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Recognise, Raise the Alarm, React

The Process and Factors that Delay Adolescent Presentation with
Testicular Pain

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Submitted in fulfilment of the requirements for the degree of MD

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Abstract

Background

Adolescent males have high rates of testicular loss after testicular torsion (TT) due to a delay in presentation to hospital after the onset of symptoms. I aim to investigate the issue two-fold: 1. to confirm the scientific basis and ongoing relevance of the need to investigate the phenomena; 2. to investigate the knowledge, views and experiences of young men regarding testicular health to understand the phenomena using qualitative methodology.

Methods

Meta-analysis following PRISMA guidelines was undertaken with a primary outcome of long-term (>12 months) testicular loss following adolescent TT, in combination with a systematic review investigating predictors of testicular loss. Two regional retrospective audits were undertaken with primary outcomes of immediate testicular loss and time to presentation to hospital after onset of scrotal pain.

One-to-one semi-structured interviews were undertaken with young men 11-19 years old with a chaperone, recruited from naturalist environments such as youth clubs. Thematic analysis was undertaken, and data was managed using framework methodology. Recruitment continued until data saturation. Validity was ensured by meticulous study design, high levels of reflexivity and regular supervision.

Findings

Meta-analysis confirmed a 39% early and 50% long term testicular loss or atrophy rate, with systematic review confirming delay to presentation to predict poor outcomes. Regional audit confirmed ongoing relevancy of the project with early testicular loss of 30% and 50% in Glasgow and Sheffield respectively. Median time from onset of pain to presentation at hospital in Sheffield was 6.25 hours (range 40 minutes to 170 hours) and 24 hours in Glasgow.

Qualitative investigation revealed adolescent males are dependent on their parents for all aspects of health, including advice, access and attitudes. The process whereby an adolescent male affects their acute healthcare needs has been revealed. The adolescent recognises there is a problem and raises the alarm by telling their parents. Their parents then synthesise the symptom information and seek help, often after a 'watch and wait policy', making an appointment with their general practitioner as the first point of health contact. This process acts as a barrier to young people gaining timely hospital assessment of painful testes. Other factors delaying this process are: poor knowledge of adolescent testicular problems; lack of education and age appropriate information resources; 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 disincentivisation of hospital attendance confounding concerns about burdening the NHS.

Recommendations

Recommendations from this study would be to introduce nationalised teaching on testicular health problems in schools, and for parents to receive education of the health conditions whereby a 'watch and wait' process is inappropriate and where children and adolescents should be taken directly to hospital.

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Preface

Whilst working on the emergency team at a children's hospital as a paediatric surgeon, I was asked to see a young man with testicular pain who clearly needed urgent surgical intervention as he had testicular torsion. We took him to theatre and luckily we were able to save the testis despite a prolonged period of severe pain, symbolising ischaemia. Unfortunately, on close inspection of the other testis it became obvious this testis had been lost due to a previously unrecognised torsion event. I was astounded by how close an articulate and academic young man had come to effective castration due to testicular torsion.

On asking my colleagues why a young man in severe testicular pain would not come to hospital immediately, the answers I received were unsatisfactory and unhelpful to provide a response to the problem. I looked for evidence describing the root cause for delay of presentation with testicular pain and find none. To develop an intervention, we need to understand the barriers to young men attending hospital with acute testicular pain. To explore this complex and sensitive issue I needed to find the right methodology to investigate attitudes and behaviour. This thesis demonstrates the workings and outcomes as I have developed a qualitative research methodology appropriate to explore views and experiences of young men toward testicles and testicular health.

This thesis is unique in its description of the pathway for young people to access acute healthcare services and explores many interesting emerging concepts, such as adolescents engagement with health issues, e-health literacy; having explored these in a naturalistic family environment. Ultimately this thesis describes the barriers in the process of a young person presenting early to hospital with testicular problems to provide an evidence base to develop strategies and resources to prevent the needless loss of adolescent male testes in future.

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I would like to thank those close to me who gave me wonderful support in my late onset student-hood, including my Parents, Pat and Liz, and my parents-in-law, Ron and Issy, and of course my wonderful husband Jamie MacDonald.



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Chapter 1: Background

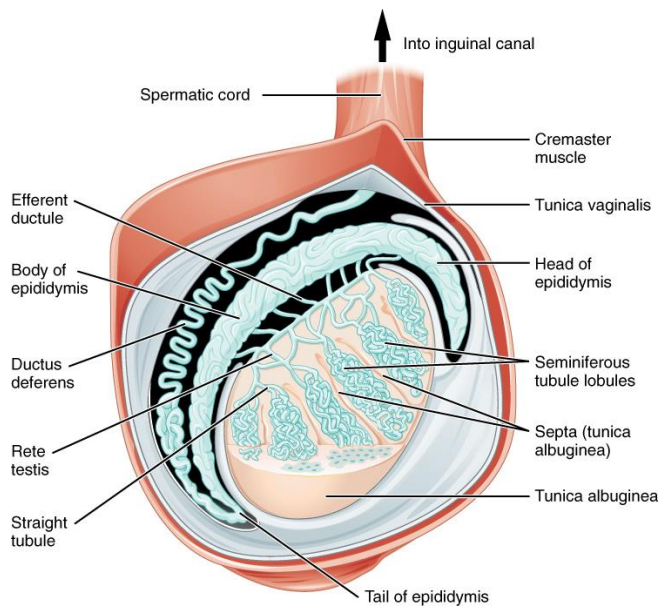
Overview

This chapter makes the case for a qualitative project investigating young men's views and experiences of testicular health problems. The background, nature and long-term outcomes of testicular torsion are described. Literature and resource review are performed, assessing current understanding of adolescent awareness of testicular health issues, adolescent access to healthcare, testicular health education for adolescents and online information available for young people.

1.1 Testicular Anatomy and Function

The male gonads are paired testes sitting within the scrotal sac as shown in Figure 1. The testes are responsible for two main functions: spermatogenesis and steroidogenesis. Human males have approximately 1 billion spermatogonia contained within each testes and can release 25000 sperm per minute (Weinbauer et al., 2010). Embryologically the male gonad performs the important function of androgen secretion, switching 'on' in the presence of the SRY gene. Testicular testosterone facilitates the abdomino-scrotal phase of testicular descent via the genitofemoral nerve (Beasley and Hutson, 1987; Hutson et al., 1997). Dihydroxy-testosterone secretion and localised diffusion leads to differentiation of tissues in male external genitalia; with the genital tubercle becoming the penis and the genital folds the scrotum (Sadler, 2000). The testicles sit within the scrotum to facilitate the thermoregulatory system which maintains testicular tissue at 3-4 degrees centigrade below core temperature which facilitates spermatogenesis (Weinbauer et al., 2010).

Figure 1-1. Showing the Anatomy of the Male Gonad¹



The testes have two compartments: the interstitial compartment and the seminiferous tubules. The interstitial compartment makes up 20-40% of the human male testicular volume and contains Leydig cells. Leydig cells secrete testosterone, with proliferation under the influence of the hypothalamic-pituitary exocrine axis, in particular, luteinising hormone. Testosterone is essential for the production and maturation of spermatogenic cells (Burkitt et al., 2000). In addition to Leydig cells the interstitial compartment contains blood and lymph cells, nerve fibres, fibroblasts, loose connective tissue and macrophages and lymphocytes. These immune cells secrete proinflammatory cytokines, reactive oxidative species, nitrogen oxide and prostaglandins, which can lead to inhibition of Leydig cell function. Decreased testicular function and spermatogenic activity is associated with histological findings of thickened collagen, tubular hyalinisation and peritubular and interstitial fibrosis (Weinbauer et al., 2010).

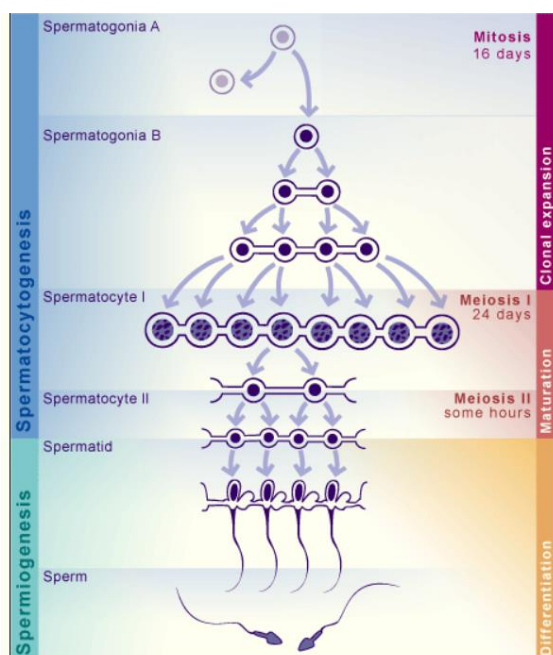
The tubular compartment, which makes up 60-80% of the testicular volume contains peritubular cells and Sertoli cells. The tubular compartment in humans is made up of approximately 250 lobules, each containing 1 to 3 convoluted seminiferous tubules. The human male has an average of 600 seminiferous tubules each 30-60 cm long. The peritubular cells form concentric layers around

¹ Download for free at <http://cnx.org/contents/14fb4ad7-39a1-4eee-ab6e-3ef2482e3e22@8.108>.

the seminiferous tubules, which are able to contract. On contracting they project sperm into the intraluminal pathway towards the efferent ductules. Peritubular cells secrete factors associated with cellular contractility, maintaining the extracellular matrix and creating and supporting the unique conditions required for spermatogenesis. Sertoli cells are supporting cells which synthesise and secrete proteins, cytokines, growth factors, opioids, steroids and prostaglandins; transport secretory products and are involved in lysosomal phagocytosis. They coordinate spermatogenesis and provide the blood - testes barrier with the production of tight junctions. The blood-testes barrier is thought to have two functions: firstly, it keeps the haploid antigenic spermatocytes separate from the immunologically active systemic circulation, which prevents autoimmune orchiditis, and secondly it maintains the special environment required for meiotic processes and sperm development.

Spermatogenesis is the process whereby progenitor germ cells differentiate to mature sperms. The process includes four key stages; mitotic proliferation of diploid cells known as spermatogonia, meiotic division to secondary spermatocytes and spermatids, transformation of spermatids to testicular sperm and release of the sperm from the germinal epithelium of the seminiferous tubules into the tubular lumen in the form of mature spermatozoa. Some authors divide the process into spermatocytogenesis and spermiogenesis. Progenitor germ cells are included in the genital ridge during embryogenesis and descend with the testes. These cells become the diploid spermatogonia type A1 which undergo mitotic division to create a population of cells of pale appearance spermatogonia B which can undergo clonal expansion in response to testosterone at puberty and decreased numbers of sperm in the adult male. At puberty the seminiferous tubules canaliculise which allows the sperm to divide and continue the process of spermatogenesis (Sadler, 2000). Figure 2 below summarises the process of spermatogenesis (Schöni-Affolter et al., 2017).

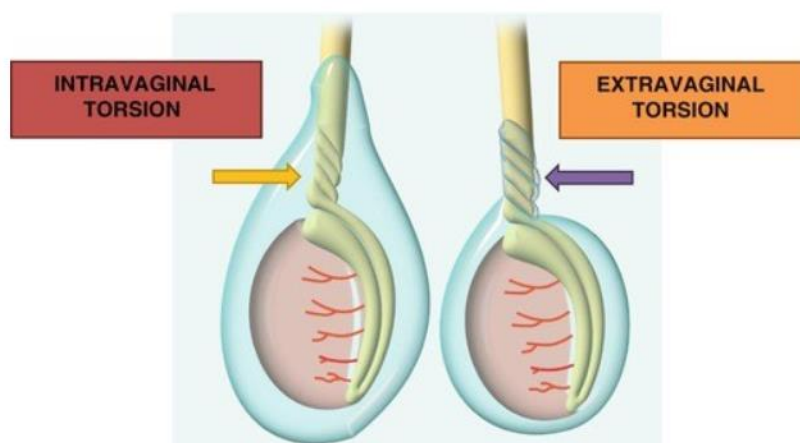
Figure 1-2. Illustrating the Process of Mitotic and Meiotic divisions during the Development of Sperm



1.2 Testicular Torsion

Testicular torsion is a condition whereby the testis twists about its own suspensory ligament. It has two manifestations: intravaginal and extravaginal (see figure 3). In both, time critical ischaemic damage develops to the testes.

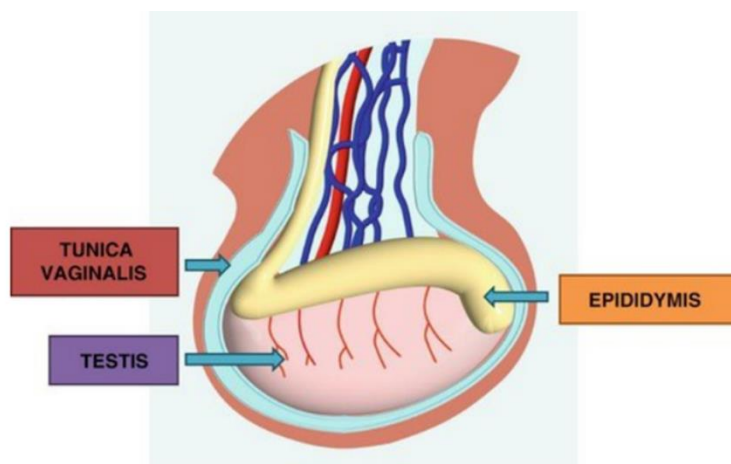
Figure 1-3. Demonstrating the Axis of Torsion in Intra and Extra-Vaginal Torsion. (“Testicular Torsion and Torsion of the Testicular or Epididymal Appendage,” 2017)



Extravaginal presents in the ante-, peri-, or early post-natal period. The testis twists outside the tunica vaginalis and outcomes remain poor (Zampieri et al., 2009), due to the delay to presentation with the duration of labour. Opinion suggests extravaginal torsion may be associated with thrombotic aetiology, and therefore detorsion may not restore blood flow leading to poor outcomes, this is supported from anecdotal findings intra-operatively and has no current evidence base. Whilst cases of testicular salvage have been described (Granger et al., 2016) generally it is accepted that perinatal torsion results in testicular loss (Brandt et al., 1992; Pinto et al., 1997), and debate remains as to the necessity of neonatal surgery and contralateral fixation (Baglaj and Carachi, 2007).

Intravaginal torsion is a condition whereby the testes twists around the axis of the suspending pedicle which includes the vas and testicular veins and arteries, within the surrounding tunica vaginalis, leading to infarction of the testes. This situation is associated with a bell clapper deformity (see Figure 4), whereby the tunica vaginalis covers the epididymis and extends high on the cord (Johnston, 1982) and tends to occur peri-puberty. In the case of intravaginal torsion salvage is possible if detorsion is performed within 6 -8 hours of onset (Saxena et al., 2012).

Figure 1-4. Illustrating the Abnormal Lie in a 'Bell Clapper' Testicular anatomical Arrangement



1.2.1 Epidemiology

Testicular torsion has an incidence of 1/1162 to 1/4000 with an adolescence prevalence of 1/889 before the age of 25 (Mansbach et al., 2005; Shteynshlyuger and Yu, 2013). 65% of the population of children presenting with torsion are between 12 and 18 years of age (Williamson and Thomas, 1984). There are no papers showing differing incidence by ethnicity. There is evidence to suggest cold weather and the winter months are associated with increased rates of torsion (Chiu et al., 2012; Gomes et al., 2015), but not all authors support these findings (Williams et al., 2003).

1.2.2 Aetiology

Torsion of testes is considered to be predisposed to by a 'bell-clapper' configuration of anatomy (Mansbach et al., 2005) which is found in up to 80% of torsion (Favorito et al., 2004), and is estimated to increase the risk of torsion by 4 to 10 times. Horizontal lie, which is the examination sign suggestive of a bell clapper anomaly is found to be highly associated with cases of torsion, and intermittent torsion (Kamaledeen and Surana, 2003) (Schulsinger et al., 1991). As the population frequency of bell clapper at autopsy was found to be 12% (Caesar and Kaplan, 1994) there must be additional anatomical and causative factors. Torsion is found more commonly on the left (Lian et al., 2016; Saxena et al., 2012).

Precipitating events have been described as trauma (Cos and Rabinowitz, 1982; Elsharty et al., 1984; Kursh, 1981; Manson, 1989; Seng and Moissinac, 2000; Wright, 1987), sex (Pan et al., 2012) and masturbation (Anjum et al., 2003). Trauma may be the precipitant in 4-8% of cases of torsion, and unfortunately in some cases testicular pain has been attributed to injury not torsion, resulting in testicular loss (Seng and Moissinac, 2000). Cold ambient air temperature seems to predispose to testicular torsion (Karakan et al., 2015) especially in cohorts from temperate climates, and seasonal association with the winter months has also been demonstrated (Rouzrokh et al., 2015) (Chiu et al., 2012) (Williams et al., 2003). It is suggested a strong pull on the cremaster muscles may be the excitatory cause in all of these scenarios (Johnston, 1982).

Intermittent torsion is described whereby acute pain comes and self resolves, but is a harbinger of impending torsion and may lead to bilateral torsion (Benge et

al., 1992). Therefore, recommendations are for fixation of the testes in cases of intermittent pain in the testicles. Torsion is more common in undescended testis and this is a well-recognised cause of groin pain (Saxena et al., 2012).

There are reported cases of bilateral synchronous torsion (Anjum et al., 2003) (Benge et al., 1992) which unfortunately if missed or surgically unsalvageable may leave the young man effectively castrated (Baker et al., 2005), or with abnormal sperm function which may lead to difficulties with fecundity in the future (Dindyal et al., 2008). Population rates of synchronous or metachronal torsion are estimated to be 2%, opposed to 17% in familial cases (Shteynshlyuger and Yu, 2013).

Medical and other surgical conditions presenting mimicking testicular torsion are numerous. Conditions that mimic torsion of testes include appendicitis (Shehzad and Riaz, 2011), intra-peritoneal perforation, haematoma (Akay et al., 2015), tension hydrocele (Dagrosa et al., 2015), idiopathic scrotal oedema (Crisci et al., 2014), omental infarct in an inguinal hernia (Patel et al., 2014), Henoch-Schonlein purpura (Akgun, 2012; Modi et al., 2016; Oomens et al., 2016), mycoplasma infection (Fukuda et al., 2009) methamphetamine use (Doherty et al., 2013), filariasis (Di Tonno et al., 2010), arteriovenous malformation (Sountoulides et al., 2007). In neonates mimics include neonatal adrenal haemorrhage (Bhatt et al., 2017), meconium peri-orchitis (Cesca et al., 2009) and neonatal thrombosed renal vein (Maas et al., 2011).

1.2.3 Familial predisposition

A recent systematic analysis sort to establish whether there are cases of familial torsion, and found from synthesis of 20 reports that familial predisposition exists (Shteynshlyuger and Yu, 2013). In 19 families 46 probands were identified with 54 torsions, i.e. a 17% torsion rate. There was found to be age clustering of presentation and a 30% testicular loss rate despite family experience. They estimated the observed to expected rate of torsion in cases of familial torsion was 2273 times increased.

The existence of familial cases of torsion might suggest an underlying genetic predisposition. The most studied candidate is the INSL3 gene and it's receptor (RXFP2) which are known to masculinise the gubernaculum and stimulate trans-inguinal testicular descent (Bay et al., 2011; Sozubir et al., 2010). Associations

with torsion may be due to the increased risk of torsion of the crypto-orchid. Investigations in familial cases of torsion in humans have failed to show mutations of INSL3 or RXFP2 (Wang et al., 2008).

1.2.4 Presentation

The classic presentation of testicular torsion is with the ‘acute scrotum’; with severe testicular pain associated with swelling and erythema. Additional features such as abdominal or groin pain, vomiting (Dindyal et al., 2008), hip pain (Sheafor et al., 1997) are not uncommon. A thickened and bulky cord, when felt, is a diagnostic sign. Horizontal lie of the testes is suggestive of a ‘bell clapper’ anomaly, and is felt to be associated with a high risk of torsion (Creagh et al., 1988). Atypical presentation leads to higher rates of missed diagnosis as illustrated by Gaither et al, who showed in 31% of state lawsuits involving missed testicular torsion, the patient presented with abdominal pain only (Gaither and Copp, 2016). Other causes of missed diagnosis include recent testicular trauma and children with developmental delay (Bayne et al., 2017). This reiterates the importance of testicular exam in cases of presentation of abdominal pain. Many young people with acute testicular torsion can retrospectively identify previous episodes of pain, which might suggest previous episodes of intermittent and self-resolving torsion (Hayn et al., 2008). Unfortunately there are reports of primary presentation of infertility men with previously missed bilateral torsion (Baker et al., 2005).

Outcomes following presentation to hospital with testicular torsion is time critical, as will be described in depth in section 1.2.7. Only 31% - 47% (Moslemi and Kamalimotlagh, 2014; Saxena et al., 2012) of males under 18 years of age present to hospital within 6 hours of the onset of pain, whereas adult series show a higher rate of early presentation (Jones et al., 1986). Mean time to presentation in a large cohort of young men with scrotal pain was 56 hours (Varga et al., 2007).

1.2.5 Diagnosis

Torsion of the testis presents as ‘the acute scrotum’ but there are many other causes of a painful swollen red testis. Approximately a quarter of acute scrotums seen by paediatric surgeons will be torsion of the testis (Burnand et al., 2011; Mäkelä et al., 2007; Pogorelić et al., 2016). The common differentials

include torted appendages of the testes and vas, reactive hydrocele, epididymorchitis, testicular trauma and an incarcerated inguino-scrotal hernia. The diagnosis is clinical, with heavy weighing applied to history and signs, such as older adolescents (Johnston et al., 2014), absent cremasteric reflex (Nelson et al., 2003), high-riding testes (Boettcher et al., 2013) and the presence of a 'blue' dot signifying a torted hydatid of Morgagni (Hart et al., 2016).

Radiology assessment is advocated in some centres as an aid to diagnosis, and to decrease need for surgical exploration (Altinkilic et al., 2013). Multi-centre trials have found high resolution ultrasound and colour doppler to increase the diagnostic accuracy of ultrasonographic diagnosis (Kalfa et al., 2007; Schalamon et al., 2006), but as yet no series report 100% diagnostic accuracy. In a recent review colour doppler ultrasound was compared with surgical findings, carried out by a surgeon blinded to ultrasound results (Altinkilic et al., 2013). They found colour doppler ultrasound to be 75.2% specific, with a positive predictive value of 80.4% and a negative predictive value of 100%. Investigation of trans-scrotal infrared spectroscopy has limited use in children, but may be of use in peri-pubertal boys, once the testicles begin to enlarge under the influence of testosterone (Schlomer et al., 2017). Utilising routine ultrasonography in every patient may delay patient transfer from the emergency department to theatre and therefore lead to higher rates of testicular loss (Afsarlar et al., 2016). Some authors describe adjuncts, such as inflammatory haematological markers (Güneş et al., 2015) or pulse-oximetry (Chen et al., 2014), to help with diagnosis and therefor support decision making in the acute scrotum. Few clinicians rely upon these as they rarely change clinical management. The management paradigm for an acute scrotum is to never miss a torsion, and an opportunity for testicular salvage. Many authors recommend scrotal exploration in all cases of acute scrotum (Murphy et al., 2006; Nason et al., 2013; Soccorso et al., 2010).

1.2.6 Treatment

Urgent detorsion of the testes is required to prevent immediate testicular loss or ischaemic injury resulting in late atrophy. Most paediatric surgeons follow the principle of surgical detorsion, assessment for viability and bilateral fixation of the testes if viable. There are exceptions to this, with a number of case series reporting successful doppler colour flow ultrasound guided manual detorsion of the testes (Cannon et al., 1995; Diaz-Ball et al., 1990). The risk of manual

detorsion includes increasing the revolutions in an atypical torsion, i.e. lateral rather than medial revolutions, which may lead to the clinician increasing the threat to the testes (Güneş et al., 2016), and the clinician failing to relieve the torsion fully. Manual detorsion may be performed prior to surgical exploration (Demirbas et al., 2017; Garel et al., 2000; Sessions et al., 2003) if a delay to theatre is unavoidable but is more often described in extreme situations such as wilderness medicine where hospital attendance may not be possible for days.

There are differing techniques for surgical exploration and fixation in viable testes. Practise varies in incision: transverse, midline scrotal or rarely inguinal; fixation methodology and suture material. The general principle is to create dense adhesions between the scrotum wall or dartos and the tunica albuginea to prevent future torsion. This may be achieved by leaving a window in the tunica vaginalis to allow adhesions to form (Morse and Hollabaugh, 1977), but most authors would advocate eversion (Gesino and Bachmann De Santos, 2001; Lent and Stephani, 1993) or excision of the tunica vaginalis (May and Thomas, 1980) and 3 point fixation of both testes with a non-absorbable suture (Frank and O'Brien, 2002) as episodes of retorsion have been associated with absorbable suture material (Bolln et al., 2006). Some authors advocate 4 point fixation (Antao and MacKinnon, 2006). Most authors advocate bilateral fixation of the testes in the setting of unilateral torsion, due risk of contralateral torsion (Rasmussen, 1996). There are concerns that suture material breaching the tunica albuginea leads to formation of anti-sperm antibodies (ASA) and therefore there are advocates of sutureless fixation (Redman and Barthold, 1995). There will be further discussion of ASA in the outcomes sections of this review.

Viability after detorsion can be assessed by relatively subjective means such as testicular texture, pinking on warming, evidence of capillary bleeding on incision of the tunica (Arda and Ozyaylali, 2001) and pre-operative testicular ultrasound findings. In patients with heterogenous ultrasonographic hyper- and hypo echogenicity prognosis was poor (Chmelnik et al., 2010; Kaye et al., 2008; Samson et al., 2017). Though this does not advocate for routine ultrasonography in all. Experiments in rats have shown altered testicular rigidity following torsion, but the clinical applicability of this finding is yet to be found (Mirilas et al., 2010). Whilst every best attempt is made at identifying viable testes

Aworanti et al (Aworanti et al., 2017) showed the histology of 66 non-neonatal orchiectomised testes, may have been compatible with recovery in 6%.

In cases where the testes are deemed non-viable there is debate as to the best surgical option. Generally immediate orchidectomy is performed, due to the risk of damage to the contralateral testes if the torsed testes is left in situ, but there are reports of alternative surgical approaches. Some authors advocate leaving the testes in situ and performing bilateral fixation, as at later follow up there appears to be better testicular function (i.e. lower FSH) where the testes has been left in situ (Taskinen et al., 2008). Rouzrokh et al described a case series where they undertook second look with assessment of salvageability at 48 hours, with a 63% salvage and only a 9% late atrophy (Rouzrokh et al., 2015). Suggestion has been made to treat testicular torsion as a compartment syndrome whereby initial venous congestion, leads to congestion within the fixed volume space created by the tunica albuginea, which then leads to subsequent arterial failure, tissue necrosis, and further oedema and swelling; and suggest an intraoperative fasciotomy to decrease intra-testicular pressure (Kutikov et al., 2008). Figueroa et al (Figueroa et al., 2012) described performing tunica albuginea fasciotomy and tunica vaginalis flap in 11 cases post detorsion. In 6 cases the testis was viable at 6 month follow up, where previously orchidectomy would have been performed.

Where the testis has been removed prosthesis should be offered in all young men. Survey in testicular cancer populations highlights the importance of offering all males a prosthesis, of whom half will take up the surgery (Adshead et al., 2001). The timing of which is some matter of debate with some authors recommending intra-operative or early prosthesis (Mohammed et al., 2015) (Bush and Bagrodia, 2012; Peycelon et al., 2016), but this must recognise the likely growth of the testes in a pre or peripubertal male.

In cases of suspected intermittent torsion, as suggested by episodes of self-resolving severe testicular pain, bilateral fixation is recommended (Kamaledeen and Surana, 2003) and has been shown to have 97-100% efficacious in resolving pain (Eaton et al., 2005; Hayn et al., 2008).

1.2.7 Outcomes

The main outcome following scrotal exploration for torsion of testis is salvage or testicular loss. This may be at the time of the operation (orchidectomy) or late due to testicular atrophy. Testicular loss leads to some men to feel unhappy about their self-image, with feelings of threat to their masculinity (Chapple and McPherson, 2004), and long term feelings of loss and uneasiness have been described in population following orchidectomy for cancer (Skoogh et al., 2011). Other adverse outcomes described in the literature include surgical complications, recurrence, long term functional outcomes, and risk of cancer, see below.

Previous studies have described predictors of poor outcomes to include time from symptom onset to presentation (DaJusta et al., 2013; Lian et al., 2016; Tryfonas et al., 1994); degree of torsion, with median 540 degrees with loss of testes and 360 with salvageability (Sessions et al., 2003); presentation to non-emergency room services (Zhao et al., 2011) and inter-hospital transfer (Bayne et al., 2017). Outcomes have been shown to be worse in prepubertal as compared to post-pubertal adolescents (Goetz et al., 2019).

1.2.7.1 Surgical Complications

Overall complication rates following scrotal exploration are 2.2-5% (Hart et al., 2016; Lala et al., 2017; Lian et al., 2016), with the most common problems being wound infection (15%), suture retention (12%) and dehiscence (5%), haematoma and ongoing pain. Representation rates are 10% with 5-7% requiring re-exploration for metachronous acute or ongoing pain, (Ben-Meir et al., 2006; Hart et al., 2016). In the majority of re-explorations, the contralateral appendix testis requires excision. Chronic pain has been described following scrotal exploration in up to 1.4% of children, which may require suture removal or chronic pain specialist intervention (Hart et al., 2016).

1.2.7.2 Recurrence

Disappointingly re-torsion has been described despite fixation of the testes, even with non-absorbable suture material, and within or without a sub-dartos pouch (Gesino and Bachmann De Santos, 2001; Gillon et al., 1986; Hart et al., 2016; Lala et al., 2017; Mor et al., 2006). Therefore, whilst every measure is taken to

surgically fix the testes the family must be warned of the risk of recurrence, and to promptly re-attend the emergency department in the situation of severe scrotal pain.

1.2.7.3 Fertility, Hormonal and Late Functional Outcomes

Outcomes for fertility and testicular function appear to be worse than would be expected by the loss of a single testis. 50% to 100% of those having had testicular torsion will develop late atrophy and abnormal spermiograms (Bartsch et al., 1980; Danner et al., 1982; Goldwasser et al., 1984; Romeo et al., 2010; Scheiber et al., 1983; Thomas et al., 1984), with findings of worse morphological appearances associated with length of time the testis was torqued. Findings suggest a greater Sertoli and spermatogenic effects, than Leydig cell or endocrine effect from the injury of torsion (Fisch et al., 1988), with reduced inhibin B levels post torsion, a marker highly sensitive for predicting spermatogenesis in adults (Romeo et al., 2010; Taskinen et al., 2008). There was found to be no difference in seminal analysis or inhibin B between those that underwent orchidectomy as compared to testicular salvage (Romeo et al., 2010). It is estimated that men following torsion of testis make up 0.5% of the infertility population ("Male Infertility," 2007).

Experimental evidence from humans and from animal models suggests that damage occurs to the contralateral testis after unilateral torsion, despite there being no acute injury to the testis directly (Chakraborty et al., 1980; Hadziselimovic et al., 1997; Laor et al., 1990; Salman et al., 1998). Findings of contralateral focal disorganisation and exfoliation of immature germ cells into the lumen (Jhunjunwala et al., 1986), atrophic Leydig cells, malformation of late spermatids and pathological changes in Sertoli cells have been seen in the contralateral testis post torsion (Hadziselimovic et al., 1997). Some authors interpret the findings of contralateral abnormal histology, especially in the prepubescent population, to suggest that these changes are evidence of pre-torsion abnormalities in testicular make up (Dominguez et al., 1994). This is further supported by pre-operative antibody and hormone profiling combined with operative contralateral testicular biopsy showing some maturation arrest of spermatogenesis (Anderson and Williamson, 1986). Experiments have shown increased blood flow in the contralateral testis following detorsion (Nguyen et

al., 1999), maximally when a testis is left in situ with stagnation of blood within the microvascular system of the contralateral testis (Chakraborty et al., 1985).

There are 2 main theories proposed to explain damage to the contralateral testis: autoimmunisation and sympathetic orchidopathy as first proposed by Williamson (Williamson and Thomas, 1984), and ischaemia and reperfusion injury with bilateral release of reactive oxidative stress species, as first proposed by Akgur et al (Akgür et al., 1993).

In the first theory the suggestion is that the blood-testis barrier is breached either due to testicular torsion itself, or due to surgical fixation of the testis, and antibodies are formed after encountering antigenic haploid sperm cells. These then lead to contralateral testicular damage due to an autoimmune orchiditis. Some authors have demonstrated the presence of antisperm and anti-testicular antibodies in humans following torsion (Mastrogiamco et al., 1982), maximally in those having undergone fixation of the salvaged testis, and in rats (Ryan et al., 1986) where it was noted similarly that when the ipsilateral testis was left in situ the immunological damage to the contralateral testis appeared worse. This theory is refuted by other authors who looked failed to find excess antisperm antibodies in men post torsion (Arap et al., 2007; Fraser et al., 1985). Due to the findings of contralateral damage in the setting of excised testicular tissue, the suggestion is immunological factors may not solely explain the findings (Karagüzel et al., 1994).

The model of ischaemic damage, with a reperfusion injury leading to oxidative stress to the contralateral testis has gained much support. Findings that support this theory include the presence of products within the reactive oxidative species pathway in the contralateral testis (Akgür et al., 1995; Lysiak et al., 2000), findings of increased vascular flow in the contralateral testis after torsion (Kolettis et al., 1996; Nguyen et al., 1999) , and the apparent ameliorating effect of multiple anti-inflammatory agents in animal models (Ates et al., 2015; Minutoli et al., 2015; Ribeiro et al., 2014; Yurtçu et al., 2008) .

Prepubertal torsion may not have the same outcomes as post or peri-pubertal torsion. A study from Puri et al (Puri et al., 1985) showed in 18 patients who had had prepubescent torsion, two had fathered children, and in the 13 unmarried only one showed a pathological semen analysis. In investigation of

familial torsion the presence of antisperm antibodies was unpredictable and conception of children had remained possible following detorsion and fixation of testis (Sinisi et al., 1993).

Despite the previous and ongoing experimental and clinical investigation it remains difficult to know whether torsion of testis leads to a significant decrease in the ability to have children in humans and whether a detorsed, but apparently viable testis should be excised or returned to the scrotum.

1.2.7.4 Cancer

Associations between torsion and testicular cancer have been described. In a recent retrospective review of cases of testicular torsion between 2003 and 2015 Uguz et al found 2 cases of malignancy of histopathology reported of excised non-salvageable torsed testis; one seminoma and one malignant mixed germ cell tumour (Uguz et al., 2016). 724 UK born males treated for testicular cancer were investigated for previous torsion. 9/724 had a previous torsion, which compared to the population frequency suggests a 3.3 increased relative risk of developing cancer after torsion. They also found 69 had previous cryptorchidism which is a known risk factor for cancer. In this study torsion was independently associated with cancer rather than due to the confounding effects of cryptorchidism. A directive causative association was not demonstrated especially as in 4 the contralateral testis developed cancer (Chilvers et al., 1987).

1.2.7.5 Medicolegal Aspects of Care

The most common cause of lawsuits in America in children is missed diagnosis of testicular torsion. The average settlement in the US between 1985 and 2015 was \$491,421 (Gaither and Copp, 2016). A review of the cases performed by Gaither et al reveal some interesting insight into why torsion was missed. In 31% of children the presenting complaint was abdominal pain alone, 25% of children received a delayed referral to the Emergency Department, 19% failed to have a testicular exam on first presentation and 64% had a false negative ultrasound result. The most common first diagnosis was epididymitis. The average time from presentation to verdict was 4.99 years, with the State finding in favour of the provider in 50% of cases (Gaither and Copp, 2016). Closed cases of missed torsion in the UK and England seem to be less prevalent than the US, with a rate

of 9% in an adult urological series and 1.5% in a recent paediatric litigation case series (Osman and Collins, 2011; Raine, 2011).

1.3 Adolescent Awareness of Testicular Health Issues

In the literature to date, two groups have surveyed young men (Clark et al., 2011; Congeni et al., 2005; Nasrallah et al., 2000), two have surveyed parents (Friedman et al., 2016; Ubee et al., 2012) and one author has posed simultaneous child and parent survey regarding knowledge of testicular health issues.

The team at Akron Children's Hospital surveyed sports players from the surrounding junior high, high schools and colleges prior to the participant's 'sports' examination with a 5-question survey aimed to assess knowledge of testicular health issues. They initially surveyed 318 (Nasrallah et al., 2000) students, then expanded this to survey 755 students (Congeni et al., 2005), with both studies showing similar results. They found that 46% did not know why they were having a testicular exam, 45-46% did not wear appropriate protective underwear during sport, and that 34% would delay presentation with a painful and swollen testis. The authors concluded that the comparable results between: 'when your testicle is swollen, when do you need to seek medical attention?' and 'when your testicle is swollen and tender, when do you need to seek medical attention?', revealed an underlying confusion regarding the difference between painless and painful swelling. This may be a result of the methodology of using a multiple-choice answer, with the likely bias that the participants were trying to mark the 'correct' answer. These studies fail to recognise survey in the school setting may introduce bias and may not be the optimal setting to assess knowledge about testicular torsion and the likely health seeking behaviours in the setting of painful testis.

Clark et al (Clark et al., 2011) gave paper copies of a questionnaire to freshmen, as they entered their dining halls, and received 267 replies. To the question: 'what would you do in the case of severe sudden onset testicular pain in a friend', 48% gave the correct response of 'go directly to the emergency room'. On asking about whether the young men had been taught: about how to do a testicular exam, about the significance of testicular pain, or knew the term

testicular torsion, affirmatives were 58%, 43% and 18% respectively. The representativeness of the sample is difficult to assess due to the lack of demographics collected, and the study may be biased as this may be a particularly motivated cohort willing to delay dinner for a questionnaire about testis.

Burnand et al extended history taking in children presenting with an acute scrotum to a tertiary centre emergency department, to include a 19-part survey with Likert grading for agreement (Burnand et al., 2011). The questions included: It felt embarrassing to tell someone about my testicle, I would not feel as embarrassed if the pain was elsewhere, I would not be happy to tell my teacher about the pain if it started in school, I would tell someone about the pain as soon as it began, my Dad has told me about the function of my testicles, and my Mum has told me about the function of my testicles. In addition to the child survey the parents were asked separately if they knew about torsion. 39.4% of 76 presentations of acute scrotal pain responded to the questionnaire. In this group 36.8% of parents knew about torsion of testis. This survey opens some interesting ideas but has some flaws in its methodology. The response rate is poor and may represent a biased motivated population. The survey setting is within hospital once the family have decided to present with testicular pain, therefore the responses must be interpreted in the light of the family's experience of having pain, making the decision to come to hospital and now having some expertise after speaking with triage and doctors. The opening question introduces the idea of embarrassment, and therefore may instil the idea of embarrassment, rather than investigate more subtly if embarrassment is an issue. Some of the language might be difficult for younger children to understand, such as asking about testicular 'function'. The authors recognised discrepancies in their data and the limitations of the survey. They showed there is lack of awareness in children and parents and recommended education in the school environment.

Ubee et al (Ubee et al., 2012) surveyed parents of children following scrotal exploration for acute scrotum to assess the parents prior knowledge and awareness of the severity of the problem. They had an 81.6% response rate. 34% of parents had some prior knowledge, either through family and friends experience, through the internet or through their family doctor. 64% did not

appreciate how severe the problem was and 96% felt there should be better public awareness. The authors felt efforts should be made through the community to improve awareness.

Friedman et al (Friedman et al., 2016) issued a survey to all parents attending paediatric urology clinic with their child and received 479 responses (a 85% response rate). They also distributed the same paper survey in ENT clinic to check for bias and received 59 responses. Results were not grossly different between urology and ENT findings. 34.2% had heard of torsion either by word of mouth (35%), their paediatrician (17%) or formal education (6%). Experience of previous testicular pain increased the likelihood of knowledge about torsion. 12.8% of parents had spoken to their children about torsion. 74% would present quickly to the paediatrician of the emergency room, and 81% would present to emergency out of hours services.

One paper of interest used qualitative methodology to investigate adult male health seeking behaviour for testicular symptoms in Ireland. Saab performed individual interviews with 12 men and 3 focus groups with 17 men to reach data saturation. Their population demographics were as follows: mean age 33.5 years (range 18-47); 17 heterosexual, 11 gay and 1 bisexual; 16 single; 20 had a university degree and 14 were employed; and 9 had previous experience of testicular symptomology (Saab et al., 2017).

He found the data showed 2 principal areas of enablers and barriers were to awareness and health seeking behaviours. It was of interest many men had heard of testicular cancer but knew nothing more about the disease and did not know about recommendations for self-examination. Few men knew about benign conditions unless they had had direct experience themselves.

Impediments to awareness included attitude to testicular disorders, perceptions of health care, awareness not promoted in schools, trivialisation of male health and sex education, and lack of screening. Enablers to awareness included: exposure and experience to information, attitudes, previous clinical testicular examinations, personal or family history of disease. Self-reporting as being health conscious or gay was perceived as enabling awareness. It was of interest that the data showed awareness increased with age. This may be due to cumulative awareness and exposure of anecdotal stories in family or the media.

Many men mentioned Lance Armstrong, a famous cyclist and survivor of testicular cancer.

Barriers to health seeking were lack of knowledge, symptom misappraisal, fear, denial, avoidance, embarrassment. Social aspects seen as barriers to health seeking were: not wanting to worry the family, false reassurance by someone you trust, busy with life, and the social norms of maleness, such as machoism, stoic, optimism and a fear of being labelled a hypochondriac. The cost and waiting times of the family doctor or hospital were a barrier for many men, the study was performed in Ireland where a GP visit may cost 50 euro. Enablers to health seeking were family or friend support, severity and duration of symptoms, having a nurse in family, an inherent 'health consciousness', and a perceived threat to fertility.

1.4 Adolescent Access to Acute Health Care

A review of Medline revealed no papers directly describing barriers to acute hospital presentation for male adolescents. Below is the summary of papers found describing adolescent presentation to emergency departments and those discussing adolescent health needs and how age and gender affect adolescent's experiences of illness.

The WHO definition of adolescence is those aged 10-19 years. Adolescents are a diverse group undergoing transition from child to adult and have specific health needs and risks (World Health Organization, 2012). A recent report from Australia and New South Wales (Jenkins and Katz, 2015) found 33% increased rates of emergency department attendance for adolescents and young adults between 2003 and 2013. The primary diagnosis of presentation was musculoskeletal (6.6%), mental and behavioural health (4.7%), respiratory tract (4.5%), digestive (4.4%), infections (3.6%) and skin and soft tissue (3.5%). They acknowledged there is a perception that adolescents are more violent than other groups, in part due to a higher proportion presenting with alcohol intoxication and behavioural problems. They could find no evidence that adolescents are more violent than any other group.

A WHO report entitled 'Making Health Services Adolescent Friendly' identified the barriers to adolescents gaining the health services they need (World Health Organization, 2012). These can be summarised in 4 key areas: availability,

accessibility, acceptability and equitability. Many young people internationally are banned from the treatment they need due to law and policy, such as emergency contraception. Young people do not know where or how to access healthcare. Services may be distant from them, difficult to reach or too expensive to attend. They may not find the services provided are acceptable, for instance if the waiting area is public. They worry about being scolded or asked difficult questions or put through unpleasant procedures. Adolescents worry that health care services favour those from affluent backgrounds, and not all young people are treated equally. They found internationally young people's priorities are to be treated with respect and have their confidentiality respected. It can be particularly difficult to maintain adolescent confidentiality (Talib et al., 2016) in a paediatric hospital environment, where currently the majority of adolescents are cared for (Hagell, 2013). Only 10% of 12 to 14 year olds and 18% of 15-17 year olds were treated as inpatients on adolescent specific wards.

In a review of adolescent male health issues for primary practice, Westwood and Pinzon (Westwood and Pinzon, 2008) note whilst males and females have similar rates of illness, the rates of attendance to healthcare services in young men is lower. They noted the most common male health concerns regard puberty, either delayed or precocious and with concerns regarding the changes in genitalia. They found delayed puberty leads to emotional distress, low self-esteem and teasing and bullying from peers. Other issues included gynaecomastia, erections, ejaculation, masturbation, cancer, illegal activity and violence, substance use and abuse, sexual health and orientation, mental health, ADHD and eating disorders. They felt adolescent men do not present to healthcare services due to feelings of invincibility and a denial of having health needs. They felt accepting the need of health services made young men feel vulnerable and that they were not living up to perceived male standards. They noted that parents may often act as a barrier due to a perception of a 'healthy' son, with Fathers at times making poor role models. 24% of adult males admitted to waiting as long as possible before seeing a clinician in the setting of ongoing symptoms. They felt the solutions were to educate parents of younger males and engage with the family for routine health maintenance appointments prior to puberty. Adolescents find it particularly difficult to talk about

themselves, and they gave advice to move between non-threatening topics and sensitive ones, remembering the importance of confidentiality in these young men (Westwood and Pinzon, 2008).

Alice McClean in 2006 in Glasgow performed 25 age and gender specific focus group interviews and analysed the results with qualitative framework methodology (McClean, 2006). She found that young people's experience of illness was integral to boys' and girls' presentation of themselves and their performances of gender and age. Their efforts to conform to gender and age expectations had significant influence on their reactions to illness, their conceptualisations and assessments of symptoms and perceptions of seeking help for illnesses in different social contexts. She found that social expectations restrict boys more than girls. Seeking help is a serious threat to boys' constructs as being successfully male, and males perceived worse consequences of seeking help.

In investigating adolescent use of ambulance services, no academic papers were found. The UK prehospital service is devolved to the regions and there are no national guidelines as to response to a call from a child or adolescent. Enquiries to the Scottish Ambulance Services and the Yorkshire Ambulance Services received the following replies:

'I can confirm that there is no policy in place for when a child under the age of 16 years old calls for an Ambulance, however I can confirm (Depending on the situation/condition of the patient) we do require an adult to travel to Hospital, we would always ask the Police to assist if there was no responsible adult.' Jill, Regional Control Manager, Scottish Ambulance Service

'In respect of the actions taken by our ambulance crews who are dispatched to patients, there is no specific procedure for them to follow for young people who are not with an adult and the crews would respond in accordance to each specific set of circumstances and the needs of the patient' Janet, Patient Relations, Yorkshire Ambulance Service.

1.5 Current UK Education

1.5.1 Schools Based Education

An Ofsted review of personal of social and health education (PSHE) in 50 schools in England, found 60% of schools were delivering good or better education, but that 40% needed improvement (Ofsted, 2013). In their report entitled ‘Not Good Enough Yet’ they found that having a dedicated PSHE lesson was associated with better lessons, that half of primary and two-thirds of secondary students had a well-developed understanding of how to lead to healthy life in terms of food, nutrition and exercise. It is of interest they report:

‘Sex and relationships education required improvement in over a third of schools. In primary schools this was because too much emphasis was placed on friendships and relationships, leaving pupils ill-prepared for physical and emotional changes during puberty, which many begin to experience before they reach secondary school. In secondary schools it was because too much emphasis was placed on ‘the mechanics’ of reproduction and too little on relationships, sexuality, the influence of pornography on students’ understanding of healthy sexual relationships, dealing with emotions and staying safe.’

Twenty percent of teachers felt they had little or no training on delivering PSHE education (Ofsted, 2013). Currently much of the training is provided by education improvement partners external to schools with courses and training being offered by groups such as Babcock Education, the Sex Education Forum (part of the National Health Education Group) and the National PSE Association. Currently their resources do not contain information about testicular health issues for young men.

In England there is currently a new Child and Social Work Act (2017) under consideration, which at the time of going to print is awaiting Royal Assent, and is expected to come into force in September 2019 (Lord Nash and Justine Greening, n.d.). The act will make personal, social, health and economic education (PSHEE) a statutory provision of schools. The aim of this aspect of the bill is to prepare children to stay safe and prepare for life in modern Britain. Whilst much of the focus is on sexual relationships, staying safe online,

recognising exploitation, there is included recommendations of education in healthy bodies and lifestyle. The curriculum is not dogmatic, as the Department of Health wants to afford schools the flexibility to develop their own programmes which are age and demographic appropriate.

NHS Scotland has produced an excellent educational resource entitled ‘SHARE’ (NHS Scotland and WHO, 2016). The resource aims to deliver a curriculum promoting physical, psychological, social and mental well-being in young people. The learning objectives of section 2 ‘Talking about bodies and sex’ include: identify appropriate language for discussing sexual issues in the classroom and with health professionals and revise sexual body parts if required. They inform that: *‘testicles (or testis): two organs that produce sperm. They are shaped like small balls or plums and are covered by the scrotum. Usually one testicle hangs lower than the other.’* In the concluding quiz a question asks, *‘what organs a male should examine on a regular basis’*, but there is no preceding information about testicular cancer or self-examination. Education Scotland is responsible for delivery of a ‘Curriculum of Excellence’ and defines broad educational policy but does not specify the personal and sexual education curriculum compulsory for each student. A freedom of information enquiry was made into the take up of the Scottish SHARE educational resource, but unfortunately this data is not available.

1.5.2 Other Sources of Education

To assess the information available for young people through the internet the search terms ‘my testicle hurts’, ‘teen health’ and ‘testicular health issues’ were run through Google. Whilst different search engines will preference different websites, and are tailored to personal search history, this search gives an idea of information available for young people. Table 1-1. illustrates the outcomes and shows information for teenage health does not include details about testicular torsion or cancer. Information about testicular health problems in general often mention torsion but not clearly stating this is an emergency and the web sites are focused at older men. Searching for ‘my testicle hurts’ came up with clear details of the emergency of torsion on one site, but surprisingly others discussed other conditions first. On one site a pop up appeared discussing

the causes of impotence and adverts for treatments. This is clearly aimed at targeting older men.

Table 1-1. Results of Three Internet General Searches for Topics as Shown

Internet search Term	Top 3 Results	Summary of Information	Information on Torsion for teenagers
'teen health'	The Better Health Channel	Information regarding alcohol, body image, bullying, drugs, media, suicide, sexual relationships and pregnancy	No
	The Women and Children's Health Network	101 topics	No
	Family Lives UK	Peer Pressure, sleep, depression, exercise, body image, piercings and tattoos, holidays, self-harm and eating disorders	No
'testicular health issues'	Andrology Australia	Mentions if you have pain or lumps you should see a doctor immediately. The most common testicular problems are cancer, UDT, lumps, infection and torsion	Aimed at men
	Men's Health Forum	Epididymitis, hydrocele, torsion, varicocele	Aimed at men
	Boots web MD	Trauma, Torsion and Cancer	Aimed at men
'my testicle hurts'	Healthline	First box Torsion: this is a medical emergency	Good clear information (picture of an older man)
	Mayo clinic	Nerve pain, drugs, epididymitis, gangrene, HSP, hydrocele, hernia, kidney stones, cancer, injury, torsion in brackets	Poor information
	Medicine.net	Pop up appeared for impotence medications advert. Torsion, epididymitis, hydatid of Morgagni, kidney stones, tumour, injuries, hernia, orchiditis	Aimed at men

1.6 Summary and Study Aims

Testicular torsion is a urological emergency with a time critical need for intervention. The testes have the pivotal role of spermatogenesis and androgenic hormone production which initiate and maintain puberty. The

incidence of testicular torsion is 1/4000, with 1/889 experiencing torsion by 25 years of age (Shteynshlyuger and Yu, 2013). A predisposing anatomical arrangement exists but a provoking episode is often associated with the onset of torsion.

Presentation of torsion of testis is with severe testicular pain, but despite this only 31-48% of young men present within 6 hours (Moslemi and Kamalimotlagh, 2014; Saxena et al., 2012), a rate lower than males over 19 years (Jones et al., 1986). The diagnosis is predominantly a clinical one, and whilst ultrasound may aid diagnosis, using ultrasound risks delay to theatre and higher testicular loss rates (Preece et al., 2017) .

Urgent surgical exploration and detorsion is required in cases of testicular torsion with outcomes are directly associated with time from onset of symptoms to surgery, as confirmed by the author's systematic review. Whilst other factors affect outcomes including degree of torsion, route of presentation, inter-hospital transfer, none are as significant as time to presentation. Torted testis operated within 6 hours of onset are generally salvaged (Pogorelić et al., 2016; Saxena et al., 2012) with lower rates of salvage after this.

The evidence shows that later presentation leads to testicular loss, and that this rate is higher in children than adults. Previous studies looking at the reasons why young men present late with testicular torsion suggest this is an issue of awareness (Friedman et al., 2016) and also of embarrassment (Burnand et al., 2011; Johnston et al., 2014). But none sufficiently investigate the barriers to young men presenting to hospital with appropriate methodology to be able to understand the phenomena in the real world. The previous surveys introduce preconceived bias with their methodology. To investigate the question 'why' and understand it within the contemporary social context qualitative methodology is required, this will be described more fully in chapter 2.

Saab (Saab et al., 2017) performed a qualitative study exploring the barriers and enablers to presentation with testicular health problems in adult males. The data analysis revealed 2 key areas of health seeking intentions in the presence of testicular symptomology: awareness and health seeking behaviours. The enablers included: exposure and experience to information, attitudes, previous clinical testicular examinations, personal or family history of disease, family or

friend support, severity and duration of symptoms, having a nurse in family, an inherent 'health consciousness', and a perceived threat to fertility. Barriers to health seeking intentions included: lack of knowledge, symptom misappraisal, fear, denial, avoidance, embarrassment, not wanting to worry the family, false reassurance by someone you trust, busy with life, the social norms of maleness, the cost and waiting times of assessing healthcare, awareness not promoted in schools, trivialisation of male health and sex education, and lack of screening. It of interest this study showed awareness increased with age, therefore it is necessary to perform a comparable study in young men 10-19 years to investigate enablers and barriers to presenting to health care services with testicular symptoms.

Current educational and awareness resources are poor, with no standardised education through schools and inadequate resources available online. Adolescents are a separate but diverse population with specific health needs (World Health Organization, 2012). Previous investigations have shown adolescent males find it particularly difficult to present with health symptoms as this erodes their developing confidence in their male-ness and the importance of 'macho-ness' (McClellan, 2006).

At present we do not know if poor awareness of benign testicular complaints or issues caught up in the core of self-identification as young men, delays adolescents presenting to health care services with acute testicular pain. To address this and facilitate early presentation with testicular torsion we need to understand the issues and develop an effective education resource tailored to the issues.

This study aims to study in-depth the enablers and barriers to adolescents and their families coming to hospital with testicular symptoms and emergencies in the UK context.

Chapter 2. Methods

Overview

The chapter below includes a description of the theoretical aspects of qualitative research. This has been written so that those new to qualitative research can understand the different ideological standpoints available and therefore the implications of application of these standpoints on data collection, interpretation and the validity of conclusions (Kelly, 2010). In addition, the theoretical assumptions made in data analysis must be explicitly stated to allow the reader to evaluate the trustworthiness of the process (Nowell et al., 2017). Following this, the chapter returns to descriptions of the research methodology to facilitate replication and interpretation of the study. This includes description of the specific choices as to research technique, protocol development, recruitment, data handling and analysis and declaration of bias and confounders.

2.1 Relevancy of Testicular Torsion in the Current Paediatric Population

In order to ensure that investigation of adolescent attitudes to testicular health is necessary and has ongoing relevancy, the author undertook two geographically diverse regional audits of time to presentation and outcomes in adolescent torsion; and undertook a systematic review and meta-analysis of the recent literature (last thirty years) to describe outcomes following testicular torsion in adolescent males.

2.2 Principles of Qualitative Research

2.2.1 Theoretical Underpinnings of Qualitative Research Methodology

Qualitative research is used to address questions requiring understanding and explanation of social phenomena (Ritchie, 2011). It allows the development of theory (Bryman, 2008), and offers the ability to develop solutions and strategies. It is possible to identify motivations and factors and influences underlying a belief or behaviour. It is particularly useful in poorly understood, delicate and complex deep-rooted issues. Qualitative research is a broad description of multiple methodologies which allow us to understand humans in their social world, through their own experiences and perspectives. There are different

approaches to qualitative research, which vary in their philosophical underpinnings.

Ontology discusses whether there is a natural or a created social reality. Realism describes the philosophy whereby it is believed there is an external reality which exists outside people's beliefs and interpretations. Materialism claims that experiences arise from the fixed material elements of the world. Idealism or constructivism describes a world whereby everything exists through human experience and therefore the world is only knowable through the exploration of the human mind.

Epistemological debate surrounds the question of how we can learn about reality; with the two paradigms being positivism and interpretivism. Positivism is where facts and values are separate, and the researcher is independent from the world and able to conduct objective research. In the interpretive model the researcher and the social world mutually impact on each other. Findings are ultimately influenced by the researcher's perspectives, and it is not possible to undertake 'objective' research. Qualitative research mostly grounds itself within interpretivism and uses social observations to induce and deduce explanations of the social world.

Despite the differences in philosophy most qualitative techniques follow a process of data collection, data transcription or management, initial description with codes or categories, identification of themes, and interpretation and conceptualisation (Ritchie, 2011).

2.2.2 Data Generation

There are many techniques or methods within qualitative research and the social sciences to gather data, these include one-to-one interviews, focus groups, life histories, ethnographies, observation and certain surveys. Data can be naturally occurring, such as ethnographic observation of a community, or generated such as interview (Spencer et al., 2003).

One-to-one semi structured interview gives the best opportunity to gain understanding of the personal context within which the research phenomena is happening. Exploratory interviews give an idea of what it is like to be in a situation, and why people behave as they do. They allow us to unearth key ideas

but also explore conceptual depths (O'Reilly, 2017). It allows to gain rich in-depth knowledge but also allows the researcher to ask specific questions. It is particularly useful in delicate and complex issues, and understanding process and experience (Ritchie, 2011). One-on-one interviews are not without disadvantage mostly due to the possibility for bias, for instance the influence of the interviewer, the perception of wanting to impress or find the right answer for the interviewee, differences in social or racial group (Bryman, 2008), but these can be ameliorated for by the development of skilled craftsmanship of the interviewer and by reflexivity of the chief investigator (CI).

Self-completion survey has the disadvantages of use of closed questions, an inability to probe the issues and explore depth of issue, the inclination to answer what it is felt by the participant to be the 'correct answer', the difference between stated and actual behaviours, and an inability to check who has actually filled out the form (Bryman, 2008). Focus groups often threaten the individual or outsider and reinforce ideas of the norm (O'Reilly, 2017).

2.2.3 Concepts of Data Analysis

There are three basic paradigms of qualitative research analysis: sociolinguistic also known as discourse analysis, thematic or inductive analysis.

The most common inductive technique used is Grounded Theory (Glaser and Strauss, 1973), which true to its name is grounded in the data. It is used to develop theories regarding basic social processes (Thorne, 2000). Classically Grounded Theory describes a research methodology where there is little understanding of the research topic, and the literature review and basic study of the research question takes place alongside the interviews and data analysis. The research questions, and theories develop with data collection. It is exploratory and rich in its descriptions, but has a high level of abstraction from a relatively early stage in the analysis (Charmaz, 2006). Many subsequent methodologies are routed in the epistemological and ontological standpoints of grounded theory but are less inductive and have been developed to allow a more practical application of a research question.

Thematic analysis describes and interprets participant views to describe a phenomena (Smith and Firth, 2011). Thematic analysis considers the apriori knowledge and is appropriate for a study where the researcher has some

understanding of the research question and the social world of the study. Within thematic analysis, there are different approaches to data analysis, with some utilising an intuitive and ad hoc fashion of interpretation and others a more organised system. Sociolinguistic focuses on exploring language to describe a social phenomenon.

The process of data analysis is often the least well described aspect of the research project and has the least literature to support methodology (Nowell et al., 2017). Practically the data analysis process follows the following steps (Braun and Clarke, 2006)

1. data familiarisation
2. generating codes
3. search for themes
4. review themes
5. define and name themes
6. produce the report

The interview transcripts are read and re-read and ideas found coded. Once the full dataset is densely coded, the codes are inspected to develop categories. These in turn will be inspected alongside the original data and from this an index of categories is developed from grouping of similar ideas, which later form themes. These themes are developed with reiteration of the process until on further testing all transcripts fit within a cogent conceptual pathway.

There are techniques of data management and handling described to help develop the descriptive codes into themes and thus begin the interpretive and conceptualisation process. Whilst papers describe the themes emerging from the data this is an active process and comes about from the re-reading, familiarisation, active comparisons between cases and consideration of ideas. Methods to develop themes include noting patterns, seeing plausibility, clustering, analysing metaphors, counting, contrasts and comparisons, and partitioning variables (Kvale and Brinkmann, 2015). To help see things more abstractly techniques include: looking at relations between variables or finding intervening variables, with the aim to assemble a coherent discussion with logical chains of evidence and conceptual and theoretical coherence (Miles and

Huberman, 1994). Themes can be identified by their prevalence or where something important has been captured.

The identification of themes can be deductive or inductive, ie heavily driven by the researcher especially if they have a particular research question in mind (Braun and Clarke, 2006) or can be entirely developed from the data. Data interpretation can be done at differing levels. Data interpreted in a 'realistic' fashion will be taken at surface value and look at personal motivations and experiences, whereas data interpreted within a constructionist model will allow a deeper level of interpretation looking at socio-cultural causes of behaviours and feelings (Braun and Clarke, 2006).

2.2.4 Coding

Coding is the route by which interview data can start to be understood through the process of 'breaking down, examining, comparing, conceptualising and categorising data' (Strauss and Corbin, 1990). The goal is to capture the richness of experiences (Fereday and Muir-Cochrane, 2006), not to describe the most common experience (Hislop et al., 2017). It is 'inductive, comparative, iterative and interactive method' (Charmaz, 2006). It can be inductive, ie all the codes coming from the data, or can be deductive, ie codes are established a priori or templates are generated from previous literature (Cassell and Symon, 2004; Nowell et al., 2017). Concerns regarding the validity of the coding process have been addressed in multiple ways within the social research community. The early work of Glaser and Strauss on the 'Discovery of Grounded Theory' described a coding formulation which legitimised methods of interview analysis by presenting explicit strategies for a coding process (Glaser and Strauss, 1973). In theory anything can be coded, but Gibbs (Gibbs, 2007) give us suggested areas for coding such as: described acts, events, activities, strategies, states, meanings, norms, symbols, levels of participation, relationships, conditions, constraints, consequences, settings, and reflexive coding i.e. the researchers role in the process (Kvale and Brinkmann, 2015).

2.2.5 Data Management

Two well described techniques enable data management and analysis: one-sheet-of-paper (OSOP) and framework analysis. In OSOP each individual code is brain stormed, relationships visualised and referenced within a single sheet of

paper, and from this synthesis enabled. This technique facilitates the development of conceptual theory.

‘Framework’ analysis was developed in the 1980s by social policy researchers at the National Centre for Social Research, to manage and analysis data in applied policy research (Ritchie and Lewis, 2003). It is now commonly used in healthcare and psychology as well as public health and policy research. Framework analysis refers to both a philosophy of research structure and analysis and a practical methodology for the management of data. Framework is a method utilising the thematic paradigm of data interpretation: ‘seeking to draw descriptive and/or explanatory conclusions clustered around themes’ (Gale et al., 2013). There is some disagreement as to whether framework is aligned to a particular philosophy of data interpretation (Gale et al., 2013). It may be used in both deductive and inductive data analysis but most commonly it is felt to be bedded in subtle realism whereby the social world is thought to exist independently of individuals subjective understanding but is only accessible to be researched via the participants interpretations, which are subsequently interpreted by the researcher (Ward et al., 2013). The process was first described by Ritchie and Lewis, published in ‘Analysing Qualitative Data’ edited by Bryman and Burgess 1994 (Ritchie and Spencer, 2001). They describe a five-step process to analysing qualitative data:

1. Familiarisation

The researcher makes themselves deeply familiar with the data, through undertaking the interviews listening to the recordings and performing the transcription.

2. Identifying a thematic framework

The data is coded line by line and during this process themes will begin to develop which will form the basis of the topic guide. This will be refined with logical and intuitive steps during further iterations of data processing, keeping the original data and the research question in mind. A hierarchy of themes and subtopics is developed.

3. Indexing

The data will be reread and indexed according to the emerging thematic framework, this will be refined, expanded and changed as appropriate and the data re indexed with each change.

4. Charting

A chart per theme is created with sub topics in columns and participants in rows, keeping original quotes to evidence deduction.

5. Mapping and Interpretation

In this step concepts are defined, the range and nature of the phenomena mapped, typologies are created, and the beginnings of explanations and strategies emerge. The researcher will use varying techniques including finding associations, comparing and contrasting perceptions, mapping polarities and searching for patterns whilst weighing salience and dynamics.

Framework is ideal for healthcare research as it applies a clear process to the generating of themes. In charting the themes and subtopics the data is transparently managed. The researcher can move quickly and easily through the datasets, comparing participants and looking for patterns within the dataset. It allows easy checking of the validity of hypothesis, and therefore improves the quality of the study. Framework is suited to cross sectional descriptive data (Smith and Firth, 2011), enabling various aspects of a phenomenon to be captured, and works well with semi-structured interviews. It particularly lends itself to explanations with easy access to the synthesised data in a matrix display, so it can be continually revisited, and facilitates the ability to look between cases across a range of different themes or phenomena.

2.2.6 Credibility, Transferability, Reliability and Validity

For the reader to accept the author's interpretation of a social phenomenon there must be trust that the study undertaken was of high quality. There are varying descriptions of the core aspects whereby the quality of a study can be assessed. The most commonly accepted is that of Lincoln and Guba (Lincoln and Guba, 1985) which are as follows:

- Credibility describes the degree to which the report is true to the original data. Aids to credibility include prolonged engagement

with the data and consistency, coherence and communicability of the write up (Rubin and Rubin, 2012).

- Transferability is the degree to which your study findings are applicable to similar populations or the ability to apply the findings in other contexts. It can be interpreted through clear and thick description of the context of data collection. Demographics of the population base are not necessary to be described per se, but the setting within which data collection takes place with researcher reflexivity is the key to understanding the transferability of the findings.
- Dependability or Reliability is the consistency and repeatability of the study. This can be aided by clear descriptions of research technique and audit trails.
- Confirmability or validity is the degree to which the findings of a study are shaped by the participants or the original data rather than the researcher bias or motivations or preconceptions. Methods to improve validity focus on researcher reflexivity.

Practically the quality of a qualitative interview study is enabled through meticulous study design, transparent methodology, researcher reflexivity and responsible reporting. Kvale et al describe seven points during study design which underpin validity (Kvale and Brinkmann, 2015). These seven points are the same at which ethical considerations are imperative, highlighting how respect for participants is integral to the quality of the study. These points of quality control are as follows:

1. Thematising: the theme of the study should aim to improve the human condition and the research question is based upon a logical derivation of prior theory.
2. Study design: choosing the correct study design whilst minimising any harm to the study participants.
3. Interview: the quality of the interviewer brings out a trustworthy report from the subject, and careful questioning of meaning within the interview increases internal validity.
4. Transcription: must be loyal and consider linguistic style of the interview

5. Analysis: the interpretation is logical, sound and responsible
6. Verification/ Validating: the researcher must reflect on data and choose appropriate methods of validation, ie two researcher data transcription, analysis and interpretation
7. Reporting: Accurate and rich description of the data, analysis and conceptual links.

Validation takes place internally within the data, checking for consistency within the case and between cases and externally, by triangulation and participant feedback. There is debate as to the need for participant validation post analysis. Some groups argue that well collected data with intra-interview checking and a high degree of researcher reflexivity are sufficient for quality control. Others suggest triangulation of data with evidence from different cases, member validation, two researcher analysis and alternative sources aid validation. In this study the CI undertook all data collection, coding and interpretation with the support of two supervisors. All authors agree that transparent process, description of context, detailed data collection and 'thick' description, acknowledgment of the researcher bias and responsible analysis and write up, maintain validity and study quality control (Lincoln and Guba, 1985). Thick description is the process by which the data is richly described, with context overtly discussed, which informs interpretation and the readers understanding of the themes (Hislop et al., 2017). In this study the CI sent updates via email, spoke on the phone and met with her supervisors, who listened to interviews, read transcripts and discussed emerging themes, helping to both validate and develop deeper data interpretation.

A 2003 UK Cabinet Office document written by the team at the National Centre for Social Research for the Government Chief Social Researcher Office offers an excellent framework for maintaining quality of qualitative research. This includes 18 points to appraise a qualitative paper but also offers the four guiding principles for excellence in research methodology. These are the study must be contributory to society, defensible in design, rigorous in conduct, and credible in claim (Spencer et al., 2003). There is a Critical Appraisal Skills Programme (CASP) checklist for assessing the quality of a qualitative study ("(CASP) Qualitative Research 10 questions to help you make sense of qualitative research," 2017). This well-known resource for clinicians helps non-qualitative

researchers understand the processes of maintaining quality and helps to read a qualitative paper. This document describes the core aspects of the study design and describes the process of researcher reflexivity: 'Does the researcher critically examine their own role, potential bias, and influence in data collection and interpretation?'

2.3 Study Methodology

2.3.1 Project Methodological Decision Making

The ideological standpoint at the outset of the project was positivist realism, whereby the researcher felt the young men's experiences were real and should be interpreted in a semantic fashion, and interpretation would be at face value. This was enhanced in that the chief investigator had some understanding of the research question and was driving data interpretation.

With the iterative process of reading and re-reading the transcripts the coding and thematic development became an inductive process, ie all codes, categories and themes came from the data itself. The development of the conceptual pathway fell back to a more deductive methodology. Literature review was undertaken prior to and during data collection. Definition of the clinical problem occurred prior to data collection but reading as to the sociological aspects and the resources available took place during the period of data collection and interpretation. In addition, the as the data was coded, categorised it became evident than some of the aspects of the young men's' attitude and experiences were socially constructed and needed a deeper level of interpretation, that of constructionist approach, allowed for discussion of the sociocultural aspects of the young men's experiences.

This study was a hybrid of inductive and deductive data analysis as previously described (Fereday and Muir-Cochrane, 2006). This allowed the interpretations to be generated by and stay close to the data and allowed the research question to be investigated deeply and therefore practical conclusions to be drawn which may be applied to a real-life situation.

In the study design one-on-one semi-structured interviews were planned. This was to maximise the confidentiality of the interview. The choice was made as to include the parents if possible as chaperone for safety but also as it was felt

this was the environment within which decisions regarding health is experienced for young people. Therefore, having the family discussion of the issues, added significant depth and realistic social context. In two instances the protocol was changed due to the circumstances and the wishes of the family. In one case the two brothers were interviewed together, due to one young man feeling shy to discuss the issues on his own. In the second a young man brought his friend and his Mother, as he wished to receive an incentive and was interested in the project. Both breaks from protocol added an interesting dimension to data analysis as described in the results.

Computer Assisted Qualitative Data Analysis Software (CAQDAS) software was used as this greatly sped up the process of coding and re-coding, especially in light of the multiple reiterations performed by the author. The choice whether to use software to help with data management is a personal one (Marshall, 2002). It is imperative to realise the software is for management alone and does not provide any intellectual support to the project (Morison and Moir, 1998). This author chose to use NVIVO (NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 11, 2015) due to training in this package and University accessibility. The programme was used solely for data management and was felt to improve the reliability of the project. Not only could each stage be audited, screen shots were easily sent to Supervisors allowing triangulation of interpretation and improved validity, but it also improved efficiency and allowed the researcher to focus on intellectual rather than the manual tasks of framework analysis (Cope, 2014). In addition the tools available allowed the researcher to investigate the data by sub group or commonalities (Zamawe, 2015) aiding the constant comparative analysis.

Decision was made to use a framework methodology to take the data from coding, categorising and indexing to conceptual analysis using the techniques of constant comparative analysis as described above.

2.4 Ethics and Safety

2.4.1 Ethical Considerations

This study had Health Research Authority Ethics Board review and was approved, IRAS project number 167713. Initial approval was gained 21/8/15, REC number 15/YH/0299. A change in location required ethics board amendment which was

given 25/11/15. The study protocol had local research and development approval with the Clinical Research Unit at Sheffield Children's Hospital, protocol number CA14013. The study was conducted in accordance with the International Conference for Harmonisation of Good Clinical Practice (ICH GCP), and the Research Governance Framework for Health and Social Care (2nd Edition).

To maintain the highest research quality much effort was made to hold the highest ethical standards for our participants. Adolescence is time of physical, cognitive, emotional, social and behavioural change (Hagell et al., 2013) which the research remained are cognisant of. The study dealt with a subject that could cause embarrassment and therefore pilot interviews and advice from adolescent advocates was undertaken to ensure language, sources and strategies for engagement were appropriate. The study design asked the participant to nominate a chaperone they and their parents are comfortable with. The chief investigator had experience of talking with the subject matter in a non-confrontational, supportive manner and aimed to interview with a manner of naïve interest.

The study offered no interventions and did not alter health outcomes. The questions asked could unearth child safety concerns and therefore a protocol was developed to deal with any safeguarding disclosures. The interview could unveil an adolescent with a previous torsion and loss of testes, if this was the case the other testis would require fixing and protocol was made for this, see Appendix 1. The interview may have caused some adolescents to become aware that may have future health issues which they had not considered prior to the study process. The researchers did not anticipate causing upset or harm to the child, and the study was likely to actively benefit the participant. The interview could have brought up a family history of testicular illness including cancer and therefore questions on this axis were dealt with sensitively. Parental and age specific young person information leaflets were designed, see Appendix 2. Fully informed consent was taken from parents and the young person, with clarity of the process to withdraw, providing contact details if any concerns were raised. Issues of anonymity and confidentiality were maintained in the anonymising of data and data handling.

The interviews were recorded and stored on external hard drive, kept on NHS property in a locked locker and were listened to and transcribed by the CI (CM)

and Supervisors (KC/MB). The family had four weeks post interview to retract the interview from analysis. The transcribed data was stored as above. The data will be kept until 5 years post study completion when it will be destroyed. All participants were given an opportunity for feedback.

2.4.2 Safety Considerations

The safety issues in this study are the unveiling of child safety concerns, previous missed torsion and interviewer safety. Protocols were developed for each of these scenarios, see Appendix 1.

A single interviewer conducted the interview on their own with the chaperone of the child and family's choice. If no chaperone is present the interview will be disbanded. For every interview an interview booking protocol was completed. This included details of where and when the interview was being performed. A telephone was available to allow arrangements to be made using an anonymous number. This was kept with the interviewer at all times for safety. A study email was set up to maintain the online safety of the CI.

2.5 Pilot

Prior to developing the research protocol, pilot interviews were performed to test the feasibility of undertaking a semi-structured interview of the young man within the family environment. This ensured the interview was tolerable and acceptable to both the young man and his family. The research was conscious of their disparity from the study population and that the questions were sensitive. Two families who had gone through the experience of adolescent torsion were invited for preliminary interview. One family accepted. The participant was a young sports man, who had nearly lost both testes. The CI met with him and his Father and Mother and discussed the project, language was checked and the questions to be asked were tested with the family who felt them feasible and acceptable.

2.6 Declaration of Bias and Confounders

To responsibly undertake and report the data and maintain validity the investigators must declare their bias and confounders. In this section Caroline MacDonald chief investigator declares her apriori confounders and bias.

2.6.1 Bias

'To ameliorate the effect of my bias on interviewing and analysis I have prepared thoughts about my personal bias prior to gathering data and will reflect upon this during and after analysis stages. I believe my personal bias comes from my experiences of social education at school, from my gender, from my interactions with young men at the contact point of testicular torsion, and from a previous behavioural change project I was involved with (Quilliam and Smith, 2016). My personal bias is that I feel young men do not come to hospital with testicular torsion due to issues of knowledge, embarrassment and how young people feel about their health and access to healthcare. I feel that some of the issues lie around the themes of young peoples' 'ownership' of their health and transition from child to adulthood'.

2.6.2 Confounders

'To perform a valid interview, I must be aware of and ameliorate the effects of confounders within the study design and therefore within the data. The study design is the correct methodology and I have appropriate support with a supervisor experienced in qualitative methodology. I am recruiting the young men from community and sports clubs and therefore may be interviewing engaged young men and families, and not hard to reach populations. The young person and their family are volunteering for the project and therefore I may be interviewing a motivated participant demographic, which may not be wholly representative of young men. I am interviewing in Sheffield and Glasgow within populations I consider to be from a relatively broad social and racial backgrounds, but there is possibility of not describing all racial groups. Glasgow has a relatively high level of Christianity, both Catholic and Church of Scotland which may influence some of the themes that emerge.

I am interviewing the young men in a home or hospital environment. I hope to avoid the confounder of association with schools. Interviews at the hospital may change the nature of the young man's feelings about 'accessing' healthcare, either for the positive or may be intimidating. I am interviewing the young man within the family context, this is not just due to the importance of protecting the young man with an appropriate chaperone, but because I feel this is the context within which health matters happened to young people. The

experience of having parents there during the interview will bring out interesting themes but may mean that young man does not speak with me as freely as he would otherwise.

I am a young professional woman. My benefit is that I am knowledgeable in this area and am happy to talk around the issues of testicular health without embarrassment. This may also bias the data as my level of ease may mean I put aside some embarrassment the young man may feel in discussing the issues with a young male. On the other hand, they may feel less able to discuss issues with me than a young man. I am attempting to use appropriate language for the young people. I have a southern accent which may lead to some accidental confounders of cultural differences. I am a professional and clearly describe myself as a doctor. There is a considerable 'power imbalance' of which I must be aware and be careful not to 'lead' the young men with questions and recognise if young people or families appear to be wanting to give me the 'correct' reply.'

2.7 Participant Sampling

Where quantitative research seeks to find a representation population and describe the norm. Qualitative research looks to find the most diverse population within the constraints of the research question and describes the breadth of experience and as such utilises differing sampling and recruitment techniques. To identify and interview an appropriate population of young men the CI utilised purposive sampling of adolescent boys from a diverse social and racial background. The CI chose youth clubs, as this group represents a socially diverse demographic. The CI on purpose avoided recruitment through schools, due to a concern the contextualisation of the young men and 'school children' may influence and bias the research findings and undermining the validity of conclusions (Kvale and Brinkmann, 2015). Recruitment was started in September 2015 after ethical approval was given. Sampling continued in a purposive fashion until analytic induction is reached, ie until analysis reveals no further themes inconsistent with the hypothetical phenomenon (Bryman, 2008). The decision was made to minimise collection of family demographics. This was to follow qualitative methodology where the description is of the population rather than

to allow clustering and subdivision of ideas around specific demographics. Demographics that were attained were participant age and postcode. Parental educational level and profession were not recorded routinely, as it was felt this may bias parental responses to confirm to the label as a particular family type.

2.8 Interview Practice and Schedule

The interview is the main data gathering tool of thematic analysis. It is a professional conversation with the purpose of obtaining descriptions of the life world of the interviewee in order to interpret the meaning of the described phenomenon (Kvale and Brinkmann, 2015). It is the researchers responsibility to correctly represent the interviewee through careful interview technique (O'Reilly, 2017). The validity and credibility of the study relies upon skilful drawing out from interviewees or co-authors, descriptions which are deep, detailed, vivid and nuanced. This is achieved through study design, research process and the skill of the interviewer.

The design of the interview should start with an opening space where the interviewer can be introduced, and their respectful knowledgeability established within an empathetic zone of non-dominance as described by Kvale et al (Kvale and Brinkmann, 2015). This allows the interviewer to demonstrate empathy early. Early mutual understanding and sympathy will allow the interviewer to ask difficult questions from an early stage in the interview and will bring out better quality data. In the semi-structured interview, there will be main questions to be asked but the interviewer should complement this with probing and follow up questions to gain greater understanding of the issues raised and to allow clarification within the interview, which is part of the validation process. The design of the interview should be flexible and the questions change with iterations. The interview schedule should be re-examined after the first early interviews and should reflect the parallel analysis, and can change. Practical mechanisms to improve the interview flow and validity include: knowing when to use open or closed questions, allowing time for answers, avoiding interruptions, giving examples, using intonations and pauses appropriately, using language appropriately, referencing back to ideas earlier in the conversation, using clues

and timelines and avoiding leading questions. It is important to close the conversation in a professional manner allowing the possibility of further contact.

The skills of the interviewer will improve with practice, but the interviewer should aim for the experience to be a positive one for all involved. It is important the interviewer has genuine interest, a countenance of naivety and sensitivity, allows the interviewee expertise and recognises the influence of the power imbalance between interviewer and interviewee. Kvale et al describe the tenets of the skilled craftsmanship of interview which include: knowledgeable, structuring, clear, gentle, sensitive, open, steering, critical, remembering and interpreting (Kvale and Brinkmann, 2015). A little of yourself must be given during the interview to allow the participant to really open up (O'Reilly, 2017).

If the interviewer is exposed during a discussion of sensitive issues it is important to help them feel protected gain, and develop skills to lower emotional tone (Rubin and Rubin, 2012). It is of note children are particularly susceptible to power imbalance and a willingness to please. An underlying concept of qualitative interviewing is phenomenology, where the belief is that the world is as the interviewee perceives it, and as such there should be no 'bad' interviewee or interviewers. In fact, bad behaviour or a difficult interview may illuminate greatly particular themes within the dataset.

The strength of the interview depends upon a genuine interest in what the young men are saying. The quality of an interview can be judged by the following criteria as set out by Kvale et al (Kvale and Brinkmann, 2015):

1. The extent of spontaneous, rich, specific, and relevant answers from the interviewee.
2. The shortest interviewer's questions and the longest subject's answers possible
3. The degree to which the interviewer follows up and clarifies the meanings of the relevant aspects of the answers
4. To a considerable extent the interview being interpreted throughout the interview
5. The interviewer attempting to verify her interpretations during the interview

6. The interview being self-reported, a self-reliant story that hardly needs additional explanations.

2.8.1 Project Topic Guide

A topic guide was used to support the interview. The structure of the interview followed a standard format with introduction; discussion of four key topics: knowledge of testes and testicular health, previous education, access to health care, and ideas for effective education; and a debrief. In the introduction time was spent setting the young men at ease and discussing the language to be used. The interview then began exploring the young mens' knowledge of testicles, what they do, what health issues there might be. The interviewer attempted to ask every young man, without leading, what he would do if he developed pain in one of his testicles. The interview then aimed to discuss the avenues the young men received testicular and health education, following on with how they accessed healthcare. Finally, the interviewer asked about effective methods of education. The topic guide evolved with the iterative process of interviewing, with the interviewer asking more questions about general health patterns and exploring how testicular health was different from other acute health experiences towards the later stages of the project. The most recent topic guide is shown in Figure 2.

Figure 2. Initial Topic Guide and Format for the Semi-Structured Interview

My name, details of the length of the interview, what to do to stop the interview at any time, assurances of confidentiality

- Check they are still happy to go ahead, check consent
- Clarify to the chaperone their job is to support the adolescent.
- Brief introduction and making adolescent feel at ease eg tell me your name, how old you are, your favourite sports team, also gathering demographics
- What word do you use for testicles? Some words people use are balls, nuggets, nads, plums. Are you happy for us to use the word testicle?

Topics

1. Testicular pain and Testicular function knowledge:

- How do you feel about talking about testicles?
- What would you do if you had painful testicles?
- What do you know about pain in the testicles?
- What do you know about testicles?
- What do you know about swelling of the testicles?
- Would you worry about pain in the testicles, what could it mean?
- What would you do if your friend had painful testicles?
- Are there any factors that might affect your decisions?
- Is the need for a physical examination something that makes you worried?

2. Inquiry as to previous education:

- What education have you had about testicular pain?
- What experience do you have of hospitals?
- How do you feel about going to hospital?
- Do you talk about other parts of your body, you ever talk about any health problems with you friends?

3. Access to Health Care:

- How do you approach the doctor?
- What do you know about health emergencies?
- What would you do in a health emergency for yourself, and for others?
- Are there factors which might affect your decisions eg who you were with, where the pain started, what time of day it was?
- What would you do if the pain started at 2 am?

4. Inquiry into Educational Methods:

- If I am to design an educational tool where should I introduce it and what methods would work? What media works best for this kind of awareness campaign?

Wind down:

- How do you feel this interview has been? Is there anything I can do to improve the questions, make you feel more at ease, or bring out more discussion?
- Discussion of likely use of information. Thanks for contribution and wrap up with Amazon voucher.

2.9 Procedure for Data Analysis

2.9.1 Familiarisation and Transcription

Transcription was delayed four weeks post interview allowing families to withdraw from the study if they so wished. Initial transcription was undertaken by Chief Investigator (CI) Caroline MacDonald. All audio recordings were listened to initially with no transcription. The first nine interviews were transcribed verbatim using simple word processing package (Microsoft Word 2015) by the CI. The pilot and subsequent six interviews were placed with a professional transcription service, all were checked to the original recording by the CI. The different family members were highlighted with colour schemes. The initial interviews and transcriptions were corroborated by supervisor Professor Collins and M. Burton. The data was saved as anonymised transcript as a hard copy on an external hard drive and uploaded to NVivo 11 © QSR International 2017.

2.9.2 Coding

Coding was undertaken by the CI, Caroline MacDonald. The first three transcripts were also co-coded by Prof Karen Collins, Academic supervisor. To confirm breadth and depth of coding and to support validity of the data analysis. Coding was done initially in hard copy with charting in a word processing package and copied into NVivo, and subsequently live using NVivo software.

2.9.3 Development of Categories, Themes, Concepts

Development of themes and concepts from the coded data took place alongside the collection of further data. Analysis began to move from descriptive to theoretical, allowing recognition of saturation of the material by the coding process, ie when no new insights and interpretations emerge from the data.

A self-critical reflexive diary was kept during the interview, coding and analysis process as per recommendations to perform high quality qualitative research (Nowell et al., 2017).

The process of moving from the in-vivo data to themes took place in a systematic step wise fashion as described by Richie and Lewis et al (Ritchie,

2011) and demonstrated by Smith and Firth in their 2011 worked example (Smith and Firth, 2011). The codes generated during line by line interrogation were exported from NVivo and the interview transcripts examined closely to describe the key themes emerging, confusingly these key ideas are termed 'initial categories'. The process of movement between code, interview data and category was charted, allowing transparency of the process and ensuring the interpretation kept true to the data.

The initial categories were then grouped into themes and a hierarchy began to appear from which an index was developed. All interview transcripts were then indexed and charted. Links and associations between the categories and themes were considered. In this iterative process the authors tried moving towards explanations and descriptions of the experiences of the young men, which might explain the phenomenon of delay in presentation to hospital with severe testicular pain.

Multiple iterations of indexing were undertaken until all data fitted with the categories intuitively a framework matrix was constructed. Any gaps or conflicts of data in individual or across cases were inspected with a return to data transcription to ensure no missing data or misunderstood coding. Cases were inspected for consistency and comparisons inspected. Literature review of the emerging themes was undertaken and added to the framework chart to contextualise understanding of the ideas and check validity of the themes in the adolescent social experience.

Chapter 3. Findings

The chapter below describes the findings of the regional audits and systematic review; the population recruited to the study; the details of the interviews undertaken; the details of the research process; the themes generated from the data analysis and feedback given by the families after the interview. Reflection on the study methodology, comparison to the literature and reflection of bias is undertaken in Discussion chapter of this thesis.

3.1 Regional testicular torsion audits

To assess the applicability of the literature local population review and audit were undertaken by the chief investigator in two centres.

3.1.1 Evaluation of Children Presenting with Testicular Pain to Sheffield Children's Hospital

Aims:

The aim of this service evaluation was to investigate the experience of adolescent males in Sheffield with testicular pain and to see if they followed National trends. In addition to this we want to assess levels of complications in those undergoing surgery.

Participants and Methods:

All children presenting with acute testicular pain over a 3-year period to Sheffield Children's Hospital were identified from the hospital coding department. A retrospective case note analysis was undertaken of those children with torsion of testis as defined by surgical note. Demographics, time to presentation and surgical technique data was collected. Primary outcomes were salvage of testis and post-operative complications. Comparative analysis of non-parametric continuous data was undertaken with Mann-Whitney U tests, non-parametric nominal by Fishers exact. Optimum time to presentation was calculated by receiver operating curve analysis.

Results:

Two hundred and sixty-five boys were referred to our department over a 3-year period with testicular pain. In 141 non-surgical management was employed, where there was no tenderness at time of exam, history was not suggestive of

intermittent torsion or where there was a clear sign of torsion of hydatid of Morgagni in the light of improving symptoms. 124 were taken to theatre. Ten were taken as urgent elective where history was suggested of intermittent torsion and tenderness had resolved.

Forty were found to have torsion of the testis at emergency operation. Median age of those presenting with torsion was 14 years (range 11-15 years). Findings were of viable testis in 21 (11 left & 10 right), non-viable in 19 (10 left & 9 right). Twenty-two presented to Sheffield Children's A&E, 12 presented to their GP, 5 to local A&E, and 1 called an ambulance. Viability was equal for those that presented to Sheffield Children's Hospital and those presenting to a District General Hospital. Presenting to the GP was associated with lower rates of testicular salvage than A&E (33% vs 59%, $p=0.15$). The child who called an ambulance had testicular salvage.

Median time to presentation was 6.25 hours (range 30 minutes to 170 hours). Median time from presentation to theatre was 2 hours for both viable and non-viable testis ($p=0.492$). One child underwent ultrasound prior to operative procedure due to a history and exam that could not exclude a neoplastic process.

In one child the diagnosis of testicular torsion was missed. The child presented with abdominal pain at 12 hours, unfortunately testicular examination was not performed, and the child was taken to theatre 17 hours after review. A non-viable testis was found and orchidectomy performed.

Median time to presentation for viable testis was 5 hours (95%CI 2.7-10.3), compared to 10.3 for non-viable testis (95%CI 10.9 - 48) ($p=0.0009$). Receiver operating curve analysis was performed to determine the optimum cut off time to presentation to predict outcomes of the torsed testicle. The optimum cut off predictive time for salvage of testis was found to presentation under 5.75 hours from onset of symptoms.

Discussion:

Results in Sheffield follow National trends with half of patients losing testis at surgical intervention for torsion of testis due to delay to presentation to surgical services. Only 1 patient was brought in by ambulance. There was no difference

in those that presented to a district general emergency department or Sheffield Children's Hospital, but presentation to the GP was associated with testicular loss.

Limitations:

This was a retrospective analysis. I took times to presentation as reported in the notes. It is likely there are instances where the history is not accurate, i.e. hours from onset of pain. Due to the retrospective nature all confounders could not be eliminated, for instance the degree of torsion was not described in most operation notes.

Conclusions:

Examination of testis should always be performed in young men with testicular or abdominal pain. At present the time to theatre is adequate and not associated with loss of testis. Our surgical technique is appropriate and no one technique can be recommended, but the results suggest that stiff non-absorbable suture material should be avoided. We are unable to improve rates of testicular loss from the time point of the young man presenting to hospital. Improved rates of testicular salvage require community-based education for young men with testicular pain. Research needs to be undertaken to determine the reasons why adolescent males do not present to health care services with testicular pain.

3.1.2 Audit of Presentation and Management of the Acute Scrotum in Young Men at Glasgow's Royal Hospital for Children

Aims:

We aimed to investigate a cohort of children and adolescents undergoing surgery for acute scrotum at Glasgow Children's Hospital Charity to assess rates of testicular torsion, salvage rates and median time to presentation of children in this region.

Methods:

A retrospective case note analysis was undertaken for children undergoing operations for acute scrotum between Jan 2016 - Jan 2017, identified through surgical records.

Results:

We identified 69 young men undergoing scrotal explorations over 12 months, median age 10 years. Average time from symptom onset to presentation was 31 hours, with median of 24 hours. 55% were brought directly to the emergency department (ED), 32% via a GP, 12% from a referring hospital and 1 child was brought in by ambulance.

Findings were as follows (n): Torsion of hydatid 41, torsion of testis 19, orchid-epididymitis 4, no pathology 3, epididymal cyst 1 and bell clapper anomaly with peri-operative detorsion 1.

Of those with torsion of testis 6/19 were non-viable and orchidectomy performed (32% orchidectomy rate). Median time to presentation in testicular loss was 37.5 hours, compared to 12.0 hours in testicular salvage ($p=0.28$ Mann Whitney u test). Outcomes were better when the young person presented directly to the emergency department rather than via their GP, i.e. of those with testicular salvage 53% came straight to ED, opposed to 16% in those who underwent orchidectomy ($p=0.17$ fisher's exact).

Discussion:

Our rate of testicular loss (32%) is on the higher side of those described in the literature. Our median age of presentation (10 years) is younger than cohorts described in the American and European literature. This may reflect the recent change in age range treated at tertiary centres in Scotland from 13 to 16 years, and as such General Surgeons and Urologists in the District General Hospitals are still trained and prepared to perform adolescent scrotal explorations. Our median time from onset of symptoms to presentation (24 hours) is longer than many series in the developed world.

Conclusions:

Our contemporary audit of young people presenting with acute scrotum and testicular torsion in the West of Scotland shows there is a current and ongoing delay to presentation with symptoms of painful testicles, which leads to a 32% testicular loss rate in cases of torsion. Education is clearly lacking, or ineffective, and needs to be urgently addressed.

3.2 A Systematic Review and Meta-analysis of Realistic Outcomes following Paediatric Torsion of Testes: A Guide for Consent

Background

MacDonald et al (MacDonald et al., 2018) performed systematic analysis and meta-analysis, aiming to describe longer term testicular salvage rates following paediatric and adolescent torsion. Additionally, they aimed to combine findings to derive predictors of outcomes following testicular torsion the under 18 years of age population.

Methods

The authors performed a Medline database search using MESH terms to identify all papers pertaining to paediatric torsion of testis. They included papers representing a population aged between 1 and 19 years from the last 30 years. The abstracts or full texts were then assessed and those describing early and late (>12 months) outcomes were included in systematic review. Systematic review was undertaken following PRISMA guidelines with 2 authors reading the full included articles and assigning a quality score. Those papers which describe long term outcomes were included in a meta-analysis of proportions.

Results

Of an initially screened 1727 papers, 57 full texts were assessed and only twelve studies met inclusion criteria for systematic review, with six describing longer term follow up which were included in meta-analysis. Most of the included studies were retrospective case series, with only one case control study and therefore only one was awarded a 'high' quality score. All studies suffered from follow up bias with poor use of objective measures of testicular outcomes.

The mean early (intra-operative) rate of testicular loss from torsion was 39%. Rates of testicular loss at longer term follow up range from 30 to 67%, suggesting a considerable late testicular atrophy rate. Meta-analysis showed weighted mean late testicular loss rates to be 50%. Only one paper reported long term functional outcomes (Yang et al., 2011) and showed no difference in testicular hormone profile between those who had underwent an orchidectomy at initial surgery or those with orchidopexy at 7 years post torsion.

Those factors that predicted testicular loss were duration of prehospital symptoms, transfer from presenting healthcare location to another hospital to perform surgery, use of ultrasound pre-surgery, and lower socio-economic family situation. Degree of torsion did not confidently predict outcomes.

Discussion

The authors concluded that there is a considerable late testicular loss rate following torsion which needs to be communicated to families, in fact where only high-quality papers are considered, there is a 60% loss of testes following torsion in the paediatric and adolescent population. It was not possible to combine the data to create a definitive cut off time to predict likely loss versus salvage but longer time from onset of symptoms to surgery predicts worse outcomes. Average time to atrophy is 12.5 months (Lian et al., 2016) therefore papers reporting outcomes under 12 months are likely to underestimate their testicular loss rates. All studies whose methodology allowed them to gather data on pre-hospital duration of symptoms and delays found this to be significantly associated with testicular loss. Therefore, to improve testicular salvage rates we, as a society, must get young men to present to hospitals earlier.

3.3 Population Description and Interview Context

Recruitment was initiated in September 2015. Recruitment occurred by contacting sports and social clubs, utilising the groups' email list, social media resources and advertising with posters at the clubs, as described in the methodology. The researcher and Chief Investigator (CI) attended practices and met the young people and families giving out information packs and consenting the families for interview.

During the study period, due to a change in life circumstance, the Chief Investigator had to move from Sheffield to Glasgow. Ethical application was made for a change in location of the project, which was approved. Due to this change in location there was a hiatus in recruitment with recruitment resuming in Glasgow September 2017. Contact was made with 35 different clubs. Recruitment occurred from five sources: a running club in Sheffield, a football

club in Sheffield, two football clubs in Glasgow and one charity to help children with weight loss.

Twenty-seven families expressed interest in the project and were recruited and verbally consented for interview. Semi-structured interviews were performed in an order determined by the families' availability and were booked in sequentially. Interviews were transcribed and analysed in parallel to interviews taking place. No new broad themes were identified after eleven interviews. Four more interviews were undertaken to test for completion within the study population. Sixteen young men were recruited for the study following pilot interviews. Table 3-1 shows the details of the interviews; including the date of interview, the chaperone chosen, the recruitment source and a social affluence score by postcode.

Pt	Date of Interview	Chaperone	Recruitment Source	Age (yrs)	IMDD	SMID
1	10/12/2015	Father	Sheffield Running Club	12	6	
2	10/12/2015	Mother and Father	Hillington Football Club	13	8	
3	25/01/2016	Mother and Father	Hillington Football Club	11	3	
4	16/10/2017	Mother	Glasgow MEND	11		3
5a	06/11/2017	Mother and Father	Budhill football club	14		3
5b	06/11/2017	Mother and Father	Budhill football club	15		3
6	15/11/2017	Mother	Glasgow MEND	11		1
7	22/11/2017	Mother and Father	Broomhill Sports Club	14		1
8	27/11/2017	Mother	Broomhill Sports Club	12		5
9	01/12/2017	Mother	Broomhill Sports Club	11		5
10	24/11/2017	Father	Broomhill Sports Club	14		5
11	05/12/2017	Father	Broomhill Sports Club	14		5
12	07/12/2017	Mother	Glasgow MEND	18		2
15	07/12/2017	Mother	Glasgow MEND	16		2
13	07/12/2017	Grandma	Glasgow MEND	11		2
14	13/12/2017	Mother	Broomhill Sports Club	14		5

Table 3-1. Showing Participant and Interview Details. Pt: Participant Identifier, MEND: weight loss campaign, IMDD: English Index of Multiple Deprivation (Score 1-10), SMID: Scottish Multiple Index of Deprivation (1-5)

Median age of the young people was 13.5 years, with a range of 11 to 18.

Indexes of deprivation were attained for each participant by postcode. The project was undertaken in two countries, England and Scotland, who utilise different indexes of deprivation. The score in England runs from one to ten, with ten the most affluent, and the Scottish index runs from one to five, with five the most affluent. From the table 3-1 it is possible to see six families were

from more affluent postcodes, five from the least affluent postcodes and four intermediate postcodes. Therefore, the population represented the spectrum of socioeconomic status in the UK. All but one participant was white Caucasian, who was Southeast Asian-British. Religious and cultural self-identification was not measured formally, but all our participants were of British-Christian heritage with no participants of Black-Asian-Minority-Ethnic heritage.

Three families were from Sheffield and twelve from Glasgow. One interview occurred in the hospital and fourteen at the family home, with three taking place during the day and twelve in the evening. Semi-structured interviews were taken with five mother-son dyads, three father-son dyads, four mother-father-son triads, one grandmother-grandson dyad where the grandmother was also legal guardian, and two combinations off protocol. One whereby mother, father and two sons were present and in another two single mothers and their two sons were interviewed together. Therefore, a total of fifteen families were interviewed.

A single researcher undertook all interviews after having recruited the families, and clearly identified as a doctor. Except from the interview in hospital the researcher drove to the family homes. The interviews took between 20 minutes and an hour and 10 minutes, with a median recorded of time 23 minutes and total recorded interview transcript time 6 hours and 28 minutes. The topic guide was completed in all interviews, all young people received their incentive voucher and all families filled in their feedback forms.

3.4 Research Process

The interview transcripts were poured over in detail and codes came intuitively from the data set. These codes were then grouped using simple techniques, for instance post-it note and grouping on large sheets of paper, and codebooks developed. Eight iterations of indexing and re-indexing of the emerging categories was undertaken with constant comparison to develop the final themes. This occurred alongside data collection. A framework matrix was developed, plotting transcript data from each family by theme and in this process further refinements were made. Three versions of the framework matrix were created as the data was reflected upon and the report was written.

3.5 Main Findings

3.5.1 Young Person's Independence for Healthcare

The study revealed reliance of adolescents on their parent for all aspects of health. They subjectively and objectively turned to their parents for health advice, alerting of health concerns, means of access to healthcare, memory of past illness events and opinions regarding health. All young men were offered chaperones of their choice, all chose one or both of their parents, suggesting that the dependent relationship of adolescents on their parents for health is a mutually accepted norm of family life.

The adolescents described three environments in which they experience life, and therefore matters of health. These environments are home, school and outside, such as sports and hobby clubs and meeting friends. In each of these their immediate responsible adult shifts but ultimately in all cases responsibility of their health reverts to their parents, for instance in schools once the problem is alerted to the teacher or nurse, they will call the parents to make the decision and get the young people to hospital.

All young people, except the eldest, when asked what they would do with a painful testicle replied that they would tell their Mum or Dad, after a period of time, Mum being most common, Mum or Dad, and finally Dad. The eldest participant felt he would speak to his friends first for advice about testes. All young people would ask their parents to make an appointment with their family doctor if they thought they needed to see a doctor, of whom only the eldest participant (aged 18) felt he would most likely see the doctor alone, 'depending on what the problem was'.

If asked what they would do without their parents, most participants expressed naivety of how to access healthcare independently:

CI: Would you come to A&E on your own?

P: I won't be able to get here.

CI: Would you ever feel comfortable calling an ambulance yourself?

P: No

(Participant 2, 13 years old)

CI: If you weren't with your parents are there any ways you'd be able to get to hospital?

P: Well probably like my Nan or my aunty N, they'd probably take me
(Participant 3, 11 years old)

Once torsion had been discussed and the urgency of need for presentation revealed in the interview, many parents reiterated to their Sons that if there were any problems in future they were to come to them, so they could go to hospital, thus supporting their children to openly communicate with them and to clarify the route to hospital within the family.

Parents played an active role within the interviews actively encouraging answers, translating and clarifying points both from the interviewer to their child and visa-versa. In many of the interviews the parents helped break the ice. This was most pronounced in the younger boys where parents helped by prompting the young people to use language that allowed them to express themselves to the interviewer:

CI: Do you know what testicles are?

Participant: Yes

CI: And what word would you tend to use for them? [Pause]

Mother: You were telling Nana Yesterday

Father: you were telling at the dining table

(Participant 3, 11 years old)

Mother: Not to feel embarrassed cos that's what you came to talk about and please what do you call them with your chat to your pals?

Participant: Just don't talk about that stuff.

Mother: If you were going to talk to [name].

Participant: Yeah,

Mother: Say you've been playing football and you kicked the ball and it hit him in his testicles.

Participant: In the balls

(Participant 9, 11 years old)

In addition to helping prompt and encourage answers at times the young people turned to their parents to check facts, check their opinions and to check previous health experiences. Mothers kept the family records of ill health, where the young men did not remember the specifics of their previous illness experiences. For example:

CI: What have you been to hospital for?

P: Uummm I don't think I've been up for me, myself, have I [look to Mum]

Mother: No, you've been okay.

(Participant 4, 11 years old)

Mother: The penis thing, what was it again, do you mind me saying?

P: I can't remember what it was again.

Mother: It was too tight,

(Participant 8, 12 years old)

Invariably the parents were supportive and encouraged the young people to express their own opinions. Occasionally conflicts between parents and their children were seen:

CI: how long do you think you wait to see if it goes away?

P: Probably like a week

Mother: I'm surprised I don't think you'd wait as long as a week, I think if you got pain you would tell me, you pretty much tell me if there's anything, if something's, you know, not quite right, you normally do.

(Participant 3, 11 years old)

CI: when you go to the doctors would you go with your mum?

P: No, [...] It depends what I'm seeing him for. If I am going for just a cold or something she'd come in.

Mother: He's never been to the doctors by himself anyway.

(Participant 12, 18 years

old)

These conflicts often represented a discrepancy in assessed levels of autonomy. In the previous examples Participant 12 feels he would see the doctor alone, but his mother reminds him he has not done this yet. Participant 3 states he would leave testicular pain a week, but his mother replies she thinks he tells her everything about his health immediately, undermining his self-assessed level of maturity. Occasionally the impression was given that the parents were limiting the autonomy of their child. For instance, when talking about the young person calling an ambulance, two of the fathers undermined their son's ability to call an ambulance or be taken seriously: 'I just wonder if they would respond to a 13-year-old boy'.

In exploring their confidence with adults other than their parents or guardians most young people described what they would do in a school environment.

There was a divide in opinion with half feeling they could speak with their teacher or school nurse and half feeling it would be difficult or uncomfortable to tell a teacher about a testicular problem. In those that felt uncomfortable the young men expressed fear of unpredictability of response or that they wouldn't be taken seriously:

I'd pretend I had a dodgy tummy and go home and then tell my Mum as soon as possible. I'd probably put my hand up and say I wasn't feeling well, because I wouldn't want to say it to my teachers and stuff. [...] They probably wouldn't take me seriously if I said my balls were hurting. [...] And my teacher would think I was just trying to show off or something.
(Participant 8, 12 years old)

I'd say I was sick and come home. [...] Because you don't know what your teachers going to do, if it's your Mum you know she going to [... fades off]
(Participant 5a, 14 years old)

Multiple examples were seen where the young people had been protected by the parents from experiences of illness within their family or community, for instance where an uncle had testicular cancer or when a grandmother was in hospital. In addition, some of the parental responses showed they felt their child to be too young for education regarding testicles. One parent responded to the recruitment adverts concerned the researchers would ask her son intimate questions and refused for her son to be involved. Parents in this study demonstrated a controlled and paternalistic role towards their child's exposure illness and health issues. This may leave them underprepared with the practical and emotional responses required in the face of poor health.

There was no age association with those that felt happier to speak with their teacher, but it was mentioned twice that the teacher was male, and this made it easier to discuss. None of the young people described a difficulty with trusting a doctor, male or female, but that is may be difficult to discuss testicles:

If it was a complete stranger then, I wouldn't feel comfortable discussing it.
(Participant 7, 14 years old)

In summary young people are reliant on their parents for all aspects of healthcare, and exert little autonomy or independence, even in the field of male health problems. Parents desire to care and protect their children from the

experiences of illness and overwhelming health knowledge. This may disempower their children to develop autonomy in their approach and responses to illness. There is some evidence that as the young men get older they are beginning to consider making appointments themselves and seeing the doctor alone, but generally most are still reliant on their parents for all aspects of healthcare access.

3.5.2 Adolescent Recognition of Testicular Pathology

To attend hospital with testicular torsion the young man must first recognise he has the problem. For recognition of the problem the young person must know a painful testis is a concern and ideally know of testicular torsion. Knowledge relies on previous education or experiences. Additionally, recognition of a health concern will be affected by the previous illness experiences the young person has had, and views and attitudes to health may hinder early presentation. If the young person does not know about testicular torsion he would need to initiate a process to find out what might be going on. The following describes the knowledge young men have about testicles, the previous education they have had, their views and experiences of health and their health information seeking behaviours.

3.5.2.1 Young Person's Knowledge of Testicular Function and Pathologies

Knowledge about the function of the testes was variable in the cohort. Over half knew they produced sperm or were involved in reproduction, but no participant knew both the hormonal and spermatogenic functions of the testes.

This study found none of the participants knew about the urgency required to attend hospital with testicular pain. All but one participant had never heard of testicular torsion. The young man that had heard of torsion and was aware of the consequences of testicular injury:

‘yeah like, if you damage them quite a bit then like you might not be able to have kids.’

(Participant 11, 14 years old)

Despite knowing about torsion, he was not aware of the urgency with which he would need to attend in the situation of testicular pain. Half the young people had heard of cancer and knew lumps in the testes were of concern, but none

were aware of the need for and recommendations regarding testicular self-examination.

There were some young men with marked misconceptions about the testes. For example, on being asked ‘what do your testicles do?’, participant 13 answered: ‘*they make you piss*’ and participant 6 ‘*help your penis pee*’. On being asked: have you ever been heard about problems with your testicles, Participant 6 replied ‘*I’ve heard of slaparification. [] you have two and if you slap them together then one will burst.*’. Additionally, Participant 2 thought the outcome of a painful testicle might be death.

The possibility of testicular torsion and details of the condition was described by the researcher during all interviews. Once revealed, the young men felt poor knowledge about the condition was universal in their friendship groups and communities. Many felt poor knowledge was a 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)

3.5.2.2 Young Person’s Experiences of Health Education

Young people gained knowledge about testicular function and health through different sources, see Table 3-2 for frequencies by different source. When asked about what they knew and what they had been taught about testes, most young men discussed schools-based education, presumably as this is the forum through which most education is delivered to young people. In our cohort the four youngest participants had not yet received any education through school about testicles. These young men were from both the study locations and were all 11 years of age. The rest of the participants had received some education at school regarding testes.

Table 3-2. Showing the Frequency (ie number of young people reporting education about testicles) by Educational Source. PSHCE: personal, social, health and community education.

Source of Testicular Health Education	Frequency
Testicular function lesson in School	9
Testicular function Lesson in Science	5
Testicular function lesson in PSHCE	3
Friend had testicular operation	1
Father told him about cancer	1
Coach had testicular cancer	1
Famous footballer with testicular cancer	1
Grandfather had testicular cancer	1
Men united campaign re cancer	1
Schools based education regarding testicular health	0

The predominant education given to the young people was labelling the parts of the male anatomy and discussing the changes of the body with puberty. This happened in both biology and the school's individual PSHE curriculum, and often within the sex-education programme:

I: What did they talk to you about when they told you about testicles?
P: Well they made us label the parts and stuff and then they talked about sex education.
I: So, do you know what testicles are actually for? Did they make that clear?
P: No not really.'

(Participant 1, 12 years old)

Some of the young men could not remember the details of their lessons in school about testes, raising concerns about the effectiveness of the methods utilised. Those that could remember the details described lessons focusing on the function of the testes, which often seemed incomplete. The role of the testes to produce sperm was mentioned but only one young man remembered being taught, on prompting, their role in producing hormones. No young person

mentioned having any lessons about testicular health in school, even those with a notably progressive attitude to personal, social and sexual education:

‘We got told they drop and semen was produced, and that’s it really.’

(Participant 7, 14 years old)

One young man described receiving general information about cancer and the generic treatments for cancer in their biology lessons, but there had been no information about testicular cancer within these lessons.

Throughout the interviews it was clear that the young people respected the education they gleaned through PSHE and how important it was for them that their teachers gave them time to discuss difficult and sensitive topics. It also became evident that PSHE was often at the discretion of the individual teachers, and where staff shortages occurred, PSHE was the first class to be disrupted. In the Family with the two brothers 5a and 5b, their mother describes how they came home from school with a leaflet about the differences between men and woman and the changes at puberty and how this disadvantaged her son with dyslexia. Additionally, when participant 5b was asked about his experience of PSHE lessons he described how because of his learning difficulties:

‘I didn’t have a lot, I had to have someone to help me get through me English and maths and stuff, so instead of PSCE I went to my help.

Father: Alright okay. That’s no right is it.

Mother: it’s no.’

(Participant 5b, 15 years old)

These parents feel their son would benefit from the life skills taught in PSHE lessons and would have preferred engagement to discuss whether PSHE was more important to him than academic educational subjects, as described by Participant 8: ‘biology is more kinda sciency. Whereas as PSHCE is more life and the stuff you need to use’.

One participant described a good experience of sex-education through school, with good retention of knowledge facilitated through videos and songs. Despite this the overall impression given was the education provided through schools is

inadequate to empower young people to respond to testicular problems if encountered in the future. One family described this well:

‘P: It feels more important than some of the things I learn in school but it’s not, [...]. It’s not super-helpful. It’s not really like—
 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)

Not all the knowledge the young men gained about testes was through traditional schools-based education. Almost all of the knowledge gained about testicular health problems came from alternative sources. Two young men describe being told about testicular problems from their parents and one from his friend after the recruitment process first meeting. One young man had a friend who underwent surgery for a painful scrotum which ended up being a torted hydatid of Morgagni (a non-emergency condition, leading to similar symptoms as testicular torsion), and one young man knew about testicular cancer from his football community, where one of the coaches had had testicular cancer and missed practices because of this.

Four of the young men knew something about testicular cancer. Two felt they had just picked it up and two could name their source of information. One had seen an article about a footballer with testicular cancer on ‘Match of the Day’, a football highlights show, and one was aware of the politician, Nigel Farage, who had testicular cancer. Television and social media news feeds by the BBC were mentioned as sources of testicular health information sources. One young man mentioned ‘Men United’ which campaigned at his school. The participant was unaware of the specific aim of the charity. It is of interest this charity was campaigning in a school, as whilst it supports a male cancer, this cancer (prostate cancer) is very unusual in young people. One young man mentioned how he had seen health adverts as a pop up whilst watching videos on YouTube and could remember the campaign title clearly: ‘5 dangerous food things that harms your body’.

3.5.2.3 Young Persons' Views and Experiences of Health

In answering questions about previous health experiences all the respondents discussed problems within the frame of classical medical conditions, opposed to the broader scope of health and wellbeing. All but one of the participants discussed a personal experience of hospital, half of whom had had surgery. Eight young men had experienced a sports injury and the rest knew of someone who had an injury related problem. Apart from musculoskeletal conditions, such as broken bones and muscle pulls, the health conditions the young people had come across from personal or vicarious experience included: asthma, eczema, dental extractions, orthodontics, appendicitis, juvenile arthritis, orthopaedic conditions, renal cysts and one young man had a friend who had undergone a heart operation. Some of the young people had had a previous experience of testicular pain which was self-resolving. This was mostly in the setting of a sports injury but the eldest participant sometimes developed testicular pain 'if he sleeps the wrong way'. Two young men had been taken to their family doctor by their parent regarding concerns about genitalia. One mother mentions taking her son to the family doctor to check his penis was growing, and another for swelling to the foreskin. The young man describes the experience as 'horrifying', but it is difficult to untangle whether the healthcare experience was unpleasant, or whether he was deeply embarrassed about the situation. Ultimately, he admitted the doctor was very nice. Twelve participants had had treatment in hospital and all described their experience positively. Three mentioned they were quite nervous prior to their attendance but it had not been as bad as they feared. Most often describing the doctors as nice, other positive aspects included: watching TV and getting a day off school. One of the young men was admitted overnight onto a general paediatric ward, rather than an adolescent ward, but he did not mind this as he felt people were just getting on with the care of children. When asked directly none of the participants felt it would matter if they meet a male or female doctor in hospital.

One young man described how he had developed a fear of hospitals as a younger child and was quite worried about the pain associated with his admission for a wire insertion after he broke a finger playing sport. He admitted that the experience was much better than he had anticipated and that need for another operation in future wouldn't put off telling someone about the problem. Many

of the young men seemed pragmatic about their health. They didn't much like hospitals, but they trusted the doctors to what was needed:

'I: Do you think needing to have an operation would put you off?
 P: Uuuurrrrr I won't really want to go under for something like that
 Mother: But you would compared to the alternative
 P: Yeh I'd much rather. You wouldn't look forward to the operation'
 (Participant 8, 12 years old)

Experiences of misadventure and the narrative associated with injury interested the participants and were often described to comic effect. One young man described how his friend broke his arm swinging from a tree and another from falling in a duck pond. One young man described an episode whereby it became evident he had broken his finger sometime after the football injury. He hyperbolised the retelling, stating 'I didn't go to hospital for months', only to be corrected by his Mother on time frames. It appeared a common theme that young people would exaggerate the extent or circumstances of an injury and suggest an element of neglect from their parents. This was felt to be non-malevolent and involved gentle teasing as part of the family narrative about injury episodes

Often testicular health issues were considered more humorous than other injuries. The reason for the humour associated with testicular health issue as opposed to limb injuries was described by one young man:

'P: coz it's your balls. It's not taken seriously as other stuff.
 I: That's a really interesting point, what if you had a sore arm or leg?
 P: I'd just tell someone.
 I: There's something specific about the testicle.
 P: Yeh'
 (Participant 8, 12 years old)

Similarly, a second young man felt the humour about a twisted testicle may be due to its perceived more trivial nature, and this in turn may increase embarrassment associated with the testes:

'I: Do you think a twisted testicle is more embarrassing than cancer?
 P Yeh. [...] I think ummm people if they had that 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.'

(Participant 7, 14 years old)

Differences were seen in the use of the humour to describe health scenarios, whereby some of the young people generally considered the events funny and in others the humour appeared to be used as a defence mechanism to hide their inexperience or worry about an issue. Contrasting to this the young men were very open about their concerns about attending a hospital. Half of the participants described being nervous about needing to have an operation and three mentioned overtly their fear of needles. Anticipation of pain was mentioned by a couple of the young people as a concern associated with hospital admission, and it was felt by a few of the participants that testicular pain was worse than other types of pain.

Two of the young men when asked about health problems mentioned concerns about aspects of puberty. One young man felt he wasn't growing and another noticed his testes were different sizes. This suggests that the perception of the changing body at odds to expectations during puberty, may be interpreted by the young people as a health problem, rather than a temporal aspect of the process.

Musculoskeletal injury was by far the most commonly experienced health problem encountered by the young people, which may affect their views of the relative health issues. Participant 5a described: 'it's more natural to break a leg or something, rather than anything to do with your nuts' potentially as a reflection of the frequency of which he had experienced these two health conditions.

In discussing hospitals three of the younger participants purported attitudes that appeared to have been inherited from their parents. An 11-year-old when asked what he thought of hospitals answered, 'long waiting times', another said he felt nervous about hospitals to which his Father answered, 'I would be' and finally one young man mentioned not taking testicular problems seriously after his mother said he would have a giggle about testes with his friends.

All the young people in this study had experienced a health problem, most commonly a musculoskeletal injury. Within the group one child had an ongoing chronic illness that affected his quality of life, suffering with asthma and severe eczema, and half had had an operation. The participants described positive

experiences of their family doctor and hospitals and felt that the need for admission to hospital or an operation would not stop them speaking up about a testicular health concern. One participant showed embarrassment about an issue with his penis. Many of the participants did feel that testes problems were different to other health problems and suggested this was because they may not be taken as seriously, they were innately funny, and they were not commonly experienced. Most of the young people appeared to take a pragmatic approach to their health and trusted their healthcare environment to deliver to their needs.

3.5.2.4 Young Persons' Health Seeking Behaviours

Young people turned to three sources for information regarding health issues: their parents, the internet and their friends. Most participants would ask their parents for health information advice. Six said they would use the internet to search for health information in combination with talking to their parents. One older participant mentioned his friends as the first port of call for testicular health information. The young people did not mention any other primary source of information such as doctors, school nurses, books or leaflets.

Most young people who looked up information on the internet used their phones. All the children in the study had their own mobile phone. The young people talked about 'googling' it or going direct to the application YouTube. The data they looked at was mostly videos or photos, with no participants mentioning articles they had read. The young people had social media accounts such as Snapchat and Instagram, with a few using Facebook, but generally these were for communication or gaming. Few of the young people discussed using the internet to look up information.

Of those that had previously searched the internet for health information, many of them had had a negative experience, where looking up information on the internet 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?
 Guardian: They were quite ghastly.
 P: They made me throw up.'

(Participant 13, 11 years old)

Another 11-year-old discussed a similar experience, where he felt upset by the images he saw after looking up testicular problems on the internet. Both these participants were at the youngest end of the study group, and this suggests the information delivered to them from an internet search was inappropriate for their level of maturity.

Further examples where anxiety was increased by an internet search, include a young man watching videos of having a Venflon put in prior to coming into hospital, and in a young man told by a friend the first time you have sex your frenulum will 'snap' and you will have severe bleeding:

'P: So I was looking up, I was googling it [...] I got in and instantly googled it, I was looking through tonnes of websites making sure it wasn't true. [...] I would just find a site and people would say stuff about it, and people would say about their stories and only occasionally ones about something stupid happening and it would bleed or something like that.
Mother: So it kinda emphasised what you were worried about because the people who had had it were writing.

(Participant 8, 12 years old)

Some of the young people discussed the importance of using credible internet resources for health information and interpreting search results with a degree of scepticism:

'CI: If you had anything you were worried about health wise would you ever turn to an internet resource.

P: Probably not unless it's a definite NHS resource or definitely proven web site.'

(Participant 7, 14 years old)

'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 that all for a cough and I sweat I could come up with I'm gonna die tomorrow or something.'

(Participant 10, 14 years old)

Whilst a few of the young people discussed their lack of trust of the internet as the reason for not using the internet, most participants who had not looked up health information simply had not been motivated to do so. In those that had previously sought out health information there were three sources of motivation: external motivators such as TV or advertising campaigns; personal worry about a symptom and occasionally curiosity.

3.5.3 Raising the alarm

Once the young man recognises concerning symptoms he must raise the alarm and let his parents know to progress towards attendance at hospital. The ability the young man to raise the alarm to his parents depends on the ease of discussion of sensitive topics, psychological factors inherent to adolescent males and perceived sociological pressures to conform to the norm.

3.5.3.1 Ability to Discuss Testicular Problems with Parents

Adolescents rely on their parents for all aspects of healthcare and therefore for a young person to access healthcare they must be able to tell their parents about their health concerns and needs. The ease to which they feel able to discuss male health issues and testicles with their parents directly impacts on the young persons' ability to get to hospital with new onset testicular pain. It is striking in this study all the young people discussed testicular health in front of and with their parents openly. In the opening phase of the interview the language to be used was established, and most commonly the young people chose the word 'balls' for testes, which they used with their parents and friends. The young people did not display embarrassment to discuss testicles in front of their parents, with two exceptions which will be discussed later in this section.

Whilst Participant 10, 12 and 15 stated it might be 'awkward' to speak to their parents about testicular problems, evidence from the rest of the interview suggested that these young men had had previous conversations with their parents about difficult topics in an open fashion:

'Mother: Remember when you had some breast bud development, do you remember? When you hit puberty and we spoke about that. [...] So, we do talk about puberty and we have various conversations about things that would happen but I don't think we've ever actually spoken about your testicles. '

(Participant 10, 14 years old)

'P: I'd probably tell you [indicating Mum after being asked who he'd talk to about health problems].

Mother: The other day we were talking about some random stuff, you know what I mean, it sudden comes up in conversation. Say something comes on telly we'll talk about that.'

(Participant 12, 18 years old)

Three of the parents described themselves or their relationship with their child as 'open'. This appeared to be a source of pride for the parent. Interestingly more of the young men would speak with their mothers, than their fathers about testicular health issues. The young men felt more comfortable discussing testicular problems with their mothers:

'CI: would you find it different speaking with your Mum or Dad?

P: Urrrm I'd probably ask Dad because he has a [...],

Mother: he has a [...]. Though you asked me first and it was me who asked Dad.

P: I'd often ask my Mum stuff first, definitely. Because I always do. I'd probably go to her first for most [health] things.'

(Participant 8, 12 years old)

In one family the father was the primary care giver for the young man's eczema and therefore in this case the father was the predominant source of health advice. This suggests that discussions of testicular problems fall more to the category of health issues rather than 'male' issues. Problems would be raised to the more common care giver, the parent the young man might feel was most sympathetic, or 'gentle' as Participant 7 stated, or the parent who was easier to discuss issues with:

'Mother: Dad's a bit funny, he's kind of don't talk about it, but he's awkward whereas I talk about it, I try to be more open. [...] It's a personality rather than a gender thing.'

(Participant 8, 12 years old)

In this study whilst parents stated embarrassment might be a reason for difficulties in discussing testicular problems, in only one interview parental embarrassment was evidenced. A father of one child asked his son whether he would be embarrassed by a female doctor rather than a male one. One parent discussed quite openly an infection he had as a child himself for which his mother was mortified, but he himself discussed the issue in a composed manner. One mother put it well:

'Mother: Because a lot of kids are embarrassed to come to their parents. I wouldntnae be. I'm a parent I have to deal with things like that.'

(Participant 6, 11 years old)

In two interviews there was a degree of embarrassment in communication between the young person and their parent or guardian. These were both within non-nuclear families, one where the participant lived with his mother in a single parent family and in the other the boys were living with their father and step-mother. Conversely in two other non-nuclear families, one single mother family and one where the young person lived with his grandmother but still had contact with his father, communication regarding testicular health was excellent. Many of the non-nuclear families mentioned the role of the extended family in health support:

‘CI: What would you do if you had severe pain?

P: Really bad pain? Oh I’d have to tell my Mum.

CI: And that would be the first person you’d tell?

P: No, it might be my Gran.

Mother: She lives nearby and he’s dead close to his Gran.’

(Participant 6, 11 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. One father thought his son would be like him and ‘wait and see if the pain goes away’, which might suggest an environment where the male role model does not encourage discussion of health concerns. In two interviews parents corrected the behaviour of their child, giving an insight into the difficulties for young people to speak to their parents if they have a disciplinarian parenting style.

Sibling interactions were demonstrated directly in one sib pair interview, observed indirectly during three interviews and alluded to during the recruitment process. It was noticed that often in the male sib pairs encountered during the study, one was assigned the role of being the confident one and the other was labelled as the quieter:

‘I asked both my boys, they’re close in age, and X said he’ll take part but not his younger brother. X is the outgoing one.’

(Quote from a Mother at a recruitment drive)

The sib pair was interviewed out of line with protocol as they were waiting together when the researcher arrived at the home and wanted to do it together.

They felt doing it together was less 'scary'. The actual impact of this was that the younger son, whom the family considered the more confident, responded to most of the questions whilst his Brother stayed quiet or agreed with him. Despite this the elder Brother 5a gave some interesting insights into his experiences of school education in the setting of learning difficulties which may not have been unearthed if he alone was too shy to agree to interview.

Interactions of the young men with sisters was seen twice, once where the participant saw his sister needed help to make a phone call and helped her and in another where the younger toddler was present during the interview and was noisy with attention being transferred from the focus of the interview to facilitating her play. In these scenarios the young men played a role in caring for their younger siblings and a dilution of parental attention was demonstrated. This may place barriers to timely discussions of health concerns if the families' attention is absorbed with another sibling, or where another sibling is perceived to have greater needs.

As mentioned above, the role of the extended family in facilitating healthcare information and access was discussed by three participants, with two feeling they could seek out advice from their Grandparents and one describing if he was not able to get hold of his Mother he would call his Grandmother or Aunt to help with healthcare access. One young man felt he would not speak to his Gran as she was too old to understand young people's issues.

3.5.3.2 Psychological Factors

Aspects of adolescent developmental psychology which influenced the participants ability to discuss testicular health issues were shyness and embarrassment, concern regarding future negative consequences, concern about revealing lack of knowledge about a topic and embarrassment about their bodies.

Embarrassment was mentioned during all the interviews, but interestingly many of the young people did not overtly appear or behave in a shy or embarrassed manner. The young men often attributed embarrassment of discussing testicular problems to others, and didn't feel shy themselves:

'I: You wouldn't be embarrassed?

P: No, I don't really get embarrassed'

(Participant 7, 14 years)

'P: I think some people might think it's embarrassing, [...] but I don't, yeah. The main thing it's embarrassing so they might not go and it would just get worse.'

(Participant 11, 14 years

old)

Five of the young men anticipated they might be embarrassed in the future if they needed to discuss a testicular problem with their family and cited this as a possible reason for delaying presentation with a painful testicular. Interestingly many of the young men described the anticipated embarrassment stemming from a concern of showing poor knowledge and having raised the alarm inappropriately rather than the embarrassment being due to the testes themselves:

'I: Would you be able to tell us what testicles do?

P: I don't wanna say it in case its 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)

Six of the young people did seem shy or embarrassed at times to discuss sensitive issues. These young people gave the impression of being the young people with lower confidence and those at the lower end of the age range. For example, Participant 4 was quite shy and defensive at times when discussing the topic of testes but in addition when discussing sport to break the ice, he showed poor confidence in his athletic abilities:

'I: Do you like football?

P: I kinda enjoy it but I'm not that good at it.

Mother: you're on the team

P: a lot of people don't play it'

(Participant 4, 11 years old)

Some participants felt they would not tell someone about testicular pain because of concerns about the unpredictability of the outcome or potential

disruption to the family. Other young people felt a major block to telling their parent or guardian about testicular problems would be the concern of their guardian having a look, or to have an intimate exam by a doctor.

Many of the young men used humour at times during the interview to embolden themselves, create a rapport with the CI, create a safe environment for discussing sensitive issues and create an appearance of emotional aloofness. In addition, they referred to the use of humour to establish hierarchy and allies within their peer groups.

One young man showed excessive cognitive and emotional lability with extreme responses to some of the questions. For instance, when asked ‘what do you think are the ways we can tell people about the problem?’, he responded: ‘surgery to take everyone’s balls off’, additionally he mimicked vomiting and testicular pain in response to the interview. It has previously been described that high levels of emotional lability are associated with conditions such as ADHD. This young man had a diagnosis of autism and displays how those with behavioural and mood conditions may respond to symptoms differently and in over dramatizing may not receive the same credibility as those presenting to healthcare more calmly.

In summary it appears embarrassment is perceived by young people to be a major barrier to discuss testicular health problems, but this was not objectively displayed by our cohort of participants. The embarrassment described may be because of poor knowledge and concern about making a fool of themselves, rather than the nature of the testicular problem itself.

3.5.3.5 Sociological Factors

The young people generally 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 in future. 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:

‘Just cos you sort of wouldn't like show them in public, so...[...] it's private.’

(Participant 9, 11 years old)

‘Cause I think your arm is always on show and everyone notices your arms but it's a bit different with your testicles. And I mean, reasonably, they're always hidden away.’

(Participant 10, 14 years)

In extension to the feeling testes are private and should not be talked about was their association with sex:

CI: Do you think it's embarrassing to talk about balls?

P: YES (definitive).

CI: Why is it embarrassing?

P: Because of what happens to grownups. S. E. X (emphatic).

CI: Because there's some association with sex it makes them embarrassing?

P: Yep.’

(Participant 6, 11 years old)

Some of the experiences surrounding the interviews highlighted the aspect of shame associated with the testes. One football club owner told me the reason he was supporting the project was because he had an unpleasant experience as an adolescent where: *‘at the age of 10 I had a testicle the size of a grapefruit and was scared to tell anybody. As a good catholic boy...anything to do with sex. This project really hits a nerve.’* And at a recruitment rally at a basketball event one 22-year-old organiser told me about his experience of testicular torsion: *‘when I had it I was scared to tell anybody because of how it reflected on me’*. Interestingly none of the participants displayed shame discussing

testicles, but a couple felt it was wrong to discuss them in public. Interviews from this group of young people might suggest that attitudes of shame regarding gonads is changing:

‘CI: Do you think you would ever think anything like that that like oh if you get a problem with your balls it’s your own fault or...?’

P12: No

P15: not really.

Mother 12: When they were younger, there wasnae as much, but noo they seem to bring it in a lot because they bring it up and other things as well just part of your body, to make sure you don’t get touched and things as well. [...] They have really stepped their game up in the past few years.’

(Participants 12 and 15 with their

Mothers)

A few of the young people stated they had not discussed testes because they did not consider testicular function or health to be a matter of relevance or interest to them. Some of the young people they did not state this attitude specifically, but it could be interpreted that they did not consider testicular health an important issue for them though their slow engagement with the topic. This was noted particularly in the younger participants. One boy mimicked a grimace and a shiver when we first started discussing testes. The younger participants described testicles as: ‘gross’, ‘they creep me out’ and ‘disgusting’:

‘P: Because you have to explain about your thingamys and all that and that would be embarrassing.

CI: And why do you think it’s particularly more embarrassing to talk about your testicles than any other things?

P: ‘Cos it sounds gross and all that.’

(Participant 13, 11 years old)

Some of the younger boys felt they would not be able to discuss the issues of testicles if their friends were present and that they were more comfortable discussing sensitive issues with their parents. One young man described a feeling of many, that they wouldn’t necessarily initiate a conversation about testes, but if it came up or if it had to be spoken about then the levels of embarrassment wouldn’t be suppressive to conversation:

‘CI: Are there situations where you might feel more difficult in talking about things like testicles?’

P: Well, it would be a bit uncomfortable in a class full of friends and stuff. It would be a bit weird but not that--I've done it before and it's not, like, life-changing. It's just a bit uncomfortable.'

(Participant 10, 14 years old)

The older participants were more at ease discussing testes and found the topic relevant and important for them. Most felt they would be able to discuss testicular problems with their best friends.

Many of the participants described how they felt discussions regarding testes would involve humour and teasing. In most of the discussions, the humour was good natured with few reports or expectations of bullying. Colloquially this was described as banter. Often it was described the first reaction within the peer group to a discussion of problems with testicles would come with laughing and not being taken seriously, but that ultimately their friends would be supportive:

'CI: if you had pain in your testicle what do you think any of them would say?

P: My best friends I'd ask them to just keep quiet about it and they'd understand. [...] Some of my friends would take it funny, you know stuff like this.

CI: Would you worry about being teased?

P: No not really no.'

(Participant 1, 11 years old)

'CI: Would you be worried about people finding out at school? Do you think?

P: My friends would laugh and then take the mick and then, like, take it serious.'

(Participant 5a, 14 years

old)

In one interview the Mother described the fact her son did not discuss issues of health with his friends being due to the behaviour of 'typical boys'. There was evidence in our cohort of young people adopting macho roles. In the following quote the young man wanted to make it clear to me they didn't have 'deep' conversation, which may be perceived as non-masculine:

'CI: do you have any health conversations with you friends?

P: Urr not particularly, just people talk about their experiences, not with deep things, just if someone is going in for an operation, their friends

might be ‘its not that bad, I’ve had this’ and other people who’ve had broken arms, and other people explaining about stuff, or getting braces and that’s all.’

(Participant 7, 14 years old)

Interestingly in this example, despite wanting to avoid being perceived as emotional, the content of the discussion is supportive and caring with his friends. This was seen often in the cohort, that whilst some of the young men did try and conform to stereotypical male roles, often the young men seemed open and able to discuss their lives and exhibit caring and thoughtful roles. One young man, during the interview, noticed his little sister needed some help and assisted her, in addition to having a new puppy which was his responsibility to care for. Many of the young men admitted to being scared of hospitals, operations and injections, quite counter to the male attributes of stoicism and toughness. More often machoistic examples were seen in the male role models observed during the study. For instance, whilst being taken around the different groups at football practise during recruitment, the coach said: ‘*they don’t have any balls after the way they played on Saturday*’. In another anecdote a football coach told his team of his recent treatment for testicular cancer to spur them on to win the match. One Father answered for his son when asked what he would do if he had testicular pain, encouraging stoic behaviour:

‘CI: What do you think you would do if you had pain in one of both of your testicles?

P: Tell Mum and Dad

CI: and do you think you would tell them straightaway?

Father: you’d be like me. See if it goes away.’

(Participant 3, 11 years old)

In one tragic case study the family described the death of the Grandfather from testicular cancer:

‘Mother: But it was testicular cancer and he held that back from us for a long time right, so we went to all these hospital visits thinking it was something else thinking it was just to do with diabetes and then they had to eventually tell us the truth what caused it, so that’s when we got a bit of insight into how bad it could be. [...] So [...] they watched him being really sick.

CI: And what do you think that was about?

Mother: Pride, they will tell you it was pride.’

(Participant 12, 18 years old)

In three interviews examples were given whereby a friend had given the participant information to scare him, such as a horror stories or urban myth. The impression from these scenarios was not that this was an act of malice, but this was an act of establishing dominance within the friendship group. Often establishing themselves as being the most knowledgeable in the group about sex.

In two interviews the parents expressed poor confidence in their child's ability due to their age and felt other members of society would not trust them. This is a recognised phenomenon of society, also known as Ephebiphobia, whereby there is excessive judgment and fear of young people and that they are excessively stereo-typified.

3.5.4 Factors Affecting Parental Reaction and Health Decision Making

In the situation of torsion of testes, once parents are alerted of their son's concern they need to assess the information available and make health access decisions for him. The parent decides if, when and how to contact the medical profession. The likelihood of a young man being brought to hospital in a timely fashion depends on the parents' knowledge and previous education regarding the testes, or their ability to find out about testicular problems, attitudes to accessing health services and practical ability to get to hospital. The following sections discuss these factors in more detail.

3.5.4.1 Parental Knowledge and Education

During the interviews seven parental sets said they had never heard of testicular torsion before the interview and two described knowing about it but were unaware of its seriousness or urgency for attending hospital with testicular pain. One parent said they thought it was a problem of adults and two thought the interview was going to be about cancer. In two families the parent present was a doctor. In one the mother said she did not know how common testicular torsion was and in the other the mother felt she could confidently recognise testicular torsion and was aware of the urgency of surgery. In the study there

was no difference between male or female parents in the level of knowledge regarding testicular torsion.

During the interview one mother has a revelation that a date she had been on many years previously was curtailed by the onset of torsion:

With you saying that, it was a first date and a guy I kinda knew, and it got really sore and he went away and I saw him like 20 years later, and still didn't know what had happened. [...] It was just kinda awkward and he went away. And now I am really surprised I didn't know about it.

(Mother of Participant 8)

It appears that embarrassment overshadowed the health aspects of the situation and that the mother did not feel it relevant to her to investigate the cause of testicular pain in her date.

Some of the parents mentioned, on considering the potential causes of testicular pain for their child, puberty and growing up. It seemed that because of the changes happening to the testes, confidence in identifying when something was wrong was lessened. One set of the parents articulated this well:

Father: Although you might get a pain down there, the mother or father could turn around and say it's something different. I know that when you're growing up, from when I was younger, you used to get a lot of pains down there and you know, my Dad would just put in down to 'accch you're just maturing'.

Mother: I was saying that, the boys say 'I've got a sore back, sore leg' and I just think growing pains [tails off]. So maybe I'm quite naïve in thinking they're growing up and it's just their hormones coz if they say my legs are sore I'm saying it's just growing pains, you're getting older and your body's changing.

(Parents of Participants 5a and 5b)

It is of interest that in this example the father discusses his own experience and the opinion of his father as the source of his information about testicular pain. Although not investigated specifically through the topic guide none of the parents mention having received any education regarding testicular health issues, either during their upbringing or once parents for the benefit of their sons. One mother discussed her experiences of sex education at school as intimidating and unhelpful to answer the questions she had:

I'm thinking back to when I was at school [...] when it was like a full school boys and girls, talking about emmm sexual health and such like. I remember feeling quite embarrassed emmm didn't wantnae say the

changes I was going through and stuff like that, when naebody else was, sitting and staring at you, and then you'd get the funny girls and boys that speak up, the more outgoing people.

(Mother of Participants 5a and 5b)

Those parents with some knowledge of testicular conditions gained this through related experiences from friends or other young men in their community, and occasionally their own personal experiences. The doctors were aware of testicular conditions through their medical school education but may have struggled to practically apply their knowledge in the event of their son developing testicular pain in their role as a parent. There was a predominance of experience of testicular cancer not torsion.

The parents displayed different levels of confidence in their knowledge which may further exacerbate further the difficulty of parents applying their knowledge if the need arose. 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 major factor for poor confidence. One further mother expressed poor confidence in her knowledge and didn't know what she would do if her son developed testicular pain. Conversely one mother who was a doctor expressed confidence she would be able to diagnose torsion in her son, which is well recognised to be incredible difficult and needs specialist opinion, and therefore may not attend hospital with him if torsion arose.

3.5.4.2 Parental Information Seeking

Generally, the feeling of the parents was that the amount and quality of the information available about testicular health is poor. None of them had previously sought out information about testicular health issues. A few of the parents mentioned their own experiences of sexual health education from school which seem to have been universally poor and draped in embarrassment. One of the parents discusses her perception that there is more information available for adult men and girls:

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 prostrate

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.
(Mother of Participant 14)

Where education for parents regarding testicular health issues is poor, engagement with the school's curriculum of Personal and Sexual Health Education (with variable acronyms between schools) would offer a valuable resource for increasing the parents and the families' knowledge of relevant health issues. Only one parent described being actively involved in the planning of the social and health curriculum for her son:

There was quite a lot which I was very supportive of, quite a lot of forthright information being given out, and they had a parents' evening before they introduced it to try and allay any of the fears and concerns that there were amongst parents about young kids maybe getting a lot of information. [...] It was talking about the terminology and different words that are used to describe your scrotum or female anatomy and male anatomy.

(Mother of Participant 10)

Four further sets of parents were aware of what year their sons had received or were likely to receive 'sex ed' but were not aware of the specific teaching they were receiving. Two of the parental sets seemed disengaged about when and how their son would be receiving their social and sexual education.

Where knowledge and education are poor parents must seek health information. In our cohort none of the parents had sought out information regarding 'testicular health' issues for their sons. Parents felt they would turn to their family doctor, a friend, their own parent, telephone advice services and the internet for information. One family mentioned attending a sexual health clinic well known in Glasgow. Many of the parents mentioned NHS services such as NHS direct, a 24-hour advice line and NHS NICE guidelines, which are resources specific to the UK. The NHS was mentioned by most of the parents as a badge of trustworthiness. Half of the parents felt they might do an internet search using a search engine as the first port of call with a health enquiry. All those doing an internet search mentioned using Google, and none would use social media applications such as Facebook or Twitter. Those that mentioned use of an internet search, unanimously mentioned the importance of assessing the quality of the information provided:

Sometimes ‘googling’, but that can be bad as you think the worst [...] it can be helpful but sometimes if you’re putting in symptoms you think you’re dying instantly.

(Mother of Participant 4)

In this cohort the facilitators and barriers to parent’s health information seeking were not investigated specifically but families in the higher socioeconomic group were more likely to use the internet and seemed more au-fait with which websites they would use, rather than running a general google search.

3.5.4.3 Parents Attitudes and Experiences of Healthcare Access

Rarely did the parents discuss their own health issues or their personal experiences of hospitals or doctors. The discussions around previous experiences of healthcare focused on the families’ experiences of the young peoples’ health service use. Most of the parents described some experience of acute healthcare issues for the family. Three families had experience of chronic illness: one father was currently actively engaged in helping his son manage his eczema and two other parents described previous prolonged hospital contact for now resolved chronic illness. The study data showed parents accesses general medical health advice and treatments through their family doctor, known as the general practitioner (GP), but utilising emergency department services for injury related concerns:

‘there were a few A&E cases where he was bundled straight in the car and off to A&E without a blink of an eye. You fell off the wooden sofa and your arms were inside your tee-shirt so he bumped his face on the concrete floor. [...] And flying your kite. You’ve had a few.’

(Mother of Participant 14)

Two parents described using NHS 24 (a UK telephone health information service) to get advice about whether they should attend healthcare services and which service would be most appropriate. Experiences of hospitals and family doctors were generally positive. Parents often described the doctor as nice or ‘good with’ their son. One father mentioned it was good because their GP knew their son, highlighting the importance of the personal relationship with their family. Three parents mentioned being dissatisfied with their health access experiences,

primarily due to seeing a different doctor every time through their GP practice or having to wait excessively long for a call back from NHS 24. The parents referred to their doctors with respect and gave the impression of trusting their healthcare services, for instance, one mother stated if she was unsure what to do she would call NHS 24 and felt confident ‘if it was bad they’d send us to hospital’.

From the interviews a general model of how parents manage their teenagers’ health symptoms emerged. Initially the parent identifies the symptoms of concern and to some extent tries to ascertain what has happened. The parent then assesses the severity of the symptoms. Some then would add in the step of self-management with analgesics and in the case of a testicular issue, three parents mentioned needing to have a look and check for injuries or physical changes. Most parents then wait to see if the symptoms resolve on their own and if they continue will make an appointment with their GP. Most felt if the pain was severe they would make the appointment first thing with the GP, and only three mentioned going straight to the hospital if the pain was serious. Figure 3-1 describes the parental acute health decision making process for their adolescent son.

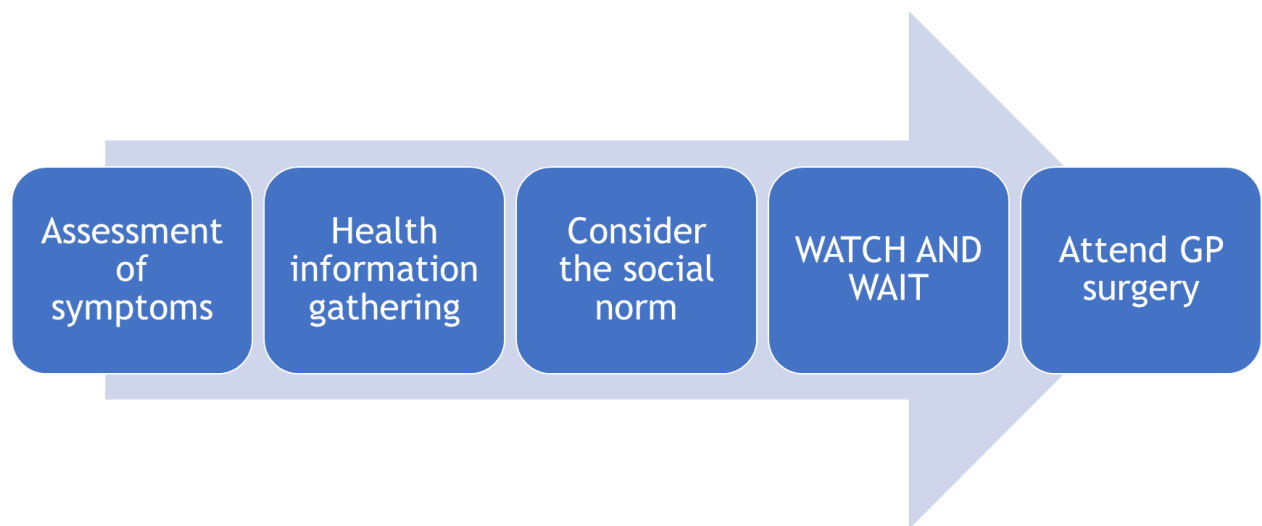


Figure 3-1. Displaying the Process by Which Parents Make Acute Health Decisions for their Adolescent Sons

At each of these steps delay could be introduced in taking the young person to hospital. Recognising that the symptoms described by the young person are of

concern might be clouded by parents attributing pain or body changes to the process of puberty or sport:

‘Especially at the moment with big growth spurts and playing lots of sports’

(Mother of Participant 8)

All the parents during the interview asked the researcher to clarify the amount of pain that testicular torsion would cause, showing the degree to which parents use pain levels to make decisions about the timing and location of health care access. Many stated the first port of call would be the GP, but if the pain started overnight and was severe some felt they would go to the hospital, but the majority would book an appointment with their GP first thing. Those parents who were medical felt they would be less likely to access their GP.

Overall there was little direct embarrassment seen from the parents regarding testicular health issues, and it was not apparent that a testicular health issue would be treated differently for health access than other concerns. It is of interest that in one interview the father felt the mother would make the decisions about testicular health access, and in another the mother felt the father should make the ultimate decision. In another interview the mother discussed whether testicular problems were a sexual thing or whether they were a health issue:

‘Would it be more health? They’re putting your private parts down as a sexual thing, rather than thinking it’s a [...] health and wellbeing thing.’

(Mother Participants 5a and 5b)

The attitude that testicular problems were a health issue rather than a sexual thing might lessen embarrassment and lead to an easier approach to healthcare access for the family. Many of the parents had a pragmatic approach to problems of the testicles, as one mother put it:

‘I’m the parent I have to deal with things like that’

(Mother of Participant 6)

The parents of the participants interviewed took their role as carer for their child’s health seriously. One parent described how she took her daughter to see a paediatric specialist not just an ordinary doctor, suggesting the health of children is somehow more important than that of an adult. In addition to these,

frequent examples were given of the time and care parents gave to their children's health, including examples of how the parents had made illness episodes more bearable for their children. In one example the mother describes how her son drove the 'motorcycle' creating a distracting narrative around exposure to hospital machinery during a time when he was having recurrent screening for eye problems. In another example a mother describes her shame when a child she was 'in charge of' broke his arm, demonstrating a recognition of transfer of responsibility when looking after other people's children. 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 a significant factor in changing attitudes to healthcare access. There did seem to be a theme running through some of the interviews of pride in not burdening the NHS:

'Well yeh, we don't rush you in here for a snotty nose. This is an accident and emergency it isn't an accident or an emergency'

(Mother of Participant 2)

Parents overall had positive experiences of their family doctors and hospitals with no clear evidence that past experiences would be a barrier to committing to health access for their sons. A clear process emerged that described the parents' decision-making pathway in accessing health care that revolved round non-resolution of symptoms and contacting the GP as the first healthcare provider. Most of the attitudes towards health and testicular health would support timely access to hospital, except for concern about not burdening the NHS.

3.5.4.4 Family Ability to Get to the Hospital

Although accessible by public transport, all the families in the study gave the impression the parents would drive their child to hospital if there were health concerns. One Mother discussed the importance to her family of having a car to get to hospital. Two families discussed the confusion about which hospital the family should attend, due to local health service design and paediatric age cuts off for care in their city. One young man mentioned that if his parents were

unable to take him to hospital his Gran or Aunt might be able to help, highlighting the role of the extended family in access of health care for children.

3.6 Codebook and Frequency of Theme

Overall 111 codes emerged which were rationalised into 75 categories, which were grouped into 12 sub-themes and further rationalised during the framework thematic process to four major themes as shown in Table 3-3. This also known as the codebook. The number of families discussing each sub-theme is show in Figure x. It can be seen from this, that the themes discussed by all the families which act as a barrier to presentation with testicular symptoms were: the reliance on young people on their parents for health access, poor knowledge of testicular health, lack of previous education regarding testicles, young peoples' attitudes to health, parental knowledge, parental attitudes to health and factors associated with adolescent psychology.

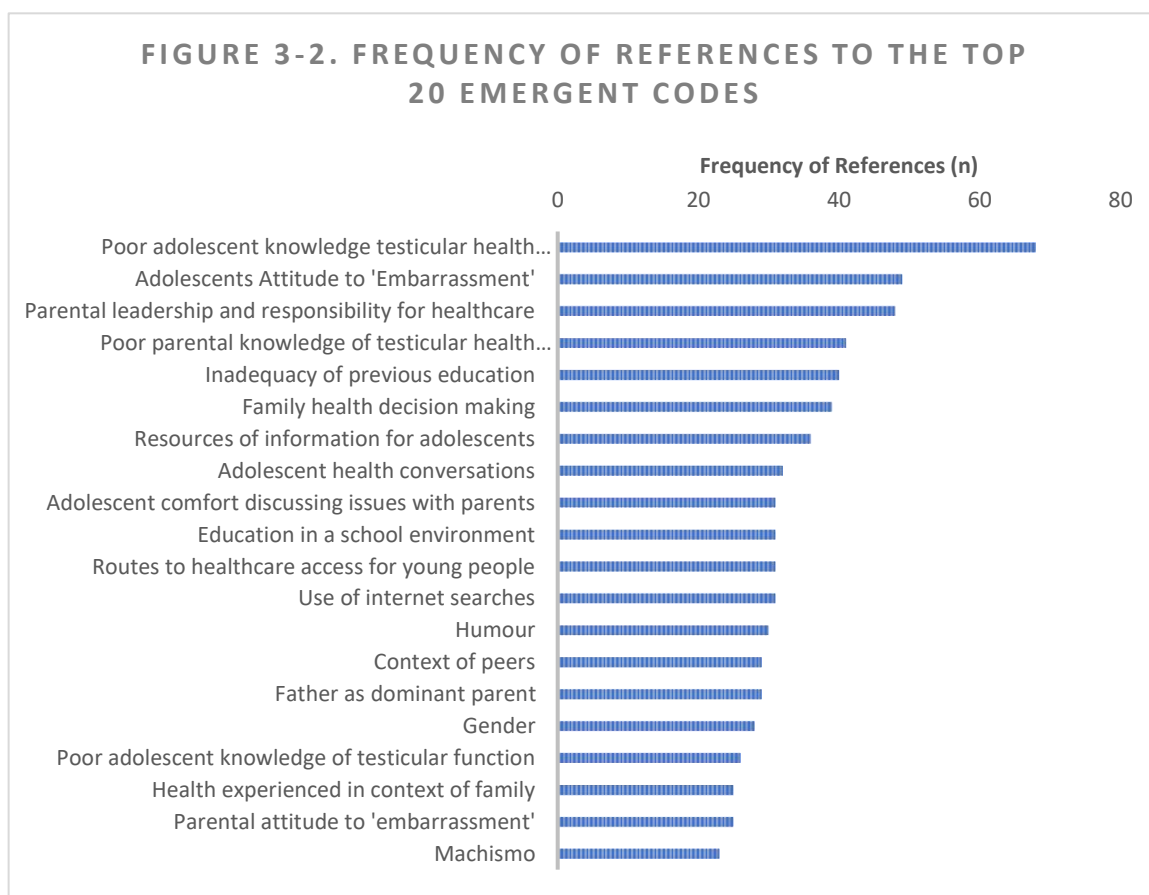
Table 3-3. Codebook showing main themes, sub-themes and categories emerging from coding and data inspection: iteration eight

Main theme	Sub-theme	Categories
1. Young Persons' Independent Access to Healthcare	1.1 Reliance on parents for all aspects of healthcare	<ul style="list-style-type: none"> • Reliance on parents for all aspects of health • Examples of disempowerment of independent access to healthcare • Poor knowledge of routes of healthcare access • Practical difficulties getting to hospital • Parents' facilitation of adolescent communication • Parental legal responsibility for care • Age at which education regarding testes is felt appropriate, Parents as protectors against exposure to inappropriate information • Trust of non-familial adults
	2.1 Young persons' knowledge of testicular function and pathologies	<ul style="list-style-type: none"> • Knowledge of testicular function • Knowledge about testicular torsion • Knowledge about testicular cancer • Awareness of consequences of testicular loss • Incorrect, myth, misconception • Previous experiences of self-resolving testicular pain
2. Young Persons' Ability to Recognise Concerning Testicular Health Problems	2.2 Young Persons' experience of health education and testicular health specifically	<ul style="list-style-type: none"> • Experience of education regarding testicular function and health in school • Knowledge gained through friends, family and community • Knowledge gained through celebrity and TV

		<ul style="list-style-type: none"> Impact of health campaigns Experiences where learning difficulty interferes with education
	2.3 Young people's Views and Experiences of health issues	<ul style="list-style-type: none"> Cancer, appendicitis Predominance of Injuries Personal experiences of health and hospitals
	2.4 Health information seeking behaviour	<ul style="list-style-type: none"> First point of contact for health advice Adolescent use of internet for health Provokers of information seeking Young people protected from illness
3. Young Person's ability to tell their parents about concerns	3.1 Ability for the Young Person to discuss male Issues with Parents	<ul style="list-style-type: none"> Parental embarrassment or projected embarrassment Testicular problems considered 'health' not male issues Fear of disruption of family routine Parents as disciplinarians, Parental infallibility Identifying as or evidence of an 'Open' family Impact of non-nuclear family Young person's role in the family Confident role assignment within the family Absorption of attention Different sex sibling
	3.2 Psychological aspects of adolescent life affecting ability to discuss testicular health	<ul style="list-style-type: none"> Anticipatory, projected or contextual embarrassment Confidence versus shyness Consideration of the future in decision making Limitations and Attitudes due to Language Use of humour Fear of drawing attention to lack of knowledge or experience Discomfort with physical aspects of testes and their body
	3.3 Sociological aspects of adolescent life affecting ability to discuss testicular health	<ul style="list-style-type: none"> Testicles considered to do with sex, social taboo and shame Testicular health considered unimportant, irrelevant and not serious Importance of playing culturally accepted male role Role models for male behaviour Ephiphobia Awareness of sex abuse Religion Intergenerational change
3. Parents Ability to Take their Adolescent Child to Hospital	3.1 Parental Knowledge and Education	<ul style="list-style-type: none"> Parental knowledge testicular torsion, urgent need to get to hospital and outcomes Parental predominance of knowledge cancer Parental education, including transfer from child/school to the home environment Misconception testicular problems are adult rather than young person's issues Expectation of body changes during puberty
	3.2 Information Available for Parents or Guardians Regarding Testicular Torsion	<ul style="list-style-type: none"> Perceived lack of information Resources for parents/ guardians for health advice Internet

		<ul style="list-style-type: none"> • NHS 24 • Family doctor • Perceived predominance of women's health information
	3.3 Parental Views and Experiences of Healthcare	<ul style="list-style-type: none"> • Pride in health, stoicism and not burdening the NHS • Personal 'deservability' assessment: Degree and duration of pain to trigger hospital attendance • Parental pride in caring • Family doctor first point of contact • Experiences and attitudes to hospital, procedures and operations • Health optimism • Symptoms attributed to puberty, injury or other benign events • Fathers for male issues
	3.4. Practical Ability to get to hospital	<ul style="list-style-type: none"> • Perceived necessity of car to attend hospital • Extended family in help to access healthcare

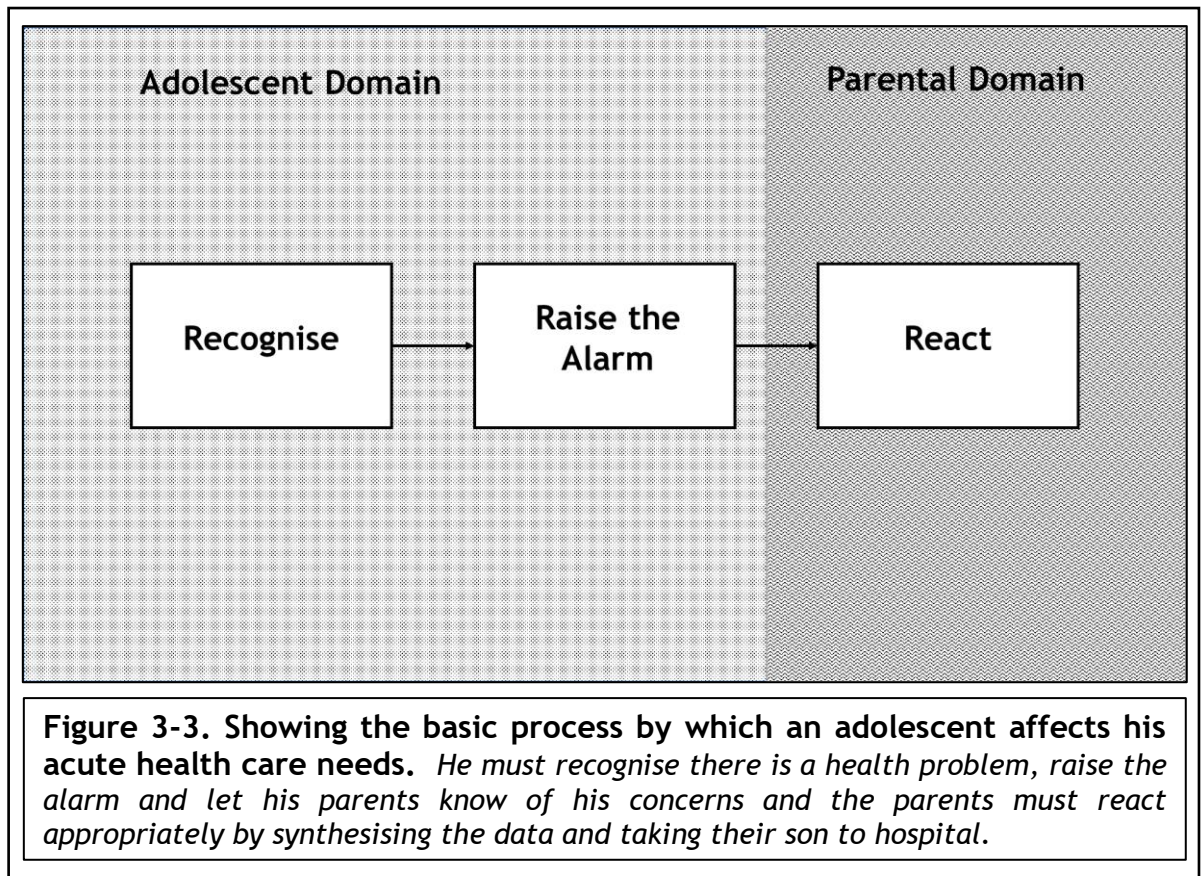
Figure 3-2 shows the frequency of any objective or subjective reference from the interview transcripts or the field or reflective notes for the twenty most common codes, ie one young person mentioning poor knowledge as to the the cause of non-presentation equates to one reference.



From this it might be suggested that poor knowledge of testicular torsion and total parental responsibility for healthcare access might be the most causative for delay in presentation with testicular symptomology. The limitation to this conclusion is that a more loquacious participants would skew the data to their particular point of view and this analysis is not supported by qualitative research methods. In qualitative the aim is to describe the breadth of the experience not to quantitate the responses.

3.7 Conceptual Analysis

Through exploring the views and experiences of testicular health the process by which a young male affects his acute healthcare needs has been revealed. It has become evident that adolescent males are reliant on their parents for all aspects of their healthcare experience. The basic process by which a young person with testicular pain gets to hospital is shown in Figure 3-3. The young person must recognise that there is a problem and then they must raise the alarm by telling their parent of their concerns. The parents then undertake the next steps of the process by reacting appropriately to the information given to them by their adolescent son. They must recognise the need for healthcare contact and get their child to an appropriate hospital. The role of the parent may be enacted by whoever is the adult with the current legal and caring responsibility for the adolescent. The sections below evidence the interpretation of the data and highlight the factors affecting each of the steps which could cause delays of presentation with acute testicular pain.



3.8 Feedback

At the end of the interview the family were given the feedback from and the CI made herself busy and disengaged so the family could fill in the feedback form without pressure. Unanimously the families felt there were no problems with the recruitment and interview process and were happy with the questions asked. One comment stated *'great, relaxed manner of interview'*.

Seven comments placed on the feedback form all discussed the new knowledge they had gained and how useful the interviews had been in increasing their knowledge. One mother mentioned it would have been useful to have information on testicular examination, and the researcher directed her to some online resources.

The feedback was done immediately to avoid any recall bias. The CI was generally in the room with the family while they filled the form, but it did not feel undue pressure was placed on the family, and since a good rapport was developed with all families it felt genuine that the feedback was positive.

Chapter 4 Discussion

4.1 Study Effectiveness and Quality

The background section introduced the concept of testicular torsion and described outcomes and predictors of poor outcome, of which the most significant, is delay to presentation with acute scrotal pain. The background then demonstrated poor understanding of this phenomena, and progressed to investigate putative contributory factors, including resources for information regarding testicular health and routes of access to acute healthcare services in young people. The ongoing relevancy of the topic was confirmed in two regional audits and a meta-analysis of recent data, proving that time delay to presentation was the major factor affecting poor outcomes in contemporary populations of young people.

The aim of this study was to investigate the views and experiences of young people regarding testicular health issues to understand how young men recognise a testicular health problem and the process for them to attend a hospital. Identifying the factors delaying this process could form the basis upon which interventions might be introduced, with the long-term goal of speeding up the process of adolescents recognising a testicular problem and getting to hospital and therefore decreasing the rates of testicular loss in cases of testicular torsion.

The study successfully investigated the research question, giving insight into the individual, family and societal factors impacting the young peoples' ability to recognise a testicular problem and affect their healthcare needs. The research methodology was successful in facilitating in-depth understanding of the research question and has generated the first hypothesis surrounding the young persons' views and experiences of testicular problems.

The design grew organically from a perceived problem by the Chief Investigator (CI), and as such was not generated by agenda or commissioned by government. It was developed from a point of clinician generated perceived need. The research question was not instigated by young people themselves, which is common in nearly all research in children (Hill, 2006). Despite calls for more child participation in the development of research ("Children and Young

People's Views on Health and Health Services" 2005) most projects involving children are developed from a source external to child community (Hill, 2006). Children's health needs are often investigated in the setting of engagement with preventative services rather than investigating their responses and experiences to active and acute health needs (Bell et al., 2013; Coker et al., 2010; Jones et al., 1997). In this way this study is unique in investigating responses to acute health needs in the general population of young adolescent males.

In the design of the study, engagement of young people with the pilot interviews showed there was clear support for the project from families who have been through the experience of torsion. The design of the study met the criteria of Kvale and Brinkman's (Kvale and Brinkmann, 2015) underpinning of study validity. The studying aimed, or as they describe thematised, to improve the human condition. Additionally, moving through their further six steps to ensure validity of interpretation. The study design was effective and safe, the interviewer trust-worthy, the transcription loyal, the analysis logical and responsible, verification was undertaken by transparent reflective practice and the report was rich and accurate. Safety of the participants was a priority, with guidelines in place in case a disclosure was made, no disclosures were made during the study period.

Young people were recruited through their sport or youth club. This clear endorsement of the Chief investigator (CI) by the coaches and volunteers whom the young men knew, respected and trusted introduced trust in the research team from the outset. Meeting the CI at club meetings with their family, set up the interview format and meant the young people could judge if they trusted the interviewer, gave them an opportunity to ask questions and started the consent process. The process of assent and consent was fully informed with information leaflets describing the participants rights, the withdrawal procedure and the aspects of confidentiality and data handling. Meeting the parents at the club nights similarly gave them an opportunity to get to know the CI and develop trust. One recruitment drive was undertaken at a national basketball competition where the CI met many young men but none of their parents were present. From this day of advertising many young men took away leaflets and expressed interest in the project, but none followed through to an interview. All successful contact to interviews were mediated through meeting with the

parents along with the young person. Reinforcing the theme that young people are reliant on their parents for facilitating their health experiences.

The recruitment process was time and labour intensive, with long delays between contacting the clubs, responses from the clubs, meeting with the club organisers, arranging advertising, putting up posters, attending club nights, recruiting and consenting families, leaving the cooling off period, contacting the families and arranging interviews. The study duration took considerably longer than expected. Ultimately it was an effective method to recruit young men and their families outside of the school environment, who did not have ongoing contact with hospitals. An online YouTube recruitment video was posted, which can be found at: <https://youtu.be/DGx7Z0pRoIQ>, which had 67 views. The research team was contacted by a family from America who found the video online. This was not an effective recruitment strategy. The researcher's priority to avoid the school environment for recruitment meant the context of the responses are within the family environment. The data must be interpreted in the context of the family environment, especially where the responses of children are particularly environmentally driven (Hill, 2006). The research team felt this was appropriate as the evidence from the study shows that decisions regarding testicular health occur within the family environment. Even if problems are discovered at school the young men would be sent home for the family to make the decision about attending healthcare. Additionally, recruiting from clubs meant discussions regarding testicular health spread through the club, and many within the communities contacted benefitted from their colleagues and friends undertaking the interview.

The CI advertised recruitment with acknowledgement from the outset she was a clinician, which this author feels gave the families' confidence to meet with her. Doctors have a privileged position whereby they are trusted in society. One parent, who was also a doctor, contacted the CI with concern after the initial advertising at a sports club about the CI asking intimate questions to young men. Once a reply was made and the study explained, and the support of the University stated, there was no further concern. The CI advertised with a poster to attract attention that revolved around a pun about looking after your ball skills. This seemed particularly apt for the football and basketball teams. Many of the young men liked the posters and the families felt it worked well. They

read it thinking about sports training and noticed it was about ‘balls’ (testicles) and appreciated the joke. The monetary incentive was mentioned by many of the young men as the reason they undertook the interview. The research team feel this did not introduce an ethical concern, as the young people were given the voucher and it was made clear if they withdrew their interview they would keep the voucher. Giving the young people a voucher for their time was symbolic of respect shown to them from the research team, to be treated fairly for their skills and efforts. It further strengthened the good rapport between the CI and the family.

The interview generally took place in the home, which alleviated potential barriers of transportation to recruitment and minimised bias. Individual adolescent - parent groups were chosen for interview, rather than group discussion. This offered a naturalistic setting in which discussions took place and decisions were made. Although some children feel more confident in a group most open up more and discuss issues more deeply when interviewed one on one (Hill, 2006; O’Reilly, 2017). Although travel expenses were offered, the one family travelling to the hospital did not take this up. The interviews ran smoothly and generally there was sufficient time to cover the topics. In all interviews a good rapport was built and the impression was of open, genuine responses from the young men and their families. It did not appear the gender of the interviewer impacted the findings, this has been shown previously (Westwood and Pinzon, 2008). It did not appear the accent, southern English, impacted the findings. The profession of the CI as doctor did impact on the responses at times. Consideration of how responses may have changed in line with perceptions of socially correct answers to a doctor, and the knowledge imbalance are described more fully later. There is always researcher - participant imbalance, especially when interviewing children. The CI tried to mitigate this through interview technique (Kvale and Brinkmann, 2015).

The interviews were recorded and transcribed accurately. Free coding took place alongside interviews, after the two weeks withdrawal period was passed, according to the values of the sociology community (Ritchie, 2011; Smith and Firth, 2011). The open coding was undertaken NVivo (NVivo 11 © QSR International 2017) which was intuitive for the CI and speeded up the process. The following additions were made to the topic guide during the process:

investigation of how testes were different to other illnesses, which revealed how the process of attending hospital with testicular pain is similar or different to other diseases; whether young people discussed any health issues when their friends as it became clear they did not discuss testes; and whether they had ever thought about what their testes do, when it was clear knowledge was generally poor, to investigate whether they lacked curiosity about health or whether they felt discouraged to look up information about sensitive topics.

No broadly new topics were discovered after interview eleven, but nuance was developed in continuing interviews. Interviews were stopped after fourteen interviews, with sixteen young men. This seems fewer than expected at the outset, when approximately twenty was predicted to be needed, though a recent paper analysing the percentage of full description of illness symptomology found that at 15 participants 92% of the final themes had been described (Turner-Bowker et al., 2018). This may be due to a relatively narrow cultural sample. Unfortunately, despite the CI's best efforts the team was unable to recruit from black and minority ethnic communities. The team recruited from the spectrum of socioeconomic status. The cohort had marked similarities in that they were all still living at home and attending school and had engaged as a family with the research question. The CI recruited from broad range of family structures which added depth to the understanding of the experience of testicular pain in the family context.

The index was re-written with subsequent examinations and coding and developed into the final structure by iteration number eight. This index was applied to the transcripts in NVivo (NVivo 11 © QSR International 2017) which then formed the code book, which allowed development of the final categories. These were placed in a framework matrix of category by participant. In inspecting, comparing, contrasting and theorising one sheet of paper analysis was utilised. The CI moved from a realist to constructivist back to realistic epistemological viewpoint during the interpretation. To clarify; the researcher considered the young people to describe the truth of their experience and that truth was an absolute truth of the young peoples' lived world. Strengthening this interpretation was the fact the worlds described by the young people were astoundingly similar across the spectrum of backgrounds. Conversely to this, was the understanding the social environment in which the young people live is a

constructed reality created by older people, previous generations, politician's, families and peers. Therefore, an interpretation of the responses mindful of these constructs allows a deeper interpretation of the data. The framework matrix was redeveloped three times.

The process of coding, forming categories, creating an index and developing concepts was supported by CI's supervisors KC and MB. Reflection happened within the interviews, checking understanding and clarifying points, and rigorously throughout the process of interpretation. The CI stayed close to the original data at all times, and performed accurate and logical interpretation, such that it was felt that validity had been maintained throughout and further credibility checks were not necessary. This was agreed with by the supervising academic team. In further support of the validity of the emerging themes the CI found the topics emerging from the data with each iterative reworking mapped very naturally onto known aspects of adolescent developmental psychology and sociology and parental-adolescent relations. The results as described below describe the reality and the social constructs of the views and experiences of young people to testicular health problems.

4.2 Limitations

This study reports the first description of young mens' views and experiences of testicular health issues and has developed a theory of how young people recognise and affect their needs in regard to testicular health. It is tempting to transfer the knowledge from this study to the processes by which young men affect all their health needs, but this would be outside the scope of the study. The limitations of the study revolve around the recruitment process, the potential bias of interviewing young people with their parents present and the difficulties of recruiting from ethnically diverse backgrounds.

The recruitment process involved the young men and their families meeting a female recruiter and CI, and the recruitment video featured the same CI advertising the project. The young men described that the gender of the doctor looking after them would not affect their decision to go to hospital and that they were happy to speak with their mother, often preferentially, or father. This may represent recruitment bias where those not affected by gender were happy to discuss testes with the research team.

All the young people chose their parents to be present during the interview. Whilst this is consistent with the model of the dependence of young people on their parents, the CI recognises this may also be a source of bias. Young men may not feel able to discuss issues with their parents present, in particular issues of internet searches for information about testicles and sex.

This study describes how young men of British-Christian heritage experience testicular problems. Whilst the issues identified are likely to apply to the Black-Asian-Minority-Ethnic (BAME) population, this is not proven in this work. There may be additional factors delaying presentation in populations of greater religious observance, such as those in the Muslim community; whereby the factors of embarrassment and difficulties of discussing testicles with parents might affect a greater barrier to early presentation with testicular problems. Reports from members of the Asian community, felt the young men would be worried that a short interview may lead to longer term conflict with their parents. It would be fascinating to perform the study in alternate populations, those of more and less openness. Additionally, whether being from an first or second immigrant population places additional difficulty in the access to healthcare.

The other major limitation to this study is to consider the exclusion criteria. The project was designed to investigate the experiences of young men naïve to testicular problems such that the findings would be applicable to the 'average' young man. Having had admission to hospital with a previous episode of acute scrotum or torsion infers expert status on the participant and would not reflect the inexperienced person. Asking what they thought prior to the hospital episode would suffer recall bias. It is difficult to interpret some of the projections of the young people of what they would do if they had testicular pain. Previous studies have found high correlation between intended and actual behaviour.

The study was performed meticulously with frequent supervision session during the processes of coding and developing themes and concepts with dual person coding for the early interviews. The steps and processes of interpretation were open and auditable and were supervised such that contextual bias was minimised during this process.

Reflecting on the declared bias of the CI reinforces the validity of the study findings. Where the chief researcher felt that knowledge and ownership of health issues might be barriers to presentation with testicular issues, the findings of the role young people take in affecting their urgent healthcare attendance, the need to break the normal family process of health decision making and the lack of embarrassment for the young people came as a surprise to the researcher and were derived in their entirety from the data.

4.3 Thematic Discussion

4.3.1 The Young Person's Independence of Access to Healthcare

This study found that adolescent males are reliant on their parents for all aspects of healthcare; from advice, to access, history and attitudes. They displayed no independence for healthcare. This reflects current legal and societal attitudes to the autonomy of young people to healthcare, whereby parents remain socially and legally responsible for the healthcare of teenagers (*Parental responsibility*, 2008). When young people were outside the family environment their responsible adult shifts to someone within that environment, such as a teacher or sports coach. In these environments the young people displayed varying degrees of trust of the allied adults which would affect their ability to raise concerns about a testicular health problem. The gender of the temporally responsible adult seemed to be a factor impacting the ability of some of the young people to raise concerns but not all. This seems to reflect more the degree to which they felt their supervising adult was approachable and predictable in their response.

Because the views and experiences of the young people were so intertwined with the parental views and experiences, the CI made a decision to report the findings of both the young people and the parents or guardians. As mentioned previously the CI found that the context of the experience of testicular health for young people is within the family. Therefore, the knowledge, views and experiences of the parents were reported. A distillation of the young peoples' voices was not felt to be possible nor desirable as reporting the parental findings added to the depth of description of the young persons experience.

All the young people interviewed would tell their parents if they developed a painful testis as their first point of health advice. Only the eldest said he thought he might discuss his concerns with his friends, which reflects previous research that suggests as young people move through adolescence their friends become more central than their parents in their lives (Robinson, 2006). This late development of autonomy for healthcare may reflect recent findings that the period of brain development equated with adolescents is lengthening in 'western' societies, with young people not reaching brain maturation and adulthood until 25 years of age (Sawyer et al., 2018).

Parents mostly worked to facilitate young people's health communication and access, but at times undermined the young people's independence and protected them from illness experiences. Therefore, disempowering them from developing autonomy towards their health needs. Parents and their children demonstrated conflicts arising from discrepancies of assessment of competence, this phenomena has been described previously (Butner et al., 2009; Moretti and Peled, 2004). It is recognised that young people want their parents to provide comfort and help with their needs in a healthcare setting (Coyne, 2015), but also want to develop autonomy as they prepare for adulthood.

The methodology of project may lead to bias in discussing young peoples' independence of access to healthcare, especially in the light of the recruitment strategy. It was necessary for all those under 16 to have consent from their parents or guardians to undertake the interview, and generally the interviews were facilitated through the parents, with the parents making practical arrangements. In recruiting from the third football club, the CI met with the young men at practise evenings and advertised through the social media sources with an advert for an incentive. The six interviews from football club 'BSC' were initiated by the young men, with the parents agreeing to and supporting the meeting. This suggests that both the more and less autonomous young men facilitated their experiences through their parents. There was no difference in findings for deference of the young person to parental opinion in those performed at home and those performed in the hospital environment.

It is of interest at the beginning of the interview the CI was never explicit whether she was interviewing the young person or the family. In the majority of interviews, the young person led the discussions and the parents contributed

equally in a complementary fashion. In three the parent actively hung back and asked later if they could add something. In two interviews the parents dominated the discussion and in both these cases the young people were particularly reticent. The position of the CI as a surgeon adds an interesting dimension to interpretation of independence of young people to issues of health. The setup of a 'doctor' asking questions to the young person and his family sets up a scenario similar to most routes of healthcare assess, and therefore may allow us to interpret interactions of autonomy in relatively naturalistic environment. Alternately it may be creating a more 'formal' setting than the family environment, whereby the young person's degree of autonomy shifts to align with the family's perception of societal expectations.

4.3.2 RECOGNISE: Young Persons' Ability to Recognise Testicular Health Concerns

The findings from this study would strongly suggest that knowledge of testicular function is incomplete for young men and knowledge of testicular pathology is poor. Poor knowledge about testicular pathology is a significant factor impacting the recognition of concerning testicular symptoms in young men, see Figure 3-2. All but one participant had not heard about testicular torsion prior to the interview, and this young man was not aware of the urgency of need to present. This appears to worse than described in the surveys of older American males where over half would go to the emergency room directly with testicular pain (Clark et al., 2011; Congeni et al., 2005). More young people had heard about testicular cancer than torsion, but despite knowing about it, few knew the details or recommendations for testicular self-examination. These findings reflect the literature where knowledge of testicular cancer does not correlate with a knowledge of the need for regular self-examination (Rudberg et al., 2005; Vaz et al., 1988).

Within this study misconceptions and urban myths were frequent suggesting in an environment where education is inadequate, incorrect knowledge, myths and misconceptions have freedom to predominate.

To test the validity of the findings of poor knowledge of testicular function, pathology and consequences, one must consider whether the context of the interviews might have induced a reticence in discussing testicular facts.

Concern about showing inexperience, immaturity or poor knowledge is a strong motivator in the young people and the format of the doctor-researcher led interviews, might have led to reticence in the young people. Conversely the young people may want to show off knowledge they have to the interviewer, especially where good rapport and mentorship was established, ameliorating concerns that power imbalance would lead to misjudgement of levels of knowledge. There seemed to be an association of those young men who were more confident being more likely to answer with knowledgeable answers, but poor knowledge of the condition was ubiquitous across confidence levels.

In all interviews the researcher gained good rapport and as mentioned above developed the role of a mentor. Trust was gained unanimously, and the researcher ended up giving information to the young person and their family regarding testicular function, pathology and practical advice on what to do with pain, testicular self-examination and lumps. In this way the interviews were mutually beneficial. Most parents thanked the researcher for their time and felt they had improved their knowledge through the experience. The environments from which the young men were recruited started widespread conversations regarding testicular torsion, and therefore benefits were seen in the wider communities associated with the project.

The other aspect of study methodology which may bias responses, was interviewing the young men with their parents or guardians present. This might mean they were less able to openly discuss their knowledge and felt curtailed to use language which would adequately allow them to express themselves. Whilst not a full discourse analysis, it felt to the CI that the language used showed most young people were able to discuss their knowledge within the interview context and were happy discussing the issues in front of their parent or guardian. In addition, at times the parents helped the young people with language and to express themselves suggesting having the parents present may have helped the young people discuss their knowledge.

This study establishes knowledge of testicular health problems is poor. In order to understand the cause for this, investigation was made into the young peoples' experiences of testicular education. When asked about what previous education the young people had received, most described school-based education. Within our cohort the learning regarding testes seemed inadequate to empower the

young men to deal with testicular health concerns such as testicular pain or finding a lump. Previous education was based on the biology of the testes, including the anatomy and the function of testes in producing sperm, rarely was the hormonal function of the testes mentioned. No young man described receiving schools-based teaching about age appropriate testicular health information and what to do with concerns. Additionally, PSHE classes were often sacrificed when staff problems arise or for children with learning difficulties. A national review of schools based PSHE education in England found that 40% of schools needed improvement or the learning provision was inadequate (Ofsted, 2013). The report suggested this left young people unprepared for the physical and emotional changes during puberty. The report found the deficiencies were often due to inadequacy of subject-specific training PSHE. Due to concerns following the report, the UK government released a guideline for PSHE teaching in schools in 2013, and in December 2017 a bill was passed through Parliament which has mandated integrative Sexual and Relationship Education in English state schools. Four of the young men were under the age at which PSHE education is initiated. It has previously been noted that schools based teaching regarding changes of puberty and sensitive topics is often left too late, where there may be benefit to teach young people these topics earlier (Poobalan et al., 2009).

Within the cohort there did appear at times poor recall of schools-based teaching, but this may reflect an element of bias. As demonstrated previously young people do not like to look unknowledgeable or wrong and may prefer to deny memory of their lessons, rather than 'get it wrong'. There is imbalance of knowledge between the young people and the researcher who is a doctor which may exacerbate this bias. To counter this the discussion was directed as: 'what have you been taught', not 'what do you know' and therefore attempting to remove any element of judgement from the interview. All our young people were engaged in full time education and therefore it would be of interest to interview adolescents engaged in apprenticeships or college courses to understand if these findings were generalisable.

It is of interest in our cohort none of the parents had educated their sons about testicles, and the majority had allowed the school to provide most of the sexual and social education to their children. All the knowledge the young people had

about testicular health problems had been gained through informal sources outside of schools, including parents, media, peers and their community. Previous studies have demonstrated that 61% of young people get some of their sexual information from their parents, and 54% from their peers and media (Bleakley et al., 2018). These studies have demonstrated that whilst young people do go to their parents for education regarding sex, they find the messages are often negative (Bleakley et al., 2018), such as the risks of sex and advice for abstinence until marriage (Epstein and Ward, 2008). Messages from peers or the media tend to be more positive, with information from peers revolving around dating, personal experiences, partner attractiveness and pleasure; and information from the media promoting how to talk and behave with potential partners. It was noted information from the media often promoted engendered behaviours (Epstein and Ward, 2008). It is of note none of the young people mentioned gaining information about testes from their family doctor or GP.

No previous studies have investigated methods of effective education for torsion of testes, but effectiveness of education of testicular self-examination (TSE) and breast self-examination have been investigated. Methods that appear to reliably increase knowledge regarding TSE include: teaching from the family doctor or a healthcare professional, reminder cards, teaching with mannequins (Thornton, 2016) and video based teaching (Nwozichi, 2015). Increase in knowledge to promote breast self-examination in young women targeted the four underlying variables for health action: perceived susceptibility, perceived seriousness, perceived benefits of taking action and breaking down the perceived barriers (Ludwick and Gaczkowski, 2001a). Interestingly the study demonstrated a 98.8% post one-off learning intervention knowledge level, but only a 23.2% monthly breast exam rate. Knowledge does not always transpose to behaviour change. In the present studies cohort education methods that seem effective for recall of testicular function were time with a teacher or expert, videos and anecdotes from friends, family, the community and in the media. Previous studies have investigated the efficacy of mass media health promotion campaigns and have found them to be effective if supported with adequate funding and healthcare service policy (Wakefield et al., 2010). Clearly lack of education about testicular health impacts negatively on a young persons' ability to recognise

testicular problems, but also lack of education about routes of healthcare access affects their independence for healthcare.

The young people discussed their previous health problems focusing on medical conditions. Many healthcare and public health groups consider health to encompass multiple dimensions of young peoples' lives including: violence, substance misuse, risky sexual practice and mental health issue (Bell et al., 2013; Laski and Expert Consultative Group for Every Woman Every Child on Adolescent Health, 2015). This disparity has been seen previously (Booth et al., 2004) and may represent how healthcare providers are failing to engage young people in the preventive aspects of health (Coker et al., 2010). All but one young person in this study had experienced injuries or sports related health problems which fits with known health patterns for adolescents. 48.5% of Emergency Department attendances by male adolescents are due to injury (Jenkins and Katz, 2015), with the predominant diagnosis musculoskeletal (Coleman et al., 2013). All but one of the participants had good health with only one with severe eczema, this fits with reports that 92% of adolescents report good health (Klein et al., 1998). The experience of pain within the study cohort varied greatly, with some of the participants considering pain something they experienced relatively regularly but something they managed as a sports player. Other young men felt squeamish and unable to cope with the possibility of pain. This reflects previous studies that show adolescents experience pain differently, often associated with early attachment issues with their parents (Brumariu and Kerns, 2010) and with their degree of autonomy from the family environment (Lagerløv et al., 2016). There may be bias in our population for the young people to report high levels of sports related injuries, as many of the participants were recruited from football clubs, and football has been found to cause 50.3% of all sports related injuries (McQuillan and Campbell, 2006). In addition, those families volunteering may be predisposed to have previous experiences of injury and illness and therefore particular interest in clinical research. Previous studies from the US and Australia have found healthcare access to be highly associated with socio-economic status (Booth et al., 2004; Newacheck et al., 2003; Saxena et al., 1999), whereas studies performed in countries with universal healthcare, for instance Spain, have not found this to be the case (Berra et al., 2006; Grøholt et al., 2003). Pan-European studies show

healthcare service design impacts adolescent health access (Berra et al., 2009), along with health needs and maternal patterns of engaging with healthcare services. Parental mental health is associated with increased teenage healthcare presentation (Berra et al., 2006). Within this study there did not appear socio-economic differences in adolescent views and experiences of healthcare, neither did there seem to be age differences with all ages of participant acknowledging some degree of concern about undergoing operations.

Most of the study participants reported satisfaction with their family doctors and hospitals, citing 'nice doctors' as a common reason for their good experiences. This compares to a study from the UK in 2000 where 86% of teenagers were satisfied with the care from the GP, and those that were not, cited lack of perceived care as the cause of dissatisfaction (Jacobson et al., 2000) and too short time with the doctor and leading to few opportunities for questions (Coker et al., 2010). Previous studies support the findings that adolescents do not care about the gender of their doctor (Westwood and Pinzon, 2008), and in this study it was often seen the parents had concern about the gender of the doctor not the young men. The degree to which the young peoples' views regarding health problems are intrinsic or to which they can be attributed to their parents is difficult to assess. It is well recognised that through their environment young people learn to regulate their feelings emotions and physiology (Lagerlöv et al., 2016), and that observation of parental illness and pain experiences model the responses of children to similar episodes in future (Hatchette et al., 2006). None of the study participants mentioned concerns about confidentiality and all demonstrated trust of healthcare providers in the interview discussions. This is at odds to some reports that suggest one of the barriers to adolescents seeking healthcare is concern about lack of confidentiality (Booth et al., 2004; Daley et al., 2017; Jones et al., 1997; World Health Organization, 2012).

It has previously been noted that adolescent health care needs include care for acute and chronic illness and injuries, but also requires information about the processes happening during puberty (Bell et al., 2013; Westwood and Pinzon, 2008). The role of family doctor for teenagers should involve in part guide the young person and family through puberty, helping normalise the process and identifying abnormalities if they occur.

In summary all the young people had experience of illness or injury, but most were in good health. Generally, the young people had positive experiences of family doctors, hospital and operations, with some stating that going to hospital wasn't as bad as anticipated. All demonstrated trust in their healthcare providers. Many of the young men used humour in talking about testicular health, some of whom used it as a defence mechanism. Half of the young people admitted to feeling nervous about the thought of needing an operation, but this would not put them off speaking up about testicular health problems. The impression was given that the views and experiences of young people of healthcare are positive and this would enable young people to engage with services when needed.

Young people sought information about health from their parents, from the internet and from their friends.

The young people all had internet enabled phones but it is surprising despite the ubiquity of access to the internet (Norris, 2007) so few used the internet for health information seeking. Similar results have been found in previous qualitative and survey based studies, where only 8- 49% of young people use the internet for health information (Rideout 2001; Borzekowski and Rickert 2001; "Children and Young People's Views on Health and Health Services" 2005). Older young people (15-24 years old) and girls are more likely to use the internet for health information (Park and Kwon, 2018). The young people used their phone for instant messaging to chat with their friends or gaming and rarely used it for information and anonymous forums. This reflects previous studies that found the virtual communication of adolescents was simply an extension of their external world (Best et al., 2014).

Within the study the young people mentioned the reason for not using the internet was concerns about the quality of information available. Previous articles have found only 17% of young people trust the internet for health information (Kanuga and Rosenfeld, 2004). The ability to effectively search the overwhelming mass of information available on the internet to find the specific information for your needs is referred to as eHealth literacy. The current study participants seemed aware of the risks of internet health information including 'cyberchondria' (Gray et al., 2005) and chose to avoid using the internet rather than learning how to seek out and navigate health information on the internet.

Previous authors have described these difficulties and suggest specific training for e-health literacy (Park and Kwon, 2018). Many of the young people had had negative experiences with an unsupervised and untailored internet search, which increased their anxiety regarding a health issue. Where the internet has great possibility of ameliorating health knowledge inequalities across disparate socioeconomic groups (Gray et al., 2005; Park and Kwon, 2018; Zhao, 2009), the current study would suggest the internet had not opened up knowledge regarding testicular health to young people, with the barriers being the quality of information available and a lack of motivation for searching regarding this particular health topic.

Only one young man felt he would talk to his friends as his first information point for health, which aligns with previous studies that suggest young people change their primary source of information regarding sexual health from parents to friends as they grow older (Borzekowski and Rickert, 2001; Whitfield et al., 2013).

Aspects of the study findings susceptible to bias include the disparity between self-reported intentions and actual behaviours, although many young people discussed examples where they had sought out and discussed health information from their parents in the recent past. Interviewing the young people with their parents may mean they did not describe some of their alternative uses of the internet, it is well known that young people's exposure to pornography has increased with ease of unsupervised internet access (Kanuga and Rosenfeld, 2004). Additionally, they may describe a more sanctimonious approach to internet use and information gathering than utilised. The young people may also claim not to trust the internet if this were seen to be the correct answer to give to the doctor-researcher.

4.3.3 RAISE THE ALARM: Ability for a Young Person to Discuss Male Health Issues within the Family Environment

As young people rely on their parents for healthcare access they must be able to tell their parents about their health concerns in the family environment to access healthcare. Parental attitudes to health conversations and sensitive health issues may work as a facilitator or barrier to young people getting to hospital. Overall in this study the findings are that young people can talk with

their parents about the topic of testicles. Occasionally evidence of embarrassment was seen, but more impressively was the openness of the family discussions about adolescent male health issues. Parental embarrassment has been shown in previous studies to create an environment where a young person may avoid conversations surrounding difficult topics such as sex (Malacane and Beckmeyer, 2016) and that good communication from parents leads to better safe sex practices in adolescents (Widman et al., 2016). Many of the families were interviewed took pride in their openness. Adolescence is a time of changing power balance between parents and their children, fraught with conflict (Branje, 2018). Parenting styles are broadly describes as authoritative, authoritarian, permissive and neglectful (Alfredsson et al., 2018; Aunola et al., 2000). All styles were seen in our study, but in relation to health specifically it appeared most of the families were authoritarian. Parents create the rules and the young people are obedient (Kuhar, 2010). As they grow older young people begin to desire and achieve more autonomy which can lead to difficulties with open conversations between the generations. In the study population there was no difference seen between the younger and older participants in their ability to talk with their parents.

It has been noted in non-nuclear families it is common for the children to have poor contact with their fathers, which might be a particular issue in matters of testicular health. Within this study the specific make-up of the family was not investigated specifically but four families described a non-nuclear configuration, with three single mothers and one grandmother guardian. In these families only one boy still had regular contact with his father. Previous evidence suggests that health and social outcomes are worse for children from non-nuclear families (Anderson, 2014; Areba et al., 2018; Vingilis et al., 2007), but the effect is small and may be due to factors more complicated than the disruption to the family itself (Mooney et al., 2009). The single mothers did describe having low confidence about testicular issues but in these interviewers it appeared they talked openly with their sons about testicles. It appeared in our population that strong mothers ameliorated the effects of absent fathers. There may be concerns that young people's health may be neglected in single parent families due to competition for time from siblings. The single mothers talked about help from the extended family and friend communities in facilitating health access

for their children, such that non-nuclear families did not seem to affect the young people's ability to speak up or access healthcare. In one family the mother described being the step-mother and she felt this may make communication harder for her step-sons.

The study findings of open and easy communication between young people and their parents regarding testicular issues, may represent recruitment bias. Young men and families volunteering for and engaging with the process of recruitment may be families with closer than normal communication. Whilst an incentive was offered, and some children acknowledged this with the motivation for taking part, generally participation was pushed through by interested parents. A higher than expected number of parents were recruited with healthcare backgrounds, who may have an interest in health and facilitate more open conversations with their children because of this. In opposition to this there was no difference in ease of communication between families from affluent areas and those from modest areas. In fact, two of the most open and supported environments for the young people came from families living in the least well-off areas. This study suffers from lack of recruitment from Black and Minority Ethnic (BME) communities. This is a significant problem and warrants further study, as this population has been shown to have less open discussions surrounding sexual health (Malacane and Beckmeyer, 2016) and therefore it would be of great interest if this also encompasses discussions involving testicular health.

Details of the participants' siblings was not undertaken or investigated specifically within the topic guide. None of the participants mentioned gaining education about testes from their older siblings. Within the course of the study interviews episodes were seen when siblings affected the interview course and gave insight into the effect of siblings as a barrier to young people raising concerns about health issues. More than embarrassment, dilution of parental attention was demonstrated, which has previously been described in the literature (McHale et al., 2012).

Whilst many aspects of a young person's personality are that of the individual, it is well recognised that certain traits seen in adolescence are due to neuroanatomical (Casey et al., 2008), endocrine (Sawyer et al., 2018) and common societal influences (Markovic and Bowker, 2015). Certain attitudes and behaviours are therefore common to adolescents due to features of

developmental psychology. An example of this is excessive sensitivity to social hierarchy and susceptibility to embarrassment (Markovic and Bowker, 2015). The findings of this study suggest embarrassment, whilst identified by the young people as a reason for delay of presentation with testicular torsion, was not a major issue for the individual. More often embarrassment was projected to the future or onto friends and compatriots. Other traits common to adolescents include cognitive traits, such as argumentativeness and self-centeredness (Gentry and Campbell, 2002); emotional traits, such as low self-esteem and emotional lability (Van Liefveringe et al., 2018), and societal traits such as increased risk taking behaviour (National Research Council (U.S.) and Institute of Medicine (U.S.), 2011).

Within the responses from the participants, multiple examples of poor confidence were seen. As the young people advanced through puberty more confidence could be seen with a certain amount of 'swagger' seen in the two eldest participants discussing testicular problems. Additionally, they felt they would be happy to discuss their sex lives with a doctor without embarrassment. This reflects previous research which shows adolescence is a period of psychological maturation with developing confidence, self-esteem, where a sense of identity is formed and the young people learn how to control their emotions (Gentry and Campbell, 2002). Lack of confidence in personal knowledge, abilities and concern about being taken seriously would certainly provide a barrier in being able to let someone know about testicular health concerns.

Young adolescents typically do not include future outcomes in decision making but respond to immediate concerns linked with emotional responses (Sawyer et al., 2018). Additionally young people develop metacognition throughout adolescence, allowing them to reflect on their thoughts and feelings (Weil et al., 2013). This was seen in our dataset whereby only one young man discussed the possibility of not having children if you have testicular injury and how that might impact his decision making, most of the young people discussed delaying presentation with testicular pain 'in case it turns out to be nothing' and they have the risk of embarrassment. Another perceived barrier for speaking up about testicular problems included worry about disruption to family life. This follows previous reports showing that young people and children often do not

disclose sexual abuse until adulthood because of feared negative consequences for themselves or their family (Lemaigre et al., 2017).

In this study humour was used in the discussion of testes, testicular health and in general. Funniness has been previously described as an important attribute for popularity in young people and in particular young men (LaFontana and Cillessen, 2002; Markovic and Bowker, 2015). In this study it appeared to be used for a range of different reasons including building rapport with the CI, displaying ease with the topic and hiding embarrassment.

The study did not investigate the frequency that young people approached their parents with health complaints and is unable to report whether raising the alarm about a testicular problem may be masked by frequency of alerting of health concerns from the young men. There is no description in the literature of the frequency of child to parent health complaint and the degree of parental action as in response. There is a risk that the finding that embarrassment does not play a major role in the ability for young men to present with testicular pain is artefactual due to the study methodology and recruitment process. The population volunteering to discuss testicular issues with a stranger may be a population less inclined to shyness and embarrassment. The chief investigator deals with testicular issues as a matter of her profession and therefore may be less embarrassed than other adults or primary healthcare workers to discuss the issues with the young men. It is of note many failed recruitment opportunities were due to young people feeling too shy to discuss sensitive issues with a stranger. Reflectively the CI felt the time of most embarrassment for herself was when asking the young people about the body changes associated with puberty, being concerned the young men were too young for the information. The nature of the interview is different to a hospital assessment where a physical exam would be compulsory, which may be a significant factor in increasing embarrassment and therefore preventing young men presenting to hospital with testicular problems.

The evidence from this cohort of young people suggests that most young people have not spoken in public, with their peers or with their parents about testicles before. Many have been taught gonads are private. Others interpret they

should avoid discussing testes in public, as they are following their experience of social norms, i.e. they have not heard or experienced other people discussing testicles before. The reason why it is societally abnormal to discuss testes seem to be due to their physical position, hidden from view, and their association with sex.

Attitudes of shame associated with sex and therefore testes were not prevalent in the study cohort. This may be that the young people in the context of a 'health interview' did not consider the testicles to be associated with sex, or that most of the study participants were not yet sexually active. There was some evidence of the participants adopting male roles and attributes. Research of adolescent development has shown there is significant pressure on young men to conform to classic masculinity roles. With desirable attributes including low emotional expression, emotional control and restrictive emotionality (Reigeluth et al., 2016), strength, stoicism, toughness and self-reliance (Courtenay, 2011). It has been shown that this pressure leads to suppressed reporting of male symptoms and therefore delayed diagnosis in adult males (Cameron and Bernades, 1998). Previous studies would suggest that as young men grow older through adolescence they feel more awkward about their body and become more private (Sawyer et al., 2012) but that this decreases again coming out of adolescence through to adulthood. This could be seen in our study where the oldest participant was interviewed with his best friend, who talked openly about a range of sensitive issues, including a supportive and open discussion about their mutual desire for children. Previous reports have shown that close male friendships allow boys to resist restrictive male behaviour expectations (Reigeluth et al., 2016).

It is well recognised that adolescents have particularly complex and shifting hierarchical friendships, and behaviours change due to group dynamics (Benson, 2002; Kilford et al., 2016). Whilst the young people admitted there might be some degree of teasing about testicles, ultimately the evidence suggested the participants were supportive of each other within their friendship groups. Previous studies have investigated the difference between prosocial teasing and bullying. Prosocial teasing is important in adolescent male lives in establishing, maintaining and enhancing personal relationships and assists in resolving inter-personal conflict (Barnett et al., 2004) (Mills and Carwile, 2009).

In our cohort there was some examples of maintaining 'masculine' attributes but overall the young men seemed able to discuss sensitive issues with minimal embarrassment, minimal expectations of bullying, and expectations of prosocial teasing. More machoistic behaviours and attitudes came through in the generation above the young people of this study. Whether this is because these attributes develop later in early adulthood rather than adolescence, or whether the culture of machismo is changing is difficult to interpret. Our population has recruitment bias limiting our interpretations to some extent. All the young people were in full time education and we failed to recruit from BME families. The recruitment was through sports club and community clubs. It might be expected the young people recruited through the football clubs would show higher levels of masculinised behaviours but interestingly this was not the case. There were clear examples of masculinised behaviours and attitudes in the role models from within the sporting community and the non-sporting community. The young people recruited were engaged in a 'club' outside school and therefore may be more socially engaged than the general population. Interviewing the young men with their parents will have changed the responses from those of peer dyad interviews or focus groups from school. It has been shown previously that interviewing young men in focus groups represses the less dominant men and their opinions (O'Reilly, 2017). As young people access healthcare through their parents, using the family interview set up is a good model for assessing the social pressures affecting their ability to speak up about testicular problems, moderated for the family environment. It could be interpreted that young men's ability to resist restrictive male roles may be helped by close male friendships (Reigeluth et al., 2016), but also by parenting with strong maternal attributes, such as gentleness, caring and tolerance. This has not been described previously in the literature and may be a new finding.

This study was performed in the UK with a socioeconomically heterogeneous cohort but from relatively similar cultural backgrounds. It would be fascinating to extend the study to cultures that are more or less physically open. Many of the examples of shame or awkwardness from this cohort were described by the parents and older generation. There is no doubt that shame and embarrassment of young people regarding their testes is a learnt social phenomenon, not an inherent one.

4.3.4 REACT: Parental ability to recognise a testicular emergency and make the decision to attend hospital urgently

Parental knowledge about testicular torsion is poor, with few having demonstrated sufficient knowledge to adequately recognise testicular torsion and attend hospital with the appropriate urgency for salvage. This is not surprising as parents suffer from the same lack of education as young people and would have to rely upon their own experience to help guide their decision making if testicular pain arose in their son. In our cohort two of the parents were general practitioners (family doctors) and one a nurse. Whilst the doctors had heard of torsion, neither knew the urgency or getting to hospital with a painful testicle. This shows that even within the medical profession knowledge of the six hour ischaemic time for testes is poor if not within the paediatric surgical or emergency medicine field.

The study topic guide did not prompt the interviewer to ask the parents questions, therefore it is not possible to derive a percentage of parents with knowledge about testicular torsion. , Fifty percent mentioned unprompted they had never heard of testicular torsion and two had heard of it but had no idea of the urgency This suggests worse parental knowledge than the previous published surveys which found a third of parents are aware of torsion (Burnand et al., 2011; Friedman et al., 2016; Ubee et al., 2014). Possibly this is a function of methodological bias, as these parents were asked once having attended hospital for their child's painful scrotum to fill in a survey, but the difference may also represent investigation of different types of knowledge. Asking a parent if they have heard of torsion in a written survey would investigate their theoretical knowledge of a health condition and may prompt the parents to answer what they feel is the correct answer. Whereas exploring what the parents think might cause testicular pain reveals the presence of practical or applied knowledge, which could be used to facilitate young people attending hospital.

The topic guide did not question the parents about where they got their information about testicular health, but from the responses given most absorbed the knowledge they had from family or community contacts rather than outreach or educational programmes. Parents showed a spectrum of confidence in their knowledge and there was noted to lower confidence levels in mothers from

single parent families, step-mothers and those from of less affluent areas. Mostly the parents seemed happy to reveal a lack of knowledge to the interviewer with only three parents trying to appear more knowledgeable than they were. Two of these were fathers and one a parent who is also a doctor. There did appear to be a degree of machismo with the fathers taking pride in knowledge about testis.

Overall parents felt there was not enough information available to them about adolescent male health issues. The parents discuss their perception that there is more information available for adult men and girls which reflects findings from other groups who find males and in particular adolescent males disadvantaged in terms of health information (Armstrong and Cohall, 2011; Cameron and Bernades, 1998).

In our cohort none of the families had experienced testicular health problems, a condition of recruitment, and none had tried to find information about testicular health problems previously. This aligns with previous studies that suggest parents seek out condition specific health information in light of new concerns , otherwise they might seek lifestyle advice such as diet and exercise for their children(Walsh et al., 2015).

The concerns from parents that websites might not be trustworthy may be appropriate. Discrepancies and inaccuracies of health information for children have been demonstrated on the internet (Walsh et al., 2015), for instance recommending antibiotics in otitis media and the ongoing perpetuation of vaccination falsehoods. Previous studies have shown that both 'online' and 'offline' information seekers prefer a healthcare provider as the gateway to information and those looking to use the internet look for guidance as to reliable sources of information (Cotten and Gupta, 2004; Poortaghi et al., 2015). Barriers for adults searching for health information include poor e-health literacy (Lee et al., 2014) due to inconsistency across the internet and an overwhelming volume of irrelevant information. Internet based health information seeking is more likely if it felt to be something good to do, i.e. has a positive association, and is perceived to be a social norm (Harmsen et al., 2013), with behaviour change in health information seeking seen to be associated with social media not news media reporting (Harmsen et al., 2013). Factors that increase the likelihood of parents searching the internet for information include

higher educational level, older age, and country of origin (Harmsen et al., 2013). In parents of children with disability Alsem et al. demonstrated that families prefer medical information from their doctors, but experience based advice and support from peers (Alsem et al., 2017), and that those that use the internet prefer closed communities rather than public forums. In this cohort the facilitators and barriers to parent's health information seeking were not investigated specifically but families in the higher socioeconomic group were more likely to use the internet and seemed more au-fait with which websites they would use, rather than running a general google search.

Previous research has suggested that people do not feel comfortable displaying health seeking behaviour in front of a doctor (Cotten and Gupta, 2004) therefore there is possibility the families would not open up and discuss their behaviours and intended behaviours with the interviewer who openly identifies as a doctor. The doctor - patient relationship is often unequal with the doctor as the purveyor and integrator of medical information. Although this may be a source of bias, the interview specifically investigated the health seeking behaviour associated with testicular health, and the interviewer felt no awkwardness on discussing the families' use of health information resources in the past. It is difficult to compare intended behaviours to actual behaviours but previous research has shown high levels of intention do correlate with subsequent health information seeking behaviours (Walsh et al., 2015). The study was designed to investigate pre - experience attitudes and likely behaviours, therefore has not investigated the experiences of parents looking for information about testicular problems in response to concerns.

The parents were focused on their son's health during the interviews and discussed their children's health experiences. Health access experiences were described from the family point of view. It did not appear that the healthcare experiences of the parents would act as a barrier to attending hospital or their GP with health concerns. The overwhelming view was that the doctors were good with their sons, and the families trusted the healthcare infrastructure. This study was carried out in the UK which has a free at point of delivery healthcare system with a diminutive private sector. None of the parents mentioned the private sector during the discussions of healthcare. Where the parents did describe dissatisfaction, this was due to seeing different doctors and

long waiting times for information. Previous studies have shown the priority parents place on having a general practitioner (GP) or family doctor with whom they have built a relationship (Cook et al., 2015). In a Department of Health sponsored qualitative investigation of choices about healthcare access, negative parental attitudes to attending a GP for their child's health were found to be: concerns regarding non-specialisation and out of date pediatric knowledge, difficulties in access due to variations and inconvenient opening hours and locations, variations in opinions, feelings they were less thorough due to the short consultation time and concern about hidden agendas (Cook et al., 2015; Jackson et al., 2008; Kai, 1996). The perception that children are more vulnerable was noted during this research which was mirrored in this study data.

A clear process emerged from the study data describing the parents' normal decision-making pathway to access health care for their sons. This was an authoritarian process with little demonstrable negotiation with their sons, which contrasts to previous studies showing greater teenager involvement and shared decision making in family environments (Butler et al., 2005). It has been shown previously that levels of shared decision making decrease when rapid decisions need to be made (Lipstein et al., 2012) or the child is sick, and that the stress involved with an unwell child affects parents decision processes significantly (Miller et al., 2011).

Parents have three decisions to make in regard to HCP access: if, when and where. This study found the parents' decision to contact a HCP depended on severity of pain but more often non-resolution of symptoms over a period of observation. This period was often the course of a day or overnight. This reflects previous research that finds the triggers for a parent to take a child to the emergency department includes the illness presentation, but that significant non-clinical aspects of the family life and external pressures have a greater impact in decisions of ED attendance. These include timing of the illness, the abnormality of the illness and degree of disruption to the child's life, pressure from family or community members, parental anxiety and feeling not able to cope (Cook et al., 2015; Ertmann et al., 2005; Lipstein et al., 2012; McGovern et al., 2017). It has been shown in multiple studies often looking at parental engagement with preventative medicine the greatest influence is perception of the social norm. Findings are that parents are more likely to take vaccination

for their children or not pressure for unnecessary antibiotics if their friends and social peers are doing the same (Cabral et al., 2015; Dore et al., 2014).

Parents contacted the GP as the first healthcare provider in almost all situations, except where the child had an injury where the hospital emergency department was attended, this pattern has been described previously in the UK and internationally (Gafforini et al., 2016). Most injuries declare their urgency more obviously with overt concerning appearances. Many Government sponsored studies focus on understanding the processes of parental decision making in the context of acute unwellness to find ways to disincentivize ED attendance. Such studies discuss the push and pull of families towards hospital attendance and recommend making ED less attractive for families (Cook et al., 2015). The effect of these campaigns to decrease hospital attendance whilst generally appropriate would be a barrier of timely attendance in the context of testicular pain where immediate attendance to hospital is required.

In case of testicular torsion, the normal rules by which parents make decisions about attending a HCP for their children do not apply. Testicular torsion is one of just a handful of conditions where outcomes are time critical, with worse outcomes occurring after delays of just a few hours. Parents receive no education about the time critical emergencies of childhood, and therefore have no framework of how to respond in these situations. It is unsurprisingly then, that breaking the normal pattern of illness recognition and presenting to the family doctor adds a barrier to appropriate presentation to hospital in the case of testicular torsion.

Most of the attitudes towards health and testicular health would support timely access to hospital. Previous attitudes of stoicism in the face of ill health were rarely upheld by parents for their children, except in two families where pride in having good health was described. This did not seem insurmountable for the family to access a HCP when needed. Within this cohort of parents, a theme emerged of pride in not burdening the NHS. In the UK there are strong feelings about the nationalised healthcare service and a politicized media often castigates those using healthcare resources inappropriately. Many of the parents asked the researcher about the type and level of pain you might expect in testicular torsion, and the researcher felt the parents were recalibrating their approach to pain in their sons. The parents demonstrated synthesising their concern about

attending hospital inappropriately and being a burden against a pain severity assessment, to decide a tipping point for attending hospital. This might be considered a deservability calculation, to illustrate, the parent balances the severity of their child's pain against their respect for the limited resources of the NHS and will take their son to hospital when the tipping point is reached, and they feel their son deserves the resources available.

It is interesting in the study data that in some families it seemed the parents felt it should be the father making decisions about testicular health and in others the mother. Previous studies have found the mother is the usual parent for child decisions (Butler et al., 2005). In the context of testicular problems, it appeared that consideration of testicular problems as health made the decision making the mothers responsibility but if they were considered 'male' or 'sex' problems a more engendered response was expected and therefore the father became the responsible decision-maker.

All the parents showed great care and attention for their child's needs and took pride in their role as carer and protector. This reflects societal attitudes towards parents which have shifted from parents holding rights over the child, to having responsibilities to care for their child (*Parental responsibility*, 2008). In cases where the parents fail to look after their child's health appropriately the state may intervene (Diekema, 2004).

In considering potential bias of the results with the study it is important to recognise the researcher openly identifying as a doctor may lessen respondents' negative comments or attitudes towards hospital and healthcare providers. The interviewer felt this was ameliorated by good rapport and interest in the families' opinions. Any negative feedback was received with investigative interest rather than defensive reactivity. The families' volunteering may have self-selected a those with positive experiences of healthcare, as those who have had bad experiences may not have volunteered for the study. People also like an opportunity to feedback if they have had negative experiences, so the impact of recruit bias is hard to predict. Additionally, a higher than average number of parents in our cohort were doctors or nurses biasing the results to a particularly positive attitude towards the NHS and healthcare environments. Within the cohort there did not seem to be overt differences between families of different levels of affluence. There also did not appear to be gross differences in

attitudes between the parents of teenagers with experience of chronic illness or with.

This study found all the families would use a car to attend hospital with none discussing public transport. In less affluent families access to a car was mentioned as an attribute of the care the parents were able to give their children. Previous studies have found the importance of a car in healthcare access (Coker et al., 2010) and in particular in rural communities (Booth et al., 2004; Schröder et al., 2018). Despite this being study including urban families all would use a car for access to a hospital. Parents generally knew which hospital to take their child to but in an increasingly complex and fragmented (Cook et al., 2015) UK landscape, confusion as to age cut offs for different emergency departments could lead to a delay from presentation to surgery. Especially if the child was taken to a non-paediatric surgical unit and required transfer to a tertiary hospital. Previous studies have suggested cost as a major barrier to attending hospital such as those set in Ireland (Daley et al., 2017; Saab et al., 2017), but due to the political set up in the UK this was not stated as a problem for any of the families in this study. The researcher interviewing people in their homes eliminated travel difficulties as a bias for the study.

4.2 Conceptual Framework

In investigating the views and experiences of young people regarding testicular health an understanding of the way that adolescents affect their urgent health needs has been revealed. This may reflect the analysis of the data was driven by a clinician-researcher hoping to understand why young men present late to hospital with testicular torsion. In not limiting the analysis to a narrow interpretation of the research question, the process by which a young person recognises a health problem and gets to hospital has been described. The symbiosis of the adolescent-centric views and experiences of testicles and the clinician-society-centric analysis of the family process of urgent health engagement, provides a complete picture of the phenomenon of young people not presenting to hospital with testicular torsion.

The study findings indicate adolescents have no independence in their experiences of health and access to healthcare. Overwhelmingly the adolescents' views and experiences of health are mediated, facilitated and created by their parents, such that what is intrinsic is inextricable from their parents' views and experiences. They are reliant on their parents for all aspects of health including: health advice, health communication, healthcare access, understanding of personal health history and attitudes to health issues. Parents work to facilitate their child's access to healthcare, but examples are seen where parenting decisions actively disempower young people from illness experiences and independence. There appears to be growing struggle for autonomy for health in the older participants but most of the adolescents happily give up responsibility of this aspect of their life to their parents. This reflects current understanding of the process of transition from childhood to adulthood, where autonomy is fought for but comfort is gleaned from continued parental support and responsibility (Coyne, 2015).

To understand the barriers and enablers for young people to affect their health needs, the research community must understand the process of family health decision making and route from teenage concern to hospital. Previous studies have investigated adolescent access to healthcare and engagement in preventative medicine (Booth et al., 2004; Vingilis et al., 2007), but have failed to recognise that adolescents do not engage with health care independently. Therefore, the results often describe an ideal health service set up rather than

the actuality of the process. The present study has revealed that the method by which a male adolescent in the UK affects his acute health needs is to: recognise a health concern and tell his parents. Their role is as an initiator of the process. Once they have recognised a problem and told their parents, the further processes of decision-making about healthcare access are made by their parents, see Figures 4 and 5.

The factors which impact a male adolescents' ability to affect their testicular health needs are those that impact their ability to recognise a problem and those that impact their ability to tell their parent about their concerns. These factors fall into three broad categories: those that are personal, those associated with the family and those that are external.

Personal factors are those impacting the resources of the individual to recognise a problem and speak up about it. Poor knowledge about testicular function and pathology limits recognition of the problem, which is caused by a lack of previous education about testes. Where knowledge and education are poor the young people need to seek out the health information. This process generally involves asking their parents for advice. Whilst all the young people have internet enabled phones, few use these for health information. The information available for young people about testicles is inadequate, with almost no age appropriate information regarding testicular health online or elsewhere. The views and experiences of young people regarding healthcare services are overwhelmingly positive which acts to enable engagement with healthcare services. Most young people have experiences of hospital attendance in association with injuries, sports or otherwise.

Young peoples' psychology has much to do with their ability to speak up about testicular health problems. It is of interest many of the core features of developmental psychology of adolescent's act as barriers for young people coming forward with testicular concerns. These are universal, not due to individual personality, and well recognised psychological developmental stages. Whilst prone to embarrassment it did not appear that embarrassment was felt by the young people at the time of discussing testes but projected onto others or into the future. Often the embarrassment seemed attached to concerns about appearing to have poor knowledge and not associated to 'shame' and the testes per se. The adolescents did seem to have poor confidence in themselves and

their knowledge which would certainly impact their ability to discuss testicular health issues. Additionally, many of the young people worried raising an alarm would disrupt family life which seemed to be a major barrier for young people speaking up about health concerns.

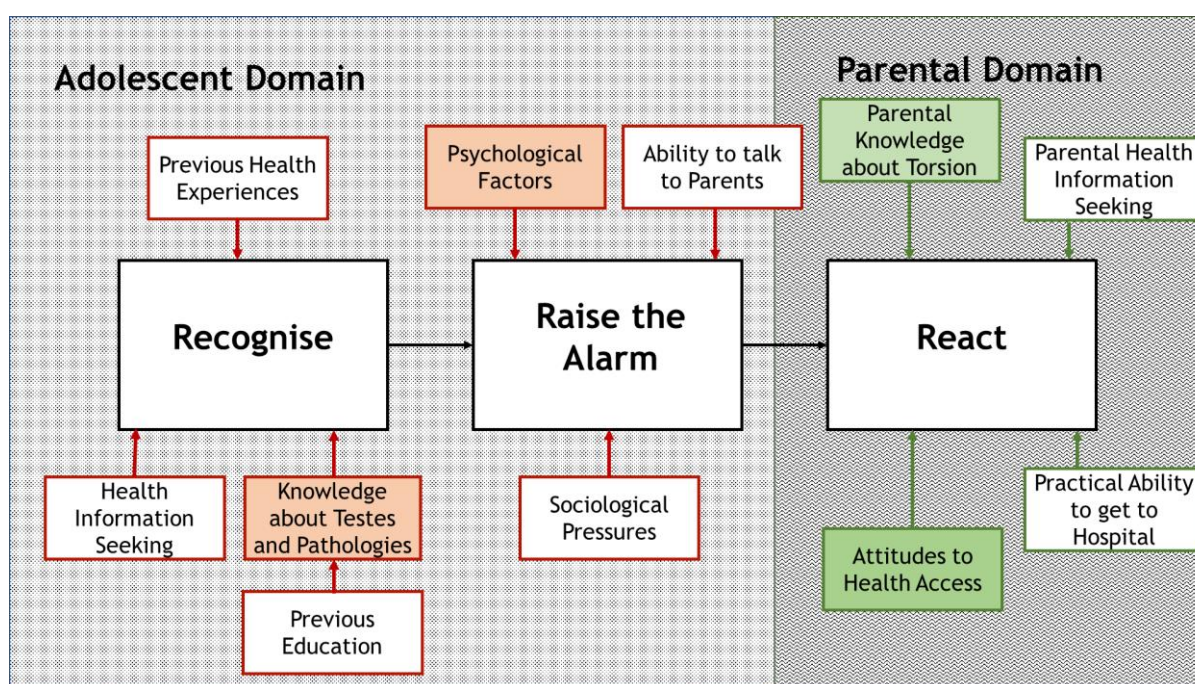
Family factors mostly affected the ability of the young people to discuss a concern about testicular health rather than recognition of the problem, but it is worth noting no parents had educated their sons about testicular health. The 'openness' of a family with low levels of parental embarrassment enabled the adolescent raising their concerns about testes. Strikingly within the study most families discussed testicles with ease.

External factors included those factors known to represent the sociological environment of adolescents. Most commonly the reason young people felt they would not speak about testes was because they had never heard anyone else discussing testes in public rather than an inherent 'shame' of testes. It was the infrequency of societal experience, rather than the nature of the discussion that seemed to put young people off. It is interesting that this is the first study to show a cohort of adolescents seemingly resilient to the pressures of masculinity. The 'macho' responses seen are from parents and grandparents not the young men themselves. Whether this is a shift due to a changing society or whether development of machismo occurs later in early adulthood is not investigated.

Once the young person had recognised a problem and alerted their parents of their concerns, the parents must then make the decision to take their child to a healthcare provider (HCP). This study revealed the normal process by which parents make these decisions and their normal route of healthcare engagement. In order to decide whether the young person needs healthcare the parents synthesise the information they have about symptoms and signs. Often the level of pain or obvious deformation is used as a guide, but more commonly the length of time the symptoms were ongoing was utilised as the trigger of healthcare engagement. Commonly the phrase 'wait and see' was used. Many parents felt they would wait a day or overnight. Once that period was exceeded they would most commonly take their child to their general practitioner (GP). The first point of contact for most families in most situations was their GP. The process by which parents recognise a problem similarly is affected by their level of knowledge and previous education. The process by which they decide to attend

hospital is shaped by their previous healthcare experiences and their attitudes to health. Previous studies have demonstrated convincingly once of the most significant factors in parent's decisions making is the perception of the social norm, doing what their friends would do (Dore et al., 2014). This was not seen in our population but the normal pattern of health assessment in parents seemed hard to deviate from and could only be broken if there is knowledge that presentation with testicular pain should be immediate. This study found the barriers to parents taking their children to hospital in the UK with testicular pain to be poor knowledge, poor e-health confidence with mistrust of online information, governmental disincentivisation of attending hospital emergency departments and concern about burdening healthcare services. Unfortunately, the normal process by which parents make health decisions for their sons is not appropriate in the context of testicular pain and therefore offers a major barrier to timely presentation in the context of torsion. Transportation was mentioned with pride as a parenting attribute by some of the families. Figure 4 illustrates the factors impacting the process by which adolescent males affect their acute healthcare needs.

Figure 4. Illustrating the process by which adolescent males affect their acute health needs and the factors impacting on the process. *The most significant are highlighted by solid fill box.*



This study takes a sympathetic adolescent-centric point of view, but through the interview process has revealed the dependent relationship of adolescents on their parents regarding health and has revealed the process by which adolescents affect their acute health needs. This has not been described previously. This study synthesises adolescent and parental views and experiences, identifying factors affecting the young persons' ability to recognise a testicular problem and tell their parents of their health concerns and factors affecting the parents' ability to make the correct decision to take their son to an emergency department in the setting of acute scrotal pain.

4.5 Recommendations

The aim of this study was to understand adolescents' views and experiences of testicular health issues in order to identify factors that might cause delay of presentation to hospital. In order to see improved outcomes in testicular torsion there is a requirement of behaviour change from a generation of young men. Designing interventions to affect behaviour change in society is a complex process and is a whole field of scientific study in its own right.

Previous studies have highlighted the importance of providing a valid evidence base for the development of behaviour change interventions (French et al., 2012) (Cane et al., 2012) (Abraham et al., 2009), which we feel this study has done. A group of experts came together in 2011 to review the spectrum of behavioural change models in existence and found none to be comprehensive (Michie et al., 2011). Through this meeting a comprehensive behaviour change model was proposed which combined individual behaviour conditions, interventions and policy changes to facilitate behaviour change. The model is referred to as the COM-B model, as the core components of understanding behaviour is to examine capability, motivation and opportunity. Capability requires knowledge of, and the psychological and physical skills to engage with, health processes. Motivation examines beliefs, self-identification, optimism and emotional responses to experiences. Opportunity reflects the social and cultural-environmental aspects of behaviours. They list effective interventions as teaching, training, incentivisation, coercion, persuasion, restriction, modelling, enablement and environmental restructuring. They suggest marketing, fiscal benefits, service design, regulation, legislation and social planning as route through which policy makers can affect change. This system has been appraised

and found to be effective (Cane et al., 2012; Francis et al., 2012; French et al., 2012).

This study has highlighted two major causes for delay to presentation in adolescents with testicular pain. These being poor knowledge from adolescents and parents and a normal process of health assessment that involves a watch and wait step. Both these steps would be amenable to education. In the first instance education for young men could be undertaken through schools or via social media. Despite previous studies showing engagement with sexual health messages on social media improve condom use (Stevens et al., 2017) and excitement about digital intervention methods (Michie et al., 2017), this study suggests the UK male adolescent population does not engage with health messages online, using the internet as a resource for maintaining and establishing friendships. Schools based education has been found to be effective for a range of issues (UK gov, 2015) including teen pregnancy and safe sex practices (Alford et al., 2003; Kirby and National Campaign to Prevent Teen Pregnancy (États-Unis), 2001), obesity, fitness, diet, tobacco use and bullying (Langford et al., 2014) and socio-emotional outcomes (Sklad et al., 2012). A recent report from Public Health England recognised the need for integrative and comprehensive approach to young peoples' health through health, local authority and school environments (*Improving young people's health and wellbeing: A framework for public health*, 2015). A one off lesson on breast exam increased monthly breast examination rates in adolescents females from 3 to 23% (Ludwick and Gaczkowski, 2001b). Unfortunately a 2011 review of needs for PSHE curriculum from the UK government did not highlight testicular health as a current need (Gibb, 2011), but this may represent poor societal knowledge of this significant health issue. Including testicular development, function and pathologies within schools-based health education would move it away from connotations of testicular problems as a sexual issue to become a health issue. It is a favourable time to be considering introducing teaching about testes into schools, as it has recently become compulsory in English schools. Delivering reproducible high-quality teaching about the testes may be difficult for a teacher without appropriate training and therefore the authors recommend production of an information video, educating about testicular health and describing the need to attend hospital urgently with testicular pain. The exact

degree and duration of the testicular pain which should initiate an acute attendance to hospital is difficult to quantify. The concern being that surgical attendances to hospital and the number of scrotal explorations with normal findings may increase if every young man with a modicum of testicular pain attends hospital. A reasonable guideline would suggest: if the pain persists despite taking paracetamol and ibuprofen and lasts more than half an hour attend the emergency department immediately. As the average time from attending hospital to receiving surgery acutely is between two and three hours, that would give time for testicular operations at less than 6 hours from onset. Additionally, pain overwhelming the use of simple analgesics has been used to guide paediatric hospital admissions for a range of conditions, for example abdominal pain.

Previous groups have highlighted that humour is not effective in educating about testicular issues (Thornton, 2016) The benefits of this would be manifold. It would educate young men about testicular pathologies and it would seem likely the young people would speak to their parents about their new knowledge educating the parents as well. It has been shown PSHE has increased effectiveness with parental consultation and engagement (Willis et al., 2013) It would also provide the young men with the knowledge to act appropriately when they themselves are parents, improving the outcomes in the long term.

Introducing an intervention to affect the normal process of parental decision making will be more difficult. It is a multifaceted socially embedded process which will take careful design of intervention strategy at a healthcare, community and governmental level. Maintaining the disincentivisation for parents to bring their child to hospital with trivial ailments whilst highlighting the conditions that do need hospital admission is a difficult balance to affect. In most situations the parental pathway including a watch and wait step and attending their GP surgery is absolutely appropriate. It might be possible to introduce an education leaflet for parents, to be distributed through GP surgeries of the conditions for which 'watch and wait' is not appropriate. Whilst in this study parents seemed keen on leaflets, the effectiveness of this intervention seems dubious. Use of a social media campaign, for instance on sites such as 'Mums-net' may be more effective at spreading this kind of information, especially where consideration of the social norm is important in

guiding parental decision-making pathway. Additionally, most families had previous experiences of hospital attendance in association with injuries, sports or otherwise. This might offer another opportunity to highlight the symptoms which would necessitate immediate attendance to the hospital for a child or adolescents.

4.6 Areas of future study

This study has some methodological weaknesses which provoke thought about areas of future study. The population of this study was limited to the UK and to non-black and minority ethnic populations. Repeating this study with a population of young people from different backgrounds would be highly desirable. Unfortunately, it may be that different recruitment techniques and resources would need to be designed to capture the data from this population. Additionally, undertaking the following study in a population with a different healthcare infrastructure would be of interest to test the findings of concerns regarding burdening the local healthcare services. Testing the hypotheses generated across broad demographics may offer insight into specific pockets of need, but the methodology of large-scale surveys would have to proceed carefully in order to maintain validity.

Ideally an area of future study would be audit following introduction of an intervention. It would be of great interest to introduce an education video into the schools in an area and audit local rates of testicular loss through torsion and rates of scrotal explorations with findings of non-torted testes. This would allow assessment of effectiveness of intervention but would also test whether introducing such a video increased rates of scrotal explorations for non-torted testes which might overwhelm acute paediatric surgical services.

4.7 Conclusion

Delay from onset of symptoms to presentation to hospital in adolescents with testicular torsion is an ongoing issue in the UK and internationally and is the major cause for higher than expected rates of testicular loss in young men. This study has revealed that adolescent males are dependent on their parents for healthcare access and describes the process whereby an adolescent male affects their acute healthcare needs. The adolescent acts as an initiator in the process, they recognise there is a problem and raise the alarm by telling their parents. Their parents then synthesise the symptom information and seek help after a 'watch and wait policy', and often make an appointment with their general practitioner as their first point of health contact. This process acts a barrier to young people gaining timely hospital assessment of testes in the scenario of acute pain. Other factors acting as barrier for this process to happen urgently are: poor knowledge of adolescent testicular problems for both young people and their parents; lack of nationalised schools based testicular health education or age appropriate information resources; 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 disincentivisation of hospital attendance confounding concerns about burdening the NHS. It was of note that embarrassment arising from notions of shame about the testes and pressure to perform a masculine role did not appear to act as major barriers to young people enacting their role as the initiator with in the acute health access process. Recommendations from this study would be to introduce nationalised teaching on testicular health problems in schools ideally during the curriculum of personal social and health education programme, and for parents to be educated of the emergency health conditions whereby a watch and wait process is inappropriate and where children and adolescents should be taken directly to hospital.

5.0 Appendices

Appendix 1. Safety Protocols

Protocol 1: What to do in the event of a Children Protection Disclosure

le if a child reveals physical or sexual abuse or exploitation

Step 1. Do not reassure the child these details are confidential; inform the child that you will have to pass on the details.

Step 2. Take the child's information including social service contact if possible.

Step 3. Accurately as possible record what information you have been given

Step 3. Call Sheffield Children's Hospital Child Assessment Unit on 0114 2267803 and email caroline.thaqs@gmail.com informing them of your concerns.

Protocol 2: What to do if an episode of missed torsion is disclosed

Book the child into clinic with the On-Call Surgeon of the week at local acute hospital. Explain you will need to do the operation to fix the other side and remove the dead testis.

Protocol 3. Procedure for Researcher Prior to Interview Booking

Step 1. Check the participant has chosen an appropriate chaperone

Step 2. Check parental consent has been gained, have a parental telephone number, and parents are happy with choice of chaperone

Step 3. Arrange meeting date and time and location with participant

Step 4. Call parents to ensure they are happy with this location and time.

Step 5. Have one other member of the steering committee sign to confirm details of the meeting.

Step 6. Have study telephone on you at all times.

Appendix 2. Information Leaflets

PARENT/LEGAL GUARDIAN INFORMATION SHEET

Study title: Testicular Health in Adolescents A Qualitative Study

We would like to invite you and your child to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you and your child if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear.

Part 1 - to give you first thoughts about the project

1. What is the purpose of the study?

Whilst there is plenty of information about adult testicular problems, there is very little available for young men. In this study we are exploring adolescent male's views and experiences of testicular problems and access to hospital care. We hope to show areas where better educational packages would improve outcomes for young men with testicular problems. Getting involved with this research may help to improve the health of young men throughout the country.

2. Why have we been invited?

We are looking for young men between the ages of 11 to 19 years who have not had long term illnesses or testicular problems in the past. Your Son's views and experiences are key to our research.

3. Do we have to take part?

It is up to you and your child to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you and your Son to sign a consent form.

You will be given a copy of the information sheets and the signed consent and assent forms to keep for your records. You are free to withdraw anytime before and up to 4 weeks after the interview when the interview will be anonymised, without giving a reason.

4. What will happen to my child if we agree take part?

We will be available after sessions to discuss the research format, the interview style, discuss interview arrangements and to answer questions.

We will take consent from the participant and his parents / guardians at the recruitment evenings. Consent can be withdrawn at any time before the interview, and 4 weeks after when we remove any personal identifying information. If we have more volunteers than we need we will pick names randomly of volunteers to proceed to interview. Volunteers not selected won't be contacted further about this research.

We will contact parents of participants selected for interview on the preferred contact method provided (eg phone or email), to arrange a convenient time and a place for the interview to be conducted. This will be after 2 weeks of providing consent. The interviews will take about an hour. The interview will be performed by the chief researcher Dr Caroline MacDonald, who is a doctor working at the children's hospital. We hope to interview about 25 young men.

Present at the interview will be the participant, the researcher and a chaperone. The young man can choose a chaperone of his choice who is over the age of 18 years old and who has been approved by his parents or guardians. We anticipate that will usually be the parent but are happy for an older sibling, family member or family friend to perform this role. The chaperone is there to support the young man during the interview.

The interviews will take place at a location of the young man's choice, but we would recommend at home, at the Club or at the Children's Hospital.

5. Expenses and payments

Travel expenses will be covered and the participant will be offered a small reward for his participation in the form of a £15 Amazon voucher.

6. What are the possible disadvantages and risks of taking part?

There are no direct risks of the interviews, but we appreciate it may be an inconvenience to you to get to the interview. We hope we can arrange it so the inconvenience is minimal.

7. What are the possible benefits of taking part?

Whilst there is no direct impact on your child's health we hope after the interview you Son may have better knowledge about testicular problems and will be empowered to go to hospital if they have concerns in future.

8. What happens when the research study stops?

We will analyse the interviews and find themes that describe the views and experiences of the young men. We will present this data in an academic journal, presentation and hope the data will be used to create an educational package in the future.

9. What if there is a problem?

Any complaint about the way you or your child have been dealt with during the study or any possible harm you or your child might suffer will be addressed. The detailed information on this is given in Part 2.

10. Will my child's taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about your child will be handled in confidence. The details are included in Part 2.

If you need to contact the chief researcher, Dr Caroline Smith, at any point please email: caroline.thaqs@gmail.com

Telephone: 07939040669

This completes Part 1.

If the information in Part 1 has interested you and you are considering your child's participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

11. What will happen if we don't want to carry on with the study?

If you withdraw from the study, we will delete the recording of your child's interview. There will be no impact on any aspect of your child's future health care.

12. What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.

Name: Dr Caroline MacDonald

Tel: 07939040669

If you remain unhappy and wish to complain formally, you can do this by contacting:

Mrs Linda Towers

Patient Advice & Liaison Co-ordinator

Sheffield Children's NHS Foundation Trust

Tel: 0114 271 7594

Harm

In the event that something does go wrong, and your child is harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation, but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

13. Will my taking part in this study be kept confidential?

All information which is collected about your child during the course of the research will be kept strictly confidential. Once the study is complete, within 3 years, all information will be destroyed.

Our procedures for handling, processing, storage and destruction of data are compliant with the Data Protection Act 1998.

The data will only be accessed by Dr Caroline MacDonald and her supervisor. Specific phrases from the interviews may be used in the final document or presentation but will be anonymised.

14. What will happen to the results of the research study?

When the study has finished we will present our findings to other researchers, and we will put the results in medical magazines and websites that researchers read. We would also like to put a brief summary on the hospital research website so that you will be able to read about our results too. This will be available at the end of the study, in 3 years, on www.sheffieldchildrens.nhs.uk/research-and-innovation.htm. They will be anonymous, which means that your child will not be able to be identified from them.

15. Who is organising and funding the research?

The research is being organised by Sheffield Children's NHS Foundation Trust and paid for by The Children's Hospital Charity.

16. Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by the Yorkshire and Humber Research Ethics Committee.

It has also been given approval by the Research Department to run at this hospital.

17. How can I find out more?

If you would like to find know more about research in general, the Clinical Research Facility at this hospital has an Information for families section on its website www.sheffieldchildrens.nhs.uk/research-and-innovation.htm or you could contact the hospital Clinical Research Facility:

Ms Wendy Swann

R&D Manager

Sheffield Children's NHS Foundation Trust

Tel: 0114 3053478

If you would like to know more specific information about this research project, please contact the project co-ordinator:

Name: Dr Caroline MacDonald

Tel: 07939040669

Email: caroline.thaqs@gmail.com

If you would like advice as to whether your child should participate you could contact the project team, or one of your child's health care professionals.

If you have any concerns during the study, you should contact the project team.

If you and your child decide to take part in this study, you will be given this information sheet and signed consent and assent forms to keep.

Thank you for taking the time to read this information sheet.

PARTICIPANT INFORMATION SHEET

FOR CHILDREN/YOUNG PEOPLE AGED 16 to 19 years

Study title: Testicular Health in Adolescents A Qualitative Study

We are asking if you would join in a research project to find out about you and your friends and colleagues views and experiences of testicular problems and

getting to hospital. Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, doctor or nurse if you want to.

Part 1 - to give you first thoughts about the project

1. Why are we doing this research?

We want to try and find out what young men think about painful testicles and what their views and experiences about this and going to hospital might be.

2. Why have I been invited to take part?

You have been chosen because you have important views that are of interest to us. We hope to interview 25 young men like yourself to create some general ideas and similarities of the experiences you have.

3. Do I have to take part?

No! It is up to you. We will ask you for your assent and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time before the interview and up to 4 weeks after without giving a reason. If you decide to stop, this will not affect the care you receive.

4. What will happen to me if I take part?

We will be available after 4 training sessions to discuss the research format, the interview style, discuss interview arrangements and to answer questions.

We will take consent from you, but this does not mean you have to go through to interview, as mentioned above you can stop at any time up to the interview and for 4 weeks afterwards. If we have more volunteers than we need we will pick names randomly to proceed to interview.

We will contact you to organise an interview. The interviews will take about an hour. The interview will be performed by the chief researcher Dr Caroline MacDonald, who is a doctor working at the children's hospital.

You will be asked to nominate a chaperone (someone to be with you to come to the interview). Usually this will be one of your parents, but it can be someone you know over 18 years like a brother or sister or an uncle or aunt. Attending the interview will be the participant, the researcher and a chaperone.

The interviews will take place somewhere that is convenient for you, but we would recommend at home, at the Club or at the Children's Hospital.

5. What will I be asked to do?

We will ask you questions about your views and experiences of testicular pain, and what you would do if you had sudden pain in your testicles. You just need to tell us what you think and feel honestly. We will record the interview onto digital recording and Dr Caroline will write this up into a document. Then we will analyse lots of the interviews together looking for similar experiences your peers might have. We may use direct quotes in our data presentation, but it will all be confidential. This means no one will know it was you who said a quote.

6. Is there anything to be worried about if I take part?

We will not affect your health in any way, we are interested in your honest opinion. Because we know it is an inconvenience and we appreciate your time there is a reward of £15 Amazon vouchers to say thank you.

7. What are the possible benefits of taking part?

You will be helping us understand better your health issues and may help direct future teaching about testicular problems for young men. You may help young men in the future have better outcomes and improve your friend's lives.

8. Contact for further information

If you would like any further information about this study you could contact:

Name: Dr Caroline MacDonald

Email: caroline.thaqs@gmail.com

Part 2 - more detail - information you need to know if you want to take part.

9. What happens when the research project stops?

We will collect all the information together and we will decide if it is useful in telling us if the doctors can help provide better education to young men about testicular problems.

10. What if there is a problem or something goes wrong?

Tell us if there is a problem and we will try and sort it out straight away. You and your mum, dad or carer can either contact the project co-ordinator:

Name: Dr Caroline MacDonald

Email: caroline.thaqs@gmail.com

or the hospital complaints co-ordinator:

Mrs Linda Towers

Patient Advice & Liaison Co-ordinator

Sheffield Children's NHS Foundation Trust

Tel: 0114 271 7594

11. Will anyone else know I'm doing this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. Wherever possible, we will only send out information that has your name and address removed.

12. Who is organising and funding the research?

The research is being organised by Sheffield Children's NHS Foundation Trust and paid for by the Children's Hospital Charity.

13. Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This study has been checked by the Yorkshire and Humber Research Ethics Committee.

It has also been checked by the Research Department at this hospital.

Thank you for reading this - please ask any questions if you need to.

PARTICIPANT INFORMATION SHEET

FOR CHILDREN/YOUNG PEOPLE AGED 11 TO 15 years old

Study title: Testicular Health in Adolescents A Qualitative Study

We are asking if you would join in a research project to find out about you and your friends and colleagues view's and experiences of testicular problems and getting to hospital. Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, doctor or nurse if you want to.

Part 1 - to give you first thoughts about the project

14. Why are we doing this research?

We want to try and find out what young men think about painful testicles and what their views and experiences about this and going to hospital might be.

15. Why have I been invited to take part?

You have been chosen because you have important views that are of interest to us. We hope to interview 25 young men like yourself to create some general ideas and similarities of the experiences you have.

16. Do I have to take part?

No! It is up to you. We will ask you for your assent and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time before the interview and up to 4 weeks after without giving a reason. If you decide to stop, this will not affect the care you receive.

17. What will happen to me if I take part?

We will be available after training sessions to discuss the research format, the interview style, discuss interview arrangements and to answer questions.

We will take consent from you and your parents, but this does not mean you have to go through to interview, as mentioned above you can stop at anytime up to the interview and for 4 weeks afterwards. If we have more volunteers than we need we will pick names randomly to proceed to interview.

We will contact your family to organise an interview. The interviews will take about an hour. The interview will be performed by the chief researcher Dr Caroline MacDonald, who is a doctor working at the children's hospital.

You will be asked to nominate a chaperone (someone to be with you to come to the interview) who your parents are happy with. Usually this will be one of your parents, but it can be someone you know over 18 years like a brother or sister or an uncle or aunt. Attending the interview will be the participant, the researcher and a chaperone.

The interviews will take place somewhere that is convenient for you, but we would recommend at home, at the Club or at the Children's Hospital.

18. What will I be asked to do?

As part of the interview conducted we will ask you questions about your views and experiences of testicular pain, and what you would do if you had sudden pain in your testicles. You just need to tell us what you think and feel honestly. We will record the interview onto digital recording and Dr Caroline will write this up into a document. Then we will analyse lots of the interviews together looking for similar experiences your peers might have. We may use direct quotes in our data presentation, but it will all be confidential. This means no one will know it was you who said a quote.

19. Is there anything to be worried about if I take part?

We will not affect your health in any way, we are interested in your honest opinion. Because we know it is an inconvenience and we appreciate your time there is a reward of £15 Amazon vouchers to say thank you.

20. What are the possible benefits of taking part?

You will be helping us understand better your health issues and may help direct future teaching about testicular problems for young men. You may help young men in the future have bad outcomes and improve your friends lives.

21. Contact for further information

If you would like any further information about this study, you could contact:

Name: Dr Caroline MacDonald

Email: caroline.thaqs@gmail.com

Phone: 07939040669

Part 2 - more detail - information you need to know if you want to take part.

22. What happens when the research project stops?

We will collect all the information together and we will decide if it is useful in telling us if the doctors can help provide better education to young men about testicular problems.

23. What if there is a problem or something goes wrong?

Tell us if there is a problem and we will try and sort it out straight away. You and your mum, dad or carer can either contact the project co-ordinator:

Caroline MacDonald

Email: caroline.thaqs@gmail.com

or the hospital complaints co-ordinator:

Mrs Linda Towers

Patient Advice & Liaison Co-ordinator

Sheffield Children's NHS Foundation Trust

Tel: 0114 271 7594

24. Will anyone else know I'm doing this?

We will keep your information in confidence. This means we will only tell those who have a need or right to know. Wherever possible, we will only send out information that has your name and address removed.

25. Who is organising and funding the research?

The research is being organised by Sheffield Children's NHS Foundation Trust and paid for by the Children's Hospital Charity.

26. Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. This study has been checked by the Yorkshire and Humber Research Ethics Committee.

It has also been checked by the Research Department at this hospital.

Thank you for reading this - please ask any questions if you need to.

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7.0 Draft of Paper for Submission for Publication

Why Adolescents Delay with Presentation to Hospital with Acute Testicular Pain: A Qualitative Study

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ABSTRACT

Background

Adolescents have poor outcomes following testicular torsion directly attributable to delay from onset of symptoms to presentation to hospital. Our aim was to investigate the views and experiences of young men to understand the barriers to urgent presentation.

Methods

Semi-structured interviews were undertaken with young men (11-19 years). Thematic analysis was undertaken, and data managed with framework methodology. Validity was ensured by meticulous study design, high levels of reflexivity and regular supervision.

Findings

Twenty-seven adolescents were recruited, data saturation was reached at sixteen participants, median age 13.5 years. Participants were recruited from five youth clubs in two countries.

The process whereby adolescents present to hospital with acute testicular pain acts as a barrier to urgent presentation. To get to hospital adolescents must recognise there is a problem and alert their parents, who must react appropriately. Parents use a 'watch and wait' policy to assess symptom severity and need for medical review. Most make an appointment with the family doctor as first contact for health advice.

Additional factors acting as barriers to early presentation include: absence of age-appropriate testicular pathology knowledge from adolescents and their parents; lack of education resources; concern from the young people about raising a false alarm; young peoples' fear of disrupting the family routine and nationalised disincentivisation of hospital attendance confounding family concerns about burdening healthcare services.

Interpretation

Recommendations include nationalised testicular health education for young men and education for parents regarding the medical conditions whereby a 'watch and wait' policy is potentially harmful to their child.

Funding

The project received funding from The Children's Hospital Charity (project number CA14013)

INTRODUCTION

Testicular torsion is a condition of young males and, rarely, neonates. The outcome following testicular torsion in adolescents is disappointing, with 50% testicular loss or atrophy at long term follow up.¹ Studies find normal paternity following unilateral torsion in peri-pubertal males,² but unilateral testicular loss increases the risk of castration if a contralateral event occurs. Loss of a testicle leads to feelings of loss of masculinity and unhappiness with self-image.³ Predictors of testicular loss include degree of twist, presentation to a GP, transfer between hospitals for surgery, but most significantly a delay between symptom onset and presentation to healthcare services^{4,5} 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 hours and 10 hours⁶⁻⁸.

Only a third to a half of adolescents present within 6 hours^{7,9} with testicular pain, with one study finding a median time to presentation of 56 hours.¹⁰ There is poor understanding of why adolescents delay in presenting with testicular pain. Previous studies have found poor knowledge from parents and adolescents about testicular pathology^{11,12} and embarrassment to be contribute,¹³ but these studies have not investigated the phenomena in a naturalistic social context.

This study aimed to investigate adolescent males knowledge and experience of testicular health issues to understand the facilitators and barriers to presentation with a painful scrotum.

METHODS

We chose a thematic qualitative methodology,^{14,15} utilising semi-structured interviews with framework analysis. This methodology is effective in investigating social issues of a complex and delicate nature.¹⁶ Quality and validity were ensured using standard qualitative procedure including: strict research integrity and data handling, reflexivity, expert supervisor-ship, triangulation and auditable movement from raw data to concepts and theory.¹⁷ The interviews were directed with a topic guide (see supplementary data).

Patient Involvement, Study Population and Recruitment

In developing the study protocol, the chief investigator (CI) interviewed families and adolescents after torsion of testis to ensure relevancy, discuss the recruitment population and strategy, and to ensure a female doctor interviewing young men about testicular issues was culturally acceptable. The target population was adolescent males 11 to 19 years who had not experienced testicular torsion. Those who had experienced testicular health issues or had frequent visits to hospital were excluded. This ensured the population closely matched the adolescent male population where torsion events occur. The author undertook purposive sampling whereby adolescent males were recruited through sports and out of school clubs. The CI contacted the clubs and asked to advertise via their email and social media listings and attended practises to meet the young men and their families. Information packs were given to the families, which included the recruitment protocol, and consent and assent forms were signed. The family were given two weeks before being contacted and an interview arranged at home, at the hospital or at the sports club. The young men were asked to choose a chaperone. The adolescents were given a gift voucher as an incentive to take part. The sampling strategy was deliberate with no convenience sampling. The aim was to recruit until data saturation as defined by standard qualitative methodology¹⁸ whereby the iterative analysis occurs alongside data collection and no further ideas are generated with further participant recruitment.

Probity and Ethical Issues

Significant considerations were made for care for the young men with age appropriate assent and consent forms, a chaperone at all times, and an offer to withdraw from the study up to four weeks from the interview. Interviews were recorded on an electronic device and transferred to an encrypted hard drive kept on NHS

property. Recordings are to be destroyed at 5 years from study end. Transcriptions were anonymised. The project went through ethical review board (REC number 15/YH/0299, HRA registration 167713), with the research protocol available from the corresponding author.

Data Analysis

The chief investigator listened to all transcripts and transcribed the first six interviews, subsequently a professional transcription service was utilised. The transcriptions were coded using NVivo software (NVivo 11 © QSR International 2017), which was for data management alone. From the initial interviews the CI coded alongside and developed category indexes. These were refined and used to adapt the topic guide in the further interviews. As the categories became more refined and the themes more concrete a framework table was used to check consistency and conflict within and between participants.

Role of the Funding Source

The project received funding from The Children's Hospital Charity (project number CA14013), who were involved in guidance of data handling and ensuring patient confidentiality. The funding was used for the practicalities of the study including materials, transport costs, transcription costs and incentives for the participants. The author has full access to the data and final responsibility for decision to submit.

RESULTS

Population

Contact was made with thirty-two clubs, recruitment occurred from five. Twenty-seven families were recruited. Semi-structured interviews were performed in an order determined by the families' availability and were booked in sequentially. No new broad themes were identified after eleven interviews. Five more interviews were undertaken to test for completion within the study population. Interviews took place between December 2015 to December 2017.

The families were recruited from a broad socioeconomic spectrum in two UK locations. All but one participant was Caucasian. Median age of the young people was 13.5 years (range of 11 to 18). One interview occurred in the hospital and fourteen at the family home. Sixteen adolescents from fifteen families were interviewed. All participants chose their parents or guardian as their chaperone. The author decided to include description and analysis of the parents' views and experiences, as well as the participants, within the results and development of the conceptual themes because the young persons' views and experiences were intimately interwoven with their parental views. The author believes describing the data within the family context represents a deep and natural account of the phenomena of testicular torsion for young men.

Research Process

The codes emerged intuitively from the interview transcripts and were grouped to form categories. The categories were indexed eight times to form codebooks which helped develop the final themes (see supplementary data). The analysis moved between realistic and constructionist in a flexible manner, recognising the reality of the world the adolescents live in, and the degree to which social construct affects their experiences. A framework matrix was developed, plotting transcript data from each family by theme and in this process further refinements were made. Three versions of the framework matrix were created as the data was reflected upon, and as the report was written, the framework is available from the corresponding author on request.

FINDINGS

Young Person's Lack of Independence for Healthcare

Adolescents rely on their parent for all aspects of health. They subjectively and objectively turned to their parents for health advice, alerting of health concerns, means of access to healthcare, memory of past illness events and opinions regarding health. All young people, except the eldest, when asked what they would do with a painful testicle replied that they would tell their Mum or Dad.

CI: What have you been to hospital for?

P: Ummm I don't think I've been up for me, myself, have I [look to Mum]

Mother: No, you've been okay.

(Participant 4, 11 years old)

Invariably the parents were supportive and encouraged the young people to express their own opinions. Occasionally conflicts were seen, or parents undermined the autonomy of their child. For instance, a father when talking about his son calling an ambulance said: 'I just wonder if they would respond to a 13-year-old boy'. Multiple examples were seen where the young people had been protected from experiences of illness within their family. Some of the parental responses showed they felt their child to be too young for education regarding testicles.

Young Person's Knowledge of Testicular Function and Pathologies

Half the cohort knew testicles produced 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. Many 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)

Young Person's Experiences of Health Education

The education at school given to the young people about testicles involved labelling 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 as PSHCE is more life and the stuff you need to use'. Overall the impression was school education about testicular health was insufficient to deal with the practicalities of torsion:

'P: It feels more important than some of the things I learn in school but it's not, [...]. It's not super-helpful. It's not really like—

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)

Most of the knowledge gained about testicular health problems came from sources such as friends, the football community or television and mostly described testicular cancer.

Young Persons' Views and Experiences of Health

All the participants having been to hospital described their experience positively. Most often describing the doctors as nice, other positive aspects included: watching TV and getting a day off school. 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 what was needed.

Often testicular health issues were considered more humorous than other injuries. The reason for the humour associated with testicular problems was described by one young man:

'P: coz it's your balls. It's not taken seriously as other stuff.

(Participant 8, 12 years old)

Similarly, a second young man felt the humour about a twisted testicle may be due to its perceived more trivial nature, and this in turn may increase embarrassment associated with the testes:

'I: Do you think a twisted testicle is more embarrassing than cancer?

P Yeh. [...] I think ummm people if they had that 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.'

(Participant 7, 14 years old)

Young Persons' Health Seeking Behaviours

Young people turned to three sources for information regarding health issues: their parents, the internet and their friends. Six said they would use the internet to search for health information in combination with talking to their parents. 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.

Cl: What did you think about the pictures?

P: They made me throw up.'

(Participant 13, 11 years old)

Further examples where anxiety was increased by an internet search, include a young man watching videos of venepuncture and in one searching the internet confirmed the myth he was told by a friend, that the first time you have sex your frenulum will 'snap'.

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

'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)

Ability to Discuss Testicular Problems with Parents

It is striking in this study all the young people discussed testicular health in front of and with their parents openly. Whilst Participant 10, 12 and 15 stated it might be 'awkward' to speak to their parents about testicular problems, evidence from the rest of the interview showed they had had easy conversations with their parents about difficult topics previously. Interestingly 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: Urrrr I'd probably ask Dad because he has a [...],

Mother: he has a [...]. Though you asked me first and it was me who asked Dad.

P: I'd often ask my Mum stuff first, definitely. 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.

Psychological Factors

Aspects of adolescent developmental psychology which influenced the participants ability to discuss testicular health issues were concern regarding future negative consequences, concern about revealing lack of knowledge about a topic and embarrassment about their bodies. The younger half of the cohort gave the impression of having lower self-confidence than the older half.

Embarrassment was mentioned during all the interviews, but objectively most participants did not behave in an embarrassed manner. The young men often attributed embarrassment of discussing testicular problems to others:

'P: I think some people might think it's embarrassing, [...] but I don't, yeah. The main thing it's embarrassing so they might not go and it would just get worse.'

(Participant 11, 14 years old)

Interesting many of the young men described the anticipated embarrassment stemming from a concern of showing poor knowledge and having raised the alarm inappropriately rather than the embarrassment being due to the testes themselves:

I: Would you be able to tell us what testicles do?

P: I don't wanna say it in case its 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)

Many of the young men used humour at times during the interview to embolden themselves, create a rapport with the CI, create a safe environment for discussing sensitive issues and create an appearance of emotional aloofness.

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 in future. 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:

‘Cause I think your arm is always on show and everyone notices your arms but it's a bit different with your testicles. And I mean, reasonably, they're always hidden away.’

(Participant 10, 14 years)

Some of the younger participants described testicles as: ‘gross’, ‘they creep me out’ and ‘disgusting’ and felt testicular health wasn’t relevant to them. The older participants were more at ease discussing testes and found the topic relevant and important for them. 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 humour was good natured with few reports or expectations of bullying and most felt ultimately their friends would be supportive:

‘CI: Would you be worried about people finding out at school?’

P: My friends would laugh and then take the mick and then, like, take it serious.’

(Participant 5a, 14 years old)

Whilst 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.

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 discussed having received any education regarding testicular health issues, either during their upbringing or once parents. The parents displayed different levels of confidence in their knowledge. 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.

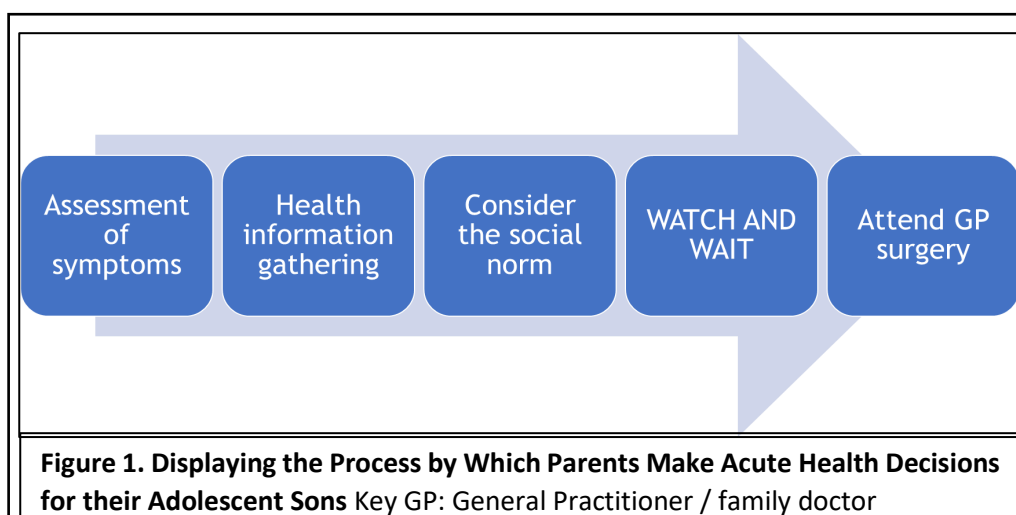
Parental Information Seeking

In our cohort none of the parents had previously sought out information regarding ‘testicular health’ issues for their sons. 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 first port of call with a health enquiry. Those that mentioned use of an internet search, unanimously mentioned the importance of assessing the quality of the information provided.

Parents Attitudes and Experiences of Healthcare Access

The study data showed parents access medical health advice and treatments through their family doctor (GP), but utilised 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 Figure 1. Initially the parent identifies the symptoms of concern and tries to ascertain what has happened. They then assess the severity of the symptoms. Most parents then wait to see if the symptoms resolve and if they continue will make an appointment with their GP. Only three mentioned going straight to the hospital if the pain was serious.



From the interviews it seemed a testicular health issue would be treated the same as any other health concern. 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 a significant factor in changing attitudes to healthcare access. There did seem to be a theme running through some of the interviews of pride in not burdening the NHS:

‘Well yeh, we don’t rush you in here for a snotty nose. This is an accident and emergency it isn’t an accident or an emergency’

(Mother of Participant 2)

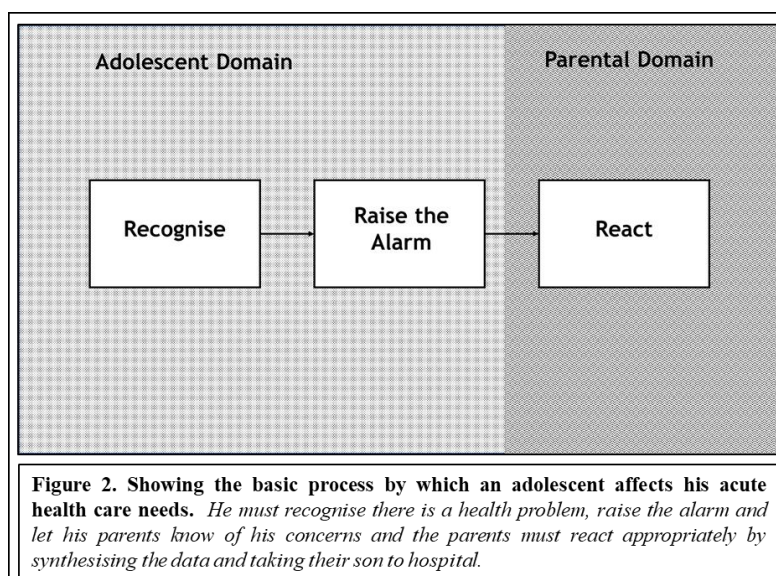
Family Ability to Get to the Hospital

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, due to local health service design and paediatric age cuts off for care in their city.

DISCUSSION / INTERPRETATION

The Process: Recognise, 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, see Figure 2. The young person must recognise 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. Adolescent males do not seek healthcare independently of their parents. Factors affecting each of these steps act as barriers to presentation with scrotal pain.



Recognise

To recognise they have a time dependent testicular problem, the adolescent needs to either know about testicular torsion or be able to find appropriate information about the condition quickly. 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.^{11,12} This compares badly with older males where over half would go to the emergency room directly with testicular pain.^{11,22} This study suggests worse parental knowledge than the previous surveys, which found a third of parents are aware of torsion^{13,23,24}, which may reflect methodological bias. Currently school education regarding testis is inadequate to empower the young men to deal with testicular health concerns.

Raise the Alarm

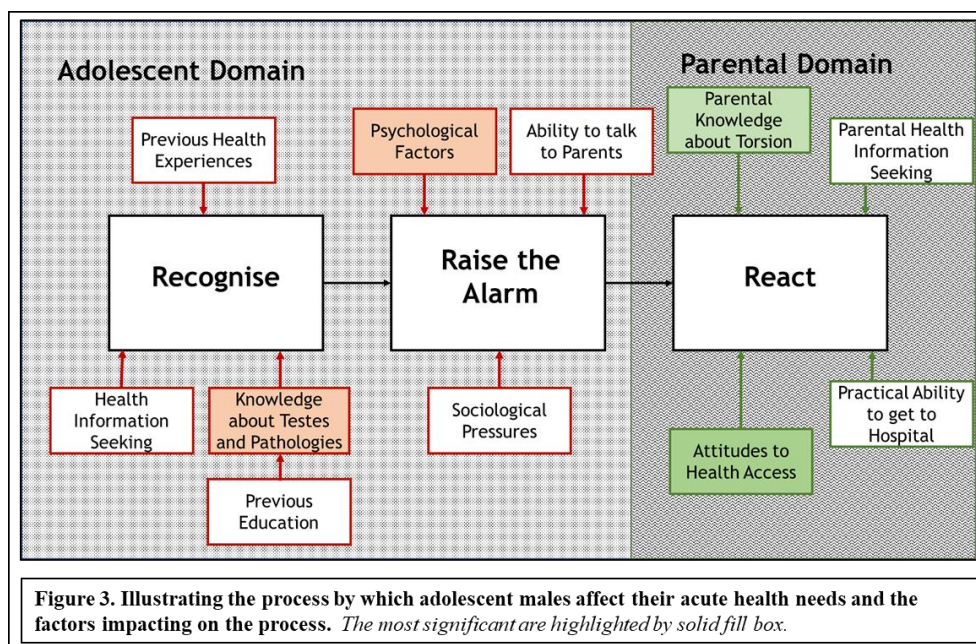
The factors affecting the young men's ability to tell their parents of a health concern include their ability to talk with their parents, and psychological and sociological factors. In this study families discussed male health issues in an open fashion. Parental embarrassment has been shown in previous studies to create an environment where a young person avoids conversations about sex²⁵ but this was not seen in our study. Similarly, embarrassment was not exhibited by participants but was often attributed to others or the future. Of the features of adolescent developmental psychology, we observed low self-esteem²⁶ in the younger participants and lack of thoughts of the future in decision making.²⁷ Humour was used in the discussion of testes and generally. Funniness has been previously described as an important attribute for popularity in young men.²⁸

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 due to 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.

React

We found the parents' decision to contact a healthcare provider (HCP) depended on severity of pain but more often non-resolution 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 medicine²⁹. Many studies focus on understanding the processes of parental decision making in the acute illness to find ways to disincentivize ED attendance³⁰. The effect of campaigns to decrease hospital attendance is a major barrier of timely attendance in the context of testicular pain.



The process of an adolescent getting to hospital with acute testicular pain makes urgent presentation from symptom onset unlikely. There are key points in the process where a halt is the norm, which increases the chances of testicular loss if the testicle is twisted, as illustrated by Figure 3. This process has been shown in the context of testicular emergencies, but it seems likely that this represents the route of the adolescent to hospital for all acute illness. This process has not previously been described in the literature. Previous studies have not described such high levels of teenage dependence on their parents, but have been performed in context of public or chronic health.^{19,20} It has been shown that levels of shared decision making decrease when rapid decisions need to be made²¹.

STRENGTHS AND LIMITATIONS

This study is the first to explore, with qualitative methodology, the experience of young men and their parents of testicular health, in the normal social context. This gives a naturalistic insight into 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. The steps and processes of interpretation were open and auditable and were supervised such that bias was minimised during this process. Reflexivity of prior declared biases revealed that the themes of the process of presentation leading to delays and the lack of embarrassment shown by young people was derived from the data.

The study recruitment strategy failed to recruit from ethnically diverse backgrounds. The strategy did not seek out 'difficult to reach' teens but aimed to represent the 'normal' experience. Recruiting a disease naïve population describes intentional behaviours, but previous studies have found high correlation between intentional and actual behaviours³¹. The chief investigator introduced herself as a doctor which gave the families confidence to speak with her but may have biased the results to trying to say the 'right' answer due to power imbalance and the 'white coat' effect.

CONCLUSION

This study has revealed that the process, and factors acting on the process, by which an adolescent male affects his acute healthcare needs acts a barrier to young people attending hospital urgently with testicular pain. Factors influencing the process 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 disincentivisation of hospital attendance. Recommendations from this study would be to introduce nationalised teaching on testicular health problems in schools, 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.

Declaration of Interests

The corresponding and additional authors of this paper declare no conflict of interest.

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Data Sharing

The interview recordings and transcripts are available from the author with email application detailing intention of the data, opportunities for collaboration and acknowledgement of data source, up to October 2022.

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