Public awareness of testicular torsion is lacking in Edmonton

Neel Phaterpekar[1], Darcie Kiddoo[1], Daniel Keefe[2], Sana Samadi[1], Troy Turner[3], Peter Metcalfe[1]
[1]Department of Urology, University of Alberta, Edmonton, AB, Canada; [2]Department of Urology, Dalhousie University, Halifax, NS, Canada; [3]Department of Pediatrics, University of Alberta, Edmonton, AB, Canada

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Corresponding author: Dr. Neel Phaterpekar, Department of Urology, University of Alberta, Edmonton, AB, Canada; nphaterp@ualberta.ca

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ABSTRACT

Introduction: The time from symptom onset to intervention dictates morbidity in testicular torsion (TT). Delayed presentation negatively impacts surgical outcomes and poor knowledge about TT is hypothesized to be a potential cause of delays. Our study characterizes baseline public awareness rates among families in Edmonton and assesses the association between awareness and TT outcomes.

Methods: Patients and their caregivers completed surveys assessing TT awareness. Families were surveyed in two groups: those who presented with TT and age-matched controls. Affected families gave additional information about symptoms, time to notify parents, and present to the hospital. Outcomes were assessed at followup and through medical record review.

KEY MESSAGES

- Most pediatric patients and caregivers in Edmonton have never heard of TT.
- The pre-presentation period often constitutes the majority of the overall timeline to intervention, placing the burden on families to present promptly.
- The total time to intervention and pain severity are predictors of outcome in TT.
- Low baseline TT awareness poses a challenge for demonstrating clinical significance for TT outcomes. Therefore, a more extensive, nationwide study of awareness is warranted.

Results: Of 61 families, 18 (29.5%) patients and 22 (36.1%) parents had heard of TT. Among TT-affected patients (n=30), time to report symptoms (3.2 vs. 20.5 hours, p<0.01) and to arrive at hospital (3.0 vs. 20.8 hours, p<0.01) was significantly longer for patients requiring orchiectomy. Total time (odds ratio [OR] 0.992, p=0.01) and pain (OR 0.904, p=0.05) were associated with outcome. No differences in awareness were seen between patients who underwent orchiopexy vs. orchiectomy (23.8% vs. 25.0%, p>0.99).
Conclusions: We demonstrate that most Edmonton families have never heard of TT and that the pre-admission interval constitutes a substantial proportion of delays in surgery. Although time and pain ratings were associated with outcomes in TT, further evidence is required to demonstrate that awareness impacts outcomes significantly.

INTRODUCTION

Testicular torsion (TT) is a serious pediatric urological emergency, occurring in approximately 3.8 per 100,000 children annually[1]. It predominantly affects adolescents aged 12 to 18 and is characterized by the twisting of the spermatic cord, preventing blood flow to the testicle, and ischemia. Patients typically present with scrotal pain but may also present with non-specific symptoms, including nausea, vomiting, and abdominal pain.[2] Immediate surgical intervention is critical. This involves surgical detorsion followed by either orchiopexy or orchiectomy if the testicle is deemed nonviable.

The primary predictor of outcome in TT is the time between symptom onset and surgical intervention. The challenge of this condition is the narrow window of opportunity for testicular salvage.[1] Research indicates a theoretical 'golden window' of up to 8 hours, during which testicular viability can be preserved at rates as high as 80-100%.[1] Beyond this period, viability declines significantly; approximately 50% of patients require orchiectomy at 12 hours and over 90% by 24 hours or more.[3] Delays in recognizing symptoms and seeking timely medical attention can lead to worse outcomes. Given the importance of early intervention, the prompt recognition of symptoms by affected individuals and swift response from caregivers is crucial. Based on local unpublished hospital data, the orchiectomy rate in Edmonton is between 12-14%, with another 15% of patients having atrophic testicles at 6-week follow-up.

Studies indicate there are low rates of TT awareness among various parental populations worldwide.[4] Given the importance of seeking timely medical attention, improving TT awareness has been promoted as a means to reduce treatment delays. [5] Despite this, the awareness rates and the clinical impact of education on outcomes in torsion are poorly understood. Currently, there are no studies of TT awareness among pediatric patients in Canada, nor are there any assessments of the association between awareness and outcomes. This study aims to characterize local rates of TT awareness and assess the association between awareness and outcomes in TT.

METHODS

We recruited children assigned male at birth (AMAB) from the Stollery Children's Hospital for our retrospective cohort study between May 1st, 2023, and November 1st, 2024. One parent participated in the study for each recruited patient. Patients needed to be between the ages of 8 and 18 to participate. Families were recruited into a control group if they presented to the hospital for non-scrotal related complaints or to the affected group if TT was their final diagnosis for their visit. Human research ethics board approval was obtained (Pro00126717). Two surveys, one for the patient and the other for their parent, were distributed using the online platform REDCap. Surveys included questions about demographics, sources of health information, comfort with testicular health and whether they were aware of TT as a condition (Appendix 1). Families that experienced TT completed an additional section that included information about their presentation, including symptoms, time taken to report symptoms, time to arrive at the hospital and overall reason for presenting (Appendix 2). An electronic chart review was completed retrospectively to assess outcomes and to calculate the total time from onset to intervention.

The primary objective was to use the survey data to quantify awareness rates of TT amongst patient and parent respondents. Descriptive statistics were used for all survey responses. Torsion awareness was reported as a proportion with 95% confidence intervals. Survey responses were reported as frequencies and proportions of the total responses. Measures of central tendency were used to describe quantitative data, including comfort with testicular health, pain rating, and presentation timeline (TT timeline).

The secondary objective was to use survey data and chart review to characterize the timelines for patients presenting with TT and assess for predictors of outcome. The TT timeline was defined by the following intervals: the time from symptom onset to patient disclosure to a caretaker, the time from disclosure to local ED presentation, the time for transfer to a tertiary site from local ED, the time from triage to the operating room, and the total time to intervention. Outcomes were defined by whether a patient underwent orchiopexy or orchiectomy for their TT. The predictors included age, subjective pain rating, torsion awareness, and the various intervals of the TT timeline. Univariate logistic regression was used to assess the association between outcomes and predictors. Associations were expressed as odds ratios with 95% confidence intervals. Results were considered statistically significant if $p < 0.05$. Analysis was conducted in RStudio.

RESULTS

Surveys were collected from 61 families in the shared surgical clinics or the pediatric ED. All participants completed the surveys in their entirety. Among all patients, 18 (29.5%) reported having heard of testicular torsion or twisting of the testicle before their hospital visit and 43 (69.5%) had not. Among parents, 22 (36.1%) reported awareness, and 49 (63.9%) did not (Table 1). The estimated population rate of awareness among patients and parents, respectively**,** was 29.5 +/- 11.4% and 36.1 +/- 12.1%). Out of all families, there were 9 (14.8%) cases where both

parent and patient reported awareness of the condition, the remaining 52 (85.2%) families had at least one individual who had never heard of torsion. Families that experienced torsion reported lower rates of awareness compared to controls in both patients (45.2% vs 26.7%; p = 0.22) and parents (35.5% vs 23.3%; p = 0.45), although these differences were not significant.

30 families that experienced TT within the study period were willing to participate. 21 underwent orchiopexy**,** 8 underwent orchiectomy, 1 spontaneously de-torsed. The overall TT timeline is described in Table 2. Patients who underwent orchiectomy experienced symptoms for significantly longer before intervention compared to orchiopexy (53.7 vs 10.1 hours; p < 0.01). Within the torsion timeline, it took significantly longer for patients to report symptoms (3.2 vs 20.5 hours; p < 0.01) and for parents to take their child to the local ED (3.0 vs 20.8 hours; p < 0.01). There were no differences in the time for ED triage to the OR between groups.

Aside from time, subjective pain rating was the only significant predictor of overall outcome (OR=0.904, p=0.05). There were no significant differences in surgical outcomes between families aware of torsion and those who had never heard of the condition prior, in either parents (OR=1.01, p = 0.99) or patients (OR=1.01, p = 0.99).

DISCUSSION

Public awareness of testicular torsion is lacking

Poor awareness of TT among parents has been observed internationally, but has not been studied in Canada or in pediatric populations.[4] We demonstrate that in Edmonton, most parents and their AMAB children have never heard of TT. Awareness is the most basic form of health literacy. Our finding represents a fundamental knowledge gap involving a potentially life-changing condition that relies heavily on early intervention. Poor baseline knowledge may leave families unprepared to recognize symptoms or appreciate that scrotal pain is a time-sensitive, potentially surgical emergency. In Edmonton, more than 4 out of 5 families with children have at least one member who has never heard of TT. From a public health perspective, there is substantial room for making this condition better known among families.

In general, little is known about how children attain health information.[6] Physicians are trusted sources of health education, but time constraints and provider shortage limit the amount of time dedicated to testicular health.[7,8] Increasing reliance on the internet for health advice raises concerns about quality and credibility of information.[9] Families must recognize that website accuracy can vary widely and should be cautious of information gaps, misinformation, and overly technical language that may hinder overall understanding.[9] Emphasis should therefore be placed on generating peer-reviewed web pages that can promoted by trusted experts and health educators in secondary schools.

With public awareness among children being so low, school curricula present a natural way to address this directly. Proactively reaching adolescents in school could address the apparent gaps in knowledge and better equip individuals to seek timely medical help and

potentially reduce morbidity in the event of a torsion. TT is not listed within Alberta's Health & Life Skills or Career & Life Management curricula and is often not taught in other international educational systems.[4,10] Furthermore, no readily available Canadian resources have been made specifically for teachers who wish to educate their students about TT. It may be valuable to consider practices in other countries for insights. For example, England's National Health Service (NHS) offers an online resource for testicular health, including family-friendly educational videos and lesson plans to help grade school teachers teach about TT.[11] Creating similar Canadian-made resources could give teachers an option to incorporate this topic into health classes in Canada.

Although TT awareness has not yet been extensively studied across Canada, we anticipate that similar trends of poor awareness may exist nationwide. As such, a comprehensive national study on TT awareness could provide valuable insights into gaps in public education and identify key areas for targeted social intervention. Moreover, a cross-sectional assessment may better establish the relationship between awareness and outcomes, thereby setting precedent for improving educational efforts around this topic.

Delays in TT timeline occur prior to presentation

The outcomes of TT are primarily influenced by the duration from symptom onset to surgical intervention.[1,12] This timeframe can be divided into two distinct phases: the pre-presentation period (PPP) and the door-to-incision time (DTI). Delays occurring in either phase can significantly impact outcomes and act as potential targets for improving management of TT. In-hospital factors such as atypical presentations of TT, the unnecessary use of ultrasound, and incorrect diagnoses can contribute to delays in intervention.[13] Quality improvement (QI) initiatives targeting DTI have shown some success in addressing in-hospital delays.[14–17] However, these efforts only resulted in modest reductions in DTI (30 - 60 minutes) and there were no significant differences in overall orchiectomy rates, resulting in limited clinical impact. This likely issue arises from the notion that PPP represents a majority of the timeline. Most delays within our study occurred before arriving at the tertiary center. Consequently, greater focus should be placed on accelerating the promptness with which families seek medical attention.

One challenge is that the PPP is largely out of the control of healthcare providers, placing the onus on families to minimize delays. Adolescents experiencing acute scrotal pain must recognize and relay their symptoms, and caregivers must react appropriately. Various factors, including education, health-seeking behaviours, previous health experiences, and sociocultural and psychological pressures, can influence how patients recognize and relay their symptoms.[18] Caregivers also play a key role in seeking medical attention, which may be influenced by education, socioeconomic status, and perceived urgency of the situation.[19]

There is evidence that parents who are aware of TT would be more likely to bring their child to the hospital immediately following the onset of scrotal pain.[20] Other retrospective survey studies demonstrate that families agree that additional educational resources would likely hasten

their responses to acute scrotal pain.[10] Overall, the understanding that TT can occur among adolescents may be the first step in faster recognition and reaction. The goal of shortening the PPP and, ultimately, the time to surgical intervention would likely improve outcomes in TT.

Awareness as a predictor for outcome

Beyond time, there are few predictors of torsion's outcome. Age, degree of twisting, presence of bell clapper deformities, and seasonality have been implicated in the development of TT and its outcomes.[21,22] However, these factors are generally not modifiable and are not great targets for QI.

Presently, it is evident that education about TT is low. However, it is not clear if awareness in either patients or parents plays a significant role in the rates of orchiectomy. Interestingly, we demonstrate that patients experiencing worse pain had better overall outcomes. In this case, the development of severe pain in the presence of torsion is protective as it likely motivates patients to relay their symptoms and caregivers can respond accordingly. Notably, regardless of awareness, pain was the top reason that patients decided to present to the hospital with torsion. Thus, it is essential to consider that in cases where symptoms are severe, education about TT may not play a role in the decision to present to the hospital. Given this, if awareness does have a true impact on the TT timeline, the effect may be obscured by the substantial influence that pain has on presentation times. From our findings, it seems unlikely that awareness alone is a sufficient predictor of reporting or reaction times. However, future studies should assess the impact of awareness on orchiectomy rates while controlling for reported pain levels. Importantly, the impact of education should be explored in atypical TT presentations or cases where testicular pain is not a prominent symptom.

Limitations

It is important to recognize that awareness is a subjective measure of education, and there is no objective threshold for ideal rates of awareness within the population. The current lack of TT awareness in Edmonton is arbitrarily defined, and there are limited studies on adolescent and parent awareness of comparable pediatric emergencies to establish normative values. Consequently, determining a reasonable expectation for population awareness of TT is challenging. Moreover, our study does not delineate the extent of knowledge individuals must possess to alter their response to a potential TT**.**

Our study is limited by the use of convenience sampling to recruit participants. The generalizability of the results relies on the assumption that this sample is representative of Edmonton’s population. However, it should be noted that families presenting to the hospital may not fully reflect the broader adolescent and parent populations, and it is unclear how this might affect the accuracy of awareness reports. Furthermore, the sample sizes for the study are limited, given the relatively low incidence of torsion.

Additionally, addressing the unexpected differences in reported awareness rates between unaffected controls and families affected by torsion is important. The TT-affected group was more likely to report having never heard of the condition. This lower reported awareness among affected families likely reflects a recall bias inherent to our study. Given their recent experience with TT and their new understanding of the condition's severity, the affected group may retrospectively feel they were unaware of TT. Conversely, there may be an over-reporting of awareness among controls, as some individuals may have misconceptions about what TT is. This phenomenon has been observed in other studies on awareness.[10] Given these contextual differences between the study groups, the generalizability of our findings may be limited. Therefore, analyzing the groups independently may provide a clearer understanding of the true rates of awareness within the population. Despite these limitations, it is evident that most families remain unaware of TT.

CONCLUSIONS

Outcomes in TT are primarily influenced by the time from symptom onset to surgical intervention. In Edmonton, the most significant delays occur before reaching major urban EDs, often due to failures in recognizing or responding to symptoms. Our study indicates that most adolescents and caregivers in Edmonton are unaware of TT. While total time to intervention and pain severity are known predictors of outcome, it is unclear whether awareness of TT affects these delays and clinical outcomes. Given our relatively small sample size, a nationwide study is needed to evaluate the clinical impact of awareness on TT outcomes.

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FIGURES AND TABLES

Table 1. Reported patient and parent awareness of testicular torsion in Edmonton			
	Control (n=31)	**Torsion (n=30)**	**Total (n=61)**
Patient response			
Number aware of TT (%)	11 (35.5%)	7 (23.3%)	18 (29.5%)
Mean patient age (range)	12.3 (8–17)	13.3 (8–17)	12.7 (8–17)
Mean comfort level with testicular health*	2.7	2.7	2.7
Parent responses			
Number aware of TT (%)	14 (45.2%)	8 (26.7%)	15 (32.6%)
Mean comfort level with testicular health*	3.6	3.2	3.4
Parent sex	Female: 23 (74.2%) Male: 8 (25.8%)	Female: 28 (93.3%) Male: 2 (6.7%)	Female: 41 (89.1%) Male: 5 (10.9%)

*Comfort levels were rated on a scale of 1–5, with 5 indicating the highest level of comfort. TT: testicular torsion.

Table 2. Clinical predictors of surgical outcomes in patients with testicular torsion					
	Orchiopexy (n=21)	**Orchiectomy (n=8)**	**p**	**OR**	**CI**
Patient age (range)	13.4 (9–17)	12.9 (8–17)	0.59	0.696	(0.467, 1.036)
Pain rating (1–10)	8.6	7.2	0.05	0.904	(0.820, 0.997)
Reported awareness of TT					
Parent (%)	5 (23.8%)	2 (25%)	1.00	1.013	(0.683,1.502)
Patient (%)	5 (23.8%)	2 (25%)	1.00	1.013	(0.683,1.502)
Mean comfort with testicular health*					
Parent	2.6	2.8	0.83	1.014	(0.897,1.146)
Patient	3	3.5	0.47	1.045	(0.93,1.173)
Testicular torsion timeline**					
Patient time to report symptoms	1 (3.2)	11 (20.5)	< 0.01	1.016	(1.006,1.026)
Time to present to local ED	2 (3)	13 (20.8)	< 0.01	1.018	(1.013,1.022)
Time to transit to urban center	1.5 (1.4)	4 (5.4)	< 0.01	1.070	(1.026,1.115)
Time from triage to operating room	2 (2.4)	2.25 (2.3)	0.90	0.992	(0.868,1.132)
Total time to Intervention	7 (10.1)	52.25 (53.7)	< 0.01	1.017	(1.013,1.02)

*Comfort levels were graded on a scale of 1 to 5, with 5 indicating the highest level of comfort.
**Time intervals are reported as median number of hours, with mean time in parentheses. CI: confidence interval; ED: emergency department; OR: odds ratio; TT: testicular torsion.