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Using freelisting to understand shared decision making in ADHD: Parents' and pediatricians' perspectives

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Abstract

Objective—To compare and contrast notions of ADHD among pediatricians and parents of affected children to understand the perspectives they bring to shared decision making (SDM).

Methods—In this freelisting study, 60 parents of children with ADHD and 30 primary care pediatricians listed words reflecting their understanding of (1) Attention Deficit Hyperactivity Disorder (ADHD), (2) getting/offering help for ADHD, (3) talking to doctors/families about ADHD, and (4) “mental health.” Smith's salience score established terms that were salient and cultural consensus analysis identified variation within subgroups of participants.

Results—Parents' terms reflected ADHD's effects on the child and family, while clinicians often mentioned school. Lists suggested differing needs and goals for clinicians and subgroups of parents in SDM: “time” for clinicians, “learning” and “understanding” for non-college educated parents, and “comfort” and “relief” for college educated parents. Neither parents nor clinicians framed ADHD in the same way as “mental health.”

Conclusion—Parents and clinicians, who conceptualize ADHD differently, should negotiate a shared understanding of ADHD as a basis for SDM. Treatment discussions should be tailored to encompass families' varied emotional and educational needs.

Practice implications—Fostering SDM in primary care is consonant with notions of ADHD as distinct from mental health.

Keywords

Shared decision making; Attention Deficit Hyperactivity Disorder; Disparities

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Conflict of interest

The authors report no conflicts of interest.

1. Introduction

As the number of conditions with multiple evidence-based treatment options has increased, promoting effective shared decision making (SDM), a strategy to match families with the most acceptable treatments, has become a public health priority. In this context, the *Institute of Medicine* highlighted the delivery of patient-centered care, the focus of SDM, as one of six priority areas for improvement in healthcare for the 21st century and encouraged study of the effectiveness of SDM [1,2]. In SDM, both clinicians and families participate in treatment decisions, exchange information, express preferences, and jointly determine a treatment plan [3]. For this process to be effective in pediatrics, parents of young children and pediatricians must have or develop an understanding of the other parties' perspectives on the child's health condition and its treatment so that communication and ultimately joint decisions reflect the needs, preferences, and goals of families as well as the scientific evidence.

ADHD is the most common neuro-developmental disorder in children and adolescents with prevalence estimates between 3 and 16% depending upon the sample and measurement techniques used [4,5]. According to the National Survey of Children's Health conducted by the Centers for Disease Control, nearly 4.5 million U.S. children between 4 and 17 years of age had ever been diagnosed with the condition as of 2003 [6]. The core symptoms of ADHD include hyperactivity, impulsivity, and inattention and impact self-esteem, interpersonal relationships, and academic achievement including high school graduation [7]. Children with ADHD rate significantly lower in health-related quality of life in all psychosocial areas, and those with comorbidities such as oppositional defiant conduct, internalizing, and learning disorders have even greater deficits [8]. In addition to its impact on the daily lives of children, ADHD impacts the health and functioning of families, schools, and the community. Individuals with ADHD have healthcare costs as much as three times greater than others, and these expenditures increase further in the presence of comorbidity [9-12].

ADHD is an ideal prototype for the study of SDM in children's health care for several reasons: there are multiple evidence-based treatment options, including behavior therapy and medication [13]; disparities exist in the receipt of evidence-based treatments [14,15] and personal and cultural values influence the acceptability of treatment. In addition, following promulgation of national guidelines from the American Academy of Pediatrics (AAP), pediatricians have increasingly assumed a leading role in managing ADHD [4,13,16]. Reflecting the importance of SDM in treatment, these guidelines emphasize involving families in treatment decisions, eliciting treatment preferences, and targeting care to families' goals [13]. However, little guidance is provided regarding how to elicit preferences and goals, how these may differ across the population, and what steps must be taken to effectively implement SDM in pediatric practice.

Prior research has documented the importance of understanding both physicians' and families' explanatory models of illness as inputs to medical decision making [17-19]. This is especially true for SDM, a process that explicitly integrates personal beliefs into health decisions [20]. For SDM to proceed most effectively, professional and varying lay explanations must be reconciled so that the professional expertise of clinicians and the personal experiences and beliefs of families jointly determine acceptable and appropriate treatment choices [3,18,21]. Differing perspectives are often a function of more than educational preparation, for clinicians and families alike. Professionals and families may focus on and derive different meanings from symptoms. In ADHD, persistent uncertainty following decision making [22] and widespread poor adherence to treatment [23-25],

support the need for detailed and ongoing investigation of how to improve the decision making process.

Freelisting has been a standard approach used in anthropology to define the elements of a domain (such as ADHD) and the extent to which group members share those definitions [26]; however, this approach has not been used widely in pediatrics or studies of doctor-patient communication. In freelisting, participants generate a list of terms, chosen from the universe of all words, to describe their perceptions or definitions of a domain. [27] In this mixed methods approach [28], the shared cultural model for the domain is determined from the word choice, order of recall, and modifying terms that are used [26,29]. Defining the cultural model and determining the extent to which members of a group have shared or divergent ideas is particularly important for SDM, a process requiring effective communication between parents and clinicians. This freelisting study was designed to systematically explore shared and divergent notions of ADHD and its treatment among pediatricians and a diverse group of parents. Findings will inform efforts to foster SDM in practice.

2. Methods

2.1. Setting

This study was conducted within The Children's Hospital of Philadelphia (CHOP) Pediatric Research Consortium (PeRC), a multi-state, hospital-owned, primary care practice-based research network including more than 235,000 children and adolescents. Study practices included four urban teaching practices where less than 35% of patients have private insurance as well as 17 primarily suburban practices not involved in resident teaching, where over 80% of children are privately insured. Parent participants were also recruited through a posting on the Internet site of Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD), an advocacy group for affected families. The CHOP Institutional Review Board approved the study. All participants consented.

2.2. Study design and patient population

We conducted a freelisting study [29] to distinguish perceptions of a domain within and between different groups [30,31]. Freelisting is particularly well-suited to comparisons of the views of medical professionals and parents [32]. This method has been used to understand individuals' notions of diseases and health practices and differences between health professional and lay perceptions [29,31-34]. Conceptually, freelisting is based on the idea that those with shared experiences (e.g. having a child with ADHD) or shared cultural values will have a common understanding of a particular domain [26,32].

We conducted individual interviews with a purposive sample of 60 parents of children between ages 6 and 12 years with ADHD and 30 pediatric clinicians between March 2008 and March 2009. Clinician participants were invited to participate in research on ADHD treatment decisions through presentations to their practice and study announcements, and parents were referred to the study by their clinicians or through the CHADD website. Participants were informed that the interviews would be audiotaped and used for research purposes. All participants were given the opportunity to decline participation or terminate the interview at any point. All of the subjects referred to us agreed to participate. The 6- to 12-year-old age range was chosen to match the age when most children are diagnosed with ADHD and the target population of national ADHD guidelines [4,13]. Since perceptions of ADHD are known to differ between Blacks and Whites, purposeful sampling was used to achieve a balanced sample of parents from these groups.

2.3. Data collection

Using a brief questionnaire, we collected demographic data including parents' education, ethnicity, gender, and urban or suburban residence. Children's difficulties were assessed based on their average response to performance items on the Vanderbilt Parent Scale, a validated instrument which has been incorporated in the AAP toolkit for the management of ADHD [4,13,35]. Parent and clinician participants generated lists in response to the following questions during semi-structured interviews with trained research assistants: What words come to mind when you (1) hear the phrase Attention Deficit Hyperactivity Disorder, (2) think about getting help (giving help to families) for ADHD, (3) think about talking to your doctor (to families) about ADHD, and (4) hear the phrase mental health? Consistent with prior work that found that freelistings required 20–30 individuals per group, we conservatively recruited 30 pediatric clinicians and 60 parents [26].

2.4. Data analysis

Freelists were reviewed by the research team in order to standardize word forms and combine synonyms. Both positive and negative comments regarding a specific domain were grouped together. For example, terms such as “assistance” and “needing help,” were coded as “help.”

The lists were then entered into Anthropac, version 4.983/X (Analytic Technologies, Kentucky), software designed for the analysis of freelists. For each of the four questions, output was reviewed to determine which words were most salient for clinicians and for parents [36,37]. Salience was derived using a salience index (Smith's S) defined as: $S = ((L - R_j + 1)/L)/N$, where L is the length of each list, R_j is the rank of item J in the list, and N is the number of lists in the sample [38]. Salience characterizes terms that are prototypes [39] for the particular domain of interest accounting for both the frequency and order of the words.

Using a previously published approach, words from each list were sorted from high to low salience and a scree plot was generated with salience scores on the y -axis [29,32]. The plots were then inspected to select a natural breaking point, indicated by a flattening of the slope as words became less frequent. Terms that fell above the breaking point were retained as salient. Based on the range and distribution of salience, the number of salient words differed for each list. Salience scores were generated for all participants, then for parents based on race (Black versus White), parental education (college educated versus others), and child's degree of difficulty in academics or interpersonal relationships.

For our primary analysis comparing the freelists of parents and clinicians, we confirmed results using a logistic regression analysis with presence (versus absence) of salient terms on an individual's list as the outcome and the respondent group (parent or clinician) as the independent variable. For each of the three ADHD-specific questions we asked, we used logistic regression to estimate the difference in the frequency of word use by parents compared to clinicians. Variances were adjusted for the clustering of responses at the level of the individual clinician or parent. In these analyses, a p -value <0.05 was considered significant. All analyses were performed using Stata 11 (College Station, Texas).

In order to understand the diversity of perceptions among subgroups of parents, we then used consensus analysis (minimum residual factor analysis) to establish the extent to which subgroups of parents shared an understanding of a particular domain. Using Anthropac, each individual's response pattern was weighed in relation to the most frequent response patterns in the group of interest [29]. The first factor derived from this analysis represented the group consensus. Following a standard approach, if at least a 3:1 ratio existed between the eigenvalue (a measure of the overall variance explained by the factor) for the first factor and

the second factor, the group of interest was considered to have a common understanding of a particular domain [29]. Subgroups for which only one factor was identified were also considered to have a consensus.

3. Results

3.1. Study population and freelist characteristics

A total of 60 parents of children with ADHD and 30 pediatricians were enrolled in the study. Purposive sampling resulted in a parent group nearly evenly divided between Black (50%) and White (45%) (Table 1). The majority of parents interviewed were mothers. Residence, education, income, as well as the extent to which children were impaired are also described in Table 1. Clinicians were mainly WHITE, female, and comfortable treating ADHD (Table 2). The time to respond to the freelist questions was similar for parents and clinicians. Parents spent an average of 3 min, 15 s on their freelists, (range: 1:06–9:18) and clinicians spent an average of 3 min, 48 s (range: 1:06–9:30). Parent freelists averaged 3.1, 4.1, 3.2, and 3.2 words for questions 1, 2, 3, and 4, respectively, while clinician freelists were longer and averaged 4.2, 5.6, 4.7, and 4.4 words.

3.2. Comparing salient terms for parents and pediatricians

Words salient uniquely to clinicians or parents, and those shared between the two groups for each ADHD-specific question are listed in Table 3. All terms listed by at least 3 parents or clinicians are summarized in Table 4. When asked what words they think of when they hear Attention Deficit Hyperactivity Disorder (Question 1), both clinicians and parents listed words related to ADHD symptoms: “hyperactive” and “focus.” However, beyond symptoms, terms clinicians and parents used to describe ADHD differed. “School,” a setting where problems from ADHD typically manifest, was salient uniquely to clinicians (listed by 43%). In contrast, parents listed “child” and a series of words that described the family’s experience with ADHD such as “frustration,” “control,” and “trouble.” Indicative of parents’ perceptions, synonyms of “control” included “out of control child,” “unable to control emotions,” and “needing to have more control.”

Questions 2 and 3 explored perceptions about help-seeking and the interaction between the clinician and family. When asked about getting or giving help to families with ADHD, both groups identified specific treatments for ADHD: “medication” and “behavioral approaches.” Among the terms that were not shared, “doctor” was most salient to families, while clinicians focused on “time,” a term that includes “time pressures” and “time consuming.”

No words were common among both parents and clinicians when asked about talking to each other about ADHD, suggesting that salient ideas regarding working together differed between these groups. The most salient words for parents were “help,” “understanding,” and “medication” while clinicians listed “time,” “explaining,” and “learning.” For clinicians, learning included such synonyms as “gathering information,” “providing written information,” and “education.”

Results from this analysis were confirmed using logistic regression. Separately for Questions 1 and 2, we found no significant difference in the odds that common terms were used by parents versus clinicians ($p = 0.5$). No terms were shared by clinicians and parents for Question 3. In contrast and as expected, significant differences in words uniquely salient to clinicians and parents were found for Questions 1, 2, and 3 (Table 3).

3.3. Parent subgroup analysis

3.3.1. Race and parental education—We also conducted analyses among subgroups of parents. Table 5 compares responses from Blacks and Whites and Table 6 compares responses from college educated versus non-college educated parents. While similar to those for race, results based on education are highlighted because our findings suggest a greater homogeneity of ideas among parents according to educational attainment rather than race (see Table 8). For all questions, college and non-college educated parents shared freelist terms in common (see Table 6). When both groups of parents heard the term Attention Deficit Hyperactivity Disorder, they mentioned the words “hyperactive,” “focus,” “frustration,” and “child.” However, unique to the less educated parents was the term “trouble,” while more highly educated parents, perhaps reflecting a different perspective, listed “control.”

When asked to list words that come to mind when you think about getting help for ADHD, all groups considered “medication” and “doctor.” Non-college educated parents were the only subgroup to list “help” and “understanding” as salient. In contrast, college educated parents listed “relief,” a term reflecting the burden of the condition on the family, and “psychiatrist.”

When asked about words that come to mind when you think about talking to your doctor about ADHD, “help” and “medication” were common to the lists of college and non-college educated parents (Table 6). However, while college educated parents mentioned terms describing the emotional experience of discussing ADHD such as “comfort” and “frustration,” less educated parents emphasized knowledge that can be gained from the encounter by listing “understanding” and “learning,” a term that has synonyms that include “questions,” “education,” and “gathering information.” Of note, “communication,” a term implying a bidirectional information flow, was uniquely salient to more educated parents.

3.3.2. Child difficulties in relationships—We next compared parents of children with difficulties in either peer relationships (Table 7) or academics to parents of children without these difficulties. Parents of children with relationship difficulties uniquely listed positive terms such as “patience,” “hope,” and “caring” in response to thinking about getting help for ADHD. When asked about talking to the doctor about ADHD, “communication,” a term emphasizing the need for information flow, and “confusion,” a term highlighting the importance of clear instructions and well-organized care, were also uniquely salient to the group of parents whose children had greater difficulties relating to others.

3.4. ADHD versus mental health

To assess whether parents or pediatricians viewed ADHD similarly to the way they viewed mental health, we compared responses to “words you think about when you hear Attention Deficit Hyperactivity Disorder” to “words that come to mind when you hear the phrase mental health” (Fig. 1). There was no overlap at all between these terms, which suggests that they fall into different domains. For clinicians, the word “behavior” was the only word shared between freelists describing ADHD and mental health.

3.5. Group consensus

The existence of a group consensus was determined for each question and for the main and subgroup analyses (see Table 8). A consensus meant that individuals within a group had a common understanding of a particular domain as reflected by an eigenvalue greater than 3. For the main analyses comparing clinicians and parents, no consensus existed among clinicians for any of the freelist questions, while parental consensus existed for both Questions 1 (words you think about when you hear Attention Deficit Hyperactivity

Disorder) and 2 (getting help for ADHD). Among the parent subgroup analyses, the broadest consensus existed among parents of children with or without difficulties in interpersonal relationships and those with or without a college education. Within each of these groups, ideas about ADHD and its treatment were shared. When consensus was assessed by race, no strong consensus existed among Whites for any of the ADHD-specific questions, and, for Blacks, consensus existed only for Question 1.

4. Discussion, conclusion, and practice implications

4.1. Discussion

This freelist study extends prior work by directly comparing and contrasting parents' and clinicians' frameworks for thinking about ADHD and exploring the implications of these distinct conceptualizations for SDM. Our findings demonstrate that parents and clinicians conceptualize ADHD and its treatment differently from one another. While school is central to how clinicians think about ADHD, parents' freelists indicate a focus on the effect of the condition on the child and family. Although these perspectives are distinct, SDM may build upon these perceptions of ADHD if parents accept clinicians' awareness of ways to help with school issues and clinicians elicit families' unique experiences, preferences, and goals for treatment. Our results suggest that this type of exchange is consistent with how parents and clinicians understand ADHD. Clinicians view learning and explaining as important ideas in talking to families, while parents, who look to the doctor for help, recognize these exchanges as opportunities for "help" and "understanding."

Our results also indicate that perceptions of ADHD and its treatment differ among subgroups of parents of children with ADHD in sometimes unexpected ways. While much research in ADHD has documented differences in help-seeking based on race and ethnicity [40-44], we found that distinctions based on parental education as well as the child's difficulty with interpersonal relationships better divided parents into groups with a common understanding of ADHD. Prior studies have demonstrated knowledge gaps among traditionally less educated groups [45], which may shed light on our finding that "learning" from the doctor was particularly salient to parents without a college education. In contrast, we found that more educated families, who, by virtue of their educational attainment might be assumed to be more interested in information, actually viewed the doctor's role as providing "comfort" and "relief." SDM may be enhanced if clinicians are able to eschew assumptions about families' needs and instead tailor care based on the stated preferences and goals of individual families.

In addition to differences in parents' perspectives based on educational attainment, we also found that parents of children with different levels of impairment had varying perspectives. Specifically, for parents of children who are having difficulties with relationships, we found that "patience," "hope," and "caring" are central to notions of help, but that "confusion" characterized conversations with the doctor. Reflecting prior work that has described the importance of both emotion and clear communication to collaborative pediatric care [22,46,47], these findings suggest that clarity and optimism may be essential traits for clinicians working with families of highly impaired children. Given these results, clinicians may best serve families if they confirm their understanding of key concepts and match educational information and the tone of treatment discussions to families' emotional as well as intellectual needs.

Our findings suggest that the development of strategies to foster SDM in primary care is especially important. This study found that both pediatricians and parents conceptualize ADHD differently than they do other mental health problems. Complementing prior research that demonstrates that the majority of visits for ADHD and most medication

prescriptions come from primary care, and that ADHD is the most common behavioral complaint to pediatricians [45,48,49], these results suggest that treating ADHD in primary care is consistent with how parents and clinicians think about the condition.

Tailoring care to children with ADHD based on their preferences, goals, and needs has been endorsed by national guidelines and the National Institute of Mental Health [4,13,50]; however, our findings are consistent with others that show that barriers persist to providing this care [16,51]. Prior research has described the impact of increasing productivity demands and inadequate reimbursement on clinicians' ability to manage ADHD, particularly in the primary care setting [51]. In this study, "time" was the term most salient to clinicians asked about talking to families about ADHD and was also salient in regard to providing help to families. Time pressures are an important concern since families, especially those from less educated backgrounds, are looking to their clinician to teach them about ADHD, which may be a time-consuming process. Innovative approaches are necessary to support clinicians in efficiently, systematically, and consistently providing easily understood and relevant information to families within or outside the office setting.

This study had several limitations. Results from this study were derived primarily from one health system and may not be generalizable to all settings. Also, since most participants were recruited through a pediatric primary care network, views of families not using primary care may not have been fully captured. However, since our goal was to explore how to best foster SDM in primary care, this setting is well suited to our study aim. Finally, freelist is a technique involving the inference of ideas from word lists. While this approach is robust for the comparison of ideas within and between groups and our main results were supported by the use of logistic regression, confirming findings with research using complementary techniques such as qualitative interviews, surveys, or the direct observation of clinical encounters is warranted.

4.2. Conclusion and practice implications

SDM has been prioritized in ADHD, yet few studies have systematically explored this process. Using freelist, an ideal approach to understand how specific domains related to health are defined by clinicians and families, we found that clinicians' and parents' ideas of giving/getting help for ADHD are distinct. These results indicate that a shared understanding of ADHD needs to be negotiated at an early stage in the process of SDM, a step that may often be missed in busy practice settings. SDM requires the effective exchange of information between clinicians and families. Since results suggest that families' preferences vary according to parents' educational attainment, and not necessarily in the ways clinicians might reasonably expect, SDM may be most successful if clinicians regularly elicit families' particular needs. Specifically, less educated parents may need more information, whereas more educated parents may often be looking to their clinician for emotional support. Given the salience of time constraints for clinicians, tools such as brief questionnaires may be especially helpful in eliciting families' preferences, needs, or goals. In addition, future study in educational settings, where children spend a considerable amount of time, may help us understand how teachers' understanding of domains related to ADHD overlaps with parents' and clinicians' perceptions. Finally, results demonstrate that clinicians and parents understand ADHD differently from mental health and underscore the importance of ongoing work to foster SDM for ADHD in primary care.

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Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
SDM	shared decision making
AAP	American Academy of Pediatrics
CHOP	The Children's Hospital of Philadelphia
PeRC	Pediatric Research Consortium
CHADD	Children and Adults with Attention Deficit/Hyperactivity Disorder
OR	odds ratio
CI	confidence interval

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Fig. 1.

Salient Terms: Notions of ADHD (Q1) versus Notions of Mental Health (Q4). (a). Clinician & Parent Participants: Notions of ADHD (Q1) versus Notions of Mental Health (Q4). (b) Parent Participants: Notions of ADHD (Q1) versus Notions of Mental Health (Q4). (c) Clinician Participants: Notions of ADHD (Q1) versus Notions of Mental Health (Q4).

Table 1

Study participants: parent characteristics.

Group	Black (n = 30)	White (n = 27)	Other ^a (n = 3)	Total (n = 60)
Residence				
Urban	25 (83%)	6 (22%)	0 (0%)	31 (52%)
Suburban	5 (17%)	21 (78%)	3 (100%)	29 (48%)
Education				
Less than college	25 (83%)	7 (26%)	2 (67%)	34 (57%)
College	5 (17%)	20 (74%)	1 (33%)	26 (43%)
Income				
Lower (\$0 to \$32,999)	17 (57%)	5 (19%)	1 (33%)	23 (38%)
Middle (\$33,000 to \$54,999)	8 (27%)	5 (19%)	0 (0%)	13 (22%)
Higher (\$55,000 ^b)	5 (17%)	17 (63%)	2 (67%)	24 (40%)
Relationship to child				
Mother	23 (77%)	22 (82%)	3 (100%)	48 (80%)
Father	1 (3%)	3 (11%)	0 (0%)	4 (7%)
Grandparent	2 (7%)	1 (4%)	0 (0%)	3 (5%)
Other legal guardian	4 (13%)	1 (4%)	0 (0%)	5 (8%)
Child's performance score ^b				
Above average academic difficulties	16 (64%)	8 (32%)	1 (33%)	25 (42%)
Above average interpersonal relationship difficulties	8 (38%)	12 (57%)	1 (33%)	21 (35%)

^aThree participants were either Hispanic or of mixed race. Due to small numbers these participants were excluded from analyses based on race.^bAccording to the NICHO Vanderbilt Assessment Scale – Parent Informant [35]. Performance scores were based on the average response to items assessing academic difficulties or difficulties with interpersonal relationships.

Table 2

Study participants: clinician characteristics.

Clinicians (<i>n</i> = 30)		
Race	Black	2 (7%)
	White	25 (83%)
	Other	3 (10%)
Gender	Female	20 (67%)
	Male	10 (33%)
Practice setting	Urban resident teaching practices	14 (47%)
	Other practices (primarily suburban)	16 (53%)
Years in practice (post-training)	Less than 10 years	5 (17%)
	10–20 years	14 (46%)
	More than 20 years	11 (37%)
Comfort in treating ADHD (completely uncomfortable (1)–completely comfortable (5))	5	7 (23%)
	4	14 (47%)
	3	7 (23%)
	2	2 (7%)
	1	0 (0%)

Table 3

Comparing salient terms for parents and clinicians.

Parents ^{a,d}	Common ^{b,d}	Clinicians ^{c,d}
Question 1: What words do you think about when you hear Attention Deficit Hyperactivity Disorder?		
Child	Hyperactive	School
Frustration	Focus	Impulsive
Control		Behavior
Trouble		
Boys		
Question 2: What words come to mind when you think about getting help (giving help to families) for ADHD?		
Doctor	Medication	Time
Frustration	Help	Psychologist
Relief	Behavioral approach	Side effects
Understanding		
School		
Question 3: What words come to mind when you think about talking to your doctor (talking to families) about ADHD?		
Help		Time
Understanding		Learning
Medication		Explaining

^aIncludes salient terms unique to parents. For Questions 1, 2, and 3, respectively, the odds ratio (OR) for terms appearing on this list being said by parents versus clinicians were 2.1 (95% confidence interval (CI): 1.1–4.1, $p = .04$), 2.0 (95% CI: 1.1–3.8, $p = .04$), and 2.1 (95% CI: 1.0–4.5, $p = .05$).

^bIncludes salient terms common to both parents and clinicians. There was no significant difference in the odds terms on this list appeared on the parent versus clinician lists ($p = .5$).

^cIncludes salient terms unique to clinicians. For Questions 1, 2, and 3, respectively, the odds ratio (OR) for terms appearing on this list being said by parents versus clinicians were 0.1 (95% CI: 0.04–2.1, $p < 0.001$), 0.2 (95% CI: 0.1–0.4, $p < 0.001$), and 0.06 (95% CI: 0.07–0.3, $p < 0.001$).

^dTerms in each column are listed in the order from highest salience to lowest salience.

Table 4

Frequency, average rank, and salience for parent and clinician freelists.

Parents				Clinicians			
Word ^a	Frequency	Average rank ^b	Smith's salience score ^c	Word ^a	Frequency	Average rank ^b	Smith's salience score ^c
Question 1. What words do you think about when you hear Attention Deficit Hyperactivity Disorder?							
Hyper-active	37	2.73	0.384	Hyper-active	16	3.438	0.333
Focus	27	2.704	0.273	School	13	3.154	0.259
Child	9	2.444	0.109	Impulsive	11	3.182	0.218
Frustration	10	3	0.088	Focus	12	3.75	0.215
Control	8	2.875	0.078	Behavior	5	1.2	0.156
Trouble	4	1.25	0.064	Boys	4	2.25	0.101
Boys	4	1.25	0.063	Parents	3	1.333	0.089
Sadness	3	3.333	0.029	Disability	3	2	0.085
Aggression	3	3.667	0.029	School performance	3	2.667	0.073
Patience	3	3	0.028	Frustration	4	4	0.067
School	3	3	0.027	Disruptive	3	4	0.065
Medication	3	4	0.024	Performance	4	3.5	0.06
Anger	3	3.333	0.022	Medication	4	6.25	0.058
Impulsive	3	3.333	0.022	Social	3	8.667	0.021
Listening	3	3.333	0.021				
Question 2. What words come to mind when you think about getting help (giving help to families) for ADHD?							
Medication	25	4.44	0.26	Time	8	2	0.219
Doctor	17	3.824	0.196	Medication	11	5.727	0.204
Help	11	5.364	0.116	Help	8	5.25	0.147
Frustration	9	2.222	0.108	Behavioral approach	7	8	0.113
Relief	6	1	0.1	Psychologist	4	4.25	0.095
Understanding	7	2.571	0.084				
Behavioral approach	9	3.667	0.076	Side effects	7	8.571	0.091
School	5	4.2	0.061	Frustration	5	5.2	0.072
Patience	4	2.75	0.049	School performance	3	2	0.072
Learning	6	3.833	0.047	School	4	7.5	0.07

Parents				Clinicians			
Word ^a	Frequency	Average rank ^b	Smith's salience score ^c	Word ^a	Frequency	Average rank ^b	Smith's salience score ^c
Psychiatrist	4	4	0.047	Behavior	3	5.333	0.069
Difficult	4	3.25	0.032	Insurance	3	4.333	0.064
Hope	3	2.667	0.031	Expectations	3	4.333	0.064
Child	3	2.333	0.028	Teacher	4	7.5	0.056
Caring	3	4	0.027	Communication	3	5	0.044
Teacher	3	8.667	0.026	Consistency	3	7	0.042
Side effects	4	14.25	0.023	Collaboration	3	4.667	0.042
Time horizon	3	9.333	0.018	Effectiveness	3	6.667	0.042
				Success	3	5.333	0.034
Question 3. What words come to mind when you think about talking to your doctor (talking to families) about ADHD?							
Help	24	1.667	0.345	Time	11	1.364	0.344
Understanding	9	3.111	0.095	Learning	9	7	0.146
Medication	8	3.625	0.085	Explaining	4	2.5	0.111
Learning	7	3	0.066	School	4	4.75	0.083
Child	4	1.25	0.063	Help	4	3.75	0.079
Comfort	5	3.8	0.059	Communication	3	2.667	0.076
Frustration	5	2	0.059	Social	3	3	0.07
Confusion	8	3.75	0.057	Listening	3	2	0.067
Knowledge	4	3.5	0.042	Medication	5	7.8	0.065
Focus	3	2.333	0.037	Patience	3	2.667	0.061
Listening	3	2.667	0.033	Home	3	5	0.055
Anxiety	3	3.667	0.032	Collaboration	3	6.333	0.054
Side effects	3	4.333	0.027	Diagnosis	3	4.667	0.053
Brushed-off	3	3.667	0.019	Side effects	3	6.667	0.048
Behavior	3	4.667	0.018	Behavioral approach	4	8.25	0.044
Question 4. What words come to mind when you hear the phrase "mental health"?							
Crazy	13	1.231	0.208	Depression	8	2.625	0.211
Help	10	2.9	0.098	Psychiatrist	5	2.2	0.145
Medication	8	3.125	0.084	Behavioral approach	7	3.429	0.14
Learning disability	8	2.125	0.082	Resources	5	1.6	0.136

\$watermark-text

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Parents				Clinicians		
Word ^a	Frequency	Average rank ^b	Smith's salience score ^c	Word ^a	Frequency	Smith's salience score ^c
Behavioral approach	5	2.2	0.064	Insurance	6	0.12
Sick	4	1.25	0.058	Medication	6	0.104
Doctor	4	2.25	0.052	Frustration	4	0.103
Depression	5	3.4	0.05	Psychologist	4	0.099
Brain	4	2.25	0.05	Behavior	3	0.089
Psychiatrist	4	3	0.048	Anxiety	4	0.087
Mental illness	3	1.667	0.043	Access	3	0.062
Disability	3	1.667	0.039	Difficult	4	0.047
Psychologist	3	2	0.037	Help	3	0.046
Anxiety	4	4.75	0.035	Family	3	0.038
Confusion	3	2.667	0.034			
Stigma	4	2.75	0.032			
Understanding	3	2.333	0.032			
Autism	3	2.667	0.024			
Difficult	3	3.667	0.019			

^aThis table reflects only those words said at least three times by either parents or clinicians.

^bAverage rank is the position in which a word appears on a list by a parent or clinician, averaged across all parents or all clinicians.

^cSalience was derived using a salience index (Smith's S) defined as: $S = ((L - R_j + 1)/L)/N$, where L is the length of each list, R_j is the rank of item J in the list, and N is the number of lists in the sample [38]. The salience score accounts for both the frequency and order of the words.

Table 5

Comparing salient terms for parents by race (Black versus White).

Black^{a,d}	Common^{b,d}	White^{c,d}
What words do you think about when you hear Attention Deficit Hyperactivity Disorder?		
Trouble	Hyper-active	Control
	Focus	Boys
	Frustration	
	Child	
What words come to mind when you think about getting help (giving help to families) for ADHD?		
Understanding	Medication	Frustration
Behavioral approach	Doctor	School
Patience	Help	Psychiatrist
	Relief	
What words come to mind when you think about talking to your doctor (talking to families) about ADHD?		
Learning	Help	Frustration
Child	Understanding	Confusion
	Medication	Comfort
		Difficult
		Focus
		Communication

^aIncludes salient terms unique to Black subjects.^bIncludes salient terms common to both Black and White subjects.^cIncludes salient terms unique to White subjects.^dTerms in each column are listed in the order from highest salience to lowest salience.

Table 6

Comparing salient terms for parents by college education.

Non-college educated ^{a,d}	Common ^{b,d}	College educated ^{c,d}
What words do you think about when you hear Attention Deficit Hyperactivity Disorder?		
Trouble	Hyper-active	Control
	Focus	
	Child	
	Frustration	
What words come to mind when you think about getting help (giving help to families) for ADHD?		
Help	Medication	Relief
Understanding	Doctor	Psychiatrist
What words come to mind when you think about talking to your doctor (talking to families) about ADHD?		
Understanding	Help	Comfort
Learning	Medication	Focus
		Communication
		Frustration
		Confusion

^aIncludes salient terms unique to non-college educated subjects.^bIncludes salient terms common to college and non-college educated subjects.^cIncludes salient terms unique to college educated subjects.^dTerms in each column are listed in the order from highest salience to lowest salience.

Table 7

Comparing salient terms for parents based on their child's difficulties with interpersonal relationships.^e

Difficulties with interpersonal relationships^{a,d}	Common^{b,d}	No difficulties^{c,d}
What words do you think about when you hear Attention Deficit Hyperactivity Disorder?		
	Hyper-active	Frustration
	Focus	Trouble
	Child	Boys
	Control	
What words come to mind when you think about getting help (giving help to families) for ADHD?		
Patience	Medication	Learning
Hope	Doctor	School
Caring	Help	Psychiatrist
	Frustration	Great
	Behavioral approach	Difficult
	Understanding	Child
	Relief	Teacher
What words come to mind when you think about talking to your doctor (talking to families) about ADHD?		
Child	Help	Comfort
Confusion	Understanding	Learning
Side effects	Medication	Frustration
Communication		Focus

^aIncludes salient terms unique to parent subjects of a child with interpersonal relationship difficulties.

^bIncludes salient terms common to both parent subjects of a child with interpersonal relationship difficulties and parent subjects of a child with no interpersonal relationship difficulties.

^cIncludes salient terms unique to parent subjects of a child with no interpersonal relationship difficulties.

^dTerms in each column are listed in the order from highest salience to lowest salience.

^eAccording to the NICHQ Vanderbilt Assessment Scale – Parent Informant [35].

Table 8

Subgroups of participants who respond similarly to freelist questions.

Question	Parents (n = 60)	Clinicians (n = 30)	Parent subgroups			
			Race ^a		Education	
			Black (n = 30)	White (n = 27)	Less than college education (n = 34)	College educated (n = 26)
What words do you think about when you hear Attention Deficit Hyperactivity Disorder?	5.0		5.0		5.0	3.6
What words come to mind when you think about getting help (giving help to families) for ADHD?	3.7				3.0	One factor
What words come to mind when you think about talking to your doctor (talking to families) about ADHD?					3.1	One factor
						3.5
						3.3
						4.3
						4.1
						4.0

The ratio of eigenvalues is listed for all subgroups of participants with a strong consensus. A strong consensus means that individuals' response patterns closely match those of the group and is indicated by a ratio 3 or the identification of only one factor [29].

^aThree participants were either Hispanic or of mixed race. Due to small numbers, these participants were excluded from analyses based on race.

^bAccording to the NICHQ Vanderbilt Assessment Scale – Parent Informant [35].