

## Main Article

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# What the blogosphere has to say about adult tonsillectomy

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## Abstract

**Objectives.** Tonsillectomy has generated extensive comment on the internet, but this content has not been examined in a scientific manner. This study aimed to determine what the blogosphere has to say about adult tonsillectomy and to report whether this information can be used to improve post-surgical care.

**Methods.** The internet was searched to find personal blogs relating to tonsillectomy. A retrospective review of data collected on these blogs was carried out and the blogs were conceptually analysed by the authors.

**Results.** Fifty blogs were included. Seventy per cent of patients had read blogs prior to their procedure. The average pain score where available was 7.2. Complications occurred in 10 per cent of patients. Only 1 patient (2 per cent) regretted having a tonsillectomy.

**Conclusion.** It is important for otolaryngologists to stay in tune with the blogosphere as this unregulated and easily accessible source of information is both friend and foe but will ultimately help in pre-operative counselling and post-operative management.

## Introduction

Tonsillectomy is one of the oldest and most commonly performed surgical procedures in otolaryngology. Adult tonsillectomy has attained significant notoriety for its post-operative morbidity, characterised by disabling pain and subsequent inability to maintain normal oral intake with increased risk of haemorrhage.<sup>1</sup> Despite this, adult tonsillectomy is regarded as a safe procedure with an estimated mortality rate of 1 death in every 20 000 procedures.<sup>2</sup>

Numerous attempts have been made to ameliorate the post-operative course. Different surgical techniques, such as coblation, have been developed in an effort to improve recovery time.<sup>3</sup> Multiple analgesic and steroid regimens have been trialled in an effort to relieve pain.<sup>4,5</sup> Post-operative diet has been scrutinised without cumulating in a universal consensus on what is most suitable to eat to aid recovery.<sup>6</sup> However, none of the aforementioned efforts have been shown to have a statistically significant impact on the challenging road that patients face after this commonplace procedure. What has been elucidated in the literature is that tonsillectomy recovery is a more painful and drawn-out process in adults than in the paediatric population; therefore, the focus of this study is on adults.

Over the past two decades, access to medical information has been revolutionised by the internet. Contemporary medicine has had to evolve to welcome the world wide web into the consultation room. A survey of patients in the USA in 2019 found that 89 per cent will research their symptoms online prior to any contact with their doctor.<sup>7</sup> Over the same time period, the process of informed consent has also been overhauled by high-profile cases such as Chester versus Afshar and Montgomery versus Lanarkshire Health Board.<sup>8</sup>

A blog (or weblog) is an informal, often diary-like, style of writing that is published on the world wide web. At its nascence in the late 1990s, blogging was reserved for those with expertise in computer software, with just 23 blogs on the entire web reported in 1999.<sup>9</sup> With the advent of more accessible technology and ease of internet access, blogging is now easier than ever, and there were over 63 343 800 blogs written in the first four months of 2020.<sup>10</sup> The blogosphere refers to the interconnected network of blogs and the plethora of information available through this forum.

Blogs offer patients a unique insight into the lives of others who have experienced a similar condition, procedure or treatment. This can offer reassurance but also inspire fear and confusion as blogging is an entirely subjective and unregulated forum. Blogs also offer a valuable learning opportunity for healthcare professionals to hear a stream of consciousness from their patients, which may otherwise never be shared in the confines of a doctor–patient relationship. Analysis of blogging on the subjects of various medical conditions and procedures has been performed in recent years; for example, bloggers' opinions about the human papilloma virus vaccine helped identify areas of concern, where more clarity was needed or where misinformation had been supplied.<sup>11</sup>

Personal experiences of adult tonsillectomy in the blogosphere have never been examined in a scientific manner to our knowledge. In this study, we report on the commentary posted by bloggers who have detailed their experience of tonsillectomy.

## Materials and methods

We identified blogs when searching the world wide web using a combination of Google®, Yahoo® and Bing®, the three most used English language search engines on the web.<sup>12</sup> English language blogs of adult patients who had personally undergone a tonsillectomy were included. Paediatric blogs, promotional blogs and opinion pieces were all excluded. Discussion boards and threads were excluded as the fragmented nature of the posts precluded adequate analysis of patient experience. All indications for tonsillectomy and all surgical techniques were included. The search was carried out between November 2019 and February 2020.

The search term used was ‘adult tonsillectomy blog’, and the search was carried out, ranking the blogs by relevance. Searches were carried out from Ireland’s internet domain ([www.google.ie](http://www.google.ie)). The top 50 blogs identified by relevance were analysed, and data were collected using Microsoft Excel® spreadsheet software (version 16.35). Statistical analysis was performed using GraphPad Prism statistical analysis software (version 8; San Diego, USA).

Given the narrative nature of blogs, conceptual analysis of the content was done by the first author, and emergent themes were identified initially using a sample of 20 blogs. Qualitative data was then collected for 50 blogs in total. Content written by bloggers was taken to be true and accurate representations of their experiences and demographic profile.

Basic demographic data were collected. Primary endpoints included exposure to blogs pre-operatively, pain score (using the Pain Numeric Rating Scale) and expressing a regret regarding the procedure. Secondary endpoints included inability to eat, whether adequate analgesia was provided, time to return to work and complications.

Google Trends was used to identify the global regions where the topic ‘tonsillectomy’ had been searched and to identify any change in search frequency over time.<sup>13</sup>

## Results

### Baseline characteristics

Out of the 50 blogs, identified characteristics are described in Table 1. Forty-one (82 per cent) were female, 5 (10 per cent) were male and 4 (8 per cent) did not specify a gender. Thirty-nine (78 per cent) of the bloggers were from the USA. The median age of bloggers was 27 years. Five (10 per cent) of the blogs were specifically health or wellness blogs and 8 (16 per cent) of the authors were professional bloggers or writers.

Thirty-five (70 per cent) of authors had read blogs by other patients prior to undertaking surgery. Twenty-one (42 per cent) bloggers stated that they had been explicitly warned by their surgeon about the morbidity associated with the post-operative period.

### Post-operative course

A breakdown of post-operative end points can be seen in Table 2. Forty-seven (94 per cent) bloggers commented on

**Table 1.** Characteristics of bloggers

Parameter*	Value
Sex (n (%))	
– Male	5 (10)
– Female	40 (80)
– Not specified	5 (10)
Age at tonsillectomy (years)	
Median	27
Interquartile range	25–36.5
Country of origin of blog (n (%))	
– USA	39 (78)
– UK	7 (14)
– Australia	2 (4)
– Canada	1 (2)
– New Zealand	1 (2)
Livelihood of blogger (n (%))	
– Blogger/writer	8 (16)
– Homemaker	6 (12)
– Student	4 (8)
– Entertainment/fashion	4 (8)
– Professionals	2 (4)
– Not specified/unclear	26 (52)
Indication (n (%))	
– Tonsillitis	36 (72)
– Diagnostic	1 (2)
– Peritonsillar abscess	1 (2)
– Sleep-disordered breathing	1 (2)
– Not specified	11 (22)
Read other adult tonsillectomy blogs prior to procedure (n (%))	
– Yes	35 (70)
– No	1 (2)
– Unclear/not specified	14 (28)

\*total n = 50

pain, with the average pain score being 7.2. Twenty-nine (58 per cent) were on opiates during the post-operative period. Five (10 per cent) patients needed to receive additional analgesics from their healthcare provider. Twenty-three (46 per cent) bloggers reported ear pain being a surprise or being much worse than anticipated. All patients were day cases, and none stated a wish to have been kept in for a night after the procedure.

Forty-two patients (84 per cent) stated they had difficulty eating after the procedure, and pain was the main reason stated in limiting intake orally. Twelve (24 per cent) also stated a difficulty tasting food or had paraesthesia of the tongue, which contributed to a lack of appetite or difficulty eating.

Five patients (10 per cent) reported a complication. There were three post-tonsillectomy bleeds and two infections requiring antibiotics. No patient required re-operation. Of the three bloggers who experienced a bleed post-operatively, only one stated they had been adequately counselled by their surgeon on what to do in the event of such a complication.

**Table 2.** Analysis of post-operative experience

Parameter	Sub-group	Value
Pain	Reported post-operative pain (n (%))	
	– All	47 (94)
	– Female	39 (97.5)
	– Male	4 (80)
	No pain (n (%))	
	– All	3 (6)
	– Female	1 (2.5)
	– Male	1 (20)
	Unspecified	
	– All	0
– Female	0	
– Male	0	
Average pain score (mean (range))	– All	7.2 (0–10)
	– Female	7 (2–10)
	– Male	4 (0–8)
	– Unspecified	
Analgesia (n (%))	Opiates	
	– All	29 (58)
	– Female	24 (60)
	– Male	3 (60)
	Needed additional analgesia	
	– All	5 (10)
– Female	4 (10)	
– Male	0	
Inability to eat (n (%))	– Yes	42 (84)
	– No	8 (16)
	– Unspecified	0 (0)
Taste disturbance/paraesthesia (n (%))	– Yes	12 (24)
	– No	38 (76)
Complications (n (%))	– Overall	5 (10)
	– Bleed	3 (6)
	– Infection	2 (4)
	– Re-operations	0 (0)
	– No complications	40 (80)
	– Unspecified	
Return to work	Median (days)	14
	Range (days)	8–30
	Unspecified (n (%))	36 (72)
Regrets (n (%))	– Yes	1 (2)
	– No	31 (62)
	– Unspecified	13 (36)
Commented on post-operative appearance (n (%))	– Yes	34 (68)
	– No	16 (32)

The median return to work was 14 days. Thirty-one patients (62 per cent) specified that they did not regret having the procedure done despite the adversity of the recovery, and one blogger stated they regretted having an adult tonsillectomy.

At statistical analysis, it was more likely that females had read blogs prior to surgery (odds ratio, 4.5;  $p = 0.1$ ; 95 per cent confidence interval, 0.79–27.05). However, this did not reach statistical significance. There was no statistically significant correlation between age and pain score.

### Google Trends

Analysis of Google Trends data over a period from 2004 to the present (the years available at time of review) showed that the search term 'tonsillectomy' was most searched in the USA, followed by Ireland, then Australia, then South Africa and the UK. There was a steady increase in the frequency of the search term 'tonsillectomy' over the same time period.<sup>13</sup>

### Discussion

The post-tonsillectomy period in adults imparts a significant economic and health burden. It is therefore imperative to try to limit the morbidity associated with this commonly performed procedure in any way possible. Information has always been key to this approach, and traditionally our knowledge has been gleaned from clinician opinions and studies.

Our study has focused on an important emerging facet of self-education in the process of informed consent. We found the majority of blogs around the subject of adult tonsillectomy were written by North American females in their twenties. This is in keeping with Google Trends data ranking the USA as the country that searched the term 'tonsillectomy' the most, and the steady increase in searches over time likely related to access to the internet and a general trend toward researching one's own healthcare.<sup>9</sup> With regard to the female predominance in our group, analysis of blogging trends has found that women are more likely to blog on personal subjects, such as experiences with tonsillectomy in this case.<sup>14</sup> Sex-related influences on pain and analgesia is an evolving area of interest in pain medicine, where post-operative pain is suggested to be more severe in women.<sup>15,16</sup> It is important to take these considerations into account, both with regard to our findings and in clinical practice; therefore, the data has been stratified by sex in Table 2.

Interestingly, only five blogs were health specific, and only eight of the bloggers were full-time bloggers or writers, reflecting a good spread across the blogosphere. The predominant indication for tonsillectomy was tonsillitis; this was in-keeping with trends acknowledged previously in the literature.<sup>3</sup> Over two-thirds of these contributors had previously read blogs on the subject of adult tonsillectomy and found themselves concerned by their fellow bloggers' experiences. Surprisingly, less than half of bloggers (40 per cent) wrote that they had been explicitly counselled on the post-operative course by their surgeon, suggesting that patients are more likely to receive information from other bloggers online than from the pre-operative consultation with their doctor. This can in part be explained by research that suggests 40–80 per cent of information provided by healthcare professionals is forgotten by the patient, supporting the provision of written information or an interlude between consultation and obtaining consent after allowing a 'cooling off' period.<sup>17</sup> However, tonsillectomy

has been found to be one of the top three highest otorhinolaryngology procedures associated with negligence claims in the National Health Service (NHS) in England; 15 per cent of claims in this study were attributed to fault in the consent process, highlighting a shortcoming at the clinician's end.<sup>18</sup>

Since 2015, following the ruling from *Montgomery versus Lanarkshire Health Board*, a clash has existed between medical paternalism and patient autonomy.<sup>19</sup> In this case, the test of materiality was introduced; this requires the surgeon to consider whether a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would likely attach significance to it.<sup>20</sup> Considering that patients' online accounts of their journey through tonsillectomy suggest a paucity of information or surprise at their own post-operative morbidity, there is a need to further examine and rectify this issue to enhance the shared decision-making process and satisfy the legal and moral duty of the operator to disclose risk. The importance of this process is reflected in the updated guidance on professional standards and ethics for doctors in terms of decision making and consent from the General Medical Council 2020. Included in the seven principles of consent outlined by this document, doctors must try to find out what matters to the patient and share relevant information about risks and benefits, tailoring the conversation to the needs and expectations of the individual.<sup>21</sup>

Almost all (94 per cent) bloggers reported pain, with an average pain score of 7.2 being observed. A pain score of above 7 is used to denote severe and disabling pain that limits activities of daily living.<sup>22</sup> Pre-operative anxiety has been linked to increased post-operative pain, with preparation and education seen to alleviate some of this.<sup>23,24</sup> Given that 70 per cent of our present contributors had been concerned about their findings online through research of other blogs pre-operatively, this offers an opportunity for clinicians to address fears proactively and offer counsel regarding the expected level of pain (severe) and unanticipated discomfort such as notable otalgia, which posed an issue for nearly half our contributors.

Another point to note is that 58 per cent of patients were prescribed opiates post-operatively, and this was largely discussed in the context of describing side-effects, most notably constipation. Ten per cent of patients needed to receive additional analgesia from their attending physicians, raising the issue that it is up to the operator to make sufficient provisions for the severity or an extended period of pain that will ultimately ensue post-operatively. This advice is particularly apposite given that all of the patients in our present study were day cases, and pain can often be less of a problem in the first 12 hours after the operation.

Secondary to pain, the inability to eat predominated post-tonsillectomy symptomatology with 84 per cent of bloggers documenting their challenges maintaining oral intake. Pain was the most notable barrier to intake, but it is worth noting that those with taste disturbance or tongue paraesthesia (24 per cent in our study) reported a prolonged period of anorexia that out-lived the painful period. There is no panacea regarding the post-tonsillectomy diet, and debate still ensues between a traditional cold liquid diet and a more contemporary textured intake. However, after reading the musings of bloggers in combination with recommendations at systematic review, it is advisable to promote the maintenance of a diet that is most palatable to the patient and not to a specific school of thought.<sup>7</sup>

In addition to pain and the inability to eat, post-tonsillectomy slough and scabbing was described by 68 per cent of bloggers, with some providing photographic accounts of themselves to counsel prospective patients on the appearance. One blogger became particularly disturbed by the presence of a retained silk tie in the oropharynx. The authors feel this is an aspect of the consent process that could be improved if we were to include sample photos of post-operative tonsillar fossae in patient information leaflets and explain briefly some of the methods used such as ties and cautery to improve patient understanding and manage expectations.

Previously, the clinician was the patient's sole source of health information, and this was subject to bias, a sometimes misplaced sense of therapeutic privilege and was at the mercy of the quality of the relationship between doctor and patient. Presently, in the technological era, a deluge of information awaits the curious patient, and it is our job as clinicians to guide them through these uncharted and unregulated waters, particularly given the majority of information online is not subject to rigorous peer review akin to medical literature.

A recent report from New Zealand found that 50 per cent of websites providing information on common otorhinolaryngological procedures omitted critical points that patients should be aware of prior to surgery. This study included hospital webpages and those written by bloggers alike.<sup>25</sup> This is a concerning thought for surgeons given that the evidence suggests 1 in 5 patients may experience a complication and again reiterates the importance of the materiality test as described in the *Montgomery* case. Therefore, it is imperative that we as clinicians reinforce the essential information that a patient needs to know pre-operatively. We must not solely rely on the patient's own efforts to ascertain information, particularly with the prevalence of inadequate medical information online as reported by Kulasegarah *et al.*<sup>25</sup>

Conversely, blogs represent an important source of information from the patient's perspective that doctors cannot offer. The blogs mentioned in this present study told tales of anxiety and misery but also relief and hope. This wide spectrum of emotion is frequently overlooked given limitations of time, insight and experience on the clinician's part. This is particularly relevant to a procedure that surgically we consider 'routine'. This is where reading a blog can be advantageous to a prospective adult tonsillectomy candidate, offering insight in what to expect. It is important to also be able to bolster patient experience with medical knowledge, and opening this forum up for discussion with a patient allows the surgeon to identify unanswered questions and inaccuracies. The diary style, uncensored narrative of a blog offers surgeons a naturalistic glimpse into the lives of their patients outside the constraints of the consultation room.

A limitation to our present study is that we searched only one internet domain. A further larger study may be best placed if it were to incorporate several domains, preferably including different languages to capture a broader blogger base. This study was intended to look at what is available to patients upon searching for a weblog online, so these patient experiences are heavily influenced by blogger demographics and the bias inherent to having a heavily female and American database. This is particularly relevant to varying indications, techniques and post-operative care geographically. It must also be taken into account that there exists a complaints bias where those who experienced a complication would be statistically more likely to publish their story online. This could lead

to outliers being present in the current group. Research into this arena can be gleaned from the customer service industry where it has been found that those who had a bad experience are three times more likely to publish an angry review online.<sup>26</sup> The haemorrhage rate in our study was 6 per cent. An event as traumatic as a post-tonsillectomy bleed is emotive and may inspire someone to share their experience. However, internationally peer-reviewed research would suggest a complication rate varying from 1.4–20 per cent, which would be in line with our finding.<sup>27–29</sup>

- Adult tonsillectomy is a commonly performed but painful surgical procedure with significant morbidity
- Blogging follows internet usage as an increasingly important source of information for patients
- Young American female bloggers made up the majority of those blogging about adult tonsillectomy in this study
- Seventy per cent had read other blogs pre-operatively and this had negatively impacted their outlook
- While 94 per cent experienced pain and 84 per cent had difficult eating, only 2 per cent (1 patient) regretted the procedure
- Blogs may be able to compliment standard medical information by adding an experiential and practical component

Based on our blogger experience, we believe that the consent process for adult tonsillectomy going forward should at the minimum include severe disabling pain (including notable otalgia), the difficulty but importance of maintaining a normal diet, warning about taste disturbance and paraesthesia, bleeding risk, and the need for two weeks' absence from work or education, in addition to all standard risks discussed regarding anaesthesia, trauma and drug reactions. The incorporation of a photo of the oropharynx post-tonsillectomy may be prudent to avoid undue concern or self-diagnosis of infection. All the aforementioned post-operative afflictions were mentioned in specific blogs as information that bloggers had not been made fully aware of before surgery. This is worrisome because previous otolaryngological research has found serious omissions on consent forms when examined.<sup>30</sup> The online information explosion has occurred in parallel to developments in the informed consent process such as the materiality test. It is now more important than ever that doctors address serious material risks; in the case of tonsillectomy, the approximate 1 in 20 000 risk of mortality is a prime example. The idea of a customisable procedure-specific tonsillectomy consent form with the above-mentioned points included is supported by our findings.

In addition, we suggest that the blogosphere is a powerful and easily accessible source of information for patients; however, given the bias and the lack of regulation inherent to unregulated weblog content, the opportunity should be given to discuss ideas, concerns and expectations in those 70 per cent who do choose to refer to the online community.

Before one may become too disillusioned by the tribulations of post-tonsillectomy patients, it is important to note that despite symptom severity and duration, only one patient regretted having a tonsillectomy. The medium-to-long term reflections of bloggers were positive compared with their short-term suffering, further reinforcing the previously questioned quality of life benefit of adult tonsillectomy.<sup>31</sup>

## Conclusion

The blogosphere offers an important opportunity for the surgical community to reflect on the detailed musings of their

patient's experience peri-procedure. This is particularly useful in the case of frequently performed procedures with significant associated morbidity, such as adult tonsillectomy. Further larger studies should be employed to further improve our consent process and patient experience. It is important for otolaryngologists to be aware of both the positive and negative impact that the blogosphere may have on our patients and address this as appropriate.

**Competing interests.** None declared

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