Experiences and perceptions of acute testicular pain, with a focus on reasons for delayed presentation to hospital: a qualitative evidence synthesis

Authors: Elizabeth Anderson[a], Wendy J Chaplin[b,c], Chloe Turner[d], Graham Johnson[a,e], Holly Blake[b,c], Andrew Tabner[a,e,*]

a. School of Medicine, University of Nottingham, Medical School, Nottingham, UK, NG7 2UH
b. School of Health Sciences, University of Nottingham, Medical School, Queen's Medical Centre, Nottingham, U.K. NG7 2HA
c. NIHR Nottingham Biomedical Research Centre, Queen's Medical Centre, Nottingham, UK, NG7 2UH
d. Library and Knowledge Service, Royal Derby Hospital, University Hospitals of Derby and Burton NHS Foundation Trust, Uttoxeter Road, Derby, UK, DE22 3NE
e. Emergency Department, Royal Derby Hospital, University Hospitals of Derby and Burton NHS Foundation Trust, Uttoxeter Road, Derby, UK, DE22 3NE

* corresponding author, andrew.tabner@nhs.net

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Abstract

Background

The annual incidence of testicular torsion is approximately 1 in 4000 males under the age of 25. Despite the 97% testicular salvage rate when surgical intervention is within 6 hours of onset, orchidectomy is required in 40% of cases. These comparatively poor outcomes are driven by delays to intervention, the majority of which take place prior to presentation to healthcare. This study synthesises existing evidence to understand factors leading to delayed presentation to hospital in individuals with acute scrotal pain.

Methods

A comprehensive literature search was performed with support from an information scientist. Two authors performed article screening, data extraction, and inductive thematic synthesis independently, with disagreements resolved by discussion at each stage. An assessment of confidence in the review findings was performed using the ConQual approach.

Results

The search identified 1251 unique articles for screening, with 5 eligible for inclusion; all included publications were drawn from 2 PhD projects. Synthesis of these articles revealed 5 descriptive themes with 5 sub-themes. A lack of knowledge and education about testicular health, embarrassment, and reliance on others for access to healthcare are major factors leading to delays in presentation. Societal and cultural impacts on health-seeking behaviour and denial were also causes of delayed presentation to healthcare.

Discussion

A lack of knowledge about testicular anatomy and health among both adults and children is amenable to improvement through education, and would likely impact many of the factors identified as contributory to delays. Communication was an overarching factor connecting the descriptive themes.

Key messages

What is already known on this topic?

Delays to presentation with acute testicular pain are common, and lead to poorer health outcomes when the pain is caused by testicular torsion. The reasons why people delay presentation to healthcare professionals are not well understood.

What this study adds?

Key factors contributing to delays in presentation are embarrassment, lack of health knowledge, denial, societal and cultural impacts on healthcare-seeking behaviour, and reliance on others for access to healthcare. The evidence base is limited; only 2 relevant studies, both of which were performed in the UK, were identified .

How might this study affect research, practice or policy?

Improvements in public health education concerning testicular health are needed. Further research in geographic settings outside the UK, and with a greater number of participants who have experienced acute testicular pain, would improve the generalisability of the existing literature.

Key words: Testicular torsion; delay; time; qualitative; review.

Introduction

Testicular torsion occurs when the testicle twists on its own blood supply, causing a reduction in testicular blood flow. This leads to testicular necrosis and can have a long-term impact on fertility unless treated urgently. Complete infarction of the testicle occurs in approximately 40% of cases and requires orchidectomy.[1] If surgical intervention takes place within six hours of the onset of symptoms there is a 97% chance that the testicle can be saved.[2]

The annual incidence of testicular torsion is approximately 1 in 4000 in males, and it presents largely in those under the age of 25. There is a bimodal distribution of presentations, with peaks in both the first months of life and the teenage years; however, 14% of cases occur in adults.[3] Testicular torsion is the cause of 15-25% of emergency department (ED) visits for scrotal pain in the younger age category.[4]

One of the key factors implicated in delayed intervention for testicular torsion is late presentation to hospital.[5,6] One single centre UK study (n=50) found that the median interval between hospital admission and surgery was just under 90 minutes; however, only 38% of patients presented to hospital within 6 hours of symptom onset.[6] A survey of parents reported that only 22% would take their children to hospital immediately if they were complaining of scrotal pain.[7] Similarly, the 2024 UK National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report highlighted that 40% of patients diagnosed with testicular torsion had delays in their presentation; in 65% of cases there were patient-related delays and 35% of cases had delays related to parents or carers.[8]

There are several hypothesised reasons for delayed presentation to a healthcare provider.. Discussions of testicular pain may be considered embarrassing, particularly amongst a younger cohort of patients.[9,10] There is also some evidence that awareness of factors relating to testicular health is poor, with the implications of testicular pain being poorly understood by parents and caregivers.[11]

This study explores the literature concerning patient perceptions and experiences of acute testicular pain, with a focus on elucidating underlying causes for delayed presentations to hospital. It is hoped that a better understanding of the reasons for delayed presentation will enable targeted work to reduce delays in presentation, and subsequently improve outcomes after testicular torsion.

Methods

This qualitative evidence synthesis used a meta-aggregative approach as described by the Joanna Briggs Institute (JBI).[12]

Search strategy

The comprehensive search strategy was developed with the support of an information specialist. An example strategy can be seen in the supplemental material, but search syntax was adapted for different databases.

Inclusion criteria

Articles for inclusion met all the following criteria:

- Discussed the phenomenon of acute testicular pain without known precipitant.
- Qualitative studies, or mixed-methods studies that included qualitative aspects, including unpublished literature and student theses.
- Focussed on 1 of 2 groups of participants with no limits applied by age or ethnicity:

  Group 1: participants who have had direct experience of acute testicular pain either personally or through those they care for,

  Or

  Group 2: participants or parents who have not had direct experience of acute testicular pain, but have a possibility of future experience and can discuss the factors that would play a role in timing for presentation if they were to be affected.

Exclusion criteria

- Expert opinion pieces without primary data collection
- Systematic reviews
- Articles not written in English

No limits were applied by date.

Data sources

The following electronic databases were searched: MEDLINE; EMBASE; EMCARE; CINAHL; PsycINFO; Cochrane central register of controlled trials; Web of Science; Scopus; Google scholar; NICE; EBSCOhost; NHS knowledge and library hub.

The following databases were searched for theses or dissertation reports: EthOS; OATD; DART.

The PROSPERO database was searched for prospectively registered systematic review protocols.

The reference lists of all eligible articles were reviewed for further relevant publications. Systematic reviews were not eligible, but their references would have been hand-searched for relevant manuscripts, had any been identified.

All searches took place on the 4th and 5th of October, 2023.

Screening

Search results were imported into EndNote and de-duplicated. Title and abstract screening were performed by two reviewers independently (EA and WJC); any article identified as potentially eligible by either reviewer underwent full text screening.

Full text screening was independently performed by the same two reviewers, with any disagreements resolved by discussion, and by consultation with a third reviewer (AT) if agreement could not be reached.

Data extraction

Data were extracted independently by two researchers (EA and WJC) to a bespoke Google form adapted from the JBI qualitative assessment and review instrument (QARI) data extraction tool for qualitative research;[12] the forms were compared and any differences were resolved through discussion. Data collected included article title, author, journal, year of publication, methodology and methods used, setting, geographical location, experience and cultural background of participants, cultural background of researcher, data analysis methods, and author conclusions.

Study findings were extracted, along with a short description and direct quotes or illustrations that either supported or were related to the finding identified. These findings were assessed as either unequivocally supported by the participant quotes, credible in light of the participant quotes, or not supported.[12]

Assessment of methodological quality

Studies which were eligible for inclusion were assessed using the Critical Appraisal Skills Programme (CASP) appraisal tool [13] for assessment of methodological quality; two reviewers (EA and WJC) performed this appraisal independently, with any disagreements resolved by discussion.

Data synthesis

Inductive thematic analysis was used to identify key themes and sub-themes present in the included texts. Two reviewers (EA and WJC), undertook initial theme generation independently, before discussing and combining identified themes into an agreed coding structure. The entire database of extracted themes was considered as a single dataset, with no within- and between-text comparisons made.

Themes and sub-themes were synthesised from the included studies. The descriptive themes were synthesised using findings directly related to the research question and developed into concepts describing potential reasons for delays across the texts.

Assessment of confidence of findings (ConQual)

The synthesised findings were assessed for confidence using ConQual 'Summary of Findings' following the JBI recommended approach.[14]

Positionality statement

The research team consisted of a medical student (EA), qualitative researchers (WJC and HB) and emergency physicians (GJ and AT). The latter have significant experience of delayed presentation leading to poor outcomes in patients with testicular torsion, and the overall rationale for delivering the project was to identify contributory factors that might be amenable to targeted improvements. It is acknowledged that this may have shaped the discussion of findings; however, EA and WJC developed the themes and their definitions independently of GJ and AT, and these were not changed significantly during manuscript preparation.

Patient and public involvement

Patients and members of the public were not involved in the design or conduct of this qualitative evidence synthesis.

Results

A total of 1841 articles were identified; deduplication left 1251 unique records for screening. Title and abstract screening identified 23 manuscripts for full text review, and 5 of these were eligible for inclusion in the evidence synthesis.[5,15–18] The flow of records through the review is shown in Figure 1. Characteristics of the included articles are shown in Table 1.

Author	Year	Type	Methods	Data analysis method	Setting	Participants	Experienced testicular pain?
MacDonald et al. [5]	2021	Journal article	One-to-one semi-structured interviews	Thematic analysis using framework approach	Out of school clubs in 2 locations (Sheffield and Glasgow)	16 males (age 11-18), each with 1 or 2 immediate family chaperone(s)	No (children and parents)
MacDonald et al. [15]	2020	Data in brief	One-to-one semi-structured interviews	Inductive thematic analysis, iterative reflexivity and framework methodology	Out of school clubs in 2 locations (Sheffield and Glasgow)	16 males (age 11-18), each with 1 or 2 immediate family chaperone(s)	No (children and parents)
MacDonald [16]	2020	Thesis	One-to-one semi-structured interviews	Thematic analysis and framework methodology using both inductive and deductive analysis	Out of school clubs in 2 locations (Sheffield and Glasgow)	16 males (age 11-18), each with 1 or 2 immediate family chaperone(s)	No (children and parents)
M. Saab [17]	2018	Thesis	One-to-one semi-structured interviews and focus groups	Inductive content analysis	Community and youth organisations in the Republic of Ireland	29 men age 18-50	Some, with a range of aetiologies
M. Saab et al. [18]	2017	Journal article	One-to-one semi-structured interviews and focus groups	Inductive content analysis	Community and youth organisations in the Republic of Ireland	29 men age 18-50	Some, with a range of aetiologies

Table 1. Characteristics of included studies

Methodological quality assessment of included articles

Two of the included articles were PhD theses, from which all data in the included articles were drawn.[16,17] Some of the included manuscripts did not contain sufficient methodological detail to satisfy the considerations addressed within the CASP checklist. However, this methodological detail was largely available when the included texts were considered together.

The only methodological issues identified were within the work by Saab et al.[17,18], where the relationship between the researcher and the participants was unclear. There was also no examination of bias of influence attributed towards the study by the researcher during formulation of the research question or data collection. The data analysis process was not described in depth and no contradictory data were provided to provide a balanced view.

Themes

Five descriptive themes with five sub-themes were identified; they are presented together with descriptions and illustrative participant quotations. Their proposed inter-relation can be seen in Figure 2.

Quote attribution: Age (where available), m= male, f = female, NTP = no experience of testicular pain, TP = experience of testicular pain, TT = experience of testicular torsion.

Theme 1: Lack of knowledge of testicular anatomy, function and pathology

Description: There was limited knowledge about testicular function and health in all age groups. This could lead to a delay in presentation to healthcare with testicular pain due to poor understanding of conditions and their urgency.

Illustration:

Interviewer: “Have you heard about sperm?”

Participant (14mNTP): “No. “

I: “Have you heard of testosterone? “

P: “No. “

I: “if you had pain in your testicle would you know what to do?”

P: “No I think if you asked everyone in my year. None of them would know!”

I: “Have you ever heard of a twisted testicle or twisted ball?”

P: “No.”

I: “Did you know this could happen?”

P: “No.”

I: “What do you think would be the reason that young people maybe don’t come to hospital in time with a twisted testicle?”

P: “It’s not knowing about it.”[16]

Sub-theme: Lack of health education and resources.

Description: Participants felt that health campaigns are often directed towards women, or towards conditions seen as more serious/life-threatening such as testicular cancer. They felt

that less is known about the urgency of testicular torsion in comparison to other disorders in both sexes.

Illustration:

P (fNTP): “I think with girls there seems to be more awareness, more promotion, more focus actually on teenage girls and their health than teenage boys and their health. […] you see more than before such as prostate awareness and testicular cancer and men’s health issues but actually that’s only recently, these sort of campaigns and awareness has not been, I mean not as much a breast cancer but they’re much more prominent.”[16]

Sub-theme: Misinformation or incorrect knowledge.

Description: Poor understanding of testicular health or pathology was evident, with a prevalence of misinformation, and therefore delays when detecting disorders that require treatment are probable.

Illustrations:

I: “What do your testicles do?”

P (11mNTP): “They make you piss.”

P (11mNTP): “Help your penis pee.”[16]

P (mNTP): “If there was a lump or a swelling there, I'd think, ‘Oh, something else. I got a bite off something.’”[17]

Theme 2: Embarrassment

Description: Testicles are seen as private and not talked about or taken seriously. Participants worried about judgement regarding their lack of knowledge, or anxiety surrounding having to show someone their testicles. All these factors were as a result of stigma surrounding genitalia. This was therefore felt likely to lead to lack of communication or help-seeking behaviour when men have worries surrounding their testes.

Illustrations:

P (mTPTT): "I didn't want to speak out about it because I felt embarrassed obviously."[17]

P (14mNTP): "When you grow up you get told they're yours, and people sort of protect those bits and their privates, not really show them or talk about them."[16]

P (22mTPTT): "When I had it I was scared to tell anybody because of how it reflected on me."[16]

P (13mNTP): (When asked why it was more embarrassing to talk about testicles compared with other things) "'Cos it sounds gross and all that."[16]

Sub-theme: Trivialisation or humour in conversations about testicles.

Description: As a result of the embarrassment surrounding discussion of testicles, men are more likely to bring humour into these conversations and not talk about them seriously.

Illustration:

P (14mNTP): "I think…people if they had [testicular torsion] they would think: 'that's quite funny' but if you have cancer I think people take cancer more seriously and wouldn't joke about it so it wouldn't be so embarrassing."[16]

Sub-theme: Embarrassment associated with someone having to look at their testicles.

Description: Reluctance for anyone to view their genitals, sometimes with increased embarrassment based upon the individual's gender. This theme primarily evidenced amongst older participants.

Illustrations:

P (mNTP): "…feel better if it was a female doctor." "…wouldn't like a man touching [them]".

P (mNTP): (Some males would prefer a male doctor as) "[they] had some (testes) also".[17]

Theme 3: Reliance on others for healthcare knowledge and/or access

Description: Testicular torsion primarily affects younger individuals who may have little health knowledge or experience, and limited ability to seek medical help independently. They are therefore reliant upon their parents or primary caregivers to act on their symptoms. This relies on communication between parties, and on the parent's knowledge of the potential urgency of the situation. Ability to travel to healthcare facilities was also identified as a problem.

Illustrations:

P (11mNTP): (If they were to experience testicular pain they would first) "…tell mum and dad."[16]

P (fNTP): (One of the mothers of a participant interviewed implied it was their job to) "…have to deal with things like that."[16]

P (mTP): (Help-seeking was said to be put off until the pain was unbearable and extreme because) "I don't drive, so I'd have to get a lift."[17]

Sub-theme: Parents influenced by society.

Description: There is an unspoken consensus within parents to use the 'watch and wait' approach to prevent burdening the healthcare system for a what might appear to be a trivial condition which will improve without intervention.

Illustrations:

P (11mNTP and father): (When asked what they would do if experiencing testicular pain, their father encouraged stoicism and said that they would "see if it goes away."[16]

P (fNTP): (…wouldn't "rush [their children] in here for a snotty nose. [It] isn't an accident or an emergency."[16]

Theme 4: Societal/cultural impacts on healthcare-seeking behaviour

Description: If worried about what pain or an abnormality could be, men can worry that seeking help makes them 'less of a man.' Avoidance was also seen as a result of subconscious fear.

Illustrations:

P (mTP): "I went along for several months with desperate pain and the fear of actually dying… It was easier at times just to block it out and fear of actually being told there was something wrong with you, when instinctively deep down within yourself, you knew there was something going wrong… I just kept thinking things would go away, but they didn't."[18]

P (mNTP): (Men fear being) "seen as hypochondriacs."[18]

Theme 5: Denial

Description: Some believe that pain or swelling is likely to be a minor issue, or will go away without intervention. Others describe a belief that bad things wouldn't happen to them. Societal norms were implicated by some participants.

Illustrations:

P (mNTP): "if there was a lump or a swelling there, I'd think, 'Oh, something else'. I got a bite off something."[17]

P (mNTP): "A lot of Irishmen have a great reluctance to go to the doctor for any reason. Ah, it'll be fine, it'll go away, the swelling will be down in a day or so, a week later and it's half the size of your body, I may consider going next week."[17]

P (mNTP): (Men) "all believe that [they] won't be the person it'll happen to, so why concern [themselves] with that?"[17]

3.6 Confidence of findings (ConQual)

All included papers were primary qualitative research and therefore received an initial ranking of 'high'. Some methodological concerns were identified in the work by Saab et al., but these did not affect the ConQual rating of the synthesised findings as all were supported by both Saab et al. and MacDonald et al. All extracted primary findings were well-supported by illustrative quotes in the included manuscripts. Therefore, a high level of confidence is present for all synthesised findings (Table 2).[14,19]

Synthesised finding	Type of research	Dependability	Credibility	ConQual rating
Lack of knowledge of testicular anatomy, function, and pathology	Primary qualitative	No change	No change	High
Embarrassment	Primary qualitative	No change	No change	High
Reliance on others for healthcare knowledge and/or access	Primary qualitative	No change	No change	High
Societal/cultural impacts on healthcare-seeking behaviour	Primary qualitative	No change	No change	High
Denial	Primary qualitative	No change	No change	High

Table 2: Description of ConQual findings at each stage of the assessment process

Discussion

This evidence synthesis demonstrates a clear gap in the knowledge of testicular health amongst both adults and children. Lack of education in schools was raised as a contributary factor by multiple participants in the work by MacDonald et al.[5]; a focus on testicular anatomy and puberty to the exclusion of other aspects of testicular health was implicated. Saab et al. found that only 18% of college students had heard of testicular torsion and only 43% had received education on the potential seriousness of scrotal pain[17]; MacDonald et al. found that only a third of adolescent patients present to hospital within 6 hours of the onset of pain.[5] Parental knowledge was also implicated in delays to presentation; this aligns with a survey by Yap et al. that found only 56% of parent respondents had awareness of testicular torsion; those that were aware of the condition were four times more likely to present to hospital immediately with acute scrotal pain than those who were not.[20] Improved education around testicular health and disease at a young age would both equip people with the tools to better manage their own health, and enable them to better support young people in their care at a later date.

MacDonald et al. describe a perceived differential in health information available for the different sexes, with there being more awareness of female disorders[16]; there is evidence to support this opinion, with only one page on the World Health Organisation's websites exclusive to men's health [21], and a suggestion that men's health outcomes are poorer than women's globally due in part to a lack of health promotion targeting men.[22] Improving the population's knowledge about testicular health and disease is therefore a vital component of any strategy to reduce time to presentation and therefore improved outcomes, and work is

ongoing to develop and deliver improved resources for the public[23,24] and for schools[25] in the UK.

Embarrassment was predictably described as a factor in delayed presentation. It was seen through trivialisation in conversations, in worry and anxiety about the judgement of others, and in fear that any concerns raised would be a source of humour for others. This is again amenable to remedy through improved understanding, with embarrassment about “taboo” health issues shown to improve with education.[27]

Multiple studies have shown greater concern amongst young people at the idea of having to disclose testicular pain to a teacher or school nurse compared to their parents[16,28], and any suggestion of waiting until the end of the school day to raise a concern will inevitably lead to a delay in accessing appropriate medical care. Improved knowledge and understanding of testicular torsion should be highlighted in settings in which it may present, as children and young people may disclose symptoms to, and be reliant upon the appropriate responses of, any adult in a position of caring responsibility

In a survey of 320 parents, over 50% had not heard of testicular torsion, and over 50% would not seek immediate help if their child had acute scrotal pain[29]. Children are frequently reliant on their parents or carers for advice on aspects of their health, including alerting of concerns[16]; they are also often reliant on others for transport and permission to attend healthcare settings. It is likely that parental and child decision-making on testicular health can be improved with subject-specific education. [30]

Communication was a pervasive subtext throughout the identified themes. Effective communication about testicular function, anatomy, health and disease at a young age is required to equip young people with the knowledge required to take ownership of their

testicular health, and avoid denial or a “watch and wait” approach when testicular pain occurs. Improved knowledge and understanding of testicular health would likely lead to reduced potential for embarrassment and prompt earlier disclosure when symptoms occur. Communication plays a key role in timely presentation to healthcare; it is required at every stage of the process between symptom onset and definitive treatment. Parents and carers also require effective public health messaging to ensure they understand the implications of testicular pain and the urgency with which medical help should be sought when it occurs in children under their care.

Limitations

Although five articles have been included in this evidence synthesis, their data is drawn from only two studies, both of which were conducted in Great Britain; a total of 45 males plus 19 familial chaperones were recruited. These considerations limit the weight and generalisability of the conclusions that can be drawn and highlights the need for further research in different settings and populations.

Furthermore, most of the participants in the included studies did not have lived experience of testicular pain; it cannot be assumed that their hypothetical responses would be actioned were they to experience testicular pain in the future. Research is needed with participants who have experienced testicular pain to explore the factors that influenced their decision-making regarding the timing of their presentation to healthcare.

It must be acknowledged that some of the *a priori* hypothesised reasons for delayed presentation are indeed themes identified in the included studies. This may be due to the

researchers' existing experience of caring for patients with testicular torsion and their knowledge of the literature base prior to conducting this study, but it is possible that researchers' pre-existing knowledge and beliefs influenced the data analysis process. However, the researchers feel that the themes identified are well-supported by illustrations in the included studies.

Conclusion

Improved knowledge amongst children and young people, and among parents, teachers, and those in a position of caring responsibility, is a vital aspect of reducing delays in presentation for testicular torsion. This may decrease the perceived embarrassment associated with discussing testicular problems, and improve the likelihood that care is sought at the earliest opportunity. Effective communication underpins every aspect of the patient journey from recognition and reporting of symptoms through to accessing definitive care.

CRediT author statement

Elizabeth Anderson: Formal analysis, Investigation, Data Curation, Writing – Original Draft, Writing – Review and Editing, Visualization. **Wendy J Chaplin:** Formal analysis, Investigation, Writing – Review and Editing. **Chloe Turner:** Methodology, Investigation, Data Curation, Writing – Review and Editing. **Graham Johnson:** Conceptualization, Methodology, Writing – Original Draft, Writing – Review and Editing, Funding acquisition. **Holly Blake:** Methodology, Writing – Review and Editing, Supervision. **Andrew Tabner:** Conceptualization, Methodology, Formal Analysis, Investigation, Data Curation, Writing – Original Draft, Writing – Review and Editing, Supervision, Project Administration, Funding acquisition**. Andrew Tabner** is the guarantor for this research.

Data sharing statement

All data are available either in the articles included in this evidence synthesis or in this manuscript.

Research ethics statement

No ethical approval was required for this systematic review of publicly available evidence.

Registration: Protocol registered on PROSPERO, registration number CRD42023469435

Figure Legends

Figure 1: PRISMA flow diagram showing identified articles and those included and excluded with reasons - adapted from Page et al.

Figure 2. Interplay between themes (dark blue) and sub-themes (light blue).

Competing interests: We have no competing interests to declare.

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