowledge of having a disorder was further stigmatizing.

Participants were reluctant to share their ADHD diagnosis with friends at school because as one participant said, “Kids are mean.” Other kids at school would call them retarded, slow, or stupid,
and then ostracize them. Participants did not want to be singled out by special education or resource teachers and preferred these support persons to be discrete. One participant told about a time when her name was announced over the school’s intercom system to “report to the special ed office.” Another participant told about a coach who called him stupid because he could not understand the instructions the first time they were given.

When teachers took extra time to help participants with their schoolwork, participants felt more a part of school and less different. Participants said that those teachers who spent extra time and really cared about them decreased their feelings of difference and isolation, and many times, this led to improved academic performance. This was conveyed in the following participant’s recollection: “In third grade, it was absolutely wonderful... the teacher, she took time for me—no one had really done that before. So I would do anything I possibly could because she showed [me] that ‘you’re important, you matter.’”

I Missed a Lot of Stuff

The experience of ADHD in school was dominated by distractibility and hyperactivity that affected participants’ ability to learn. Participants reported “missing a lot of stuff” in school due to their ADHD. They had trouble listening, paying attention, completing homework, and staying on task; they were forgetful, had trouble standing still, and could not focus; they daydreamed—staring blankly into space. Deepening their difficulties in school, many participants had comorbid learning disabilities. As one participant said, recalling the fourth grade, “In class, I had a kind of lag time, ‘cause in-between me figuring out what had been going on, the entire class moved on, so I missed out on information. So that was one of the biggest things—missing out—taking a longer time to get the entire idea.” Even after treatment began, participants described ongoing challenges, albeit less severe.

I Learned How to Manage

Not surprisingly, these children and adolescents with ADHD who described their struggles through school learned how to manage their illness and behaviors, especially once they had a name or reason for their behavior. They adapted, used resources, and allowed parents to assist and advocate when needed. Participants understood that they needed more time for tests, they needed to be in a quiet area away from other students, or they needed to take tests using a computer rather than take handwritten tests. They learned that rewriting notes at home after the end of the school day was helpful; they taped or digitally recorded lectures to put on their iPods so that they could listen to lectures repeatedly.

Friendships

The experience of ADHD within the context of friendships was expressed in two figural themes: “I was different,” and “I was misunderstood.”

I Was Different

ADHD during childhood had profound effects on participants’ friendships. They felt different and, because of this, believed that they could not make friends. For example, one recalled,

I didn’t have that many friends...I was outcast and I had low self-esteem. I dropped out of my eighth grade for a year and a half “cause I was so unhappy there. I think it was more of a self-esteem issue and the respect. It may have had something to do with the ADHD, them finding out... people looked at me differently, like, oh, she has a disability, oh, she’s stupid, she’s retarded. I mean... I just don’t get things as easily as others. And I don’t think they understood that.

Having difficulty making friends resulted in disconnection from others in the social world. As recalled by one participant,

ADHD affects me in the area of speech, and sometimes I talk gibberish. I had a lot of people make fun of me. Most of the children around me, they always stayed away, as if there was something wrong. I always thought there was something wrong with me because no one really wanted to be my friend or to play with me.

Even participants who had friends experienced interpersonal difficulties with them. ADHD symptoms such as distractibility, difficulty focusing, and hyperactivity had an impact on their communication. For example, one said, “Interacting with friends is a very complex area for me... the greatest problem I have is communicating with them.” Another participant said,

Not only do I have a tendency to interrupt... but the main problem I have is, you need to think before you say something that can offend other people, or when you ask too many questions...they’ll say it makes them feel uncomfortable.

Another participant described the effect her distractibility had on her interactions with friends: “I’ve been told that when talking with a whole bunch of people, I’m thinking of
something else and not paying attention... I’m usually hearing what they are saying but not responding,” and,

Sometimes we’d be talking about something and then I’d start tuning them out and start thinking about whatever I’d be thinking about and then they’d ask me a question about it and then get mad at me ‘cause I didn’t know what they were talking about and stuff. In middle school and high school it affected me emotionally. I was affected by it—why don’t people like me? Why are you getting mad at me? And stuff like that.

Some participants described themselves as shy or loners, preferring not to be around a lot of people: “Sometimes I didn’t want to interact with people ’cause talking about the books they read or something like that, things that they did that I didn’t participate in; I didn’t want to deal with the frustration. I kind of felt a little left out at times.”

I Was Misunderstood

Friendships for children and adolescents with ADHD were fraught with misunderstandings. As noted by one participant, “I don’t think they understand. Getting things is hard for me.” Another said, “It was hard for them at first to understand and of course I had to explain it to them.” One participant described a lack of understanding and compassion by her friends, who made jokes about having ADHD when they did not want to complete a task, although they knew the participant had ADHD. In the words of this participant: “I have friends who say, ‘Oh, it’s my ADD and I don’t want to do my work. It’s my ADD kicking in.’… and they’ll say it in front of me when they know I have it…and I’ll have it the rest of my life. I’ve gotten very mad at them…I’ve told them that ‘If you say that again, I’ll go off on you.’ It’s not fair to me.” Other participants told of friends who were more blatant in their teasing, but one noted, “My friends tease me about it, but in a joking way.”

Advice was offered by participants about ways to handle friends who misunderstood them. For example, “Don’t get discouraged when people get mad at you ’cause they don’t understand. ’Cause usually if you don’t get upset about it, you’ll feel a little better and you’d get through it a little better.” Another participant made a suggestion about friends and schoolwork: “Get a friend who understands, who can call out your name, or tap you or something, to get you to focus when you’re zoned out.”

DISCUSSION

These participants with ADHD recalled a childhood and adolescence shaped by feelings of difference, isolation, and misunderstanding. The parent–adolescent conflicts we found differed from the relationships observed in a study of hyperactive adolescent girls (Young, Chadwick, Heptinstall, Taylor, & Sonuga-Barke, 2005); in that study, parent–adolescent relationships were normal and functional. The differences, however, could be explained by the sample and design: Young et al. (2005) sampled adolescents, and we sampled young adults and asked them to look back upon their childhood and describe their home life. As adolescents become young adults, their perceptions of their relationships with parents may become more accurate, a supposition supported by Jones and Foreland (2003), Rabiner (n.d.), and Young et al. (2005), who hypothesized that “Teenagers may not be aware of the impact of their behaviour on parents” (p. 251).

Completing household tasks was most often the cause of conflict in our study, a finding consistent with Noller and Callan (1991) and Tessor, Forehand, Bordy, and Long (1989). We did not find conflict in areas such as power and sexuality (Grovetant & Cooper, 1986); possessions, time, status, and emotional support (Schenk & Schenk, 1978); or social activities (Riesch, Jackson, & Chanchong, 2003). The positive impacts of parental support on the self-esteem, well-being, and mental health of children and adolescents seen in our study are consistent with the findings of Armstrong, Hill, and Secker (2000), Parker and Benson (2004), and van Wel, ter Bogt, and Raaijmakers (2002).

The problems with friendships reported here may help elucidate previous studies that found that adolescents with ADHD had difficulties with peer relationships and low self-esteem (Barber, Grubbs, & Cottrell, 2005; Heptinstall & Taylor, 2002; Young et al., 2005). Our qualitative findings at least partially explain why children and adolescents with ADHD had these problems and how they coped with them. They felt different and misunderstood often responded by avoiding social situations, which resulted in having few friends. The interpersonal difficulties may not be due to a lack of knowledge of social rules as earlier studies suggested (Grenell, Glass, & Katz, 1987; Landau & Milich, 1988; Whalen & Henker, 1992). Rather, our findings suggest that children and adolescents were aware of the rules of social interaction; they just had difficulty following them.
NURSING IMPLICATIONS

Our sample was composed of college-enrolled volunteers, primarily non-Hispanic White women, and thus, the findings from the study must be considered preliminary. Another limitation of the study was that the researchers were all White women. In addition, because the young adults in the study were enrolled in college and thus had attained some measure of success in their lives, at least academically, they may not be representative of the “typical” person with ADHD. Furthermore, because the sample was obtained from an office of disability services, our participants were probably receiving services and could have had different childhood experiences from college-enrolled students with ADHD who do not receive these services. In addition, all of the young adults in our study had received treatment for their ADHD during childhood, the most common of which was via medications. A more rigorously designed study would be useful for understanding various aspects of individuals with ADHD so that appropriate recommendations can be made to those parenting or working with the children, based on specific individuals’ needs.

Nevertheless, our findings have implications for pediatric nurses and school nurses. As this study shows, the world of children with ADHD is not an easy one. It is filled with struggle—a struggle wherein they want potentially helpful others (teachers, parents, and health care professionals) to acknowledge, understand, and then do something about. Parents need encouragement and support to seek assessment services for their child if symptoms warrant. Nurses can help parents who report that their child has ADHD-type symptoms get an appropriate evaluation for the child. A multifunctional and multi-informant assessment is important for diagnosing ADHD in children (Crystal, Ostrander, Chen, & August, 2001; Stevens, 2005; Vlam, 2006). Examining symptoms from a developmental perspective is also important. With early diagnosis of ADHD and proper education of parents, children, and school personnel, appropriate interventions can help them cope with behaviors associated with the disorder and lead to improved outcomes for children with ADHD.

In addition, nurses can help parents recognize that seeking help to learn to appropriately parent a child with ADHD in no way indicates weakness or lack of success as a parent and will ultimately help both children with ADHD and their parents. Because they are trusted by the public, nurses are in a unique position to support parents and direct them to available services for them and their child with ADHD.

Because some behaviors exhibited by children with ADHD seem willful and deliberately disobedient, helping parents and school personnel learn about the symptoms that constitute ADHD and ways to manage these symptoms is another important intervention. Those with ADHD need adult caregivers and teachers who are knowledgeable and understanding and who will be helpful to them. With their access to children and families, their knowledge, and the confidence in them, nurses can be vital to families struggling with this disorder.

A strong theme throughout these interviews was the value of being understood and supported. Helping persons who have ADHD to access needed support is an important intervention for these children. Academic settings challenge children and adolescents with ADHD because of their hyperactivity, impulsivity, and distractibility. These symptoms also make it difficult for children and adolescents with ADHD to make friends and to maintain friendships, thus limiting their social support. Social support from peers and parents has been found to correlate with academic success (Domagała-Zyśk, 2006); thus, future research should test interventions aimed at increasing parental and peer support of children and adolescents with ADHD. Another theme was the wish not to be singled out and publicly identified as diagnosed with a disorder; nevertheless, to best help these children, pediatric and school nurses need to advocate for and identify creative strategies so that these children can become connected to a supportive peer group and supportive teachers.

Nurses can provide education about ADHD not only for parents and teachers but also for all children. Schools are filled with children with all kinds of differences—difficulties in learning, attention, able-bodiedness, hearing, and sight, to name but a few. The participants in our study noted the challenges they faced in environments where there was a lack of understanding of their disorder. Increasing knowledge and understanding of the differences among schoolchildren could lead to increased empathy and less teasing of those with differences. The long-term impact of this greater understanding could be positive not only for those with differences but also for society as a whole.

A useful resource to those affected by ADHD is the organization CHADD (n.d.). A national organization with local chapters, CHADD provides...
support and education for members, and it works to influence national and state policies with the goal of improving the lives of those affected by ADHD. CHADD’s web site offers a wealth of information for persons with ADHD, teachers, parents, and health care professionals. CHADD’s National Resource Center on ADHD is a clearinghouse for current evidence about ADHD. Government web sites provide links to the clearinghouse and receive funding from the CDC, providing credibility for the information it provides. The clearinghouse can be accessed at http://www.help4adhd.org/.

CDC (2005) offers those accessing its web site information about the symptoms of ADHD and how it affects various areas of a person’s life. It also provides links to other useful resources. Another federal agency that provides useful information about ADHD is the National Institute of Mental Health (NIMH) (2006). In addition to descriptions about ADHD, NIMH provides treatment information, including some behavioral interventions that children, parents, and teachers may find useful, for example, the use of schedules for persons with this disorder.

Finally, many communities offer support groups for parents of children with ADHD. Directing parents to these resources can help link them with others facing similar struggles and offer them an outlet for sharing their trials and frustrations while also providing them with strategies that may prove useful for them and their child.

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