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“If he doesn’t buy in, it’s a waste of time”: Perspectives from diverse parents and adolescents on engaging children in ADHD treatment

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Abstract

Engaging children and adolescents in ADHD care is critical for future independent disease management. However, there is a lack of evidence guiding health professionals and parents on how best to engage their children and adolescents in ADHD care. We recruited 41 diverse parents of children and adolescents with ADHD and 11 adolescents with ADHD from an urban, safety-net hospital to participate in in-depth, semi-structured qualitative interviews and then analyzed this data using thematic analysis. Children’s level of illness insight about ADHD and self-esteem emerged as two major contributors to engagement of children and adolescents in ADHD care, and their intersection created four styles of engagement: proactive (high insight, high self-esteem), anxious (high insight, low self-esteem), apathetic (low insight, high self-esteem), and resistant (low insight, low self-esteem). This framework can help health professionals engage children and adolescents in care for ADHD and guide development of interventions to improve engagement in care.

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Declarations

Conflict of interest The authors have no competing interests as defined by Springer, or other interests that might be perceived to influence the results and/or discussion reported in this paper.

Keywords

ADHD; Engagement in care; Qualitative research; Self-esteem; Illness insight

Introduction

In the United States, roughly 9.4% (6.1 million) children and adolescents have ever received a diagnosis of attention-deficit/hyperactivity disorder (ADHD) (Danielson et al., 2018). In most cases, ADHD is chronic, and children with ADHD will experience symptoms and related impairments (e.g., educational, occupational, health, social, and relationship difficulties) throughout their life (Faraone et al., 2015; Nigg, 2013). Effective treatments exist for ADHD that can improve symptoms and outcomes throughout the lifespan (Enns et al., 2017). However, maintaining ADHD treatment continuity and symptom self-management into adulthood depends on engaging children and adolescents in their own ADHD care and preparing them for the transition to independence and treatment autonomy (Swift et al., 2013; Walker-Noack et al., 2013).

While treatment continuity includes the health systems-centered concepts of treatment access, adherence, and retention (O'Donohue et al., 2017), patient engagement extends further to include patient-centered components of activation, empowerment, and disease self-management (McWilliam, 2009). In a concept analysis of 96 studies, Higgins, Larson, and Schnall (2017) define engagement in care as, “the desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a healthcare provider or institution, for the purposes of maximizing outcomes or improving experiences of care” (p. 30). They describe a willingness to participate in care - i.e., treatment “buy-in” - which provides the basis for engagement, empowerment, and activation, and may be most important as a focus for children and adolescents (Alegría et al., 2014; Barnert et al., 2020; Gopalan et al., 2010; Thomas et al., 2017). While caregivers control if, how, and when a child accesses treatment, the child's buy-in to care lays the foundation for future independent decision-making related to their own care.

However, there is very little evidence to guide our understanding of how to assess and improve child and adolescent buy-in and active engagement in ADHD care. There is also very little known about parents' perspectives on when, why, and how they choose to engage their children and adolescents in ADHD treatment. Recent research on adolescents with ADHD and their families has identified a lack of adolescent “desire” for treatment as the most common barrier to engaging in behavioral therapy (Sibley et al., 2022). Additional barriers include the perception that treatment is not useful, that providers are not supportive or trustworthy, and that health decisions are not within adolescents' power to make (Barnert et al., 2020; Gopalan et al., 2010). In order to thoroughly prepare children and adolescents with ADHD for the future, we must gain a better understanding of how to improve their motivation to engage in ADHD treatment.

In this study, we present styles of child and adolescent engagement in ADHD care based on perspectives from parents of children and adolescents with ADHD, subsequently triangulated (i.e., validated) with perspectives from adolescents with ADHD (Carter et al.,

2014). Our findings emerged unexpectedly during the analysis of qualitative data originally collected from parents on their experiences engaging their children and adolescents in ADHD care (Spencer et al., 2021). To expand upon parent findings, we conducted interviews with adolescents whose parents had participated in the study to better understand their perspective and triangulate the themes present in parent data. Our goal is to generate ideas for interventions that could improve the engagement of children and adolescents in their own ADHD treatment.

Methods

Study Setting and Participants

We recruited parents of children aged 3–17 years old with a diagnosis of ADHD from clinical practices at Boston Medical Center (BMC) between June 2018 and October 2019. Adolescents with ADHD aged 13–17 years old whose parent participated in the study were also invited to participate. Potential participants were not eligible if the child with ADHD had a comorbid diagnosis of autism, psychotic disorder, or intellectual disability. Parents with more than one child meeting eligibility criteria were instructed to choose one child whose treatment journey they would primarily discuss and whose demographic information would be collected. A “parent” in this study refers to the primary caregiver and legal guardian of any child regardless of relation. BMC is the largest safety-net hospital in New England and serves largely low-income and racial and ethnic minoritized individuals, thus ensuring that our sample represents families from diverse cultural backgrounds. Participants were recruited from various pediatric treatment settings throughout the hospital, screened for eligibility, and then scheduled for in-person study visits.

Data Collection Procedures

This study was approved by the Boston University Medical Campus Institutional Review Board. Research staff obtained written informed consent from parents and written informed assent from adolescents. Participants engaged in one 45 to 60-minute semi-structured interview and then completed questionnaires to collect information on sociodemographics, symptoms, and treatment utilization. Interviews were conducted by trained research staff fluent in the participant’s preferred language (English, Spanish, Haitian Creole), and questionnaires were provided in the participant’s preferred language.

Parents and adolescents were interviewed individually. We used a separate interview guide for parents and adolescents consisting of open-ended questions designed to explore participant perspectives on (1) barriers to ADHD diagnosis and care; (2) personal and community attitudes towards ADHD and its treatment; and (3) delivery preferences for an engagement intervention being developed. The adolescent interview guide was adapted from the parent’s version and altered to be developmentally appropriate, including (1) addition of questions to build rapport at the start of the interview and (2) modification of questions to improve understanding and relevance for adolescents. The interview guide was modified iteratively to explore new topics as they emerged in the interviews. Interview guides are available as supplemental material.

Data Analysis

All interviews were audio-recorded, transcribed verbatim, and translated to English if needed. Transcriptions were then de-identified for participants' privacy, reviewed for accuracy, and analyzed using thematic analysis (Braun & Clarke, 2006). For the thematic analysis, pieces of text were coded and then used to identify patterns across participant narratives from which themes (i.e., overarching understandings of a construct) were developed. Transcriptions were uploaded to and coded using NVivo 11 Software (NVivo 12, 2018).

Parent and adolescent data sets were analyzed using the same procedures, described previously by Spencer (2021). Separate codebooks were created for parent and adolescent data sets. Transcripts were independently reviewed and open coded by at least 2 authors, who then discussed their impressions with the research team. A codebook was developed from these discussions and subsequently refined as team members reviewed additional interviews. Once thematic saturation was reached (no new concepts emerged from the data), the finalized codebook was applied to all interviews, which were each coded independently by two authors. After reaching an inter-coder reliability of 81%, the remaining interviews were single-coded, checking every 5th interview to ensure Cohen's kappa remained above 75%. Once all interviews were fully coded, the full research team conducted axial coding (examining the relationship between codes to create themes) in weekly meetings (Corbin & Strauss, 1990). Throughout this thematic analysis, parent and adolescent themes were triangulated across participants.

Results

Sample Characteristics

A total of 130 parents were screened; 104 were eligible, 63 declined or could not be reached after screening, and 41 consented to participate. Demographic data for these parents were previously published by Spencer (2021) and are also presented in Table 1. The vast majority were female (93%), with a mean age of 41 years ($SD = 7.6$). Most interviews were conducted in English ($N = 31, 76\%$), nine were conducted in Spanish (22%) and one in Haitian Creole (2%). A little less than half of all participants were born outside of the United States (42%) and 29% spoke a language other than English at home. Roughly half completed some postsecondary education (51%), and median income was \$20,000.

Demographic and treatment characteristics of the 41 children and adolescents with ADHD that were previously published (Spencer et al., 2021) are presented in Table 2. Children were 56% Black/African American, 20% White, 37% of Hispanic/Latino/Spanish origin, and 61% publicly insured. Almost all children and adolescents had a history of receiving medication, therapy, and school services for ADHD, and most were still in treatment.

Out of these 41 children and adolescents, 11 adolescents assented to complete interviews themselves. Demographic and treatment characteristics for this sub-sample of adolescents is included in the right-hand column of Table 2. Most adolescents were male (82%), with a mean age of 14 ($SD = 2.0$). Nine interviews were conducted in English (82%) and two

in Spanish (18%). Most adolescents identified as Black/African American (64%), and 45% identified as Hispanic/Latino/Spanish.

Engaging Children in ADHD Care

Parents described their considerations and strategies for engaging children and adolescents in ADHD care. Adolescents also discussed their perspectives on ADHD, experience with treatment, and how their parents communicated with them about ADHD and its treatment. Ultimately, both parents and adolescents spoke of two themes that most affected a child's engagement in care: (1) the child's *ADHD "illness insight"* (i.e. ADHD-related knowledge and capacity for self-reflection); and (2) the child's *self-esteem* (i.e. global sense of self-respect and self-worth). Parents and adolescents spoke about the intersection of insight and self-esteem, and how this interplay impacted interest and participation in care. Figure 1 depicts the result of this intersection between the spectra (from low to high) of insight and self-esteem, resulting in four basic styles of child and adolescent engagement in care described by both parents and adolescents:

1. *Proactive* (high insight, high self-esteem).
2. *Anxious* (high insight, low self-esteem).
3. *Apathetic* (low insight, high self-esteem).
4. *Resistant* (low insight, low self-esteem).

Parents described different ways of interacting and communicating with their child or adolescent about ADHD that influenced their child's level of ADHD insight and self-esteem, perpetuating a particular engagement style. Adolescents reflected upon their own engagement style, impacted by ADHD knowledge, self-esteem, and the interaction with their parent.

Four Styles of Child Engagement in ADHD Treatment

Proactive Engagement (High Insight, High Self-Esteem)—Proactive engagement (Fig. 1) emerged as the ideal style for child engagement in ADHD care.

Proactively engaged children had parents who encouraged child knowledge about ADHD and involvement in treatment as a path to empower their children and elevate their self-esteem. Parents viewed pharmacological and psychological treatments as generally effective and helpful, including for improving self-esteem.

"I think that [treatment] is a huge help, and that can be a big confidence-booster for kids that struggle with it." (40-year-old mother of a 9-year-old girl with ADHD)

Parents sought to involve their children in the treatment process by encouraging their child's input and participation. They communicated to their children that treatment providers are there to help them.

"[A]s far as the diagnosis and coming up with a plan, I feel like parent and child should be together with the doctor to communicate. I feel like that is effective. That way if the parent has any questions you can ask and the provider can also break

it down in a way that both the parents and the child understands.” (30-year-old mother of a 12-year-old boy with ADHD)

“He would try this [medication] and have input of how it made him feel. What was working. What wasn’t working. Then, he could try something new, and then that was better. And then well what if we try this? I think he felt like he had more options. [...] [N]obody could say except for him, what was going on with him.” (49-year-old mother of a 14-year-old boy with ADHD)

Correspondingly, adolescents reported feeling central to and in control of their treatment and thus empowered to engage. They viewed treatment as helpful and providers as allies.

“Doctors always make sure to check on you, they are always tracking them, asking questions and making sure that you are well and that the medication is in check.” (17-year-old male adolescent with ADHD)

Parents described taking an encouraging approach to their child’s difficulties, utilizing positive reinforcement and praise, and believing in their child’s potential and future success, particularly with the help of treatment. They emphasized the importance of accepting the child as they are and providing help without implying that the child is deficient in any way.

“Either I accept it and help her or keep in denial and I’m not helping her. I just choose to accept it and help her.” (38-year-old mother of a 16-year-old girl with ADHD)

Relatedly, adolescents described self-acceptance, not feeling abnormal or deficient because of their ADHD, and feeling supported by their providers, peers, family, and others in their community.

“You’re no different than the person that doesn’t have it. Like, your brain can work a little different from that other person’s, but you’re still a person.” (16-year-old female adolescent with ADHD)

Parents strove to communicate about ADHD with their child openly and in a direct, collaborative, and developmentally appropriate manner, thereby promoting self-efficacy.

“I explain to him what can happen, and we have been like this since he was little. I explain things to him and sometimes he would ask questions that I could not answer because of his age, but eventually [...] he would say, ‘Well, now that I am older, you can explain it to me.’” (41-year-old mother of a 15-year-old boy with ADHD)

Anxious Engagement (High Insight, Low Self-Esteem): Anxious engagement (Fig. 1) occurred when parents promoted a high level of ADHD insight in their child, but worried about their child’s low self-esteem, in part as a result of having high illness insight. Parents acknowledged treatment as essential to symptom relief but were concerned about the burden of stigma associated with treatment for their child.

“[It] took me a long time to really settle to, ‘Okay, yeah. I’m going to give this to her, for her.’ It still bothers me until this day to give her her medicine.” (38-year-old mother of a 16-year-old girl with ADHD)

Parents worried that treatment would make their children feel like, “something [was] wrong” with them when, above all, they wanted their child to feel, “normal.” At the same time, they urged their children to participate in treatment in order to encourage agency over their condition.

“I was always looking for information but I was also scared of putting them under medication [...] I’ll admit, I’ve even told this to my oldest child “Since you are taking pills and you already have a mental health file, they’re not going to accept you in (college).” Things like that scare me. It also happened to me personally [...] I was scared of people saying “Oh, she’s crazy” and stuff like that.” (34-year-old mother of a 10-year-old boy with ADHD)

Adolescents in this quadrant, despite having a high level of illness insight, perceived treatment as helpful but undesirable, isolating, and stigmatizing.

“[Treatment feels] bad because on top of not being able to focus on things I have to tell people about it too as if it should help me or make me forget that I have attention deficit disorder. For example, my mom always asks me: “Are you going to take your medication or do you feel like you don’t need it?” to see if I can manage or not. And sometimes I just say: “Yes, I need the medication.” Sometimes I feel normal and other times I feel like I have the attention deficit. (15-year-old male adolescent with ADHD)

Parents delivered inconsistent messages about the acceptability of ADHD and its treatment to their children. They were unsure of whether to blame a behavior on their child or their child’s ADHD and worried that the child might use their diagnosis as an “excuse” to avoid negative life consequences.

“Then sometimes he’ll say, “I didn’t take the medicine or the medicine is not working.” What I say to him is, “The medicine is just a little extra help, don’t rely on it.” I tell him things like that so that he doesn’t use these things for an excuse.” (30-year-old mother of a 12-year-old boy with ADHD)

Adolescents reported being impacted by both public and self-stigma. Experiences of feeling judged for their ADHD symptoms and treatment (e.g., medication, special education services) by peers, family, and community members impeded their ability to feel self-acceptance.

“If I am showing a lot of attention deficit signs, he’ll think that I’ll be like another special kid, I won’t be normal.” (15-year-old male adolescent with ADHD)

Apathetic Engagement (Low Insight, High Self-Esteem): Apathetic engagement (Fig. 1) occurred when parents promoted a high level of self-esteem in their child but expressed a lack of interest in cultivating ADHD illness insight. Parents perceived treatment as inconsequential to their child’s welfare and felt indifferent towards their child’s involvement in treatment.

“[S]ome people ask me why she’s on that type of medication, what is the reason, and I can’t answer it [...] because I don’t know anything about ADHD. I just know

that it's something that people have.” (43-year-old mother of an 8-year-old girl with ADHD)

Adolescents felt that treatment was similarly irrelevant to their wellbeing. They chose not to participate in medical appointments and lacked an understanding of how treatment might mitigate ADHD symptoms.

“My mom just kind of does whatever the doctors say and I just kind of do the same because they know more about it than I do, so.” (14-year-old male adolescent with ADHD)

“Like I said, the question you're asking me, like, I don't... Like, I only have one, like... Like I said, I don't even know what ADH... Only, like – that I move a lot. I don't really know...” (15-year-old male adolescent with ADHD)

Nonetheless, parents described a positive relationship with their child, expressing pride, interest in promoting positive self-esteem, and confidence in their child's future success.

“I think the kid's self-esteem is more important than all the things you learn between the first grade and the fifth grade. You can always learn to multiply and add. [He] was a very early reader. He's been reading since early first grade. [...] When a kid starts to doubt their own intelligence and their own abilities, that's the point that I think something really has to be done.” (49-year-old mother of a 14-year-old boy with ADHD)

Adolescents felt that having ADHD did not define them, and did not reflect deeply on how ADHD impacted their behavior or daily lives. They chose not to disclose their diagnosis or seek out support from others for ADHD.

“I like to talk about other things that are more important than [my ADHD].” (13-year-old female adolescent with ADHD)

Parents did not reflect on the relevance or importance of illness insight and reported not having conversations about ADHD often or at all.

“I never thought about how she would think [others] views her [because of her ADHD.] This is the first time I'm asked that question, this is the first time I'm thinking about it. So, I really don't have a positive answer for you.” (40-year-old mother of a 3-year-old girl with ADHD)

Resistant Engagement (Low Insight, Low Self-Esteem): Resistant engagement (Fig. 1) occurred when parents did not encourage ADHD illness insight and did not intentionally support their child's self-esteem. They ascribed negative attributes to ADHD, its treatment, and their child's behaviors. In some cases, parents spoke of treatment as punitive (i.e., a consequence of poor behaviors as opposed to an effective aid).

“Well, I see you can't control yourself. So, this means you're not going to get off your medicine early.” (53-year-old mother of a 15-year-old boy with ADHD)

Parents reported resistance to the child's input in treatment. They shared doubts about their child's ability to make responsible and independent decisions. Some viewed provider efforts to engage with adolescents as undermining parental authority.

"They're always going to be choosing bad choices. I can see it. It's going to be a huge problem in their life when they get older [...] Sometimes I just feel like it's a waste of time to me because it's going in one ear and out the other." (62-year-old mother of a 10-year-old girl with ADHD)

"Sometimes they'll say, 'Well, she has a voice,' [...] to listen to her, she has her opinion. I get it, but too much of that stuff is not cool to me, it's just not. Then, she feels that she shouldn't have to listen to anyone, but, um, she got that twisted. She gotta listen to me." (56-year-old mother of a 15-year-old girl with ADHD)

Comparably, adolescents resented and felt disempowered by treatment. They reported feeling that care was forced upon them, unhelpful, and even harmful (e.g., due to adverse side effects of medication or stigma), and indicative of their own bad decisions.

"We would argue sometimes, like, I don't want to take the medicine, but she says I have to, like, and then she ends up...she ends up winning. So, like, it's not even worth it." (15-year-old male adolescent with ADHD)

Parents described inaccurate knowledge of ADHD and endorsed myths about ADHD and treatment that negatively influenced both their understanding of the disorder and of their children.

"My family believes that pills to regulate behaviors are man-made disease things. They don't actually help fix the problem, they help cause more problems [...] My family would rather do church blessings, family gathering, prayer. Probably, things you could buy in the grocery store and use at home, as opposed to these medications that sometimes make the kid zombie-like." (34-year-old mother of a 14-year-old boy with ADHD)

Parents described taking a critical approach to their child's difficulties, holding them accountable for behaviors symptomatic of ADHD, and doubting their future success. They felt it unwise to accept undesirable aspects of their child's character as part of ADHD, concerned that doing so might encourage misbehavior.

"To me, [my kids] don't care. The ADHD... I don't really call it out like that. I call it out as bad behavior. But this in-home therapy always brings it back to me, "You have to remember, the ADHD, the PTSD, this is why this is happening." But I say to them, "But they should know right from wrong." (62-year-old mother of a 10-year-old girl with ADHD)

"Yeah, we've got her a behavioral health service in place, so we try to do stickers and stuff like... It's like a reward system. [...] So, I just took it as that, but I was feeling like, okay, we're giving her rewards for what? She should be able to behave without us giving her rewards." (43-year-old mother of an 8-year-old girl with ADHD)

Adolescents did not report self-acceptance and described feeling inadequate. They also reported feeling unsupported by providers, peers, family, and others in their community.

“Like, [my teacher] would rather help... another student then help me but just like... They’d rather just spend their time on someone else or like, whatever they say to me is brief, or like they not really invested in me.” (17-year-old male adolescent with ADHD)

Discussion

In this qualitative study on engagement in ADHD care, parents described the importance of engaging children and adolescents in care, and adolescents described their own experiences participating in treatment. Both parents and adolescents described child engagement in care as related to their level of illness insight and self-esteem, and at the intersection of these emerged four distinct styles of child engagement in care (proactive, anxious, apathetic, and resistant). There is very little literature on engagement of children in care for ADHD, and specifically on its importance to parents. These parent perspectives emphasize that the task of engaging children in care is important for parents but not always well guided. Our novel model of child engagement provides clinicians and researchers with a framework to better understand child and adolescent engagement in care and to use for the development of interventions to improve engagement.

Of the four styles, proactive engagement emerged as ideal, with the combination of positive self-esteem and high ADHD illness insight supporting treatment buy-in. Youth who were proactive engagers had accurate knowledge of ADHD, accepted ADHD as part of their identity, and perceived treatment as helpful. Parents communicated with children in a direct and collaborative manner, both imparting knowledge and encouraging children to participate in decision-making about treatment. The parent-child relationship was described as strong and supportive. These findings support literature that has connected attributes of positive parenting (i.e., responsiveness, warmth, and empathy) with increased treatment engagement and higher levels of self-esteem for both children and adolescents (Bench, 2019; Swift et al., 2013). Specifically, parents that bolster children and adolescent’s self-esteem tend to express acceptance of their children’s shortcomings, encourage their children to make independent decisions, and provide scaffolding for child and adolescent behaviors (Grolnick et al., 1991; O’Donnell et al., 2010; Swift et al., 2013). Given the diversity of this sample, it is worth noting that this parenting framework remains valid across cultures within and outside of the U.S. (Barber et al., 2005). In the current study, this was illustrated by parents who accepted ADHD as part of their child or adolescent’s identity, who invited them to participate in age-appropriate decision-making about treatment, and who scaffolded their treatment experiences by providing them with accurate knowledge about ADHD and encouraging autonomous decision-making.

Self-esteem on the low end of the spectrum was associated with either anxious or resistant engagement styles, both of which were less conducive to engagement in care. Anxious engagement was characterized by recognition of symptoms but a pessimistic outlook on diagnosis and treatment, which could hinder future engagement in care. Families questioned

or avoided treatment because of its negative connotation. Resistant engagement was characterized by less understanding/recognition of the role of ADHD in symptoms and behaviors, with frequent parent-child conflict, blame, and even overt treatment rejection. In this case, treatment could be viewed as unhelpful or even damaging. Our findings here are consistent with past research that repeated discussion around the negative aspects of a child's problem leads to heightened distress, as well as internalizing and depressive symptoms (Ying et al., 2018). Evidence-based interventions such as CBT, anti-stigma campaigns in schools, parent training, and family therapy could be employed to improve self-esteem and parent-adolescent interactions for families with these engagement styles (Evans et al., 2018; Heary et al., 2017).

Apathetic engagement was the consequence of indifference towards ADHD and characterized by an otherwise positive outlook. Parents tended not to communicate about ADHD with their children but were encouraging and positive about their child's future. Adolescents viewed treatment as unimportant and were unconcerned about their symptoms. Due to lack of distress, providers could overlook these families despite their need for more support around illness insight, engagement, and communication about ADHD. Effective interventions could include psychoeducation, parent training, family partner interventions, and a focus on informed assent of adolescents in their treatment decisions (Montoya et al., 2011).

Our findings have significant clinical implications for providers who treat children and adolescents with ADHD. Providers may be able to encourage proactive engagement styles through psychoeducational means, such as openly discussing the typically chronic nature of ADHD, the fact that most children with ADHD will be managing some symptoms throughout their lifetime, the link between self-esteem and engagement in care, and the importance of using non-stigmatizing and supportive approaches for children with ADHD. To promote ongoing engagement in care as children gain increasing independence, providers could proactively facilitate and support developmentally appropriate parent/child communication about ADHD and emphasize the non-punitive role of treatment. Providers might also model proactive engagement by including the child in medical appointments about ADHD early on — thus, illustrating the importance of empowering children to take part in their medical care —, normalizing the concept of having a diagnosis, and naming individuals with ADHD who could be good role models.

Our research also suggests that improvement in ADHD symptoms should not be the only target for treatment intervention. Increasing knowledge about ADHD and promoting self-acceptance and self-worth are important treatment targets to encourage proactive, long-term management of this chronic condition. In the future, parent/child therapies that emphasize effective parent/child communication about diagnosis and treatment could be tested for ADHD, with the goal of improving ADHD knowledge for children and parents, child self-esteem, and the parent/child relationship.

A strength of our study is its focus on the voices of under-researched and underserved groups. Our sample provides insight into the engagement attitudes of low-income, racially and ethnically diverse families, including many parent participants who were single mothers

and a substantial minority who were born outside of the United States or speak a primary language other than English. The median reported income of our sample was 109% of the 2022 federal poverty line. Thus, our results and engagement framework are informed by this diverse and predominantly low-income population of mothers, who are disproportionately likely to take primary responsibility for child-rearing (Esping-Andersen, 2009). Although our study was not designed to report on cultural or racial differences in engagement framework, our work is informed by all of these perspectives, and clinicians should consider the capacity and cultural context of families with limited resources when seeking to engage them in care.

Our study has a few limitations. We recruited subjects from one safety-net hospital system and most families were actively in treatment, with parents being mostly mothers and adolescents being mostly male. Therefore, these findings may not translate to other populations. Importantly, fathers are underrepresented in the literature, and more pointed recruitment of this group in future studies may yield valuable perspectives on engagement in care. The reality that most families identified as Black or Hispanic and that a significant portion of parents were born outside of the United States further prevents generalization. While we did not identify how families of specific racial groups or nativity status might engage uniquely with care, future research exploring these differences would strengthen the clinical utility of this engagement model. Furthermore, we did not have information about years of treatment received, which might have informed our findings. Our data did not allow us to determine the causality of engagement styles (e.g., to the degree parenting engagement influences child engagement), which would be an important area for further research. Finally, the present study was aligned with the literature on ADHD as a medical diagnosis. There has been a concerted effort in the field to discuss not only the deficits associated with neurodevelopmental dysfunction but also how neurodiversity can be leveraged to promote patient well-being. Future research that involves families in strengths-based discussions of ADHD may produce novel insights into how to optimize families' engagement with ADHD treatment.

Summary

This qualitative study of engagement in ADHD treatment reveals the importance of engaging children and adolescents in ADHD treatment early and describes four distinct styles of child engagement in ADHD care that lie at the intersection of illness insight and self-esteem: proactive, anxious, apathetic, and resistant engagement. Our research exposes new areas of interest in ADHD care for children and adolescents and highlights potential treatment targets to promote future engagement in treatment as children with ADHD transition toward independence. Future research will be needed to confirm these findings, develop standardized measures of engagement styles, and determine the relationship between ADHD knowledge, self-esteem, and engagement style on treatment adherence, symptom burden, and functional impairment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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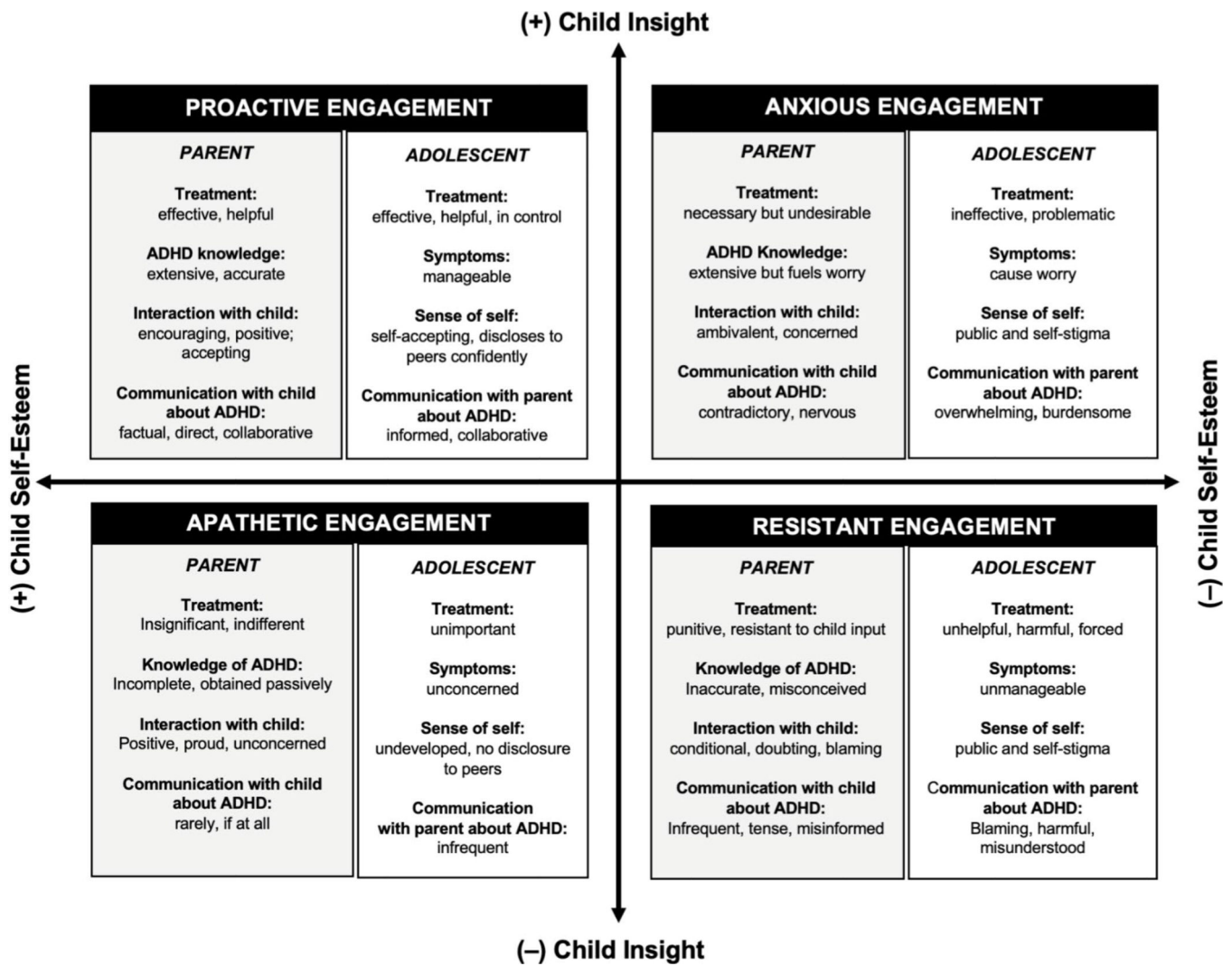


Fig. 1. Four styles of child engagement in ADHD care. Parents and adolescents described how child self-esteem and child insight intersected to impact a child’s ability and willingness to engage with ADHD treatment.

Table 1

Sociodemographic characteristics of parent participants.

	N = 41
Age (years): Mean ± SD	41 ± 7.6
Sex: n (%)	
Female	38 (93%)
Male	3 (7%)
Marital status: n (%)	
Married or living with a partner	20 (49%)
Divorced or separated	6 (15%)
Never married	15 (37%)
Study visit language: n (%)	
English	31 (76%)
Spanish	9 (22%)
Haitian Creole	1 (2%)
Primary language spoken at home: n (%)	
English	29 (71%)
Spanish	10 (24%)
Haitian Creole	2 (5%)
Birthplace: n (%)	
In the United States	28 (68%)
Mainland United States	24 (59%)
Puerto Rico	4 (10%)
Outside the United States	13 (32%)
Mexico	3 (7%)
Guatemala	2 (5%)
Haiti	2 (5%)
Jamaica	2 (5%)
Bulgaria	1 (2%)
El Salvador	1 (2%)
Dominican Republic	1 (2%)
Ghana	1 (2%)
Education level: n (%)	
Less than high school degree	10 (24%)
High school degree/ GED	10 (24%)
Postsecondary education	14 (34%)
College degree or higher	7 (17%)
Employed at least 50 out of 52 weeks: n (%)	25 (61%)
Household income: median (range)	\$20,000 (\$0 to \$200,000)

Table 2

Demographic and treatment characteristics of children and adolescents with ADHD.

	Total Sample N = 41	Sub-sample N = 11
Age (years): Mean \pm SD	11 \pm 3.3	14 \pm 2.0
Sex: n (%)		
Male	27 (66%)	9 (82%)
Female	14 (34%)	2 (18%)
Ethnicity: n (%)		
Hispanic, Latino, or Spanish Origin	15 (37%)	5 (45%)
Not of Hispanic, Latino, or Spanish Origin	26 (63%)	6 (55%)
*Race: n (%)		
Black/African American	23 (56%)	7 (64%)
White/Caucasian	8 (20%)	2 (18%)
Native American/Alaskan Native	2 (5%)	2 (18%)
Asian/Native Hawaiian/Other Pacific Islander	0 (0%)	0 (0%)
Other race	6 (15%)	2 (18%)
More than one race	5 (12%)	1 (9%)
Birthplace: n (%)		
In the United States	36 (88%)	8 (73%)
Outside the United States	5 (12%)	3 (27%)
Health insurance: n (%)		
Public	25 (61%)	7 (64%)
Commercial/Private	15 (37%)	3 (27%)
Other	1 (2%)	1 (9%)
Other psychiatric conditions: n (%)		
Behavioral or conduct problem	25 (61%)	8 (73%)
Depression or anxiety	16 (39%)	3 (27%)
Any other mental health condition	2 (5%)	0 (0%)
Treatment history: n (%)		
Ever taken medication for ADHD	40 (98%)	11 (100%)
Currently taking medication for ADHD	38 (93%)	11 (100%)

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	Total Sample N = 41	Sub-sample N = 11
Ever received therapy	36 (88%)	10 (91%)
Currently has special school services	37 (90%)	11 (100%)
Repeated a grade: n (%)	5 (12%)	2 (18%)

* Some participants reported more than one race category