

Evaluation of Parental Perspectives and Concerns About Pediatric Tonsillectomy in Social Media

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IMPORTANCE Tonsillectomy is common in children, but little is known about parental preferences and values concerning this surgical procedure. Twitter offers an opportunity to evaluate parental understanding and experience of tonsillectomy care.

OBJECTIVE To identify parental perspectives about tonsillectomy in children that may not be apparent in a routine clinical encounter.

DESIGN, SETTING, AND PARTICIPANTS In this qualitative study, social media platform Twitter was searched for posts (tweets) published between January 1, 2008, and December 31, 2017, by US-based parents about their child's tonsillectomy. Modified grounded theory was applied to develop a coding taxonomy to classify the tweets. Tweets were assessed for thematic synthesis and classification, and descriptive statistics were obtained for each theme.

MAIN OUTCOMES AND MEASURES Themes of parental experiences and perspectives about their child's tonsillectomy.

RESULTS Of the 5801 total tweets retrieved, 782 (13.5%) satisfied the inclusion criteria. Tweets were categorized under 2 overarching themes: procedural concerns (549 tweets [70.2%]) and attitudes or experiences (498 [63.7%]). Common tweets under procedural concerns mentioned surgical indication for tonsillectomy (55 tweets [7.0%]); eg, "strep-I think it's tonsil removing time..." and recovery (227 tweets [29.0%]), including child's attitude (89 tweets [11.4%]; eg, "so hard to get my daughter to eat") and parental experience (87 tweets [11.1%]; eg, "tonsillectomy recovery sucks for the parent as much as the kid!"). Common tweets regarding attitudes or experiences included the tenor of overall care (225 tweets [28.6%]; eg, "Tonsillectomy is a bear") and fears or apprehensions (209 tweets [26.6%]).

CONCLUSIONS AND RELEVANCE These social media findings may be used to guide clinicians in educating and counseling parents as well as further engaging parents and children in shared decision making for tonsillectomy.

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Tonsillectomy is one of the most common surgical procedures performed in children in the United States,¹ with 530 000 performed annually.² Sleep-disordered breathing, ranging from snoring to obstructive sleep apnea, is the most common indication for pediatric tonsillectomy.^{3,4} Parents experience moderate conflict over the surgical decision because of its associated morbidities.⁵ Risks and sequelae of tonsillectomy include severe postoperative pain; bleeding or dehydration; and complications of general anesthesia, including respiratory distress and, in rare cases, mortality.⁶ Furthermore, a multicenter randomized clinical trial, the Childhood Adenotonsillectomy Study, showed that a sizable minority of

children with obstructive sleep apnea have resolution of symptoms over time without tonsillectomy.⁷ As such, the surgical decision may be complex and multifaceted for the parents,⁸ and they may seek information from external (eg, online) sources to enhance their decision and knowledge.⁹

Shared decision making, whereby physicians present all treatment alternatives and make joint decisions with parents on the basis of the preferences and values of the child and family, is known to reduce decision conflict.^{5,10} However, parental concerns are often not shared with, or made clear to, the clinician during surgical consultation.¹¹ Posts on social media about tonsillectomy provide insight into parental perspec-

tives that may not be expressed to clinicians or researchers. Such social media sources may assist in evaluating patient-centered outcomes of health care. Specifically, Twitter has been used to gauge public education and awareness about breast cancer prevention modalities and treatment¹² as well as public response to the US Preventive Services Task Force 2013 draft guidelines on lung cancer screening with low-dose chest computed tomography.¹³

Social media perspectives may augment previous qualitative research that examined parental reactions to tonsillectomy. For example, in a qualitative study of parental experiences with pediatric tonsillectomy, fear of anesthesia persistently overshadowed the risks of the direct procedural complications of the surgical procedure. However, parents rarely discussed, and surgeons rarely addressed, anesthesia risks during their child's consultation.¹⁴ In this study, we systematically review parental comments on Twitter to gauge parents' questions, concerns, and ideas about tonsillectomy in children. We expected that findings will enhance counseling and shared decision making for tonsillectomy.

Methods

Data Source and Extraction

The Johns Hopkins University Institutional Review Board approved the study protocol. Informed consent was waived by the Johns Hopkins Institutional Review Board because all of the data were derived from publicly posted tweets. The search strategy was created using a 4-phase process flow, similar to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) method of reporting systematic literature reviews.¹⁵ We conducted this search on Twitter because of its global and vast use. Twitter is a microblogging social media platform with more than 320 million active monthly users who send approximately 6000 tweets (Twitter posts) per second, totaling up to 500 million tweets per day, about "what is happening in the world and what people are talking about right now."^{16,17}

We searched every publicly posted tweet written between January 1, 2008, and December 31, 2017. The time range was broad to allow the retrieval of a large sample of tweets and the identification of trends as well as to facilitate the retrieval of themes that could emerge as a result of a time difference. A list of 10 search phrases was created by combining a primary phrase that searched for tweets involving tonsillectomy (eg, tonsillectomy) with a pediatric phrase that narrowed the search to pediatric tonsillectomy (eg, daughter). In some search items, an operator (ie, keyword typed into the search bar) was included to further exclude extraneous tweets and narrow the search parameters (Table 1). Duplicate tweets from the same user were removed.

The entire database of collected tweets was screened using specific inclusion and exclusion criteria. Tweets were included if they (1) were written in English and (2) included an opinion, reaction, or view regarding the tonsillectomy of the user's child. Tweets were excluded if they (1) were posted from a location outside of the United States; (2) were written by a user younger than 18 years; (3) were unrelated to pediatric tonsillectomy; (4) had identical thematic content from the same user (ie, "my son's tonsillectomy was rough" and "I can't believe my son's tonsillectomy

Key Points

Question What do parents post on Twitter regarding their perspectives and experience of their child's tonsillectomy?

Findings In this qualitative study of 782 tweets (Twitter posts) from US-based parents of children who underwent or needed a tonsillectomy, parents expressed concerns about their child's surgical indications, their child's attitude and nutrition during recovery, and their own experiences.

Meaning Identifying parent-reported perspectives and experience of pediatric tonsillectomy may guide clinicians in surgical counseling and engaging children and their parents in shared decision making.

was that hard!" conveyed similar information); (5) were affiliated with or represented a health care organization or if the user provided any professional medical advice in current or past tweets; or (6) contained a fragmented or unfinished comment because of Twitter's character limit. We also excluded secondary tweets (ie, comments made in response to a primary tweet). Figure 1, following the PRISMA systematic review format, details tweet extraction and inclusion methods.¹⁵

Prior to analysis, data were evaluated to ensure that they met the qualitative recommendations for valid content analysis. Unlike quantitative analysis, which requires large samples, the methodological goal of this qualitative study was to achieve thematic saturation. This saturation occurs when the collection of new data offers no additional insight.¹⁸ Saturation is considered by many to be a criterion standard in qualitative methods in which smaller samples are acceptable.¹⁹ Concrete sample size requirements for qualitative research are rarely provided. However, Van Kaam²⁰ estimated a minimum of 25 participant descriptions in phenomenological studies, and Guest et al²¹ determined that saturation occurred within the first 12 interviews in field studies with West African women.²²

Statistical Analysis

All tweets were analyzed using directed content analysis, in which a final coding scheme was created that combined relevant initial thematic content with emerging themes based on cumulative tweet content. The coding scheme was developed according to knowledge and findings from previous research (eg, parental fear of anesthesia,¹¹ physician communication, and recommendations) and emerging themes.²³ A representative sample of 100 tweets was initially used to identify major themes and create initial coding categories before the complete analysis.^{24,25} After the initial categories were created, all collected tweets were read and manually coded word by word by one of us (T.K.H.). Themes were not considered mutually exclusive. Therefore, each tweet was coded for relevance to all identified themes. All initial and emergent themes were categorized into domains, major themes, and sub-themes (Figure 2). Two hundred tweets (approximately 25%) were manually double-coded by another one of our researchers (V.H.) and evaluated to establish high interrater agreement.²⁶ Analyses were performed to confirm adequate interrater reliability. Tweets within each theme were enumerated, and frequencies

Table 1. Keywords Searched on Twitter^a

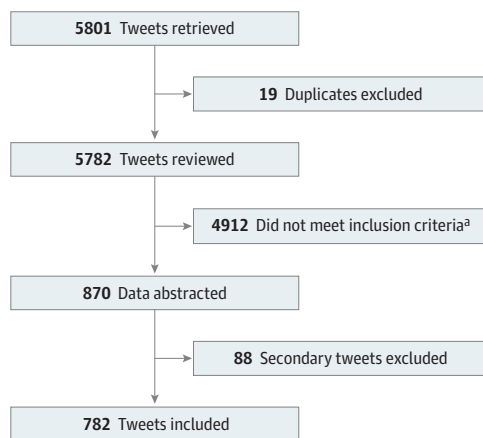
Primary Identifier	Pediatric Identifier	Operator ^b	Search Phrase
Tonsillectomy	Kid	- Tonsillectomy	Tonsillectomy kid
Tonsil	Baby	- Tonsil	Tonsillectomy baby
	Child		Tonsillectomy child
	Son		Tonsillectomy son
	Daughter		Tonsillectomy daughter

^a Search = Primary identifier + Pediatric identifier - Operator.

^b Operators are functions typed into the search bar with keywords to help narrow the quantity and content of retrieved tweets. The -tonsillectomy operator excluded tweets that included the word *tonsillectomy* to prevent

duplicates in data retrieval. The -tonsil operator was needed because of the large number of extraneous tweets that did not contain any content on tonsillectomy.

Figure 1. Process of Exclusion



^a Number of excluded tweets represents the difference between the number of tweets meeting inclusion criteria, and the total number of tweets procured during the initial search. Tweets were excluded cumulatively and not logged on an individual thematic basis of age, nationality, content, or other factors.

were generated by obtaining the frequency of each theme and calculating a percentage of the 782 total tweets that met the inclusion criteria. All analyses were performed using Stata, version 13.0 (StataCorp LLC).

Results

In total, 5801 tweets were retrieved and 782 (13.5%) satisfied the inclusion criteria (Figure 1). The demographics of Twitter users were not available. After the evaluation of all tweets identified in the search using content analysis, we identified no further emergent themes, and we considered this sample appropriate to reach thematic saturation.²⁷ Of the 782 tweets, 265 (33.9%) were posted before, 40 (5.1%) were posted during, and 441 (56.4%) were posted after the child's tonsillectomy, and 36 tweets (4.6%) were posted at an undetermined time. κ Analysis showed an overall high interrater reliability and exceeded the agreement threshold of 80%, with greater than 80.9% observed agreement ($\kappa = 0.32$; 95% CI, 0.17-0.48). Two overarching themes were identified: procedural concerns (549 [70.2%]) and attitudes or experiences (498 [63.7%]). The tweets within the domains, themes, and subthemes of procedural concerns are outlined in Table 2.

Overarching Theme 1: Procedural Concerns

Parents often focused on aspects of the tonsillectomy procedure (664 [84.9%]) (Table 2). These themes included beliefs regarding the indication for tonsillectomy (55 [7.0%]) as well as the physical issues (227 [29.0%]) and nonphysical experiences (251 [32.1%]) of recovery, including postsurgical complications.

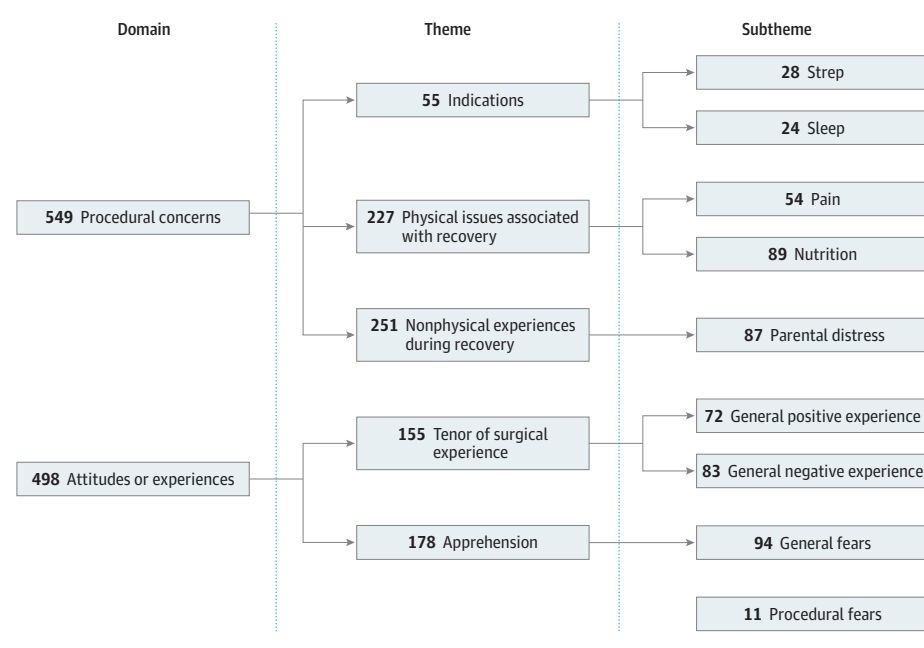
The most common parent-tweeted indication for their child's tonsillectomy was a recurring illness (55 tweets [7.0%]; eg, "strep- I think it's tonsil removing time..."), followed by sleep issues (24 tweets [3.1%]; eg, "it's going to help him sleep and breathe"). Parents posted about aspects of recovery (579 tweets [74.0%]). The most common parent-tweeted aspect of physical issues in the child's recovery was nutrition (89 tweets [11.4%]; eg, "so hard to get my daughter to eat"), which included any aspect of diet or hydration regarding the child's recovery from tonsillectomy. Parents reported their child having pain or discomfort (54 tweets [6.9%]; eg, "Seeing your child in pain and not being able to fix it is the worst"). In addition, parents occasionally tweeted about their child's voice changes (16 tweets [2.0%]), bad breath after the procedure (26 tweets [3.3%]; eg, "breath of a child after a tonsillectomy is what killed the dinosaurs"), issues with taking medication (33 tweets [4.2%]; eg, "forcing medication down your child's throat is heart breaking"), and postsurgical bleeding (9 tweets [1.2%]).

The most common parent-tweeted aspect regarding nonphysical experiences was their child's attitude and/or behavior during the recovery process (89 tweets [11.4%]; eg, "still no smiles"). Parents also often tweeted about their own difficulties associated with their child's tonsillectomy, such as loss of sleep, time off from work, or juggling multiple medical issues in the family (87 tweets [11.1%]; eg, "tonsillectomy recovery sucks for the parent as much as the kid!"). Parents tweeted about how long their child took to recover or the specific days in which recovery was better or worse (41 tweets [5.2%]; eg, "day 3 is the worst"), whether or not they believed the procedure was a success during the recovery period (21 tweets [2.7%]; eg, "used to snore like a freight train, but since her tonsillectomy on Mon she's so quiet"), and their child missing school (13 tweets [1.7%]).

Overarching Theme 2: Attitudes or Experiences

Parents tweeted about their attitudes and experiences regarding their child's tonsillectomy (634 tweets [81.1%]) that were not associated with the indications for tonsillectomy or the re-

Figure 2. Thematic Content Analysis Flowchart



covery process (Table 3). These major themes included the tenor of their overall surgical experience (225 tweets [28.7%]; eg, “Tonsillectomy is a bear”), any apprehensions they had before their child’s surgery (209 tweets [26.7%]), previously existing attitudes about tonsillectomy (76 tweets [9.7%]), financial issues (49 tweets [6.2%]), surgeon or hospital experience (40 tweets [5.1%]), and whether or not they initially wanted a tonsillectomy for their child (34 tweets [4.3%]).

Parents posted a range of perspectives on tonsillectomy, but they tweeted slightly more frequently about negative experiences (83 tweets [10.6%]; eg, “long week”) than positive experiences, including gratitude and thanks (72 tweets [9.2%]; eg, “everything went great!”). Parents tweeted most frequently about general fears and apprehensions they had before their child’s tonsillectomy (94 tweets [12.0%]; eg, “dreading tonsil surgery”) and asked for prayer for their child (73 tweets [9.3%]; eg, “Please say a little prayer for my baby today”). Infrequently, they also tweeted about specific procedural fears they had, such as general anesthesia (11 tweets [1.4%]).

Parents expressed multiple preexisting beliefs about tonsillectomy. They occasionally expressed perspectives about tonsillectomy as a routine procedure (19 tweets [2.4%]; eg, “Minor surgery but always nervous with kiddos”). Parents tweeted about financial issues of their child’s tonsillectomy, including insurance and access to affordable care (35 tweets [4.5%]; eg, “my daughter’s routine tonsillectomy cost more than an iPhone, even with excellent insurance”).

In addition, parents used Twitter to recommend and/or thank a particular surgeon and health care team (10 tweets [1.3%]). Some parents tweeted their desire for a tonsillectomy for their child (22 tweets [2.8%]; eg, “Desperately needed #tonsillectomy!”). Some tweets did not fall into the previous subthemes (24 tweets [3.1%]) and were about any scheduling (13 tweets [1.7%]) or systematic

issues regarding their child’s tonsillectomy, such as registration or speed of surgery (11 tweets [1.4%]).

Discussion

To our knowledge, this study is the first to identify and analyze parent-reported experiences and attitudes regarding pediatric tonsillectomy using social media posts. Analysis of social media posts allowed us to identify parental perspectives that may not have been expressed or elucidated during a medical encounter with the surgeon. Tweets provided a broad variety of perspectives and experiences that parents felt important enough to share spontaneously. Beyond prompted responses to standardized questions, these Tweets represent the range of diverse parental experiences before, during, and after their child’s tonsillectomy.

Patient-centered outcomes research helps physicians gain information on what outcomes matter to patients and what their expectations and fears are for surgical procedures. Surgeons may incorporate findings to help parents best assess the value of treatment options and make informed health care decisions for their children.²⁸ Studies that report patient-centered outcomes, including this current study, have helped to inform surgeons of shared decision making, a collaborative process in which patients, caregivers, and clinicians work toward a mutually agreed-on treatment plan.²⁹ Our team has previously reported qualitatively on parental experience and decision making for sleep-disordered breathing treatment,³⁰ as described during in-depth interviews. The current study contributes knowledge on additional, unreported parental concerns and broadly identifies the fears and concerns of parents.

Other research that evaluates parent-centered outcomes in pediatric tonsillectomy focus on outcomes such as disease-specific

Table 2. Representative Tweets for Procedural Concerns
Overarching Theme

Domain	Subtheme	Representative Tweet
Indications	Strep, tonsillitis, recurring sore throats, illness Sleep	Kid has strep, looks like a tonsillectomy is in his near future ...
		We got the results of The Girl's sleep study... severe sleep apnea. I'm calling the ENT today to talk about a tonsillectomy. Poor kid.
Physical issues associated with recovery	Pain	My son just woke up, lots of pain from his recent tonsil and [adenoid] removal.
	Voice, velopharyngeal incompetence	Wondering why a tonsillectomy and adenoidectomy has reduced my 3 y old to baby talk?
	Breath	But my child's post tonsillectomy breath smells like the breath of a dog that has been dead for 2 weeks in the middle of a [T]exas summer.
	Medication	Tonsillectomy recovery sucks. Not shocking, I know. Sucks to see your kid suffer & sucks when he fights taking meds. Sorry this is a downer.
	Nutrition: foods eaten, weight loss, dehydration	Yay! Becca gets to eat baby food! Or smushed and blended tater tot casserole. Tonsil removal recovery day 2 is over!
	Bleeding	I watched my son puke about a pint of blood today 5 d post tonsillectomy. That was fun.
Nonphysical experiences during recovery	Time to recover	9 y old daughter recovering from surgery last week; tonsillectomy. Ouch. Seems to be a LONG recovery. Ugh.
	Parent distress	Got 5 h of sleep. Kid with recent tonsillectomy is slightly high maintenance.
	Efficacy of procedure	Daughter's tonsillectomy successful! No snoring & no clusters since May 10! Sleep quality, a must. We hope for seizure free days. #Epilepsy
	School	My son is going back to school today after 10 d of recovering from tonsil surgery. So glad to see him better! #PTL
	Child attitude or behavior during recovery	Reading before bed. Paige is recuperating from her tonsillectomy but still makes time to read to baby brother.

Abbreviation: ENT, ear, nose, throat.

and health-related quality of life, parental knowledge about otolaryngologic disease and surgical procedures, parental satisfaction with care, and parental surgical decision conflict.^{5,31-33} Our study complements these previous studies by looking at parental experiences outside of the clinical context. True patient concerns and fears are rarely expressed in the medical visit,³⁴ and anticipating the desired outcomes from the parental point of view may add value to establishing and maintaining parent-physician relationships associated with improved results.³⁵ Our research that directly evaluated live patient consultations indicates that parents express concerns in less than 40% of encounters and that clinicians rarely directly ask about parental concerns or fears during consultations for tonsillectomy.³⁰ Moreover, clinicians may neglect to discuss aspects of the surgical procedure important to parents, such as anesthesia, and may tend to be authoritative.^{11,36} Research has demonstrated communication pitfalls, such as the clinician tendency to be verbally dominant, ask few open-ended questions, and not respond to patient fears with direct empathy.^{37,38} Furthermore, many parents exhibit limited understanding about their children's medical conditions and treatment options.^{39,40} This lack of understanding may limit the opportu-

Table 3. Representative Tweets for Attitudes or Experiences
Overarching Theme

Domain	Subtheme	Representative Tweet
Tenor of surgical experience	General positive experience or attitude	Sarah's tonsillectomy followup went great - she's good to go; got her broken baby tooth pulled and now she's ready for Galveston! #fb
	General negative experience	Tonsillectomy recovery sucks. Not shocking, I know. Sucks to see your kid suffer & sucks when he fights taking meds. Sorry this is a downer.
Apprehension	General fears	Taking my baby in the morning for her tonsillectomy and adenoid removal. Please keep us in your thoughts. It's routine, but I'm scared.
	Procedural fears	Morning "Snack Boy" goes under 2day tonsillectomy. I'm weird but he's my baby & I'm secretly freaking out abt anesthesia! #grantmepeace
	Asking for prayers for health or success	Need everyone's happy thoughts, prayers, whatever you got. My son is having tonsillectomy in am. #nervousbutterflies
	Previously existing attitudes regarding tonsillectomy	I know tonsillectomy/adenoidectomy are routine, but nothing is routine watching your child in pain. It's been 1 week, when will it end?
	Age at surgery	To parents and future parents: let your child have a tonsillectomy when he/she is young, don't wait when they are get older [sic].
	Preventive	Another defective kid. I thought we already repaired this one with the tonsillectomy, but we're off to the Dr to check for strep.
	Risky	My fear when my daughter had same procedure: (Girl Left Brain Dead From Tonsillectomy, To Be Kept On Life Support. https://www.huffpost.com/entry/girl-brain-dead-tonsil-surgery_n_4455178)
Financial		Son needs tonsil/adenoidectomy. Won't have all the \$ by 6-19, but hope kindness of Internet folks can help. Thank u. http://www.gofundme.com/2zjm40
Physician		My son is out of tonsil/adenoids surgery. Time to breathe again. God Bless the staff at Ruby.
Advocating	For	Is sick again. July 29 & tonsil surgery can't get here soon enough.
	Against	Searching for info on chronic tonsil swelling, no infection, in child. ENT consult tomorrow. Prefer natural remedies.
Other	Scheduling issues	Needs a tonsil removal but can't even see the specialist until 11/9. I'm so scared for my son!
	Systems issues	Frustrated at hospital for daughter's Tonsillectomy...dr's office screwed up told us 7:30 surgery when they planned noon.

Abbreviation: ENT, ear, nose throat.

nity for parents or patients to gather information and express concerns during consultations. As such, it is imperative to understand the concerns and priorities parents express in other media to peers, who may not be health care professionals but may be more open to listening to parental opinions.

Most tweets centered around aspects of the recovery process for children after tonsillectomy. Parents frequently tweeted about their child's post-tonsillectomy nutrition that included questions of which foods should be avoided (eg, "pretzels ... can't have them"), problems with eating or drinking (eg, "completely uninterested in Popsicles"), and issues with appetite (eg, "appetite still is low"). Nutrition made up only 11% of the full sample tweets, but 40% of the tweets regarding physical issues associated with recovery mentioned food or eating habits, which is the most frequent subtheme in that category. Parents posted more questions or comments regarding what their child could or could not eat

compared with questions or comments about any pain or bleeding, which are aspects typically prioritized in a postoperative visit.^{41,42} These findings are particularly relevant considering previous research on nutritional aspects of recovery and shortcomings in the current recommendation. Purcell et al⁴³ reported that parents were often not prepared to deal with nutritional issues for their child. Current tonsillectomy clinical practice guidelines contain no specific recommendations about diet because of the paucity of evidence about the association of diet type with recovery or complications.⁴⁴ The proportional concerns about diet and nutrition tweeted by parents suggest a need to provide additional counseling to parents around the time of the surgical procedure.

Parents frequently expressed their personal difficulties during their child's recovery. These experiences included lack of sleep (eg, "haven't slept much the last two nights"), frustration (eg, "cannot handle this child anymore"), and missed work time (eg, "so much work to catch up on ... with my son's tonsillectomy"). Because parents are the primary caregivers for the pediatric patient,⁴⁵ the surgeon may advise parents to anticipate the potential difficulties, probe for parental concerns when discussing the surgical decision, and offer recommendations when needed. Few parents tweeted about their fears regarding the procedure, including issues with general anesthesia; anesthesia was only mentioned in 8 tweets. This finding differed from the results of previous research, which indicated concerns about general anesthesia as a principal parental fear and deterrent for tonsillectomy.³⁰

Limitations

To our knowledge, this is the first analysis of parental perspectives of tonsillectomy as evidenced on social media. Despite the value of using Twitter as a legitimate data source, our analysis has some limitations. First, parents who post on Twitter may not be representative of the entire group of parents with children who undergo tonsillectomy, as differences between those who do and do not use Twitter are largely unknown.²⁶ This study reports the views of parents willing to post comments publicly on a social media platform. Therefore, it does not represent the experience of all parents with children undergoing tonsillectomy and may indicate more extreme experiences of parents wishing to voice their complaints. However, previous research on patient satisfaction surveys showed that most patients rated their physicians highly.²³ Similarly, we anticipate that most parents posting on social media are seeking to share their experiences rather than voice frustration for the sake of attention.^{46,47}

Second, this analysis does not account for temporal changes, such as the association between media coverage of tonsillectomy-related deaths and parental fears, or the changing views toward the surgical decision over time. Third, mining Twitter for terms may be limited given the type of language and symbols (eg, emoticons) used. Although language and symbols can be used to represent expressions and attitudes, evaluating them in a systematic way is difficult. Fourth, tweets could be missed either because the search did not pick them up or because parents did not explicitly state procedures (ie, "surgery" instead of "tonsillectomy" or "went to sleep" instead of "anesthesia"). Tweets could also be missed while using the selected pediatric search terms for how parents referred to the child. Finally, the demographics of Twitter users were not available, and neither the truth of a tweet nor the identity of the user can be verified. In addition, Twitter posts are brief and limited to 280 characters, which may have influenced the depth of information expressed in this study. The qualitative nature of this study also poses methodological limitations. Data were double-coded to reduce bias, but qualitative analysis is subjective by nature, and our findings may not be generalizable to the overall population of patients and their families. Furthermore, although our sample size was adequate for this qualitative analysis, it represents a small portion of the 530 000 pediatric tonsillectomies performed annually.⁴⁸ Data and thematic saturation, along with independent data coding, were employed during analysis to address these concerns.

Conclusions

This qualitative study sought to understand patient and parent-centered outcomes through qualitative thematic analysis of experiences with children tonsillectomy as reported by parents on Twitter. Parents commonly tweet their perceptions and concerns about aspects of tonsillectomy that may be underestimated or even absent in routine surgeon-parent perioperative dialogue. On Twitter, parents were able to freely discuss their child's recovery (ie, diet and nutrition), share personal difficulties, ask questions regarding cost and financial burden, and express negative attitudes regarding tonsillectomy. Some or all of these themes may not be addressed by general postoperative surveys or during postoperative medical encounters. Clinicians may find these tweets to be relevant, self-reported parental perspectives on tonsillectomy that could guide their surgical counseling and engage parents and children in shared decision making.

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Invited Commentary

The Tonsillectomy Tweet

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The phrase social media is quickly becoming a misnomer. Although initially intended to be used for networking, marketing, and entertainment purposes, social media has extended its utility into the academic and research realms. Previous research has demonstrated the ability of social media to disseminate health information quickly as well as connect individuals around the globe with similar diseases, conditions, and procedures.

In this issue of *JAMA Otolaryngology-Head & Neck Surgery*, Hairston et al¹ present a proof of concept study. The authors reviewed tweets by parents of patients needing tonsillectomy to identify concerns and aspects of their treatment course that may otherwise never be communicated or documented. This analysis is especially important given that the authors' previous research demonstrated that less than 40% of parents express their concerns and fears regarding tonsillectomy with their surgeon.² Hairston et al¹ found that most tweets centered on the child's recovery, especially as it relates to nutrition. Evidence-based nutritional guidelines are lacking, despite the ubiquitous nature of tonsillectomy.³ Broader insight into these underappreciated aspects of postoperative care may improve patient counseling and parental comfort with their child's surgical experience.

The potential for social media study to guide future research directions is also nicely demonstrated in this study. Research tends to be clinician-centric: The outcomes that matter most to clinicians are typically the most well studied. For

example, much of the recent tonsillectomy literature focuses on bleeding, postoperative pain management, and quality-of-life indexes.^{4,5} Preoperative counseling also tends to emphasize these facets of surgical procedure and recovery. This approach is intuitive, given that these are factors in readmission and/or associated with quality metrics for surgical success. However, parents most frequently tweeted about what their children could or could not eat during the recovery process. Nutrition is clearly important to parents, but there is a relative paucity of literature on nutrition in this pediatric tonsillectomy population. Mining the data available on social media represents a novel mechanism to passively survey experiences and opinions to guide future, and truly patient-centered, research.

Of course, using social media as a data source has limitations. Previous literature suggests that, similar to online reviews, social media posts may represent extremes of opinion.^{6,7} Certainly, posted content may be an accurate representation of experience. However, creative liberties may be taken to generate more buzz with sensationalized posts. In addition, millions of new posts are published each day, and analyzing each separately would not be feasible. This approach necessitates a strong qualitative method for clearly defining inclusion criteria and determining when data saturation is reached. This study demonstrates the appropriate use of qualitative data and serves as a good resource for those interested in pursuing similar studies in the future.

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