

An Observational Pragmatic Quality of Life Study on Paediatric Tonsillectomy and Waiting for Surgery

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Abstract

Introduction Paediatric tonsillectomy performed for sleep disordered breathing or recurrent tonsillitis and the effects on a child's quality of life symptoms while waiting for surgery in an Australian public health system have not previously been investigated. This study investigated parental perceptions of the effects of tonsillectomy on their child's quality of life while awaiting tonsillectomy and following surgery. **Design, Setting and Participants** An observational study was undertaken at a tertiary Australian hospital. Parents of paediatric patients (2 to 16 years of age) listed for tonsillectomy completed a validated quality of life questionnaire (T-14 Paediatric Throat Disorders Outcome Test) at the initial consultation, on day of surgery, 6 weeks post-operatively and 6 months post-operatively. T-14 scores were compared using the Related-Samples Wilcoxon Signed Rank Test. **Results** Parents of 167 children participated in this study. There was a median wait time of 174 days (IQR 108 – 347) from the initial consultation until the day of surgery, with no significant change in median T-14 scores (35 [IQR 22 - 42] vs 36 [IQR 22 - 42]; n= 63; p > 0.05). There was a significant decrease from pre-operative T-14 scores to 6 weeks post-operatively (33.5 [IQR 22 - 42] vs 2 [IQR 0 - 5]; n = 160; p < 0.001), and this was sustained with a minor improvement at 6 months post-operatively (6-week 2 [IQR 0 - 5] vs 6-month 0 [IQR 0 - 2]; n = 148; p < 0.001). **Conclusion** Paediatric tonsillectomy improves the patient's quality of life as perceived by their parents with a sustained benefit in the long term. There is no improvement to the patient's quality of life while awaiting tonsillectomy, thus patient welfare can be improved through reducing waiting times for surgery.

Abstract

Objectives: To investigate parental perceptions of the effects of tonsillectomy on their child's quality of life while awaiting and following surgery in an Australian public health system.

Design: An observational pragmatic study.

Setting: A tertiary Australian Hospital.

Participants: Parents of paediatric patients (2 to 16 years of age) listed for tonsillectomy.

Main outcome measures: Parents completed a validated quality of life questionnaire (T-14 Paediatric Throat Disorders Outcome Test) at the initial consultation, on day of surgery, 6 weeks post-operatively and 6 months post-operatively. T-14 scores were compared using the Related-Samples Wilcoxon Signed Rank Test.

Results: Parents of 167 children participated in this study. There was a median wait time of 174 days (IQR 108 – 347) from the initial consultation until the day of surgery, with no significant change in median

T-14 scores (35 [IQR 22 - 42] vs 36 [IQR 22 - 42]; $n = 63$; $p > 0.05$). There was a significant decrease from pre-operative T-14 scores to 6 weeks post-operatively (33.5 [IQR 22 - 42] vs 2 [IQR 0 - 5]; $n = 160$; $p < 0.001$), and this was sustained with a minor improvement at 6 months post-operatively (6-week 2 [IQR 0 - 5] vs 6-month 0 [IQR 0 - 2]; $n = 148$; $p < 0.001$).

Conclusion: Paediatric tonsillectomy improves quality of life with a sustained benefit in the long term. There is no improvement to the patient's quality of life while awaiting tonsillectomy, thus patient welfare can be improved through reducing waiting times for surgery.

Keywords

tonsillectomy, quality of life, adenotonsillectomy, child, sleep disordered breathing, tonsillitis, sleep apnoea

Key Points

- The effect on a child's quality of life while awaiting tonsillectomy in an Australian public health system has not previously been investigated
- There are long wait times for tonsillectomy in the Australian public system compared to the private sector
- Paediatric tonsillectomy improves quality of life with a sustained benefit in the long term
- There is no improvement to the patient's quality of life while awaiting tonsillectomy
- Patient welfare can be improved through reducing waiting times for surgery

Introduction

Paediatric tonsillectomy is a commonly performed surgical procedure. In Australia in 2017-18, paediatric tonsillectomy accounted for 750 hospitalisations per 100 000.(1) The main indications include sleep disordered breathing (SDB) and recurrent tonsillitis (RT).(2, 3) These conditions adversely impact the child's quality of life (QoL) and behaviour. Furthermore, there are consequential effects on the child's parents and the health system, such as days off school translating to days off work for their parents, and an increase in presentations at primary care clinics and emergency rooms.(4-6)

Australia has a mixed public and private healthcare system where the former is entirely government-funded whereas the latter is government-subsidised with the remainder paid by the patient and their private health insurer. In 2017-18, the median waiting time for tonsillectomy (after initial specialist consultation) in an Australian public hospital was 121 days.(7) Private hospitals in Australia perform 50% more tonsillectomies than public hospitals, yet public patients wait almost 3 times longer.(8, 9) This highlights an inequality in healthcare access where there are higher rates of tonsillectomies in patients of higher socioeconomic status despite higher rates of SDB and RT in patients of a lower socioeconomic status.(10)

This study aimed to evaluate changes in QoL of paediatric patients while awaiting tonsillectomy in an Australian public hospital, following recovery from surgery, and long term.

Methods

This manuscript has been prepared with reference to the STROBE checklist for observational studies.(11)

Ethical approval was obtained from the Southern Adelaide Clinical Human Research Ethics Committee (Project number 123.17, HREC reference: HREC/17/SAC/206, approved 31 July 2017). Participants were

recruited consecutively from August 2017 to August 2018 during preadmission clinic or on the day of surgery. Parents provided written, informed consent.

An observational study was undertaken in paediatric patients placed on the elective surgical waiting list for a tonsillectomy in a public tertiary hospital in South Australia. Inclusion criteria included: age 2 – 16 years; undergoing a tonsillectomy with or without an adenoidectomy and/or grommet insertion as an elective procedure for sleep disordered breathing and/or recurrent tonsillitis.(12) Exclusion criteria comprised of: non-English speaking parents; undergoing an emergency procedure; undergoing tonsillectomy combined with additional procedure (excluding adenoidectomy/grommet insertion); cranio-facial anomalies – congenital or acquired; diagnosed with a neuromuscular disorder, a recognised congenital syndrome, a coagulation/bleeding disorder, and/or severe laryngomalacia; malignancy; tracheostomy *in situ* .

The T-14 Paediatric Throat Disorders Outcome Test was utilised to measure the patient’s symptoms and health-related QoL via parental reports.(13) This validated, sensitive tool was developed by Hopkins et al. in 2010 for use in the UK population and was adapted for use in the Australian population (Supplementary Material).(14) It is comprised of fourteen Likert-scale questions, with a total score calculated (range 0 – 70), where a higher score signifies greater burden of symptoms and lower health-related QoL (mean score of healthy controls is 0.78 [range 0 – 11]).(13) The T-14 also comprises of two sub-scores, with questions 1-6 totalling for an ‘obstruction’ symptom sub-score and questions 7-14 totalling for an ‘infection’ symptom sub-score.

Administration of the T-14 questionnaire to parents is part of the standard clinical process during the initial consultation clinic and responses were extracted from the patients’ medical chart. Whilst awaiting surgery, all patients received ongoing medical management from their primary care physician. The T-14 questionnaire was also administered on day of surgery, at 6 weeks post-operative (the standard timeframe for post-operative review at this institution as surgical recovery is assessed as completed), and at 6 months. T-14 questionnaires were administered either in person or via telephone call from an ENT doctor or member of the research team.

Data collected included: age; gender (male, female); surgical indication (SDB, RT, both); date of initial consultation, surgery, post-operative review, and 6-months follow-up; Brodsky Tonsil Grade (1 - 4, a scale to describe tonsil size)(15); surgical procedure (tonsillectomy, adenotonsillectomy, tonsillectomy & grommets, adenotonsillectomy & grommets); and T-14 scores (at initial consultation, at surgery, 6-weeks post-operatively, and 6-months post-operatively). T-14 total scores and sub-scores were calculated for each time point.

Data analysis

T-14 data was not normally distributed and therefore presented as medians with interquartile ranges (IQR). A sub-group analysis of children (age 2 – 4 years) undergoing tonsillectomy for SDB was undertaken. Statistical analysis utilised non-parametric tests, specifically T-14 scores were compared using the Related-Samples Wilcoxon Signed Rank Test. Statistical analysis utilised IBM SPSS Statistics for Windows, IBM Corp, Sydney, Australia (released 2017). Graphs were generated in Prism 9.0TM (GraphPad Software, Inc, La Jolla, CA, USA).

Results

Patient Demographics

All caregivers for 167 patients (94 males and 73 females, median age of 5.19 years) completed the pre-operative T-14 questionnaire at the time of surgery (Table 1). T-14 questionnaire data was available from the time of the initial consultation for 63 participants. Post-operative T-14 questionnaires were collected from 160 and 148 participants at 6 weeks and 6 months, respectively, with an overall drop-out rate of 12%. The demographics of the patients, surgical indications for tonsillectomy, Brodsky tonsil grade, surgical

techniques and surgical waiting times are presented in Table 1. Duration of waiting times for surgery was median 174 (IQR 7 – 529) days, with 85% of patients waiting longer than 90 days for surgery (median 184 [IQR 146.5 - 379] days). Three patients had their surgery expedited due to worsening symptoms (failure to thrive, repeated hospital admissions for treatment of recurrent tonsillitis, and worsening obstructive sleep apnoea).

T-14 Outcomes

Changes in QoL as measured using the T-14 are presented in Figure 1. Over the waiting period between initial consultation and day of surgery, there was no statistically significant difference in median total T-14 scores (35 [IQR 22 - 42] vs 36 [IQR 22 - 42]; $n = 63$; $p > 0.05$). Following surgery there was a significant decrease in median total T-14 scores at the 6-week post-operative follow up (33.5 [IQR 22 - 42] vs 2 [IQR 0 - 5]; $n = 160$; $p < 0.001$). At 6-month follow up there was a further reduction in median total T-14 score (6-week median of 2 [IQR 0 - 5] vs 6-month median of 0 [IQR 0 - 2]; $n = 148$; $p < 0.001$), with T-14 scores at a normal range.(13) Similarly, median T-14 obstructive and infection sub-scores also demonstrated no significant change while they were waiting for elective tonsillectomy (obstructive: initial 16 [IQR 12 - 19] vs day of surgery 16 [IQR 12 - 21]; $n = 63$; $p > 0.05$) (infection: initial 19 [IQR 8 - 26] vs day of surgery 17 [IQR 6 - 26]; $n = 63$; $p > 0.05$), but significant improvement at 6 weeks (obstructive: day of surgery 16 [IQR 12 - 20] vs 6 weeks 1 [IQR 0 - 4]; $n = 160$; $p < 0.0001$) (infection: day of surgery 16 [IQR 8 - 24] vs 6 weeks 0 [IQR 0 - 1]; $n = 160$; $p < 0.0001$), which was sustained with further minor improvement at 6 months post-operatively (obstructive: 6 weeks 1 [IQR 0 - 4] vs 6 months 0 [IQR 0 - 0]; $n = 148$; $p < 0.0001$) (infection: 6 weeks 0 [IQR 0 - 1] vs 6 months 0 [IQR 0 - 1]; $n = 148$; $p < 0.0001$).

A sub-group analysis of children aged between 2 – 4 years, undergoing tonsillectomy for SDB was undertaken ($n=28$; Figure 2). This sub-group waited a median of 134 (IQR 94 – 205) days for surgery from initial consultation. The median T-14 scores at initial consultation compared to day of surgery showed no significant change (34 [IQR 22 - 43] vs 33 [IQR 22 - 40]; $n = 63$; $p = 0.4224$). The median T-14 scores significantly decreased from initial consultation to 6 months post-operatively (34 [IQR 22 - 43] vs 1 [IQR 0 - 3]; $n = 28$; $p < 0.0001$). A similar response was observed for T-14 obstructive sub-scores (initial 18 [IQR 14-21] vs day of surgery 18.5 [IQR 13.25-22]; $p > 0.05$) (day of surgery 18.5 [IQR 13.25-22] vs 6 months 1 [IQR 0-2]; $p < 0.0001$).

Discussion

SDB and RT, both have significant impacts to the health and QoL of children, their families, and the healthcare system (4, 5). Tonsillectomy is a surgical treatment with reported efficacy for improving the symptom burden of children with SDB and/or RT.(2) However, tonsillectomy is generally considered a non-urgent elective procedure resulting in a large discrepancy in waiting times for paediatric tonsillectomy between the patients of the Australian public and private healthcare systems.(1) This observational study demonstrates that a child's QoL remains adversely impacted whilst waiting for elective tonsillectomy, which was often 6 months or longer, for the majority of patients undergoing treatment in a public hospital.

Children's QoL, adversely impacted whilst waiting for paediatric tonsillectomy, demonstrated minimal improvement in T-14 scores in those that met the indications for surgery.(2, 16) However, surgery significantly improved QoL by 6 weeks post-operatively and this improved QoL was maintained at 6 months post-operatively.(13) Analysis of the T-14 infection and obstruction sub-scores showed similar results with no improvement while waiting for surgery. The group of children waiting for surgery could represent a 'watchful waiting' group, who ultimately had improved T-14 scores after surgery and importantly, the improvement was sustained at 6 months post-operatively. These findings highlight the health benefit of paediatric tonsillectomy to the child's QoL and raises the importance of reducing wait times for elective surgery in the Australian public healthcare system.

These study outcomes are supported by other investigations using the T-14 questionnaire. The present study is supported by Hopkins *et al* (13) demonstrating, in a UK population, little change to QoL while awaiting tonsillectomy and a large improvement in QoL post-operatively that is sustained in the longer term. These findings are reinforced by Konieczny *et al* who used the T-14 questionnaire to demonstrate the continued benefits of tonsillectomy at follow-up after 5 years.(17) Similar findings showing substantial improvements to QoL post-operatively were reported in the Childhood Adenotonsillectomy Trial (CHAT) and other randomised clinical trials (RCTs).(18-21)

The Karolinska Adenotonsillectomy (KATE) study was an RCT comparing adenotonsillectomy with 6 months watchful waiting for management of non-severe obstructive sleep apnoea (OSA) in 53 children aged 2 - 4 years.(16) The KATE study used the Obstructive Sleep Apnea-18 (OSA-18) questionnaire as the tool to measure QoL.(22) A sub-group analysis consisting of children of similar age, SDB and wait duration showed no improvement in QoL using the T-14 scores whilst waiting for surgery and we infer our study's findings strongly support the KATE study findings and recommendations for treatment with paediatric tonsillectomy in these patients.

The strengths of this study include its pragmatic observational design, highlighting the effectiveness of paediatric tonsillectomy on patient's QoL in routine real-life clinical practice.(23) Each participant served as their own control and were followed longitudinally to determine changes in their QoL. We have previously reported that the T-14 questionnaire has high compliance with parents and is suitable for Australian patients undergoing tonsillectomy, as well as its use in assessing clinical efficacy of the BiZact tonsillectomy device.(14, 24) This study has demonstrated that parents perceive their child's symptoms do not significantly change while waiting for elective surgery. However, parents perceive a significant improvement in their child's symptoms following tonsillectomy and that this benefit is sustained even at 6 months post-operatively. We can also infer that QoL while waiting for elective surgery in children who meet criteria for tonsillectomy does not improve and therefore shortening waiting times for tonsillectomy in an Australian public hospital system would benefit a child's QoL. There are limitations in this study. Patients with SDB and/or RT are typically referred by the general practitioner to either a public hospital clinic or a private clinic. The waiting time for the public pathway to be seen in clinic is predictably longer, for example 9 months median waiting time for an appointment in an ENT clinic in our institution or 14 months at the state's children's hospital(25); whereas the estimated time for a patient to be seen in a private clinic is generally shorter. The reasons for and number of parents requesting removal of their child from the elective waiting list for tonsillectomy could not be determined, though common anecdotal reasons include improvement of symptoms, relocation to another public hospital catchment area, or undergoing tonsillectomy at a private institution. This may be a confounding factor for interpretation of this data if this occurred in large numbers.

Conclusion

This study demonstrated that children awaiting paediatric tonsillectomy have impaired quality of life, which improved to levels comparable to healthy children following tonsillectomy and this was sustained long term. This study highlights both the benefit of tonsillectomy to a child's health and wellbeing, as well as the need to address the long waiting times for patients to have their elective surgery in an Australian public hospital.

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3. Figure 2: Parental perspective of young child's quality of life with sleep disordered breathing whilst waiting for and following tonsillectomy. Legend: Children aged 2-4y with a surgical indication including sleep disordered breathing (n = 28). T-14 total scores (A) and T-14 obstruction scores (B) pre-operatively at initial consultation, day of surgery, at 6 weeks post-operatively, and 6 months post-operatively.

Supplementary Material

Table 1. Pre-surgery T-14 Questionnaire (Flinders modification)

Considering how severe the problem is when your child experiences it & how often it has happened *over the last 6 months* for your child, please rate each item on how 'bad' it is by circling the number that corresponds with how you feel using this scale:

	No problem	Very mild problem	Mild or slight problem	Moderate problem	Severe problem	Problem as bad as it can be
Snoring loudly during sleep	0	1	2	3	4	5
Irregular or stopped breathing (apnoea) during sleep	0	1	2	3	4	5
Daytime sleepiness	0	1	2	3	4	5

Noisy breathing during the day	0	1	2	3	4	5
Breathing through the mouth during the day	0	1	2	3	4	5
Problems with poor appetite or poor eating habits (choking on food etc)	0	1	2	3	4	5
Frequent earache or ear infections	0	1	2	3	4	5
Repeated short term throat infections that last less than 2 weeks	0	1	2	3	4	5
Constant or chronic throat infections that last more than 2 weeks	0	1	2	3	4	5
Many phone calls to the GP	0	1	2	3	4	5
Many visits to the family doctor or an Emergency department	0	1	2	3	4	5
Taking antibiotics over & over for less than 2 weeks at a time	0	1	2	3	4	5
Taking antibiotics for more than 2 weeks straight	0	1	2	3	4	5
Missing school days due to sore throats	0	1	2	3	4	5
TOTAL:						

Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>
	0	1	2	3	4	5
	0	1	2	3	4	5
	0	1	2	3	4	5
TOTAL: GRAND TOTAL						

Table 2. Post-surgery T-14 Questionnaire (Flinders modification)

Considering how severe the problem is when your child experiences it & how often it has happened *over the last 4 weeks* for your child, please rate each item below on how 'bad' it is by circling the number that corresponds with how you feel using this scale:

	No problem	Very mild problem	Mild or slight problem	Moderate problem	Severe problem	Problem as bad as it can be
Snoring loudly during sleep	0	1	2	3	4	5
Irregular or stopped breathing (apnoea) during sleep	0	1	2	3	4	5
Daytime sleepiness	0	1	2	3	4	5
Noisy breathing during the day	0	1	2	3	4	5
Breathing through the mouth during the day	0	1	2	3	4	5

Problems with poor appetite or poor eating habits (choking on food etc)	0	1	2	3	4	5
Frequent earache or ear infections	0	1	2	3	4	5
Repeated short term throat infections that last less than 2 weeks	0	1	2	3	4	5
Constant or chronic throat infections that last more than 2 weeks	0	1	2	3	4	5
Many phone calls to the GP	0	1	2	3	4	5
Many visits to the family doctor or an Emergency department	0	1	2	3	4	5
Taking antibiotics over & over for less than 2 weeks at a time	0	1	2	3	4	5
Taking antibiotics for more than 2 weeks straight	0	1	2	3	4	5
Missing school days due to sore throats	0	1	2	3	4	5
TOTAL:						

Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>	Please enter <i>any further important symptoms that occur as a result of your child's throat problems that we have missed from the list above and give each a rating:</i>
	0	1	2	3	4	5
	0	1	2	3	4	5
	0	1	2	3	4	5
TOTAL: GRAND TOTAL						

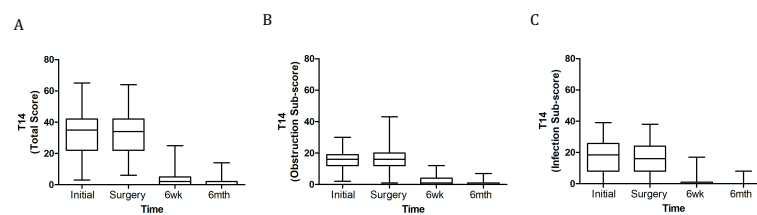


Figure 1: Parental perspective of child's quality of life whilst waiting for and following tonsillectomy.

T-14 total scores (A), obstructive sub-scores (B) and infection sub-scores (C) pre-operatively at initial consultation (n=63), day of surgery (n=167), at 6 weeks post-operatively, (n=160), and 6 months post-operatively (n=148).

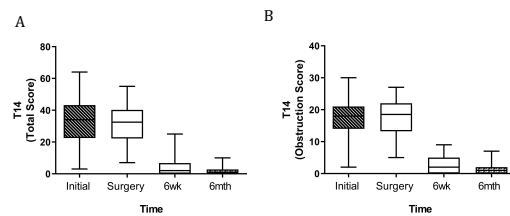


Figure 2: Parental perspective of young child's quality of life with sleep disordered breathing whilst waiting for and following tonsillectomy.

Children aged 2-4y with a surgical indication including sleep disordered breathing (n = 28). T-14 total scores (A) and T-14 obstruction sub-scores (B) pre-operatively at initial consultation, day of surgery, at 6 weeks post-operatively, and 6 months post-operatively.

Demographics	Count n (%)
n	167
Male : Female	94 : 73 (56% : 44%)
Age, years (median [range])	5 [2 – 16]
Indication	
Sleep Disordered Breathing	108 (65%)
Recurrent tonsillitis	8 (5%)
Both	51 (31%)
Waiting time for tonsillectomy	
Duration, days (median [IQR])	174 [IQR 7 - 529]
< 90 days	n = 25 (15%)
Duration, days (median [IQR])	69 [63 - 81]
≥ 90 days	n = 142 (85%)
Duration, days (median [IQR])	184 [147 - 379]
Brodsky Tonsil Grade	
1	3 (2%)
2	26 (16%)
3	106 (63%)
4	32 (19%)
Surgical Procedure	
Tonsillectomy	2 (1%)
Adenotonsillectomy	121 (72%)
Adenotonsillectomy & Grommets	43 (26%)
Tonsillectomy & Grommets	1 (1%)
Surgical Tonsillectomy Technique	
BiZact	97 (58%)
Cold Steel	56 (34%)
Bipolar Diathermy	14 (8%)

Table 1: Patient demographics, waiting time for tonsillectomy, and surgical details