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**Exploring Awareness and Help-Seeking Intentions for Testicular Symptoms Among** Heterosexual, Gay, and Bisexual Men in Ireland: A Qualitative Descriptive Study Mohamad M. Saab a,\*, Margaret Landers a, Josephine Hegarty a <sup>a</sup> School of Nursing and Midwifery, University College Cork, Cork, Ireland \*Corresponding author at: School of Nursing and Midwifery, University College Cork, Brookfield Health Sciences Complex, College Road, Cork, Ireland. Tel.: +353 21 490 1518 E-mail address: <a href="msaab@ucc.ie">msaab@ucc.ie</a>; <a href="msaab@gmail.com">msaab@gmail.com</a> 

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2 Heterosexual, Gay, and Bisexual Men in Ireland: A Qualitative Descriptive Study

#### 1 ABSTRACT

# 2 Background

- 3 The incidence of malignant and benign testicular disorders among young men is on the rise.
- 4 Evidence from three reviews suggest that men's knowledge of these disorders is lacking and
- 5 their help-seeking intention for testicular symptoms is suboptimal. Qualitative studies have
- 6 addressed men's awareness of testicular cancer, with none exploring their awareness of non-
- 7 malignant diseases such as epididymitis, testicular torsion, and varicocele and none including
- 8 sexual minorities.

# 9 Objective

- To explore, in-depth, heterosexual, gay, and bisexual men's awareness of testicular disorders
- and their help-seeking intentions for testicular symptoms in the Irish context.

# 12 Design

- 13 This study used a qualitative descriptive approach. Data were collected via face-to-face
- individual interviews and focus groups.

# 15 **Settings**

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- Participation was sought from a number of community and youth organisations and one
- 17 university in Southern Ireland.

# **Participants**

- 19 Maximum variation and snowball sampling were used to recruit a heterogeneous sample. A
- total of 29 men partook in this study. Participants were men, aged between 18 and 50 years,
- and residents of the Republic of Ireland.

#### 22 Methods

- 1 All interviews were audio-recorded and transcribed verbatim. Reflective field notes were
- 2 taken following each interview. A summary of the interview was shared with selected
- 3 participants for member-check. Data were analysed and validated by three researchers.
- 4 Inductive qualitative analysis of manifest content was used. Latent content was captured in
- 5 the field notes. Data analysis yielded two key themes.

#### Results

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- 7 The themes that emerged from the interviews were: Awareness of testicular disorders and
- 8 their screening, and help-seeking intentions for testicular symptoms. Although most
- 9 participants heard of testicular cancer, most did not know the different aspects of this
- malignancy including its risk factors, symptoms, treatments, and screening. Several men had
- a number of misconceptions around testicular disorders which negatively impacted their
- intentions to seek prompt help. Intentions to delay help-seeking for testicular symptoms were
- often linked to a number of emotional factors including fear and embarrassment, and social
- 14 normative factors such as machoism and stoicism. In this study, culture was perceived by
- some participants as a barrier to awareness and help-seeking. In contrast, many believed that
- young men, especially those who self-identify as gay, are becoming increasingly interested in
- their own health.

# Conclusion

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- 19 Findings suggest the need to educate young men about testicular disorders and symptoms.
- 20 This could be achieved through conducting health promotion campaigns that appeal to
- younger men, drafting national men's health policies, and normalising open discussions about
- testicular health at a young age.

# Keywords

1	Awareness; help-seeking behaviour; homosexuality; intentions; men; qualitative research;
2	testicular cancer; testicular diseases.
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#### 1 INTRODUCTION

2 Globally, health outcomes for males continue to be markedly poor, and efforts to promote men's health remain scarce. Moreover, health organizations and national governments tend to 3 assume that gendered approaches to health promotion should be primarily focused on 4 5 women's health rather than on both genders equally (Hawkes and Buse, 2013); which might 6 lead to gender-based health disparity and poorer health outcomes, and discourages men from 7 engaging with health services (Leone and Rovito, 2013; Whitaker et al., 2015). In order to address this issue, Baker et al. (2014) urged national governments and global health 8 9 institutions to move men's health higher up on their agenda. Of the diseases that are seldom 10 discussed in current men's health policies, disorders of the testes can have a major impact on a man's wellbeing. 11 Testicular cancer (TC) is the most common solid tumour among young men in the United 12 States, with a mean age of 33 years at diagnosis (National Cancer Institute [NCI], 2015). The 13 incidence of this malignancy doubled globally over the past four decades and is highest in 14 15 Western countries (Manecksha and Fitzpatrick, 2009; Shanmugalingam et al., 2013). TC is one of the most curable solid tumours with a five-year relative survival rate of 95.4% (NCI 16 2015). The surgical resection of the affected testis (e.g. orchiectomy) remains the treatment of 17 18 choice for TC. Every so often, orchiectomy is followed by chemotherapy and/or radiotherapy (Saab et al., 2016b). Evidence suggests that TC survivors often face long-term complications 19 secondary to the disease and/or its treatment; these include chronic fatigue, neuropathy, and 20 fertility impairment (Huddart et al., 2005; Rossen et al., 2009; Saab et al., 2014). 21 22 Contrary to popular belief, testicular pain, lumpiness, and swelling are not symptoms of TC exclusively. In fact, the likelihood of testicular symptoms occurring secondary to a benign 23 24 disease rather than TC is quite significant. Each year, 1 in 4,000 males aged less than 25

- 1 years are diagnosed with testicular torsion in the United States (Ringdahl and Teague, 2006).
- 2 Moreover, epididymitis and subsequent orchitis make up 1 in every 144 outpatient visits
- among younger men, and each year 600,000 men aged 18 to 35 years are diagnosed with this
- 4 disorder in the United States (Centers for Disease Control and Prevention [CDC], 2015).
- 5 Testicular torsion is known to cause excruciating pain and swelling (Ringdahl and Teague,
- 6 2006), epididymitis and orchitis often lead to discomfort, swelling, and lumpiness, and
- varicocele, hydrocele, and spermatocele can be painful (Trojian et al., 2009). A number of
- 8 these conditions can be life-threatening. An example is testicular torsion that can lead to
- 9 testicular necrosis if help-seeking is delayed by six hours or more from the onset of pain
- 10 (Ringdahl and Teague, 2006). Moreover, epididymitis and orchitis can lead to sepsis if left
- 11 untreated (CDC, 2015).
- 12 Evidence suggests that men are often reluctant to seek help for testicular symptoms, mainly
- due to lack of symptom awareness, symptom misappraisal, fear, and embarrassment (Fish et
- al., 2015). In a systematic review of 25 papers on TC awareness, Saab et al. (2016c) found
- that men were unaware of TC risk factors, signs and symptoms, and screening; very few
- practiced testicular self-examination; and those who performed testicular self-examination
- were unsure what to look for. Moreover, men's perceived risk for TC was found to be low
- 18 (Roy and Casson, 2016). Saab et al. (2016b) conducted a second systematic review to
- synthesize evidence from 11 studies promoting TC awareness. Similarly, men's awareness of
- 20 TC and self-examination was lacking at baseline. Nevertheless, interventions including a
- 21 university campaign (Wanzer et al., 2014), mass media (Trumbo 2004), and awareness
- sessions and hands-on practice (Shallwani et al., 2010) were instrumental in raising TC
- 23 awareness and getting young men to self-examine. In contrast, evidence from an integrative
- 24 review of four studies on awareness of non-malignant testicular diseases, suggests that men's
- knowledge of testicular torsion (Clark et al., 2011) and hydrocele (Babu et al., 2004) is

- 1 deficient, and their intention to seek medical help for testicular swelling and/or pain is
- 2 suboptimal.
- 3 Of the reviewed studies, very few offered an in-depth understanding of men's awareness of
- 4 TC (Dubé et al., 2005; Daley, 2007; Evans et al., 2010), none explored, qualitatively, men's
- 5 awareness of and help-seeking intentions for symptoms of non-malignant testicular disorders,
- and none aimed at raising men's awareness of diseases beside TC. Moreover, only one study
- 7 involved men who are at risk for health inequities (Babu et al., 2004), and none included
- 8 gender and sexual minorities. This is worrisome, as gay men are twice more likely to report a
- 9 cancer diagnosis in comparison to heterosexual men (Boehmer et al., 2011).
- In order to address the gaps identified in the literature, this study aims to explore, in-depth,
- 11 heterosexual, gay, and bisexual men's awareness of testicular disorders and their help-
- seeking intentions for testicular symptoms in the Irish context.

# 13 **METHODS**

#### 14 Study design

- 15 This is a qualitative descriptive study that draws from the naturalistic paradigm. Therefore,
- the phenomenon of interest was explored in its natural state rather than adhering to prior
- views or theories (Guba and Lincoln, 1994). Qualitative description is suitable for obtaining
- candid and predominantly unadorned responses to questions that are of interest to
- 19 researchers, practitioners, and policymakers. Examples include: "What are the concerns of
- 20 people about an event? What are people's responses toward an event? What factors facilitate
- and hinder recovery from an event?" (Sandelowski, 2000, p.337). These questions are well
- suited for the present study that is aimed at exploring men's awareness and help-seeking
- 23 intentions for testicular symptoms. The 21 items of the Standards for Reporting Qualitative
- Research (SRQR) were used in the reporting of this study (O'Brien et al., 2014).

# **Participants**

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- 2 Purposive sampling, specifically maximum variation and snowball sampling were used to
- 3 locate and recruit a heterogeneous sample of information-rich key participants (Grove et al.,
- 4 2013; Patton, 1990). Maximum variation sampling allows researchers to describe a certain
- 5 phenomenon from the viewpoint of a diverse sample. In this study, a sample that was varied
- 6 in terms of age, socioeconomic status, ethnicity, and sexual orientation was sought.
- 7 Participants were then asked to invite other men who fitted the inclusion criteria to partake in
- 8 the study, which is the key feature of snowball sampling (Patton, 1990). It is worth noting
- 9 that both sampling strategies are recommended and are widely used in qualitative descriptive
- nursing research (Sandelowski, 1995).
- Participants eligible for this study were: (i) males; (ii) aged between 18 and 50 years; (iii)
- self-identifying as heterosexual, gay, or bisexual; and (iv) residing in the Republic of Ireland.
- 13 The inclusion criteria were selected based on the gaps identified in the literature on awareness
- of testicular disorders, whereby men at risk for health inequities, including those who self-
- identify as gay or bisexual, were underrepresented (Saab et al., 2016a,b,c). In addition, men
- aged 18 to 50 years were invited to participate, since evidence suggests that men who fall in
- this age bracket are at the highest risk for developing one or more testicular disorders (CDC,
- 18 2015; NCI, 2015; Ringdahl and Teague, 2006).

# Data collection

- 20 Ethical approval was obtained from the Clinical Research Ethics Committee at University
- 21 College Cork. A standardised invitation letter was sent by e-mail to members of an inclusive
- 22 community choir, youth organization, surfing club, family community centre, and all students
- and staff in a university in Southern Ireland. In addition, study flyers were hung in a
- 24 university sports centre and on campus. Those who replied to the e-mail and agreed to

- 1 participate were asked to identify other men who would be potentially interested in taking
- 2 part in the study.
- 3 Data were collected between December 2015 and February 2016 using face-to-face
- 4 individual interviews and focus groups. The combination of individual interviews and focus
- 5 groups is known to enrich qualitative data (Lambert and Loiselle, 2008). In the present study,
- 6 focus groups and individual interviews were conducted simultaneously for pragmatic reasons.
- 7 Each participant was given the choice to participate, either in a focus group discussion or in
- 8 an individual interview. This was attempted in order minimize refusals and withdrawals
- 9 among those who did not feel comfortable discussing intimate topics in front of other men.
- 10 Participants were asked to indicate a suitable date, time, and location for the interview. Ten
- interviews were conducted in the primary investigator's workplace, two interviews (one
- individual interview and one focus group) were conducted in the participants' workplace, one
- focus group discussion was conducted in a surfing club and another in a youth organisation,
- and one participant was interviewed in a family community centre. Each of the focus groups
- comprised a mixed sample of men from different sociodemographic backgrounds (e.g. age,
- nationality, sexual orientation, marital status, level of education, and occupation). This was
- thought to facilitate open discussions and enrich the collected data.
- 18 All interviews were audio-recorded and transcribed verbatim. The interviewer and primary
- investigator (M.M.S.) had no previous relationship with the participants. He was male, a
- 20 doctoral-level graduate student in nursing, formally trained in qualitative research, and had
- 21 experience in interviewing men about sensitive health issues. This was thought to facilitate
- data collection get men to openly share their insights.
- The right for full disclosure was ensured by providing participants with an information leaflet
- 24 listing the aim of the study and what their participation entailed. Participants were also

- 1 provided with a referral form with the contact details of free counselling and support services
- 2 in case they experienced psychological distress. Informed consent was obtained and
- 3 participants were requested to fill a brief sociodemographic questionnaire that was designed
- 4 by the researchers to collect data on the participants' age, nationality, sexual orientation,
- 5 relationship status, highest level of education, employment status, and past history of a
- 6 testicular disease.
- 7 The opening question was: "What is the first thing that comes to your mind when I say
- 8 'testicular diseases or disorders'?" Open-ended probes were used to explore the participants'
- 9 responses in greater depth. Examples include: "How come (the answer) crossed your mind?
- 10 Can you please tell me more about it? Are you aware of any other testicular disorders? Can
- you please elaborate?" The second key question and associated probes were: "I would like
- you to think about two scenarios; let's suppose you, or someone you know started feeling
- pain in the testes, how would you/they react? Can you please elaborate?" and "let's suppose
- 14 you, or someone you know happens to discover a lump in the testes, how would you/they
- react? Can you please elaborate?" Reflective field notes were taken immediately following
- each interview to capture non-verbal cues (Grove et al., 2013).
- Data saturation was achieved at 24 participants; five additional individual interviews were
- conducted to confirm saturation (Elo et al., 2014). In total, 12 individual interviews and three
- 19 focus groups were conducted with 29 men. Two focus groups included six participants each
- 20 and one focus group comprised five participants. Participants in each focus group were
- sociodemographically diverse. Interviews lasted between 31 and 62 minutes.
- A brief summary of the transcripts was shared with five participants via e-mail. Participants
- 23 were asked to provide their feedback as to whether the summary was reflective of the key
- 24 issues discussed during the interview. The plan was to share the summary with more

- 1 participants if discrepancies arose; however, all five participants agreed to the summary. This
- 2 measure is commonly known as member check and is often regarded as a crucial technique to
- 3 establish credibility (Lincoln and Guba, 1985).

# Data analysis

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- 5 Data analysis took place concurrently with data collection. Identifiers were omitted to
- 6 maintain anonymity and confidentiality. Transcripts were analysed using inductive content
- 7 analysis (Elo and Kyngäs, 2008). Unlike deductive content analysis, inductive content
- 8 analysis is recommended when prior knowledge of a certain phenomenon is limited (Lauri
- 9 and Kyngäs, 2005). Moreover, this analytical framework was selected to explore manifest
- 10 content (e.g. participants' own words) and to a lesser extent, latent content (e.g. non-verbal
- 11 cues including laughter, crying, and silence).
- 12 A coding sheet was created following an iterative process of discussion among the primary
- investigator and supervisors (J.H. and M.L.). Transcripts were read carefully and a summary
- of excerpts (e.g. condensed meaning units) was generated and reduced into codes. Codes
- were then transferred to the coding sheet, and similar codes were gathered under sub-
- categories. A category scheme was then developed to group similar sub-categories together.
- 17 Finally, themes that connect the various categories were identified. Non-verbal cues that were
- 18 highlighted in the field notes were used to enrich the data collected. Audio-taped memos
- were used throughout data analysis to enable the primary investigator to clarify his thoughts
- and reflect on the analysis process (Birks et al., 2008; Grove et al., 2013).

# Enhancing trustworthiness

- 22 Credibility was enhanced by selecting a heterogeneous sample, performing member check,
- and using field notes and excerpts (Elo et al., 2014). Dependability was established by having
- 24 the primary investigator and two experienced researchers review the coding process and

- 1 agree on the analysis. Confirmability was addressed through constant dialogue among the
- 2 researchers (Graneheim and Lundman, 2004), and the use of audit trails (Saldaña, 2009).
- 3 Additionally, transferability was enhanced by thickly describing the data collection process
- 4 and sample characteristics, and seeking a heterogeneous sample (Graneheim and Lundman,
- 5 2004). Reflexivity was established by keeping audio-taped memos (Birks et al., 2008).
- 6 Finally, authenticity was ensured by using icebreakers to establish a trusting relationship with
- 7 the participants and get them to openly discuss their experiences (Holloway and Wheeler,
- 8 2010).

#### 9 **FINDINGS**

# Sample characteristics

- 11 The age of participants ranged between 18 and 47 years (mean=33.5, standard
- deviation=8.8). Seventeen men self-identified as heterosexual, 11 as gay, and one as bisexual.
- 13 The majority of participants were single (n=16), held a university degree (n=20), and were
- employed full-time (n=14) (Table 1). Twenty-one participants had no history of a testicular
- disorder. Of those who reported a personal history of a testicular disorder (n=8), three had a
- 16 history of epididymitis, two were diagnosed with varicocele, two developed testicular torsion,
- and one was a survivor of metastatic TC. It is worth noting that participants'
- 18 sociodemographic characteristics were found to be reflective of those of men living in Ireland
- in terms of employment status and level of education (Central Statistics Office, 2011).
- 20 Two key themes emerged from the interviews namely: Awareness of testicular disorders and
- 21 their screening, and help-seeking intentions for testicular symptoms. Associated categories
- 22 included: Impediments to and enablers for awareness, and barriers and facilitators to help-
- seeking. All the themes, categories, sub-categories, and abbreviated codes are highlighted in
- Table 2. Pseudonyms are used in referring to the participants.

# 1 Awareness of testicular disorders and their screening

- 2 A number of participants were aware of testicular disorders and others lacked awareness. A
- 3 thorough analysis of this dichotomy yielded a number of impediments to and enablers for
- 4 awareness.

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# Impediments to awareness

- 6 All the participants have heard of TC and many perceived it as the most 'advertised'
- 7 testicular disease. However, having heard of TC did not necessarily imply that men were
- 8 aware of its risk factors, treatment, and screening. Lack of awareness was attributed to a
- 9 multitude of factors including the prevailing beliefs and attitudes towards testicular disorders,
- 10 perceptions of the healthcare system, awareness not being promoted in the school system, and
- 11 lack of screening for testicular disorders.
- When asked about his knowledge of testicular disorders, Henry stated that he heard of TC.
- However, when probed to share his knowledge of this disease; he answered: "I didn't really
- 14 hear anything specific about it... But I know it exists and I wouldn't really know what the
- 15 treatments are." Similarly, Ziad who reported knowing about TC, was unsure whether he
- was at risk for developing this malignancy; he seemed worried and asked: "What are the
- 17 ages at risk?... If I don't have testicular cancer now, so it's harder for me to get it later?" In
- 18 contrast, very few participants heard of other testicular disorders. For example, when asked
- 19 about his awareness of diseases of testes, Juan said: "I have heard about testicular cancer, so
- 20 I think that's probably really the only one that I know, I cannot name any other disorder."
- 21 Trivialisation of testicular symptoms and uncertainty regarding testicular diseases were also
- 22 identified as barriers to awareness. As he was discussing how men take testicular symptoms
- 23 for granted, Patrick said:

- 1 "You get a kick in the balls. Oh, it's painful, it's quite painful, but then it goes away and a lot
- 2 of people think the issue is like that and they don't really think much further because they
- 3 don't like thinking about their balls. They're there, that's it, I'm done with them!"
- 4 In many cases, the lack of awareness was linked to a number of misbeliefs. For example,
- 5 Ziad had a number of misconceptions about TC. As he was recalling his sexual encounter
- 6 with two men who had TC; he laughed nervously and said: "... If it happened to those people
- 7 that I met, it's going to happen to me. Or oh, it can infect me."
- 8 A number of men believed that national health campaigns tend to focus on women's rather
- 9 than men's health. For instance, Denis said in a jokey tone: "I would nearly have more
- awareness of the risk of breast cancer than I would of testicular cancer, and like I won't be
- checking my breasts obviously!" In addition, many stated that cancer awareness campaigns
- have the tendency to highlight serious conditions more than TC. An example is Patrick who,
- while recalling an advertisement on lung cancer, said:
- "He (the patient in the advertisement) is like: 'Oh, I wish I had stopped smoking before it was
- 15 too late'. And then at the end of it, it says, 'Jerry died shortly after making this ad'. I mean
- 16 that's powerful stuff; it really hits home. The thing that testicular cancer doesn't have that
- punch is because it's not that fatal... It doesn't have that wow factor..."
- 18 Trivialisation of sexual health in schools and the unpreparedness of educators to deal with
- such topics were also identified as barriers to awareness. For instance, Ziad, a teacher in a
- 20 boys' school, believed that class conversations about sexual health are not facilitated by the
- 21 teachers and/or curricula; he said:
- 22 "When it comes to teaching about reproduction and the reproductive system, they (curricula)
- 23 talk a little bit about sexually-transmitted diseases... As if the students are not entitled to have
- 24 this kind of knowledge... Even teachers, they just skip those chapters... In SPHE (Social,

- 1 Personal and Health Education) there is a chapter about sexuality but still, it is done just to
- 2 tick a box."
- 3 Most participants reported not practicing testicular self-examination either because they did
- 4 not know how or because they were unfamiliar with their own testes. For instance, Juan
- 5 stated that he was unaware that the scrotal raphe was part of the normal anatomy of the
- 6 scrotum. Although it worried him for many years, he never discussed it with anyone; he said:
- 7 "In my testicles, there is a small line between the two testicles in the skin. For a very long
- 8 time, I thought that that was not normal... I was not able to ask anybody. When my son was
- 9 born and I was changing his diaper, I saw that he had the same skin there and I was like, Oh!
- 10 it's normal!"
- 11 Furthermore, not being exposed to clinical testicular examination was reported as an
- impediment to awareness. For example, Shane said: "I went to the GP (general practitioner)
- in the last 20 years once a year for a check-up and he's never checked me for that (testicular
- cancer). So like where's the education needed?" Similarly, Luke believed that the lack of
- endorsement of clinical testicular examination by his physician contributed to him not
- 16 knowing about testicular disorders; he said: "I am not an extremely ignorant person, I am 41
- 17 years of age and I don't know how to check myself, you know GPs probably don't do it as a
- 18 standard for physical check-up..."

# **Enablers to awareness**

- 20 A number of men reported being aware of testicular disorders, especially TC due to prior
- 21 exposure to pertinent information, positive attitudes, testicular self-examination, exposure to
- 22 clinical testicular examination, a personal or family history of a testicular disorder, cultural
- and lifestyle factors, and identifying as gay.

- 1 Most participants believed that TC is curable and has a low fatality rate. This was evident in a
- 2 focus group whereby Conor and Patrick were discussing the prognosis of TC among each
- 3 other and said: "If caught early it (TC) is very curable... It's got a 95% cure rate in this
- 4 country."
- 5 A number of men reported being inherently health-conscious which served as an enabler to
- 6 awareness. In addition, awareness was linked to increasing age and the cumulative impact of
- 7 poor diet and lifestyle over time. This was evident in the following excerpt by Jack:
- 8 "I'm in my mid-30s now and when you're in your mid-30s, this might sound a bit grim, you
- 9 start thinking... Time gets faster as you get older. It really, really does... When I was in my
- early 20s, I used to just eat junk food all the time or drinking all the time and I was like, 'I don't
- care'. But then you realise that that's going to affect you later on..."
- Prior exposure to information on testicular disorders also helped increase awareness of these
- diseases among a number of participants. Examples include, Adam who learned about
- 14 checking while watching a TV program, Liam who learned about testicular disorders during
- his work with urology patients, and William who learned about testicular self-examination in
- school. Interestingly, media exposure to information on TC was often linked to idols or
- celebrities. For instance, Denis, Mark, and Adam who were interested in cycling, heard about
- 18 TC from the news about Lance Armstrong, a celebrity cyclist who survived TC. Moreover,
- 19 Daniel's awareness of TC increased after his doctor checked his testes; he said:
- 20 "I remember recently I had to go to the doctor for something not related to testicular disorders
- 21 and then the doctor was asking me about how aware are you of testicular cancer and she
- 22 examined me around that area then for lumps, this never happened before, so maybe I have
- 23 more awareness now."

- 1 As for testicular self-examination, only a few participants endorsed this practice. An example
- 2 is Tom who reported practicing testicular self-examination occasionally in the toilet.
- 3 However, when asked whether he knew what he was looking for; he said: "No, I'm going by
- 4 look and touch."
- 5 Men with a personal or family history of a testicular disease and those who knew someone
- 6 who developed a testicular disorder, were clearly more aware. This was the case for William
- 7 and Richard who became aware of testicular torsion after developing it and Shane who
- 8 became aware of TC after his father was diagnosed with it; he said: "It wouldn't have been in
- 9 my thoughts at all until my dad was diagnosed." This was also the case for Henry who had a
- friend who developed TC; he said: "I wouldn't check as a routine thing and six months might
- even be a bit generous. Only I think purely because I know of somebody, a person who has
- had testicular cancer that I think about it more. That is the most powerful factor for me
- 13 *anyway*."
- A number of participants stated that, in comparison to older generations, the present
- generation is more health aware. This was evident in the following excerpt by Liam: "From
- my own generation, we're very open like to learn things like that (testicular disorders) about
- 17 *ourselves...*"
- 18 Interestingly, many participants stated that self-identifying as gay was an enabler to
- 19 awareness. For instance, Mark and Tom who self-identified as heterosexual, assumed that
- 20 gay men have higher health awareness, and are more comfortable with their own testes as
- 21 well as the testes of other men. For instance, Tom said: "A gay man has potentially the
- 22 benefit of a partner with the same, you know, biological structure." This was echoed in the
- 23 interview with Kevin who self-identified as gay; he said:

- 1 "I think when you're a gay man, you're probably a little bit more in tune... So like trimming
- 2 here around your testicles is probably a more common thing among the gay community... And
- 3 because of that, you inadvertently check your testes more regularly... You also are exposed to
- 4 other testes. And so I think when you are, you're probably more interested in being aware of
- 5 *them.*"

# 6 Help-seeking intentions for testicular symptoms

- 7 Men's help-seeking intentions for symptoms of testicular disease were explored using two
- 8 scenarios. First, participants were asked to describe how they would react in the event of
- 9 sudden testicular pain. They were then asked the same question in relation to finding a
- painless lump. Each participant had his own theory as to which of the symptoms was more
- severe and which required medical attention. While trying to make sense of the participants'
- decision making processes, a number of barriers and facilitators to help-seeking emerged.

# **Barriers to help-seeking intentions**

- 14 Several men intended to delay help-seeking because they did not know what to look for
- during testicular self-examination and doubted their ability to detect changes. This was
- apparent in the interview with Daniel who said that he rarely checks his testes since,
- according to him, checking felt "like trying to find a lump in a bag of lumps."
- 18 Symptom mildness, fluctuation, and the thought that the symptom was caused by 'something
- 19 else' also negatively influenced men's help-seeking intentions. For example, symptom
- 20 misappraisal stopped Ross, a surgeon and a survivor of advanced TC, from seeking help for
- 21 scrotal pain and swelling; he said: "The primary tumour, which started in my testicle, shrunk,
- but the disease went rampant inside...I was checking and saying, this has got smaller, it's
- 23 great there's nothing wrong." Other factors that stopped Ross from seeking help were fear
- and denial. Though he knew deep-down that something was wrong with him, he kept on

- thinking that his pain was going to go away. As he was telling his story, Ross got emotional
- 2 and said:
- 3 "I went along for several months with desperate pain and the fear of actually dying... It was
- 4 easier at times just to block it out and fear of actually being told there was something wrong
- 5 with you, when instinctively deep down within yourself, you knew there was something going
- 6 wrong... I just kept thinking things would go away, but they didn't."
- 7 Beside fear, a number of participants identified embarrassment and dysfunctional coping as
- 8 emotional factors that would impede help-seeking. An example is Rafael who said: "If we
- 9 were to go to our GP we're going to just strip naked and let an old guy see your junk."
- 10 Richard who developed severe pain in his testes secondary to torsion, delayed help-seeking
- due to embarrassment; he hesitated and said: "I didn't want to speak out about it because I
- 12 *felt embarrassed obviously.*"
- Dysfunctional coping (e.g. denial and avoidance) also pushed a number of men to intend to
- delay help-seeking. An example is Shane who said: "If there was a lump or a swelling there,
- 15 *I'd think, 'Oh, something else'. I got a bite off something."* In addition, Tom intended to use
- the 'wait and see approach' until the lump/swelling becomes "a bit more painful."
- Social factors that were thought to lead to help-seeking delay were worry about one's family,
- false reassurance by others, and being busy with life. As aforementioned, Tom intended to
- delay help-seeking until his pain becomes unbearable. When probed about the reason, he
- said: "I don't drive, so I'd have to get a lift. That's one part of it." Rami, on the other hand,
- 21 was falsely reassured by his friend who was a medical student that the yellow discoloration in
- 22 his semen was "something that is negligible" when in fact it was a sign of a severe sexually
- transmitted epididymitis that caused excruciating pain later on and pushed Rami to seek

- 1 emergency care. Ron, on the other hand, had no intention to seek help and visiting a doctor
- 2 was not on his list of priorities; he said:
- 3 "Honestly, that kind of a thing goes way down my to-do list. Like I'm busy, I'm hardly going to
- 4 clear off my agenda so that I can go... I've got other things to worry about... And I don't
- 5 prioritise it... There are more important things."
- 6 A number of participants stated that the social norms that often define a man (e.g. machoism,
- 7 stoicism, and unrealistic optimism), stand in the face of help-seeking. In addition, the Irish
- 8 sheltered upbringing was perceived by many to negatively affect men's intention to seek
- 9 help. For instance, while discussing his brothers' and father's reluctance to visit a doctor,
- 10 Kevin said: "I think there must be a case of a slight gender machoism... They're all bionic in
- their own heads." This was echoed in Patrick's response; he said:
- "A lot of Irishmen have a great reluctance to go to the doctor for any reason. Ah, it'll be fine,
- it'll go away, the swelling will be down in a day or so, a week later and it's half the size of your
- 14 body, I may consider going next week."
- 15 Interestingly, these findings were not exclusive to Irish participants, as similar cultural
- barriers were reiterated by Lebanese participants including Rami and Ziad as well as Juan
- who grew up in Mexico.
- 18 The fear from being labelled as hypochondriacs also pushed a number of men to intend to
- delay help-seeking. This is reflected in the following excerpt by Patrick: "We don't visit the
- 20 doctor as regularly because we're like oh, we don't want to be seen as hypochondriacs."
- 21 Also, unrealistic optimism was identified by many as an impediment to help-seeking. For
- instance, Kevin said: "Maybe it's the idea of unrealistic optimism, where we all believe that
- 23 we won't be the person it'll happen to, so why concern yourself with that?" Others thought

- 1 that they were too young to develop a disease in their testes. An example is Omar who was
- 2 19 years old; he said: "Do young people like us get it (testicular disease)? I don't think so!"
- Finally, the existing healthcare system was identified by at least 10 participants as a major
- barrier to help seeking, especially that a visit to a GP in Ireland costs at least 50 euros. Others
- 5 stated that the waiting time and long queues in the GP's clinic and the emergency department
- 6 would make them think twice before seeking help. This was the case for Tom who said: "We
- 7 have the second-worst waiting lines in Europe." The gender of the physician also seemed to
- 8 influence men's intentions to seek help. For instance, Rafael said: "I'd feel better if it was a
- 9 female doctor. I wouldn't like a man touching me", whereas Henry reported that he would
- 10 feel more comfortable with a male doctor since "he has some (testes) also."

# 11 Facilitators to help-seeking intentions

- Many participants identified a number of key factors that would positively affect their
- decision to seek help; these include access to support, severity and duration of pain, detection
- of a lump, inherent health-seeking drive, perceived threats, and cultural factors. Presence of
- pain and lump
- The mothers of Scott, Antonio, John, and Tom were nurses. These men stated that having a
- healthcare provider in the family provided them with a point of contact at home who,
- according to Scott, "would never leave things off." In addition, Kevin's partner was
- identified as the first person he would talk to if he felt a lump in his testes; he said: "I'd ask
- 20 my partner (male) to check it because I would just need that affirmation to be like, 'No, you're
- 21 definitely right'."
- The severity and duration of pain and changes in symptoms were identified by those with a
- 23 history of a testicular disorder as facilitators to help-seeking. For instance, it was the intensity
- 24 and abruptness of pain that urged William to seek emergency care for symptoms of testicular

- torsion. When asked about the time difference between the onset of pain and the time he got
- 2 to the hospital, he said:
- 3 "Immediately when I found it... Luckily so because they said it would be four or six hours
- 4 and it (the testicle) could have been dead... When I touched it, it was the size of a tennis ball.
- 5 Close to that. It was just so abnormally large and it was so taut!"
- 6 Participants who reported being inherently health-conscious stated that it was 'alright' to seek
- 7 help and said that they would not wait for symptoms to get worse. An example is Adam who
- 8 said: "If there was something amiss with me and there was pain, I would be investigating."
- 9 Many participants identified a number of threats that would push them to seek medical
- attention for testicular symptoms. For instance, a perceived threat to fertility, pushed Liam to
- seek timely medical attention and agree to undergo a surgery for his varicocele; he said:
- "What scared me with the whole varicocele thing was the thought of not being able to have
- 13 kids when I get older... That was the first thing the doctor said to me, so as a young man, I
- was thinking family straight away, that I had to get this (surgery) done for the future..."
- 15 The openness of the present generation did not only serve as an enabler to awareness, but was
- also perceived by many as a facilitator to help-seeking. While discussing men's perceptions
- 17 regarding help-seeking, Liam said that men now are more inclined to seek help. When asked
- about the reason, he said: "We're definitely more in touch with our feelings."

# **DISCUSSION**

- In this study, men's awareness of testicular disorders and their help-seeking intentions for
- 21 testicular symptoms were explored. Overall, participants heard of TC but were unaware of
- 22 the different aspects of this malignancy. Similarly, having heard of TC screening did not
- 23 necessarily imply that men knew how to perform testicular self-examination. These findings

- 1 concur with those by Muliira et al. (2013), who found that men who reported hearing of TC
- were ill-informed about its risk factors and treatment, and the studies by Sirin et al. (2006)
- and Kennett et al. (2014) whereby very few men knew how to perform self-examination.
- 4 As for non-malignant testicular disorders, only participants who were diagnosed with
- 5 varicocele, testicular torsion, and epididymitis were aware of these diseases and only one
- 6 participant heard of the 'bag of worms' but failed to link it to a specific disease, varicocele in
- 7 this case. Varicocele is typically described as feeling like a 'bag of worms' due to the
- 8 "dilation of the venous pampiniform plexus of the spermatic cord" (Crawford and Crop,
- 9 2014, p.725). Similar findings were reported in the literature on benign testicular diseases
- whereby awareness of testicular torsion was as low as 8% in one study (El Anzaoui, 2015)
- and did not exceed 18% in another (Clark et al., 2011).
- 12 In contrast, men with a personal or family history of a testicular disorder, those with an
- inherent health-seeking drive, and those who have access to support seemed more informed
- about testicular disorders and had better intentions to seek help for testicular symptoms.
- 15 These findings are supported by evidence from a systematic review on the barriers and
- facilitators for TC and self-examination (Saab et al., 2016c), and a review on men's help-
- seeking behaviours (Fish et al., 2015). Furthermore, exposure to information on testicular
- disorders and self-examination served as a major facilitator to awareness and led to better
- help-seeking intentions. This was echoed in the study by Casey et al. (2010), whereby
- 20 participants who practiced testicular self-examination had higher knowledge scores than
- 21 those who did not. Additionally, having prior information about TC and testicular self-
- examination served as a facilitator to awareness in the studies by Kuzgunbay et al. (2013) and
- 23 Rovito et al. (2011).

- 1 In the present study, many participants linked testicular disorders, specifically TC, to a
- 2 number of celebrities. These findings are consistent with those of Trumbo (2004) and Daley
- 3 (2007) whereby a number of men heard about TC through TV shows about celebrities who
- 4 survived it.
- 5 A number of participants believed that gay men are more in touch with their body and are
- 6 more at ease when it comes to dealing with their testes. In addition, exposure to other men's
- 7 genitalia was perceived to have a positive impact on awareness. Little empirical evidence
- 8 exists to support these findings. However, in a study on awareness of TC and self-
- 9 examination screening, men who reported performing regular testicular self-examination
- were more likely to be gay or bisexual (Reece et al., 2010).
- Generally, participants who were unaware of testicular disorders, failed to appraise the
- seriousness of testicular pain, lumpiness, and swelling and linked them to sports injuries or
- trauma rather than to a serious disease. As a result, they chose to adopt the wait and see
- approach. Similar findings were reported in the studies by Nasrallah et al. (2000), Congeni et
- al. (2005), and Clark et al. (2011) whereby symptom misappraisal and lack of symptom
- awareness have led to suboptimal help-seeking intentions.
- Other than symptom misappraisal, a number of emotional factors had a negative impact on
- men's intention to seek help. This is not unusual in the literature on help-seeking behaviours
- 19 for cancer symptoms and has been documented among patients experiencing symptoms of
- breast (O'Mahony et al., 2011), colorectal, (Mitchell et al., 2008), and urogenital cancers
- 21 (Macleod et al., 2009). Similarly, embarrassment identified by a number of participants as an
- 22 excuse not to visit a doctor, was highlighted in previous studies as a key factor leading to
- 23 help-seeking delay among males (Fish et al., 2015; Yousaf et al., 2015). Also, findings in
- 24 relation to the prevailing beliefs and attitudes towards testicular disorders and the meaning

- 1 men attach to their testes are echoed in a number of studies; these include machismo
- 2 (Buckley and Ó Tuama, 2010), stoicism (Emery et al., 2013), the perception of health as a
- 3 female rather than a male issue (Hajdarevic et al., 2011), and the engrained social and gender
- 4 roles (Leone and Rovito, 2013).
- 5 Interestingly, the gender of the examining physician also influenced men's help-seeking
- 6 intentions as some felt comfortable being examined by a female doctor and others could
- 7 identify more with a male doctor. It is suggested, however, that female clinicians are more
- 8 inclined to discuss general health prevention than male physicians especially when it comes
- 9 to sensitive issues (Ramirez et al., 2009).
- 10 False reassurance by trusted healthcare acquaintances also served as a barrier to help-seeking
- among a number of participants. Similarly, false reassurance by others was identified by
- Mason and Strauss (2004), Macleod et al. (2009), and Taghipour et al. (2011) as a major
- barrier to help-seeking for symptoms of testicular and prostate diseases.
- On many occasions, the healthcare system in Ireland was held responsible for the lack of
- awareness of testicular diseases since, according to many participants, it tends to focus on
- women's health rather than men's health. In fact, the National Cancer Screening Service
- 17 (2009, 2016) was successful in implementing two national gynaecological cancer screening
- programs over the past two decades. This, however, was unmatched by any increase in the
- 19 preventive or screening services offered to males. Moreover, despite being among the few
- 20 countries to address men's health through national, male-centred strategies (Department of
- Health and Children 2008), little is known on whether such strategies are being implemented
- in mainstream practices (Baker et al., 2014). In addition, findings in relation to the cost of a
- 23 GP visit and the long waiting time in the emergency room were echoed in previous Irish
- studies (Buckley and Ó Tuama, 2010; Scanlon et al., 2006).

# 1 IMPLICATIONS FOR POLICY, RESEARCH, AND PRACTICE

- 2 The European Commission (2011) published a report highlighting gender-based health
- 3 disparities and proposing action plans to promote men's health in a number of European
- 4 countries. Nevertheless, much needs to be done to promote men's health in policy, research,
- 5 education, and clinical practice.
- 6 National and international governments are encouraged to shed light on men's and women's
- 7 health equally while instigating health promotion and cancer prevention campaigns. In
- 8 addition, reinforcing pre-existing men's health strategies and drafting new ones might be
- 9 instrumental in raising awareness of male-specific disorders (Baker et al., 2014).
- 10 Theory-based, interpretative studies can be effective in offering an in-depth understanding of
- men's experiences, and highlighting the meaning they attach to such experiences. In addition,
- researchers interested in raising awareness of testicular disorders and enhancing helping-
- seeking intentions are encouraged to explore, in-depth, men's information needs and
- preferred modes of learning a priori. Researchers are also encouraged to learn from previous
- interventions that had a positive impact on men's awareness of TC and testicular self-
- examination and to tailor educational interventions that appeal to the present generation.
- 17 Examples include mass, social, and interactive media.
- 18 From an educational perspective, school educators are advised to start normalising topics that
- are of a sensitive nature at a young age. Doing so may help men feel more comfortable
- 20 talking about their testes when they get older. Also, it is important to educate partners about
- 21 testicular symptoms and diseases as they may be the ones who detect abnormalities during
- 22 sexual activity.
- 23 Clinicians, including nurses, are also encouraged to educate at-risk males about the
- seriousness of testicular symptoms such as abrupt pain and newly occurring lumps, and to

- 1 highlight the importance of early help-seeking. Clinicians are also encouraged to examine the
- 2 testes during the well male physical examination.

# LIMITATIONS

- 4 Although rigour was attempted while conducting this study, a number of limitations are
- 5 worthy of note. Qualitative description is often criticized for lacking rigour (Neergaard et al.,
- 6 2009). For this reason, a number of strategies were employed to enhance trustworthiness.
- 7 Given the study design and aim, generalisability was not sought; instead transferability was
- 8 attempted by seeking data saturation and recruiting a heterogeneous sample in terms of age,
- 9 socioeconomic status, ethnicity, and sexual orientation. However, only participants who
- voluntarily consented to partake in the study were interviewed, which increases the risk for
- self-selection bias (Robinson, 2014). Moreover, sampling from a heterogeneous pool of
- participants increases the risk for selection bias and makes the comparison of findings
- difficult. This was accounted for by seeking and achieving data saturation.
- 14 Accidental alteration of the data was accounted for by performing member checks and having
- two experienced researchers verify the analysed data. Due to the sensitive nature of this
- study, participants could have concealed certain aspects of their experiences, since an open
- discussion of sensitive topics is uncommon among males (Scanlon et al., 2006). However,
- those who were hesitant in the beginning the interviews, seemed to be more at ease as the
- interviews went on and openly discussed their experiences upon probing. Finally, having
- 20 participants with a history of a testicular disorder share their experiences, and including men
- of different age groups in the same focus group could have biased the responses from the
- other men in attendance. However, this could also be a strength by providing space for
- educating others.

# CONCLUSION

This study explored men's awareness of testicular disorders and their help-seeking intentions for testicular symptoms in the Irish context. It is worth noting that this study serves as the only initiative that addressed testicular disorders inclusive of non-malignant conditions and, to our knowledge, is the only qualitative study that purposely included men who are at risk for health inequities. Given the varied sociocultural backgrounds of the participants in this study, findings can be transferrable to other contexts. Examples include the impact of the healthcare and educational systems, and cultural beliefs on men's awareness and help-seeking intentions. In addition, findings from this study echo what had been previously discussed in the international literature such as the effect of fear, maladaptive coping, embarrassment, and social normative factors on symptom appraisal and help-seeking. 

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<b>Table 1.</b> Socio-demographic data (n=29)					
Age (years)	Range	18-47			
	Mean(standard deviation)	33.5(8.8)2			
Nationality	Irish	20	2		
	Dual citizenship	3	3		
	British	1	4		
	Danish	1			
	Dutch	1	5		
	Italian	1			
	Lebanese	1	6		
	Mexican	1	7		
Sexual orientation	Heterosexual	17			
	Gay	11	8		
	Bisexual	1	9		
Marital status	Single	16	9		
	In a relationship/partnered	6	10		
	Married	5			
	Divorced	1	11		
	Separated	1	12		
Highest level of education	Primary	1	12		
	Secondary	2	13		
	High school	6			
	University	20	14		
Occupation	Employed (full-time)	14	15		
	Employed (part-time)	2	13		
	Self-employed	1	16		
	Student and employed (part-time)	2	47		
	Student	6	17		
	Intern	1	18		
	Unemployed	3	10		

**Table 2.** Emerging themes, categories, sub-categories, and abbreviated codes

Theme	Category	Sub-category	Abbreviated code
		Lack of knowledge	Risk factors
	Impediments to awareness		Treatment
			Benign testicular disorders
	re	Beliefs and attitudes	Trivialisation
	wa]		Misconceptions
ing	<b>a</b>		Uncertainty
<b>en</b>	ts t	Perceptions of the healthcare system	Focus on female cancers
cre	en(		Focus on more serious conditions
S	<b>.</b>	Awareness not promoted in school system	Trivialisation of sexual health/testicular disorders
ıei	peq		Unpreparedness of educators
Ē	ď	Lack of screening for testicular disorders	Lack of knowledge on how to self-examine
pu	Ħ		Lack of clinical testicular examination
Š G			Lack of familiarity with own testes
der		Prior knowledge	Risk factors
ord			Perception of prognosis
Dis	ess		Treatment
r D		Beliefs and attitudes	Personal interest in health
alla			Confidence to learn about testicular disorders
stic		Exposure to pertinent information	School School
Te S	ren		College
Awareness of Testicular Disorders and Their Screening	Enablers for awareness		Workplace
			Media
anc.	<b>fo</b>	Testicular self-examination practices	Regular/irregular conscious checking of the testes
are	ILS	Clinical testicular examination	Part of doctor check-ups
A	ple	History of testicular disorders	Personal/family history
4	Ena	·	Knowing someone with a testicular disorder
		Changes over time	Irish men, then and now
		Identifying as gay	Ease in talking about testes
		, , ,	More in tune with own body

	Lack of knowledge	Don't know what to look for
		Don't know how to look for it
		Not sure if there is something new or not
Ø	Symptom misappraisal	Symptom not severe
O		Symptom fluctuates
'nť		Symptom caused by something else
nte	Emotional factors	Fear from diagnosis/dying
<b>ĕ</b>		Embarrassment due to the private nature of complaint
Barriers to help-seeking intentions		Coping (denial and avoidance)
see	Health beliefs and attitudes	Perceived hypochondria
g-d		Unrealistic optimism
hel		Beliefs about being male and young
10	Social factors	Concern about impact on family and friends
SIS		False reassurance by healthcare professionals
Ţ		Busy with life, no time
3aı	Cultural influences	Older generation more reluctant to seek medical help
		Sheltered upbringing
	Process of seeking help	Expensive
		Waiting time and queues
		Gender of clinician
	Access to support	Mother/father is a healthcare provider
1		Talking to partner
elp		Working in a healthcare setting
o <b>h</b>	Presence of pain and lump	Severity
Š		Duration
tor	H bn	Changes
ita	Inherent health-seeking drive	Wouldn't wait
Facilitators to help-	Presence of pain and lump  Inherent health-seeking drive  Perceived threats	It is ok to seek help
<u> </u>	Perceived threats	Personal/family history of a testicular disorder
		Knowing/hearing about someone with a testicular disorder

		Threat to fertility	
	Cultural factors	Men in Ireland then and now	
1			