

SCIENTIFIC INVESTIGATIONS

# “It made all the difference”: a qualitative study of parental experiences with pediatric obstructive sleep apnea detection

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**Study Objectives:** To assess parental experience of their child’s obstructive sleep apnea (OSA) detection process and inform the development of interventions and health communication strategies to improve OSA detection.

**Methods:** Semistructured interviews were conducted with 30 parents of children (ages 3–14) who snored and were referred for an overnight polysomnogram (PSG). Parents (60.0% Black race, 93.3% mothers) described how their child was referred for PSG and their perceptions and feelings throughout the detection process. Parents also completed an OSA knowledge measure. Interview data were analyzed using a descriptive approach and thematic analysis was conducted using the NVivo 12 software system.

**Results:** Twenty-one themes were identified across 5 categories (first steps; PSG facilitators and barriers; health information; health care experiences; parent experiences). Respondents experienced multiple pathways to OSA detection, with more than half of referrals initiated by parental concerns (vs. screening efforts). Parents reported a willingness to take any necessary steps to help their child. Both barriers and facilitators to completing a PSG were described. Parents observed both nighttime and daytime symptoms related to OSA in their child but often did not connect the symptoms to each other until later in the process. Participants had varying degrees of OSA knowledge, with a mean knowledge score of 56% correct (range 10%–90% correct).

**Conclusions:** Parental experiences highlight aspects of the health care system that are both effective and ineffective in detecting children with OSA. Implications include a need for strategies to promote timely detection and to provide parents with accurate information about pediatric OSA.

**Keywords:** sleep-disordered breathing, obstructive sleep apnea, qualitative research, sleep, children, youth, early detection of disease

**Citation:** Honaker SM, Gopalkrishnan A, Brann M, Wiehe S, Clark AA, Chung A. “It made all the difference”: a qualitative study of parental experiences with pediatric obstructive sleep apnea detection. *J Clin Sleep Med.* 2022;18(8):1921–1931.

## BRIEF SUMMARY

**Current Knowledge/Study Rationale:** Obstructive sleep apnea is prevalent in children yet often remains undetected. An understanding of parental experiences, perspectives, and knowledge around obstructive sleep apnea detection is currently lacking.

**Study Impact:** Themes reflecting parental experiences, perspectives, and knowledge around pediatric obstructive sleep apnea detection were identified. These themes can inform health communication and intervention strategies to promote timely detection of pediatric obstructive sleep apnea.

## INTRODUCTION

Pediatric obstructive sleep apnea (OSA), characterized by full or partial airway obstruction during sleep, presents in an estimated 2%–5% of children.<sup>1</sup> Untreated OSA is consistently linked to a number of negative sequelae for children, including sleepiness,<sup>2</sup> neurobehavioral impairment,<sup>3</sup> and cardiovascular morbidity.<sup>4</sup> Despite established guidelines for evidence-based diagnosis and management of OSA,<sup>5</sup> many children with OSA remain undetected.<sup>6–8</sup> Under-identification of OSA may be particularly problematic for children of Black race as well as for children from families with fewer economic resources. Both Black race and living in a disadvantaged neighborhood have been independently linked to higher OSA risk<sup>9–11</sup> and to lower likelihood of timely diagnosis and evidence-based care.<sup>12–14</sup> Barriers to pediatric OSA detection include limited provider sleep training in medical education<sup>15,16</sup> and resulting knowledge gaps,<sup>17</sup> lack of parental

knowledge about sleep-disordered breathing,<sup>18</sup> and problematic rates of follow-up in children referred for polysomnography (PSG).<sup>19</sup>

A few studies have examined strategies to improve OSA detection, with promising findings. Approaches include primary care clinical decision support systems,<sup>19,20</sup> provider-delivered sleep screening,<sup>21,22</sup> and screening in community settings such as childcare centers.<sup>23</sup> Yet these interventions have been primarily provider-focused, with providers playing a gatekeeper role in determining whether OSA risk is discussed or evaluated during an office visit. Parents, however, are key drivers for disease detection and follow-up for children,<sup>24,25</sup> and activated parents could play an important role in OSA detection. To develop effective parent-focused interventions and health communication strategies for OSA detection, it is important to obtain a better understanding of parental perspectives, beliefs, knowledge, and experiences around pediatric OSA detection.

Studies examining parental perspectives around OSA detection have been limited to date. In a qualitative study of care experiences and treatment decision-making in 11 parents of children diagnosed with OSA, Boss et al<sup>26</sup> described parental problem recognition of OSA symptoms in their child, including recognition of both daytime (eg, fatigue) and nighttime (eg, snoring) symptoms. However, this study focused primarily on parental decision-making and experiences around adenotonsillectomy and did not fully examine parental experiences regarding their child's OSA detection (ie, how their child came to be referred for PSG and why they did or did not complete the PSG visit).

To address these gaps and inform the development of parent-focused interventions and health communication strategies for OSA detection, the aim of the present study was to assess parental experience of OSA detection in their child. Specific constructs of interest included: 1) pathways to OSA referral and detection, 2) barriers and facilitators to PSG completion, 3) parental experience with the health care system, and 4) parental knowledge of OSA. Qualitative methodology was selected as the primary analysis method for this study, as this approach allows a richer understanding of parental experiences around this relatively complex phenomenon (OSA detection). We conducted purposeful sampling to include parents of children at higher risk for OSA, specifically those living in neighborhoods of Black race and/or with fewer economic resources.

## METHODS

### Participants

Eligible participants were parents or primary caregivers (hereafter referred to as parents) of children who were referred to the Riley Sleep Disorders Center for an overnight PSG for the indication of sleep-disordered breathing. Riley Sleep Disorders Center is located in Indianapolis and serves children throughout the state of Indiana. Additional eligibility criteria included: 1) child between the ages of 2 and 12 years at the time of the referral, 2) parent able to participate in an interview conducted in English, and 3) the referral date less than 1 year prior to the interview date. We targeted children in this age range to capture developmental periods with high rates of OSA prevalence and to inform interventions aimed at early OSA detection. As one study objective was to inform the development of parent-centered interventions for OSA detection, we over-recruited parents of children at particular risk for under-identification of OSA, specifically those of Black race and/or living in neighborhoods with fewer economic resources. Purposeful sampling was also used to include parents whose children were at different stages of OSA detection. To that end, we sampled some parents whose child had completed a PSG, and others whose child had been referred but had not completed a PSG. Qualitative data saturation determined the final sample size of 30 parents. Informed consent was obtained from all participants.

We attempted to contact 92 parents by phone, reaching 58 (65.2%) parents. Of those reached, 11 declined and 5 were not eligible (3 were not English-speaking; 1 was not a legal guardian; 1 reported their child was not referred for PSG). Four additional children met study eligibility criteria but were

not invited to participate, as at that time we were only recruiting children who had not yet completed a PSG. Forty-one parents consented to participate and completed measures; of these, 11 were not interviewed due to difficulty reaching them at a time they were available for an interview. Thus, 30 parents were interviewed and included in the final sample.

### Procedure

Eligible parents were contacted by phone and invited to participate in the study. During this initial phone call, a research associate verified eligibility, obtained informed consent, verbally administered demographic and knowledge items to the parent, and scheduled a subsequent phone interview. This initial phone call lasted approximately 15 minutes.

Interviews were conducted during a second phone call with the interviewer (A.A.C. or S.H.) located in a private room in an academic building with the parent located in their home, between February 2019 and March 2020. A semistructured interview guide (**Appendix A** in the supplemental material) was initially developed by S.H. Interview questions were selected to cover 4 areas of interest, specifically the parent's: 1) experience with their child's OSA detection, as well as associated feelings and perceptions; 2) barriers and facilitators to PSG completion; 3) perceived threshold for raising concerns with their child's primary care provider (PCP); and 4) OSA knowledge. The guide was pilot-tested with 2 parents and refined by study team members (S.H., S.W., A.A.C.). Interviews lasted approximately 30 minutes. Participants were mailed a \$40 gift card as compensation for study participation. Interviews were audio recorded and transcribed verbatim by an external transcription service. Due to concerns for the heightened risk of a loss of confidentiality, transcripts were not sent to participants for verification. The study was approved by the Indiana University School of Medicine Institutional Review Board.

### Measures

#### Sociodemographics

Parents reported their age, race/ethnicity, relationship to the child about whom the interview was conducted, their sex, highest level of education completed, and their child's age (in years), race, ethnicity, and sex.

#### Parental knowledge of pediatric OSA

Participants were asked to respond to a series of 10 OSA knowledge items, selecting 1 of the following 3 response options: True, False, and Don't Know. Items were developed by the first author (S.H.) to assess parental knowledge of OSA symptoms, causes, and treatment; item content was informed by prior work examining parental knowledge of OSA.<sup>27,28</sup>

#### Analytic approach

Participant and child sociodemographic factors and parental OSA knowledge were examined using descriptive analysis (means and proportions). Interview transcriptions were reviewed for accuracy by a study team member (A.G.), then uploaded into NVivo Version 12 for analysis. Data were coded in 2 phases.

In phase 1, units of data were organized into broad categories, using a system of nodes within the NVivo software. Nodes were developed collaboratively with several team members (S.H., A.A.C., A.G.) through a review of each unit of data (ie, sentence, phrase) from the first 5 interviews and reflected the topical content (eg, OSA knowledge statements, OSA symptoms, PSG barriers). Categories were determined via open-coding and were not developed a priori. Interview content was organized into nodes by A.G., who earmarked any interview content that did not clearly fit into 1 or more existing nodes. This content was reviewed and discussed at team meetings (S.H., A.A.C., A.G., and A.C.), resulting in the development of additional nodes where appropriate. If new nodes were added, A.G. reviewed all prior interviews to determine whether previously coded content should be assigned to the new node. Data could be assigned to more than 1 node where applicable. Disagreement was resolved by discussion.

In phase 2, team members reviewed interview content (S.H., A.C., A.G.) within nodes and conducted thematic analysis to identify key themes most relevant to the study aims. Thematic analysis occurred both within and across nodes. Again, an open-coding approach was used in which themes were developed to reflect interview content and were not specified a priori. Twenty-one themes were organized into categories and subcategories. Consistent with qualitative reporting guidelines,<sup>29</sup> themes that were relevant but endorsed by only a minority of respondents were also included. For example, the theme “misplaced blame” was derived from content from only 3 respondents; however, this theme was important to those respondents (ie, mentioned frequently) and is relevant to the study aim of identifying parental perspectives and experiences around OSA detection, and was thus included. The codebook included a detailed description of each of the themes as well as content examples. This same team then coded the first 5 interviews into themes using a data organization instrument developed by S.H. within the Research Electronic Data Capture (REDCap) electronic data capture tools<sup>30</sup> at Indiana University. Whereas almost all interview content was coded (with the exception of content that was clearly not relevant to the interview topic) in phase 1, only content that fit an identified theme was coded in phase 2. We estimate that this represented approximately 60% of overall interview content. Subsequent interviews were coded using the same process as in phase 1: A.G. coded interviews, identified any content that may have but did not clearly fit into a specified theme, and reviewed identified content at team meetings. Content was discussed (S.H., A.G., A.C.) until consensus was reached. A sample of interviews (n = 5; 16.6%) randomly selected from the interviews coded independently by A.G. were double-coded by S.H., yielding a percent agreement of 93.1% and a Cohen’s kappa of 0.81.

## RESULTS

### Participant sociodemographic information

Participant sociodemographic information is presented in **Table 1**. Parents were predominantly mothers (93.3%) from diverse racial or ethnic backgrounds (60% Black non-Hispanic;

**Table 1**—Participant sociodemographic characteristics.

Characteristics	Participants (n = 30)
Age, mean (SD), years	36.8 (10.1)
Parent sex, female, n (%)	30 (100)
Race/ethnicity, n (%)	
Black/African American non-Hispanic	18 (60)
White non-Hispanic	8 (26.7)
White Hispanic	2 (6.7)
Asian	1 (3.3)
Biracial (White non-Hispanic / Black non-Hispanic)	1 (3.3)
Highest educational attainment, n (%)	
Some high school	2 (6.7)
High school degree or GED	5 (16.7)
Some college	14 (46.7)
College degree	9 (30)
Relationship to child	
Mother	27 (93.3)
Grandmother	1 (3.3)
Aunt	1 (3.3)
Child age, mean (SD), years	8.1 (3.0)
Child sex, female, n (%)	15 (50)

GED = General Educational Development, SD = standard deviation.

26.7% White non-Hispanic) with a range in educational attainment (23.3% high school or less; 50% some college; 26.7% college degree or more). Children about whom parents were interviewed were 50% female with a mean age of 8.07 years (standard deviation = 3.04). The majority (86.6%) of children had Medicaid insurance.

### Child status in the OSA detection process

At the time of the interview, participants varied with regard to their child’s status in the OSA detection process, though all had received a PSG referral. A few participants had elected for their child not to receive a PSG (n = 2), others were awaiting a scheduled PSG (n = 4), some children had a negative PSG (n = 6), and still others had already completed OSA treatment (n = 7) (**Figure 1**).

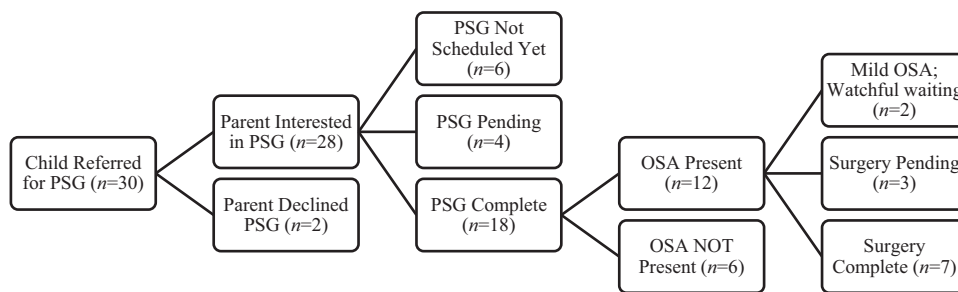
### Parental knowledge of pediatric OSA

The proportion of parents who responded correctly ranged by item from 26.7% to 90.0% (**Table 2**). The 2 items answered correctly by the fewest parents both pertained to OSA treatment; in contrast, most parents (90%) correctly identified a sleep study as the appropriate diagnostic test for OSA detection.

### Qualitative themes

Parent interview data were coded into 5 categories, 5 subcategories, and 21 themes (**Table 3**). We report the number of

**Figure 1**—Flow chart of child status in OSA detection at the time of the interview.



OSA = obstructive sleep apnea, PSG = polysomnogram.

parents whose observations were coded into each theme to add context for the reader. It is important to consider, however, that these reported frequencies do not necessarily indicate the importance, frequency, or universality of the theme. Some themes or categories were often generated by explicit interview questions (eg, first steps) and thus reported by more parents; other themes or categories may have been experienced by many parents but were less likely to be reported as they were not directly linked to specific interview questions (eg, misplaced blame). In addition, some of the themes would only be applicable to a subsample of participants. For example, the theme “benefits of OSA detection and treatment” would only apply to those 7 parents whose child had a positive PSG followed by treatment.

**First steps**

This category describes parental experience early in the detection process, from symptom onset to the time of referral for PSG and includes 5 themes. Every parent was asked to tell the story of how his/her child was referred for PSG.

**Something is wrong**

Parents described a variety of paths leading to their child’s OSA referral. Most commonly (n=24), this path began with parental observation of a problem in their child. In describing this observation, parents described relying on an instinct or a sense that what they were observing was a problem (“I just knew that was not, it wasn’t supposed to be like that.” Participant identification number [ID]14). Only in a small number of cases (n=5) did parents recognize what they were observing as symptoms of OSA (“I knew that he had sleep apnea because he had it when he was a baby.” ID10). Another pathway to referral that occurred less frequently was that of universal screening by a health care provider (n=3), or an OSA evaluation in the presence of a risk factor (n=7). For example, in 1 case, a child presented to the PCP with a sore throat. During physical exam, an observation of large tonsils led the PCP to ask about snoring, ultimately resulting in an OSA referral and diagnosis.

**Day and night**

In many cases (n=24), there were one or more symptoms that parents described as the initial impetus leading to a PSG referral.

**Table 2**—Parental OSA knowledge.

Knowledge Item (Correct Response) <sup>a</sup>	Parents Who Answered Correctly <sup>b</sup>
The only way to find out for sure if a child has OSA <sup>c</sup> is to do a sleep study (True)	27 (90.0)
OSA can cause learning problems in children (True)	23 (76.7)
Snoring is a sign that a child is sleeping well (False)	21 (70.0)
OSA can cause a child to be hyperactive (True)	20 (66.7)
Having big tonsils is a common cause of OSA in children (True)	18 (60.0)
Most children with OSA are overweight (False)	15 (50.0)
OSA can cause cardiovascular problems like high blood pressure (True)	14 (46.7)
It is normal for children to seem sleepy after school (False)	12 (40.0)
Surgery is usually enough to cure OSA in most children (True)	10 (33.3)
Most children with OSA will need to use a pressure mask when they sleep (False)	8 (26.7)

Values are presented as n (%). <sup>a</sup>Parents could respond “True,” “False,” or “I don’t know.” <sup>b</sup>The number of correct responses was divided by the total number of respondents, including both those who responded incorrectly and those who responded “I don’t know.” <sup>c</sup>When reading questions to parents, the examiner used the full term “obstructive sleep apnea” rather than the abbreviation “OSA.”

**Table 3**—Parental experience with pediatric OSA detection: categories, subcategories, and themes.

Category	Subcategory	Theme	Sample Quotations
First steps	–	Something is wrong	So now we are trying to figure out what’s really going on, because now we know there’s problems. <i>ID1</i>
			I just knew that it was not, it wasn’t supposed to be like that. <i>ID14</i>
			I felt like she was suffering, and I didn’t know where to find the problem. <i>ID4</i>
		Day and night	Before she had sleep apnea, she could sleep until you woke her up. <i>ID1</i>
			Just his behavior. He was starting to act pretty bad. <i>ID29</i>
			Maybe choking or something, not choking, gasping for breath or sometimes just wake up and breathe weird. <i>ID21</i>
		Missing the night-day connection	In fact, we thought it’s maybe, my mom was thinking maybe it’s ADHD or something. <i>ID21</i>
			That’s where her bad attitude comes from, sleeping. She’s always got a bad attitude, in a bad mood, so that’s where the problem is, she’s sleepy. <i>ID2</i>
		It takes a village	I had brought it up to her pediatrician who referred us to have a sleep study. <i>ID10</i>
			[The neurologist] said she’s not having seizures, so that’s fine. Then she said why don’t we do the sleep study? <i>ID26</i>
			I wanted to figure out what was going on with him ... because the school kept saying he’s sleeping at school. <i>ID3</i>
		Misplaced blame	I’m like okay, I kind of know why he’s sleeping [in school]. You all are saying it like I just don’t put him to bed on time or something. <i>ID3</i>
She’s not being rebellious. It’s a medical issue. <i>ID2</i>			
Facilitators and barriers to PSG	Facilitators	Wanting to know	I wanted to find out what it was, and I wanted to help her ... <i>ID14</i>
			I wanted to know what was going on. <i>ID22</i>
		Trust in provider	He’s a good, good doctor, I love him a lot. I love him a lot, because any time, in any concern that I’ve got, he helped me a lot. <i>ID9</i>
			She has an excellent doctor, so it goes well. <i>ID22</i>
	Barriers	Institutional follow-up	It started when my son was little and nobody did nothing about it. <i>ID18</i>
			Until I followed up with them, I would have never heard anything. <i>ID23</i>
		Is it really needed?	So, since, after I saw that things are not as bad as they were, I kind of relaxed. <i>ID21</i>
			She already did one [last] summer. Right now, she, she a lot better, so I don’t want to do it no more. <i>ID19</i>
		Structural barriers	I was just too busy with work and my daughter and everything to do that, because we’d have to do it overnight. <i>ID27</i>
			So, financially, I know I was totally unstable. <i>ID21</i>
Health information	Misinformation	Snoring is normal	I thought her snoring was, I thought it was normal, because all of us basically snore in my house. My other two children both snore. <i>ID26</i>
			I thought she was just snoring. Most people snore, so I just thought she was snoring, that’s normal. <i>ID1</i>
	Missing information	Cardiovascular consequences	I didn’t learn about ... the high blood pressure though, that is new. <i>ID8</i>
	Sources of knowledge	Own experience	I was really familiar with it because I had one before. <i>ID3</i>
			I actually stayed one night with one of my cousins a long time ago who had a sleep study. So I’m more familiar with it. <i>ID30</i>

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**Table 3**—Parental experience with pediatric OSA detection: categories, subcategories, and themes. (Continued)

Category	Subcategory	Theme	Sample Quotations
		Health care provider	[The PCP] said that it would be an overnight sleep, that she would be hooked up to the little machines and everything for them to monitor her sleep. <i>ID2</i>
			They did tell me about his airway. It could be bothering his sleep as far as breathing and things like that and also with his brain not having oxygen. <i>ID4</i>
Health care experience	–	Low threshold for raising concerns	Any time I find an issue with any of my kids, I go straight to their PCP. <i>ID10</i>
			If I have a concern about anything I feel like if a situation can't get better unless you address it. <i>ID8</i>
			Every time I talk to [PCP] about something ... she goes so far as to call me and see how the medication is doing or whatever. So, I just love her. <i>ID22</i>
		Parent as advocate	[PCP] keep saying maybe she having some maybe cold allergy or something. I told them no, this is no cold allergy. <i>ID16</i>
			The patient has to be a little more proactive and responsible for taking care of [health care system's] job. <i>ID23</i>
		Institutional delays	Funny thing about my sleep study when she had it and they told me that something would come in the mail, but I never get the paper in the mail. <i>ID13</i>
			I called back and see what was taking so long. They were booked up and this and that. They never got back with me. <i>ID22</i>
		Lingering questions and concerns	Actually, they told me he'll sleep better after the surgery, but I don't think that was true because he's still not sleeping. <i>ID3</i>
			I don't know if she grew out of [snoring] though. I don't know what happened. <i>ID17</i>
		Parent experiences	–
Actually I was a little nervous because at times I did, I kind of caught him stop breathing. <i>ID4</i>			
I honestly just wish he was like a normal sleeper. I wish I didn't have to get woken up every night in the middle of our sleep because I'm getting scared or concerned. <i>ID21</i>			
Whatever it takes	I just basically was like okay whatever we need to do to kind of get him to sleep better, I down for it. <i>ID8</i>		
	And I'm like, I gotta hurry up and do something. <i>ID14</i>		
	Anything to figure out what the problem is ... <i>ID2</i>		
Benefits of OSA detection and treatment	From that day to now, I see him and he's doing great. <i>ID9</i>		
	She wakes up, because like on the weekends, before she had sleep apnea, she could sleep until you woke her up. Now, she will get up. <i>ID1</i>		
	He's really improved now and what else ever since his admission in the hospital. Some of the things have changed, but the hyperactivity is so much better. <i>ID21</i>		
	She breathes easily and easier now and its more consistent breathing pattern and it made all the difference. <i>ID14</i>		

Often (n = 19) these were nocturnal symptoms observed by the parent, such as snoring or pauses in breathing. For example, one parent (*ID14*) reported that her daughter's breathing would "... stop in the middle of the night like she couldn't breathe." She brought this concern to the child's PCP, who referred her for a PSG. In a few cases (n = 5), daytime symptoms such as sleepiness were identified as starting the process.

### **Missing the night-day connection**

Even when nighttime symptoms (eg, snoring) and daytime symptoms (eg, sleepiness or mood difficulties) were both present and noticed by the parent, parents often did not perceive these symptoms as potentially associated with one another until much later in the detection process. One parent (*ID1*) noted, after observing her child's apnea during the PSG, "I could see

why she was falling asleep at school. There was no comfortable sleep at all, none.”

### **It takes a village**

Many different types of individuals played a role in initiating the OSA detection process. In most cases (n=21), parents played an active role by relaying concerns to their child's health care provider. For a few parents (n=4), their child's teacher was the one who first brought a problematic symptom such as daytime sleepiness to the parent's attention. One parent (ID3) noted, “The school kept saying he's asleep at school again.” Health care providers also played an important role, either through universal screening for OSA, screening for OSA in the context of a risk factor, and/or conducting an evaluation and making a referral in response to parental concerns. PCPs (n=26) most often played an initial role, as well as other medical specialists (n=12), such as neurologists, otolaryngologists treating a child for another reason (eg, ear tubes), dentists, and others.

### **Misplaced blame**

Two respondents reported experiencing misplaced blame as a result of their child's daytime sleepiness, specifically, blame from a teacher for not providing sufficient sleep opportunity for their child. One parent (ID3) said, “You all are saying it like I just don't put him to bed or something.” In two other cases, parents reported previously attributing their child's behavior to a trait (eg, rebelliousness) rather than to untreated OSA. One parent (ID2) noted her realization after the OSA diagnosis, “So, she's not being rebellious. It's a medical issue.”

## **Barriers and facilitators to PSG**

This category describes parent-identified barriers and facilitators to completing their child's PSG. Most parents in the sample reported that their child had already completed a PSG (n=18) or had one scheduled (n=4). Themes included 2 facilitators and 3 barriers.

### **Wanting to know (facilitator)**

Most parents (n=19) perceived the PSG as providing valuable information about their child's health and functioning. This information from the PSG was conceptualized as valuable in different ways, including for ruling out a problem (“I thought [getting a sleep study] was a good idea because I actually would like to know if everything is normal in a child.” ID21), or for understanding what might be behind a symptom or concern that a parent had observed (eg, “... I wanted to know what's going on.” ID22). Of the parents whose child had a negative PSG (n=6), none expressed regret or discontentment about having done the PSG, with one parent (ID23) noting “I'd rather be safe than sorry.”

### **Trust in provider (facilitator)**

Trust in the provider who recommended PSG was also identified as a facilitator to PSG completion (n=7). This trust appeared to be derived from parental perception that the provider was competent (eg, “... seems pretty knowledgeable.”

ID23), had helped the child with other concerns in the past (eg, “... because any time, in any concern that I've got, [the PCP] helped me a lot.” ID9), and explaining the issue to the parent (eg, “[PCP] did a good job by keeping me informed.” ID2).

### **Institutional follow-up (barrier)**

Some parents (n=6) referenced delays or lack of institutional follow-up in PSG scheduling (eg, “... they did not get back to us.” ID21). Another parent (ID12) described problematic care coordination: “[PCP's office] kept saying [sleep lab] kept calling to schedule an appointment but I never received a phone call.”

### **Is it really needed? (barrier)**

In some cases (n=6), parents reported uncertainty regarding the necessity or priority of the PSG for their child's care. One parent (ID27) didn't see symptoms suggestive of OSA, “I'm not real convinced that it needs to be done, because he doesn't snore ...” In other cases (n=3), parents whose child had an initial PSG didn't see the need for a follow-up PSG due to improvement in symptoms (“Right now she, she a lot better, so I don't want to do it no more.” ID19).

### **Structural barriers (barrier)**

One structural barrier to PSG completion reported by parents (n=2) was cost (“I couldn't afford it.” ID15). The number of parents describing cost as a barrier was low, likely due in part to the fact that most children whose parents participated in the study had Medicaid insurance, which would have covered the full cost of the procedure. Another barrier noted by a few parents (n=2) was that of competing responsibilities and priorities. One parent (ID27) noted, “I was just too busy with work and my daughter and everything.”

## **Health information**

Some interview questions directly asked parents about their OSA knowledge, yielding 4 themes across 3 subcategories.

### **Snoring is normal (misinformation)**

A few parents (n=4) initially (before their child's OSA detection) perceived their child's snoring as normal (“I thought it was normal.” ID26) rather than a potential sign of sleep-disordered breathing. In 3 cases, parents specifically referred to their perception of snoring as normal because they or other family members also snored (eg, “I snore so I just maybe thought it was just hereditary.” ID8).

### **Cardiovascular consequences (missing information)**

The interview guide (**Appendix A**) included a series of factual statements about OSA, to which parents were asked to identify any information they had not previously known. Almost half of parents (n=12) expressed that they had not previously been aware of the link between OSA and cardiovascular risk in children. Other information included in the factual statements (eg, OSA signs and symptoms; treatment options; see **Appendix A**) was infrequently identified as a knowledge gap for parents in the sample.

### **Own experience (sources of knowledge)**

A common source of parental knowledge about OSA was personal experience. Parents described knowing about OSA or PSGs based on the experience of a family member (n=5; eg, “My husband actually has sleep apnea.” ID10) or their experience as a patient (n=5; eg, “I have sleep apnea. So, it’s like I know how that works.” ID6).

### **Health care provider (sources of knowledge)**

Many parents (n=17) learned about OSA from health care providers, including PCPs, specialists, and PSG technicians. One parent (ID5) said “I felt like the [PSG technicians] were great. They explained everything to me.”

### **Health care experience**

Interview content yielded four themes pertaining to parental experiences with the health care system.

#### **Low threshold for raising concerns**

In addition to interview questions specifically about OSA detection, we also asked parents how they decided when to bring a concern to their child’s PCP. The majority of parents (n=23) reported having minimal hesitation or reservation about raising concerns with their child’s PCP. In some cases, parents described the PCP as their first step when they perceive a problem (eg, “Any time I find an issue with any of my kids, I go straight to their PCP.” ID10)

#### **Institutional delays**

Some parents (n=8) reported experiencing delays in the detection process that resulted from a problem with care coordination (vs, eg, a delay in the availability of appointments). Specific examples included not being called to schedule a PSG after a referral (see institutional follow-up), not getting the PSG results (“I never got the paper in the mail” ID13), or delays in follow-up care after the PSG (“So we were just sitting there laying in limbo for a good month.” ID13).

#### **Parent as advocate**

A minority of parents in the sample (n=5) described their experience advocating to their child’s provider or others in the health care system. This theme included parental actions that: 1) went beyond reporting symptoms or raising concerns with the provider, and 2) were characterized as attempts to actively overcome barriers during the process. This included overcoming a provider initially minimizing symptoms (“They are trying to say it is not a big thing. Which I say to them, big deal.” ID16), directly asking for a referral (“I’m the one that had to kind of take the reins and tell them, hey guys, look, let’s do this.” ID23), or reaching out to providers to identify next steps (“So I had to call a month later and talk to my doctor about her sleep study.” ID13).

#### **Lingering questions and concerns**

A minority of parents (n=5) described lingering questions or concerns after the OSA detection process had concluded. Lingering issues included lack of symptom reduction (“They told

me he’ll sleep better after the surgery, but I don’t think that’s true.” ID3), residual OSA symptoms (“I am not convinced he is 100% apnea free.” ID5), or the perception that their child could have OSA despite a negative study (“... you’re describing her to a T, but they said she doesn’t have [OSA]” ID12).

### **Parent experiences**

Three parent experiences were identified that did not fit into specific categories, specifically parental worries at various points throughout the process, observed benefits of OSA detection and treatment in their child, and a desire to do what was necessary to help their child.

#### **Worries**

Worries were reported by many parents (n=12) related to their child’s breathing at night. Some worries pertained to the potential short- and long-term consequences of poor breathing at night (eg, “Will that affect his brain?” ID3). Other parents (n=5) reported worries about upcoming surgery for OSA (eg, “I was nervous for her to go ahead and have the surgery of course.” ID14). In a few cases, parents (n=3) reported their current or prior belief that their child could die in his/her sleep (eg, “[OSA] can even kill you in your sleep.” ID23).

#### **Whatever it takes**

Parents (n=5) described a willingness to take any necessary steps to promote their child’s wellbeing. One parent (ID2) noted she would do “... anything to figure out what the problem is.” Another parent (ID4) described feeling “like [her son] was suffering, and I didn’t know where to find the problem, so I just did everything.”

#### **Benefits of OSA detection and treatment**

Of those whose child had a positive PSG and subsequent treatment (n=7), many (n=4) noted improved functioning in their child. Parents observed benefit during the day (eg, “She doesn’t sleep in class anymore.” ID1), at night (“... he’s sleeping better.” ID15), and more globally (“[Provider] said she would be a different child ... It’s a big difference.” ID1).

## **DISCUSSION**

This study is the first to use qualitative methodology to identify parental experiences around OSA detection in their child. One study strength is the inclusion of a diverse sample of parents from backgrounds associated with higher risk of OSA and lower likelihood of timely detection. Several findings emerged with important implications for intervention efforts to promote timely OSA detection in children.

### **Role of the community**

Routes to OSA detection described by parents were highly heterogeneous and involved individuals from a variety of roles (*it takes a village*), including parents, PCPs, specialists, and teachers. While intervention efforts to improve OSA detection have focused primarily on provider education and activation to date,



study findings highlight opportunities to engage other community stakeholders in OSA detection. A pilot study<sup>23</sup> demonstrated feasibility and promising initial outcomes for an intervention in which childcare teachers were trained to identify symptoms of OSA in napping children. Others<sup>31</sup> have recommended school as an important setting for universal OSA screening and guidance, though we are not aware of any studies that have evaluated this approach. Research on OSA detection in adults has leveraged other community settings and approaches (eg, health fairs, peer health educators)<sup>32</sup> to raise awareness around OSA.

### Role of providers and the health care system

Notably, most children in our sample were not identified through universal screening for OSA in primary care, despite American Academy of Pediatrics guidelines<sup>5</sup> recommending this practice. This is consistent with prior work showing low rates of screening for snoring and other OSA symptoms in pediatric primary care.<sup>6</sup> For many parents in our sample, the health care system was ultimately successful in providing evidence-based care (ie, appropriate referral for snoring children) and, where appropriate, treatment and positive outcomes (benefits of OSA detection and treatment). Less clear is whether earlier OSA detection could have yielded even better outcomes for children in our sample, as well as for the many children whose OSA remains undetected. It will be important to continue to test interventions that promote universal OSA screening in primary care and other medical settings.

Encouragingly, parents reported a clear willingness to bring up concerns about their child with the PCP (low threshold for raising concerns), which, in many cases, led to OSA detection in their child. Providers were also identified as a source of OSA information for families (sources of knowledge), and trust in providers was a common facilitator for parental follow-through with the PSG referrals (trust in provider). On the contrary, themes highlighted several ways in which aspects of the health care system provided barriers to OSA detection. This included minimization of symptoms and institutional delays in scheduling and follow-up care (institutional follow-up) which, in a few cases, resulted in a child not receiving a PSG.

Interestingly, wait times for PSGs did not emerge as a parent-reported barrier despite a wait of several months for PSG appointments in our community during the study timeframe. This suggests that problems or delays in care coordination (eg, getting a PSG scheduled, hearing results) may be more problematic for parents. One possible explanation is that problematic care coordination could result in a child not receiving testing or treatment at all, arguably a worse outcome than delayed care. It will be important to examine systems-level factors (between and within health care systems) that promote OSA detection and follow-up care. A number of strategies have been identified to improve care coordination in other areas of health<sup>33,34</sup> and could be applied to pediatric OSA. For example, use of patient portals to promote access to results and patient-provider communication, electronic medical record interoperability across health systems, electronic alerts to the referring provider when a referral appointment is not completed, and

active case management are strategies that could help reduce delays and missed opportunities for OSA detection and treatment.

### Role of parents

Parents in our sample played a critical and active role in their child's OSA detection through actions such as identifying daytime and nighttime symptoms (day and night), raising concerns with their child's provider, taking their child to referral appointments (eg, PSG, otolaryngology), and, in a few cases, advocating to overcome barriers (parent as advocate). Factors that facilitated successful parental involvement included identification of a problem in their child (something is wrong) and taking steps to understand (wanting to know) and address (whatever it takes) that problem. It will be important to consider ways that interventions can leverage these parental strengths to activate parents in promoting OSA detection.

It is also important for researchers and providers to appreciate that the detection journey may be difficult for parents who experience barriers to care (institutional delays), worry about their child's health (worries), and even, in a few cases, experience misplaced blame from teachers (misplaced blame). Similarly, children with undetected OSA may experience blame from parents for OSA symptoms (eg, sleeping conceptualized as laziness).

### Role of OSA knowledge

Both qualitative and quantitative data yielded insights about the potential role of parental OSA knowledge in the OSA detection process. Parental knowledge was highly variable between parents and between OSA topics. A few key areas were identified with important implications. Many parents perceived a problem during the day or the night (something is wrong) but didn't have the required information to identify OSA as the potential problem. Relatedly, many parents observed both nighttime symptoms (eg, snoring) and daytime problems (eg, sleepiness or mood problems) in their child but did not initially connect these occurrences (missing the night-day connection). Another knowledge gap identified in the study was parental perception of snoring as normal, endorsed by 30% of the sample in the knowledge assessment, and emerging as an interview theme (snoring is normal). This estimate is slightly lower than that identified in previous studies (31%–51%)<sup>18,27,28</sup> likely because many parents in our sample had enhanced knowledge of OSA due to their experience with their child's OSA symptoms or diagnosis. As snoring can arguably be considered a gateway sign of OSA, the presence of which should trigger further evaluation,<sup>5</sup> parental perception of snoring as signifying normal or even high-quality sleep can be considered a significant barrier to OSA detection. Cardiovascular consequences also emerged as a common knowledge gap even among the more experienced parents in our sample, though it is less clear the extent to which this knowledge might have impacted parental activation and promoted OSA detection.

Taken together, gaps in OSA knowledge represent a barrier to OSA detection. Enhanced parental awareness around OSA signs and symptoms could activate parents to raise concerns with their

child's health care provider and complete follow-up appointments. Health communication messaging could play an important role by helping parents to recognize nighttime OSA symptoms (eg, snoring) as problematic and potentially connected to daytime problems (eg, mood problems, sleepiness). Given higher prevalence and lower likelihood of timely detection in some demographic groups (eg, lower rates of detection in both Black children and in children living in disadvantaged neighborhoods), health communication strategies should be developed for and with these individuals at greater risk for unidentified OSA. A tailored website for promoting awareness of OSA among Black adults has been developed for adult OSA<sup>35</sup>; we are not aware of a comparable resource for pediatric OSA.

## Limitations

Generalizability may be limited by the use of a sample that included overrepresentation of parents from minoritized racial and ethnic groups (73.3%) and from lower socioeconomic status backgrounds (86.6% with Medicaid insurance). However, inclusion of underrepresented groups also constitutes a strength of the study because this is a population that has higher risk for OSA yet has historically been silenced. A related limitation was that our sample did not include many parents from some racial or ethnic minority groups (eg, only 6.7% Hispanic). Further, we only included parents of younger children (2–12 years), which did not allow us to assess parental perspectives on OSA in adolescents. Some of the themes may be specific to our local health care systems and less likely to apply universally to other systems, such as institutional delays in PSG scheduling. Our assessment of OSA knowledge provides important comparative insights about which areas of OSA are more or less understood by parents during the detection process, but interpretability is somewhat limited by the use of a sample of parents whose children were at various stages in the detection process (eg, some awaiting PSG, others postsurgery). Further, study findings may have underestimated the role of certain structural barriers to PSG completion, given that most of our sample lived within 20 miles of the sleep center and had Medicaid insurance (which covers procedure cost and transportation to the sleep center) for their child. Nonetheless, this study is the first to examine parental perception of OSA detection and yields promising findings to guide future work.

## CONCLUSIONS

In sum, this study identified several key components of parental experience around OSA detection in their child. Although the critical role of the health care system in OSA detection has long been recognized, this study highlighted the important roles that activated parents and other community members can play. Several themes inform potential intervention targets to improve OSA detection. Better parental awareness of OSA symptoms as problematic and relating to daytime sequelae could activate parents to discuss OSA with their child's provider. Like a pharmaceutical advertisement, health communication materials could prompt parents to recognize symptoms in their child and ask their child's

doctor about OSA. Study findings are currently being used to develop a health communication infographic about pediatric OSA that could be disseminated through a variety of avenues. Studies examining community-engaged approaches for screening, detecting, and treating OSA in adults have identified effective channels to reach the Black community<sup>32</sup>; these approaches should be extended to reach parents of young children. In addition, OSA awareness and screening in community settings such as schools or churches could further identify at-risk children and activate parents to raise concerns with their child's provider. Relatedly, it is important for PCPs to directly screen for snoring to identify children whose parents do not perceive snoring as worrisome or problematic. Knowledge gaps could be addressed through parent-provider interactions as well as accessible health communication materials, which might also serve to alleviate parental worries and support parents in advocacy and decision-making around their child's OSA. Finally, study findings speak to the importance of detecting pediatric OSA, as treatment can have a significant positive impact on children and families ("It made all the difference." *IDI4*).

## ABBREVIATIONS

ID, participant identification number  
OSA, obstructive sleep apnea  
PCP, primary care provider  
PSG, polysomnogram

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## SUBMISSION & CORRESPONDENCE INFORMATION

**Submitted for publication November 8, 2021**

**Submitted in final revised form March 29, 2022**

**Accepted for publication March 29, 2022**

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## DISCLOSURE STATEMENT

All authors have seen and approved the final manuscript. Institution Where the Work was Performed: Indiana University School of Medicine. The study and Dr. Honaker's time was funded, in part, with support from the Indiana Clinical and Translational Sciences Institute, funded in part by grant number UL1TR002529 from the National Institutes of Health, National Center for Advancing Translational Sciences, Clinical and Translational Sciences Award. Dr. Honaker's time was also supported by the National Heart, Lung, and Blood Institute of the National Institutes of Health under award number K23HL150299. The authors are grateful to the study participants for sharing their experiences. We also acknowledge the technical expertise and efforts of the individual members of the Child Health Informatics and Research Development Lab (CHIRDL) team and the Pediatric Research Network (PREsNet) at Indiana University School of Medicine. Study data were collected and managed using REDCap electronic data capture tools hosted at Indiana University.<sup>1,2</sup> REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The authors report no conflicts of interest.