

Perspectives on paediatric sleep disordered breathing in the UK: A qualitative study

Catherine Haighton^{1*} PhD, Rose Mary Watson¹ MSc, Janet A Wilson² MD FRCS, Steven

Powell^{2,3} MSc FRCS

1. Faculty of Health and Life Sciences, Northumbria University, UK
2. Population Health Sciences Institute, Newcastle University, UK
3. The Department of Otolaryngology (Ear, Nose and Throat) Newcastle upon Tyne Hospitals NHS Foundation Trust, UK

*Corresponding author:

Catherine Haighton, B125, Coach Lane Campus West, Northumbria University, Newcastle Upon Tyne, NE7 7XA, Email: katie.haighton@northumbria.ac.uk

Twitter: @HaightonKatie, @Esor84, @JanetAnnWilson, @steve_m_powell

Abstract

Background

There is limited understanding of treatment pathways for paediatric sleep disordered breathing. We explore current UK pathways and what is important to well-being for parents/children.

Methods

In-depth qualitative interviews (n=22) with parents of children (2-9 years), with symptoms of sleep disordered breathing referred to a regional ENT clinic (n=11), General Practitioners who might refer these children to ENT (n=5), Hospital Doctors involved in treating these children (n=6). Interviews were audio recorded, transcribed verbatim, anonymised, and analysed thematically.

Results

General Practitioners rarely identify seeing paediatric sleep disordered breathing; conversely Hospital Doctors identify unsuspected issues. Parents are worried their child will stop breathing. Routes to referral/diagnosis are not straightforward. Modern technology can aid investigation/diagnosis. Patient weight is an issue for General Practitioners and Hospital Doctors; adenotonsillectomy is the treatment of choice; information on paediatric sleep disordered breathing is needed.

Conclusions

Guidelines for the management of paediatric sleep disordered breathing are needed.

Word count 150

Keywords: Sleep Apnea Syndromes; Sleep Apnea, Obstructive; Tonsillectomy, Adenoidectomy; Child; Parents; Quality of Life; Decision making, shared; Referral and Consultation

Introduction

Paediatric sleep disordered breathing is a spectrum from simple snoring to partial or complete temporary airway obstruction during sleep (obstructive sleep apnoea (OSA))^{1,2}. UK studies show 12% of 4–5-year-olds snore and up to 2% have OSA^{1,2}. Snoring can cause micro-arousals and impact sleep quality, while obstruction causes sleep fragmentation or even hypoxia^{3,4}. Paediatric sleep disordered breathing has been linked to disturbances in concentration and behaviour during the day⁵ leading to reductions in academic performance⁶; quality of life issues for both children and their families^{7,8}; and anxiety and concern for the family overnight⁵.

A common cause of sleep disordered breathing is large adenoids and tonsils and the most common treatment is adenotonsillectomy⁹. Around 16,000 paediatric tonsillectomies took place in England in 2016 for OSA, at a cost of £30m to the NHS, making it one of the most common surgical procedures for children in the UK⁹. Surgery has benefits but also risks, especially bleeding and in very rare cases can be life-threatening¹⁰. There is also inter-regional variation in UK surgical rates¹¹, in part reflecting variation in natural history - some children have no long-term sequelae¹², some improve spontaneously without surgery¹³.

There is limited exploration of treatment pathways for paediatric sleep disordered breathing. A USA qualitative study, of parent¹⁴ and health professional¹⁵ decision making in paediatric sleep disordered breathing found that parents reported urgently seeking treatment due to fear that their child would stop breathing, or for behavioural/cognitive delays. Tonsillectomy is the third most common surgical procedures in the USA¹⁶. In 2011 it was reported that more than 530,000 tonsillectomies were performed in children and adolescents in the USA every year because of recurrent throat infections or sleep-disordered breathing¹⁷. However, according to parents, surgery was often considered as a last resort and parents had explored

alternate therapies prior to seeing a surgeon. The authors concluded that shared decision making, in which parents receive evidence-based information regarding risks, benefits, and alternative treatments may reduce parental decision conflict and improve decision quality¹⁴¹⁵. However, no decision support tools were generated and a similar study within the UK context is warranted.

Therefore, we explored UK parents', general practitioners' (GPs) and hospital doctors' (HDs) views, concerns and decision making about sleep disordered breathing of children in their care. The aim was to better understand the care pathway for these children and determine what is important to the well-being and peace of mind for parents and children.

Materials and methods

Ethical approval

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. A favourable ethical opinion was obtained from: South Central - Hampshire B Research Ethics Committee (ref number 18/SC/0378); approval to go ahead with the study was obtained from the Health Research Authority (IRAS ID: 239892); R&D approval was received from Newcastle Upon Tyne Hospitals NHS Foundation Trust (R&D number: 8841).

Recruitment

A clinical secretary screened upcoming ENT appointments on a monthly basis to identify eligible patients aged 2-9 years with sleep disordered breathing symptoms. The appointment letter included a study information sheet. At the appointment, parents of patients were invited by their clinician to consent to the collection of a small amount of clinical data about their child and for the parent to complete a validated questionnaire. Patients with serious

comorbidities or existing health conditions were excluded. With consent, parent contact details were passed on to the study team who invited them to participate in an in depth qualitative interview.

Sample

Parents were purposively sampled in order to ensure variation in regard to gender and age of child. GPs who might refer children to ENT for sleep disordered breathing and HDs involved in treating children with sleep disordered breathing (such as respiratory paediatricians and consultant ENT surgeons) were approached by the study team through known contacts as a convenience sample.

Interviews

All participants were sent a letter confirming their interview along with an information sheet and were asked to sign a consent form prior to the interview taking place. A study ID number was allocated to each participant once consent had been given. Parent participants received a £10 high street shopping voucher to compensate for time and travel expenses. Interviews were carried out either face to face or over the telephone at the convenience of the participant. Interviews lasted up to one hour and were semi-structured based on flexible topic guides (see supplementary data). The topic guides, based on the literature and discussion among the study team, explored symptoms, impact, management and treatment of paediatric sleep disordered breathing (reported here) plus views about data collection tools and willingness to be randomised into a surgical trial (reported elsewhere). Interviews, conducted between 09/2018 and 04/2019 by a trained and experienced qualitative researcher (RW) unknown to the participants, were audio recorded, transcribed verbatim, anonymised and coded following standard procedures of rigorous qualitative analysis¹⁸. Coding was then discussed within the research team as part of the development of the themes presented here.

Results and analysis

Participants

Eleven parents, out of 23 approached, consented to participate in the in depth qualitative interviews (three declined, six were unable to be contacted using the details provided, three lost contact before consent and interview completed). Five parents were interviewed face to face and six by telephone (see table I). Five GPs and six HDs also participated, and most were interviewed over the telephone, with two face to face interviews (see table II).

Table I and Table II here

The emergent themes are presented below, with illustrative quotations.

GPs rarely identify seeing children with sleep disordered breathing even when parents raise concerns; conversely HDs pick up unsuspected issues

All GPs sampled regularly recalled seeing adults with sleep disordered breathing but very rarely children despite regular paediatric consultations. Our sample of HDs by nature of their role, regularly saw children with sleep disordered breathing. In fact, one ENT consultant commented on seeing more patents for sleep disordered breathing than they did for tonsillitis. This was reported to be as a result of increased patient awareness and the increasingly strict guidelines for the management of sore throat and indications for tonsillectomy:

“I’ve seen more for sleep disordered breathing, rather than tonsillitis now...15 years ago, it would have pretty much all been tonsillitis...the guidelines for not doing as many tonsillectomies for tonsillitis has certainly had an impact, I think.” (DIPS HD6)

Parents in our sample fell into one of two distinct categories of lived experience of a child’s sleep disordered breathing. Just over half of the parents knew that there was an issue with their child’s breathing at night but had struggled to get the problem acknowledged by their

GP. One parent recalled being made to feel dishonest. While this lack of acknowledgement motivated most parents to push for a referral, it led one parent to stop bringing up the issue:

“I just feel like I was never really listened to...we’ve been to two doctors’ medical groups because we moved and even the first one, they were the same...almost like a brush off, ‘He’s fine. Yes, they’re big [tonsils] but they’re fine.’ I do feel as a parent...when it’s your child and you’re being ignored that makes you quite annoyed about it, doesn’t it? ...when I’m pushing for [child’s name] and just being ignored you almost then think, ‘I’m just making it up. It’s me, I’m making it up. That’s not really happening.’ You do start to question whether you’re just imagining it, or, you know, is it Munchausen that you have when you push illnesses on your children? ... so, I just stopped even mentioning it.” (DIPS P1)

The second group of parents in our sample had not considered sleep disordered breathing as an issue. Their children had either been under hospital investigation for another chronic issue such as hearing loss or had attended hospital for an acute problem such as tonsillitis or a chest infection. Sleep disordered breathing had emerged during a comprehensive paediatric ENT assessment. A couple of parents recalled feeling guilty about their oversight although both recounted having previously spoken to their health visitor and having been reassured that there was nothing to worry about:

“She’s always made a bit of a noise when she was a baby. I just put it down to being normal because nobody told me. The health visitor witnessed her sleeping, and nobody really said, ‘Oh, that’s not normal.’ So, I didn’t really realise.” (DIPS P15)

Parents are really worried their child will stop breathing

Parents in our sample were unanimous in their concern about the serious night-time consequences of sleep disordered breathing. Parents described their children as having large tonsils which resulted in snoring and stopping breathing at night:

“Just massively enlarged tonsils...he was sleeping in our bed and we noticed that he actually did hold his breath...and he is quite a bad snorer.” (DIPS P13)

Parents also spoke about the significant psychological effects on them and their child’s sibling(s) including anxiety, stress, and sleep deprivation from co-sleeping or watching to make sure their child was breathing:

“Well, it disturbed my sleep, so it had an effect on me because I was constantly watching her and making sure she was breathing.” (DIPS P6)

In addition, many parents reported that their child would be tired in the morning and more prone to mood swings or behavioural issues. Other less frequently cited symptoms included nasal congestion, mouth breathing, poor academic performance, susceptibility to ear/throat infections and bed wetting. Two parents cited problems with hearing as their primary concern.

There was a disconnect in our study between parents being concerned about serious night-time consequences and GPs being more worried about the daytime symptoms. For the few children with sleep disordered breathing that GPs could recall seeing, GPs reported a variety of physical, behavioural, and emotional symptoms such as: tiredness, low mood, irritability, tantrums, lack of concentration, grunting, being spaced out, restlessness, high temperature, reduction in school performance and high rates of upper respiratory infections. GPs did however also acknowledge loud snoring, stopping breathing, and adopting unusual positions in bed a night. Many of the GPs in our sample reported that it was mainly parental worry or family anxiety that triggered further investigation and that many parents wanted things

“fixed”. GPs recalled this was often because of family sleep deprivation with siblings sharing with noisy snorers and parents staying awake to check on their child:

“The parents are worried. That’s the main thing I suppose...Most of them are quite worried about it and I confirm that there might be some obstruction and they want it sorted really.” (DIPS GP2)

Some GPs felt that they should take more notice of daytime behavioural symptoms as this was often a more common presentation:

“If what they’re doing is being dozy during in the day and sleeping and bad behaviour...maybe we should have a higher index or suspicion that there’s something going on during the night...I think that might be worth eliminating if somebody is presenting with these kinds of symptoms.” (DIPS GP2)

HDs in our sample made a very clear distinction between night-time and daytime symptoms relying primarily on those experienced during the night. The most common night-time symptoms were reported to be regular night-time waking and snoring, but HDs reported other symptoms such as spells when children stop breathing, restlessness, disturbed sleeping patterns, bedwetting, and mouth breathing (with neck extended):

“You know, it’s often first of all the night-time itself, I usually like to know a little bit about what time they go to bed and what time they wake up to set the context...I then focus on when they’re asleep as to whether they are noisy or not and then trying to ascertain whether it’s snoring or something else...then we get into the morning time symptoms. How easy are they to wake up, are they full of beans and full of life?”
(DIPS HD5)

HDs were naturally cautious when only behavioural symptoms were reported:

“The most common reason that they would come and see me...would be that they're waking, all the time, through the night, and coming into the parents' room. But in my experience, that's more often behavioural than OSA.” (DIPS HD1)

Daytime symptoms were reported by HDs to include tiredness, irritability, naughtiness, picky eating, difficulty breathing, and hyperactivity. Reduced academic performance, inattention and poor behaviour at school were also reported by HDs as symptoms but of less importance to overall diagnosis as this could be a result of several different factors:

“I always ask about how they're doing at school, but I think, in the kids we see, there are so many variables feed into how they do at school that, again, it's difficult to say how much is due to their sleep and how much isn't.” (DIPS HD3)

Other symptoms reported by HDs included upper respiratory infections, runny nose, tonsillitis, very large tonsils/adenoids, delayed growth, and failure to thrive. Once again parental anxiety featured heavily in HDs account of reported symptoms:

“Usually, when a child's got sleep-disordered breathing, the parents have got a bit of sleep disturbance as well. Sometimes they're overly anxious – well, 'overly' depends on the severity of the apnoea, I suppose, but sometimes parents are very anxious.”
(DIPS HD4)

Routes to referral and diagnosis are not always straight forward

In terms of diagnosis, some GPs in our sample reported that sleep disordered breathing would not be their first concern given this combination of symptoms and lack of time within a single consultation. In addition, one GP would want to rule out more serious and rarer conditions (such as leukaemia) first:

“It’s probably one which I wouldn’t go to straight away because there can be so many reasons for this presentation...it’s often that they’re all intertwined with physical and mental health, and working out what the initial factor may be outside of the scope of the first 10-minute consultation” (DIPS GP1)

HDs in the sample reported identifying children with sleep disordered breathing whether they had been referred for it or not:

“Yes, but more often than not, they're [GPs] not referring for that [OSA]. Certainly, in my experience, they refer them with respiratory problems, and then it's something that gets picked up as part of the clinic. The parents say that they snore all the time.” (DIPS HD1)

Just over half of the parents reported asking their GP for a referral to ENT where sleep disorder breathing was diagnosed. One request followed information gleaned from an overnight trip to A&E for tonsillitis while another from social media:

“So, he had behavioural issues at school...I was doing some reading online, and somebody shared a post on Facebook about the amount of children who are wrongly diagnosed, and it’s to do with their sleep pattern. Some of the things that they were talking about was, “Does your child snore at night? Does he sleep with his mouth open? Does he have instances where they stop breathing?” and in all those situations, the answer was yes. So, I went to see the doctor and they saw us pretty much straightaway...she referred him.” (DIPS P4)

Three parents were referred to ENT by their GP but for hearing problems or tonsillitis and were only subsequently diagnosed with sleep disordered breathing. One parent, who had spoken to their GP a number of times about their child’s sleep disordered breathing

symptoms was eventually referred to ENT and ultimately diagnosed via a recommendation from a hospital allergologist

“We found out he had a peanut allergy two years ago and we’ve been having the tests with Dr [name] at [local hospital]. The last time we went I mentioned it to her that I thought in the night-time he was really struggling with his breathing again. He’s allergic to dust mites as well, so that’s another... You know, it all mixes in doesn’t it? So, when she looked, she said, ‘Oh yes his tonsils are really big.’ And I said, ‘Yes, but I’ve said this to the doctor [GP] numerous times and I just kept getting fobbed off,’ and she said, ‘Well I’ve put it in my notes to the doctor and I’ll say that I think he should be referred to ENT.’ So sure enough as soon as she did that we got a referral.” (DIPS P1)

Modern technology can aid investigation and diagnosis

In terms of investigation, most GPs in our sample reported wanting to look in the patient’s throat to see if they had large tonsils. However, they might also measure neck size, listen to the chest, take the patient’s temperature, a blood test for thyroid function or a chest x-ray but as there were other issues that cause tiredness some GPs would request a full blood count, a ferritin (iron) level and renal function test. Some GP would ask the family to keep a sleep diary to establish the severity and frequency of symptoms including standing outside the child’s room listening to what their breathing was like. For some GPs this would also aid in making a funding request for NHS tonsil surgery access:

“So, symptom diary. Not just to check out if anything else is causing the sleep problems, but also if there needs to be a funding request, if you can demonstrate the severity of the symptoms and the feature of the symptoms, that would be really helpful

for when the ENT team come, or whoever is seeing the patient in hospital, complete a funding request.” (DIPS GP1)

HDs in the sample were unanimous that they would start with a detailed history of the patient’s symptoms, followed by a thorough examination of the child. For those children where the history was unclear, HDs reported requesting sleep studies. These either took place in hospital overnight or with home pulse oximetry. HDs reported that modern technology was making history taking much easier as many parents recorded their child’s sleep disordered breathing on their smart phones, a sentiment echoed by one of the parents:

“Increasingly we ask people if they can, and often they bring it in without being asked, bring us a video of it. That’s incredibly helpful if they’ve managed to capture the top part of the child and you can see their face and neck and top chest. The top of the chest you can often tell quite a lot by watching, so that’s useful.” (DIPS HD5)

Some parents had done their own investigating either by searching online, reading literature provided by the doctor or by asking friends for their experience. However, other parents reported they either did not want to, or did not need to, do any research as they had experienced similar symptoms themselves or had another child with similar symptoms:

“I’m more one for going to the doctor and seeing what they say. I’ve got my own health problems at the minute and I don’t think Dr Google is always what it’s cracked up to be.” (DIPS P15)

Patient weight is an issue for GPs and HDs but was not mentioned by parents

Many of the GPs in the sample talked about the issue of sleep disordered breathing and weight and that if the child was overweight, they would suggest weight loss and only refer for further investigation if the child had a normal BMI. Weight was also raised as an issue by a couple of the HDs and was a reason to discuss potential issues with sleep however it was also

a reason not to refer for surgery. Parents did not talk about their child's weight in any of the interviews.

Adenotonsillectomy is the treatment of choice, particularly for parents

In the first instance GPs in our sample would advise diet and lifestyle changes plus weight loss and making sure bedding was allergy free and positioned so that the child's head was upright as well as trying different sleep positions. Some GPs felt that another option might be a steroid nasal spray, commonly used with adults with congestion, but only within the permitted age groups and only if they were proven effective in children. For children with an uncertain aetiology, or a clear history of OSA, or if the symptom diary revealed a disrupted sleep pattern and altered behaviour during the day then GPs would request a referral for further investigation. GPs reported that parents of children with sleep disordered breathing simply wanted to be referred and like most patients, were looking for a quick fix:

“So, ‘I have these symptoms. Well, I need to have an operation, or I need a pill.’”

(DIPS GP1)

GPs reported making a shared decision with parents to refer patients for a definitive diagnosis from an ENT specialist early on. GPs would explain to parents that a referral was for further investigation and/or management explaining that there may or may not be the need for an operation under general anaesthetic with the associated risks such as bleeding, sore throat, and infection. GPs also reported the importance of involving children in the decision-making process giving them age-appropriate explanations of what might happen. Although GPs reported that parents worried about the risks of surgery this concern was outweighed by the fear that their child might stop breathing:

“... ‘I’m just so worried that they’ll stop breathing at night.’ That fear, I think, seems to outweigh, for most parents, the risk of surgery.” (DIPS GP3)

GPs also felt that as a child's anatomy was going to change, and they were more prone to snoring at a young age then watchful waiting might be the best option. Despite this, GPs felt it important to let parents know that they were taking their concerns seriously and would review patients being treated via watchful waiting "*...so, they don't feel they are just being abandoned.*" (DIPS GP2). GPs felt they had limited treatment options other than watchful waiting or referral:

"There's a limit to what you can do, really. It's either wait and see or refer." (DIPS GP3)

For HDs in the sample, where there was clear indication of sleep disordered breathing, the primary treatment choice was adenotonsillectomy. Despite clearly explaining the associated risk, such as bleeding, infection and anaesthetic risks, HDs reported that this was often the preferred treatment option for parents too. For less clear cases most HDs reported a more cautious wait and see approach. Despite being the lowest risk treatment strategy HDs reported watchful waiting was often the most difficult strategy to recommend:

"So sometimes doing nothing is the safest thing to do but isn't the easiest thing to persuade people to do." (DIPSHD5)

Other treatments, each mentioned by a single doctor, included antibiotics, nasal steroids and positioning to prevent children sleeping on their backs.

Most parents in the sample were (pleased to be) offered an adenotonsillectomy and many of them recalled having been informed of the associated risks and benefits. The remaining couple of parents were happy to either have their child monitored via a sleep study or to wait and see if their child grew out of their symptoms. Previously parents had managed their child's sleep disordered symptoms with decongestants, pain relief, antibiotics and other

measures including leaving the window on a night vent, propping up with pillows, reassurance and being relaxed about food avoidance.

More information is needed for General Practitioners, Health Visitors, Teachers, and parents/children

GPs in the sample suggested more education for teachers and health visitors might help in highlighting the symptoms of sleep disordered breathing:

“...more education for health visitors, because I suspect they’re the group that probably are at the best position to identify it...because they’re the ones; they’re the ones that will get the parents saying they don’t sleep.” (DIPS GP3)

HDs in the sample suggested more information be made available for parents and children as much of the literature was focussed on sleep disordered breathing in adults:

“I don’t know whether there is enough information out there to be honest. It’s dominated by the adult market, I think. Very dominated.” (DIPS HD5)

While one patient thought that guidelines targeted at GPs would be useful:

“Maybe it’s just something they’re [GPs] not, not, not trained in...just to help have some guidelines probably.” (DIPS P1)

Discussion

Our research echoes that from the US^{14 15} in that parents sought treatment for paediatric sleep disordered breathing due to fear that their child would stop breathing. However, it differs in that, in our sample, surgery was considered the treatment of choice in the UK - rather than as a last resort as in the US.

Despite GPs being asked to be vigilant for paediatric OSA ¹⁹ the GPs in our study reported rarely seeing children with sleep disordered breathing. Our findings are consistent with other research evidence that has shown that GP consultations can result in under reporting of sleep problems in children. For example, in one study, parents reported that GPs raised sleep problems in only 10.1% of symptomatic children ²⁰. Another study reported that only 15% of symptomatic children from two community-based general paediatric clinics had documentation of sleep problems in case notes, with diagnosis recorded in 2% and treatment not recorded at all ²¹. A further study reported that only 34% of US paediatricians were confident in evaluating sleep problems in children and adolescents, with only 25% confident to treat them ²².

Other research has also highlighted problems with securing appropriate GP referral to ENT. In one study parents of children experiencing recurrent sore throat and tonsillitis also reported the need to request or even demand referral for the surgical removal of the child's tonsils ²³. Adult ENT patients experiencing recurrent sore throat have also reported negotiating the potential barriers facing them in accessing treatment ²⁴.

It was interesting to note that modern technology was reported to aid investigation in our study. With the emergence of covid-19 and guidance published in January 2021 by the World Health Organization recommending "use of pulse oximetry monitoring at home as part of a package of care" ²⁵ there has been widespread enthusiasm for, and ownership of, pulse oximeters by lay people with many people with acute covid-19 able to learn how to use a pulse oximeter and willing to take regular readings ²⁶. An increase in use of paediatric pulse oximeters at home may consequently increase the identification of symptoms related to sleep disordered breathing by parents.

There was a clear disconnect in our study between parents being concerned about serious night-time consequences of paediatric sleep disordered breathing and GPs being more worried about the daytime symptoms. Similar disparities have been reported between physician and adult patients' perceptions of the problems of habitual snoring²⁷. While GPs have recently been encouraged to focus on daytime symptoms,¹⁹ we found that the HDs in our study made a very clear distinction between night-time and daytime symptoms, relying primarily on those experienced during the night. Some GPs in our study also reported that sleep disordered breathing would not be their first concern given the combination of symptoms and lack of time within a single consultation.

Our results confirm the views of Savini et al that there is a need to increase clinician awareness of paediatric OSA to reduce the rate of late diagnosis and avoid OSA-related sequelae²⁸. The NHS patient website does not refer directly to [paediatric] sleep disordered breathing but only to OSA and there is no information specific to children (<https://www.nhs.uk/conditions/sleep-apnoea/>). While the NHS site recommends consulting a GP who “may refer to a specialist sleep clinic for tests” the 'gold standard' treatment for adult OSA is Continuous Positive Airway Pressure (CPAP)²⁹ but this is not well tolerated by children²⁸. According to the National Institute for Health and Care Excellence (NICE) children should be referred to a paediatric ENT specialist if they have clinical features of adenotonsillar hypertrophy, symptoms of persistent snoring, and features of OSAS³⁰. NICE also state that secondary care treatments for OSA in children with clinical evidence of adenotonsillar hypertrophy should be adenotonsillectomy but that CPAP may need to be considered in rare cases where adenotonsillectomy is contraindicated or not likely to be beneficial³¹.

Guidelines for the management of OSA are only available for adult patients³². In the current study parents suggested a need for guidelines for GPs to aid diagnosis of sleep disordered

breathing in children. This is particularly important as GPs are well placed to identify and refer children with sleep disordered breathing. In contrast GPs reported that more education and training should be aimed at health visitors and teachers who, they believed, were more likely to see first-hand the symptoms of sleep disordered breathing. Therefore, multidisciplinary guidelines for the management of obstructive sleep apnoea in children may be needed.

This paper reports the first qualitative study to investigate parent and health professional decision making in paediatric sleep disordered breathing in the UK. Data is based on 22 in depth qualitative interviews carried out by an experienced qualitative researcher, but the research was carried out in only one geographical location and the sample of parents included only one father. Further research is needed within other regions and with a greater variation in sample.

Acknowledgements

We thank all the parents, hospital doctors and general practitioners who participated in this research.

Financial Support

This work was supported by the Newcastle upon Tyne Hospitals NHS Charity. The authors have no competing financial interests.

References

1. Ali N, Stradling J, Loughlin G, et al. Sleep and breathing in children: A developmental approach. 2000
2. Bonuck KA, Chervin RD, Cole TJ, et al. Prevalence and persistence of sleep disordered breathing symptoms in young children: a 6-year population-based cohort study. *Sleep* 2011;**34**:875-84
3. Biggs SN, Walter LM, Nisbet LC, et al. Time course of EEG slow-wave activity in pre-school children with sleep disordered breathing: A possible mechanism for daytime deficits? *Sleep Medicine* 2012;**13**:999-1005
4. Primhak R, Kingshott R. Sleep physiology and sleep-disordered breathing: the essentials. *Archives of Disease in Childhood* 2012;**97**:54-58.
5. Mitchell RB, Kelly J. Behavior, neurocognition and quality-of-life in children with sleep-disordered breathing. *Int J Pediatr Otorhinolaryngol* 2006;**70**:395-406
6. Galland B, Spruyt K, Dawes P, et al. Sleep Disordered Breathing and Academic Performance: A Meta-analysis. *Pediatrics* 2015;**136**:e934-46
7. Lee C-H, Kang K-T, Weng W-C, et al. Quality of life after adenotonsillectomy in children with obstructive sleep apnea: Short-term and long-term results. *International Journal of Pediatric Otorhinolaryngology* 2015;**79**:210-15
8. Torretta S, Rosazza C, Pace ME, et al. Impact of adenotonsillectomy on pediatric quality of life: review of the literature. *Italian journal of pediatrics* 2017;**43**:107-07
9. NHS Digital. Hospital Episode Statistics. UK, 2016
10. Connolly H, Tomaselli L, McKenna Benoit M. Adenotonsillectomy for pediatric obstructive sleep apnea: how to predict those at risk for postoperative complications. *Journal of Clinical Sleep Medicine* 2020;**16**:3-4
11. Suleman M, Clark MPA, Goldacre M, et al. Exploring the variation in paediatric tonsillectomy rates between English regions: a 5-year NHS and independent sector data analysis. *Clinical Otolaryngology* 2010;**35**:111-17
12. Tal A, Veloso P, Goldbart A. Obstructive Sleep Apnea Syndrome in Children. In: Springer, ed. *Pediatric Respiratory Diseases* 2020
13. Marcus CL, Moore RH, Rosen CL, et al. A Randomized Trial of Adenotonsillectomy for Childhood Sleep Apnea. *New England Journal of Medicine* 2013;**368**:2366-76
14. Boss EF, Links AR, Saxton R, et al. Parent experience of care and decision making for children who snore. *JAMA Otolaryngology-Head & Neck Surgery* 2017;**143**:218-25
15. Boss EF, Links AR, Saxton R, et al. Physician Perspectives on Decision Making for Treatment of Pediatric Sleep-Disordered Breathing. *Clinical Pediatrics* 2017;**56**:993-1000
16. Wilkes J. Tonsillectomy in Children: AAO-HNS Updates Guideline. *American family physician* 2019;**100**:316-17
17. Randel A. AAO-HNS guidelines for tonsillectomy in children and adolescents. *American family physician* 2011;**84**:566-73
18. Rapley T. Some pragmatics of qualitative data analysis. In: Silverman D, ed. *Qualitative Research Fourth Edition* 2016
19. Harrison R, Edmiston R, Mitchell C. Recognising paediatric obstructive sleep apnoea in primary care: diagnosis and management. *British Journal of General Practice* 2017;**67**:282-83
20. Blunden S, Lushington K, Lorenzen B, et al. Are sleep problems under-recognised in general practice? *Archives of disease in childhood* 2004;**89**:708-12
21. Chervin R, Archbold K, Panahi P, et al. Sleep problems seldom addressed at two general pediatric clinics. *Pediatrics* 2001;**107**:1375-80
22. Owens J. The practice of pediatric sleep medicine: results of a community survey. *Pediatrics* 2001;**108**:e51
23. Lock C, Baker R, Brittain K. 'I've just taken you to see the man with the CD on his head': the experience and management of recurrent sore throat in children. *J Child Health Care* 2010;**14**:95-110
24. McSweeney LA, Rousseau NS, Wilson JA, et al. Stakeholders' views of recurrent sore throat, tonsillitis and their management: a qualitative interview study for the National Trial of Tonsillectomy IN Adults (NATTINA Part 1). *Clin Otolaryngol* 2017;**42**:301-06

25. World Health Organization. COVID-19 clinical management: living guidance, 25 January 2021., 2021
26. Greenhalgh T, Knight M, Inada-Kim M, et al. Remote management of covid-19 using home pulse oximetry and virtual ward support. *BMJ* 2021;**372**
27. Scott S, Ah-See K, Richardson H, et al. A comparison of physician and patient perception of the problems of habitual snoring. *Clinical Otolaryngology* 2003;**28**:18-21
28. Savini S, Ciorba A, Bianchini C, et al. Assessment of obstructive sleep apnoea (OSA) in children: an update. *Acta Otorhinolaryngol Ital* 2019;**39**:289-97
29. National Institute for Health and Care Excellence. Continuous positive airway pressure for the treatment of obstructive sleep apnoea/hypopnoea syndrome (NICE technology appraisal 139). <http://www.nice.org.uk>, 2008
30. National Institute for Health and Care Excellence. Obstructive sleep apnoea syndrome Management <https://cks.nice.org.uk/topics/obstructive-sleep-apnoea-syndrome/management/management/>, 2015
31. Powell S, Kubba H, O'Brien C, et al. Paediatric obstructive sleep apnoea. *BMJ* 2010;**340**
32. Scottish Intercollegiate Guidelines Network. Management of Obstructive Sleep Apnoea/Hypopnoea Syndrome in Adults. (SIGN 73) A national clinical guideline 2003

Summary

What is already known

- Sleep disordered breathing is common and OSA may affect up to 1 in 30 children.
- Paediatric OSA can be associated with serious consequences if left untreated but children may present with behavioural problems and poor attention, which parents may not necessarily link to a sleep disorder.
- Obesity is a risk factor and is thought to be responsible for rising levels of paediatric OSA.

What this study adds

- GPs reported rarely seeing children with sleep disordered breathing despite hospital doctors regularly doing so with parents reporting being worried their child would stop breathing.
- Routes to referral and diagnosis were not straightforward but modern technology, such as smart phones, aided investigation.
- Patient weight was an issue for GPs and HDs but not was not mentioned by parents.
- Adenotonsillectomy was the treatment of choice particularly for parents.
- More information, for GPs, Health Visitors, Teachers, and parents/children was reported to be needed.

Tables

Table I: Parent/guardian participants

Number	ID code	Parent gender	Child gender	Child age
1	DIPSP1	Mother	Male	9
2	DIPSP3	Father	Male	5
3	DIPSP4	Mother	Male	3
4	DIPSP6	Mother	Female	4
5	DIPSP8	Mother	Female	7
6	DIPSP9	Mother	Male	9
7	DIPSP10	Mother	Female	4
8	DIPSP11	Mother	Female	9
9	DIPSP12	Mother	Female	4
10	DIPSP13	Mother	Male	8
11	DIPSP15	Mother	Female	6

Table II: Health professional participants

Number	ID Code	Role	Gender
1	DIPSGP1	GP, ad-hoc primary care GP sessions	Male
2	DIPSGP2	Senior partner in GP practice	Female
3	DIPSGP3	Locum GP	Female
4	DIPSGP4	Practice GP	Female
5	DIPSGP5	Practice GP	Male
1	DIPSHD1	General and respiratory paediatrician	Female
2	DIPSHD2	Consultant ENT surgeon	Male
3	DIPSHD3	Respiratory paediatrician	Female
4	DIPSHD4	Consultant ENT surgeon	Male
5	DIPSHD5	Consultant in respiratory paediatrics	Male
6	DIPSHD6	Consultant ENT surgeon	Male

Supplementary data

GP Topic Guide

Opener

- Can you tell me about how your role in treating children with sleep disordered breathing?

Symptoms

- Can you tell me about the symptoms that children report in relation to sleep-disordered breathing?
 - Physical?
 - Emotional?
 - Behavioural?
 - History/pattern?

Effects

- Can you tell me what parents/children report are the effects of sleep-disordered breathing on the child/parent(s)/family?
 - School/Work?
 - Social Life?
 - Family Life?

Management/Treatment

- How do you manage/treat their symptoms?
- How/who are involved in these decisions?
- In your opinion what treatment do parents/children want?
- What do you consider the risk/benefits of these treatments?

Research

- Experience of RCTS
- Equipoise?
- Willingness to refer?
- Value of research?
- Views of potential outcome measure?

Hospital Doctor Topic Guide

Opener

- Can you tell me about how your role in treating children with sleep disordered breathing?

Symptoms

- Can you tell me about the symptoms that children report in relation to sleep-disordered breathing?
 - Physical?
 - Emotional?
 - Behavioural?
 - History/pattern?

Effects

- Can you tell me what parents/children report are the effects of sleep-disordered breathing on the child/parent(s)/family?
 - School/Work?
 - Social Life?
 - Family Life?

Management/Treatment

- How do you manage/treat their symptoms?
- How/who are involved in these decisions?
- In your opinion what treatment do parents/children want?
- What do you consider the risk/benefits of these treatments?

Research

- Equipoise?
- Willingness to randomise?
- Value if research?
- Views of potential outcome measure?

Parent/Guardian Topic Guide

Opener

- Can you tell me about how your child ended up under the care of ENT at the Great North Children's Hospital?

Symptoms

- Can you tell me about the symptoms that your child has experienced in relation to sleep-disordered breathing?
 - Physical?
 - Emotional?
 - Behavioural?
 - History/pattern?

Effects

- Can you tell me how sleep-disordered breathing effects your child/you/your family?
 - School/Work?
 - Social Life?
 - Family Life?

Management

- How do you and your child manage their symptoms?
- How/who were involved in these decisions?

Treatment

- Tell me about your treatment journey
- What treatment have you tried for your child's condition?
 - GP?
 - Consultant?
- What treatment would you like to have for your child's condition?
- How/who were involved in these decisions?
- What do you consider the risk/benefits of these treatments?

Research

- Experience of questionnaires?
- Views of potential outcome measure?
- Willingness to be randomised? Toss coin to demonstrate randomisation