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## Ollscoil na hÉireann, Corcaigh

#### **National University of Ireland, Cork**



# ENHANCING MEN'S AWARENESS OF TESTICULAR DISORDERS USING A VIRTUAL REALITY INTERVENTION: THE E-MAT STUDY

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(Nursing Research)

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January 2018

	uture, for tomorrow	belongs to those w	ho prepare
"Education is the for it today." – M	uture, for tomorrow	belongs to those w	ho prepare
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#### **Glossary**

**AIDS** Acquired Immunodeficiency Syndrome

**ANOVA** Analysis of Variance

**BTDs** Benign Testicular Disorders

**CASP** Critical Appraisal Skills Programme

**CBC** Complete Blood Count

**CDC** Centers for Disease Control and Prevention

**CI** Confidence Interval

**CONSORT** Consolidated Standards of Reporting Trials

CT Computed Tomography
CVI Content Validity Index

**E-MAT** Enhancing Men's Awareness of Testicular Disorders

**EPHPP** Effective Public Health Practice Project

**GAA** Gaelic Athletic Association

**GP** General practitioner

**GRADE** Grading of Recommendation, Assessment, Development, and Evaluation

**HIV** Human Immunodeficiency Virus

**HPV** Human Papilloma Virus

**HR** Hazard Ratio

**I-CVI** Item Content Validity Index

**IOR** Interquartile Range

**LGBT** Lesbian, Gay, Bisexual, and Transsexual

MeSHMedical Subject HeadingMRCMedical Research CouncilMRIMagnetic Resonance ImagingNCINational Cancer Institute

**OR** Odds Ratio

**PRISMA** Preferred Reporting Items for Systematic Reviews and Meta-Analyses

**QAT** Quality Assessment Tool

OO Ouantile-Ouantile

**RCT** Randomised Controlled Trial

**RR** Relative Risk

**S-CVI** Scale Content Validity Index

**SD** Standard Deviation

**SPHE** Social, Personal, and Health Education

**SROR** Standards for Reporting Qualitative Research

STDs Sexually Transmitted Diseases STIs Sexually Transmitted Infections

SUS System Usability Scale TC Testicular Cancer

**TNM** Tumour, Lymph Nodes, and Metastasis

TSE Testicular Self-Examination
UCC University College Cork
UE4 Unreal Engine 4.12

**USPSTF** United States Preventive Services Task Force

VO Voiceover VR Virtual Reality

# **Declaration**

Word count

This is to declare that the con	tent of this thesis is my own	work and has not been
submitted for another degree,	either at University College Co	ork or elsewhere, where
the work of others has been u	used to augment an argument	it has been referenced
accordingly. I have read and u	inderstood the regulations of U	University College Cork
concerning plagiarism.		
Name	Signature	Date

#### **Dedication**

Mother and father, your positive thoughts and constant support conquered the physical distance that separates us. You have taught me perseverance and have shown me what unconditional love is. Mama and baba, I am forever indebted to you and I cannot think of any person who is worthy of this dedication more than you.

#### Acknowledgments

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I would like to sincerely thank Mr. Eoghan Cooke, the interactive media expert who helped me design and test the intervention. Eoghan, I cannot repay you for your patience and unceasing support. I would also like to thank Mr. David Murphy for supervising the design of the intervention and facilitating data collection as well as Dr Martin Davoren for helping with the recruitment of study participants.

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Last but not least, a big thank you to my parents Mama Nabila and Baba Mounib, my aunt Khalto Nour who inspired me to become a nurse, my sisters Abir, Rola, and Mayssam, and my friends Leila, Loubna, Cady, and Sari. Another big thank you goes to my close friend Seán who stood by my side throughout the PhD journey, and my fabulous choir, Choral Con Fusion which helped me sing the stress away!

#### **Abstract**

**Introduction:** Testicular cancer is the most common solid tumour among men aged less than 50 years. The incidence of this malignancy is on the rise in Western countries. Benign testicular disorders such as testicular torsion and epididymitis can be life-threatening if left untreated. Men's knowledge of testicular disorders is deficient and their intentions to seek help for testicular symptoms are low.

**Aim:** To design an intervention aimed at enhancing men's testicular awareness and promoting early help-seeking for testicular symptoms in the Irish context.

Methods: The Medical Research Council framework guided the development and testing of the E-MAT intervention. The evidence-base was identified by conducting one systematic review of studies exploring testicular cancer awareness and screening; one systematic review of studies promoting testicular cancer awareness and screening; and one integrative review of studies exploring awareness of benign testicular disorders. A qualitative descriptive study was conducted to explore men's (n=29) awareness of testicular disorders; help-seeking intentions for testicular symptoms; and preferred strategies for learning about testicular symptoms and disorders. The Pre-Conscious Awareness to Action framework was developed to underpin the E-MAT intervention. The feasibility and usability of the E-MAT intervention were tested with 15 men and its effectiveness was tested by conducting a one-group pre-post pilot study. Data for the pilot study were collected from 49 men at three time points. The following outcomes were measured: knowledge; testicular awareness; perceived risk; implementation intentions; help-seeking intentions; and behaviours.

**Results:** Men in the reviewed literature and qualitative study lacked awareness of testicular disorders in general and benign testicular disorders in particular, very few endorsed testicular self-examination, and many had misconceptions regarding testicular disorders. Men's intentions to seek help for testicular symptoms were low due to a number of factors including fear, embarrassment, and masculine social constructs. Men recommended using humorous, brief, interactive, and visually stimulating strategies to raise testicular awareness. The Pre-Conscious Awareness to Action framework was comprised of seven stages (i.e. pre-conscious awareness, unconscious awareness, conscious awareness [testicular awareness], unconscious appraisal, conscious appraisal, intentions, and behaviours) and was used to underpin the E-MAT intervention. E-MAT was developed as an educational experience and virtual reality game with three levels aimed at familiarising men with the normal testes and common testicular symptoms and diseases using visual, aural (i.e. voiceover), and haptic (i.e. vibrational) feedbacks. The intervention was perceived as feasible, enjoyable, and user-friendly. The pilot study was successful in enhancing men's knowledge, testicular awareness, help-seeking intentions, and intentions and behaviours pertaining to feeling their testes and advising other men to do the same.

Conclusion: Based on the study findings, full-scale testing of the E-MAT intervention is warranted. This could be achieved through conducting a randomised controlled trial with a large sample size across different settings and a longitudinal study that captures the long-term effect of the intervention. E-MAT can be made publicly available using various platforms or as part of men's health promotion campaigns. Virtual reality and the developed theoretical framework can be used to promote awareness of different health topics including sexually transmitted infections and healthy lifestyle changes.

#### Introduction

Globally, health outcomes for men continue to be markedly poor and their life expectancy remains four years lower than that of women (Robertson & Baker 2017). Moreover, efforts promoting men's health remain scarce and health organisations and national governments tend to assume that gendered approaches to health promotion should be primarily focused on women's health, rather than on both genders equally (Hawkes & Buse 2013, Baker *et al.* 2014, Rovito *et al.* 2017). This might lead to gender-based health disparity and poorer health outcomes among men, and would discourage them from engaging with health services (Leone & Rovito 2013, Whitaker *et al.* 2015). For instance, men are more likely to die by suicide and less likely to seek help for symptoms of depression in comparison to women (Peate 2010, Patrick & Robertson 2016, Robertson *et al.* 2016b).

In order to address the health disparity between the two genders, Baker *et al.* (2014) urged national governments and global health organisations to move men's health higher up on their agenda. Similarly, Rovito *et al.* (2017) called for a gender-inclusive global health strategy. To the researcher's knowledge, only three countries – Ireland, Australia, and Brazil – possess national male-centred strategies (Baker *et al.* 2014). Of the diseases that are seldom discussed in such strategies, disorders of the testes can have a major impact on a man's life.

The location, anatomy, and physiology of the testes predispose men to a number of benign and malignant conditions (Wampler & Llanes 2010). Testicular cancer (TC) is the most commonly diagnosed solid tumour among young men in the USA, with a mean age of 33 years at diagnosis (National Cancer Institute [NCI] 2017b). Similarly, 91% of TC cases in Ireland are diagnosed before the age of 50 years

(National Cancer Registry Ireland 2017). The incidence of this malignancy has doubled globally over the past four decades and is highest in Western countries (Manecksha & Fitzpatrick 2009, Shanmugalingam *et al.* 2013). Nevertheless, TC is one of the most curable solid tumours, with a five-year relative survival rate of 95.8% (National Cancer Registry Ireland 2017). Orchiectomy remains the treatment of choice for TC and is often followed by chemotherapy and/or radiotherapy (Saab *et al.* 2016b). Evidence suggests that TC survivors often face long-term complications secondary to the disease itself and/or its treatment; these include chronic fatigue, neuropathy, and infertility (Huddart *et al.* 2005, Rossen *et al.* 2009, Saab *et al.* 2014).

Testicular pain, lumpiness, and swelling are not symptoms of TC exclusively. In fact, the likelihood of these symptoms occurring secondary to a benign disease rather than TC is quite significant. Each year, 1 in 4,000 males aged less than 25 years are diagnosed with testicular torsion in the USA (Ringdahl & Teague 2006, Bayne et al. 2017). Moreover, epididymitis and 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 disorder in the USA (Trojian et al. 2009, Centers for Disease Control and Prevention [CDC] 2015a). Testicular torsion is known to cause excruciating pain and swelling and epididymitis and orchitis often lead to discomfort, swelling, and lumpiness (Ringdahl & Teague 2006, Trojian et al. 2009, Bayne et al. 2017). Moreover, varicocele, hydrocele, and spermatocele can be painful (Trojian et al. 2009). A number of these conditions can be life-threatening and necessitate prompt treatment. An example is testicular torsion that can lead to necrosis if help-seeking is delayed by six hours or more from the onset of pain (Ringdahl & Teague 2006, Bayne et al. 2017). Moreover, epididymitis and orchitis can lead to sepsis and infertility if left untreated (CDC 2015a).

Evidence suggests that men are often reluctant to seek help for testicular symptoms for a number of reasons, including lack of symptom awareness, symptom misappraisal, fear, and embarrassment (Fish *et al.* 2015, Saab *et al.* 2017a). In a systematic review of 25 studies on men's awareness of TC and testicular self-examination (TSE), Saab *et al.* (2016c) found that men were unaware of TC risk factors, signs and symptoms, and screening; very few practiced TSE; and those who performed TSE were not sure what they were looking for. In addition, men's intention to seek medical help for a testicular lump was suboptimal and their perceived risk for TC was low (Roy & Casson 2017).

Saab *et al.* (2016b) conducted a systematic review to synthesise evidence from 11 studies promoting TC awareness and TSE practices. Men's awareness of TC and TSE was found to be lacking at baseline. Nevertheless, a number of interventions succeeded in improving men's knowledge of TC and in promoting TSE in the short-term. Examples include: videos about TC and self-examination (Folkins *et al.* 2005, Sacks *et al.* 2013), a university campaign (Wanzer *et al.* 2014), and mass media (Trumbo 2004).

Saab *et al.* (2016a) conducted an integrative review of studies that explored men's awareness of benign testicular disorders (BTDs). Only four studies were included in the review. Men's knowledge of testicular torsion and hydrocele was deficient, and their intention to seek medical help for testicular swelling and/or pain was suboptimal (Nasrallah *et al.* 2000, Babu *et al.* 2004, Congeni *et al.* 2005, Clark *et al.* 2011).

Cancer prevention and health disparity reduction are two key priorities of the latest National Cancer Strategy in Ireland (Department of Health 2017). The National

Cancer Strategy also emphasised the role of cancer prevention and awareness as costeffective and long-term approaches for cancer control. In fact, early detection of TC
is associated with a reduced cost of treatment (Aberger *et al.* 2014), and public health
initiatives promoting testicular self-examination (TSE) are believed to be linked to a
reduced tumour size at presentation (McGuinness *et al.* 2017). Therefore, raising
men's awareness of testicular disorders is pivotal.

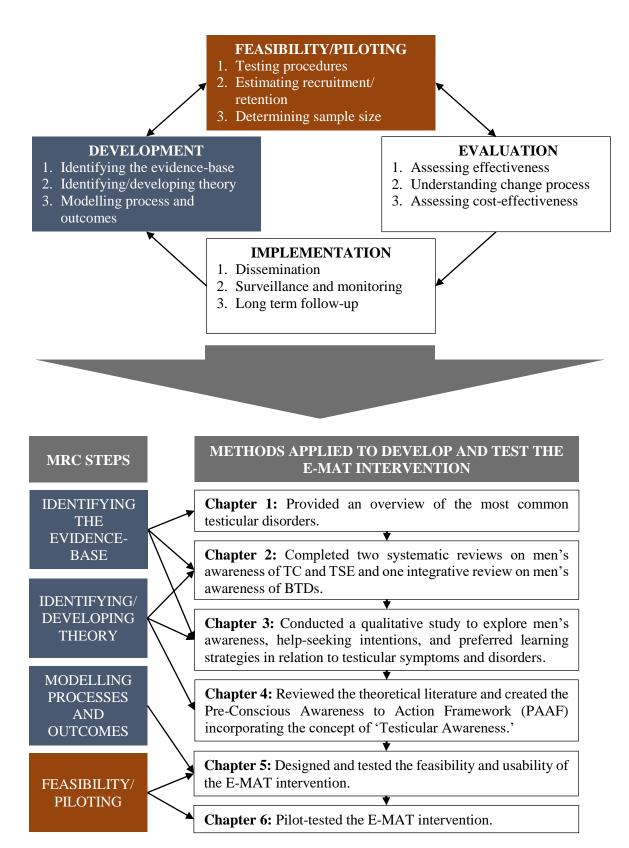
#### **Aims**

The overall aim of this thesis was to design an intervention aimed at enhancing testicular awareness and promoting early help-seeking for testicular symptoms in the Irish context. The intervention was designed using the Medical Research Council (MRC) framework which was developed in the UK in the year 2000 and updated in 2006 (Craig *et al.* 2013). This framework offers step-by-step guidance regarding the development, pilot and/or feasibility testing, evaluation, reporting, and implementation of complex interventions aimed at improving health.

In the development step, the evidence-base pertaining to the topic of interest is reviewed, preferably by conducting a systematic review. This is followed by identifying/developing an underpinning theory (Craig *et al.* 2013). This step is key as interventions underpinned by theory are more likely to produce an effect (Savage *et al.* 2010). Findings from the reviewed literature and identified/developed theory are then used to design and test the intervention (Craig *et al.* 2013).

The development step is followed by feasibility and/or pilot testing. This step is essential to determine whether the intervention can work, does work, and will work prior to conducting full-scale testing (Craig *et al.* 2013, Orsmond & Cohn 2015). The

work undertaken in this thesis mapped onto the MRC framework is presented in Figure 1.1.



**Figure 1.1** The work undertaken in the thesis chapters mapped onto the Medical Research Council (MRC) framework (Craig *et al.* 2013)

This PhD thesis is presented as a series of publications. With the exception of the introduction (Chapter 1) and discussion (Chapter 7), the thesis chapters were either published, accepted for publication, or in preparation for submission in peer-reviewed journals. The thesis layout and objectives are as follows:

**Chapter 1:** Introducing common testicular disorders, namely TC, testicular torsion, epididymitis and orchitis, cryptorchidism, varicocele, hydrocele, and spermatocele.

**Chapter 2:** Reviewing the empirical literature aimed at exploring and promoting men's awareness of TC, TSE, and BTDs. 1,2,3

**Chapter 3:** Exploring men's awareness of testicular disorders, help-seeking intentions for testicular symptoms, and preferred strategies for learning about testicular symptoms and disorders in the Irish context.<sup>4,5</sup>

**Chapter 4:** Presenting a theory-focused analysis of the Pre-Conscious Awareness to Action Framework (PAAF) developed to enhance men's testicular awareness and help-seeking intentions and behaviours.<sup>6</sup>

<sup>&</sup>lt;sup>1</sup> Saab M. M., Landers M. & Hegarty J. (2016a) Males' awareness of benign testicular disorders: an integrative review. *American Journal of Men's Health*, 1-11. doi:0.1177/1557988315626508

<sup>&</sup>lt;sup>2</sup> Saab M. M., Landers M. & Hegarty J. (2016b) Promoting testicular cancer awareness and screening: a systematic review of interventions. *Cancer Nursing* **39**(6), 473-487.

<sup>&</sup>lt;sup>3</sup> Saab M. M., Landers M. & Hegarty J. (2016c) Testicular cancer awareness and screening practices: a systematic review. *Oncology Nursing Forum* **43**(1), E8-E23.

<sup>&</sup>lt;sup>4</sup> Saab M. M., Landers M. & Hegarty J. (2017a) Exploring awareness and help-seeking intentions for testicular symptoms among heterosexual, gay, and bisexual men in Ireland: a qualitative descriptive study. *International Journal of Nursing Studies* **67**, 41-50.

<sup>&</sup>lt;sup>5</sup> Saab M. M., Landers M. & Hegarty J. (2017b) Exploring men's preferred strategies for learning about testicular disorders inclusive of testicular cancer: a qualitative descriptive study. *European Journal of Oncology Nursing* **26**, 27-35.

<sup>&</sup>lt;sup>6</sup> Saab M. M., Landers M. & Hegarty J. (2018) The preconscious awareness to action framework: an application to promote testicular awareness. *Nursing Research* **67**(2) [*In Press*].

**Chapter 5:** Describing the development and feasibility and usability testing of a novel intervention (i.e. E-MAT) aimed at enhancing men's awareness of testicular disorders and symptoms using virtual reality (VR).<sup>7</sup>

**Chapter 6:** Discussing the pilot study conducted to test the E-MAT intervention and its effect on enhancing men's testicular awareness.<sup>8</sup>

**Chapter 7:** Discussing the key findings from this thesis, strengths and limitations, and recommendations.

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<sup>&</sup>lt;sup>7</sup> A manuscript titled: "Enhancing Men's Awareness of Testicular Disorders (E-MAT) Using Virtual Reality: Intervention Development and Feasibility and Usability Testing" is currently in preparation for submission.

<sup>&</sup>lt;sup>8</sup> A manuscript titled: "Enhancing Men's Awareness of Testicular Disorders (E-MAT) Using Virtual Reality: A Pilot Study" is currently in preparation for submission.

# CHAPTER

# 1

## **TESTICULAR DISORDERS:** AN OVERVIEW

An overview of the anatomy of the testes is presented in this chapter. Testicular cancer (TC) and benign testicular disorders (BTDs; i.e. testicular torsion, acute epididymitis and orchitis, cryptorchidism, varicocele, hydrocele, and spermatocele) are then discussed in terms of epidemiology, aetiology, risk factors, diagnosis, and management.

#### 1.1 Anatomy of the Testes

They are located behind the peritoneum during foetal development. Shortly before birth, both testes descend into a cutaneous pouch known as the scrotum (Standring 2016). Each testis is 4 to 5 centimetres in length and 2.5 cm in width, with an anteroposterior diameter of 3 centimetres. Each testis weighs between 10.5 and 14 grams. Both testes are suspended by the right and left spermatic cords, which extend from the abdomen and are made up of arteries, veins, lymphatic vessels, and nerves (Standring 2016). The left cord is slightly longer than the right cord consequently, the left testis hangs slightly lower than the right testis. This is essential to avoid compression in the event of impact (Bogaert 1997). Sperm produced in the testes is stored in the epididymis, a convoluted tubule that lies lateral to the testes' posterior border and connects the testes to the vas deferens. The vas deferens transports sperm

from the epididymis to the ejaculatory ducts during ejaculation (Standring 2016). Key features of the testis are highlighted in Figure 1.2.

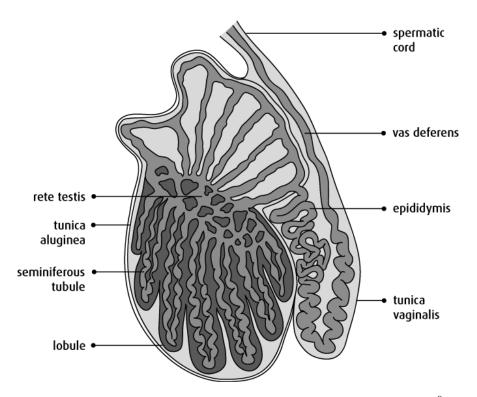


Figure 1.2 Structure of the testis (Canadian Cancer Society 2015)<sup>9</sup>

#### 1.2 Testicular Cancer

TC is a rare and relatively curable malignancy that predominantly affects males aged 15 to 35 years. TC constitutes 1.5% of all invasive cancers and 0.2% of all cancer deaths in Ireland (National Cancer Registry Ireland 2017). The cumulative lifetime risk of TC diagnosis is 1 in 189 (National Cancer Registry Ireland 2017). It is estimated that 55,300 males have been diagnosed with TC worldwide in the year 2012 (Cancer Research UK 2014b) and that 172 men will be diagnosed with this malignancy in Ireland each year (National Cancer Registry Ireland 2017). In this section, TC is

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<sup>&</sup>lt;sup>9</sup> Permission to reproduce Figure 1.2 was granted by the Canadian Cancer Society (2015; Appendix 1.1).

discussed in terms of epidemiology, pathological classification, risk factors, diagnosis, staging, management, and survivorship.

#### 1.2.1 Epidemiology

TC incidence significantly increased in Western countries over the past four decades and doubled globally over the past 30 years (Manecksha & Fitzpatrick 2009). Almost half of TC cases are diagnosed in European countries that have 'High' and 'Very High' Human Development Index (Manecksha & Fitzpatrick 2009, Znaor *et al.* 2014, Cancer Research UK 2014b). This malignancy, however, is rare in Asian and African countries.

An epidemiological study conducted in more than 172 countries found that TC incidence is highest among Caucasians living in "Western Europe (7.8%), Northern Europe (6.7%), Australia (6.5%), and North America (5.1%)" (Rosen *et al.* 2011 p. 375). Norway has the highest TC incidence (10.5 per 100,000 man-years) followed by Denmark (10.1 per 100,000 man-years). In contrast, Uganda has the lowest TC incidence (0.3 per 100,000 man-years; Trabert *et al.* 2015). Interestingly, this is not the case when it comes to mortality. TC death rate is highest in Central America, Western Asia, and Central and Eastern Europe and is as low as 1% in Western countries (Rosen *et al.* 2011, Znaor *et al.* 2014).

The global differences with regard to TC incidence are poorly understood. It is speculated, however, that such variations are caused by a multitude of genetic and environmental factors, as well as factors pertinent to public awareness and healthcare priorities (Rosen *et al.* 2011, Znaor *et al.* 2014, Trabert *et al.* 2015, Saab *et al.* 2016a, 2016c).

#### 1.2.2 Pathological Classification

Testicular tumours are classified as either germinal or sex cord/gonadal stromal (Albers *et al.* 2015). Ninety-five percent of testicular tumours are germinal in nature and are divided into three main groups: seminomas (55%), non-seminomas (44%), and spermatocytic seminomas (1%; Trabert *et al.* 2015).

Seminomas arise from sperm-producing cells and tend to affect men aged 30 to 45 years, whereas non-seminomas arise from cells that are not involved in sperm production and are known to affect men aged 20 to 35 years (Trabert *et al.* 2015). Non-seminomas are further divided into four subtypes: embryonal carcinoma (most common), teratoma, yolk sac tumour, and choriocarcinoma (Russell 2014, Albers *et al.* 2015). As for germinal tumours that are of mixed nature, they are classified and treated as non-seminomas (Trabert *et al.* 2015; Table 1.1).

**Table 1.1** Pathological classification of testicular cancer

<b>Tumour classifications</b>	Tumour types and subtypes	
Germ cell tumours	Non-seminomas (embryonal carcinoma,	
	choriocarcinoma, teratoma, and yolk sac tumour)	
	• Seminoma	
	Spermatocytic seminoma	
Sex cord/gonadal stromal tumours	• Leydig cell tumour	
	Malignant Leydig cell tumour	
	Sertoli cell tumour	
	Malignant Sertoli cell tumour	
	Granulosa cell tumour	
	• Thecoma/fibroma tumour	
	• Incompletely differentiated/mixed	
Others	Ovarian epithelial tumour	
	<ul> <li>Collecting ducts and rete testis tumour</li> </ul>	
	Non-specific stromal tumour	

(Russell 2014, Albers et al. 2015).

#### 1.2.3 Risk Factors

A number of medical conditions, modifiable, non-modifiable, and pre- and perinatal risk factors have been associated with an increased risk of TC. For instance, being overweight has been associated with an increased risk of cancer of the testes (overweight vs normal weight, odds ratio [OR] 0.92, 95% confidence interval [CI] 0.86 to 0.98, p=0.011; Lerro *et al.* 2010). Other modifiable risk factors include exposure to toxins such as asbestos and a low socio-economic status (Dieckmann *et al.* 2009).

As for non-modifiable risk factors, a strong relationship exists between ethnicity and TC. For instance, TC incidence is highest among individuals who are Caucasians and/or of European ancestry (Manecksha & Fitzpatrick 2009, Lerro *et al.* 2010, Russell 2014). Height has also been associated with an increased risk of TC (per 5-cm increase OR 1.13, 95%CI 1.07 to 1.19, p<0.001; Lerro *et al.* 2010). Other non-modifiable risk factors include late puberty and a family or personal history of TC.

There is evidence that a number of pre-existing medical conditions increase risk of TC. For instance, the relative risk (RR) of TC in men with cryptorchidism is 2.75 to 8. The RR, however, is reduced to 2 to 3 in males who undergo orchiopexy before the age of 12 (Wood & Elder 2009). Having had an inguinal hernia was also found to increase the risk for TC (OR 1.63, 95%CI 1.37 to 1.94; Cook *et al.* 2010). Other medical conditions linked to TC include testicular microlithiasis, hypospadias, subfertility, Human Papilloma Virus (HPV) infection, Human Immunodeficiency Virus (HIV) infection, and Acquired Immune Deficiency Syndrome (AIDS;

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<sup>&</sup>lt;sup>10</sup> Orchiopexy is the surgical repair of undescended testes whereby the cryptorchid testis is moved into the scrotum (van der Plas *et al.* 2015).

Manecksha & Fitzpatrick 2009, Peng *et al.* 2009, Lerro *et al.* 2010, Yousif *et al.* 2013, Wang *et al.* 2015).

A number of pre and perinatal risk factors have been associated with an increased risk of TC including low birth weight (OR 1.34, 95%CI 1.08 to 1.67), high birth weight (OR 1.05, 95%CI 0.96 to 1.14), preterm birth (hazard ratio [HR] 3.95, 95%CI 1.67 to 9.34), older maternal age (OR 1.31, 95%CI 1.07 to 1.59), and being a twin (OR 1.22, 95%CI 1.03 to 1.44; Cook *et al.* 2010). Other maternal risk factors include bleeding during pregnancy (OR 1.33, 95%CI 1.02 to 1.73), low birth order (OR 1.08, 95%CI 1.01 to 1.16), having several biological siblings (2 vs 1; OR 0.93, 95%CI 0.75 to 1.15), and delivery by caesarean section (OR 1.67, 95%CI 1.07 to 2.56; Cook *et al.* 2009, Crump *et al.* 2012). Controversy exists with regard to the relationship between TC risk and dietary habits, cigarette smoking, vasectomy, scrotal trauma, and pharmacological intake of growth factors (Manecksha & Fitzpatrick 2009; Table 1.2).

**Table 1.2** Summary of the key risk factors for testicular cancer

Tuble 1:2 building of the key 115.	R factors for testicatal cancer
	<ul> <li>High body mass index</li> </ul>
Modifiable risk factors	<ul> <li>Asbestos exposure</li> </ul>
	<ul> <li>Low socio-economic status</li> </ul>
	• White ethnicity
	<ul> <li>European ancestry</li> </ul>
	• Age (15-35 years)
Non-modifiable risk factors	• Height
	• Late puberty
	<ul> <li>Positive family history of testicular cancer</li> </ul>
	<ul> <li>Personal history of testicular cancer</li> </ul>
	• Subfertility
	<ul> <li>Cryptorchidism</li> </ul>
	Inguinal hernia
Medical conditions	<ul> <li>Testicular microlithiasis</li> </ul>
Wedical conditions	<ul> <li>Hypospadias</li> </ul>
	<ul> <li>HPV infection</li> </ul>
	<ul> <li>HIV infection</li> </ul>
	• AIDS
	• Low birth order
	<ul> <li>Gestational bleeding</li> </ul>
	<ul> <li>Having several biological siblings</li> </ul>
Pre- and perinatal risk factors	<ul> <li>Low birth weight</li> </ul>
	• Being a twin
	<ul> <li>Preterm birth</li> </ul>
	<ul> <li>Testicular dysgenesis syndrome<sup>11</sup></li> </ul>
	<ul> <li>High fat intake</li> </ul>
	<ul> <li>High dairy intake</li> </ul>
Possible risk factors	<ul> <li>Pharmacological intake of growth factors</li> </ul>
1 OSSIDIC HIST IACIOIS	• Smoking
	<ul> <li>Vasectomy</li> </ul>
	Scrotal trauma
(5.1.1.1.2000.35.1.1.	1 0 7 1 1 1 2000 7 1 2000 7 1

(Dieckmann *et al.* 2009, Manecksha & Fitzpatrick 2009, Peng *et al.* 2009, Cook *et al.* 2010, Lerro *et al.* 2010, Crump *et al.* 2012, Richardson *et al.* 2012, Yousif *et al.* 2013, Russell 2014, Wang *et al.* 2015).

#### 1.2.4 Diagnosis

Men with TC often present with a unilateral testicular or scrotal mass (Russell 2014, Albers *et al.* 2015). Other signs and symptoms include pain (20 to 27%) and gynecomastia (7%; Moul 2007, Albers *et al.* 2015). Back and flank pain (11%) are

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<sup>&</sup>lt;sup>11</sup> Testicular dysgenesis syndrome is a disorder of sexual development caused by a number of environmental and genetic factors. This condition increases the risk of TC, hypogonadism, hypospadias, and cryptorchidism (Rajpert-De Meyts *et al.* 2012).

common in metastatic disease (Albers *et al.* 2015). Ten percent of TC cases are confused with epididymitis or orchitis, consequently causing delay in TC diagnosis (Shin & Kim 2013). However, TC is suspected when antibiotics fail to alleviate testicular discomfort and reduce swelling (Motzer *et al.* 2012).

A thorough physical examination that includes palpation of the testicular mass is essential to highlight the features of the tumour and detect possible lymph node involvement. The abdomen is also palpated for masses and the breast is examined for gynecomastia (Albers et al. 2015). Testicular ultrasound is recommended when a lump is detected during physical examination and is known to be 100% sensitive in confirming the presence of a mass (Kim et al. 2007, Motzer et al. 2012, Albers et al. 2015). A complete blood count (CBC) as well as kidney and liver function tests are recommended (Motzer et al. 2012). Serum tumour marker levels are essential to establish a TC diagnosis, determine prognosis, stage the disease, and evaluate response to treatment. They include alpha-fetoprotein, β-human chorionic gonadotropin, and at times lactate dehydrogenase (Motzer et al. 2012, Shin & Kim 2013, Albers et al. 2015). Testicular biopsy is considered if a hypoechoic mass or microcalcifications were identified on ultrasound. A chest x-ray is performed since TC is known to metastasise to the lungs and mediastinal lymph nodes (Motzer et al. 2012). Abdominal and pelvic computed tomography (CT) scans are recommended to rule out metastasis. A chest CT is essential if the abdominal CT was positive or if the chest x-ray showed metastasis. Brain magnetic resonance imaging (MRI) and a bone scan are performed when clinically indicated (Motzer et al. 2012).

#### 1.2.5 Staging

TC is staged using the American Joint Committee on Cancer (2010) TNM staging system. 'T' refers to the size of the primary tumour, 'N' refers to lymph node

involvement, and 'M' stands for distant metastasis. 'S' was added in the staging of TC; it stands for the serum tumour marker levels (Albers *et al.* 2015). There are three main stages for TC, with each stage divided into three sub-stages. TC staging helps guide treatment and is considered as a key prognostic indicator (Edge *et al.* 2010; Table 1.3).

**Table 1.3** Testicular cancer staging

Stage 1	Stage 1A	Tumour confined to the testis and epididymis without vascular and lymphatic involvement	
	Stage 1B	Tumour confined to the testis and epididymis with	
		vascular and lymphatic involvement	
	Stage 1S	Tumour marker levels are high following orchiectomy	
		regardless of the size of the tumour	
	Stage 2A	Lesions in the lymph nodes that are smaller than 2cm	
Stage 2	Stage 2B	Lesions in the lymph nodes that are between 2 and 5cm	
	Stage 2C	Lesions in the lymph nodes that are larger than 5cm	
	Stage 3A	Spread to distant lymph nodes or lungs. Tumour marker levels can be either normal or slightly increased	
	Stage 3B	Spread to proximal lymph nodes with moderately high	
Stage 3	Stage 3D	tumour marker levels or Spread to the lungs or distant	
Stage 0		lymph nodes with moderately high tumour marker levels	
	Stage 3C	Same as stage 3B but with high tumour marker levels or	
		metastasis to organs such as the liver and the brain	
/T 1	1 0010		

(Edge et al. 2010).

#### 1.2.6 Management

The treatment of TC can dramatically affect gonadal function and fertility. Therefore, sperm banking prior to initiation of treatment is key (Albers *et al.* 2015).

Inguinal orchiectomy remains the primary treatment modality for TC. Other treatments include chemotherapy and radiation therapy (Kim *et al.* 2011, Shin & Kim 2013, Russell 2014, Albers *et al.* 2015). TC management is determined according to the tumour type and stage. For instance, seminomas tend to respond better to radiation therapy, while non-seminomas and mixed tumours are more sensitive to chemotherapy

(Russell 2014, Trabert *et al.* 2015, American Cancer Society 2016b). At times, surveillance is indicated following orchiectomy. During surveillance, relapse rate is estimated to be 30%, with 80% occurring within the first year of follow-up (Albers *et al.* 2015). The risk of recurrence, however, drops to 1% four to five years following orchiectomy (Zuniga *et al.* 2009, Albers *et al.* 2015). Radiotherapy is often initiated seven days following orchiectomy and administered five days a week (Motzer *et al.* 2012). As for chemotherapy, a number of chemotherapeutic agents are used to treat TC. Examples include etoposide, cisplatin, bleomycin, and ifosfamide (NCI 2017).

#### 1.2.7 Survivorship

The 5-year relative survival rate for TC is 97%, which makes it the most curable solid tumour (Siegel *et al.* 2015). TC survivors are expected to face a number of long-term complications secondary to cancer, its treatment, or both (Dahl *et al.* 2005, Saab *et al.* 2014).

Chronic fatigue, peripheral neuropathy, ototoxicity, and Raynaud phenomena are common among men who receive chemotherapy and radiotherapy (Rossen *et al.* 2009, Glendenning *et al.* 2010). Moreover, cytotoxic drugs and mediastinal radiotherapy increase the risk of myocardial injury (van den Belt-Dusebout *et al.* 2006, Vaughn *et al.* 2008, Haugnes *et al.* 2015) and pulmonary toxicity (Haugnes *et al.* 2012). Gonadal dysfunction is common with radiotherapy; it often leads to a low sex drive, erectile and ejaculatory dysfunction, muscle weakness, decreased sense of wellbeing, and metabolic syndromes (Joly *et al.* 2002, Haugnes *et al.* 2007, Kim *et al.* 2012, Rossen *et al.* 2012, Oldenburg 2015). Furthermore, evidence suggests that men who receive chemotherapy for TC have a lower cognitive performance (p<0.001; Amidi *et al.* 2015) and tend to perform poorly on tests that involve multiple cognitive domains (p=0.03) in comparison to healthy males (Stouten-Kemperman *et al.* 2015).

Despite lack of evidence regarding the effect of early diagnosis of TC on mortality (Ilic & Misso 2011), it is speculated that early detection of this malignancy might spare men from aggressive treatment modalities, which in turn would reduce the occurrence of the aforementioned complications (Rovito *et al.* 2016).

TC is not the only testicular disorder that can impact a man's life. Certain non-malignant conditions can also be debilitating and can cause irreversible damage including the loss of a testis and infertility (Ringdahl & Teague 2006, Trojian *et al.* 2009, Bayne *et al.* 2017). Below is an overview of the most common BTDs, with a focus on conditions that constitute the acute scrotum, namely testicular torsion and acute epididymitis and orchitis. Disorders that seldom cause symptoms, such as cryptorchidism, varicocele, hydrocele, and spermatocele can also predispose men to a number of complications and are discussed in the upcoming section.

## 1.3 Benign Testicular Disorders

BTDs can be either harmless and painless or debilitating and life-threatening (Wampler & Llanes 2010). In the literature on BTDs, there is mention of the acute scrotum which is a medical emergency characterised by an acute onset of scrotal pain, swelling, and redness (D'Andrea *et al.* 2013). Differential diagnoses include testicular torsion, infection, trauma, or tumour. If left untreated, the acute scrotum can cause pain, swelling, the loss of a testis, and at times sepsis (Ringdahl & Teague 2006, Bayne *et al.* 2017). The acuteness of this condition highlights the importance of timely diagnosis and management. On the other hand, some testicular conditions can be asymptomatic and are often detected accidentally by the men themselves or during routine physical check-ups. Examples include varicocele, hydrocele, and spermatocele

(Wampler & Llanes 2010). Below is a comprehensive overview of the most common BTDs.

#### 1.3.1 Testicular Torsion

Testicular torsion is a medical emergency whereby the spermatic cord becomes twisted, causing a reduction in blood supply to the testes (Summers 2008, Wampler & Llanes 2010). This condition affected 1 in 4,000 males who are younger than 25 years in the year 2002 (Ringdahl & Teague 2006, Bayne *et al.* 2017).

#### **1.3.1.1 Aetiology**

The exact aetiology of testicular torsion is poorly understood. A number of factors have been associated with an increased risk of testicular torsion including TC, cryptorchidism, testicular trauma, horizontal lie of the testes, and large testicular size (Ringdahl & Teague 2006, Srinath 2013).

#### **1.3.1.2 Diagnosis**

Testicular torsion is characterised by a sudden onset of unilateral scrotal pain, oedema, nausea, and vomiting (Wampler & Llanes 2010, Srinath 2013). Testicular ischemia usually starts six hours following the onset of symptoms (Srinath 2013). In the absence of oedema, a hard and tender nodule is palpable on the upper pole of the affected testis. Moreover, due to the twisting of the spermatic cord, the affected testis might appear higher in the scrotum in comparison to the unaffected one (Ringdahl & Teague 2006, Srinath 2013). In addition, the absence of the cremasteric reflex is a key warning sign for testicular torsion and is important to rule out other testicular conditions such as epididymitis (Wampler & Llanes 2010). <sup>12</sup> Testicular ultrasound

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<sup>&</sup>lt;sup>12</sup> The cremasteric reflex is characterised by contraction of the ipsilateral cremaster muscle drawing the testis upward when the inner aspect of the thigh is stroked (Gordhan & Sadeghi-Nejad 2015).

with Doppler and scintigraphyare recommended to confirm the diagnosis of testicular torsion (Lavalle & Cash 2005, Ringdahl & Teague 2006, Wampler & Llanes 2010, Srinath 2013).<sup>13</sup> There is a 90% chance to salvage the affected testis if torsion was diagnosed within the first six hours from the onset of pain. This chance, however, drops to 50% if help-seeking was delayed by 12 hours and 10% by 24 hours (Davenport 1996, Ringdahl & Teague 2006, Bayne *et al.* 2017).

#### 1.3.1.3 Management

Testicular torsion management can be either invasive or non-invasive. The ultimate goal of treatment is to restore blood supply, salvage the affected testis, and prevent necrosis and sepsis (Summers 2008). Non-invasive treatment involves manual detorsion, whereby a urologist manually twists the spermatic cord back to its normal state. This procedure is performed under sedation, with or without local anaesthesia. This technique is known to have a relatively low success rate; for this reason, immediate surgery is preferred (Hawtrey 1998, Cornel & Karthaus 1999, Ringdahl & Teague 2006, Srinath 2013). If the affected testis is non-salvageable, an emergency orchiectomy is performed (Srinath 2013).

#### 1.3.2 Acute Epididymitis and Orchitis

Epididymitis and orchitis are genitourinary tract conditions that are characterised by inflammation of the epididymis and testes lasting less than six weeks (Ludwig 2008, Tracy *et al.* 2008, Trojian *et al.* 2009, Workowski & Berman 2015). This condition affects approximately 600,000 men per year in the USA and accounts

<sup>13</sup> Scintigraphy is a diagnostic test whereby radioisotopes are ingested and the emitted radiation is captured by external detectors (Ringdahl & Teague 2006).

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for 1 in 144 outpatient visits among males aged between 18 and 50 years (Trojian *et al.* 2009, Workowski & Berman 2015).

#### **1.3.2.1 Aetiology**

Epididymitis is often caused by a bacterial infection transmitted sexually among men aged 18 to 35 years (Tracy *et al.* 2008, Trojian *et al.* 2009, Workowski & Bolan 2015). The most common pathogens for sexually transmitted epididymitis include Neisseria gonorrhoea and Chlamydia trachomatis (Tracy *et al.* 2008, Trojian *et al.* 2009, Workowski & Berman 2015). In those who are younger than 14 years and older than 35 years, epididymitis is caused by urinary tract pathogens, most commonly Escherichia coli. This pathogen is common among older men who have bladder outlet obstruction secondary to benign prostate hyperplasia (Workowski & Bolan 2015). Escherichia coli epididymitis is also linked to anal intercourse. Although rare, Mycobacterium tuberculosis exposure can lead to epididymitis. Acute epididymitis can also be caused by fungal or viral pathogens among men who are HIV positive (Tracy *et al.* 2008, Trojian *et al.* 2009, Workowski & Berman 2015).

Non-infectious epididymitis and orchitis can occur in patients with vasculitis or children with a history of Mycoplasma pneumoniae, and enteroviral and adenoviral infections (Trojian *et al.* 2009). Non-infectious epididymitis and orchitis can also be caused by medications such as amiodarone (Nikolaou *et al.* 2007, Shen *et al.* 2014, Bradford *et al.* 2015). Isolated orchitis is known to be blood-borne and is associated with mumps (Trojian *et al.* 2009). Other risk factors for epididymitis and orchitis include: urinary tract surgery or instrumentation, anatomic abnormalities, strenuous physical exercise, bicycle or motorbike riding, and long periods of sitting (National Center for Health Statistics 2002, Trojian *et al.* 2009, Wampler & Llanes 2010).

#### 1.3.2.2 Diagnosis

Acute epididymitis is known to be the most common cause of acute scrotal pain (National Center for Health Statistics 2002, Wampler & Llanes 2010). Other than pain, epididymitis and orchitis cause swelling and inflammation of the epididymis (Lopez & Beasley 2012). A thorough physical examination is required to diagnose epididymitis. Unlike testicular torsion, the cremasteric reflex is present in epididymitis. Laboratory tests used to diagnose acute epididymitis and orchitis include: CBC, urinalysis, urine culture, urethral culture, and Gram stain (Bradford *et al.* 2015, Gordhan & Sadeghi-Nejad 2015, Workowski & Bolan 2015). Testicular ultrasound is only recommended to rule out testicular torsion in men presenting with scrotal pain (Bradford *et al.* 2015, Workowski & Bolan 2015).

#### 1.3.2.3 Management

If left untreated, epididymitis can cause permanent damage to the epididymis and consequently infertility (Hedger 2011). The goal of treatment is to alleviate symptoms, treat the underlying cause, and prevent damage (Bradford *et al.* 2015). Sexually transmitted chlamydia and gonorrhoea infections are treated with ceftriaxone and doxycycline (Workowski & Bolan 2015). For acute epididymitis caused by chlamydia, gonorrhoea, and enteric organisms, ceftriaxone and levofloxacin or ofloxacin are prescribed. Levofloxacin or ofloxacin are administered for patients with epididymitis caused by enteric organisms alone (Workowski & Bolan 2015). Sexual partners of infected men are also treated. It is important to note that the discomfort caused by epididymitis does not subside until a few weeks after completion of therapy (CDC 2015a). As for non-bacterial epididymitis, symptomatic treatment is offered and includes periods of rest, scrotal elevation, and non-steroidal anti-inflammatory drugs.

If epididymitis was caused by amiodarone, the patient's cardiologist is notified and the drug is either discontinued or its dose is reduced (Bradford *et al.* 2015).

#### 1.3.3 Cryptorchidism

Commonly known as undescended testes, cryptorchidism is a congenital defect whereby the testes fail to descend into the scrotum or normally descended testes retract and become cryptorchid during childhood (Wampler & Llanes 2010). This disorder affects 2 to 8% of full-term births and is more common among infants with a low birth weight (Virtanen *et al.* 2007).

#### 1.3.3.1 Aetiology

The exact aetiology of cryptorchidism is poorly understood. It is thought, however, that an interplay between maternal, environmental, and genetic factors increases the risk of this condition (Kollin & Ritzén 2014). For instance, a strong relationship exists between cryptorchidism and low birth weight (HR 1.4, 95%CI 1.3 to 1.5) and early delivery (HR 7.8, 95%CI 6 to 10; Jensen *et al.* 2012). Other risk factors include placental and uterine dysfunction, maternal diabetes, preeclampsia, breech position, caesarean section, difficult delivery, and a family history of cryptorchidism (Wampler & Llanes 2010).

#### 1.3.3.2 Diagnosis

Cryptorchid testes are palpable in 70 to 80% of the cases. Therefore, cryptorchidism is often diagnosed during physical examination. MRI and ultrasound are required only when the testes are non-palpable (Abacı *et al.* 2013).

#### 1.3.3.3 Management

Approximately, 70 to 77% of cryptorchid testes descend spontaneously in the first three months of life. This percentage, however, decreases at three to six months

which may require a surgical intervention known as orchiopexy (Wampler & Llanes 2010). If left untreated, cryptorchidism predisposes to infertility and has long been associated with an increased risk of TC (Farrer *et al.* 1985, Wampler & Llanes 2010). Therefore, pre-pubertal orchiopexy is vital for testicular development, spermatogenesis, and TC risk reduction (Walsh *et al.* 2007a, Kollin & Ritzén 2014).

#### 1.3.4 Varicocele

Varicocele is characterised by "a dilation of the testicular vein and pampiniform plexus within the scrotum" (Wampler & Llanes 2010 p. 619). <sup>14</sup> It is the most frequently diagnosed non-infectious testicular disorder affecting 10 to 20% of adolescents and young adults (Mohammed & Chinegwundoh 2009, Lee *et al.* 2011, Gordhan & Sadeghi-Nejad 2015).

#### 1.3.4.1 Aetiology

Varicocele often affects the left testis. The exact pathophysiological process is poorly understood (Wampler & Llanes 2010). It has been postulated, however, that the longer length of the left gonadal vein and the insertion into the left renal vein cause an increased hydrostatic pressure which leads to blood pooling around the left testis (Kwak & Siegel 2014, Gordhan & Sadeghi-Nejad 2015). Unlike testicular torsion, testicular blood supply is not impaired in varicocele (Gordhan & Sadeghi-Nejad 2015).

#### 1.3.4.2 Diagnosis

Varicocele is often detected accidentally in 40% of patients attending fertility clinics, making it the most common cause of infertility among adult males (Jarow

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<sup>&</sup>lt;sup>14</sup> The pampiniform plexus is a network of veins that drain the testes. They play a key role in testicular temperature regulation and cooling (Marieb & Hoehn 2007).

2001, Khera & Lipshultz 2008, Mohammed & Chinegwundoh 2009). Khera and Lipshultz (2008) speculated that the poor venous return leads to an increased scrotal temperature which impairs spermatogenesis. It is also thought that varicocele affects testosterone and follicle-stimulating hormone levels, thus causing a decline in sperm count and viability (Wampler & Llanes 2010).

Varicocele is often asymptomatic and very rarely causes a dull and aching sensation in the scrotum. Varicocele is usually detected during physical examination and is typically described as a "bag of worms" (Kwak & Siegel 2014, Gordhan & Sadeghi-Nejad 2015). Although physical examination is normally sufficient to detect varicocele, colour Doppler imaging can be used to confirm the diagnosis (Kwak & Siegel 2014). Trum *et al.* (1996) graded varicocele as follows: grade 0, non-palpable varicocele; grade I, varicocele palpable during Vasalva manoeuvre; grade II, varicocele visible while the patient is standing during Vasalva manoeuvre; and grade III, varicocele is visible while the patient is standing without Vasalva manoeuvre.

#### **1.3.4.3 Management**

According to the Male Infertility Best Practice Policy Committee of the American Urological Association and the Practice Committee of the American Society for Reproductive Medicine (2004), varicocele repair is recommended when the patient has grade II or III varicocele in addition to low sperm count. Microsurgical varicocelectomy is regarded as the best approach to repair varicocele and restore fertility (Cho & Seo 2014).

#### 1.3.5 Hydrocele

Hydrocele is characterised by fluid collection in the tunica vaginalis.<sup>15</sup> It is known to affect 4.7% of neonates and 1% of adult males (Osifo & Osaigbovo 2008).

#### **1.3.5.1 Aetiology**

Congenital hydrocele is caused by an incomplete closure of the processus vaginalis, whereas hydrocele following the first year of life is often associated with a venous or lymphatic obstruction secondary to infection or trauma (Wampler & Llanes 2010). In Western countries, hydrocele is caused by viral or bacterial infections. In tropical countries, however, hydrocele among adults is strongly associated with filariasis, a parasitic infection transmitted via mosquito bite (Babu *et al.* 2004). Other aetiologies include testicular trauma, torsion, and a history of a recent testicular surgery. TC is suspected in men who develop hydrocele in their thirties and forties (Wampler & Llanes 2010).

#### **1.3.5.2 Diagnosis**

Hydrocele is often found accidentally and is generally asymptomatic. Large hydroceles, however, can cause scrotal pain that radiates to the back. On physical examination, hydrocele appears as a smooth scrotal mass that transluminates. Ultrasound is used to rule out TC in adults (Wampler & Llanes 2010).

<sup>&</sup>lt;sup>15</sup> During the eighth week of pregnancy, a peritoneal outpouching called the processus vaginalis descends into the scrotum and forms the cover of the testis. Later during pregnancy, the cranial end of the processus vaginalis closes and forms a cavity known as the tunica vaginalis (Bertolotto *et al.* 2015).

#### **1.3.5.3 Management**

Watchful waiting is recommended for asymptomatic hydrocele (Wampler & Llanes 2010). Surgical resection of the hydrocele is the gold standard for adult hydroceles that are large and painful (Rioja *et al.* 2011).

#### 1.3.6 Spermatocele

Spermatocele is a BTD that is characterised by testicular fluid collection arising from the epididymis, rete testis, <sup>16</sup> or efferent ductuli (Rioja *et al.* 2011). <sup>17</sup>

#### **1.3.6.1 Aetiology**

Spermatocele is often idiopathic. Testicular inflammation, infection, and trauma might predispose to the development of spermatocele (Rioja *et al.* 2011).

#### 1.3.6.2 Diagnosis and Management

Spermatocele is often painless and non-life-threatening. Similar to hydrocele, spermatocele is discovered accidentally, transluminates, is rarely symptomatic, and is surgically excised in males who complain of pain and discomfort (Walsh *et al.* 2007b).

## 1.4 Summary

Testicular disorders can range from benign and asymptomatic to malignant and debilitating with the majority affecting men aged between 18 and 50 years (Ringdahl & Teague 2006, Trojian *et al.* 2009, Workowski & Berman 2015, Bayne *et al.* 2017, National Cancer Registry Ireland 2017). Some disorders, however, can occur at an

<sup>&</sup>lt;sup>16</sup> "Rete testis is an anastomosing network of delicate tubules located in the hilum of the testicle (mediastinum testis) that carries sperm from the seminiferous tubules to the vasa efferentia" (Gadodia *et al.* 2010 p. 593).

<sup>&</sup>lt;sup>17</sup> The efferent ductuli attach the rete testis to the epididymis and conduct the sperm between these two structures (Hossler 2014).

earlier age including cryptorchidism and hydrocele (Virtanen *et al.* 2007, Osifo & Osaigbovo 2008).

Generally, testicular lumpiness, pain, and swelling are the symptoms of a number of testicular disorders including TC, testicular torsion, and acute epididymitis and orchitis (Moul 2007, Wampler & Llanes 2010, Srinath 2013, Russell 2014, Albers *et al.* 2015). These disorders often require immediate interventions to avoid lifethreatening and life-limiting complications such as testicular necrosis, sepsis, infertility, and metastasis (Kim *et al.* 2011, Shin & Kim 2013, Srinath 2013, Russell 2014, Albers *et al.* 2015).

Cryptorchidism, varicocele, hydrocele, and spermatocele are often asymptomatic. Men diagnosed with these conditions are usually observed and surgery is recommended only in the presence of pain and/or infertility (Wampler & Llanes 2010, Kwak & Siegel 2014, Gordhan & Sadeghi-Nejad 2015). The key characteristics of the testicular disorders discussed in this chapter are summarised in Table 1.4.

**Table 1.4** Summary of the key characteristics of testicular disorders

	Testicular cancer	Testicular torsion	Epididymitis/ Orchitis	Cryptorchidism	Varicocele	Hydrocele	Spermatocele
Age of Onset	18-35 years	< 25 years	18-50 years	Neonates	Adolescents and young adults	Neonates and rarely adults	Adults
Aetiology	Unknown	Testicular cancer Trauma Cryptorchidism Horizontal lie of testes Large testicular volume	Sexually transmitted infections (STIs) Bladder outlet obstruction Tuberculosis Mumps	Maternal factors Low birth weight Early birth Breech position Positive family history	Unknown	Unknown	Unknown
Signs and symptoms	<ul><li>Testicular mass</li><li>Pain</li><li>Gynecomastia</li></ul>	Pain (sudden) Oedema Nausea/vomiting Hard/tender nodule	Pain (insidious) Swelling Inflammation	Asymptomatic	Asymptomatic Dull and aching sensation (rare)	Asymptomatic Pain (if large)	Asymptomatic Pain (if large)
Diagnosis	Mass upon palpation and on ultrasound, elevated tumour markers	Absent cremasteric reflex Decreased circulation on Doppler and scintigraphy	Elevated white blood cells Positive urinalysis and culture	Empty scrotum Ultrasound and MRI to locate non-palpable testes	Palpation of a 'bag of worms' Blood pooling on colour Doppler	Smooth scrotal mass that transluminates Ultrasound to confirm diagnosis	Smooth scrotal mass that transluminates Ultrasound to confirm diagnosis
Treatment	Orchiectomy and/or chemotherapy and/or radiotherapy	Surgery Manual detorsion (not recommended)	Antibiotics if bacterial Symptomatic treatment	Observation in infancy Surgery prepuberty	Observation Surgery if painful or affecting fertility	Observation Surgical resection if painful	Observation Surgical resection if painful
Complications	Metastasis	Ischemia Necrosis Sepsis	Sepsis Infertility	Infertility TC risk	Infertility	Pain radiating to the back (if large)	Pain radiating to the back (if large)

(Saab et al. 2016a).

## 1.5 Conclusion

Evidence suggests that men are often unaware of TC and BTDs and tend to delay help-seeking for testicular symptoms such as lumpiness and/or pain (Saab *et al.* 2016a, 2016b, 2016c, 2017a). This is quite alarming as complications such as testicular necrosis, sepsis, and infertility, can be prevented if prompt medical help was sought (Ringdahl & Teague 2006, Bayne *et al.* 2017).

TC awareness is associated with a reduced tumour size at presentation (McGuinness *et al.* 2017) and the early detection of TC is linked to a reduced cost of treatment (Aberger *et al.* 2014), which stresses the need to raise men's awareness of testicular disorders.

The empirical literature on men's awareness of TC, TSE, and BTDs was reviewed and is presented and appraised in the upcoming chapter (Chapter 2).

## CHAPTER

# MEN'S AWARENESS OF TESTICULAR DISORDERS & THEIR SCREENING: REVIEWS OF THE EMPIRICAL LITERATURE

Testicular cancer (TC) screening by a clinician or by means of testicular self-examination (TSE) continues to be a controversial issue, mainly due to the lack of empirical evidence to support or discourage these practices (Law 2004, NCI 2017a). For instance, the United States Preventive Services Task Force (USPSTF 2011) issued a statement against TC screening among asymptomatic males. This statement was based on a Cochrane review conducted by Ilic and Misso (2011) in which no evidence was found regarding the effect of TC screening on mortality. Similarly, the NCI (2017a) believes that TC screening would not reduce mortality, "in part because therapy at each stage is so effective." <sup>18</sup>

In contrast, key cancer organisations, such as the American Cancer Society (2016a), recommend TC screening as a component of routine cancer-related physical examinations and encourage men to perform TSE. Moreover, the Irish Cancer Society (2015) offers infographic material to encourage young males to perform TSE. In the UK, men are encouraged to be aware of the normal anatomy of their testes without

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<sup>&</sup>lt;sup>18</sup> The NCI (2017a) advised against TSE because, based on fair evidence, TC screening would not result in decreased mortality and because TC treatment is often effective regardless of the stage of the disease. This statement is available from <a href="https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032653/">https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032653/</a>

necessarily performing scheduled TSE (Cancer Research UK 2014a). In contrast, no guidelines exist to screen for benign testicular disorders (BTDs; Saab *et al.* 2016a).

Despite the controversy surrounding TSE, a number of studies have been conducted to explore men's awareness of TC and BTDs and promote TC screening and self-examination. To date, no reviews collated and critically analysed evidence from these studies. To address this gap, two systematic reviews of studies exploring and promoting men's awareness of TC and TSE (Saab *et al.* 2016b, 2016c) and one integrative review of studies exploring men's awareness of BTDs (Saab *et al.* 2016a) were conducted. Each of the three reviews is presented and discussed in this chapter. Of note, the term "testicular cancer screening" used throughout this chapter is considered to comprise both, testicular examination by a clinician as well as TSE.

## 2.1 Testicular Cancer Awareness and Screening Practices:

## **A Systematic Review**

#### 2.1.1 Significance and Aim

Studies exploring TC knowledge and TC screening practices among healthy men have been conducted; however, no systematic reviews aimed at pooling findings from these studies in order to inform nursing research, education, and practice.

The aim of this systematic review was to critically appraise evidence from studies that explored: (i) men's knowledge, awareness, and attitudes toward TC and its screening; (ii) addressed their TSE practice; (iii) and/or highlighted barriers and facilitators to this practice. This systematic review was published in "Oncology Nursing Forum" (Saab *et al.* 2016c; Appendix 2.1).<sup>3</sup>

#### **2.1.2 Methods**

Systematic reviews help gather empirical evidence using specific inclusion and exclusion criteria as well as specific review aims and questions. A systematic review uses clear and systematic methods to minimise bias and provide reliable findings from which conclusions can be drawn and decisions can be made (Antman 1992, Oxman 1993, Higgins & Green 2011).

The 27-item Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist guided the reporting of this review (Moher *et al.* 2009; Appendix 2.2).

#### 2.1.2.1 Eligibility Criteria

Studies included in this review were (i) quantitative and qualitative; (ii) published in or translated to English; (iii) published between January, 2004 and November, 2014; (iv) comprised findings from men only; (v) assessed knowledge, awareness, and attitudes towards TC; (vi) assessed knowledge, awareness, attitudes, and practice of TC screening including TSE; and (vii) examined barriers and facilitators to TC knowledge and screening. Of note, there is no golden rule for limiting publications by date; however, scientific evidence published within a 10-year timeframe is considered to be recent (Wilhelm & Kaunelis 2005, Cottrell & McKenzie 2011).

#### 2.1.2.2 Study Selection and Data Extraction

Three electronic databases (MEDLINE, CINAHL, and Embase) were searched between September and November, 2014. Boolean operators "OR" and "AND", Medical Subject Headings (MeSH), and truncation "\*" were used. Keywords and their synonyms were combined and yielded the following search history: (cancer\* OR tumor\* OR tumour\* OR malignan\* OR neoplas\*) AND (testicul\* OR testes OR testis

OR testicle\*) AND (self-exam\* OR "self exam\*" OR screening OR "early detection" OR awareness OR knowledge OR attitudes OR practice OR "health promotion" OR symptoms). The search was limited to papers published in or translated to English between January, 2004 and November, 2014.

Studies were exported to a software for research and reference management (EndNote X7) and duplicates were deleted. Records were screened on title and abstract and irrelevant papers were excluded. Data from the included studies were extracted by the researcher using a standardised extraction table (Goossens *et al.* 2014) and was later cross-checked by one of the thesis supervisors. The reference lists of the included records were checked for potentially eligible studies that were not identified during database search.

The search results were independently reviewed by the researcher and one of the two thesis supervisors and a kappa coefficient was calculated (Viera & Garrett 2005, Higgins & Green 2011). Data collected included: name of the author(s), year of publication, and country and setting where the studies were conducted. Demographic data of the study population (i.e. sample size, mean age, and age range) were extracted along with the study design and instruments. Findings were then extracted and organised according to the review aims. The methodological quality of the reviewed studies was then appraised.

#### 2.1.2.3 Quality Appraisal

Quality appraisal of studies included in systematic reviews helps reduce bias, gain insight about possible comparisons, and interpret findings. Factors warranting

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<sup>&</sup>lt;sup>19</sup> The kappa coefficient is a statistic used to measure the level of agreement between two observers. A score of 0 signifies that there is no agreement; 0.01–0.20 slight agreement; 0.21–0.40 fair agreement; 0.41–0.60 moderate agreement; 0.61–0.80 substantial agreement; and 0.81–0.99 almost perfect agreement (Viera & Garrett 2005).

quality appraisal relate to the appropriateness of findings, validity of individual studies, and the characteristics of certain research designs (Higgins & Green 2011). The choice of quality appraisal tools depends on the study design (Whittemore & Knafl 2005). Three quality appraisal tools were used in this review.

A tool used in previous reviews (Louw *et al.* 2007, Wong *et al.* 2008, Roman & Frantz 2013, Davids & Roman 2014) was deemed appropriate to evaluate the quality of cross-sectional studies. In this tool, the methodological quality was appraised based on the representativeness of the sample, response rate, reliability and validity of data collection instruments, and whether a primary data source was used for data collection. The tool was then modified to match the findings from the reviewed studies with the review questions. A score was then calculated and the quality of the studies was ranked as either weak (0-33.9%), moderate (34-66.9%), or strong (67-100%).

A tool developed by the Critical Appraisal Skills Programme (CASP 2017a) was used to assess the quality of the integrative review included in this review. Quality was assessed in terms of clarity of the review question, appropriateness of the types of papers included, inclusion of relevant studies, quality assessment of included studies, and accurate collation of study results. Items pertinent to the precision of findings, applicability and importance of outcomes, and the review risks and benefits were also part of this tool (CASP 2017a).

The 10-item CASP (2017b) checklist was used to appraise the quality of qualitative studies in terms of clarity of research aims, appropriateness of the methodology, relevance of the design to the research aims, appropriateness of the recruitment strategy, and clarity of data collection. The remaining items assessed for clarity of the relationship between the researcher and participants, explicitness of

ethical considerations, rigour of data analysis, clarity of findings, and the overall value of the research (CASP 2017b).

#### **2.1.3 Results**

#### 2.1.3.1 Study Selection

A total of 3,076 records were identified through database searching. Following the deletion of duplicates, 1,731 papers were independently screened on title and abstract by the researcher and one of the two thesis supervisors and irrelevant articles were excluded. A kappa coefficient of 0.72 was obtained and was perceived as satisfactory. A total of 126 full-text articles were assessed for eligibility. Following the exclusion of 101 articles, 21 quantitative cross-sectional studies, three qualitative descriptive studies, and one integrative review were deemed eligible for review. Reference list checks did not yield any additional records. Record identification, screening, and selection process is illustrated in Figure 2.1.

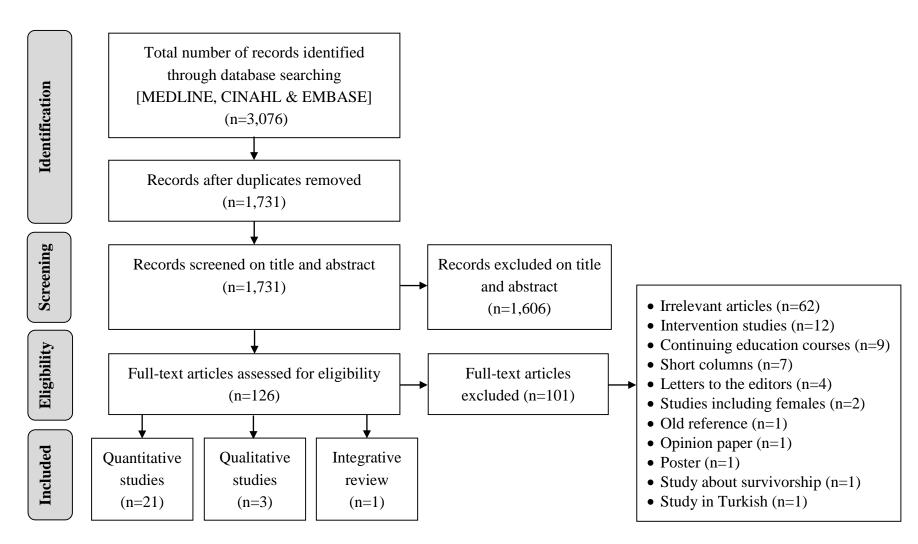


Figure 2.1 Record identification, screening, and selection process (Moher et al. 2009, Saab et al. 2016c)

#### 2.1.3.2 Study Characteristics

The majority of the reviewed studies were conducted in the USA (n=7) and in the year 2011 (n=5). Since TC is most common among young adults, the majority of data were collected in universities (n=13). The smallest sample size in quantitative studies was 177 (Beydag 2012) and the largest sample size was 8,680 (Evans *et al.* 2006). As for qualitative studies, the minimum sample size was 20 (Dubé *et al.* 2005) and the maximum was 37 (Evans *et al.* 2010).

Non-probability purposive sampling was used in all the reviewed qualitative studies (n=3) as well as the majority of the quantitative studies (n=19). Random sampling was utilised in only two quantitative studies (Powe *et al.* 2007, Muliira *et al.* 2013). Ages of participants ranged between 14 and 78 years (Kennett *et al.* 2014). Finally, with the exception of one integrative review (de Souza *et al.* 2011), all included records used a descriptive approach.

#### 2.1.3.3 Quality Appraisal

The methodological quality of the reviewed cross-sectional studies ranged between weak (n=3), moderate (n=9), and strong (n=9). Quality appraisal of quantitative studies is presented in Appendix 2.1, Table 1; quality appraisal of qualitative studies is presented in Appendix 2.1, Table 2; and quality appraisal of the integrative review is presented in Appendix 2.1, Table 3.

#### 2.1.3.4 Synthesis of Results

Researchers used a multitude of questionnaires to collect data with the majority being researcher designed surveys (n=18). Therefore, given the heterogeneous nature of the data collected, it was not feasible to combine the data for a meta-analysis. Based on the aims of this review, findings from the included papers are presented under four

main themes namely: (i) TC knowledge, awareness, and attitudes; (ii) TC screening knowledge, awareness, attitudes, and practices; (iii) barriers to TC awareness and screening; and (iv) facilitators to TC and screening. Findings from individual studies are presented in the data extraction table (See Appendix 2.1, APPENDIX A).

#### Testicular cancer knowledge, awareness, and attitudes

Having heard of TC did not necessarily equate to knowledge about the various aspects of this malignancy. On a scale of 0 to 10, 11.1% (n=89) of men knew about TC; of those, 1.4% (n=11) answered all the questions about TC correctly (Kuzgunbay *et al.* 2013). Similarly, only 8% (n=54) of those who reported knowing about TC (99.4%, n=673) were able to identify possible causes of this malignancy (Casey *et al.* 2010). Generally, TC knowledge fluctuated between 10.4% (n=78; Ugboma & Aburoma 2011) and 84% (n=160; Powe *et al.* 2007).

From a chronological perspective, the number of men who have heard about TC is increasing. This trend, however, is not evident in studies conducted in developing countries such as Nigeria (Ugboma & Aburoma, 2011) and Turkey (Kuzgunbay *et al.* 2013).

The majority of participants perceived TC as a very serious illness (87.4%, n=635; Rudberg *et al.* 2005) and were afraid of developing it. In addition, 57.6% (n=186) of Ugandan university students did not know the chance of curability from TC (Muliira *et al.* 2013). These findings echo the overall perception of cancer as a serious, debilitating, and life threatening illness (Saab *et al.* 2014).

Age was found to be the most commonly addressed risk factor for TC. The majority of participants knew the age group at risk for TC. In contrast, 66.6% (n=215)

of males in a Ugandan study did not know the age group affected by TC and 60.7% (n=196) were not aware of the risk factors of TC (Muliira *et al.* 2013).

Awareness of TC signs and symptoms ranged between 29.4% (n=95; Muliira et al. 2013) and 71% (n=481; Casey et al. 2010). In a Swedish study, almost half of the participants were not familiar with common signs and symptoms of TC and were unaware that radiotherapy is a treatment modality for TC (Rudberg et al. 2005). Likewise, the majority of men interviewed in an American study failed to identify orchiectomy as the main TC treatment modality. They also believed that removal of one testis was emasculating and felt uncomfortable discussing the psychological effect of TC (Daley 2007). Similarly, more than half of the participants in a Turkish study believed that a man's sexual life is negatively affected by TC (Urgurlu et al. 2011). These findings may reflect men's perception of manhood as well as the importance they attach to it (Saab et al. 2014).

#### Testicular cancer screening knowledge, awareness, attitudes, and practices

Being aware of TC screening did not necessarily imply that men knew how and when to perform TSE. On the whole, TSE knowledge ranged between 1% (n=7; Ugboma & Aburoma 2011) and 79.9% (n=591; Kennett *et al.* 2014). Of those who heard about TC screening, 14.2% (n=15) knew how to perform TSE (Sirin *et al.* 2006) and 40.5% (n=300) knew what to look for (Kennett *et al.* 2014).

The majority of participants displayed a favourable attitude towards testicular examination by a clinician and/or TSE. For instance, only 0.1% (n=2) of German soldiers refused to have their testes examined by a clinician (Roemer *et al.* 2006) and only 18.2% (n=37) of American university students would delay seeking medical help in the event of a painless testicular lump (Cronholm *et al.* 2009). As for intentions to

perform TSE, 66.7% (n=125) expressed their readiness to perform TSE occasionally (Brewer *et al.* 2011). Likewise, on a scale of 0 to 10, men in the study by Rovito *et al.* (2011) stated that they would consider performing TSE (Mean 7.52/10). McGilligan *et al.* (2009) found that attitude towards TC screening was one of the key predictors of TSE intention.

Only few participants reported performing TSE; of those, very few performed TSE regularly. The percentage of men who performed TSE at least once per month varied between 0% (Daley 2007) and 79.2% (n=586; Kennett *et al.* 2014). Evans *et al.* (2006) compared men's TC screening practices (n=8,680) in 2000 to those of 1990 in 13 different European countries and found that TSE rates have significantly increased (p<0.0001).

#### Barriers to testicular cancer awareness and screening

Health system-level barriers relate to information transmission and education. Men who reported not performing TSE were often uninformed about TC screening, were given pamphlets about TSE with no explanation, or did not know what their physician was looking for during testicular examination (Dubé *et al.* 2005, Rudberg *et al.* 2005, Daley 2007, Handy & Sankar 2008, Cronholm *et al.* 2009, Urgurlu *et al.* 2011, Onyiriuka & Imoebe 2013). These findings are alarming as participants who reported never having heard of TSE were more likely to delay seeking care in the event of a painless testicular lump (Cronholm *et al.* 2009).

Fear of cancer also impacted on TSE. It is notable that 27% (n=200) of participants in one study refused to perform TSE due to fear of detecting a lump (Ugboma & Aburoma 2011). Nevertheless, Brewer *et al.* (2011) found that fear from

TC was associated with increased TSE. Others identified anxiety from false positive findings as a reason not to educate adolescents about TC (Evans *et al.* 2010).

Some of the men's unfavourable attitudes towards TC screening were associated with decreased screening practices. At times, TSE was perceived as unimportant, time consuming, embarrassing, and/or painful (Urgurlu *et al.* 2011, Özbas *et al.* 2012, Muliira *et al.* 2013).

Participants' ethnicity played a key role in shaping their responses. For instance, African American youths were least knowledgeable about TC, were less likely to perform TSE, and were more likely to identify non-risk factors, such as being gay, as a risk factor for TC (Ward *et al.* 2005, Powe *et al.* 2007). The participants' cultural background also affected their knowledge of TC and TSE. Compared to participants in developed countries, men who lived in developing countries were found to be least knowledgeable about TC and its screening. Examples include Turkey (Sirin *et al.* 2006, Urgurlu *et al.* 2011, Özbaş *et al.* 2012, Kuzgunbay *et al.* 2013); Nigeria (Ugboma & Aburoma 2011, Onyiriuka & Imoebe 2013); and Uganda (Muliira *et al.* 2013).

#### Facilitators to testicular cancer awareness and screening

Overall, men were interested in obtaining information on TSE (Casey *et al.* 2010), expressed their willingness to practice TSE, if educated about this practice (Ugboma & Aburoma 2011), and thought that men should be taught about TC through the school or through healthcare providers (Handy & Sankar 2008). A number of men believed that there were no harms from TC education and that positive aspects of TC, such as high curability, must be highlighted in order to overcome anxiety associated with cancer (Evans *et al.* 2010). A number of participants also believed that men

should be encouraged to perform TSE the same way women are encouraged to perform breast self-examination (Dubé *et al.* 2005, Evans *et al.* 2010).

Men who were informed about TC and its screening were more likely to practice TSE (Rudberg *et al.* 2005, Ward *et al.* 2005, Powe *et al.* 2007, Casey *et al.* 2010, Brewer *et al.* 2011, Rovito *et al.* 2011, Kuzgunbay *et al.* 2013, Muliira *et al.* 2013). Mass media and internet served as the most common means through which men learned about the different aspects of TC (Rudberg *et al.* 2005, Daley 2007, Özbaş *et al.* 2012, Kuzgunbay *et al.* 2013, Muliira *et al.* 2013). Other information sources included physical education classes (Ward *et al.* 2005), healthcare providers (Reece *et al.* 2010), and friends and peers (Özbaş *et al.* 2012, Onyiriuka & Imoebe 2013).

Findings from the reviewed studies suggest that knowledge deficit exists regarding TC and its screening. Overall, men who did not know about TC expressed fear of developing it and perceived it as a serious condition. As for TC screening, very few men reported performing TSE either due to lack of education, fear of detecting a lump, or misconceptions about this practice. The majority of those who performed TSE learned about it through mass media. Generally, men expressed their readiness to perform TSE, if educated about this practice.

#### 2.1.4 Discussion

Having heard of TC did not equate to knowing about the various aspects of this malignancy, such as its risk factors, signs and symptoms, and treatment. Evidence suggests that men's knowledge of TC increased over time. However, this increase in knowledge was not found in studies conducted in developing countries. This trend may be attributed to the lack of public awareness and education about TC and its

symptoms in the developing world (Ugboma & Aburoma 2011, Kuzgunbay *et al.* 2013, Muliira *et al.* 2013).

Fear of TC was found to be the most commonly reported feeling. Participants perceived TC as a serious illness, believed that they were at risk for TC, and were afraid of developing it. These participants were more likely to be unaware that TC is curable and believed that TC is not preventable. Such perceptions may stem from the general views of cancer, especially that a cancer diagnosis in general and TC in particular has long been associated with fear (Skaali *et al.* 2009, Saab *et al.* 2014).

A certain degree of knowledge deficit regarding TC screening was noted. Like TC awareness, having heard of TC screening did not equate to practicing TSE or undergoing TC screening by a clinician. Of those who claimed to have heard of TSE, very few knew what to look for while checking their testes. Like TC knowledge, the lowest TSE knowledge scores were noted among men living in developing countries, which was attributed to the lack of public awareness about health surveillance, insufficient health education in schools and universities, and the lack of endorsement of TC practices by policymakers.

Of the risk factors for TC, age was addressed the most. A difference exists between the knowledge of TC risk factors among men living in developed countries (Daley 2007, Powe *et al.* 2007, Cronholm *et al.* 2009, Casey *et al.* 2010) and that of men living in developing countries (Muliira *et al.* 2013, Onyiriuka & Imoebe 2013). Again, this can be attributed to the lack of public awareness and education about TC in the developing world.

Almost all men in the reviewed studies showed a positive attitude toward TC screening. As for help-seeking behaviours, very few stated that they would delay

seeking medical attention in the event of a painless testicular lump. Delay in seeking medical care was strongly associated with not knowing about and/or not practicing TSE, as well as fear from developing TC. Attitudes toward TC screening were thought to be shaped by cultural norms, health education, and the media. In addition, of the small amount of men who reported performing TSE, few did so regularly.

Evidence suggests that participants who did not perform TSE were often uninformed about this practice. Ambiguity of messages delivered by healthcare providers and men's negative attitudes toward TC and TSE served as barriers to TC screening. Evidence suggests that fear of detecting a lump and anxiety from false-positive results played a key role in the participants' refusal to perform TSE. In addition, those who perceived TSE as unimportant, time consuming, embarrassing, and/or painful were more likely to refrain from performing it. Of note, misconceptions about TC screening were predominant in developing countries and stemmed from the pre-existing knowledge deficit about TC and its screening.

As aforementioned, the lowest TC knowledge scores and TC screening practices were noted in studies conducted in developing countries. Conceivably, education could have affected their scores. However, the majority of participants in these studies were university students, including medical students (Kuzgunbay *et al.* 2013). Of note, the risk of developing TC is highest in the USA and Europe and lowest in Africa and Asia (American Cancer Society 2016c). This could be another reason why efforts were not made to increase TC awareness and screening practices in developing countries.

Participants' ethnic backgrounds also were found to influence TC knowledge and screening. In the USA, African American men scored the lowest on questions

about TC and TSE. Despite the fact that the incidence of TC is higher among Caucasians, African Americans are more likely to have advanced TC at time of diagnosis (American Cancer Society 2013). To date, no clear explanation exists for this trend; however, a number of factors could have contributed to these findings. For instance, African Americans learned about TC and TSE through healthcare providers and schools, yet they were less inclined to visit their doctors on a regular basis in comparison to Caucasians (Powe *et al.* 2007). African Americans generally have a lower socio-economic status, which is often associated with lower screening rates, advanced stage of disease at diagnosis, and decreased survival rates (American Cancer Society 2013).

Evidence from the reviewed studies suggests that men who were educated about TC and TSE were more likely to undergo TC screening. In the majority of the studies, mass media served as the key means through which knowledge about TC and its screening was transmitted. Despite its numerous detrimental effects, such as exposure to violent content and harmful lifestyle habits, mass media can play a key role in providing information about safe health practices (Strasburger *et al.* 2012).

The majority of participants believed that TC education is a positive step towards raising awareness of TC and promoting TC screening. They displayed interest in obtaining information about TSE, showed willingness to practice TSE, and thought that men should be taught about TC. Participants also believed that no harm could come from TC education and suggested that delivering useful information and highlighting the high curability rate of TC can help overcome cancer-related anxiety (Evans *et al.* 2010). They also believed that men should be encouraged to perform TSE the same way women are encouraged to perform BSE and assumed that the

normalization of TSE would lead to increased TC screening (Dubé *et al.* 2005, Evans *et al.* 2010).

#### 2.1.5 Limitations

During the review process, a number of methodological limitations were noted. All the reviewed articles fall under the level of evidence C (Armola et al. 2009). Focus groups rather than individual interviews were conducted in all the three qualitative studies. Therefore, some participants may not have been totally forthcoming in their answers which could have led to omission of important details. Furthermore, no metaanalyses or meta-syntheses were identified during literature search. It is worth noting that a multitude of researcher designed questionnaires were used in the majority of the reviewed survey studies which has led to heterogeneous results that could not be combined for a meta-analysis. In addition, the majority of these studies did not report on reliability and validity. Moreover, almost all the reviewed studies used nonprobability purposive sampling which is known to increase the risk of selection bias and yield a sample that is less likely to be representative of the target population (Cochrane Bias Methods Group 2017). Finally, the majority of participants were Caucasians and university students. Data from ethnic, sexual, gender, and religious minorities as well as people with disabilities were not sought, which hinders the generalisability and transferability of findings.

Although rigour was sought while conducting this systematic review, a number of limitations need to be addressed. To serve the aims of this review, the selected quantitative papers were all descriptive survey studies (level C evidence) rather than randomised controlled trials (RCTs; level A or B evidence). Only three qualitative studies were fit for inclusion and were also descriptive (level C evidence) and the only included review was an integrative review (level C evidence) rather than a meta-

analysis or a meta-synthesis. In addition, the heterogeneity of the data collected made it impossible to conduct a meta-analysis, therefore this review falls under level C evidence (Armola *et al.* 2009). It is worth mentioning that the search was limited to three databases (MEDLINE, CINAHL, and Embase) and did not include data from the Grey literature. Moreover, the search was limited to studies conducted between January, 2004 and November, 2014 and studies that were published in or translated to English which leaves room for study selection bias. Reporting bias might have taken place since only findings pertinent to the review aims were extracted and synthesised (Cochrane Bias Methods Group 2017). Finally, some descriptive statistics were calculated using data from the studies which leaves room for error. The risk for this error was minimised by having one of the thesis supervisors cross-check the extracted data.

Despite the limitations, the strengths of this systematic review must not be overlooked. Rigour and thoroughness were sought throughout the review process. In addition, the items of the PRISMA checklist were used to guide the write-up of this systematic review (Moher *et al.* 2009). It is worth mentioning that this is the first and only systematic review that critically appraised the evidence relating to TC knowledge, awareness, attitudes, and screening practices.

#### 2.1.6 Implications

Future research on TC and its screening is needed to close the gap in the literature and address the limitations. The use of standardised, valid, and reliable instruments should be encouraged to allow the replication of studies in different contexts. Moreover, the use of random sampling should be encouraged to minimise the risk of selection bias and yield a representative sample. Despite assessing men's knowledge of TC and TSE, very few studies addressed the means through which this

knowledge is transmitted. For this reason, future research should focus on assessing men's information needs and exploring the preferred means through which they wish to acquire new knowledge. From a qualitative perspective, there is a need to explore the individual man's experience with TC screening and to offer an in-depth interpretation of the psychosocial constituents of this experience. Research on cancer prevention in minority groups is among the top priorities of key oncology nursing organisations such as the Oncology Nursing Society (Wood *et al.* 2014). For this reason, future studies should be targeted towards assessing TC knowledge and screening practice as well as exploring the experiences of ethnic, sexual, gender, and religious minorities as well as people with physical and/or intellectual disabilities. Finally, given that the majority of existing data were collected from universities, future studies that focus on TC knowledge and screening in men with low educational and/or socio-economic background should be considered.

As aforementioned, controversy surrounds educating men about regular TSE. In the UK men are still encouraged to be aware of normal testicular findings without necessarily promoting regular TSE (Cancer Research UK 2014a). In the USA, however, USPSTF (2011) discourages this practice due to lack of evidence regarding the effect of TSE on mortality (Ilic & Misso 2011). The controversy and lack of consensus regarding TC screening might instil a sense of ambiguity amongst healthcare providers and educators. A middle ground could be reached by informing nurses who are involved in health promotion to encourage young men to seek medical attention in the event of scrotal abnormalities such as pain, lumpiness, and/or swelling.

#### **2.1.7 Summary**

A certain degree of knowledge deficit regarding TC and its screening exists.

Generally, men perceived TC as a serious illness, were unaware of its curability, and

were often uninformed about TSE. In addition, not all who claimed having heard of TC screening knew what to look for during TSE. The majority of men perceived TC education as a positive step towards raising awareness of TC and TSE. Men who were educated about TC and TSE were more likely to undergo TC screening. Mass media served as the key means through which men learned about TC and its screening.

Evidence from experimental studies promoting TC awareness and screening is presented in the upcoming section.

## 2.2 Promoting Testicular Cancer Awareness and Screening:

## **A Systematic Review of Interventions**

#### 2.2.1 Significance and Aim

Despite the debate on TC surveillance, a number of organisations still fund TC educational programmes and TC awareness is still being addressed by clinicians, in colleges, and in the mass media (Trumbo 2004, Roemer *et al.* 2006, Evans *et al.* 2011, Kedzierewicz *et al.* 2011, Wanzer *et al.* 2014). Moreover, research efforts are still being made to enhance men's awareness of TC and to promote TC screening. Heretofore, no systematic reviews have been conducted to critically appraise findings from recent studies that aimed at increasing men's awareness of TC and its screening.

The aim of this systematic review was to systematically review studies that were conducted to enhance men's knowledge and awareness regarding TC and its screening and increase their TC screening intentions and practices. The research questions that guided the write-up of this review are as follows: What are the men's: (i) knowledge, awareness, and attitude towards TC; (ii) knowledge, awareness, and attitude, towards TC screening; (iii) TC screening intentions; and (iv) TC screening

practices? This systematic review was published in "Cancer Nursing" (Saab *et al.* 2016b; Appendix 2.3).<sup>2</sup>

#### 2.2.2 Methods

#### 2.2.2.1 Eligibility Criteria

The same eligibility criteria used in first systematic review were used in the present review. However, all included records were interventions that aimed at: (i) increasing men's TC knowledge and awareness; (ii) enhancing their attitudes towards TC; and/or (iii) improving their TC screening intentions and practices.

#### 2.2.2.2 Study Selection and Data Extraction

The same search strategy, keywords, and data extraction table used in the first systematic review were used in the present review. Findings in the extraction table were sorted according to the review questions as follows: What are the men's: (i) knowledge, awareness, and attitude towards TC; (ii) knowledge, awareness, attitude, towards TC screening; (iii) TC screening intentions; and (iv) TC screening practices?

#### 2.2.2.3 Quality Appraisal

The valid and reliable Quality Assessment Tool (QAT) developed by the Effective Public Health Practice Project (EPHPP) was used to evaluate the quality of the intervention studies (National Collaboration Centre for Methods and Tools 2008). This tool is extensively used in systematic reviews and was recommended in the Cochrane Handbook for Systematic Reviews of Interventions as one of the best tools to appraise the quality of health promotion studies (Higgins & Green 2011). The quality of intervention studies is ranked as either strong, moderate, or weak on the basis of six items namely: selection bias, study design, confounders, blinding, data

collection methods, and withdrawals and dropouts (National Collaboration Centre for Methods and Tools 2008).

#### 2.2.2.4 Level of Evidence Assessment

The level of evidence considering the review outcomes was assessed using the Grading of Recommendation, Assessment, Development, and Evaluation (GRADE) tool (Guyatt *et al.* 2008). This step is essential in systematic reviews especially when interventions score low on the QAT. It is worth noting that failure to assess the level of evidence often yields inaccurate recommendations (Higgins & Green 2011). The quality of evidence was assessed in terms of methodological limitations, heterogeneity and/or inconsistency of findings, indirectness of evidence, imprecision of results, and publication bias (Guyatt *et al.* 2008).

Level of evidence assessment is normally a component of a summary of findings table (Schünemann *et al.* 2013). However, given the heterogeneity of the research instruments, times of measurement, and research designs, it was not possible to conduct comparative analysis and to pool data from the reviewed interventions using a summary of findings table.

#### **2.2.3 Results**

#### 2.2.3.1 Study Selection

Database search yielded 3,076 records. Following deletion of duplicates, 1,731 records were independently screened by the researcher and one of the thesis supervisors. Agreement between the two reviewers was found to be satisfactory (kappa coefficient=0.77). Eleven studies were deemed eligible for inclusion. No studies that met the review inclusion criteria were identified during reference list

checks. Record identification, screening, and selection process is illustrated in Figure 2.2.

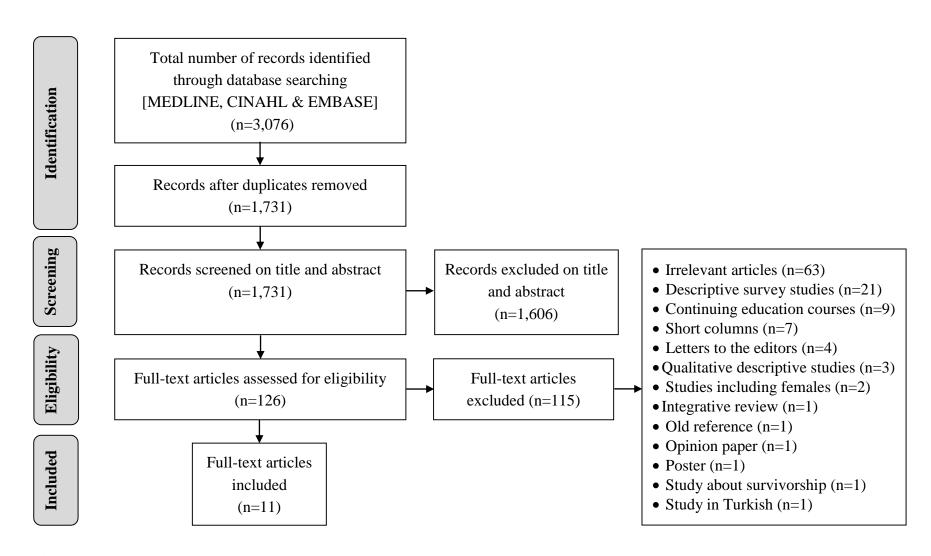


Figure 2.2 Record identification, screening, and selection process (Moher et al. 2009, Saab et al. 2016b)

### 2.2.3.2 Study Characteristics

The reviewed interventions were conducted in the USA (n=5) the UK (n=4), France (n=1), and Pakistan (n=1). Most of the data were collected from university students (n=5). The sample size ranged between 74 (Umeh & Chadwick 2016) and 874 (McCullagh *et al.* 2005) and participants' ages ranged between 15 (McCullagh *et al.* 2005) and 86 (Folkins *et al.* 2005). Pre- and post-test research design was used in the majority of the reviewed studies (n=6), followed by post-test only research design (n=2), randomised controlled design (n=2), and randomised factorial design (n=1).

Of the reviewed studies, six were underpinned by theories, namely: Extended Parallel Process Model (Evans et al. 2011); Standard Model of Health Communication (Wanzer et al. 2014); Theory of Reasoned Action (Trumbo 2004); Implementation Intentions (Steadman & Quine 2004); Health Belief Model (Brown et al. 2012); and Rogers' Protection Motivation Theory (Umeh & Chadwick 2016). Researchers used a number of interventions to increase TC awareness, TC screening knowledge, These intentions, and/or practice. interventions included: self-reflection questionnaires and briefing sessions (Kedzierewicz et al. 2011); information about TC and TSE (Evans et al. 2011); a university campaign using social media, print messages, TC events, videos, and mass media (Wanzer et al. 2014); 'mass-mediated' information delivery (Trumbo 2004); a video about TC using the American Sign Language (Folkins et al. 2005, Sacks et al. 2013); implementation intentions (Steadman & Quine 2004); educational and awareness sessions, symposia, lectures, and hands-on practice (Shallwani et al. 2010); printed educational material about TSE, a shower card, and a peer-taught video (Brown et al. 2012); shower gel sachets with TSE instructions, waterproof stickers and posters (McCullagh et al. 2005) and persuasive messages about TC and TSE (Umeh & Chadwick 2016). Given the use of different interventional approaches and outcome measurements, it was not possible to conduct a meta-analysis, therefore a narrative synthesis is presented.

### 2.2.3.3 Quality Appraisal

The quality of the studies varied between weak (n=6), moderate (n=4), and strong (n=1). The majority of the studies that were considered weak did not use probability sampling and/or did not address blinding of the outcome assessor. Quality rating per study is presented in the data extraction table (Appendix 2.3, Table 1).

### 2.2.3.4 Level of Evidence Assessment

Since the majority of the studies scored low on the QAT, the GRADE tool was utilised to assess level of evidence considering the review outcomes (Guyatt *et al.* 2008; Appendix 2.3, Table 2). The quality of evidence was found to be very low with regard to TC awareness and low in terms of TSE awareness, intentions, and practices. This was attributed to major methodological limitations as well as imprecision in the results. For instance, none of the reviewed studies addressed blinding of the outcome assessor. In addition, the effectiveness of the reviewed interventions was assessed using researcher-designed questionnaires that were neither valid nor reliable. As for imprecision, a number of studies had a small sample size whereby participants were purposely selected and exposed to very few research events (Schünemann *et al.* 2013).

### 2.2.3.5 Synthesis of Results

Based on the review questions, findings from the included intervention studies were presented under four main themes namely: (i) awareness of TC; (ii) TC screening awareness; (iii) TC screening intentions; and (iv) TC screening practices. Findings from individual studies are presented in Appendix 2.3, Table 1.

### Awareness of testicular cancer

Of the reviewed studies, ten addressed awareness of the different aspects of TC. At baseline, knowledge of TC risk factors ranged from 78% (n=31; Kedzierewicz et al. 2011); 47.5% (n=48; Folkins et al. 2005); to 50.6% (n=80; Steadman & Quine 2004). The majority of the interventions that were tailored to increase TC awareness were successful in doing so. For instance, following exposure to a video about TC, TC knowledge increased from 47.5% (n=48) pre-test, to 93.1% (n=94) immediately after the video and remained significantly higher (84.2%, n=80; p<0.05) two months later (Folkins et al. 2005). Likewise, men who were provided with shower gel sachets, stickers, and posters about TC scored significantly higher on questions that assessed TC knowledge in comparison to men in the control group (p=0.014; McCullagh et al. 2005). Similarly, TC knowledge scores were significantly higher among men who received information about TC and TSE as compared to those who received information about TC only and those who did not receive any information (p=0.007; Evans et al. 2011). Following exposure to a university campaign about TC and TSE, students scored higher post-test as compared to pre-test (p<0.001) and had significantly higher TC knowledge scores than the control group (p<0.001; Wanzer et al. 2014). It is worth noting that racial, ethnic, socio-economic, geographical, and sexual disparities were not addressed in the reviewed literature.

### Testicular cancer screening awareness

Knowledge about TC screening was addressed in seven interventions. Knowledge of TSE ranged between 4% (n=3; Shallwani *et al.* 2010) and 16.3% (n=65; Kedzierewicz *et al.* 2011) and did not exceed 53.2% (Steadman & Quine 2004). This was mainly due to lack of education about this practice. University students who

watched a television show about TSE reported significantly higher TSE knowledge scores (p<0.001) and had a more positive attitude towards TSE (p<0.01) in comparison to those who did not watch the show (Trumbo 2004). A series of interventions including lectures, discussions, role-plays, and presentations were successful in increasing men's knowledge of TSE from 4% (n=3) pre-test to 72% (n=41) four months following the interventions (p<0.001; Shallwani *et al.* 2010). In another study, high self-efficacy messages enabled men to feel more capable of performing TSE and improved their attitudes towards this practice as compared to men who got exposed to low self-efficacy messages (p<0.0001; Umeh & Chadwick 2016). Similarly, on a scale of 0 to 10, men who were exposed to messages about TC and TSE had higher TSE self-efficacy (Mean 5.24, 95% CI 6.06 to 6.42, p=0.004) and learned the most about TSE (p=0.004) in comparison to those who were exposed to information about TC only and those who were not exposed to any messages (Evans *et al.* 2011).

### **Testicular cancer screening intentions**

Intention to perform TSE was addressed in six studies. With the exception of the study by Steadman and Quine (2004), the reviewed interventions were successful in increasing men's intentions to perform TSE. For instance, TC screening intentions increased among men who were exposed to TC facts and TSE advice (p=0.002; Evans *et al.* 2011); took part of a TC campaign (p<0.001; Wanzer *et al.* 2014); watched a television show about TSE (p<0.001; Trumbo 2004); and those who were provided with a number of messages about TSE (p<0.0001; Umeh & Chadwick 2016).

### **Testicular cancer screening practices**

Implementation of interventions (n=7) led to a statistically significant increase in TC screening practices among participants. For example, men who were provided with information about TSE using shower gel sachets, posters, and stickers scored higher on TSE practice in comparison to men who were not exposed to TSE information (p=0.006; McCullagh et al. 2005). Similarly, an increase in TSE practices from 2% (n=1) at pre-test to 26% (n=15) at post-test was seen among men who were exposed to a number of TSE interventions (e.g. lectures, discussions, role-plays, and so on; Shallwani et al. 2010). Although small, this change was found to be statistically significant (p<0.001). Moreover, men who were exposed to high self-efficacy messages were found to have the highest odds of performing TSE (OR 3.09; Umeh & Chadwick 2016). Likewise, participants who took part in a series of TC and TSE activities had a significant increase in their TSE practices (p<0.001) and were more likely to perform TSE in comparison to those who were not involved in the activities (p<0.001; Wanzer et al. 2014). Only one study addressed TC screening by a clinician (Kedzierewicz *et al.* 2011). Following a physician-led briefing session, 31.37% (n=16) of those who declined TC examination earlier (n=51), agreed to have their testes examined. Of note, there was no mention of men at risk for health disparities in the reviewed studies.

### 2.2.4 Discussion

A deficit in TC knowledge was seen at baseline in a number of studies. However, the majority of interventions that aimed at increasing TC knowledge were successful in doing so. Men's knowledge of TC risk factors was addressed the most. The remaining studies focused on general TC knowledge rather than knowledge of particular aspects of this malignancy such as its signs and symptoms, prognosis, and

treatment. Interventions that succeeded in increasing TC knowledge included: information about TC and TSE (Evans *et al.* 2011); a university campaign that aimed at raising awareness about TC and its screening (Wanzer *et al.* 2014); a video about TC (Trumbo 2004); and shower gel sachets, stickers, and posters about TC and TSE (McCullagh *et al.* 2005). Overall, limited details were provided regarding the intervention content and the use of underpinning theory. There is evidence, however, that interventions that are underpinned by a theory have a greater efficacy than interventions that lack a theoretical basis (Savage *et al.* 2010).

Lack of education was perceived as the main reason why men did not know about TC screening (Steadman & Quine 2004). Interventions that aimed at educating men about TSE were successful in enhancing their knowledge about this practice. Interventions were also successful in increasing their intentions to perform TSE. Examples include: exposure to information about TC and TSE (Evans *et al.* 2011); a television show that featured a celebrity who survived TC (Trumbo 2004); lectures, discussions, role-plays, and presentations about TSE (Shallwani *et al.* 2010); and exposure to high self-efficacy messages about TC and TSE (Umeh & Chadwick 2016). TC screening practices also increased following various interventions including physician-led briefing sessions (Kedzierewicz *et al.* 2011); a series of TC and TSE activities (Wanzer *et al.* 2014); questions about the time and place where participants plan on performing TSE (Steadman & Quine 2004); exposure to lectures, discussions, and role-plays featuring TSE (Shallwani *et al.* 2010); information about TSE using shower gel sachets, posters, and stickers (McCullagh *et al.* 2005); and high self-efficacy information (Umeh & Chadwick 2016).

Of note, only one intervention was conducted in a developing country (Shallwani *et al.* 2010). Findings from this intervention reflect the overall situation

with regard to cancer screening in the developing world. In Iran, for instance, breast cancer is diagnosed at an advanced stage; this was attributed to the absence of formal screening programmes (Harirchi *et al.* 2011). Similarly, despite clear evidence that breast cancer screening would help reduce mortality among Indian women, no initiatives have been taken to develop a national screening programme (Okonkwo *et al.* 2008). This was thought to be caused by conflicting healthcare priorities and economic circumstances. Another example is a population-based survey that was administered in 57 different developing countries to explore screening practices for cervical cancer. It was found that coverage of screening for this malignancy was on average 19% and was as low as 1% in Bangladesh as compared to 63% in developed countries (Gakidou *et al.* 2008). Alarmingly, women who were at the highest risk for developing cervical cancer were least likely to undergo screening. Once again, these findings were attributed to the absence of adequate healthcare infrastructure and the limited access to health services in the developing world.

Culture is also known to affect cancer screening and is at times perceived as the prime cause of health inequities (Singer *et al.* 2010). For instance, in a survey that explored Chinese-American women's colon cancer screening practices, it was found that older women with a strong Eastern cultural background were least likely to get screened (Wang *et al.* 2006). Straughan *et al.* (2000) and Yu *et al.* (2003) explained this finding in terms of the traditional Eastern culture whereby individuals put a great emphasis on traditional Chinese medicine and often believe that cancer is inevitable and incurable.

Findings from the aforementioned studies on breast, cervical, and colon cancers can be transferred to the TC context. For instance, men in developing countries have a number of misconceptions about TC which hinders screening for this

malignancy. Lebanese men, for example, perceived TC as a life-threatening illness (Saab *et al.* 2014). Moreover, compared to men living in the West, Eastern and African men were found to be least knowledgeable about TC and TSE which was attributed to the lack of national cancer screening initiatives and lack of public awareness with regard to TC screening (Sirin *et al.* 2006, Ugboma & Aburoma 2011, Özbaş *et al.* 2012, Kuzgunbay *et al.* 2013, Muliira *et al.* 2013, Onyiriuka & Imoebe 2013).

Overall, the reviewed interventions were effective in enhancing men's knowledge of TC and its screening, improving their intentions to perform and/or undergo screening, and increasing their screening practices. These findings, however, are presented from men living in developed countries with the majority being university students. Only one study was conducted in the developing world in a community setting (Shallwani *et al.* 2010). Despite addressing TC knowledge among deaf men (Folkins *et al.* 2005, Sacks *et al.* 2013), none of the reviewed interventions included racial, ethnic, socio-economic, geographical, religious, sexual, and gender minorities. This is believed to impede the generalisability of the findings and the applicability of the interventions to minority groups (CDC 2015b).

### 2.2.5 Limitations

Methodologically, the reviewed interventions have a number of limitations that are worthy of discussion. For instance, researchers used different questionnaires to collect data and provided little information about the reliability and validity of their instruments. Moreover, a number of interventional approaches were used to measure different outcomes, which made it impossible to conduct a meta-analysis. Very few researchers reported on how their interventions were tailored and whether they were piloted or not. Furthermore, very few studies addressed the informational needs of men prior to designing and implementing the interventions and a number of studies

had a high attrition rate. For instance, Brown *et al.* (2012) had to change their study design from pre- and post-test to post-test only due to the large number of drop-outs. Moreover, some of the pre- and post-test design studies had a significantly smaller number of participants during post-test, and only two studies reported on the long-term effects of their interventions (Folkins *et al.* 2005, Evans *et al.* 2011).

Despite improving men's awareness of TC and TSE and increasing their TSE intentions and practices, the methodological quality of the majority of the interventions as well as the quality of evidence per review outcome were found to be low, which negatively affects the recommendations made.

Rigour was sought during the review process through the use of the PRISMA checklist (Moher *et al.* 2009). Moreover, to the researcher's knowledge, no previous systematic reviews have been conducted to pool, analyse, and critically appraise findings from recent interventions designed to improve knowledge of TC and its screening and to increase TC screening intentions and practices. Critical appraisal of this review, however, yielded a number of limitations that are worth discussing.

Firstly, the evidence presented within this review cannot be rated as high using the American Association of Critical Care Nurses' hierarchy of evidence (level C evidence; Armola *et al.* 2009). Secondly, selection bias could have taken place due to a number of methodological limitations. For instance, only three databases were used during the search process, studies from the Grey literature were not sought, and the search was limited to studies published in English between the year 2004 and 2014. Moreover, the search strategy was developed to be as comprehensive as possible which limited its sensitivity and specificity, and yielded a large number of hits that were reviewed separately by the researcher and one of the thesis supervisors. Thirdly,

reporting bias could have taken place since only findings that serve the aim of the review and answer the review questions were extracted and discussed. This could have led to missing valuable data. For instance, the effect of the intervention by Shallwani *et al.* (2010) on female participants was not extracted because findings were originally sought from males only. Fourthly, the researcher had to calculate some descriptive statistics that were not explicit in the reviewed studies. This could have led to mathematical errors and consequently faulty data. However, one of the thesis supervisors cross-checked the statistics separately in order to minimise such errors.

Finally, the quality of evidence was assessed based on the review outcomes; therefore, the quality scores could have been different if other outcomes have been considered. In addition, given the heterogeneity of data collection instruments, times of measurement, and research designs, it was not plausible to conduct comparative analysis and to pool data from the reviewed interventions using a summary of findings table.

### 2.2.6 Implications

Minority groups were underrepresented in the reviewed literature which hinders the generalisability of findings and limits their applicability to individuals who are at risk for health disparities. For this reason, researchers are urged to create interventions that are tailored to fit the needs of minority groups, bearing in mind the individual variations within each group. Examples are the studies conducted by Folkins *et al.* (2005) and Sacks *et al.* (2013) whereby videos recorded using the American Sign Language succeeded in increasing the deaf men's TC knowledge. Moreover, the majority of the reviewed interventions were conducted in universities and included relatively educated men, which informs the need to include men with low educational and/or socio-economic background in future research.

It is worth considering the informational needs and the preferred intervention format suited for men prior to designing and implementing interventions. Given the age group at risk for TC, social media and mass media may serve as potentially interesting channels through which men can learn about TC and its screening.

From a methodological perspective, random sampling should be encouraged to yield a representative sample and decrease the risk of selection bias. In addition, researchers should be encouraged to use valid and reliable instruments to assess TC knowledge and screening practices and to utilise theoretical frameworks and models to underpin their interventions (Savage *et al.* 2010). For instance, Wanzer *et al.* (2014) made good use of the elements of the Standard Model of Health Communication to tailor a number of TC events that were designed to appeal to college students. Moreover, behavioural change theories and intervention-based models can assist researchers in promoting awareness of TC and TSE. Examples include: Health Belief Model (Rosenstock 1966); Theory of Reasoned Action (Fishbein & Ajzen 1975); Theory of Planned Behaviour (Ajzen 1985); Social Cognitive Theory (Bandura 1989); Self-Determination Theory (Deci & Vansteenkiste 2004); Transtheoretical Model (Prochaska & Velicer 1997); Precaution Adoption Process Model (Glanz & Rimer 2005); and Tannahill Model (Tannahill 2009).

Findings from this review would enable researchers to plan, design, and test an intervention to raise awareness of TC and its screening. A mixed-methods research approach may be used for this purpose. Researchers could interview the general public and specific minority groups about their knowledge, attitudes, and TSE practices as well as their educational needs and preferred learning strategies. Findings form these interviews would inform the planning, designing, and pilot-testing of a comprehensive intervention aimed at raising awareness of TC and TSE. Adopting this methodological

approach necessitates the integration of one or more of the aforementioned behavioural change theories and intervention-based models.

From a practical standpoint, as mentioned in the previous systematic review, lack of consensus regarding screening for cancer of the testes exists due to the absence of clear guidelines about this practice (Saab *et al.* 2016c). Given the controversy that surrounds TC screening, nurses involved in health promotion could learn from successful interventions to increase men's awareness of TC without necessarily promoting monthly TSE. For instance, nurses could make good use of high self-efficacy messages to increase TC awareness and decrease the fear and anxiety associated with a cancer diagnosis, while bearing in mind the specific needs of minority groups. Nurses could also educate young men about the signs and symptoms of testicular disorders and encourage them to seek timely medical attention in the event of testicular abnormalities.

### **2.2.7 Summary**

In this systematic review, data were extracted from studies conducted to enhance men's knowledge and awareness regarding TC and its screening and increase their TSE intentions and practices. The quality of the majority of the reviewed interventions and the quality of evidence per review outcome were found to be low.

Overall, participants were uninformed about TC screening. Lack of education about this practice has led to decreased TC screening intentions and practices. The majority of the reviewed interventions succeeded in increasing men's awareness of TC and TSE and in enhancing their intentions to undergo screening and perform TSE. Examples of interventions that succeeded in enhancing men's TC and TSE awareness include: TC facts and TSE advice (Evans *et al.* 2011); a university campaign (Wanzer

et al. 2014); information about TSE using shower gel sachets and waterproof stickers and posters (McCullagh et al. 2005); and high self-efficacy messages (Umeh & Chardwick 2016).

It is worth mentioning that men who are at risk for health disparities were underrepresented in the reviewed literature, which raises a number of questions in relation to the generalisability of findings and their applicability to different sociocultural contexts.

Evidence from studies exploring men's awareness of BTDs is presented in the upcoming section.

### 2.3 Males' Awareness of Benign Testicular Disorders: An

### **Integrative Review**

### 2.3.1 Significance and Aim

Numerous research efforts have been made to explore and improve men's awareness of TC and its screening. In addition, two systematic reviews have been conducted to pool and analyse findings from these studies in order to inform research, practice, and education (Saab *et al.* 2016b, 2016c). This is not the case when it comes to BTDs. While a number of papers tackled the diagnosis, clinical presentation, and management of BTDs (Khera & Lipshultz 2008, Osifo & Osaigbovo 2008, Tracy *et al.* 2008, Mohammed & Chinegwundoh 2009, Trojian *et al.* 2009, Wampler & Llanes 2010, Lopez & Beasley 2012, D'Andrea *et al.* 2013, Srinath 2013, Gordhan & Sadeghi-Nejad 2015), very few studies explored males' awareness of these conditions, no identified studies have been conducted to enhance males' knowledge of benign

diseases of the testes, and no reviews have been conducted to critically analyse evidence from studies exploring men's awareness of BTDs.

The aim of this integrative review was to extract and analyse evidence from studies that explored males' knowledge, awareness, and attitudes with regard to BTDs and their screening, and their help-seeking behaviours in the event of abnormal scrotal findings. This review was published in the "American Journal of Men's Health" (Saab *et al.* 2016a; Appendix 2.4).<sup>4</sup>

### 2.3.2 Methods

Integrative reviews are known to be the broadest type of literature review methods allowing for the inclusion of experimental and non-experimental studies as well as theoretical and empirical literature (Whittemore & Knafl 2005). Integrative reviews enable researchers to summarise evidence, understand a particular clinical problem, identify gaps in the literature, appraise the strength of evidence, and determine the need for future research (Russell 2005).

The widely used method proposed by Whittemore (2005) was used to guide the write-up of the integrative review presented in this chapter. This method comprises five key steps namely: problem identification, literature search, data evaluation, data analysis, and presentation (Whittemore 2005, Whittemore & Knafl 2005).

### 2.3.2.1 Eligibility Criteria

Data were sought from records published between the year 1985 and 2015 in peer-reviewed academic journals. Quantitative and qualitative studies that assessed and/or explored men's knowledge of BTDs as well as experimental studies that aimed at increasing men's awareness of these disorders were sought. Systematic reviews, integrative reviews, meta-analyses, and meta-syntheses that addressed BTDs

awareness were also considered in the literature search. As the quality of non-English papers could not be assessed, the search was limited to studies published in or translated to English. Given the paucity of the literature on BTDs, no limits other than language were applied during the literature search.

Studies that offered an overview of BTDs, addressed TC awareness, and included men with pre-existing testicular disorders were excluded based on the assumption that a prior diagnosis of one or more testicular conditions would affect knowledge scores. Assuming that women's awareness of BTDs and their educational needs might differ from those of men, papers that presented findings from females were also excluded. Screening, diagnosis, and treatment guidelines as well as epidemiological studies and expert opinions were also omitted.

### 2.3.2.2 Study Selection and Data Extraction

Four e-databases (CINAHL, MEDLINE, PsychINFO, and PubMed) were systematically searched in July, 2015 to identify studies that were in line with the review aims. Keywords were combined using Boolean operators, MeSH terms, and truncation. Subheadings were also used to yield a wider search and the following search history was generated: (non-maligan\* OR benign OR mass OR lump OR pain OR hydrocele OR varicocele OR torsion OR epididymitis OR orchitis OR swelling OR inflamm\*) AND (testicul\* OR testes OR testis OR testicle\* OR scrot\*) AND (self-exam\* OR "self exam\*" OR screening OR "early detection" OR awareness OR knowledge OR attitude OR practice OR "health promotion" OR symptoms). In addition, the reference lists of potentially eligible studies were checked to find papers that could not be identified during database search.

All the records were exported to and pooled in EndNote X7, duplicates were then deleted. The title and abstract of the remaining records were screened separately by the researcher and one of the thesis supervisors, and the full-text of potentially relevant articles was read. Irrelevant articles were then excluded based on title and abstract. The reviewers' level of agreement was calculated using the kappa coefficient. A score of 0.89 was obtained and was interpreted as satisfactory.

Data were extracted using a standardised extraction table and included: author(s) and year; aim(s); country and setting; study population; research design; data collection instruments; and findings. The extracted data were cross-checked for accuracy by one of the thesis supervisors. The methodological quality of the included studies was then appraised.

### 2.3.2.3 Quality Appraisal

The methodological quality of the reviewed studies was appraised using the tool by Louw *et al.* (2007), Wong *et al.* (2008), Roman and Frantz (2013), and Davids and Roman (2014) discussed in the first systematic review (Saab *et al.* 2016c).

### **2.3.3 Results**

### 2.3.3.1 Study Selection

Database search yielded 4,506 records. A large number of duplicates were deleted (n=2,831) since PubMed is an interface of MEDLINE (Motschall & Flack-Ytter 2005). A total of 1,675 records were screened on title and abstract and full-texts of potentially relevant records (n=55) were read thoroughly. Only four articles were deemed eligible for inclusion. Record identification, screening, and selection process is illustrated in Figure 2.3.

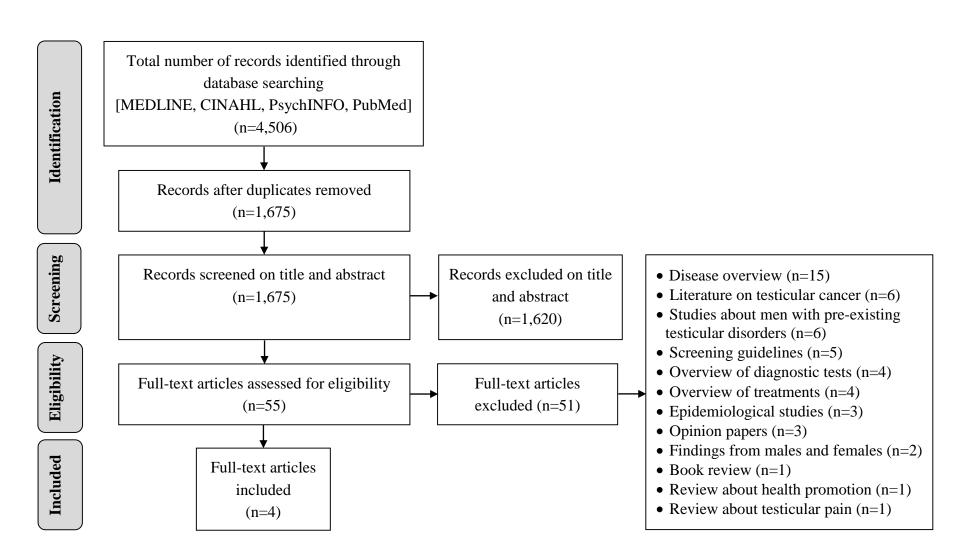


Figure 2.3 Record identification, screening, and selection process (Moher et al. 2009, Saab et al. 2016a)

### 2.3.3.2 Study Characteristics

Studies reviewed were conducted between the year 2000 and 2011. All but one study (Babu *et al.* 2004) were conducted in the USA. Data were sought from schools (Nasrallah *et al.* 2000, Congeni *et al.* 2005), a community setting (Babu *et al.* 2004), and a university (Clark *et al.* 2011). All the studies were descriptive cross-sectional using researcher-designed questionnaires. Only one study reported having a qualitative element (Babu *et al.* 2004), data from this study, however, were collected using a researcher-administered questionnaire and findings were presented and discussed quantitatively. The sample size ranged between 318 (Nasrallah *et al.* 2000) and 755 (Congeni *et al.* 2005) and participants' ages ranged between 12 years (Nasrallah *et al.* 2000) and above 51 years (Babu *et al.* 2004). Two of the reviewed studies addressed general awareness of testicular disorders (Nasrallah *et al.* 2000, Congeni *et al.* 2005), one addressed hydrocele awareness in an endemic area (Babu *et al.* 2004), and the fourth study explored young men's awareness of testicular torsion (Clark *et al.* 2011).

### 2.3.3.3 Quality Appraisal

Quality scores ranged between 43 and 57%. No studies scored high on the quality appraisal tool. Sample representativeness was addressed in one study (Babu *et al.* 2004) and response rate was reported in another study (Clark *et al.* 2011). Data collection instruments were researcher-designed with no information on how the instruments were developed and whether they were pre-tested or pilot-tested. The number of items per data collection instrument ranged between two (Clark *et al.* 2011) and five (Nasrallah *et al.* 2000, Congeni *et al.* 2005). Of the instruments used to collect data, only one reported on reliability (Babu *et al.* 2004) and none reported on validity which makes it difficult to ascertain the consistency, dependability, and accuracy of

findings (Sullivan 2011). Quality assessment of the reviewed studies is presented in Appendix 2.4, Table 3.

### 2.3.3.4 Synthesis of Results

Findings from the included studies were presented under two themes: (i) awareness of BTDs, and (ii) help-seeking behaviours. The complete findings from individual studies are presented in Appendix 2.4, Table 2.

### Awareness of benign testicular disorders

All the participants in the study by Nasrallah *et al.* (2000) and Congeni *et al.* (2005) were exposed to genital examination as part of sports-related check-ups, yet only 54% (n=172) and 50% (n=380) understood the reason behind genital examination respectively. With regard to hydrocele, 69.9% (n=262) of men living in an endemic area in India were aware of the seriousness of hydrocele in their community, yet only 45.5% (n=171) knew that this disease can be transmitted via mosquito bite (Babu *et al.* 2004). Awareness was lowest among individuals belonging to "scheduled tribes, scheduled castes and backward castes" (p. 123) as well as men with primary education or no education (Babu *et al.* 2004). As for testicular torsion, only 18% (n=48) of college students heard of this complication and 43% (n=116) were educated about the seriousness of scrotal pain (Clark *et al.* 2011).

### **Help-seeking behaviours**

Three of the reviewed studies addressed help-seeking in the event of scrotal abnormalities (Nasrallah *et al.* 2000, Congeni *et al.* 2005, Clark *et al.* 2011). Only 15% (n=49) of participants in the study by Nasrallah *et al.* (2000) and 15% (n=112) of participants in the study by Congeni *et al.* (2005) would seek help in the event of

testicular swelling. However, when asked about help-seeking in the event of testicular swelling together with pain, 64% (n=204) and 66% (n=495) stated that they would seek medical attention respectively. In contrast, less than half of the college students (48%, n=110) in the study by Clark *et al.* (2011) chose to seek emergency care in the event of testicular pain and 39% (n=102) chose to delay help-seeking for a day or two.

### 2.3.4 Discussion

Contrary to the literature on TC awareness, very little is known about males' knowledge of BTDs. Only hydrocele and testicular torsion were addressed in the reviewed literature which leaves us with no data regarding males' awareness of other common testicular diseases such as epididymitis, orchitis, and varicocele.

Lack of awareness with regard to BTDs (Nasrallah *et al.* 2000, Babu *et al.* 2004, Congeni *et al.* 2005, Clark *et al.* 2011) and delay in help-seeking in the event of testicular swelling and/or pain (Nasrallah *et al.* 2000, Congeni *et al.* 2005, Clark *et al.* 2011) were the overarching findings across the reviewed studies. Furthermore, very few participants were educated about TSE and scrotal signs and symptoms, which could have contributed to their lack of awareness with regard to BTDs. These findings are echoed in the literature on TC awareness, whereby participants' low knowledge scores were attributed to lack of education about this malignancy (Saab *et al.* 2016c).

Findings from the study by Babu *et al.* (2004) regarding lack of awareness of hydrocele reflect the overall knowledge deficit with regard to TC in the developing world (Sirin *et al.* 2006, Ugboma & Aburoma 2011, Urgurlu *et al.* 2011, Özbaş *et al.* 2012, Kuzgunbay *et al.* 2013, Muliira *et al.* 2013, Onyiriuka & Imoebe 2013).

Low knowledge of BTDs was attributed to a number of factors namely: lack of public awareness with regard to health screening; lack of health education in schools

and colleges; and lack of endorsement of health screening and disease prevention by legislators in the developing world (Ugboma & Aburoma 2011, Kuzgunbay *et al.* 2013, Muliira *et al.* 2013).

As for help-seeking, there is very little evidence with regard to this behaviour in the event of abnormal scrotal findings. It was reported that help-seeking is best in the event of testicular swelling together with pain and worst in the event of swelling alone (Congeni *et al.* 2005). This finding is alarming since, the longer one delays seeking medical attention for scrotal pain, the lower the chances to salvage the affected testis. This is particularly important in cases such as testicular torsion (Ringdahl & Teague 2006, Gordhan & Sadeghi-Nejad 2015, Bayne *et al.* 2017).

Barriers and facilitators to help-seeking were not explored in the reviewed studies and no correlations were made between participants' awareness of BTDs and help-seeking. Drawing from studies on TC, however, one can assume that the more males are aware of BTDs, the more likely they would seek timely medical attention in the event of scrotal symptoms (Casey *et al.* 2011). In the literature on TC, delay in seeking medical attention was attributed to fear from TC as well as lack of knowledge with regard to its screening (Cronholm *et al.* 2009, Saab *et al.* 2016c). Patients with TC in Australia who delayed help-seeking, lacked knowledge about this disorder, misinterpreted their symptoms, had slowly progressing or mild symptoms, were embarrassed from genital examination, were too busy to seek help, and feared orchiectomy (Carbone *et al.* 2009). Similarly, lack of prior knowledge of TC, its risk factors, and its screening contributed to delay in help-seeking among long-term survivors of TC in Lebanon (Saab *et al.* 2014).

Despite the apparent lack of awareness regarding BTDs and delay in seeking help in the event of abnormal scrotal findings, the literature lacks experimental studies to close the knowledge gap and enhance help-seeking. In addition, none of the reviewed studies addressed barriers to knowledge and help-seeking and none highlighted men's information needs and preferred modes of information delivery, which was also reported as one of the major gaps in the literature on TC (Rovito *et al.* 2015, Saab *et al.* 2016b, 2016c).

It is worth noting that minority groups and individuals who are at risk for health disparities were underrepresented in the literature on BTDs, which hinders the generalisability of findings and their applicability to different contexts. This gap was also identified in the literature on TC awareness (Saab *et al.* 2016b, 2016c).

### 2.3.5 Limitations

A number of methodological limitations were identified during the review process. Firstly, all the reviewed studies were descriptive, therefore they do not rank high (Level 4.a) on The Joanna Briggs Institute levels of evidence (Sullivan 2011). Secondly, no experimental studies were identified during literature search which leaves the BTDs knowledge gap unaddressed. Thirdly, only one study reported having a qualitative element (Babu *et al.* 2004), data from this study, however, were collected using a questionnaire and findings were reported quantitatively. No other qualitative studies were conducted to explore males' awareness of BTDs and understand the reasons behind the delay in help-seeking. Fourthly, data were collected using researcher-designed questionnaires. Only one study reported on the reliability of the questionnaire (Babu *et al.* 2004) and none addressed the validity of the instrument used to collect data which hinders the consistency, dependability, and accuracy of findings. Fifthly, non-probability purposive sampling was used to recruit participants

in all the reviewed studies; this could have led to selection bias, thus affecting sample representativeness (Cochrane Bias Methods Group 2017). Finally, only one study included a sample with a relatively low socio-economic background (Babu *et al.* 2004). Other health inequities were not represented in the reviewed studies which adversely influences the generalisability of findings and applicability of recommendations.

Rigour was sought throughout the review process by using the integrative review methodology proposed by Whittemore (2005) and assessing the methodological quality of the included studies. Moreover, this is the first integrative review where findings from studies on BTDs awareness were collated and critically discussed. Some limitations, however, are worthy of discussion.

The lack of evidence regarding awareness of BTDs did not warrant the execution of a systematic review therefore a broader review method was selected. Study selection bias could have taken place due to a number of factors. Firstly, only studies that served the aim of this review were selected therefore discounting other studies that could have offered a different insight with regard to BTDs. Secondly, literature search was limited to four databases and did not include studies from the Grey literature which could have led to omission of potentially important records. Thirdly, reporting bias could have taken place since only findings that answer the review questions were extracted and discussed. For example, in the study by Babu *et al.* (2004), findings regarding women's awareness of hydrocele were not presented or discussed since only data from men were sought. Lastly, during the extraction process the researcher had to calculate some statistics that were not explicit in the reviewed papers, which could have led to statistical errors. These errors were minimised by having one of the thesis supervisors independently cross-check the extraction table.

### 2.3.6 Implications

Knowledge regarding BTDs is suboptimal, which is alarming since a number of testicular disorders can be life-threatening and can have tremendous effects on the man's life. Given the paucity of research on this topic, closing the knowledge gap with regard to BTDs awareness and help-seeking is key. Minority groups were underrepresented in the literature on BTDs, which impedes the generalisability of findings and hinders their applicability to males who are at risk for health inequities. This stresses the need to address BTDs awareness among these groups. In addition, all but one study (Babu *et al.* 2004) included high school and university students who are relatively educated, which warrants exploring BTDs awareness among males from a low educational background.

From a methodological perspective, researchers are encouraged to use valid and reliable data collection instruments in future studies on BTDs. This is thought to yield consistent, accurate, and generalizable findings. Researchers are also encouraged to use standardised methods to plan, develop, and test these instruments prior to collecting data. The use of random sampling must be emphasised to enhance sample representativeness.

The absence of experimental studies in the literature on non-malignant testicular conditions highlights the need to plan, design, and implement educational and health-promoting interventions in this regard. Research efforts should be made to explore BTDs knowledge and understand barriers to help-seeking. Men's educational needs as well as their preferred learning strategies should also be explored. This could be achieved using face-to-face interviews and/or focus groups. Findings from these interviews as well as frameworks for intervention development would help develop, evaluate, and implement complex interventions to raise awareness of BTDs and

encourage early help-seeking (Craig et al. 2013). The use of behavioural change theories and intervention-based models to underpin such interventions is key (Savage et al. 2010). Examples include the Health Belief Model (Rosenstock 1966); Theory of Reasoned Action (Fishbein & Ajzen 1975); and the Theory of Planned Behaviour (Ajzen 1985). Alternatively, researchers can make use of past interventions that succeeded in increasing men's awareness of TC. Examples include university campaigns (Wanzer et al. 2014); mass-mediated information delivery (Trumbo 2004); and educational material printed on shower gel sachets and waterproof stickers (McCullagh et al. 2005).

Findings from the studies reviewed suggest that many of the participants who underwent sports-related physical examination were not informed as to the purpose of scrotal examination (Nasrallah *et al.* 2000, Congeni *et al.* 2005). This stresses the need to prompt clinicians to educate young adults about the usefulness of genital examination in the early detection of both benign and malignant testicular disorders. Clinicians are also encouraged to educate young men about the signs and symptoms of the acute scrotum in order to seek timely medical attention. Moreover, as young men are counselled to practice TSE for the early detection of TC, findings from this review suggest that males ought to be counselled to practice self-examination in order to familiarise themselves with what is normal for them. This can be achieved through the use of a number of creative educational strategies that are tailored to the needs of the younger generation. For instance, clinician-provided websites were identified as the best means to offer quality information about hydrocele, therefore access to such websites must be encouraged (Nason *et al.* 2013). Other examples include: posters, campaigns, videos, and mass and social media.

### **2.3.7 Summary**

In this integrative review, findings from studies that explored males' awareness of BTDs were extracted and analysed. It was identified that, contrary to the literature on TC, very little is known about men's awareness of BTDs and no research efforts have been made to close the knowledge gap. Furthermore, as there is evidence that men's awareness of TC is increasing over the years (Evans *et al.* 2006, Saab *et al.* 2016c), their knowledge of BTDs remains suboptimal.

From a help-seeking perspective, very few males would seek immediate medical attention in the event of testicular pain and fewer would seek it if they noticed testicular swelling. Finally, minority groups as well as individuals who are at risk for or suffer from health inequities were underrepresented in the literature on BTDs.

### 2.4 Overall Conclusion

Evidence from the three reviews showed that a certain level of knowledge deficit exists with regard to awareness of testicular disorders across all three reviews. Participants perceived TC as a serious disease, were unaware of its curability, and were often uninformed about TC screening. Lack of education about this practice had led to decreased TC screening intentions and practices (Saab *et al.* 2016c). The majority of the reviewed interventions were successful in enhancing men's awareness of TC and its screening and in increasing their intentions to self-examine, at least in the short-term (Saab *et al.* 2016b).

Contrary to the literature on TC, very little is known as to men's awareness of BTDs, and no interventions have been conducted to raise awareness of these disorders. As men's awareness of TC is increasing over the years (Evans *et al.* 2006, Saab *et al.* 2016c), their knowledge of BTDs remains deficient. Furthermore, help-seeking

intentions and behaviours in the event of testicular swelling were suboptimal due to a number of psychosocial factors.

The majority of men perceived education as a positive step towards raising awareness of testicular disorders. Participants who were educated about TC and TSE were more likely to self-examine. Mass media was suggested as an essential means to raise awareness of TC (Saab *et al.* 2016b). Alarmingly, individuals who are at risk for health disparities were underrepresented in the studies scrutinised in all three reviews. This is thought to hinder the generalisability of findings and their applicability to various sociocultural contexts (Saab *et al.* 2016, 2016b, 2016c).

None of the reviewed studies addressed men's educational needs and preferred modes of learning (Saab *et al.* 2016, 2016b, 2016c). Moreover, very few studies offered an in-depth understanding of men's awareness of TC (Dubé *et al.* 2005, Daley 2007, Evans *et al.* 2010), none explored, qualitatively, men's awareness of and help-seeking intentions for symptoms of BTDs, and none aimed at raising men's awareness of diseases beside TC. This is essential for the early detection of testicular conditions that could be at times fatal. A summary of the gaps and limitations identified from all three reviews is presented in Table 2.1.

**Table 2.1** Gaps identified in the three literature reviews

Awareness and Screening: A Screening Practices: A Systematic Review of Systematic Review Interventions Integrative Review	
Systematic Review Interventions Integrative Review	W
	W
1. Researcher-designed 1. Very few studies reported 1. Studies were	
questionnaires used on the reliability and descriptive	
2. Focus groups rather validity of data collection 2. No experimental	
than individual instruments studies identified	
interviews 2. Various interventional 3. No qualitative	
conducted in approaches used to measure studies identified	
qualitative studies different outcomes 4. No meta-analyse	S
3. No meta-analyses or 3. Very few studies reported or meta-synthese	S
meta-syntheses on how interventions were identified	
identified designed 5. Researcher	
4. Very few studies 4. Very few studies addressed designed	
reported on the men's information needs questionnaires	
reliability and and preferred learning used	
validity of data strategies 6. Very few studies	
collection 5. High attrition rate across a reported on the	
instruments number of studies reliability and	
5. Non-probability 6. Methodological quality of validity of data	
purposive sampling the majority of collection	
used interventions was low instruments	
6. Men at risk for 7. Level of evidence 7. Non-probability	
health disparities considering the research purposive	
were outcomes was low sampling used	
underrepresented 8. Men at risk for health 8. Men at risk for	
disparities were health disparities	
underrepresented were	
(Soch et al. 2016), 2016b, 216c) underrepresented	

(Saab et al. 2016a, 2016b, 216c).

In order to address many of the gaps identified in all three literature reviews, a qualitative descriptive study was conducted to explore men's awareness of testicular diseases, their help-seeking intentions for testicular symptoms, and their preferred learning strategies in relation to testicular diseases and symptoms, whilst purposely including men who self-identified as gay and bisexual (Chapter 3). Like the literature reviews, the qualitative study helped identify the evidence-base underpinning the E-MAT intervention.

### **CHAPTER**

## 3

# EXPLORING MEN'S AWARENESS, HELP-SEEKING INTENTIONS & PREFERRED LEARNING STRATEGIES IN RELATION TO TESTICULAR SYMPTOMS AND DISEASES: A QUALITATIVE DESCRIPTIVE STUDY

The interventions reviewed in Chapter 2 failed to mention men's education needs and preferred modes of learning a priori (Saab *et al.* 2016b). Similarly, quantitative and qualitative studies exploring men's awareness of testicular cancer (TC) and benign testicular disorders (BTDs), seldom addressed their information needs and preferred learning strategies (Saab *et al.* 2016a, 2016c). For men to be engaged with health promotion initiatives, they must perceive them as relevant to them (Saab *et al.* 2017c). This could be achieved by involving men in the planning stages of health promotion programmes/initiatives (Lefkowich *et al.* 2015).

Very few of the reviewed studies offered an in-depth understanding of men's awareness of TC (Dubé *et al.* 2005, Daley 2007, Evans *et al.* 2010) and none explored, qualitatively, men's awareness of and help-seeking intentions for symptoms of testicular disease. In addition, very few studies included men at risk for health inequities (Babu *et al.* 2004, Folkins *et al.* 2005, Sacks *et al.* 2013) and only one study reported that gay and bisexual men were more likely to perform testicular self-examination (TSE) than heterosexual men (Reece *et al.* 2010). This is quite alarming,

especially that gay men are twice more likely to report a cancer diagnosis than heterosexual men (Boehmer *et al.* 2011).

### **3.1 Aim**

In order to address the gaps identified in the reviewed empirical literature, the study presented in this chapter aimed to explore, in-depth, heterosexual, gay, and bisexual men's: (i) awareness of testicular disorders; (ii) help-seeking intentions for testicular symptoms; and (iii) preferred strategies for learning about testicular symptoms and disorders in the Irish context.

Findings from this study were published in the "International Journal of Nursing Studies" (Saab *et al.* 2017a; Appendix 3.1)<sup>4</sup> and the "European Journal of Oncology Nursing" (Saab *et al.* 2017b; Appendix 3.2).<sup>5</sup>

### 3.2 Methods

### 3.2.1 Study Design

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 & Lincoln 1994). Qualitative description is suitable for obtaining candid and predominantly unadorned responses to questions that are of interest to researchers, practitioners, and policymakers. Examples include: "What are the concerns of 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, help-seeking intentions, and preferred learning strategies in relation to testicular symptoms and diseases. The 21

items of the Standards for Reporting Qualitative Research (SRQR) were used in the reporting of this study (O'Brien *et al.* 2014; Appendix 3.3).

### 3.2.2 Sample Selection

Purposive sampling, specifically maximum variation and snowball sampling, were used to locate and recruit a heterogeneous sample of information-rich key participants (Patton 1990, Grove *et al.* 2015). Maximum variation sampling allows researchers to describe a certain phenomenon from the viewpoint of a diverse sample. In this study, a sample that was varied in terms of age, socio-economic status, ethnicity, and sexual orientation was sought. Participants were then asked to invite other men who fitted the inclusion criteria to partake in the study, which is the key feature of snowball sampling (Patton 1990). It is worth noting that both sampling strategies are recommended and are widely used in qualitative descriptive nursing research (Sandelowski 1995). Moreover, these strategies serve as efficient means to recruit hard-to-reach participants (Sadler *et al.* 2010). This is key, as an open discussion of intimate subjects is uncommon among men, let alone young and relatively healthy men from different socio-demographic backgrounds.

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. 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, 2016b, 2016c). In addition, men aged 18 to 50 years were invited to participate, since those who fall in this age bracket are at the highest risk for developing one or more testicular disorders (Ringdahl & Teague 2006, CDC 2015a, Bayne *et al.* 2017).

### 3.2.3 Data Collection

Ethical approval was obtained from the Clinical Research Ethics Committee at University College Cork (Appendix 3.4). A standardised invitation letter was sent by e-mail to members of an inclusive community choir, youth organisation, surfing club, family community centre, and all students and staff in a university in the Republic of Ireland (Appendix 3.5). In addition, study flyers were hung in a university sports centre and on campus (Appendix 3.6). Those who replied to the e-mail and agreed to participate were asked to identify other men who would be potentially interested in participating.

Data were collected between December, 2015 and February, 2016 using faceto-face individual interviews and focus groups. The combination of individual interviews and focus groups, also known as data source triangulation, is known to enrich qualitative data (Lambert & Loiselle 2008, Carter et al. 2014). Data source triangulation in qualitative research offers a better understanding of complex phenomena and provides strengths from conducting both, individual interviews and focus groups (Lambert & Loiselle 2008, Carter et al. 2014). For instance, individual interviews "allow for spontaneity, flexibility, and responsiveness to individuals" (Carter et al. 2014 p. 545), whereas, focus groups "elicit data from a group of participants who can hear each other's responses and provide additional comments that they might not have made individually" (Carter et al. 2014 p. 545). In the present study, focus groups and individual interviews were conducted simultaneously for pragmatic reasons. Each participant was given the choice to participate, either in a focus group discussion or in an individual interview. This was attempted in order to minimise refusals and withdrawals among those who did not feel comfortable discussing intimate topics in front of other men.

Participants were asked to indicate a suitable date, time, and location for the interview. Ten interviews were conducted in the researcher'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 socio-demographic backgrounds (e.g. age, nationality, sexual orientation, marital status, level of education, and occupation). This was thought to foster open discussions and enrich the collected data.

All interviews were audio-recorded and transcribed verbatim. The researcher had no previous relationship with the participants. He was male, a doctoral-level graduate student in nursing, formally trained in qualitative research, and had experience in interviewing men about sensitive health issues. This was thought to facilitate data collection and get men to openly share their experiences and insights.

The right for full disclosure was ensured by providing participants with an information leaflet listing the aims of the study and what their participation entailed (Appendix 3.7). Participants were also provided with a referral form with the contact details of free counselling and support services in case they experienced psychological distress (Appendix 3.8). Informed consent was obtained (Appendix 3.9) and participants were requested to fill a brief socio-demographic questionnaire that was designed by the researchers to collect data on the participants' age; nationality; sexual orientation; relationship status; highest level of education; employment status; and past history of a testicular disease (Central Statistics Office 2011). Participants were also asked whether they were previously educated about testicular diseases. Finally,

participants were asked to rate the importance of learning about testicular diseases on a Likert scale from 0 to 10; 10 being "Very Important" (Appendix 3.10).

An interview protocol was developed to address the gaps identified in the reviewed literature on men's awareness of testicular disorders (Saab et al. 2016a, 2016b, 2016c; Appendix 3.11). Interview questions were guided by the aims of the present study. The opening question was: "What is the first thing that comes to your mind when I say 'testicular diseases or disorders'?" Open-ended probes were used to explore the participants' responses in greater depth. Examples include: "How come (the answer) crossed your mind? 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 you, or someone you know happens to discover a lump in the testes, how would you/they react? Can you please elaborate?" The third key question was: "What are your views and opinions regarding increasing men's awareness of testicular diseases?" Probes were in relation to the participants' preferred learning strategies, whether the same strategies could be used to promote awareness of testicular symptoms and disorders, and whether the same strategies are suited for men with different sexual orientations. Reflective field notes were taken after each interview to capture non-verbal cues (Grove et al. 2015).

Interestingly, getting men to openly discuss their insights in front of others during focus groups was found to be more challenging than recruiting them into the study. As a result, a number of participants were holding back during focus groups, especially those with a past history of a testicular disorder. However, a lot of those

who were silent in the beginning of the interview, seemed more relaxed and outspoken as the interview went on.

Data saturation was achieved at 24 participants; five additional individual interviews were conducted to confirm saturation. In total, 12 individual interviews and three focus groups were conducted with 29 men. Two focus groups included six participants each and one focus group comprised five participants. On average, interviews lasted between 31 and 62 minutes (Mean 45 minutes).

A brief summary of the transcripts was shared with five participants via e-mail. Participants were asked to provide their feedback as to whether the summary was reflective of the key issues discussed during the interview. The plan was to share the summary with more participants if discrepancies arose; however, all five participants agreed to the summary. This measure is commonly known as member-check and is often regarded as a crucial technique to establish credibility (Lincoln & Guba 1985). Member-check also gives the participants the opportunity to reflect on their responses and correct misinterpretations.

# 3.2.4 Data Analysis

Data analysis took place concurrently with data collection. Identifiers were omitted to maintain anonymity and confidentiality. Transcripts were analysed using inductive content analysis (Elo & Kyngäs 2008). Unlike deductive content analysis, inductive content analysis is recommended when prior knowledge of a certain phenomenon is limited (Lauri & Kyngäs 2005). Moreover, this analytical framework was selected to explore manifest content (e.g. participants' own words) and to a lesser extent, latent content.

A coding sheet was created following an iterative process of discussion among the researcher and thesis supervisors and based on the literature on qualitative content analysis (Graneheim & Lundman 2004). The coding sheet had four sections divided into four columns; the first column contained the question asked, the meaning unit (i.e. excerpt) was included in the second column, the third column comprised the condensed meaning unit (i.e. summary of the excerpt), and the last column contained the code. A sample coding sheet for one of the individual interviews in presented in Appendix 3.12. Transcripts were read carefully and a summary of excerpts 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. Finally, themes that connect the various categories were identified. Non-verbal cues that were highlighted in the field notes were used to enrich the data. Audio-recorded memos were used throughout data analysis to enable the researcher to clarify his thoughts and reflect on the analysis process (Birks *et al.* 2008, Grove *et al.* 2015).

# 3.2.5 Enhancing Trustworthiness

Credibility was enhanced by recruiting a heterogeneous sample of participants from a university and a number of community organisations. Credibility was also addressed by sharing a summary of transcripts with selected participants in order to confirm that the researcher's analysis reflected the key points discussed during the interviews (Cope 2014). Moreover, field notes were taken immediately following each interview in order to capture the participants' non-verbal responses to the researcher's inquiries including moments of silence, laughter, crying, nervousness, and so on; this approach is also known to enhance credibility and to enrich qualitative data (Elo *et al.* 2014, Phillippi & Lauderdale 2017).

Dependability was established by having the researcher and thesis supervisors independently review the coding process and agree on the sub-categories, categories, and themes. Moreover, an audit trail was provided in the present study and was shared with the thesis supervisors in order to clarify the complete data collection and analysis processes. Confirmability was addressed through maintaining constant dialogue between the researcher and thesis supervisors and using audit trails. Confirmability was also enhanced by including excerpts from the participants in order to help determine how conclusions were drawn and assumptions were made (Graneheim & Lundman 2004, Saldaña 2009).

Transferability was enhanced by thickly describing the data collection process and sample characteristics and seeking a heterogeneous sample (Graneheim & Lundman 2004). Reflexivity was established by keeping audio-recorded memos during data analysis, which enabled the researcher to reflect on the data analysis process, clarify his thoughts, and group similar codes together (Birks *et al.* 2008). Finally, authenticity was ensured by establishing a trusting relationship with the participants and putting them at ease through the use of icebreakers such as providing healthy snacks, coffee, and tea during interviews and asking participants questions about work/university prior to data collection (Holloway & Wheeler 2010).

# 3.3 Results

# 3.3.1 Sample Characteristics

The age of participants ranged between 18 and 47 years (Mean 33.5, standard deviation [SD] 8.8). Seventeen men self-identified as heterosexual, 11 as gay, and one as bisexual. The majority of participants were single (n=16), held a university degree (n=20), and were employed full-time (n=14; Table 3.1).

**Table 3.1** Socio-demographic characteristics of the participants in the qualitative study (n=29)

Age (years)	
Range	18-47
Mean(SD)	33.5(8.8)
Nationality	
Irish	20
Other European	4
Dual citizenship	3
Lebanese	1
Mexican	1
Sexual orientation	
Heterosexual	17
Gay	11
Bisexual	1
Marital status	
Single	16
In a relationship/partnered	6
Married	5
Separated/divorced	2
Highest level of education	
Primary	1
Secondary	2
High school	6
University	20
Occupation	
Employed (full-time)	14
Employed (part-time)	2
Self-employed	1
Student and employed (part-time)	2
Student	6
Intern	1
Unemployed	3
(0 1 1 2015 20151)	

(Saab et al. 2017a, 2017b).

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 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' sociodemographic characteristics were reflective of those of men living in Ireland in terms of employment status and level of education (Central Statistics Office 2011).

Almost half of the men were uninformed about testicular disorders. Those who reported having heard of these disorders, did so through school, college, their physician, peers, family history, a video, a movie, a journal, and a campaign by the Irish Cancer Society. Twenty-one participants intended to seek information about testicular disorders, 27 men rated education about testicular disorders as "Very Important" and two rated it as "Important."

Three themes emerged from the interviews as follows:

- (i) Awareness of testicular disorders and their screening (Categories: impediments to and enablers for awareness).
- (ii) Help-seeking intentions for testicular symptoms (Categories: barriers and facilitators to help-seeking intentions).
- (iii) Preferred learning strategies in relation to testicular symptoms and disorders (Categories: strategies to enhance awareness, educational dos and don'ts, implications of raising awareness, and learning among gay and bisexual men).

All themes, categories, and sub-categories are presented in Table 3.2. Pseudonyms were used while referring to the participants.

**Table 3.2** Themes, categories, and subcategories

Table 3.2 Themes, categories, and subc Sub-category	Category	Theme
Lack of knowledge	Caugury	1 Hellie
<ul><li>Beliefs and attitudes</li></ul>		
<ul><li>Perceptions of the healthcare</li></ul>		
system	Impediments to	
<ul> <li>Awareness not promoted in</li> </ul>	awareness	Awareness of testicular disorders and their screening
school system		
<ul> <li>Lack of screening for testicular</li> </ul>		
disorders		
Prior knowledge		
<ul> <li>Beliefs and attitudes</li> </ul>	Enablers for awareness	
• Exposure to pertinent information		
<ul> <li>Testicular self-examination</li> </ul>		
practices		
<ul> <li>Clinical testicular examination</li> </ul>		
<ul> <li>History of testicular disorders</li> </ul>		
<ul> <li>Changes over time</li> </ul>		
Identifying as gay		
<ul> <li>Lack of knowledge</li> </ul>	Barriers to help- seeking intentions	Help-seeking intentions for testicular symptoms
<ul> <li>Symptom misappraisal</li> </ul>		
<ul> <li>Emotional factors</li> </ul>		
<ul> <li>Health beliefs and attitudes</li> </ul>		
<ul> <li>Social factors</li> </ul>		
<ul> <li>Cultural influences</li> </ul>		
Process of seeking help		
<ul> <li>Access to support</li> </ul>	Facilitators to help- seeking intentions	
<ul> <li>Presence of pain and lump</li> </ul>		
<ul> <li>Inherent health-seeking drive</li> </ul>		
<ul> <li>Perceived threats</li> </ul>		
Cultural factors		
<ul> <li>Television</li> </ul>	Strategies to enhance awareness	Preferred learning strategies
• Internet		
<ul> <li>Campaigns</li> </ul>		
Print media		
Tailoring effective messages	Educational dos and	in relation to
• Drawbacks of national initiatives	don'ts	testicular symptoms and disorders
Ineffective learning strategies		
Risks of increasing awareness	Implications of	
Benefits of increasing awareness	raising awareness  Learning among gay and bisexual men	
• Learning needs		
• Educational strategies		

(Saab *et al.* 2017a, 2017b).

# 3.3.2 Awareness of Testicular Disorders and Their Screening

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

# 3.3.2.1 Impediments to Awareness

All the participants had heard of TC and many perceived it as the most 'advertised' testicular disease. However, having heard of TC did not necessarily imply that men were aware of its risk factors, treatment, and screening. Lack of awareness was attributed to a multitude of factors, including the prevailing beliefs and attitudes towards testicular disorders, perceptions of the healthcare system, awareness not being promoted in the school system, and 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 hear anything specific about it... But I know it exists and I wouldn't really know what the 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 ages at risk?... If I don't have testicular cancer now, so it's harder for me to get it later?" In contrast, very few participants heard of other testicular disorders. For example, when asked about his awareness of diseases of testes, Juan said: "I have heard about testicular cancer, so I think that's probably really the only one that I know, I cannot name any other disorder."

Trivialisation of testicular symptoms and uncertainty regarding testicular diseases were also identified as barriers to awareness. As he was discussing how men take testicular symptoms for granted, Patrick said:

"You get a kick in the balls. Oh, it's painful, it's quite painful, but then it goes away and a lot of people think the issue is like that and they don't really think much further because they don't like thinking about their balls. They're there, that's it, I'm done with them!"

In many cases, the lack of awareness was linked to a number of misbeliefs. For example, Ziad had a number of misconceptions about TC. As he was recalling his sexual encounter with two men who had TC; he laughed nervously and said: "...If it happened to those people that I met, it's going to happen to me. Or oh, it can infect me."

A number of men believed that national health campaigns tend to focus on women's rather 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 too late'. And then at the end of it, it says, 'Jerry died shortly after making this ad'. I mean 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..."

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 boys' school, believed that class conversations about sexual health are not facilitated by the teachers and/or curricula; he said:

"When it comes to teaching about reproduction and the reproductive system, they (curricula) talk a little bit about sexually-transmitted diseases... As if the students are not entitled to have this kind of knowledge... Even teachers, they just skip those chapters... In SPHE (Social, Personal and Health Education) there is a chapter about sexuality but still, it is done just to tick a box."

Most participants reported not practicing TSE either because they did not know how or because they were unfamiliar with their own testes. For instance, Juan stated that he was unaware that the scrotal raphe was part of the normal anatomy of the scrotum. Although it worried him for many years, he never discussed it with anyone; he said:

"In my testicles, there is a small line between the two testicles in the skin. For a very long time, I thought that that was not normal... I was not able to ask anybody. When my son was born and I was changing his diaper, I saw that he had the same skin there and I was like, Oh! it's normal!"

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 (TC). 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 knowing about testicular disorders; he said: "I am not an extremely ignorant person, I am 41 years of age and I don't know how to check myself, you know GPs probably don't do it as a standard for physical check-up..."

#### 3.3.2.2 Enablers for Awareness

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

Most participants believed that TC is curable and has a low fatality rate. This was evident in a focus group whereby Conor and Patrick were discussing the prognosis of TC among each other and said: "If caught early it (TC) is very curable... It's got a 95% cure rate in this country."

A number of men reported being inherently health-conscious which served as an enabler to awareness. In addition, awareness was linked to increasing age and the cumulative impact of poor diet and lifestyle over time. This was evident in the following excerpt by Jack:

"I'm in my mid-30s now and when you're in your mid-30s, this might sound a bit grim, you 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 checking while watching a television programme, Liam who learned about testicular disorders during his work with urology patients, and William who learned about TSE 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 TC from the news about Lance Armstrong, a celebrity cyclist who survived TC. Moreover, Daniel's awareness of TC increased after his doctor checked his testes; he said:

"I remember recently I had to go to the doctor for something not related to testicular disorders and then the doctor was asking me about how aware are you of testicular cancer and she examined me around that area then for lumps, this never happened before, so maybe I have more awareness now."

As for TSE, only few participants endorsed this practice. An example is Tom who reported practicing TSE occasionally in the toilet. However, when asked whether he knew what he was looking for; he said: "No, I'm going by look and touch."

Men with a personal or family history of a testicular disease and those who knew someone who developed a testicular disorder, were clearly more aware. This was the case for William and Richard who became aware of testicular torsion after developing it and Shane who became aware of TC after his father was diagnosed with it; he said: "It wouldn't have been in 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 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 ourselves..."

Interestingly, many participants stated that self-identifying as gay was an enabler to awareness. For instance, Mark and Tom who self-identified as heterosexual, assumed that gay men have higher health awareness, and are more comfortable with their own testes as well as the testes of other men. For instance, Tom said: "A gay man has potentially the benefit of a partner with the same, you know, biological structure." This was echoed in the interview with Kevin who self-identified as gay; he said:

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

The second theme (i.e. help-seeking intentions for testicular symptoms) and associated categories are presented in the upcoming section.

# 3.3.3 Help-Seeking Intentions for Testicular Symptoms

Men's help-seeking intentions for symptoms of testicular disease were explored using two scenarios. First, participants were asked to describe how they would react in the event of 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.

# 3.3.3.1 Barriers to Help-Seeking Intentions

Several men intended to delay help-seeking because they did not know what to look for during TSE 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."

Symptom mildness, fluctuation, and the thought that the symptom was caused by 'something else' also negatively influenced men's help-seeking intentions. For example, symptom misappraisal stopped Ross, a surgeon and a survivor of advanced TC, from seeking help for 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 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 thinking that his pain was going to go away. As he was telling his story, Ross got emotional and said:

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

Beside fear, a number of participants identified embarrassment and dysfunctional coping as emotional factors that would impede help-seeking. An example is Rafael who said: "If we were to go to our GP we're going to just strip naked and let an old guy see your junk." 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 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, 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, was falsely reassured by his friend who was a medical student that the yellow discoloration in 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 emergency care. Ron, on the other hand, had no intention to seek help and visiting a doctor was not on his list of priorities; he said:

"Honestly, that kind of a thing goes way down my to-do list. Like I'm busy, I'm hardly going to clear off my agenda so that I can go... I've got other things to worry about... And I don't prioritise it... There are more important things."

A number of participants stated that the social norms that often define a man (e.g. machoism, stoicism, and unrealistic optimism), stand in the face of help-seeking. In addition, the Irish sheltered upbringing was perceived by many to negatively affect men's intention to seek help. For instance, while discussing his brothers' and father's reluctance to visit a doctor, 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 body, I may consider going next week."

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.

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 doctor as regularly because we're like oh, we don't want to be seen as hypochondriacs." 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 we won't be the person it'll happen to, so why concern yourself with that?" Others thought that they were too young to develop a disease in their testes. An example is Omar who was 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 stated that the waiting time and long queues in the GP's clinic and the emergency department would make them think twice before seeking help. This was the case for Tom who said: "We have the second-worst waiting lines in Europe." The gender of the physician also seemed to influence men's intentions to seek help. For instance, Rafael said: "I'd feel better if it was a female doctor. I wouldn't like a man touching me", whereas Henry reported that he would feel more comfortable with a male doctor since "he has some (testes) also."

# 3.3.3.2 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.

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 my partner (male) to check it because I would just need that affirmation to be like, 'No, you're definitely right'."

The severity and duration of pain and changes in symptoms were identified by those with a history of a testicular disorder as facilitators to help-seeking. For instance, it was the intensity 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 to the hospital, he said:

"Immediately when I found it... Luckily so because they said it would be four or six hours and it (the testicle) could have been dead... When I touched it, it was the size of a tennis ball. Close to that. It was just so abnormally large and it was so taut!"

Participants who reported being inherently health-conscious stated that it was 'alright' to seek help and said that they would not wait for symptoms to get worse. An example is Adam who said: "If there was something amiss with me and there was pain, I would be investigating."

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 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..."

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 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."

The third and final theme (i.e. preferred learning strategies in relation to testicular symptoms and disorders) and associated categories are presented in the upcoming section.

# 3.3.4 Preferred Learning Strategies in Relation to Testicular Symptoms and Disorders

# 3.3.4.1 Strategies to Enhance Awareness

Participants were asked to reflect on a health topic that they recently learned about and is of interest to them. They were then asked about the means through which they learned about this topic and whether the same strategy could be used to raise men's awareness of testicular disorders. As a result, a number of media were identified including television, internet, campaigns, and to a lesser extent, print media.

#### **Television**

For many participants, the television served as the primary source of health information. For instance, all five participants in a focus group came across TC and its screening while watching the same television programme. Of these participants, Aaron said: "I've learned more about medical issues in that programme than I've ever learned in my life!" when asked what drew his attention to this specific programme, he said: "It's kind of real people coming in and they make it sexy a little bit." This was reiterated by Hans who, when asked whether he got exposed to prior information on testicular disorders, said:

"It was in a documentary about sexual health in young people and I thought it was a really good thing. They didn't actually censor anything. They sent the young people in to the doctor's. You saw full frontal; you saw everything getting checked."

#### **Internet**

The internet in general, and social media in particular, were perceived by many as the best methods to deliver health information to younger men. This was evident in the following excerpt by Ziad: "A lot of young people are always on social media, so Snapchat, viral videos, Facebook viral videos, YouTube viral videos." Similarly, Kevin believed that awareness of testicular disorders can be raised using social marketing; he said: "We're a Facebook, Twitter generation... The 20s, 30s and 40s are going to be on Facebook or Instagram." Mobile applications were also identified as methods to promote awareness. For instance, William found out about free HIV testing through an advertisement on a gay dating mobile application; he said: "I actually think that they probably would do it for free because that's how I found out about the first prick test, from Grindr (gay dating mobile application)."

# **Campaigns**

A number of participants stated that awareness of testicular disorders could be enhanced via campaigns in schools, colleges, sports clubs, and workplaces. For instance, the "Movember" campaign was identified by many as an effective method to raise men's awareness of testicular diseases. Of these participants, Ross said: "Most people would be aware of Movember. Like oh yes, prostate cancer. It's men's health. Like that part of it and it happens every year. There's some kind of a novelty." To which Daniel responded:

"For Movember, you had all the Irish rugby team all of a sudden growing beards. Jeez! the whole country had beards!... You had a couple of good-looking guys playing rugby for Ireland and all of a sudden, it's trending."

More than half of the participants believed that, unlike men in the workplace, young males in schools and universities are easily accessible. This was evident in the following excerpt by Tom:

"You need people talking in universities and schools, because fundamentally that's where you're going to find people because once again, into adulthood, you're not going to really get the same kind of level of attention."

This was reiterated by Shane who said:

"I think when you're in school or you're in college, you're in a collective audience and maybe you'll get exposure to information about health on some level...

But as soon as you go into the workplace, it doesn't really seem to happen."

In order to address this issue, Patrick proposed targeting men in large firms and involving the human resources department within large organisations in promoting the wellbeing of their male employees.

A number of participants recommended delivering educational messages to young men attending Gaelic Athletic Association (GAA) sports clubs. For instance, Luke said:

"I would think groups or organisations that would be focused on young men if they had some sort of a campaign running focusing on these groups like a lot of the GAA would have men you know 18 to 30 group if you could go up to their clubs..."

Of note, GAA is known as Ireland's largest sporting organisation promoting Gaelic games such as hurling and Gaelic football (Lane *et al.* 2017).

#### Print media

Leaflets, posters, and booklets were suggested by very few participants as tools to raise awareness of testicular disorders. For instance, Juan believed that the leaflets used to promote breast cancer awareness can be used to promote TC awareness and screening; he said: "Sometimes when I go to the medical doctor, I don't find one of these brochures there, which says, 'Check your testicles'. Something like the breast cancer thing that is always there"; he laughed and added: "I mean I don't have breasts, but I know how to check!" Juan did, however, warn from flyers that are of a promotional nature; he said: "You need to check if this is like from a pharmaceutical or this is from the government, who is guiding the thing (flyer) because you feel like

they are trying to sell you something." Tom on the other hand, suggested putting together and distributing a booklet that covers all male specific diseases.

#### 3.3.4.2 Educational Dos and Don'ts

When asked about the strategies that can be adopted to educate men about testicular disorders, participants recommended approaches that might work and warned from others that they thought are ineffective in fostering learning.

# Tailoring effective messages

Many participants perceived an effective educational intervention as being brief, visually stimulating, innovative, positively worded, and delivered frequently using light and simple language. For instance, Patrick who recommended using creative messages, said:

"You could have some sort of a catchphrase, like you know, a ball in the hand or that kind of thing... Sort of a play on words... People will laugh and they'll gather and they'll talk to each other about it."

To grab men's attention, Henry recommended advertisements that lighten the mood and that are visually appealing; he said:

"I think if a man saw an ad that kind of lightened his mood, rather than brought him down, it'd be more inclined to get his attention... But if it was just figures and words, they'd be like inclined to change channel, but if it was a funny ad, they'd be more inclined to watch it, rather than switch over."

He also believed that men are visual rather than book learners; he added: "We're not book learners. I mean some people are. But I think we're a lot more visual and hands-on in how we get educated. So I think it has to be more of that approach

rather than just words." Similarly, Luke recommended messages that are light and positively rather than negatively worded; he said:

"Make it light-hearted... Make it look like it's part of your monthly routine...

Make it come across that it's something because you are doing this doesn't mean you are going to find something you are doing this because everybody else is doing it."

Antonio who had an interest in media and marketing, said that educational messages must be repeated otherwise they "will wear thin"; he added: "You need to change approach every couple of years, regardless of what the message is." This, according to Kevin, would help achieve a "top-up effect." Ziad and Daniel believed that "brief and frequent messages" as well as "very snappy and appealing" messages are more likely to be effective in raising awareness of testicular diseases. Furthermore, Hans and Jack believed that, for an educational strategy to be effective, it must be delivered "in small chunks on a regular basis" in order to avoid "overloading people."

A number of participants recommended having a celebrity who appeals to the masses deliver the educational messages. For instance, Mark said: "If you get those people who are looked up to, like you've soccer stars, rugby stars, GAA stars, you know, if they're talking about it, people might talk about it." This was echoed in the interview with Harry who believed that having an idol teach men about TSE helps "remove some of the embarrassment." Similarly, Kevin believed that having a celebrity discuss testicular diseases "immediately takes away the stigma"; he added: "People only really like shock tactics, so there's no point in you coming out and talking about testicular diseases after having never had one because nobody would care."

#### **Drawbacks of national initiatives**

According to a number of participants, campaigns such as "Movember" became more about growing facial hair rather than raising awareness of male cancers. For instance, Patrick stated:

"It (Movember) just seems to be an excuse to grow a moustache and look funny because I see a load of people doing it, but I never hear them actually talking about getting checked themselves..."

Connor nodded in agreement and said: "I'd say a lot of people have lost the message of Movember." Ziad, on the other hand, believed that national campaigns are a waste of resources and are conducted to tick a box, rather than to raise awareness; he said:

"With national campaigns, you feel as if they are just a waste of money because this is just my own general personal feeling, is that oh, we have to do something, we are a charity, we have this amount of money, we have to spend it, we just do it because we have to do it, we tick a box so it's done."

Targeting the wrong age group was also perceived as a drawback of national initiatives; for instance, as he was recalling a television campaign by the Irish Cancer Society, Tom said "I remember the advertisement being typically targeted at older men rather than younger men, as a result, I lost interest automatically."

# **Ineffective learning strategies**

Strategies that were perceived by many participants as ineffective in fostering awareness include print media as well as messages containing medical jargon. At first, Tom was recommending a booklet that includes the most common male diseases; he

then hesitated and said: "I think I have read one study on that actually and it did say that people don't look at the booklets, basically. About 15% to 20% of people do and then the other 80% don't." This was reiterated by Henry who believed that no one is going to pay attention to leaflets as well as Ziad who said that he will be disaffected by people giving him flyers about TC; he said: "I won't read them, even if it's something that I'm interested in."

As one of the participants in a focus group was recommending leaflets to teach men about testicular disorders, Donal interrupted saying: "Just giving leaflets to people? I don't think so... Well, it is useful, but there's probably better ways in this age." Similarly, Rami said: "The classical way of giving a brochure and putting paintings in hospitals saying, 'Look'... They didn't really mark me." He also warned from the use of an academic tone; he said: "Not a rigid academic tone and seriousness. This is not going to work. It should be something that teenagers will accept and not see as condescending." This was reiterated by Mark who believed that the use of medical jargon would "take away the human element out of it (educational intervention) and would make a man feel like a test subject."

# 3.3.4.3 Implications of Raising Awareness

Participants were asked to reflect on the potential risks and benefits of raising men's awareness of testicular disorders. They were then probed as to whether the benefits outweighed the risks or vice versa.

# Risks of increasing awareness

Very few men stated that increased awareness can lead to emotional worry and can increase the likelihood of false positives. For instance, despite being supportive of educating men about testicular symptoms, Adam stated that increased awareness would cause people to become "needlessly or overly concerned." Similarly, Harry warned from the dangers of over-scanning and panicking people; he said:

"There are false positives, aren't there? So there's always the risk of over-scanning people, there's a risk of panicking people and there's also, whenever you do any kind of scanning, there are false positive dangers."

#### Benefits of increasing awareness

The majority of the participants believed that there were no risks from increasing awareness of testicular disorders since, according to Hans, "awareness of every disease, no matter where it is, is a good thing." This was reiterated by Kevin who believed that initiatives targeted at raising awareness of testicular symptoms, serve as an opportunity to promote men's heath; he said:

"I think there are potential benefits around that (raising awareness) for improving men's health in terms of their knowledge of how to deal with the situation and their knowledge of how to mind their own health and to be a bit independent."

# 3.3.4.4 Learning among Gay and Bisexual Men

The participants' views regarding the learning needs of gay and bisexual men were explored. Participants were then probed as to whether the same educational strategies can be used to raise awareness of testicular disorders among heterosexual, gay, and bisexual men simultaneously.

# **Learning needs**

Participants unanimously believed that heterosexual, gay, and bisexual men have the same learning needs. For instance, Scott said: "Gay men don't need to know anything more than anyone else, unless they are doing things to their testicles that

straight men do which I'm highly doubtful of." This was echoed in the interview with Harry who said: "I try to treat everyone the same unless there's a really good reason for not doing." Rami, on the other hand, warned from the dangers of addressing the needs of gay and bisexual men differently; which, according to him, would lead to discrimination.

#### **Educational strategies**

As for the strategies used to raise awareness, responses were divided between those who believed that educational messages should be the same for heterosexual, gay, and bisexual men and those who believed that health marketing should be different. According to Luke, educational strategies "could be quite standardised", when asked to elaborate, he said: "Because like that now if you see those programmes on telly... people have the same reaction and I don't think whether you are straight or gay or whatever you'd need a different approach." Similarly, Henry believed that there should be a strategy that "fills all areas, rather than having several different ones because if you're having several different ones, that's kind of inferring a difference between them (heterosexual, gay, and bisexual men)"; he laughed and added: "Like testicles are testicles!"

On the other hand, Tom stated that "what's going to work for a straight man isn't going to work for a gay man", when probed about the reason; he said:

"I would say that it should be something more, how would I put it? More nuanced...

A gay man has potentially the benefit of a partner with the same, you know,
biological structure. So it's a case of using that to your advantage if you were
targeting gay men... I mean gay men are more likely to get STDs (sexually
transmitted diseases) than straight men. So obviously if there's that much of a

difference between the two groups, it makes sense to separate the kind of health marketing out."

Similarly, Ziad and Kevin who self-identified as gay, stated that they would not identify with an advertisement that is targeted towards heterosexual men only. For this reason, they recommended, either inclusive marketing strategies or strategies that are exclusive to gay men. For instance, Kevin said:

"For the gay community, probably something more vain and for the straight community, probably something more macho. So if someone showed me a soccer player telling me that he was checking his testes, he would want to be a cute soccer player for me to pay interest in him... But if it was more to do with vanity or sexual prowess, I would be more likely to listen."

# 3.4 Discussion

In this study, men's awareness of testicular disorders, help-seeking intentions for testicular symptoms, and preferred learning strategies in relation to testicular symptoms and disorders were explored. Overall, participants heard of TC but were unaware of the different aspects of this malignancy. Similarly, having heard of TC screening did not necessarily imply that men knew how to perform TSE. These findings 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.

As for non-malignant testicular disorders, only participants who were diagnosed with varicocele, testicular torsion, and epididymitis were aware of these diseases and only one participant heard of the 'bag of worms' but failed to link it to a

specific disease, varicocele in this case. Varicocele is typically described as feeling like a 'bag of worms' due to the "dilation of the venous pampiniform plexus of the spermatic cord" (Crawford & Crop 2014 p. 725). Similar findings were reported in the literature on BTDs, 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).

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. These findings are supported by evidence from a systematic review on the barriers and facilitators for TC and TSE (Saab *et al.* 2016c), and a systematic 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 participants who practiced TSE had higher knowledge scores than those who did not. Additionally, having prior information about TC and TSE served as a facilitator to awareness in the studies by Rovito *et al.* (2011) and Kuzgunbay *et al.* (2013).

In the present study, many participants linked testicular disorders, specifically TC, to a number of celebrities. These findings are consistent with those of Trumbo (2004) and Daley (2007) whereby a number of men heard about TC through television shows about celebrities who survived it.

A number of participants believed that gay men are more in touch with their body and are more at ease when it comes to dealing with their testes. In addition, exposure to other men's genitalia was perceived to have a positive impact on

awareness. Little empirical evidence exists to support these findings. However, in a study on awareness of TC and TSE, men who reported performing regular TSE 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 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 (Macleod *et al.* 2009). Similarly, embarrassment identified by a number of participants as an excuse not to visit a doctor, was highlighted in previous studies as a key factor leading to help-seeking delay among males (Fish *et al.* 2015, Yousaf *et al.* 2015). Also, findings in relation to the prevailing beliefs and attitudes towards testicular disorders and the meaning men attach to their testes are echoed in a number of studies. These include machismo (Buckley & Ó Tuama 2010), stoicism (Emery *et al.* 2013), the perception of health as a female rather than a male issue (Hajdarevic *et al.* 2011), and the engrained social and gender roles (Leone & Rovito 2013).

Interestingly, the gender of the examining physician also influenced men's help-seeking intentions, as some felt comfortable being examined by a female doctor and others could identify more with a male doctor. It is suggested, however, that female physicians are more inclined to discuss general health prevention than male physicians, especially when it comes to sensitive issues (Ramirez *et al.* 2009).

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 accountable 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 (2009, 2016) was successful in implementing two national gynaecological cancer screening programmes over the past two decades. This, however, was unmatched by any increase in the preventive or screening services offered to males. Moreover, despite being among the few 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 GP visit and the long waiting time in the emergency room were echoed in previous Irish studies (Scanlon *et al.* 2006, Buckley & Ó Tuama 2010).

Despite lacking awareness of testicular disorders and intending to delay helpseeking for testicular symptoms, participants expressed their interest in learning about testicular diseases through a number of means. These include television shows, campaigns, fundraisers, the internet, and to a lesser extent, print media. In fact, many participants recommended moving away from conventional print messages that contain medical jargon. This recommendation is echoed in the literature on men's preferred learning strategies. For instance, while exploring gender differences in learning style preferences among college students, Wehrwein *et al.* (2007) found that, unlike females, males preferred multimodal learning using auditory and kinaesthetic strategies rather than diagrams, charts, and graphs. Similarly, Thornton (2015) found that interventions using written materials to promote TSE among young men were unsuccessful in doing so.

Many participants believed that social media and mobile phone applications are instrumental in fostering awareness of testicular disorders among young men. These means are commonly used among youths who spend, on average, 7.5 hours online every day (Rideout *et al.* 2010). Moreover, evidence suggests that adolescents in the USA and the UK acquire most of their health information from the internet especially when it comes to health topics that are of a private nature (Gray *et al.* 2005). Also, the internet serves as the primary source of information on HIV and STIs among gay and bisexual men (Holloway *et al.* 2014). For instance, social networking sites, such as Facebook and YouTube, were instrumental in engaging gay men with information on sexual health (Pedrana *et al.* 2013). Another common method of acquiring health information, is through mobile dating applications such as Grindr (Hooper *et al.* 2008). This echoes findings from the present study, whereby one of the participants learned about free HIV testing through an advertisement on Grindr and recommended the same approach to get men to check their testes and to seek help for any abnormalities.

School and university campaigns were also perceived as ideal to promote awareness. These findings are echoed in two systematic reviews whereby 16 of 25 studies exploring men's awareness of TC and self-examination (Saab *et al.* 2016c) and five of 11 studies aimed at enhancing TC awareness and screening (Saab *et al.* 2016b) were conducted among school and university students. Moreover, educational campaigns that were conducted in colleges (Wanzer *et al.* 2014) and schools (Jones *et al.* 2015) have shown to be instrumental in raising men's awareness of TC and promoting TSE. In contrast, many participants believed that men who work are hard to reach, and are therefore underrepresented in health promotion initiatives. The same concern was highlighted in the Irish National Men's Health Policy (Department of Health and Children 2008).

Another strategy that was perceived as ideal to reach out to younger men, was through their local sporting clubs. These clubs (e.g. GAA) serve as a hub for over one million youths in Ireland (GAA 2016). In recent years, GAA clubs have been making efforts to foster a culture of health promotion. To better understand this culture, Lane et al. (2017) surveyed 16 GAA clubs about their health promotion policy, ideology, practice, and environment. Overall, clubs perceived health promotion as an integral part of their work, yet they scored low on policy and coaching health promotion activities. It is worth noting that health promoting sports clubs are not exclusive to Ireland as they are common in other countries including Denmark (Persson 2008), Sweden (Engström 2008), Belgium (Frisch et al. 2009), Finland (Kokko et al. 2006), the UK (Flintoff 2003, 2008), as well as the USA (Daniels 2007), Canada (Fraser-Thomas et al. 2005, 2008), and Australia (Casey et al. 2009).

In contrast, not all participants perceived national campaigns, including the internet campaign Movember, as instrumental in raising men's awareness of testicular

disorders. In fact, many were sceptical about the effectiveness of this strategy and believed that men lost the message behind it. These findings are supported by evidence from a Canadian study whereby Bravo and Hoffman-Goetz (2016) analysed 4,222 tweets about Movember and found that there were significantly fewer health-related than non-health-related tweets. It was also found that men were engaged in activities such as growing a moustache, rather than discussing the health implications of the campaign. These findings concur with those of a larger study conducted by Jacobson and Mascaro (2016), whereby an analysis of 1,879,994 tweets showed that young men were engaged with Movember as a branded movement rather than a health promotion campaign.

A number of participants recommended having a survivor of a testicular disorder deliver health promoting messages. Examples include comedians Tom Green and Des Bishop, cyclist Lance Armstrong, as well as GAA player Noel McGrath. Having celebrities teach men about testicular disorders is not uncommon in the literature on TC. For instance, Daley (2007) found that men who were knowledgeable about TC often linked it to cyclist Lance Armstrong. Moreover, a television show featuring comedian Tom Green's journey with TC (Trumbo 2004), and a high school campaign delivered by young cancer survivors (Jones *et al.* 2015), were successful in raising TC awareness and promoting TSE.

According to many participants, for a learning strategy to be effective, it must be tailored to meet the needs of younger men. Therefore, it must be visually appealing, original, humorous, and delivered frequently using simple, brief, and positively worded messages. This was reiterated by Gold *et al.* (2012) who designed an intervention to promote sexual health among at-risk groups. One arm of this intervention was targeted at young gay men and was delivered in the form of a short

series that was uploaded on Facebook and YouTube (Pedrana *et al.* 2013). Participants were prompted to discuss sexual health issues online between episodes. Overall, men felt comfortable watching the series, were able to identify with the characters, found that the information were easy to understand, and perceived the interactive part of the intervention as ideal to initiate open discussions about sexual heath with their peers (Pedrana *et al.* 2013). This echoes the responses of a number of participants who believed that health promoting strategies targeting gay men should be nuanced or inclusive rather than generic, as well as those who perceived a successful intervention as one that features real people discussing real health issues.

# 3.5 Implications

The European Commission (2011) published a report highlighting gender-based health disparities and proposing action plans to promote men's health in a number of European countries. Nevertheless, much needs to be done to promote men's health in policy, research, education, and clinical practice.

National and international governments are encouraged to shed light on men's and women's health equally while instigating health promotion and cancer prevention campaigns. In addition, reinforcing pre-existing men's health strategies and drafting new ones might be instrumental in raising awareness of male-specific disorders (Baker *et al.* 2014).

Researchers should be cognizant of men's preferred modes of learning. They are also advised to adopt strategies that appeal to young men; these include but are not limited to, mobile phone applications, interactive websites, and virtual reality (VR). For instance, the use of VR is gaining popularity in research. In recent years, this technology has been used in a number of fields including rehabilitation (Laver *et al.*)

2012), mental health (Hone-Blanchet *et al.* 2014), and education (Bailenson *et al.* 2008). In contrast, very little is known as to the effectiveness of VR in health promotion, let alone its use in promoting men's health. Moreover, researchers are encouraged to use theory to develop and test health-promoting interventions as evidence suggests that interventions with a theoretical underpinning are more likely to achieve the desired outcomes (Savage *et al.* 2010).

National initiatives, including Movember, should stress the health implications of their campaigns in order to avoid the messages getting lost. In addition, these campaigns should be delivered frequently to achieve a top-up effect, must be altered occasionally so that young men would not lose interest, and should cater to the needs of men who are at risk for health inequities. Such campaigns are best delivered in schools, universities, and sports centres to reach out to a wide audience and normalise topics that are often perceived as taboo. Men who work must not be excluded from such initiatives, for this reason, a number of strategies should be put in place to instigate health promotion in the workplace. These include partnerships with employers, unions, and governmental bodies (Department of Health and Children 2008).

From a clinical perspective, recent evidence suggests that it is important to ask men about their sexual orientation and gender identity in healthcare settings (Center for American Progress 2013). Moreover, collecting data about sexual orientation and gender identity is thought to help reduce lesbian, gay, bisexual, and transsexual (LGBT) invisibility in health care and is perceived as the key to end LGBT health disparities (Cahill & Makadon 2013). For this reason, clinicians, including nurses, are encouraged to address the individual needs of young men while educating them about the seriousness of testicular symptoms and the importance of seeking timely medical

attention for any abnormalities (e.g. abrupt pain, swelling, and newly occurring lumps). To do so, and for feasibility purposes, clinicians can make use of print media including infographics and flyers that are colourful, written in large fonts, and easy to comprehend among men with low health literacy (Wanzer *et al.* 2014). Moreover, clinicians are encouraged to examine the testes during the 'well male' physical examination.

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 talking about their testes when they get older. Also, it is important to educate partners about testicular symptoms and diseases as they may be the ones who detect abnormalities during sexual activity.

# 3.6 Limitations

Although rigour was attempted while conducting this study, a number of limitations are noteworthy. Qualitative description is often criticised for lacking rigour (Neergaard *et al.* 2009). For this reason, a number of strategies were employed to enhance trustworthiness.

Given the study design and aims, the sample recruited cannot be considered to be representative of all the men in Ireland; instead transferability was attempted by seeking data saturation and recruiting a heterogeneous sample in terms of age, socioeconomic status, ethnicity, and sexual orientation. However, only participants who voluntarily consented to take part 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 of selection bias and makes the

comparison of findings difficult. This was accounted for by seeking and achieving data saturation.

Accidental alteration of the data was accounted for by performing memberchecks and having the thesis supervisors verify the analysed data. Given the intimate nature of the topic discussed during the interviews, some of the participants could have concealed a few aspects of their experiences, especially that an open discussion of sensitive topics is uncommon among males (Scanlon *et al.* 2006). For this reason, a number of icebreakers were used before each interview. Moreover, having an experienced male conduct the interviews, facilitated open discussions about testicular health. Therefore, 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 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.

## 3.7 Conclusion

This study explored men's awareness of testicular disorders, their help-seeking intentions for testicular symptoms, and their preferred learning strategies in relation to testicular symptoms and disorders 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 the researcher's knowledge, is the only qualitative study to purposely include men who are at risk for health inequities (i.e. men who self-

identify as gay and bisexual) and to explore the educational needs of men with regard to testicular symptoms and disorders.

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 (Fish *et al.* 2015).

Findings from this study suggest that men prefer brief, visually appealing, and creative messages over conventional approaches like leaflets and brochures. Interventions that account for men's preferred learning strategies and the needs of men who are at risk for health inequities, may be promising in promoting awareness of both, malignant and benign testicular diseases.

Findings from the reviewed empirical literature (Chapter 2) and qualitative study (Chapter 3) guided the design of the E-MAT intervention that is aimed at enhancing men's awareness of testicular symptoms and diseases using VR. As aforementioned, interventions underpinned by theory are known to be more likely to achieve the desired outcomes (Savage *et al.* 2010). Therefore, a review of the theoretical literature was conducted and a theoretical framework, namely the PAAF, was developed to underpin the E-MAT intervention. This framework is presented and discussed in the upcoming chapter (Chapter 4).

## **CHAPTER**

## 4

## THE PRE-CONSCIOUS AWARENESS TO ACTION FRAMEWORK: AN APPLICATION TO PROMOTE TESTICULAR AWARENESS

Experimental studies aimed at raising men's awareness of benign testicular disorders (BTDs) are lacking (Saab *et al.* 2016a), and only six of the 11 studies promoting testicular cancer (TC) awareness reviewed by Saab *et al.* (2016b) were underpinned by theory. Sidani and Fleury (2016) defined interventions as "a set of inter-related activities directed toward attaining common goals" (p. 190). Evidence suggests that theory-based interventions are more effective than interventions that lack a theoretical basis (Michie *et al.* 2008, Savage *et al.* 2010). Moreover, the development of an underpinning theory is a key step in the Medical Research Council (MRC) framework (Craig *et al.* 2013). Therefore, a good theoretical understanding of a phenomenon is key to modelling an intervention, understanding how it instigates change, and exploring the role of moderating and influencing variables (Sidani & Fleury 2016).

In nursing, theory helps in the design, implementation, and evaluation of interventions (Sidani & Fleury 2016). Theory building involves the identification of concepts and relational statements (Walker & Avant 2011). Concepts are a mental image of a phenomenon and are regarded as the building blocks of a theory. Statements

specify the context of theory building, either by defining the concepts (i.e. non-relational) or describing the relationship between them (i.e. relational).

Walker and Avant (2011) defined theory as "an internally consistent group of relational statements that presents a systematic view about a phenomenon and that is useful for description, explanation, prediction, and prescription or control" (p. 7). It is often used to express a new idea or insight into the nature of a phenomenon. Theory is built using three key processes; synthesis, derivation, and analysis. Synthesis involves using information to construct a new concept or theory, derivation allows researchers to redefine a concept to fit a new context, and analysis involves clarifying refining, or sharpening concepts or theories (Walker & Avant 2011).

## **4.1** Aim

Data from the empirical literature (Chapter 2) and qualitative study (Chapter 3) and theoretical perspectives in this chapter, helped plan an interactive educational intervention aimed at enhancing men's awareness of testicular disorders (E-MAT). This chapter presents a theory-focused analysis of the Pre-Conscious Awareness to Action Framework (PAAF) developed to underpin the E-MAT intervention. This chapter was published in "Nursing Research" (Saab *et al.* 2018; Appendix 4.1).<sup>6</sup>

## 4.2 Methods

The PAAF was developed following a synthesis of evidence from the empirical literature (Saab *et al.* 2016a, 2016b, 2016c), qualitative study (Saab *et al.* 2017a, 2017b), and theoretical literature (Saab *et al.* 2018). The processes guiding the development of the PAAF are summarised in Table 4.1

**Table 4.1** The processes guiding the development of the Pre-Conscious Awareness to Action Framework

Steps	Methods	Key findings		
	• Systematic review of 25 quantitative and qualitative studies exploring men's knowledge, awareness, and attitudes towards testicular cancer and self-examination (Saab <i>et al.</i> 2016c).	<ul> <li>Men lacked awareness of testicular cancer risk factors, signs and symptoms, and treatment.</li> <li>Few men practiced self-examination, with the majority not knowing what to look for.</li> <li>Many reported an intention to delay help-seeking for testicular lumpiness.</li> <li>Men perceived education about testicular cancer and self-examination as important.</li> </ul>		
Empirical literature reviews	• Systematic review of 11 experimental studies promoting men's awareness of testicular cancer and self-examination (Saab <i>et al.</i> 2016b).	• Ten of the 11 studies successfully raised men's awareness of testicular cancer and self-		
	• Integrative review of four quantitative studies exploring men's awareness of benign testicular disorders (Saab <i>et al.</i> 2016a).	<ul> <li>Men's awareness of benign testicular disorders was lacking.</li> <li>Many reported an intention to delay help-seeking for testicular lumpiness and pain.</li> <li>No qualitative or experimental studies were sourced.</li> </ul>		
Qualitative descriptive study	<ul> <li>To explore men's (n=29) awareness of testicular disorders, help-seeking intentions for testicular symptoms, and preferred strategies for learning about testicular disorders and symptoms (Saab <i>et al.</i> 2017a, 2017b).</li> <li>12 semi-structured individual interviews and three focus groups were conducted with men aged 18-47 years.</li> <li>Data were analysed using qualitative content analysis.</li> <li>Trustworthiness was enhanced by selecting a heterogeneous sample, cross-checking the analysed data, member-checks, memoing, and using field notes and audit trails.</li> </ul>	<ul> <li>Men lacked awareness of testicular cancer; very few reported having heard of benign testicular disorders; and many intended to delay help-seeking for lumpiness, swelling, and/or pain.</li> <li>Barriers to awareness and help-seeking included: lack of prior knowledge, symptom misappraisal, fear, embarrassment, machoism, lack of endorsement by the health system, cost and access to care, and inability to differentiate between normal and abnormal lumps.</li> <li>Facilitators to awareness and help-seeking included: prior knowledge, regular self-examination, clinical testicular examination, history of testicular disease, aging, being gay, access to support, inherent health-seeking drive, and perceived threats to fertility.</li> <li>Men stressed the importance of raising testicular awareness using educational interventions that are brief, simple, visually appealing, novel, and positively worded.</li> </ul>		
Theoretical literature review	<ul> <li>An iterative narrative review process of the theoretical literature on health promotion, symptom appraisal, and neurobehavioral psychology was undertaken.</li> <li>Six categories of multidisciplinary theories used in health promotion were identified: behavioural change theories; intervention-based models; ecological theories and models; planning models; communication theories; and evaluation models (Nutbeam 2013, Raingruber 2014).</li> </ul>	<ul> <li>The five stages of the Transtheoretical Model guided the development of the seven stages of the Pre-Conscious Awareness to Action Framework.</li> <li>The literature on neurobehavioral psychology helped derive the concepts of pre-conscious, unconscious, and conscious awareness.</li> <li>The empirical literature, the qualitative study, and the concept of "breast awareness" helped create and define the concept of "testicular awareness" (Thornton &amp; Pillarisetti 2008).</li> <li>The literature on symptom appraisal helped derive the concepts of unconscious and conscious appraisal (Whitaker <i>et al.</i> 2015).</li> </ul>		

(Saab et al. 2018).

An iterative narrative review process of the theoretical literature on health promotion and symptom appraisal was undertaken to source and derive an underpinning theory. Derivation involves redefining a concept, statement, or theory from one context to another (Walker & Avant 2011).

Six categories of multidisciplinary theories and models used in health promotion were identified as follows: behavioural change theories; intervention-based models; ecological theories and models; planning models; communication theories; and evaluation models (Nutbeam 2013, Raingruber 2014). A behavioural change model, namely the Transtheoretical Model (TTM), provided insight into the cognitive domains involved in the thinking processes underpinning the development of awareness and intentions to alter behaviour (Prochaska & DiClemente 1986). Therefore, the five stages of the TTM (i.e. pre-contemplation, contemplation, preparation, action, and maintenance) served as a stepping stone to the construction of the PAAF.

The TTM and PAAF are process models that use predefined and interconnected stages in order to achieve a certain goal (Prochaska & DiClemente 1986, Wislon & Schlam 2004). However, while the TTM aims to 'treat' harmful behaviours, the primary goal of the PAAF is to raise awareness in order to promote healthy behaviours. Moreover, the TTM is comprised of five stages, whereas the PAAF is comprised of seven stages (i.e. pre-conscious awareness, unconscious awareness, conscious awareness, unconscious appraisal, conscious appraisal, intention, and behaviour) derived from the TTM (Prochaska & DiClemente 1986), and the literature on neurobehavioral psychology (Dehane & Naccahe 2001, Baumeister *et al.* 2011) and symptom appraisal (Whitaker *et al.* 2015). Furthermore, while the TTM addresses the effect of consciousness on behaviour, the PAAF acknowledges the

impact of three stages of awareness (i.e. pre-conscious, unconscious, and conscious awareness) on behaviour. Another difference pertains to symptom appraisal, which is an integral part of the PAAF and not the TTM. A side-by-side comparison between the TTM and PAAF is presented in Table 4.2.

Table 4.2 Comparison between the Transtheoretical Model and the Pre-Conscious Awareness to Action Framework

Characteristic	Transtheoretical Model <sup>a</sup>	Pre-Conscious Awareness to Action Framework <sup>b</sup>		
Discipline	Clinical psychology and psychotherapy	Health promotion and neurobehavioral psychology		
Primary goal To treat and change pre-existing		To raise awareness and promote new and healthy behaviours (e.g. early		
	addictive/harmful behaviours (e.g. smoking)	help-seeking)		
Development	Comparative analysis of 29 systems of	Iterative process of synthesis, derivation, and analysis		
	psychotherapy			
Stages	Five stages: pre-contemplation,	Seven stages: pre-conscious awareness, unconsciousness awareness,		
	contemplation, preparation, action, and	conscious awareness, unconscious appraisal, conscious appraisal,		
	maintenance	intention, and behaviour		
Pre-contemplation vs.	People in the pre-contemplation stage are	People in the pre-conscious awareness stage are uninformed, under-		
pre-conscious	uninformed or under-informed about the	informed, have relevant discrete pieces of unlinked information, or are		
awareness	consequences of their behaviour	somewhat informed but not consciously thinking about the information		
Consciousness vs. Highlights the role of consciousness raising				
conscious awareness	promoting intentions to change a behaviour	procedural memories in retaining new information, combining various		
		mental processes, and shaping behaviour		
Symptom appraisal	No symptoms involved, as the primary goal is	Involves labelling, categorising, and evaluating bodily changes		
	to treat pre-existing addictive behaviours			
Intention	Intention to change and take action imbedded	Intention to act (i.e. seek help) is a separate stage that is impacted by		
	in the contemplation and preparation stages	motivation and ability to seek help and access to healthcare services		
	respectively			
Action vs. behaviour	Course of action needed to modify one's	•		
	lifestyle. It must be maintained to avoid	symptom of concern		
	relapse			
Context	Emphasis on the impact of the harmful	Emphasis on the impact of intrinsic and extrinsic factors on the seven		
	behaviour on the social environment	stages of the framework		
Testing	Tested in various contexts (e.g. smoking	Was used to develop and pilot test an interactive intervention aimed at		
a (Prochaska & Di Clamar	cessation, alcohol use, and weight reduction)	raising men's testicular awareness		

<sup>&</sup>lt;sup>a</sup> (Prochaska & Di Clemente 1986). <sup>b</sup> (Saab *et al.* 2018).

## 4.3 Results

Movement between the stages of the PAAF is a fluid process (Figure 4.1). Individuals move in and out of unconscious and conscious awareness/appraisal, as thoughts move in and out of consciousness and as the individual and the environmental context of thinking changes. This is thought to impact on intentions and subsequent behaviours.

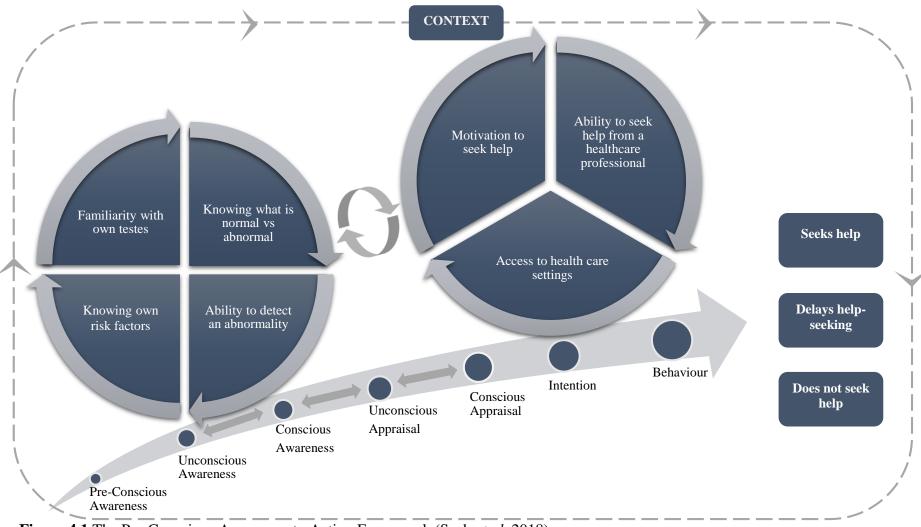


Figure 4.1 The Pre-Conscious Awareness to Action Framework (Saab et al. 2018)

### **4.3.1 Pre-Conscious Awareness**

According to Sigmund Freud, pre-consciousness and unconsciousness are not synonymous (Natsoulas 1996). While lack of awareness is a possibility, individuals in the pre-conscious awareness stage can be either under-informed about certain behaviours, have relevant discrete pieces of unlinked information, or are somewhat informed but not consciously thinking about the information. For instance, notwithstanding that men in the qualitative study lacked knowledge of TC risk factors, signs and symptoms, treatment, and screening; almost all of them reported having heard of TC through the media, school, college, family members, friends, and/or colleagues (Saab *et al.* 2017a, 2017b). In other words, men were not oblivious to testicular disorders, as they were able to recall certain discreet pieces of information in relation to these disorders when prompted. For instance, when asked about his knowledge of TC, one of the participants in the qualitative study said: "I didn't really hear anything specific about it (TC)... But I know it exists..."

There are a number of hypotheses as to why men in the reviewed literature and qualitative study lacked awareness of testicular disorders. One explanation is that men are often preoccupied with life matters that they may perceive as more important than their own health, such as starting college, building a career, or establishing a family (Saab *et al.* 2014). Therefore, conflicting responsibilities have the potential to mask health awareness or push it to the bottom of their list of priorities. Furthermore, illness is globally linked to old age, which might cause younger men to think that they are not prone to getting sick (Saab *et al.* 2017a). Another explanation could be what Leone and Rovito (2013) referred to as "social norms and gender scripting" (p. 246), which depict how men should and should not behave. These can impact negatively on men's health awareness and subsequent health outcomes.

### 4.3.2 Conscious and Unconscious Awareness

If one does not deliberately think about a certain behaviour, it does not mean that he or she is not aware of it, which requires differentiating between conscious and unconscious awareness (Baumeister *et al.* 2011). This is key, since the impact that both types of awareness have on health behaviour had been overlooked in behavioural change theories, including the TTM.

According to Dehane and Naccahe (2001), "durable and explicit information maintenance, novel combinations of operations, and intentional behaviour" (p. 9) are not possible without conscious awareness which is divided into two subtypes; phenomenal awareness and conscious thought (Baumeister *et al.* 2011). Phenomenal awareness involves subjective experiences. An example is Armstrong's (1981) absentminded driver, as driving involves automaticity and, despite being a learned behaviour, is often instinctive rather than a purposefully planned course of action. In contrast, conscious thought involves reflection and reasoning that can be either rational or irrational. An example is a man trying to make sense of a newly discovered testicular lump. Moreover, conscious awareness helps combine various mental operations in order to plan, evaluate, and execute a novel behaviour that cannot be attained unconsciously. Of note, certain mental processes are possible without conscious awareness; nonetheless, they are often short-lived (Baumeister *et al.* 2011).

Memory plays a vital role in awareness and is divided into three types; sensory, short-term (i.e. working memory), and long-term memories. Long-term memory can be either explicit (i.e. conscious) or implicit (i.e. unconscious). Explicit memory includes the declarative memory which is comprised of two sub-types; episodic memory and semantic memory. As for the implicit memory, it includes the procedural memory (Mastin 2010).

Episodic memory involves the capacity for recollecting events from the past that happened within certain spatial and temporal contexts. Examples include memorable life events such as weddings and concerts (Squire & Zola 1998). In the context of testicular disorders, episodic memory involved recalling instances when men had heard of TC after celebrities developed it (Saab *et al.* 2016c, 2017a). Semantic memory involves the recollection of facts and general knowledge regarding a certain phenomenon, such as scientific knowledge acquired by attending a conference or reading a textbook (Squire & Zola 1998). As for procedural memory, it receives, stores, and recovers information outside one's conscious awareness and is often acquired by trial and error. Examples include riding a bicycle and typing (Taylor 2001, Mochizuki-Kawai 2008). Another example is Armstrong's (1981) absentminded driver discussed earlier. Therefore, with the exception of procedural memory, a long-lasting memory of a certain phenomenon or recently acquired information cannot be generated without conscious awareness (Sperling 1960).

## **4.3.2.1 Testicular Awareness**

In order to address the lack of awareness of testicular disorders, researchers could adopt a novel and comprehensive concept namely "testicular awareness." To help define this concept, it is necessary to consult the literature on the concept of "breast awareness" which was defined by Thornton and Pillarisetti (2008) as "a woman becoming familiar with her own breasts and the way they will change throughout her life. It encourages women to know how their own breasts look and feel normally so that they gain confidence about noticing any change" (p. 2119).

In order to achieve awareness, early detection of an abnormality must be followed by a specific course of action (Scott & Walter 2010). However, a prerequisite to symptom detection, is familiarity with the normal state of the body. In the case of

testicular awareness, familiarity would enable a man to establish a baseline of what is normal for him so that he would be able to recognise changes (e.g. swelling, lumpiness, and pain). This is key, since lack of familiarity with one's own testes has been linked to intentions to delay help-seeking (Saab *et al.* 2017a). For example, one of the participants in the qualitative study said that testicular self-examination (TSE) felt "like trying to find a lump in a bag of lumps."

Testicular awareness would also help promote heightened body awareness since it encourages men to become attentive to a body area that is seldom spoken about (Saab *et al.* 2014). Moreover, knowing the risk factors for testicular disorders would alert men to the aforementioned symptoms and disorders. For instance, men must recognise that having a first degree relative with TC increases their risk for this malignancy, and that unprotected sex exposes them to epididymitis and orchitis (CDC 2015a). Therefore, it is presumed that testicular awareness is a form of conscious rather than unconscious awareness.

Of note, testicular awareness does not necessarily involve scheduled TSE; especially that the risks and benefits of this practice are debatable (Ilic & Misso 2011). The U.S. Preventive Services Task Force (2011) discourages TSE, mainly due to the potential harms of false positives, and concomitant anxiety. In contrast, proponents of TC screening argue that recommendations discouraging this practice are based on speculations rather than empirical evidence, since early diagnosis of TC was found to be more cost-effective than late diagnosis (Aberger *et al.* 2014, Rovito *et al.* 2016). A middle ground could be reached by educating and encouraging men to feel their testes in order to establish a baseline of what is normal for them without necessarily promoting monthly TSE.

## 4.3.3 Conscious and Unconscious Appraisal

Symptoms, described as bodily sensation or changes, are subject to complex psychosocial processes. In a conceptual review of nine symptom appraisal models, Whitaker *et al.* (2015) defined the process of symptom appraisal as the "detection of bodily changes, interpretation of bodily changes, and responses to interpretation" (p. S28).

Detection of bodily changes involves recognising a disturbance that can be general, localised, visible, palpable, and/or audible. This disturbance can differ in intensity and frequency (Whitaker *et al.* 2015). Therefore, for a bodily change to be detected, it must be of a significant magnitude. For example, a testicular lump must be large enough for a man to be able to detect it.

Symptom detection is followed by appraisal, which involves "labelling, categorising, and evaluating the bodily changes" (Whitaker *et al.* 2015 p. S28). Like awareness, appraisal is subject to conscious and unconscious influences as it involves reflection and reasoning in order to make sense of a symptom (i.e. conscious appraisal), and at the same time it can be impacted by past attitudes, beliefs, experiences, and/or behaviours (i.e. unconscious appraisal).

Symptom appraisal is a "delicate" stage as it is subject to misinterpretation which can cause people to delay help-seeking; this was the case for a number of men in the qualitative study (Saab *et al.* 2017a). For example, one of the participants said: "If there was a lump or a swelling there, I'd think, 'Oh, something else.' I got a bite off something." In addition, the impact of the external environment on the detection of bodily changes must not be overlooked (Pennebaker 1982). For instance, excessive stimulation from the external environment can shift a person's attention away from a

symptom. For example, one of the participants decided not to seek help for a testicular symptom because he was busy; he said: "Honestly, that kind of a thing goes way down my to-do list. Like I'm busy, I'm hardly going to clear off my agenda so that I can go... I've got other things to worry about... And I don't prioritise it... There are more important things."

## 4.3.4 Help-Seeking Intention and Behaviour

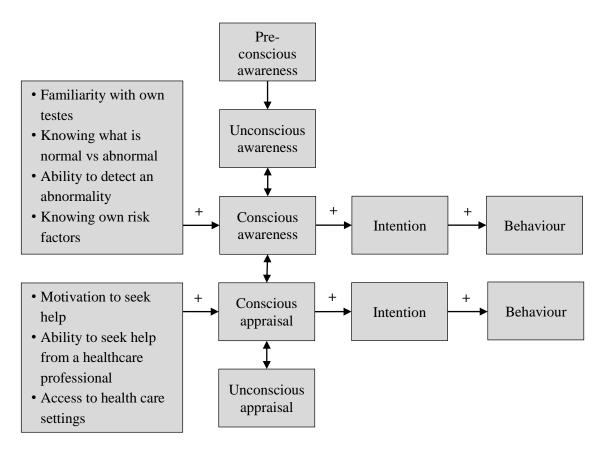
Following awareness and appraisal, a response is generated, which involves reaching a decision regarding the action that must be taken in relation to the symptom experienced. In the case of testicular awareness, a man decides either to seek medical attention or not. Alternately, he can revert to self-help measures, inform his family and friends, delay help-seeking, or adopt dysfunctional coping strategies such as denial and avoidance. For example, fear and denial pushed one of the participants in the qualitative study to delay help-seeking for symptoms of TC; he said: "I went along for several months with desperate pain and the fear of actually dying... It was easier at times just to block it out and fear of actually being told there was something wrong with you, when instinctively deep down within yourself, you knew there was something going wrong... I just kept thinking things would go away, but they didn't."

Various definitions for help-seeking exist. O'Mahony and Hegarty (2009) defined this concept as "a response to health changes and part of the broader process of health-seeking behaviour" (p E182). Similarly, in their concept analysis, Cornally and McCarthy (2011) defined help-seeking behaviour as "a problem focused, planned behaviour, involving interpersonal interaction with a selected health-care professional" (p 286).

As aforementioned, a number of barriers to help-seeking exist; these include lack of knowledge, symptom misappraisal, fear, embarrassment, machoism, and conflicting responsibilities. On the other hand, having the motivation and ability to seek help, and having access to healthcare settings positively influence one's intention to seek medical care (Leventhal *et al.* 1998). Social support, disclosure of symptoms to friends, having an inherent help-seeking drive, and greater symptom severity also serve as enablers for help-seeking (Saab *et al.* 2017a). Finally, the researcher assumes that, when a man becomes 'testes aware', he is more likely to seek medical attention for testicular symptoms. This also is supported by evidence from the reviewed literature on men's awareness of TC and TSE (Saab *et al.* 2016c).

## 4.3.5 Relational Statements

Relational statements are key to specifying the relationship between the concepts of a theory (Walker & Avant 2011). Relational statements pertaining to the concepts of the PAAF were simplified and presented in Figure 4.2, with the "-" sign depicting a negative relationship and the "+" sign depicting a positive relationship.



**Figure 4.2** Simplified statements illustrating the relationship between the key concepts of the PAAF (Saab *et al.* 2018)

## 4.4 Conclusion

The PAAF is the first framework to highlight the impact of three stages of awareness (i.e. pre-conscious, unconscious, and conscious awareness) and two stages of symptom appraisal (i.e. unconscious and conscious appraisal) on help-seeking intentions and behaviours. Moreover, The PAAF was applied to the concept of "testicular awareness" that was introduced in this chapter for the first time. This concept would help familiarise men with their own testes and would enable them to detect abnormalities, which could influence their decision to seek timely medical attention, thus preventing complications that are linked to delayed help-seeking; such as testicular ischemia, sepsis, and infertility.

In order to tailor effective health-promoting messages, researchers are encouraged to underpin their interventions with behavioural change theories, intervention-based models, and/or theories of health communication; an example is the PAAF discussed in the present chapter. The PAAF was used to design and test an interactive intervention aimed at raising men's testicular awareness (i.e. E-MAT). The development, feasibility, and usability testing of the E-MAT intervention are discussed in the upcoming chapter (Chapter 5).

## **CHAPTER**

# ENHANCING MEN'S AWARENESS OF TESTICULAR DISORDERS (E-MAT) USING VIRTUAL REALITY: INTERVENTION DEVELOPMENT, FEASIBILITY & USABILITY

Studies promoting awareness of testicular cancer (TC) and testicular self-examination (TSE) have been conducted (Saab *et al.* 2016b). In contrast, interventions aimed at raising men's awareness of benign disorders of the testes are lacking (Saab *et al.* 2016a), and none of the interventions reviewed by Saab *et al.* (2016b) reported on involving men in intervention design. However, men's active participation in health promotion initiatives is highly dependent on their engagement in the early planning stages for these initiatives (Lefkowich *et al.* 2017, Saab *et al.* 2017c). Moreover, in a report exploring the health research landscape in Ireland, the Medical Research Charities Group (2014) stressed the importance of patient and public involvement in research in order to achieve better health outcomes. Therefore, although members of the public were not directly involved in the planning of the E-MAT intervention, their feedback was taken into account while designing this intervention (Saab *et al.* 2017b).

## **5.1** Aim

The aim of this chapter is to describe the development of a novel intervention aimed at Enhancing Men's Awareness of Testicular disorders (E-MAT) using virtual reality (VR), and to report on the feasibility and usability testing of this intervention.

## **5.2 Methods**

The development and feasibility and usability testing of the E-MAT intervention were conducted in accordance with the Medical Research Council (MRC) framework (Craig *et al.* 2013). The evidence-base was identified through conducting two systematic reviews (Saab *et al.* 2016b, 2016c) and one integrative review (Saab *et al.* 2016a; Chapter 2) as well as a qualitative study (Saab *et al.* 2017a, 2017b; Chapter 3). The theoretical literature was then reviewed and the Pre-Conscious Awareness to Action Framework (PAAF) was developed to underpin the intervention (Saab *et al.* 2018; Chapter 4). The E-MAT intervention was then designed based on findings from the empirical literature, qualitative study, and the PAAF. A feasibility and usability study was then conducted to explore whether the E-MAT intervention can work, does work, and will work (Orsmond & Cohn 2015), and whether the system was user-friendly (Brooke 1996, 2013).

## **5.2.1 Intervention Design**

The recommendations made by participants in the qualitative study regarding the use of innovative and unconventional strategies to raise awareness of testicular disorders, helped select the technology involved in the E-MAT intervention (Saab *et al.* 2017b). As a result, E-MAT was developed as an educational experience and a 3-level virtual reality (VR) game with that meets the key features of serious games, including: self-representation using an avatar, in this case a hand avatar; using a 3D environment and 3D models to represent the testes; having different game levels; having a narrative context; and providing visual, haptic (i.e. vibrational), and aural (i.e. voiceover) feedbacks (Reeves & Read 2009).

VR is increasingly gaining popularity among youths. An assessment of the VR market found that the total number of active VR users is forecast to reach 171 million by the year 2018 (Statista 2017). As for the use of sensory feedbacks, evidence from a review of studies on multimodal feedbacks suggested that visual, aural, and haptic feedbacks are most applicable to real life, since humans often use more than one sense in their day-to-day life (Sigrist *et al.* 2013). Moreover, in the health literature, the effectiveness of haptic feedback was established on a number of occasions, including robot-assisted surgery and VR training (van der Meijden & Schijven 2009), neurosurgical education (Lemole *et al.* 2007), and physical therapy and neuro-rehabilitation (Gomez-Rodriguez *et al.* 2011). Similarly, the use of voiceover was effective in chronic disease management education (Oosterom-Calo & López 2016), social cognition training (Kandalaft *et al.* 2013), and cardiac life support training (Vankipuram *et al.* 2014).

The researcher hypothesised that the use of multiple feedbacks during the three game levels would help build a long-lasting memory of the experience. Firstly, the use of VR, especially among first-time users, would generate episodic memory of the technology. Secondly, having the voiceover deliver information and scientific facts that are easy-to-understand would create semantic memory. Thirdly, self-representation using a hand avatar and the use of a controller with haptic feedback would generate procedural memory.

The E-MAT intervention was developed by an expert in interactive media using Unreal Engine 4.12 (UE4), a freely available game engine that supports the development of several platforms. The intervention was developed for use with an Oculus VR headset and an Xbox controller with haptic feedback. UE4 allowed for level development through the use of various tools that can manipulate models in a 3D

space. This allowed for the introduction of a 3D scanned model of a walnut into the simulation.

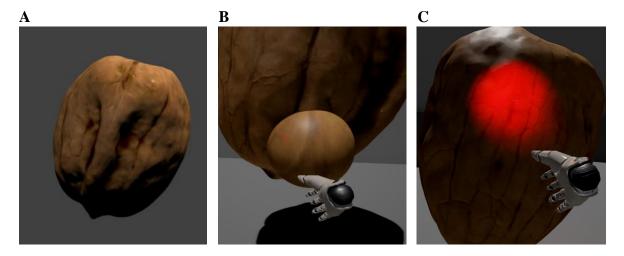
A voiceover was used to provide prompts and factual information and help transition between the game levels. It was recorded in a sound-proofed studio and played using over-ear headphones. The script used in the voiceover was guided by the stages of the PAAF and was written by the researcher and verified by the thesis supervisors (Appendix 5.1). The face validity of the script was established with two General Practitioners using a 7-item checklist (Appendix 5.2). The readability of the script was evaluated using the Flesch-Kincaid test (Flesch 1981). The script scored 83.4 on the test, indicating that it was suitable for 6<sup>th</sup> Graders and written using conversational English.

The intervention began with a scrolling series of words that passed from the bottom to the top of the screen as the voiceover read them out. These included commonly used synonyms for the testes (e.g. balls, nuts, gonads, and so on). The game comprised three levels. The user was required to complete one level in order to move to the next level.

The first level (Level 1) involved a 3D space with two walnuts hanging side by side and required the development of three changes in the walnuts representing common testicular symptoms (i.e. lumpiness, swelling, and pain). For the lump, a sphere was created and textured with a segment of the walnut's texture. As for swelling, the size of one of the walnuts was increased. Finally, to illustrate pain, a throbbing red light appeared on one of the two walnuts. Each of the three changes was accompanied by a reaction from the voiceover.

During the first level, the user was asked by the voiceover to move around the walnuts using the controller. As the user was moving, the voiceover provided factual information about the normal size and shape of the testes (Figure 5.1A). This step was crucial as lack of familiarity with the normal testes was identified as one of the reasons men do not perform self-examination and delay help-seeking for testicular symptoms (Saab *et al.* 2017a).

After familiarising themselves with the normal testes, a lump appeared on one of the walnuts and was accompanied with a humorous emotional response from the voiceover (Figure 5.1B). The user was then asked to walk towards the lump while using the controller and to 'touch' it using the hand avatar. Once touched, the lump triggered further voiceover and eventually the next change, namely swelling of one of the walnuts occurred. Similarly, the user was asked to walk towards the swollen walnut and to touch it in order to move to the next abnormality. The last abnormality was sharp pain, represented as a pulsating red light over one of the walnuts (Figure 5.1C). Once the pulsating light was touched, the voiceover emitted a cry of pain and the rate of pulsation increased in order to indicate increased pain and to highlight the seriousness of sudden and worsening testicular pain. In order to successfully complete the first level and move to the second level, the user was required to find and touch all three changes.



**Figure 5.1** Models representing the normal testis (A), testicular lumpiness with the hand avatar (B), and testicular pain (C)

During the second level (Level 2), a 3D model of a testis was created (Figure 5.2A) and the spermatic cord (Figure 5.2B), epididymis (Figure 5.2C), and tumour (Figure 5.2D) were represented. The user was loaded into the second level on top of the testis. Blocking volumes were used to allow the user to explore the testicular structures within certain limits without "falling off" the model (Figure 5.1E). During this level, the voiceover linked some of the abnormalities experienced in the first level to testicular structures. For instance, the spermatic cord lighted up with a red hue in order to indicate torsion and a large purple lump appeared on the surface of the testis, indicating a cancerous growth.

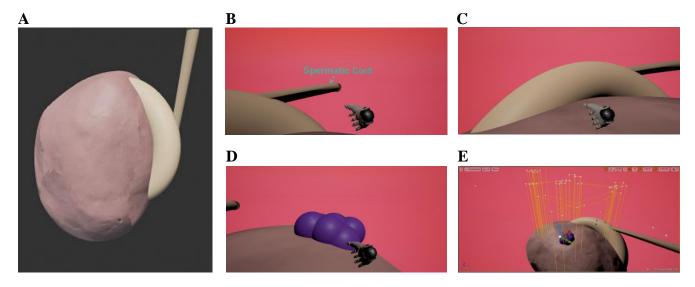
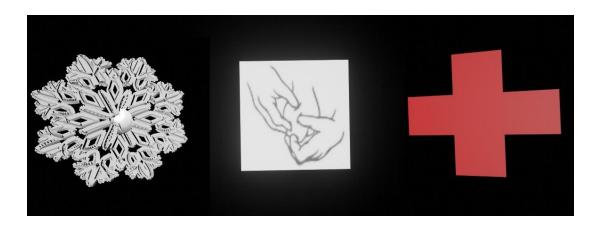


Figure 5.2 3D representation of the testis (A), spermatic cord (B), epididymis (C), testicular cancer (D), and blocking volumes (E)<sup>20</sup>

<sup>&</sup>lt;sup>20</sup> The true colour of the background in Figure 5.2 is sky blue and the writing in Figure 5.2B is in black. In addition, users did not see the blocking volumes in Figure 5.2E; these were illustrated exclusively in this thesis in order to show the reader that users were allowed to "walk" around the 3D testis within predefined limits, without "falling off" the model.

During the third and final level (Level 3), the key messages provided by the voiceover during the course of the game were reiterated. Three icons appeared in this level (Figure 5.3). The first icon was a snowflake, whereby the voiceover reminded the user that each pair of testes is unique, therefore it is important to familiarise himself with his own testes and to know what is normal for him. Next, was an infographic showing the method for TSE while the voiceover explained how and where one can check his testes. <sup>21</sup> The third icon was a red cross that appeared as the voiceover reminded the user to check with a healthcare professional in case he felt something unusual and to seek immediate medical attention if he experienced sudden or sharp pain.



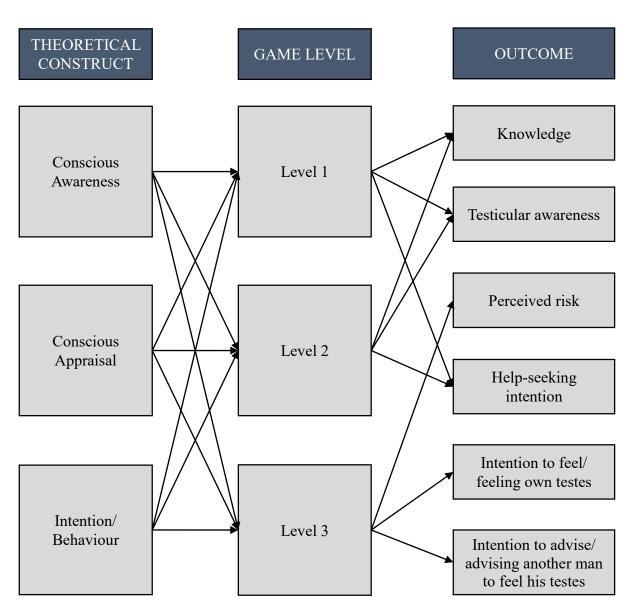
**Figure 5.3** Icons highlighting the importance of knowing one's own testes, performing self-examination, and seeking medical help for testicular symptoms

The game levels are mapped onto the theoretical construct of the PAAF and matched with the outcomes of the pilot study (Chapter 6) in Figure 5.4.

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<sup>&</sup>lt;sup>21</sup> Permission to use the infographic was granted by the Testicular Cancer Awareness Foundation (2017; Appendix 5.3).



**Figure 5.4** The game levels mapped onto the theoretical construct of the PAAF and matched with the outcomes of the pilot study

## 5.2.2 Feasibility and Usability Testing

## 5.2.2.1 Study Design

The distinction between pilot and feasibility testing remains a grey area. In a review of definitions of feasibility and pilot testing, Whitehead *et al.* (2014) concluded that feasibility studies are conducted as part of the preliminary work required to conduct a pilot study, whereas a pilot study often mimics the definitive study. Moreover, feasibility studies help determine whether an intervention can work

(Orsmond & Cohn 2015), whereas a pilot study determines whether an intervention does work (Van Teijlingen *et al.* 2001). A usability study, on the other hand, helps evaluate the appropriateness of a certain system to the purpose of an intended intervention (Brooke 1996, 2013).

## **5.2.2.2 Sample**

Non-probability convenience and snowball sampling strategies were used to recruit (i) males; (ii) residing in the Republic of Ireland; and (iii) aged between 18 and 50 years. The plan was to exclude men with a history of VR sickness, which is characterised by ocular (i.e. eyestrain, blurred vision, and pain) and/or non-ocular (fatigue, drowsiness, dizziness, and nausea) symptoms that occur among 20% of VR users (Ames *et al.* 2005, Fernandes & Feiner 2016).

Of note, there is no gold standard for sample size calculation in feasibility and usability studies; however, a sample of 15 participants has been recommended in feasibility studies (Orsmond & Cohn 2015).

## **5.2.2.3 Procedures**

The study was granted ethical approval by the Clinical Research Ethics Committee at University College Cork in Ireland (Appendix 5.4). A standardised email was circulated to university students and staff inviting them to take part in a feasibility and usability study and encouraging them to invite other men to participate (Appendix 5.5).

Data were collected in a VR lab located on campus. Participants were provided with an information leaflet with detailed information about the study (Appendix 5.6).

A standardised script was used to provide the participants with a full explanation

regarding the use of the VR headset and controller and to notify them of the risk of VR sickness (Appendix 5.7).

After providing informed consent (Appendix 5.8), participants were exposed to a short demonstration using the VR headset, controller, and over-ear headphones in order to become familiar with the technology. After which, they were exposed to the E-MAT intervention. The researcher and interactive media expert were present at all times to ensure that the participants did not experience any technical difficulties and did not develop VR sickness. Immediately following the intervention, participants completed a questionnaire (Appendix 5.9).

## **5.2.2.4 Instruments**

Data were collected using a socio-demographic questionnaire, a feasibility scale, a satisfaction item, the System Usability Scale (SUS; Brooke 1996, 2013), and open-ended questions. A full description of the instruments in terms of purpose; source; number of items; answer options; scoring; interpretation of scores; and reliability is provided in Table 5.1.

**Table 5.1** The instruments used to collect data for the feasibility and usability study

Instrument	Purpose	Source	Number of items	Answer options	Scoring	Interpretation of scores	Reliability
Socio-Demographic Questionnaire	To assess men's socio-demographic characteristics (discussed below)	Researcherdesigned, based on the qualitative study by Saab <i>et al.</i> (2017a, 2017b) and data from the Central Statistics Office (2011)	7	Closed-ended questions	NA	NA	NA
Feasibility Scale	To assess the feasibility of the intervention in terms of the technology, the representation of the testes, and its appropriateness for men from different backgrounds	Researcherdesigned based on the literature on feasibility testing (Bowen <i>et al.</i> 2009, Arain <i>et al.</i> 2010, Tickle-Degnen 2013, Orsmond & Cohn 2015)	21	The level of agreement for each of the 21 items was assessed on a 5-point Likert scale	Answers ranged between "Strongly Disagree=1"; "Disagree=2"; "Neutral=3"; "Agree=4"; and "Strongly Agree=5" Scores ranges between 1 and 5 (originally 21- 105)	Higher scores indicate greater feasibility	Cronbach's alpha=0.9
Satisfaction Item	To assess men's level of satisfaction with the intervention	Researcherdesigned based on the literature on feasibility testing (Bowen <i>et al.</i> 2009, Arain <i>et al.</i> 2010, Tickle-Degnen 2013, Orsmond & Cohn 2015)	1	The level of agreement for this item was assessed on a 5-point Likert scale	Answers ranged between "Extremely Dissatisfied=1"; "Dissatisfied=2"; "Neutral=3"; "Satisfied=4"; and "Extremely Satisfied=5" Scores ranged between 1 and 5	Higher scores indicate greater satisfaction	NA

Instrument	Purpose	Source	Number of items	Answer options	Scoring	Interpretation of scores	Reliability
System Usability Scale	To assess the usability of the technology in terms of ease/complexity, various functions, and level of confidence while playing the game	The valid and reliable System Usability Scale (SUS; Brooke 1996, 2013)	10	The level of agreement for each of the 10 items was assessed on a 5-point Likert scale	Answers ranged between "Strongly Disagree=0"; "Disagree=1"; "Neutral=2"; "Agree=3"; and "Strongly Agree=4" Scores per item ranged between 0 and 4. The sum of scores was multiplied by 2.5 to obtain an overall score ranging from 0 to 100 (Brooke 1996, 2013)	Higher scores indicate greater usability	Cronbach's alpha=0.8
Open-Ended Questions	To explore what elements of the intervention worked/ did not work, recommendations for change, and additional comments	Researcher- designed, based on the literature on feasibility testing (Orsmond & Cohn 2015)	4	Open-ended questions	Analysed using qualitative content analysis (Elo & Kyngäs 2008)	NA	NA

**Abbreviations:** NA: Not applicable; SUS: System usability scale.

**Socio-demographic questionnaire:** This questionnaire was adopted from the qualitative study to assess the sample characteristics (Saab *et al.* 2017a, 2017b) and data from the Central Statistics Office (2011). It comprised 7 items as follows: age; nationality; sexual orientation; marital status; highest level of education; current occupation; and prior use of VR.

**Feasibility scale:** The feasibility of the intervention was measured using a researcher-designed questionnaire with 21 items. Eight items pertained to the feasibility of the technology, 7 items pertained to the representation of the testes, and 6 items assessed the appropriateness of the intervention for men from different sociodemographic backgrounds. The level of agreement for each of the 21 items was assessed on a 5-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree." For each participant, a mean score was calculated if he answered at least 80% of the items (17 of 21 items) so that an overall score could be calculated. Cronbach's alpha was 0.9, indicating excellent reliability (Hinton *et al.* 2004).

**Satisfaction item:** Participants' level of satisfaction with the intervention was measured using a single researcher-designed item and assessed on a 5-point Likert scale ranging from "Extremely Dissatisfied" to "Extremely Satisfied." Scores ranged between 1 and 5, with higher scores indicating greater satisfaction.

**System usability scale:** The 10-item valid and reliable SUS was used to assess the usability of the technology in terms of ease/complexity, various functions, and level of confidence while playing the game (Brooke 1996, 2013). In their empirical evaluation of the SUS, Bangor *et al.* (2008) concluded that the SUS was a "highly robust and versatile tool for usability professionals" (p. 574).

The level of agreement for each of the 10 items of the SUS was assessed on a 5-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree." For each participant, a mean score was calculated if he answered at least 80% of the items (8 of 10 items) so that an overall score could be calculated. The scores per item were added and ranged between 0 and 4. The sum of scores was then multiplied by 2.5 in order to obtain an overall score ranging between 0 and 100 (Brooke 1996, 2013). Cronbach's alpha was 0.8, indicating high reliability.

**Open-ended questions:** Four researcher-designed, open-ended questions explored what elements of the intervention worked, what elements of the intervention did not work, recommendations for change, and additional comments.

## 5.2.2.5 Data Analysis

A codebook was developed to code possible responses to the items in the questionnaire. Each question was coded and inputted into IBM SPSS Statistics (Version 22.0, IBM Corp, Armonk, NY, USA). Missing values were coded as 999, the dataset was checked thoroughly for data-entry mistakes, and negatively worded items were reverse coded prior to data analysis.

"Descriptive statistics are summary statistics that allow the researcher to organise data in ways that give meaning and facilitate insight" (Grove *et al.* 2015 p. 319). In the present study, descriptive statistics were used to describe the sample characteristics and study variables. These included: frequencies (n) and percentages (%) for categorical variables, and measures of central tendency (mean and median), and dispersion (minimum, maximum, standard deviation [SD], and interquartile range [IQR]) for continuous variables (Marston 2010). Findings from the open-ended questions were analysed using content analysis (Elo & Kyngäs 2008).

## **5.3 Results**

## **5.3.1 Sample Characteristics**

A total of 15 men participated in the feasibility and usability study. Participants were aged between 19 and 31 years (Mean 26, SD 3.8). The majority of the participants were college educated (n=11), single (n=12), and were either employed full-time (n=5) or students (n=4). One man self-identified as gay, the remaining 14 self-identified as heterosexual. Twelve participants reported never having used VR before. On average, it took the participants five to six minutes to complete the intervention. The socio-demographic characteristics of the study participants are presented in Table 5.2.

**Table 5.2** Socio-demographic characteristics of the participants in the feasibility and usability study (n=15)

participants in the leasibility and usability st	uuy (II=13)
Age (years)	
Range	19-31
Mean (standard deviation)	26.1(3.8)
Nationality	
Irish	15
Sexual orientation	
Heterosexual	14
Gay	1
Marital status	
Single	12
In a relationship/partnered	3
Highest level of education	
Secondary	3
High school	1
University	11
Occupation	
Employed (full-time)	5
Employed (part-time)	1
Student and employed (part-time)	2
Student	4
Unemployed	3
Prior use of virtual reality	
Yes	3
No	12

## **5.3.2 Feasibility**

The majority of participants (n=12) were in agreement that the headset was comfortable and none found the elements of the game confusing. Moreover, all 15 participants "Agreed" and "Strongly Agreed" that the controller was easy to use; the testes were well represented using walnuts; testicular pain, swelling, and lumps were well represented; and the verbal instructions provided by the voiceover were clear. In addition, 14 of the 15 participants were in agreement that the elements of the game were humorous; the font, colour, and size of the written words were clear; the "inside look" (i.e. 3D testis in Level 2) was well represented; and the scientific facts were easy to understand.

As for the appropriateness of the intervention, 14 participants believed that the intervention would work with men aged 18 to 50 years and men with different sexual orientations and one participant was neutral. The majority of the participants (n=10) were in agreement that the intervention would work with men from different educational backgrounds; the remainder were either neutral (n=4) or in disagreement (n=1). All 15 participants found the intervention to be applicable to real life and 14 believed that they have learned something valuable. The mean score on the feasibility scale was 4.5 (SD 0.3, range 4-4.9). Findings from the feasibility scale are presented in Table 5.3.

**Table 5.3** Findings from the feasibility scale (n=15)

Feasibility questions	n(%) a						
	SD	D	N	A	SA		
1. VR headset comfortable to use <sup>b</sup>	-	-	2(13)	7(47)	5(33)		
2. Controller is easy to use	-	-	-	2(13)	13(87)		
3. Element of the game confusing	12(80)	3(20)	-	-	-		
4. Testicles well represented using walnuts	-	-	-	2(13)	13(87)		
5. Use of the word 'nuts' is appropriate	-	-	1(7)	5(33)	9(60)		
6. Verbal/oral instructions easy to understand	-	-	-	2(13)	13(87)		
7. Elements of the game were humorous	-	-	1(7)	6(40)	8(53)		
8. Font, colour, and size of the written words are clear	-	-	1(7)	6(40)	8(53)		
9. 'Inside look' at the testicle well presented	-	-	1(7)	8(53)	6(40)		
10. Testicular enlargement/ swelling well represented	-	-	1(7)	7(47)	7(47)		
11. Testicular lumpiness well represented	-	-	1(7)	7(47)	7(47)		
12. Testicular pain well represented	-	-	-	5(33)	10(67)		
13. Scientific facts about epididymitis easy to understand	-	-	1(7)	6(40)	8(53)		
14. Scientific facts about testicular torsion easy to understand	-	-	-	5(33)	10(67)		
15. Scientific facts about testicular cancer easy to understand	-	-	-	5(33)	10(67)		
16. Intervention would work with men aged 18-50 years	-	-	1(7)	9(60)	5(33)		
17. Intervention would work with men from different educational backgrounds	-	1(7)	4(27)	2(13)	8(53)		
18. Intervention would work with men from different ethnic/cultural backgrounds	-	-	3(20)	6(40)	6(40)		
19. Intervention would work with men with different sexual orientations	-	-	1(7)	4(27)	10(67)		
20. Intervention applicable to real life	-	-	-	5(33)	10(67)		
21. I learned something valuable from this intervention	-	-	1(7)	6(40)	8(53)		

<sup>&</sup>lt;sup>a</sup> Raw data presented in this table.
<sup>b</sup> Missing n=1.

Abbreviations: A: Agree; D: Disagree; N: Neutral; SA: Strongly agree; SD: Strongly disagree; VR: Virtual reality.

#### **5.3.3 Satisfaction**

All 15 participants were either "Satisfied" or "Extremely Satisfied" with the intervention (Median 5, IQR 4 to 5).

#### **5.3.4** Usability

Overall, 14 of 15 participants either "Agreed" or "Strongly Agreed" that they would like to use the system frequently and only one disagreed with this statement. Moreover, all the participants believed that the system was easy to use; found that the different functions within the system were well integrated; believed that people would learn how to use the system quickly; and reported feeling very confident using the system. Participants "Disagreed" and "Strongly Disagreed" that the system was complex; that they needed assistance to use the game; that there was inconsistency in the system; that the system was cumbersome; and that they needed to learn a lot of things before using the system. The overall score on the SUS was 91.7. Findings from the SUS are presented in Table 5.4.

**Table 5.4** Findings from the system usability scale (SUS; n=15)

Usability questions	n(%) <sup>a</sup>				
	SD	D	N	A	SA
1. I think I would like to use this system frequently	-	1(7)	-	6(40)	8(53)
2. I found this game unnecessarily complex	14(93)	1(7)	-	-	-
3. I thought this system was easy to use	-	-	-	3(20)	12(80)
4. I think that I would need assistance to be able to use this game	9(60)	6(40)	-	-	-
5. I found the various functions in this system were well integrated	-	-	1(7)	7(47)	7(47)
6. I thought there was too much inconsistency in this system	11(73)	4(27)	-	-	-
7. I would imagine that most people would learn to use this system very quickly	-	-	-	9(60)	6(40)
8. I found the system very cumbersome/awkward to use	11(73)	4(27)	-	-	-
9. I felt very confident using this system	-	-	-	3(20)	12(80)
10. I needed to learn a lot of things before I could get going with this system	13(87)	2(13)	-	-	-

<sup>a</sup> Raw data presented in this table. **Abbreviations:** A: Agree; D: Disagree; N: Neutral; SA: Strongly agree; SD: Strongly disagree.

#### **5.3.5 Open-Ended Questions**

When asked what elements of the intervention worked for them, participants identified a number of factors. These include: the interactive aspect of the intervention; the information provided by the voiceover in terms of clarity, conciseness, and humour; the use of walnuts to represent the testes; the representation of pain, swelling, and lumpiness; being able to move around the walnuts and view them from different angles; haptic feedback provided by the controller; the hand avatar used to find changes; and the ease of control and immersion in the game.

As for the elements that did not work, some participants reported that the finer details were hard to see and suggested a prior explanation of the use of sound to indicate direction. One participant suggested that the voiceover should adopt a stronger tone and another reported that the icons used in the final level were difficult to read. One participant reported that he could not visualise the spermatic cord and one was unsure whether the scientific facts in relation to the epididymis were clearly explained.

Overall, participants stated that they would not change anything in the intervention as they "really enjoyed it." One participant stated that he would improve the graphical quality of the "inside look." Others suggested placing the walnuts in the bathroom or shower, elongating the spermatic cord, seeing more of the testis, and having more textual information.

As for final comments, one of the participants stated that he "did not expect to be so engaged on a topic so technical" and that "technical terms and definitions were well-tempered to suit a non-medical audience." Also, "the use of vibrations to indicate problems was very effective" for one participant. He also believed that the

intervention was "very enjoyable, relatable, and fun." One participant stated that he was "impressed with the information provided in such a short space of time" and another stated that he was "very impressed by the overall aesthetic packaging of the game."

# **5.4 Discussion**

The novelty of the E-MAT intervention is attributed to a number of factors. This is the first intervention aimed at raising men's awareness of both, benign and malignant testicular disorders. This is crucial since none of the reviewed studies promoted awareness of non-malignant life-threatening testicular disorders (Saab *et al.* 2016a). Moreover, the MRC framework guided the development and feasibility and usability testing of the E-MAT intervention and the stages of the PAAF and men's feedback from the qualitative study and reviewed literature helped develop the intervention, which is unique to this study.

Overall, participants were positive that the intervention would work in terms of layout and content and were comfortable using the technology. These findings were echoed in a number of feasibility studies conducted in different health contexts. For example, Oliveira *et al.* (2016) conducted a study to discuss the development and feasibility of a VR intervention aimed at assessing cognitive functioning in older adults. The intervention was found to be feasible and appropriate for older adults, including those who were not familiar with the technology. Another example is a study conducted to assess the feasibility of a VR interface in promoting motor rehabilitation (Foreman & Engsberg 2017). Overall, participants perceived the interface as motivating, engaging, and safe.

The usability of the E-MAT intervention was established using the valid and reliable SUS. Similarly, the usability of VR-based interventions has been established on a number of occasions. For instance, Dhiman *et al.* (2016) used the SUS to evaluate the usability of a VR-based rehabilitation intervention with audio, visual, and haptic feedbacks. The intervention was found to be user-friendly and was perceived as potentially effective in the rehabilitation of patients with upper limb movement disorders. Similarly, high SUS scores have been reported in an RCT evaluating the effectiveness of a VR-based tele-rehabilitation programme among patients with stroke (Lloréns *et al.* 2015). Of note, VR is gaining popularity in mental health research and VR exposure therapy is being increasingly used in the management of phobias including fear of spiders (Miloff *et al.* 2016), and fear of flying (Cardoş *et al.* 2017). On the other hand, the use of VR to promote men's health was lacking.

Participants in the feasibility and usability study highlighted the importance of using visual, auditory, and haptic feedbacks to help raise testicular awareness. Similar findings have been reported in a review of studies on multimodal feedbacks (Sigrist *et al.* 2013), whereby it was found that visual, auditory, and haptic feedbacks are most applicable to real life, since humans tend to use more than one sense in order to perform certain tasks. This was reflected in studies that used multimodal feedbacks in robot-assisted surgery (van der Meijden & Schijven 2009); medical education (Lemole *et al.* 2007); neuro-rehabilitation (Gomez-Rodriguez *et al.* 2011); management of chronic illnesses (Oosterom-Calo & López 2016); social cognition training (Kandalaft *et al.* 2013); and cardiac life support training (Vankipuram *et al.* 2014).

Humour was highlighted as an effective aspect of the E-MAT intervention. The use of humour is not unusual in studies involving men. An example is a study conducted among prostate cancer survivors, whereby humour was instrumental in

promoting inclusivity and discussions about sexual health (Oliffe *et al.* 2009). Moreover, participants in the qualitative study recommended using humour and light-hearted messages in order to engage men in addressing sensitive topics that are seldom discussed, including testicular health (Saab *et al.* 2017b). However, Thornton (2015) cautioned against using "cheeky humour" and puns that can be offensive and potentially ineffective.

In the present study, the researcher hypothesised that a VR-based intervention was feasible for men in general and younger men in particular. This was based on the feedback from the qualitative study (Saab *et al.* 2017b), whereby men recommended moving away from traditional strategies, such as print media, and stressed the importance of innovative and stimulating strategies. In fact, 14 of the 15 participants in the feasibility and usability study were in agreement that the study was suited for men aged 18 to 50 years. These findings were echoed in a study that compared the use of technology as an educational tool between male and female students (He & Freeman 2010). It was found that males were more computer-oriented and reported greater computer self-efficacy than females. Evidence also suggests that younger men are more likely than older men to engage with health information delivered using technological rather than traditional strategies (Jensen *et al.* 2010).

Despite using a demonstration to familiarise men with the technology, writing the voiceover script using a language suited for 6<sup>th</sup> Graders, and ensuring socio-cultural neutrality, some participants were not in agreement that the intervention would work with men from different socio-demographic backgrounds. These findings were reflected in the qualitative study, whereby some participants suggested tailoring health interventions based on the needs of minority groups (Saab *et al.* 2017b). Moreover, in a systematic review of 31 studies exploring men's information-seeking

behaviours in relation to cancer prevention, it was found that men with low literacy and health literacy levels were unlikely to engage with interventions involving technology (Smith *et al.* 2008, Jensen *et al.* 2010, Smith *et al.* 2014, Saab *et al.* 2017c). In addition, evidence from a number of studies exploring men's uptake of scientific information suggested that, for men to engage with health information, they must perceive them as applicable to them. For example, African American men were more likely to engage with prostate cancer information delivered by other African American men (Friedman *et al.* 2009).

## 5.5 Limitations

Rigor was sought by following the steps of the MRC framework to develop and test the feasibility and usability of the E-MAT intervention. Nevertheless, there are a number of limitations that are worthy of note. A key limitation is the risk of VR sickness which usually resolves upon removing the VR headset. For this reason, a full explanation regarding the technology was offered to the participants who were asked to report any discomfort. Another limitation is the cost of equipment; while cheaper alternatives to VR are available, the technology itself remains relatively expensive. Despite using a gender and socio-culturally neutral tone throughout the game, the intervention might not be applicable to men from different socio-demographic backgrounds. This was reflected in the fact that a third of the participants did not agree that the game was suitable for men who are socio-demographically diverse.

From a methodological perspective, the generalisability of findings from the feasibility and usability study is compromised due to the small sample size and the lack of sample size calculation. However, a 15-person sample size for feasibility and usability testing is regarded as appropriate (Orsmond & Cohn 2015). Although the E-

MAT intervention was intended for men aged between 18 and 50 years, participants in the feasibility and usability study were university students aged 18 to 31 years, which further hinders generalisability. Moreover, participants were recruited using non-probability convenience and snowball sampling, which hinders sample representativeness, compromises the generalisability of findings, and increases the risk of self-selection bias (Robinson 2014).

# **5.6 Implications**

The E-MAT intervention can be used as a public educational tool by making it available on public platforms that men can access at their own leisure. Examples include websites of national and international cancer organisations, organisations involved in health promotion, and high schools and universities.

VR is increasingly gaining popularity among youths and the number of VR users is expected to increase by 147% between 2016 and 2021 (Mind Commerce 2016). The fast-paced growth of this technology has led to a significant reduction in the cost of access to VR headsets such as Google Daydream, Samsung Gear VR, and Google Cardboard. Furthermore, it is possible to disperse the game as a traditional, non-VR experience that would run in a normal desktop environment. This format is best suited for those who do not have access to VR or who suffer from VR sickness. However, each mode of implementation ought to be investigated to ensure that the platform of delivery does not compromise information delivery and retention. Finally, VR can be used to promote men's awareness of various health topics such as sports injuries, sexually transmitted infections, and prostate cancer.

# 5.7 Conclusion

In this chapter, the development, feasibility, and usability testing of the E-MAT intervention were discussed. E-MAT was designed as an educational experience and VR game using a VR headset, a controller with haptic feedback, and over-ear headphones with aural (i.e. voiceover) feedback. The three game levels were aimed at familiarising men with the normal testes and common testicular symptoms and disorders; highlighting the importance of touching/feeling one's own testes; and increasing men's ability to differentiate between normal and abnormal testicular findings. The intervention also stressed the importance of early help-seeking for testicular symptoms. The feasibility and usability of the intervention were established with 15 men who were satisfied with the game and perceived it as user-friendly and interactive and enjoyed its different elements including the voiceover, haptic feedback, and humour.

The effectiveness of the E-MAT intervention in raising testicular awareness and promoting early help-seeking for testicular symptoms was evaluated through conducting a pilot study, which is discussed in the upcoming chapter (Chapter 6).

# **CHAPTER**

# ENHANCING MEN'S AWARENESS OF TESTICULAR DISORDERS (E-MAT): A ONE-GROUP PRE-POST PILOT STUDY

Studies promoting testicular cancer (TC) awareness and testicular self-examination (TSE) have been conducted, with none focusing on enhancing men's awareness of the normal testes, testicular symptoms, or benign testicular disorders (BTDs; Saab *et al.* 2016a, 2016b). Moreover, none of the experimental studies reviewed used innovative technologies or reported on men's information needs and preferred learning strategies a priori (Saab *et al.* 2016b). Therefore, a one-group prepost pilot study was conducted to test the E-MAT intervention and its effect on enhancing men's testicular awareness and help-seeking intentions for testicular symptoms. Data were collected at three time points; at baseline (T0), immediately following the intervention (T1), and one month following the intervention (T2).

# **6.1 Objectives**

The objectives of the present study are to test the effect of the E-MAT intervention at three time points (i.e. T0, T1, and T2) on men's:

 Knowledge of the normal testes and common testicular symptoms (i.e. swelling, lumpiness, and pain) and disorders (i.e. TC, epididymitis, and testicular torsion).

- 2. Testicular awareness (i.e. familiarity with their own testes, knowledge of what is normal versus abnormal, and ability to detect and abnormality).
- 3. Perceived risk for testicular diseases.
- 4. Intention to seek help for three testicular symptoms (i.e. swelling, lumpiness, and pain).
- 5. Intention to purposefully feel their own testes.
- 6. Intention to advise at least one man to feel his own testes.
- 7. Behaviour pertaining to purposefully feeling their own testes.
- 8. Behaviour pertaining to advising at least one man to feel his own testes.

The study objectives are mapped onto the Pre-Conscious Awareness to Action Framework (PAAF) in Figure 6.1.

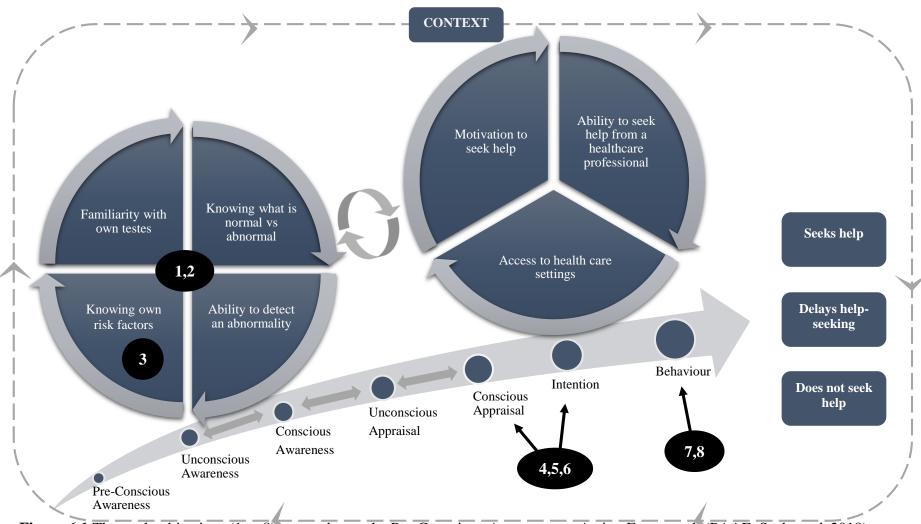


Figure 6.1 The study objectives (1 to 8) mapped onto the Pre-Conscious Awareness to Action Framework (PAAF; Saab et al. 2018)

# **6.2 Hypotheses**

"A hypothesis is a formal statement of the expected relationship(s) between two or more variables in a specified population" (Grove et al. 2015 p. 149). Hypotheses are known to impact on study design, sampling strategy, data collection process, and data analysis (Fawcett & Garity 2009). Grove et al. (2015) grouped hypotheses into four categories as follows: "(1) associative versus causal; (2) simple versus complex; (3) non-directional versus directional; and (4) statistical versus research" (p.149). An associative hypothesis suggests that a relationship exists between the variables, whereas a causal hypothesis proposes a cause and effect interaction between the variables. A simple hypothesis proposes a relationship – associative or causal – between two variables, whereas a complex hypothesis involves three or more variables. A non-directional hypothesis suggests that there is a relationship between the variables without specifying the nature of this relationship, whereas a directional hypothesis suggests that there is either a positive or negative interaction between the study variables. Finally, a statistical hypothesis, also known as null hypothesis, suggests that there is no relationship between the variables, whereas a research hypothesis, also referred to as alternative hypothesis, suggests that a relationship exists between the study variables (Grove *et al.* 2015).

In order to address the objectives of this pilot study, associative, simple and complex, non-directional research hypotheses were formulated as follows:

**H1:** There are changes in mean knowledge scores at T1 and/or T2 in comparison to T0.

**H2:** There are changes in mean testicular awareness scores at T1 and/or T2 in comparison to T0.

**H3:** There are changes in mean perceived risk scores at T1 and/or T2 in comparison to T0.

**H4:** There are changes in mean help-seeking intentions scores for at least one testicular symptom at T1 and/or T2 in comparison to T0.

**H5:** There are changes in mean implementation intentions scores in relation to purposefully feeling one's own testes at T1 and/or T2 in comparison to T0.

**H6:** There are changes in mean implementation intentions scores in relation to advising at least one man to feel his own testes at T1 and/or T2 in comparison to T0.

**H7:** There are changes in behaviours pertaining to purposefully feeling one's own testes at T2 in comparison to T0.

**H8:** There are changes in behaviours pertaining to advising at least one man to feel his own testes at T2 in comparison to T0.

**H9:** There is an association between implementation intentions at T0 and behaviours pertaining to purposefully feeling one's own testes at T2.

**H10:** There is an association between implementation intentions at T0 and behaviours pertaining to advising at least one man to feel his own testes at T2.

## 6.3 Methods

# 6.3.1 Study Design

This pilot study was conducted using a one-group pre- and post-test design. Pilot studies help examine the uncertainties surrounding the development of health interventions including attrition rates, effectiveness, and acceptability (Craig *et al.* 2013). The key benefits of conducting a pilot study are as follows: developing and

testing research instruments; assessing the feasibility of conducing full-scale testing; determining sample size for full-scale testing; assessing people's willingness to participate; establishing whether the sampling strategy is effective; identifying unforeseeable risks; determining the financial and human resources needed for full-scale testing; assessing data analysis techniques; and developing a research question (van Teijlingen *et al.* 2001, van Teijlingen & Hundley 2001, Thabane *et al.* 2010).

# **6.3.2 Sample**

Participants eligible for inclusion were: (i) males; (ii) residing in the Republic of Ireland; and (iii) aged between 18 and 50 years since, as aforementioned, men who fall within this age group are at the highest risk for testicular disorders (Saab *et al.* 2017a, 2017b). Men were excluded if they reported a past history of VR sickness.

Men who were interested in the study were invited to participate; hence, probability sampling was not feasible. Instead, non-probability convenience and snowball sampling strategies were used to recruit study participants. Convenience sampling is commonly used in experimental nursing studies (Grove *et al.* 2015). Samples recruited using this strategy are considered to be "inexpensive, accessible, and usually less time-consuming to obtain than other types of samples" (Grove *et al.* 2015 p. 264). Moreover, those who expressed an interest in participating were asked to invite other men to participate. This is a key feature of snowball sampling, which is known to be effective in recruiting hard-to-reach participants, in this case young and relatively healthy males (Sadler *et al.* 2010).

There is no gold standard for sample size calculation in pilot studies and sample sizes as small as 10 and as large as 59 have been recommended in the literature (Mooney & Duval 1993, Isaac & Michael 1995, Hill 1998, van Belle 2002, Julious

2005, Hertzog 2008, Johanson & Brooks 2010, Viechtbauer *et al.* 2015). For example, Julious (2005) recommended a sample size of 12 per group, whereas Viechtbauer *et al.* (2015) proposed a simple formula to calculate the sample size in pilot studies and reported that "if a problem exists with 5% probability in a potential study participant, the problem will almost certainly be identified (with 95% confidence) in a pilot study including 59 participants" (p. 1375).

In the present study, a sample size of 59 men would also have a power of 99% to detect a medium effect (f=0.25, Cohen 1992) in a repeated measures analysis of variance (ANOVA) with three waves, a level of significance of 0.05 and a 2-tailed test, assuming sphericity and correlations of 0.5 between waves of data (from G-Power 3.1 program, Erdfelder *et al.* 1996).

#### **6.3.3 Procedures**

Ethical approval to conduct the pilot study was granted by the Clinical Research Ethics Committee at University College Cork (Appendix 6.1). A standardised invitation letter was sent by e-mail to students and staff in a university in the Republic of Ireland (Appendix 6.2), and study flyers were hung in the university's Gaelic Athletic Association (GAA) sports club and on campus (Appendix 6.3). Men who responded to the e-mail or flyer and expressed an interest in participating were asked to identify other men who would be potentially interested in the study. Data were collected between February and April 2017 in a virtual reality (VR) lab at T0 and T1 and in the researcher's office or the participants' workplace at T2. All data collection sites were located on a university campus.

**Baseline testing (T0):** Upon arrival to the VR lab, participants were provided with a study pack comprised of an information sheet with the details of what their

participation entailed (Appendix 6.4), an informed consent form (Appendix 6.5), a referral form with the contact details of free counselling services and cancer support hotlines (Appendix 6.6), and a questionnaire (Appendix 6.7).

The right to full disclosure was ensured by providing the participants with information about the study. Participants were informed that their participation was voluntary. Confidentiality was maintained by using codes instead of names on the study documents. However, a master document linking the names of the participants to their codes was essential in order to track the responses from each participant at three time points. All the study documents were kept in a locked cabinet accessed only by the researcher. Participants were advised about the risks and benefits of using VR. For instance, the risk of VR sickness was reiterated and participants were assured that this complication is often mild and short-term (Ames *et al.* 2005, Fernandes & Feiner 2016). As for the benefits, participants were informed that VR was being used for the first time to promote testicular awareness and that the study has the potential to impact on the way men's health is promoted in the future. Moreover, participants were informed that upon completing the questionnaires at T0, T1, and T2, they would be entered into a draw to win one of five online shopping vouchers, £30 each.

Following a full explanation of the study process and after obtaining informed consent, participants (n=53) were asked to fill-out the first questionnaire which took, on average, 15 minutes to complete and included socio-demographic questions.

The intervention: After signing the informed consent and completing the first questionnaire, a full explanation of the game was provided by the interactive media expert and the risk from using VR was reiterated using a standardised script (Appendix 6.8). Participants were then exposed to a brief demonstration where they could move

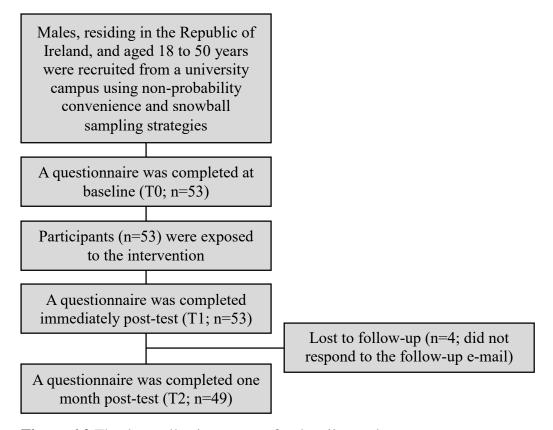
freely in a virtual environment using the VR headset and controller. The purpose of the demonstration was to help participants become familiar with the technology and ensure that they did not experience VR sickness. Following the demonstration, information regarding the three game levels was provided (Appendix 6.8) and participants were asked to play the game. The researcher and interactive media expert were present throughout the game to ensure that the participants did not experience any discomfort or technical difficulties. Only one participant reported eyestrain, which subsided directly after the game. On average, it took the participants 5 to 6 minutes to complete all three levels. A full description of the game can be found in Chapter 5, section 5.2.1.

**First follow-up (T1):** Immediately following the game, participants were asked to complete a second questionnaire (Appendix 6.9), and to write down their email address so that they could be contacted a month after the game to complete the third and final questionnaire. On average, it took the participants 10 minutes to complete the second questionnaire.

**Second follow-up** (**T2**): One month following the game, an e-mail was sent to the participants, inviting them to choose a suitable time and place to complete the third and final questionnaire (Appendix 6.10). A reminder was sent to those who did not respond to the first e-mail. In total, 49 participants completed the questionnaire at T2; 37 in the researcher's office and 12 in their own workplace. On average, it took the participants 10 minutes to complete the final questionnaire.

At the conclusion of the study, the email addresses of those who completed the questionnaires at T0, T1, and T2 were entered into an online software to select, at

random, the five winners of the online shopping vouchers. Winners were then notified by e-mail. The data collection process is summarised in Figure 6.2.



**Figure 6.2** The data collection process for the pilot study

#### **6.3.4 Instruments**

Data were collected using a socio-demographic questionnaire, a knowledge questionnaire, a testicular awareness scale, a perceived risk item, an implementation intentions scale, a general help-seeking questionnaire, and a behaviour questionnaire. A full description of these instruments in terms of purpose; source; number of items; answer options; scoring; interpretation of scores; and validity and reliability is provided in Table 6.1.

Table 6.1 The instruments used to collect data for the pilot study

Instrument	Purpose	Source	Number of items	Answer options	Scoring	Interpretation of scores	Validity and reliability
Socio- Demographic Questionnaire	To assess men's socio-demographic characteristics at T0	Researcher-designed, based on the qualitative study by Saab <i>et al.</i> (2017a, 2017b) and data from the Central Statistics Office (2011)	11	Closed- ended questions	NA	NA	S-CVI=0.98 Cronbach's alpha=NA
Knowledge Questionnaire	To assess men's knowledge of the normal testes, symptoms of testicular disease, TSE, and the most common testicular diseases at T0, T1, and T2	Researcher-designed based on the physiology/ pathophysiology of the testes (Standring 2016) and empirical literature reviews (Saab <i>et al.</i> 2016a, 2016b, 2016c)	12	8 multiple choice questions 4 "True" and "False" -type questions	All 12 items were dichotomised into "Correct=1" and "Incorrect/Don't know=0" Scores ranged between 0 and 12	Higher scores indicate greater knowledge	S-CVI=0.98 Cronbach's alpha not calculated due to the multidimensional construct of the questionnaire (Toh <i>et al.</i> 2015)
Testicular Awareness Scale	To assess men's familiarity with their own testes, what is normal and what is not normal, and ability to differentiate between what is normal and what is normal and what is not normal at T0, T1, and T2	Researcher-designed based on the PAAF and empirical literature reviews (Saab <i>et al.</i> 2016a, 2016b, 2016c)	5	The level of agreement for each of the 5 items was assessed on a 5-point Likert scale	Answers ranged between "Strongly Disagree=1"; "Disagree=2"; "Neutral=3"; "Agree=4"; and "Strongly Agree=5" Scores ranged between 1 and 5 (originally 5-25)	Higher scores indicate greater awareness	S-CVI=0.98 Cronbach's alpha=0.81 at T0, 0.80 at T1, and 0.87 at T2
Perceived Risk Item	To assess men's perceived risk of developing a	Researcher-designed based on an empirical	1	The level of agreement for this item	Answers ranged between "Strongly Disagree=1";	Higher scores indicate greater perceived risk	I-CVI=1 Cronbach's alpha=NA

Instrument	Purpose	Source	Number of items	Answer options	Scoring	Interpretation of scores	Validity and reliability
	testicular disease at T0, T1, and T2	literature review (Saab <i>et al.</i> 2016c)		was assessed on a 5-point Likert scale	"Disagree=2"; "Neutral=3"; "Agree=4"; and "Strongly Agree=5" Scores ranged between 1 and 5		·
Implementation Intentions Scale	To assess men's intentions to purposefully feel their own testes and advise at least one man to feel his own testes in the shower/bath at least once over a onemonth period at T0, T1, and T2	Based on implementation intentions described by Gollwitzer (1999)	3	The level of agreement for each of the 3 items was assessed on a 5-point Likert scale	Answers ranged between "Strongly Disagree=1"; "Disagree=2"; "Neutral=3"; "Agree=4"; and "Strongly Agree=5" Scores ranged between 1 and 5 (originally 3-15)	Higher scores indicate greater implementation intentions	S-CVI=1 Cronbach's alpha=0.80 at T0, 0.6 at T1, and 0.67 at T2
General Help- Seeking Questionnaire	To assess men's intentions to seek help for three testicular symptoms from different sources at T0, T1, and T2	Adopted from the valid and reliable General Help-Seeking Questionnaire (Wilson <i>et al.</i> 2005)	3	The likelihood for each item was assessed on a 7-point Likert scale	Answers ranged between "Extremely Unlikely=1"; "Unlikely=3"; "Likely=5"; and "Extremely Likely=7" The 7 sources of help were combined into one item.	Higher scores indicate greater intentions to seek help	S-CVI=1 Cronbach's alpha=0.88 at T0, 0.94 at T1, and 0.94 at T2

Instrument	Purpose	Source	Number of items	Answer options	Scoring	Interpretation of scores	Validity and reliability
					Scores ranged between 1 and 7 for each symptom		·
Behaviour Questionnaire	At T0: to assess men's past behaviours pertaining to feeling their testes and having their testes examined by a healthcare professional	Researcher-designed based on the literature reviews (Saab <i>et al.</i> 2016a, 2016b, 2016c)	3	"Yes" and "No"-type questions	All items were dichotomous: "Yes=1" and "No=0"	Yes: purposefully examined own testes within past year; purposefully examined own testes within past month; and had testes examined by a healthcare professional No: did not perform the above behaviours	S-CVI=0.94 Cronbach's alpha not calculated due to the multidimensional construct of the questionnaire (Toh <i>et al.</i> 2015). Moreover, the elements of this instrument were operationalised as discreet items
	At T2: to assess men's behaviours in relation to feeling their own testes and advising at least one man to do the same	Researcher-designed based on the literature reviews (Saab <i>et al.</i> 2016a, 2016b, 2016c)	2	"Yes" and "No"-type questions	All items were dichotomous: "Yes=1" and "No=0"	Yes: purposefully examined own testes within past month and advised at least one man to do the same No: did not perform the above behaviours	S-CVI=0.94 Cronbach's alpha not calculated due to the multidimensional construct of the questionnaire (Toh <i>et al.</i> 2015) Moreover, the elements of this instrument were operationalised as discreet items

**Abbreviations:** I-CVI: Item content validity index; NA: Not applicable; S-CVI: Scale content validity index; T0: Time 0 (pre-test); T1: Time 1 (first post-test), T2: Time 2 (second post-test).

**Socio-demographic questionnaire:** This questionnaire was adopted from the qualitative study (Saab *et al.* 2017a, 2017b) and data from the Central Statistics Office (2011) to assess the sample characteristics and was administered at T0. It comprised 11 items as follows: age; nationality; sexual orientation; marital status; highest level of education; current occupation; personal history of testicular disorder(s); prior information about testicular disorders; plan to seek information about testicular disorders; importance of learning about testicular disorders; and prior use of VR.

Knowledge questionnaire: Participants' knowledge was measured at T0, T1, and T2 using a researcher-designed questionnaire with 12 items. Eight items were multiple choice questions pertaining to: the anatomy of the normal testes (2 items); symptoms of testicular disease (3 items); TSE (1 item); and the most common testicular diseases (2 items). Four items were "True" and "False"-type questions in relation to the anatomy of the normal testes. These items also had a "Don't Know" option. There was only one correct answer per item. Therefore, each of the 12 items was dichotomised into "Correct" and "Incorrect/Don't Know." Participants' knowledge was expressed as a mean score ranging between 0 and 12, with higher scores indicating greater knowledge. Participants were required to provide an answer for at least 80% of the items (10 of 12 items) so that an overall score could be calculated.

**Testicular awareness scale:** Testicular awareness was measured at T0, T1, and T2 using a researcher-designed scale with 5 items assessing the participants' familiarity with their own testes, knowing what is normal and what is not normal, and ability to differentiate between what is normal and what is not normal. The level of agreement for each of the 5 items was assessed on a 5-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree." For each participant, a mean score for the

scale was calculated if he answered at least 80% of the items (4 of the 5 items). Possible scores ranged between 1 and 5, with higher scores indicating greater testicular awareness.

**Perceived risk item:** Participants' perceived risk of developing a testicular disease was measured at T0, T1, and T2 using a single researcher-designed item. The level of agreement for this item was assessed on a 5-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree." Scores ranged between 1 and 5, with higher scores indicating greater perceived risk.

Implementation intentions scale: Implementation intentions "specify the when, where, and how of responses leading to goal attainment" (Gollwitzer 1999 p. 121). In a meta-analysis of 94 independent tests, Gollwitzer and Sheeran (2006) found that implementation intentions had a positive effect on goal attainment. In the present study, participants' intentions to feel their own testes in the shower/bath at least once over the coming month and their intentions to advise at least one man to do the same were assessed using 3 items. The level of agreement for each of the items was measured at T0, T1, and T2 on a 5-point Likert scale ranging from "Strongly Disagree" to "Strongly Agree." For each participant, a mean score for the scale was calculated if he answered at least 80% of the items (all 3 items). Possible scores ranged between 1 and 5, with higher scores indicating greater intentions.

General help-seeking questionnaire: This questionnaire was developed by Wilson *et al.* (2005) to assess an individual's intention to seek help for different problems from various sources using "a matrix format that can be modified according to purpose and need. Within this format, help sources and problem-types can be modified to meet sample characteristics and study requirements" (Wilson *et al.* 2005)

p. 18). The questionnaire's reliability and construct validity were established in a study on help-seeking and counselling among high school students (Wilson *et al.* 2005). In the present study, help-seeking intentions were measured at T0, T1, and T2. Participants were provided with 3 different symptoms (i.e. testicular swelling, lumpiness, and pain) and were asked to rate the likelihood of seeking help for each of these symptoms from 7 different sources (i.e. intimate partner, friend, parent, other relative, colleague, phone helpline, and healthcare professional) on a 7-point Likert scale ranging from "Extremely Unlikely" to "Extremely Likely." For each symptom, the 7 sources of help were combined into one scale. For each participant, mean scores for the scales were calculated if he answered at least 80% of the items (6 items) within that scale. Possible scores per symptom ranged between 1 and 7, with higher mean scores indicating greater intentions to seek help for that symptom.

**Behaviour questionnaire:** Men's past behaviours pertaining to feeling their testes and having their testes examined by a healthcare professional were assessed at T0 using a researcher-designed questionnaire with 3 items. Men's behaviours in relation to feeling their own testes and advising at least one man to do the same were then assessed at T2 using a researcher-designed questionnaire with 2 items. All items were dichotomous, whereby men were asked to indicate whether they did or did not perform the behaviours ("Yes" and "No"-type questions).

# 6.3.5 Validity

"Content validity concerns the degree to which a sample of items, taken together, constitute an adequate operational definition of a construct" (Polit & Beck 2006 p. 490). In the present study, content validity was calculated using the Content Validity Index (CVI), which is the most commonly used measure of validity in nursing

research. Item CVI (I-CVI) was used for single-item questionnaires and scale CVI (S-CVI) was used for scales with two or more items (Polit & Beck 2006, Polit *et al.* 2007). "Evaluating a scale's content validity is a critical early step in enhancing the construct validity of an instrument" (Polit *et al.* 2007 p. 459).

A total of eight nursing and public health experts were asked to rate the relevance of each of the items on a 4-point Likert scale ranging from "Not Relevant" to "Highly Relevant" (Appendix 6.11). Scores of 1 and 2 were combined and interpreted as "Not Relevant" and scores of 3 and 4 were combined and interpreted as "Relevant." I-CVI and S-CVI scores greater than 0.8 were regarded as satisfactory (Davis 1992, Polit *et al.* 2007). In the present study, the overall mean I-CVI and S-CVI scores for the instruments used were 0.98 (Appendix 6.12).

# **6.3.6 Reliability**

The reliability (i.e. internal consistency) of the scales was assessed using Cronbach's (1951) alpha. A reliability score of 0.9 and above indicated excellent reliability, 0.7 to 0.89 indicated high reliability, 0.5 to 0.69 indicated moderate reliability, and 0.49 and below indicated low reliability (Hinton *et al.* 2004).

The construct of the instruments used to measure knowledge and behaviour was considered to be multi-dimensional. Therefore, an overall Cronbach's alpha was unsuitable (Toh *et al.* 2015). Cronbach's alpha for the testicular awareness scale was 0.81 at T0, 0.80 at T1, and 0.87 at T2, indicating high reliability. Cronbach's alpha for the implementation intentions scale was 0.80 at T0, indicating high reliability and 0.6 at T1 and 0.67 at T2, indicating moderate reliability. Cronbach's alpha for the general help-seeking questionnaire was 0.88 at T0, indicating high reliability and 0.94 at T1 and T2, indicating excellent reliability.

# **6.3.7 Data Analysis**

#### **6.3.7.1 Coding and Data Entry**

Before the questionnaire was distributed and prior to data entry, a codebook was developed for coding the possible responses to the items in the questionnaire. Following data collection, each question was coded and inputted into IBM SPSS Statistics (Version 22.0, IBM Corp, Armonk, NY, USA). These included the time of measurement, the instrument number, and the question number. For example, at baseline (T0), the first question in the knowledge questionnaire was coded as T0\_1\_1. The same question was coded as T1\_1\_1 at first post-test (T1) and T2\_1\_1 at second post-test (T2). This step is important to avoid confusion and to keep a permanent record of the coding of the dataset (Marston 2010). Missing values, including those from participants who lost to follow-up at T2, were coded as 999. The dataset was checked thoroughly for data-entry mistakes.

#### **6.3.7.2 Statistical Analyses**

Descriptive and inferential statistics were used to analyse data from the pilot study. All statistical analyses were performed using SPSS. All tests were two-sided and statistical significance was set at  $p \le 0.05$ .

Descriptive statistics were used to describe the socio-demographic characteristics of the sample and key study variables. The descriptive statistics used were: frequencies (n) and percentages (%) for categorical variables, and measures of central tendency (mean and median), and dispersion (minimum, maximum, standard deviation [SD], and interquartile range [IQR]) for continuous variables (Marston 2010). Moreover, the distribution of continuous data was represented graphically using boxplots.

"Inferential statistics are designed to address objectives, questions, and hypotheses in studies to allow inference from the study sample to the target population" (Grove *et al.* 2015 p. 319). Parametric tests were used to analyse normally distributed data and non-parametric tests were used to analyse data that were not normally distributed and data from single-item instruments (Parahoo 2014).

Prior to selecting the appropriate statistical test, continuous variables were assessed for normality and the presence of outliers at each time point using histograms and boxplots. Normality was also assessed using quantile-quantile (QQ) plots, analysis of skewness and kurtosis coefficients, and statistical tests (i.e. Kolmogorov-Smirnov and the Shapiro-Wilk tests). If no outliers were present and the data were normally distributed at each time point, a one-way repeated measures ANOVA was conducted to investigate if there were statistically significant changes over the three time points. When a statistically significant difference was found, pairwise comparisons were performed with a Bonferroni correction for multiple comparisons. If the assumption of sphericity was not met, as assessed by Mauchly's test of sphericity, the p-value with the Greenhouse-Geisser correction was reported. In situations where the assumption of normality at each time point was violated or outliers were present, the nonparametric Friedman test was conducted with Bonferroni adjustment for multiple comparisons, where appropriate (Grove et al. 2015). Friedman's test was also used to compare responses to single-item instruments (on a Likert scale) across the three time points.

For paired binary variables, McNemar's test was conducted to investigate if there was a statistically significant change in proportions over time. For non-paired binary variables, Fisher's exact test was conducted to investigate whether the proportions of one variable were different depending on the value of the other variable (Campbell *et al.* 2010, Parahoo 2014).

# **6.4 Results**

Unless otherwise indicated, the results, including sample characteristics, are reported from the 49 participants who completed the questionnaire at pre-test (T0), first post-test (T1), and second post-test (T2).

# **6.4.1 Sample Characteristics**

Overall, 53 men participated in the study at T0 and T1. Four participants dropped out at T2; yielding a sample size of 49 participants and an attrition rate of 7.5%, which is regarded as acceptable in experimental studies, as it falls below 20% (Sackett *et al.* 2000, Fewtrell *et al.* 2008). It was found that a sample size of 49 men has a power of 97% to detect a medium effect (f=0.25, Cohen 1992) in a repeated measures ANOVA with three waves, a level of significance of 0.05 and a 2-tailed test, assuming sphericity and correlations of 0.5 between waves of data (from G-Power 3.1 program, Erdfelder *et al.* 1996).

The age of participants ranged between 18 and 50 years (Median 26, IQR 21 to 33.5) with 67.5% (n=33) aged 30 years or younger. The majority of participants were Irish (79.6%, n=39); single (55.1%, n=27); university students (56.7%, n=28); self-identified as heterosexual (85.7%, n=42); and completed an undergraduate degree (55.1%, n=27). Moreover, the majority of the participants had no history of testicular disorder(s) (87.8%, n=43); had no prior information about testicular disorders (69.4%, n=34); did not plan on seeking information about testicular disorders (57.1%, n=28); rated the importance of learning about testicular disorders as "Important" (44.9%, n=22) and "Very Important" (42.9%, n=21); and had never used VR in the past

(69.4%, n=34; Table 6.2). Of note, the characteristics of the four participants who dropped out from the study at T2 did not differ from those of the 49 participants who completed the study.

**Table 6.2** Socio-demographic characteristics of the participants in the pilot study (n=49)

(n=49)	
Characteristic	n(%)
Age (years)	
≤20	11(22.5)
21-30	22(45)
31-40	9(18.1)
41-50	7(14.1)
Range	18-50
Median(IQR)	26(21 to 33.5)
Nationality	,
Irish	39(79.6)
Indian	3(6.1)
Dual citizenship	1(2)
American	1(2)
Brazilian	1(2)
Italian	1(2)
Iraqi	1(2)
Lebanese	1(2)
Syrian	1(2)
Sexual orientation	. ,
Heterosexual	42(85.7)
Gay	4(8.2)
Bisexual	3(6.1)
Marital status	, ,
Single	27(55.1)
In a relationship/partnered	17(34.7)
Married	5(10.2)
Highest level of education	
Primary	1(2)
Secondary	21(42.9)
University (Undergraduate)	27(55.1)
Occupation	
Student	28(56.7)
Employed (Full-time)	19(38.8)
Employed (Part-time)	1(2)
Unemployed	1(2)
Personal history of a testicular disorder	
Yes (Cyst)	1(2)
Yes (Epididymitis)	2(4.1)
Yes (Hydrocele)	1(2)
Yes (Trauma)	1(2)
Unsure	1(2)

No	43(87.8)
Prior information about testicular disorders	
Yes (Source not indicated)	3(6.1)
Yes (School)	3(6.1)
Yes (University)	3(6.1)
Yes (Doctor)	2(4.1)
Yes (Doctor and media)	2(4.1)
Yes (Literature)	1(2)
Yes (Media)	1(2)
No	34(69.4)
Plan to seek information about testicular disorders	
Yes	21(42.9)
No	28(57.1)
The importance of learning about testicular disorders	
Very Important	21(42.9)
Important	22(44.9)
Neutral	6(12.2)
Prior use of VR	
Yes	15(30.6)
No	34(69.4)

# 6.4.2 Knowledge

At T0, less than half of the participants knew that: TC was not very common (18.4%, n=9); epididymitis and orchitis were the most common causes of testicular swelling (20.4%, n=10); testicular torsion was the most common cause of sharp and sudden testicular pain (32.7%, n=16); the epididymis was the tube that stores the sperm (34.7%, n=17); the spermatic cord was the tube from which the testes hang (38.8%, n=19); and unsafe sex was a risk factor for epididymitis and orchitis (44.9%, n=22). The proportion of participants who answered the items of the knowledge questionnaire correctly at each time point is presented in Table 6.3.

**Table 6.3** Proportion of participants who answered the items of the knowledge questionnaire correctly at each time point

Question	T0	T1	T2
	n(%)	n(%)	n(%)
1. Your right testicle is a different size from your left testicle	29(59.2)	44(89.8)	45(91.8)
2. Your testicles are identical to other men's testicles	30(61.2)	44(89.8)	46(93.9)
3. Sometimes, one testicle lies slightly lower than the other	47(95.9)	48(98)	48(98)
4. Testicles are round in shape	32(65.3)	40(81.6)	37(75.5)
5. What is the name of the tube that stores the sperm?	17(34.7)	41(83.7)	34(69.4)
6. What is the name if the tube from which the testicles hang?	19(38.8)	37(75.5)	25(51)
7. Which symptom below does not commonly occur in the testicles?	36(73.5)	41(83.7)	44(89.8)
8. What is the most common reason for an enlarged/swollen testicle?	10(20.4)	34(69.4)	22(44.9)
9. What is the most common reason for sharp and sudden pain in the testicle?	16(32.7)	28(57.1)	29(59.2)
10. The best time to check the testicle is	39(79.6)	47(95.9)	47(95.9)
11. What puts a man at risk for epididymitis and orchitis	22(44.9)	43(87.8)	36(73.5)
12. Which statement about testicular cancer is not true	9(18.4)	32(65.3)	24(49)

**Abbreviations:** T0: Time 0 (pre-test); T1: Time 1 (first post-test), T2: Time 2 (second post-test).

Out of a possible maximum score of 12, mean knowledge scores were 6.2 (SD 1.8, range 3-11) at T0, 9.8 (SD 1.5, range 5-12) at T1, and 8.9 (SD 1.8, range 4-12) at T2. The distribution of the knowledge scores at each time point is presented in Figure 6.3.

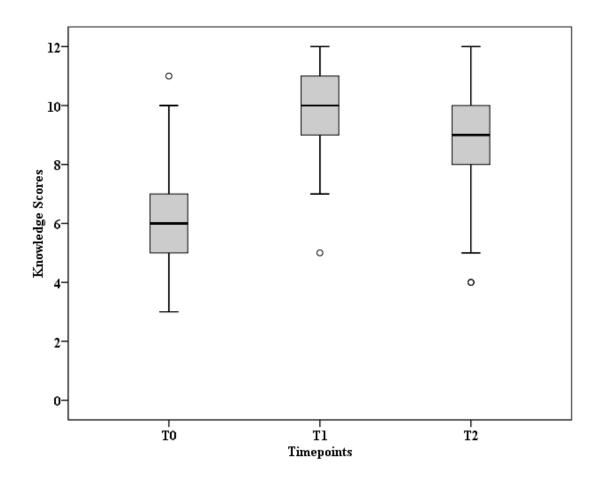


Figure 6.3 The distribution of the knowledge scores at T0, T1, and T2

Repeated measures ANOVA showed a statistically significant change in mean knowledge scores between the three time points (p<0.001). Pairwise comparisons showed a statistically significant increase in knowledge scores between T0 and T1 (Mean difference [T1-T0] 3.5, 95%CI 2.80 to 4.26; p<0.001) and between T0 and T2 (Mean difference [T2-T0] 2.7, 95%CI 1.95 to 3.40; p<0.001). Knowledge scores decreased between T1 and T2, which was statistically significant (Mean difference [T2-T1] -0.9, 95%CI -1.57 to -0.14; p=0.014; Table 6.4).

**Table 6.4** Pairwise comparison for knowledge (n=49)

Pairwise comparison	Mean difference(95%CI)	p-value*
T1 vs T0	3.5(2.80 to 4.26)	< 0.001
T2 vs T0	2.7(1.95 to 3.40)	< 0.001
T2 vs T1	-0.9(-1.57 to -0.14)	0.014

<sup>\*</sup>Pairwise comparison with Bonferroni adjustment following repeated measures ANOVA.

#### **6.4.3 Testicular Awareness**

At T0, the majority of participants were in agreement (i.e. answered with "Agree" and "Strongly Agree") that they were familiar with the way their own testes looked and felt (83.6%, n=41) and that they knew what was normal and what was not normal when they felt their testes (69.4%, n=34). Approximately, half of the participants were in agreement that they could tell if something was wrong with their testes (57.1%, n=28); that they can differentiate between what is normal and what is not normal when they felt their testes (55.1%, n=27); and that they were able to detect any changes in their testes (53.1%, n=26).

Out of a possible maximum score of 5, mean testicular awareness scores were 3.6 (SD 0.6, range 2.2-4.8) at T0, 3.8 (SD 0.8, range 1.8-5) at T1, and 4 (SD 0.6, range 2.4-5) at T2. The distribution of the testicular awareness scores at each time point is presented in Figure 6.4.

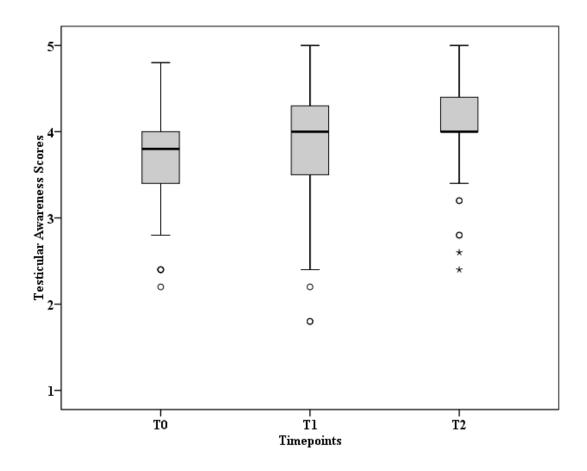


Figure 6.4 The distribution of the testicular awareness scores at T0, T1, and T2

Repeated measures ANOVA showed a statistically significant increase in mean testicular awareness scores between the three time points (p<0.001). Pairwise comparisons showed a statistically significant increase in testicular awareness scores between T0 and T1 (Mean difference [T1-T0] 0.2, 95%CI 0.01 to 0.41; p=0.038), T0 and T2 (Mean difference [T2-T0] 0.4, 95%CI 0.25 to 0.60; p<0.001), and T1 and T2 (Mean difference [T2-T1] 0.2, 95%CI 0.01 to 0.42; p=0.033; Table 6.5).

**Table 6.5** Pairwise comparison for testicular awareness (n=49)

Pairwise comparison	Mean difference(95%CI)	p-value*
T1 vs T0	0.2(0.01 to 0.41)	0.038
T2 vs T0	0.4(0.25 to 0.60)	< 0.001
T2 vs T1	0.2(0.01 to 0.42)	0.033

<sup>\*</sup>Pairwise comparison with Bonferroni adjustment following repeated measures ANOVA.

#### **6.4.4 Perceived Risk**

Data pertaining to perceived risk were available from 48 participants at T0, T1, and T2. Out of a possible maximum score of 5, median perceived risk scores were 3 (IQR 2 to 3) at T0, 3 (IQR 2 to 3.8) at T1, and 3 (IQR 2 to 4) at T2. The distribution of the perceived risk scores at each time point is presented in Figure 6.5.

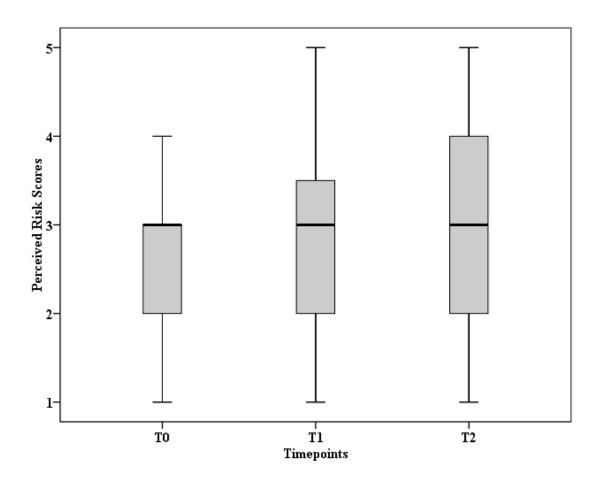


Figure 6.5 The distribution of the perceived risk scores at T0, T1, and T2

Friedman test showed no statistically significant change in perceived risk scores between the three time points (p=0.146; Table 6.6).

**Table 6.6** Perceived risk (n=48)

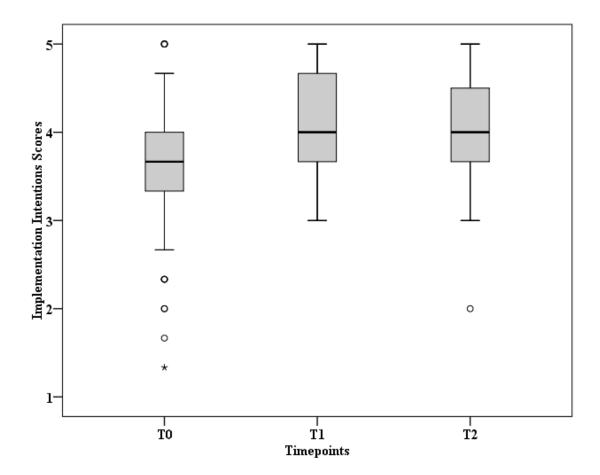
Time of measurement	easurement Median(IQR)		
T0	3(2 to 3)		
<b>T</b> 1	3(2 to 3.75)	0.146	
T2	3(2 to 4)		

<sup>\*</sup>Friedman test.

#### **6.4.5 Implementation Intentions**

Data pertaining to implementation intentions were available from 48 participants at T0, T1, and T2. At T0, the majority of participants were in agreement that they "intended" to feel their testes in the shower/bath at least once over the coming month (77.6%, n=38) and that they "will" be feeling their testes in the shower/bath at least once over the coming month (71.4%, n=35). On the other hand, only 34.3% (n=17) were in agreement that they intended to advise at least one man to feel his own testes in the shower/bath at least once over the coming month. The remainder were either in disagreement (i.e. answered with "Disagree" and "Strongly Disagree; 32.6%, n=17) or were neutral (30.6%, n=15).

Out of a possible maximum score of 5, mean implementation intentions scores were 3.6 (SD 0.9, range 1.3-5) at T0, 4.2 (SD 0.6, range 3-5) at T1, and 4 (SD 0.6, range 2-5) at T2. The distribution of the implementation intentions scores at each time point is presented in Figure 6.6.



**Figure 6.6** The distribution of the implementation intentions scores at T0, T1, and T2

Repeated measures ANOVA showed a statistically significant change in mean implementation intentions scores between the three time points (p<0.001). Pairwise comparisons showed a statistically significant increase in implementation intentions scores between T0 and T1 (Mean difference [T1-T0] 0.6, 95%CI 0.33 to 0.90; p<0.001) and between T0 and T2 (Mean difference [T2-T0] 0.5, 95%CI 0.15 to 0.78; p=0.002). Implementation intentions scores decreased between T1 and T2, which was not statistically significant (Mean difference [T2-T1] -0.2, 95%CI -0.37 to 0.06; p=0.24; Table 6.7).

**Table 6.7** Pairwise comparison for implementation intentions (n=48)

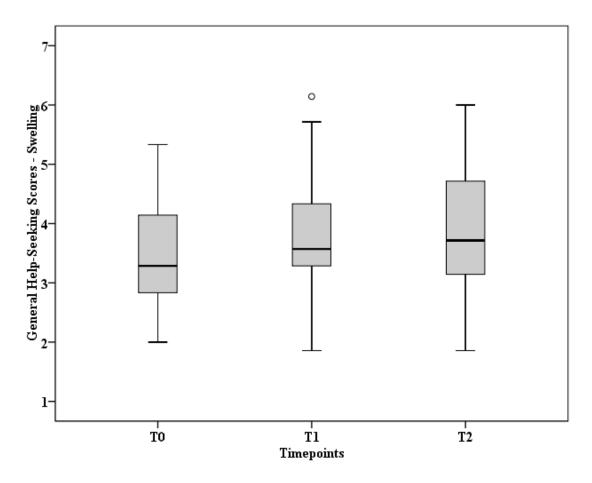
Pairwise comparison	Mean difference(95%CI)	p-value*
T1 vs T0	0.6(0.33 to 0.90)	< 0.001
T2 vs T0	0.5(0.15 to 0.78)	0.002
T2 vs T1	-0.2(-0.37 to 0.06)	0.24

<sup>\*</sup>Pairwise comparison with Bonferroni adjustment following repeated measures ANOVA.

## **6.4.6 General Help-Seeking Intentions**

#### **6.4.6.1** Swelling

Out of a possible maximum score of 7, mean general help-seeking scores for swelling were 3.5 (SD 0.9, range 2-5.3) at T0, 3.8 (SD 1, range 1.9-6.1) at T1, and 3.9 (SD 1, range 1.9-6) at T2. The distribution of the help-seeking intentions scores for swelling at each time point is presented in Figure 6.7.



**Figure 6.7** The distribution of the general help-seeking scores for swelling at T0, T1, and T2

Repeated measures ANOVA showed a statistically significant change in help-seeking intentions scores for swelling between the three time points (p=0.003). Pairwise comparisons showed a statistically significant increase in help-seeking intentions scores between T0 and T1 (Mean difference [T1-T0] 0.3, 95%CI 0.12 to 0.51; p=0.001) and between T0 and T2 (Mean difference [T2-T0] 0.4, 95%CI 0.08 to 0.72; p=0.01). Help-seeking intentions scores increased between T1 and T2, which was not statistically significant (Mean difference [T2-T1] 0.1, 95%CI -0.21 to 0.38; p=1; Table 6.8).

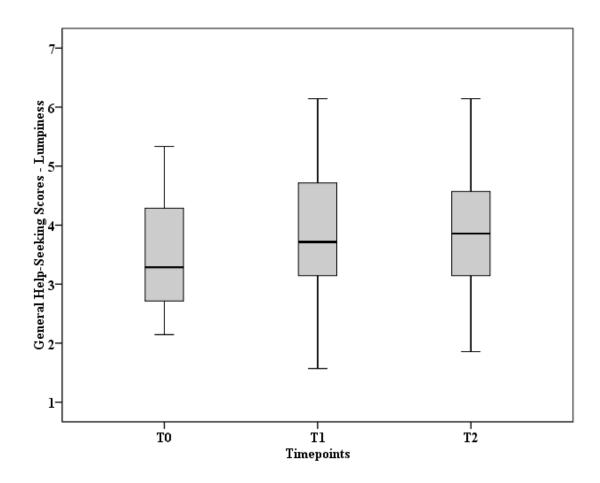
**Table 6.8** Pairwise comparison for general help-seeking for swelling (n=49)

Pairwise comparison	Mean difference(95%CI)	p-value*
T1 vs T0	0.3(0.12 to 0.51)	0.001
T2 vs T0	0.4(0.08 to 0.72)	0.01
T2 vs T1	0.1(-0.21 to 0.38)	1

<sup>\*</sup>Pairwise comparison with Bonferroni adjustment following repeated measures ANOVA.

#### **6.4.6.2** Lumpiness

Out of a possible maximum score of 7, mean general help-seeking scores for lumpiness were 3.5 (SD 0.9, range 2.1-5.3) at T0, 3.8 (SD 1.1, range 1.6-6.1) at T1, and 3.9 (SD 1, range 1.9-6.1) at T2. The distribution of the help-seeking intentions scores for lumpiness at each time point is presented in Figure 6.8.



**Figure 6.8** The distribution of the general help-seeking scores for lumpiness at T0, T1, and T2

Repeated measures ANOVA showed a statistically significant change in help-seeking intentions scores for lumpiness between the three time points (p=0.013). Pairwise comparisons showed a statistically significant increase in help-seeking intentions scores between T0 and T1 (Mean difference [T1-T0] 0.3, 95%CI 0.08 to 0.46; p=0.003) and between T0 and T2 (Mean difference [T2-T0] 0.3, 95%CI 0.02 to 0.67; p=0.04). Help-seeking intentions scores increased between T1 and T2, which was not statistically significant (Mean difference [T2-T1] 0.1, 95%CI -0.22 to 0.37; p=1; Table 6.9).

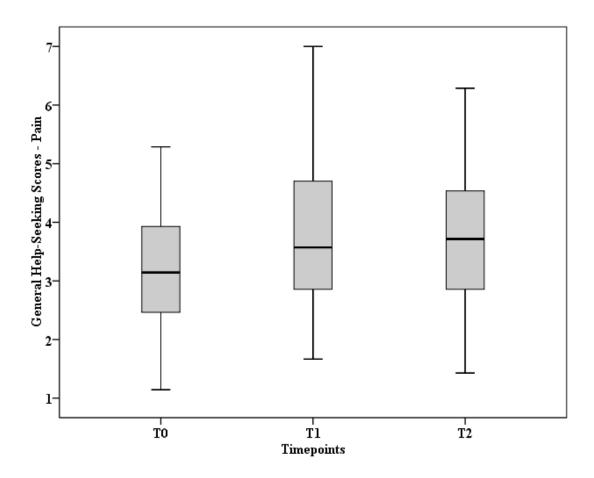
**Table 6.9** Pairwise comparison for general help-seeking for lumpiness (n=49)

Pairwise comparison	Mean difference(95%CI)	p-value*
T1 vs T0	0.3(0.08 to 0.46)	0.003
T2 vs T0	0.3(0.02 to 0.67)	0.04
T2 vs T1	0.1(-0.22  to  0.37)	1

<sup>\*</sup>Pairwise comparison with Bonferroni adjustment following repeated measures ANOVA.

#### **6.4.6.3** Pain

Data pertaining to help-seeking for pain were available from 48 participants at T0, T1, and T2. Out of a possible maximum score of 7, mean general help-seeking scores for pain were 3.2 (SD 0.9, range 1.1-5.3) at T0, 3.8 (SD 1.3, range 1.7-7) at T1, and 3.7 (SD 1, range 1.4-6.3) at T2. The distribution of the help-seeking intentions scores for pain at each time point is presented in Figure 6.9.



**Figure 6.9** The distribution of the general help-seeking scores for pain at T0, T1, and T2

Repeated measures ANOVA showed a statistically significant change in help-seeking intentions scores for pain between the three time points (p<0.001). Pairwise comparisons showed a statistically significant increase in help-seeking intentions scores between T0 and T1 (Mean difference [T1-T0] 0.6, 95%CI 0.25 to 1.01; p<0.001) and between T0 and T2 (Mean difference [T2-T0] 0.6, 95%CI 0.28 to 0.89; p<0.001). Help-seeking intentions scores decreased between T1 and T2, which was not statistically significant (Mean difference [T2-T1] -0.04, 95%CI -0.38 to 0.29; p=1; Table 6.10).

**Table 6.10** Pairwise comparisons for general help-seeking for pain (n=48)

Pairwise comparisons	Mean difference(95%CI)	p-value*
T1 vs T0	0.6(0.25 to 1.01)	< 0.001
T2 vs T0	0.6(0.28  to  0.89)	< 0.001
T2 vs T1	-0.04(-0.38 to 0.29)	1

<sup>\*</sup>Pairwise comparisons with Bonferroni adjustment following repeated measures ANOVA.

#### 6.4.6.4 Sources of help

Healthcare professionals served as the main source of help for each of the three symptoms and each of the three time points. This was followed by intimate partners, parents, friends, phone helpline, other relatives/family members, and colleagues. The sources of help for testicular swelling, lumpiness, and pain at each time point are presented in Table 6.11.

Table 6.11 The sources of help for testicular swelling, lumpiness, and pain at each time point

Source					Symptom				
		Swelling			Lumpiness			Pain	
	Т0	T1	<b>T2</b>	TO	T1	<b>T2</b>	T0	T1	T2
	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)	Mean(SD)
Healthcare professional	6.1(1.1)	6.6(0.7)	6.4(1.2)	6.4(0.8)	6.4(1.2)	6.5(0.8)	5.5(1.5)	6.6(0.8)	6.3(1.1)
2. Intimate partner	4.8(1.9)	4.9(1.9)	5.1(2)	4.9(1.9)	4.8(2)	5.1(2)	4.2(2)	5(2)	5(2)
3. Parent	3.5(2.1)	3.7(2.2)	3.9(2.1)	3.6(2.2)	3.8(2.3)	3.8(2.1)	3.2(2.2)	3.7(2.3)	3.8(2.1)
4. Friend	3(1.7)	3.1(1.8)	3.5(1.7)	2.8(1.7)	3(1.9)	3.3(1.8)	2.7(1.7)	3(1.9)	2.3(2)
5. Phone helpline	2.9(1.9)	3.5(2.1)	3.5(2)	3.1(2.2)	3.9(2.3)	3.6(2)	2.7(1.9)	3.7(2.4)	3.4(2)
6. Other relative/family member	2.4(1.7)	2.7(1.7)	2.7(1.6)	2.4(1.6)	2.6(1.7)	2.7(1.6)	2.3(1.5)	2.7(1.9)	2.6(1.6)
7. Colleague	1.78(1.2)	2(1.2)	2.2(1.4)	1.7(1.1)	2(1.3)	2.2(1.4)	1.6(0.9)	2.2(1.6)	2.1(1.2)

**Abbreviations:** SD: Standard deviation; T0: Time 0 (pre-test); T1: Time 1 (first post-test), T2: Time 2 (second post-test).

#### 6.4.7 Behaviour

At T0, 39 (79.6%) participants reported having purposefully examined their testes within the past year, 20 (40.8%) reported having done that within the past month, and 24 (49%) reported that a healthcare professional examined their testes in the past.

At T2, 40 (75.5%) participants reported having purposefully examined their testes within the past month (i.e. the month that followed exposure to the intervention). McNemar's test showed a statistically significant increase in the percentage of participants who reported examining their testes at T2 in comparison to T0 (p<0.001). Also at T2, 22 (41.5%) participants reported that they advised at least one man to examine his own testes.

#### **6.4.8 Implementation Intentions and Behaviour**

The effect of implementation intentions on behaviour was assessed. At T0, 38 (77.6%) participants were in agreement that they "intend" to feel their testes in the shower/bath at least once over the coming month (i.e. by T2). Of those, 34 (89.5%) reported having done that at T2. Of the 11 (22.4%) participants who were not in agreement that they "intend" to feel their testes in the shower/bath at least once over the coming month, 6 (54.5%) reported having done that at T2. Fisher's exact test showed a statistically significant difference in the percentages between the two groups (p=0.019).

At T0, 36 (73.5%) participants were in agreement that they "will" feel their testes in the shower/bath at least once over the coming month (i.e. by T2). Of those, 31 (86.1%) reported having done that at T2. Of those who were not in agreement at T0 (n=13, 26.5%), over two-thirds (n=9, 69.2%) reported having purposefully

felt/examined their testes at T2. Fisher's exact test showed no statistically significant difference in the percentages between the two groups (p=0.22).

As for intending to advise at least one man about the importance of examining his testes in the shower/bath at least once over the coming month (i.e. by T2), 17 (34.7%) participants were in agreement at T0. Of those, 14 (82.4%) reported having done that at T2. Of the 32 (65.3%) participants who were not in agreement that they "intend" to advise at least one man about the importance of examining his testes in the shower/bath at least once over the coming month, 8 (25%) reported having done that at T2. Fisher's exact test showed a statistically significant difference in the percentages between the two groups (p<0.001).

#### 6.5 Discussion

The E-MAT intervention was successful in enhancing men's knowledge of the normal testes and common testicular symptoms and diseases as well as testicular awareness in terms of familiarity with their own testes and knowledge of and ability to differentiate between normal and abnormal testicular findings.

Braga *et al.* (2017) made a distinction between awareness and knowledge of TC, whereby awareness was assessed in terms of being "aware of the TC existence" (p. 106), whereas knowledge was explored in terms of knowing common TC symptoms, risk factors, and age of onset. It was found that, out of 507 males, 78% (n=399) reported being aware of TC; yet, 48.9% (n=244) did not recognise the most common symptoms of TC and only 15% (n=76) knew the age at diagnosis (Braga *et al.* 2017). Similarly, participants in the pilot study scored low on the knowledge questionnaire at baseline, despite agreeing that they were aware of testicular disorders.

While awareness significantly increased at T1 and T2, knowledge significantly decreased between T1 and T2 but remained significantly higher than T0. The researcher speculates that, given the small sample size, these findings could be due to chance (Grove *et al.* 2015). Alternatively, knowledge decline, sometimes referred to as knowledge decay, is not uncommon in health promotion interventions (Nimmons *et al.* 2017). In fact, a number of organisations involved in health promotion, including cancer organisations, tend to design new campaigns every so often in order to keep the public informed and ensure that the public does not lose interest. An example is a controversial campaign titled "Get Cancer" launched by the Irish Cancer Society (2017) to raise the public's awareness regarding the high cancer incidence in Ireland. This was also supported by evidence from the qualitative study, whereby participants recommended changing intervention formats periodically in order to keep men engaged with health information, preventing the message from "wearing thin", and achieving a "top-up effect" (Saab *et al.* 2017b).

Messages provided by the voiceover regarding the risk factors for testicular disorders and the increase in mean knowledge and awareness scores at post-test did not yield an increase in the participants' perceived risk for testicular disorders. Contradicting evidence exists regarding men's perceived risk and vulnerability to TC. For instance, Powe *et al.* (2007) found that perceived risk for TC was low among African American men and high among Caucasian men and Muliira *et al.* (2013) reported that perceived risk for TC was low in a sample of Ugandan men. In contrast, Rovito *et al.* (2011) reported relatively high scores on perceived vulnerability for TC. Of note, low perceived risk for diseases such as cancer was identified as a barrier to early help-seeking for symptoms of cancer (Scanlon *et al.* 2006, Fish *et al.* 2015). On

the other hand, the literature on men's perceived risk for BTDs is lacking (Saab *et al.* 2016a).

There are a number of explanations as to why men often have low risk perceptions for testicular disorders. One hypothesis is that diseases of the testes tend to affect younger men who are relatively healthy. This was reflected in the qualitative study, whereby men aged 18 and 19 did not perceive themselves to be at risk for developing a testicular disorder (Saab *et al.* 2017a). Another explanation is that cancer worry tends to be higher among individuals who are predisposed to this disease. For example, Yeh *et al.* (2015) found that breast cancer worry was higher among women who were notified that they had a "dense breast tissue" (Yeh *et al.* 2015 p. 261). Similarly, Molina *et al.* (2015) found that women who had a positive family history of breast cancer were significantly more likely to report a greater risk perception for this malignancy (Molina *et al.* 2015). These findings could be transferrable to the context of testicular disorders, while bearing in mind the potential impact of gender differences and masculine social constructs on risk perception.

Overall, the E-MAT intervention succeeded in increasing men's intentions to seek help for testicular swelling, lumpiness, and pain. Contradicting evidence exists regarding the effectiveness of VR-based interventions in promoting help-seeking. For instance, a systematic review of 24 controlled studies using VR in a mental health context found that, in comparison to control situations, VR was effective in the treatment of phobias, social anxiety, post-traumatic stress disorder, and eating disorders (Valmaggia *et al.* 2016). In contrast, a computer game featuring a virtual human did not succeed in increasing psychological help-seeking among suffers of posttraumatic stress disorder and depression (Meeker *et al.* 2016). Similarly, Gahm *et al.* (2014) found that VR exposure therapy was less effective than traditional

prolonged exposure therapy in the management of posttraumatic stress disorder. Of note, these studies were conducted in a mental health context in order to enhance behaviours rather than increase intentions. Therefore, these findings may not be transferrable to the context of testicular symptoms.

Participants in the present study identified healthcare professionals as the key source of help in the event of testicular lumpiness, pain, and/or swelling. This finding is echoed in a number of studies exploring men's help- and health-seeking behaviours for cancer symptoms (Fish et al. 2015, Saab et al. 2017c). For example, participants in a study aimed at exploring prostate cancer knowledge, reported that their primary physician was the key source of screening information (Kroger-Jarvis 2014). Similarly, participants in the study by Bass et al. (2011) cited their primary physician as the key source of information on colorectal cancer screening. Moreover, having access to a healthcare professional and having a family member who is a healthcare professional served as facilitators to help-seeking in the qualitative study (Saab et al. 2017a). Of note, these findings are echoed in the literature on help-seeking for mental health problems and substance abuse (Goodwin et al. 2016, Lubman et al. 2017, Redmond et al. 2017). For instance, Goodwin et al. (2016) examined university students' help-seeking intentions and experiences in terms of mental wellbeing and found that almost a third of the participants reported having sought help from a mental health professional.

Intimate partners were also identified as a key source of help that men would revert to in case they experienced a testicular symptom. Similarly, intimate partners have been listed as an important source of informal help in a mental health context (Goodwin *et al.* 2016). Of note, partners do not only serve as a key source of help, but also play a pivotal role in encouraging men to seek medical help (Saab *et al.* 2017a).

For instance, a study exploring factors linked to help-seeking for cancer "alarm symptoms" among 3,766 participants, found that those who were married/cohabiting rather than single, were more likely to report seeking help (Whitaker *et al.* 2016).

Men's intentions and behaviours in relation to feeling their own testes and advising other men to do the same significantly increased following the E-MAT intervention. These findings are supported by evidence from a number of studies on cancer prevention and screening. An example is a study aimed at increasing colorectal screening uptake using implementation intentions (Orbell *et al.* 2016). It was found that participants who received leaflets with messages written using implementation intentions statements were more likely to get screened that those who did not receive any leaflets. Of note, participants in the study by Orbell *et al.* (2016) were predominantly older than 50, therefore the applicability of these findings to the context of testicular awareness is debatable. Moreover, in the pilot study, it was unclear whether men's intentions and behaviours pertaining to feeling their own testes and advising other men to do the same increased as a result of the E-MAT intervention, the questions written using implementation intentions, or both, which warrants further investigation.

#### **6.5.1 Implications**

This pilot study has a number of implications for research, education, and practice. From a research perspective, rigour, generalizability, and sample representativeness could be enhanced by conducting an RCT with a larger sample size across different settings. It is also important to explore the long-term effect of the E-MAT intervention on knowledge, awareness, intentions, and behaviours. This could be achieved by conducting a longitudinal study. Furthermore, men's perceived risk for

testicular diseases remained low following the E-MAT intervention, which warrants further exploration.

From an educational standpoint, the E-MAT intervention can be made available on public platforms such as websites of cancer organisations and schools and universities. In addition, the intervention could be used as an element of large campaigns such as Movember. It is also important to consider the needs of men at risk for health inequities while disseminating the E-MAT intervention. This could be addressed by making the intervention available in settings frequented by these men, such as men's sheds, sports clubs, and youth organisations. For those who suffer from VR sickness or have limited access to VR, the intervention could be customised to run in a normal desktop environment. Finally, VR can be used to raise men's awareness of a number of health topics. These include but are not limited to sexually transmitted infections and cancer prevention and risk reduction.

Clinicians, including nurses, must be made aware of the importance of initiatives such as the E-MAT intervention in promoting testicular awareness and early help-seeking for testicular symptoms. It is also important to advise men to familiarise themselves with the way their own testes look and feel and to seek timely medical attention for testicular symptoms, just like women are encouraged to become familiar with their breasts and to seek help for abnormalities. This could be achieved by directing men to platforms where the E-MAT intervention is readily accessible.

#### **6.5.2 Strengths**

The benefits of pilot-testing (Section 6.3.1) were matched with the processes undertaken in the present study. These are presented in Table 6.12.

**Table 6.12** The benefits from conducting the pilot study

•	<u> </u>
Developing and testing	An instrument with 7 questionnaires/scales was
research instruments	developed and its content validity was established. The
	instruments had moderate to excellent reliability. More
	comprehensive psychometric testing is needed.
Assessing the feasibility	Full-scale testing is warranted, given the results
of conducing full-scale	achieved and the processes involved in the development
testing	and pilot-testing of the E-MAT intervention.
Assessing people's	Participants readily answered the invitation e-mail and
willingness to	invited other men to participate. Retention rate was
participate	92.5%.
Establishing whether	Non-probability convenience and snowball sampling
Establishing whether the sampling strategy is	Non-probability convenience and snowball sampling strategies proved effective in recruiting study
O	•
the sampling strategy is	strategies proved effective in recruiting study
the sampling strategy is effective	strategies proved effective in recruiting study participants.
the sampling strategy is effective  Identifying	strategies proved effective in recruiting study participants.  No unforeseeable risks were identified. The risk of VR
the sampling strategy is effective Identifying unforeseeable risks	strategies proved effective in recruiting study participants.  No unforeseeable risks were identified. The risk of VR sickness was accounted for prior to data collection.
the sampling strategy is effective  Identifying unforeseeable risks  Assessing data analysis	strategies proved effective in recruiting study participants.  No unforeseeable risks were identified. The risk of VR sickness was accounted for prior to data collection.  Statistical support by an expert statistician was
the sampling strategy is effective  Identifying unforeseeable risks  Assessing data analysis	strategies proved effective in recruiting study participants.  No unforeseeable risks were identified. The risk of VR sickness was accounted for prior to data collection.  Statistical support by an expert statistician was provided during data analysis and findings were cross-
the sampling strategy is effective Identifying unforeseeable risks Assessing data analysis techniques	strategies proved effective in recruiting study participants.  No unforeseeable risks were identified. The risk of VR sickness was accounted for prior to data collection.  Statistical support by an expert statistician was provided during data analysis and findings were cross-checked.

(van Teijlingen et al. 2001, van Teijlingen & Hundley 2001, Thabane et al. 2010).

Unlike many of the reviewed studies that failed to report on the validity and reliability of data collection instruments (Saab *et al.* 2016a, 2016b, 2016c), the content validity of the instruments developed and used in this pilot study was established. In addition, Cronbach's alpha scores showed moderate to excellent reliability. However, further psychometric testing is required. Moreover, despite the limitations of non-probability convenience and snowball sampling, these strategies proved effective in recruiting study participants. Retention rate was high (92.5%, n=49), which can be attributed to: performing intensive and timely follow-up; having the same researcher collect data at different time points; having a researcher from the target population (i.e. young, male, and a university student); offering social support by providing the contact details of free counselling and support services; and having accessible data collection sites (i.e. university campus). All these strategies are supported by evidence from a

review of 95 public health studies on the challenges and opportunities involved in the recruitment of hard-to-reach participants (Yancey *et al.* 2006).

Another strategy that could have led to the high retention rate, is the financial incentive offered to participants upon completing the study. Contradicting evidence exists around the use of financial incentives in research. Groth (2010) argues that such incentives increase the cost of a study and provide inducements to participate for financial reasons only. Nevertheless, evidence suggests that financial incentives help increase participation and retention and motivate participants to change certain behaviours (Yancey *et al.* 2006, Finkelstein *et al.* 2007). Of note, the model of payment that was used in the present study is an appreciation model offered to selected participants at the conclusion of the study; a major advantage of this model is avoiding undue inducement (Dickert & Grady 1999, Grady 2005).

The risks from the E-MAT intervention were minimal and no unforeseeable risks arose during pilot testing. In addition, the researcher and interactive media expert asked the participants whether they had a history of motion sickness and assessed them for VR sickness using a brief demonstration. Of the 53 participants who played the game at baseline, only one complained of eye strain which subsided immediately following the game. As for data analysis, statistical support by an expert statistician was provided and the findings were cross-checked for correctness and accuracy.

#### 6.5.3 Limitations

This study is not without limitations. Firstly, findings cannot be considered generalizable, mainly due to the small sample size. However, sample sizes smaller than 49 have been recommended and used in previous pilot studies (Julious 2005, Hertzog 2008, Johanson & Brooks 2010). In addition, generalizability was

compromised due to the homogeneity of the sample. For instance, participation was sought from one university and the majority of the participants were younger than 30, Irish, heterosexual, single, and university educated. Secondly, participants were recruited using non-probability convenience and snowball sampling. Despite being widely used in experimental nursing studies, this sampling strategy is known to increase the risk of self-selection bias and reduce sample representativeness (Grove et al. 2015). Thirdly, given the lack of a control group, it was unclear whether the changes in outcomes over three time points were caused by the intervention, the administration of repeated measures, or unforeseeable factors (Parahoo 2014, Grove et al. 2015). Fourthly, despite successfully promoting men's behaviours in terms of feeling their own testes and advising other men to do the same, it was unclear whether these behaviours were caused by the implementation intentions statements, the intervention, or both. Fifthly, despite using appropriate statistical tests, correlations and regression analyses were not plausible, mainly due to the small sample size (Marston 2010). Sixthly, the cost of the technology and the risk of VR sickness can limit full-scale testing. However, cheaper alternatives to VR exist and the game can be dispersed as a traditional, non-VR experience.

Finally, despite the significant increase in the number of VR users worldwide, only a third of the participants reported a prior use of VR, which led the researcher to believe that many of the participants chose to participate in order to try the technology for the first time. While this could be considered as a strength in terms of attracting more participants into the study, the risk of bias caused by the novelty of the technology must not be discounted.

#### **6.5.4 Plan for Full-Scale Testing**

There were a number of human and financial resources involved in this pilot study. Human resources included: designing the E-MAT intervention; writing, validating, recording, and mapping the voiceover onto the intervention; designing and validating the data collection instruments; applying for ethical approval; sending invitation e-mails and responding to queries about the study; hanging study flyers; booking the VR lab; assigning timeslots for testing; printing surveys and preparing study packs; ensuring the availability of both, the researcher and interactive media expert for testing; e-mailing and reminding the participants to complete the final questionnaire; and preparing a codebook, entering, and analysing the data. As for the financial resources, these included: the cost of equipment; the cost of the online shopping vouchers; the cost of printing the study documents; and the cost of statistical support. All human and financial resources need to be factored into the planning of an RCT.

An RCT protocol will be registered and the RCT will be reported using the 25item checklist and diagram of the Consolidated Standards of Reporting Trials
(CONSORT) statement (Schulz *et al.* 2010). Moreover, a standard operating
procedure in the form of a booklet will be created in order to ensure the uniformity of
data collection, effectively manage the RCT, minimise errors, facilitate corrective
actions, and enable knowledge and skill transfer (European Medicines Agency 2017).

In order to conduct an RCT, repeated measures ANOVA will be used to investigate if changes over time in knowledge differ between the intervention group and the control group. The repeated measures ANOVA model will contain the main effects of time (baseline, immediately following the intervention, and one month after the intervention) and group (intervention and control) and the interaction of time by

group. The test for a time by group interaction is of primary interest, as this investigates if changes over time differ by group.

Based on the pilot study, the researcher predicts the correlations among repeated measures to be 0.3 and the non-sphericity correction to be 1 (i.e. sphericity is assumed). A sample size of 38 men (19 per group) would be sufficient to detect a medium interaction effect (f=0.25; Cohen 1992) in a repeated measures ANOVA with two groups, three waves, a power of 80%, a level of significance of 0.05 and a 2-tailed test. Allowing for an estimated 10% non-completion rate, 42 men (21 per group) would be required to be recruited initially.

If the interaction term was statistically significant (i.e. changes over time differed between the intervention group and the control group), a separate comparison between the two groups at each of the time points post-intervention (immediately post-test and one month post-test) will be conducted. In order to be able to detect a medium effect (d=0.5; Cohen 1992) between the two groups, a sample size of 156 men (78 per group) would be required, assuming a level of significance of 0.05, a two-tailed test and adjustment for multiple comparisons using a Bonferroni correction. The sample size calculations were performed using the G-Power 3.1 program (Erdfelder *et al.* 1996).

#### 6.5.5 Conclusion

This pilot study successfully enhanced men's testicular awareness and increased their intentions to feel their testes and to seek help for testicular symptoms at three time points. To the researcher's knowledge, this study serves as the only initiative taken to increase men's knowledge of testicular diseases other than TC, raise

their awareness of the normal testes and common testicular symptoms regardless of the diagnosis, and promote early help-seeking for testicular symptoms.

A longitudinal study would help determine whether knowledge gain and increase in intentions were maintained over time. Moreover, given the positive outcomes achieved and the low attrition rate, this pilot study merits moving to full-scale testing of the intervention, while bearing in mind the risks and benefit from conducting an RCT. Risks may include cancer worry, anxiety, false positives, and unnecessary visits to healthcare professionals. On the other hand, benefits include an increase in knowledge, awareness, help-seeking intentions, and intentions and behaviour pertaining to self-examination, which may lead to early diagnosis and treatment.

In the final chapter (Chapter 7), the key findings from this thesis are discussed; strengths and limitations are presented; recommendations for future research, education, practice, and policy are made; and an overall conclusion is drawn.

# CHAPTER 7

# **DISCUSSION & RECOMMENDATIONS**

In this final chapter, the key findings from this thesis are presented and discussed in line with similar findings from the literature. These include: (i) lack of testicular awareness; (ii) low help-seeking intentions; (iii) under-exploration of men's preferred learning strategies; and (iv) development, feasibility, usability, and pilot testing of the E-MAT intervention. This chapter also comprises an evaluation of the Pre-Conscious Awareness to Action Framework (PAAF) using Fawcett's (1999, 2005) criteria.

The strengths and limitations of the thesis are discussed and recommendations for future research, education, practice, and policy are made. Finally, an overall conclusion is drawn. The key discussion points are matched with the steps undertaken in this thesis in Table 7.1.

**Table 7.1** Key findings from the thesis matched with the steps undertaken in the E-MAT study

Key findings	Literature review of studies:			Qualitative	Feasibility	Pilot
	Exploring TC awareness	Promoting TC awareness	Exploring BTDs awareness	study	and usability study	study
Testicular awareness						
• Awareness of TC is lacking	++	++	0	++	0	++
• Awareness of TSE is lacking	++	++	-	++	0	++
• Awareness of BTDs is lacking	0	0	++	++	0	++
Barriers and facilitators to awareness are explored	+	0	-	++	0	-
• Awareness of TC can be enhanced using targeted interventions	0	++	0	0	0	++
• Awareness of TSE can enhanced using targeted interventions	0	++	-	0	0	++
• Awareness of BTDs can enhanced using targeted interventions	0	0	-	0	0	++
Help-seeking intentions						
• Help-seeking intentions for testicular symptoms are low	+	0	+	++	0	++
Barriers and facilitators to help-seeking are explored	-	-	-	++	0	-
• Help-seeking intentions for testicular symptoms can be enhanced using targeted interventions	0	-	-	0	0	++
Preferred learning strategies						
• Men's preferred learning strategies are explored	-	-	-	++	0	0
• Men's preferred learning strategies are accounted for during intervention design	0	-	0	0	++	++
The E-MAT intervention						
• Interventions are underpinned by theory	0	+	0	0	++	++
• The E-MAT intervention was underpinned by theory (PAAF)	0	0	0	0	++	++
• VR used as a gaming and educational tool to enhance testicular awareness	0	-	0	0	++	++
• Feasibility and usability of the E-MAT intervention was established	0	0	0	0	++	++
• The E-MAT intervention was effective in enhancing testicular awareness	0	0	0	0	0	++
• RCT to test the effectiveness of the E-MAT intervention is recommended	0	0	0	0	0	++

**Abbreviations:** -: Not evident; +: Evident; ++: Very evident; 0: Not applicable; BTDs: Benign testicular disorders; E-MAT: Enhancing men's awareness of testicular disorders; PAAF: Pre-conscious awareness to action framework; TC: testicular cancer; TSE: Testicular self-examination; VR: Virtual reality.

#### 7.1 Testicular Awareness

Despite reporting having heard of testicular disorders, men's knowledge of these disorders was lacking in the reviewed empirical literature (Saab *et al.* 2016a, 2016b, 2016c), qualitative study (Saab *et al.* 2017a), and pilot study at baseline. Participants in the studies reviewed by Saab *et al.* (2016c) and qualitative study by Saab *et al.* (2017a) reported having heard of TC since it is the most "*advertised*" testicular disease. Nevertheless, many did not know the risk factors, signs and symptoms, diagnosis, and treatment of TC. Similarly, participants in the pilot study scored low on the knowledge questionnaire at baseline, despite agreeing that they were aware of testicular disorders.

These findings suggest that, contrary to popular belief, awareness and knowledge are not synonymous. While awareness is defined in terms of being aware about the existence of something, knowledge constitutes knowing the various details of a certain subject. This assumption is supported by evidence from the literature on cancer knowledge and awareness. For example, Braga *et al.* (2017) distinguished between TC awareness (i.e. being aware that TC exists) and knowledge (i.e. TC symptoms, risk factors, and age of onset). Similarly, in a systematic review of studies on cervical cancer, human papilloma virus (HPV), and HPV vaccine, Perlman *et al.* (2014) made a distinction between the participants' awareness and knowledge of cervical cancer, with the former being often greater than the latter.

Testicular self-examination (TSE) was another outcome addressed in this thesis. Although men reported being aware of this practice, very few examined their testes and knew what they were looking for (Saab *et al.* 2016c). These findings were echoed in the qualitative study, whereby men described TSE as trying to "find a lump"

in a bag of lumps" and stated that they were going by "look and touch" rather than checking for something in particular (Saab et al. 2017a). These findings were reiterated in a number of studies on breast cancer awareness and breast selfexamination. For instance, a cross-sectional study evaluating women's knowledge, attitude, and practice of breast self-examination in Cameroon, found that nearly threequarter of the participants had heard about this practice, yet very few reported performing it (Nde et al. 2015). Similarly, over two third of the participants in the study by Akhtari-Zavare et al. (2015) had heard about breast self-examination; however, only a third knew how to examine their breasts. It is worth mentioning that, unlike TSE which remains a grey area, breast self-examination is being increasingly discouraged. This is based on evidence from two randomised controlled trials (RCTs) which found that breast self-examination increased unnecessary screening and did not have a significant impact on breast cancer mortality (Thomas et al. 2002, Semiglazov et al. 2003). As a result, researchers are increasingly encouraging women to become breast aware rather than promoting scheduled breast self-examination (Thornton & Pillarisetti 2008).

Men's awareness and knowledge of benign testicular disorders (BTDs) were deficient in the qualitative study (Saab *et al.* 2017a) and the reviewed literature (Saab *et al.* 2016a). This was further supported by evidence from the pilot study at baseline. Likewise, a cross-sectional study aimed at exploring men's (n=400) understanding and practices regarding BTDs in Pakistan, found that 53.8% (n=215) of the participants were unfamiliar with BTDs and 78.8% (n=324) were unaware of the symptoms of these disorders (Saleem *et al.* 2017).

A number of barriers and facilitators to awareness were identified in the qualitative study (Saab *et al.* 2017a). Barriers included: lack of prior knowledge of

testicular disorders in general and BTDs in particular; beliefs and attitudes including misconceptions, trivialisation, and uncertainty; perception of the healthcare system as focusing on serious cancers and female cancers rather than male cancers; awareness not being promoted in schools; and lack of screening by means of self-examination and/or clinical examination (Saab *et al.* 2017a). These findings are supported by evidence from the systematic review by Saab *et al.* (2016c), whereby men's negative attitudes towards TC and TSE served as barriers to awareness and contributed to men's refusal to perform TSE (Evans *et al.* 2010, Brewer *et al.* 2011). Moreover, men who perceived TSE as unimportant, timely, embarrassing, and painful were more likely to refrain from endorsing this practice (Urgurlu *et al.* 2011, Özbaş *et al.* 2012, Muliira *et al.* 2013). Similar barriers have been identified in the literature on cervical and breast cancer screening (Curmi *et al.* 2016, Leinonen *et al.* 2017).

Another explanation for the lack of awareness, is the health inequity between the two genders, whereby health campaigns are predominantly targeted towards women rather than both genders equally (Baker *et al.* 2014). This was reiterated in the qualitative study, as a number of men could not identify with televised cancer awareness campaigns targeting women (Saab *et al.* 2017a, 2017b). In fact, evidence from the literature on health communication and social marketing suggests that one of the elements that contribute to the success of health campaigns, is audience segmentation which helps ensure that health messages are delivered to relevant groups and sub-groups in meaningful and actionable ways (Friedman *et al.* 2016). For example, educational campaigns targeting males in schools and colleges were instrumental in raising TC awareness and TSE practices (Wanzer *et al.* 2014, Jones *et al.* 2015).

Facilitators to testicular awareness included: prior knowledge of the risk factors, prognosis, and treatment of testicular disorders; beliefs and attitudes such as personal interest in health and confidence to learn about testicular disorders; prior exposure to information through school, college, workplace, and mass media; performing TSE; undergoing testicular examination by a clinician; past history of a testicular disorder; and changes over time (Saab *et al.* 2017a). A number of these facilitators were also identified in the reviewed literature (Saab *et al.* 2016c). For instance, men with higher TC knowledge scores were more likely to report practicing TSE (Kuzgunbay *et al.* 2013, Muliira *et al.* 2013). In addition, mass media (Özbaş *et al.* 2012, Kuzgunbay *et al.* 2013, Muliira *et al.* 2013), school (Ward *et al.* 2005), healthcare providers (Reece *et al.* 2010), and friends and peers (Özbaş *et al.* 2012, Onyiriuka & Imoebe 2013) served as sources of information on TC and TSE. These information sources are not exclusive to TC, as they have been identified on a number of occasions as channels through which men learn about prostate, colorectal, and skin cancers (Saab *et al.* 2017c).

Interestingly, self-identifying as gay was identified as a facilitator to awareness, since gay men were considered to be more "in tune" with their own bodies as well as the bodies of other men (Saab et al. 2017a). This finding was reiterated in the study by Reece et al. (2010) who reported that men who practiced TSE were more likely to self-identify as gay or bisexual. Similar findings were reported in a qualitative study exploring the acceptability of self- and partner anal exam as a means to detect anal cancer among men who have sex with men (Butame et al. 2017). Overall, participants expressed self-efficacy in performing self- and partner anal exam and expressed their intention to adopt this practice as a routine. Of note, participants in the

pilot study were homogeneous in terms of sexual orientation. Therefore, findings might not be generalizable to this population.

Interventions promoting TC awareness and screening successfully increased men's awareness of TC and improved their intentions and behaviours in relation to TSE, at least in the short-term. Examples include: TC facts and TSE advice (Evans et al. 2011), a university campaign (Wanzer et al. 2014), and high self-efficacy messages (Umeh & Chardwick 2016). In contrast, the integrative review by Saab et al. (2016a) did not identify any experimental studies aimed at raising men's awareness of BTDs. This is worrisome since disorders such as testicular torsion can be life-threatening if not diagnosed and treated promptly (Ringdahl & Teague 2006, Trojian et al. 2009, Bayne et al. 2017). In addition, while increased awareness of TC and TSE was achieved, none of the studies reviewed by Saab et al. (2016b) attempted to educate men about the normal testes or common testicular symptoms, regardless of the ultimate diagnosis. This is alarming, since a number of men in the qualitative study did not know how their own testes normally looked and felt and were unaware of common testicular symptoms (Saab et al. 2017a). Similarly, a study exploring women's knowledge, attitude, and practice of breast self-examination, reported that only a third of the participants knew how to examine their breasts (Nde et al. 2015).

## 7.2 Help-Seeking Intentions

Men's help-seeking for testicular symptoms and disorders was poorly explored in the reviewed empirical literature (Saab *et al.* 2016a, 2016b, 2016c). In one of the reviewed studies on TC awareness, a number of university students intended to delay help-seeking for a painless testicular lump (Cronholm *et al.* 2009). As for BTDs, men's intention to seek help for testicular swelling and/or pain was low (Nasrallah *et* 

al. 2000, Congeni et al. 2005). Similarly, less than half of the participants in the study by Clark et al. (2011) chose to seek emergency care for testicular pain and many intended to delay help-seeking for a few days. These findings were echoed in the literature on help-seeking for symptoms of breast (O'Mahony et al. 2011), colorectal (Mitchell et al. 2008), and urogenital cancers (Macleod et al. 2009).

Barriers to help-seeking identified in the qualitative study can be divided into personal and contextual barriers. Personal barriers included: lack of awareness; inability to differentiate between new and pre-existing lumps; symptom misappraisal; fear from cancer; embarrassment; dysfunctional coping (i.e. denial and avoidance); perceived hypochondria; unrealistic optimism; sense of invincibility; concerns about the family; and conflicting responsibilities (Saab et al. 2017a). Similar barriers have been identified in the literature on help-seeking for symptoms of breast, colorectal, and prostate cancer. For instance, Gözüm and Tuzcu (2017) conducted a quantitative descriptive study to determine the factors that contributed to the delay in help-seeking for breast cancer symptoms. These were found to be as follows: "not knowing where to go, existence of more important problems, not caring/minding, fear, worry, shame, refusing to believe, and fatalism" (p. 5,6). Similarly, fear, symptom misinterpretation, embarrassment, machoism, and the male-gender role served as barrier to help-seeking for symptoms of prostate and colorectal cancer (Oberoi et al. 2016, Medina-Perucha et al. 2017). These findings may be transferrable to the context of help-seeking for testicular symptoms, while bearing in mind the potential effect of gender and age on help-seeking intentions and behaviours.

As for contextual barriers, these were in relation to the Irish culture as well as the healthcare system (i.e. cost of care, waiting time, the gender of the clinician, and false reassurance by healthcare professionals; Saab *et al.* 2017a). In fact, the

perception of help-seeking as being a 'feminine' rather than a 'masculine' behaviour has been identified as a key barrier to help-seeking for cancer symptoms among Irish men (Scanlon 2006, Buckley & Ó Tuama 2010).

Using sociological theories such as Connell's Theory of Hegemonic Masculinity, it is speculated that masculine social constructs including machismo, stoicism, and risk-taking, impact on the way men seek help (Emery et al. 2013, Saab et al. 2017c). These speculations were supported by Vogel et al. (2011) who studied the "relationships between conformity to dominant masculine gender roles, selfstigma, and attitudes toward seeking counselling" (p 371). It was found that men who endorsed dominant masculine beliefs had less favourable attitudes towards helpseeking. Similarly, a systematic review of 37 studies exploring the impact of masculinity on men's help-seeking for depression, found that conformity to social masculine constructs impacted on symptom expression and management as well as help-seeking attitudes, intentions, and behaviours (Seidler et al. 2016). Findings from these studies may not be transferrable to the context of help-seeking for testicular symptoms, especially that men are less likely to seek help for psychological issues than physical ill-health symptoms (Hunt et al. 1999, Wang et al. 2013, Robertson et al. 2016a). Moreover, fewer men than women seek help and treatment for mental health problems (Addis 2008, Deverill & King 2009, Richards & Borglin 2011). Wang et al. (2013) analysed primary care consultation data from 3,786,047 patients (1,869,149 men and 1,916,898 women) in the UK and found that consultation rates were 32% lower in men in comparison to women. This rate varied across the life course, with the highest differences seen among patients aged between 16 and 60 years. However, this different decreased significantly when reproductive-related consultations were accounted for. Wang et al. (2013) also found that men and women

who had comparable morbidities has similar consultation rates, yet men receiving antidepressants were significantly less likely to consult a doctor as compared to women.

Another explanation for help-seeking delays, is the health inequality between the two genders (Baker *et al.* 2014). In fact, the National Cancer Screening Service (2009, 2016) in Ireland successfully implemented two national gynaecological cancer screening programmes. This was unmatched by any increase in the preventive and screening services offered to men. Other health-related barriers to help-seeking included: the cost of a GP visit, the long waiting time in the emergency room, the gender of the examining physician, and false reassurance by healthcare acquaintances. In fact, an observational quantitative study exploring factors affecting delay in TC diagnosis over a 3-year period, found that misdiagnosis by a physician and late referrals to a specialist were associated with delay in TC diagnosis (Median delay=14 and 7 days respectively; Öztürk *et al.* 2015). Similarly, Bayne *et al.* (2017) found that help-seeking delay for testicular torsion was linked to misdiagnosis, which has led to orchiectomy among all the males who were misdiagnosed. Of note, those who were misdiagnosed were more likely to suffer from developmental, cognitive, or social disorders (Bayne *et al.* 2017).

As for the facilitators to help-seeking, those who intended to seek timely medical attention for testicular symptoms were more likely to: be of an older age; have access to support; appraise the severity and duration of the symptom; and possess an inherent health-seeking drive (Saab *et al.* 2017a). Similar facilitators have been identified in a systematic review of studies exploring factors influencing help-seeking for cancer symptoms among men (Fish *et al.* 2015), as well as the literature on help-seeking for mental health problems and substance abuse (Goodwin *et al.* 2016,

Lubman *et al.* 2017, Redmond *et al.* 2017). For example, intimate partners have been identified as important sources of help and were found to play a vital role in encouraging men to seek help from a healthcare professional (Whitaker *et al.* 2016, Saab *et al.* 2017c).

The E-MAT intervention aimed to address the barriers and facilitators to awareness and help-seeking through familiarising men with the normal testes; using excerpts from participants in the qualitative study in order to elicit the lack of awareness and the intentions to delay help-seeking; stressing the importance of early help-seeking on a number of occasions, especially in the event of sudden and sharp pain; and using a non-judgemental and reassuring tone throughout the game in order to reduce the fear attached to a cancer diagnosis (Appendix 5.1).

McGuiness *et al.* (2017) conducted a retrospective analysis of histopathology reports of 215 orchiectomies preformed in the UK over two time points; 1975-1985 and 2007-2012. It was found that tumour size was reduced significantly between the two time points (7.2 vs. 4.1cm respectively) and the proportion of men presenting in the youngest age group (16 to 29 years) was significantly higher between 2007-2012 in comparison to 1975-1985. McGuiness *et al.* (2017) attributed this trend to the increase in the public health efforts promoting TSE and TC awareness. In fact, the role of cancer prevention and awareness in cancer control and early detection was highlighted in Ireland's latest National Cancer Strategy (Department of Health 2017). The researcher is in agreement with these assumptions since, intuitively, when one's awareness of a certain disease increases, he/she is more likely to seek help for this disease, which could lead to early diagnosis and treatment. This stresses the need for interventions such as E-MAT. However, prior to discussing the E-MAT intervention,

it is worth looking at men's preferred learning strategies, which helped develop the intervention.

### 7.3 Preferred Learning Strategies

Men in the reviewed empirical literature came across information about TC and TSE through the media, internet, celebrity endorsements, school, healthcare providers, and friends and peers (Saab *et al.* 2016c). On the other hand, it remains unclear whether interventions aimed at raising men's awareness of TC and TSE accounted for their preferred learning strategies a priori (Saab *et al.* 2016b). This is key, since men are more likely to engage with health promotion initiatives if they were involved in the planning of such initiatives (Lefkowich *et al.* 2017). Moreover, the Medical Research Charities Group (2014) stressed the importance of patient and public involvement in research in order to achieve better health outcomes.

Gaining an in-depth understanding of the population of interest has been identified as one of the key elements for high-quality and effective health communication and social marketing campaigns and interventions (Friedman *et al.* 2016). Therefore, exploring men's preferred strategies for learning about testicular disorders and taking their feedback into account while designing the E-MAT intervention were key elements of this thesis.

Overall, men recommended the television (e.g. health programmes, documentaries, and advertisements); the internet (e.g. social media and mobile applications); campaigns (e.g. schools, colleges, sports centres, and workplaces); and to a lesser extent print media (e.g. leaflets, booklets, and posters) to raise testicular awareness. Similar modes of learning have been identified by Saab *et al.* (2017c) in a systematic review of studies exploring men's information-seeking behaviours

regarding cancer risk and screening. It was recommended that men's daily sphere of information (i.e. the source of information an individual comes across on a day-to-day basis) is taken into account while providing men with information on cancer prevention. Examples include sports clubs, colleagues, peers, religious groups, neighbours, journals, magazines, television, internet, brochures, family members, and men with similar experiences (Saab *et al.* 2017c).

Saab *et al.* (2017c) stressed the need to take men's age into account while providing information. For instance, older men identified their physician as the key source of information, whereas younger men preferred to acquire information using the internet. Indeed, the internet serves as a key source of information for youths (Hooper *et al.* 2008, Rideout *et al.* 2010, Pedrana *et al.* 2013, Holloway *et al.* 2014). Campaigns also proved to be effective in raising awareness of TC and promoting TSE. Examples include educational campaigns conducted in schools and colleges (Wanzer *et al.* 2014, Jones *et al.* 2015). Moreover, sports clubs are increasingly adopting health promoting philosophies and can be therefore used as repertoires to instigate healthy behaviours (Lane *et al.* 2017). Campaigns such as Movember can also be effective in promoting testicular awareness. However, a drawback of such campaigns is men's engagement with non-health-related (e.g. growing facial hair) rather than health-related activities; this was based on evidence from the qualitative study as well as an analysis of 1,879,994 tweets about Movember (Jacobson & Mascaro 2016).

As for print media, despite effectively increasing TC awareness and TSE practices on a number of occasions (Saab *et al.* 2016b), very few participants in the qualitative study recommended using written materials to raise awareness (Saab *et al.* 2017b). Moreover, those who initially recommended using print media, said that there were "probably better ways in this age", whereas others stated that they were

"disaffected" by written materials and that brochures "didn't really mark" them. Contradicting evidence exists regarding the use of print media in health promotion. For instance, written materials in the form of persuasive messages and shower gel sachets and stickers were effective in raising awareness of TC and TSE (McCullagh et al. 2005, Umeh & Chadwick 2016). In contrast, Thornton (2015) found that written materials were ineffective in promoting TSE among adolescents and young adults. Participants in the qualitative study also advised against using medical jargon in health promotion interventions (Saab et al. 2017b). This recommendation was reiterated in a number of studies on colorectal and prostate cancer prevention (Saab et al. 2017c).

For men to be able to identify and engage with health information, they must perceive such information as relevant to them. One way to achieve that, is through the use of gender- and age-appropriate celebrities to promote awareness (Bryan *et al.* 2008). For example, participants in the qualitative study learned about TC after watching television shows featuring TC survivors namely comedians Tom Green and Des Bishop, cyclist Lance Armstrong, and Gaelic Athletic Association (GAA) player Noel McGrath (Saab *et al.* 2017b). These findings are echoed in many of the reviewed studies on TC and TSE awareness (Saab *et al.* 2016b, 2016c).

Participants in the qualitative study stressed the importance of using innovative and creative strategies that are visually stimulating, brief, simple, and light-hearted with the use of survivors and/or celebrities as educators. These findings are echoed in a review of best practice in teaching men to perform TSE (Thornton 2015), and a review of strategies recommended by men to improve the uptake of information on cancer risk reduction and screening (Saab *et al.* 2017c). However, Thornton (2015) warned against using "cheeky humour" and puns that were perceived as offensive to

survivors and were ineffective in increasing TSE. Instead, the use of interactive educational interventions was encouraged. An example is the E-MAT intervention.

# 7.4 The E-MAT Intervention

### 7.4.1 Development, Feasibility, and Usability Testing

Rigorous processes were involved in the development of the E-MAT intervention. These include: reviewing the empirical literature on TC and BTDs awareness (Saab *et al.* 2016a, 2016b, 2016c), conducting a qualitative study to explore men's preferred learning strategies (Saab *et al.* 2017b), and developing an underpinning theoretical framework (i.e. PAAF; Saab *et al.* 2018).

The E-MAT intervention was developed as an educational and interactive serious game using VR. It involved the use of different 3D environments, 3D models of the testes, multiple game levels, and multimodal feedbacks (i.e. visual, haptic, and aural). Contrary to traditional health interventions where participants passively acquire information, the game was interactive and engaging as it required the user to move around testicular models, find changes, and navigate through three different game levels at his own leisure using the controller. The first level (Level 1) included two models of testes hanging side by side, represented using walnuts. The user was required to move freely around the models as the voiceover provided feedback regarding the normal testes. This step was essential, since a number of participants in the qualitative study were not familiar with the way their own testes looked and felt (Saab *et al.* 2017a). The user was then asked to find and "touch" three common testicular abnormalities namely a lump, swelling, and pain that is increasing in intensity. Once all three abnormalities have been found, the user was transported to the second virtual environment (Level 2), whereby he "landed" on a 3D model of a

real testis. During this level, the user could move freely on the surface of the testis, while the voiceover provided facts about the most common testicular diseases and linked these diseases to the abnormalities seen in Level 1. After which, the user was transported to the final level (Level 3), whereby the key messages from the game were reiterated using three icons. These included the importance of knowing one's own testes, the correct technique to perform TSE, and the importance of seeking medical attention for testicular symptoms. Of note, repetition has shown to enhance information retention and habit formation in behaviour change interventions (Wood & Neal 2016). Moreover, the use of multimodal feedbacks (i.e. visual, aural, and haptic) were thought to generate long-lasting episodic, semantic, and procedural memories of the experience (Saab *et al.* 2018).

VR was chosen over other educational tools for various reasons. Firstly, VR is a relatively new technology that proved effective in a number of health contexts such as the treatment of phobias, social anxiety, post-traumatic stress disorder, and eating disorders (Valmaggia *et al.* 2016); neurological rehabilitation among children and adolescents with cerebral palsy (Ravi *et al.* 2016); and the management of obesity and diabetes (Skip Rizzo *et al.* 2011). In contrast, to the researcher's knowledge, VR had never been used to promote men's health, let alone promoting testicular awareness.

Secondly, men are more likely than women to engage with multimodal learning using auditory, kinaesthetic, and technological strategies (Wehrwein *et al.* 2007, He & Freeman 2010). Moreover, in comparison to older men, younger men are more inclined to learn about health-related topics using technological means (Weekley 2016, Saab *et al.* 2017c). Therefore, it was hypothesised that VR was suited for men aged 18 to 50 years.

Thirdly, VR is increasingly gaining popularity around the world. In fact, a recent assessment of the VR market revealed that the total number of active VR users is expected to reach 171 million by 2018 and to increase by 147% between 2016 and 2021 (Mind Commerce 2016, Statista 2017).

Fourthly, the E-MAT intervention involved the use of a number of sensory feedbacks (i.e. visual, aural, and haptic), which are known to be most applicable to real life (Sigrist *et al.* 2013). Of note, the effectiveness of multimodal feedbacks using VR had been established in the literature on medical education, robot-assisted surgery (van der Meijden & Schijven 2009), neuro-rehabilitation (Gomez-Rodriguez *et al.* 2011), chronic disease management (Oosterom-Calo & López 2016), and social cognition training (Kandalaft *et al.* 2013).

Friedman *et al.* (2016) identified ten elements of high-quality and effective health communication and social marketing campaigns. The processes undertaken in the development of the E-MAT intervention mapped onto the Friedman *et al.*'s (2016) elements are presented in Table 7.2.

Table 7.2 The E-MAT intervention development mapped onto the elements for effective health communication and social marketing campaigns			
Audience involvement through the use of consumer	Men (n=29) were asked about their preferred learning strategies in relation to testicular		
research to gain in-depth understanding of the	symptoms and disorders. Their feedback was then taken into account in the design of the		
population	E-MAT intervention.		
Audience segmentation to ensure that messages reach The intervention included a number of messages targeting men. The voice			
relevant sub-groups in meaningful and actionable ways	predominantly socio-culturally neutral tone. However, some of the humorous elements		
	the game were specific to the Irish context.		
Use of theory, including behavioural theory, to guide	The E-MAT intervention was underpinned by a behavioural change theoretical		
formative research, programme strategies, message	framework, namely the researcher-developed Pre-Conscious Awareness to Action		
content, and evaluation	Framework.		
Professional training of staff in communication, social-	The E-MAT intervention was designed in collaboration with an expert in interactive media		
marketing, and/or media	who was formally trained in social marketing.		
Access to needed products/services/policies to support	Public access to the intervention is currently limited as the intervention is still in its early		
behaviour change	stages. However, there is a plan to make the intervention freely accessible via public		
	platforms and health promotion campaigns.		
Partnerships and stakeholder engagement (e.g.	The intervention is in its early stages. There is a plan to make the intervention freely and		
community, business, and media)	readily accessible once its effectiveness has been established.		
Adequate audience exposure to the campaign,	The intervention is accessible using VR but can be customised for use using non-VR		
including the use of multiple channels	platforms for those who have no access to the technology or suffer from VR sickness.		
Continuous process evaluation to assess reach, A feasibility and usability study was conducted to assess whether the E-MAT in			
exposure, and fidelity of implementation and to identify can work, does work, and will work and whether it was user-friendly.			
potential gaps, challenges, and needed redirection			
Outcome evaluation to measure impact. When possible,	, A pilot study was conducted with 49 men to evaluate the effect of the E-MAT intervention		
this should involve rigorous independent evaluation of	on knowledge, awareness, perceived risk, help-seeking intentions, and intentions and		
outcomes	behaviours pertaining to feeling one's own testes and advising other men to do the same.		
Long-term investment to sustain the campaign and its	There is a plan to conduct a randomised controlled trial in order to test the intervention		
effects	with a larger sample size across different settings. There is also a plan to conduct a		
	longitudinal study in order to track the impact of the intervention over time.		

(Friedman et al. 2016).

The feasibility and usability of the E-MAT intervention was tested with 15 men. The majority of the participants agreed that the VR headset and controller were comfortable to use and none found the game confusing. Moreover, all the participants were satisfied with the overall aesthetic of the game and were in agreement that the various testicular symptoms and disorders were well represented. Humour and light-hearted messages were also perceived as potentially effective aspects of the E-MAT intervention. In fact, the use of humour is not uncommon in studies targeting men. For example, humour successfully promoted inclusivity and sexual health discussions among survivors of prostate cancer (Oliffe *et al.* 2009). However, a fine line exists between the use of constructive and offensive humour. Therefore, it is key to know the target audience prior to using humour, especially when it comes to intimate and sensitive subjects (Thornton 2015).

As for the appropriateness of the game to men from different sociodemographic backgrounds, a third of the participants did not agree that the game was suitable for men from different educational, ethnic, and cultural backgrounds. This could be due to many reasons. For instance, the voiceover script was suited for 6<sup>th</sup> Graders and above; therefore, men with low literacy levels might find it difficult to engage with the information provided during the game. Moreover, the E-MAT intervention required basic computer literacy and basic grasp of moving in a game environment using a controller. However, this was not a prerequisite to playing the game, since a full explanation regarding the use of the VR headset and controller was provided by an interactive media expert and participants were exposed to a brief demonstration in order to become familiar with the technology.

It is possible that some of the light-hearted messages provided by the voiceover were too specific to Irish men and/or to those whose first language was English. Examples include the synonyms of testes (e.g. gonads, bollox, goolies, plums, spuds, and stones) as well as certain expressions (e.g. nuts are unique like snowflakes, go nuts, that escalated quickly, looks like you didn't ball it up after all, and I hope I didn't wreck your head with all that information), and only statistics relevant to the Irish context were provided during the game (e.g. it [TC] affects only 6 in 100,000 men in Ireland). Finally, the sample recruited into the feasibility and usability study was small (n=15) and was homogenous in terms of geographical location, age, nationality, level of education, and sexual orientation. Therefore, sample representativeness and generalisability of findings were compromised.

### 7.4.2 Pilot Testing

The E-MAT intervention was deemed successful in enhancing men's knowledge of the normal testes and common testicular symptoms and diseases and in raising their testicular awareness. Similar findings were reported in the literature on TC and TSE awareness. For instance, a university campaign succeeded in raising men's awareness of TC and promoting TSE (Wanzer *et al.* 2014). Similarly, educational sessions and hands-on experiences successfully increased TC awareness and screening in the community (Shallwani *et al.* 2010). Of note, none of the reviewed interventions used interactive media to promote awareness and very few were underpinned by theory. In addition, none of the reviewed interventions aimed to raise awareness of BTDs. These gaps were taken into account while designing and pilot testing the E-MAT intervention. However, E-MAT reported on men's awareness of testicular disorders without distinguishing between TC and BTDs. Therefore, it was unclear whether men's awareness increased for TC, BTDs, or both, which warrants further investigation.

While awareness increased significantly immediately after and one month following the E-MAT intervention, knowledge declined one month following the intervention but remained significantly higher than baseline. This could be attributed to the small sample size, whereby the decline in knowledge could have happened due to chance. Another explanation is knowledge decay, which is common following health promotion interventions (Nimmons *et al.* 2017). This might necessitate administering the E-MAT intervention on more than one occasion and/or making it freely available so that men could access it at their own leisure. This strategy might prove effective, since participants in the feasibility and usability study were in agreement that they would use the technology again. Moreover, exposing men to the E-MAT intervention on more than one occasion might be instrumental in promoting information retention and healthy habit formation (Wood & Neal 2016).

The E-MAT intervention did not lead to an increase in risk perception for testicular disorders. In the literature on TC, men's perceived risk of this malignancy was found to be high in some studies (Powe *et al.* 2007, Muliira *et al.* 2013), and low in others (Rovito *et al.* 2011). One explanation for low risk perceptions is that testicular disorders tend to occur in young and relatively healthy males who would have had limited exposure to and interaction with the healthcare system. This was supported by evidence form the qualitative study, whereby younger participants (i.e. those aged 18 and 19) did not believe that they were at risk for testicular disorders as they were young and healthy (Saab *et al.* 2017a). For example, one participant said: "Do young people like us get it (testicular disease)? I don't think so!"

Men's help-seeking intentions for testicular swelling, lumpiness, and pain increased following the E-MAT intervention. A number of recent studies have been conducted to test the effect of VR-based interventions on help-seeking, predominantly

in mental health contexts. For example, Valmaggia *et al.* (2016) reported that a number of VR-based interventions were successful in increasing help-seeking for phobias, social anxiety, post-traumatic stress disorder, and eating disorders. Nevertheless, an intervention that used a virtual human to increase help-seeking for symptoms of posttraumatic stress disorder and depression, did not succeed in doing so (Meeker *et al.* 2016). Likewise, in comparison to prolonged exposure therapy, VR exposure therapy was not effective in the treatment of posttraumatic stress disorders (Gahm *et al.* 2014). Given that these studies were conducted in mental health contexts and included patients rather than healthy individuals, their transferability to the context of help-seeking for testicular symptoms is debatable.

In the pilot study, men who had higher implementation intention scores (i.e. intentions to feel their own testes and to advise at least one man to do the same) at baseline were more likely to report performing the behaviours (i.e. feeling their own testes and advising at least one man to do the same) one month following the intervention. These findings were supported by evidence from a meta-analysis of 94 independent tests, whereby implementation intentions positively affected goal attainment (Gollwitzer & Sheeran 2006). Similarly, in recent studies, implementation intentions were deemed successful in promoting healthy behaviours, including colorectal cancer screening (Orbell *et al.* 2016), smoking cessation (Armitage 2016), and goal attainment for mental health problems (Toli *et al.* 2016). In contrast, a 2x2x2 between-participants RCT featuring an online intervention aimed at reducing alcohol consumption among university students, found that implementation intention messages did not significantly impact on the students' cognition regarding the harms of alcohol, did not impact on the number of units of alcohol consumed, and did not lead to a reduction in binge drinking (Norman *et al.* 2017). Therefore, the success of

studies using implementation intentions to promote healthy behaviours is context dependent. Of note, in the pilot study, it was unclear whether men's intentions and behaviours pertaining to feeling their own testes and advising other men to do the same increased as a result of the E-MAT intervention, the questions written using implementation intentions, or both, which warrants further investigation.

At the end of the game, the voiceover provided advice regarding the importance of spreading the word among other men and the implementation intentions statements included messages about advising at least one other man to feel his testes. This was attempted given the important role that peer support plays in improving health outcomes. For example, a meta-analysis of 17 studies on peer support and diabetes care found that interventions that used peer support significantly reduced blood glycated haemoglobin levels among patients with diabetes (Patil *et al.* 2016). Similarly, women with breast cancer exposed to peer support groups reported a greater life purpose and displayed less depressive symptoms than women in the control group (Mens *et al.* 2016).

From a methodological perspective, the different study outcomes were measured using a number of instruments. With the exception of one instrument (i.e. General Help-Seeking Questionnaire), the instruments were researcher-designed and their content validity and reliability were established. Furthermore, the E-MAT intervention was successful in retaining 92.5% of the study participants, which was attributed to a number of strategies such as: using convenience and snowball sampling; following-up with the study participants; having the same researcher collect data at three time points; providing the contact details of free counselling and support services; having an accessible site for data collection; and offering a financial

incentive at the conclusion of the study (Dickert & Grady 1999, Grady 2005, Yancey et al. 2006, Finkelstein et al. 2007).

The development and testing of the E-MAT intervention was challenging as it required various human and financial resources. For instance, a number of human resources were needed to design the intervention; write, validate, and record the voiceover; develop and validate data collection instruments; recruit study participants; book the facility (i.e. VR lab) to test the intervention; assign timeslots for testing; print and prepare study packs; ensure the availability of both the researcher and interactive media expert during testing; follow-up with participants at second post-test; and conduct data analysis. In addition, several financial resources were involved in this intervention. These included: the cost of equipment; the cost of printing; the gift vouchers; and the statistician fees. Therefore, all human and financial resources need to be factored into the planning of an RCT. In fact, cost-effectiveness assessment was recommended in the MRC framework following feasibility and pilot testing (Craig *et al.* 2013).

In conclusion, the E-MAT intervention has the potential to positively impact on men's knowledge of the normal testes and common testicular disorders; testicular awareness in terms of familiarity with one's own testes and ability to differentiate between normal and abnormal findings; implementation intentions; help-seeking intentions for testicular lumpiness, swelling, and pain from various sources; and behaviour pertaining to feeling one's own testes and advising at least one other man to do the same. The pilot study also helped determine the sample size needed for full-scale testing, showed that men were willing to participate as evidenced by the high retention rate, and involved minimal risks such as VR sickness.

In the upcoming section, an evaluation and critique of the theoretical framework underpinning the E-MAT intervention (i.e. PAAF) is provided.

# 7.5 The Pre-Conscious Awareness to Action Framework

Evidence from the reviewed empirical and theoretical literature as well as the qualitative study helped develop the PAAF, which was used to underpin the E-MAT intervention. This process model uses seven predefined and interconnected stages (i.e. pre-conscious awareness, unconscious awareness, conscious awareness, unconscious appraisal, conscious appraisal, intention, and behaviour) in order to achieve a certain goal; in this case, enhancing men's testicular awareness and increasing their intentions to seek prompt help for testicular symptoms (Saab *et al.* 2018). The stages comprising the PAAF were derived from the Transtheoretical Model (TTM; Prochaska & DiClemente 1986), and the literature on neurobehavioral psychology (Dehane & Naccahe 2001, Baumeister *et al.* 2011), and symptom appraisal (Whitaker *et al.* 2015).

The feasibility and usability of the E-MAT intervention, underpinned by the PAAF, were established. Moreover, evidence from the pilot study demonstrated that the E-MAT intervention was successful in enhancing men's knowledge and awareness of the normal testes and common testicular symptoms and disorders; intentions to seek help for testicular symptoms; and intentions and behaviour pertaining to examining their own testes and advising other men to do the same. These findings were echoed in the reviewed literature, whereby interventions underpinned by theory yielded increased TC awareness and TSE practices (Saab *et al.* 2016b). Examples include: The Extended Parallel Process Model (Evans *et al.* 2011); Standard Model of Health Communication (Wanzer *et al.* 2014); Theory of Reasoned Action (Trumbo 2004);

Health Belief Model (Brown *et al.* 2012); and Rogers' Protection Motivation Theory (Umeh & Chadwick 2016).

Various criteria exist to evaluate theories used in nursing (Meleis 1997, Fawcett 1999, George 2002, Marriner-Tomey & Alligood 2002). Fawcett's (1999, 2005) nine evaluative criteria were selected to evaluate the PAAF. This theoretical framework was found to fit the research questions depicted in this thesis, particularly those pertaining to the pilot testing of the E-MAT intervention. Moreover, the PAAF was readily operationalised and its key concepts were discussed in detail (Chapter 4). It was also deemed successful in answering the research questions and addressing the hypotheses that were tested in the pilot study. Furthermore, the PAAF was instrumental in addressing outcomes that are critical to men by raising their testicular awareness and prompting timely help-seeking for testicular symptoms. Finally, the stages of the PAAF guided the development of the instruments used in the pilot study.

A detailed evaluation of the PAAF using Fawcett's (1999, 2005) criteria is presented in Table 7.3.

**Table 7.3** Evaluation of the Pre-Conscious Awareness to Action Framework (PAAF)

Questions for evaluation	Responses to questions		
1. Does the theory fit the research that you wish to do?	The PAAF fits the research undertaken in the present thesis as it aims to raise awareness (i.e. testicular awareness) and promote new and healthy behaviours (i.e. early help-seeking for symptoms of testicular disease) using seven stages.		
2. Is it readily operationalised?	The Transtheoretical Model (TTM) provided insight into the cognitive domains involved in the thinking processes underpinning the development of awareness and intentions to alter behaviour. Therefore, the five stages of the TTM helped in the construction of the PAAF (Prochaska & DiClemente 1986).		
3. How well has the theory performed at describing, predicting, and/or explaining the phenomena to which it relates?	This was the first time the PAAF was being used to underpin a health promotion intervention (i.e. E-MAT) which proved successful in enhancing men's knowledge and awareness of the normal testes and testicular symptoms and disorders; help-seeking intentions for testicular symptoms; and intentions and behaviours related to examining their own testes and advising other men to do the same.		
4. Does the theory relate to and address the research hypotheses in its description and explanation?	The hypotheses tested in the pilot study were constructed based on the key stages of the PAAF. Accordingly, the following outcomes were tested: knowledge, testicular awareness, perceived risk, implementation intentions, help-seeking intentions, and behaviours.		
5. Does the theory flow from the research question?	The objectives of the pilot study were constructed and mapped onto the PAAF (Chapter 6, Figure 6.1). Therefore, the PAAF flows from the research question.		
6. Does the theory address the primary and secondary research questions?	Multiple phases were involved in the present thesis, with each phase having its own set of research questions. The PAAF aimed to address the research question in relation to enhancing men's testicular awareness and promoting early help-seeking for testicular symptoms.		
7. Are the assumptions congruent with the assumptions that are made for research?	The assumptions are congruent with the assumptions made for research. For example, participants in the pilot study who intended to feel their testes and advise other men to do the same before the intervention were more likely to report having done that following the intervention; therefore, intentions successfully predicted behaviours.		
8. Is the theory oriented to outcomes that are critical to patients?	The PAAF is oriented to outcomes that are critical to men's health promotion since it was used to underpin an intervention aimed at enhancing men's awareness of the normal testes and common testicular symptoms and disorders as well as increasing their intentions to seek help for testicular diseases that can be life-threatening if left untreated.		
9. Are tools available to test relationships of the theory or do they need to be developed?	The instruments used in the pilot study (i.e. knowledge questionnaire, testicular awareness scale, perceived risk item, implementation intentions scale, general help-seeking questionnaire, and behaviour questionnaire) were all developed based on the stages of the PAAF.		

(Fawcett 1999, 2005, Landers 2014).

Despite its novelty and its effectiveness in measuring awareness and help-seeking, the PAAF is not without limitations. This theoretical framework was developed to integrate the concept of 'testicular awareness.' Therefore, the PAAF can be further developed for use in different contexts, such as breast awareness. Moreover, not all the concepts of the PAAF have been operationalised in the pilot study. For instance, questions pertaining to pre-conscious awareness, unconscious awareness, and unconscious appraisal were not included in the questionnaire. However, the researcher speculates that, while answering the multiple choice questions on knowledge and rating their testicular awareness, the participants attempted to recall instances where they came across information about testicular disorders. Consequently, they endeavoured to use this information in order to correctly answer the questions. In other words, the participants' pre-conscious and unconscious awareness of testicular disorders could have played a role in helping them complete the questionnaire.

# 7.6 Strengths and Limitations

This thesis has a number of strengths and limitations. These are discussed below.

#### 7.6.1 Strengths

To the best of the researcher's knowledge, E-MAT is the first intervention aimed at raising men's awareness of testicular disorders and promoting early help-seeking for testicular symptoms using VR. Rigorous processes were involved in the development of this thesis.

Firstly, various guidelines, frameworks, and standardised checklist guided the development and testing of the E-MAT intervention, including: the steps of the MRC framework (Craig *et al.* 2013); the Cochrane handbook for systematic reviews of

interventions (Higgins & Green 2011); the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher *et al.* 2009); the integrative review methodology proposed by Whittemore and Knafl (2005); the Standards for Reporting Qualitative Research (SRQR) checklist (O'Brien *et al.* 2014); and the Walker and Avant (2011) strategies for theory construction.

Secondly, each phase in this thesis involved a different research methodology. This helped answer more than one research question, provided quantitative and qualitative strengths, and enabled the strengths of one design to overcome the weaknesses of another (Johnson & Onwuegbuzie 2004).

Thirdly, the evidence-base was identified following a thorough search of electronic databases using predetermined questions. The methodological quality of the reviewed studies and the level of evidence considering the review outcomes were assessed. Moreover, the search and data extraction were cross-checked for relevance and accuracy by the thesis supervisors.

Fourthly, trustworthiness of the data collected in the qualitative study was enhanced through: seeking a heterogeneous sample; using diverse data collection approaches (i.e. individual interviews, focus groups, and field notes); conducting member checks; using audit trails; keeping reflexive memos; using icebreakers; and cross-checking the data with the thesis supervisors.

Fifthly, a theoretical framework, namely the PAAF, was developed to underpin the E-MAT intervention. This was regarded as a strength, since interventions underpinned by theory are more likely to succeed in achieving the desired outcome(s) (Savage *et al.* 2010). The PAAF was guided by findings from the reviewed empirical literature, qualitative study, and an iterative review process of the theoretical literature

on behaviour change, neurobehavioral psychology, and symptom appraisal. Moreover, the concept of "testicular awareness" was first introduced in this thesis. This concept would help men become more familiar with their testes and would enable them to detect abnormalities, which impacts on symptom appraisal and help-seeking.

Sixthly, the E-MAT intervention was planned and designed jointly by the researcher and interactive media expert, while using findings from the empirical literature, men's feedback from the qualitative study, and the stages of the PAAF. The feasibility and usability of the intervention were established and its effectiveness was tested at three time points using valid and reliable instruments.

Finally, the studies comprising this thesis were either published, are under review, or are under preparation for publication in peer-reviewed journals. This was considered as another major strength in this piece of work.

### 7.6.2 Limitations

Despite its numerous strengths, this thesis is not without limitations. Firstly, while systematically reviewing the literature, it was not possible to conduct a meta-analysis (level of evidence A), mainly due to the variety of outcomes measured and the heterogeneity of the instruments used to collect data. Instead, two systematic and one iterative reviews were conducted (level of evidence C; Armola *et al.* 2009).

Secondly, small sample sizes and non-probability sampling strategies (i.e. purposive, convenience, maximum-variation, and snowball sampling) were employed across the reviewed studies, qualitative study, feasibility and usability study, and pilot study. These strategies are known to increase the risk of self-selection bias and limit the generalisability of findings as well as sample representativeness (Robinson 2014, Grove *et al.* 2015, Cochrane Bias Methods Group 2017). Furthermore, although a

heterogeneous sample was sought across the study phases, most participants were Irish, university educated, and recruited from the same geographical area, which further hinders generalisability.

Thirdly, two key limitations of the E-MAT intervention include the risk of VR sickness and the cost of equipment. However, as discussed earlier, cheaper alternatives exist, such as using non-VR platforms.

Finally, given the lack of a control group in the pilot study, it was unclear whether the increase in knowledge, awareness, intentions, and behaviours at post-test were caused by the intervention, the repeated times of measurement, or unforeseen factors (Parahoo 2014, Grove *et al.* 2015).

# 7.7 Recommendations

This thesis yielded a number of recommendations for research, education, practice, and policy. These are summarised in Table 7.4.

**Table 7.4** Summary of the key recommendations from this thesis

Research	Education	Practice	Policy
1. Test the PAAF in different	1. Promote testicular awareness	1. Educate clinicians about	1. Reinforce pre-existing men's
health contexts.	and early help-seeking at a	current health promotion	health policies and strategies.
2. Conduct an RCT to test the E-	young age (e.g. schools) using	activities.	2. Draft new men's health
MAT intervention with a larger	campaigns (e.g. Movember).	2. Encourage clinicians to use	policies while addressing
sample and in different settings.	2. Educate men's partners about	educational methods suited for	men's awareness of testicular
3. Conduct a cost-benefit analysis	testicular symptoms and	men in order to increase	disorders.
as part of the RCT.	diseases.	testicular awareness.	3. Increase preventive and
4. Conduct a longitudinal study to	3. Enable men to access the E-	3. Educate clinicians about	screening services offered to
test the long-term effect of the	MAT intervention via VR and	interventions such as E-MAT.	men.
E-MAT intervention.	non-VR public platforms.	4. Encourage clinicians to be	4. Adopt blame-free and non-
5. Ensure the representation of		sensitive to the needs of men at	judgmental approaches to
men at risk for health inequities.	of different health topics.	risk for health inequities.	men's health promotion.

**Abbreviations:** E-MAT: Enhancing men's awareness of testicular disorders; PAAF: Pre-conscious awareness to action framework; RCT: Randomised controlled trial; VR: Virtual reality.

#### 7.7.1 Recommendations for Research

Only the qualitative study purposely included men at risk for health inequities, namely gay and bisexual men (Saab *et al.* 2017a, 2017b). Therefore, ethnic, sexual, gender, and religious minorities as well as people with physical and/or intellectual disabilities were underrepresented. This requires exploring the experience of these men, addressing their learning needs and preferred learning strategies, and designing health promotion interventions accordingly. In addition, the majority of the participants in this thesis were university educated, which necessitates the inclusion of men from a low educational and/or socio-economic background in future research.

Interventions unpinned by theory are more likely to achieve the desired goal(s) (Michie *et al.* 2008, Savage *et al.* 2010). Nevertheless, very few of the reviewed studies had a theoretical underpinning (Saab *et al.* 2016a, 2016b, 2016c), which requires using theoretical models and frameworks in future research. An example is the PAAF that was developed to underpin the E-MAT intervention. This framework can be further developed and adopted to promote awareness and help-seeking for a variety of health problems. Examples include: prostate cancer; breast cancer; sexually transmitted infections; sports injuries; and acute myocardial injury.

For men to engage with health promotion initiatives, they must perceive these initiatives as relevant to them (Lefkowich *et al.* 2017). This was addressed in the present thesis by asking men about their preferred learning strategies and taking their feedback into consideration while designing and testing the E-MAT intervention (Saab *et al.* 2017b). Moreover, researchers are urged to take men's socio-demographic characteristics into account while planning health promotion interventions. For example, younger men are more likely to engage with interventions that involve

technology, whereas older men are more likely to use print media to learn about health topics (Saab *et al.* 2017c).

Overall, the E-MAT intervention successfully enhanced men's knowledge, awareness, intentions, and behaviours. Therefore, full-scale testing through conducting an RCT with a larger sample size across different settings is warranted. Given the short follow-up time, conducting a longitudinal study is merited. Moreover, since several human and financial resources were involved in the development and testing of the E-MAT intervention, the researcher recommends a cost-benefit analysis within an RCT.

Finally, the E-MAT intervention did not increase men's perceived risk for testicular disorders. This compels further investigation, either by reviewing the literature on men's perceived risk, exploring men's perceived risk using in-depth interviews, and/or developing instruments to assess this outcome.

#### 7.7.2 Recommendations for Education

The lack of exposure to information on testicular diseases at a young age was identified as a barrier to awareness (Saab *et al.* 2017a). This stresses the need to teach schoolboys about testicular health. In addition, promoting testicular awareness in schools would help males become more attentive to a body part that they seldom talk about, would help them feel more comfortable discussing their testes when they get older, and would help fight the stigma, misconceptions, fear, and embarrassment associated with testicular diseases.

Interventions aimed at educating men about testicular symptoms and diseases must be cognisant of their informational needs and preferred learning strategies. For instance, given the age group at risk for testicular diseases, social media and mass

media may serve as effective channels through which testicular awareness could be promoted. Moreover, younger men are more likely than older men to use the internet in order to learn about sensitive health topics (Gray *et al.* 2005, Rideout *et al.* 2010).

Large campaigns, such as Movember, can be instrumental in promoting testicular awareness and stressing the importance of early help-seeking for testicular symptoms. Such campaigns can be delivered in schools, universities, sports clubs, workplaces, and community organisations. Furthermore, the effectiveness of health promotion campaigns can be enhanced by delivering them frequently, altering the modes of delivery occasionally, using multimodal delivery, and catering to the needs of the target population.

Participants in the qualitative study identified the presence of a partner as a facilitator to help-seeking (Saab *et al.* 2017a). These findings are echoed in the literature on help-seeking for mental health problems, whereby being married was a predictor of help-seeking among men (Vogel & Wade 2009, Doherty & Kartalova-O'Doherty 2010). Therefore, partners of men must be educated about testicular symptoms and diseases since they may be the ones to detect abnormalities during sexual activity. Partners can also play a key role in prompting men to seek timely medical attention for testicular symptoms.

The E-MAT intervention was effective in raising testicular awareness and promoting early help-seeking for testicular symptoms, which warrants public dissemination. This could be achieved by including the E-MAT intervention in large campaigns such as Movember as well as making it accessible via social media, websites of cancer organisations, health promotion organisations, and high schools and universities. It is also important to consider disseminating the E-MAT intervention

among those who are at risk for health inequities. This could be achieved by making the intervention available in settings frequented by these men, such as men's sheds, sports clubs, and youth organisations.

The rapid growth of the VR industry has led to a reduction in the cost of access to VR headsets. However, for those who have no access to VR and those who suffer from VR sickness, the E-MAT intervention can be customised for use using non-VR platforms such as desktops and laptops. However, new modes of implementation ought to be investigated in order to ensure that the mode delivery does not compromise the intervention outcomes.

Finally, given its feasibility and usability, VR can be used to promote men's awareness of various health topics, including sports injuries, healthy lifestyle changes, cancer prevention and risk reduction, and sexually transmitted infections.

#### 7.7.3 Recommendations for Practice

The lack of endorsement of clinical testicular examination was identified as a barrier to awareness in the reviewed literature and qualitative study (Saab *et al.* 2016c, 2017a). However, prior to encouraging clinicians, including nurses, to endorse clinical testicular examination, it is important to explore their attitudes towards this practice. This could be achieved through face-to-face interviews or surveys. In addition, it is important to ensure that clinicians are aware of the benefits of promoting testicular awareness and early help-seeking for testicular symptoms among their patients and the wider community. This could be made possible by encouraging them to participate in health promotion activities such as workshops, conferences, and continuing education.

The lack of consensus regarding monthly TSE might instil a sense of ambiguity amongst clinicians. A middle ground could be reached by advising clinicians to educate and encourage men to familiarise themselves with the way their own testes look and feel and to seek timely medical attention for testicular symptoms, just like women are encouraged to become familiar with their breasts and to seek help for abnormalities.

Evidence from the literature and qualitative study suggests that participants who underwent clinical testicular examination did not know what the clinician was looking for. Therefore, clinicians are urged to educate men about the usefulness of genital examination in the early detection of testicular disorders, and to encourage them to become familiar with the signs and symptoms of the acute scrotum. This could be achieved using infographics and flyers that are colourful, written in large fonts, and easy to comprehend among men from different socio-demographic backgrounds. Clinicians should also be made aware of interventions such as E-MAT and should be encouraged to direct men to platforms where E-MAT is readily accessible.

Finally, clinicians are encouraged to be sensitive to the needs of men at risk for health inequities. For example, the Center for American Progress (2013) reported that it is important to ask men about their sexual orientation and gender identity in healthcare settings. Moreover, collecting data about sexual orientation and gender identity is thought to help reduce the invisibility of minority groups in healthcare (Cahill & Makadon 2013).

### 7.7.4 Recommendations for Policy

Men's health is increasingly gaining visibility both, nationally and internationally (Department of Health and Children 2008, European Commission

2011). Nonetheless, the health gap between the two genders remains inadequately addressed at the policy level (Hawkes & Buse 2013). For example, the World Health Organisation issued a strategy to improve the health of women, children, and adolescents (Every Woman Every Child 2015). This was unmatched by any increase in the global health services targeting men (Rovito *et al.* 2017).

It is worth noting that Ireland was the first of three countries to adopt a National Men's Health Policy (Department of Health and Children 2008, Baker *et al.* 2014). One of the strategic aims of this policy was to "develop health promotion initiatives that support men to adopt positive health behaviours and to increase control over their lives" (p. 8). In fact, a review of the policy conducted by Baker (2015), found that a number of information resources targeting males have been produced. An example is a booklet on prostate and testicular cancer launched by the Irish Cancer Society (2013). Nevertheless, information regarding BTDs is lacking, which warrants addressing these disorders in future policies. This is key, since, as aforementioned, BTDs are more common than TC, men's awareness of these disorders is lacking, and if not treated promptly, BTDs can have detrimental effects on a man's life.

On a number of occasions, participants in the qualitative study blamed the lack of testicular awareness on the current healthcare system in Ireland, since it was perceived to focus on women's health rather than men's health. Indeed, two national gynaecological cancer screening programmes were implemented in Ireland over the past two decades (National Cancer Screening Service 2009, 2016). In contrast, there was no increase in the preventive services offered to men. Barker *et al.* (2010) and Baker *et al.* (2014) attributed this "neglect" by policy makers to a number of factors, including the negative stereotypes of men as non-health-seekers and the assumption that men are inherently disinterested in their own health. Therefore, there is a dire need

to challenge such stereotypes and adopt blame-free and non-judgmental approaches to men's health promotion.

Finally, findings from the different phases of this thesis can be used to urge policymakers to shed light on men's and women's health equally while instigating health promotion and cancer prevention campaigns. This has the potential to reduce the health gap between the two genders and engage more men with health promotion initiatives. Moreover, reinforcing pre-existing men's health strategies, ensuring their implementation in mainstream practice, and drafting new men's health policies can help raise men's awareness of male-specific disorders, including disorders of the testes.

## 7.8 Overall Conclusion

Rigorous processes guided the development and testing of the E-MAT intervention. Firstly, the empirical literature was reviewed by conducting two systematic and one integrative reviews of studies on men's awareness of TC, TSE, and BTDs. It was found that men lacked awareness of TC and BTDs, very few participants practiced TSE, and many had misconceptions regarding testicular disorders. Moreover, men's intentions to seek help for symptoms of testicular disorders were underexplored and none of the reviewed studies addressed, qualitatively, men's awareness of BTDs, and no interventions promoting BTDs were sourced.

Secondly, gaps from the literature guided a qualitative study which aimed at exploring men's (n=29) awareness of testicular disorders, help-seeking intentions for testicular symptoms, and preferred learning strategies pertaining to testicular symptoms and disorders. Similar to the empirical literature, men's awareness of TC and BTDs was lacking and very few participants reported performing TSE. In

addition, many reported not knowing how their own testes looked and felt and were not sure whether they could differentiate between normal and abnormal testicular lumps. Men's intentions to seek help for testicular symptoms varied, with the majority intending to delay help-seeking due to misconceptions, lack of endorsement of self-examination by clinicians, fear, embarrassment, and gender role and masculine social constructs. Those who were more testes aware and who intended to seek help were more likely to have access to support, have an inherent health-seeking drive, perceive testicular disorders as threatening, and report a history of a testicular disorder. Overall, men recommended using the television, the internet, campaigns, and to a lesser extent, print media to promote awareness. Men also recommended interventions that are humorous, brief, interactive, and visually stimulating.

Thirdly, the PAAF was developed based on the reviewed empirical literature, findings from the qualitative study, and an iterative review of the theoretical literature on behaviour change, symptom appraisal, and neurobehavioral psychology. The PAAF comprised seven stages as follows: pre-conscious awareness, unconscious awareness, conscious awareness, unconscious appraisal, conscious appraisal, intentions, and behaviours (Saab *et al.* 2018). A key concept in the PAAF is "testicular awareness", which was first introduced in this thesis in order to enable men to become familiar with their own testes and help them differentiate between what is normal and what is not normal while feeling their testes. This was thought to impact on symptom appraisal and subsequent help-seeking.

Fourthly, the E-MAT intervention was designed as an educational experience using a novel technology, namely VR. To the researcher's knowledge, this emerging technology has never been used to promote men's health, let alone enhancing their awareness of testicular disorders. The content of the E-MAT intervention was guided

by findings from the reviewed literature, men's feedback from the qualitative study, and the stages of the PAAF. The layout of the E-MAT intervention was developed in collaboration with an expert in interactive media. The feasibility and usability of E-MAT were established with 15 men who perceived the intervention as feasible, enjoyable, and user-friendly.

Fifthly, instruments were developed to pilot test the E-MAT intervention. These aimed to assess knowledge, testicular awareness, implementation intentions, perceived risk, help-seeking intentions, and behaviours. Data from the pilot study were collected from 49 participants at three time points. It was found that the E-MAT intervention significantly increased men's knowledge of the normal testes and the most common testicular symptoms and disorders; awareness of the normal and abnormal testes; intentions to seek help for testicular lumpiness, swelling, and pain from various sources; and intentions and behaviours pertaining to feeling their own testes and advising at least one man to do the same. However, the E-MAT intervention did not increase men's perceived risk of testicular disorders.

In conclusion, the intervention developed and pilot tested in the present thesis was deemed successful in enhancing men's testicular awareness and increasing their intentions to seek help for symptoms of testicular disease. Therefore, full-scale testing using rigours methodologies is warranted. This could be achieved through conducting an RCT with a larger sample size across different settings, as well as conducting a longitudinal study that captures the long-term effect of the E-MAT intervention. Moreover, in order to ensure wider outreach, E-MAT can be made available on public platforms and as part of large men's health promotion campaigns, such as Movember. It can also be made available to policymakers and clinicians who are involved in health promotion.

Finally, the use of VR and the PAAF can be extended beyond the context of testicular awareness and can be used to develop and test interventions aimed at promoting men's awareness of various health topics such as: sexually transmitted infections, healthy lifestyle changes, and cancer prevention and risk reduction.

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### **APPENDICES**

## Appendix 1

### **Appendix 1.1** Permission to use Figure 1.2

To Whom It May Concern,

I am a PhD student in Cork, Ireland and writing a thesis about men's awareness of testicular disorders including testicular cancer. I visited the Canadian Cancer Society's page earlier and I came across a very interesting figure titled "Structure of the Testicle" available from:

http://www.cancer.ca/en/cancer-information/cancer-type/testicular/anatomy-and-physiology/?region=on

I would kindly like to ask for permission to use this figure in my dissertation while citing the Canadian Cancer Society.

Thank you

Best,

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Tel: +353 21 490 1518 Email: msaab@ucc.ie

### Dear Mohamad,

Thank you for contacting me about using Canadian Cancer Society content. We have a very open policy on permissions. In using the graphic you mention from cancer.ca, we do require that you give credit to us as the source. Credit includes citing the full name of the Canadian Cancer Society, the title and URL of the web page, and the date on which the information was captured. You can use them in any order according to your preferred reference style. Read more: <a href="http://www.cancer.ca/en/about-our-site/terms-and-conditions/?region=on#ixzz2z9gfpnEy">http://www.cancer.ca/en/about-our-site/terms-and-conditions/?region=on#ixzz2z9gfpnEy</a>

Good luck with your dissertation. If you have any other questions, please let me know.

### Jennifer Moorcroft

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## Appendix 2

**Appendix 2.1** Testicular Cancer Awareness and Screening Practices: A Systematic Review (Saab *et al.* 2016c)<sup>3</sup>

**ONLINE EXCLUSIVE ARTICLE** 

# Testicular Cancer Awareness and Screening Practices: A Systematic Review

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No financial relationships to disclose.

Saab, Landers, and Hegarty contributed to the conceptualization and design and manuscript preparation. Saab and Landers completed the data collection. Saab and Hegarty provided statistical support. Saab contributed to the analysis.

Saab can be reached at msaab@ucc.ie, with copy to editor at ONFEditor@ons.org.

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Key words: attitude; awareness; knowledge; practices; screening; testicular cancer

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Purpose/Objectives: To critically appraise empirical evidence gathered from studies that (a) explored men's knowledge, awareness, and attitudes toward testicular cancer (TC) and its screening; (b) addressed their testicular self-examination (TSE) practice; and/or (c) highlighted barriers and facilitators to this practice.

Data Sources: MEDLINE®, CINAHL®, and EMBASE®

**Data Synthesis:** 25 articles met the inclusion criteria. Knowledge deficits regarding TC and its screening were seen. Participants who did not perform TSE often were uninformed about this practice. The majority of men perceived TC education as a positive step toward raising awareness about this malignancy.

Conclusions: Very few men were informed about TC and TSE. Future studies should include valid and reliable tools to assess TC knowledge and screening, address the means through which TC knowledge is delivered, explore the individual's experience with TC screening, and focus on TC awareness and screening among minority groups.

Implications for Nursing: Although regular screening for TC is a controversial issue, nurses should encourage young men to seek medical attention in the event of discovering scrotal abnormalities.

esticular cancer (TC) is a rare malignancy that constitutes 0.5% of all new cancer cases and 0.1% of all cancer deaths in the United States. About 1 in every 263 men will develop TC in their lifetime and 8,430 men will be diagnosed with TC in 2015 (National Cancer Institute, 2014a). Men aged 20–34 years are at the highest risk for TC, with a median age of 33 years at diagnosis. However, in the United States, TC has one of the highest cure rates, with a five-year survival rate of 95% (National Cancer Institute, 2014a).

TC screening in asymptomatic males continues to be a controversial issue because of a lack of empirical evidence that supports or discourages the practice (Law, 2004; National Cancer Institute, 2014b). The U.S. Preventive Services Task Force ([USPSTF], 2011) issued a statement against TC screening among asymptomatic males. This statement was based on a Cochrane review conducted by llic and Misso (2011) in which no evidence was found regarding the beneficial effect of TC screening on mortality. In addition, it was suggested that TC screening may cause unnecessary anxiety and increase the likelihood of having false-positive findings that would consequently expose men to invasive diagnostic tests. However, key cancer organizations, such as the American Cancer Society ([ACS], 2014c), recommend TC screening as a component of routine cancer-related physical examinations. In the United Kingdom, men are encouraged to be aware of the normal anatomy of their testes (Cancer Research UK, 2014) despite having no evidence to support weekly or monthly testicular self-examination (TSE). Similarly, the Irish Cancer Society (2014) offers infographic material to

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encourage young men to perform TSE. In addition, a number of foundations have been established to raise awareness about TC and its screening. One of those organizations, the Testicular Cancer Awareness Foundation (2014), uses 89% of its funds to educate young men about the importance of periodically practicing TSE.

Studies that have assessed TC knowledge and TC screening practices among healthy men have been conducted; however, no systematic reviews have been conducted to pool findings from these studies to inform practice. The aim of this review was to critically appraise evidence gathered from studies that explored men's knowledge, awareness, and attitudes toward TC and its screening; addressed their TSE practice; and/or highlighted barriers and facilitators to this practice.

### Methods

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) checklist was used in this review (Moher, Liberati, Tetzlaff, & Altman, 2009). Studies included in this systematic review are quantitative or qualitative; published in or translated to English; published from 2004–2014; included findings from men only; assessed knowledge, awareness, and attitudes toward TC; assessed knowledge, awareness, attitudes, and practice of TC screening, including TSE; and examined barriers and facilitators to TC knowledge and screening. The term *TC screening* was considered to comprise TC examination by a clinician and TSE.

Three electronic databases (MEDLINE®, CINAHL®, and EMBASE®) were searched. Boolean terms "OR" and "AND," Medical Subject Headings (MeSH), and truncation "\*" were used. Keywords and their synonyms were combined and yielded the following search history: (cancer\* OR tumor\* OR tumour\* OR malignan\* OR neoplas\*) AND (testicul\* OR testes OR testis OR testicle\*) AND (self-exam\* OR 'self exam\*' OR screening OR 'early detection' OR awareness OR knowledge OR attitudes OR practice OR 'health promotion' OR symptoms).

Studies were exported to EndNode® X7 and duplicates were deleted. Records were screened on title and abstract and irrelevant articles were excluded. Data from the included studies were extracted by the primary reviewer (MS) using a standardized research matrix (Gooseens et al., 2014) and later crosschecked by another reviewer (JH). Data collected included name of the author(s), year of publication, and country and setting where the studies were conducted. Demographic data of the study population (sample size, mean age, and age range) were ex-

tracted along with the study design and instruments. The search results were independently reviewed by two authors (MS and ML), and a kappa coefficient was calculated.

A total of 3,076 records were identified through database search. Following the deletion of duplicates, 1,731 articles were independently screened on title and abstract by two reviewers (MS and ML) and irrelevant articles were excluded. A Cohen's kappa coefficient of 0.715 was obtained and was perceived as satisfactory (Higgins & Green, 2011). The authors assessed 126 full-text articles for eligibility. Following the exclusion of 101 articles, 21 quantitative cross-sectional surveys, 3 qualitative descriptive studies, and 1 integrative review were deemed eligible for review. Figure 1 summarizes the study selection process.

### Results

### **Study Characteristics**

The majority of the reviewed studies were conducted in the United States (n = 7). Because TC is most common among young adults, the majority of data was collected in universities (n = 13). The smallest sample size in quantitative studies was 177 (Beydag, 2012) and the largest sample size was 8,680 (Evans, Steptoe, & Wardle, 2006). As for qualitative studies, the minimum sample size was 20 (Dub , Fuller, Rosen, Fagan, & O'Donnell, 2005) and the maximum was 37 (Evans, Simon, & Wardle, 2010). Non-probability purposive sampling was used in all of the reviewed qualitative studies as well as the majority of the quantitative studies (n = 19). Random sampling was used in only two quantitative studies (Muliira, Nalwanga, Muliira, & Nankinga, 2013; Powe, Ross, Wilkerson, Brooks, & Cooper, 2007). Ages of participants ranged from 14–78 years. With the exception of one integrative review (de Souza, dos Reis, Gomes, & de Carvalho, 2011), all included records used a descriptive approach.

### Quality Appraisal of Included Studies

Three tools were used to assess the quality of the included studies. A quality-appraisal tool was used to assess the quality of the quantitative studies (Davids & Roman, 2014; Louw, Morris, & Grimmer-Somers, 2007; Roman & Frantz, 2013; Wong, Cheung, & Hart, 2008). Studies that scored from 0%–33.9% were considered weak (n = 3), 34%–66.9% were considered moderate (n = 9), and 67%–100% were interpreted as strong (n = 9). The quality of the qualitative studies and the integrative review was assessed using two tools developed by the Critical Appraisal Skills Programme (2013a, 2013b). Quality appraisal of the included literature is presented in Tables 1–3.

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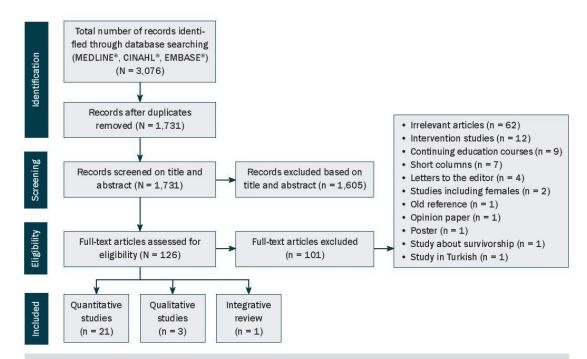


FIGURE 1. Record Identification, Screening, and Selection Process

### Discussion

Researchers used a multitude of questionnaires to collect data, with the majority being researcher designed surveys (n = 18). Therefore, given the heterogeneous nature of the data collected, it was not feasible to combine the data for a meta-analysis. Findings from individual studies are presented in Appendix A.

# Knowledge, Awareness, and Attitudes Toward Testicular Cancer

Having heard of TC did not equate to knowledge about the various aspects of this malignancy, such as its risk factors, signs and symptoms, and treatment modalities. Evidence shows that men's knowledge of TC increased over time. This increase in knowledge, however, was not found in studies conducted in developing countries. This trend may be attributable to the lack of public awareness and education about TC and its symptoms in the developing world (Kuzgunbay et al., 2013; Muliira et al., 2013; Ugboma & Aburoma, 2011).

While exploring the different attitudes toward TC, fear was found to be the most commonly reported feeling. Participants perceived TC as a serious illness, believed that they were at risk for TC, and were afraid of developing it. These participants were more likely to be unaware that TC is curable and believed that TC is not preventable. These perceptions may stem

from the general views of cancer. Cancer diagnosis in general and TC in particular has long been associated with fear (Saab, Noureddine, Huijer, & DeJong, 2014; Skaali et al., 2009).

Of the risk factors for TC, age was addressed the most. A difference exists between the knowledge of TC risk factors among men living in developed countries (Casey, Grainger, Butler, McDermott, & Thornhill, 2010; Cronholm, Mao, Nguyen, & Paris, 2009; Daley, 2007; Powe et al., 2007) and that of men living in developing countries (Muliira et al., 2013; Onyiriuka & Imoebe, 2013). Again, this can be attributed to the lack of public awareness and education about TC in the developing world.

# Knowledge, Awareness, Attitudes, and Practice of Testicular Self-Examination

A certain degree of knowledge deficit regarding TC screening was noted. Like TC awareness, having heard of TC screening did not equate to practicing TSE or undergoing TC screening by a clinician. Of those who claimed to have heard of TSE, very few knew what to look for while checking their testes. Like TC knowledge, the lowest TSE knowledge scores were noted among men living in developing countries, which was attributed to the lack of public awareness about health surveillance, insufficient health education in schools and universities, and the lack of endorsement of TC practices by policymakers.

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Almost all men in the reviewed studies showed a positive attitude toward TC screening. As for help-seeking behaviors, very few stated that they would delay seeking medical attention in the event of a painless testicular lump. Delay in seeking medical care was strongly associated with not knowing about and/or not practicing TSE, as well as fear from contracting TC. Attitudes toward TC screening were

thought to be shaped by cultural norms, health education, and the media. In addition, of the small amount of men who reported performing TSE, few did so regularly.

### Barriers to Awareness and Screening

Evidence suggests that participants who did not perform TSE often were uninformed about this practice. Ambiguity of messages delivered by healthcare providers and men's negative attitudes toward TC and TSE served as barriers to TC screening. The evidence suggests that fear of detecting a lump and anxiety from false-positive results played a key role in the participants' refusal to perform TSE. In addition, those who perceived TSE as unimportant, time consuming, embarrassing, and/ or painful were more likely to refrain from performing it. Of note, misconceptions about TC screening were predominant in developing countries and stemmed from the preexisting knowledge deficit about TC and its screening.

The lowest TC knowledge scores and TC screening practices were noted in studies conducted in developing countries. Conceivably, education could have affected their scores. However, the majority of participants in these studies were university students, including medical students (Kuzgunbay et al., 2013). Of note, the risk of developing TC is highest in the United States and Europe and lowest in Africa and Asia (ACS, 2014b). This

could be another reason why efforts were not made to increase TC awareness and TC screening practices in developing countries.

Participants' ethnic backgrounds also were found to influence TC knowledge and TC screening practices. In the United States, African American men scored the lowest on questions about TC and TSE. Despite the fact that the incidence of TC is higher among Caucasians,

**TABLE 1. Quality Assessment of Quantitative Studies** 

	As	Q	uality ment		ıs			Relev		
Study	A	В	С	D	E	F	G	Н	1	Score %
Rudberg et al., 2005	1	1	1	1	1	1	1	1	1	100
Ward et al., 2005	1	1	1	0	1	1	1	1	1	88.9
Evans et al., 2006	1	1	1	1	0	0	1	0	0	55.6
Roemer et al., 2006	1	1	0	0	1	0	1	0	0	44.4
Sirin et al., 2006	1	0	0	0	1	0	1	0	0	33.3
Powe et al., 2007	1	0	1	0	1	1	1	1	1	77.8
Handy & Sankar, 2008	1	0	0	0	1	0	1	1	1	55.6
Cronholm et al., 2009	1	0	0	0	1	1	1	1	0	55.6
McGilligan et al., 2009	1	0	0	0	1	0	1	0	0	33.3
Ca sey et al., 2010	0	1	0	0	1	1	1	0	1	55.6
Reece et al., 2010	1	0	0	0	0	0	1	0	1	33.3
Brewer et al., 2011	0	1	0	0	1	0	1	1	1	55.6
Rovito et al., 2011	1	0	1	1	1	1	1	0	1	77.8
Ugboma & Aburoma, 2011	1	1	0	0	1	1	1	1	1	77.8
Urgurlu et al., 2011	1	1	0	0	1	1	1	1	1	77.8
Beydag, 2012	1	1	0	0	1	1	0	0	0	44.4
Özbaş et al., 2012	1	0	0	0	1	0	1	1	1	55.6
Kuzgunbay et al., 2013	0	0	0	0	1	1	1	0	1	44.4
Muliira et al., 2013	1	1	0	1	1	1	1	1	1	88.9
Onyiriuka & Imoebe, 2013	1	1	0	0	1	1	1	1	1	77.8
Kennett et al., 2014	1	1	0	0	1	1	1	1	1	77.8

<sup>a</sup> Total score divided by the total number of items multiplied by 100.

0—no or not reported; 1—yes; A—Was sample likely to be representative of the study population?; B—Was a response rate mentioned within the study?; C—Was the instrument used reliable?; D—Was the instrument used valid?; E—Was it a primary data source?; F—Was TC knowledge, awareness, and/or attitudes assessed?; G—Was TC screening knowledge, awareness, attitude, and/or practice assessed?; H—Were barriers to TC knowledge and TC screening explored?; I—Were facilitators to TC knowledge and TC screening explored?; TC—testicular cancer

Note. Quality appraisal score and match with the objectives of current review: weak: 0-33.9%, moderate: 34%-66.9%, strong: 67%-100%

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TABLEO	O 114.	/ Assessment		Orra likakina	Charding	Danie
IABLE	Onamy	ν Assessment	OI	Ollalitative	Studies and	Reviews

	Q	uestio	ns Froi	n the C	critical	Apprai	sal Sk	ills Pr	ogram	me
Study	A	В	С	D	E	F	G	Н	1	J
Dubé et al., 2005	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Very
Daley, 2007	Yes	Yes	Yes	Yes	Yes	PA	Yes	No	Yes	Very
Evans et al., 2010	Yes	Yes	Yes	Yes	Yes	PA	PA	No	Yes	Very

A—Was there a clear statement of the aims of the research?; B—Is a qualitative method appropriate?; C—Was the research design appropriate to address the aims of the research?; D—Was the recruitment strategy appropriate to the aims of the research?; E—Was the data collected in a way that addressed the research issues?; F—Has the relationship between researcher and participants been adequately considered?; G—Have ethical issues been taken into consideration?; H—Was the data analysis sufficiently rigorous?; I—Is there a clear statement of findings?; J—How valuable is the research?; PA—partially addressed

Note. Based on information from Critical Appraisal Skills Programme, 2013b.

African Americans are more likely to have advanced TC at time of diagnosis (ACS, 2014c). To date, no clear explanation exists for this trend; however, a number of factors could have contributed to these findings. For instance, African Americans often learn about TC and TSE through healthcare providers and schools. African Americans are, as a group, less likely than Caucasians to visit physicians on a regular basis (Powe et al., 2007). African Americans also generally have a lower socioeconomic status, which often is associated with lower screening rates, advanced stage of disease at diagnosis, and decreased survival rates (ACS, 2014a).

### Facilitators to Awareness and Screening

The evidence suggests that men who were educated about TC and TSE were more likely to undergo TC screening. In the majority of the reviewed studies, mass media served as the means through

which knowledge about TC and TC screening was conveyed. Despite its numerous detrimental effects, such as exposure to violent content and harmful lifestyle habits, the evidence suggests that mass media can play a key role in providing information about safe health practices (Strasburger, Jordan, & Donnerstein, 2012).

The majority of participants believed that TC education is a positive step toward raising awareness about TC and increasing TC screening practices. They displayed interest in obtaining

information about TSE, showed willingness to practice TSE, and thought that men should be taught about TC. Participants also believed that no harm could come from TC education and suggested that delivering useful information and highlighting the TC high curability rate can help overcome cancer-related anxiety (Evans et al., 2010). They also believed that men should be encouraged to perform TSE the same way women are encouraged to perform breast self-examination and assumed that the normalization of TSE would lead to increased TC screening practices (Dub et al., 2005; Evans et al., 2010).

### Limitations

During the review process, a number of methodologic limitations were noted. Using the American Association of Critical Care Nurses' hierarchy of evidence, all the reviewed papers fall under the level of evidence C (Armola et al., 2009). Focus groups rather than individual interviews were conducted in all three qualitative studies; therefore, some participants may not have been forthcoming in their answers, which could have led to omission of important details. In addition, no meta-analyses or meta-syntheses were identified during the literature search. Of note, a multitude of researcher-designed questionnaires were used in the majority of the reviewed survey studies, which has led to heterogeneous results that could not be combined for a meta-analysis. In addition, the majority of these studies did not report on reliability and validity. Almost all the reviewed studies used nonprobability purposive sampling, which is known to

TABLE 3. Quality Assessment of the Integrative Review

	Ques	tions F	rom th	e Criti	cal App	ra isa l	Skills I	Prograi	nme
Study	A	В	С	D	E	F	G	н	1
de Souza et al., 2011	Yes	PA	PA	No	Yes	-	No	PA	PA

A—Did the review address a clearly focused question?; B—Did the authors look for the appropriate sort of papers?; C—Were the important, relevant studies included?; D—Did the review's authors do enough to assess the quality of the included studies?; E—If the results of the review have been combined, was it reasonable to do so?; F—What are the overall results of the reviews?; G—Were the results clearly presented?; H—Were all important outcomes considered?; I—Do the benefits exceed the risks and costs?; PA—partially addressed

Note. Based on information from Critical Appraisal Skills Programme, 2013a.

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### **Knowledge Translation**

- Some organizations still recommend testicular cancer (TC) screening as a component of routine cancer-related physical examinations, despite a lack of evidence to support this practice.
- Lack of knowledge and misconceptions about TC can lead to decreased testicular self-examination practices.
- Very few studies included ethnic minorities, and none included sexuality and gender or religious minorities who are at risk for health disparities.

increase the risk of selection bias and yield a sample that is less likely to be representative of the target population (Cochrane Bias Methods Group, 2013). Finally, the majority of participants were Caucasian university students. Data from ethnic, sexuality, and gender, as well as religious minorities and people with disabilities was not sought, which hinders the generalizability and transferability of the findings.

The search was limited to three databases and did not include data from the grey literature. In addition, the search was limited to studies conducted from 2004 to 2014 and studies that were published in or translated to English, which leaves room for study selection bias. Reporting bias may have taken place since only findings pertinent to the review aims are presented (Cochrane Bias Methods Group, 2013). Finally, some descriptive statistics were calculated using data from the publications, which leaves room for error. Minimizing the risk for this error was attempted by having a second reviewer (JH) cross-check the extracted data.

### **Implications for Future Research**

Future research on TC and TC screening is needed to close the gap in the literature and address the identified limitations. The use of standardized, valid, and reliable tools should be encouraged to allow the replication of studies in different contexts. In addition, the use of random sampling should be encouraged to minimize the risk of selection bias and yield a representative sample.

Despite assessing men's knowledge of TC and TSE, very few studies addressed the means through which this knowledge is delivered. For this reason, future research should focus on assessing men's information needs and exploring the preferred means through which they wish to acquire new knowledge. From a qualitative perspective, a need exists to explore the individual man's experience with TC screening and to offer an in-depth interpretation of the psychosocial constituents of this experience.

Research on cancer prevention in minority groups is among the top priorities of key oncology organizations, such as the Oncology Nursing Society (Wood et al., 2014). For this reason, future studies should be targeted toward assessing TC knowledge and screening practices as well as exploring the experiences minority groups.

Finally, given that the majority of existing data was collected from universities, future studies that focus on TC knowledge and screening in men with low educational and/or socioeconomic background should be considered.

### **Implications for Nursing**

The controversy and lack of consensus regarding TC screening might instill a sense of ambiguity amongst healthcare providers and educators. A middle ground could be reached by informing nurses who are involved in health promotion to encourage young men to seek medical attention in the event of scrotal abnormalities, such as pain or the presence of a testicular lump or swelling.

### Conclusions

A certain degree of knowledge deficit regarding TC and its screening exists. Generally, men perceived TC as a serious illness, were unaware that it is curable, and often were uninformed about TSE. In addition, not all who claimed having heard of TC screening knew what to look for during TSE. The majority of men perceived TC education as a positive step toward raising awareness about TC and TSE. Men who were educated about TC and TSE were more likely to undergo TC screening. Mass media served as the key means through which participants learned about TC and its screening.

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APPENDIX	APPENDIX A. Research Matrix					
					Findings	
Study	Sample	Design	Instruments	Q1	42	Q3
Quantitative Studies	e Studies					
Rudberg et al., 2005	727 high school students in Sweden $\overline{X}$ age = 17 years, SD = 1.17, range = 15-21).	Descrip- tive cross- sectional survey	Researcher- designed questionnaire (60 items)	82 (11%) knew about TC; 521 (72%) were afraid of getting TC; 635 (87%) per- ceived TC as a very serious illness; 236 (33%) did not know that a swollen tes- ticle can be a sign of TC	40 (6%) knew about TSE; 74 (10%) performed TSA a few times per year; 9 (1%) performed TSE once per month.	Barriers: The majority of participant were uninformed about TC and TSE. Facilitators: Of those who were informed about TC and TSE, 55 (68%) and 24 (61%), respectively, learned about TC and TSE via mass media.
Ward et al., 2005	213 males from a community-based youth organization in the United States $\overline{X}$ age = 15.4 years, SD = 1.1, range = 13-19)	Descrip- tive cross- sectional survey	Boy Scout Health and Safety Survey Two questions designed by the research- er sabout TC and TSE	about TC	90 (42%) had performed a TSE at least once; 22 (10%) performed TSE 10 or more times per year.	Barriers: African Americans were least knowledgeable about TC (p < 0.0001) and less likely to perform TSE (p = 0.024). Facilitators: Participants who were Caucasian (p = 0.0006), had future educational goals (p = 0.0376), and who participated in physical education classes (p = 0.0206) were more likely to know about TC.
Evans et al., 2006	8,680 males from university settings in 13 European countries (ages not provided)	Descriptive comparative survey	Researchers used a questionnaire adapted from Wardle and Steptoe (1991).	N.	In 1990, 289 (4%) practiced TSE less than once a year, 436 (6%) practiced TSE 1–9 times per year, and 210 (3%) practiced TSE at least 10 times per year. TSE practice across Europe significantly increased from 1990 (13%) to 2000 (18%) (p < 0.0001).	NR.
Roemer et al., 2006	1,600 males from a military medical cen- ter affiliated with the German armed forces (ages not provided)	Descrip- tive cross- sectional survey	Researchers designed a standardized face-to-face interview.	NR.	1,527 (95%) reported having their testes examined; 2 (0.1%) refused to have the examination.	NR (Continued on the next page)
CI-confider knowledge, TC-testicula	CI–confidence interval; df–degrees of freedom; NR–knowledge, awareness, attitude, and practice of TC scr TC–testicular cancer; TSE–testicular self-examination	freedom; NR- actice of TC scr If-examination	not reported; OR reening?; Q3—Wh:	odds ratio; Q1—What are motare men's barriers and facili	en's knowledge, awareness, and attit tators to TC and TC screening knowled	CI—confidence interval; df—degrees of freedom; NR—not reported; OR—odds ratio; Q1—What are men's knowledge, awareness, and attitude toward TC?; Q2—What are men's knowledge, awareness, attitude, and practice of TC screening?, Q3—What are men's barriers and facilitators to TC and TC screening knowledge, awareness, attitude, and practice?; TC—testicular cancer; TSE—testicular self-examination

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APPENDIX	APPENDIX A. Research Matrix (Continued)	ntinued)				
					Findings	
Study	Sample	Design	Instruments	Q1	42	රු
Quantitativ	Quantita tive Studies (Continued)					
Sirin et al., 2006	195 men in a shopping center in Turkey (age range = 20-60 years)	Descrip- tive cross- sectional survey	Researchers designed a 38-item questionnaire.	N.	15 (14%) knew how to perform TSE; of those, 5 performed monthly TSE.	NR
Powe et al., 2007	190 males in a university setting in the United States $\overline{X}$ age = 21.8 years, SD = 5.7, range = 18-56)	Descriptive compara- tive survey using Powe's Fatalism Model	Powe Fatal- ism Inventory TC knowledge survey Perceived cancer risk survey Student de- mographic data ques- tionnaire	160 (84%) had heard of TC; 133 (70%) knew that men aged 20–40 years are at risk for TC.	95 (50%) performed TSE; of those, 15 performed monthly TSE.	Barriers: African Americans had lower TC knowledge (df = 188, t = 3.15, p = 0.002), scored higher on perceptions of cancer fatalism $(\chi^2 = 4.46)$ , and were more likely to identify non-risk factors as risk factors for TC (df = 2, $\chi^2 = 10.52$ , p = 0.005). Facilitators: Participants who were taught about TSE (df = 2, $\chi^2 = 46.2$ , p = 0.0001) and those who were freshmen or sophomores (df = 1, OR = 0.39, p = 0.027) were more likely to perform TSE.
Handy & Sankar, 2008	1,000 males in a genitourinary medicine clinic in the United Kingdom (age range = 16-44 years)	Descrip- tive cross- sectional survey	Researchers designed an eight-item questionnaire.	W.	859 (86%) performed TSE; 132 (13%) were taught to perform TSE by a general practitioner, 79 (8%) at school, and 88 (9%) in a genitourinary clinic. A total of 503 (51%) knew what to look for during TSE.	Barriers: No education about TSE Facilitators: 980 (98%) think that men should be taught about TSE through school (n = 598, 60%) and/or by their general practitioner (n = 548, 55%).
Gronholm et al., 2009	203 high school students in the United States (age not available)	Descriptive cross-sectional survey	Researchers designed a seven-item questionnaire.	139 (69%) identified the age group at risk for TC.	74 (37%) believed that TSE should be performed monthly, 75 (37%) knew how to perform TSE, 51 (25%) never heard of TSE, and 37 (18%) would delay seeking medi- cal help if they detected a lump.	Barriers: Participants who reported never having heard of TSE were more likely to delay seeking care (OR = 2.83, 95% CI [1.32, 6.04], p = 0.007). Facilitators: NR (Continued on the next page)

Cl—confidence interval; df—degrees of freedom; NR—not reported; OR—odds ratio; Q1—VVhat are men's knowledge, awareness, and attitude toward TC?; Q2—VVhat are men's howledge, awareness, attitude, and practice of TC screening?; Q3—VVhat are men's barriers and facilitators to TC and TC screening knowledge, awareness, attitude, and practice?; TC-testicular cancer; TSE-testicular self-examination

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APPENDIX	APPENDIX A. Research Matrix (Continued)	ntinued)				
					Findings	
Study	Sample	Design	Instruments	41	42	63
Quantitative	Quantitative Studies (Continued)					
McGilligan et al., 2009	500 university students in Northern Ireland (X age = 25.67 years, SD = 9.77, range = 17-35)	Descriptive cross-sectional survey using the Extended Theory of Planned Behavior	Researchers designed the questionnaire in a format based on Theory of Planned Behavior.	N N	Attitude, subjective norm, and self-efficacy contributed to TSE intention. Planned behavior and anticipated regret increased the variance in intention scores (5.9% and 5.7%). Attitude, anticipated regret, planned behavior, subjective norm, and self-efficacy were significantly associated with TSE intention.	N N
Casey et al., 2010	677 men at a banking institution in Ireland (X age = 44.9 years, range = 18-67)	Descriptive comparative cross-sectional survey	Researchers designed an eight-item questionnaire.	2010 data compared to 1986: 673 (99%) versus 269 (68%) were aware of TC, 413 (61%) versus 52 (13%) identified the age group at risk for TC, and 481 (71%) versus 90 (23%) were aware of TC symptoms. In 2010, 54 (8%) stated possible causes of TC.	210 (31%) were aware of TSE; of those, 183 (87%) performed TSE, 27 (4%) performed TSE monthly compared to 5 (1.3%). 657 (97%) were interested in obtaining information about TSE and TC compared to 357 (90%) in 1986.	Barriers: NR Facilitators: Participants who practiced TSE had a higher knowledge score than those who did not $(\overline{X} = 5.11, SD = 0.04  \text{versus}  \overline{X} = 4.06, SD = 0.003; p < 0.01).$
Rece et al., 2010	665 males in the United States (X age = 31.75 years, SD = 8.04, range = 18-44)	Descrip- tive cross- sectional survey	Researchers designed a three-part questionnaire. International index of Erectile Function Male Genital Self-Image Scale	N.	264 (40%) reported performing TSE in the past month.	Facilitators: NR Facilitators: Men who performed TSE were more likely to be gay or bisexual (p = 0.021), report physical examination by a clinician within the past year (p = 0.002), score high on the Index of Erectile Function desire subscale (p < 0.001), and score high on the Male Genital Self-Image Scale (p = 0.035). (Continued on the next page)

Cl-confidence interval; df-degrees of freedom; NR-not reported; OR-odds ratio; Q1—What are men's knowledge, awareness, and attitude toward TC?; Q2—What are men's knowledge, awareness, attitude, and practice of TC screening?, Q3—What are men's barriers and facilitators to TC and TC screening knowledge, awareness, attitude, and practice?; TC-testicular cancer; TSE-testicular self-examination VOL. 43, NO. 1, JANUARY 2016 . ONCOLOGY NURSING FORUM

resulted in 15 (2%) participants de- tecting a testicular abnormality.

CL-confidence interval; df-degrees of freedom; NR-not reported; OR-odds ratio; Q1-What are men's knowledge, awareness, and attitude toward TC?; Q2-What are men's knowledge, awareness, attitude, and practice of TC screening?; Q3-What are men's barriers and facilitators to TC and TC screening knowledge, awareness, attitude, and practice?; TC-testicular cancer; TSE-testicular self-examination

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APPENDIX	APPENDIX A. Research Matrix (Continued)	ntinued)				
					Findings	71
Study	Sample	Design	Instruments	Q1	42	රිදු
Quantitative	Quantitative Studies (Continued)					
Urgurlu et al., 2011	634 students in a university setting in Turkey $\overline{X}$ age = 21.3 years, SD = 2.14, range = 17-34)	Descrip- tive cross- sectional survey	Researchers designed a 32-tem questionnaire.	279 (44%) heard about TC. Agreement with the statements came as follows: 444 (70%) were afraid of having TC, 401 (63%) thought that TC is a very serious illness, and 373 (59%) thought that TC negatively affects a man's sex life.	38 (6%) received information on TSE, 111 (18%) performed TSE prior; of those, 21 (19%) per- formed monthly TSE.	Barriers: 596 (94%) were not educated about TSE, and 291 (56%) did not think that TSE is important. Facilitators: 543 (86%) wanted to be informed about early diagnosis and prevention of TC.
Beydag, 2012	Students in a university setting in Turkey (age range = 18-21 years)	Descrip- tive cross- sectional survey	Researchers designed a sociodemographic data survey and a 10-item questionnaire.	Females' knowledge of breast cancer was higher than that of males about TC (p < 0.05).	N.	A.
Özbaş et al., 2012	275 students in a university setting in Turkey (age range = 20-25 years)	Descrip- tive cross- sectional survey	Researchers designed a 27-item questionnaire.	NR	33 (12%) knew how to perform TSE; of those, 12 (36%) per- formed TSE.	Barriers: 17 (6%) did not think that TSE is important, and 11 (4%) were afraid to perform TSE.  Facilitators: 14 (20%) learned about TSE from the television, and 11 (16%) learned from their friends.
Kuzgun- bay et al., 2013	799 students in a university setting in Turkey (\$\times\$ age = 1.3.7 years, SD = 1.1, range = 17-25)	Descrip- tive cross- sectional survey	Researchers designed a 10-item questionnaire.	89 (11%) knew about TC; of those, 11 (1%) answered all the questions about TC correctly.	20 (3%) performed TSE; of those, 8 (1%) performed monthly TSE.	Barriers: NR Facilitators: 60 (67%) of those who knew about TC did so from the Inter- net and the media. Participants who performed TSE answered questions about TC correctly (p = 0.01). (Continued on the next page)
Cl—confider knowledge, TC—testicula	CI—confldence interval; df—degrees of knowledge, awareness, attitude, and pra TC—testicular cancer; TSE—testicular sel	freedom; NR- actice of TC scr elf-examination	-not reported; OR reening?; Q3-Wh:	k-odds ratio, Q1-What are me at are men's barriers and facilit	en's knowledge, awareness, and attil rators to TC and TC screening knowled	CL-confidence interval; df-degrees of freedom; NR-not reported; OR-odds ratio; Q1-What are men's knowledge, awareness, and attitude toward TC?; Q2-What are men's knowledge, awareness, attitude, and practice of TC screening?; Q3-What are men's barriers and facilitators to TC and TC screening knowledge, awareness, attitude, and practice?; TC-testicular cancer; TSE-testicular self-examination

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APPENDIX	APPENDIX A. Research Matrix (Continued)	ntinued)				
					Findings	
Study	Sample	Design	Instruments	Q1	φ2	Q3
Quantitative	Quantita tive Studies (Continued)					
Muliira et al., 2013	323 students in a university setting in Uganda (x age = 22 years, SD = 2.5, range = 18-32)	Descrip- tive cross- sectional survey	Researchers designed a self-administered question-naire.	The majority did not know the age group affected by TC (n = 215, 66%), that a lump is a common symptom of TC (n = 228, 71%), the chance of curability (n = 186, 57.6%), and risk factors for TC (n = 196, 61%).	The majority never performed TSE (n = 194, 60%) and did not know the most appropriate time to perform TSE (n = 186, 58%).	Barriers: Perceiving TSE as time con suming (n = 280, 87%), embarrassing (n = 255, 79%), and painful (n = 240, 74%) Facilitators: 200 (62%) heard of TC in the media. Those who reported practicing TSE knew that a lump is a sign of TC (p = 0.0001) and that TC is curable if diagnosed early (p = 0.001). They identified the age group at risk for developing TC (p = 0.003), knew how to perform TSE (p = 0.0001), and that they were at risk for developing TC (p = 0.0001).
Onyiriuka & Imoebe, 2013	540 students at a secondary school in Nigeria (X age = 16.8 years, SD = 1.7, range = 15-20)	Descrip- tive cross- sectional survey	Researchers designed a two-part questionnaire.	3 (0.6%) knew that risk for TC is highest among men aged 15–35 years. None knew that TC can occur in men younger than age 20 years.	7 (1%) heard about TSE; 314 (58%) did not know about the TSE steps.	Barriers: No education about TSE Facilitators: Information about TSE was obtained from friends and peers; 255 (47%) expressed their willingness to perform TSE following the questionnaire.
Kennett et al., 2014	740 males in a genito- urinary medicine clinic in the United Kingdom (X age = 32.9 years, range = 14-78)	Descrip- tive cross- sectional survey	Researchers designed a nine-item questionnaire.	561 (76%) heard about TC.	591 (80%) heard about TSE, 303 (41%) were taught how to perform TSE, and 586 (79%) performed TSE; of those, 336 (57%) did so at least once a month and 1.11 (19%) weekly.	Barriers: 440 (60%) did not know what to look for during TSE. Facilitators: 548 (74%) wanted to be informed about TSE, 375 (51%) would like to learn about TSE through a leaflet, 337 (46%) through discussion, and 277 (37%) during their clinic visit.

(Continued on the next page)

CL-confidence interval; df-degrees of freedom; NR-not reported; OR-odds ratio; Q1—VMat are men's knowledge, awareness, and attitude toward TC?; Q2—VMat are men's knowledge, awareness, attitude, and practice of TC screening?, Q3—VMat are men's barriers and facilitators to TC and TC screening knowledge, awareness, attitude, and practice?; TC-testicular cancer; TSE-testicular self-examination

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(Continued on the next page)

APPENDIX	APPENDIX A. Research Matrix (Continued)	tinued)				
					Findings	
Study	Sample	Design	Instruments	Q1	Q2	<b>Q3</b>
Review						
de Souza et al., 2011	14 participants in Brazil	Integrative review	Databases searched include Cochrane, PubMed*, MEDLINE*, LILACS, BDENF, and CINAHL*.	NR	According to the review authors, "The studies were unanimous in concluding that self-examination of testicles is the best way to iden- tify a possible event of testicular cancer" (p. 270).	

CL-confidence interval; df-degrees of freedom; NR-not reported; OR-odds ratio; Q1—What are men's knowledge, awareness, and attitude toward TC?; Q2—What are men's knowledge, awareness, attitude, and practice of TC screening?, Q3—What are men's barriers and facilitators to TC and TC screening knowledge, awareness, attitude, and practice?; TC-testicular cancer; TSE-testicular self-examination

# **Appendix 2.2** The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher *et al.* 2009)

# PRISMA 2009 Checklist

			5
Section/topic	#	Checklist item	Reporter on page
TITLE			
Title	-	Identify the report as a systematic review, meta-analysis, or both.	
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	
INTRODUCTION			
Rationale	က	Describe the rationale for the review in the context of what is already known.	
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	
Eligibility criteria	9	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	
Search	œ	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	
Study selection	6	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	
Synthesis of results	41	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., 1²) for each meta-analysis.	

# PRISMA 2009 Checklist



Section/topic	#	Checklist item o	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	
Study characteristics	28	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	

From: Moher D, Liberati A, Teizlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097.

For more information, visit: www.prisma-statement.org.

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**Appendix 2.3** Promoting Testicular Cancer Awareness and Screening: A Systematic Review of Interventions (Saab *et al.* 2016b)<sup>2</sup>

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# Promoting Testicular Cancer Awareness and Screening

A Systematic Review of Interventions

### KEY WORDS

Awareness
Intentions
Interventions
Knowledge
Screening
Self-examination
Systematic review
Testicular cancer

Background: Testicular cancer (TC) is a relatively curable malignancy that predominantly affects young males. Key decision makers discourage TC screening because of lack of evidence about the benefits of this practice, whereas others argue that men must be aware of normal versus abnormal testicular findings. Despite the debate on TC surveillance, a number of research efforts are still being made to increase men's awareness of TC and its screening. Objective: The aim of this study was to systematically review studies that were conducted to enhance men's knowledge and awareness regarding TC and its screening and increase their TC screening intentions and practices. Methods: Studies published in English between 2004 and 2014 were reviewed using 3 e-databases, and interventions that were in line with the review aims were selected. Results: A total of 3076 records were screened for eligibility, and 11 studies met the inclusion criteria. The majority of the reviewed interventions successfully enhanced men's awareness of TC and its screening and increased their intentions to perform testicular self-examination. Examples include videos about TC, shower gel sachets, stickers, and posters, a television show, a university campaign, and high self-efficacy messages about TC screening. Men at risk of health disparities were underrepresented in the reviewed literature. Conclusions: A number of interesting channels through which men can learn about TC were identified. Examples include social media and mass media. Implications for Practice: Given the controversy that surrounds TC screening, nurses can play a key role in increasing men's awareness of TC rather than advising periodical TC self-examination.

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ancer remains one of the leading causes of mortality and morbidity worldwide. It is expected that cancer cases will increase from 14 million in the year 2012 to 22 million in 20 years' time. A number of malignancies can be prevented by means of screening; an example is testicular cancer (TC), a rare and relatively curable malignancy that predominantly affects men aged 20 to 34 years. Testicular cancer constitutes 0.5% of new cancer cases and is expected to affect 8430 men in the United States in the year 2015.

Orchiectomy remains the primary treatment modality for TC and is often followed by chemotherapy and/or radiation therapy, depending on the staging of the disease.3 Given the high curability of TC, survivors are expected to face a number of problems secondary to their illness, its treatment, or both. 4 Although TC survivors' quality of life is comparable to that of healthy males, there is evidence that men who receive aggressive treatment suffer from a number of physical and psychosocial complications.<sup>5</sup> For instance, chemotherapy and radiotherapy are known to cause chronic fatigue, peripheral neuropathy, ototoxicity, Raynaud-like phenomena, and reduction in gonadal function. <sup>5,6</sup> From a psychosocial standpoint, men who receive aggressive treatment for TC are at a high risk of body image disturbance, decreased sexual desire, and impaired sense of masculinity. 4,7 Both the physical and psychosocial sequelae of TC and its treatment highlight the importance of awareness and early detection of this rather curable malignancy.

Controversy surrounds screening for cancer of the testes in healthy males.  $^{8-10}$  Key decision makers such as the US Preventive Services Task Force and the National Cancer Institute discourage TC screening because of lack of evidence about the benefits of this practice and its effect on reducing mortality. 10-12 For instance, the National Cancer Institute believes that TC screening would result in unnecessary diagnostic tests and that screening for TC would not reduce mortality "in part because therapy at each stage is so effective." Furthermore, the US Preventive Services Task Force issued a statement about the harms of false-positive results on the man's well-being.11 Others, however, argue that TC screening should be part of cancer-related medical check-ups and that men must be aware of normal versus pathologic testicular findings and must be encouraged to perform routine testicular self-examination (TSE). <sup>13–16</sup> In the literature on TC, men were found to be unaware of TC and its screening; however, they expressed their willingness to learn about TC and to practice TSE if instructed. 17-22

Despite the debate on TC surveillance, a number of organizations still fund TC educational programs, and TC awareness is being addressed by clinicians, in colleges, and in the mass media. <sup>23–28</sup> Moreover, research efforts continue to explore men's TC awareness, enhance their knowledge of the various aspects of this malignancy, and increase their TC screening practices. Heretofore, to the authors' knowledge, no systematic reviews have been conducted to critically appraise findings from recent studies that aimed at increasing TC awareness and screening. Therefore, the aim of this article is to systematically review studies that were conducted to enhance men's knowledge and awareness regarding TC and its screening and increase their TC screening intentions and practices. The specific research questions that guided this

review were as follows: What are men's (i) knowledge, awareness, and attitude toward TC; (ii) knowledge, awareness, and attitude toward TC screening; (iii) TC screening intentions; and (iv) TC screening practices?

### Methods

A systematic review is a thorough and rigorous scientific method that pools studies and aggregates their findings under specific aims and research questions. Systematic reviews are widely used to guide research and practice. <sup>29</sup> A number of standardized checklists that guide the write-up of a systematic review exist. The PRISMA-P (Preferred Reporting Items for Systematic Reviews and Meta-analysis Protocols) checklist was used in this review. <sup>30</sup> Data from the reviewed studies were extracted using a standardized extraction matrix, <sup>17,31</sup> and the quality of the reviewed articles was appraised using the Quality Assessment Tool (QAT). <sup>32</sup> The quality of evidence considering the review outcomes was assessed using the GRADE (Grading of Recommendations Assessment, Development, and Evaluation) tool, <sup>33</sup> and the review was rated as level C based on the American Association of Critical Care Nurses' hierarchy of evidence. <sup>34</sup>

### Eligibility Criteria

The included studies were published in English between 2004 and November 2014 and comprised findings from men only. Records published in other languages were excluded as their quality could not be assessed. Although there is no well-accepted rule with regard to selecting publications by date, the currency and recency of scientific articles that are more than 10 years old are often questionable. <sup>35,36</sup> All the included records were intervention studies that aimed at increasing men's TC knowledge and awareness, enhancing their attitudes toward TC, and/or improving their TC screening intentions and practices. "TC screening" was considered to include either TSE, TC examination by a clinician, or both.

### Information Sources and Search Strategy

The search was limited to 3 electronic databases, namely, MEDLINE, CINAHL, and EMBASE. The reference lists of the included records were checked for intervention studies that were potentially appropriate for inclusion and that could not be identified during the database search. The literature was systematically searched between September and November 2014. Boolean operators "AND" and "OR," truncation, and MeSH (Medical Subject Headings) were used. The "Explode" and "Major Concept" features were selected to identify a wider range of articles that were potentially pertinent to the review questions; subsequently, the following search history was generated: (cancer\* OR tumor\* OR tumour\* OR malignan\* OR neoplas\*) AND (testicul\* OR testes OR testis OR testicle\*) AND (self-exam\* OR "self exam\* OR screening OR "early detection" OR awareness OR knowledge OR attitudes OR practice OR "health promotion" OR symptoms).

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No limits other than English language and year of publication were used during the literature search.

### **Data Extraction**

All records were exported to and pooled in a software for research and reference management (EndNode X7). Duplicates were deleted and the remaining records were screened on title and abstract, and unrelated articles were segregated. Articles that were potentially appropriate for inclusion were read. Studies that were deemed eligible for inclusion were sorted chronologically.

Data from the included studies were extracted by the primary reviewer using a standardized form. <sup>17,31</sup> Data extracted included the source citation, the country and setting where the reviewed interventions took place, the sample characteristics, the study design and theoretical underpinning, the data collection process, and the results (Table 1). Findings were sorted according to the following review questions: What are the men's knowledge, awareness, and attitude toward TC; knowledge, awareness, attitude, toward TC screening; TC screening intentions; and TC screening practices? The extraction form was independently cross-checked by a second reviewer to ensure accuracy of findings and minimize mathematical and statistical errors.

### Quality Appraisal

The valid and reliable QAT developed by the Effective Public Health Practice Project was used to evaluate the quality of the reviewed interventions (Table 1).  $^{32}$  This tool is extensively used in systematic reviews and recommended by the Cochrane Review Group as one of the best tools to appraise the quality of health promotion studies.  $^{37}$  In this review, the quality of the studies was appraised as weak (n = 6),  $^{25,28,38-41}$  moderate (n = 4),  $^{27,42-44}$  and strong (n = 1).  $^{26}$  The majority of the studies that were considered weak did not use probability sampling and/or did not address blinding of the outcome assessor.

### Level of Evidence Assessment

Because the majority of the studies scored low on the QAT, the GRADE tool was utilized to assess the level of evidence considering the review outcomes (Table 2).33 This step is essential in systematic reviews, as failure to do so often yields inaccurate recommendations. In this review, the quality of the evidence was assessed in terms of methodological limitations, heterogeneity and/or inconsistency of findings, indirectness of evidence, imprecision of results, and publication bias.<sup>33</sup> The quality of evidence was found to be very low with regard to TC awareness and low in terms of TSE awareness, intentions, and practices. This was attributed to major methodological limitations, as well as imprecision in the results. For instance, none of the reviewed studies addressed blinding of the outcome assessor. In addition, the effectiveness of the reviewed interventions was assessed using researcher-designed questionnaires that were neither valid nor reliable. As for imprecision, a number of studies had a small sample size whereby participants were purposely selected and exposed to very few research events. 45

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### ■ Results

### **Data Selection**

The database search yielded 3076 records (Figure). Following deletion of duplicates, 1731 records were independently screened by the primary reviewer and a second reviewer. Agreement between the 2 reviewers was found to be satisfactory ( $\kappa$  coefficient = 0.77).<sup>37</sup> Eleven studies were deemed eligible for inclusion. No studies that met the review inclusion criteria were identified during reference list checks.

### Characteristics of the Included Studies

The reviewed interventions were conducted in the United States (n=5),  $^{27,28,38,39,42}$  the United Kingdom (n=4),  $^{26,40,43,44}$  France (n = 1),25 and Pakistan (n = 1).41 Most of the data were collected from university students (n = 5).  $^{26-28,40,44}$  The sample size ranged from 74 subjects 44 to 874 subjects, 43 and participants' ages ranged between 15 years 43 and 86 years. 38 A pretest-posttest research design was used in the majority of the reviewed studies (n = 6),  $^{25,27,38,39,41,43}$  followed by posttest-only research design (n = 2),  $^{28,42}$  randomized controlled design (n = 2),  $^{26,40}$  and randomized factorial design (n = 1).44 Of the reviewed studies, 6 were underpinned by theories, namely, the Extended Parallel Process Model,<sup>26</sup> the Standard Model of Health Communication,<sup>2</sup> the Theory of Reasoned Action, <sup>28</sup> Implementation Intentions, <sup>40</sup> the Health Belief Model, <sup>42</sup> and Rogers Protection Motivation Theory. 44 Researchers used a number of interventions to increase TC awareness, TC screening knowledge, intentions, and/or practice. These interventions included self-reflection questionnaires and briefing sessions<sup>25</sup>; information about TC and TSE<sup>26</sup>; a university campaign using social media, print messages, TC events, videos, and mass media 27; "mass-mediated" information delivery28; a video about TC using the American Sign Language 38,39; implementation of intentions 40; educational and awareness sessions, symposia, lectures, and hands-on practice<sup>41</sup>; printed educational material about TSE, a shower card, and a peer-taught video<sup>42</sup>; shower gel sachets with TSE instructions, waterproof stickers, and posters<sup>43</sup>; and persuasive messages about TC and TSE.<sup>44</sup> Given the use of different interventional approaches and outcome measurements, it was not possible to conduct a meta-analysis; therefore, a narrative synthesis is presented.

### **Awareness of Testicular Cancer**

Of the reviewed studies, 10 addressed awareness of the different aspects of TC.  $^{25-28,38-40,42-44}$ At baseline, knowledge of TC risk factors ranged from 7.75% (n = 31), $^{25}$  47.5% (n = 48), $^{38}$  to 50.6% (n = 80). $^{40}$  The majority of the interventions that were tailored to increase TC awareness were successful in doing so. For instance, following exposure to a video about TC, TC knowledge increased from 47.5% (n = 48) pretest to 93.1% (n = 94) immediately after the video and remained significantly higher (84.2%, n = 80, P< .05) 2 months later. $^{38}$  Likewise, men who were provided with shower gel sachets, stickers, and posters about TC scored significantly higher on questions that assessed TC

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	Quality Appraisal <sup>d</sup>	Weak	Weak	
	Q4	T2: 65.2% (n = 30) of EG performed TSE compared with 40% in CG (n = 12) ( $\chi^2 = 4.61$ , P < .05)	Ä	
50	03	T2: no difference T2: 65.2% between EG (n = 30) and CG in performeterms of compared intentions to perform TSE (n = 12) (nor statistically (x² = 4.6 significant) P < .05)	T2: EG had a greater intention to perform TSE $(R^2 = 0.01, P < .001)$	
Findings	00	T1: 46.8%  (n = 74) were not aware that most abnormalities are found during TSE	T2: EG had greater knowledge (P < .001) and a more positive attitude (P < .001) toward TSE	
	Ø	T1: on a scale of 0-9, 50.6% (n = 80) scored <3 on items related to TC causes and outcomes (mean, 3.62), 92.2% (n = 147) did not know that TC is more prevalent among whites	T2: on a scale of 0-10, EG had higher knowledge scores about TC (mean, 5.7) han the CG (mean, 5.2) (P < .001)	
	Data Collection <sup>b</sup>	T1: CG: questionnaire and pamphlet EG: questionnaire, pamphlet, and an item asking where and when they plan to perform TSE. T2 (after 3 wk) CG and EG: questionnaire on whether they	performed TSE and whether they intend to do so Economic data: NR Intervention: EG wardred a show that featured a celebrity discussing TC and TSE.  CG did not watch the show. T2 (after 4-6 mo): a phone survey with both groups	Economic data: NR
Design and	Theoretical Underpinning	Prospective randomized control design using Implementation Intentions	Quasi-experimental design using the Theory of Reasoned Action	
10	Study Population <sup>a</sup>	T1: n = 159 (EG n = 93, CG n = 60) T2: n = 76 (EG n = 46, CG n = 30) 20.6 (3.4) y, 18–35 y	n = 524 (EG n = 165, CG n = 359) 21.2 y, NR	
	Country and Setting	UK University	USA University	
	Reference (Year)	Sreadman and Quine 40 (2004)	Trumbo <sup>28</sup> (2004)	

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	Q4 Appraisal <sup>d</sup>	NR Weak	T1: No Moderate difference in TSE practice between EG and CG (P not reported) T2: EG scored higher than CG on TSE practice (P = .006)	TSE practices weak increased significantly from 2% (n = 1) at T1 to 26% (n = 15) at T2 (P < .001)
Findings <sup>c</sup>	Q2 Q3	ZN N	Z Z Z Z Z Z Z Z Z Z Z Z Z Z Z Z Z Z Z	TSE knowledge NR increased significantly from 4% (n = 3) at T1 to 72% (n = 41) at T2 (n > 700)
	Q	Knowledge TC risks such as age increased significantly from T1 (47.5%, n = 48) to T2 (93.1%, n = 94) up until T3 (84.2% n = 80) (P<.05) Knowledge of TC rearment increased significantly between T1 (73%, n = 73) and T2 (92%, n = 92) (P<.05)	T1: on a scale of 0-5, the EG and CG had similar TC knowledge (median score, 3) T2: EG scored significantly higher (median score, 4; P = .014)	Ϋ́Z
	Data Collection <sup>b</sup>	T1: survey about TC and prostate cancer Intervention: video about TC and prostate cancer filmed in the American Sign Language T2: survey immediately after the video T3: survey 2 mo after the video Economic data: NR	edge oof oof	T1: questionnaire about TSE knowledge and practice Interventions: lectures, discussions, role plays, poster presentations, pamphlets, booklets,
Design and	Ineoretical Underpinning	Pre and posttest survey design	Quasi-experimental, pre and posttest design	Pretest and posttest study design
-	Study Population <sup>a</sup>	n = 102 44.35 (17.39), 18–86 y	n = 874 (T1 n = 518, T2 n = 356) NR, 15-44 y	n = 127 Males (n = 57) 36.5 (11.9) y, NR
,	Country and Setting	USA Community settings for the deaf	UK 14 workplace and leisure sites	Pakistan Community
_	Keterence (Year)	Folkins et al <sup>38</sup> (2005)	McCullagh et al <sup>43</sup> (2005)	Shallwani et al <sup>41</sup> (2010)

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0.00	Quality Appraisal <sup>d</sup>	Moderate	
	Q4	T1: 58.6%  (n = 75) performed TSE in the past year and had their restes checked by a clinician T2: 75.7% (n = 56) reported performing TSE in the past month; those in the high-efficacy condition had higher odds of performing TSE (OR, 3.09)	
Sc	03	T2: men in the T1: 58.6% high self-efficacy (n = 75) group and high-vulnenbility TSE in t group intended past year to perform had their to perform TSE (P < .06) clinician perform TSE T2: 75.7% increased (n = 56) significantly in reported T2 (P < .0001) performin TSE in the month; the high-condition higher od performin TSE in the month; the high-condition high-cond	
Findings	02	T2: participants exposed to the high self-efficacy message perceived themselves as more capable of performing TSE (mean, 22.16) than those who read the low-self efficacy message (mean, 19.31) Attitude toward TSE increased significantly in T2 (P < .0001)	
	ō	T2: participants who read the low vulnerability information (mean, 19.31) and high severity condition information (mean, 19.34) perceived themselves to be more susceptible to TC than those who read the high vulnerability (mean, 16.3) and low severity information (mean, 16.27)	
Design and	Data Collection <sup>b</sup>	T2 (after 3 mo): questionnaire about TSE knowledge and practices Economic data: NR T1: survey about TSE, clinical testicular exam and TSE artitudes and intentions Intervention: participants assigned to 1 of 8 experimental groups that included different messages about TC and TSE, fact sheets recommending regular TSE, and testimony and photograph of a fictitious patient T2 (after 1 mo): participants e-mailed to assess their TSE practices	
Design and	Theoretical Underpinning	Between-participant 2 (vulnerability) × 2 (severity) × 2 (self-efficacy) randomized factorial design using the Rogers Protection Motivation Theory	
-	Study Population <sup>a</sup>	T1 and T2: n = 128 21.8 (3.87) y, 18-35 y T3: n = 74 21.93 (4.01) y, 18-34 y	
0000	Country and Setting	UK University	
*	Reference (Year)	Umeh and UK Chadwick <sup>44</sup> University (2010)	

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Collection <sup>b</sup> Q1  Part I:  stionnaire T1: 26.75%  gness to information about resticular TC, 7.75%  performed (n = 31) were obvisician educated about	_ Fa T T T T T T T T T T T T T T T T T T	Theoretical Underpinning Pretest and posttest I prospective study design	<b>►</b>	S 2 3 5 5 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6 6	Reference Country Study (Year) and Setting Population <sup>a</sup> Kedzierewicz France Part I: et al <sup>25</sup> Army n = 400 (2011) 31.3 y, 21–44 Part II: n = 360 NR
Par T T1	T T T		osp rudy	21–44 y	Parr I: n = 400 31.3 y, 21-44 y Parr II: n = 360 NR
ton gge scricice e e e o o o o o nr nned in	about degree of willingness to have testicular exam performed by a physician Part II: Short II: Short medical briefing (time NR) Economic data: NR	ш 0) ш			

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* Table 1	Characteristics	and Quality A	Appraisal of the R	* Table 1 • Characteristics and Quality Appraisal of the Reviewed Interventions, Continued	ons, Continued				
		-	Design and			Findings <sup>c</sup>			(
Reterence (Year)	Country and Setting	Country Study and Setting Population <sup>a</sup>	Theoretical Underpinning	Data Collection <sup>b</sup>	Ø	07	83	Q4	Quality Appraisal <sup>d</sup>
(2012)	University	n = 443 (EG1 Randomized n = 145, controlled EG2 n = 146, using the CG n = 152) Extended 24 y, 23–25 y Process M	kandomized controlled trial using the Extended Parallel Process Model	T1: TC knowledge T2: on a scale of and TSE practices drawledge scor the highest all groups assessed for knowledge scor Intervention: (mean, 8.9; CI, EG1: TC facts and tSE advice asverity of TC (CG: no intervention postintervention questionnaire T3 (5-7 d after T2): measure of TSE intentions  Economic data: NR Spielberger State Trait Anxiety Inventory, The Breast Cancer Fear Scale, and Threat and Efficacy Perceptions measured at each time	T2: on a scale of 0–10, EG2 had the highest knowledge scores (mean, 8.9, CI, 8.3–9.14) and the lowest perceived severity of TC (P = .007)	T2: EG2 had the highest TSE response efficacy (mean, 6.34; CI, 6.19–6.49; <i>P</i> = 0.03) and TSE self-efficacy (mean, 6.24; CI, 6.06–6.42; <i>P</i> = .004)  EG2 reported significantly greater learning from the message ( <i>P</i> = .004)	EG2 had the greatest intentions to perform TSE at T2 (P = .002) and T3 (P = .011)	₩ ₩	Strong
									(continues)

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ı _	Design and	esign
etical inning Data Collection <sup>b</sup>	Theoretical Underpinning [	
ly design Intervention: e Health EG1: Printed educational nnt shower card about TSE EG2: shower card about TSE about TSE about TSE con intervention T2 (time NR): the Health Beliefs Survey for TC and TSE ECOnomic data: NR	= 92 Postest only design Int EG2 n = 27, using the Health EG CG n = 21, Belief Model CG n = 44) instrument 18-34 y EG CC CC T72	
survey on TC Intervention: general and TC education chapters of a video T2 (immediately after the video): knowledge survey on TC Economic data: NR	Deaf young design survadulum males, design lntervadulum males, egen capa 25.75 egen c5.56) y, NR Hearing n = 90 aftre design n	

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	93	Quality Appraisal <sup>d</sup>	Moderate
	83	Q4	EG: compared Moderate with T1, there was a significant increase in monthly TSE (P < .001) T2: EG was more likely to perform TSE than the CG (P < .001)
	Findings	Q3	EG: intention to perform TSE within a month increased significantly from T1 to T2 (P < .001) as compared with CG
	1	Q2	<del>ž</del>
lions, Continued	83	O I	EG: TC awareness increased significantly from T1 to T2 (P < .001) T2: TC awareness in EG was higher than CG (P < .001) T2: Significant increase in awareness among EG (P < .001)
* Table 1 • Characteristics and Quality Appraisal of the Reviewed Interventions, Continued		Data Collection <sup>b</sup>	T1 and T2 (after 2 wk): Knowledge, awareness, behavior and intentions in regard to TC assessed using the same tool Intervention: EG: exposed to Information disseminated across campus during TC events + messages about TC and TSE CG: not exposed to the campaign Economic data: description of the campaign
uality Appraisal of	Design and	Theoretical Underpinning	Pretest-posttest and posttest-only pre-experimental design using the Standard Model of Health Communication
ristics and Q	2.5	Study Population <sup>a</sup>	n = 272 (EG = 220, CG = 52) NR, NR
1 • Characte		Country and Setting	USA University
米 Table		Reference (Year)	Wanzer et al <sup>27</sup> (2014)

Abbreviations: CG, control group; CI, confidence interval; EG, experimental group; M, mean; NR, not reported; NS, not significant; OR, odds ratio; T1, time 1; T2, time 2; T3, time 3; TC, testicular cancer; TSE, testicular self-examination.

\*Sample size (n); mean age (SD) in years, age range in years; gender: males unless otherwise reported.

\*Data collected using researcher-designed questionnaires unless otherwise reported.

\*What are the men's (Q1) knowledge, awareness, and attitude toward TC; (Q2) knowledge, awareness, attitude, toward TC screening; (Q3) TC screening intentions; (Q4) TC screening practices.

\*Quality appraisal of the interventions using the Quality Assessment Tool (QAT) for quantitative studies.

\*Accordance of the interventions using the Quality Assessment Tool (QAT) for quantitative studies.

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Outcomes	No. of Participants (No. of Studies)	Risk of Bias	Inconsistency	Indirectness	Imprecision	Publication Bias	Overall Quality (GRADE)
TC awareness	3046 (10)	Yes	No	No	Yes	Yes	+OOO, Very low
TSE awareness	1750 (7)	Yes	No	No	Yes	No	++OO, Low
TSE intentions	1803 (6)	Yes	No	No	Yes	No	++OO, Low
TSE practices	1929 (7)	Yes	No	No	Yes	No	++OO, Low

Abbreviations: GRADE, Grading of Recommendations Assessment, Development, and Evaluation; TC, testicular cancer; TSE, testicular self-examination.

knowledge in comparison to men in the control group (P = .014). Similarly, TC knowledge scores were significantly higher among men who received information about TC and TSE as compared with those who received information about TC only and those who did not receive any information (P = .007). Following exposure to a university campaign about TC and TSE, students scored higher posttest as compared with pretest (P < .001) and had significantly higher TC knowledge scores than did the control group (P < .001). It is worth noting that racial, ethnic, socioeconomic, geographical, and sexual disparities were not addressed in the reviewed literature.

# **Testicular Cancer Screening Awareness**

Knowledge about TC screening was addressed in 7 interventions.  $^{25,26,28,40-42,44}$  Knowledge of TSE across the reviewed interventions was as low as 4% (n = 3) $^{41}$  and did not exceed 53.2% (n = 83).  $^{40}$  This was mainly due to lack of education about this practice. University students who watched a television show about TSE reported significantly higher TSE knowledge scores (P<.001)

and had a more positive attitude toward TSE (P < .01) in comparison to those who did not watch the show. <sup>28</sup> A series of interventions including lectures, discussions, role plays, and presentations were successful in increasing men's knowledge of TSE from 4% (n = 3) pretest to 72% (n = 41) at 4 months following the interventions (P < .001). <sup>41</sup> In another study, high self-efficacy messages enabled men to feel more capable of performing TSE and improved their attitude toward this practice as compared with men who got exposed to low self-efficacy messages (P < .0001). <sup>44</sup> Similarly, on a scale of 0 to 10, men who were exposed to messages about TC and TSE had higher TSE self-efficacy (mean, 5.24; confidence interval, 6.06–6.42; P = .004) and learned the most about TSE (P = .004) in comparison to those who were exposed to information about TC only and those who were not exposed to any messages. <sup>26</sup> Only 1 study was conducted in a developing country. <sup>41</sup>

# **Testicular Cancer Screening Intentions**

Intention to perform TSE was addressed in 6 studies. <sup>25–28,40,44</sup> With the exception of 1 study, <sup>40</sup> the reviewed interventions were

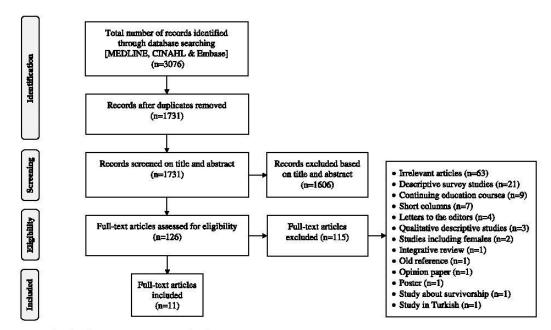


Figure ■ Study Identification, Screening, and Selection Process.

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successful in increasing men's intentions to perform TSE. For instance, TC screening intentions increased among men who were exposed to TC facts and TSE advice (P = .002), <sup>26</sup> took part of a TC campaign (P < .001), <sup>27</sup> and watched a show about TSE (P < .001), <sup>28</sup> as well as those who were provided with a number of messages about TSE (P < .0001). <sup>44</sup>

### **Testicular Cancer Screening Practices**

Implementation of interventions (n = 7) led to a statistically significant increase in TC screening practices among participants. 25,27,40-43 For example, men who were provided with information about TSE using shower gel sachets, posters, and stickers scored higher on TSE practice in comparison to men who were not exposed to TSE information (P = .006). Similarly, an increase in TSE practices from 2% (n = 1) pretest to 26% (n = 15) posttest was seen among men who were exposed to a number of TSE interventions (ie, lectures, discussions, role plays, and so on).41 Although small, this change was found to be significant (P < .001). Moreover, men who were exposed to high selfefficacy messages were found to have the highest odds of performing TSE (odds ratio, 3.09).44 Likewise, participants who took part in a series of TC and TSE activities had a significant increase in their TSE practices (P < .001) and were more likely to perform TSE in comparison to those who were not involved in the activities ( $P \le .001$ ). Only 1 study addressed TC screening by a clinician.<sup>25</sup> Following a physician-led briefing session, 31.4% (n = 16) of those who declined TC examination earlier (n = 51) agreed to have their testes examined. With the exception of 1 study, 41 TC screening practices were not addressed in developing countries. Moreover, there was no mention of health disparities in the reviewed studies.

# ■ Discussion

A deficit in TC knowledge was seen at baseline in a number of studies. However, the majority of interventions that aimed at increasing TC knowledge were successful in doing so. <sup>27,40,43</sup> Men's knowledge of TC risk factors was addressed the most. <sup>28,40,42</sup> The remaining studies focused on general TC knowledge rather than knowledge of particular aspects of this malignancy, namely, its signs and symptoms, prognosis, and treatment. Interventions that succeeded in increasing TC knowledge included information about TC and TSE, <sup>26</sup> a university campaign that aimed at raising awareness about TC and its screening. <sup>27</sup> a video about TC, <sup>38</sup> and shower gel sachets, stickers, and posters about TC and TSE. <sup>43</sup> Overall, limited details were provided regarding the intervention content and the use of underpinning theory. There is evidence, however, that interventions that are guided by a theory have greater efficacy than interventions that lack a theoretical basis. <sup>46</sup>

Lack of education was perceived as the main reason why men did not know about TC screening. <sup>40</sup> Fortunately, interventions that aimed at educating men about TSE were successful in enhancing their knowledge about this practice. Interventions were also successful in increasing their intentions to perform TSE. Examples include exposure to information about TC and TSE<sup>26</sup>; a

television show that featured a celebrity who survived TC<sup>28</sup>; lectures, discussions, role plays, and presentations about TSE<sup>41</sup>; and exposure to high self-efficacy messages about TC and TSE. Testicular cancer screening practices also increased following various interventions including physician-led briefing sessions<sup>25</sup>; a series of TC and TSE activities<sup>27</sup>; questions about the time and place where participants plan on performing TSE<sup>40</sup>; exposure to lectures, discussions, and role plays featuring TSE<sup>41</sup>; information about TSE using shower gel sachets, posters, and stickers<sup>43</sup>; and high self-efficacy information.

Developing countries were poorly represented in the eligible studies as only 1 intervention was from a developing country. Findings from this intervention reflect the overall situation with regard to cancer screening in the developing world. In Iran, for instance, breast cancer is diagnosed at an advanced stage; this was attributed to the absence of formal screening programs.<sup>47</sup> Similarly, despite clear evidence that breast cancer screening would help reduce mortality among Indian women, no initiatives have been taken to develop a national screening program. 48 This was thought to be caused by conflicting healthcare priorities and economic circumstances. Another example is a population-based survey that was administered in 57 different developing countries to explore screening practices for cervical cancer. Coverage of screening for this malignancy was on average 19% and was as low as 1% in Bangladesh as compared with 63% in developed countries. 49 Alarmingly, women who were at the highest risk of developing cervical cancer were least likely to undergo screening. These findings were attributed to the absence of adequate healthcare infrastructure and the limited access to health services in the developing world. Culture is also known to affect cancer screening and is at times perceived as the prime cause of health inequities.<sup>50</sup> For instance, in a survey that explored Chinese American women's colon cancer screening practices, it was found that older women with a strong Eastern cultural background were least likely to get screened.<sup>51</sup> Straughan and Seow<sup>52</sup> and Yu et al<sup>53</sup> explained this finding in terms of the traditional Eastern culture whereby individuals put a great emphasis on traditional Chinese medicine and often believe that cancer is inevitable and incurable.

Findings from the aforementioned studies can be transferred to the TC context. For instance, men in developing countries have certain misconceptions about TC that hinder screening for this malignancy. <sup>17</sup> Lebanese men, for example, perceived TC as a life-threatening illness. <sup>4</sup> Moreover, compared with men living in the West, Eastern and African men were found to be least knowledgeable about TC and TSE, which was attributed to the lack of national cancer screening initiatives and lack of public awareness with regard to TC screening. <sup>22,54–59</sup>

Overall, the reviewed interventions were effective in enhancing men's knowledge of TC and its screening, improving their intentions to perform and/or undergo screening, and increasing their screening practices. These findings, however, are presented from men living in developed countries, with the majority being university students. <sup>26–28,40,44</sup> Only 1 study was conducted in the developing world in a community setting. <sup>41</sup> Despite addressing TC knowledge among deaf men, <sup>38,39</sup> none of the reviewed interventions included racial, ethnic, socioeconomic, geographical, religious, and sexual and gender minorities, <sup>60</sup> which impedes the generalizability

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of the findings and the applicability of the interventions to minority groups who are at a high risk of health disparities.<sup>61</sup>

#### Limitations of the Reviewed Studies

Methodologically, the reviewed interventions have a number of limitations that are worthy of discussion. For instance, researchers used different questionnaires to collect data and provided little information about the reliability and validity of their tools. In addition, a number of interventional approaches were used to measure different outcomes that made it impossible to conduct a meta-analysis. Very few researchers reported on how their interventions were tailored and whether they were piloted. Furthermore, very few studies addressed the informational needs of men prior to designing and implementing the interventions, and a number of studies had a high attrition rate. For instance, Brown et al<sup>42</sup> had to change their study design from pretest and posttest to posttest only because of the large number of dropouts. Moreover, some of the pretest and posttest design studies had a significantly smaller number of participants during posttest, and only 2 studies reported on the long-term effects of their interventions.<sup>26,38</sup> Despite improving men's awareness of TC and TSE and increasing their TSE intentions and practices, the quality of the majority of the interventions and the quality of evidence per review outcome were found to be low, which negatively affects the recommendations made in the reviewed studies.

# Limitations of the Systematic Review

Rigor was sought during the review process through the use of the PRISMA-P checklist.<sup>30</sup> Moreover, to the authors' knowledge, no previous systematic reviews were conducted to pool, analyze, and critically appraise findings from recent interventions designed to improve knowledge about TC and its screening and to increase TC screening intentions and practices. Critical appraisal of this review, however, yielded a number of limitations that are worth discussing. First, the evidence presented within this review cannot be rated as high using the American Association of Critical-Care Nurses' hierarchy of evidence (level C evidence).34 Second, selection bias could have taken place because of a number of methodological limitations. For instance, only 3 databases were used during the search process, studies from the gray literature were not sought, and the search was limited to studies published in English between the year 2004 and 2014. Moreover, the search strategy was developed to be as comprehensive as possible, which limited its sensitivity and specificity and yielded a large number of hits that were reviewed separately by 2 authors. Third, reporting bias could have taken place because only findings that serve the aim of the review and answer the review questions were extracted and discussed. This could have led to missing valuable data. For instance, the effect of the intervention by Shallwani et al<sup>41</sup> on female participants was not extracted because findings were originally sought from males only. Fourth, one of the reviewers had to calculate some descriptive statistics that were not explicit in the reviewed studies. This could have led to mathematical errors and consequently faulty data. A second reviewer, however, cross-checked the statistics separately in order to minimize these errors. Finally, the quality of evidence was assessed based on the review outcomes; therefore, the quality scores could have been different if other outcomes had been considered. In addition, given the heterogeneity of the research tools, times of measurement, and research designs, it was not possible to conduct comparative analyses and to pool data from the reviewed interventions using a summary of findings table.

# **Implications for Future Research**

Minority groups were underrepresented in the reviewed literature, which hinders the generalizability of findings and limits their applicability to individuals who are at risk of health disparities. <sup>61</sup> For this reason, researchers should be urged to create interventions that are tailored to fit the needs of minority groups, bearing in mind the individual variations within each group. Examples are the studies conducted by Folkins et al<sup>38</sup> and Sacks et al,<sup>39</sup> whereby videos recorded using the *American Sign Language* succeeded in increasing the deaf men's TC knowledge. Moreover, the majority of the reviewed interventions were conducted in universities and included relatively educated men, which informs the need to include men with low educational and/or socioeconomic background in future research.

It is worth considering the informational needs and the preferred intervention format suited for men prior to designing and implementing interventions. Given the age group at risk of TC, social media and mass media may serve as potentially interesting channels through which men can learn about TC and its screening. From a methodological perspective, random sampling should be encouraged to yield a representative sample and decrease the risk of selection bias. In addition, researchers should be encouraged to use valid and reliable tools to assess TC knowledge and screening practices and to utilize theoretical frameworks and models to underpin their interventions. 46 For instance, Wanzer et al 27 made good use of the elements of the Standard Model of Health Communication to tailor a number of TC events in colleges, designed to appeal to students. Moreover, behavioral change theories and intervention-based models can assist researchers in promoting awareness of TC and TSE; examples include the Health Belief Model, 62 the Theory of Reasoned Action, 63 the Theory of Planned Behaviour, 64 the Social Cognitive Theory, 65 the Self-determination Theory, <sup>66</sup> the Stages of Change Model, <sup>67</sup> the Precaution Adoption Process Model, <sup>68</sup> and the Tannahill Model. <sup>69</sup>

The findings from this review will enable researchers to plan, design, and test an intervention to raise awareness of TC and its screening. A mixed-methods research approach may be used for this purpose. First, researchers could interview clinicians about their clinical experiences and practices with regard to testicular examination and TC screening. Second, the general public and specific minority groups could be interviewed about their knowledge, attitudes, and TSE practices. To address the aforementioned gaps in the literature on TC, the educational needs and the preferred learning strategies of the general public and minority groups should be explored throughout the interview process. Finally, adopting the mixed-methods approach permits researchers to plan, design, pilot test, and implement a comprehensive intervention to raise awareness of TC among the public including individuals who

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are at risk of health inequities. Adopting this methodological approach necessitates the integration of 1 or more of the aforementioned behavioral change theories and intervention-based models.

# **Implications for Practice**

From a practical standpoint, lack of consensus regarding screening for cancer of the testes exists because of the absence of clear guidelines about this practice. For instance, in the United Kingdom, awareness of normal testicular findings is still recommended. <sup>14</sup> Moreover, in its cancer screening guidelines, the American Cancer Society still recommends TC examination by a clinician as part of the cancer-related check-ups. <sup>13</sup> The US Preventive Services Task Force, however, believes that TC screening might cause unnecessary anxiety and therefore discourages this practice. <sup>11</sup>

Given the controversy that surrounds TC screening, nurses involved in health promotion could learn from successful interventions to increase men's awareness of TC without necessarily promoting regular TSE. For instance, nurses could make good use of high self-efficacy messages to increase TC awareness and decrease the fear and anxiety associated with a cancer diagnosis while bearing in mind the specific needs of minority groups. Nurses could also educate young men about signs and symptoms of testicular disorders and encourage them to seek medical help in the event of testicular abnormalities.

#### Conclusion

In this systematic review, data were extracted from studies conducted to enhance men's knowledge and awareness regarding TC and its screening and increase their TSE intentions and practices. The quality of the majority of the reviewed interventions and the quality of evidence per research outcome were found to below. Overall, participants were uninformed about TC screening. Lack of education about this practice has led to decreased TC screening intentions and practices. Fortunately, the majority of the reviewed interventions succeeded in increasing men's awareness of TC and TSE and in enhancing their intentions to undergo screening and perform TSE. Examples of interventions that succeeded in enhancing men's TC and TSE awareness include TC facts and TSE advice, <sup>26</sup> a university campaign, <sup>27</sup> information about TSE using shower gel sachets and waterproof stickers and posters, <sup>43</sup> and high self-efficacy messages. <sup>44</sup>

Men living in developing countries as well as individuals who are at risk of health disparities were underrepresented in the reviewed literature, which raises a number of questions with regard to the generalizability of findings and their applicability to different sociocultural contexts.

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# **Appendix 2.4** Males' Awareness of Benign Testicular Disorders: An Integrative Review (Saab *et al.* 2016a)

Article

# Males' Awareness of Benign Testicular Disorders: An Integrative Review

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#### Abstract

Disorders that affect the testes can range from painless and benign to debilitating and life threatening. Despite the availability of literature on the etiology, diagnosis, and treatment of benign testicular disorders (BTD), very little is known about men's awareness of these conditions. The aim of this review was to extract and analyze evidence from studies that explored males' awareness of BTD. Four e-databases (CINAHL, MEDLINE, PsychINFO, and PubMed) were thoroughly searched and four articles met the review inclusion criteria. The quality of the included studies was appraised and data were extracted and cross-checked using a standardized data extraction table. It was determined that participants lacked education about testicular self-examination and scrotal signs and symptoms which contributed to their lack of awareness of BTD. Help seeking in the event of scrotal abnormalities was suboptimal which is alarming given the acuteness of some BTD such as testicular torsion. Individuals who are at risk for health disparities were underrepresented in the reviewed literature. Findings from this review highlight the need to address barriers to BTD knowledge and help seeking. This could be achieved through making use of past interventions that succeeded in increasing men's awareness of testicular cancer such as university campaigns and mass media. From a practical standpoint, clinicians must be encouraged to educate young men about BTD. This could be attained through tailoring creative educational interventions that are sensitive to the needs of individuals who are at risk for health disparities.

#### Keywords

benign testicular disorders, awareness, knowledge, help seeking, males

# **Background and Aim**

# Overview

Disorders that affect the testes are numerous and can range from painless and benign to debilitating and malignant (Table 1; Wampler, 2010). Testicular torsion, infection, trauma, and tumor are frequently discussed in the literature on testicular disorders. Testicular cancer predominantly affects men aged 18 to 35 years. It constitutes 0.5% of all cancer cases and accounts for 0.1% of all cancer mortalities in the United States (National Cancer Institute, 2014). Testicular torsion, epididymo-orchitis, and trauma are benign conditions that constitute the acute scrotum, a medical emergency characterized by a sudden onset of scrotal pain, swelling, and redness (D'Andrea et al., 2013). Serious complications such as ischemia, necrosis, and sepsis can occur in testicular torsion (Gordhan & Sadeghi-Nejad, 2015). Epididymo-orchitis, a sexually transmitted infection, can cause a number of symptoms and can affect men's relationships with their partners (Trojian, Lishnak, & Heiman, 2009; Centers for Disease

Control and Prevention, 2015). Nonacute benign testicular disorders (BTD) can also affect the male's life. Varicocele, for instance, is known to be the prime cause of infertility among males attending fertility clinics (Khera & Lipshultz, 2008; Mohammed & Chinegwundoh, 2009).

# Review Significance and Aim

In the past two decades, numerous research efforts have been made to explore and improve males' awareness of testicular cancer and its screening. In addition, three systematic reviews have been conducted to pool and analyze findings from these studies in order to inform research, practice, and education (Rovito, Cavayero, & Harlin, 2015;

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Table 1. Characteristics of Various Testicular Disorders.

	Testicular cancer	Testicular torsion	Epididymitis/ orchitis	Cryptorchidism	Varicocele	Hydrocele	Spermatocele
Age of onset	18-35 Years	<25 Years	18-50 Years	Neonates	Adolescents and young adults	Neonates and rarely adults	Adults
Etiology	Unknown	Testicular cancer Trauma Cryptorchidism Horizontal lie of testes Large testicular volume	transmitted infections	Maternal factors Low birth weight Early birth Breech position Positive family history	Unknown	Unknown	Unknown
Signs and symptoms	Testicular mass	Pain (sudden) Oedema	Pain (insidious)	Asymptomatic	Asymptomatic	Asymptomatic	Asymptomatic
	Pain Gynecomastia	Nausea/vomiting Hard and tender nodule			Dull and aching sensation (rare)	Pain (if large)	Pain (if large)
Diagnosis	Mass on palpation and on unltrasound Elevated tumor markers	Absent cremasteric reflex Decreased circulation on Doppler and scintigraphy	Elevated white blood cell count Positive urinalysis and culture	Empty scrotum— Ultrasound and MRI to locate nonpalpable testes	Palpation of a "bag of worms" Blood pooling on color Doppler	Smooth scrotal mass that transluminates Ultrasound to confirm diagnosis	Smooth scrotal mass that transluminates Ultrasound to confirm diagnosis
Treatment	Orchiectomy and at times chemotherapy and/or radiation therapy	Surgery Manual detorsion (undesirable)	Antibiotics for bacterial infection Symptomatic treatment	Observation in infancy Surgery prepuberty	Observation Surgery if painful or affecting fertility	Observation Surgical resection if painful	Observation Surgical resection if painful
Complications	Metastasis	Ischemia Necrosis Sepsis	Sepsis Infertility	Infertility Testicular cancer risk	Infertility	Pain radiating to the back (if large)	Pain radiating to the back (if large)

Note. MRI = magnetic resonance imaging. Adapted from D'Andrea et al. (2013), Gordhan and Sadeghi-Nejad (2015), Khera and Lipshultz (2008), Lopez and Beasley (2012), Mohammed and Chinegwundoh (2009), Osifo and Osaigbovo (2008), Srinath (2013), Tracy, Steers, and Costabile (2008), Trojian et al. (2009), Wampler (2010).

Saab, Landers, & Hegarty, 2016a, 2016b). This is not the case when it comes to BTD. While a number of papers tackled the diagnosis, clinical presentation, and management of BTD (D'Andrea et al., 2013; Gordhan & Sadeghi-Nejad, 2015; Khera & Lipshultz, 2008; Lopez & Beasley, 2012; Mohammed & Chinegwundoh, 2009; Osifo & Osaigbovo, 2008; Srinath, 2013; Tracy, Steers, & Costabile, 2008; Trojian et al., 2009; Wampler, 2010), very few studies explored males' awareness of these conditions, no identified studies have been conducted to enhance males' knowledge of benign diseases of the testes, and, to the authors' knowledge, no reviews have been conducted to critically analyze evidence from studies on BTD. The aim of this review was to extract and analyze evidence from studies that explored males' awareness of BTD. The specific review questions are as follows: What are the males' (a) knowledge, awareness, and attitudes with regard to BTD and their screening and (b) their help-seeking behaviors in the event of abnormal scrotal findings?

#### Method

Integrative reviews enable researchers to summarize evidence, understand a particular clinical problem, identify

gaps in the literature, appraise the strength of evidence, and determine the need for future research (Russell, 2005). Theoretical literature, research literature, or both are often included in integrative reviews. The broad nature of this review methodology might hinder rigor and increase the risk for bias (Whittemore & Knafl, 2005). To enhance rigor and reduce bias, the method proposed by Whittemore (2005) and Whittemore and Knafl (2005) was used to guide the write-up of this review. First, the problem was identified and the significance of the review was highlighted. The literature was searched systematically according to specific eligibility criteria. Data from the included studies were then extracted and presented using a standardized extraction table (Goossens et al., 2014; Saab et al., 2016a, 2016b). There is no gold standard for appraising the quality of studies included in a review. Moreover, the choice of quality appraisal tools depends on the study design (Whittemore & Knafl, 2005). On this basis, the quality of the studies included in this review was appraised using a tool that evaluated the quality of cross-sectional studies in previous reviews (Davids & Roman, 2014; Louw, Morris, & Grimmer-Somers, 2007; Roman & Frantz, 2013; Saab et al., 2016b; Wong,

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Cheung, & Hart, 2008). Finally, findings from the included studies were discussed in line with relevant literature and recommendations for research, practice, and education were made accordingly.

#### Eligibility Criteria

Data were sought from records published between the year 1985 and 2015 in peer-reviewed academic journals. Quantitative and qualitative studies that assessed and/or explored men's knowledge of BTD as well as experimental studies that aimed at increasing men's awareness of these disorders were sought. Systematic reviews, integrative reviews, meta-analyses, and metasyntheses that addressed BTD awareness were also considered in the literature search. As the quality of non-English papers could not be assessed, the search was limited to studies published in or translated to English. Given the paucity of the literature on BTD, no limits other than language were applied during the literature search.

Studies that offered an overview of BTD, addressed testicular cancer awareness, and included men with preexisting testicular disorders were excluded based on the assumption that a prior diagnosis of one or more testicular conditions would affect knowledge scores. Assuming that women's awareness of BTD and their educational needs might differ from those of men, papers that presented findings from females were also excluded. Screening, diagnosis, and treatment guidelines as well as epidemiological studies and expert opinions were also omitted.

#### Information Sources and Search Strategy

Four e-databases (CINAHL, MEDLINE, PsychINFO, and PubMed) were systematically searched in July 2015 to identify studies that are in line with the review aim and questions. Keywords were combined using Boolean terms, medical subject headings, and truncation. Subheadings were also used to yield a wider search and the following search history was generated: (non-maligan\* OR benign OR mass OR lump OR pain OR hydrocele OR varicocele OR torsion OR epididymitis OR orchitis OR swelling OR inflamm\*) AND (testicul\* OR testes OR testis OR testicle\* OR scrot\*) AND (self-exam\* OR "self exam\*" OR screening OR "early detection" OR awareness OR knowledge OR attitude OR practice OR "health promotion" OR symptoms). In addition, the reference lists of potentially eligible studies were checked to find papers that could not be identified during e-database search.

# Screening and Extraction Process

All the records were exported to and pooled in a software for research and reference management, duplicates were then deleted. The title and abstract of the remaining records were screened separately by two reviewers and the full text of potentially relevant articles was read. Irrelevant articles were then excluded based on title and abstract. The reviewers' level of agreement was calculated using Cohen's kappa coefficient. A score of .89 was obtained and was interpreted as satisfactory (Higgins & Green, 2011).

A standardized table was used to extract data from the included studies (Goossens et al., 2014; Saab et al., 2016a, 2016b) and was later cross-checked for accuracy by another reviewer. Data extracted included the source citation, the study aim, and the country and setting where data were collected. The study population, design, and instruments were also presented. Findings that support the review questions were then extracted and the quality of the included studies was appraised.

#### Quality Appraisal

Quality appraisal of studies included in integrative reviews is thought to enhance rigor and reduce the risk for bias (Whittemore & Knafl, 2005). A tool that was developed to appraise the quality of cross-sectional studies in previous reviews was deemed appropriate to evaluate the quality of the studies included in this review (Davids & Roman, 2014; Louw et al., 2007; Roman & Frantz, 2013; Saab et al., 2016b; Wong et al., 2008).

The methodological quality of the included studies was appraised based on the representativeness of the sample, response rate, reliability and validity of the tools used to collect data, and whether a primary data source was used for data collection. The tool was then modified to match the findings from the reviewed studies with the review questions. A score was then calculated and the quality of the studies was ranked as either weak (0% to 33.9%), moderate (34% to 66.9%), or strong (67% to 100%).

# Results

Database search yielded 4,506 records (Figure 1). A large number of duplicates were deleted (n=2,831) since PubMed is an interface of MEDLINE (Motschall & Flack-Ytter, 2005). A total of 1,675 records were screened on title and abstract. Irrelevant articles were then excluded. Potentially relevant records (n=55) were read thoroughly. Only four articles were deemed eligible for inclusion. The remaining records (n=51) did not meet the review eligibility criteria either because they offered an overview of BTD (n=15), presented findings from studies on testicular cancer (n=6), or included findings from men with preexisting testicular disorders (n=6). Screening guidelines (n=5), diagnostic tests (n=4),

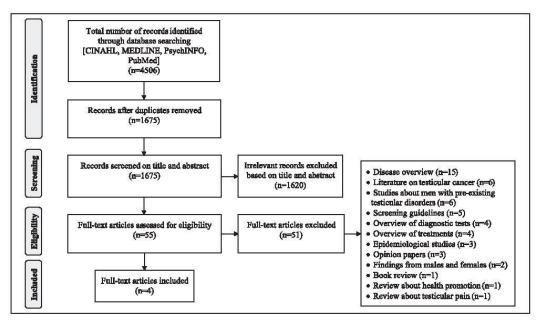


Figure 1. Record identification, screening, and selection.

treatment modalities (n = 4), epidemiological studies (n = 3), expert opinions (n = 3), and studies that presented findings from both males and females (n = 2) were also excluded. In addition, excluded records comprised one book review, one review about health promotion, and an overview of testicular pain. No intervention studies, qualitative studies, systematic reviews, meta-analyses, or metasyntheses were identified during literature search and none of the studies identified through reference list checks met the review inclusion criteria.

# Characteristics of the Reviewed Studies

Studies reviewed were conducted between the year 2000 and 2011 (Table 2). All but one (Babu, Hazra, Chhotray, & Satyanarayana, 2004) were conducted in the United States. Data were sought from schools (Congeni, Miller, & Bennett, 2005; Nasrallah, Nair, Congeni, Bennett, & McMahon, 2000), a community setting (Babu et al., 2004), and a university (Clark, JaNeille, & Gerry, 2011). All the studies were descriptive cross-sectional using researcher-designed questionnaires. Only one study reported having a qualitative element (Babu et al., 2004), data from this study, however, were collected using a researcher-administered questionnaire and findings were presented and discussed quantitatively. The sample size ranged between 318 (Nasrallah et al., 2000) and 755 (Congeni et al., 2005) and participants' ages ranged

between 12 years (Nasrallah et al., 2000) and above 51 years (Babu et al., 2004). Two of the reviewed studies addressed general awareness of testicular disorders (Congeni et al., 2005; Nasrallah et al., 2000), one addressed hydrocele awareness in an endemic area (Babu et al., 2004), and the fourth study explored young men's awareness of testicular torsion (Clark et al., 2011). In terms of quality appraisal (Table 3), scores ranged between 43% and 57%. No studies scored high on the quality appraisal tool. Sample representativeness was addressed in one study (Babu et al., 2004) and response rate was reported in another study (Clark et al., 2011). All data collection instruments were researcher-designed with no data on how the instruments were developed and whether they were pretested or pilot tested. The number of items per data collection instrument ranged between two (Clark et al., 2011) and five (Congeni et al., 2005; Nasrallah et al., 2000). Of the tools used to collect data, only one reported on reliability (Babu et al., 2004) and none reported on validity which makes it difficult to ascertain the consistency, dependability, and accuracy of findings (Sullivan, 2011).

#### Key Findings

Awareness of BTD. All the participants in the study by Nasrallah et al. (2000) and Congeni et al. (2005) were exposed to genital examination as part of sports-related

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Table 2. Characteristics of the Reviewed Studies.

Author(s) and		Country and				Findi	ings <sup>b</sup>
year year	Aim(s)	setting	Study population <sup>a</sup>	Design	Instruments	QI	Q2
Nasrallah et al. (2000) <sup>c</sup>	"Identify the level of knowledge about testicular health in adolescent male athletes"(p. 1115).	USA	n = 318	Descriptive cross- sectional survey		54% (n = 172) Understood why genital examination was part of sports physical examination  55% (n = 174) Correctly identified gear used to protect testes during sports	I 5% (n = 49) Would seek help in the event of testicular swelling within the correct time frame
		Schools	NR, I2 to I8 years			36% (n = 115) knew the at risk categories for testicular cancer	64% (n = 204) Would seek help in the even of testicular swelling and pain within the correct time frame
Babu et al. (2004)	"Report the knowledge and beliefs about filarial elephantiasis and hydrocele of people from an endemic area" (p. 121).	India	n = 749	Descriptive cross- sectional survey (n = 375) and face-to-face interviews (n = 36)		Of 375 men: 45.5% (n = 171) stated that mosquitoes can spread hydrocele; 69.9% (n = 262) stated that hydrocele was a problem in their community	
			Males (n = 375)			Of 257 men: 87% (n = 221) stated that a lot of people suffer from hydrocele; 35% (n = 89) believed that people with hydrocele cannot work	
		Community	NR, I7 to older than 51 years	Participants aged 31 to 50 years; belonging to "scheduled tribes, scheduled castes, and backward castes" (p. 123), with primary school education and no schooling were found to be least aware of hydrocele (p < .05)			

(continued)

Table 2. (continued)

Author(s) and		Country and				Findi	ings <sup>b</sup>
year	Aim(s)	setting	Study population <sup>a</sup>	Design	Instruments	QI	Q2
Congeni et al. (2005) <sup>c</sup>	"Assess young male athletes' understanding of the need for a genital examination during the sports physical, the signs and symptoms of serious testicular pathology, and the type of genital protection worn for specific sports" (p. 22).		n = 755	Descriptive cross- sectional survey	Researchers designed a (five-item) questionnaire	50% (n = 380) Understood why genital examination was part of sports physical examination	15% (n = 112) Would seek help in the event of testicular swelling within the correct time frame
						53% (n = 397) Correctly identified gear used to protect testes during sports	66% (n = 495) Would seek help in the event of testicular swelling and pain within the correct time frame
		Schools	NR, 12 to 25 years			38% (n = 285) Knew the at risk categories for testicular cancer	name
Clark et al. (2011)	"Examine an illustrative case and investigate the knowledge of freshman males regarding testicular torsion" (p. 35).	USA	n = 267	Descriptive cross- sectional survey	Researchers designed a (two-item) questionnaire	43% (n = 116) Were taught about the seriousness of testicular pain	48% (n = 110) Chose to go to the emergency room in the event of testicular pain
	(p. 99).	University	NR			18% (n = 48) Heard of testicular torsion 58% (n = 157) Were taught how to perform testicular self- examination	39% (n = 102) Chose to delay seeking help for a day or two

Note. NR = not reported.

aSample size (n); [mean age in years  $\pm$  standard deviation, age range in years]; gender: males unless otherwise reported. What are the males': (Q1) knowledge, awareness, and attitudes with regard to benign testicular disorders and their screening? (Q2) help-seeking behaviors in the event of abnormal scrotal findings? The sample in the study by Congeni et al. (2005) includes all the participants in the study by Nasrallah et al. (2000). The same tool was used for data collection in both studies.

checkup, yet only 54% (n = 172) and 50% (n = 380) understood the reason behind genital examination, respectively. With regard to hydrocele, 69.9% (n = 262) of men living in an endemic area in India were aware of the seriousness of hydrocele in their community, yet only 45.5% (n = 171) knew that this disease can be transmitted via mosquito bite (Babu et al., 2004). Awareness was

lowest among individuals belonging to "scheduled tribes, scheduled castes and backward castes" (Babu et al., 2004, p. 123) as well as men with primary education or no education. As for testicular torsion, only 18% (n = 48) of college students heard of this complication and 43% (n = 116) were instructed about the seriousness of scrotal pain (Clark et al., 2011).

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Table 3. Quality Assessment of the Reviewed Studies.

		Quality	assessment ite	ems			Relevance to cu	rrent review	W
References	Was the sample likely to be representative of the study population?	Was a response rate mentioned within the study?	Was the instrument used reliable?	Was the instrument used valid?	Was it a primary data source?	Were knowledge, awareness, and attitudes toward BTD and their screening assessed?	Were help-seeking behaviors in the event of abnormal testicular findings addressed?	Scorea	Quality ranking <sup>b</sup>
Nasrallah et al. (2000)	0	0	0	0	j	1	Ī	43%	Moderate
Babu et al. (2004)	Ľ	0	1	0	1	1	0	57%	Moderate
Congeni et al. (2005)	0	0	0	0	1	1	I	43%	Moderate
Clark et al. (2011)	0	1	0	0	1	T	Ť	57%	Moderate

Note. BTD = benign testicular disorders; 0 = no/not reported; 1 = yes.

aTotal score divided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by the total number of items multiplied by 100. Department of the provided by 100. Department 34% to 66.9%; Strong = 67% to 100%.

Help-Seeking Behaviors. Three of the reviewed studies addressed help seeking in the event of scrotal abnormalities (Clark et al., 2011; Congeni et al., 2005; Nasrallah et al., 2000). Only 15% (n = 49) of participants in the study by Nasrallah et al. (2000) and 15% (n = 112) of participants in the study by Congeni et al. (2005) would seek help in the event of testicular swelling. However, when asked about help seeking in the event of testicular swelling together with pain, 64% (n = 204) and 66%(n = 495) stated that they would seek medical attention. In contrast, less than half of the college students (48%, n = 110) in the study by Clark et al. (2011) chose to seek emergency care in the event of testicular pain and 39% (n = 102) chose to delay help seeking for a day or two.

### Discussion

Contrary to the literature on testicular cancer awareness, very little is known about males' knowledge of BTD. Only hydrocele and testicular torsion were addressed in the reviewed literature which leaves us with no data regarding males' awareness of other common testicular diseases such as epididymitis and varicocele.

Lack of awareness with regard to BTD (Babu et al., 2004; Clark et al., 2011; Congeni et al., 2005; Nasrallah et al., 2000) and delay in help seeking in the event of testicular swelling and/or pain (Clark et al., 2011; Congeni et al., 2005; Nasrallah et al., 2000) were the overarching findings across the reviewed studies. Furthermore, very few participants were instructed about testicular selfexamination and scrotal signs and symptoms which could have contributed to their lack of awareness with regard to BTD. These findings are echoed in the literature on testicular cancer awareness whereby participants' low knowledge scores were attributed to lack of education about this malignancy (Saab et al., 2016a, 2016b). Findings from the study by Babu et al. (2004) regarding lack of awareness of hydrocele reflect the overall knowledge deficit with regard to malignant testicular disorders in the developing world (Kuzgunbay et al., 2013; Muliira, Nalwanga, Muliira, & Nankinga, 2013; Onyiriuka & Imoebe, 2013; □zbaş, □avdar, Findik, & Akyüz, 2012; Sirin, Atan, & Tasci, 2006; Ugboma & Aburoma, 2011; Urgurlu et al., 2011).

Low knowledge of BTD was attributed to a number of factors namely the lack of public awareness with regard to health screening, the lack of health education in schools and colleges, and the lack of endorsement of health screening and disease prevention by legislators in the developing world (Kuzgunbay et al., 2013; Muliira et al., 2013; Ugboma & Aburoma, 2011).

As for help seeking, there is very little evidence with regard to this behavior in the event of abnormal scrotal findings. It was reported that help seeking is best in the event of testicular swelling together with pain and worst in the event of swelling alone (Congeni et al., 2005). This finding is alarming since, as previously discussed, the longer one delays seeking medical attention in the event of scrotal pain, the lower the chances to salvage the affected testicle. This is particularly important in cases such as testicular torsion (Gordhan & Sadeghi-Nejad, 2015; Ringdahl & Teague, 2006). Barriers and facilitators to help seeking were not explored in the reviewed studies and no correlations were made between participants awareness of BTD and help seeking. Drawing from studies on testicular cancer, however, one can assume that the

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more males are aware of BTD, the more likely they would seek medical attention in the event of abnormal scrotal findings (Casey, Grainger, & Butler, 2011). In the literature on testicular cancer, delay in seeking medical attention was attributed to fear from testicular cancer as well as lack of knowledge with regard to its screening (Cronholm, Mao, Nguyen, & Paris, 2009; Saab et al., 2016b). Testicular cancer patients in Australia who delayed help seeking lacked knowledge about this disorder, misinterpreted their symptoms, had slowly progressing or mild symptoms, were embarrassed from genital examination, were too busy to seek help, and feared orchiectomy (Carbone, Walker, Burney, & Newton, 2009). Similarly, lack of prior knowledge of testicular cancer, its risk factors, and its screening contributed to delay in help seeking among long-term survivors of testicular cancer in Lebanon (Saab, Noureddine, Huijer, & DeJong, 2014).

Despite the apparent lack of awareness regarding BTD and delay in seeking help in the event of abnormal scrotal findings, the literature lacks intervention studies to close the knowledge gap and enhance help seeking. In addition, none of the reviewed studies addressed barriers to knowledge and help seeking and none highlighted men's informational needs and preferred modes of information delivery which was also reported as one of the major gaps in the literature on testicular cancer (Rovito et al. 2015: Saab et al., 2016a, 2016b). It is worth noting that minority groups as well as individuals who are at risk for health disparities were underrepresented in the literature on BTD which hinders the generalizability of findings and their applicability to different contexts. This gap was also identified in the literature on testicular cancer awareness (Saab et al., 2016a, 2016b).

# **Implications**

Implications for Future Research. The knowledge regarding BTD is suboptimal which is alarming since a number of testicular disorders can be life threatening and can have tremendous effects on the man's life. Given the paucity of research on this topic, closing the knowledge gap with regard to BTD awareness and help seeking is key. Minority groups were underrepresented in the literature on BTD which impedes the generalizability of findings and hinders their applicability to males who are at risk for health inequities. This highlights the need to address BTD awareness among these groups. In addition, all but one study included high school and university students who are relatively educated which informs the need to explore BTD awareness among males with a low educational background.

From a methodological perspective, researchers must be encouraged to use reliable and valid data collection instruments in future studies on BTD. This is thought to yield consistent, accurate, and generalizable findings. Researchers must also be encouraged to use standardized methods to plan, develop, and test these instruments prior to collecting data. The use of random sampling must be emphasized to enhance the sample representativeness.

The absence of intervention studies in the literature on nonmalignant testicular conditions highlights the need to plan, design, and implement educational and health-promoting interventions in this regard. First, research efforts should be made to explore BTD knowledge and understand barriers to help seeking. Second, men's educational needs as well as their preferred learning strategies should be explored. This could be achieved using face-to-face interviews and/or focus groups. Findings from these interviews as well as frameworks for intervention development would help develop, evaluate, and implement complex interventions to raise awareness of BTD and encourage early help seeking (Craig et al., 2008). The use of behavioral change theories and intervention-based models to underpin such interventions is key (Savage, Farrel, McManus, & Grey, 2010). Examples include the health belief model (Rosenstock, 1966), the theory of reasoned action (Fishbein & Ajzen, 1975), and the theory of planned behavior (Ajzen, 1985). Alternatively, researchers can make use of past interventions that succeeded in increasing men's awareness of testicular cancer. Examples include university campaigns (Wanzer, Foster, Servoss, & LaBelle, 2014), mass-mediated information delivery (Trumbo, 2004), and educational material printed on shower gel sachets and waterproof stickers (McCullagh, Lewis, & Warlow, 2005).

Implications for Practice and Education. Findings from the studies reviewed suggest that many of the participants who underwent sports-related physical examination were not informed as to the purpose of scrotal examination (Congeni et al., 2005; Nasrallah et al., 2000). This informs the need to prompt clinicians to educate young adults about the usefulness of genital examination in the early detection of both benign and malignant testicular disorders. Clinicians must also be encouraged to instruct young men about the signs and symptoms of the acute scrotum in order to seek timely medical attention. Moreover, as young men are counseled to practice testicular self-examination for the early detection of testicular cancer, findings from this review suggest that males ought to be counseled to practice self-examination in order to familiarize themselves with what is normal for them. This can be achieved through the use of a number of creative educational strategies that are tailored to the needs of the younger generation. For instance, clinician-provided websites were identified as the best means to offer quality information about hydrocele, therefore access to such website must be encouraged (Nason, Tareen, & Quinn, 2013). Other examples of means to raise awareness of Saab et al. 9

BTD include posters, campaigns, videos, and mass and social media (Saab et al., 2016a).

#### Limitations

Methodological Limitations. A number of methodological limitations were identified during the review process. First, all the reviewed studies were descriptive, therefore they do not fall high (Level 4.a) on the Joanna Briggs Institute (2014) levels of evidence. Second, no intervention studies were identified during literature search which leaves the BTD knowledge gap unaddressed. Third, only one study reported having a qualitative element (Babu et al., 2004), data from this study, however, were collected using a questionnaire and findings were reported quantitatively. No other qualitative studies were conducted to explore males' awareness of BTD and understand the reasons behind the delay in help seeking. Third, data were collected using researcher-designed questionnaires. Only one study reported on the reliability of the questionnaire (Babu et al., 2004) and none addressed the validity of the instrument used to collect data which hinders the consistency, dependability, and accuracy of findings. Fourth, nonprobability purposive sampling was used to recruit participants in all the reviewed studies: this could have led to selection bias consequently affecting the sample representativeness (Cochrane Bias Methods Group, 2013). Finally, only one study included a sample with a relatively low socioeconomic background (Babu et al., 2004). Other health inequities were not represented in the reviewed studies which adversely influences the generalizability of findings and applicability of recommendations.

Critical Appraisal of the Review Process. Rigor was sought throughout the review process by using the method proposed by Whittemore (2005) and Whittemore and Knafl (2005) and assessing the methodological quality of the included studies. Moreover, to our knowledge, this is the first integrative review where findings from studies on BTD awareness were collated and critically discussed. Some limitation, however, are worthy of discussion. The lack of evidence regarding awareness of BTD did not warrant the execution of a systematic review, therefore, a broader review method was selected. Study selection bias could have taken place due to a number of factors. First, only studies that serve the aim of this review were selected, therefore, discounting other studies that could have offered a different insight with regard to BTD. Second, literature search was limited to four databases and did not include studies from the gray literature which could have led to omission of potentially important records. Third, reporting bias could have taken place since only findings that answer the review questions were extracted and discussed.

For example, in the study by Babu et al. (2004), findings regarding women's awareness of hydrocele were not presented or discussed since only data from men were sought. Last, during the extraction process, the primary reviewer had to calculate some statistics that were not explicit in the reviewed papers which could have led to statistical errors. These errors were minimized by having a second reviewer independently cross-check the extraction table.

#### Conclusions

In this review, findings from studies that explored males' awareness of BTD were extracted and analyzed. It was identified that, contrary to the literature on testicular cancer, very little is known about awareness of BTD and no research efforts have been made to close the knowledge gap. Furthermore, as there is evidence that men's awareness of testicular cancer is increasing over the years (Evans, Steptoe, & Wardle, 2006; Saab et al., 2016b), their knowledge of BTD remains suboptimal. From a help-seeking perspective, very few males would seek immediate medical attention in the event of testicular pain and fewer would seek it if they noticed testicular swelling. Finally, minority groups as well as individuals who are at risk for or suffer from health inequities were underrepresented in the literature on BTD.

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The primary author is on a scholarship from University College Cork

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# Appendix 3

**Appendix 3.1** Exploring Awareness and Help-seeking Intentions for Testicular Symptoms among Heterosexual, Gay, and Bisexual Men in Ireland: A Qualitative Descriptive Study (Saab *et al.* 2017a)<sup>4</sup>

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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



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#### ABSTRACT

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

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.

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

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

Participants: Maximum variation and snowball sampling were used to recruit a heterogeneous sample. A

Participants: 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.

Methods: All interviews were audio-recorded and transcribed verbatim. Reflective field notes were taken following each interview. A summary of the interview was shared with selected participants for membercheck. Data were analysed and validated by three researchers. Inductive qualitative analysis of manifest content was used. Latent content was captured in the field notes. Data analysis yielded two key themes. Results: The themes that emerged from the interviews were: Awareness of testicular disorders and their screening, and help-seeking intentions for testicular symptoms. Although most 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 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: Findings suggest the need to educate young men about testicular disorders and symptoms. 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.

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# What is already known about the topic?

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- The incidence of testicular cancer is on the rise, and benign disorders such as testicular torsion and epididymitis can be lifethreatening if left untreated.
- Evidence from three reviews suggests that men lack awareness of testicular disorders and intend to delay help-seeking in the event of testicular symptoms.

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 It is unknown how at-risk men, including sexual minorities, perceive and appraise testicular symptoms such as pain, lumpiness, and swelling.

#### What this paper adds

- A number of barriers and facilitators to awareness of and helpseeking for testicular symptoms were identified.
- Key barriers include: health beliefs and attitudes, symptom misappraisal, social normative factors, and barriers in relation to the healthcare system.
- Many participants believed that gay men have higher health awareness and are more comfortable with their own testes.

#### 1. Introduction

Globally, health outcomes for males continue to be markedly poor, and efforts to promote men's health remain scarce. Moreover, health organisations and national governments tend to assume that gendered approaches to health promotion should be primarily focused on women's health rather than on both genders equally (Hawkes and Buse, 2013); which might lead to gender-based health disparity and poorer health outcomes, and discourages men from engaging with health services (Leone and Rovito, 2013; Whitaker et al., 2013). In order to address this issue, Baker et al. (2014) urged national governments and global health institutions to move men's health higher up on their agenda. Of the diseases that are seldom discussed in current men's health policies, disorders of the testes can have a major impact on a man's wellbeing.

Testicular cancer (TC) is the most common solid tumour among young men in the United States, with a mean age of 33 years at diagnosis (National Cancer Institute, 2015). The incidence of this malignancy doubled globally over the past four decades and is highest in 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% (National Cancer Institute, 2015). The surgical resection of the affected testis (e.g. orchiectomy) remains the treatment of 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 secondary to the disease and/or its treatment; these include chronic fatigue, neuropathy, and fertility impairment (Huddart et al., 2005; Rossen et al., 2009; Saab et al., 2014)

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 disease rather than TC is quite significant. Each year, 1 in 4000 males aged less than 25 years are diagnosed with testicular torsion in the United States (Ringdahl and Teague, 2006). 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 disorder in the United States (Centers for Disease Control and Prevention, 2015). Testicular torsion is known to cause excruciating pain and swelling (Ringdahl and Teague, 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 these conditions can be life-threatening. An example is testicular torsion that can lead to testicular necrosis if help-seeking is delayed by six hours or more from the onset of pain (Ringdahl and Teague, 2006). Moreover, epididymitis and orchitis can lead to sepsis if left untreated (Centers for Disease Control and Prevention, 2015).

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 selfexamination; 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 (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 TC and self-examination was lacking at baseline. Nevertheless, interventions including a 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 awareness and getting young men to self-examine. In contrast, evidence from an integrative 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 deficient, and their intention to seek medical help for testicular swelling and/or pain is suboptimal (Saab et al. 2016a).

Of the reviewed studies, very few offered an in-depth understanding of men's awareness of TC (Dubé et al., 2005; Daley, 2007; Evans et al., 2010), none explored, qualitatively, men's 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 involved men who are at risk for health inequities (Babu et al., 2004), and none included gender and sexual minorities. This is worrisome, as gay men are twice more likely to report a 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, heterosexual, gay, and bisexual men's awareness of testicular disorders and their help-seeking intentions for testicular symptoms in the Irish context.

#### 2. Methods

#### 2.1. Study design

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 researchers, practitioners, and policymakers. Examples include: "What are the concerns of 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 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).

#### 2.2. Participants

Purposive sampling, specifically maximum variation and snowball sampling were used to locate and recruit a heterogeneous sample of information-rich key participants (Grove et al., 2013; Patton, 1990). Maximum variation sampling allows researchers to describe a certain phenomenon from the viewpoint of diverse sample. In this study, a sample that was varied in terms of age, socioeconomic status, ethnicity, and sexual orientation was sought. Participants were then asked to invite other men who

fitted the inclusion criteria to partake in the study, which is the key feature of snowball sampling (Patton, 1990). It is worth noting 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. 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 (Centers for Disease Control and Prevention, 2015; National Cancer Institute, 2015; Ringdahl and Teague, 2006).

#### 2.3. Data collection

Ethical approval was obtained from the Clinical Research Ethics Committee at University College Cork. A standardised invitation letter was sent by e-mail to members of an inclusive community choir, youth organisation, surfing club, family community centre, and all students and staff in a university in Southern Ireland. In addition, study flyers were hung in a university sports centre and on campus. Those who replied to the e-mail and agreed to participate were asked to identify other men who would be potentially interested in taking part in the study.

Data were collected between December 2015 and February 2016 using face-to-face individual interviews and focus groups. The combination of individual interviews and focus groups is known to enrich qualitative data (Lambert and Loiselle, 2008). In the present study, focus groups and individual interviews were conducted simultaneously for pragmatic reasons. Each participant was given the choice to participate, either in a focus group discussion or in an individual interview. This was attempted in order minimize refusals and withdrawals among those who did not feel comfortable discussing intimate topics in front of other men.

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.

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 doctoral-level graduate student in nursing, formally trained in qualitative research, and had 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 listing the aim of the study and what their participation entailed. Participants were also provided with a referral form with the contact details of free counselling and support services in case they experienced psychological distress. Informed consent was obtained and participants were requested to fill a brief sociodemographic questionnaire that was designed by the researchers to collect data on the participants' age, nationality, sexual orientation,

relationship status, highest level of education, employment status, and past history of a testicular disease.

The opening question was: "What is the first thing that comes to your mind when I say 'testicular diseases or disorders'?" Openended probes were used to explore the participants' responses in greater depth. Examples include: "How come (the answer) crossed your mind? 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 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 focus groups were conducted with 29 men. Two focus groups included six participants each and one focus group comprised five participants. Participants in each focus group were sociodemographically diverse. Interviews lasted between 31 and 62 min.

A brief summary of the transcripts was shared with five participants via e-mail. Participants were asked to provide their feedback as to whether the summary was reflective of the key issues discussed during the interview. The plan was to share the summary with more participants if discrepancies arose; however, all five participants agreed to the summary. This measure is commonly known as member check and is often regarded as a crucial technique to establish credibility (Lincoln and Guba, 1985).

#### 2.4. Data analysis

Data analysis took place concurrently with data collection. Identifiers were omitted to maintain anonymity and confidentiality. Transcripts were analysed using inductive content analysis (Elo and Kyngäs, 2008). Unlike deductive content analysis, inductive content analysis is recommended when prior knowledge of a certain phenomenon is limited (Lauri and Kyngäs, 2005). Moreover, this analytical framework was selected to explore manifest content (e.g. participants' own words) and to a lesser extent, latent content (e.g. non-verbal cues including laughter, crying, and silence).

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. Finally, themes that connect the various categories were identified. Non-verbal cues that were highlighted in the field notes were used to enrich the data collected. Audiotaped 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).

#### 2.5. Enhancing trustworthiness

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 the primary investigator and two experienced researchers review the coding process and agree on the analysis. Confirmability was addressed through constant dialogue among the researchers (Graneheim and

Lundman, 2004), and the use of audit trails (Saldaña, 2009). Additionally, transferability was enhanced by thickly describing the data collection process and sample characteristics, and seeking a heterogeneous sample (Graneheim and Lundman, 2004). Reflexivity was established by keeping audio-taped memos (Birks et al., 2008). Finally, authenticity was ensured by using icebreakers to establish a trusting relationship with the participants and get them to openly discuss their experiences (Holloway and Wheeler, 2010).

#### 3. Findings

#### 3.1. Sample characteristics

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. 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 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' 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).

Two key themes emerged from the interviews namely: Awareness of testicular disorders and their screening, and help-seeking intentions for testicular symptoms. Associated categories included: Impediments to and enablers for awareness, and barriers and facilitators to help-seeking. All the themes, categories, subcategories, and abbreviated codes are highlighted in Table 2. Pseudonyms are used in referring to the participants.

Table 1
Socio-demographic data (n = 29).

Age (years)	Range	18-47
Market Control	Mean(standard deviation)	33.5(8.8
Nationality	Irish	20
	Dual citizenship	3
	British	1
	Danish	1
	Dutch	1
	Italian	1
	Lebanese	1
	Mexican	1
Sexual orientation	Heterosexual	17
	Gay	11
	Bisexual	1
Marital status	Single	16
	In a relationship/partnered	6
	Married	5
	Divorced	1
	Separated	1
Highest level of education	Primary	1
OUT OF THE PROPERTY AND ADDRESS OF THE PROPERTY OF THE PROPERT	Secondary	2
	High school	6
	University	20
Occupation	Employed (full-time)	14
•	Employed (part-time)	2
	Self-employed	1
	Student and employed (part-time)	2
	Student	6
	Intern	1
	Unemployed	3

#### 3.2. Awareness of testicular disorders and their screening

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

#### 3.3. Impediments to awareness

All the participants have heard of TC and many perceived it as the most 'advertised' testicular disease. However, having heard of TC did not necessarily imply that men were aware of its risk factors, treatment, and screening. Lack of awareness was attributed to a multitude of factors including the prevailing beliefs and attitudes towards testicular disorders, perceptions of the healthcare system, awareness not being promoted in the school system, and 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 hear anything specific about it... But I know it exists and I wouldn't really know what the 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 ages at risk?... If I don't have testicular cancer now, so it's harder for me to get it later?" In contrast, very few participants heard of other testicular disorders. For example, when asked about his awareness of diseases of testes, Juan said: "I have heard about testicular cancer, so I think that's probably really the only one that I know, I cannot name any other disorder."

Trivialisation of testicular symptoms and uncertainty regarding testicular diseases were also identified as barriers to awareness. As he was discussing how men take testicular symptoms for granted, Patrick said:

"You get a kick in the balls. Oh, it's painful, it's quite painful, but then it goes away and a lot of people think the issue is like that and they don't really think much further because they don't like thinking about their balls. They're there, that's it, I'm done with them!"

In many cases, the lack of awareness was linked to a number of misbeliefs. For example, Ziad had a number of misconceptions about TC. As he was recalling his sexual encounter with two men who had TC; he laughed nervously and said: "...If it happened to those people that I met, it's going to happen to me. Or oh, it can infect me."

A number of men believed that national health campaigns tend to focus on women's rather 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 too late'. And then at the end of it, it says, 'Jerry died shortly after making this ad'. I mean 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. . "

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 boys' school, believed that class conversations about sexual health are not facilitated by the teachers and/or curricula; he said:

"When it comes to teaching about reproduction and the reproductive system, they (curricula) talk a little bit about sexually-transmitted diseases . . . As if the students are not entitled to have this kind of knowledge . . . Even teachers, they just skip those

 Table 2

 Emerging themes, categories, sub-categories, and abbreviated codes.

Theme	Category	Sub-category	Abbreviated code
Awareness of Testicular Disorders and Their	Impediments to awareness	Lack of knowledge	Risk factors
Screening	51 /A	9	Treatment
			Benign testicular disorders
		Beliefs and attitudes	Trivialisation
		beliefs and attitudes	Misconceptions
			Uncertainty
		Perceptions of the healthcare	Focus on female cancers
		system	Focus on more serious conditions
			Trivialisation of sexual health/testicular disorder
		Awareness not promoted in school	
		system	Unpreparedness of educators
	2.00	Lack of screening for testicular disorders	Lack of knowledge on how to self-examine
			Lack of clinical testicular examination
			Lack of familiarity with own testes
	Enablers for awareness	Prior knowledge	Risk factors
			Perception of prognosis
			Treatment
		Beliefs and attitudes	Personal interest in health
			Confidence to learn about testicular disorders
		Exposure to pertinent information	School
			College
			Workplace
			Media
		Testicular self-examination	Regular/irregular conscious checking of the teste
		practices	negular/irregular conscious encenting of the test
		Clinical testicular examination	Part of doctor check-ups
		History of testicular disorders	Personal/family history
			Knowing someone with a testicular disorder
		Cl.	
		Changes over time	Irish men, then and now
		Identifying as gay	Ease in talking about testes
	108 0 000 20 20 020		More in tune with own body
Help-Seeking Intentions For Testicular	Barriers to help-seeking	Lack of knowledge	Don't know what to look for
Symptoms	intentions		Don't know how to look for it
			Not sure if there is something new or not
		Symptom misappraisal	Symptom not severe
			Symptom fluctuates
			Symptom caused by something else
		Emotional factors	Fear from diagnosis/dying
			Embarrassment due to the private nature of
			complaint
			Coping (denial and avoidance)
		Health beliefs and attitudes	Perceived hypochondria
			Unrealistic optimism
			Beliefs about being male and young
		Social factors	Concern about impact on family and friends
			False reassurance by healthcare professionals
			Busy with life, no time
		Cultural influences	Older generation more reluctant to seek medic
		Cultural influences	
			help
		Charles Conservation of the Conservation of th	Sheltered upbringing
		Process of seeking help	Expensive
			Waiting time and queues
			Gender of clinician
	Facilitators to help- seeking	Access to support	Mother/father is a healthcare provider
	intentions		Talking to partner
			Working in a healthcare setting
		Presence of pain and lump	Severity
			Duration
			Changes
		Inherent health-seeking drive	Wouldn't wait
		milerent meatin-seeking drive	It is ok to seek help
		Paraginal throats	
		Perceived threats	Personal/family history of a testicular disorder
			Knowing/hearing about someone with a
			testicular disorder
			Age risk
			Threat to fertility
			Tilled to leftlifty

chapters . . . In SPHE (Social, Personal and Health Education) there is a chapter about sexuality but still, it is done just to tick a box."

Most participants reported not practicing testicular selfexamination either because they did not know how or because they were unfamiliar with their own testes. For instance, Juan stated that he was unaware that the scrotal raphe was part of the normal anatomy of the scrotum. Although it worried him for many years, he never discussed it with anyone; he said:

"In my testicles, there is a small line between the two testicles in the skin. For a very long time, I thought that that was not normal . . . I

was not able to ask anybody. When my son was born and I was changing his diaper, I saw that he had the same skin there and I was like, Oh! it's normal!"

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 knowing about testicular disorders; he said: "I am not an extremely ignorant person, I am 41 years of age and I don't know how to check myself, you know GPs probably don't do it as a standard for physical check-up..."

#### 3.4. Enablers to awareness

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

Most participants believed that TC is curable and has a low fatality rate. This was evident in a focus group whereby Conor and Patrick were discussing the prognosis of TC among each other and said: "If caught early it (TC) is very curable . . . It's got a 95% cure rate in this country."

A number of men reported being inherently health-conscious which served as an enabler to awareness. In addition, awareness was linked to increasing age and the cumulative impact of poor diet and lifestyle over time. This was evident in the following excerpt by Jack:

"I'm in my mid-30s now and when you're in your mid-30s, this might sound a bit grim, you 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 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 TC from the news about Lance Armstrong, a celebrity cyclist who survived TC. Moreover, Daniel's awareness of TC increased after his doctor checked his testes; he said:

"I remember recently I had to go to the doctor for something not related to testicular disorders and then the doctor was asking me about how aware are you of testicular cancer and she examined me around that area then for lumps, this never happened before, so maybe I have more awareness now."

As for testicular self-examination, only a few participants endorsed this practice. An example is Tom who reported practicing testicular self-examination occasionally in the toilet. However, when asked whether he knew what he was looking for; he said: "No, I'm going by look and touch."

Men with a personal or family history of a testicular disease and those who knew someone who developed a testicular disorder, were clearly more aware. This was the case for William and Richard who became aware of testicular torsion after developing it and Shane who became aware of TC after his father was diagnosed with it; he said: "It wouldn't have been in 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 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 ourselves . . . "

Interestingly, many participants stated that self-identifying as gay was an enabler to awareness. For instance, Mark and Tom who self-identified as heterosexual, assumed that gay men have higher health awareness, and are more comfortable with their own testes as well as the testes of other men. For instance, Tom said: "A gay man has potentially the benefit of a partner with the same, you know, biological structure." This was echoed in the interview with Kevin who self-identified as gay; he said:

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

#### 3.5. Help-seeking intentions for testicular symptoms

Men's help-seeking intentions for symptoms of testicular disease were explored using two scenarios. First, participants were asked to describe how they would react in the event of 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.

#### 3.6. Barriers to help-seeking intentions

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."

Symptom mildness, fluctuation, and the thought that the symptom was caused by 'something else' also negatively influenced men's help-seeking intentions. For example, symptom misappraisal stopped Ross, a surgeon and a survivor of advanced TC, from seeking help for scrotal pain and swelling; he said: "The primary tumour, which started in my testicle, shrunk, but the disease went rampant inside...? Was checking and saying, this has got smaller, it's 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 and said:

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

Beside fear, a number of participants identified embarrassment and dysfunctional coping as emotional factors that would impede help-seeking. An example is Rafael who said: "If we were to go to our GP we're going to just strip naked and let an old guy see your junk." 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 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, 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, was falsely reassured by his friend who was a medical student that the yellow discoloration in 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 emergency care. Ron, on the other hand, had no intention to seek help and visiting a doctor was not on his list of priorities; he said:

"Honestly, that kind of a thing goes way down my to-do list. Like I'm busy, I'm hardly going to clear off my agenda so that I can go . . . I've got other things to worry about . . . And I don't prioritise it . . . There are more important things."

A number of participants stated that the social norms that often define a man (e.g. machoism, stoicism, and unrealistic optimism), stand in the face of help-seeking. In addition, the Irish sheltered upbringing was perceived by many to negatively affect men's intention to seek help. For instance, while discussing his brothers' and father's reluctance to visit a doctor, 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 body, I may consider going next week."

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.

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 doctor as regularly because we're like oh, we don't want to be seen as hypochondriacs." 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 we won't be the person it'll happen to, so why concern yourself with that?" Others thought that they were too young to develop a disease in their testes. An example is Omar who was 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 stated that the waiting time and long queues in the GP's clinic and the emergency department would make them think twice before seeking help. This was the case for Tom who said: "We have the second-worst waiting lines in Europe." The gender of the physician also seemed to influence men's intentions to seek help. For instance, Rafael said: "I'd feel better if it was a female doctor. I wouldn't like a man touching me", whereas Henry reported that he would feel more comfortable with a male doctor since "he has some (testes) also."

3.7. 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 my partner (male) to check it because I would just need that affirmation to be like, 'No, you're definitely right'."

The severity and duration of pain and changes in symptoms were identified by those with a history of a testicular disorder as facilitators to help-seeking. For instance, it was the intensity 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 to the hospital, he said:

"Immediately when I found it . . . Luckily so because they said it would be four or six hours and it (the testicle) could have been dead . . . When I touched it, it was the size of a tennis ball. Close to that. It was just so abnormally large and it was so taut!"

Participants who reported being inherently health-conscious stated that it was 'alright' to seek help and said that they would not wait for symptoms to get worse. An example is Adam who said: "If there was something amiss with me and there was pain, I would be investigating."

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 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..."

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 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."

#### 4. Discussion

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

As for non-malignant testicular disorders, only participants who were diagnosed with varicocele, testicular torsion, and epididymitis were aware of these diseases and only one participant heard of the 'bag of worms' but failed to link it to a specific disease, varicocele in this case. Varicocele is typically described as feeling like a 'bag of worms' due to the "dilation of the venous pampiniform plexus of the spermatic cord" (Crawford and Crop, 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).

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. 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 helpseeking 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 participants who practiced testicular self-examination had higher knowledge scores than 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 Rovito et al. (2011).

In the present study, many participants linked testicular disorders, specifically TC, to a number of celebrities. These findings are consistent with those of Trumbo (2004) and Daley (2007) whereby a number of men heard about TC through TV shows about celebrities who survived it.

A number of participants believed that gay men are more in touch with their body and are more at ease when it comes to dealing with their testes. In addition, exposure to other men's genitalia was perceived to have a positive impact on awareness. Little empirical evidence exists to support these findings. However, in a study on awareness of TC and self-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 for cancer symptoms and has been documented among patients experiencing symptoms of breast (O'Mahony et al., colorectal, (Mitchell et al., 2008), and urogenital cancers (Macleod et al., 2009). Similarly, embarrassment identified by a number of participants as an excuse not to visit a doctor, was highlighted in previous studies as a key factor leading to help-seeking delay among males (Fish et al., 2015; Yousaf et al., 2015). Also, findings in relation to the prevailing beliefs and attitudes towards testicular disorders and the meaning men attach to their testes are echoed in a number of studies; these include machismo (Buckley and Tuama, 2010), stoicism (Emery et al., 2013), the perception of health as a female rather than a male issue (Hajdarevic et al., 2011), and the engrained social and gender roles (Leone and Rovito, 2013).

Interestingly, the gender of the examining physician also influenced men's help-seeking intentions as some felt comfortable being examined by a female doctor and others could identify more with a male doctor. It is suggested, however, that female clinicians are more inclined to discuss general health prevention than male physicians especially when it comes to sensitive issues (Ramirez et al., 2009).

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 (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 preventive or screening services offered to males. Moreover, despite being among the few 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 GP visit and the long waiting time in the emergency room were echoed in previous Irish studies (Buckley and Tuama, 2010; Scanlon et al., 2006).

#### 5. Implications for policy, research, and practice

The European Commission (2011) published a report highlighting gender-based health disparities and proposing action plans to promote men's health in a number of European countries. Nevertheless, much needs to be done to promote men's health in policy, research, education, and clinical practice.

National and international governments are encouraged to shed light on men's and women's health equally while instigating health promotion and cancer prevention campaigns. In addition, reinforcing pre-existing men's health strategies and drafting new ones might be instrumental in raising awareness of male-specific disorders (Baker et al., 2014).

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. Examples include mass, social, and interactive media.

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 talking about their testes when they get older. Also, it is important to educate partners about testicular symptoms and diseases as they may be the ones who detect abnormalities during sexual activity.

Clinicians, including nurses, are also encouraged to educate atrisk males about the seriousness of testicular symptoms such as abrupt pain and newly occurring lumps, and to highlight the importance of early help-seeking. Clinicians are also encouraged to examine the testes during the well male physical examination.

#### 6. Limitations

Although rigour was attempted while conducting this study, a number of limitations are worthy of note. Qualitative description is often criticized for lacking rigour (Neergaard et al., 2009). For this reason, a number of strategies were employed to enhance trustworthiness.

Given the study design and aim, generalisability was not sought; instead transferability was attempted by seeking data saturation and recruiting a heterogeneous sample in terms of age, 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.

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 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.

#### 7. 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 nonmalignant 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.

This study highlights the importance of addressing men's awareness of testicular symptoms in pre-existing men's health strategies, addressing their education needs in future research, normalising sensitive topics at a young age, and encouraging clinicians to examine the testes during the well male physical check-up.

# Ethical approval

Ethical approval was obtained in July 2015 from the Clinical Research Ethics Committee of the Cork Teaching Hospitals, University College Cork, Ireland.

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# **Conflicts of interest**

None to declare.

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**Appendix 3.2** Exploring Men's Preferred Strategies for Learning about Testicular Disorders Inclusive of Testicular Cancer: A Qualitative Descriptive Study (Saab *et al.* 2017b)<sup>5</sup>

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# Exploring men's preferred strategies for learning about testicular disorders inclusive of testicular cancer: A qualitative descriptive study



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#### ABSTRACT

Purpose: Men's awareness of testicular disorders is lacking and their intention to seek help for testicular symptoms is sub-optimal. Studies conducted to explore and raise men's awareness of testicular disorders did not address their preferred learning strategies and failed to include men who are at risk for health inequities. The aim of this study was to explore, in-depth, the preferred strategies for learning about testicular disorders inclusive of testicular cancer among men who self-identify as heterosexual, gay, or bisexual.

Methods: Maximum variation and snowball sampling were used to recruit 29 men aged 18—47 years. Participation was sought from community and youth organizations and a university in the Republic of Ireland. Semi-structured individual interviews and focus groups were conducted. Interviews were audio-recorded and transcribed verbatim. Inductive analysis of manifest content was used.

Results: Seventeen informants self-identified as heterosexual, 11 as gay, and one as bisexual. Four main categories emerged, namely: strategies to enhance awareness (television, internet, campaigns, print media), educational dos and don'ts (tailoring effective messages, drawbacks of national initiatives, ineffective learning strategies), implications of raising awareness (risks and benefits of increasing awareness), and learning among gay and bisexual men (learning needs and strategies).

Conclusion: Future studies promoting awareness of testicular disorders should take into account men's preferred learning strategies. National campaigns should be delivered frequently and altered occasionally in order to achieve a top-up effect. Clinicians are encouraged to educate young men about the seriousness of testicular symptoms and the importance of seeking timely medical attention for any abnormalities.

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# 1. Introduction

The location, anatomy, and physiology of the testes can put men at risk for a number of diseases ranging from painless and benign to incapacitating and malignant (Wampler, 2010). TC<sup>1</sup> is most prevalent among men aged 20–44 years in the United States (National Cancer Institute, 2016). Similarly, 91% of TC cases in Ireland are diagnosed before the age of 50 (National Cancer Registry Ireland, 2016). Although rare and curable, TC incidence is on the rise in Western European countries and in the United States (Shanmugalingam et al., 2013). Orchiectomy is the main treatment

http://dx.doi.org/10.1016/j.ejon.2016.11.001 1462-3889/© 2016 Elsevier Ltd. All rights reserved. modality for TC and is often followed by chemotherapy and/or radiotherapy (Saab et al., 2016b). TC treatment is associated with a multitude of long-term complications including chronic fatigue, Reynaud like phenomena, and reduced gonadal function (Huddart et al., 2005; Rossen et al., 2009; Saab et al., 2014).

Public health initiatives promoting TSE<sup>2</sup> are linked to a reduced tumour size at presentation, which highlights the need to raise men's awareness of TC (McGuinness et al., 2016). In a systematic review of 25 studies exploring men's awareness of TC and its screening, Saab et al. (2016c) found that, despite having heard of TC, men were often uninformed about the different aspects of this malignancy. Subsequently, their TSE practices and intention to seek medical help for a testicular lump were suboptimal. In addition, men's perceived risk for TC is known to be low (Roy and Casson,

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 $<sup>\</sup>hbox{\it E-mail addresses: } msaab@ucc.ie, mohamad.m.saab@gmail.com (M.M. Saab). \\ ^1 TC: testicular cancer.$ 

<sup>&</sup>lt;sup>2</sup> TSE: testicular self-examination.

2016).

Non-malignant disorders, such as testicular torsion, epididymitis, and orchitis, are more prevalent than TC, and if left untreated, can cause various complications that can be life-threatening (Centers for Disease Control and Prevention [CDC], 2015; Ringdahl and Teague, 2006). Testicular torsion, for instance, is a medical emergency that leads to ischemia and necrosis if helpseeking is delayed by 6 h or more from the onset of pain (Ringdahl and Teague, 2006). Epididymitis, often transmitted sexually among men aged less than 50, can lead to severe orchitis, sepsis, and infertility if left untreated (CDC, 2015). Like TC, men often lack awareness of benign testicular disorders and tend to delay help-seeking in the event of testicular pain, lumpiness, and/or swelling (Babu et al., 2004; Clark et al., 2011).

Saab et al. (2016b) conducted a systematic review of 11 interventions targeted at raising TC awareness and screening. A number of these interventions succeeded in improving men's knowledge of TC and in promoting TSE; examples include videos about TC and self-examination (Folkins et al., 2005; Sacks et al., 2013), a university campaign (Wanzer et al., 2014), and mass media (Trumbo, 2004). It is worth noting that none of these interventions mentioned men's education needs and preferred modes of learning a priori. Similarly, quantitative and qualitative studies that explored men's awareness of testicular diseases, seldom addressed their information needs and preferred learning strategies (Saab et al., 2016a, 2016c). Moreover, very few studies included men who are at risk for health inequities (Folkins et al., 2005; Sacks et al., 2013) and only one study reported that gay men were more likely to perform TSE than heterosexual men (Reece et al., 2010). This is quite alarming, especially that gay men are twice more likely to report a cancer diagnosis than heterosexual men (Boehmer et al., 2011). Therefore, the aim of this study was to explore, in-depth, the preferred strategies for learning about testicular disorders inclusive of TC among men who self-identify as heterosexual, gay, or bisexual.

#### 2. Methods

#### 2.1. Study design

The qualitative descriptive design was used. This approach is the least theoretical among the different qualitative designs; therefore, the phenomenon of interest was described using the informants' own words and insights, rather than adhering to pre-existing theories (Guba and Lincoln, 1994). Furthermore, qualitative description is appropriate to obtain unadorned responses to specific questions; examples include: "What are the concerns of people about an event? What factors facilitate and hinder recovery from an event?" (Sandelowski, 2000, p.337). The Standards for Reporting Qualitative Research (SRQR) guided the reporting of this study (O'Brien et al., 2014).

#### 2.2. Sample selection

Informants eligible for this study were: (i) men; (ii) aged between 18 and 50 years; (iii) residing in the Republic of Ireland; and (iv) self-identifying as heterosexual, gay, or bisexual.

Snowball and maximum variation sampling approaches were used. Both strategies are subtypes of non-probability purposive sampling and are used to recruit a varied sample of information-rich key informants (Grove et al., 2013; Patton, 1990). In this study, a sample that was heterogeneous in terms of age, employment status, level of education, ethnic background, and sexual orientation was sought. In addition, informants who expressed an interest in partaking in the study were asked to invite other men to

participate, hence snowball sampling. This sampling strategy serves as an efficient means to recruit hard-to-reach informants (Sadler et al., 2010). This is key as an open discussion of intimate subjects is uncommon among men, let alone young and relatively healthy men from different sociodemographic backgrounds (Saab et al., 2014).

#### 2.3. Data collection

This study was reviewed and approved by the Clinical Research Ethics Committee at University College Cork. Participation was sought from a youth organization, an inclusive choir, a surfing club, a family community centre, and a university in the Republic of Ireland. Potential informants were invited to participate by e-mail using a standardized letter, and study flyers were hung in a university sports centre and on campus.

Twelve semi-structured individual interviews and three focus groups were conducted concomitantly between December 2015 and February 2016. The combination of both interview approaches is known to enrich data collection in qualitative research (Lambert and Loiselle, 2008). Due to the intimate nature of the subject and in order to minimize withdrawals and refusals, men were given the choice to partake, either in focus groups or in individual interviews. They were also asked to find a suitable date, time, and location for the interview. Ten interviews took place in the primary investigator's office; one individual interview and one focus group discussion were conducted in the informants' workplace; one focus group discussion took place in a surfing club and another in a youth organization; and one informant was interviewed in a community organization. All interviews were conducted face-to-face and were audio-recorded.

The primary investigator and interviewer was male and a PhD in nursing candidate who was formally trained in oncology nursing and qualitative research; was experienced in conducting qualitative interviews; and had no previous relationship with the informants.

Informants were provided with a study information sheet and a referral form with the contact details of a cancer support hotline and free counselling services. They were then asked to sign a consent form and fill out a socio-demographic questionnaire. Questions included: whether they had a past history of a testicular disorder, whether they were previously educated about testicular disorders, and whether they intended to seek information in relation to testicular diseases. Finally, informants were asked to rate the importance of learning about testicular diseases on a Likert scale from zero to 10; 10 being "Very Important."

An interview protocol was developed to address the gaps identified in the reviewed literature on men's awareness of testicular disorders (Saab et al., 2016a, 2016b, 2016c) and was guided by the aim of the present study. The opening question was: "What are your views and opinions regarding increasing men's awareness of testicular diseases?" Probing was used to allow the informants to elaborate. Reflective field notes were taken immediately after each interview to capture non-verbal cues (Grove et al., 2013). The full interview protocol is presented in Table 1.

Interestingly, getting men to openly discuss their insights in front of others during focus groups was found to be more challenging than recruiting them into the study. As a result, a number of informants were holding back during focus groups, especially those with a past history of a testicular disorder. However, a lot of those who were silent in the beginning of the interview, seemed more relaxed and outspoken as the interview went on.

Data saturation was achieved following seven individual interviews and three focus group discussions. Five additional individual interviews with five new informants were conducted in order to confirm data saturation (Elo et al., 2014). In total, 29 men

Table 1 Interview protocol.

Key questions	Probing questions	
What are your views and opinions regarding increasing men's	Is it important? Why?	
awareness of testicular diseases?	<ul> <li>What do you think about its risks and benefits?</li> </ul>	
	<ul> <li>What helps men become more aware of testicular diseases? (prompts: knowledge, skills, tools)</li> </ul>	
Think of your awareness of another health-related topic that you	What is the topic?	
remember in detail, and is of interest to you	<ul> <li>How did you learn about it?</li> </ul>	
	<ul> <li>What drew your attention to it/what makes it interesting?</li> </ul>	
	<ul> <li>Could the same method be used to raise men's awareness of testicular disorders? If no, why? If yes, how?</li> </ul>	
	<ul> <li>What do you think about the learning needs of gay, bisexual, and transsexual (GBT) people?</li> </ul>	
	<ul> <li>Do GBT people have different educational needs? Why? If yes, how can they be addressed?</li> </ul>	
	<ul> <li>Could the same method be used to raise awareness of testicular disorders among GBT people?</li> </ul>	
Are you personally interested in learning more about testicular	<ul> <li>Why? Can you please elaborate?</li> </ul>	
diseases?	<ul> <li>If yes, how confident are you in your ability to learn about testicular diseases?</li> </ul>	
	<ul> <li>What would you like to know about testicular disorders?</li> </ul>	
	<ul> <li>How would you like to learn about them?</li> </ul>	

were interviewed with each interview lasting on average, 45 min. Twelve men were interviewed individually, two focus groups comprised six informants each, and one focus group included five informants.

#### 2.4. Data analysis

Data were collected and analysed concurrently. Interviews were transcribed verbatim and identifiers were deleted to maintain anonymity. Two to three weeks following the initial interview, a summary of the transcripts was sent to selected informants for member check. This step is crucial to ensure credibility in qualitative research (Lincoln and Guba, 1985). Member check also gives the informants the opportunity to reflect on their responses and correct misinterpretations. All the contacted informants agreed to the summaries.

Inductive analysis of manifest content was used (Elo and Kyngäs, 2008). Transcripts were read thoroughly and underlying clusters of concepts were identified and coded. Codes were later transferred to a coding sheet that was developed following an iterative discussion process among the authors. Similar codes were then assigned to sub-categories that were later gathered under generic categories. Finally, main categories that connect the various generic categories were identified. The primary investigator kept audio-recorded memos to reflect on the data analysis process (Birks et al., 2008; Grove et al., 2013).

#### 2.5. Trustworthiness of the data

Credibility was established through selecting a heterogeneous sample, field note-taking, the use of excerpts, and member check (Elo et al., 2014). Dependability was enhanced by having the primary investigator and two co-investigators who are experienced in qualitative research review the analysis process and agree on the findings. Audit trails were used to ensure confirmability (Graneheim and Lundman, 2004; Polit and Beck, 2012; Saldaña, 2009). Transferability was enhanced by seeking a heterogeneous sample as well as achieving and confirming data saturation (Graneheim and Lundman, 2004). Authenticity was ensured by using icebreakers and establishing rapport with the informants prior to data collection (Holloway and Wheeler, 2010). Finally, audio-recorded memos and reflective field notes were used to

enhance reflexivity (Birks et al., 2008).

#### 3. Results

#### 3.1. Sample characteristics

Informants were aged between 18 and 47 years (mean = 33.5). Of the 29 informants, 20 were Irish, 16 were single, 20 held a university degree, and 14 were employed on a full-time basis. Seventeen informants self-identified as heterosexual, 11 as gay, and one as bisexual (Table 2). Three men reported a personal history of epididymitis, two had varicocele, two were diagnosed with testicular torsion, and one was a survivor of metastatic TC. Almost half of

**Table 2** Socio-demographic characteristics of the informants (n = 29).

Age (years)	
Range	18-47
Mean(standard deviation)	33.5(8.8)
Nationality	
Irish	20
Other European	4
Dual citizenship	3
Lebanese	1
Mexican	1
Sexual orientation	
Heterosexual	17
Gay	11
Bisexual	1
Marital status	
Single	16
In a relationship/partnered	6
Married	5
Separated/divorced	2
Highest level of education	
Primary	1
Secondary	2
High school	6
University	20
Occupation	
Employed (full-time)	14
Employed (part-time)	2
Self-employed	1
Student and employed (part-time)	2
Student	6
Intern	1
Unemployed	3

the men were uninformed about testicular disorders. Those who reported having heard of these disorders, did so through school, college, their physician, peers, family history, a video, a movie, a journal, and a campaign by the Irish Cancer Society. Twenty-one informants intended to seek information about testicular disorders, twenty-seven men rated education about testicular disorders as "Very Important", and two rated it as "Important".

Four main categories emerged from the interviews, namely: (i) strategies to enhance awareness; (ii) educational dos and don'ts; (iii) implications of raising awareness; and (iv) learning among gay and bisexual men (Table 3). Fictitious names are used to maintain the confidentiality of the informants.

#### 3.2. Strategies to enhance awareness

Informants were asked to reflect on a health topic that they recently learned about and is of interest to them. They were then asked about the means through which they learned about this topic and whether the same strategy could be used to raise men's awareness of testicular disorders. As a result, a number of media were identified including television, internet, campaigns, and to a lesser extent, print media.

#### 3.2.1. Television

For many informants, the television served as the primary source of health information. For instance, all five informants in a focus group came across TC and its screening while watching the same television program. Of these informants, Aaron said: "I've learned more about medical issues in that program than I've ever learned in my life!" when asked what drew his attention to this specific program, he said: "It's kind of real people coming in and they make it sexy a little bit." This was reiterated by Hans who, when asked whether he got exposed to prior information on testicular disorders, said:

"It was in a documentary about sexual health in young people and I thought it was a really good thing. They didn't actually censor anything. They sent the young people in to the doctor's. You saw full frontal, you saw everything getting checked."

#### 3.2.2. Internet

The internet in general, and social media in particular, were perceived by many as the best methods to deliver health information to younger men. This was evident in the following excerpt by Ziad: "A lot of young people are always on social media, so Snapchat, viral videos, Facebook viral videos, YouTube viral videos." Similarly, Kevin believed that awareness of testicular disorders can be raised using social marketing; he said: "We're a Facebook, Twitter generation ... The 20s, 30s and 40s are going to be on Facebook or Instagram." Mobile applications were also identified as methods to promote awareness. For instance, William found out about free HIV testing through an advertisement on a gay dating mobile application; he said: "I actually think that they probably would do it for free because that's how I found out about the first prick test, from Grindr (gay dating mobile application)."

#### 3.2.3. Campaigns

A number of informants stated that awareness of testicular disorders could be enhanced via campaigns in schools, colleges, sports clubs, and workplaces. For instance, the "Movember" campaign was identified by many as an effective method to raise men's awareness of testicular diseases. Of these informants, Ross said: "Most people would be aware of Movember. Like oh yes, prostate cancer. It's men's health. Like that part of it and it happens every year. There's some kind of a novelty." to which Daniel responded: "For Movember, you had all the Irish rugby team all of a sudden growing beards. Jeez! the whole country had beards! ... You had a couple of good-looking guys playing rugby for Ireland and all of a sudden, it's trending."

More than half of the informants believed that, unlike men in the workplace, young males in schools and universities are easily accessible. This was evident in the following excerpt by Tom: "You need people talking in universities and schools, because fundamentally

**Table 3**Sub-categories, generic categories, and main categories.

Sub-category	Generic category	Main category
Health programs	Television	Strategies to enhance awareness
Documentaries		
<ul> <li>Advertisements</li> </ul>		
Social media	Internet	
Mobile applications		
<ul> <li>Schools</li> </ul>	Campaigns	
Colleges		
Sports centers		
Workplaces		
Leaflets	Print media	
Booklets		
Posters		
<ul> <li>Innovative and creative</li> </ul>	Tailoring effective messages	Educational dos and don'ts
Visually stimulating		
<ul> <li>Brief, simple, and lighthearted messages</li> </ul>		
<ul> <li>Survivors and/or celebrities as educators</li> </ul>		
Lost messages	Drawbacks of national initiatives	
<ul> <li>Print media are too old</li> </ul>	Ineffective learning strategies	
Medical jargon		
False positives	Risks of increasing awareness	Implications of raising awareness
Emotional worry		
<ul> <li>Promoting community and men's health</li> </ul>	Benefits of increasing awareness	
Early detection		
<ul> <li>Same for heterosexual, gay, and bisexual men</li> </ul>	Learning needs	Learning among gay and bisexual men
<ul> <li>Similar to those of heterosexual men</li> </ul>	Educational strategies	
<ul> <li>More nuanced for gay and bisexual men</li> </ul>		

that's where you're going to find people because once again, into adulthood, you're not going to really get the same kind of level of attention." This was reiterated by Shane who said: "I think when you're in school or you're in college, you're in a collective audience and maybe you'll get exposure to information about health on some level... But as soon as you go into the workplace, it doesn't really seem to happen." In order to address this issue, Patrick proposed targeting men in large firms and involving the human resources department within large organizations in promoting the wellbeing of their male employees.

A number of informants recommended delivering educational messages to young men attending Gaelic Athletic Association (GAA) sports clubs. For instance, Luke said: "I would think groups or organizations that would be focused on young men if they had some sort of a campaign running focusing on these groups like a lot of the GAA would have men you know 18 to 30 group if you could go up to their clubs ..." Of note, GAA is known as Ireland's largest sporting organization promoting Gaelic games such as hurling and Gaelic football (Lane et al., 2016).

#### 3.2.4. Print media

Leaflets, posters, and booklets were suggested by very few informants as tools to raise awareness of testicular disorders. For instance, Juan believed that the leaflets used to promote breast cancer awareness can be used to promote TC awareness and screening; he said: "Sometimes when I go to the medical doctor, I don't find one of these brochures there, which says, 'Check your testicles'. Something like the breast cancer thing that is always there"; he laughed and added: "I mean I don't have breasts, but I know how to check!". Juan did, however, warn from flyers that are of a promotional nature; he said: "You need to check if this is like from a pharmaceutical or this is from the government, who is guiding the thing (flyer) because you feel like they are trying to sell you something." Tom on the other hand, suggested putting together and distributing a booklet that covers all male specific diseases.

#### 3.3. Educational dos and don'ts

When asked about the strategies that can be adopted to educate men about testicular disorders, informants recommended approaches that might work and warned from others that they thought are ineffective in fostering learning.

#### 3.3.1. Tailoring effective messages

Many informants perceived an effective educational intervention as being brief, visually stimulating, innovative, positively worded, and delivered frequently using light and simple language. For instance, Patrick who recommended using creative messages, said: "You could have some sort of a catchphrase, like you know, a ball in the hand or that kind of thing ... Sort of a play on words ... People will laugh and they'll gather and they'll talk to each other about it." To grab men's attention, Henry recommended advertisements that lighten the mood and that are visually appealing; he said: "I think if a man saw an ad that kind of lightened his mood, rather than brought him down, it'd be more inclined to get his attention ... But if it was just figures and words, they'd be like inclined to change channel, but if it was a funny ad, they'd be more inclined to watch it, rather than switch over." He also believed that men are visual rather than book learners; he added: "We're not book learners. I mean some people are. But I think we're a lot more visual and hands-on in how we get educated. So I think it has to be more of that approach rather than just words." Similarly, Luke recommended messages that are light and positively rather than negatively worded; he said: "Make it lighthearted ... Make it look like it's part of your monthly routine . Make it come across that it's something because you are doing this doesn't mean you are going to find something you are doing this because everybody else is doing it."

Antonio who had an interest in media and marketing said that educational messages must be repeated otherwise they "will wear thin"; he added: "You need to change approach every couple of years, regardless of what the message is." This, according to Kevin, would help achieve a "top-up effect." Ziad and Daniel believed that "brief and frequent messages" as well as "very snappy, and appealing" messages are more likely to be effective in raising awareness of testicular diseases. Furthermore, Hans and Jack believed that, for an educational strategy to be effective, it must be delivered "in small chunks on a regular basis" in order to avoid "overloading people."

A number of informants recommended having a celebrity who appeals to the masses deliver the educational messages. For instance, Mark said: "If you get those people who are looked up to, like you've soccer stars, rugby stars, GAA stars, you know, if they're talking about it, people might talk about it." This was echoed in the interview with Harry who believed that having an idol teach men about TSE helps "remove some of the embarrassment". Similarity, Kevin believed that having a celebrity discuss testicular diseases "immediately takes away the stigma"; he added: "People only really like shock tactics, so there's no point in you coming out and talking about testicular diseases after having never had one because nobody would care."

#### 3.3.2. Drawbacks of national initiatives

According to a number of informants, campaigns such as "Movember" became more about growing facial hair rather than raising awareness of male cancers. For instance, Patrick stated: "It (Movember) just seems to be an excuse to grow a moustache and look funny because I see a load of people doing it, but I never hear them actually talking about getting checked themselves ..." Connor nodded in agreement and said: "I'd say a lot of people have lost the message of Movember." Ziad, on the other hand, believed that national campaigns are a waste of resources and are conducted to tick a box, rather than to raise awareness; he said:

"With national campaigns, you feel as if they are just a waste of money because this is just my own general personal feeling, is that oh, we have to do something, we are a charity, we have this amount of money, we have to spend it, we just do it because we have to do it. we tick a box so it's done."

Targeting the wrong age group was also perceived as a drawback of national initiatives; for instance, as he was recalling a television campaign by the Irish Cancer Society, Tom said "I remember the advertisement being typically targeted at older men rather than younger men, as a result, I lost interest automatically."

#### 3.3.3. Ineffective learning strategies

Strategies that were perceived by many informants as ineffective in fostering awareness include print media as well as messages containing medical jargon. At first Tom was recommending a booklet that includes the most common male diseases; he then hesitated and said: "I think I have read one study on that actually and it did say that people don't look at the booklets, basically. About 15% to 20% of people do and then the other 80% don't." This was reiterated by Henry who believed that no one is going to pay attention to leaflets as well as Ziad who said that he will be disaffected by people giving him flyers about TC; he said: "I won't read them, even if it's something that I'm interested in."

As one of the informants in a focus group was recommending leaflets to teach men about testicular disorders, Donal interrupted saying: "Just giving leaflets to people? I don't think so ... Well, it is useful, but there's probably better ways in this age." Similarly, Rami

said: "The classical way of giving a brochure and putting paintings in hospitals saying, 'Look' ... They didn't really mark me." He also warned from the use of an academic tone; he said: "Not a rigid academic tone and seriousness. This is not going to work. It should be something that teenagers will accept and not see as condescending." This was reiterated by Mark who believed that the use of medical jargon would "take away the human element out of it (educational intervention) and would make a man feel like a test subject."

#### 3.4. Implications of raising awareness

Informants were asked to reflect on the potential risks and benefits of raising men's awareness of testicular disorders. They were then probed as to whether the benefits outweighed the risks or vice versa.

#### 3.4.1. Risks of increasing awareness

Very few men stated that increased awareness can lead to emotional worry and can increase the likelihood of false positives. For instance, despite being supportive of educating men about testicular symptoms, Adam stated that increased awareness would cause people to become "needlessly or overly concerned." Similarly, Harry warned from the dangers of over-scanning and panicking people; he said:

"There are false positives, aren't there? So there's always the risk of over-scanning people, there's a risk of panicking people and there's also, whenever you do any kind of scanning, there are false positive dangers."

#### 3.4.2. Benefits of increasing awareness

The majority of the informants believed that there were no risks from increasing awareness of testicular disorders since, according to Hans, "awareness of every disease, no matter where it is, is a good thing." This was reiterated by Kevin who believed that initiatives targeted at raising awareness of testicular symptoms, serve as an opportunity to promote men's heath; he said:

"I think there are potential benefits around that (raising awareness) for improving men's health in terms of their knowledge of how to deal with the situation and their knowledge of how to mind their own health and to be a bit independent."

#### 3.5. Learning among gay and bisexual men

The informants' views regarding the learning needs of gay and bisexual men were explored. Informants were then probed as to whether the same educational strategies can be used to raise awareness of testicular disorders among heterosexual, gay, and bisexual men.

#### 3.5.1. Learning needs

Informants unanimously believed that heterosexual, gay, and bisexual men have the same learning needs. For instance, Scott said: "Gay men don't need to know anything more than anyone else, unless they are doing things to their testicles that straight men do which I'm highly doubtful of." This was echoed in the interview with Harry who said: "I try to treat everyone the same unless there's a really good reason for not doing." Rami, on the other hand, warned from the dangers of addressing the needs of gay and bisexual men differently; which, according to him, would lead to discrimination.

#### 3.5.2. Educational strategies

As for the strategies used to raise awareness, responses were divided between those who believed that educational messages should be the same for heterosexual, gay, and bisexual men and those who believed that health marketing should be different. According to Luke, educational strategies "could be quite standard-ized", when asked to elaborate he said: "Because like that now if you see those programs on telly ... people have the same reaction and I don't think whether you are straight or gay or whatever you'd need a different approach." Similarly, Henry believed that there should be a strategy that "fills all areas, rather than having several different ones because if you're having several different ones, that's kind of inferring a difference between them (heterosexual, gay, and bisexual men)"; he laughed and added: "Like testicles are testicles!"

On the other hand, Tom stated that "what's going to work for a straight man isn't going to work for a gay man", when probed about the reason; he said:

"I would say that it should be something more, how would I put it? More nuanced ... A gay man has potentially the benefit of a partner with the same, you know, biological structure. So it's a case of using that to your advantage if you were targeting gay men ... I mean gay men are more likely to get STDs (sexually transmitted diseases) than straight men. So obviously if there's that much of a difference between the two groups, it makes sense to separate the kind of health marketing out."

Similarly, Ziad and Kevin who self-identified as gay, stated that they would not identify with an advertisement that is targeted towards heterosexual men only. For this reason, they recommended, either inclusive marketing strategies or strategies that are exclusive to gay men. For instance, Kevin said:

"For the gay community, probably something more vain and for the straight community, probably something more macho. So if someone showed me a soccer player telling me that he was checking his testes, he would want to be a cute soccer player for me to pay interest in him ... But if it was more to do with vanity or sexual prowess, I would be more likely to listen."

#### 4. Discussion

The present study aimed at exploring men's preferred strategies to raise awareness of testicular disorders. Almost half of the men were uninformed about testicular disorders, especially the nonmalignant ones. They did, however, express their interest in learning about these diseases through a number of means, including television shows, campaigns, fundraisers, the internet, and to a lesser extent, print media. In fact, many informants recommended moving away from conventional print messages that contain medical jargon. This recommendation is echoed in the literature on men's preferred learning strategies. For instance, while exploring gender differences in learning style preferences among college students, Wehrwein et al. (2007) found that, unlike females, males preferred multimodal learning using auditory and kinaesthetic strategies rather than diagrams, charts, and graphs, Similarly, Thornton (2015) found that interventions using written materials to promote TSE among young men were unsuccessful in doing so.

Many informants believed that social media and mobile phone applications are instrumental in fostering awareness of testicular disorders among young men. These means are commonly used among youths who spend, on average, 7.5 h online every day

(Rideout et al., 2010). Moreover, evidence suggests that adolescents in the United States and the United Kingdom acquire most of their health information from the internet especially when it comes to health topics that are of a private nature (Gray et al., 2005). Also, the internet serves as the primary source of information on HIV and STIs among gay and bisexual men (Holloway et al., 2014). For instance, social networking sites, such as Facebook and YouTube, were instrumental in engaging gay men with information on sexual health (Pedrana et al., 2013). Another common method of acquiring health information, is through mobile dating applications such as Grindr (Hooper et al., 2008). This echoes findings from the present study, whereby one of the informants learned about free HIV testing through an advertisement on Grindr and recommended HV same approach to get men to check their testes and to seek help for any abnormalities.

School and university campaigns were also perceived as ideal to promote awareness. These findings are echoed in two systematic reviews whereby 16 of 25 studies exploring men's awareness of TC and self-examination (Saab et al., 2016c) and five of 11 studies aimed at enhancing TC awareness and screening (Saab et al., 2016b) were conducted among school and university students. Moreover, educational campaigns that were conducted in colleges (Wanzer et al., 2014) and schools (Jones et al., 2015) have shown to be instrumental in raising men's awareness of TC and promoting TSE. In contrast, many informants believed that men who work are hard to reach, and are therefore underrepresented in health promotion initiatives. The same concern was highlighted in the Irish National Men's Health Policy (Department of Health and Children, 2008).

Another strategy that was perceived as ideal to reach out to younger men, was through their local sporting clubs. These clubs (e.g. GAA) serve as a hub for over one million youths in Ireland (GAA, 2016). In recent years, GAA clubs have been making efforts to foster a culture of health promotion. To better understand this culture, Lane et al. (2016) surveyed 16 GAA clubs about their health promotion policy, ideology, practice, and environment. Overall, clubs perceived health promotion as an integral part of their work. yet they scored low on policy and coaching health promotion activities. It is worth noting that health promoting sports clubs are not exclusive to Ireland as they are common in other countries including Denmark (Persson, 2008), Sweden (Engström, 2008), Belgium (Frisch et al., 2009), Finland (Kokko et al., 2006), the United Kingdom (Flintoff, 2003, 2008), as well as the United States (Daniels, 2007), Canada (Fraser-Thomas et al., 2005, 2008), and Australia (Casey et al., 2009).

In contrast, not all informants perceived national campaigns, including the internet campaign Movember, as instrumental in raising men's awareness of testicular disorders. In fact, many were sceptical about the effectiveness of this strategy and believed that men lost the message behind it. These findings are supported by evidence from a Canadian study whereby Bravo and Hoffman-Goetz (2016) analysed 4,222 tweets about Movember and found that there were significantly fewer health-related than non-health-related tweets. It was also found that men were engaged in activities such as growing a moustache, rather than discussing the health implications of the campaign. These findings concur with those of a larger study conducted by Jacobson and Mascaro (2016), whereby an analysis of 1,879,994 tweets showed that young men were engaged with Movember as a branded movement rather than a health promotion campaign.

A number of informants recommended having a survivor of a testicular disorder deliver health promoting messages. Examples include comedians Tom Green and Des Bishop, cyclist Lance Armstrong, as well as GAA player Noel McGrath. Having celebrities teach men about testicular disorders is not uncommon in the literature on TC. For instance, Daley (2007) found that men who

were knowledgeable about TC often linked it to cyclist Lance Armstrong. Moreover, a television show featuring comedian Tom Green's journey with TC (Trumbo, 2004), and a high school campaign delivered by young cancer survivors (Jones et al., 2015) were successful in raising TC awareness and promoting TSE.

According to many informants, for a learning strategy to be effective, it must be tailored to meet the needs of younger men. Therefore, it must be visually appealing, original, humorous, and delivered frequently using simple, brief, and positively worded messages. This was reiterated in the study by Gold et al. (2012) who designed an intervention to promote sexual health among at-risk groups, namely men aged 16-29 years and gay men. The intervention was delivered using social network sites. One arm of this intervention was targeted at gay men and was delivered in the form of a short series that was uploaded on Facebook and YouTube (Pedrana et al., 2013). Participants were prompted to discuss sexual health issues online between episodes. Overall, men felt comfortable watching the series, were able to identify with the characters, found that the information were easy to understand, and perceived the interactive part of the intervention as ideal to initiate open discussions about sexual heath with their peers (Pedrana et al., 2013). This echoes the responses of a number of informants who believed that health promoting strategies targeting gay men should be nuanced or inclusive rather than generic, as well as those who perceived a successful intervention as one that features real people discussing real health issues.

#### 4.1. Implications

Findings from the present study stress the need to address awareness of testicular disorders in research, education, and clinical practice. Researchers should be cognizant of men's preferred modes of learning. They are also advised to adopt strategies that appeal to young men; these include but are not limited to, mobile phone applications, interactive websites, and virtual reality. For instance, the use of virtual reality is gaining popularity in research. In recent years, this technology has been used in a number of fields including rehabilitation (Laver et al., 2012), mental health (Hone-Blanchet et al., 2014), and education (Bailenson et al., 2008). In contrast, very little is known as to the effectiveness of virtual reality in health promotion, let alone its use in promoting men's health.

National initiatives, including Movember, should stress the health implications of their campaigns in order to avoid the messages getting lost. In addition, these campaigns should be delivered frequently to achieve a top-up effect, must be altered occasionally so that young men would not lose interest, and should cater to the needs of men who are at risk for health inequities. Such campaigns are best delivered in schools, universities, and sports centres to reach out to a wide audience and normalize topics that are often perceived as taboo. Men who work must not be excluded from such initiatives. For this reason, a number of strategies should be put in place to instigate health promotion in the workplace; these include partnerships with employers, unions, governmental bodies (Department of Health and Children, 2008).

From a clinical perspective, recent evidence suggests that it is important to ask men about their sexual orientation and gender identity in health care settings (Center for American Progress, 2013). Moreover, collecting data about sexual orientation and gender identity is thought to help reduce lesbian, gay, bisexual, and transsexual (LGBT) invisibility in health care and is perceived as the key to end LGBT health disparities (Cahill and Makadon, 2013). For this reason, clinicians, including nurses, are encouraged to address the individual needs of young men while educating them about the seriousness of testicular symptoms and the importance of seeking timely medical attention for any abnormalities. To do so, and for

feasibility purposes, clinicians can make use of print media including infographics and flyers that are colourful, written in large fonts, and easy to comprehend among men with low health literacy (Wanzer et al., 2014).

#### 4.2. Limitations

Findings from this study must be considered in light of a number of limitations. For instance, the sample recruited cannot be considered to be representative of all the men in Ireland. Nevertheless, transferability was enhanced through seeking a heterogeneous sample. Also, self-selection bias could have occurred due to the fact that only those who provided consent to participate were interviewed. Moreover, accidental alteration of the data could have occurred. This was accounted for through performing member check and having the primary investigator and co-investigators independently review and agree on the analysis. Given the intimate nature of this topic, informants could have concealed some aspects of their experiences. For this reason, a number of icebreakers were used before each interview. Finally, having an experienced male interviewer conduct the interviews, facilitated open discussions about a subject that is seldom spoken about.

#### 5. Conclusion

The present qualitative study addressed men's preferred strategies to raise awareness of testicular disorders. Findings from this study suggest that young men prefer brief, visually appealing, and creative messages over conventional approaches like leaflets and brochures. Interventions that account for men's preferred learning strategies and the needs of men who are at risk for health inequities, may be promising in promoting awareness of both, malignant and benign testicular diseases.

To the best of the authors' knowledge, this is the first study to explore the educational needs of men with regard to testicular disorders and to purposely include men who self-identify as gay and bisexual. Given the sampling strategies (e.g. maximum variation and snowball sampling), findings may be transferrable to different contexts.

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None.

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**Appendix 3.3** Standards for Reporting Qualitative Research (SRQR; O'Brien *et al.* 2014 p. 1247-1248)

No.	Topic	Item
<b>S</b> 1	Title	Concise description of the nature and topic of the study
		Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement
S4	Purpose or research question	Purpose of the study and specific objectives or questions
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/ experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability
\$7 \$8	Context Sampling strategy	Setting/site and salient contextual factors; rationale How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/ methods, and modification of procedures in response to evolving study findings; rationale
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts

S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalisability; identification of unique contribution(s) to scholarship in a discipline or field
S19	Limitations	Trustworthiness and limitations of findings
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting

#### Appendix 3.4 Ethical approval to conduct the qualitative study



# COISTE EITICE UM THAIGHDE CLINICIÚIL Clinical Research Ethics Committee

Lancaster Hall, 6 Little Hanover Street, Cork, Ireland.

Coláiste na hOllscoile Corcaigh, Éire University College Cork, Ireland

Our ref: ECM 4 (c) 11/08/15

15th July 2015

Professor Josephine Hegarty School of Nursing and Midwifery Catherine McAuley School of Nursing & Midwifery University College Cork Brookfield Health Sciences Complex College Road Cork

Re: Exploring awareness and screening for testicular disorders.

Dear Professor Hegarty

Expedited approval is granted to carry out the above study at:

The following documents have been approved:

- Signed Protocol Submission Form
- Research Proposal dated 3rd July 2015
- > Invitation Letters Version 1 dated 3rd July 2015
- Consent Form Version 1 dated 3rd July 2015
- Interview Questions Version 1 dated 3rd july 2015
   Study Poster Version 1 dated 3rd July 2015
- > Insurance Certificate
- CV for Chief Investigator.

We note that the co-investigators involved in the study will be:

> Mohamad Saab, PhD in Nursing Student and Margaret Landers, Lecturer.

Yours sincerely

Professor Michael G Molloy

Chairman

Clinical Research Ethics Committee

of the Cork Teaching Hospital

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good

**Appendix 3.5** Letter inviting potential participants to take part in the qualitative

study

Dear Colleagues,

I, Mohamad Saab, a PhD student at University College Cork, School of Nursing and

Midwifery invite you to participate in a research study entitled 'Exploring Awareness

of Testicular Disorders.'

The study aims at exploring men's understanding of testicular disorders and their

opinions regarding increasing awareness of these disorders.

Should you choose to participate, you will be asked to partake in an individual or group

discussion.

Your participation would contribute to the body of knowledge about this topic, which

is important given that this area has not been previously studied. Moreover, this study

will provide us with valuable information which will help us develop an educational

intervention that is sensitive to the needs of all men.

If you are interested in participating or have any questions, please feel free to contact

me.

Light refreshments and snacks will be served during the discussion.

Thank you for your time and consideration and looking forward to hearing from you.

Sincerely,

Mohamad Saab, PhD student, MSc, BSc, RN

College of Medicine and Health

Catherine McAuley School of Nursing and Midwifery

University College Cork, Ireland

Email: msaab@ucc.ie

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**Appendix 3.6** Flyer inviting potential participants to take part in the qualitative study



# GO NUTS!

### **ARE YOU**

- √ A male?
- √Aged between 18 and 50 years?

We are conducting a study titled:

EXPLORING AWARENESS OF TESTICULAR DISORDERS

Interested in knowing more?

Contact Mohamad Saab on msaab@ucc.ie

**Appendix 3.7** Participant Information Leaflet

Dear Participant,

You are invited to participate in a study titled: "Exploring Awareness of Testicular Disorders" conducted by Mr Mohamad Saab, a PhD in nursing student, Professor Josephine Hegarty at University College Cork, and Dr Margaret Landers, a lecturer at University College Cork.

The study aims at exploring your understanding of testicular disorders and your opinion regarding increasing awareness of these disorders.

If you agree to take part of this study, you will be invited to participate in one individual or group interview. You will be asked to sign an informed consent and provide some information about yourself prior to the interview. The interview is expected to take between 30 and 60 minutes depending on your preference.

If agreeable to you, you might be contacted a few weeks following the interview to confirm the information that you provided earlier.

Your name will not appear anywhere. The informed consent form will be kept in a locked cabinet and the interview recordings will be stored on a password protected computer accessed only by the researchers.

Your participation is completely voluntary. You can choose not to participate or to withdraw whenever you feel like it. Your refusal to participate will have no effect on you whatsoever.

There are no direct benefits to you from this study. However, your participation would contribute to the body of knowledge about this topic, which is important given that this area has not been covered in prior studies. This study will provide information which will help in the development of an educational intervention that is sensitive to the needs of men.

There are no risks from your participation.

Please do not hesitate to contact me if you have any questions or suggestions.

Sincerely,

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

#### **Appendix 3.8** Referral Form

#### Dear Participant,

We do not anticipate that the content of this interview will upset you, however, please do not hesitate to inform me at any time in case you feel uncomfortable or experience emotional distress during the interview. We can either pause the recording and resume our interview at a later stage or stop the recording and end the interview. In addition, if you have any further questions or concerns in relation to testicular health/conditions, you can contact the nurses in one of the Irish Cancer Society Daffodil Centres in Cork:

#### **Daffodil Centre – Cork University Hospital**

Contact person: Colette Grant

Tel: 0214234536

Email: daffodilcentrecuh@irishcancer.ie

#### **Daffodil Centre – Bon Secours Hospital Cork**

Contact person: Catriona O'Mahony

Tel: 0214941941

Email: daffodilcentrebonsecours@irishcancer.ie

#### For students at University College Cork:

If you have questions or concerns with regard to your health, do not hesitate to contact:

#### **UCC Student Health Department**

Tel: 0214902311

If you feel like talking to someone, please visit <a href="http://www.ucc.ie/en/studentcounselling/">http://www.ucc.ie/en/studentcounselling/</a> to check the latest counselling workshops and online programmes or contact:

#### **UCC Student Counselling & Development**

Tel: 0214903565

Email: counselling@ucc.ie

#### Sincerely,

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

#### **Appendix 3.9** Informed Consent Form

#### CONSENT BY SUBJECT FOR PARTICIPATION IN RESEARCH PROTOCOL

Section A Protocol Number:	Subject's initials:
Title of Protocol: Exploring Aware	eness of Testicular Disorders

PI Directing Research: Prof. Josephine Hegarty

Co-investigator: Mr. Mohamad Saab, Dr. Margaret Landers

You are being asked to participate in a research study. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

#### **Section B**

#### I. NATURE AND DURATION OF PROCEDURE(S):

The purpose of this study is to explore the screening for and awareness of testicular problems among healthcare providers who are involved in promoting men's health, healthcare professionals health well working sexual services, as as the general population. If you wish to participate in the study, you will be asked to participate in an interview where we will talk about your experiences regarding testicular disorders. The duration of the interview can 15 and 60 minutes depending Mr. Mohamad Saab, a PhD in nursing student, will be conducting the interviews and will be taking a few notes during the discussion. All the study documents will be securely stored within the UCC and all the collected data will be kept You have the full right to refuse to participate or to withdraw from the study. Your refusal to participate or withdrawal will not affect you in any way.

#### II. POTENTIAL RISKS AND BENEFITS:

There are no potential psychological or physical harms from your participation in this study. Findings from this study would influence policy makers to make changes regarding screening for testicular problems if need be. Findings would also help us create educational opportunities for healthcare providers and the general population with regards to screening for problems that affect the testes. This study will be the first of its kind and is expected to pave the way for future studies on this important topic.

#### III. POSSIBLE ALTERNATIVES:

You may choose not to participate in this study.

#### Section C AGREEMENT TO CONSENT

The research project and the relevant procedures associated with it have been fully explained to me. All the purposes and procedures have been identified and no guarantee has been given about the possible results. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. I am aware that findings from this study will be anonymous and might be presented in a thesis, oral presentations, and/or publications. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.

I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at the Cork Teaching Hospitals. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the researcher listed above. If I have further queries concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals, Lancaster Hall, 6 Little Hanover Street, Cork.

After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

Researcher:	<u></u>
	Signature of Participant
	Date: Time: AM
	(Circle) PM

### Appendix 3.10 Socio-demographic Questionnaire

1. Gender	7. Current occupation (please tick what applies to you)
Male	11 ,
☐ Female	Student
Other (please specify):	Employed (full-time)
2. Age: Years	<ul><li>Employed (part-time)</li><li>Self-employed</li><li>Unemployed</li></ul>
3. Nationality(ies)	Other (please specify):
☐ Irish	8. Have you got a personal
Other (please specify):	history of one or more
	testicular disorder(s)?
4. Sexual orientation	000000000000000000000000000000000000000
	Yes (please specify):
Heterosexual	No
Gay/Lesbian	Unsure
Bisexual	<u> </u>
Transsexual/Transgender	9. Have you been previously
Other (please specify):	informed/educated about
	testicular disorders?
5. Marital status	**************************************
_	Yes (please specify how):
Single	$\overline{\square}$ No
Married	<del>_</del>
Engaged	10. Do you plan on seeking
In a relationship/Partnered	information/more
Divorced	information in relation to
Separated	testicular diseases in the near
Widowed	future?
6. Highest level of education	Yes
	□ No
None	
Primary	
Lower secondary	11. On a scale of 0 to 10 (10 being
Higher secondary	the most important), how
Post leaving cert.	important do you think it is for
Third level degree or above	you to learn about testicular
Other (please specify):	diseases? (Please circle your
	answer)
	0 1 2 3 4 5
	6 7 8 9 10

#### **Appendix 3.11** Interview Protocol

Firstly, I would like to welcome you all and to thank you for agreeing to be part of this discussion.

I would like to draw your attention to the consent form and short socio-demographic questionnaire that you have in front of you, please make sure that these are completed and handed up before our discussion.

The discussion will take between 15 minutes and one hour.

The purpose of this discussion is to explore your understanding of testicular disorders and your opinions regarding increasing awareness of these disorders.

Feel free to add in anything else you think is important as we work through the questions. There are no right or wrong answers therefore feel free to openly discuss your opinions, views, and experiences.

Before we begin I would like to remind you that whatever you say will be kept confidential. Your name and personal details will not be mentioned in any report, publication, or presentation.

I am using a digital recorder to record our conversation because it is difficult for me to write down everything you say. I might take a few notes during the interview.

Focus group/individual interview	number:
Date:	
Starting time:	Ending time:

#### **Questions and probes**

#### 1. What is the first thing that comes to your mind when I say 'testicular diseases/disorders'?

- a. How come [the answer] crossed your mind?
- b. Can you tell me more about [the answer]? (Risk factors, treatment, screening...)
- c. Have you heard of other testicular problems? If yes, what, how, and where did you hear about them?
- d. In the past, did you or did anyone you know suffer from a testicular disease? If yes, what was it? How was it discovered? How was it treated?

#### 2. I would like you to think about two scenarios:

- a. Let's suppose you, or someone you know started feeling pain in the testes, how would you/they react?
- b. Let's suppose you, or someone you know happens to discover a lump in the testes, how would you/they react?

#### 3. What is your views and opinions regarding increasing men's awareness of testicular diseases?

- a. Is it important? Why?
- b. What do you think about its risks and benefits?
- c. What helps men become more aware of testicular diseases? (prompts: knowledge, skills, tools)

#### 4. Think of your awareness of another health-related topic that you remember in detail, and is of interest to you:

- a. What is the topic?
- b. How did you learn about it?
- c. What drew your attention to it/what makes it interesting?
- d. Could the same method be used to raise awareness of testicular disorders? If no, why? If yes, how?
- e. What do you think about the learning needs of gay, bisexual, and transsexual (GBT) people?
- f. Do GBT people have different educational needs? Why? If yes, how can they be addressed?
- g. Could the same method be used to raise awareness of testicular disorders among GBT people?

#### 5. Are you personally interested in learning more about testicular diseases?

- a. Why? Can you please elaborate?
- b. If yes, how confident are you in your ability to learn about testicular diseases?
- c. What would you like to know about testicular disorders?
- d. How would you like to learn about them?

#### 6. Do you think an increased awareness of testicular disorders can be achieved in Ireland?

- a. Why?
- b. If yes, how?

Appendix 3.12 Sample Coding Sheet

Question	Meaning unit	Condensed meaning unit	Code
What was the first thing that	So I thought about maybe in the first place about STDs,	First thought STDs and cancer	Thinking about STDs and
came to your mind when I	sexually transmitted disease, and cancer mainly	mainly	cancer
said that we were discussing			
testicular disorders?			
	One particular case that I was told about from a friend	•	_
	of mine, who was a medical student and now he's a	testicular torsion	torsion from a doctor friend
	doctor, and that's testicular torsion.		
	Cancer can get to any part of the body, so tell me about	• • •	Thinking of cancer because
	any disorder and any part of the body, so this is one of	is the first thing I will think about	it affects any part of the body
	the first thing that I'm going to think about.		
	Maybe it's a little bit of an obsession everyone is	,	Everyone is thinking and
	thinking about all the time, cancer.	about cancer	obsessed about cancer
	And STDs, yes, because I have this experience of	1 0 0	Having a history of STDs
	getting an STD and affecting my testicles.	that affected the testicles	
	I felt a swelling in my testicles, so I went to the hospital,	Felt a testicular swelling, went to the	Feeling testicular swelling
	to the ER, and there they did all the echo scan. They	ER, urine culture and blood tests	and going to the ER and
	did all the culture. Like they took a urine culture,	done but there was no known STD	getting tested for STDs
	they took blood samples from me and there was no sign		
	of any known STD.		
	They said it might be chlamydia because it's the most	Got diagnosed with chlamydia	<b>U</b> .
	common STD in Lebanon, where I got it from my	caught from the partner, that's why	•
	partner. So that's how I know about it. That's why I	the answer was STD in the first	think about STDs
	said STD in the first place.	place	

### Appendix 4

**Appendix 4.1** The Preconscious Awareness to Action Framework: An Application to Promote Testicular Awareness (Saab et al. 2018)<sup>6</sup>



Special Issue: Theory

### The Preconscious Awareness to **Action Framework**

An Application to Promote Testicular Awareness

AQ1 Mohamad M. Saab ▼ Margaret Landers ▼ Josephine Hegarty

Background: Health outcomes among men are markedly poorer than women. Testicular disorders can be life-threatening if left untreated. Few studies promoting awareness of testicular disorders have been underpinned by theory. Theory-based interventions are more likely to achieve positive health outcomes than interventions that lack a theoretical foundation.

Objectives: The purpose of the study is to present a theory-focused analysis of the preconscious awareness to action framework (PAAF), developed to enhance testicular awareness and help-seeking intentions and behaviors among men.

Methods: The following approach was used to develop the PAAF: The empirical literature on men's awareness of testicular disorders was reviewed. A qualitative study was conducted to explore men's awareness of testicular disorders, help-seeking intentions for testicular symptoms, and preferred learning strategies in relation to testicular disorders and symptoms. An iterative narrative review process of the theoretical literature on health promotion and symptom appraisal was undertaken.

Results: The PAAF comprises seven steps: preconscious awareness, unconscious awareness, conscious awareness, unconscious appraisal, conscious appraisal, intention, and behavior. The concept of testicular awareness was developed to familiarize men with their own testes and promote timely help-seeking

Discussion: Researchers are encouraged to use the PAAF to design health-promoting interventions aimed at enhancing testicular awareness, symptom appraisal, and help-seeking.

Key Words: awareness . men's health . nursing theory . testicular disease

Nursing Research, Month 2018, Vol 00, No 0, 00-00

lobally, health outcomes among men continue to be markedly poorer than women, and efforts to promote men's health remain scarce (Baker et al., 2014). This, coupled with the assumption that men are disinterested in their own health, leads to gender-based health disparity and discourages men from engaging with health services (Leone & Rovito, 2013).

Of the diseases that are seldom discussed in current men's health initiatives, disorders of the testes can have a major impact on a man's well-being. Testicular cancer (TC) is the most frequently diagnosed solid tumor among men aged 18-50 years in the United States (National Cancer Institute, 2015). The incidence of TC in developed countries doubled over the past four decades (Rosen, Jayram, Drazer, & Eggener, 2011), and TC mortality is highest in the developing world due to late presentation and limited access to care (Znaor, Lortet-Tieulent, Jemal, & Bray, 2014). TC treatment is associated with chronic complications including

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fatigue, neuropathy, metabolic syndromes, and infertility (Saab, Noureddine, Huijer, & DeJong, 2014).

Like TC, a number of benign testicular disorders can be life-threatening if left untreated; an example is testicular torsion, which involves idiopathic twisting of the testes. This condition is a medical emergency that can lead to testicular ischemia and necrosis (Ringdahl & Teague, 2006). Another example is epididymitis and orchitis (i.e., inflammation of the epididymis and testes) that result from sexually transmitted disease among men aged 50 and younger and can lead to sepsis and infertility if not treated promptly (Centers for Disease Control and Prevention [CDC], 2015).

Experimental studies aimed at raising men's awareness of benign testicular disorders are lacking (Saab, Landers, & Hegarty, 2016a), and only half of the studies promoting TC awareness reviewed by Saab, Landers, and Hegarty (2016b) were underpinned by theory. Sidani and Fleury (2016, p. 190) defined interventions as "a set of inter-related activities directed toward attaining common goals." Theory-based interventions help achieve positive health outcomes more than interventions that lack a theoretical basis (Michie, Johnston, Francis, Hardeman, & Eccles, 2008; Savage, Farrell, McManus, & Grey, 2010). Moreover, theory development is a key step in the Medical Research Council framework used to develop and evaluate complex

Nursing Research www.nursingresearchonline.com health interventions (Craig et al., 2013). Therefore, a good theoretical understanding of a phenomenon is key to modeling an intervention, understanding how an intervention instigates change, and exploring the role of potential moderating and influencing variables (Michie et al., 2008; Sidani & Fleury, 2016).

In nursing, theory serves as a roadmap to design, implement, and evaluate interventions to promote health, maintain health, manage illness, and provide comfort at end of life (Sidani & Fleury, 2016). The elements of theory building include concepts, statements, and theories (Walker & Avant, 2011). Concepts are a mental image of a phenomenon and are regarded as the building blocks of a theory. Statements specify the context of theory building, either by defining the concepts (i.e., nonrelational) or describing the relationship between them (i.e., relational). Walker and Avant (2011) defined theory as "an internally consistent group of relational statements that presents a systematic view about a phenomenon and that is useful for description, explanation, prediction, and prescription or control" (p. 7). It is often used to express a new idea or insight into the nature of a phenomenon. Theory is built using three key processes: synthesis, derivation, and analysis. Synthesis involves using information to construct a new concept or theory; derivation allows researchers to redefine a concept to fit a new context; and analysis involves clarifying, refining, or sharpening concepts or theories (Walker & Avant, 2011).

This study presents a theory-focused analysis of the preconscious awareness to action framework (PAAF) developed to enhance testicular awareness and help-seeking intentions and behaviors among men aged 18–50 years because those who fall within this age group are at the highest risk for testicular disorders (CDC, 2015; National Cancer Institute, 2015; Ringdahl & Teague, 2006).

#### **METHODS**

The PAAF was developed following a synthesis of evidence from the empirical and theoretical literature on awareness, 11 help-seeking, and symptom appraisal (Table 1).

#### Reviews of the Empirical Literature

A systematic review of exploratory studies on men's awareness of TC and self-examination (n=25 studies; Saab, Landers, & Hegarty, 2016c), a systematic review of experimental studies promoting awareness of TC and self-examination (n=11 studies; Saab et al., 2016b), and an integrative review of exploratory studies on men's awareness of benign testicular disorders (n=4 studies; Saab et al., 2016a) were conducted. It was found that men lacked awareness of TC, self-examination, and benign testicular disorders, and many intended to delay help-seeking for testicular lumpiness, swelling, and pain (Saab et al., 2016a, 2016c). Ten of the 11 reviewed interventions promoting awareness of TC and self-examination succeeded in doing so.

Moreover, six studies mentioned using theories, yet failed to map them onto the development and testing of the interventions (Saab et al., 2016b). Of note, none of the reviewed studies reported on men's preferred learning strategies, explored qualitatively their awareness of benign testicular diseases, or attempted to raise their awareness of diseases other than TC.

#### Qualitative Study

Findings and gaps from the reviewed empirical literature informed a qualitative study aimed at exploring men's (n = 29) awareness of benign and malignant testicular disorders, help-seeking intentions for testicular symptoms, and preferred learning strategies in relation to testicular disorders and symptoms. This study is reported in detail in Saab, Landers, and Hegarty (2017a, 2017b).

Overall, men were unaware of the risk factors, signs and symptoms, and treatment of TC. Moreover, men's awareness of nonmalignant testicular disorders was lacking—which echoes findings from the empirical literature (Saab et al., 2016a, 2016b, 2016c). A number of men intended to delay help-seeking for testicular symptoms due to knowledge deficit, symptom misappraisal, fear, embarrassment, cultural factors, cost and access to care, and inability to differentiate between normal and abnormal lumps (Saab et al., 2017a; Figure 1). To [FI] help raise awareness, men recommended using educational interventions that are brief, visually stimulating, novel, and positively worded, with the use of light and simple language (Saab et al., 2017b).

#### Review of the Theoretical Literature

Data from the empirical literature and qualitative study helped plan an interactive educational intervention aimed at enhancing men's awareness of the normal testes and the most common testicular symptoms (e.g., lumpiness, swelling, and pain) and disorders (e.g., TC, epididymitis, orchitis, and testicular torsion). The ultimate goal of this intervention was to enable men to seek timely medical attention for testicular symptoms.

An iterative narrative review process of the theoretical literature on health promotion and symptom appraisal was undertaken to source and derive an underpinning theory/model. Derivation involves redefining a concept, statement, or theory from one context to another (Walker & Avant, 2011).

Six categories of multidisciplinary theories and models used in health promotion were identified as follows: behavioral change theories, intervention-based models, ecological theories and models, planning models, communication theories, and evaluation models (Nutbeam, 2013; Raingruber, 2014). A behavioral change model, namely the transtheoretical model (TTM), provided insight into the cognitive domains involved in the thinking processes underpinning the development of awareness and intentions to alter behavior (Prochaska &

#### TABLE 1. Development of the Preconscious Awareness to Action Framework

#### AQ2 Step/approach Key findings

Review of empirical literature

- Systematic review: 25 quantitative/qualitative studies/knowledge, awareness, attitudes toward testicular cancer, self-exam<sup>a</sup>
- Systematic review: 11 experimental studies promoting awareness of testicular cancer, self-exam<sup>b</sup>
- Integrative review: 4 quantitative studies/awareness of benign testicular disorders<sup>e</sup>

Qualitative descriptive study

- To explore awareness of testicular disorders; help-seeking intentions for testicular symptoms; preferred strategies for learning about testicular disorders, symptoms (n = 29)<sup>f.g.</sup>
- Men 18-47 years; 12 semistructured interviews; 3 focus groups
- · Qualitative content analysis
- Trustworthiness: heterogeneous sample, cross-checked analyzed data, member-checks, memoing, field notes, audit trails

Review of theoretical literature

- Iterative narrative review: theoretical literature on health promotion, symptom appraisal, neurobehavioral psychology
- Six categories of multidisciplinary theories for health promotion identified: behavioral change theories, intervention-based models, ecological theories and models, planning models, communication theories, evaluation models<sup>h,i</sup>

- Men lacked awareness of testicular cancer risk factors; signs/symptoms; treatment
- · Few practiced self-examination; most did not know what to look for
- . Many reported intention to delay help-seeking for testicular lumpiness
- Education about testicular cancer and self-exam perceived as important
- Testicular cancer, self-exam awarenessness raised (10/11; 90.9%)<sup>c,d</sup>
- · A priori preferred learning strategies not addressed
- Theoretical underpinning: 6/11 (54.5%)
- Intention to delay help-seeking for testicular lumpiness and pain
- Unawareness of benign testicular disorders
- · No qualitative or experimental studies found
- Men lacked awareness of testicular cancer; very few had heard of benign testicular disorders; many intended to delay help-seeking for lumpiness, swelling, pain
- Barriers to awareness, help-seeking: lack of prior knowledge, symptom misappraisal, fear, embarrassment, machoism, lack of endorsement by the health system, cost and access to care, inability to differentiate between normal and abnormal lumps
- Facilitators to awareness, help-seeking: prior knowledge, regular self-exam, clinical testicular exam, personal/family history of testicular disease, aging, being gay, access to support, inherent health-seeking drive, perceived threats to fertility
- Importance of raising awareness using educational interventions: brief, simple, visually appealing, novel, positively worded
- 5 TMM stages guided development of 7 PAAF stages
- Neurobehavioral psychology literature helped derive concepts of preconscious, unconscious, and conscious awareness
- Émpirical literature, qualitative study, concept of "breast awareness" helped create, define concept: "testicular awareness"
- Literature on symptom appraisal helped derive concepts: unconscious, conscious appraisal<sup>k</sup>

Note. PAAF = preconscious awareness to action framework; TMM = transtheoretical model. "Saab et al. (2016c). "Saab et al. (2016b). "For example, a college campaign (Wanzer et al., 2014). "For example, a mass media intervention (Trumbo, 2004). "Saab et al. (2016a). "Saab et al. (2017a). "Saab et al. (2017b). "Nutbeam (2013). Raingruber (2014). "Thomton & Pillarisetti (2008). "Whitaker et al. (2015).

DiClemente, 1986). Therefore, the five stages of the TTM (i.e., precontemplation, contemplation, preparation, action, and maintenance) served as a stepping stone to the construction of the PAAF.

A side-by-side comparison between the TTM and PAAF is T2 presented in Table 2. The TTM and PAAF are process models that use predefined and interconnected stages in order to achieve a certain goal (Prochaska & DiClemente, 1986; Wislon & Schlam, 2004). However, although the TTM aims to "treat" harmful behaviors, the primary goal of the PAAF is to raise awareness in order to promote healthy behaviors. Moreover, the TTM comprises five stages, whereas the PAAF comprises seven stages (i.e., preconscious awareness, unconscious awareness, conscious awareness, unconscious appraisal, intention, and behavior) derived from the TTM (Prochaska & DiClemente, 1986) and the literature on neurobehavioral psychology (Baumeister, Masicampo, & Vohs, 2011; Dehane & Naccahe, 2001) and symptom appraisal

(Whitaker, Scott, & Wardle, 2015). Furthermore, although the TTM addresses the effect of consciousness on behavior, the PAAF acknowledges the impact of three stages of awareness (i.e., preconscious, unconscious, and conscious awareness) on behavior. Another difference pertains to symptom appraisal, which is an integral part of the PAAF and not the TTM.

#### **RESULTS**

Movement across the steps of the PAAF is a fluid process (Figure 2). Individuals move in and out of unconscious and [F2] conscious awareness/appraisal as thoughts move in and out of consciousness and as the individual and the environmental context of thinking changes.

#### Preconscious Awareness

As discussed in Natsoulas (1996), Freud did not describe AQ3 preconsciousness and unconsciousness as synonymous (Natsoulas, 1996). Although lack of awareness is a possibility,

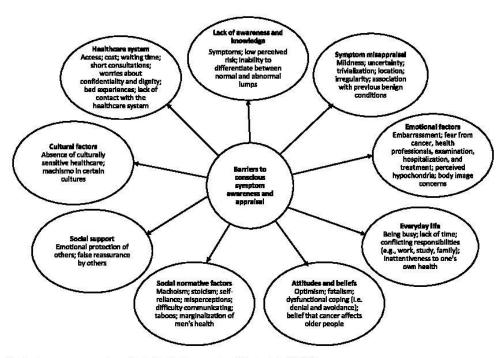


FIGURE 1. Barriers to awareness and appraisal of testicular symptoms (Saab et al., 2017a).

individuals in the preconscious awareness stage can be either underinformed about certain behaviors, have relevant discrete pieces of unlinked information, or are somewhat informed but not consciously thinking about the information. For instance, notwithstanding that men in the qualitative study lacked knowledge of TC risk factors, signs and symptoms, treatment, and screening, almost all of them reported having heard of TC through the media, school, college, family members, friends, and/or colleagues (Saab et al., 2017a, 2017b). In other words, men were not oblivious to testicular disorders, as they were able to recall certain information in relation to these disorders when prompted.

There are a number of hypotheses as to why men in the reviewed literature and qualitative study lacked awareness. One explanation is that men are often preoccupied with life matters that they may perceive as more important than their own health, such as starting college, building a career, or establishing a family (Saab et al., 2014). Therefore, conflicting responsibilities have the potential to mask health awareness or push it to the bottom of their list of priorities. Furthermore, illness is globally linked to old age—which might cause younger men to think that they are not prone to getting sick (Saab et al., 2017a). Another explanation could be what Leone and Rovito (2013) referred to as "social norms and gender scripting" (p. 246) that depict how men should and should not behave. These are thought to negatively affect men's health awareness and subsequent health outcomes.

#### Conscious and Unconscious Awareness

If one does not deliberately think about a certain behavior, it does not mean that he or she is not aware of it, which requires differentiating between conscious and unconscious awareness (Baumeister et al., 2011). This is key because the impact both types of awareness have on health behavior had been overlooked in behavioral change theories, including the TTM.

According to Dehane and Naccahe (2001), "durable and explicit information maintenance, novel combinations of operations, and intentional behavior" (p. 9) are not possible without conscious awareness, which is divided into two subtypes: the phenomenal awareness and conscious thought (Baumeister et al., 2011). Phenomenal awareness involves subjective experiences, for example, Armstrong's (1981) absentminded driver, as driving involves automaticity and, despite being a learned behavior, is often instinctive rather than a purposefully planned course of action. In contrast, conscious thought involves reflection and reasoning, for example, a man trying to make sense of a newly discovered testicular lump. Moreover, conscious awareness helps combine various mental operations in order to plan, evaluate, and execute a novel behavior that cannot be attained unconsciously. Of note, certain mental processes are possible without conscious awareness; nonetheless, they are often short lived (Baumeister et al., 2011). Therefore, a longlasting memory of a recently acquired intentional behavior cannot be generated in the absence of conscious awareness (Sperling, 1960).

TABLE 2. Comparison: Transtheoretical Model and Preconscious Awareness to Action Framework

Characteristic	TMM <sup>a</sup>	PAAF
Discipline	Clinical psychology psychotherapy	Health promotion     Neurobehavioral psychology
Primary goal	<ul> <li>To treat and change preexisting addictive/harmful behaviors (e.g., smoking)</li> </ul>	<ul> <li>To raise awareness, promote new healthy behaviors (e.g., early help-seeking)</li> </ul>
Development	<ul> <li>Comparative analysis of 29 systems of psychotherapy</li> </ul>	<ul> <li>Iterative process: synthesis, derivation, analysis</li> </ul>
Stages	<ul> <li>5: precontemplation, contemplation, preparation, action, maintenance</li> </ul>	<ul> <li>7: preconscious awareness, unconsciousness awareness, conscious awareness, unconscious appraisal, conscious appraisal, intention, behavior</li> </ul>
Precontemplation vs. preconscious awareness	<ul> <li>Precontemplation: people are uninformed or underinformed about consequences of their behavior</li> </ul>	<ul> <li>Preconscious awareness: people are uninformed, underinformed, have relevant discrete pieces of unlinked information, or are somewhat informed but not consciously thinking about the information</li> </ul>
Consciousness vs. conscious awareness	<ul> <li>Highlights the role of consciousness raising in promoting intentions to change a behavior</li> </ul>	<ul> <li>Highlights the role of conscious awareness and memory in retaining new information, combining various mental processes, and understanding and shaping behavior</li> </ul>
Symptom appraisal	<ul> <li>Not involved; primary goal is to treat preexisting addictive behaviors</li> </ul>	Involves labeling, categorizing, evaluating bodily changes
Intention	<ul> <li>Intention to change, take action are imbedded in contemplation and preparation stages, respectively</li> </ul>	<ul> <li>A separate stage; impacted by motivation, ability to seek help, access healthcare services</li> </ul>
Action vs. behavior	Course of action needed to modify lifestyle that must be maintained to avoid relapse	<ul> <li>Ultimate behavior: seek timely medical attention in response to a symptom</li> </ul>
Context/emphasis	<ul> <li>Impact of the harmful behavior on the social environment</li> </ul>	<ul> <li>Impact of intrinsic and extrinsic factors on the seven PAAF stages</li> </ul>
Testing	Tested in various contexts (e.g., smoking cessation, alcohol use, weight reduction)	Currently being used to build and test an interactive intervention aimed at raising men's testicular awareness

Note. PAAF = preconscious awareness to action framework; TTM = transtheoretical model. <sup>a</sup>Prochaska & Di Clemente (1986).

Taylor (2001) highlighted a form of long-term memory that is linked to unconscious awareness, namely, the implicit memory, which receives, stores, and recovers information outside one's conscious awareness. It is also thought to affect present behaviors as it involves habits, attitudes, and preferences shaped by past events (Taylor, 2001). An example is the ingrained gender roles that often impact on men's health-seeking behaviors (Leone & Rovito, 2013).

#### **Testicular Awareness**

In order to address the lack of awareness of testicular disorders, researchers could adopt a novel and comprehensive concept, namely, "testicular awareness." To help define this concept, it is necessary to consult the literature on the concept of "breast awareness" defined as "a woman becoming familiar with her own breasts and the way they will change throughout her life. It encourages women to know how their own breasts look and feel normally so that they gain confidence about noticing any change" (Thornton & Pillarisetti, 2008, p. 2119).

In order to achieve awareness, early detection of an abnormality must be followed by a specific course of action (Scott & Walter, 2010). However, a prerequisite to symptom detection is familiarity with the normal state of the body. In the case of testicular awareness, familiarity would enable a man to establish a baseline of what is normal for him so that he would be able to recognize changes (e.g., swelling, lumpiness, and pain). This is key because lack of familiarity with one's own testes

has been linked to intentions to delay help-seeking (Saab et al., 2017a).

Testicular awareness would also help promote heightened body awareness because it encourages men to become attentive to a body area that is seldom spoken about (Saab et al., 2014). Moreover, knowing the risk factors for testicular disorders would alert men to the aforementioned symptoms and disorders. For instance, men must recognize that having a first-degree relative with TC increases their risk for this malignancy and that unprotected sex exposes them to epididymitis and orchitis (CDC, 2015). Therefore, it is presumed that testicular awareness is a form of conscious rather than unconscious awareness.

Of note, testicular awareness does not necessarily involve scheduled self-examination—especially because the risks and benefits of this practice are debatable (Ilic & Misso, 2011). The U.S. Preventive Services Task Force (2011) discourages self-examination, mainly due to the potential harms of false positives and concomitant anxiety. In contrast, proponents of TC screening argue that recommendations discouraging this practice are based on speculations rather than empirical evidence, especially that early diagnosis of TC was found to be more cost-effective than late diagnosis (Rovito, Manjelievskaia, Leone, Lutz, & Nangia, 2016). A middle ground could be reached by instructing men to feel their testes in order to establish a baseline of what is normal for them without necessarily promoting monthly testicular self-examination.

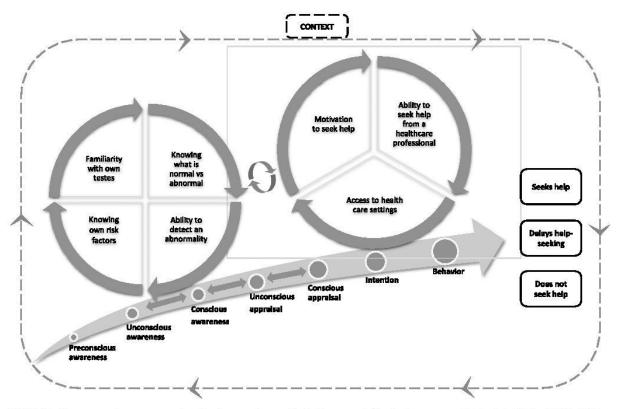


FIGURE 2. The preconscious awareness to action framework as applied to the concept of testicular awareness (Saab et al., 2016a, 2016b, 2016c; Whitaker et al., 2015).

#### Conscious and Unconscious Appraisal

Symptoms, described as bodily sensation or changes, are subject to complex psychosocial processes. In a conceptual review of nine symptom appraisal models, Whitaker et al. (2015, p. S28) defined the process of symptom appraisal as the "detection of bodily changes, interpretation of bodily changes, and responses to interpretation."

Detection of bodily changes involves recognizing a disturbance that can be general, localized, visible, palpable, and/or audible. This disturbance can differ in intensity and frequency (Whitaker et al., 2015). Therefore, for a bodily change to be detected, it must be of a significant magnitude. For example, a testicular lump must be large enough for a man to be able to detect it.

Symptom detection is followed by appraisal which involves "labeling, categorizing, and evaluating the bodily changes" (Whitaker et al., 2015, p. S28). Like awareness, appraisal is subject to conscious and unconscious influences as it involves reflection and reasoning in order to make sense of a symptom (i.e., conscious appraisal), and at the same time, it can be impacted by past attitudes, beliefs, experiences, and/or behaviors (i.e., unconscious appraisal).

Symptom appraisal is a "delicate" stage as it is subject to misinterpretation, which can cause people to delay helpseeking; this was the case for a number of men in the qualitative study (Saab et al., 2017a). In addition, the impact of the external environment on the detection of bodily changes must not be overlooked (Pennebaker, 1982). For instance, excessive stimulation from the external environment can shift a person's attention away from a symptom.

#### Help-Seeking Intention and Behavior

Following awareness and appraisal, a response that involves reaching a decision regarding the action that must be taken in relation to the symptom experienced is generated. In the case of testicular awareness, a man decides either to seek medical attention or not. Alternately, he can revert to self-help measures, inform his family and friends, delay help-seeking, or adopt dysfunctional coping strategies such as denial and avoidance (Saab et al., 2017a).

As aforementioned, a number of barriers to help-seeking exist; these include lack of knowledge, symptom misappraisal, fear, embarrassment, machoism, and conflicting responsibilities. On the other hand, having the motivation and ability to seek help and having access to healthcare settings positively influence one's intention to seek medical care (Leventhal, Leventhal, & Contrada, 1998). Social support, disclosure of

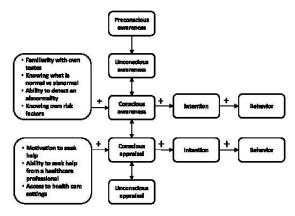
symptoms to friends, having an inherent help-seeking drive, and symptom severity also serve as enablers for help-seeking (Saab et al., 2017a). Finally, one can speculate that, when a man becomes "testes aware," he is more likely to seek medical attention for testicular symptoms. This is also supported by evidence from the reviewed literature on men's awareness of TC and self-examination (Saab et al., 2016c).

A number of barriers to help-seeking exist; these include lack of knowledge, symptom misappraisal, fear, embarrassment, machoism, and conflicting responsibilities.

Relational statements are specifying the relationships among the concepts of the PAAF (Walker & Avant, 2011) are shown [F3] in Figure 3. These were simplified, with the "–" sign depicting a negative relationship and the "+" sign depicting a positive relationship.

#### Conclusions

To the best of our knowledge, the PAAF is the first framework to highlight the impact of three stages of awareness (i.e., preconscious, unconscious, and conscious awareness) and two stages of symptom appraisal (i.e., unconscious and conscious appraisal) on help-seeking intentions and behaviors. Moreover, The PAAF was applied to the concept of "testicular awareness" that was first introduced in this study. This concept can be instrumental in familiarizing men with their own testes and enabling them to detect abnormalities. This could influence their decision to seek timely medical attention, thus preventing potential complications that are linked to delayed help-seeking, such as testicular ischemia, sepsis, and infertility. In order to tailor effective health-promoting messages,



**FIGURE 3.** Simplified statements illustrating the relationship between the key concepts of the preconscious awareness to action framework, following the guidelines of Walker and Avant (2011).

researchers are encouraged to underpin their interventions with behavioral change theories, intervention-based models, and/or theories of health communication; an example is the PAAF discussed in the present study. The authors are currently using the PAAF to build and test an interactive intervention aimed at raising men's testicular awareness.

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### Appendix 5

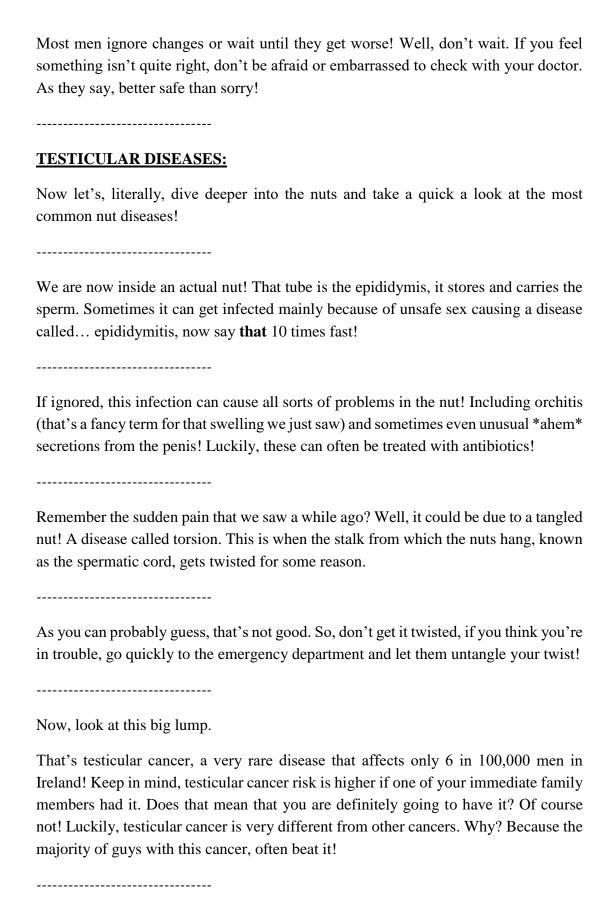
Appendix 5.1 The script guiding the voiceover

CINEMATIC:
BALLS! Also known as: Gonads! Bollox! Testicles! Testes! Goolies! Plums! Spuds! Stones! and of course, NUTS!
You have enough names for them, but do you REALLY know them? And do you REALLY know what can go wrong with them?
Anyhow, let's get the ball rolling, shall we?
WALNUT SIMULATION:
Normal walnuts
Let's have a look at some normal nuts. We asked men how well they know their nuts, turns out, they don't know what's normal for them, and they don't even check their nuts!
What about you? Do you know how your OWN nuts look and feel?
First, no two pairs of nuts are the same and no two nuts are similar, YES! Your nuts are unique, like snowflakes!
Take a good look, notice the size, one nut might be slightly bigger or lie more horizontally than the other. Also, the left nut tends to hang slightly lower.
Now, notice the surface, nuts aren't exactly smooth, that's why they're bumpy to the touch!
Walk around them and take a closer look, notice the shape, nuts aren't quite round,

they're actually oval!

### **Abnormal walnuts**

Now that you know what's normal, let's see if you can notice any changes. Mind you, many guys can't!
Don't forget to touch the nut when you notice the change!
Ok then, it's time to play, let's GO NUTS!
Swelling:  WOOH! It's not supposed to be that big! It might also feel more rigid than usual.
Torsion: OUF! That doesn't look good! What's with this pain all of a sudden?
OUCH! It's getting worse! That escalated quickly!
Lump: That's not supposed to be there!
When we asked men about checking their nuts, one guy said: "it's like trying to find a lump in a bag of lumps", well, congratulations my friend, you found it!
CINEMATIC/TRANSITION:
Looks like you didn't <b>ball</b> it up after all! Now that you know what can go wrong, what do you intend to do if <b>you</b> encounter any changes?



#### **Information:**

I hope I didn't wreck your head with all that information! Now let's quickly recap:

1. Remember your nuts are unique! That's why it is important to know what is normal for YOU. To do so, check your nuts in the shower or while taking a bath.
Cup one nut at a time using both hands, then gently roll each nut between your thumb and fingers. You will notice a bump on top of each nut, don't worry that's the epididymis. You'll also feel a tube from which each nut is hanging, that's the spermatic cord.
2. Take notice of any changes that might occur to the nuts and tell your doctor straightaway!
3. Go to the emergency department if you feel sudden and very unpleasant pain, you got to get them untwisted, the sooner the better!
4. If you find something unusual or some swelling, remember, it's probably something your doctor can easily fix, like orchitis, it's most likely not cancer.
5. Last but not least, remember no one knows your nuts better than you! That's why it's important to have a feel of them every now and then.
Now you know how to keep your nuts healthy, spread the word and tell your friends!
Thanks for playing!
fin

**Appendix 5.2** The items used to establish face validity of the voiceover script

Dear Doctor,

This file contains a brief script that will guide the development of an interactive intervention aimed at enhancing men's awareness of testicular symptoms and disorders. The intervention also aims at improving men's intention to seek medical help in the event of one or more testicular symptoms.

This script comprises a number of scientific facts and statements that are delivered in a simplified and humorous manner to cater to the needs of men with low health literacy. The testes are referred to as nuts throughout the script. The factual statements presented in the script are drawn from articles published in peer-reviewed journals, three systematic reviews of the literature on awareness of testicular disorders, as well as governmental websites including the National Cancer Registry Ireland.

You are kindly requested to evaluate the below script in terms of scientific content and to provide your feedback as you see fit. Please read the blow statements and put an "X" in the corresponding box:

	YES	NO
1. The scientific facts in the script are accurate		
2. The scientific facts in the script are recent		
3. The scientific facts in the script are factual		
4. The scientific facts in the script are clear		
5. The scientific facts in the script are easy to understand		
6. The scientific facts in the script have clinical implications		
7. There is constancy in the way the scientific facts are presented		

you answered any of the above questions with <b>NO</b> , please provide an explanation
otherwise, please feel free to provide your feedback/suggestions if need be:

Thank you for your time

Sincerely,

Mohamad Saab, PhD student, MSc, BSc, RN
College of Medicine and Health
Catherine McAuley School of Nursing and Midwifery
University College Cork, Ireland

Email: msaab@ucc.ie

**Appendix 5.3** Permission to use the infographic on testicular self-examination

To Whom It May Concern,

My name is Mohamad Saab; I am a researcher on testicular cancer as well as other diseases that might affect the testes.

I am in the process of developing an educational intervention to help young men recognise the changes that might occur with their testes and to seek timely medical help for testicular abnormalities.

I am wondering if it would be alright to use the infographic on testicular selfexamination that is available on your website as part of the educational intervention.

Please note that the Testicular Cancer Awareness Foundation will be cited and acknowledged as the source of the infographic.

Thank you in advance for your help and please let me know if you have any queries.

Best regards,

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Tel: +353 21 490 1518 Email: msaab@ucc.ie

\_\_\_\_\_

Hello Mohamad,

Thank you for requesting permission to use our information. You have our permission to use any information on our site as long as it is correctly cited.

Thank you for helping educate young men about this disease.

Respectfully,

#### Breanna Jones

Direct Line: 970-778-2507 Email: <u>breanna@tcafinfo.org</u>



#### **Appendix 5.4** Ethical approval to conduct the feasibility and usability study



## COISTE EITICE UM THAIGHDE CLINICIÚIL Clinical Research Ethics Committee

Lancaster Hall, 6 Little Hanover Street, Cork, Ireland.

Coláiste na hOllscoile Corcaigh, Éire University College Cork, Ireland

ECM 4 (ss) 15/11/16

15th November 2016

Professor Josephine Hegarty Professor of Nursing University College Cork School of Nursing and Midwifery Brookfield Health Sciences Complex College Road Cork

Re: Enhancing men's awareness of testicular disorders: The E-MAT Study.

Dear Professor Hegarty

Approval is granted to carry out the above study at:

The following documents have been approved:

- Cover letter dated 26 October 2016
- > Application form version 2 dated 26 October 2016
- Study protocol version 2 dated 26 October 2016
- > Invitation letter version 2 dated 26 October 2016
- Participant information sheet Version 2 dated 26 October 2016
- Consent form version 2 dated 26 October 2016
- Socio-demographic questionnaire version 2 dated 26 October 2016
- Knowledge quiz version 2 dated 26 October 2016
- Testicular awareness and implementation intentions questionnaire version 2 dated 26 October 2016
- > General help seeking questionnaire version 2 dated 26 October 2016
- Behaviour questionnaire version 2 dated 26 October 2016
- > Pilot study at first posttest questionnaire pack version 2 dated 26 October 2016
- Pilot study at second posttest questionnaire pack version 2 dated 26 October 2016.

We note that the co-investigators involved in this study will be:

Mohammad Saab, PhD candidate, Margaret Landers, Lecturer, Eoghan Cooke, MSc in Interactive Media, David Murphy, Lecturer and Martin Davoren, Lecturer.



# COISTE EITICE UM THAIGHDE CLINICIÚIL Clinical Research Ethics Committee

Lancaster Hall, 6 Little Hanover Street, Cork, Ireland.

# Coláiste na hOllscoile Corcaigh, Éire University College Cork, Ireland

Yours sincerely

Professor Michael G Molloy

Chairman

Clinical Research Ethics Committee of the Cork Teaching Hospital

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.

Ollscoil na hÉireann. Corcaidh - National University of Ireland. Cork.

**Appendix 5.5** Letter inviting potential participants to take part in the feasibility and usability study

Dear Participant,

Are you interested in using a virtual reality headset?

I, Mohamad Saab, a PhD student at University College Cork, am inviting you to participate in a research study entitled "Enhancing Men's Awareness of Testicular Disorders: The E-MAT Study." This study aims at assessing the user-friendliness of a game aimed at raising young men's awareness of testicular diseases using virtual reality. If you wish to participate, you will be asked to engage in a game using a virtual reality headset and controller and to fill out a brief questionnaire immediately after.

If you are interested in participating, do not hesitate to contact me.

Looking forward to hearing from you!

Thank you

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

#### **Appendix 5.6** Participant Information Leaflet

Dear Participant,

You are invited to participate in a study titled: "Enhancing Men's Awareness of Testicular Disorders: The E-MAT Study" conducted by Professor Josephine Hegarty, Mr Mohamad Saab, Dr Margaret Landers, Mr Eoghan Cooke, Mr. David Murphy, and Dr Martin Davoren at University College Cork. This study aims at assessing the user-friendliness of a game aimed at raising young men's awareness of testicular diseases using virtual reality.

If you agree to take part of this study, you will be asked to engage in an educational game using a virtual reality headset and controller, and to fill out a questionnaire after. The game takes on average 6 minutes to complete and the questionnaire takes 10 to 15 minutes to fill.

The study documents will be kept in a locked cabinet accessed only by the researchers. Your participation is completely voluntary. You can choose not to participate or to withdraw whenever you feel like it. Your refusal to participate will have no effect on you whatsoever.

The use of a virtual reality headset can very rarely cause motion sickness. If you experienced motion sickness, please inform us immediately.

Thank you for your time

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

**Appendix 5.7** Instructions provided before and after the demo

Before the demo:

Before starting with the actual game, we would like you to take a minute or two to watch and interact with a demo in order to familiarise yourself with the virtual reality

headset and controller.

Follow these simple steps:

Put the headset on, it might be blurry at first, adjust the head strap until the blur is

gone

You will be handed a controller; use the joysticks of the controller to move around

The camera will move with the movements of your head, so feel free to look

around

4. We will place headphones on your ears so that you can hear the instructions

Remember, if at any stage you felt uncomfortable, let us know immediately. We will

be here the whole time.

After the demo:

Now that you have a reasonably good idea of how this system works, let us get started!

During the game, you will come across two walnuts. You will be instructed to look at them carefully and touch them when you notice changes. There will be a total of 3 changes. Simply walk up to any change you notice and touch it with the hand then step

back and keep an eye out for any further changes.

Remember, if at any stage you felt uncomfortable, let us know immediately. We will

be here the whole time.

Thank you

Mohamad Saab, PhD student, MSc, BSc, RN

College of Medicine and Health

Catherine McAuley School of Nursing and Midwifery

University College Cork, Ireland

Email: msaab@ucc.ie

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#### **Appendix 5.8** Informed Consent Form

#### CONSENT BY SUBJECT FOR PARTICIPATION IN RESEARCH PROTOCOL

Section A Protocol Number:	Subject's initials:
Title of Protocol: Enhancing Men's . Study	Awareness of Testicular Disorders: The E-MAT

PI Directing Research: Prof. Josephine Hegarty, 021 4901462

Co-investigator: Mr. Mohamad Saab, Dr. Margaret Landers, Mr. Eoghan Cooke, Mr. David Murphy, and Dr. Martin Davoren.

You are being asked to participate in a research study. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

#### **Section B**

#### I. NATURE AND DURATION OF PROCEDURE(S):

The purpose of this study is to assess and the user-friendliness of a game aimed at raising young men's awareness of testicular diseases. If you wish to participate in the study, you will be asked to: (1) engage in an educational game using a virtual reality headset and controller, and (2) fill out a questionnaire. The game takes on average 6 minutes to complete and the questionnaire takes 10 to 15 minutes to fill. Mr. Mohamad Saab, a PhD in nursing student, and Mr. Eoghan Cooke, an expert in interactive media will be administering the game and questionnaire. All the study documents will be securely stored within the premises of UCC and all the collected data will be kept confidential. You have the full right to refuse to participate or to withdraw from the study. Your refusal to participate or withdrawal will not affect you in any way.

#### II. POTENTIAL RISKS AND BENEFITS:

There are no potential psychological harms from your participation in this study. The use of a virtual reality headset can very rarely cause motion sickness. If you experienced motion sickness, please inform the researcher immediately.

Findings from this study would influence policy makers to make changes regarding screening for testicular problems if need be. Findings would also help test this game among a larger number of young men.

#### III. POSSIBLE ALTERNATIVES:

Participation in this study is voluntary.

#### **Section C**

#### AGREEMENT TO CONSENT

The research project and the relevant procedures associated with it have been fully explained to me. All the purposes and procedures have been identified and no guarantee has been given about the possible results. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. I am aware that findings from this study will be anonymous and might be presented in a thesis, oral presentations, and/or publications. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.

I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at University College Cork. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the researcher listed above. If I have further queries concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals, Lancaster Hall, 6 Little Hanover Street, Cork, 021 4901901.

After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

I have read and understood the study: Yes	No
I agree to participate in this research: Yes	No
Researcher:	Signature of Participant
	Date: Time:AM (Circle) PM

## Appendix 5.9 The instrument used in the feasibility and usability study

## **Socio-Demographic Questionnaire**

Please tell us about yourself

1. Age:	Years	5. Highest level of education
2. Nationality(ies)		None
		Primary
Irish		Lower secondary
Other ( <i>Please specify</i> ):		Higher secondary
		Post leaving cert.
3. Sexual orientation		Third level degree or above
		Other ( <i>Please specify</i> ):
Heterosexual (Straight)		1 337 =====
Gay		6. Current occupation (Please tick wha
Bisexual		applies to you)
Transsexual		off was to you,
Other ( <i>Please specify</i> ):		Student
		Employed (full-time)
4. Marital status		Employed (part-time)
		Self-employed
☐ Single		Unemployed
Married		Other (Please specify):
Engaged		
In a relationship/Partnered	1	7. Have you used Virtual Reality
Divorced		before?
Separated		Deluie.
Widowed		Yes
Widowed		☐ No

## **Feasibility Scale**

Please take the time to read the below statements and put an  $\boldsymbol{X}$  in the corresponding box

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. The virtual reality headset is					
comfortable to use					
2. The controller is easy to use					
3. Elements of the game were					
confusing					
4. The testicles are well represented using models (walnuts)					
5. The use of the word 'nuts'					
throughout the game is appropriate					
6. The verbal/oral instructions are easy to understand					
7. Elements of the game were					
humorous to you					
8. The font, colour, and size of the written words are clear					
9. The 'inside look' at the testicle was					
well presented 10. Testicular enlargement/swelling is					
well represented					
11. Testicular lumpiness is well					
represented					
12. Testicular pain is well represented					
13. The scientific facts about					
epididymitis are easy to understand					
14. The scientific facts about testicular					
torsion are easy to understand					
15. The scientific facts about testicular					
cancer are easy to understand					
16. The intervention would work with men who are 18 to 50 years of age					
17. The intervention would work with					
men from different educational					
backgrounds					
18. The intervention would work with					
men from different ethnic/cultural					
backgrounds					
19. The intervention would work with					
men with different sexual					
orientations					
20. The intervention is applicable to					
real life					
21. I learned something valuable from					
this intervention		l			

22. Please rate your overall satisfaction with this intervention
Extremely Dissatisfied
☐ Dissatisfied
☐ Neutral
☐ Satisfied
Extremely Satisfied
23. What are the elements of the game that worked for you? (Please list below):
24. What are the elements of the game that did not work for you? (Please list below, if any):
25. What would you change about this game? (Please list below, if any):
26. Any other comments?

## **System Usability Scale**

Please take the time to read the below statements and put an  $\mathbf{X}$  in the corresponding box:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
27. I think that I would like to use this	8				
system frequently					
28. I found this game unnecessarily					
complex					
29. I thought this system was easy to use					
30. I think that I would need assistance					
to be able to use this game					
31. I found the various functions in this					
system were well integrated					
32. I thought there was too much					
inconsistency in this system					
33. I would imagine that most people					
would learn to use this system very					
quickly					
34. I found the system very					
cumbersome/awkward to use					
35. I felt very confident using this					
system					
36. I needed to learn a lot of things					
before I could get going with this					
system					

### Appendix 6

#### **Appendix 6.1** Ethical approval to conduct the pilot study



COISTE EITICE UM THAIGHDE CLINICIÚIL
Clinical Research Ethics Committee

Lancaster Hall, 6 Little Hanover Street, Cork, Ireland.

Coláiste na hOllscoile Corcaigh, Éire University College Cork, Ireland

ECM 4 (ss) 15/11/16

15th November 2016

Professor Josephine Hegarty Professor of Nursing University College Cork School of Nursing and Midwifery Brookfield Health Sciences Complex College Road Cork

Re: Enhancing men's awareness of testicular disorders: The E-MAT Study.

Dear Professor Hegarty

Approval is granted to carry out the above study at:

The following documents have been approved:

- Cover letter dated 26 October 2016
- > Application form version 2 dated 26 October 2016
- > Study protocol version 2 dated 26 October 2016
- Invitation letter version 2 dated 26 October 2016
- Participant information sheet Version 2 dated 26 October 2016
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- General help seeking questionnaire version 2 dated 26 October 2016
- > Behaviour questionnaire version 2 dated 26 October 2016
- Pilot study at first posttest questionnaire pack version 2 dated 26 October 2016
- Pilot study at second posttest questionnaire pack version 2 dated 26 October 2016.

We note that the co-investigators involved in this study will be:

Mohammad Saab, PhD candidate, Margaret Landers, Lecturer, Eoghan Cooke, MSc in Interactive Media, David Murphy, Lecturer and Martin Davoren, Lecturer.



# COISTE EITICE UM THAIGHDE CLINICIÚIL Clinical Research Ethics Committee

Lancaster Hall, 6 Little Hanover Street, Cork, Ireland.

#### Coláiste na hOllscoile Corcaigh, Éire University College Cork, Ireland

Yours sincerely

Professor Michael G Molloy

Chairman

Clinical Research Ethics Committee of the Cork Teaching Hospital

The Clinical Research Ethics Committee of the Cork Teaching Hospitals, UCC, is a recognised Ethics Committee under Regulation 7 of the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004, and is authorised by the Department of Health and Children to carry out the ethical review of clinical trials of investigational medicinal products. The Committee is fully compliant with the Regulations as they relate to Ethics Committees and the conditions and principles of Good Clinical Practice.

Ollscoil na hÉireann. Corcaidh - National University of Ireland. Cork.

**Appendix 6.2** Letter inviting potential participants to take part in the pilot study

Dear Participant,

Are you interested in using a virtual reality headset and winning 1 of 5 online shopping vouchers?

I, Mohamad Saab, a PhD student at University College Cork (UCC), am inviting you to participate in a research study entitled "Enhancing Men's Awareness of Testicular Disorders: The E-MAT Study." This study aims at raising young men's awareness of testicular diseases using virtual reality.

If you wish to participate, you will be asked to fill out a short questionnaire, engage in a game using a virtual reality headset and controller, fill out a short questionnaire immediately after the game, and come back to UCC a month following the game to fill out another short questionnaire.

In addition to using an exciting technology, you will enter a draw to win 1 of 5 online shopping vouchers (£30 each).

If you are interested in participating, do not hesitate to contact me.

Looking forward to hearing from you.

Thank you

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

## **ARE YOU**

- ✓ A MALE?
- ✓ AGED BETWEEN 18 AND 50 YEARS?

## **WOULD YOU LIKE TO**

- ✓ PLAY AN EDUCATIONAL HEALTH
  GAME USING VIRTUAL REALITY (VR)?
- ✓ WIN ONE OF FIVE ONLINE SHOPPING VOUCHERS?

Interested in knowing more?

Contact Mohamad Saab on msaab@ucc.ie



#### **Appendix 6.4** Participant Information Leaflet

Dear Participant,

You are invited to participate in a study titled: "Enhancing Men's Awareness of Testicular Disorders: The E-MAT Study" conducted by Professor Josephine Hegarty, Mr Mohamad Saab, Dr Margaret Landers, Mr Eoghan Cooke, Dr David Murphy, and Dr Martin Davoren at University College Cork. The study aims at raising young men's awareness of diseases that affect the testes.

If you agree to take part of this study, you will be asked to fill out a questionnaire, engage in an educational game using a virtual reality headset and controller, fill out a short questionnaire immediately after the game, and come back to UCC after a month to fill out another short questionnaire. The questionnaire takes 10 to 15 minutes to fill and the game takes on average 6 minutes to complete.

The study documents will be kept in a locked cabinet accessed only by the researchers. Your participation is completely voluntary. You can choose not to participate or to withdraw whenever you feel like it. Your refusal to participate will have no effect on you whatsoever.

Upon completion of this study, you will enter a draw to win 1 of 5 online shopping vouchers (£30 each). The use of a virtual reality headset can very rarely cause motion sickness. If you experienced motion sickness, please inform us immediately.

Thank you for your time

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

#### **Appendix 6.5** Informed Consent Form

#### CONSENT BY SUBJECT FOR PARTICIPATION IN RESEARCH PROTOCOL

Section A	
Protocol Number:	Subject's initials:
<u></u>	

Title of Protocol: Enhancing Men's Awareness of Testicular Disorders: The E-MAT Study

PI Directing Research: Prof. Josephine Hegarty, 021 4901462

Co-investigators: Mr. Mohamad Saab, Dr. Margaret Landers, Mr. Eoghan Cooke, Dr. David Murphy, and Dr. Martin Davoren.

You are being asked to participate in a research study. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

#### Section B

#### I. NATURE AND DURATION OF PROCEDURE(S):

The purpose of this study is to raise young men's awareness of testicular diseases. If you wish to participate in the study, you will be asked to (1) fill out a short questionnaire, (2) engage in an educational game using a virtual reality headset and controller, (3) fill out the same questionnaire immediately after the game, and (4) come back to UCC after a month to fill out a short questionnaire. The questionnaire takes 10 to 15 minutes to fill and the game takes on average 6 minutes to complete. Mr. Mohamad Saab, a PhD in nursing student, and Mr. Eoghan Cooke, an expert in interactive media will be administering the questionnaire and game. All the study documents will be securely stored within the premises of UCC and all the collected data will be kept confidential. You have the full right to refuse to participate or to withdraw from the study. Your refusal to participate or withdrawal will not affect you in any way.

#### II. POTENTIAL RISKS AND BENEFITS:

There are no potential psychological harms from your participation in this study. The use of a virtual reality headset can very rarely cause motion sickness. If you experienced motion sickness, please inform the researcher immediately.

Once you complete this study (including the questionnaire after one month), you will enter a draw to win 1 of 5 online shopping vouchers (£30 each). Findings from this study would influence policy makers to make changes regarding screening for testicular problems if need be. Findings would also help test this game among a larger number of young men.

#### III. POSSIBLE ALTERNATIVES:

Participation in this study is voluntary.

#### Section C AGREEMENT TO CONSENT

The research project and the relevant procedures associated with it have been fully explained to me. All the purposes and procedures have been identified and no guarantee has been given about the possible results. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. I am aware that findings from this study will be anonymous and might be presented in a thesis, oral presentations, and/or publications.

Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.

I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at University College Cork. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the researcher listed above. If I have further queries concerning my rights in connection with the research, I can contact the Clinical Research Ethics Committee of the Cork Teaching Hospitals, Lancaster Hall, 6 Little Hanover Street, Cork, 021 4901901.

After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

I have read and understood the study: Yes	No
I agree to participate in this research: Yes	No
Researcher:	Signature of Participant
	Date: Time:AM (Circle) PM

#### **Appendix 6.6** Referral Form

#### Dear Participant,

We do not anticipate that the content of this study will upset you, however, please do not hesitate to inform me at any time in case you feel physically or emotionally uncomfortable. We can either pause or stop the game. In addition, if you have any further questions or concerns in relation to testicular health/conditions, you can contact the nurses in one of the Irish Cancer Society Daffodil Centres in Cork:

#### **Daffodil Centre – Cork University Hospital**

Contact person: Colette Grant

Tel: 0214234536

Email: daffodilcentrecuh@irishcancer.ie

#### **Daffodil Centre – Bon Secours Hospital Cork**

Contact person: Catriona O'Mahony

Tel: 0214941941

Email: daffodilcentrebonsecours@irishcancer.ie

#### For students at University College Cork:

If you have questions or concerns with regard to your health, or would like to see a doctor, do not hesitate to contact:

#### **UCC Student Health Department**

Tel: 0214902311

If you feel like talking to someone, please visit <a href="http://www.ucc.ie/en/studentcounselling/">http://www.ucc.ie/en/studentcounselling/</a> to check the latest counselling workshops and online programmes or contact:

#### **UCC Student Counselling & Development**

Tel: 0214903565

Email: counselling@ucc.ie

#### Sincerely,

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

Appendix 6.7 Questionn	aire
administered at baseline	(T0)

Code:
-------

# I. Please answer a few questions about yourself

	Age: Years  Nationality(ies)	14. Have you got a personal history of one or more testicular disorder(s)?
	Irish Other (Please specify):	Yes (Please specify): No Unsure
	Heterosexual (Straight) Gay Bisexual Transsexual Other (Please specify):	15. Have you been previously informed/educated about testicular disorders?  Yes (Please specify how):
	Marital status  Single Married Engaged In a relationship/Partnered Divorced Separated Widowed	16. Do you plan on seeking information/more information in relation to testicular diseases in the near future?  Yes No  No  17. Have you used Virtual
13.	None   Primary   Secondary   Third level degree or above   Other (Please specify):	Reality before?  Yes No  No  18. Please rate the importance of learning about testicular diseases? (Please tick what is true for you)  Very Unimportant Unimportant Neutral Important Very Important Very Important

# II. (Questions 1 to 12) Please read the questions below carefully, and circle the answer you believe is correct.

1)	Your right testicle is a different size from your left testicle a) True b) False c) Don't know
2)	Your testicles are identical to other men's testicles a) True b) False c) Don't know
3)	Sometimes, one testicle lies slightly lower than the other a) True b) False c) Don't know
4)	Testicles are round in shape a) True b) False c) Don't know
5)	What is the name of the tube that stores sperm?  a) Epididymis b) Urethra c) Spermatic cord d) Ureter
6)	What is the name of the tube from which the testicles hang?  a) Epididymis b) Urethra c) Spermatic cord d) Ureter
7)	Which symptom below <b>DOES NOT</b> commonly occur in the testicles?  a) Pain  b) Swelling  c) Lumpiness  d) Bleeding
8)	What is the <b>MOST COMMON</b> reason for an enlarged/swollen testicle?

a) Trauma

b) Testicular torsionc) Testicular cancer

d) Epididymitis and orchitis

- 9) What is the **MOST COMMON** reason for sharp and sudden pain in the testicle?
  - a) Trauma
  - b) Testicular torsion
  - c) Testicular cancer
  - d) Epididymitis and orchitis
- 10) The **BEST** time to check the testicles is:
  - a) In the shower or bath
  - b) While playing sports
  - c) While using the toilet
  - d) In bed
- 11) What puts a man at risk for epididymitis and orchitis?
  - a) Trauma
  - b) Unsafe sex
  - c) Cancer
  - d) Masturbation
- 12) Which statement about testicular cancer is **NOT** true?
  - a) It is generally diagnosed in young guys
  - b) It is very common
  - c) The risk is higher if a guy has a father or a brother who have it
  - d) It can be cured

III. (Questions 13 to 21) Please read the statements below carefully and indicate whether you Strongly Disagree, Disagree, Agree, Strongly Agree, or whether you are Neutral by putting an X in the corresponding box. Remember there are no right or wrong answers!

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
13) I believe that I am <b>familiar</b> with the way my own testicles normally look and feel	8				0
14) I believe that I <b>know</b> what is normal and what is not normal when I feel my testicles					
15) I believe that I can differentiate between what is normal and what is not normal when I feel my testicles					
16) I believe that I can tell if something is wrong with my testicles					
17) I believe that I am able to detect any changes in my testicles					
18) I believe that I am at risk for developing one or more testicular disease(s)					
19) I <b>intend to feel</b> my testicles in the shower/bath at least once over the coming month					
20) I will feel my testicles in the shower/bath at least once over the coming month					
21) I <b>intend to advise</b> at least one man (e.g. friend, colleague, partner, family member) about the importance of examining his testicles in the shower/bath at least once in the coming month					

#### YOU ARE HALFWAY THERE!

IV. (Questions 22 to 24) Please read the questions below and indicate your response by circling the number that best describes your intention to seek help from each of the sources. Please note these questions are quite similar, so please read them carefully. Remember there are no right or wrong answers!

1=Extremely Unlikely 3=Unlikely 5=Likely 7=Extremely Likely

22) If you discovered a **significant enlargement/swelling in one of your testicles without any pain**, how likely is it that you would seek help from the following people?

a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)	1	2	3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)	1	2	3	4	5	6	7
h. I would not seek help from anyone	1	2	3	4	5	6	7
i. I would seek help from another not listed above	1	2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

23) If you discovered a **lump in your testicle without any pain**, how likely is it that you would seek help from the following people?

a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)			3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)	1	2	3	4	5	6	7
h. I would not seek help from anyone	1	2	3	4	5	6	7
i. I would seek help from another not listed above	1	2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

24) If you felt a **sudden and sharp pain in one or both testicles without any enlargement/swelling or lump**, how likely is it that you would seek help from the following people?

a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member				4	5	6	7
e. Colleague (e.g. work, classmate)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)			3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)			3	4	5	6	7
h. I would not seek help from anyone			3	4	5	6	7
i. I would seek help from another not listed above	1	2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

 $V.\ (Questions\ 25\ to\ 27)$  Please read the below statements carefully and tick what applies to you:

25) Have you <b>purposefully</b> to	felt/examined your tes	ticles within the past year?
	Yes	No
26) Have you <b>purposefully</b> to	felt/examined your tes	ticles within the past month?
	Yes	No
27) Did a healthcare professi	onal (e.g. doctor/nurse	e) <b>ever</b> examine your testicles?
	Yes	No

THANK YOU!

**Appendix 6.8** Instructions provided before and after the demo

**Before the demo:** 

Before starting with the actual game, we would like you to take a minute or two to watch and interact with a demo in order to familiarise yourself with the virtual reality

headset and controller.

Follow these simple steps:

5. Put the headset on, it might be blurry at first, adjust the head strap until the blur is gone

6. You will be handed a controller; use the joysticks of the controller to move around

7. The camera will move with the movements of your head, so feel free to look

around

8. We will place headphones on your ears so that you can hear the instructions

Remember, if at any stage you felt uncomfortable, let us know immediately. We will

be here the whole time.

After the demo:

Now that you have a reasonably good idea of how this system works, let us get started!

During the game, you will come across two walnuts. You will be instructed to look at them carefully and touch them when you notice changes. There will be a total of 3 changes. Simply walk up to any change you notice and touch it with the hand then step back and keep an eye out for any further changes.

Remember, if at any stage you felt uncomfortable, let us know immediately. We will be here the whole time.

Thank you

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

Code:
-------

# I. (Questions 1 to 12) Please read the questions below carefully, and circle the answer you believe is correct.

- 1) Your right testicle is a different size from your left testicle
  - a) True
  - b) False
  - c) Don't know
- 2) Your testicles are identical to other men's testicles
  - a) True
  - b) False
  - c) Don't know
- 3) Sometimes, one testicle lies slightly lower than the other
  - a) True
  - b) False
  - c) Don't know
- 4) Testicles are round in shape
  - a) True
  - b) False
  - c) Don't know
- 5) What is the name of the tube that stores sperm?
  - a) Epididymis
  - b) Urethra
  - c) Spermatic cord
  - d) Ureter
- 6) What is the name of the tube from which the testicles hang?
  - a) Epididymis
  - b) Urethra
  - c) Spermatic cord
  - d) Ureter
- 7) Which symptom below **DOES NOT** commonly occur in the testicles?
  - a) Pain
  - b) Swelling
  - c) Lumpiness
  - d) Bleeding

- 8) What is the **MOST COMMON** reason for an enlarged/swollen testicle?
  - a) Trauma
  - b) Testicular torsion
  - c) Testicular cancer
  - d) Epididymitis and orchitis
- 9) What is the **MOST COMMON** reason for sharp and sudden pain in the testicle?
  - a) Trauma
  - b) Testicular torsion
  - c) Testicular cancer
  - d) Epididymitis and orchitis
- 10) The **BEST** time to check the testicles is:
  - a) In the shower or bath
  - b) While playing sports
  - c) While using the toilet
  - d) In bed
- 11) What puts a man at risk for epididymitis and orchitis?
  - a) Trauma
  - b) Unsafe sex
  - c) Cancer
  - d) Masturbation
- 12) Which statement about testicular cancer is **NOT** true?
  - a) It is generally diagnosed in young guys
  - b) It is very common
  - c) The risk is higher if a guy has a father or a brother who have it
  - d) It can be cured

II. (Questions 13 to 21) Please read the statements below carefully and indicate whether you Strongly Disagree, Disagree, Agree, Strongly Agree, or whether you are Neutral by putting an X in the corresponding box. Remember there are no right or wrong answers!

#### YOU ARE MORE THAN HALFWAY THERE!

III. (Questions 22 to 24) Please read the questions below and indicate your response by circling the number that best describes your intention to seek help from each of the sources. Please note these questions are quite similar, so please read them carefully. Remember there are no right or wrong answers!

1=Extremely Unlikely 3=Unlikely 5=Likely 7=Extremely Likely

22) If you discovered a **significant enlargement/swelling in one of your testicles without any pain**, how likely is it that you would seek help from the following people?

MS pospio.							
a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)	1	2	3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)	1	2	3	4	5	6	7
h. I would not seek help from anyone	1	2	3	4	5	6	7
i. I would seek help from another not listed above	1	2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

23) If you discovered a **lump in your testicle without any pain**, how likely is it that you would seek help from the following people?

a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)	1	2	3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)	1	2	3	4	5	6	7
h. I would not seek help from anyone	1	2	3	4	5	6	7
i. I would seek help from another not listed above	1	2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

# 24) If you felt a **sudden and sharp pain in one or both testicles without any enlargement/swelling or lump**, how likely is it that you would seek help from the following people?

a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)	1	2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)		2	3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)		2	3	4	5	6	7
h. I would not seek help from anyone	1	2	3	4	5	6	7
i. I would seek help from another not listed above	1	2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

# I. (Questions 1 to 12) Please read the questions below carefully, and circle the answer you believe is correct.

- 1) Your right testicle is a different size from your left testicle
  - a) True
  - b) False
  - c) Don't know
- 2) Your testicles are identical to other men's testicles
  - a) True
  - b) False
  - c) Don't know
- 3) Sometimes, one testicle lies slightly lower than the other
  - a) True
  - b) False
  - c) Don't know
- 4) Testicles are round in shape
  - a) True
  - b) False
  - c) Don't know
- 5) What is the name of the tube that stores sperm?
  - a) Epididymis
  - b) Urethra
  - c) Spermatic cord
  - d) Ureter
- 6) What is the name of the tube from which the testicles hang?
  - a) Epididymis
  - b) Urethra
  - c) Spermatic cord
  - d) Ureter
- 7) Which symptom below **DOES NOT** commonly occur in the testicles?
  - a) Pain
  - b) Swelling
  - c) Lumpiness
  - d) Bleeding

- 8) What is the **MOST COMMON** reason for an enlarged/swollen testicle?
  - a) Trauma
  - b) Testicular torsion
  - c) Testicular cancer
  - d) Epididymitis and orchitis
- 9) What is the **MOST COMMON** reason for sharp and sudden pain in the testicle?
  - a) Trauma
  - b) Testicular torsion
  - c) Testicular cancer
  - d) Epididymitis and orchitis
- 10) The **BEST** time to check the testicles is:
  - a) In the shower or bath
  - b) While playing sports
  - c) While using the toilet
  - d) In bed
- 11) What puts a man at risk for epididymitis and orchitis?
  - a) Trauma
  - b) Unsafe sex
  - c) Cancer
  - d) Masturbation
- 12) Which statement about testicular cancer is **NOT** true?
  - a) It is generally diagnosed in young guys
  - b) It is very common
  - c) The risk is higher if a guy has a father or a brother who have it
  - d) It can be cured

II. (Questions 13 to 21) Please read the statements below carefully and indicate whether you Strongly Disagree, Disagree, Agree, Strongly Agree, or whether you are Neutral by putting an X in the corresponding box. Remember there are no right or wrong answers!

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
13)	I believe that I am <b>familiar</b>					
	with the way my own					
	testicles normally look and					
	feel					
14)	I believe that I <b>know</b> what is					
	normal and what is not					
	normal when I feel my					
15)	testicles  I believe that I can					
13)	I believe that I can differentiate between what					
	is normal and what is not					
	normal when I feel my					
	testicles					
16)	I believe that I can tell if					
	something is wrong with my					
	testicles					
17)	I believe that I am able to					
	detect any changes in my					
	testicles					
10)						
18)	I believe that I am at risk for					
	developing one or more					
10)	testicular disease(s)					
19)	I <b>intend to feel</b> my testicles in the shower/bath at least					
	once over the coming month					
20)	I will feel my testicles in the					
20)	shower/bath at least once					
	over the coming month					
21)	I <b>intend to advise</b> at least					
	one man (e.g. friend,					
	colleague, partner, family					
	member) about the					
	importance of examining his					
	testicles in the shower/bath at					
	least once in the coming					
	month					

#### YOU ARE HALFWAY THERE!

III. (Questions 22 to 24) Please read the questions below and indicate your response by circling the number that best describes your intention to seek help from each of the sources. Please note these questions are quite similar, so please read them carefully. Remember there are no right or wrong answers!

1=Extremely Unlikely 3=Unlikely 5=Likely 7=Extremely Likely

22) If you discovered a **significant enlargement/swelling in one of your testicles without any pain**, how likely is it that you would seek help from the following people?

the following people:							
a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)		2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)		2	3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)		2	3	4	5	6	7
h. I would not seek help from anyone	1	2	3	4	5	6	7
i. I would seek help from another not listed above	1	2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

23) If you discovered **a lump in your testicle without any pain**, how likely is it that you would seek help from the following people?

a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)		2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)		2	3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)		2	3	4	5	6	7
h. I would not seek help from anyone		2	3	4	5	6	7
i. I would seek help from another not listed above		2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

24) If you felt a **sudden and sharp pain in one or both testicles without any enlargement/swelling or lump**, how likely is it that you would seek help from the following people?

a. Intimate partner (e.g. girlfriend, boyfriend, wife,	1	2	3	4	5	6	7
husband)							
b. Friend (not related to you)	1	2	3	4	5	6	7
c. Parent	1	2	3	4	5	6	7
d. Other relative/family member	1	2	3	4	5	6	7
e. Colleague (e.g. work, classmate)		2	3	4	5	6	7
f. Phone helpline (e.g. Irish Cancer Society, Niteline)		2	3	4	5	6	7
g. Healthcare professional (e.g. GP, doctor, nurse)		2	3	4	5	6	7
h. I would not seek help from anyone		2	3	4	5	6	7
i. I would seek help from another not listed above		2	3	4	5	6	7
(please list in the space provided. If no, leave blank):							

# IV. (Questions 25 and 26) Please read the below statements carefully and tick what applies to you:

25) Have you <b>purposefully</b>	felt/examined y	our testicles with	in the past month?
	Yes	No	
26) Have you advised at lea	st one man (e.g	. friend, colleague	e, partner, family
member) about the im	portance of exa	amining his testicl	es in the
shower/bath at least once	e in the <b>past</b> me	onth?	
	Yes	No	

THANK YOU!

#### Appendix 6.11 Instructions for instrument validation

Dear Reviewer,

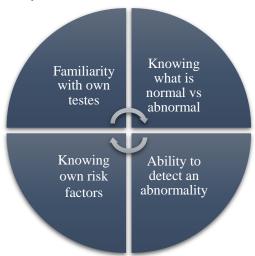
Thank you for agreeing to partake in the validation of the attached instrument.

The aim of the study is to enhance men's awareness of testicular symptoms and disorders.

This instrument will be used to collect data before an intervention (T0), immediately following the intervention (T1), and one month following the intervention (T2).

The intervention comprises three scenarios and is delivered using a virtual reality headset and controller. In the first scenario, men are familiarised with the normal testes, in the second scenario men are introduced to the most common testicular symptoms (swelling, lumpiness, and pain), and in the third scenario men are exposed to the most common testicular disorders (epididymitis, testicular torsion, and testicular cancer).

Both, the intervention and the instrument were constructed on the basis of the concept of 'Testicular Awareness' (Figure below) that we developed through a review of the literature and a qualitative study.



The instrument includes six brief sections:

- Socio-demographic section
- Knowledge quiz
- Testicular awareness scale
- A question on perceived risk
- Implementation intentions scale
- General help-seeking scale
- Behaviour scale

You are kindly required to indicate whether each of the items is 'Not Relevant', 'Somewhat Relevant', 'Quite Relevant', or 'Highly Relevant' to the study aim and the concept of 'Testicular Awareness' by putting an 'X' in the corresponding box. Please rate items.

Please feel free to write any comments as you see fit, do not hesitate to contact me if you have any queries, and return the instrument back to me.

Sincerely,

Mohamad Saab, PhD student, MSc, BSc, RN College of Medicine and Health Catherine McAuley School of Nursing and Midwifery University College Cork, Ireland

Email: msaab@ucc.ie

Item	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
Questions 1 to 11 comprise the Socio-demographs					
1. Age:Years					
2. Nationality(ies)  Irish Other (Please specify):					
3. Sexual orientation  Heterosexual (Straight)  Gay  Bisexual  Transsexual  Other (Please specify):					
4. Marital status Single Married Engaged In a relationship/Partnered Divorced Separated Widowed					

Item	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
5. Highest level of education  None Primary Secondary Higher secondary Third level degree or above Other (Please specify):	Kelevant	Reievant	Relevant	Kekvant	
6. Current occupation (Please tick what applies to you)  Student (please specify your course):  Employed (full-time)  Employed (part-time)  Self-employed  Unemployed  Other (Please specify):					
7. Have you got a personal history of one or more testicular disorder(s)?  Yes (Please specify):  No Unsure					
8. Have you been previously informed/educated about testicular disorders?  Yes (Please specify how):  No					

Item	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
9. Do you plan on seeking information/more information in relation to testicular diseases in the near future?  Yes No					
10. Have you used Virtual Reality before?  Yes No					
11. Please rate the importance of learning about testicular diseases? (Please tick what is true for you)  Extremely unimportant  Unimportant  Neutral Important Very Important					
Questions 12 to 23 comprise the Knowledge Quiz administered at T0,  12. Your right testicle is different from your left testicle  a) True  b) False c) Don't know	T1, and T2.	Men are asked	to circle the c	orrect answer	

Item	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
13. Your testicles are identical to other men's testicles		Troic value	1tere varie	Trefe valit	
a) True					
b) False					
c) Don't know					
14. Sometimes, one testicle lies slightly lower than the other					
a) True					
b) False					
c) Don't know					
15. Testicles are round in shape					
a) True					
b) False					
c) Don't know					
16. What is the name of the tube that stores the sperm?					
a) Epididymis					
b) Urethra					
c) Spermatic cord					
d) Ureter					
17. What is the name of the tube from which the testicles hang?					
a) Epididymis					
b) Urethra					
c) Spermatic cord					
d) Ureter					

Item	Not	Somewhat	Quite	Highly	Comments
	Relevant	Relevant	Relevant	Relevant	
18. Which of the symptoms below <b>DOES NOT</b> commonly occur in the testicles?					
a) Pain					
b) Swelling					
c) Lumpiness					
d) Bleeding					
19. What is the <b>MOST COMMON</b> reason for an enlarged/swollen testicle?					
a) Trauma					
b) Testicular torsion					
c) Testicular cancer					
d) Epididymitis and orchitis					
20. What is the <b>MOST COMMON</b> reason for sharp and sudden pain in the					
testicle?					
a) Trauma					
b) Testicular torsion					
c) Testicular cancer					
d) Epididymitis and orchitis					
21. The <b>BEST</b> time to check the testicles is:					
a) In the shower or bath					
b) While playing sports					
c) While using the toilet					
d) In bed					

Item	Not	Somewhat	Quite	Highly	Comments
	Relevant	Relevant	Relevant	Relevant	
22. What puts a man at risk for epididymitis and orchitis?					
a) Trauma					
b) Unsafe sex					
c) Cancer					
d) Masturbation					
23. Which statement about testicular cancer is <b>NOT</b> true?					
a) It is generally diagnosed in young guys					
b) It is very common					
c) The risk is higher if a guy has a father or a brother who have it					
d) It can be cured					
Questions 24 to 28 comprise the Testicular Awareness Scale administered at T0, T1, a Scale (Strongly Disagree, Disagree, Neut			Ü		•
24. I believe that I am <b>familiar</b> with the way my own testicles normally look and					
feel					
25. I believe that I <b>know</b> what is normal and what is not normal when I feel my testicles					
26. I believe that I can <b>differentiate</b> between what is normal and what is not normal when I feel my testicles					
27. I believe that I can tell if something is wrong with my testicles					
28. I believe that I am able to detect any changes in my testicles					

Item	Not Relevant	Somewhat Relevant	Quite	Highly Relevant	Comments
Question 29 assesses perceived risk for testicular disorders and is administered at T Likert Scale (Strongly Disagree, Disagree, N	70, T1, and T2	. Men are aske			w on a 5-point
29. I believe that I am at risk for developing one or more testicular disease(s)					
Questions 30 to 32 comprise the Implementation Intentions Questionnaire administer 5-point Likert Scale (Strongly Disagree, Disagre				ate each of the	statements on a
30. I <b>intend to feel</b> my testicles in the shower/bath at least once over the coming month					
31. I will feel my testicles in the shower/bath at least once over the coming month					
32. I <b>intend to advise</b> at least one man (e.g. friend, colleague, partner, family member) about the importance of examining his testicles in the shower/bath at least once in the coming month					

Item									Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
Questions 33 to 35 comprise the General Help-Seeking Que on a 7-point Likert Scale (1										, T1, and T2.		d to rate each o	f the statements
33. If you discovered a <b>significant enlargement/swelling without any pain</b> , how likely is it that you would seek people?			•										
a. Intimate partner (e.g. girlfriend, boyfriend, wife, husband)	1	2	3	4	5	6	7	,					
b. Friend (not related to you)	1	2	3	4	5	6	7	'					
c. Parent	1	2	3	4	5	6	7						
d. Other relative/family member	1	2	3	4	5	6	7						
e. Colleague (e.g. work, classmate)	1	2	3	4	5	6	7						
f. Phone helpline (e.g. Irish Cancer Society, Niteline)	1	2	3	4	5	6	7						
g. Healthcare professional (e.g. GP, doctor, nurse)	1	2	3	4	5	6	7						
h. I would not seek help from anyone	1	2	3	4	5	6	7						
i. I would seek help from another not listed above (please list in the space provided. If no, leave blank):	1	2	3	4	5	6	7						

Item									Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
34. If you discovered a lump in your testicle without any that you would seek help form the following people?  a. Intimate partner (e.g. girlfriend, boyfriend, wife, husband)  b. Friend (not related to you)  c. Parent  d. Other relative/family member  e. Colleague (e.g. work, classmate)  f. Phone helpline (e.g. Irish Cancer Society, Niteline)  g. Healthcare professional (e.g. GP, doctor, nurse)  h. I would not seek help from anyone  i. I would seek help from another not listed above (please	7 <b>pai</b> 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2	3 3 3 3 3 3 3 3	1ik 4 4 4 4 4 4 4 4 4	ely 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5 5	6 6 6 6 6 6 6	7 7 7 7 7 7 7	,	Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
list in the space provided. If no, leave blank):													

Item									Not Relevant	Somewhat Relevant	Quite Relevant	Highly Relevant	Comments
35. If you felt a <b>sudden and sharp pain in one or both testicles without any enlargement/swelling or lump</b> , how likely is it that you would seek help form the following people?								m					
a. Intimate partner (e.g. girlfriend, boyfriend, wife, husband)	1	2	3	4	4	5 6	5	7					
b. Friend (not related to you)	1	2	3	4	4	5 6	5	7					
c. Parent	1	2	3		_		5	7					
d. Other relative/family member	1	2	3	4	4	5 6	5	7					
e. Colleague (e.g. work, classmate)	1	2	3	4	4	5 6	5	7					
f. Phone helpline (e.g. Irish Cancer Society, Niteline)	1	2	3	4	4	5 6	5	7					
g. Healthcare professional (e.g. GP, doctor, nurse)	1	2	3	4	4	5 6	5	7					
h. I would not seek help from anyone	1	2	3	4			5	7					
i. I would seek help from another not listed above (please	1	2	3	4	4	5 6	5	7					
list in the space provided. If no, leave blank):													

Item	Not	Somewhat	Quite	Highly	Comments
	Relevant	Relevant	Relevant	Relevant	
Questions 36 to 39 comprise the Behaviour Quest			ed at T0		
Questions 39 and 41 are adm	iinistered at T	<b>T2</b>			
36. Have you <b>purposefully</b> felt/examined your testicles within the past year?					
Yes No					
37. Have you <b>purposefully</b> felt/examined your testicles within the past month?					
Yes No					
38. Did a healthcare professional (e.g. doctor/nurse) <b>ever</b> examine your testicles?					
Yes No					
39. Have you <b>advised</b> at least one man (e.g. friend, colleague, partner, family					
member) about the importance of examining his testicles in the shower/bath					
at least once in the <b>past</b> month?					
Yes No					

Appendix 6.12 Content validity scores for the instrument used in the pilot study

Instrument	Item	Expert 1	Expert 2	Expert 3	Expert 4	Expert 5	Expert 6	Expert 7	Expert 8	Number in Agreement	I-CVI	S-CVI
	1	<b>√</b>	8	1								
	2	_	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	7	0.88	
	3	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	4	_	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	$\checkmark$	7	0.88	
Socio-demographic	5	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	0.00
Questionnaire	6	✓	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	$\checkmark$	8	1	0.98
	7	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	8	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	8	1	
	9	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	10	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	11	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	12	<b>√</b>	8	1								
	13	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	8	1	
	14	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	15	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	16	$\checkmark$	$\checkmark$	$\checkmark$	_	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	7	0.88	
	17	$\checkmark$	$\checkmark$	$\checkmark$	_	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	7	0.88	
Knowledge Questionnaire	18	✓	$\checkmark$	$\checkmark$	$\checkmark$	✓	✓	$\checkmark$	$\checkmark$	8	1	0.98
	19	✓	✓	✓	✓	✓	✓	✓	✓	8	1	
	20	√	√	√	√	√	✓	√	√	8	1	
	21	✓	✓	✓	✓	✓	✓	✓	✓	8	1	
	22	✓	✓	✓	✓	✓	√	✓	✓	8	1	
	23	✓	✓	✓	✓	✓	✓	✓	✓	8	1	
Testicular Awareness Scale	24	<b>√</b>	8	1	0.98							

	25	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	26	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	_	$\checkmark$	$\checkmark$	7	0.88	
	27	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
	28	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
Perceived Risk Item	29	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	8	1	-
	30	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	✓	8	1	
Implementation Intentions	31	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	1
Scale	32	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	✓	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
General Help-Seeking	33	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	8	1	
Questionnaire	34	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	1
	35	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	
Behaviour Questionnaire	36	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	8	1	
	37	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	8	1	0.04
	38	_	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	7	0.88	0.94
	39	_	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	7	0.88	
Mean CVI											0.98	0.98

(Polit & Beck 2006, Polit *et al.* 2007). **Abbreviations:** CVI: Content validity index; I-CVI: Item content validity index; S-CVI: Scale content validity index.