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Why adolescents delay with presentation to hospital with acute testicular pain: A qualitative study

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ABSTRACT

Background/purpose: Adolescents have poor outcomes following testicular torsion directly attributable to delay from onset of symptoms to presentation to hospital. The aim of this study was to investigate the barriers to urgent presentation in young men.

Methods: Semistructured interviews were undertaken with young men (11–19 years), using a topic guide exploring issues surrounding testicular pain and health. Thematic analysis was undertaken using a framework approach.

Results: Twenty-seven adolescents were recruited, data saturation was reached at sixteen participants, and median age was 13.5 years (range 11–18). The process by which an adolescent gets to hospital with testicular pain is slow. They must recognize the problem and alert their parents, who then use a 'watch and wait' policy to assess need for medical review, often leaving it 'a day' or overnight. Adolescent males do not engage with healthcare services independently of their parents. Additional factors preventing early presentation include: absence of knowledge about testicular pathology from adolescents and their parents; concern from the young people about raising a false alarm and family concerns about burdening healthcare services.

Conclusions: Recommendations include designing a testicular health education campaign for young men and educating parents regarding the medical conditions where a 'watch and wait' policy may be harmful to their child.

Level of evidence: VI

Contents

1. Methods . . . 615
   1.1. Study population . . . 615
   1.2. Study protocol . . . 615
   1.3. Data analysis . . . 615
   1.4. Validity/rigor . . . 615
2. Results . . . 615
   2.1. Population . . . 615
   2.2. Main findings . . . 616
   2.3. Factors affecting speed of presentation . . . 616
      2.3.1. Young person's knowledge of testicular function and pathologies . . . 616
      2.3.2. Young person's experiences of testicular education . . . 616
      2.3.3. Young persons' views and experiences of health . . . 616
      2.3.4. Young persons' health seeking behaviors . . . 617
      2.3.5. Ability to discuss testicular problems with parents . . . 617
      2.3.6. Psychological factors . . . 617
      2.3.7. Youth culture . . . 617
      2.3.8. Parental knowledge and education . . . 617

Abbreviation: CI, Chief Investigator.

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0022-3468/

2.3.9. Parental information seeking . . . 617
2.3.10. Parents' attitudes and experiences of healthcare access . . . 617
2.3.11. Family ability to get to the hospital . . . 618
3. Discussion . . . 618
3.1. The process: recognize, raise the alarm, react . . . 618
3.1.1. Recognize . . . 618
3.1.2. Raise the alarm . . . 618
3.1.3. React . . . 618
3.2. Study strengths and limitations . . . 618
4. Conclusion . . . 619
Acknowledgments . . . 619
Funding source . . . 619
Data sharing . . . 619
References . . . 619

Testicular torsion is predominantly a condition of young men. The outcome following testicular torsion in adolescents is disappointing, with 50% testicular loss or atrophy at long term follow up [1]. Loss of a testicle leads to feelings of loss of masculinity and unhappiness with self-image [2] and risks of castration if contralateral torsion occurs. Predictors of testicular loss include degree of twist, presentation to a GP rather than hospital, transfer between hospitals for surgery, but most significantly a delay between symptom onset and presentation to healthcare services [3,4] as shown by systematic review [1]. The critical time point for salvage of a testicle at scrotal exploration for torsion of testis lies between 6 h and 10 h [5–7].

Only a third to a half of adolescents present within 6 h with testicular pain [6,8]. There is poor understanding of why adolescents delay in presenting with testicular pain. Previous studies have shown poor knowledge from parents and adolescents about testicular pathology [9,10] and embarrassment to contribute [11], but these studies have not investigated the phenomena in a naturalistic context.

This study aimed to investigate adolescent males' knowledge and experience of testicular health issues to understand why presentation with a painful scrotum is routinely delayed in adolescent males.

1. Methods

A qualitative methodology was undertaken [12,13] utilizing semistructured interviews and thematic analysis using a framework approach. The project went through ethical review board (REC number 15/YH/0299, HRA registration 167713), with the research protocol (IRAS 167713) available from the corresponding author.

1.1. Study population

Adolescent males (11–19 years) were purposely and snowball recruited through sports and out of school clubs, whereby the recruitment strategy focused on the target population and the participants were encouraged to nominate people for recruitment approach. The target population was adolescent males who had not experienced testicular torsion, as those young people who have had torsion have knowledge and experience which would differ to those of the disease naïve population where torsion occurs. Out of school clubs were chosen to avoid the bias of recruiting from schools or healthcare environments [14].

1.2. Study protocol

The Chief Investigator (CI) contacted clubs, advertised via their social media or email lists, met the families at designated practices, agreed on chaperone with the young people and their parents, and consent was taken. Semistructured interviews were undertaken with the young person and their chaperone, utilizing a topic guide developed by the CI combining knowledge of the clinical phenomena and data from pilot interviews with families of young men who had experienced torsion (see Fig. 1 within the accompanying Data-in-brief article). Interviews were performed two weeks later in a location chosen by the family. The adolescents were given a gift voucher as an incentive to take part. Recruitment continued until data saturation was achieved as defined by standard qualitative methodology [15] whereby the iterative analysis occurs alongside data collection and no further ideas are generated with further participant recruitment.

1.3. Data analysis

The interviews were audio recorded and transcribed verbatim. The CI listened to the recordings, performed transcription and coded the transcriptions using NVivo software (NVivo 11 © QSR International 2017). Transcriptions were examined for codes and themes by two independent investigators and agreement was reached through discussion. Analysis was from a realist point of view, ie assumption was there is a common reality that the young men experienced and can be discovered through observation and description. Themes and a conceptual pathway were developed through reflexive practice, utilizing a framework matrix, with input from supervisors. Transcriptions were anonymized. Analysis focused on identifying barriers to precipitant presentation with acute testicular pain.

1.4. Validity/rigor

Quality and validity were ensured using standard qualitative procedure including: strict research integrity and data handling, reflexivity, expert supervisorship, triangulation and auditable movement from raw data to concepts and theory [16]. An inductive approach was utilized, with all findings staying close to the original data. A framework methodology aided data handling and allowed auditable transparent analysis. Reporting of the study demographic allows clinicians to assess transferability to their population.

2. Results

2.1. Population

Thirty-five clubs were contacted; five agreed to support recruitment. Twenty-seven families were recruited. Semistructured interviews were performed in an order determined by the families' availability and were booked sequentially. Interviews took place between December 2015 and December 2017. The families were recruited from a broad socioeconomic spectrum in two UK locations. All but one participant were Caucasian. Median age of the young people was 13·5 years (range of 11 to 18). Recruitment occurred across the social spectrum, with English Index of Multiple Deprivation median score 6 (range 3–8) and Scottish Multiple Index of Deprivation 3 (range 1–5). One interview occurred in

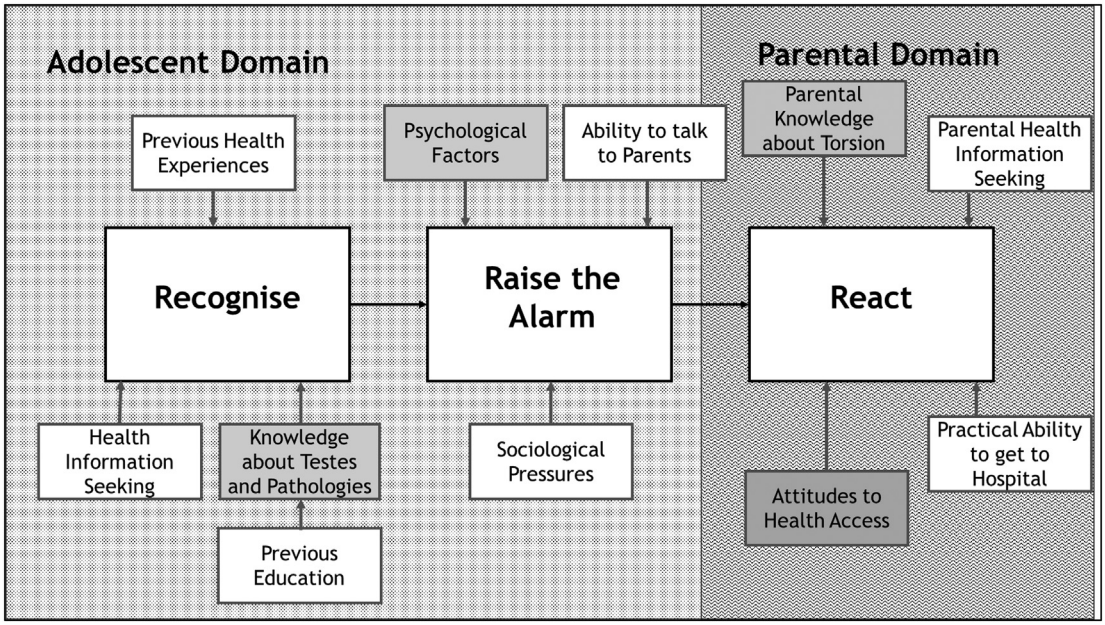

Fig. 1. Illustrating the process by which adolescent males affect their acute health needs and the factors impacting on the process. The most significant factors are highlighted by solid fill box.

the hospital and fourteen at the family home. All participants chose their parents or guardian as their chaperone. Sixteen adolescents from fifteen families were interviewed. No new broad themes were identified after eleven interviews. Five more interviews were undertaken to test for completion within the study population.

2.2. Main findings

The main themes fell into four domains: the dependence of young people on their parents for health, the knowledge about testicles from the young people, their ability to let their parents know about their testicular health concerns and the factors affecting the parents' ability to get the young people to hospital. The quotes supporting the development of themes and the codebook displaying main categories and themes are shown respectively in Tables 1 and 2 of the accompanying Data-in-brief article.

It was found that young people do not have independence from their parents for any healthcare experiences and rely on them for health information, health decision making, liaison with healthcare practitioners, and practically to get to hospital. During the course of the early interviews it was also evident that the young people's views and experiences were inseparable from those of their parents. Therefore, a decision was made to include the parental views and experiences in the data analysis, as well as the young peoples', to provide a realistic description of how a young person gets to hospital with painful testicles in their natural context, ie that of the family.

The process whereby young men attend hospital with acute testicular pain was revealed, as shown in Fig. 1.

2.3. Factors affecting speed of presentation

2.3.1. Young person's knowledge of testicular function and pathologies

Half the cohort knew testicles produce sperm, but none knew they produce testosterone. Only one participant had heard of testicular torsion. None of the participants knew about the urgency required to attend hospital with testicular pain. Half the young people had heard of cancer, but none were aware of the need for testicular self-examination. Both young men and their parents felt poor knowledge was the major reason why young people would not seek out health advice with a painful testis.

> '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.'
>
> (Participant 14, 14 years old)

2.3.2. Young person's experiences of testicular education

Most of the knowledge about testicular health problems in the population was regarding cancer, and came from sources such as friends, the football community or television. None had had education about torsion. The education at school given to the young people about testicles involved labeling the parts of the male anatomy and discussing the changes of the body at puberty. This happened in both biology and the school's health and social curriculum (PSHE). PSHE was really valued by the participants, as described by Participant 8: 'biology is more kinda sciency, whereas PSHCE is more life and the stuff you need to use'. Overall the impression was that school's education about testicular health was insufficient to deal with the practicalities of torsion:

> Mother: So knowing the labels wouldn't increase or decrease the chance of you going to someone if you had pain?
> P: No.'
>
> (Participant 10, 14 years old)

2.3.3. Young persons' views and experiences of health

All the participants having been to hospital described their experience positively. Most often described the doctors as nice. None of the participants felt it would matter if they have a male or female doctor. One young man described how he was quite worried about the pain involved in an operation but felt this wouldn't put off telling someone about a problem. Many of the young men seemed pragmatic about their health. They didn't much like hospitals, but they trusted the doctors to do what was needed.

2.3.4. Young persons' health seeking behaviors

Young people turned to three sources for information regarding health issues: their parents, the internet and their friends. Most felt in an emergency situation they would just ask their parents. Six said they would use the internet to search for health information in combination with talking to their parents in a nonemergency situation. Those that had looked up health conditions on the internet were motivated by television or advertising campaigns, personal worry about a symptom, and occasionally curiosity. Many of the participants had had a negative experience of looking up health information on the internet whereby the findings increased their anxiety:

'P: I just sort of typed in twisted testicles and it just popped up pictures.
CI: What did you think about the pictures?
P: They made me throw up.'

(Participant 13, 11 years old)

Many of the young people discussed the importance of using credible internet resources for health information and interpreting search results with skepticism:

'Well, I know not to believe everything I see and not to just click on the first thing that comes up and, just like, if I've got a cough and I could search for a cough and it could come up with I'm gonna die tomorrow.'

(Participant 10, 14 years old)

2.3.5. Ability to discuss testicular problems with parents

It is striking that in this study all the young people discussed testicular health in front of and with their parents openly. More of the young men would speak with their mothers than their fathers about testicular health issues:

'CI: Would you find it different speaking with your Mum or Dad?
P: Urrrm I'd probably ask Dad because he has a […],
Mother: Though you asked me first…
P: I'd often ask my Mum stuff first. Because I always do. I'd probably go to her first for most [health] things.'

(Participant 8, 12 years old)

Reasons why young people thought they would not speak to their parents included fear of disrupting the family routine or waking their parents at night, worrying that their parents might need to look at their testicles, fear their parents would make a fuss and in one child that his guardian, who was his grandmother, was too old and didn't understand young people's issues.

2.3.6. Psychological factors

Common aspects of adolescent developmental psychology influenced the participants' ability to discuss testicular health issues. These included concerns regarding future negative consequences, concern about revealing lack of knowledge about a topic and embarrassment about their bodies. The younger half of the cohort objectively had lower self-confidence than the older half. Interestingly many of the young men described the anticipated embarrassment stemming from a concern of showing poor knowledge and raising the alarm inappropriately rather than the embarrassment being because of the testes themselves:

'I: Would you be able to tell us what testicles do?
P: I don't wanna say it in case it's wrong and I don't want to embarrass myself but I'm pretty sure that they produce sperm.
I: So you said that you'd be a bit worried to be wrong. Is that something that would probably bother quite a lot of young men your age?
P: Yeah, if they're—yeah, because it would be quite embarrassing to not actually know.'

(Participant 10, 14 years old)

2.3.7. Youth culture

The young people had not discussed testicular problems with their friends or family, and many felt that it wasn't a topic they were likely to speak with their friends about. The lack of previous experience or frequency of discussing testicles in public seemed to be a major barrier for many young people with a standard phrase being; 'we just don't talk about things like that'. When asked why they didn't talk about 'things like that', half said testes were private:

'Just when you grow up you get told their yours, and people sort of protect those bits and their privates, not really show them or talk about them.'

(Participant 7, 14 years old)

When pushed for further explanation, most could not explain why they felt testes were private, but two of the young men suggested because they were physically covered it made people consider them private.

Most felt they would be able to discuss testicular problems with their best friends but expected there would be banter. In most of the discussions, the humor was good natured with few reports or expectations of bullying and most felt ultimately their friends would be supportive. While there was evidence in our cohort of young people adopting stereotypical males roles, the young men seemed open and able to exhibit caring. Machoistic examples were seen more in the older male role models observed during the study, for instance, while being taken around the different groups at football practice during recruitment, one coach said in front of the young men: 'they don't have any balls after the way they played on Saturday'.

2.3.8. Parental knowledge and education

During the interviews seven parental sets said they had never heard of testicular torsion and two described knowing about it but were unaware of the urgency to attend hospital. In the study there was no difference between male or female parents in the level of knowledge regarding testicular torsion. None of the parents had received any education regarding testicular health issues, either during their upbringing or once parents. Three mothers expressed poor confidence in knowledge about boys' health issues. Two mothers caring for their sons within a single parent family cited gender being a factor for poor confidence.

2.3.9. Parental information seeking

Parents felt they would turn to their family doctor, a friend, their own parent, telephone advice services and the internet for information. Half of the parents felt they might do an internet search as the primary information source for a health enquiry. Those that mentioned use of an internet search unanimously mentioned the importance of assessing the quality of the information provided.

2.3.10. Parents' attitudes and experiences of healthcare access

The study data showed parents access medical health advice and treatments through their family doctor (GP), but utilized emergency departments for injury related concerns. Experiences of hospitals and family doctors were generally positive. Parents often described the doctor as nice or 'good with' their son. The parents referred to their doctors with respect and gave the impression of trusting their healthcare services. From the interviews a model of how parents manage their teenagers' health symptoms emerged; see Fig. 2. Only three mentioned going straight to the hospital if the pain was serious. The evidence from the interviews was that testicular health would be treated the same as any other health concern.

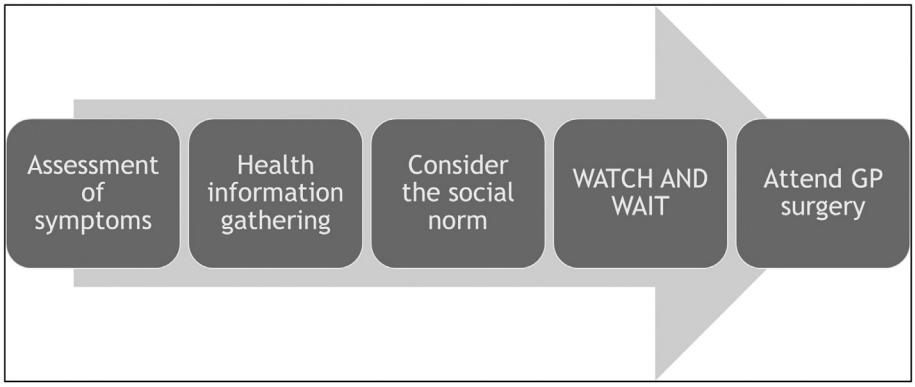

Fig. 2. Displaying the process by which parents make acute health decisions for their adolescent sons. Key: GP, General Practitioner/family doctor.

Parents were proud of health boasting 'I've got healthy kids' and 'he's never had a day off school'. Attitudes of pride in stoicism in the face of poor health were seen occasionally, particularly from fathers but did not appear to be a significant factor in delaying healthcare access. There was a theme running through the interviews of pride in not burdening the NHS:

> 'Well yeah, we don't rush you in here for a snotty nose. [It] isn't an accident or an emergency'.
>
> (Mother of participant 2)

2.3.11. Family ability to get to the hospital

One mother explicitly discussed the importance of having a car to get to hospital. Two families discussed the confusion about which hospital the family should attend, owing to local health service design and pediatric age cutoffs for care in their city.

3. Discussion

3.1. The process: recognize, raise the alarm, react

Through exploring the views and experiences of testicular health, the process by which a young male affects his acute healthcare access in the context of testicular pain has been revealed. Adolescent males do not seek healthcare independently of their parents. The young person must recognize that there is a health emergency and raise the alarm by telling their parent/s, who must then react and get their child to an appropriate hospital. Previous studies have not described such high levels of teenage dependence on their parents, but these have been all conducted in the context of public or chronic health [17,18]. It has been shown that levels of shared decision making decrease when rapid decisions need to made [19], which may explain the predominance of authoritarian parenting styles in this acute health emergency.

3.1.1. Recognize

This study revealed poor knowledge of testicular function and pathology and what to do in the scenario of testicular pain from both participants and their parents. This reflects previous survey based studies [9,10] and compares badly with older males, where more than half would go to the emergency department directly with testicular pain [9,20]. This study suggests worse parental knowledge than the previous surveys, which found that a third of parents are aware of torsion [11,21,22]. Currently education regarding testis is inadequate to empower the young men or families to deal with testicular health concerns.

3.1.2. Raise the alarm

In this study families discussed male health issues in an open fashion. Parental embarrassment has been shown in previous studies to create an environment where a young person avoids conversations about sex [23], but this was not seen in our study. Similarly, embarrassment was not exhibited by participants but was often attributed to others or the future. Whether this is a feature of the current cohort of young people or reflects a self-selecting sample of the population is difficult to elucidate. Of the features of adolescent developmental psychology, we observed low self-esteem [24] in the younger participants and lack of thoughts of the future in decision making [25]. Humor was used in the discussion of testes and generally. Funniness has been previously described as an important attribute for popularity in young men [26].

Most participants had not spoken in public, with their peers or with their parents about testicles before. Many have been taught gonads are private. The reason why it is societally abnormal to discuss testes seems to be because of their physical position, hidden from view, rather than attitudes of shame associated with sex. Machoism was seen in the generation above the young people of this study, but our participants seemed resilient to pressure to conform to male stereotypes. Whether this is because these attributes develop later, in early adulthood, or whether the culture of machismo is changing is difficult to interpret. This has not been described elsewhere.

3.1.3. React

We found that the parents' decision to contact a healthcare provider (HCP) may depend on the severity of pain but more often nonresolution of symptoms over a period of observation. It has been shown that perception of the social norm is the single greatest influencer of parents' engagement with preventative medicine [27]. Many studies focus on understanding the processes of parental decision making in acute illness to find ways to disincentivize emergency department attendance [28]. The effect of campaigns to decrease hospital attendance may present a barrier of timely attendance in the context of testicular pain.

3.2. Study strengths and limitations

This study is the first to explore, using qualitative methodology, the experience of young men and their parents of testicular health. The choice of nonexposed participants allowed us to describe the naturalist response to testicular torsion in a disease naïve family. This gives an insight of the barriers to urgent presentation with testicular pain, and sheds light on the process of adolescent engagement with healthcare in the setting of acute unwellness. Although the views were hypothetical, previous studies have shown high correlation between intentional and actual behaviors [29].

The recruitment did not seek out 'difficult to reach' teens and has possibility of selection bias, with those families volunteering for recruitment being more 'open' and the young people more resistant to embarrassment. It is of interest that the study failed to recruit from ethnically diverse

backgrounds despite the Chief Investigator specifically targeting groups from BAME communities. Therefore, transferability may be an issue to some communities, when embarrassment and religion may present a greater barrier. The chief investigator introduced herself as a doctor which gave the families confidence to speak with her but may have introduced bias with the families describing their health experiences as positive and emphasizing the need to not overburden the national healthcare service.

4. Conclusion

This study has revealed, using qualitative methodology, the process whereby adolescent males affect their acute healthcare in the context of testicular health. The time taken for this process to occur acts as a barrier to young men attending hospital urgently with testicular pain. Factors acting upon this process further decrease the chance of speedy presentation. These include poor knowledge of adolescent testicular problems from both young people and their parents; concern from the young people about getting it wrong and raising a false alarm; poor confidence; young peoples' fear of disrupting the family routine; and disincentivization of hospital attendance. Recommendations from this study would be to design an effective education campaign for young people regarding testicular torsion, and for parents to be educated about the emergency health conditions where a watch and wait step is inappropriate and children and adolescents should be taken directly to hospital.

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Data sharing

The interview recordings and transcripts are available within a Mendeley dataset at http://dx.doi.org/10.17632/cvfxm2j3w8.2.

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