UNIVERSITY OF KWAZULU-NATAL ™

INYUVESI YAKWAZULU-NATALI

The Neglected Sexual Side Effects After Prostate Cancer Treatment. A Mixed Methods Study of the Prevalence, Screening and Psychosocial Impact on South African Men

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A thesis submitted to the College of Health Sciences, University of KwaZulu Natal, In fulfilment of the requirements for the degree of

Doctor of Philosophy (PhD) Clinical Medicine (Urology)
April 2023

As the candidate's supervisor, I have approved this thesis for submission

Signed:
Name: **Prof. Jacqueline van Wyk** **Date:**

DECLARATION

I, Pierre Röscher declare that,

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(ii) This dissertation has not been submitted for any degree or examination at any other university.

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Student No: [redacted]

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DEDICATION

I dedicate this thesis to my family.

To my wife, Mandy and my children Emma and Oliver.

Thank you all for the love, support, and encouragement.

I also dedicate this to my late grandfather, Marthinus Albertus Joubert, who had himself experienced significant distress and bother after his own prostate cancer treatment.

Lastly, it is no coincidence that I ended up completing a PhD at the Nelson R Mandela School of medicine. I acknowledge the man who inspired the world, and who inspired me.

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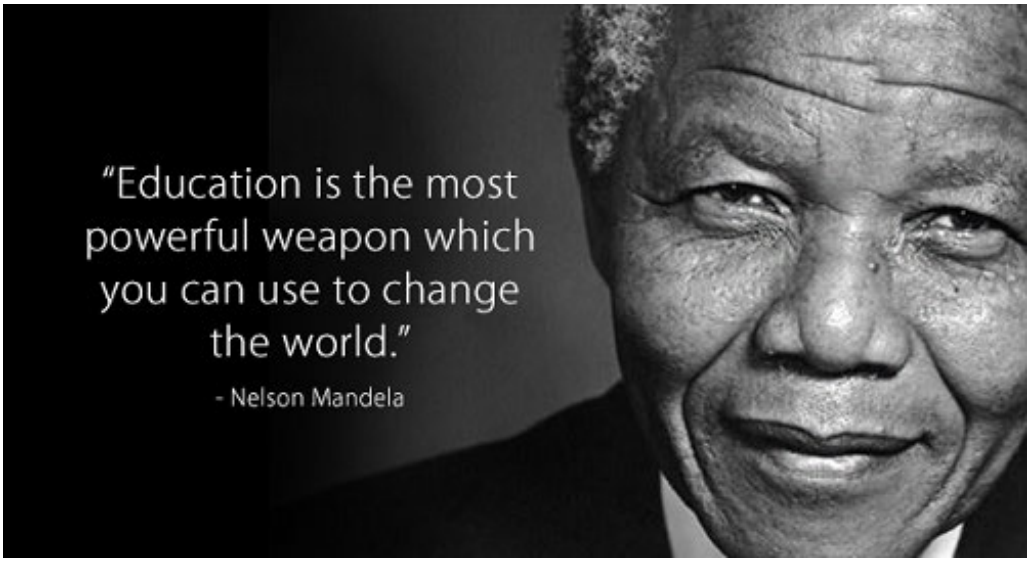

[1] www.artsculturesa.com

ACKNOWLEGMENTS

My Supervisor

Prof Jacqueline Van Wyk, who has been on this wonderful journey with me for 6 years, guiding me through the process and supporting my personal growth and development as a researcher. I will always be grateful for the guidance that you have given me.

Participants

Thank you to all the participants in this study, both professionals and patients, without you, this study would not have been possible

Co Authors and Colleagues

I would like to acknowledge a colleague Dr. Joanne Milios, who also co-authored on two papers. Jo, you were the one who inspired me to do a PhD when you presented your research in 2017, and subsequently helped me not only with my PhD concept, but also helped me to publish some of my research. Your knowledge and experience in the field has directly and indirectly helped so many men around the world. Thank you for everything that you have done for me.

I would like to thank Dr. Ronisha Sathiram and Dr. Kimesh Naidoo for their valuable input, advice, and guidance through their roles as co-authors on my papers.

I would like to thank Helen Shaw, an inspirational clinician in the field of prostate cancer rehabilitation. Much of my clinical practice and research identity has been based on the principles of your management philosophy to these patients. You continue to inspire me!

My wife Mandy

For her unconditional love and support, and for affording me the time and capacity to pursue my PhD whilst running and managing our young family. Thank you for being on this journey with me, for never complaining, and for always keeping me focussed.

My children Emma and Oliver

For their love and support, as this PhD started with the birth of my eldest child and has grown into something special as they have grown over the years.

Funders

I would like to acknowledge that UKZN provided me with three academic years of fee remission.

I would also like to acknowledge that I was the recipient of an R11 000 PhD grant from the South African Society of Physiotherapy.

ABSTRACT

Introduction/Background: The neglected sexual side effects after prostate cancer treatment are poorly understood and understudied, especially with regards to their prevalence rates and detection methods. A barrier to understanding the neglected sexual side effects is that there are currently no questionnaire-based screening tools available to detect them, effectively preventing early intervention and promoting long term disability for some patients after prostate cancer treatment. It is unknown what the prevalence rates are of the neglected sexual side effects after prostate cancer treatment in South African men, and whether these side effects impact on their psychosocial life.

Aim: This study reviewed the literature of the prevalence and detection trends of the neglected sexual side effects after prostate cancer treatment. It further aimed to develop the items of a neglected sexual side effects after prostate cancer treatment questionnaire-based screening tool. After it was developed, the tool was used in a South African population to gather neglected sexual side effects after prostate cancer treatment prevalence rates, and to determine how bothersome the NSSE were to participants. Lastly, the study aimed to determine the psychosocial impact of sexual dysfunction after prostate cancer treatment.

Methods: This thesis by manuscript provides the evidence using mixed methods to achieve the aims stated above through the submission of linked papers, some of which have been published or are under review in peer-reviewed medical journals. The papers included i) a scoping review of the neglected sexual side effects after prostate cancer treatment, ii) a Delphi study where the neglected sexual side effects after prostate cancer questionnaire-based screening tool was developed, iii) a prevalence and bothersomeness of neglected sexual side effects after prostate cancer treatment paper and iv) a psychosocial impact of sexual dysfunction after PCT paper.

Results: This thesis provides information on the prevalence of the neglected sexual side effects after PCT and how they are detected based on the current literature. The Delphi study provided a robust rationale for an 8-item neglected sexual side effects after prostate cancer treatment questionnaire-based screening tool. South African neglected sexual side effects

after prostate cancer treatment prevalence and bothersomeness trends were discovered as well as the psychosocial impact of sexual dysfunction in men after prostate cancer treatment.

Conclusion: Neglected sexual side effects after prostate cancer treatment could be detected early by using a questionnaire-based screening tool that could be made freely available and self-administered by men after prostate cancer treatment. Early awareness and management of the neglected sexual side effects could minimise the long-term disability associated with sexual dysfunction and improve the psychosocial wellbeing of men after their prostate cancer treatment.

ABSTRACT (ZULU)

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OPERATIONAL DEFINITIONS

Anejaculation

Anejaculation refers to **no ejaculation**. When an orgasm occurs in men but semen isn't expelled, it's called anejaculation. Anejaculation is a type of male sexual dysfunction that can affect one's ability to enjoy sex. It can also lead to male infertility.

Anorgasmia

Anorgasmia is **delayed, infrequent or absent orgasms, or significantly less-intense orgasms after sexual arousal and adequate sexual stimulation**. Men who have problems with orgasms and who feel significant distress about those problems may be diagnosed with anorgasmia.

Arousal Incontinence

An under-appreciated type of sexual incontinence is arousal incontinence (AI), which is **urinary leakage that occurs during either physical or psychological arousal**.

Bothersomeness:

The state or condition of being bothersome or bothered by something.

Climacturia

Climacturia, also known as orgasm-associated incontinence, is a condition in which a man leaks urine as he ejaculates.

Health Care Professional:

Health care professionals maintain health in humans through the application of the principles and procedures of evidence-based medicine and caring.

Localised/Early Prostate cancer:

Early (localised) prostate cancer refers to **cancer cells that have grown but do not appear to have spread beyond the prostate**. There are two stages of advanced prostate cancer: locally advanced prostate cancer where the cancer has spread outside the prostate to nearby parts of the body or glands close to the prostate.

Neglected Sexual Side Effects:

A group sexual side effects that are underdiagnosed and remain largely undetected. They are i) Anorgasmia, Orgasmic pain, iii) arousal incontinence, iv) Climacturia, v) Anejaculation, vi) penile pain, vii) penile length shortening and viii) penile curvature changes.

Penile Length Shortening

Shortening of the penis, as measured by its flaccid length changes measured by a ruler. Penile length shortening may also be perceived, in the absence of actual penile length shortening.

Peyronies disease/ Penile curvature changes

Penises vary in shape and size and having a curved erection isn't necessarily a cause for concern. In Peyronie's disease, the bend is significant, and may occur along with pain or interfere with sexual function. Peyronie's disease is caused by repeated penile injury, typically during sex or physical activity. Medication or surgery may be recommended if symptoms persist or worsen.

Prostate Cancer:

Prostate cancer develops when abnormal cells in the **prostate gland** grow in an uncontrolled way, forming a malignant tumour.

Prostate Cancer Treatment:

Such treatments include **surgery and radiation therapy**. For early-stage prostate cancer, local treatments may get rid of the cancer completely. If the cancer has spread outside the prostate gland, other types of treatment (such as medications) may be needed to destroy cancer cells located in other parts of the body.

ABBREVIATIONS AND ACRONYMS

AI: Arousal Incontinence

Covid-19: Coronavirus 19 pandemic

ED: Erectile Dysfunction

HCP: Health Care Professional

MDT: Multi-Disciplinary Team

MeSH: Medical Subject Heading,

MMAT: Mixed Method Appraisal Tool,

NSSE: Neglected Sexual Side Effects,

PCa: Prostate Cancer,

PCC: Population Concept Context,

PCFSA: Prostate Cancer Foundation of South Africa

PCT: Prostate Cancer Treatment,

PLS: Penile Length Shortening

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews,

QBST: Questionnaire Based Screening Tool,

QOL: Quality of Life

RP: Radical Prostatectomy,

RSA: Republic of South Africa

RT: Radiation Therapy.

SD: Sexual Dysfunction

SA: South African

TA: Thematic Analysis

UI: Urinary Incontinence

PEER REVIEWED PUBLICATIONS LINKED TO THE CURRENT STUDY

1. Röscher P, Van Wyk JM. Mapping the prevalence of the neglected sexual side effects after prostate cancer treatment and the questionnaires used in their screening: a scoping review protocol. Systematic Reviews. 2020 Dec;9(1):1-6.

2. Röscher P, Sathiram R, Milios JE, van Wyk JM. Mapping the prevalence and use of questionnaires to detect the neglected sexual side effects after prostate cancer treatment: a scoping review. Systematic reviews. 2022 Dec;11(1):1-2.

3. Röscher P, Naidoo K, Milios JE, van Wyk JM. A modified Delphi study to identify screening items to assess neglected sexual side-effects following prostate cancer treatment. BMC urology. 2022 Dec;22(1):1-3.

Manuscripts in review

1. Röscher P, van Wyk JM. Prevalence and Bothersomeness of the Neglected Sexual Side Effects After Prostate Cancer Treatment in South Africa. (2023)
2. Röscher P, van Wyk JM. Psychosocial impact of sexual dysfunction related to prostate cancer treatment in South African Men. (2023)

CONFERENCE PRESENTATIONS

International

Platform Presentation

Röscher, P., Naidoo, K., Milios, J. E., & van Wyk, J. M. The validation of a neglected sexual side effects after prostate cancer treatment questionnaire using a modified e Delphi study. Platform Classic number PL-01706. **World Physiotherapy Congress 2021 Online, 9-11 April 2021.**

Poster

Röscher, P., Sathiram, R., Milios, J. E., & van Wyk, J. M. Mapping the prevalence and use of questionnaires to detect neglected sexual side effects after prostate cancer treatment: A scoping review. Australian Physiotherapy Association THRIVE conference.
*The conference was rescheduled twice, and finally cancelled due to continuous **Covid 19 Outbreaks in Brisbane, Australia. (2022)**

Other

Röscher, P. Sexual Dysfunction after prostate cancer treatment. Presentation to the South African Society of Physiotherapy. Online. 23 January 2023.

PREAMBLE

The format of this thesis is in accordance with the recommendations for a PhD via manuscript format, as presented within the School of Clinical Medicine, College of Health Sciences, University of KwaZulu Natal. It includes a submission of a thesis with a collection of research articles, in conjunction with introduction and summary chapters.

This thesis comprises published journal articles, and articles that are in the review process for publication. The integrative material links the chapters and the findings to the overall aim of the study in relation to the prevalence of the Neglected Sexual Side Effects after prostate cancer treatment, and the psychosocial impact that it has on men.

The synthesis chapter at the end outlines the conclusions formed based on a combination of results from the papers presented and included recommendations for the way forward. The contribution of the candidate is indicated for each manuscript, with details of the journals and their submission and review process where necessary.

The candidate essentially followed the same process in terms of planning, conducting, and preparing the research for examination with the same key milestones as for a traditional thesis. A large proportion of the methodology and literature is revealed within each of the publications. The literature review and methodology are also presented within the integrative material, especially in Chapter One (Introduction), Chapter Two (Literature Review), Chapter Three (Methodology) and Chapter Eight (Synthesis), with a summative page after each article to establish the link between chapters. This may lead to a fair amount of repetition between the integrative material and the manuscripts, which is necessitated by virtue of the manuscript format of PhD presentation.

Please note the following with respect to this thesis report:

i. The Vancouver referencing style has been observed in the integrative material. All references which are not specific to each manuscript are consolidated in Chapter 9.
ii. Manuscripts are presented in the format required of the specific journal, and thus stylistic differenced should be expected.

iii. Use of active (first person) and passive voice (third person) have been used in the manuscripts and the integrative material.

CHAPTER 1: INTRODUCTION

1.1 Context of the Study

Prostate cancer (PCa) is the second most common cancer affecting males across the world, making up 14,1 % of all male cancers detected in 2020, and 7,3 % of all cancers detected in both sexes globally [1]. PCa constitutes a major global public health burden [2], and significant resources are spent on managing PCa in populations [3]. PCa is a major cause of disease and mortality, and each year around 1.6 million men are diagnosed with, and 366,000 men die of PCa [4]. Many inequalities exist around the world, especially in middle to low-income countries when it comes to PCa care, and these inequalities exists mainly due to a of a lack of financial resources available in these regions [5]. These inequalities prevent appropriate and affordable cancer care for some patients [6].

For men who are lucky enough to be diagnosed early where financial resources are available, PCa is treatable, and survival rates remain high [7, 8]. Patients face various treatment options, with the two main options being a radical prostatectomy (RP) and radiation therapy (RT). It is at this point in a patient's journey where they must make a decision that may have long lasting effects on them. They must way up the possibility of experiencing side effects with the curative nature of the chosen treatment approach [9, 10]. Many factors also influence their choices, including their chosen medical professional (Urologist or Oncologists) and their speciality, and the experiences and opinions of their friends and family members (especially their partners), and the information that they have researched on the internet [11].

Once the intervention has been completed, men may experience a variety of side effects depending on their chosen treatment. Some of the most notable side effects include post procedure pain, urinary incontinence (UI), and sexual dysfunction (SD) [12]. The post procedure pain usually normalizes first, whilst urinary incontinence and SD may take much longer to improve in most patients depending on the patient and the procedure [9].

SD after early prostate cancer treatment (PCT) is a major health concern, regardless of the type of treatment received to treat the disease [13]. Long-lasting SD symptoms can have disabling consequences for men and impact negatively on the relationships that they have with their partners [12, 14]. Amongst the SD symptoms are a group of neglected sexual side

effects (NSSE) that have been clearly defined in recent literature [15-17]. These symptoms remain largely undiagnosed due to nondisclosure by affected men and lack of awareness by medical professionals [17-19]. The NSSE are divided into 3 categories namely: i) *urinary incontinence during sexual activity* (arousal incontinence and climacturia), ii) *orgasmic related disorders* (anorgasmia and dysorgasmia), iii) *ejaculation related disorders* (anejaculation) and iv) *penile tissue related disorders* (penile pain, penile curvature changes and penile shortening).

Sexual communication could be regarded as a taboo subject, and many patients simply continue living with bothersome symptoms continuously causing them physical and emotional distress [20]. More so, few medical professionals are knowledgeable on the presentations and management of NSSE [13, 21].

A potential answer to address this dilemma is to have a questionnaire based screening tool (QBST) available that helps to bridge this conversation between patients and their health care professional, empowering patients to have their symptoms recognised and addressed [9]. These sexual side effects may effectively be flagged with the use of a patient QBST, as it may be an ideal non-threatening strategy for a patient to voice their presenting symptoms.

Screening for specific conditions have many benefits and positive health outcomes, and early detection and intervention of conditions are often more cost effective that late detection and management [22]. SD questionnaires and screening tools currently available in the field of men's health and PCa do not recognise the full scope of symptoms experienced by men who undergo early PCT, leaving the NSSE unrecognised and undetected [19].

1.2 Significance

This study aimed to produce a QBST to assess the NSSE after early PCT.
In the absence of literature about the prevalence and scope of this condition, the first step entailed conducting a scoping review into published literature on the NSSE after early PCT and the use of screening tools and questionnaires to detect them. The second step involved a group of multidisciplinary experts whereby the contents of the screening tool was developed, and consensus was established on the appropriateness of each specific screening statement to include in the QBST. In the third step, the QBST was applied to a sample of the target

population to determine the prevalence of NSSE after PCT, and to determine the psychosocial impact of SD on patients after PCT.

The QBST will be made available free of charge to patients and clinicians with the aim to serve as a catalyst to improve the knowledge and awareness of NSSE amongst health care professionals and patients alike. The study has the potential to change the scope of men's health, post-PCT protocols and the management for the NSSE of men in South Africa. The low costs associated with the duplication of the QBST, may have far reaching impact for PCa patients in low to middle income countries (LMIC) contexts and possibly elsewhere in the world.

This study envisaged to reduce disability amongst men undergoing PCT as it generated new information into the field of male sexual health that could inform future treatment and policies.

1.3 Problem Statement

Men who undergo PCT may experience a range of sexual side effects that are less likely to be detected by health care professionals. The NSSE after PCT are not routinely screened for, and many health care professionals may not even be aware of them. NSSE contributes to significant distress and bother in men who have had PCT. There was a need to explore the prevalence of the NSSE after PCT, and look at how these symptoms are being detected, and whether were readily available for this purpose. In the absence of appropriate questionnaires or screening tools, the development of a NSSE after PCT QBST would prove valuable to enable patients to self-screen and health care professionals to screen patients who experience one or multiple NSSE. The availability of a QBST would enable data to be collected on specific populations of patients. Available data on NSSE will improve the knowledge around the field of SD in men after PCT and would impact on management approaches for these patients, therefor improving the overall physical and psychological wellbeing of patients.

1.4 Overall Aim

The aim of this study was to collect clinical evidence on the prevalence and detection methods of the NSSE after PCT, and to create a QBST to determine the prevalence of the

NSSE in a target population. The study also aimed to explore the psychosocial impact of SD in men who have had PCT.

1.5 Objectives

The objectives of the study were:

- To determine the differences in prevalence in the NSSE after early PCT between RP and RT.
- To determine how the NSSE after early PCT are being reported and detected and whether questionnaires play a role in the assessment and treatment of the NSSE.
- To create a "NSSE" QBST for men who have received PCT.
- To establish multidisciplinary consensus on the appropriateness of a NSSE after PCT QBST.
- To determine the differences in prevalence in the NSSE after early PCT between RP and RT.
- To establish how bothersome NSSE are after PCT.
- To determine the psychosocial impact of sexual side effects after PCT in a population.
- To achieve the stated objectives of this study, the following specific questions were formulated and pursued:

1.6 Research Questions

- What is the prevalence of the NSSE after early PCT, and how do they differ between RP and RT?
- How are the NSSE after early PCT are being detected and do questionnaires play a role in the assessment and treatment of these NSSE.
- What questions would be included in a NSSE after PCTQBST, and how would the appropriateness of these questions be determined by a multidisciplinary group of sexual health experts?
- What is the prevalence of the NSSE in South African men who have had early PCT?
- How bothersome are the NSSE for South African men who have had early PCT?
- What is the Psychosocial impact of SD for South African men who have had early PCT.

1.7 Theoretical frameworks

The approach to this thesis can be explained through the integration of the Biopsychosocial (BPS) model by Engel (1977) and the International Classification of Functioning, Disability and Health (ICF) framework (World Health Organization, 2001). The integration of the BPS model and the ICF Framework recognises that health and wellness is not only due to physical attributes, but that it is equally influenced by psychological and social attributes.

1.7.1 The Bio-Psycho-Social Framework

The BPS model, originally published in 1977 proposed that traditional model of illness based purely on underlying pathology of biological impairments was not sufficient. The traditional biomedical model used at the time left no room for the dimensions of healthcare that included the social, psychological and behavioural aspects of illness [23].

The BPS has been widely accepted since then as a modern and appropriate framework for research, teaching, development and management in healthcare in most healthcare fields, apart from acute medical and surgical fields [24]. Sexual health related to cancer has been further integrated into the BPS model by Bober and Varela (2012) and more recently by Wittmann et al (2022), providing a model where sexual recovery is viewed as multi-dimensional [25, 26]. In this model, previously neglected psychological, social, and interpersonal factors are included as follows

Psychological:

Emotions (e.g., depression and anxiety), cognitions (e.g., body image, negative thinking) and motivation (self-efficacy).

Social/Cultural:

Religious beliefs, cultural beliefs, and social norms.

Interpersonal:

Relationship discord, fear of intimacy, lack of communication.

Furthermore, six guiding principles were developed to create a BPS based sexual health recovery guideline.

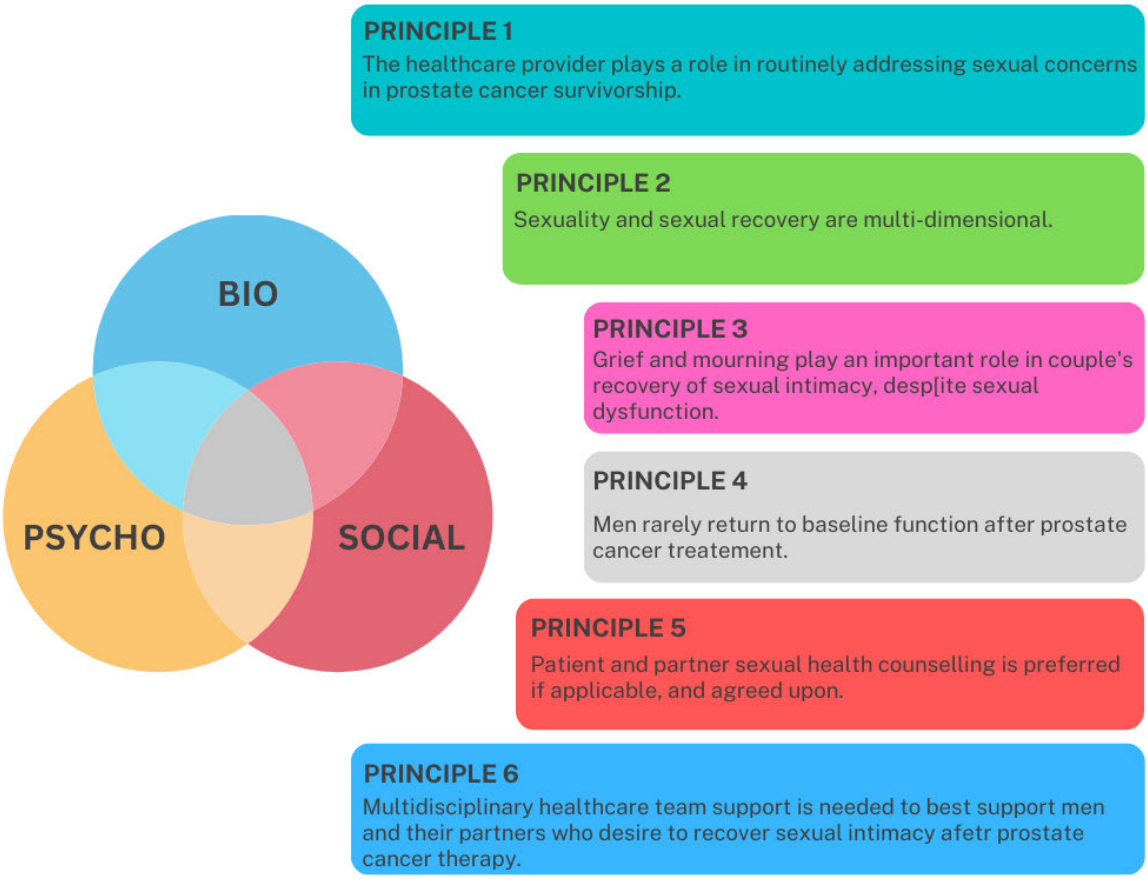

Figure 1: Guidelines for sexual health care for prostate cancer patients (25)

1.7.2 The International Classification of Functioning, Disability and Health Framework (ICF)

The ICF is both a framework and a classification system that allows the function of an individual to be measured and assessed [27]. The ICF was accepted and universally adopted by the World Health Organization in 2003, and it allows for a universal language to be used when describing the health status of a person [27]. The purpose of the ICF is to conceptualise the shift of healthcare from a traditional "cure the disease" perspective to a more modern "enable participation and function" model, and it achieves this by its integration with the BPS model. In the ICF, "functioning" describes the body functions and structures, activities and participation, where "disability" describes the impairments, activity limitations and participation restrictions [28]. In addition, the ICF also considers environmental and personal factors. The ICF is an ideal tool for health care professionals to use to address sexual health in their clinical practice, facilitate sexual health rehabilitation for patients [28]. The ICF allows for other health assessment and measurement tools to be based on the framework [27].

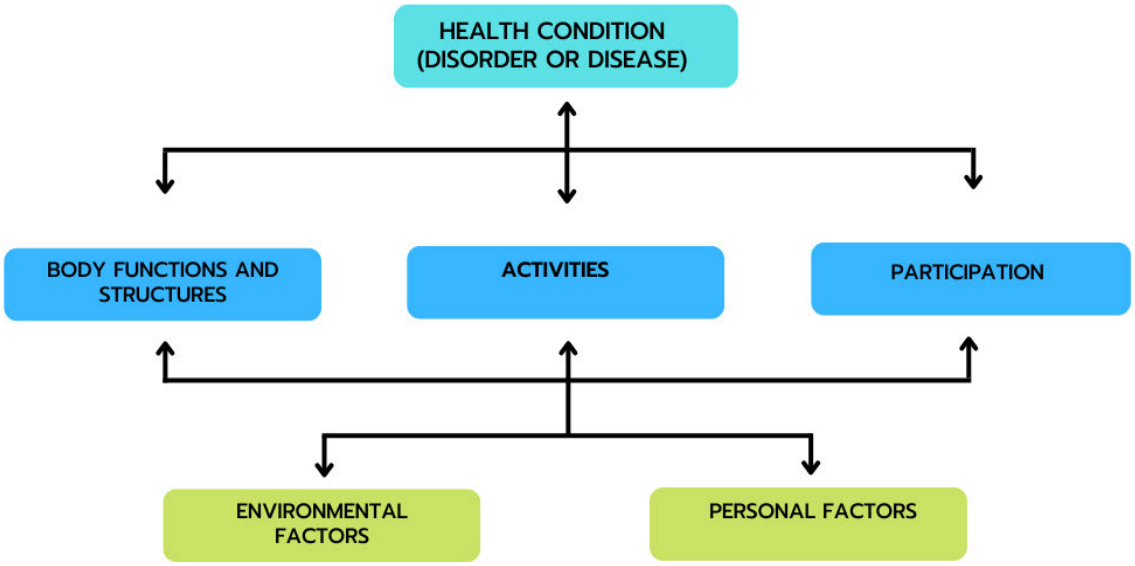

Figure 2: ICF Model (WHO 2003)

The ICF has a unique role in sexual health and rehabilitation, as it can describe functioning, patient's goals, results, current and future investigations, treatment, prevention and continued care pertaining to the sexual health of an individual by using its unified terms and health codes [28].

Table 1: ICF Hierarchical Structure

ICF Hierarchical Structure			
Body Structures (S-codes)	Body Functions (B-codes)	Activities and Participation (D-codes)	Environmental Factors (E-codes)
s630 *Structure of reproductive systems*	b640 *Sexual Functions*	d570 *Looking after one's sexual health*	e115 *Products and technology for personal use in daily living*
	b670 *Sensations associated with genital and reproductive functions*	d5706 *Managing one's sexual health*	e310 *Support of immediate family*
		d770 *Engaging in intimate relationship*	E410 *Individual attitudes of immediate family members*

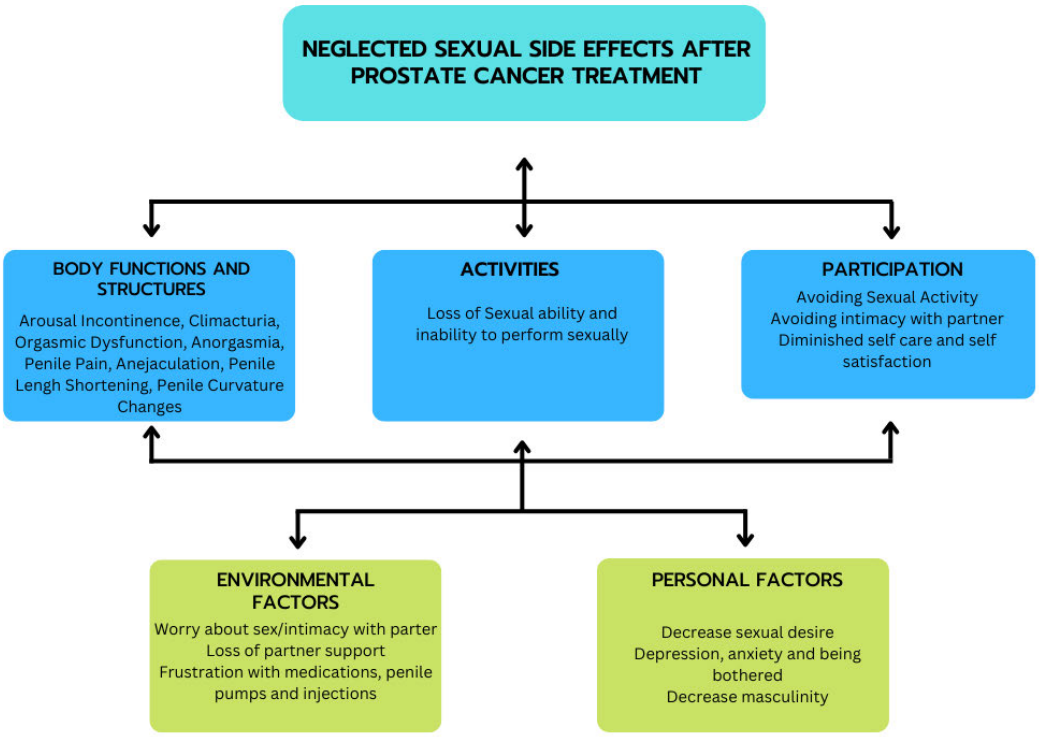

Figure 3: Integrating NSSE after PCT into the Sexual Health integrated ICF Model

PCa is a unique condition where for many patients who are diagnosed early and appropriately managed, survival rates are high. The side effects of PCT, however, may be long lasting physical and psychosocial in nature. PCa survivors may also experience long lasting side effects which are a direct result of their treatment. These sexual side effects affect not only the physical aspects of health, but also the psychosocial aspects of men after PCT.
In this study, we were able to link up how the ICF Framework could be applied in our study population, where SD (the Impairment) had a clear impact on the Activity (loss of sexual ability). What is less known in the literature, is how the Impairment and Activity limitations contribute to the Participation limitations, where men may become distant from their partners, and avoid normal sexual behaviour, and tend to neglect themselves and become more dissatisfied. These are further explored in this study.

1.8 Outline of Thesis

This thesis will be presented in the "thesis by manuscript" format and is in line with the College of Health Sciences guidelines of the University of KwaZulu Natal (Appendix 1). In

this format, the answer to each question is addressed in the format of a manuscript. This study consists of four manuscripts where the researcher is the prime author. The thesis consists of eight chapters. Each manuscript is included (Chapter 4-7) with a brief introduction, publication details and concluding summary and the chapters are presented as a coherent thesis through integrative material that explains the purpose of each publication. This thesis consists of eight chapters which are presented as follows.

Chapter 1 provides the **orientation to the study**. It introduces the background to the study and the nature of the problem, goals of the study, objectives, and research questions. It also describes the structure of the thesis by manuscript and the organisation of the content. The positionality of the researcher is also described in this chapter.

Chapter 2 provides a **brief literature review** as the appropriate literature is addressed in each manuscript. This is not a compulsory chapter for this type of manuscript. It provides an overview of PCa, its treatment approaches, and the side effects. Prevalence and detection methods through questionnaires and screening tools are discussed as well as the long-term psychosocial impact of PCT on patients.

Chapter 3 provides an **outline of the methods** used to address the research questions of this study.
This chapter discusses the research design, population sampling, data collection and management strategies, data analysis during different phases, issues relating to validity and reliability and ethical considerations used in this study.

Chapter 4 provides the introduction and details to manuscript one. This chapter presents the results in relation to the first objective that investigated the prevalence of the NSSE after PCT and the extent to which questionaries are used to detect them. The paper has been published in a peer reviewed journal.

Röscher, P., Sathiram, R., Milios, J. E., & van Wyk, J. M. (2022). Mapping the prevalence and use of questionnaires to detect the neglected sexual side effects after prostate cancer treatment: a scoping review. Systematic reviews, 11(1), 1-12.

Chapter 5 presents the results in relation to the second objectives that describes the process of developing a screening tool to assess the NSSE after PCT. This manuscript has been published.

Röscher, P., Naidoo, K., Milios, J. E., & van Wyk, J. M. (2022). A modified Delphi study to identify screening items to assess neglected sexual side-effects following prostate cancer treatment. BMC Urology, 22(1), 1-13.

Chapter 6 presents details to manuscript three that investigated objective three. This chapter addresses the prevalence of the NSSE after early PCT in South African men, and reports on the degree to which this sample reported on how bothersome they had found the symptoms. This manuscript has been submitted for publication.

Röscher P, van Wyk J. M. (2023). Prevalence and Bothersomeness of the Neglected Sexual Side Effects After Prostate Cancer Treatment in South Africa.

Chapter 7 presents the details in relation to the fourth objective in the format the of a manuscript and address objective five. The chapter describes the psychosocial impact of SD on a sample of South African Men who received early PCT. This manuscript has been submitted for publication.

Röscher P, van Wyk J. M. (2023). Psychosocial impact of sexual dysfunction related to prostate cancer treatment in South African Men.

Chapter 8 concludes the findings of the study together with the synthesis of the research.

1.9 Positionality of the researcher

I am a white, South African, male who was born in Gauteng and who is currently living and working in Brisbane, Australia with my wife and 2 young children. I completed my schooling and subsequently trained as a Physiotherapists at the University of the Witwatersrand (RSA). It was during this time that my grandfather had experienced significant distress and bother due to the complications of RT after having been diagnosed with PCa. My grandfather passed

on soon after my graduation, and I had somehow known that I might one day contribute to easing the suffering of PCa survivors. I initially embarked on working in the field of musculoskeletal physiotherapy, and thereafter pursued a master's degree that centred around questionnaire development and applicability. My life changing event occurred when I attended the World Conference of Physiotherapy in 2017, and I heard clinician researcher physiotherapist Dr. Jo Milios speak on her experience and research into men with PCa. At that time, Dr. Milios was presenting work from her PhD on PCa interventions. Afterwards, I contacted her and explained my interests and ideas, and she guided me towards an area of study that would eventually develop into my PhD concept. At the time, I was one of a handful of clinicians working in the field of male pelvic physiotherapy, and I was struck daily by the suffering of men due to the side effects and consequences of their treatment. I developed the desire for my research to contribute to the managements of PCa survivors, and it was my wish to ease the burden of distress and bothersome experiences of these men.

1.10 Conclusion

This chapter highlighted the context of the study. The background to this study, the problem statement, the aims, and the objectives were discussed. The research questions were listed, and the researcher's stance was introduced. The next chapter will present an overview of literature pertaining to the problem/thesis.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

The previous chapter introduced the problem and the context of this study. It introduced the concept of the long-lasting debilitating effects of NSSE as a group of symptoms of SD that men may experience after they have received PCT. This chapter expands on the literature around these concepts.

2.2 The prostate

The prostate gland is anatomically located inferior to the bladder, anterior to the rectum , and it wraps around the proximal urethra [29]. The prostate gland is classified as a male reproductive accessory organ and produces secretions that travel to combine with semen. These secretions are vital to formulating ejaculate and ensuring sperm viability, playing a vital role in male fertility and reproduction [30]. The normal prostate gland is roughly the size of a walnut and it is covered by a fibrous capsule, making it the largest male accessory gland [29]. Underneath the prostate lies the urethral sphincter, and adjacent to the prostate gland lies a complicated network of neural and vascular structures (Neurovascular bundle) that include the cavernous nerves (prostatic nerves) [31].

2.3 PCa

The prostate gland is commonly affected by benign and malignant diseases such as prostatitis, benign prostatic hyperplasia and PCa [30]. PCa and benign prostatic hyperplasia are the two most prevalent diseases in the aging male population, accounting for significant financial costs spent on morbidity and mortality [3]. PCa is the second most frequent cancer diagnosed in men, the fourth most frequent cancer diagnosed across all sexes, and the eight-leading cause of death across both sexes [1]. GLOBECON 2020 estimated that 1,414259 new cases of PCa were reported in 2020, accounting for 7,3% of all the cancers globally in 2020 [3].

PCa incidence rates have steadily been more prevalent in developed regions over recent years with 2020 data indicating incidence rates in regions such as Northern Europe (83,4/100 000 people), Western Europe (76,7/100 000 people), Australia and New Zealand (75,8/100 000 people) and Northern America (73/100 000) respectively [1, 7, 32]. These high incidence rates

may be due to the fact that the Prostate Screening Antigen (PSA) test has become more available in these countries and has thus lead to an age shift in incident rates worldwide, with younger men more frequently being diagnosed with PCa [7, 8].

Less developed regions such as the Caribbean (75,8/100 000 people), Southern Africa (65,9/100 000 people) and South America (62,5/100 000 people) also showed a high incidence of PCA over recent years [1, 7, 32]. Evidence is suggesting that most new cases of cancers are now found in Africa and lower to middle class income countries, increasing from 15% in 1970, to 56% in 2008 [2]. These changes are mostly due to rapid population growth, increasing life expectancy, urbanization with progressively westernized lifestyles, and high prevalence of HIV/AIDS in these regions [33]. PCa is projected to reach a prevalence of about 70% by 2030 in these regions [2, 5].

A major cause for concern arises when regional incident rates are compared alongside mortality rates. Whilst the mortality rates in Northern Europe (13/100 000 people), Western Europe (9,8/100 000 people), Australia and New Zealand (10,3/100 000 people) and Northern America (8,3/100 000) are respectively low, mortality rates in low income regions such as the Caribbean (27,9/100 000 people), Middle Africa (24,8/100 000), Southern Africa (22/100 000 people), Polynesia (20,5/100 000 people) and Western Africa (20,5/100 000 people) remain surprisingly high in comparison [1]. This trend highlights some of the inequalities that exist regarding access to essential health care services in LMIC regions. Global inequalities prevent access to appropriate, affordable and equitable cancer care for people in these regions [6]. even with the rise in new cases, the global mortality rate of PCa has remained relatively unchanged throughout the years [1, 7, 32], indicating an improved detection of PCa, but not necessarily any improvement in its curing .

2.4 Screening and diagnosis of PCa

The evidence for PCa screening, diagnosis and its managements is evolving rapidly. The latest available European PCa guidelines describe the diagnostic pathway in such a way that PCa is usually suspected based on a digital rectal examination (DRE) that raises suspicion and abnormally high PSA levels [34]. A definitive diagnosis of PCa depends on the histopathological verification of adenocarcinoma in prostate biopsy cores or operative specimens [35, 36], but unnecessary biopsies should be avoided where further risk assessment

may be indicated [34]. The decision of whether to proceed with further diagnostic or staging work-up is guided by which treatment options are available to the patient, taking the patient's age and comorbidity into consideration. Tumours are then usually staged and graded to help determine the best course of action [34, 36].

2.5 Localised vs advanced PCa

Once a PCa tumour has been staged, a patient may be classified in one of three categories namely having i) low risk PCa, ii) intermediate risk localized PCa and iii) high risk locally advanced PCa [34]. Localised PCa or often referred to as "early or low risk PCa" describes PCa where the cancer is confined to the prostate within the capsule, and advanced PCa would describe a cancer that has spread beyond the prostate gland [37, 38]. The focus of this manuscript is further on localised/early PCa.

2.6 Intention to cure principles for localised PCa

The focus on a localized PCa is to manage it with an intention to cure the cancer. Intention to cure approaches include active surveillance (AS), RP surgery and RT [34, 36, 39]. The AS approach usually leads to the RP or RT approached when the time is right.

2.7 Localised PCT Approaches

2.7.1 RP

A RP is commonly used as a curative measure in the treatment of PCa, with the aim to retain urinary continence and sexual function during the procedure of removing the prostate [40 39]. A RP is however a challenging urologic procedure because the prostate is in close proximity to the bladder, rectum, and neurovascular supply to the penis. An adequate resection of the prostate without damaging surrounding tissue presents trade-offs between cancer control and preservation of functional outcomes such as continence and potency [41, 42].

Additional factors such as prostate size and pelvic visceral fat obscuring the visual field may complicate the surgical procedure, making it more challenging for the surgeon and prolonging the operative time [43, 44]. A nerve sparring procedure is the recommended route for surgeons to use on men with normal pre-operative erectile function [39]. For older asymptomatic men, an AS approach may be considered instead of a RP for low risk localised

PCa, but that decision would be based on the patient's preference, the possible side effects of treatment and the disease progression [34].

2.7.2 RT

The aim of RT is to deliver a high enough dose of therapeutic radiation to the tumour to maximise disease control, whilst keeping the dose to normal tissue as low as possible, aiming to minimise any complications [45]. The balance achieved between the two is known as the therapeutic ratio. The two applications for RT discussed in this manuscript are external beam radiation therapy (EBRT) and brachytherapy (BT).

EBRT for localised PCa treats the whole of the prostate gland, and depending on the risk of spread, the seminal vesicles and possibly the pelvic lymph nodes [45]. In RT, the extent to which the radiation dose can be increased (either the total dose or the daily dose), is limited by the proximity of the bladder and in particular the rectum to the prostate gland. Methods are employed which enable the RT dose to be planned and delivered more precisely to the prostate, thereby facilitating dose escalation to the tumour, and still minimising the dose to the bladder and rectum [46].

BT involves the insertion of radioactive sources into the prostate gland. A benefit of BT is that the radiation dose is deposited close to the radioactive source, rapidly decreasing in intensity as the distance from the source increases [47, 48]. This helps to spare surrounding organs at risk i.e., the bladder and rectum. There are two types of BT namely low dose rate (LDR) (permanent BT) and high dose rate (HDR) (temporary BT) .The dose rate refers to the speed with which the dose is delivered from the source [49].

2.8 Localised PCT side effects

Once the intervention has been completed, men may experience a variety of physical and psychological side effects depending on their chosen treatment approach, but the most notable primary physical side effects are post procedure pain, urinary incontinence (UI), and SD [50]. In a RP, the post procedure pain usually normalizes first, whilst UI and SD may much take longer to improve in most patients depending on the patient and the procedure [9, 12, 51]. In RT, there may initially be no side effects apart from the post procedure pain, with side effects gradually increasing, peaking between 2-5 years after the RT [45].

2.8.1 UI

UI in the form of stress urinary incontinence (SUI) is usually initially associated as a RP side effect, and urge urinary incontinence (UUI) is usually initially associated as a RT side effect, but in clinical practice there is often an overlap over time [9]. During a RP, the internal urethral sphincter is removed along with the prostate, and this mechanical deficiency in sphincteric function causes post operative SUI [52, 53]. RT affects the bladder wall function through impaired blood circulation due to endarteritis within the detrusor with subsequent apoptosis and tissue loss. These radiation affects then manifests as overactive bladder symptoms such as frequency, urgency or UUI [9]. It has been reported that 98-100% of men who have undergone RP surgery will have UI and impotence after the procedure. Of this group, 98% of these patients will recover from their UI but just over 30% of patients will recover from erectile dysfunction (ED) [54].

2.8.2 ED

Despite meticulous dissection in an attempt to preserve the neurovascular bundle during a RP, there is evidence that neurapraxia, hypoxic nerve insults, fibrosis, and apoptosis of cavernous smooth muscle affect sexual function and create drastic effects on a patients' experience and sexual satisfaction after their RP [55]. Urologists performing a RP should discuss the occurrence of postsurgical ED (temporary or permanent) with every candidate for RP [21]. RT also present with similar sexual side effects, but the pathophysiology is different compared to that of a RP [45]. Similar to the effects on the bladder, RT induced ED, or RiED, is caused by morphological arterial damage that influences pudendal arterial tone, and also reduces motor function in the cavernous nerves by inflicting axonal degeneration, contributing to RiED [56].

2.8.3 NSSE

A host of understudied sexual side effects have been identified, referred to as NSSE after PCT. These side effects affect the quality of life (QOL) in many men [17, 57]. These complications include UI during sexual activity (climacturia) and orgasmic disturbances that encompass i) anorgasmia, ii) changes in orgasmic sensation, and iii) painful orgasm, among others. They also include anejaculation and changes in the penile length and curvature.

2.9 Distress and Psychological Wellbeing after PCT

Physical disability, distress and poorer QOL are common after cancer [58]. Disability amongst men is high during and after PCT [12]. Men experience psychological stress and anxiety when they are diagnosed. Additional psychological distress may occur after the PCT, presenting as secondary side effects stemming from primary physical side effects that may have not yet improved or are still significantly impaired [59]. There is strong evidence to suggest that worse urinary, sexual and bowel function after PCT causes psychological and emotional distress in patients [60]. Psychological distress and depression have been more associated with lasting UI side effects compared to SD side effects, and anxiety is associated with both UI and SD [59].

It has been reported that men often won't seek or receive help for emotional or psychosocial problems from a formal source due to anticipated awkwardness, autonomous coping, not burdening others, unwanted sympathy and retaining privacy. PCa can cause considerable emotional and social burden for some men, and many are unlikely to seek or receive help [20].

Amidst multiple physical and psychosocial factors, erectile function has been shown to be an independent predictor of both bother and depression in men after a RP[61]. Sexual function is inversely associated with depressive symptoms in patients treated for PCa [62]. This association remains evident for at least four years after the diagnosis of PCa, even after correction for possible confounders [63]. Sexual function has been identified as the quality-of-life domain most strongly associated with outcome satisfaction for men after their PCT [64].

2.10 Assessing Sexual Side Effects After PCT

An important factor in managing SD is understanding how SD is assessed. A recent study found that only a fifth of men will discuss issues of SD with their health care practitioner after cancer [65]. Sexual communication could be regarded as a taboo subject, especially for elderly patients. These sexual side effects may otherwise effectively be detected with the use of a patient questionnaire and or screening tools [9]. These may be ideal non-threatening strategies for a reluctant patient to voice their presenting symptoms, especially if they are sexual side effects.

The Expanded Prostate Cancer Index Composite (EPIC) and International Index of Erectile Function (IIEF) are both validated instruments that assess general SD and were recommended

at the Fourth International Consultation for Sexual Medicine in 2015 [13]. These questionnaires, however, do not address the neglected symptoms of SD as mentioned earlier. There is thus a scope to develop a questionnaire or a screening tool that will effectively and quickly pick up the NSSE after early-stage localised PCT.

2.11 Managing Physical Sexual Side Effects After PCT

The principles of managing physical sexual and erectile side effects after PCT aim to i) improve the oxygenation of cavernosal tissue within the penis, and ii) preventing structural changes by improving blood flow [9, 13, 66]. Non-surgical approaches include pharmacological and physical treatments that are used to aid penile rehabilitation and sexual function rehabilitation [9, 57, 66, 67]. Surgical approaches include the insertion of a penile prosthesis, but this is considered as the final treatment line. There are many psychotherapy approaches to manage sexual side effects, but that is beyond the scope of this manuscript.

2.12 The scope for developing new evidence in the field

With PCa screening and detection methods rapidly improving, more men are undergoing early PCT, and more men are potentially being exposed to potential sexual side effects that may have a major impact on their physical, social, and emotional wellbeing.

The motivation to undergo this study was to find a cost effective and easy to access way of detecting NSSE in men after PCT, and to educate both medical professionals and patients alike that sexual side effects after PCT plays a major role in the wellbeing of a man. Through the dissemination of our study outputs, we aim to empower men to not just survive after PCT, but to thrive after PCT.

2.13 Conclusion

SD after PCT has a high likelihood of causing significant physical and emotional distress and dysfunction in men, critically impacting on their QOL and wellbeing. Sexual dysfunction in these patients remains under reported and undetected, exacerbating the long-term disability experienced by these patients.

CHAPTER 3: METHODOLOGY

3.1 Introduction

Chapter 1 introduced the context of this study within a theoretical framework, whilst chapter 2 introduced the current knowledge relevant to the problem and identified the gaps in the literature that needed to be addressed. This chapter locates the study within the appropriate research paradigm and justifies the research design, research processes, data collection methods and data analysis. Owing to the design of this thesis by manuscript, each manuscript describes the methods used as indicated by Chapters 4-7. This chapter therefore serves to provide an overview of the methodological decisions that guided the overall study.

3.2 Research Paradigm

In this study, the researcher used a merged research paradigm as the research questions had their footing in multiple research paradigms, and thus a mixed method methodology was used to answer each research question. The positivist paradigm was used in the quantitative components of the study, where as a constructivist paradigm was associated with the qualitative components of the study. The constructivist paradigm in our study focussed on focus groups and interviews, aiming to gain understanding of the study participants perspectives, whereas the positivist paradigm aimed to establish relationships between two or more variables. The methods used in this study to collect data were a desktop study, a self-administered questionnaire, focus group discussion, interviews and document reviews.

3.3 Pragmatism

The pragmatic philosophy applied in research is heavily dependent on the research questions themselves, and pragmatists often combine constructivist and positivists principles in the same study using mixed method methodologies [68, 69]. Pragmatists believe that data is continually interpreted against the background of ever-changing situations. The research conducted in this study stemmed from the researchers needs as a clinician to addresses relevant issues in clinical practice that were neglected. The research conducted in this study is relevant and meaningful, and therefore the research philosophy in this study is pragmatism.

3.4 Mixed Methods Research

A mixed method research methodology is a powerful way of integrating quantitative data into qualitative data through the process of adding context and information to numbers [70].
The mixed methods approach used in this study allowed valuable qualitative and quantitative data to be gathered and analysed simultaneously, enabling the participant experience and impact to be highlighted in their own words. The Scoping Review in chapter 4 provided an essential foundation for the study as it mapped the landscape of literature within the research topic. In this study, quantitative data was used to describe the relationships between multipble variables, and qualitative data was thematically analysed according to the themes of each symptom investigated. A modified Delphi study in Chapter 5 gathered data from a multidisciplinary team of health care providers where quantitative data was used to establish agreement rates between participants, but quantitative data was analysed and used to formulate new questions that would make up a QBST. The creation of a QBST allowed for quantitative data to be collected on prevalence rates in Chapter 6, qualitative data to be collected and thematically analysed through and a range of phenomenological open-ended questions answered by study participants in Chapter 7.

3.5 Overview of Methodology

This study included four exploratory and sequential phases, namely an initial needs assessment phase, the screening tool creation phase, the qualitative phase , and the quantitative phase. Table 2 demonstrates the research process and how each phase had been executed to address the specific research objective. The first phase of the study included a desktop scoping review into .

Table 2: Schematic Representation of the Study: Research process to developing a NSSE after PCT screening tool, and determining the prevalence of NSSE and the psychosocial impact on South African Men after PCT

Preparation and planning	Ethical clearance obtained from UKZN: October 2019 Completed and published a phase 1 protocol of the scoping review: December 2020			
Phase	Phase 1- Scoping review	Phase 2-Screening tool development study	Phase 3- Prevalence study	Phase 4-Pychosocial impact study
General description	Systematic Review	Delphi Study	Prevalence Study	Open ended question survey
Link between objective and data	Following early PCT; this phase addressed objective 1 that mapped the prevalence of each of the NSSE and compared the outcomes in NSSEs caused by either RP and/or RT. Secondly it addressed objective 2 in answering how the NSSE are reported, detected and whether	Based on the results from phase I, the second phase set out to develop the questions that would make up a QBST to detect the NSSE after PCT (objective 3). In addition, this phase also addressed objective 4, to establish the appropriateness of a NSSE after PCT QBST.	In phase 3, objective 5 was addressed, where the differences in prevalence in the NSSE after early PCT between RP and RT in a population were determined. Phase 3 also addressed how bothersome the NSSE after PCT were in a population(objective 6).	Lastly, phase 4 addressed objective 7, determining the psychosocial impact of sexual side effects after PCT in a population.

	questionnaires are being used in the assessment and treatment of the NSSE.			
Summary of methods/data analysis.	Five step process of Arksey and O'Malley (2005), based on predefined research question and inclusion and exclusion criteria. Data extraction sheet and excel spreadsheet for thematic analysis.	Multidisciplinary three round online E-Delphi study with defined consensus parameters	Structured survey with a 5-point Likert scale. Quantitative data analysed in Excel spreadsheet.	Phenomenological open-ended questions. Thematic analysis
Data sources: /participants	Published literature	Panel of experts: Urologists, Oncologists, Medical Sexologists, Psychologists, Pelvic Physiotherapists	South African men who have had PCT.	South African men who have had PCT

3.6 Phases of Study

In (phase 1), the researcher reviewed original current global literature through a systematic, predefined process (protocol published) , and presented the results in the scoping review format.
In Phase Two, a modified Delphi study was executed to determine the content to be included for screening of the NSSE after PCT . The information was to be included in a questionnaire and multidisciplinary consensus was established on the appropriateness of the items was determined for use in a clinical setting.
Phase Three of the study applied the screening questionnaire to a representative patient population where prevalence rates for the NSSE had been established amongst the participants.
Phase Four used a qualitative phenomenological approach that used open-ended questions to investigate/explore the psychosocial impact of SD after PCT in a representative sample who use the questionnaire.

3.7 Study Setting

The site for the study was based in the province of KwaZulu-Natal, and it is important to note that the initial intention was to interact with participants remotely and in a face-to-face setting, but due to the Covid-19 pandemic, the participant interactions during 2020 and 2021 were done entirely remotely.

Phase One did not have a provincial representation as it was a Scoping review. Phase Two had a provincial representation that was difficult to establish as some of the multidisciplinary expert panellists were involved in multiple research and clinical aspects across multiple provinces. An additional expert panellist was sourced from the Netherlands due to the small number of medical sexologists currently practicing in South Africa.

The geographical setting of participants during Phase 3-4 of the study are illustrated in Figure 4.

[2]

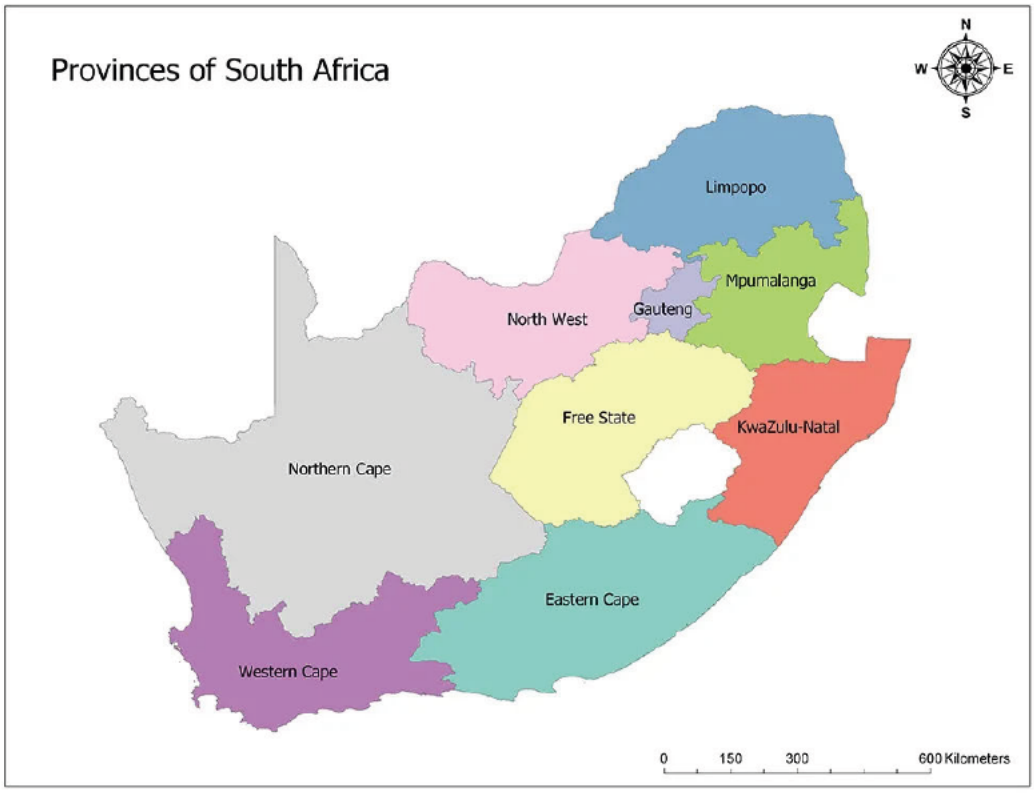

Figure 4: Provincial map of South Africa

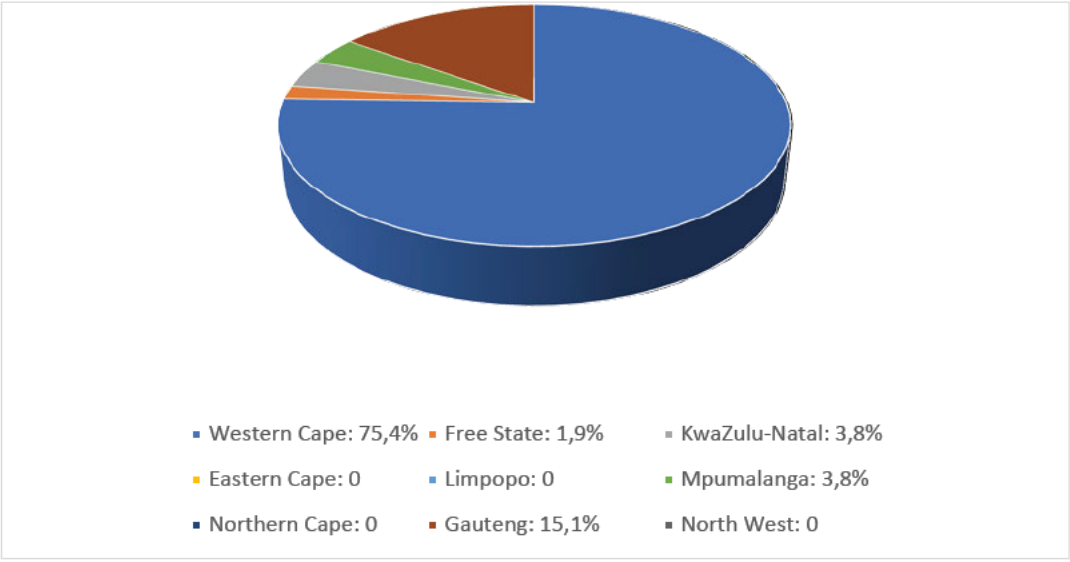

Figure 5: PCT Participants Provincial Representation

[2] https://www.mappr.co/counties/south-africa/

3.8 Subjects/Participants

Phase One did not have any human participation as it was a Scoping Review.
The study population for Phase Two were a group of multidisciplinary experts in the field of PCa and SD This group included urologists, oncologists, medical sexologists, psychologists, and pelvic physiotherapists. Phase Three and Four participants involved our target population of South African men who had received PCT.

3.9 Sampling

Phase One was a desktop study. The study targeted original research within the last 10 years that was available in English.
Phase Two was a modified Delphi study. In addition to working in the PCa field, most of the identified expert panellists were either members of the South African Sexual Health Association or affiliated to the Prostate Cancer Foundation of South Africa (PCFSA). Thirty-five potential participants were invited via email to participate in this study. This multi-disciplinary group consisted of urologists in the field of radical prostatectomies, urologists in the field of prostate RT, oncologists, medical sexologists, psycho-sexologists, psychologists, and pelvic health physiotherapists. There is no set participant number needed to conduct a Delphi study in the literature, but most Delphi studies usually use between 15-20 participants [71, 72].
Phase Three and Four included 53 participants of our target population of South African men who had received PCT. Potential Participants were initially asked to follow an electronic link to be screened for their eligibility to participate and were then asked to complete a set of questions. The participants were considered as eligible for inclusion if they were SA citizen, received a RP or RT for PCa in the last 1-5 years, aged between 45-75 and proficient to complete the survey in English.

3.10 Data Management

Data storage followed the UKZN policies and procedures. All data was stored electronically in encryption cloud-based storage software. No physical data was collected. The researcher, research assistants, supervisors and additional journal article authors had access data in this study.

3.11 Ethical Considerations

Prior to undertaking any research, a proposal was submitted to the Humanities and Social Sciences Ethics Committee of the University of KwaZulu-Natal for ethical approval. Ethical approval was obtained from the Ethics Committee at the University of KwaZulu-Natal (Appendix 2). Phases Two to Four involved study participants that remained Anonymous where they gave electronic consent to participate in the various aspects of the study. All participants were able to withdraw from the study at any time. Patient database owners gave consent to disseminate the survey links to potential participants, and each participant provided consent for participating in the study after they were informed about the study process (Appendix 10).

3.12 Data Analysis

The data were analysed according to each phase of the study as illustrated by figure …

3.12.1 Phase 1

The relevant studies were selected through a thorough methodological process described Arksey and O' Mally [73] and the processing of the data was done through a data extraction sheet that was developed, as well as using a Mixed Method Appraisal Tool [74]. The authors, study design, participants, location, interventions, prevalence, outcomes, and conclusions were recorded in the data extraction sheet. A thematic analysis (TA) was conducted to produce the outcomes of the review.

3.12.2 Phase 2

The analysis of our3 round Delphi study data modelled the processed outlined by Diamond et al.[75].Data sets were extracted from a Google Forms based research instrument into an excel sheet. Consensus agreement rates were calculated to determine whether statements were finalized, and changes and suggestions to statements were themed and grouped to be considered for inclusion and or incorporation into statements for the subsequent rounds.

3.12.3 Phase 3

Quantitative survey data were extracted from the survey software Jotforms (© 2022, Jotforms Inc.) and populated into an excel sheet. Demographic statistics were calculated from the raw data, and individual prevalence rates for various SD presentations were established. Bothersomeness rates were determined and matched to prevalence rates.

3.12.4 Phase 4

The data were extracted into NVivo (version 17.1/ © 1999-2022 QSR International Pty Ltd.) for analysis. This study used a hybrid approach to TA where i) there was an early theme development due to previous research in this field (coding reliability approach) and ii) a reflexive approach was used as there was scope for codes to develop additional themes throughout the process of the interpretation of data [76]. The six phases of reflexive TA by Braun & Clarke (2006) framed the main phases to engage with the TA process were followed , namely i) familiarisation, ii) coding, iii) generating initial themes, iv) reviewing and developing themes, v) refining, defining and naming themes and vi) writing up [77]. Phases i-iii including text coding of the participants' responses were performed and analysed in NVivo by two separate coders independently. During phase iv, the relevant quotes from the coded statements were then organized systematically in NVivo with the coding stripes. After initial coding, the two primary coders met with a third coder to discuss and reconcile the statement coding to produce a single code book of themes with subthemes to conclude phase v.

3.13 Trustworthiness of the study

In a mixed method study, the researcher uses different methods which add the strengths of the various methods to the study[78, 79]. In qualitative studies, trustworthiness is established though five criteria that were proposed by Lincoln and Guba (1985) being i) credibility, ii) dependibility, iii) confirmability, iv) transferability, iii) dependability, iv) confirmability authenticity [80].

Credibility refers to how confident the researchers are that the data has been interpreted truthfully. In phase 1, a PRISMA-SCR checklist was used to report on the study to authenticate its methodology. In Phase 2, a modified Delphi study was completed using a robust methodology outlined by Diamond et al. [75]. The expert panel consisted of credible and experienced sexual health experts. Transcripts were sent to each participant during each round for evaluation and interpretation. Triangulation of data from multiple sources reduces bias and helps the investigator reduce bias. In this study, a combination of data sources was used [81, 82].

Dependability refers to the stability of the data over time, and in the case of our study,the continuous processing of the same transcripts where the interpretation thereof does not

change. Phase 1 was proceeded by a protocol study, using the same search terms. There was dependability between the results in the protocol study [83] and the phase 1 Scoping review study[19]. The data in our study was clarified and its analysis strengthened with subsequent rounds of processing of the same information data sets

Confirmability in this study was established in phase 1, where the search parameters and search terms produced the same search results between different researchers. In Phase 4, two separate researchers interpreted the coding and analysis of data independently, and together resolved differences in their interpretations of the data. An audit trail of all research activities was maintained i.e. all decisions and research activities were recorded [82, 84]. The researcher reviewed themes with the supervisor in all stages of the study.

Transferability refers to the ability of the research to be applied to different populations in different settings, based on the description of the study participants and the study environments. The study populations for phases 2-4 mirrored populations that would fit into predominantly white, English-speaking populations in other middle to high income countries, as they would have access to the same medical procedures and processes as our study population. The study also used standard recognised methodologies such as the reporting framework used in Phase 1 (PRISMA-ScR), and the set parameters using in Phase 2 during the Delphi study.

Authenticity refers to how well the researchers have conveyed the feelings, perceptions, and emotions of the participants. In phase 2, our Delphi study afforded participants to not only rate the appropriateness of a statement, but they we also allowed to comment and suggest changes during each of the 3 rounds. In Phase 4, actual snippets of statements were used as is to convey the feeling and emotions of each participant were used [85].This added depth and context to this study [82].

CHAPTER 4: PREVELANCE AND USE OF QUESTIONAIRES RELATED TO SEXUAL SIDE EFFECTS AFTER PCT.

4.1 Introduction

This chapter reviews the current literature on the NSSE after PCT. The aim of this study was to perform a detailed review of the prevalence rates of various NSSE after PCT as reported in original research dating back ten years. What was of particular interest was how the prevalence rates differed, across the RP and RT approaches. Chapter 2, the NSSE were introduced, and it was explained how these NSSE may contribute to long term deterioration of QOL for an individual. Furthermore, this study also investigated how the NSSE after PCT were being assessed, and whether questionnaires were being used to detect them, and which questionnaires were being used for this purpose. This chapter finally aimed to determine whether there would be a scope for the development of a NSSE after PCT questionnaire or screening tool.

4.2 Publication Details

Title	Mapping the prevalence and use of questionnaires to detect the neglected sexual side effects after prostate cancer treatment: A scoping review.
Authors	Röscher, Pierre Sathiram, Ronisha Milios, Joanne E Van Wyk, Jacqueline M
Journal	BMC Systematic Reviews
Journal Details	Open Peer Reviewed Listed of the Department of Higher Education & Training (DoHET)
Status	Published

4.2.1 Journal Information

BioMed Central, founded in 2000, is an open access publication company that produces over 250 scientific journals. BMC Systematic Reviews, first published in 2012, is an online only peer reviewed medical journal published by BioMed Central, and it focusses specifically on

systematic reviews, protocols, methodologies, and the overall science of discussing systematic reviews.

4.2.2 Publication Record

The manuscript was submitted on 9 June 2020, Accepted 2 December 2021, and published 3 January 2022

4.2.3 Contribution Record

The candidate conceived the study and participated in the design involved in drafting and finalising the manuscript. Dr. Ronisha Sathiram revised the manuscript and provided clinical input and approved the manuscript for final submission. Dr. Joanne Milios came up with the study idea and provided clinical input and revised the manuscript for final submission. Prof. Jacqueline van Wyk participated in the conceptual design of the study, drafting the manuscript, and revising it critically providing final approval of the version to be published.

4.3 Publication

Röscher *et al. Systematic Reviews* (2022) 11:2
https://doi.org/10.1186/s13643-021-01865-5

Systematic Reviews

RESEARCH Open Access

Mapping the prevalence and use of questionnaires to detect the neglected sexual side effects after prostate cancer treatment: a scoping review

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Abstract

Background: Early prostate cancer (PCa) treatment interventions may leave men with debilitating sexual side effects, especially when not diagnosed or present at initial follow-up treatment. Men are often embarrassed to disclose their sexual dysfunction. This may lead to sexual side effects related to PCa treatment remaining untreated, adding to their burden of disability. This study was conducted to map the evidence on the prevalence of neglected sexual side effects (NSSE) after radical prostatectomy (RP) surgery or radiation treatment (RT) for PCa treatment and the reported use of questionnaires to identify such side effects.

Methods: This systematic scoping review's search strategy involved searching MEDLINE/PubMed, Science Direct and Google Scholar databases. Guided by eligibility criteria, two independent reviewers conducted title, abstract and full-text screening. Data from the included studies were extracted. The review team explored the implications of the findings in relation to the research question and aims of the study. The Mixed Method Appraisal Tool was used to appraise the quality of the included studies. This review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis guidelines.

Results: Searches of the databases identified 1369 articles, with 23 eventually included for review. The prevalence of NSSE ranged between 0 and 78% in studies reporting on early PCa treatment of RP and RT patients. Orgasmic dysfunction (5–78%), penile curvature changes (10–15.9%) and penile length shortening (0–55%) similarly showed a low to moderate prevalence. Climacturia had low prevalence (4–5.2%) after RT and moderate prevalence (21–38%) after RP, whilst anejaculation had low to high prevalence (11–72%) after RT. No validated questionnaire was used to detect any NSSE after early PCa treatment. Studies mainly modified other questionnaires, and two studies used non-validated questionnaires to identify some NSSE. Participants in the included studies reported being inadequately informed about the possible sexual side effects of their treatment.

Conclusion: This study showed a low to a high prevalence of NSSE in men after RP and RT for early PCa treatment. Questionnaires helped detect individual NSSEs after PCa treatment but there is currently no evidence of a valid, reliable and comprehensive questionnaire to detect the NSSE collectively.

Scoping review registration: N/A

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Keywords: Prostate cancer, Prevalence, Questionnaire use, Neglected sexual side effects

Background

Prostate cancer (PCa) is a major cause of disease and morbidity amongst men, and it is the second most common cancer affecting men on a global scale [1]. Early PCa or localised PCa is cancer within the prostate described as stage I or II on the tumour-node-metastasis system [2]. Early PCa treatment consists of radical prostatectomy (RP) surgery or radiation therapy (RT), either offered through external beam radiotherapy or brachytherapy. The treatment may result in side effects such as sexual dysfunction [3] and less common physical deformities such as penile length shortening and penile curvature changes (Peyronie's disease) [4, 5]. Sexual dysfunction from PCa treatment is common regardless of whether the treatment modality included surgical or non-surgical interventions. Sexual dysfunction is reported to increase during each year of follow-up after the initial intervention of RT, and it affects an average of 50% of patients within 5 years of receiving treatment [6].

Most men generally recover from pain and incontinence after RP but sexual side effects often remain untreated, leaving them with long-lasting and debilitating sexual dysfunction [7]. Men and their partners also suffer psychologically after PCa treatment due to anxiety and depression relating to sexual dysfunction [8]. Specific conditions related to physical, sexual dysfunction are common after PCa treatment. These conditions include orgasm-associated incontinence/climacturia, urinary incontinence during sexual stimulation, altered perception of orgasm, pain with orgasm, anejaculation, penile length shortening, and penile deformity [4, 5, 7, 9]. They are collectively referred to as the "neglected sexual side effects" (NSSE), and the symptoms are reportedly prevalent in 20–93% of RP patients [7].

Only a fifth of the men who have been diagnosed with PCa will ever discuss issues related to sexual dysfunction with their health care practitioners [10]. Clinicians may be able to use the responses from a specific patient questionnaire as a starting point to discussing issues relating to the patient's specific symptoms of sexual dysfunction. Two validated questionnaires, the Expanded Prostate Cancer Index Composite [11] and International Index of Erectile Function [12], were recommended for use in this context in 2015 [3]. Whilst the Expanded Prostate Cancer Index Composite and International Index of Erectile Function are available to stimulate the conversation around general urinary and sexual function, there is currently no validated instrument to identify the collective symptoms specific to NSSE after early PCa treatment [4, 5, 13].

Two previous systematic reviews have explored and reported on the collective prevalence and assessment of NSSE [4, 7]. It has furthermore been established that there is no validated questionnaire to screen for NSSE and no evidence on the availability of a questionnaire to inquire about symptoms relating to NSSE in patients who had undergone treatment for PCa. It was, therefore, essential to map the evidence on the prevalence and use of questionnaires relating to the neglected sexual side effects after prostate cancer treatment to improve our understanding of NSSE and highlight knowledge gaps on the role of questionnaires in the assessment of the NSSEs.

Methodology

A protocol for this scoping review by Roscher and van Wyk [14] can be accessed at https://rdcu.be/b7i8I.

The scoping review followed the five steps described by Arksey and O' Malley [15] that included the following;

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting on the data

Quality assessment of each of the included primary studies was to be done as described by Levac et al. [16].

Identifying the research questions

The research was conducted to map the prevalence of NSSE and the use of a questionnaire to identify the NSSE after prostate cancer treatment. The research questions were as follows:

- What is the prevalence of the common NSSE's following early PCa treatment through surgical interventions/RP?
- What is the prevalence of the common NSSE following early PCa treatment through non-surgical interventions/RT?
- What are the role and use of questionnaires in detecting NSSE after early PCa treatment?

Search strategy

A literature search was conducted using the databases MEDLINE/PubMed, Science Direct and Google Scholar

to search for articles matching the research questions. Boolean terms and MeSH (Medical Subject Heading) terms were employed using the keywords: *Orgas* OR Pencil* OR Climacturia OR Dysorgasmia OR anejaculation OR Peyronie OR neglected AND (prostate cancer OR prostatectomy).*

Eligibility criteria

The population, concept context (PCC) framework was used to determine the eligibility of studies for inclusion. The concept of interest was to identify studies on the prevalence of NSSE and the use of questionnaires to identify NSSE in a population of men after they had received surgical and non-surgical treatment following early PCa diagnosis.

The search was conducted on articles published between 1 January 2009 and 31 December 2019 only to include the most recent evidence on the use of questionnaires to identify NSSE. Other search parameters included original studies that were available in English and related to humans. Only studies that matched our aim in their titles were selected for further processing. The review excluded literature and grey literature outside the search period, unavailable in English and unrelated to sexual dysfunction.

Study selection

The identification of the relevant literature followed a systematic approach. The results of all three databases were combined into one Excel spreadsheet after applying the search parameters.

The primary reviewer performed the search strategy on the databases to retrieve publications and then removed all duplicates. The titles of studies were screened to determine their eligibility for inclusion. Two reviewers screened all retrieved abstracts and they were evaluated for eligibility using the inclusion criteria. Agreement between the reviewers about potentially relevant studies was reached, and the full text was obtained for screening. Two independent reviewers did the full-text screening, and a third investigator was engaged to resolve disagreements between reviewers.

Charting the data

A data charting form was developed to extract information on each publication and organise and synthesise information about each study (Additional file 1). The data collected included details on the author(s) and date of publication, the aim and research questions, the geographical context of the study, the population, study design and the number of participants. We also extracted information on the time reported since participants started the PCa treatment, the prevalence of NSSE and the reported use of questionnaires to identify NSSE after PCa.

The data sets were organised to answer each research question. Furthermore, the data relating to the prevalence of NSSE was organised according to the two main approaches for treating PCa, those relating to surgical approaches (RP) and those following non-surgical approaches (RT).

Quality appraisal

An electronic version of the Mixed Method Appraisal Tool (MMAT) [17] was adapted to assess the quality of the included studies. The study designs included in this scoping review were qualitative, quantitative descriptive and mixed methods studies. The specific criteria to determine the appropriateness of each included study are outlined in Additional file 2.

Two reviewers independently performed the quality assessment, and the final scores were discussed for consensus. The overall quality for each included study was calculated according to the following MMAT guidelines (score = number of criteria met/total score in each domain). One point was allocated when the study met each of the five criteria, and a total score in the form of a percentage represents the quality of the included studies (Additional file 2).

The results used the following descriptors.

- Very poor quality (20%) where minimal criteria are met
- Poor quality (40%) where less than half the criteria are not met
- Fair quality (60%) where just more than half the criteria is met
- Good quality (80%) where most of the criteria are being met
- Excellent quality (100%) all criteria are met

The overall quality of a combination of components cannot be more than its weakest component in mixed-methods studies, making the overall score equal to the lowest-scoring component [17].

Collating, summarising and reporting on the data

The findings of this scoping review were analysed using a deductive content analysis approach, where themes were reported to answer each research question [18]. The review team discussed findings, resolved issues, and finalised findings. The review team explored the implications of the findings in how they relate to the study's aims and further research in the field.

The collected data was organised into subgroups (Additional file 1). The findings were analysed and reported

according to the research questions. The data relating to the prevalence of the NSSE was quantitative, and the data about the use of a questionnaire yielded either one of 3 results: (i) a commonly used standardised questionnaire, (ii) an informal questionnaire, or (iii) no questionnaire. In addition to the methodologies mentioned above, the PRISMA-ScR checklist [19] guided the reporting of the scoping review (Additional file 3).

Results

A total of 1162 articles remained after removing the duplicates. After screening of titles, 66 articles remained, and 23 articles were found eligible and were included for full-text assessment after abstract screening. No additional studies were added after further consultation and screening of reference lists (Fig. 1).

Two studies were rated as being of excellent quality (100% MMAT score), and the rest of the studies ($n=21$) were rated as being of high quality (80% MMAT score) (Additional file 2). As indicated in Table 1, the NSSE reported after RP were collectively reported 27 times, whereas NSSE's after RT were reported only 12 times.

Frey et al. published two studies in 2014 and 2017 that reported all 8 NSSEs of interest in our review. The 2017 study reported on NSSE following RT interventions, and the 2014 study reported on the prevalence of NSSE after RP interventions [4, 5].

All the studies included for review ($n=23$) had cross-sectional study designs and specifically examined NSSEs after PCa treatment. A summary is provided in Table 2. The included studies represented data from 9 countries, with 11 of the studies having been conducted in the USA. Eleven of the remaining studies were conducted in European countries; one study was conducted in South America (Brazil), and one was in Asia (Japan). No African or Australasian studies matched the inclusion criteria (see Fig. 2.)

Orgasmic dysfunction/anorgasmia (7 studies)

Six RP studies met the inclusion criteria [5, 20–24], whilst only one RT study reported on the prevalence of anorgasmia [4]. A low- to high prevalence range (5–78%) was reported between studies for orgasmic dysfunction. Two thirds of men reported poor ability to orgasm at

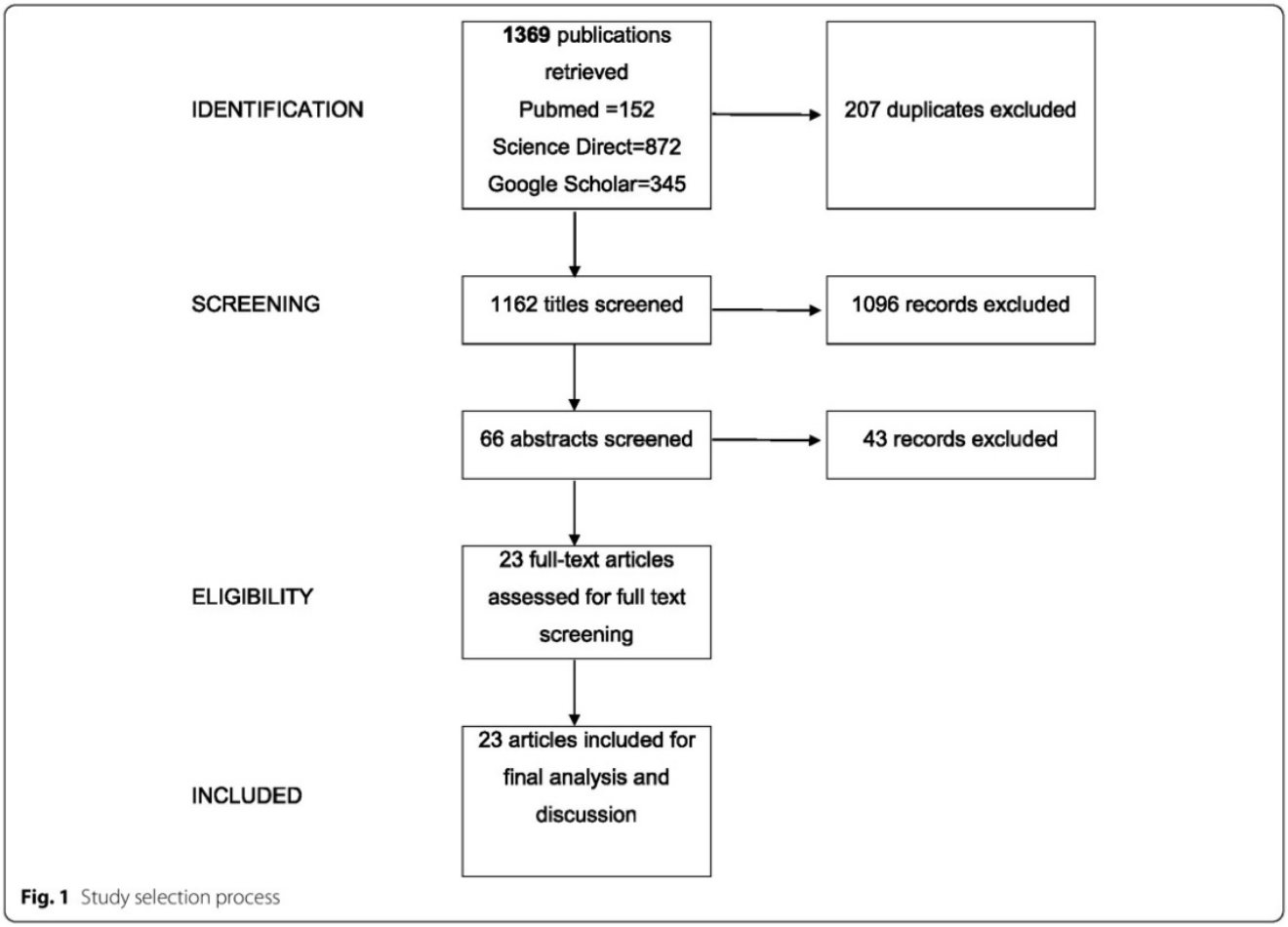

Fig. 1 Study selection process

Table 1 Studies reporting of specific NSSE after PCa treatment

NSSE after early PCa treatment after surgical and non-surgical intervention					
	27 studies	Surgical interventions (RP)	Non-surgical interventions (RT)	12 studies	
Reference	Number of studies	NSSE		Number of studies	Reference
[5, 20–24]	6	*Orgasmic dysfunction*		1	[4]
[5]	1	*Altered perception of orgasm*		1	[4]
[5, 24–26]	4	*Orgasm-associated pain*		1	[4]
[5, 27–30]	5	*Climacturia*		2	[4, 27]
	0	*Anejaculation*		3	[4, 31, 32]
[5]	1	*Penile sensory changes*		1	[4]
[5, 33–39]	8	*Penile length shortening*		2	[4, 36]
[5, 40]	2	*Penile deformity/Peyronie's disease*		1	[4]

3 years [20, 21], and one third of men reported no orgasm at 2–5 years after an RP [23, 24]. Orgasmic function improved postoperatively with time [24], also deteriorated with age [20, 22–24]. Nerve-sparing RP procedures predicted better post-operative orgasmic function [20, 22]. Increased time needed to reach orgasm was experienced by almost half the men, 5 years after RT [4].

Altered perception of orgasm (2 studies)

One RP study [5] and one RT study [4] reported decreased orgasm intensity. Similar results were found in the RP study and the RT study. The RP study [5] showed that 60% of participants and almost 50% of the RT participants reported decreased orgasm intensity [4].

Orgasm-associated pain/dysorgasmia (5 studies)

Four studies included in this review reported on decreased orgasmic function after RP [5, 24–26] and one after RT [4]. Similar results were found between the RP studies, in that between 10 and 12% of RP participants reported orgasmic pain in RP [5, 25, 26]. The RT study reported a 15% prevalence of orgasmic pain in their study population [4].

Orgasm-associated incontinence/climacturia (6 studies)

Four RP studies met the inclusion criteria [5, 27–30], and one RT study was included for climacturia [4]. One study reported on both RP and RT participants [27]. The prevalence was reported between 21% [29] to 38% [5] of participants across the five RP studies after 12–24 months (5, 27–30). The collaborative study recorded orgasm-associated incontinence/climacturia in 22.6% of the total study group (RP and RT participants), but the RT participants only represented 5.2% of the total participants [27]. The RT study reported a 4% prevalence of symptoms, but the symptoms were defined as urinary incontinence during sexual activity [4].

Anejaculation (3 studies)

No RP studies in the current review reported this issue, and three RT studies were included [4, 31, 32]. Anejaculation worsened with time after RT in one study and peaked at 5 years after treatment, with 89% of the study group being affected [32]. An older study reported a conflicting rate of anejaculation, with 81.3% of their participants conserving their ejaculatory function [31]. This study reported that 75% of the participants had a reduction in ejaculate volume and that 19% of the men experienced dry ejaculation [31]. The final study reported an anejaculation prevalence of 11% in their study population [4]

Penile sensory changes (2 studies)

Only one RP study [5] and one RT [4] study were included, with similar results being reported across the two studies. Penile sensory changes were reported in 25% of the RP study participants [5] and 27% of the RT study participants [4].

Penile length shortening (10 studies)

Eight RP studies met the inclusion criteria for review [5, 33–39], and two RT studies [4, 36] studies were included for review. Only one study reported both on RT and RP and concluded that no RT participants had penile length shortening [36]. Penile length shortening was reportedly worse at 7–10 days postoperatively [33, 34] but started recovering at 3–6 months [39]. However, self-perceived penile length shortening was still experienced by 55% of men two years after RP [37]. Men who eventually did not fully regain their penile length had experienced up to a 24% loss in length at 7 days postoperatively [33]. The second RT study reported that 42% of participants reported more than 1 cm subjective penile length shortening [4].

Table 2 Prevalence of NSSE

NSSE reported	First author/year/reference	Participant numbers/age	Time frame after intervention	Reported prevalence in the study population
Multiple	***Frey, 2017*** [4]	109 men (median age 71)	Three months to 5 years	24% reported anorgasmia 11% reported anejaculation 44% reported a decrease in orgasm intensity 4% reported urinary incontinence during sexual activity 40% reported an increased time needed to achieve orgasm 15% reported pain during orgasm 27% reported sensory changes in their penis 42% reported penile length shortening 12% reported an abnormal curve in the penis
Multiple	***Frey, 2014*** [5]	316 men (median age 64)	3–36 months	5% of the sexually active participants had reported anorgasmia 60% of the sexually active participants had reported a decrease in orgasm intensity 57% reported delayed orgasms 10% of sexually active participants had painful orgasms 38% reported urinary incontinence during sexual activity 25% reported sensory changes in their penis 47% reported a self-reported penile length loss of more than 1 cm 10% reported an abnormal curve in the penis
Orgasmic pain	***Mogorovich, 2013*** [25]	1288 men (median age 63)	Six months to 5 years	11% of participants reported a painful orgasm in the previous 6 months
Orgasmic pain	***Matsushita, 2012*** [26]	702 men (mean age 64)	6–24 months	12% of participants reported dysorgasmia
Orgasmic dysfunction	***Du, 2017*** [20]	415 men (median age 60)	36 months	60.2% of participants had a worse orgasmic function
Orgasmic dysfunction	***Ostby-Deglum, 2016*** [21]	609 men (median age 63)	Three years	78% of participants had poor ability to reach orgasm
Orgasmic dysfunction	***Tewari, 2012*** [22]	408 men (median age 60)	36 months	11.6% of participants under age 60 unable to achieve orgasm/17.4% over 60
Orgasmic dysfunction	***Dubbelman, 2010*** [23]	458 men (median age 64)	Up to 2 years	33.2% had orgasmic dysfunction afterwards with an age-related decline
Orgasmic dysfunction + pain	***Salonia, 2010*** [24]	334 men (median age 62)	Over 48 months	37% of participants reported complete inability to achieve orgasm, 14% of participants reported pain during orgasm
OAI/climacturia	***O'Neil, 2014*** [27]	412 men (mean age 62)	10–20.3 months	Climacturia was reported in 22.6% of the study group
OAI/climacturia	***Manassero, 2012*** [28]	*Seven men (mean age 64))*	One year	28.6% Climacturia reported as baseline investigations for a N/A study

Table 2 (continued)

NSSE reported	First author/year/reference	Participant numbers/age	Time frame after intervention	Reported prevalence in the study population
OAI/climacturia	***Nilsson, 2011*** [29]	1261 men (median age 63)	Two years	21% of the participants had experienced orgasm-associated incontinence
Incontinence during sexual activity	***Mitchell, 2011*** [30]	1421 men (median age 58,4)	3–24 months	44% and 36.1% at 3 months and 24 months
Ejaculation function	***Sullivan, 2013*** [32]	364 men (median age 64)	Six years	72% lost the ability to ejaculate in an anterograde fashion
Ejaculatory function	***Huyghe, 2009*** [31]	198 men (median age 65)	36 months	18.7% had impaired ejaculatory function
Penile length shortening	***Kwon, 2018*** [33]	507 men (median age 59,3)	Seven days to 12 months	60.2% of the participants regained their pre-op penile length at 12 months
Penile length shortening	***Kadono, 2017*** [34]	102 men (median age 64,4)	Seven days to 24 months	MRI results concluded that the distal end of the membranous urethra moved proximally (mean proximal displacement of 3.9 mm) at 10 days after RP and then returned to the preoperative position at 12 months
Penile length shortening	***Berookhim, 2014*** [35]	118 Men (median age 58)	Baseline, 2 months, 6 months	2.4 mm difference (shortening) in stretched flaccid penis length compared to baseline, at 6 months, there was no difference compared to baseline
Penile length shortening	***Parekh, 2013*** [36]	948 (¾ of the participants = 60–80 years old)	Unavailable	3.73% of surgical cases had reduced penile length shortening, 0% RT cases
Penile length shortening	***Carlson, 2012*** [37]	1288 men (median age 64.8)	24.2 months	55% of participants had self-perceived penile length shortening.
Penile length shortening	***Vasconcelos, 2012*** [38]	105 men (median age 65)	3–60 months	1 cm mean penile length loss at 3 to 24 months, baseline penile length re-established at 48 months
Penile length shortening	***Engel, 2011*** [39]	127 men (median age 56.5)	1–11 months after	11.77 cm to 11.13 cm at 1 month after the surgery Mean stretched penile length was not significantly different from baseline at 9, 10 and 11 months
Penile length deformity/Peyronie's disease	***Tal, 2010*** [40]	1011 men (median age 60.2)	Up to 3 years	Peyronie's disease incidence, 15.9% in RP population, developed on average at 13.9 months, mean curvature magnitude was 31°

Penile deformity/Peyronie's disease (3 studies)

Two RP studies [5, 40] and one RT study [4] were included for review. Ten per cent of participants in a 2014 study were found to have an abnormal curvature of their penis [5]. Two studies on RP participants found that 10–15.9% of participants reported the presence of penile curvature or penile deformity [5, 40]. The average reported curvature angle was 31° [40]. A similar result was reported in the only RT study, where 12% of the participants reported an altered curve of the penis [4].

Questionnaire use in NSSE studies

The included studies used a variety of questionnaires that included validated and non-validated questionnaires. Some studies included a mixed-method design and added either an interview or a physical examination component

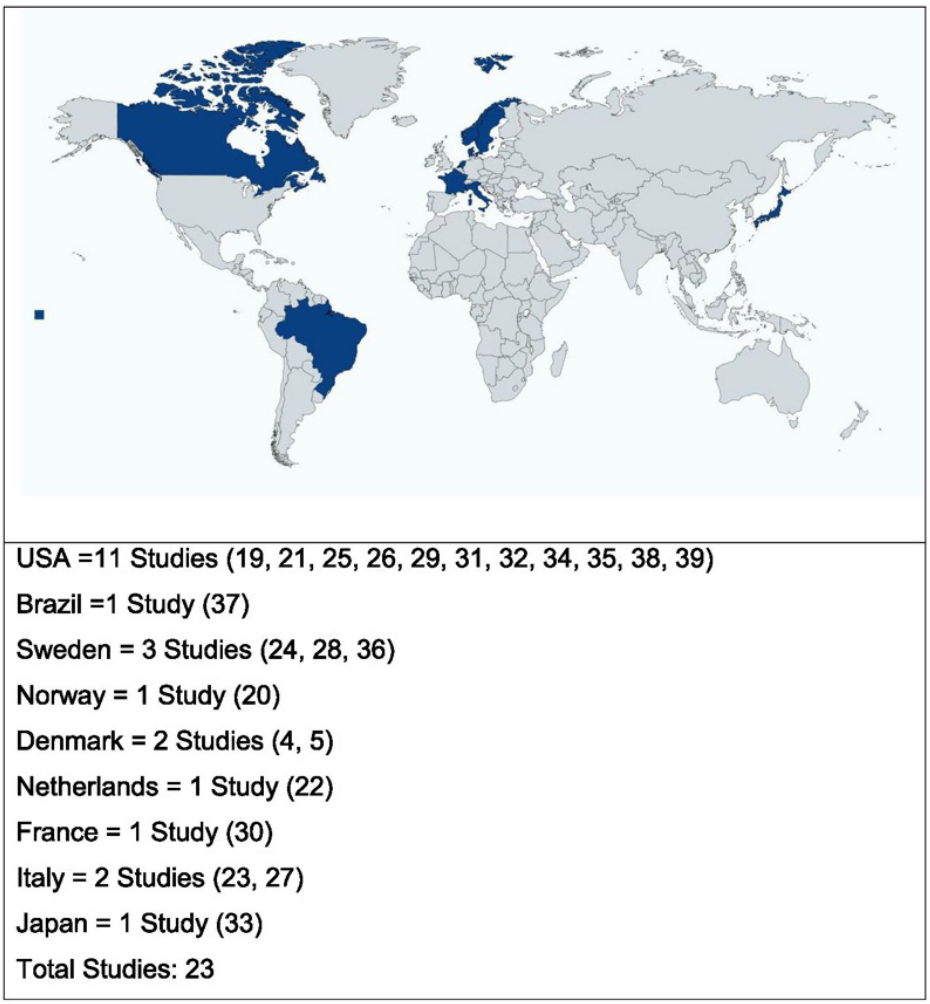

Fig. 2 Distribution of study origin

to the questionnaire. Table 3 outlines how questionnaires were used in the included studies.

Discussion

The NSSE after PCa treatment has gained some attention over the last few years. However, more attention is given to individual NSSE rather than the collective group, and more studies focus on the NSSE related to RP than RT. Comparisons across studies were limited as different methodologies, assessment time frames, varying treatment approaches, and the use of non-validated questionnaires varied and impacted the criteria for comparisons.

Prevalence of NSSE

Orgasmic dysfunction had a low to high prevalence. However, it was almost exclusively reported in RP studies (5–78%), except for one RT study reporting a 24% prevalence amongst their participants [4]. Possible reasons for the considerable variation in the results across studies may be due to the variable lengths of time reported after the intervention, participant age, nerve sparing status and various methods/questionnaires to determine orgasmic dysfunction. This observation concurs with a 2014 systematic review where 80% of RP patients were reported to have some degree of orgasmic dysfunction after RP with similar variables influencing the prevalence [7].

Altered perception of orgasm showed a similar moderate prevalence (50–60%) between RP and RT studies [4, 5]. Orgasmic pain similarly showed a low prevalence (10–15%) between RP and RT studies [4, 5, 25, 26, 41]. One study further described that the orgasmic pain felt mainly (70% of the time) was felt in the penis [26]. At the same time, another made the association between bilateral seminal vesicle sparing procedures as a possible cause of orgasmic pain [25]. This notion was concurred in the systematic review by Frey et al., who reported that sparing the tips of the seminal vesicles doubles the risk of orgasmic pain [7].

Table 3 Questionnaire used after early PCa treatment

NSSE reported	First author, year, reference	Questionnaire used to report NSSE
Multiple	***Frey, 2017*** [4]	Study-specific questionnaire based on various other questionnaires and tools, including the Erection Hardness Scale and International Consultation of Incontinence-Short Form
Multiple	***Frey, 2014*** [5]	Study-specific questionnaire based on various other questionnaires and tools including the International Index of Erectile Function, International Consultation of Incontinence-Short Form and Erection Hardiness Scale
Orgasmic pain	***Mogorovich, 2013*** [25]	Study-specific questionnaire consisting of 145 questions—5 pertaining to orgasmic characteristics
Orgasmic pain	***Matsushita, 2012*** [26]	Dysorgasmia Frequency Scale and Visual Analogue Scale
Orgasmic dysfunction	***Du et, 2017*** [20]	Expanded Prostate Index Composite, American Urological Association Symptom Index and Sexual Health Inventory for Men. Participants were asked to rate their post-operative orgasmic function
Orgasmic dysfunction	***Ostby-Deglum, 2016*** [21]	Expanded Prostate Index Composite 26—one single question asked
Orgasmic dysfunction	***Tewari, 2012*** [22]	Health-Related Quality of Life questionnaire, Expanded Prostate Index Composite and International Index of Erectile Function. Participants were asked to rate their post-operative orgasmic function
Orgasmic dysfunction	***Dubbelman, 2010*** [23]	N/A
Orgasmic dysfunction	***Salonia, 2010*** [24]	International Index of Erectile Function and International Consultation of Incontinence -Short Form. Structured Interviews
Orgasm-associated incontinence/climacturia	***O'Neil, 2014*** [27]	A non-validated questionnaire was used
Orgasm-associated incontinence/climacturia	***Manassero, 2012*** [28]	International Index of Erectile Function (5 Item) and International Prostate Symptom Score. Telephonic interview about orgasm-associated incontinence/climacturia
Orgasm-associated urinary incontinence	***Nilsson, 2011*** [29]	The author designed a study-specific questionnaire based on the Scandinavian prostate cancer group 4 questionnaire.
Incontinence during sexual activity	***Mitchell, 2011*** [30]	The University of California and Los Angeles Prostate Cancer Index.
Ejaculation function	***Sullivan, 2013*** [32]	International Index of Erectile Dysfunction
Ejaculatory function	***Huyghe, 2009*** [31]	The author designed a study-specific questionnaire based on an adapted Male Sexual Health questionnaire
Penile length shortening	***Kwon, 2018*** [33]	Sexual Health Inventory for Men and Physical measurement
Penile length shortening	***Kadono, 2017*** [34]	International Index of Erectile Function and Erection Hardness Score. The physical exam using a ruler to measure stretched flaccid penile length
Penile length shortening	***Berookhim, 2014*** [35]	International Index of Erectile Function questionnaire. Physical exam to measure stretched flaccid penile length
Penile length shortening	***Parekh, 2013*** [36]	A non-validated questionnaire was used
Penile length shortening	***Carlsson, 2012*** [37]	The author designed a study-specific questionnaire based on previous work of the study group
Penile length Shortening	***Vasconcelos, 2012*** [38]	International Index of Erectile Function. Physical Assessment
Penile length shortening	***Engel, 2011*** [39]	International Index of Erectile Function. The physical exam using a semi-rigid ruler to measure stretched flaccid penile length
Peyronie's disease	***Tal, 2010*** [40]	Descriptive statistics. Physical examination with a goniometer

Penile length changes showed a low to moderate prevalence (0–55%) after RP and RT [4, 5, 33–39]. Nerve-sparing procedures reportedly reduced the risk of self-perceived penile length shortening [37], whilst younger age and better preoperative erectile function were associated with complete penile length recovery [33]. Penile length shortening was also associated with treatment regret [36]. Furthermore, the self-perceived penile length shortening was found to be much more than actual penile length shortening measured using a ruler [37]. The study by Parekh et al. is of particular interest as an outlier study, as they only reported a 3.73% RP and a 0% RT prevalence of penile length shortening [36]. This study relied on self-reported patient outcomes, but participants were not instructed on the required measuring procedures (stretched or relaxed flaccid penile length or erect penile length). Furthermore, the majority of the participants (75.4%) in Park et al.'s study were aged between 60 and 80 years old. The lack of available baseline data compromised the ability to determine penile length loss objectively. Frey et al. reported a 15–68% prevalence of penile length shortening in their study [7],

placing the results of a 42% (RT study) [4] and 47% (RP study) [5] more within the expected range.

Penile curvature changes were also similar between RP and RT studies, showing a low prevalence (10–15.9%) [4, 5, 40], and the average reported abnormal penile curvature angle was 31° [40]. Penile sensory changes showed an almost similar moderate prevalence between RP (25%) and RT (27%) participants [4, 5].

Anejaculation was found to have a low to high prevalence (11–72%) after RT [4, 31, 32]. According to this review, anejaculation is a consequence of RT [31, 32], and it is at its worst 5 years after treatment [32]. Conserved ejaculatory function is often associated with a reduction in ejaculate volume. Higher RT dose, older age and smaller prostates at the time of treatment increased the likelihood of failure to ejaculate [32]. Anejaculation is, however, also a given consequence of RP, as the ejaculatory apparatus (prostate, seminal vesicles and ejaculatory ducts) are removed [7, 42]. However, the authors could not source any studies within our search parameters that met the study inclusion criteria.

Climacturia has a reported moderate prevalence (21–38%) after RP [5, 27–30] and a low prevalence (4–5.2%) after RT [4, 27]. A comparative study concluded that the orgasm-associated incontinence rates after RP were six times more than that of RT (28.3% vs 5.2%) [27]. Climacturia is associated with major sexual inconvenience and bother [29].

Questionnaire used in assessing NSSE

None of the retrieved studies reported on a validated, standardised questionnaire to investigate the NSSE after early PCa treatment. Most studies incorporated either some aspects of other questionnaires or designed their own. Two studies used a non-validated questionnaire that was able to identify the majority of the collective group of NSSE [4, 5]. This questionnaire enquired about orgasmic dysfunction, orgasm-associated pain, climacturia, penile sensory changes, penile length shortening and penile deformity. These two studies looked mainly and the prevalence and predicting factors of the NSSE.

Interestingly, a limited number of studies reportedly described the use of the Expanded Prostate Cancer Index questionnaire [11] to gather patient data relating to orgasmic dysfunction [20–22]. However, the Expanded Prostate Cancer Index questionnaire was inadequate to report on the NSSE, and additional questions that inquired into orgasmic function were added [20, 22]. The Expanded Prostate Cancer Index-26 questionnaire was similarly inadequate to detect NSSE. It merely asked respondents to "rate their ability to reach orgasm" without exploring any symptoms relating to the other NSSE [21].

A 2011 study used the Expanded Prostate Cancer Index questionnaire similarly at regular intervals after surgery to investigate orgasmic outcomes [22]. In addition, patients were asked to evaluate their orgasm and state whether they experienced any pain during orgasms. One study also incorporated the Dysorgasmia Frequency Scale [26]. The International Index Erectile Function was used in many studies [5, 22, 24, 28, 32, 34, 35, 38, 39] but served no purpose in detecting any of the NSSE. The Erection Hardness Scale [43] was used in a few studies [5, 34] and had no role in detecting the NSSE. The Sexual Health Inventory for Men questionnaire (a modified 5-item version of the International Index Erectile Function) was used in two studies [20, 33], and another study [31] based their informal questionnaire on the Male Sexual Health Questionnaire [44].

Orgasm-associated incontinence/climacturia was further assessed by a non-validated author designed questionnaire [27] and a study-specific questionnaire based on the Scandinavian Prostate Cancer Group 4 questionnaire [29] in two separate studies. A telephonic interview was added to a non-NSSE questionnaire to probe the presence of climacturia in a 2012 study [28].

Anejaculation was assessed in a study that used the International Index of Erectile Function questionnaire [32]. A sexual medicine physician initially interviewed the participants. They were then questioned about their ejaculatory function (presence/absence, intensity and ease of achievement) and orgasm (presence/absence, intensity and ease of achievement). Only those who were sexually active were asked to complete the questionnaire. Questions 9 and 10 respectively asked: "When you had sexual stimulation or intercourse, how often did you ejaculate?" and "When you had sexual stimulation or intercourse, how often did you have the feeling of orgasm or climax?" [32]. A 2009 study used a modified version (5 items, not 7) of the Male Sexual Health questionnaire that specifically addressed: (i) frequency, (ii) volume, (iii) dryness, (iv) pleasure and (v) pain during ejaculation [31].

Penile length shortening was assessed in a 2012 study using an author designed questionnaire containing questions relating to self-perceived penile length shortening [37]. Penile length shortening and penile deformity/Peyronie's disease were not assessed by any other questionnaires apart from the collective NSSE questionnaire mentioned [4, 5], but rather through physical examinations. Three studies used a semi-rigid ruler for a physical penile length examination [34, 35, 39]. Vasconcelos et al. used an anthropometric ruler as a physical measurement to assess shortening [38]. Parekh et al. reported in their study that physicians completed a questionnaire based on their patients, and one question includes under "the

complaints section" referred to reduced penile length [36].

Penile deformity was assessed in one additional study by Tal et al., where they assessed a penile curvature with a goniometer if the patient reported an abnormal curvature [40].

Strengths and limitations of the study

The methodology used and the search period used allowed for the systematic and extensive literature search, which sought to map only the most recent developments on the prevalence of NSSE and the use of questionnaires to identify NSSE. Additionally, the scoping review results were presented following the PRISMA recommendations, which ensured complete and transparent reporting. The MMAT tool version 2011 was used to assess the methodological quality of the included studies.

Limitations of this study included the fact that the studies included variables that were not consistent between studies. The reader should be cautioned when interpreting the results of the prevalence indicators for different NSSEs.

Furthermore, only original research was included, and other sources of information could have further clarified some discrepancies in the results.

Conclusion

This study found a low to a high prevalence of NSSE reported in men after RP and RT. Penile deformity, orgasmic dysfunction, and penile length shortening were low to moderately prevalent, similar to RP and RT. Anejaculation prevalence was low to high after RT. Climacturia was shown to have a low prevalence after RT and a moderate prevalence after RP (six times more than RT). A common theme through most of the studies was that the participants expressed not being adequately informed about the possible sexual side effects before commencing their PCa treatment. Questionnaires effectively assess sexual dysfunction, and many modified informal non-specific questionnaires are used to detect conditions related to sexual dysfunction. There is currently no valid and reliable questionnaire to detect the collective NSSE after PCa treatment. There is a need to develop a validated and reliable NSSE questionnaire for use after PCa treatment for quick and effective diagnosis.

Abbreviations

PCa: Prostate cancer; NSSE: Neglected sexual side effects; PCC: Population concept context; MeSH: Medical Subject Heading; MMAT: Mixed Method Appraisal Tool; PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews; RP: Radical prostatectomy; RT: Radiation therapy.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s13643-021-01865-5.

Additional file 1. Collected data organised into subgroups.

Additional file 2. The specific criteria to determine the appropriateness of each included study.

Additional file 3. Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.

Acknowledgements

None

Authors' contributions

PR conceived the study and participated in the design involved in drafting and finalising the manuscript. RS revised the manuscript and provided clinical input and approved the manuscript for final submission. JM came up with the study idea, provided clinical input and revised the manuscript for final submission. JvW participated in the conceptual design of the study, drafting the manuscript and revising it critically, providing final approval of the version to be published. The authors read and approved the final manuscript.

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Funding

Not applicable

Availability of data and materials

Not applicable

Declarations

Ethics approval and consent to participate

Full ethical clearance was obtained from the University of KwaZulu-Natal, School of Health Sciences Research Committee (Biomedical Research Ethics Committee) with registration no: BREC/00000478/2019.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests.

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Received: 9 June 2020 Accepted: 2 December 2021
Published online: 03 January 2022

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Publisher's Note

4.4 Key Findings and Contribution of the Manuscript to the Thesis

By comparing the available literature on NSSE after PCT, this study was able to establish its prevalence and trends across most recently published original literature. Overall, there was a large range (low to high) perveance when looking at the set of NSSE. The study concluded that three of the NSSE were moderately prevalent, namely orgasmic dysfunction, penile length shortening and abnormal penile curvature, and these trends were comparable between the RP and RT approaches. Anejaculation had shown to have a variable prevalence rate (low to high), but it was exclusive to the RT approach, as it would be considered a consequence of a RP, rather than a preventable or manageable side effect. Climacturia was shown to be six times more prevalent in RP patient (moderate prevalence) compared to RT patients (low prevalence). The study also found that from the twenty-three papers that were analysed in its final inclusion, there was a great disparity between assessment methods to detect the NSSE, and a combination of non-validated questionnaires, non-specific NSSE questionnaires and verbal assessment were used in the studies. The study concluded that there is no current NSSE assessment tool available that could detect and or screen the collective NNSE after PCT. There was a need to develop an appropriate NSSE after PCT screening tool.

To establish the NSSE prevalence rates in a specific population, the creation of such a screening tool was commenced, and the process of developing an appropriate NSSE after PCT screening tool is described in Chapter Five.

CHAPTER 5: ASSESSING NSSE AFTER PCT

5.1 Introduction

The previous Chapter explained the need for a tool or questionnaire to be developed for use by an HCP to detect the NSSE after PCT. This manuscript describes the process of putting together a MDT of experts in the field of PCT, and through the process of a Delphi study, producing an appropriate NSSE after PCT screening tool. The panel was tasked with developing the wording and structure of the screening tool and the researcher established consensus with regards to the appropriateness of each item included in the tool.

5.2 Publication Details

Title	A Modified Delphi study to identify the screening items to assess neglected sexual side effects following prostate cancer treatment.
Authors	Röscher, Pierre Kimesh Naidoo Milios, Joanne E Van Wyk, Jacqueline M
Journal	BMC Urology
Journal Details	Open Peer Reviewed Listed of the Department of Higher Education & Training (DoHET)
Status	Published

5.2.1 Journal Information

BMC Urology is an open access journal publishing original peer-reviewed research articles in all aspects of the prevention, diagnosis, and management of urological disorders, as well as related molecular genetics, pathophysiology, and epidemiology.

5.2.2 Publication Record

The manuscript was submitted on 29 January 2021, accepted for publication 20 February 2022, published 11 March 2022.

5.2.3 Contribution Record

The candidate conceptualised the paper and was the main author. All authors were involved in drafting and finalising the manuscript. KN and JM provided additional clinical input for the study, and all authors approved the final version that had been published.

5.3 Publication

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Röscher *et al. BMC Urology* (2022) 22:34
https://doi.org/10.1186/s12894-022-00982-0

BMC Urology

RESEARCH Open Access

A modified Delphi study to identify screening items to assess neglected sexual side-effects following prostate cancer treatment

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Abstract

Background: Neglected sexual side effects (NSSE) are a group of less common sexual side effects that may present after Prostate Cancer (PCa) treatment. There is currently no valid and reliable tool to identify these side effects. A modified Delphi study is an effective way of developing the content of such a screening tool.

Methods: A modified Delphi study was used to obtain consensus from a multi-disciplinary group of experts over 3 rounds during a 12 week period. Ten statements were presented containing 8 closed-ended statements on individual NSSEs, and 2 open-ended statements on psychosocial impact related to NSSE. Consensus was defined as a 75% strongly agree achievement on each statement, or the final statement evolution at the end of 3 rounds. Statement support in each round was determined by mean, standard deviation and range, after a numerical value was allocated to each statement during specific rounds. All three rounds were structured and suggestions and additions were incorporated in the statement evolution of the three rounds.

Results: Thirty-five participants were invited, and 27 completed Round 1 (RD 1), 23 participants completed RD2, and 20 participants completed RD3. All 3 rounds were completed in 12 weeks. Statement 1 (sexual arousal incontinence), statement 2 (climacturia) and statement 3 (orgasm intensity) reached consensus after RD2, and statement 9 (sexual dysfunction impact) and statement 10 (experiences) were removed after RD3. Statement 4 (orgasmic pain), statement 5 (anejaculation), statement 6 (sensory disturbances), statement 7 (penile length shortening) and statement 8 (penile curvature) were finalised after the conclusion of RD3. Statements 1–3 were the most stable statements with the most support and least amount of disagreement. Statements 4–8 were less stable, but support for them improved over the 3 rounds. Statements 9–10 both had good stability, but the support indicated that they needed to be removed from the set of statements. Statement 5 had the poorest range due to an outlier opinion.

Conclusions: Consensus was reached on the items making up the NSSE screening tool. Health care practitioners will be able to use this tool to identify the evidence of NSSE after PCa treatment. Further testing will be undertaken to confirm the reliability and validly of the tool.

Background

Disability amongst men related to sexual dysfunction is high following their diagnosis and treatment for prostate cancer (PCa) [1, 2]. The reported incidence of PCa globally was 1.3 million cases in 2017, but more importantly, this was responsible for 7.1 million disability adjusted life years in these diagnosed men [3]. The average age of PCa diagnosis in South Africa is

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68 years, and the average age of death due to PCa is 74 years [4]. The risk of developing PCa increases exponentially after the age of 50 years for South African men, and older age and ethnicity (African black men) are the most notable non-modifiable risk factors leading to more aggressive PCa [5]. Treatment of localized PCa may include surgical (radical prostatectomy) and non-surgical interventions (radiation therapy) amongst others [6]. These interventions may cause disabling side effects that may include pain, incontinence and sexual dysfunction [2, 7–9]. Only 20% of men will reportedly ever discuss issues of sexual dysfunction with their health care practitioner after PCa [10] and while they may recover from pain and incontinence, they will suffer debilitating and long-lasting effects because their sexual dysfunction remained undetected [1, 11].

The less common symptoms of sexual dysfunction after PCa treatment may present in the form of a variety of complications that are collectively referred to as "Neglected Sexual Side Effects (NSSE)" [12, 13]. These NSSE drastically impacts the quality of life in many men, as their urinary, sexual, bowel and hormone functions may be already adversely affected, creating additional daily challenges for them [9]. NSSE range from anejaculation, change in penile length and curvature, urinary incontinence during sexual activity (climacturia), arousal incontinence, orgasmic disturbances that encompass anorgasmia, changes in orgasmic sensation and painful orgasm among others [12, 14]. Sexual function is the quality indicator most strongly associated with outcome satisfaction after PCa treatment [9] and sexual dysfunction is a predictor of bother and depression after PCa treatment [15, 16]. Poor sexual function has been associated with a higher prevalence and severity of depressive symptoms, and these symptoms may have a lasting psychological impact after the diagnosis of PCa [17].

A literature review indicated a few original publications on the NSSEs after PCa treatment, but only two publications address issues on how to assess the NSSEs [12, 14]. Both studies used an informal non-validated outcome measure to determine the extent of the NSSE. Other common PCa related sexual dysfunction outcome measures includes the Expanded Prostate Cancer Index Composite (EPIC) [18] and the International Index of Erectile Function (IIEF) [19]. The EPIC and IIEF are both validated instruments and both were recommended at the Fourth International Consultation for Sexual Medicine in 2015 [11]. However, both instruments only address general sexual dysfunction and there are no questionnaires to assist in diagnosing the NSSEs after PCa. There was thus a need to develop and validate an instrument that will effectively confirm the evidence of the NSSE after PCa treatment.

The aim of this study was to bring together a group of experts to develop an instrument that could be used as a self-administered clinical screening tool to identify NSSE 1–10 years after PCa treatment. A Delphi technique study provides such an opportunity where experts can give controlled feedback to develop a group opinion on a specific subject [20]. The Delphi technique has proven to be a reliable measurement instrument to develop and to refine a new concept, and to direct future research [21]. The Delphi technique is also a cost effective and efficient method to collect information from an expert panel of participants, and is ideally suited for electronic administration [22].

The study explored the questions that should be included in a screening tool to investigate the NSSE after PCa and it sought gather consensus on the appropriate wording of statements from a group of experts to include in the NSSE screening tool.

Methods

Study design

A modified Delphi study was performed according to the methodological criteria of Diamond et al. [20]. The Delphi technique was used to obtain consensus among experts on the questions to include in a screening tool for NSSE after PCa treatment, where patients would be asked to indicate their experienced NSSE symptoms relating to the previous 3 months. Three rounds of the study survey were circulated [23]. The participants were recruited via email and a Google Forms link was provided for their participation. The duration of the study was predetermined [20], and was set as 3 rounds each consisting of 3 weeks, with a one-week collation time after each round, making the total duration of the study 12 weeks. The time to complete each round was suggested to take only 10–15 min. Participants were assured anonymity and informed of their right to withdraw at any time. All the participating experts gave informed consent to participate in the study. Consensus was defined, and the termination of the study was described. Each participant was asked to complete the study survey independently and were given instructions on how to complete each round of the study. The original research statements that were used in round 1 can be found in Additional file 1: Appendix 1.

The first round (RD 1) collected demographic information from the expert panel. All three rounds (RD1-3) presented a set of statements in the form of questions to be posed to a potential patient. The experts were asked to indicate how appropriate they thought the statement was by ranking it on a 5-point Likert scale ("strongly agree, agree, neutral, disagree and strongly disagree") and they were asked to comment on each statement. This allowed

for the identification of statements that were unclear or required additional attention. Once a participant submitted their survey answers, the study moderator was able to collate their information and code each participants' data into an Excel spreadsheet. Participants who had not yet responded during each round were received two additional reminders to complete the round, and the Google form link was closed after three weeks. The research team discussed and implemented all the comments and suggestions and communicated the changes and the new version of the screening tool to the experts during subsequent rounds. The experts were thus asked to rank the appropriateness of a new set of statements in RD2 an RD3 according to the changes that the collective group of experts requested in the previous rounds.

Data analysis

Quantitative and qualitative data was produced in all three rounds of this study. The quantitative data was represented by the percentage of participants choosing the "strongly agree option on the Likert scale, as we aimed to achieve a 75% approval rating in each round. In addition to this, RD 1 produced quantitative demographic data. The qualitative data was represented by the comments and the suggestions submitted by the experts in each round. A deductive approach was used to code the comments and suggestions (the perceptions of the participants) into a specific framework [24]. This framework included the directional views of the experts (positive/negative/indifferent) and were applied by the authors where these themes matched the theory regarding the NSSE after PCa treatment. This data dictated the changes made to the statements in each subsequent round.

Expert panel

We identified a group of multi-disciplinary medical experts working in the field of prostate cancer and sexual medicine in South Africa. An additional international (Netherlands) expert (medical sexologist) was identified from outside the setting due to the small number of appropriately qualified medical sexologists practicing in South Africa. In addition to working in the prostate cancer field, the overwhelming majority of the identified experts were either members of the South African Sexual Health Association or where affiliated to the Prostate Cancer Foundation of South Africa. Thirty-five potential participants were invited via email to participate in this study. This multi-disciplinary group consisted of urologists in the field of radical prostatectomies, urologists in the field of prostate radiation therapy, oncologists, medical sexologists, psycho-sexologists, psychologists, and pelvic health physiotherapists. There is no set participant number needed to conduct a Delphi study in the literature, but most Delphi studies usually use between 15 and 20 participants [25, 26].

Consensus criteria

Consensus was predetermined as one of two scenarios. In scenario one consensus was defined as a 75% agreement/or disagreement amongst the participants on each questionnaire statement description on the final option of the 5-point Likert scale [27], in this case "strongly agree that the statement is appropriate". In cases where scenario 1 was not achieved, scenario 2 would be actioned. Consensus via scenario 2 was defined as the majority agreement of statements after the three-round process where consensus was not previously reached [20].

Statement support

The support of the statement between panellists in each round were determined by the mean, standard deviation and the range of each statement. A numerical value was matched with each Likert scale answer as follows: Strongly Agree = 1, Agree = 2, Disagree = 3 and Strongly Disagree = 5. The ideal mean would be 1, meaning that all the participants strongly agreed on a specific statement. A smaller standard deviation meant a bigger convergence towards strongly agree within a round, and a smaller range in each round meant a more unified opinion between experts within a round.

Questionnaire content

The content covered in the questions circulated in RD 1 was derived from available literature on the NSSE after radiation therapy for PCa [12] and on NSSE after a prostatectomy [13, 14]. The questionnaire consisted of eight specific questions relating to each of the NSSE after PCa and a matching 5-point Likert scale for each question, and 2 open-ended questions on the psychosocial impact of having and dealing with PCa.

Results

This section presents the results of the Delphi study and how consensus and stability evolved over the RD1-RD3 by looking at:

- The composition of the expert panel
- Agreement percentages
- The evolution of statements
- The support of statements by the expert panel.

Thirty-five participants were initially invited to participate in the study, and 27 responded and completed round one, 23 participants responded and completed round two, and 20 participants completed round three (Fig. 1).

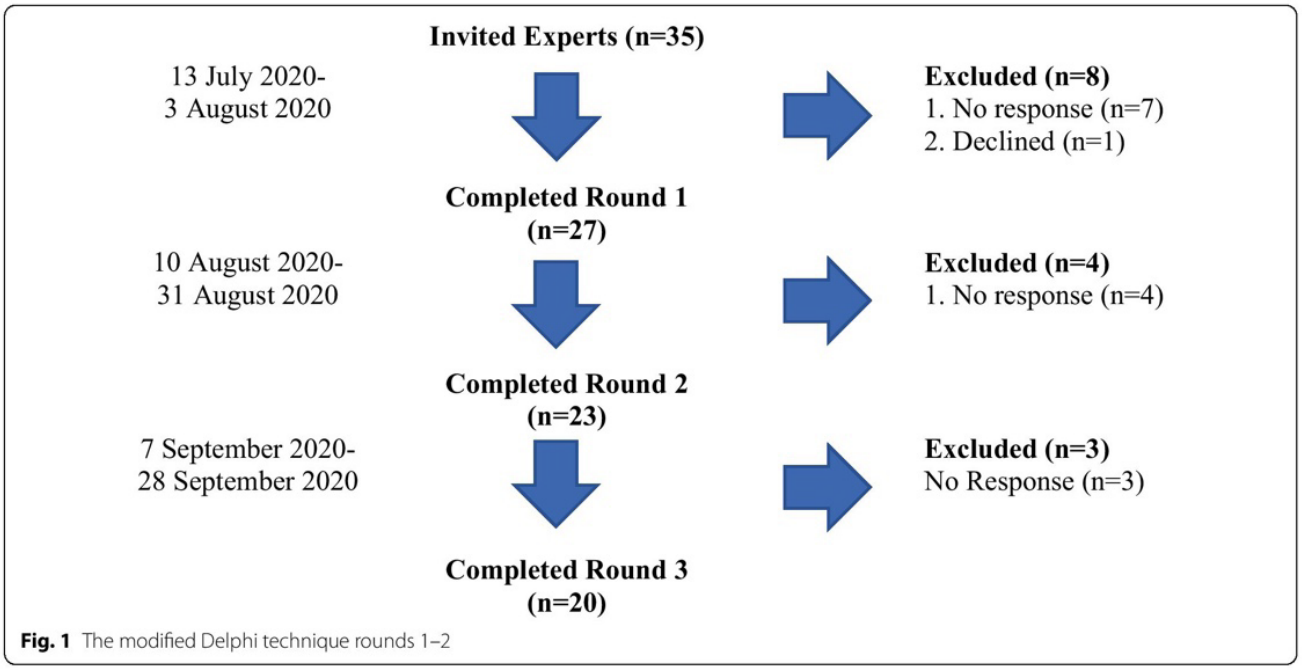

Fig. 1 The modified Delphi technique rounds 1–2

The 3 rounds were successfully executed in the planned 12-week time frame.

Participant demographics: RD 1–3

Table 1 describes the detailed demographic information of the participants during each round. The largest professional representation of the experts during round 1 were the combined group of urologists (30%), followed by the combined group of sexologists (26%) followed by the physiotherapists (22%). This trend remained consistent during round 2 except for the sexologists making up the majority of the group at 30%. This was similar in round 3 with the sexologists constituting 30% of the expert group and the urologists and physiotherapists each representing 25%.

The ratio of male to female participants were equally split throughout the rounds. Two thirds of the participants had a minimum of 15 years' or more experience in the field. The overwhelming majority of the participants were qualified at Masters level or PhD throughout the rounds (R1: 78%, R2: 83% R3: 80%). Most participants were practicing in the private sector (74%).

Statement agreement between participants: RD 1–3

The agreement for each statement for Rd1-3 is presented in Table 2. The results include the total responses received for each round, and percentage breakdown between the strongly agree, agree, neutral, disagree and strongly disagree options.

Statement 1: Please refer to box 1.

Box 1: Agreement, statement support and statement evolution for statement 1

Agreement and statement support for statement 1

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	n/a
	Strongly Agree	54%	78%	n/a
Statement Support	Mean	1.60	1.23	n/a
	Standard Deviation	0.94	0.58	n/a
	Range	1–4	1–3	n/a

Evolution for Statement 1

R1: Have you experienced involuntary loss of urine associated with sexual arousal during the last 3 months

R2: Have you experienced involuntary leaking of urine associated with sexual arousal (besides during an orgasm)? *Arousal can be defined as the state of being sexually excited"

Round 1: The word "loss" and "arousal" was found to be problematic and replaced with "leaking" and "arousal (besides during an orgasm)". A definition of arousal was suggested and included in round 2. Adjustments were proposed related to the Likert scale that was used, and the "never to always" scale was replaced with a "very rarely to very frequently" scale. One expert

Table 1 Participant demographics round 1–3

Participant demographics	Round 1	Round 2	Round 3
Number	27	23	20
Age			
31–40	5 (19%)	3 (13%)	2 (10%)
41–50	11 (41%)	9 (39%)	8 (40%)
51–60	8 (30%	8 (35%)	8 (40%)
>61	3 (11%)	3 (13%)	2 (10%)
Gender			
Male	13 (48%)	11 (48%)	9 (45%)
Female	14 (52%)	12 (52%)	11 (55%)
Profession			
Oncologist	4 (15%)	3 (13%)	2 (10%)
Physiotherapist	6 (22%)	5 (22%)	5 (25%)
Psychologist	2 (7%)	2 (9%)	2 (10%)
Sexologist (with a medical background i.e. a GP)	3 (11%)	3 (13%)	2 (10%)
Sexologist (with a psychology background)	4 (15%)	4 (17%)	4 (20%)
Urologist (involved in brachytherapy/radiation therapy)	3 (11%)	2 (9%)	2 (10%)
Urologist (performing radical prostatectomies)	5 (19%)	4 (17%)	3 (15%)
Highest academic qualification			
Bachelor's degree	3 (11%)	2 (9%)	2 (10%)
Honours degree	3 (11%)	2 (9%)	2 (10%)
Master's degree	15 (56%)	13 (57%)	11 (55%)
PhD	6 (22%)	6 (26%)	5 (25%)
Health sector			
Government	1 (4%)	1 (4%)	1 (5%)
Private	20 (74%)	17 (74%)	15 (75%)
Private, govt and academic	2 (7%)	2 (9%)	2 (10%)
Private and academic	4 (15%)	3 (13%)	2 (10%
Years of experience			
<5 years	1 (4%)		
5–10 years	4 (15%)	4 (17%)	3 (15%)
11–15 years	4 (15%)	4 (17%)	3 (15%)
16–20 years	6 (22%)	3 (13%)	3 (15%)
>20 years	12 (44%)	12 (52%)	11 (55%)

(a urologist) stated that this was not a side effect, especially not after brachytherapy.

Round 2: It was suggested that "with or without a partner" and "with or without an erection" needed to be added to the definition of arousal. Consensus was reached.

Statement 2: Please refer to *box 2*:

Box 2: Agreement, statement support and evolution of statement 2

Agreement and statement support for statement 2				
		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	n/a
	Strongly Agree	60%	91%	n/a
Statement Support	Mean	1.40	1.09	n/a
	Standard Deviation	0.61	0.29	n/a
	Range	1–2	1–2	n/a

Table 2 Round 1–3 agreement results for statement 1–10

Statement	Round	Responses received			% Agreement				
		Total received	Eligible responses	Out of scope	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Statement 1	R1	27	26	1	53.8	34.6	3.8	0.0	7.7
	R2	23	23	0	78.3	13.0	4.3	4.3	0.0
	R3	–	–	–	–	–	–	–	–
Statement 2	R1	27	25	2	60.0	40.0	0.0	0.0	0.0
	R2	23	23	0	91.3	8.7	0.0	0.0	0.0
	R3	–	–	–	–	–	–	–	–
Statement 3	R1	27	27	0	59.3	37.0	0.0	3.7	0.0
	R2	23	23	0	82.6	17.4	0.0	0.0	0.0
	R3	–	–	–	–	–	–	–	–
Statement 4	R1	27	27	0	59.3	29.6	3.7	0.0	7.4
	R2	23	23	0	73.9	26.1	0.0	0.0	0.0
	R3	20	20	0	0.65	0.2	0	0	0.15
Statement 5	R1	27	27	0	44.4	33.3	0.0	14.8	7.4
	R2	23	23	0	65.2	21.7	4.3	8.7	0.0
	R3	20	20	0	0.7	0.15	0	0.1	0.05
Statement 6	R1	27	26	1	42.3	46.2	11.5	0.0	0.0
	R2	23	23	0	65.2	30.4	4.3	0.0	0.0
	R3	20	20	0	0.75	0.15	0	0	0.1
Statement 7	R1	27	27	0	48.1	37.0	7.4	7.4	0.0
	R2	23	23	0	56.5	39.1	0.0	4.3	0.0
	R3	20	20	0	0.7	0.15	0	0.1	0.05
Statement 8	R1	27	27	0	51.9	37.0	3.7	7.4	0.0
	R2	23	22	1	59.1	22.7	13.6	4.5	0.0
	R3	20	20	0	0.7	0.2	0	0	0.1
Statement 9	R1	27	27	0	59.3	25.9	3.7	11.1	0.0
	R2	23	23	0	73.9	21.7	0.0	4.3	0.0
	R3	–	–	–	–	–	–	–	–
Statement 10	R1	27	27	0	59.3	29.6	11.1	0.0	0.0
	R2	23	23	0	69.6	21.7	4.3	4.3	0.0
	R3	–	–	–	–	–	–	–	–

Statement evolution for statement 2

R1: Have you experienced involuntary loss of urine associated with orgasm during the last 3 months
R2: Have you experienced any involuntary leaking of urine during an orgasm?

Round 1: It was suggested that "with your orgasm" be replaced with "during an orgasm", "loss" to be replaced with "leaking". There was confusion between "orgasm" and "ejaculation",

Round 2: The experts asked that a statement needed to be added that an orgasm may occur with or without ejaculation. C*onsensus was reached.*

Statement 3: Please refer to *box 3*:

Box 3: Agreement, statement support and evolution of statement 3

Agreement and statement support for statement 3

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	n/a
	Strongly Agree	59%	83%	n/a
Statement Support	Mean	1.44	1.17	n/a
	Standard Deviation	0.58	0.39	n/a
	Range	1–3	1–2	n/a

Statement evolution for statement 3

R1: Within the last 3 months, when you have had an orgasm, how would you characterize the intensity compared to before your prostate cancer treatment
R2: Are you able to achieve an orgasm, and if yes, how would you rate the intensity of your orgasm?

Round 1: In relation to the wording some experts thought that the statement implied that an orgasm was already being achieved. The first part of this statement was subsequently changed to establish whether an orgasm was being achieved. Other suggestions required an amendment to the response on the Likert scale by changing the wording from a "decrease to increase scale to "much less to much more scale".

Round 2: It was suggested to swap the order of statement 2 and 3 to improve the flow of questioning. This was implemented in the final round. Consensus *was reached.*

Statement 4: Please refer to *box 4*:

Box 4: Agreement, statement support and evolution of statement 4

Agreement and statement support for statement 4

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	20
	Strongly Agree	59%	74%	83%
Statement Support	Mean	1.54	1.26	1.65
	Standard Deviation	0.89	0.45	1.09
	Range	1–4	1–2	1–2

Evolution for statement 4

R1: Within the last 3 months, have you experienced pain or discomfort when you had an orgasm
R2: Have you experienced pain during an orgasm; if yes, how often does this occur; if applicable, in what area of your body do you experience the pain during an orgasm; if applicable, please describe your pain experienced during an orgasm and finally, please rate the pain you have described on the following scale (NPRS)
R3: How often have you experienced pain during an orgasm; If applicable, in what area of your body have you experienced pain during an orgasm; if applicable, please describe your pain that you experienced during an orgasm; please rate the pain described above on the following scale

Round 1: Suggestions were made to add a description of the area of symptoms, and to allow a way to quantify/measure the pain on a scale. This question was elaborated in round 2 to include frequency value to how often symptoms occur, a measuring capacity using the numeric pain rating scale (NPRS) and the allowance for descriptive words in the answers to allow for more detail on area of symptoms and descriptions of symptoms.

Round 2: A suggestion was made to replace the NPRS with the visual analogue scale. This was rejected due to the fact that sizing of the scale may change on different screens/platforms losing its reliability.

Round 3: A comment was made to simply state "Have you… instead of how often have you ". Another comment was made that the description of the patient's pain would not be valuable, as it could not be used to distinguish different types of pain.

Statement 5: Please refer to *box 5*:

Box 5: Agreement, statement support and evolution of statement 5

Agreement and statement support for statement 5

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	20
	Strongly Agree	44%	65%	70%
Statement Support	Mean	1.85	1.41	1.50
	Standard Deviation	0.95	0.71	0.89
	Range	1–4	1–4	1–4

Evolution for statement 5

R1: Within the last 3 months, have you experienced an orgasm without ejaculating?"This statement aimed to identify anejaculation
R2: When you ejaculate, has the volume of ejaculatory fluid decreased; If Yes, how much has the volume of ejaculatory fluid decreased?
R3: When you ejaculate, has the volume of ejaculatory fluid decreased; If Yes, how much has the volume of ejaculatory fluid decreased?

Round 1: The urologists on the panel expressed strong concern that this statement may be misleading to patients, as anejaculation is a given consequence for most post- prostatectomy patients. This was addressed in round 2, where the question was first asked whether ejaculation is able to occur. There were also concerns that some men may associate the ejaculation event as the actual orgasm event, and not be aware that an orgasm is possible without ejaculating.

Round 2: A comment was once again made whether prostatectomy patients would get confused, as they will not be able to ejaculate after their treatment. It was thought that the question may confuse patients and that it may leave patients concerned that their surgery was performed poorly/incorrectly.

Round 3: Suggestions were made to remove sections of the question. Some experts also expressed that it would be inappropriate to ask about a change in volume of ejaculate.

Statement 6: Please refer to *box 6*:

Box 6: Agreement, statement support and evolution of statement 6

Agreement and statement support for statement 6

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	20
	Strongly Agree	44%	65%	70%
Statement Support	Mean	1.52	1.32	1.45
	Standard Deviation	0.72	0.54	0.94
	Range	1–3	1–3	1–4

Evolution of statement 6

R1: Have you experienced one or more of the following sensory disturbances in the penis in the last 3 months? i) no disturbances, ii) sensation of cold, iii) sensation of warm, iv) felt that all or part of the penis was "asleep", v) increased sensitivity, vi) decreased sensitivity
R2: "Have you experienced any sensory changes in your penis; if yes, please indicate the sensory changes that you have experienced; if applicable, describe in your own words any other sensory changes in your penis you have experienced? i) no disturbances, ii) sensation of cold, iii) sensation of warm, iv) felt that all or part of the penis was "numb", v) increased sensitivity, vi) decreased sensitivity
R3: Have you experienced any sensory changes in your penis; if yes, please indicate the sensory changes that you have experienced; if applicable, describe in your own words any other sensory changes in your penis you have experienced? i) no disturbances, ii) sensation of cold, iii) sensation of warm, iv) felt that all or part of the penis was "numb", v) increased sensitivity, vi) decreased sensitivity

Round 1: A suggestion was made to include a section for other options that were not mentioned. The word "asleep" was queried, and suggested to be changed to "numb", which was done.

Round 2: A grammar comment was made relating to the Likert scale and implemented in round 3.

Round 3: Suggestions were made to add the "how problematic" section to this question, similar to some of the other statement, and to remove the option to identify the type of sensation change that has occurred. These adjustments were made. Consensus was reached.

Statement 7: Please refer to *box 7*:

Box 7: Agreement, statement support and evolution of statement 7

Agreement and statement support for statement 7

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	20
	Strongly Agree	48%	57%	70%
Statement Support	Mean	1.56	1.48	1.50
	Standard Deviation	0.75	0.59	0.89
	Range	1–3	1–3	1–3

Evolution of statement 7

R1: Have you noticed that your penis has become shorter after your prostate cancer treatment, and if so, how much do you estimate it has changed; If you answered yes to the question above, how bothersome is it when you engage in sexual activity?
R2: Has your penis become shortened in length; If yes, how problematic is it when you engage in sexual activity?
R3: Has your penis become shorter in length; If yes, how problematic is it when you engage in sexual activity?

Round 1: Suggestions were made to remove the options of how much the decrease in size was estimated at, and to keep the question more general. There were suggestions to change the word "bothersome" which was done in round 2.

Round 2: Some comments were made related to the impact of the penile shortening on self-confidence and self-image, but these were not considered for this questionnaire.

Round 3: Suggestions were made to add a time scale and the partners' perspective to the question. These suggestions were not considered as the partners perspective was already invited at the start of the questionnaire, and the time scale was already included for referencing purposes.

Statement 8: Please refer to *box 8*:

Box 8: Agreement, statement support and evolution of statement 8

Agreement and statement support for statement 8

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	20
	Strongly Agree	52%	59%	70%
Statement Support	Mean	1.54	1.37	1.50
	Standard Deviation	0.75	0.76	0.89
	Range	1–3	1–3	1–4

Evolution of statement 8

R1: Have you noticed a different curvature of your penis after your prostate cancer treatment? If you answered yes to the question above, how bothersome is it when you engage in sexual activity?
R2: Has your penis developed any new curvatures; If yes, how problematic is it when you engage in sexual activity?
R3: Has your penis developed any new curvatures or bends; If yes, how problematic is it when you engage in sexual activity?

Round 1: A suggestion was made to change the phrase "different curvature" to "any new curvatures", as some minor penile curves were deemed normal. One suggestion from a urologist was to remove this question as it was not a known consequence. The same

suggestions that were made to change "bothersome" in statement 7 were again made, and changes were implemented in round 2.

Round 2: A statement was made by a urologist that this question does not belong as it does not occur with cancer treatment. A comment was made to replace the word "curvature" with "change in shape." This was not considered for the final round. Another comment suggested to include the word "bend" along with "curvature", this was included in the final round.

Round 3: Similar comments were made to statement 7 regarding the partners perspective and time scale. A urologist on the expert panel stated that this side effect was not a consequence of PCa treatment. There was also again a suggestion to include "shape" in this question. This was not included as shape was seen as a misleading inclusion as it could mean many different things.

Statement 9: Please refer to *box 9*:

Box 9: Agreement, statement support and evolution of statement 9

Agreement and statement support for statement 9

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	n/a
	Strongly Agree	59%	74%	n/a
Statement Support	Mean	1.50	1.30	n/a
	Standard Deviation	0.75	0.56	n/a
	Range	1–3	1–3	n/a

Evolution of statement 9

R1: Please describe your journey with sexual dysfunction after prostate cancer treatment and/or how has sexual dysfunction impacted your life after prostate cancer
R2: Describe your journey with sexual dysfunction and intimacy after prostate cancer treatment; How has this (answer above) impacted your life

Round 1: Suggestions were made to split the 2 questions completely. It was also suggested to include "intimacy" with the phrase. there were many positive comments regarding the fact that this was an open-ended question, and this would give context to the symptoms.

Round 2: Most panellists agreed that this was an important question, but its appropriateness for inclusion in this quantitative questionnaire was questioned. Comparisons were made with other similar questionnaires that did not have open ended questions. *This question was therefore completely removed from the questionnaire.*

Statement 10: Please refer to *box 10*:

Box 10: Agreement, statement support and evolution of statement 10

Agreement and statement support for statement 10

		Round 1	Round 2	Round 3
Agreement	Number of participants	27	23	n/a
	Strongly Agree	59%	70%	n/a
Statement Support	Mean	1.33	1.26	n/a
	Standard Deviation	0.62	0.62	n/a
	Range	1–2	1–3	n/a

Evolution of statement 10

R1: Is there anything else you want to tell us about your experience or that you think other people going through this or treating people going through this should know
R2: is there anything else from your experience with your prostate cancer treatment that you want medical professionals to know; Is there anything you would like other future patients to know about?

Round 1: It was suggested that the statement be split into two statements, or be rephrased as the question seemed a bit wordy.

Round 2: As with statement 9, most panellist agreed that this was an important question, but its appropriateness for inclusion in this quantitative questionnaire was questioned. Comparisons were made with other similar questionnaires that did not have open ended questions. This question was therefore removed from the questionnaire.

At the conclusion of the three rounds, a final screening tool was produced, and is outlined in Table 3.

Discussion

The awareness of the NSSE after PCa is growing rapidly amongst health care practitioners, and with that preventative approaches are being targeted at an early stage after PCa treatment. There are currently no statistics on the prevalence rates of the NSSE after PCa on South African patients. There are however two landmark studies of the prevalence of NSSE after PCa treatment on Danish participants [12, 14]. In a 2014 study, a group of radical prostatectomy patients presented with a; 47% penile length shortening, 10% penile deformity, 38% climacturia, 25% penile sensory disturbances and 60% decreased orgasm intensity prevalence [14]. In a follow up 2017 prostate radiation (external beam radiation) study, participants presented with a; 42% penile length shortening, 12% penile deformity, 4% climacturia, 27% penile sensory disturbances, 44% decreased orgasm intensity and 11%

Table 3 The NSSE after prostate cancer screening tool

Think about the last 3 months and compare this time to the time before your prostate cancer treatment, and then answer each of these questions.

1. **Have you experienced any involuntary leaking of urine associated with sexual arousal (besides during an orgasm)?** *Arousal can be defined as the state of being sexually excited with or without ejaculation, and with or without a partner.

Yes	No	I am currently unable to experience any sexual arousal
If applicable, how problematic is this when you engage in sexual activity?		
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4		

2. **Have you been able to achieve an orgasm?** *An orgasm may be achieved with or without ejaculating

Yes	No	I am currently unable to achieve an orgasm
If applicable, how problematic is this when you engage in sexual activity?		
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4		

3. **Have you experienced any involuntary leaking of urine during an orgasm?** *An orgasm may be achieved with or without ejaculating

Yes	No	I am currently unable to achieve an orgasm
If applicable, how problematic is this when you engage in sexual activity?		
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4		

4. **Have you experienced pain during an orgasm?** *An orgasm may be achieved with or without ejaculating

Yes	No	I am currently unable to achieve an orgasm
If applicable, how problematic is this when you engage in sexual activity?		
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4		

5. **When you ejaculate, has the volume of ejaculatory fluid decreased?**

Yes	No	I have had a prostatectomy and do not ejaculate anymore
If applicable, how problematic is this when you engage in sexual activity?		
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4		

6. **Have you experienced any sensory changes in your penis?**

Yes	No
If applicable, how problematic is this when you engage in sexual activity?	
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4	

7. **Has your penis become shorter in length?**

Yes	No
If applicable, how problematic is this when you engage in sexual activity?	
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4	

8. **Has your penis developed any new curvatures or bends?**

Yes	No
If applicable, how problematic is this when you engage in sexual activity?	
Never..... 0 Seldom..... 1 Sometimes..... 2 Often..... 3 Always..... 4	

*The full screening tool can be found as Additional file 2: Appendix 2, and gives the option for a partner of the patient to complete the questionnaire

anejaculation prevalence [12]. The scope and need to develop a screening tool to identify the evidence of a NSSE in a population of PCa survivors who have had an intervention is immense [28, 29].

A Delphi study provides an appropriate methodology to create content where there is a lack of information, incomplete knowledge or uncertainty regarding a specific topic [20, 30]. This Delphi study was conducted to establish agreement on the questions and its wording to be used for a self-administered screening tool to explore the evidence of the NSSE with a patient after their PCa treatment. A robust methodology was followed to execute this Delphi study, ensuring the quality and the consistency of the screening tool being produced. This methodology includes the composition of the expert panel, predetermining the amount of rounds, defining consensus and ensuring a short turnaround time between rounds [20].

A Delphi technique study is defined by the quality and expertise of the panel of experts that participate in the study [20]. Our expert panel included an experienced and multidisciplinary team of whom all but one (a medical sexologist) were based in South Africa. Most of these experts rendered services in private practice where the majority of early stage PCa patients are managed in South Africa due to resource limitations in the public health sector [4, 31]. These flaws in the public healthcare system have been highlighted in KwaZulu Natal where the average diagnosis of PCa is 100 days, and the vast majority diagnosis presents as advanced disease and are found in black men [32]. This trend was also seen in an earlier study looking at PCa diagnosis in in the Western Cape [5]. Sourcing an expert panel from the private sector was therefore an appropriate selection for the purposes of knowledge around early stage prostate cancer interventions in South Africa.

Three rounds of a Delphi technique study is considered optimal [30], and this Delphi technique study was completed as planned after 3 rounds, following the set out methodology [23]. Other methodological strengths of this study are that consensus was defined within the scope of 2 scenarios being that either a 75% agreement was reached or that the study rounds had expired, and the use of a Likert scale to determine participant consensus [30]. This study was also completed in 12 weeks, with a short turnaround time of 1 week between rounds, ensuring appropriate engagement from the expert panel.

Stability of consensus in this study was measured using agreement percentages and statement support parameters. Statement 2 was the most stable statement, as it had the smallest mean (1.40 and 1.09), smallest standard deviation (0.61 and 0.29) and the lowest range (1–2 and 1–2) between rounds. Statements 1 and 3 were also stable and were well supported by panellists with improvements made from round 1 to 2, and reaching consensus in round 2. While statements 4–8 all had increased in stability from round 1 to 2, they weakened from round 2 to 3 with regards to statement support from the panellists. Most comments and deliberations were made on these statements. Statements 4–8 all improved in their agreement over the 3 rounds. Statement 9 and 10 both had good stability but were removed after round 2.

Statement 5 consistently had the poorest range of statement support due to an outlier opinion of one panellist. The urologists on the panel expressed concern about the definition and wording of statement 5 (round 1) that relates to "anejaculation". They expressed the need for unambiguity in stating that anejaculation was a given consequence after a prostatectomy and not a side effect of PCa treatment. Similar outlier opinions were noted in round 3 of statement 8, weakening the statement support in round 3 for the statement. In statement 8, one expert (urologist), repeatedly requested the removal of the Peyronies disease/penile curvature statement and argued that the disease was not a known side effect after PCa treatment. Published literature relating to Peyronies disease, however showed the presence of an abnormal penile curvature in 10% of participants in a 2014 study [14], and in 12% of the participants in a 2017 study after radiation treatment [12]. This statement was retained as part of the screening tool for statement 8. Each professional group of experts displayed specific areas of interest within the scope of the screening tool being developed. The sexologists were more interested in the details relating to the NSSE and requested for additional descriptions to further explain the sexuality aspects that may be impacted. The urologists view were biomedical and clinical, and the psychologists were concerned with the impact of the NSSE on the view of the partner of a patient. The physiotherapists and oncologists offered general comments throughout the study.

Ultimately, the experts reached 75% agreement or disagreement on 4 of the statements, and a majority agreement as per scenario 2 was reached on 4 statements. Two statements were removed and the final screening tool consisting of 8 statements was created. The argument to remove two statements (open ended questions) was successfully made by the expert panel, and their suggestion was to include this in an expansion of the screening tool or as part of a follow up conversation that would be stimulated by the screening tool.

All the experts were supportive of the development of a screening tool to screen for the NSSE's following PCa diagnosis. The South African health care system allows for health care practitioners to work in the public sector and to spend a limited number of hours of Private remunerative work. Despite the fact that the South African

health care system is still grossly inequitable, and due the severe shortages of health care personal, there is much enthusiasm to translate knowledge and interventions such as the development of a screening tool (initially for use in well-resourced private facilities) for use in the public health sector.

Final screening tool considerations

General suggestions included the desire for the questionnaire to remain brief and uncomplicated and this was implemented in the final questionnaire. Suggestions were made to remove the subjective options describing each of the side effects, and to focus on the impact it had on sexual activity, as was the case in the initial phrasing of statements 7 and 8. These were carefully considered and subsequently implemented. All the statements in round 1 ended with "during the last 3 months". This phrase was removed from each individual statements in round 2 and included as an instruction for patients to "think about the last 3 months and compare that to the time before your prostate cancer treatment, and then answer the question". The final screening tool produced is outlined in Table 3.

Study limitations

Continued commitment is required from participants who are being asked a similar question multiple times, and this may be a reason for the experts dropping out in subsequent rounds of the study. There is also no evidence of the reliability of Delphi studies if the same set of questions is presented to two different panels, and thus the success of a Delphi depends highly on the quality and experience of the expert panel. The study focuses on expected symptoms associated with current management modalities for Pea in South Africa.The findings are thus relevant to current contexts only. It will require updating with changes in treatment and would need to be tested in different populations.

Conclusions

This study adds value in that it will assist health care practitioners to identify a variety of sexual dysfunction complications, collectively referred to as NSSE in men after PCa treatment. Currently these symptoms are often undiagnosed and remain untreated, especially in a low to middle income country such as South Africa. Consensus was reached on the statements making up the NSSE screening tool by a panel of experts. This screening tool may be applied on patients who have had treatment for early stage PCa that includes prostate surgery and prostate radiation therapies. This screening tool will need to undergo further psychometric testing to establish its validity and reliability.

Abbreviations

PCa: Prostate cancer; NSSE: Neglected Sexual Side Effects, Expanded Prostate Cancer Index; IIEF: International Index of Erectile Function.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12894-022-00982-0.

Additional file 1: Appendix 1. Original research statements.

Additional file 2: Appendix 2. NSSE after PCa Screening Tool (Full Version).

Acknowledgements

The authors would like to thank the panel of experts for their contributions to this study.

Authors' contributions

All authors conceived and designed the study. All authors were involved in drafting and finalising the manuscript. KN and JM provided additional clinical input for the study, and all authors approved the final version to be published.

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Funding

None.

Availability of data and materials

The datasets used and/or analysed during the current study available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Full ethical clearance was obtained from the University of KwaZulu-Natal, School of Health Sciences Research Committee (Biomedical Research Ethics Committee) with registration no: BREC/00000478/2019. All the participating experts gave informed consent to participate in the study. All methods were performed in accordance with the relevant guidelines and regulations set out by the Declaration of Helsinki.

Consent for publication

All participants consented that the data produced from this study would be published.

Competing interests

None.

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Received: 29 January 2021 Accepted: 22 February 2022
Published online: 11 March 2022

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Publisher's Note

5.4 Key Findings and contribution of this publication to the Thesis

This study described the process of developing the NSSE after PCT screening tool, using an MDT of experts who participated in a 3 round Delphi study. Twenty-seven experts started in round 1, twenty-three experts participated in round 2 and twenty experts finished the process in round 3. The panel consisted of a variety of HCP with knowledge and experience in the field of PCT, and the goal was to produce a tool that could be used in a variety of setting by a variety of HCP. Initially the panel was given eight draft statements that would enable patients to indicate whether they experienced a NSSE, along with three open ended questions. In the end, through the panel recommendations and seeking consensus with the regards to the wording and structure of the instrument, the three open ended questions were removed from the final version of the screening tool and eight final statements were produced. This study plays an important role in the management of men who have PCT, as there is now a tool available that could be used by HCP to screen them for NSSE. Currently, these symptoms are being underdiagnosed, especially in low to middle income countries like SA.

CHAPTER 6: PREVALANCE AND BOTHER OF NSSE AFTER PCT IN SOUTH AFRICAN MEN

6.1 Introduction

The previous Chapter described the process of developing a NSSE after PCT screening tool. This study describes how the tool developed in Chapter 5 was used in a population of SA men who had had PCT, where the aim was to establish their prevalence of NSSE, and how bothersome these were to them. The study aimed to compare the prevalence rates between different NSSE, and to match those rates to the prevalence rates found in Chapter 4 as part of the scoping review that was published.

6.2 Publication Details

Title	Prevalence and bother of neglected sexual side effects after prostate cancer treatment in South African men
Authors	Röscher, Pierre Van Wyk, Jacqueline M
Journal	Prostate Cancer and Prostatic Diseases
Journal Details	Open Peer Reviewed Listed on the International Scientific Indexing List (ISI)
Status	Manuscript submitted to journal

6.2.1 Journal Information

Prostate Cancer and Prostatic Diseases is a quarterly peer-reviewed medical journal covering all aspects of prostatic diseases, in particular prostate cancer, the subject of intensive basic and clinical research world-wide.

6.2.2 Manuscript Submission Details

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Detailed Status Information

Manuscript #	PCAN-23-0248
Current Revision #	0
Submission Date	24th Apr 23
Current Stage	Manuscript Received
Title	Prevalence and Bother Related to the Neglected Sexual Side Effects After Prostate Cancer Treatment in South African Men.
Manuscript Type	Article
Category	Clinical
Word Count	2944
Corresponding Author	Mr Pierre Roscher (University of KwaZulu Natal)
Contributing Author	Professor Jacquiline van Wyk
Abstract	Objectives: To identify and compare the prevalence and extent of distress caused by the neglected sexual side effects after prostate cancer treatment. Subjects: Sixty-one South African men aged 45-65, who received prostate cancer treatment between 1-5 years ago, were surveyed. Methods: include study design. Participants were purposively sampled from a database and surveyed to indicate whether they experienced any of the symptoms such as i) arousal incontinence, ii) anorgasmia, iii) climacturia, iv) orgasmic pain, vi) anejaculation, vii) penile sensory changes, viii) penile length shortening and ix) penile curvature changes. The respondents were also asked to indicate the degree to which they were bothered by the symptoms. Results: Anorgasmia was prevalent in (83%) of our participant group, whilst 55% of them reported penile length changes and 47% of them reported penile sensation changes. Arousal incontinence and Climacturia were experienced by 34% and 26% of participants respectively, whilst penile curvature changes (9,5%), and orgasmic pain (5,6%) were less prevalent. Anejaculation is a known consequence of radical prostatectomy. climacturia, with anejaculation, arousal incontinence and penile curvature changes showing low prevalence in our study. Penile length shortening and curvature changes bothered men the most, followed by climacturia. Fifty-three respondents participated in this study, representing an average age of 65 years and the time since the intervention 27 months. Conclusion: Men who have had prostate cancer treatment need to be routinely screened for neglected sexual side effects. Healthcare professionals also need to explore how bothersome sexual side effects are to a patient by exploring their perspective. Keywords Bothersomeness Neglected sexual side effects Prevalence Prostate cancer treatment Questionnaire-based screening tool
Editor	
Techniques	Not Applicable;
Subject Terms	Health sciences/Diseases/Cancer Health sciences/Diseases/Urogenital diseases/Prostatic diseases/Prostate cancer
Research Square author dashboard	I understand that my manuscript and associated personal data will be shared with Research Square for the delivery of the author dashboard.
In Review	Yes, my co-authors and I would like to opt in to *In Review*
Conflict of Interest Statement	**Yes** there is potential conflict of interest.
Applicable Funding Source	No Applicable Funding

6.2.3 Contribution Record

The candidate conceptualised the paper and was the main author. Prof van Wyk contributed to drafting and finalising the manuscript.

6.3 Manuscript

Prevalence and Bother Related to the Neglected Sexual Side Effects After Prostate Cancer Treatment in South African Men.

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Abstract

Objectives: To identify and compare the prevalence and extent of distress caused by the neglected sexual side effects after prostate cancer treatment.

Subjects: Sixty-one South African men aged 45-65, who received prostate cancer treatment between 1-5 years ago, were surveyed.

Methods: include study design. Participants were purposively sampled from a database and surveyed to indicate whether they experienced any of the symptoms such as i) arousal incontinence, ii) anorgasmia, iii) climacturia, iv) orgasmic pain, vi) anejaculation, vii) penile sensory changes, viii) penile length shortening and ix) penile curvature changes. The respondents were also asked to indicate the degree to which they were bothered by the symptoms.

Results: Anorgasmia was prevalent in (83%) of our participant group, whilst 55% of them reported penile length changes and 47% of them reported penile sensation changes. Arousal incontinence and Climacturia were experienced by 34% and 26% of participants respectively, whilst penile curvature changes (9,5%), and orgasmic pain (5,6%) were less prevalent. Anejaculation is a known consequence of radical prostatectomy.

climacturia, with anejaculation, arousal incontinence and penile curvature changes showing low prevalence in our study. Penile length shortening and curvature changes bothered men the most, followed by climacturia. Fifty-three respondents participated in this study, representing an average age of 65 years and the time since the intervention 27 months.

Conclusion: Men who have had prostate cancer treatment need to be routinely screened for neglected sexual side effects. Healthcare professionals also need to explore how bothersome sexual side effects are to a patient by exploring their perspective.

Keywords
Bothersomeness
Neglected sexual side effects
Prevalence
Prostate cancer treatment
Questionnaire-based screening tool

Introduction

The Neglected Sexual Side Effects (NSSE) after prostate cancer treatment (PCT) are a group of lesser-known physical sexual side effects [1]. These side effects include arousal incontinence, anorgasmia, climacturia, orgasmic pain, anejaculation, penile sensation changes, penile length shortening and penile curvature changes. The NSSE after PCT prevalence vary from low to high in men who have undergone either radical prostatectomy (RP) or radiation therapy (RT) [2]. Sexual dysfunction (SD) affects the quality of life in prostate cancer (PCa) survivors and contributes to feelings of depression and anxiety in these men [3].

It has been well established that men are reluctant to disclose symptoms related to sexual health with their doctors [4]. There is a stigma connected to PCa due to the involvement of sexual organs and the nature of the sexual side effects, and the challenges that this may pose to their masculinity [5]. Men feel embarrassed to ask for help, even though they recognise that the support available may help them [6]. It was hypothesized that the creation of a questionnaire-based screening tool (QBST) to identify the NSSE after PCT would improve

the communication about a specific sexual dysfunction symptom between affected men and their healthcare professionals [7].

The study aimed to determine the prevalence of NSSE among South African (SA) men who had PCT. The objectives of this study were to establish the prevalence of the various NSSE in participants who had received surgical and non-surgical PCT. We also aimed to determine how bothersome these NSSE were to participants.

Methods

Study Design

This phase formed part of a larger study where a mixed method methodology was used, but for this paper, only the quantitative data has been described concerning rates, ranges, and averages.

Population Sample

Potential respondents were recruited nationally in SA with the help of patient databases from: the Cancer Association of South Africa, the Prostate Cancer Foundation of South Africa, the South African Urological Association, and the South African Society of Physiotherapy.

Participant Recruitment

Potential Participants were invited to participate and asked to follow an electronic link to be screened for their eligibility.

Eligibility Criteria

The eligibility criteria for inclusion required men to be SA citizens should have received RP or RT for PCa in the last 1-5 years, be aged between 45-75 and be proficient to complete the survey in English. Informed consent was obtained electronically. Participants were informed of their right to withdraw at any stage and their anonymity was assured and there was no financial incentive to complete the study.

Data Collection

Participants were asked to complete an electronic survey hosted on a secure encrypted and user-friendly survey platform Jotforms (© 2022 Jotforms Inc) by following a link. The data were collected over a period of 8 months between October 2021 to May 2022. In-person, participant data collection was not considered due to the Covid-19 pandemic. Participants were given the option to i) answer the questions on their own, ii) do so with a partner or iii) have their partner complete the questions on their behalf.

The first part of the survey collected demographic data including their age, SA racial classification, geographical location, and prostate treatment details. The second part of the survey asked participants to indicate whether they had experienced any of the NSSE and to indicate how bothersome any of the specific NSSE had been to them. They were asked to use a 5-point Likert scale where 1 indicated never Bothersome, 2=Seldom Bothersome; 3=Sometimes Bothersome; 4= Often Bothersome and 5= Always Bothersome.

Data Analysis

After the data collection phase, the data was extracted into an Excel spreadsheet, cleaned and verified by a research assistant and analysed by the principal researcher.

Results

A total of 61 participants responded to the survey and 8 responses were excluded as they did not meet the selection criteria. Finally, 53 responses were included in this study.

Table 1: ***Characteristics of the Respondents***

Number of Study Participants	*N=53*
Age	
Range	*52-75 years*
Average	*65 years*
Race	
White	*92,5% (49)*
Coloured	*5,7% (3)*
Black	*1,8% (1)*
Intervention	
A) Surgery (Radical Prostatectomy)	*92,5% (49)*
i) Robotic	*77,4% (41)*
ii) Laparoscopic	*5,6% (3)*
iii) Open	*9,5% (5)*
B) Radiation Therapy	*7,5% (4)*
i) Brachytherapy	*1,9% (1)*
ii) External Beam Radiation	*5,6% (3)*
Time Since Intervention	

Range	*12-56 Months*
Average	*27 Months*
Treatment Facility	
Private	*96,2% (51)*
Public	*1,9% (1)*
Private and Public	*1,9% (1)*
Treatment Location	
Western Cape	*75,4% (40)*
Gauteng	*15,1% (8)*
KwaZulu Natal	*3,8% (2)*
Mpumalanga	*3,8% (2)*
Free State	*1,9% (1)*

Participants were given the option to complete the survey on their own or with a partner, and 96,2% (51) completed the survey on their own. All the study participants were sexually active (with or without a partner) before receiving their PCT. Only 79,2% (42) of the participants reported current attempts to engage in some form of sexual activity.

NSSE Prevalence and Bothersome (ness)

Respondents were asked to indicate whether they had experienced any of the symptoms linked to NSSE in the previous 3 months. Their responses are presented in Table 2. They were also asked to indicate how bothersome the symptoms had been to them, and these results are presented in (Table 3).

Table 2: NSSE Prevalence

Condition	**Total**	**RP**	**RT**
Arousal Incontinence			
Yes	34% (18)	36,8% (18)	-
No	49% (26)	51% (25)	25% (1)
Unable to experience arousal	17% (9)	12,2% (6)	75% (3)
Anorgasmia			
Yes	83% (44)	87,8% (43)	25% (1)
Unable to Reach Orgasm	17% (9)	12,2% (6	75% (3)
Climacturia			
Yes	26% (14)	28,6% (14)	-
No	57% (30)	59,2% (29)	25% (1)
Unable to achieve an orgasm	17% (9)	12,2% (6)	75% (3)
Orgasmic Pain			
Yes	5,6% (3)	4,2% (2)	25% (1)
No	77,4 (41)	83,6% (41)	-
Unable to achieve an orgasm	17% (9)	12,2% (6)	75% (3)
Anejaculation			
Yes	1,9% (1)	-	25% (1)
No	5,6% (3)	-	75% (3)
Unable to ejaculate	92,5% (49)	100% (49)	-
Penile Sensation Changes			
Yes	47% (25)	47% (23)	50% (2)
No	53% (28)	53% (26)	50% (2)
Penile Length Changes			
Yes	55% (29)	55,1 % (27)	50% (2)
No	45% (24)	44,9% (22)	50% (2)
Penile Curvature Changes			

Yes	*9,5% (5)*	*10,3% (5)*	-
No	*90,5% (48)*	*89,7% (44)*	*100% (4)*

Table 3: *Bothersome (ness) of NSSE*

NSSE	***Never/Seldom***	***Sometimes***	***Often/Always***
Arousal Incontinence (18)	44,4% (9)	38,9 (7)	16,7% (3)
Anorgasmia (44)	47,8% (21)	29,5% (13)	22,7% (10)
Climacturia (14)	42,8% (6)	35,8% (5)	21,4% (3)
Orgasmic Pain (3)	33,3%(1)	33,3% (1)	33,3% (1)
Anejaculation (1)	100% (1)	-	-
Penile Sensation Changes (25)	44% (11)	32% (8)	24% (6)
Peniel Length Changes (29)	45% (13)	10% (3)	45% (13)
Penile Curvature Changes (5)	80% (4)	-	20% (1)

Discussion

NSSE Prevalence

Arousal Incontinence was experienced by 36,8% of the RP participants and it was not reported by any of the RT participants. In this group and regarding being bothered by this symptom, 38.9% of participants were bothered sometimes and 16,7% were often or always bothered. These prevalence results concur with that of a 2011 RP study, where 36,1% of the participants in that study experienced arousal incontinence at 24 months after their intervention [8], and a 2014 study where 38% of the participants had experienced arousal incontinence [9].

Most (83%) of the participants in this study reported difficulty in ***reaching orgasm (Anorgasmia)***. A total of 87,8% of the RP participants reported difficulty in reaching orgasm compared to 25% of the RT group. The majority (75%) of the RT group were unable to reach an orgasm. Of participants who experienced this NSSE, 29,5% reported being bothered by it at times while 22,7% of the participants were often or always bothered by this side effects. Similar results for RP were reported in previous studies, with high prevalence rates of 78% [10], 60,2% [11] and 57% [9] being reported. The prevalence of difficulty reaching orgasm (25%) in

RT participants in this study was similar to that of a 2017 RT study, which reported a 24% prevalence [12].

Climacturia was experienced by 28,6% of the RP group, and most (75%) of the RT group were unable to achieve an orgasm. A total of 35,8% of the participants who experienced this NSSE found it sometimes bothersome, while 22,7% were often or always bothered by this side effect. These results are similar to those reported for RP patients in a 2014 study, where 24,6% of the participants also reported climacturia [13]. Two other studies showed similar results with a 21% prevalence [14], and a 22,6 % prevalence [15]. A large 2020 study reported a 23% prevalence of Climacturia, but also a 45% bother rate, although bother was assessed by its severity, and not its frequency [16].

Orgasmic pain was only experienced by a few participants in the current study, two (4,2%) RP and one (25%) RT participants of which one (33,3%) was seldom bothered, one (33,3%) was sometimes bothered, and one (33,3%) was often bothered by this side effect. Other studies have shown higher prevalence rates among RP participants at 12% [17]; 11% [18], and 10% [9]. A 2017 RT study reported a 15% prevalence rate for orgasmic pain [12], which is lower than the results in the current study of 25%. We are however cautious with the interpretation as the current study had relatively fewer RT participants.

Anejaculation was experienced by one RT participant, and the RP participants were reminded that this was a given consequence of an RP. The RT participant that indicated that he had experienced anejaculation stated that he was never bothered by this symptom. A 2013 study investigated men following RT at 6 years after treatment and reported the prevalence rate of anejaculation to be 72% [19]. An earlier study in 2009 indicated an anejaculation prevalence rate of 18,7% [20], however, the participants in that study were assessed 36 months after their intervention. From this, we can speculate that anejaculation worsens over time for RT patients.

Penile sensation changes were experienced by 47% of the RP group and 50% of the RT group. Of the participants that experienced this NSSE, 32% were sometimes and 24% were often or always bothered by this side effect. Other studies have shown a lower prevalence of 25% in RT participants [9], and 27% in RT participants [12].

Penile length changes were experienced by 55,1% of the RP participants and 50% of RT participants in the current study. Penile length changes were overall ranked as the most bothersome NSSE. Participants experiencing this NSSE reported that 10% of them were sometimes, but 45% of participants were often or always bothered by this side effect. Not surprisingly, the bulk of the NSSE-related literature focuses on penile length shortening [2]. Similar penile length shortening prevalence in RP participants has been reported as 55% [21], 47% [9], and 39,8% [22]. A study published in 2017 on RT intervention showed similar prevalence results as our study, with 42% of their participants reporting penile length shortening [12]. It is important to note that many studies have reported that the loss in penile length is "perceived", and that most of the "loss in length" returns to normal with time [23-25].

Penile curvature changes were only experienced by participants in the RP group and reported by 10,3% of them. The majority (60%) of these men were never bothered by this, and one participant (20%) was always bothered by this NSSE. A 2014 RP study [9] reported a 10% penile curve change prevalence in their participants, and a 2010 study [26] reported a 15,9% prevalence in RT participants. A 2017 RT study [12] reported a 12% penile curve prevalence in the participants.

There is currently no published literature available in English that reports on the prevalence of the combined NSSE in PCa patients after RP and RT interventions simultaneously. Some notable studies have contributed to this field. Multiple single NSSE prevalence studies, and a few studies that cover a single NSSE across both the RP and RT approaches [2] have been published. There are however two landmark studies that combined NSSE prevalence papers by Frey et al, with the 2014 paper reporting on the RP approach [9], and the 2017 paper on the RT approach [12]. These papers yielded a few interesting comparisons and differences to our study. Penile curvature changes were 10% RP and 12 % RT in the Frey studies vs 10,3% RP and 0% RT in our study. Penile length changes were reported at 47% RP and 42% RT in the Frey studies as opposed to 51,1% RP and 50% RT in the current study. Arousal incontinences were 38% RP and 4 % RT in the Frey studies compared to 36,8% RP and 0% RT. Interestingly, the current study had double the prevalence rates of penile sensation changes, but half the prevalence rates of orgasmic pain compared to the two Frey studies.

This is the first study that has reported on the extent to which a participant group had been bothered by their NSSE after PCT, by asking participants how often they are bothered by it.

Conclusion

This study highlighted the prevalence range of the NSSE amongst a group of SA men who have undergone PCT. Difficulty reaching orgasm was highly prevalent in our study population, followed by a moderate prevalence of penile length and penile sensation changes. Climacturia was mildly prevalent in our study group, and anejaculation, arousal incontinence and penile curvature changes had a low prevalence. The most bothersome NSSE was penile length shortening and changes in penile curvature, followed closely by climacturia. NSSE screening after PCT should be done routinely, and clinicians should consider how the symptoms affect men psychologically.

List of Abbreviations

PCT: Prostate cancer treatment

PCa: Prostate cancer

RP: Radical prostatectomy

RT: Radiation Therapy

NSSE: Neglected Sexual Side Effects

SA: South Africa

Declarations

Ethics approval and consent to participate

Full ethical clearance was obtained from the University of KwaZulu-Natal, School of Health Sciences Research Committee (Biomedical Research Ethics Committee) with registration no: BREC/00000478/2019.

Consent for publications

All participants consented that the data produced from this study would be published.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author upon reasonable request.

Competing interests

None

Funding

None

Authors Contributions

All authors conceived and designed the study. All authors were involved in drafting and finalising the manuscript. All authors approved the final version to be published.

Acknowledgements

The authors would like to thank the study participants for their contribution.

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6.4 Key Findings and Contribution of the Manuscript to the Thesis

This study is the first study to explore the NSSE in an SA context, and the first study internationally to look at the multiple NSSE after different PCT approaches. This study highlights not only the NSSE after PCT prevalence, but also whether men are bothered by these specific side effects.

Anorgasmia was highly prevalent in our study population, followed by a moderate prevalence of penile length and penile sensation changes. Climacturia was mildly prevalent in our study group, and anejaculation, arousal incontinence and penile curvature changes had a low prevalence. When comparing the NSSE, the penile aesthetics issues such as penile length and penile curve changes were most bothersome to our study participants, with 21,6% of men often, and 24% of men always being bothered by their penile length shortening, and 20% of men always being bothered buy their abnormal penile curve. Climacturia also caused significant bother in our participants, with 14,3% always, 7,1 % often, and 35,8% sometimes being bothered by this side effect. Most of our participants had a RP (92,5%), so it was impossible to establish the differentiate between NSSE due to their matched treatment approach.

CHAPTER 7: PSYCHOSOCIAL IMPACT OF SD RELATED TO PC IN SOUTH AFRICAN MEN.

7.1 Introduction

The previous chapter established the prevalence rates of the NSSE after PCT in a sample of SA men. It also explored bother, and how bothersome these participants experienced the NSSE to be. This chapter reports on the psychosocial impact of SD on men who have had PCT. This part of the study explored the lived experiences of men, through a series of open-ended questions that were coded and analysed through thematic analysis. There was also a reflexive analysis component to this study, where the text references produced additional subthemes in terms of their psychosocial experiences with life after PCT.

7.2 Publication Details

Title	Psychosocial impact of sexual dysfunction related to prostate cancer treatment in South African Men.
Authors	Röscher, Pierre Van Wyk, Jacqueline M
Journal	Journal of Psychosocial Oncology
Journal Details	Open Peer Reviewed Listed on the International Scientific Indexing List (ISI)
Status	Manuscript submitted to journal

7.2.1 Journal Information

The Journal of Psychosocial Oncology is an essential source for up-to-date clinical and research material geared toward health professionals who provide psychosocial services to cancer patients, their families, and their caregivers. The journal is the first interdisciplinary resource of its kind and is in its third decade of examining exploratory and hypothesis testing and presenting program evaluation research on critical areas, including: the stigma of cancer; employment and personal problems facing cancer patients; patient education; family involvement in patient care; children with cancer; the psychosocial needs of cancer patients; hospital and hospice staff; and volunteers.

7.2.2 Manuscript Submission Details

Routledge
Taylor & Francis Group

Dear Pierre Roscher,

Thank you for your submission.

Submission ID	**235489581**
Manuscript Title	**Psychosocial impact of sexual dysfunction after prostate cancer treatment in South African Men.**
Journal	**Journal of Psychosocial Oncology**

You can check the progress of your submission, and make any requested revisions, on the Author Portal.

Thank you for submitting your work to our journal.
If you have any queries, please get in touch with WJPO-peerreview@journals.tandf.co.uk.

Kind Regards,
Journal of Psychosocial Oncology Editorial Office

7.2.3 Contribution Record

The candidate conceptualised the paper and was the main author. Prof van Wyk contributed to drafting and finalising the manuscript and supervised the study.

7.3 Manuscript

Psychosocial impact of sexual dysfunction after prostate cancer treatment in South African Men.

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Abstract

Objectives: Sexual dysfunction after prostate cancer treatment has major psychosocial implications for patients, but it is unknown what the impact is on South African men. This study aimed to explore the psychosocial impact of sexual dysfunction on South African men who had prostate cancer treatment.

Methods: Written submissions were obtained regarding the impact of sexual dysfunction from fifty-three participants and then analysed using thematic analysis.

Findings: Four themes were identified being "sexual function impact", "psychological impact", 'partner support", and "accurate information".

Conclusion: Health care professionals dealing with prostate cancer patients should be aware of the importance of screening for and including psychological care in the basket of care that are offered to patients. Communication strategies need to be inventive to ensure that men feel safe to communicate their need for psychological help.

Keywords

distress, erectile dysfunction, partner support, prostate cancer treatment, psychological impact, sexual dysfunction, survivorship, treatment regret

1. Purpose/Objectives

A diagnosis of Prostate Cancer (PCa) is a potential source of anxiety, fear, and despair amongst male patients at the start of their cancer journey [1]. Once treated, men report experiencing common disabling physical side effects that include pain, urinary incontinence (UI), and sexual dysfunction (SD) which includes erectile dysfunction (ED) [2, 3]. Physical disabilities in PCa patients are likely to drive psychological distress in patients and impact on their quality of life after their prostate cancer treatment (PCT) [4]. Of all the physical side effects, SD is the side effect that impacts on a patient's quality-of-life the most, and it is also the side effect that is most strongly associated with outcome satisfaction for patients after their PCT [5].

Amidst multiple physical and psychosocial factors, SD has been shown to be an independent predictor of both bother and depression in men after their radical prostatectomy (RP) [6]. Sexual function is inversely associated with depressive symptoms in patients after PCT [7] and this association remains evident for at least four years after the PCT, even after the correction for possible confounders [8]. Despite meticulous dissection in an attempt to preserve the neurovascular bundle during a RP, there is evidence that neurapraxia, hypoxic nerve insults, fibrosis, and apoptosis of cavernous smooth muscle are responsible for ED, causing SD in patients after PCT [9]. Unfortunately, only 30% of patients will eventually recover from ED after their RP[10]. A 2017 study showed that other non-surgical treatment approaches such as radiation therapy (RT) also present with similar side effects, but the pathophysiology is different compared to that of a RP [11]. The same study found that ED is common regardless of the treatment modality used, it increases during each year of follow-up, and it was prevelant in approximately 50% of patients at five years after their treatment.

A 2017 European study explored the SD experiences of 27 men and identified four themes that described the participants' experiences i.e., the need for accurate information, partner support, frustration with SD and psychological distress [12]. It is, however, unknown how SD impacts on the well-being of South African (SA) men who have had PCT, and whether their experiences are in any way similar to previous reported studies (12).

This study was conducted to explore the psychosocial impact of SD after PCT in SA men, through a private electronic survey, where phenomenological open-ended questions were used to explore the experiences of a specify group or participants[13].

2. Design/Research Approach

Full ethical clearance was obtained from the University of KwaZulu-Natal, College of Health Sciences Biomedical Research Ethics Committee. Participants were recruited over a period of 8 months between October 2021 to May 2022 through patient databases from i) the Cancer Association of South Africa, ii) the Prostate Cancer Foundation of South Africa, iii) the South African Urological Association and the South African Society of Physiotherapy. In person participant data collection was not considered due to restrictions related to the COVID-19 pandemic at the time. Participants were asked to complete the electronic survey hosted on a security encrypted and user-friendly survey platform Jotforms (© 2022 Jotforms Inc).

Participants were asked to complete a series of closed questions regarding their demographic information, their intervention, and the time since their intervention. In addition, they were asked three questions on depression medication and psychosocial support interventions, along with three open ended questions that are outlined in Table 1. These questions were developed by a multidisciplinary group of experts who previously published a Delphi study [14]. These questions also closely matched a previous study that explored the psychosocial aspects of SD after PCT [12].

Table 1: Patient questionnaire schedule

1	Are you currently using medication to manage depression?
2	Are you currently involved with any support groups
3	Are you currently seeing a psychologist?
4	Describe your journey with sexual dysfunction after your prostate cancer treatment
5	Describe the impact of sexual dysfunction on your life after prostate cancer treatment
6	Do you have any advice for other men who may be undergoing PCT?

The anonymity of participants was assured; they were also informed of their rights to exit the study at any stage and that they would not receive any financial incentives for their participation in the study.

3. Sample/Participants

Inclusion criteria were being SA men aged 45-75, able to speak and understand English, having had their PCT (RP or RT) in the last 1-5 years, and being sexually active prior to the PCT.

Participant characteristics and clinical characteristics are shown in table 2. A total of 61 responses were received from potential participants. Eight responses were excluded on the grounds of not meeting the selection criteria resulting in a total of 53 remaining responses that were included for final analysis.

Table 2: Participant demographics and clinical details.

Characteristic	*Number (%)*
Total number of participants	*53*
Age	
• *Range*	*52-75 years*
• *Average*	*65 years*
Racial classification	
• *White*	*49 (92,5%)*
• *Coloured*	*3 (5,7%)*
• *Black*	*1 (1.8%)*
Intervention	
• *Surgery (Radical Prostatectomy)*	*49 (92,5%)*
• *Radiation Therapy*	*4 (7,5%)*
Time Since Intervention	
• *Range*	*12-56 months*
• *Average*	*27 months*
Other	
• *Depression*	*6 (11,3%)*
• *Engaged in Support Groups*	*26 (49%)*
• *Received help from Psychologist*	*3 (5,6%)*

4. Methods/Methodological Approach

This study used a hybrid approach to thematic analysis (TA) where i) there was an early theme development due to previous research in this field (coding reliability approach) and ii) a reflexive approach was used as there was scope for codes to develop additional themes throughout the process of the interpretation of data [15]. The six phases of reflexive TA by Braun & Clarke (2006) framed the main phases to engage with the TA process[16]. Phases i-iii including text coding of the participants' responses though data extraction into NVivo (version 17.1/ © 1999-2022 QSR International Pty Ltd.) for analysis, whereafter the relevant quotes from the coded statements were then organized systematically with coding stripes represented in Appendix 1. After initial coding, the two primary coders met with a third coder to discuss and reconcile the statement coding to produce a single code book of themes with subthemes to conclude phase v (Appendix 2) according to a coding tree (Table 3).

5. Findings

5.1 Thematic Framework

The analysis of our participant transcripts allowed the separation of data into four main themes, namely i) sexual function impact, ii) psychological impact, iii) partner support and iv) accurate information (Table 3) . Under each theme, participant responses were further organised into positive, negative, and neutral responses related to the specific them. Finally, statements were organised into subthemes where applicable.

Table 3: Thematic Analysis Coding Tree

	Themes	Subthemes
1	**Sexual Function Impact**	***Negative***
		a) No function with extreme frustration
		b) Partial function with some frustration
		c) Function with assistive device or medication with frustration
		d) Function with discomfort
		Positive
		e) No Dysfunction no Impact

		f) Minimal dysfunction with assistive device g) Exploring new ways with partner ***Neutral*** h) Acceptance and avoidance
2	**Psychological Impact**	***Negative*** a) Masculinity b) Frustration, fear, and depression ***Positive*** c) Survivorship
3	**Partner Support**	***Negative*** a) Partner friction ***Positive*** b) Understanding and support c) Willingness to adapt to meet needs ***Neutral*** d) No or reduced intimacy
4	**Accurate Information**	***Negative*** a) Realistic timeframes b) Disclosure of side effects ***Positive*** a) Getting good quality information

5.2 Theme 1. Sexual Function Impact.

The most prolific theme highlighted by the participants in this study were their frustration with SD and ED, and the distress caused by these conditions. In total, 50 of the 53 participants referenced their experiences with SD, with 35 references depicting negative experiences. The responses were organised into the following subthemes:

a) No function with extreme frustration:

Most participants explored their experiences of significant frustration related to SD and described how this had affected them. *P1 Described this as "unable to engage in sexual activity" and "Very disappointing." These* participants were unable to achieve any sort of erection, and many of them just gave up trying, *such as P16 who stated, "Just gave up."*

b) Partial function with some frustration

Some participants reported some level of an erection, but this was not sufficiently firm to achieve nor maintain after penetration. *P2 said "I still manage to get erections, but it is not as firm as they used to be before the operation". It was also stated that not all erections are the same or are useful as stated by P15 "Seldom get a hard on. And when I do - it's not a real hard, hard on." P18 stated "Increasingly I find it difficult to maintain an erection after penetration."*

c) Function with assistive device or medication but some frustration.

Some participants indicated some ability to achieve an erection with the use of an assistive device and or erection enhancing medication, but still expressed frustration with the result. *P3 stated "My erection without the pump is only about half as strong as before my operation" and P5 stated "Before the removal I experienced very strong erections, however, for months and still now I am unable to gain and erection without Viagra and even then, it is not as strong as I would want. The orgasm last longer but is more difficult to reach."*

d) Function with discomfort

A few participants reported negative experiences associated with sexual activity, or function with discomfort, as indicated by *P11 "I get these spurts of urine sometimes, so we don't do that anymore." P13* also stated their experience with SD being due *to "the pain that was associated with an orgasm.*

e) No dysfunction no impact

And

f) Minimal dysfunction with assistive device

Some participants experienced little to no impact following the surgery

g) Exploring new ways with partner

Some participants reported on behavioural adaptations with their partners which enabled them to reach some sexual satisfaction such as *P21 "My partner and I have developed a way to have sex both pre the op and post that enables us both to have an orgasm almost every time."*

h) Acceptance and avoidance

In the final subtheme, some participants either reached an age where sexual intimacy did not matter as much, or they had made a firm decision to no longer attempt to engage in sexual activities. *P12 stated "If I was younger, I believe that I would be concerned" and "I have not indulged in any form of sexual activity since the radiation therapy and am unlikely to attempt it."* Another participant (*P29) stated "Decided not to engage in sexual activities."*

5.3 Theme 2: Psychological Impact

This theme described how the participants experienced psychological distress . Negative psychological impact was referenced 9 times and expressed as complete loss of confidence, distress and depression, and periods of emotional trauma though various subthemes.

a) Masculinity

In the first subtheme, some participants described the process of being emasculated and the psychological destruction due to that as described by *P1 "Being emasculated is psychologically destructive." P32 stated "I am a naturally confidant man, but this has definitely been a setback mentally."*

b) Frustration, fear, and aggression

Some participants expressed their frustrations, fear, and depression because of the PCa diagnosis and treatment such as *P5"It has been a very traumatic and emotional period" and P26 "Traumatic, loss of confidence. Feelings of depression."*

c) Survivorship

In this last subtheme, some participants expressed a sense of having overcome the cancer and celebrating survivorship. The respondents were generally grateful to be alive after having received a cancer diagnosis. *P3 stated "peace of mind that the cancer has been removed." And P23 stated "Consequences can be severe and life changing, but so would dying of prostate cancer be."*

5.4 Theme 3: Partner Support

This theme explored how participants viewed the support they received from their partners. Partner support was referenced 26 times, with 10 positive and 2 negative references being

made. Positive references referred to partner "support" and "understanding" whilst other participants referred to positive partner support in a sexual context.

a) Partner Friction

In the first subtheme, a small number of participants experienced friction with their partners after their PCT. Such as *P17 "Friction with my wife and other marital issues."*

b) Understanding and Support

The negative viewpoint in subtheme a) was in strong contrast with the rich positive descriptive statements received from multiple other respondents. Participants described the exceptional support and understanding given to them from their partners . *P27 stated "My wife has been very supporting and understanding right from the beginning" and P37 stated "My wife is understanding and accepts the new reality."*

c) Willingness to adapt to needs

Some participants expressed how their partners were willing to explore new options to meet the intimacy needs of participants such as *P21"My partner and I have developed a way to have sex", and P29 "we have fun in other ways."*

d) No or reduced intimacy

This final subtheme explored situations where partner support was not possible due to aging partners or where the partner was experiencing medical conditions themselves, and where both parties had stopped engaging intimately. *P4 stated "Partner suffers from severe dementia so sexual activity is self-help only"* and *P47 "Mostly due to me partner not being sexually active at the moment due to age."*

5.5 Theme 4: Accurate Information

This final theme explored the need for accurate information, and it was referenced 3 times in this study. These participants expressed disillusionment between the estimated recovery period given by their doctor, and the actual time needed for recovery. Participants also explored how useful it is to be aware of other critical information that can aid recovery.

a) Accurate timeframes and disclosure of side effects

In the first subtheme, participants explored their experiences with the information that medical professionals had given them with regards to recovery time, and how that had upset them when their own recovery did not match those timeframes. *P17* stated that he was told *"you will be fine in three months*" and that he felt frustrated and angered by that. *P46 stated "It would have been helpful to know that it was going to be a long journey of recovery after the operation and that I would need to live with certain limitations."P34 stated "No one told me that after my prostate was removed, I would not be able to ejaculate."*

b) Information sharing

In the second and final subtheme, participants expressed the importance of accessing good quality information to aid in the recovery process such as:

Different treatment options,

P5 stated "Choose the options offered to you wisely, they will have a lifelong impact of your life. Always get a second opinion before settling on a final decision."

The benefits of exercise

P27 stated "lose weight and be as fit as I possibly could be."

The value of support groups

P24 stated "The advantage of support groups and being able to talk about these experiences openly with like-minded people cannot be over-stated."

And finally,

The use of assistive devices

P26 stated *"Vacuum pump should be used during times of inactivity or when dysfunction sets in"*

6. Conclusions/Interpretation

Our study resonates with findings from previous research regarding experiences of sexual function frustration, psychological impact, partner support and the need for accurate information [12].

A recent study identified depression is a major challenge for PCa survivors, and up to 40% of men will experience probable depression within the first two years after their diagnosis, with this prevalence remaining stable at 5 years after their diagnosis [17]. This study also highlighted the association between treatment regret, regretting passivity in treatment decisions, and

depression, highlighting the need for shared decision making to prevent depression after PCT[18].

A 2020 study described the difference between the distress caused by ED and other forms of SD such as orgasmic pain, urinary leakage during sex and penile tissue changes [19]. That study established that men with greater sexual distress after PCT were more depressed and experienced more sexual concerns [19]. In addition, greater sexual distress leads to communication avoidance in PCa patients [19]. Shared decision making is once again emphasized, and the need for patients to be willing and brave to communicate their sexual distress and needs after PCT is essential to ensure better outcomes.

Participants in our study expressed their gratefulness for being alive and described their SD as a small price to pay i.e., sacrifice to make to survive . A study found that despite the negative impact of SD and ED, many men were able to adjust their lifestyle accordingly by demonstrating reconciliation, adaptation, and compensation for being rid of the cancer [20]. Our study also found that 49% of our respondents had engaged in PCa support groups, however men generally engage in support groups after diagnosis, and then exit 12 months later [21], with group dynamics such as demographics, meeting formats, politics and philosophy playing a role. It is unclear how Covid-19 impacted on our respondents attending support groups.

One participant mentioned having to accept the “new reality” with regards to sexual interaction and intimacy with their partner as a positive way forward. A study exploring the PCa partners’ perspective highlighted that notwithstanding the 71% experiencing a change in their sex life, that 30% of the partners expressed an improved relationships after the PCa diagnosis [22]. Interestingly, that study found that the information given to the patient and the spouse by their doctor predicted (influenced) the degree of emotional support that the spouse would eventually give to a patient. Partners provided more emotional support if the patient had more severe side effects [22]. A 2018 systematic review found that the impact and consequences of ED is often experienced vastly different between a man and his partner, and that this difference was often the source of arguments in relationships, especially when communication was compromised [20]. The same study indicated that men require physical support, emotional support and communication from their partners to cope [20].

To make accurate decisions that will affect their mortality and long-term disability, patients rely heavily on current and correct information given to them at a time when they are deciding on their PCT[23]. Apart from SD, the recovery time experienced impacted heavily on treatment regret amongst PCa patients [23]. One participant in our study revealed that they were not informed about their inability to ejaculate after their prostatectomy, a routine discussion that needs to be highlighted as a given consequence of the procedures.

Participants referred to "choosing options wisely" and the loss of erectile function even with medication use. Treatment regret in PCa patients was found to be as high as 23% in a recent study [24]. These regrets were exacerbated in those patients that had not experienced any SD before their intervention and had more severe side effects after their treatment [24]. Similar findings were reported in a systematic review, where it was shown that ED is a significant problem that men feel ill prepared for. The study also reported that men had more concerns about dealing with the psychological aspects of ED than the physical aspects of ED after receiving PCT [20]. These participants expressed that they had based their treatment options on incorrect timeframes that had been given by their doctor. Shared decision making between doctor and patient is often negatively influenced by the speciality of the doctor and their perceived preference of treatment [25]. A 2017 study showed that a patients treatment decision will usually be based on their Urologist recommendation [26]. PCa patients who are actively involved in shared decision making with their doctor, are less likely to experience treatment regret, and those who are indecisive with regards to treatment options would benefit heavily from additional counselling and support [23].

In our study population, only half of the men had engaged/joined a support group (49%). Although 11,3% of our group were being treated for depression pharmacologically, only 5,6% had sought the help of a psychologist. A previous paper has shown that some men simply do not want any support, and even though professional guidance was deemed important by them, they felt that they had received inadequate support because they were simply too embarrassed to ask for help [20].

6.1 Study Strengths and Limitations

To our knowledge, this is the first study of its kind highlighting the psychosocial impact of SD after PCT on a SA population. A strength of this study was that it allowed participants to answer questions anonymously in a safe and private environment, with no clinician bias

influencing their response. Many participants expressed gratitude for being allowed to for the first time, to be heard.

A limitation of our study is the fact that we had mostly white participants, and only a few participants were managed in the public healthcare sector, but these issues were anticipated and have been well described in the literature. The right to universal healthcare is enshrined in the SA Constitution, but reality of the state of the public healthcare system is that is does not allow for equitable access to universal healthcare by all South Africans, especially poor, uninsured black South Africans [27]. The distinctive features of the South African history with racial and income inequalities have had a long-lasting impacted on the ability for black South African to access specialised healthcare, and poor healthcare leadership and management in recent years have not done any justice to closing this gap [28]. PCa care is of particular concern in the public health sector, especially affecting black men leaving them with delayed management and advanced disease presentations, and generally poor outcomes when compared to privately funded white South African men [29, 30].

This study took place during the peak of the COVID -19 pandemic, which may have affected representative participation from different social and racial groups. Our population sample also heavily favoured RP patients, and these patients are typical managed in private health care facilities driven by expensive surgery and clinician preference, but this trend has been noted in other similar papers [12]. Our study only included English speaking participants, so we have not captured the cultural aspects of SD of all South Africans.

7. Implications for Psychosocial Providers and Future Research

This study has important clinical practice implications as it highlights the need for clinicians to focus more on the patient perspective by understanding not only the physical but also the psychological implications of SD [31]. There is a need to push for the continual shift of the standard PCa care model post-intervention to include not only the "bio", but also the "psychosocial" aspects of healthcare. HCP should ensure that appropriate support interventions are in place for men who have undergone PCT [20], regardless of whether they are able to offer these interventions themselves. Communication strategies to gain adequate information from patients should evolve and strive to allow patients to raise their SD concerns in a safe and private environment. Future research should aim to gain the psychosocial perspective of different racial groups including black men and should also include populations that have only received RT as an intervention.

Consent for publications

All participants consented that the data produced from this study would be published.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

None

Funding

None

Authors Contributions

All authors conceived and designed the study. All authors were involved in drafting and finalising the manuscript. All authors approved the final version to be published.

Acknowledgements

The authors would like to thank the study participants for their contribution.

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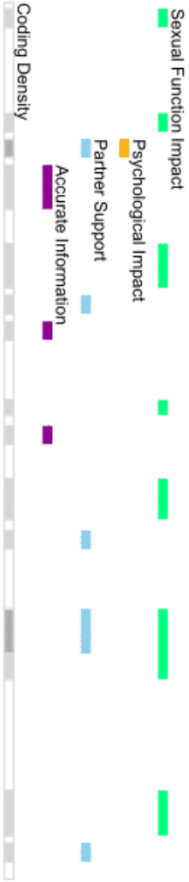
Question 1: Please describe your journey with sexual dysfunction after prostate cancer treatment? **Question 2: How has sexual dysfunction impacted your life after your prostate cancer treatment?** **Question 3: Do you think that there is anything else that other people who are going through prostate cancer treatment should know?** **P= Participant** **I, ii, iii = answers to questions i-iii**		
P1		
	i	Unable to engage in sexual activity. VERY DISAPPOINTING.
	ii	BEING EMASCULATED IS PSYCOLOGICALLY DESTRUCTIVE
	iii	IT'S TOO EARLY FOR ME TO COMMENT.
P2		
	i	In the first 3 months, erections were achieved with a penis pump. Sensation or sensitivity was enhanced with the fact that I took Cialis. After about 3 months, I was able to get erections on my own without the assistance of the pump (still using Cialis). I'm currently still making use of a combination of the 2 approaches.
	ii	I expected it to be worst. I'm currently still using Cialis daily which I think helps with the sensitivity feeling. I still manage to get erections, but it is not as firm as they used to be before the operation.
	iii	I was personally afraid of the bladder control, but I adjusted very quickly. Maybe not everyone is as lucky as I was. This was one of my biggest fears, which in the end is not a problem anymore. Bladder control was something that I had to get used to (had 1 or 2 accidents while sneezing, coughing, or bending down), hut currently I have very good control and almost no more accidents. In summary, you start realising how amazing the human body is and how you eventually adjust to your new circumstances.
P3		
	i	My erection without the pump is only about half as strong as before my operation.
	ii	Yes, to a small degree but this is a small price to pay for the peace of mind that the cancer has been removed. At my age sexual activity while important is not as important as showing affection in other ways.
	iii	Yes, firstly the work with my Physio both before and after the operation was so important both for my mental preparation and physical afterwards (incontinence etc) My advice is do your research beforehand to choose a skilled surgeon who is expert in Da Vinci robotic surgery and a physiotherapist who specialises in this field. I took my partner to all consultations with the urologist/surgeon who was excellent and explained every part of the journey so well. I am extremely happy with the results especially since I am a very active person fitness wise etc and have resumed a normal life with no pads etc.
P4		
	i	Partner suffers from severe dementia so sexual activity is self-help only
	ii	Very little
	iii	Good to know that it is not the end of the road for sexual activity
P5		
	i	It has been a very traumatic and emotional period. Before the removal I experienced very strong erections, however, for months and still now I am unable to gain and

	erection without Viagra and even then, it is not as strong as I would want.
ii	Self-confidence around woman is not at all good.
iii	Choose the options offered to you wisely, they will have a lifelong impact of your life. Always get a second opinion before settling on a final decision.
P6	
i	No erections and leaks
ii	100%
iii	Even if you know, you can never be prepared..... its a long journey
P7	
i	Partner unwilling to participate
ii	Completely
iii	No
P8	
i	N/A
ii	N/A
iii	Exercise beforehand.
P9	
i	My sex life deteriorated from about age 70 until it was almost non-existent by the time, I had my prostrate removed. so, perhaps having my prostrate removed had no effect
ii	I don't think it has affected my life at all. I have a very understanding wife who puts no pressure on me.
iii	No
P10	
i	No sexual dysfunction.
ii	Thanks to Dr ... who spared the nerves in the operation.
iii	Once the Prostate Cancer has been detected. Have the RALP operation as soon as possible so that the nerves can be saved. This will help sexual functionality after the removal of the prostate.
P11	
i	I have struggled before i had PC, so my partner has not been surprised about the outcome. I used to take tablets, which she does not want me to do, and I feel flushed when I take them, so not a comfortable feeling. Being on all these tablets does not help, so it has got worse, but I don't believe because I had my prostate removed.
ii	It has impacted, because when I can't get a proper erection, we have to resort to oral sex, which my partner does not like, because i get these spurts of urine sometimes, so we don't do that anymore. I end up masturbating a lot as I have been told " use it or lose it" and right now I don't want to lose it. What worries me is if I had to find a new partner, she could be chased away because of my condition, so i fear this. One positive, when i had a swollen prostate when i reached orgasm, it felt very tender. Now with no prostate when I reach orgasm, it's feels like a " packman" moving around inside looking to eat whatever, this is a wonderful feeling.

	I have told people about this, and they think I am crazy. And then in 10 minutes I am ready again, because there is no tender after feeling.
	iii I think everyone is different, try to have a positive mind and believe you will be okay. People frown upon masturbation, but 2 doctors and a therapist have told me to keep doing it to keep your sex life alive. If you can't have enough with a partner one needs to do it yourself, don't be shy to ask your doctor.
P12	
i	My wife lost interest in sex many years ago, which I found to be very frustrating. However, I made peace with that and adapted my sexual activities to suit. I no longer badger my wife about our lack of intimacy. Now after starting a hormone inhibitor, it does not really matter.
ii	If I was younger, I believe that I would be concerned. Sex is no longer part of my life, and it does not really bother me. I have not indulged in any form of sexual activity since the radiation therapy and am unlikely to attempt it.
iii	I wrote a two-page story about my ordeal for my friends and supporters and anyone else who could benefit from it. This is an excerpt from that: "Do not to fall into my complacency trap. Advanced prostate cancer cannot be cured. It can only be controlled. If it does grab you by the boo boo deal with it sooner than later. You must have faith in your God, your doctors, your family, your friends and above all, your ability to endure and overcome this ordeal. Your attitude is contagious. Be aware that family and friends are very much affected. It exacts a tremendous toll on spouses and children. You need to be informed and you are entitled to straight answers. Be wary of Dr Google. Self-diagnosis can be very disturbing. Rather ask questions of those who know what they are talking about. Oncophobia is very real. You must deal with it. Do not to let it get the better of you. Your imagination can run wild, especially in the lulls between events. Don't suffer alone, no one is dishing out medals for bravery. You will find that there is an enormous amount of support out there. Keep an open mind. Take comfort from whatever source you can find, even if it surprises you. I found that if I talked about the problem things became a bit clearer in my head. I wish I had listened to that advice before. I might have avoided some disastrous episodes in my life. Writing a story is even better for me. I put the words down on paper and massage them until they make sense."
P13	
i	The main impacts of the treatment on sexual activity were the pain associated with orgasm/ejaculation and the impact on erectile function. Medication (Cialis) has addressed the erectile challenges in the main, but there is still pain with ejaculating
ii	It has impacted my sex life in that I now need medication to get an erection and there is still pain involved when ejaculating
iii	No
P14	
i	I have been lucky. My sexual function has not changed much because both nerves were saved. There have only been a few occasions when I struggled to reach organism.
ii	Not much.
iii	Remain strong in the head; exercise and maintain bodily fitness.
P15	
i	Seldom get a hard on. And when I do - it's not a real hard, hard on
ii	Definitely impacted my sex life - My wife and I now have a very reduced sex life
iii	Be thankful you are alive
P16	

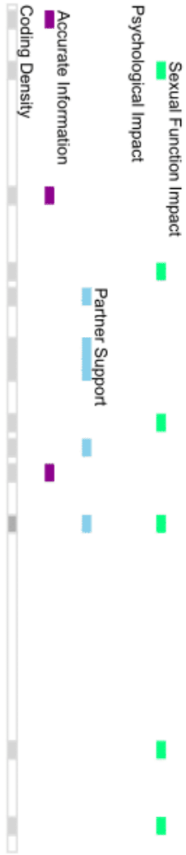
	i	Just gave up. But then sexual activity was never of high importance prior to my prostatectomy
	ii	Zip – nothing
	iii	Depends on how sexually active they were pre prostatectomy
P17		
	i	Unable to achieve, and sexual activity and have given up trying. Not a good state to be in.
	ii	Depression, friction with my wife and other marital issues.
	iii	Is not as easy as the Urologists and the Oncologists make it out to be. There, you will be fine in three months is a load of rubbish and leads to further frustration and depression later.
P18		
	i	Can achieve erection and orgasm through masturbation without problems and sometimes through sexual intercourse. However, increasingly I find it difficult to maintain an erection after penetration.
	ii	Less sexual relations with my wife.
	iii	That Viagra type medications are sometimes ineffectual.
P19		
	i	Time it took after prostatectomy to have sexual activity with partner. No penile rehabilitation treatment prescribed after prostatectomy.
	ii	Minimal effect.
	iii	Adequate information upfront about different prostate cancer treatment options, pro- and-cons on quality of life.
P20		
	i	I have been fortunate; I achieved a non-spontaneous erection within the first 2 months. I now have partial spontaneous erections after a year. I use a penis ring to achieve and maintain s full erection.
	ii	Not very much at all. I had a very good physiotherapist that guided my wife and I through the process.
	iii	Our RALP Forum in the Western Cape has been very informative.
P21		
	i	My partner and I have developed a way to have sex both pre the op and post that enables us both to have an organism almost every time. Might not be the sex I had in my 30s, but it works for us!! Also, after the op my climax is longer and more enjoyable!
	ii	Not a lot
	iii	I'm sure there is but it seems that everyone reacts differently. Only advise is, don't be in a rush to sort everything out from your incontinence to your sexual activity. Be patient and allow your body and mind to adjust.
P22		
	i	I have total erectile dysfunction and a smaller flaccid penis. As matters stand (no pun intended as you will understand), I'm not keen to use 'assistance' and my levels of desire seldom reach levels which are problematic. I can only achieve orgasm through fairly difficult manual efforts!
	ii	I have been married for 41 years and I'm approaching 69 years of age. I've had a very satisfactory sex life and my wife, and I are not unhappy to um....'let things lie'?



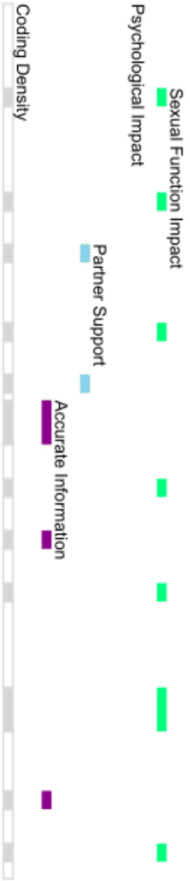
	If this changes, I'll only consider the vacuum pump approach. The needle and the tablets really don't do it for me.
iii	Anything else? There is so much they should know and consider. Not least that not having the ability to have an erection or having ongoing dribbles are not the end of the world. I operate a little support group off a larger group of those who have had successful prostatectomies, for those like me, who are either on 'further treatment' or have to consider further treatment. It is scary how little 'the patient knows' about the possible consequences - medium and long term - of treatment such as radiation. Prostate cancer sufferers should be speaking to oncologists far sooner than they do. Urologists have this strange idea that in the expression 'prostate cancer', it is the prostate which is the important bit. Not at all. What we hear is 'cancer' - and cancer is the preserve of the oncologist...
P23	
i	It has been severe. At present I try not to think about it much.
ii	Has impacted a great deal. I focus on other aspects. Have continued to work. This may require a new approach when I retire finally in May 2022.
iii	Consequences can be severe and life changing, but so would dying of prostate cancer be.
P24	
i	Having had the RALP procedure it took a lot of effort to regain erections and (dry) orgasms, but now after 4 years, I believe that my sexual activity is normal, if not slightly better than it may have been at my age had I not put in so much effort!
ii	I do still fear 'failure', so usually take Viagra (Dynafil, 50mg) just to achieve a greater level of self-confidence.
iii	The advantage of support groups and being able to talk about these experiences openly with like-minded people cannot be over-stated.
P25	
i	I had a unilateral op, and nerves were only spared on one side. As a result, an erection is almost impossible to achieve. A vacuum pump didn't really work satisfactorily. Nor Viagra type tablets. I can achieve a weak orgasm with masturbation, but not easy. Penis injection work up to a point and I have persevered and tried different dosages. I live in hope! My women partner is open to all the methods and is open and understanding. Damn, I miss erections, and ejaculations.
ii	See above. But hey, I am healthy, happy, and don't get too bogged down about sexual dysfunction. Yet I miss it!
iii	Can't think now. I have shared my story with a few blokes. Typed up a summary. I feel that there is SO MUCH that can be shared. I wish that some researcher would ask questions about the psychological aspects. I am talking post the RALP op.
P26	
i	Up and down. Long periods of dysfunction following treatment, improving with time.
ii	Traumatic, loss of confidence. Feelings of depression
iii	Vacuum pump should be used during times of inactivity or when dysfunction sets in
P27	
i	In the beginning I had to use Viagra to get a lasting erection. After about 2 years the meds was no longer necessary. To help get a stronger and longer lasting erection I found a vibrating penis ring. I have been using it for the past 4 years. My wife has been very supporting and understanding right from the beginning. Without her I am sure my journey would have been much more challenging and bad.
ii	After 9 years I can safely say that I have no worse than any man of 67 years of age
iii	The best advice my urologist Dr .... gave me, when the cancer diagnosis was made, was to lose weight and be as fit as I possibly could be. At the time of my operation that took 367minutes, I was very fit and only about 5kg overweight. My fitness and other health had a very positive effect on my recovery.

	The other very important factor was that my wife engulfed me in positive information and environment. She did not allow contact with negative information or negative conversation
P28	
i	Can't get an erection.
ii	Not really.
iii	No
P29	
i	Penetrative intercourse is not possible, but we have fun in other ways. I have not tried any form of treatment for erectile disfunction
ii	Definitely less fulfilling, but First prize was life,
iii	Adopt the attitude that 1st prize is life. Anything else is a bonus.
P30	
i	I have a very patient and understanding wife. Decided not to engage in sexual activities until after i -have completed all my treatments Will revisit this aspect of our relationship next year sometime
ii	As above
iii	Patience
P31	
i	ED has caused some interference which has led to lower libido
ii	As mentioned, lower libido but trying to work on it. Using Vacurect for rehabilitation and hoping all will improve as desire is still there.
iii	Think it is very individual, but support group helps.
P32	
i	I was single so resorted to masturbation which allowed me to achieve orgasms. Now I have a partner who is understanding. The single biggest problem in my mindset and disappointment with my body.
ii	A lot, I am a naturally confidant man, but this has definitely been a setback mentally. I also do physically train a lot at gym, but it requires very hard work to get rid of belly fat and man boobs.
iii	Yes, the physiological impact that it has.
P33	
i	No sexual function after operation. Cialis has helped and now have about 50% erection. Urologist wants to try injections which I am considering
ii	Having sex without penetration
iii	Yes, the impact on bladder control and erectile dysfunction.
P34	
i	Frustrating.
ii	Not really affected my life.

iii	No one told me that after my prostate was removed, I would not be able to ejaculate.
P35	
i	I had nerve sparing surgery and my sex life is back to normal. I'm 56 and have no problems getting an erecting, having, and enjoying sex. Most mornings I still wake up with erections. I lost a bit of sensation and have weaker organism but still a very satisfying sex life. I'm most fortunate
ii	Very, very little.
iii	I had no symptoms but was diagnosed at 53 as an otherwise healthy fit individual. With nerve sparing robotic surgery I recovered really quickly, and it has had little impact on my life. Feel most grateful to have discovered it early and the decision to have it removed by doctors with the equipment and skill to do such an excellent job and give me such great care. I got very good advice on exercises to prepare myself for surgery. I had sex 6 days after my op and have never had problems with leaks. I'm very fortunate.
P36	
i	I take Cialis daily and have no sexual dysfunction
ii	Not at all. My wife has been fantastic in her participation. I have normal sexual intercourse but not at the same level as before my operation, although very satisfactorily. My penis is not as erect nor for as long as before the operation.
iii	If they plan to have intercourse after treatment they need the full participation, buy-in and commitment from their partners/spouses. That is vital in continuing to enjoy a healthy sexual relationship.
P37	
i	Since having the RALP,my sexual function is very weak and not improving/ I have total erectile dysfunction. Achieving an orgasm is a problem and then very weak.
ii	My wife is understanding and accepts the new reality.
iii	Yes. I feel strongly that Oncologists should become involved in the treatment regime from the word go. It should not be the sole preserve of the urologist.
P38	
i	It's more difficult to reach orgasm with penetrative sex, but my partner and I are very creative with toys as well as mutual oral sex and it is always mutually satisfying. It took about a year of persevering to get back to regular routine and some days we even have sex twice.
ii	Fortunately, not, but it was a worry for a while. I found that after I was diagnosed and my biopsy, I only had RALP 6 months later, and being off my libido and on antidepressants made orgasm and sex very difficult.
iii	Make sure that you don't have sleep apnoea, as this can affect your testosterone levels. See an endocrinologist to check your testosterone and other hormones. See the physio before and after your operation and do the Kegels. If your partner doesn't enjoy oral sex, then maybe she can learn from watching porn movies with you. Same goes for you! You have to get down, to get down!
P39	
i	Only require a little more mental preparation, otherwise not really dysfunctional
ii	Not really much in terms of dysfunction, but a weak erection when talking comparatively, but not problematical.
iii	The Robotic (RALP) option is quite miraculous and, in my case, highly (100%) successful. Only issue being the Hospital levy(!) over and above Medical Aid.
P40	
i	No problems



	ii	No
	iii	No
P41		
	i	Inability to achieve an erection. Orgasm only with enormous difficulty.
	ii	Still experience arousal but often unable to address it
	iii	Every one's journey seems different. Knew erectile dysfunction may be a problem but hoped for the best
P42		
	i	I am with the same partner and after the operation it seems sex is no longer an option as my libido is almost non-existent and we simply have written off sexual activity for that reason.
	ii	Hardly at all. I am still with my original sexual partner but there is no longer sexual activity.
	iii	Don't rush into radiation if the PSA reading is still a little elevated. It might not be significant, and the effects of radiation might not be worth going through.
P43		
	i	My sexual activity has definitely waned, but age is also a factor and not unexpectedly our sexual activity is "occasional". I do not get as much satisfaction from orgasm as before the operation, but again age (and waning testosterone levels?) is probably a factor.
	ii	No really, we have been married a long time and both of our sexual desires have waned.
	iii	I think that the age at which one has the PC treatment should form part of the advice given to patients - expectations of recovery of full sexual activity are not realistic in the aged patient.
P44		
	i	Do not believe I have experienced dysfunction after the operation
	ii	No, it has not.
	iii	It is a process and if you follow the steps you are given by the Physio then you should be a lot better prepared for life after the operation.
P45		
	i	Less sensation in the penis due to a partial nerve sparing prostatectomy. This has not been bad for my partner and me.
	ii	Not really.
	iii	The sooner you get treatment the better. I have no life changing side effects.
P46		
	i	I naively expected that it would not be long after my robotic prostatectomy and I would be back to normal. However, after 2,5 years there is no such thing as a spontaneous erection, and I am still dependent on medication for erectile dysfunction. I have had to accept that this is the 'new normal.'
	ii	There is a sense of loss since my erectile function is not what it used to be. I try to balance this with an appreciation of the fact that my prostate cancer has been dealt with.
	iii	It would have been helpful to know that it was going to be a long journey of recovery after the operation and that I would need to live with certain limitations.
P47		
	i	Due to partial destruction of my nervous system, the recovery has been slow.



ii	Yes - only had intercourse once since operation, but that is hopefully going to increase. Mostly due to me partner not being sexually active at the moment due to age.
iii	They should not hesitate to do the REALP operation even if Gleeson scores are low.
P48	
i	I have reasonable erections for penetrative sex. But I choose to be content with this physiological change in my body.
ii	The Impact is Negligible
iii	Positive mindset and a Christian values-based existence.
P49	
i	Libido/arousal is very low and sometimes difficult to achieve without lots of stimulation from pornography The orgasm last longer but is more difficult to reach
ii	After 18 months I'm still not able to achieve an orgasm with my partner.
iii	It's a challenge... and EVERYTHING needs to be discussed and tried. I think support groups are VERY important to share information and experiences.
P50	
i	Extremely disappointed to learn post-op that no nerves were spared during the RP procedure.
ii	Frustration / Depression.
iii	To accept one's fate and focus on the positives of being alive and that it was diagnosed in time.
P51	
i	Loving relationship with my wife. She is a wonderful partner who has supported and helped. Gradual reduction in the usage of Dynafil (now down to occasional 25mg usage)
ii	Minimally
iii	For sexual functionality, don't give up.
P52	
i	Before treatment I was using Viagra 100mg with total success. After treatment and getting worse, erection does not last long enough to achieve orgasm, usually move to oral sex to achieve orgasm. Occasionally this doesn't achieve orgasm, so I masturbate to achieve it.
ii	The experience I have as mentioned above, my sexual self-confidence is now less. A supportive partner helps with this matter though.
iii	No.
P53	
i	For the first 6 weeks I thought I was going to be OK. Then from Month 2 to about Month 10 I had fairly complete erectile dysfunction. I still had plenty of libido and slowly learned to get help from VED, Manta, and masturbation. My wife was very supportive, and we learned to be sexual without be having an erection which was awkward but ultimately very satisfying. Since about Month 11 I have occasionally been able to engage in penetrative sex, usually with help of VED and/or cock ring and/or Viagra. Since 18 months, a few times we have been able to have mutually orgasmic penetrative (PIV) sex with no external help at all.
ii	At first it was very depressing, and I felt bewildered. I found lots of non-sexual outlets for the energy that couldn't emerge sexually. It was also lonely. Then I learned to

	be sexual in new ways, joined and built support networks, and learned to communicate very openly with my wife about the changes going on in my body. I had to ask for what I want with this new body and she and I both had to get used to the changes. Overall, I would say the impact has been difficult, but positive.
iii	How to get into support groups. How to get pelvic floor physiotherapy. How to get a VED and more importantly, coaching in how to use it and how to introduce it into the bedroom. Encouragement to get couples counselling/sex therapy. A roadmap of typical recovery pathways and recognisable milestones. For at least a year I had no idea if I was on track for recovery or not.

Sexual Function Impact
Psychological Impact
Partner Support
Accurate Information
Coding Density

Appendix 2: Participant Responses according to TA.
See Appendix 1 for the full table of responses.

	Negative	Subthemes	Positive	Subthemes	Neutral	Subthemes
Theme 1: Sexual Function Impact	**Subtheme 1: No function with extreme frustration.** **Subtheme 2: Partial function with some frustration.** **Subtheme 3: Function with assistive devices or medication with some frustration.** **Subtheme 4: Function with non rewarding result/ discomfort**		**Subtheme1: No dysfunction, no impact** **Subtheme 2: Minimal dysfunction with assive device and or medication** **Subtheme 3: New ways with partner**		**Subtheme 1: Acceptance or avoidance**	

	P1. Unable to engage in sexual activity. VERY DISAPPOINTING.	1	P4. Very little	1	P12. If I was younger, I believe that I would be concerned. Sex is no longer part of my life, and it does not really bother me. I have not indulged in any form of sexual activity since the radiation therapy and am unlikely to attempt it.	1
	P2. I still manage to get erections, but it is not as firm as they used to be before the operation.	2	P9. I don't think it has affected my life at all.	1	P29. "Decided not to engage in sexual activities"	1
	P3. My erection without the pump is only about half as strong as before my operation.	3	P10. No sexual dysfunction.	1		
	P5 Before the removal I experienced very strong erections, however, for months and still now I am unable to gain and erection without Viagra and even	3	P14. I have been lucky. My sexual function has not changed much because both nerves were saved. There have only been a few occasions when I struggled to reach organism.	2		

	then, it is not as strong as I would want.						
	P6. No erections	1	P19. “Minimal effect”.	2			
	P7. Completely	1	P20. “I have been fortunate; I achieved a non-spontaneous erection within the first 2 months. I now have partial spontaneous erections after a year. I use a penis ring to achieve and maintain s full erection”.	3			
	P11. It has impacted, because when I can’t get a proper erection, we have to resort to oral sex, which my partner does not like, because i get these spurts of urine sometime s, so we don’t do that anymore.	4	P21. “My partner and I have developed a way to have sex both pre the op and post that enables us both to have an organism almost every time. Might not be the sex I had in my 30s, but it works for us!! Also, after the op my climax is longer and more enjoyable”!	2			
	P13. The main impacts of the treatment on sexual activity were the pain associated with	4	P24. “I believe that my sexual activity is normal”	2			

	orgasm/ejaculation and the impact on erectile function.						
	P15. Seldom get a hard on. And when I do - it's not a real hard, hard on	2	P27. "In the beginning I had to use Viagra to get a lasting erection. After about 2 years the meds was no longer necessary. To help get a stronger and longer lasting erection I found a vibrating penis ring. I have been using it for the past 4 years".	3			
	P16. Just gave up.	1	P35. "my sex life is back to normal"	1			
	P17. Unable to achieve, and sexual activity and have given up trying. Not a good state to be in.	1	P36. "have no sexual dysfunction"	1			
	P18. "Increasingly I find it difficult to maintain an erection after penetration".	2	P40. "No problems"	1			
	P22. "I have total erectile dysfunction and a smaller flaccid penis. As matters stand (no pun intended as you will understand), I'm not keen to use 'assistance' and my levels of desire seldom reach levels which	1	P44. "Do not believe I have experienced dysfunction after the operation "	1			

	are problematic. I can only achieve orgasm through fairly difficult manual efforts”!						
	P23. “It has been severe. At present I try not to think about it much.	1	P48. “The Impact is Negligible”	1			
	P25. “… an erection is almost impossible to achieve”	1					
	P26. “Long periods of dysfunction following treatment”	1					
	P28. “Can’t get an erection”	1					
	P29. “Penetrative intercourse is not possible “	1					
	P31. “ED has caused some interference “	1					
	P33. “No sexual function after operation”.	1					
	P34. “Frustrating”.	1					
	P37. “My sexual function is very weak and not improving/ I have total erectile dysfunction”.	1					

	P38. “It’s more difficult to reach orgasm with penetrative sex”	2					
	P39. “a weak erection when talking comparatively”	2					
	P41. “Inability to achieve an erection. Orgasm only with enormous difficulty”.	2					
	P42. “…it seems sex is no longer an option”	1					
	P43. “My sexual activity has definitely waned”	2					
	P45. “Less sensation in the penis”	1					
	P47. “The recovery has been slow”	1					
	P49. “Libido/arousal is very low and sometimes difficult to achieve without lots of stimulation from pornography. The orgasm last longer but is more difficult to reach “	2					
	P50. “Extremely disappointed to learn post-op that no nerves were spared during the RP procedure”	1					

	P52. "…erection does not last long enough to achieve orgasm" P53. "I had fairly complete erectile dysfunction"	2 1				
Theme 2: Psychological Impact	**Subtheme 1: Masculinity** **Subtheme 2: Frustration, fear and depression**		**Subtheme 1: Survivorship**			
	P1. "BEING EMASCULATED IS PSYCOLOGICALLY DESTRUCTIVE" P5. "It has been a very traumatic and emotional period." P11. What worries me is if I had to find a new partner, she could be chased away because of my condition, so I fear this. P12. "My wife lost interest in sex many years ago, which I found to be very frustrating. However, I made peace with that and	1 2 1 2	P3. "peace of mind that the cancer has been removed." P23. "Consequences can be severe and life changing, but so would dying of prostate cancer be."	1 1	P2. "I expected it to be worst. "	

	adapted my sexual activities to suit. P17. “Depression, friction with my wife and other marital issues.” P26. “Traumatic, loss of confidence. Feelings of depression” P32. “I am a naturally confidant man, but this has definitely been a setback mentally.” P50. “Frustration / Depression.” .	2 1 and 2 1 2				
Theme 3 **Partner Support**	**Subt-theme 1: Partner friction.**		**Subtheme 1: Understanding of situation** **Subtheme 2: Understanding and Support** **Subtheme 3: Willingness to adapt to meet needs**		**Subtheme 1: No or reduced intimacy**	
	P7. “Partner unwilling to participate”		P9. “ I have a very understanding wife who puts no pressure on me.”	1	P4. “Partner suffers from severe dementia so sexual activity is self-help only”	1

	P17. “friction with my wife and other marital issues”		P20. “guided my wife and I through the process”	2	P11. “If you can’t have enough with a partner one needs to do it yourself ”	1
			P21. “My partner and I have developed a way to have sex both pre the op and post that enables us both to have an organism almost every time. Might not be the sex I had in my 30s, but it works for us!!”	3	P12. “I no longer badger my wife about our lack of intimacy.”	1
			P22. “I’ve had a very satisfactory sex life and my wife, and I are not unhappy to um....’let things lie “	1	P15. “My wife and I now have a very reduced sex life”	1
			P27. “My wife has been very supporting and understanding right from the beginning. Without her I am sure my journey would have been much more challenging and bad.”	2	P18. “Less sexual relations with my wife.”	1
			P29. “we have fun in other ways”	3	P42. “I am still with my original sexual partner but there is no longer sexual activity.”	1

			P30. “I have a very patient and understanding wife.”	1	P43. “we have been married a long time and both of our sexual desires have waned.”	1
			P32. “I have a partner who is understanding.”	1	P47. “Mostly due to me partner not being sexually active at the moment due to age”	1
			P36. “If they plan to have intercourse after treatment they need the full participation, buy-in and commitment from their partners/spouses. That is vital in continuing to enjoy a healthy sexual relationship. “	3	P49. ‘still not able to achieve an orgasm with my partner.”	1
			P37. “My wife is understanding and accepts the new reality.”	1		
			P38. “my partner and I are very creative with toys as well as mutual oral sex and it is always mutually satisfying”	3		
			P51. “Loving relationship with my wife. She is a	2		

			wonderful partner who has supported and helped." P52. "A supportive partner helps with this matter though." P53. "My wife was very supportive, and we learned to be sexual without be having an erection which was awkward but ultimately very satisfying."	2 3		
Theme 4: Accurate Informati on	**Subtheme 1: Realistic timeframes** **Subtheme 2: Disclosure of side efefcts**		**Getting good quality information**			
	P17. "It's not as easy as the Urologists and the Oncologists make it out to be. There, you will be fine in three months is a load of rubbish and leads to further frustration and depression later."	1	P3. "do your research beforehand to choose a skilled surgeon"	1	P22. "It is scary how little 'the patient knows' about the possible consequences - medium and long term"	

	P34. “No one told me that after my prostate was removed, I would not be able to ejaculate.”	2	P5. “Choose the options offered to you wisely, they will have a lifelong impact of your life. Always get a second opinion before settling on a final decision.”	1	P37. “I feel strongly that Oncologists should become involved in the treatment regime from the word go. It should not be the sole preserve of the urologist.”		
	P46. “It would have been helpful to know that it was going to be a long journey of recovery after the operation and that I would need to live with certain limitations.”	1	P8. “Exercise beforehand.”	2	P44. “It is a process and if you follow the steps you are given by the Physio then you should be a lot better prepared for life after the operation.”		
			P11. “don’t be shy to ask your doctor.”	1			
			P12. “You need to be informed and you are entitled to straight answers. Be wary of Dr Google. Self-diagnosis can be very disturbing. Rather ask	1			

			questions of those who know what they are talking about."				
			P14. "exercise and maintain bodily fitness."	2			
			P18. "That Viagra type medications are sometimes ineffectual."	4			
			P19. "Adequate information upfront about different prostate cancer treatment options, pro- and-cons on quality of life."	1			
			P24. "The advantage of support groups and being able to talk about these experiences openly with like-minded people cannot be over-stated."	3			
			P26. "Vacuum pump should be used during times of inactivity or when dysfunction sets in"	4			
			P27. "lose weight and be as fit as I possibly could be"	2			
			P31. "support group helps"	3			

			P35. “I got very good advice on exercises to prepare myself for surgery.”	2			
			P43. “I think that the age at which one has the PC treatment should form part of the advice given to patients - expectations of recovery of full sexual activity are not realistic in the aged patient.”	1			
			P49. “EVERYTHING needs to be discussed and tried. I think support groups are VERY important to share information and experiences.”	3			
			P53. “How to get into support groups. How to get pelvic floor physiotherapy. How to get a VED and more importantly, coaching in how to use it and how to introduce it into the bedroom. Encouragement to get couples counselling/sex therapy. A roadmap of typical recovery pathways and recognisable milestones. For at least a year I had no idea if	3			

			I was on track for recovery or not.”			

7.4 Key Findings and Contribution of the Manuscript to the Thesis

This study describes the psychological impact that SD had on men who had PCT. Our participants were asked to answer three open ended questions that related to their experienced with SD after their interventions for PCa. Participant responses were coded and matched to themes that developed through TA. These themes were i) sexual function impact, ii) psychological impact, iii) partner support, and iv) accurate information. Additional subthemes were explored within each main theme. Our study showed that men experienced major psychosocial events after their PCT that included distress, mourning the loss of sexual function, depression, frustration, anger and in some cases loss of intimacy and support from their partners. Shared decision making between patient and doctor, and unconditional partner support suggested less treatment regret and outcome satisfaction. We also asked our study group to indicate whether they had been treated for depression, and whether they had used support groups or sought advice from a mental HCP. Half of our study population (n=26) had engaged in support groups while only 6 participants were being medicated for depression and only 3 participants had accessed help from a psychologist. Most participants had experienced some degree of psychosocial distress and bother due to their SD.

CHAPTER 8: SYNTHESIS

8.1 Introduction

This chapter summarises the findings that were included in the manuscripts and illustrates how each research question had been answered. The aim of this study was to explore the prevalence of the NSSE after PCT and its impact, to determine how the NSSE after PCT are detected, to create an appropriate NSSE after PCT screening tool, and to apply it on to a specific population of SA men. The main conclusions are drawn, and the recommendations will be discussed in this chapter. The novelty, limitations of this study and the significance of the study will also be discussed.

8.2 Summary of Objectives and Main Findings

In this study of the NSSE after PCT, the aim of this study was to collect the best clinical evidence to inform prevalence rates, assessment methods, and its impact on men after PCT.

This study was based on the following core assumptions that underpinned this study:

1. Men who have PCT experience physical and non-physical side effects, but psychosocial aspects of health and wellbeing are often neglected
2. PCT options are often only discussed with the biomedical model in focus, neglecting the “psycho” and "social” determents of health and wellbeing. There is a need to strengthen the bio-psycho-social model of healthcare in PCT care.
3. SD is the physical and emotional side effect after PCT that impacts on QOL the most in men, and men struggle with the long-lasting psychological impact of SD.
4. Men often do not communicate their SD concerns (whether physical or non-physical) to their HCP
5. Understudied and under reported SD symptoms have been identified as the NSSE after PCT.
6. The NSSE are i) arousal incontinence, ii) anorgasmia, iii) climacturia, iv) orgasmic pain, vi) anejaculation, vii) penile sensory changes, viii) penile length shortening and ix) penile curvature changes.
7. The prevalence and impact of the NSSE after PCT in SA men are unknown.

8. The NSSE could be detected by a HCP, or a survivor may even be able to use a QBST themselves , but there is currently no such tool available for self-screening.
9. Greater awareness of the NSSE amongst HCP is needed and having a QBST readily available could assist men who have had PCT to be managed better and sooner, reducing the long terms physical and psychological consequences they may face.

This study followed an exploratory, sequential quanti-quali mixed methodology design with each phase informed and dependant on the previous stage. It collected both qualitative and quantitative data. Using both qualitative and quantitative methods health sciences allow for an approach that is not only robust in its statistical data, but also rich in qualitative information that describes concerns and impacts on SD a population.

Contributions of Manuscript and Alignment to Research Objectives

Table 4 displays a summary of the research questions and manuscripts produced to answer each research question. It provides a summary of the implications of the results and findings towards the overall thesis.

Table 3: Contributions of Manuscripts and Alignment to the Research Objectives

No	Objectives	Manuscript	Implications
1	To determine the differences in prevalence in the NSSE after early PCT between RP and RT.	Chapter 4 Mapping the prevalence and use of questionnaires to detect the NSSE after PCT: a scoping review.	Findings from the scoping review provided evidence in relation to objective 1 and 2 about the prevalence of the NSSE after PCT, and how they are assessed by HCP. In summary, • There is a low to high prevalence of NSSE after PCT in men • Men find it difficult to report NSSE to their HCP • Questionnaires play an important role in detecting sexual side-effects • There is currently no evidence of a valid and reliable questionnaire for use to detect/screen for NSSE after PCT. **Implications for clinical practice** • Studies reported a low to high prevalence of NSSE after PCT, and thus clinicians need to be aware of these symptoms. • Detection of NSSE could be enhanced by using an appropriate questionnaire or screening tool. • Early detection of NSSE may improve quality of care, and prevent long term disability and distress in patients **Implications for education and research** • Research about NSSE after PCT can inform patients and HCP through educational courses and programs that could include aspects about the NSSE in up-to-date curricula. • Increased clinician awareness of NSSE will benefit patients who have or have had PCT • There is scope for further research in the field of NSSE after PCT
2	To determine how the NSSE after early PCT are being reported, detected and whether questionnaires play a role in the assessment and treatment of these NSSE.		

3	To create a QBST to detect the "NSSE" after PCa in men who have received PCT.	Chapter 5 A modified Delphi study to identify screening items to assess NSSE following PCT.	A three round Delphi study was conducted where a panel of MDT experts were asked to create a screening tool, by giving their input with regards to the content and wording of the screening tool. The MDT panel of experts consisted of variety of disciplines including urologists, oncologists, sexologists, psychologists, and pelvic physiotherapists. The panel was also tasked with establishing consensus on the appropriate ness of the screening tool items. **Implications for practice** • A NSSE after PCT screening tool is now available to assist HCP to detect NSSE, and patients will be able to do self-screening of their symptoms too. These screening tools could be printed and made available at health care settings, or may even for part of routine subjective assessments of patients by urologists, oncologists, general practitioners, nurses, phycologists, and pelvic physiotherapists etc. • Patients will be more encouraged to monitor the NSSE as they may develop over time as more awareness is created amongst support groups, whether in person or social media-based supports groups. • The NSSE screening tool can also be used as an outcome measure by HCP and may assist to track how SD symptoms improve or regress when used clinically. • Clinician awareness of NSSE will continue to grow, making it easier for HCP to communicate with their patients about SD. **Implications for education and research**
4	To establish consensus from a multidisciplinary team on the appropriateness of items to include in the screening tool.		

			• Due to the publications being made available, up to date educational courses and programs will need to include the NSSE after PCT research in their updated curriculum. • Research related to NSSE will continue to be published, possibly looking at different populations, and applying it to different PCa interventions. • The NSSE after PCT screening tool may also be used in future academic research, where SD is being explored after PCT. • The use of the tool can help to create awareness add on the existence of NSSE, can aid discussions about treatment options, and rehabilitation options. **Implications for Policy** • Medical funders & rehabilitation funding should be considered to support patients with NSSE and assist in their recovery. • Early diagnosis and intervention initiatives could prevent or reduce long term medical costs for medical funders.
5	To determine the differences in prevalence in the NSSE after early PCT between RP and RT in a population.	Chapter 6 Prevalence and Bothersomeness of the NSSE After PCT in South Africa.	Our study on SA men highlighted the prevalence range of the NSSE amongst men who have received PCT, and specifically aimed to establish how bothersome these side effects were to them. Anorgasmia was highly prevalent in our study population, followed by a moderate prevalence of penile length and penile sensation changes. Climacturia was mildly prevalent in our study group, and anejaculation, arousal incontinence and penile curvature changes had a low prevalence. When

6	To establish how bothersome the NSSE are after PCT.		comparing the NSSE, the penile aesthetics issues such as penile length and penile curve changes were most bothersome to our study participants, with 21,6% of men often, and 24% of men always being bothered by their penile length shortening, and 20% of men always being bothered buy their abnormal penile curve. Climacturia also caused significant bother in our participants, with 14,3% always, 7,1 % often, and 35,8% sometimes being bothered by this side effect. Most of our participants had a RP (92,5%), so it was impossible to establish the differentiate between NSSE due to their matched treatment approach. **The implications for clinical practice** • Pre intervention counselling information needs to include NSSE information • Preventative measures could be employed to prevent NSSE, for e.g., the preservation of penile integrity can be enhanced (penile length shortening and abnormal curvatures) by educating patients on early penile rehabilitation approaches. **The implications for education and research** • Clinician awareness of NSSE will continue to grow. • Research related to NSSE will continue to be published **Implication for policy**

			• South African data could be used to improve specific support and funding for patients experiencing NSSE, whether in the private or public sector, or through non-profit organisations. • Awareness campaigns by relevant stakeholders could include information about the NSSE after PCT, to help guide patients to make informed treatment choices during their PCa journey
7	To determine the psychosocial impact of sexual side effects after PCa treatment in a population.	Chapter 7 Psychosocial impact of SD related to PCT in South African Men.	This study describes the psychological impact that SD had on men who had PCT. Our participants were asked to answer three open ended questions, and their responses were coded, and matched to pre-determined themes through TA. These themes were SD impact, psychological impact, Partner Support, and the need for accurate information. Additional subthemes of surviving PCa, treatment regret and advice for future patients were generated by the coders. Our study showed that men experienced major psychosocial events after their PCT that included distress, mourning the loss of sexual function, depression, frustration, anger and in some cases loss of intimacy and support from their partners. Shared decision making between patient and doctor, and unconditional partner support suggested less treatment regret and outcome satisfaction. We also asked our study group to indicate whether they had been treated for depression, and whether they had used support groups or mental HCP. Half of our study population had engaged in support groups, but only a few (5,6%) had received helped from a psychologist, whilst only 6,3% of the group was being medicated for depression. Most participants had experienced some degree of psychosocial distress and bother due to their SD.

			The implications for clinical practice • Results of this study can be used to help health care practitioners improve and promote psychological and social care for these men who have PCT, by providing comprehensive information about the physical and psychological aspects of SD. • HCP should establish themselves in an MDT that includes clinicians that look after the psychological wellbeing of men who have PCT. **Implications for education and research** • Education is needed to enable clinicians to routinely incorporate early screening of SD and the psychological impact of it in men, and to action appropriate early referral to mental health clinicians. **Implication for policy** • An MDT should include early identification of Psychosocial distress, and patients need to be routinely referred for Mental health and wellbeing interventions after PCT.

8.3 Main Insights of the Study

The following key insights emerged:

- Insights into the differences between LMIC and high-income countries approaches to PCa diagnosis and management.
- Insights into the prevalence of the NSSE after PCT in the current literature
- Insights into "the absence of discussions about the NSSE after PCT and the possible role of a QBST in facilitating a conversation between patient and HCP
- Insights into the necessary questions needed to develop a NSSE after PCT QBST .
- Insights into the prevalence of the NSSE after PCT in SA men
- Insights into how bothersome the NSSE are for SA men after PCT
- Insights into the psychosocial impact of SD in men after PCT

8.3.1 The prevalence of the NSSE in the current literature, and how the NSSE are detected and the role of questionnaires according to the available literature

By comparing the available literature on NSSE after PCT, this study was able to establish its prevalence trends across the most recent original literature. Overall, there was a large range (low to high) perveance when looking at the set of NSSE. The study concluded that three of the NSSE were moderately prevalent, namely orgasmic dysfunction, penile length shortening and abnormal penile curvature, and these trends were comparable between the RP and RT approaches. Anejaculation had shown to have a variable prevalence rate (low to high), but it was exclusive to the RT approach, as it would be considered a consequence of a RP, rather than a preventable or manageable side effect. Climacturia was shown to be six times more prevalent in RP patient (moderate prevalence) compared to RT patients (low prevalence). The study also found that from the twenty-three papers that were analysed in its final inclusion, there was a great disparity between assessment methods to detect the NSSE, and a combination of non-validated questionnaires, non-specific NSSE questionnaires and verbal assessment were used in the studies. The study concluded that there is no current NSSE assessment tool available that could detect and or screen the collective NNSE after PCT. There was a need to develop an appropriate NSSE after PCT screening tool.

To establish the NSSE prevalence rates in a specific population, the creation of such a screening tool was commenced, and the process of developing an appropriate NSSE after PCT screening tool is described in Chapter Five.

8.3.2 The necessary questions of a NSSE after PCT screening tool

This phase of the study describes the process of developing the NSSE after PCT screening tool, using an MDT of experts who participated in a 3 round Delphi study. Twenty-seven experts started in round 1, twenty-three experts participated in round 2 and twenty experts finished the process in round 3. The panel consisted of a variety of HCP with knowledge and experience in the field of PCT and sexual health rehabilitation, and the goal was to produce a QBST for use in a variety of settings by a variety of HCPs. Initially the panel was given eight draft statements that would enable patients to indicate whether they experienced a NSSE, along with three open ended questions. In the end, through the panel recommendations and seeking consensus with regards to the wording and structure of the instrument, the three open ended questions were removed from the final version of the screening tool and eight final statements were agreed upon. This study plays an important role in the management of men who have PCT, as there is now a QBST available that could be used by HCP to screen for NSSE when consulting. Currently, these symptoms are being underdiagnosed, especially in low to middle income countries like SA.

8.3.3 The prevalence of the NSSE after PCT in SA men, and how bothersome NSSE are for SA men after PCT

This study was the first study that explored the NSSE in the SA context, and the first international investigation that investigated the multiple NSSE after different PCa treatment approaches. This study added new knowledge, not only the NSSE after PCT prevalence, but also reported on how bothersome these specific side effects are to men.

Anorgasmia was highly prevalent in our study population, followed by a moderate prevalence of penile length and penile sensation changes. Climacturia was mildly prevalent in our study group, and anejaculation, arousal incontinence and penile curvature changes had a low prevalence. When comparing the NSSE, the penile aesthetics issues such as penile length and penile curve changes were most bothersome to our study participants, with 21,6% of men

often, and 24% of men always being bothered by their penile length shortening, and 20% of men always being bothered buy their abnormal penile curve. Climacturia also caused significant bother in our participants, with 14,3% always, 7,1 % often, and 35,8% sometimes being bothered by this side effect. Most of our participants had a RP (92,5%), which made it impossible to differentiate between NSSE due to either RP or RT .

8.3.4 The psychosocial impact of SD in men after PCT

This phase of study describes the psychological impact that SD had on men who received PCT. Our participants were asked to answer three open ended questions, and their responses were coded, and analysed deductively. These themes were the impact of SD impact, psychological impact, Partner Support, and the need for accurate information. Additional subthemes of surviving PCa, treatment regret and advice for future patients were also identified. This study showed that men experienced major psychosocial events after their PCT that included distress, mourning the loss of sexual function, depression, frustration, anger and in some cases loss of intimacy and support from their partners. Shared decision making between patient and doctor, and unconditional partner support suggested less treatment regret and greater outcome satisfaction.

Most participants had experienced some degree of psychosocial distress and bother due to their SD. In response to questions about their help seeking behaviour, half of the study population reported having engaged in support groups, but only a few (5,6%) accessed help from a psychologist and 6,3% received medicated for depression.

8.4 Implications of the Study

- The literature reports a low to high prevalence of NSSE after PCT, and there is a need for greater awareness amongst clinician about these symptoms and side effects of PCT.
- Detection of SD, especially NSSE, could be enhanced by using an appropriate questionnaire or instrument for screening or to initiate discussions with affected men.
- Early detection of NSSE may improve quality of care, and prevent long term disability and distress in patients and their partners
- A NSSE after PCT screening questionnaire is now available to assist HCP who work with patients who have had PCT, to detect NSSE. The questionnaire is basic enough also for

use by patients for self-screening. This screening questionnaire could be printed and made available at health care settings, and/or may be included as part of routine subjective assessments of patients by urologists, oncologists, general practitioners, nurses, phycologists, and pelvic physiotherapists etc.

- Patients will be more encouraged to monitor the NSSE as they may develop over time, as more awareness is created amongst support groups, whether they are in person or social media-based supports groups.
- The NSSE screening questionnaire can be used as an outcome measure by HCP and may assist in tracking how SD symptoms improve or regress in the clinical context.
- Clinician awareness of NSSE will continue to grow, making it easier for HCP to communicate with their patients about SD.
- Pre- intervention counselling information should include information about the possibility and severity of NSSE
- Preventative measures could be employed to prevent NSSE, for e.g., the preservation of penile integrity can be enhanced (penile length shortening and abnormal curvatures) by educating patients on early penile rehabilitation approaches.
- The Phycological wellbeing of men should be prioritised and pre-empted after PCT, especially where there is evidence of SD.
- Results of this study can be used to help HCP to improve and promote psychological and social care for men who have PCT, by providing comprehensive information about the physical and psychological aspects of SD and ensuring that patients receive accurate information about their options.
- HCP should consider forming part of a MDT that includes clinicians to provide a holistic perspective on treatment and recovery, including psychological wellbeing, for men who have PCT.

8.5 Implications for Future Research

- Educational courses and continuous professional development programs can add new information on NSSE to update their curricula.
- Increased clinician awareness of NSSE will benefit patients directly and lead to better health and QOL outcomes after PCT
- There is scope for further research in the field of NSSE after PCT

- Research related to NSSE should include aspects related to whether different PCT have a greater or lesser effect on NSSE development. Research is also needed to be conducted in and across different populations, social and cultural settings to see how the questionnaire is being used, adapted, or applied.
- The NSSE after PCT screening questionnaire will need to be translated and validated for other contexts where English may not be the first language
- The questionnaire can aid in discussion about NSSE, the symptoms and treatment - and rehabilitation options.
- Education is needed to enable clinicians to routinely incorporate early screening of SD and the psychological impact of it in men, and to action appropriate early referral to mental health clinicians.

8.6 Study Limitations

This study did not capture the full picture of SD after PCT in SA men, as with many other middle-to-low-income countries, major inequalities exist in health care. The patient participants in this study were mainly privately funded patients, who could afford private health care. Most of the population in SA would not have access to private health care and there is no current database to access them in the public health care system, and in many geographical areas PCa services simply do not exists or waiting times are excessive, eliminating early diagnosis opportunities [86]. Most of our patient participants received a RP, and of that group, 77,4% of participant received the robotic RP procedure, which would incur additional costs in SA, even for privately funded patients. Most of our participants were from the Western Cape (75,4%) and Gauteng (15,1%), with very little representation from other provinces. This further reflects of the geographic challenges facing the SA health care system. We have a small representation of Black (1,8%) and Coloured (5,7%) participants in our study, and our study included only patients who were proficient in English. Further research is needed to address the study limitations with regards to more diverse patient representation across different geographical locations, and in different languages.

8.7 Conclusion

This study has contributed to new knowledge in the field of SD after PCT and has highlighted not only the prevalence rates of the NSSE in the literature, but also in a population of SA

men. The study produced a NSSE after PCT QBST that is immediately available for use in a clinical setting. The QBST may well assist HCP to start conversations with men about possible SD after PCT and its impact on them. This study explored the psychosocial impact of SD in SA men and contributed to the knowledge around the lived experiences of these men. These experiences contribute to the evidence for a greater biopsychosocial focus when considering the wellbeing of men after PCT. Psychosocial care should routinely form part of the management package, and HCP should position themselves in an MDT that could consider all aspects of health and wellbeing of a patient.

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APPENDICES

APPENDIX 1: CHS PHD THESIS GUIDELINES

GUIDELINES FOR PRESENTATION OF MASTERS AND PHD DISSERTATIONS/THESES BY RESEARCH

1. Purpose

The purpose of this document is to provide guidance to students and supervisors on how to prepare a dissertation/thesis for Masters by Research and PhD degrees using the manuscript or publication format..

2. Introduction

These guidelines must be read together with the College of Health Sciences (CHS) Handbook as well as the Jacobs documents on examination policies and procedures for PhD degrees. The rules on thesis format are based on modification of point 1 of the definition of terms section in the Jacobs document. In this section a thesis is defined as *"the supervised research component of all PhD degrees, whether by supervised research only, or coursework and research, or by papers that are either published or in manuscript form (the supervised research component of the PhD degree by paper(s) comprises the introduction, literature review, account of the methodology, selection of manuscripts, and conclusion)."* A dissertation is defined as "*the supervised research component of all Masters degrees, whether by supervised research only, or coursework and research, or by papers that are either published or in manuscript form (the supervised research component of the Masters degree by paper(s) comprises the introduction, literature review, account of the methodology, selection of manuscripts, and conclusion*)."

2.1 PhD thesis

In the CHS Handbook the rules for a PhD thesis are not in one place; they are stated in DR8 a i & ii, DR9 c and CHS 16. DR8 a i & ii and direct that a thesis be presented in the standard format together with one published paper or an unpublished manuscript that has been submitted to an accredited journal, arising from the doctoral research. CHS16 (thesis by publications states that the thesis may comprise of at least three published papers or in press in accredited journals; such papers must have the student as the prime author. The same CHS16 provides for a thesis by manuscripts that may have at least 3 papers with the student as the prime author that have not yet been published but are in the form of manuscripts; at least two of such papers must constitute original research. In both cases (thesis by publications and manuscripts), there must be introductory and concluding integrative material sections.

The standard type thesis is being phased out in many African countries in favour of the other options that originate from the Scandinavian countries. While this format ensures that all details of the work done for the doctoral degree are captured and thoroughly interrogated, they often remain as grey literature which is mainly useful to other students, usually within the same university, although with digitization of theses, such work may become more accessible beyond the source university. Apart from the risk of losing good work because of it not being on the public domain, as students rarely publish such work after graduating, this approach denies the college additional productivity units (PUs) emanating from publications.

The thesis by publication encourages students to publish key aspects of their doctoral research as they will not graduate if the papers are not published or in press. This approach ensures that the work of the student enters the public domain before the thesis is examined, providing the examiner with some assurance of prior peer review. The thesis must constitute a full study of the magnitude expected of a PhD with the papers providing a sound thread or storyline. Furthermore, the college maximizes the students' work as PUs are awarded for the papers as well as for graduating. However, this approach may negatively affect throughput and frustrate students as

they cannot graduate unless all the papers are published or in press, in addition to the synthesis chapter demonstrating the story line of the thesis.

The option of a thesis by manuscripts ensures that students make efforts to start publishing. The risk of not passing because of failure to publish all papers (as in the thesis by publication) does not exist under this option. However, the PUs emanating from publications from the doctoral work are not guaranteed as the submitted papers may eventually be rejected. Thus there is a possibility of the doctoral work remaining on the university library shelves as is the case for the standard thesis format. The standard thesis does have the advantage that more details of the doctoral work are usually included.

In view of the above, the best option for the college is that of a thesis by publication. However, in the interim, the attractive option is that of thesis by manuscripts, as it provides the possibility of publication without putting the student at risk of delayed graduation when some of the manuscripts are not published/accepted, which also disadvantages the college in terms of PU earnings. The standard thesis option should ultimately be phased out for the stated reasons and students are not encouraged to present their theses in that format. Consequently this document does not describe the standard thesis.

2.2 MSc dissertation

The rules on presentation of MSc dissertations are presented in CR13 (course work), CHS 14 (course work) and MR9 (research) in the CHS Handbook. CR13 c and MR9 c direct that a dissertation "may comprise one or more papers of which the student is the prime author, published or in press in peer-reviewed journals approved by the relevant college academic affairs board or in manuscripts written in a paper format, accompanied by introductory and concluding integrative material." Such a dissertation should include a detailed description of the student's own distinct contribution to the papers. Both CHS14 and CR13 specify that reviews and other types of papers in addition to original research paper/s may be included, provided they are on the same topic.

3 *Length of thesis and dissertation by word count*

Table 1 provides a guide of the length of a thesis or dissertation by word count excluding preliminary pages and annexes.

Table 1: Thesis length by word count

Sections				
	Minimum	Maximum	Minimum	Maximum
Introduction	2700	2700	2000	2000
Chapters	10000	25000	6000	11000
synthesis	2000	2000	1700	1700
bridging	300	300	300	300
Total	15000	30000	10000	15000

4. *Intention to submit*

A written intention to submit a thesis or dissertation should be submitted to the appropriate postgraduate office with endorsement of the supervisor at least three months before the actual date of submission which should be before November if the student intends to graduate in the following year. The actual submission will under normal circumstances require approval of the supervisor.

5. Format for theses/dissertation

There is little variation in the actual format of the PhD thesis and Masters dissertation for the various types described above. The box below summarise the outline of a thesis/dissertation for the thesis by manuscripts and thesis by publications.

Box 1: Outline of thesis

Preliminary pages

i. Title page
ii. Preface and Declaration
iii. Dedication
iv. Acknowledgements
v. Table of contents
vi. List of figures, tables and acronyms (separately presented)
vii. Abstract

Main Text

1. Chapter 1: Introduction
   Introduction including literature review
   Research questions and/or objectives
   Brief overview of general methodology including study design
2. Chapter 2
   First manuscript/publication
3. Chapter 3
   Second manuscript/publication
4. Chapter n
   Final manuscript/publication
5. Chapter n+1: Synthesis
   Synthesis
   Conclusions
   Recommendations
6. References Appendices

NB. Between the manuscripts or publications there must be a 1 page (maximum) bridging text to demonstrate the link between them

6. Details for thesis/dissertation subheadings

This section summarizes what is expected under each subheading shown in Boxes 1 and indicates where there might be variations between a Masters Dissertation and PhD Thesis.

6.1 Title Page

The officially approved title that is concise (Fewest words that adequately describe the contents of the thesis/dissertation – usually 15 or fewer words) is presented at the top. This should be followed by the candidate's name in a new line. At the bottom the thesis statement should be presented. The thesis statement may be stated as "*Submitted in fulfillment of the requirements for the degree of ____ in the School of _____, University of KwaZulu-Natal"* for a PhD/Masters by Research thesis. In the case of a Masters Dissertation it should be stated as "Submitted as the dissertation component in partial fulfilment (% stated) for the degree of _____ in the School of _____, University of KwaZulu-Natal". For both Masters and PhD the date of submission must be stated.

6.2 Preface (Optional)

The preface merely states the reason (motivating factors) why the study was conducted without getting into details of what was investigated.

6.3 Declaration

This must be structured as follows:

I, Dr/Mr _____, declare as follows:

1. That the work described in this thesis has not been submitted to UKZN or other tertiary institution for purposes of obtaining an academic qualification, whether by myself or any other party.

   Where a colleague has indeed prepared a thesis based on related work essentially derived from the same project, this must be stated here, accompanied by the name, the degree for which submitted, the University, the year submitted (or in preparation) and a concise description of the work covered by that thesis such that the examiner can be assured that a single body of work is not being used to justify more than one degree.

2. That my contribution to the project was as follows:
   This is followed by a concise description of the candidate's personal involvement in and contribution to the project, in sufficient detail that the examiner is in no doubt as to the extent of their contribution.

3. That the contributions of others to the project were as follows:
   This is followed by a list of all others who contributed intellectually to the project, each accompanied by a concise description of their contribution. This does not include people who ordinarily would be "acknowledged" as opposed to considered for authorship.

4. Signed _____ Date_____

6.4 Dedication

This is an optional section. Should it be included it must be very brief merely indicating to whom the work is dedicated. Avoid anything too flowery

6.5 Acknowledgements

This section acknowledges all individuals, groups of people or institutions that the candidate feels indebted to for the support they rendered. The funding source for the work should also be acknowledged.

6.6 Table of contents

Table of contents must be inserted after the preliminary sections and must capture all major sections of the thesis at the various levels (primary, secondary, tertiary subheadings). It should be electronically generated and should be able to take the reader to specific headings in the thesis.

6.7 Lists of figures, tables and acronyms

These lists must be presented separately. All titles of figures presented in the thesis/dissertation must be listed indicating on what page they appear. Similarly for tables the titles must be presented indicating on what page they appear. In the case of acronyms, the acronym is stated and all the words describing the acronym are presented. Only key acronyms should be stated. In some cases they may not be listed as long as full text is presented whenever the acronym is used for the first time.

6.8 Abstract

The abstract should summarize the thesis mainly stating the purpose of the study, highlights of chapters and the new knowledge contributed by the thesis. The abstract must be approved by the supervisor of the thesis and should not be more than 350 words in length.

6.9 Introduction

The introductory chapter for both types of thesis is similar. The section should include literature review and have the following information. Headings are used as appropriate and need not correspond exactly to the following.

i. Background and the context of the study
ii. Description of the core research problem and its significance
iii. A comprehensive, critical, coherent overview of the relevant literature leading to clearly defined knowledge gaps
iv. A coherent problem statement highlighting the nature and magnitude of the problem, the discrepancy, knowledge gaps therein and possible factors influencing the problem.
v. Clear and SMART research questions, objectives and hypothesis and/or theoretical framework
vi. A conceptual framework (optional)
vii. Description of the study area and general methodology *(in a standard thesis this should be a stand-alone section)*
viii. Layout of the thesis (thesis structure) indicating what chapters are presented in the thesis and how they address the objectives.

6.10 Literature review

This section is subsumed in the introduction within the stipulated word count for a thesis or dissertation.

6.11 Methodology

A standalone section is not needed as the methods are adequately described in each manuscript/publication.

6.12 Data chapters/manuscripts/publications

The full published paper or manuscript submitted for publication should be presented as published or submitted to the journal. The actual published paper should be scanned and inserted

in the chapter. There should be a separator page between chapters that has text linking the previous chapter to the next and providing details of the next manuscript/publication indicating publication status.

6.13 General discussion/Synthesis chapter

This is a general discussion that demonstrates the logical thread that runs across the various manuscripts/publications (synthesis). There should be no doubt that the manuscripts/publications complement each other and address the original objectives stated in the general introduction of the thesis. The general discussion/synthesis chapter should end with a conclusion and recommendations where necessary.

6.14 References

Only references cited in the introduction and synthesis chapters should be listed as all other references should be within the manuscripts presented under data chapters.

6.15 Annexes

All information (questionnaires, diagrams, ethics certificates, etc) considered important but not essential for inclusion in the actual thesis is put in this section as reference material. In addition papers that emanated from the work but not directly contributing to the thesis may be included.

7. Thesis formatting

For standardisation of thesis the following formatting specifications should be followed.

7.1 Font

Times New Roman 11pt should be used throughout the thesis. However, major headings may be made bigger (12pt) but using the same font type

7.2 Paper size and margins

A4 (297 x 210 mm) should be used and in the final thesis both sides of the paper should be used. However, the loose bound copy submitted for examination should be printed on only one side. The recommended margins are 30mm for all the left, right, top and bottom margins.

7.3 Line spacing

The copy submitted for examination should have 1.5 line spacing but the final copy should have single line spacing. Paragraphs should be separated by a blank line. Published or submitted manuscripts should remain in their original format in all aspects as they are inserted in their published format in appropriate places.

7.4 Headings

A consistent numbering system and captions should be maintained with first level being in CAPS and centred, second level being **normal bold** font and third level being ***italics bold***. If there is need for 4th level it should be *normal italics*.

7.7 Pagination

Page numbers should be centred at the bottom of the page. All preliminary pages should be numbered in lower case Roman numerals and subsequent pages should be numbered as indicated in the Box The title page should not be numbered.

The body of the thesis (chapter 1 onwards) should be numbered consecutively with Arabic numerals. The numbers should continue consecutively from the introduction through the through the publications or submitted manuscripts and subsequent sections. The published papers will therefore bear two numbers: a set specific to the manuscript (it is recommended to place these in the upper right hand corner) or published paper, as well as the consecutive numbers belonging to the thesis as a whole. Care must be taken to distinguish these in terms of position and font.

7.8 Referencing

Supervisors have the freedom to decide the type of citation of references but there must be consistency. This is mainly applicable to the standard type of thesis. In the case of thesis by manuscripts or publications, individual papers will maintain the reference system of the journal but the supervisor can decide on the type of referencing for the introductory and synthesis chapters.

8. Final thesis submission

The thesis should be submitted for examination in a loose bound form accompanied by a PDF copy. After the examination process the final version PDF copy of the thesis must be submitted to PG office for onward submission to the library. It is not a requirement to submit a copy fully bound in leather cloth or similar material.

APPENDIX 2: ETHICS APPROVAL FROM THE UKZN BIOMEDICAL REASERCH ETHICS COMMITTEE

UNIVERSITY OF
KWAZULU-NATAL
INYUVESI
YAKWAZULU-NATALI

17 October 2019

Mr Roscher, Pierre [redacted]
School Of Health Sciences (College Of Hs)
[redacted]

Dear Mr Pierre

Protocol reference number: BREC/00000478/2019
Project title: **Exploring Neglected Symptoms of Sexual Dysfunction after early Prostate Cancer Treatment.**
Degree Purposes: PhD

PROVISIONAL APPROVAL

BREC FULL COMMITTEE APPLICATION

This letter serves to advise you that the Biomedical Research Ethics Committee at its meeting of **08 October 2019** considered the application for the above study.

The committee provisionally approved the above protocol subject to a response to the following queries:

1. Section: Aims and Objectives. Aim 2 refers to "incidence" (that is the occurrence of new cases) whereas the study design is estimating a "prevalence" (i.e. the proportion of cases in the population sampled). Please clarify.
2. Section: "Research Question". The proposed study designs are descriptive or analytical observational in nature and best served by research questions rather than hypotheses, which are used in experimental or quasi-experimental studies. Please consider.
3. Section "Summary of the proposed research"
    a. Part A: typographical error; "scope and" should be "scoping".
    b. Part B: There are issues surrounding consent for acquisition of data. Firstly, have the patients on the databases that are to be used consented for their contact details to be used in the proposed fashion? Secondly, the use of relevant health care practitioners as a source of information is potentially a breach of confidentiality between them and their patients. Will the practitioners involved contact their patients requesting consent to divulge contact details before the investigator approaches the patients for recruitment? Considering the sensitive nature of the information required the practitioners should also provide information as to its nature. Once permission to contact the patients has been obtained they would then have the choice as to whether or not they will complete the form, so completion and return could be taken as implicit consent.
    c. Part C: validation of the instrument. Why not use the questionnaire proposed in part B as the starting point for a Delphic process, test it for reliability as a pilot in 33 cases and then use the instrument for what is currently phase B in a much larger group (NB not including the 33)? This would mean that the information obtained from the larger group of participants would be derived from a validated instrument. Further modification might still be made as a final Delphic phase using new information emerging from the open-ended questions of the instrument.
    d. Protocol: 4.5 Data analysis. Reliability testing is here stated to be a Delphic process from a panel of experts on "professional development". Please explain. Which discipline would they be from, and why?
4. Section "for qualitative studies". Please provide more detail as to the methods to be used in the content analysis of the responses to the two open-ended questions and the emerging themes and topics. Will member checks with a sample of participants be used to verify the researchers'

interpretation of the written material? Also will all the researchers (i.e. PI and both supervisors) be involved in the process? Will this be, for example, by independent evaluation and then consensus review, or sequential (the PI's interpretation then reviewed by one supervisor, then by the second reviewing both?)

5. The research instrument (questionnaire). The final two (open-ended) questions are requesting a narrative response from the participants. This should be in the participants' own words and in full sentences to maximize the scope for subsequent interpretation. More space is needed for the participants to express themselves. At least half a page for each question.
6. The protocol for the scoping review needs to be in detail (not tabular).
7. The protocol needs to follow accepted guidelines for scoping reviews- detail regarding search strategy, study selection, data extraction and synthesis of results. It is suggested that the PI consult the many available guidelines for constructing scoping reviews.
8. The informed consent form must be based on the BREC Template (see website).
9. Please detail how the verbal interviews/consent will be obtained.
10. The partner must be included in the consent form.

PLEASE NOTE: Provisional approval is valid for 6 months only - should we not hear from you during this time - the study will be closed and reapplication will need to be made.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2015), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at http://research.ukzn.ac.za/Research-Ethics/Biomedical-Research-Ethics.aspx.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

Yours sincerely,

[redacted]

Prof V Rambiritch (Chair)

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

06 May 2021

Mr Pierre Roscher [redacted]
School of Clinical Medicine
Medical School

Dear Mr Roscher,

Protocol reference number: BREC/00000478/2019
Project title: Exploring Neglected Symptoms of Sexual Dysfunction after early Prostate Cancer Treatment.
Degree Purposes: PhD

RECERTIFICATION APPLICATION APPROVAL NOTICE

Approved:	**18 February 2021**
Expiration of Ethical Approval:	**17 February 2022**

I wish to advise you that your application for recertification received on 03 May 2021 for the above study has been **noted and approved** by a subcommittee of the Biomedical Research Ethics Committee (BREC).The start and end dates of this period are indicated above.

If any modifications or adverse events occur in the project before your next scheduled review, you must submit them to BREC for review. Except in emergency situations, no change to the protocol may be implemented until you have received written BREC approval for the change.

The committee will be notified of the above approval at its next meeting to be held on 08 June 2021.

Yours sincerely

[redacted]

Ms A Marimuthu
(for) Prof D Wassenaar
Chair: Biomedical Research Ethics Committee

APPENDIX 3: ORAL PRESENTATION AT WORLD PHYSIOTHERAPY CONGRESS DUBAI 2021

Gmail Pierre Roscher [redacted]

World Physiotherapy 2021: your abstract confirmation

[redacted] Wed, Feb 10, 2021 at 8:33 PM

Dear Pierre Roscher,

Thank you for confirming that the following abstract will be presented at World Physiotherapy Congress 2021 online.

Abstract reference number: ABSTRACTS-WCPT2021-01706
Abstract title: THE VALIDATION OF A NEGLECTED SEXUAL SIDE EFFECTS AFTER PROSTATE CANCER TREATMENT QUESTIONNAIRE USING A MODIFIED E-DELPHI STUDY
Presenter: Pierre Röscher[redacted]
Presentation format: Platform: classic (PL)

If you have any questions regarding your presentation please contact [redacted]

Best wishes,

The World Physiotherapy Congress 2021 online abstract team

World Physiotherapy Congress2021 online

9 – 11 April

CERTIFICATE OF PRESENTATION

This is to certify that

Pierre Röscher

presented

Platform: Classic (PL) number PL-01706
THE VALIDATION OF A NEGLECTED SEXUAL SIDE EFFECTS AFTER PROSTATE CANCER TREATMENT QUESTIONNAIRE USING A MODIFIED E-DELPHI STUDY

at the World Physiotherapy Congress 2021 online

[redacted]
President, World Physiotherapy

World Physiotherapy

[redacted]
Chair, congress programme committee

APPENDIX 4: POSTER PRESENTATION ACCEPTANCE AT THE AUSTRALIAN PHYSIOTHERAPY ASSOCIATION CONFERENCE 2021

Gmail

Pierre Rosche [redacted]

E-Poster Confirmation

[redacted] Tue, Jun 15, 2021 at 2:44 PM

Dear Pierre

You have been offered the opportunity to present one or more of your submission for the APA Conference as an E-Poster, but have not yet confirmed whether you are taking up this offer. As we are finalising the program for publication and preparing the database of e-posters, we need you to either confirm this or withdraw.

Can you let us know your intention by return email ([redacted] no later than midday 23 June. If we do not hear from you, we will assume you wish to withdraw the poster.

Regards
APA Conference Team

Speaker Presentations

Title	Mapping the prevalence and use of questionnaires to detect neglected sexual side effects after prostate cancer treatment: A scoping review.
Paper Status	Offered E- Poster
Theme	Women's, Men's & Pelvic Health
Sub Theme	Chronic & complex
Presenting Author	Mr Pierre Roscher

APPENDIX 5: PRESENTATION CERTIFICATE: SOUTH AFRICAN SOCIETY OF PHYSIOTHERAPY RESEARCH UPDATE

CERTIFICATE OF CPD ATTENDANCE

This is to certify that

Pierre Roscher

HPCSA nr:

PT0102598

Has presented:

Sexual dysfunction after Prostate Cancer Treatment

Presented by:

The Pelvic & Women's Health Physiotherapy Group of the SASP

Date:

23 January 2023

Number of CEU's:

4 General Level 1 CEUs

Lauren Ellis

PWPHG Chairperson

Accreditation No **PPB007/PT007/2023/001**

APPENDIX 6: SCOPING REVIEW PROTOCOL (CHAPTER 4)

Röscher and van Wyk *Systematic Reviews* (2020) 9:214
https://doi.org/10.1186/s13643-020-01473-9

Systematic Reviews

PROTOCOL Open Access

Mapping the prevalence of the neglected sexual side effects after prostate cancer treatment and the questionnaires used in their screening: a scoping review protocol

Pierre Röscher* and Jacqueline M. van Wyk

Abstract

Background: Interventions to treat early prostate cancer (PCa) can leave men with debilitating sexual side effects. The cluster of side effects referred to as the neglected sexual side effects (NSSE) may remain permanent, undiagnosed and untreated because men are hesitant to disclose them. Questionnaires offer a discreet way into the discussion, subsequent diagnosis and possible treatment of the NSSE. This study will be conducted to map the evidence about the prevalence of the neglected sexual side effects (NSSE) after PCa treatment, and use of questionnaires in its diagnosis and screening.

Methods: This systematic scoping review will involve searching the following electronic databases: PubMed, Science Direct and Google Scholar. Following title searching, two-independent reviewers will conduct screening of abstracts and full articles. Eligibility criteria will guide the screenings. Data will be extracted from the included studies, and the emerging themes will be analysed. The review team will analyse the implications of the findings concerning the research question and aim of the study. The mixed method appraisal tool (MMAT) will be employed for quality appraisal of included studies.

Discussion: We anticipate finding a number of studies that describe the prevalence of NSSE after early PCa treatment and that report on using questionnaires to screen for the presence of symptoms including orgasm-associated incontinence, urinary incontinence during sexual stimulation, altered perceptions of orgasm, orgasm associated pain, penile shortening and penile deformity. The study findings will be disseminated through publication in a peer-reviewed journal, peer presentations and presentations at relevant conferences.

Keywords: Prostate cancer, Prevalence, Questionnaire use, Screening tool, Orgasm-associated incontinence, Urinary incontinence during sexual stimulation, Altered perception of orgasm, Orgasm associated pain, Penile shortening, Penile deformity

* Correspondence: pierre.roscher@gmail.com
Nelson R. Mandela School of Medicine, University of KwaZulu-Natal, 719 Umbilo Rd, Umbilo, Berea 4001, South Africa

Background

Prostate cancer (PCa) is a significant cause of disease and mortality amongst men, and it is the second most common cancer affecting men on a global scale [1]. Early PCa or localised PCa is cancer contained within the prostate described as being stage I or II on the tumour-node-metastasis system [2]. Early PCa treatment consisting of surgery or radiotherapy, either through external beam radiotherapy or brachytherapy, results in side effects including sexual dysfunction. Other common side effects could include both pain and incontinence [1]. Sexual dysfunction from PCa treatment is common regardless of whether the treatment modality included surgical or non-surgical interventions. Studies suggest that sexual dysfunction increase during each year of follow-up after the initial intervention, and it affects an average of 50% of patients within 5 years of receiving treatment [3].

Most men generally recover from pain and incontinence after PCa surgery, but sexual dysfunction often remains untreated, leaving them with long-lasting and devastating sexual dysfunction [1]. Specific conditions related to sexual dysfunction are common after PCa treatment. The conditions include orgasm-associated incontinence, urinary incontinence during sexual stimulation, altered perception of orgasm, orgasm associated pain, penile shortening and penile deformity [1, 4, 5]. These conditions are collectively referred to as the 'Neglected Sexual Side Effects' (NSSE), and the symptoms are reportedly prevalent in 20–93% of post-prostatectomy patients [1].

Only a fifth of the men who are diagnosed with PCa will ever discuss issues relating to sexual dysfunction with their health care practitioners (HCP) [6]. A questionnaire may provide a non-threatening strategy to initiate such a discussion and allow the patient to indicate their presenting symptoms. Two validated questionnaires, the expanded prostate cancer index composite (EPIC) [7] and the international index of erectile function (IIEF) [8], were recommended for use in this context in 2015 [9].

Reason for this review

Whilst the EPIC and IIEF both help to stimulate the conversation around general urinary and sexual function, they do not address the NSSE after PCa treatment. There is a need to map the evidence about the use of a questionnaire to help health care providers screen for any of the NSSEs after PCa treatment. It is therefore essential to conduct a systematic scoping review to improve our understanding of the prevalence of NSSE and to highlight knowledge gaps on the role of questionnaires in diagnosis and screening of the NSSEs.

Methodology

A systematic scoping review will be conducted to map the evidence on (i) the prevalence of NSSEs after early treatment PCa and (ii) summarise the literature on the use of questionnaires in the screening of NSSE after early treatment for PCa.

The scoping review will follow the five steps described by Arksey and O'Malley [10] that include the following:

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarising and reporting on the data

Quality assessment of each of the included primary studies will be done as guided by Levac et al. [11].

Identifying the research question

This review aims to identify current academic literature on the NSSE after men have undergone early treatment for PCa. This early treatment includes radical prostatectomy surgery and radiation therapy.

The research questions are as follows:

What is the prevalence of NSSE after early treatment for PCa?

Which questionnaires are being used to assess NSSE after early treatment for PCa?

Identifying relevant studies

A search will be conducted for published and unpublished (grey) literature to identify eligible studies in the following electronic databases: PubMed, Science Direct and Google Scholar databases. We will also include relevant studies found in citations and reference lists of included articles. The search will include publications available in English and published between January 2009 and December 2019.

Eligibility criteria

The population concept context (PCC) framework will inform the eligibility of the research question, as illustrated in Table 1.

Boolean terms (AND, OR) and Medical Subject Headings (MeSH) will be used, as indicated in Table 2. The search results will be captured on an Excel spreadsheet where the duplicates will be removed. The selected studies will be screened against the eligibility criteria. The study search strategy was piloted to determine the appropriateness and feasibility of conducting this study, and the results are presented in Table 2.

Table 1 The PCC framework

	Criteria	Determinants
P	Population	Men who received surgical and non-surgical treatment following early PCa diagnosis
		• Surgical treatment (radical prostatectomy surgery)
		• Non-surgical treatment (radiation therapy)
C	Concept	Neglected sexual side effects (NSSE)
		• Anejaculation
		• Orgasmic pain
		• Orgasmic dysfunction
		• Climacturia
		• Urinary incontinence from sexual stimulation
		• Peyronies disease
		• Penile length shortening
C	Context	Prevalence of NSSE
		Questionnaires used to screen for the prevalence NSSE

Selection of eligible studies

A set of eligibility criteria was developed to ensure that the included studies are relevant to address the research question. The results of the databases will be combined into one Excel spreadsheet after applying the search parameters. The eligibility criteria were developed to ensure that selected studies contain relevant information to answer the review questions.

The study's inclusion and exclusion criteria are summarised in Table 3.

The primary investigator will conduct a comprehensive search and screening of the study titles from the databases, as mentioned above. All the relevant studies with appropriate titles will be extracted and entered into an Excel spreadsheet for processing. All articles that cannot be extracted will be requested from the University of KwaZulu Natal library services, or the authors will be contacted via email. All duplicates will be removed before the titles are screened. Two reviewers will review the abstracts of the eligible studies. The principal researcher and a medically trained research assistant will each conduct an independent full-text screening. The inclusion and exclusion criteria will be applied to identify the qualifying articles. The inter-rater agreement (Cohen's kappa coefficient (k) statistic) between reviewers will be calculated after full-text screening [12].

Any discrepancies in reviewers' results during the abstract and full-text screening stage will be resolved through discussion until agreement is reached. If needed, a third reviewer will be used to settle discrepancies. The screening result will be reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) chart [13].

Charting the data

The information will be extracted and organised using a data charting form. Data will be processed so that the relevant information can be summarised to answer the research questions. The data charting tool, as illustrated in Table 4, will be used by a second reviewer to validate all the information.

Quality appraisal

An electronic version of the mixed method appraisal tool (MMAT) [14] will be adapted to assess the quality of the included studies. The study designs included in this scoping review will include qualitative, quantitative descriptive and mixed methods studies. The specific criteria to determine the appropriateness of each included study are outlined in Appendix.

Two reviewers will assign a score to assess each article that will assess the appropriateness of the study aims and its relevance for inclusion on the review. The overall

Table 2 Pilot database search results

Keyword search	Date of search	Search engine used	No. of publications retrieved
(Orgas* OR Penil* OR Climacturia (MeSH Terms) OR Dysorgasmia (MeSH Terms) OR anejaculation (MeSH Terms) OR Peyronie OR neglected AND [prostate cancer (MeSH Terms) OR Prostatectomy (MeSH Terms)]	1 September 2019	Pubmed	152

Table 3 Inclusion and exclusion criteria of the study

The inclusion criteria	The exclusion criteria
Only primary studies that present evidence on the following:	• Review articles
• The prevalence of NSSE after early stage PCa treatment	• Non-peer reviewed articles (e.g. books, magazines, policy briefs)
• The use of questionnaires to screen for the prevalence of NSSE after early stage PCa treatment	• Commentaries, editorials, programme evaluations and letters
• Original studies available in English and published between 1 January 2009-31 December 2019	• Publications on sexual dysfunction not relating to the prevalence and the use of questionnaires to screen for NSSE after early PCa treatment
	• Studies outside the period of interest and studies not available in English

quality for each included study will be calculated according to the following MMAT guidelines (score = number of criteria met/total score in each domain). One point will be given for each question, and a total score out of 5 will be calculated. The calculation will be presented as a percentage which correlates to the degree to which the identified was assessed to provide relevant information to answer the research question (Appendix).

The results will use the following descriptors.

- Very poor quality (20%) where minimal criteria are met
- Poor quality (40%) where less than half the criteria are not met
- Fair quality (60%) where just more than half the criteria are met
- Good quality (80%) where most of the criteria are met
- Excellent quality (100%) all criteria are met

The overall quality of a combination of components cannot be more than its weakest component when it comes to mixed-methods studies, making the overall score equal to the lowest-scoring component [14].

Collating, summarising and reporting on the data

The collected data will firstly be reported by using descriptive statistics about (i) the geographical setting of studies, (ii) study populations, (iii) study designs, (iv) number of participants, (v) period post-PCa investigated, (vi) prevalence of NSSE, (vii) reported use of a questionnaire and (viii) quality of the studies.

Table 4 Data charting form

Author, date and reference
Aims and research questions
Geographical setting
Study population
Study design
Number of participants
Period post-PCa investigated
Prevalence of NSSE
Reported use of questionnaire to screen for NSSE after PCa
Quality of the study

Secondly, the findings of this scoping review will be analysed using a content analysis approach of the themes emerging from the extracted data. The themes will be collated to answer each research question.

The review team will discuss findings, resolve issues, and finalise findings. The review team will analyse the implications of the findings in relation to the study aims and further research in the field.

Discussion

PCa constitutes a global public health burden [15], and surgical and non-surgical interventions are routinely administered [16]. Men who receive treatment for early stage PCa are often unaware of the debilitating, long-lasting side effects following the treatment [4]. Sexual function has been identified as the quality of life domain most strongly associated with outcome satisfaction after prostate cancer treatment [17]. With most research in the field of PCa focused around incontinence and erectile dysfunction, the NSSE remains understudied and neglected [1, 18]. This review will report on the prevalence of the NSSE after early PCa treatment.

Only two studies have been published on the NSSE related to PCa treatment [5, 19]. There is also no current valid and reliable questionnaire being used in the field of the NSSE after early PCa treatment. Such a questionnaire would assist health care practitioners to screen for possible NSSEs in patients who had undergone treatment for early PCa.

A review of the literature related to the prevalence of the NSSE after PCa treatment and the questionnaires used to screen for them may help to inform future clinical practice around the NSSE in PCa survivors.

Appendix

Selection of MMAT questions: Specific criteria to determine the appropriateness for inclusion of each study

Qualitative, quantitative descriptive and mixed methods studies

The methodological quality criteria applied to evaluate qualitative studies included the folowing:

1. Is the qualitative approach appropriate to answer the research question?
2. Are the qualitative data collection methods adequate to address the research question?
3. Are the findings adequately derived from the data?
4. Do data sufficiently substantiate the interpretation of results?
5. Is there coherence between qualitative data sources, collection, analysis and interpretation?

The criteria to evaluate quantitative descriptive studies include the following:

1. Is the sampling strategy relevant to address the research question?
2. Is the sample representative of the target population?
3. Are the measurements appropriate?
4. Is the risk of non-response bias low?
5. Is the statistical analysis appropriate to answer the research question?

The criteria to evaluate mixed methods studies include the following:

1. Is there an adequate rationale for using a mixed-method design to address the research question?
2. Are the different components of the study effectively integrated to answer the research question?
3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?
4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?
5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?

Each study will be evaluated according to its study design based on the above criteria. One point was given for each question, and a total score out of 5 was calculated. This was represented as a percentage, which correlated to the quality of the included studies (Appendix). The principal investigator will perform each quality assessment.

Abbreviations

PCa: Prostate cancer; HCP: Health care practitioner; NSSE: Neglected sexual side effects; EPIC: Expanded prostate cancer index; IIEF: International index of erectile function; MMAT: Mixed method appraisal tool

Acknowledgements

None

Authors' contributions

PR conceived the study and participated in the design involved in drafting and finalising the manuscript. JvW participated in the design of the study, drafting the manuscript and revising it critically providing final approval of the version to be published. The author(s) read and approved the final manuscript.

Authors' information

Pierre Röscher is a PhD student in the discipline of Urology, at Nelson R Mandela School of Medicine, University of KwaZulu Natal, South Africa. Prof. Jacqueline van Wyk is an associate professor at the Nelson R Mandela School of Medicine, University of KwaZulu Natal, South Africa.

Funding

Not applicable

Availability of data and materials

Not applicable

Ethics approval and consent to participate

Full ethical clearance was obtained from the University of KwaZulu-Natal, School of Health Sciences Research Committee (Biomedical Research Ethics Committee) with registration no: BREC/00000478/2019.

Consent for publication

Not applicable

Competing interests

The authors declare that they have no competing interests

Received: 11 May 2020 Accepted: 2 September 2020
Published online: 17 September 2020

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Publisher's Note

APPENDIX 7: STUDY RECRUITMENT LETTER DELPHI STUDY (CHAPTER 5)

Round 1

Delphi Study-Neglected Sexual Side Effects After Prostate Cancer Treatment

Dear Panelist

My name is Pierre Röscher, and I am a PhD student at the Nelson R Mandela School of Clinical Medicine (University of KwaZulu-Natal; South Africa). I am studying the neglected sexual side effects after early prostate cancer treatment. My study proposal has received ethical clearance (BREC/00000478/2019).

This is a request to ask whether you would be willing to participate in my study, by serving as an expert on my panel to review a 10-item questionnaire during a 3 round Delphi study. The purpose of this Delphi process is to reach consensus on items to include when administering a questionnaire to affected patients. This study forms part of a larger project to eventually create a valid and reliable new questionnaire.

ABOUT THE PROCESS

As an expert on the panel, you are requested to review 10 potential Items that will form a questionnaire, and provide your valuable input regarding the appropriateness of each item. We also ask for your input regarding other important information we may need from our participants (Prostate Cancer survivors) who will eventually complete the questionnaire. You will be given the option of doing the process electronically via a specific link, or if you choose, we can provide you with a hardcopy and we will arrange delivery and pick up of the document. During the first round, we will ask you some additional questions about yourself. You will not receive individual feedback on your suggestions, but the necessary changes will be implemented in the second round and third of the study.

STUDY OBJECTIVE

The objective of this study is to achieve a consensus amongst a panel of experts regarding 10 possible items/questions to include in a neglected sexual side effects after Prostate Cancer treatment questionnaire.

PARTICIPANT SELECTION

Participants are selected due to their clinical and/or academic involvement in male sexual health patients in the field of prostate cancer treatment and management.

ANONYMITY

You will remain anonymous to your fellow panelist, and your identity will only be known to the researchers.

HOW LONG WILL IT TAKE TO COMPLETE?

Each of the 3 rounds of the Delphi study should take a panelist no more than 10-15 min to complete. There is a maximum of 3 rounds.

WHEN WILL THE STUDY START, AND WHEN WILL IT FINISH?

The aim is to conclude the 3 rounds of the Delphi study over a 3 month period, and cut of points for each round have been imposed.

The time frame to complete all 3 rounds are limited to between 13 July 2020 and 28 September 2020

- Round 1 will be completed in 3 weeks: 13 July 2020 to 3 August 2020
- Collation Time of 1 week
- Round 2 will be completed in 3 weeks: 10 August 2020-31 August 2020
- Collation Time of 1 week
- Round 3 will be completed in 3 weeks: 7 September 2020-28 September 2020
- Collation Time of 1 week

HOW DO I COMPLETE EACH ROUND?

The instructions on how to complete each round are described below in 3 easy STEPS described below.

WILL I GET PAID FOR MY PARTICIPATION IN THIS STUDY?

Unfortunately, not

CAN I WITHDRAW FROM PARTICIPATING IN THE STUDY?

Yes, you may at any stage withdraw your participation in the study

CAN THE DELPHI STUDY BE STOPPED EARLY?

Yes, if a consensus agreement of 75 % is reached before round three.

WHAT ARE THE CONSENSUS PARAMETERS IN THIS STUDY?

We will define consensus as per the SCENARIO 1 description, and if that does not apply, we will revert to the SCENARIO 2 description:

DEFINITION OF CONSENSUS

Scenario 1:
Consensus will be defined as a 75% agreement/or disagreement on each questionnaire item description.
Reference (Schneider et al.,2016)

Scenario 2:
Consensus will be defined as the majority agreement of statements after the three-round process, if scenario 1 has not been reached.
Reference: (Diamond et al., 2014)

CAN ITEMS BE CHANGED?

Yes, low scoring items will be analysed and the recommended suggestions will be considered and implemented.

MORE ABOUT THIS STUDY

Disability amongst men is high during and after their treatment for prostate cancer. Common disabling effects include pain, incontinence and sexual dysfunction. These disabling effects impact on the quality of life for affected men. Most men recover from pain and incontinence, but most men will have long-lasting and debilitating sexual dysfunction that remains untreated and unresolved. There is an increase in research that is being done in post-prostate treatment patients, especially in erectile dysfunction and urinary incontinence. There however remains a host of understudied complications that have been referred to as "neglected side effects". These side effects affect the quality of life in many men (A. Frey et al., 2017; A. U. Frey, Sonksen, & Fode, 2014; Salonia et al., 2012). These complications include urinary incontinence during sexual activity (climacturia) and orgasmic disturbances that encompass anorgasmia, changes in orgasmic sensation, and painful orgasm, among others. They also include anejaculation and changes in the penile length and curvature.

The Expanded Prostate Cancer Index Composite (EPIC) and the International Index of Erectile Function (IIEF) are both validated instruments that assess only general sexual dysfunction. These instruments were recommended at the Fourth International Consultation for Sexual Medicine in 2015 (Salonia et al., 2017). These questionnaires, however, do not address the neglected symptoms of sexual dysfunction as mentioned earlier.

There is thus a scope to develop a questionnaire that will effectively and quickly pick up the neglected symptoms of sexual dysfunction after early-stage prostate cancer treatment.

This part of the study is part of the validation process of the neglected sexual side effects after Prostate Cancer treatment questionairre. A further study will test the reliability of the questionairre.

If you have any further questions, please feel free to contact me:

Researcher: Mr. Pierre Roscher
Cell Number: [redacted]
Email: [redacted]

Please provide us with your email address (This is to track which panelists have completed the study, and which are still outstanding)

* Required

Informed Consent

Informed Consent to participate in the study

Your participation and completion of the questionnaire will serve as an indication that you consent to be part of the study.

By completing this questionnaire, you also understand the following:

1. Your participation in this study is voluntary and you can withdraw at any stage.

2. You have been given an opportunity to answer questions about the study and have had answers returned to your satisfaction.

3. You have been informed that you will not be compensated for my participation in this study.

If you have any further questions/concerns or queries related to the study, you understand that you may contact the researcher at:

Researcher: Mr. Pierre Roscher
Cell Number: [redacted]
Email [redacted]

If you have any questions or concerns about your rights as a study participant, or if you are concerned about an aspect of the study or the researchers, then you may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
[redacted]

Ethical Clearance Details
BREC/00000478/2019

Participant Details

Thank you for participating in this study.
Before we start the Delphi Process, could you please provide us with more information regarding yourself.

1. What is your current Age? *

_____

2. What is your gender? *

Mark only one oval.

- ◯ Female
- ◯ Male
- ◯ Prefer not to say
- ◯ Other: _____

3. What is your highest academic degree? *

Mark only one oval.

- ◯ PhD
- ◯ Masters Degree
- ◯ Honours Degree
- ◯ Bachelors Degree
- ◯ Other: _____

4. Indicate your professional background *

Check all that apply.

- [ ] Urologist (performing radical prostatectomies)
- [ ] Urologist (involved in brachytherapy/radiation therapy)
- [ ] Oncologist
- [ ] Sexologist (with a medical background i.e. a GP)
- [ ] Sexologist (with a psychology background)
- [ ] Psychologist
- [ ] Physiotherapist (pelvic health physiotherapist)
- [ ] Other: _____

5. Which sector/s do you work in? *

Check all that apply.

- [ ] Private
- [ ] Government
- [ ] Academic
- [ ] Other: _____

6. Please indicate your experience in your field in years. *

_____

INSTRUCTIONS (How to complete Round 1 of the Delphi Study)

- There are 10 Items that we would like you to review, labeled item 1-10
- Please read each item, along with the answer options, that we would pose to patient in its entirety.
- We would like to capture your opinion on each individual item, one at a time.

STEP 1:

- Please indicate the extent to which you Agree that each of these items should be included in a questionnaire given to patients to explore any of the Neglected Sexual Side Effects after Prostate Cancer treatment. Please choose one option:

o You strongly disagree that the item is appropriate
o You disagree that the item is appropriate
o You neither agree or disagree that item is appropriate
o You agree that the item is appropriate
o You strongly agree that the item is appropriate

- You also have the option NOT to give your opinion by choosing the following option:

o This item falls outside the scope of my expertise. I am unable to advise on this item

STEP 2:

- Please also indicate any issues with the specific Item or make any suggestions to adapt/change the Item, especially if you strongly disagreed, disagreed or neither agreed or disagreed with the Item. All feedback would be welcomed.
- If you think that the response options listed to each item should be simplified, then please include a suggestion

STEP 3:
Please complete this process for all 10 items/questions, and submit your answers.

7. 1.1 Please Indicate how appropriate you think the following question and possible answers are with regards to sexual arousal urinary incontinence. *

Have you experienced involuntary loss of urine associated with sexual arousal during the last 3 months?	**Mark X**
No arousal possible	
Almost never or never	
A few times (less than half)	
Sometimes (about half the time)	
Most of the time (more than half the time)	
Almost always or always	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

8. 1.2 Any comments or suggested changes?

9. 2.1 Please choose how appropriate you think the following question and possible answers are with regards to Climacturia/ Orgasm Associated Incontinence *

Have you experienced involuntary loss of urine associated with your orgasms during the last 3 months?	Mark **X**
No Orgasms	
Almost never or never	
A few times (less than half)	
Sometimes (about half the time)	
Most of the time (more than half the time)	
Almost always or always	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

10. 2.2 Any comments or suggested changes?

11. 3.1 Please choose how appropriate you think the following question and possible answers are with regards to Changes in Orgasm *

Within the last 3 months, when you have had an orgasm, how would you characterize the intensity compared to before your prostate cancer treatment?	**Mark X**
No orgasm (you have not been able to achieve an orgasm)	
Decreased intensity	
Unchanged intensity	
Increase intensity	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

12. 3.2 Any comments or suggested changes?

13. 4.1 Please choose how appropriate you think the following question and possible answers are with regards to Pain Associated with Orgasm *

Within the last 3 months, have you experienced pain or discomfort when you have had an orgasm?	**Mark X**
No orgasms	
Almost never or never	
A few times (less than half)	
Sometimes (about half the time)	
Most of the time (more than half the time)	
Almost always or always	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

14. 4.2 Any comments or suggested changes?

15. 5.1 Please choose how appropriate you think the following question and answers are with regards to Anejaculation *

Within the last 3 months, have you experienced an orgasm without ejaculating?	**Mark X**
No orgasms	
Almost never or never (you are ejaculating as before the treatment)	
A few times (less than half)	
Sometimes (about half the time)	
Most of the time (more than half the time)	
Almost always or always	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

16. 5.2 Any comments or suggested changes?

17. 6.1 Please choose how appropriate you think the following question and possible answers are with regards to Penile Sensation Changes *

Have you experienced one or more of the following sensory disturbances in the penis in the last 3 months?	**Mark X**
No disturbances	
Sensation of cold	
Sensation of warm	
Felt that all or part of the penis was "asleep"	
Increased sensitivity	
Decreased sensitivity	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

18. 6.2 Any comments or suggested changes?

19. 8.1 Please choose how appropriate you think the following question and possible answers are with regards to Changes in Penile Size. *

Have you noticed that your penis has become shorter after your prostate cancer treatment, and if so, how much do you estimate it has changed?	**Mark X**
No change	
0–1 cm	
1–3 cm	
3–5 cm,	
More than 5 cm.	

If you answered yes to the question above, how bothersome is it when you engage in sexual activity?	**Mark X**
Not bothersome at all	
Slightly bothersome	
Moderately bothersome	
Quite a bit bothersome	
Extremely bothersome	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

20. 7.2 Any comments or suggested changes?

21. 8.1 Please choose how appropriate you think the following question and possible answers are with regards to Peyronie-like disease/Penile Curvature *

Have you noticed a different curvature of your penis after your prostate cancer treatment?	**Mark X**
Yes	
No	

If you answered yes to the question above, how bothersome is it when engaging in sexual activity?	**Mark X**
Not bothersome at all	
Slightly bothersome	
Moderately bothersome	
Quite a bit bothersome	
Extremely bothersome	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

22. 8.2 Any comments or suggested changes?

23. 9.1 Please choose how appropriate you think the following question is with regards to the following open ended question *

Experiences. Please answer the following questions in your own words: Please describe your journey with sexual dysfunction after prostate cancer treatment and/or how has sexual dysfunction impacted your life after prostate cancer treatment?

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

24. 9.2 Any comments or suggested changes?

25. 10.1 Please choose how appropriate you think the following question is with regards to the following open ended question *

Experiences. Please answer the following questions in your own words: Is there anything else you want to tell us about your experience or that you think other people going through this or treating people going through this should know?

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

26. 10.2 Any comments or suggested changes?

Round 2

Delphi Study-Neglected Sexual Side Effects After Prostate Cancer Treatment

Dear Panelist

Thank you for participating in the initial part of this study, we really appreciate your input and suggestions.

Please will you complete Round 2 of the Validation- Delphi Study below. Round 2 will be much quicker to complete, as we only need your email details this time.

Round 2 of the study is open for the next 3 weeks: 10 August 2020- 31 August 2020. After that, if consensus has not yet been reached, there will be one final round.

Round 3 will be completed between 7 September 2020- 28 September 2020

CAN THE DELPHI STUDY BE STOPPED EARLY?

Yes, if a consensus agreement of 75 % of the STRONGLY AGREE option is reached before round three.

CAN ITEMS BE CHANGED?

Yes, low scoring items from round 1 have been analysed and the recommended suggestions have been included as far as possible. The same will apply for the round 2 analysis.

If you have any further questions, please feel free to contact me:

Researcher: Mr. Pierre Roscher
Cell Number: [redacted]
Email: [redacted]

Please provide us with your email address (This is to track which panellists have completed the study, and which are still outstanding)

* Required

Informed Consent

Informed Consent to participate in the study

Your participation and completion of the questionnaire will serve as an indication that you consent to be part of the study.

By completing this questionnaire, you also understand the following:

1. Your participation in this study is voluntary and you can withdraw at any stage.

2. You have been given an opportunity to answer questions about the study and have had answers returned to your satisfaction.

3. You have been informed that you will not be compensated for my participation in this study.

If you have any further questions/concerns or queries related to the study, you understand that you may contact the researcher at:

Researcher: Mr. Pierre Roscher
Cell Number [redacted]
Email: [redacted]

If you have any questions or concerns about your rights as a study participant, or if you are concerned about an aspect of the study or the researchers, then you may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
[redacted]

Ethical Clearance Details
BREC/00000478/2019

INSTRUCTIONS (How to complete Round 2 of the Delphi Study)

- There are 10 Items that we would like you to review, labeled Item 1-10
- Please read each item, the question and answer, that we would pose to a patient in its entirety.
- We would like to capture your opinion on each individual item, one at a time.

STEP 1:

- Please indicate the extent to which you Agree that each of these items should be included in a questionnaire given to patients to explore any of the Neglected Sexual Side Effects after Prostate Cancer treatment. Please choose one option:

o You strongly disagree that the item is appropriate
o You disagree that the item is appropriate
o You neither agree or disagree that item is appropriate
o You agree that the item is appropriate
o You strongly agree that the item is appropriate

- You also have the option NOT to give your opinion by choosing the following option:

o This item falls outside the scope of my expertise. I am unable to advise on this item

STEP 2:

- Please also indicate any issues with the specific Item or make any suggestions to adapt/change the Item, especially if you strongly disagreed, disagreed or neither agreed or disagreed with the Item. All feedback would be welcomed.
- If you think that the response options listed to each item should be simplified, then please include a suggestion

STEP 3:
Please complete this process for all 10 items/questions, and submit your answers.

"Please think about the last 3 months and compare that to the time before you had your prostate cancer treatment"

This is the instruction that will be given at the start of the patient questionnaire. All questions are based on the respondents experience within the last 3 months compared to before their prostate cancer treatment started.

Participants will be given the option to fill in the questionnaire themselves, or for their partner to fill it in on their behalf/or from their perspective, whichever may be applicable at the time.

Please also note that we do enquire about medication use, penile pumps, penile injections and level of sexual activity in the participant details section, but that does not form part of this study.

1. 1.1 Please Indicate how appropriate you think the following question and possible answers are with regards to sexual arousal and urinary incontinence. *

Have you experienced any involuntary leaking of urine associated with sexual arousal (besides during an orgasm)? *Arousal can be defined as the state of being sexually excited	**Mark X**
Yes	
No	
I am currently unable to experience any sexual arousal	

If yes, how often does this occur?	**Mark X**
Very rarely	
Rarely	
Occasionally	
Frequently	
Very Frequently	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

2. 1.2 Any comments or suggested changes?

3. 2.1 Please indicate how appropriate you think the following question and possible answers are with regards to Climacturia/ Orgasm Associated Incontinence *

Have you experienced any involuntary leaking of urine during an orgasm?	**Mark X**
Yes	
No	
I am currently unable to achieve an orgasm	

If yes, how often does this occur?	**Mark X**
Very rarely	
Rarely	
Occasionally	
Frequently	
Very Frequently	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

4. 2.2 Any comments or suggested changes?

5. 3.1 Please indicate how appropriate you think the following question and possible answers are with regards to Changes in Orgasm Intensity. *

Are you able to achieve an orgasm?	Mark x
Yes	
No	

If yes, how would you rate the intensity of your orgasm/s?	Mark x
Much less than before	
Less than before	
The same as before	
More than before	
Much more than before	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

6. 3.2 Any comments or suggested changes?

7. 4.1 Please indicate how appropriate you think the following question and possible answers are with regards to Pain with Orgasm/s *

Have you experienced pain during an orgasm?	Mark x
Yes	
No	
I am currently unable to achieve an orgasm	

If yes, how often does this occur?	Mark x
Very rarely	
Rarely	
Occasionally	
Frequently	
Very Frequently	

If applicable, in what area of your body do you experience pain during an orgasm?
Please Answer in your own words...

If applicable, please describe your pain that you experience during orgasm?
Please Answer in your own words...

Please rate the pain described above on the following scale (0= no pain 10= worst possible pain)										
0	1	2	3	4	5	6	7	8	9	10

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

8. 4.2 Any comments or suggested changes?

9. 5.1 Please indicate how appropriate you think the following question and answers are with regards to Anejaculation *

When you ejaculate, has the volume of ejaculatory fluid decreased?	Mark x
Yes	
No	
I am currently unable to ejaculate	

If yes, how much has the volume of ejaculatory fluid decreased?	Mark x
I produce the same amount of ejaculate	
I produce slightly less ejaculate	
I produce less ejaculate	
I produce significantly less ejaculate	
I produce no ejaculate	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

10. 5.2 Any comments or suggested changes?

11. 6.1 Please indicate how appropriate you think the following question and possible answers are with regards to Penile Sensation Changes *

Have you experienced any sensory changes in your penis?	**Mark x**
Yes	
No	

If yes, please indicate the sensory changes that you have experienced.	**Mark x**
A cold sensation	
A warm sensation	
A numb sensation	
An increased in sensitivity	
A decreased in sensitivity	

If applicable, describe in your own words any other sensory changes in your penis, you have experienced?
Please Answer in your own words...

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

12. 6.2 Any comments or suggested changes?

13. 7.1 Please indicate how appropriate you think the following question and possible answers are with regards to Changes in Penile Size. *

Has your penis become shorter in length?	Mark x
Yes	
No	

If yes, how problematic is this when you engage in sexual activity?	Mark x
Not problematic at all	
Slightly problematic	
Moderately problematic	
Very problematic	
Extremely problematic	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

14. 7.2 Any comments or suggested changes?

15. 8.1 Please indicate how appropriate you think the following question and possible answers are with regards to Peyronie-like disease/Penile Curvature. *

Has your penis developed any new curvatures?	Mark x
Yes	
No	

If yes, how problematic is this when you engage in sexual activity?	Mark x
Not problematic at all	
Slightly problematic	
Moderately problematic	
Very problematic	
Extremely problematic	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

16. 8.2 Any comments or suggested changes?

17. 9.1 Please indicate how appropriate you think the following open ended question is. *

a) Describe your experience with sexual dysfunction and intimacy after your prostate cancer treatment.
Please Answer in your own words...

b) How has this (your answer above in a) impacted on your life?
Please Answer in your own words...

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

18. 9.2 Any comments or suggested changes?

19. 10.1 Please indicate how appropriate you think the following open ended question is. *

a) Is there anything else from your experience with your prostate cancer treatment that you would like medical professionals to know?
Please Answer in your own words...

b) Is there anything you would like other future patients to know about?
Please Answer in your own words...

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

20. 10.2 Any comments or suggested changes?

Round 3

FINAL ROUND: Delphi Study-Neglected Sexual Side Effects After Prostate Cancer Treatment

Dear Panelist

Thank you!!

I would like to take this opportunity to thank you for your valuable input over the last 8 weeks during this Delphi Validation study of the Neglected Sexual Side Effects (NSSE's) after Prostate Cancer Treatment questionnaire. The MDT of professionals who also took part in this study consisted of urologists, oncologists, sexologists, psycho -sexologists, psychologists and pelvic health physiotherapists.

--- 5 Items Left to Consider (Items 4, 5, 6, 7 and 8) ---

Round 3 is the final round of this validation study. I would like to ask you for your input for one last time. In this round, there are only 5 items to consider.
Round 2's resulted in item 1-3 from round 2 reaching consensus of over 75% strongly agree. Based on the feedback from round 1 and round 2 items 9 and 10 (the open-ended questions) were removed.

Round 3 will close on 28 September 2020.

--- The importance of your rating that you decide on:----

If you do not agree that an Item deserves the STRONGLY AGREE rating, please let us know why. Because round 3 is the final round, a rating lower than strongly agree with NO comment/ suggestion cannot be used to improve the questionnaire.

Our consensus has been defined as a 75% agreement between panellists of the STRONGLY AGREE option. At this stage, we have incorporated all the comments and the suggestions from round 1 and 2, and to our knowledge, this final version is the most appropriate draft of this final questionnaire, as decided by you the panellists.

Please remember that each one of the original 8 NSSE mentioned in item 1-8 are known side effects after PCa treatment. I have included references below that describe all 8 NSSE's as side effects after PCa treatment

--- Suggestions/Comments ---

We have incorporated the suggestions and comments as far as possible, especially where there was a strong consensus amongst the comments. The scope of the questionnaire is

not to replace a comprehensive subjective examination but rather to screen for the presence of NSSE in patients. This questionnaire does not aim to replace other general sexual dysfunction questionnaires.

--- Relevant Research Related to NSSE ---

NSSE after Prostatectomy:

https://www.sciencedirect.com/science/article/abs/pii/S1743609515306706

https://www.sciencedirect.com/science/article/abs/pii/S174360951530864X

and

NSSE after Radiation Therapy

https://www.sciencedirect.com/science/article/abs/pii/S1743609517300668

If you have any further questions, please feel free to contact me:

Researcher: Mr. Pierre Roscher
Cell Number: 071 364 7686
Email: pierre.roscher@gmail.com

Please provide us with your email address (This is to track which panellists have completed the study, and which are still outstanding)

* Required

Informed Consent

Informed Consent to participate in the study

Your participation and completion of the questionnaire will serve as an indication that you consent to be part of the study.

By completing this questionnaire, you also understand the following:

1. Your participation in this study is voluntary and you can withdraw at any stage.

2. You have been given an opportunity to answer questions about the study and have had answers returned to your satisfaction.

3. You have been informed that you will not be compensated for my participation in this study.

If you have any further questions/concerns or queries related to the study, you understand that you may contact the researcher at:

Researcher: Mr. Pierre Roscher
Cell Number [redacted]
Email: [redacted]

If you have any questions or concerns about your rights as a study participant, or if you are concerned about an aspect of the study or the researchers, then you may contact:

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000
KwaZulu-Natal, SOUTH AFRICA
[redacted]

Ethical Clearance Details
BREC/00000478/2019

INSTRUCTIONS (How to complete Round 3 of the Delphi Study)

- There are 5 items that we would like you to review, labelled Item 4-8
- Please read each item, the question and answer, that we would pose to a patient in its entirety.
- We would like to capture your opinion on each individual item, one at a time.

STEP 1:

- Please indicate the extent to which you Agree that each of these items should be included in a questionnaire given to patients to explore any of the Neglected Sexual Side Effects after Prostate Cancer treatment. Please choose one option:

o You strongly disagree that the item is appropriate
o You disagree that the item is appropriate
o You neither agree or disagree that item is appropriate
o You agree that the item is appropriate
o You strongly agree that the item is appropriate

- You also have the option NOT to give your opinion by choosing the following option:

o This item falls outside the scope of my expertise. I am unable to advise on this item

STEP 2:

- Please also indicate any issues with the specific Item or make any suggestions to adapt/change the Item, especially if you strongly disagreed, disagreed or neither agreed or disagreed with the Item. All feedback would be welcomed.
- If you think that the response options listed to each item should be simplified, then please include a suggestion

STEP 3:
Please complete this process for all 10 items/questions, and submit your answers.

"Please think about the last 3 months and compare that to the time before you

had your prostate cancer treatment"

This is the instruction that will be given at the start of the patient questionnaire. All questions are based on the respondents experience within the last 3 months compared to before their prostate cancer treatment started.

Participants will be given the option to fill in the questionnaire themselves, or for their partner to fill it in on their behalf/or from their perspective, whichever may be applicable at the time.

Please also note that we do enquire about medication use, penile pumps, penile injections and level of sexual activity in the participant details section, but that does not form part of this study.

Question 1: CONSENSUS REACHED

Question 2: CONSENSUS REACHED

Question 3: CONSENSUS REACHED

1. 4.1 Please indicate how appropriate you think the following question and possible answers are with regards to Pain with Orgasm/s *

How often have you experienced pain during an orgasm?	Mark x
I am currently unable to achieve an orgasm	
Never	
Seldom	
Sometimes	
Often	
Always	

If applicable, in what area of your body have you experienced pain during an orgasm?
Please Answer in your own words...

If applicable, please describe your pain that you experienced during an orgasm?
Please Answer in your own words...

Please rate the pain described above on the following scale (0= no pain 10= worst possible pain)										
0	1	2	3	4	5	6	7	8	9	10

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate

- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

2. 4.2 If you DO NOT Strongly Agree, please suggest final recommendations for changes?

3. 5.1 Please indicate how appropriate you think the following question and answers are with regards to Anejaculation *

When you ejaculate, has the volume of ejaculatory fluid decreased?	Mark x
Yes	
No	
I am currently unable to ejaculate	
I have had a prostatectomy and are therefore do not ejaculate anymore	

If yes, how much has the volume of ejaculatory fluid decreased?	Mark x
I produce the same amount of ejaculate	
I produce slightly less ejaculate	
I produce less ejaculate	
I produce significantly less ejaculate	
I produce no ejaculate	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

4. 5.2 If you DO NOT Strongly Agree, please suggest final recommendations for changes?

5. 6.1 Please indicate how appropriate you think the following question and possible answers are with regards to Penile Sensation Changes *

Have you experienced any sensory changes in your penis?	**Mark x**
Yes	
No	

If yes, please indicate the sensory changes that you have experienced.	**Mark x**
A cold sensation	
A warm sensation	
A numb sensation	
An increase in sensitivity	
A decrease in sensitivity	

If applicable, describe in your own words any other sensory changes in your penis, you have experienced?
Please Answer in your own words...

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

6. 6.2 If you DO NOT Strongly Agree, please suggest final recommendations for changes?

7. 7.1 Please indicate how appropriate you think the following question and possible answers are with regards to Changes in Penile Size. *

Has your penis become shorter in length?	Mark x
Yes	
No	

If yes, how problematic is this when you engage in sexual activity?	Mark x
Never	
Seldom	
Sometimes	
Often	
Always	

Mark only one oval.

- You strongly disagree that the item is appropriate
- You disagree that the item is appropriate
- You neither agree or disagree that the item is appropriate
- You agree that the item is appropriate
- You strongly agree that the item is appropriate
- This item falls outside the scope of my expertise. I am unable to advise on this item

8. 7.2 If you DO NOT Strongly Agree, please suggest final recommendations for changes?

9. 8.1 Please indicate how appropriate you think the following question and possible answers are with regards to Peyronie-like disease/Penile Curvature. *

Has your penis developed any new curvatures or bends?	Mark x
Yes	
No	

If yes, how problematic is this when you engage in sexual activity?	Mark x
Never	
Seldom	
Sometimes	
Often	
Always	

Mark only one oval.

- ◯ You strongly disagree that the item is appropriate
- ◯ You disagree that the item is appropriate
- ◯ You neither agree or disagree that the item is appropriate
- ◯ You agree that the item is appropriate
- ◯ You strongly agree that the item is appropriate
- ◯ This item falls outside the scope of my expertise. I am unable to advise on this item

10. 8.2 If you DO NOT Strongly Agree, please suggest final recommendations for changes?

Question 9: REMOVED FROM QUESTIONNAIRE

Question 10: REMOVED FROM QUESTIONNAIRE

APPENDIX 8: ADVERT FOR RECRUITING SOUTH AFRICAN PARTICIPANTS WHO HAD PCT. (CHAPTER 6 AND 7)

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

PROSTATE CANCER RESEARCH STUDY

We are investigating sexual side effects after Prostate Cancer treatment, and how they impact patients. We are looking for participants to complete an anonymous survey.

STUDY INCLUSION CRITERIA	STUDY EXCLUSION CRITERIA
1. Participants must have undergone treatment for Prostate Cancer consisting of radical prostate surgery (Prostatectomy) or prostate radiation (Brachytherapy or External Beam Radiation) in the last 1-5 years. 2. Participants must be aged between 45 and 75 years. 3. Participants must be South African and have had their treatment in South Africa. 4. Patients must be able to understand, read and write in English. 5. Participants must be otherwise medically stable. 6. Participants must consent to partake in the study. 7. Participants must not have any of the exclusion criteria.	1. Erectile dysfunction due to other conditions before being diagnosed with Prostate Cancer. 2. Incontinence due to other conditions before being diagnosed with Prostate Cancer. 3. Previous nerve conditions of the lower spine causing any pelvic pain, incontinence or erectile dysfunction. 4. Previous pelvic trauma/fractures. 5. Other cancers of the spine, vital organs and or pelvis. 6. Undergoing treatment for any other type of cancer.

Please follow this link
https://form.jotform.com/212726582612859

or

Scan This QR Code with your Camera Function on your Smartphone

This study has obtained full ethical approval (BREC/00000478/2019)

If you have any concerns, you are welcome to contact the research office at: BIOMEDICAL RESEARCH ETHICS ADMINISTRATION, Research Office, Westville Campus, Govan Mbeki Building, Private Bag X 54001, Durban, 4000, KwaZulu-Natal, SOUTH AFRICA, Tel: 27 31 2604769 - Fax: 27 31 2604609. Email: BREC@ukzn.ac.za

APPENDIX 9: GATEKEEPER PERMISSION FROM DATABASES

To: CANSA/Prostate Cancer SA/ Health Care Professional

Re: Permission to conduct a research study

Dear: Sir / madam

I, Pierre Röscher would like to request permission to conduct my study "neglected symptoms of sexual dysfunction after early prostate cancer treatment" through your database of prostate cancer patients. I am a registered doctoral student at the University of KwaZulu-Natal. I have decided to undertake the study to investigate the incidents and prevalence of sexual dysfunction after early prostate cancer treatment. The objectives of the study are to successfully collect data from patients who have undergone prostate cancer treatment. The outcome of this study is to develop a questionnaire that will assess the neglected side effects that men experience after they have been diagnosed and managed with prostate cancer. Ethical approval to conduct the study has been granted by the University of KwaZulu-Natal (Please see attached letter). The study will be conducted through various platforms similar to yours, and we are aiming to attract a large sample size. I am not undertaking any other research project apart from this one. There will be no financial or human resource implication to your organization as a result of my study.

I believe that this study will reduce disability amongst men and improve their quality of life after they have been diagnosed and managed for prostate cancer.

If you require any further information with regards to the ethical aspects of this study, please feel free to contact the UKZN Biomedical Research Ethics Committee

Telephone: 031 2604769
e-mail: BREC@ukzn.ac.za

Should you require further information please feel free to contact me. I thank you for your attention in the above motivation and I sincerely look forward to hearing from you.

Yours faithfully,

[redacted]

Mr. Pierre Röscher
071 364 7686

I,…….the representative/research coordinator at……. at the physical address……..hereby give Pierre Röscher ID 8605295055089 permission to conduct his research study “sexual dysfunction after prostate cancer treatment” through my platform and database of Prostate cancer patients.

I acknowledge that this does not give the researcher consent to conduct his research on patients from my database, and that individual written patient consent still has to be obtained from each patient participating in the study.

…….

……..

Organisation and Designation Date

APPENDIX 10: PATIENT CONSENT AND SURVEY

In order to submit this form, you should open it with Adobe Acrobat Reader.

Prostate Cancer Research Study

Have you or your partner had treatment for Prostate Cancer in the last 1-5 years? We are looking for South African men who have had either a Prostatectomy OR Radiation Therapy (Brachytherapy or External Beam Radiation).

If this sounds like you or your partner, we would be grateful if you could complete this survey, it should only take 10-15 min of your time.

About the Researchers

My name is Pierre Röscher, and I am part of a research team at the Clinical Urology department at the Nelson R Mandela School of Medicine, UKZN. The research team includes urologists, physiotherapists and professional researchers. This study forms part of my PhD that I am completing related to Prostate Cancer side effects. I can be contacted via email if you require any additional information: pierre.roscher@gmail.com

About the Study

We are investigating sexual side effects after Prostate Cancer treatment, and how they impact patients. We are looking for participants to complete a set of demographic questions such as age and race, procedure details and general health, as well as some more specific questions relating to the impact of sexual side effects after Prostate Cancer treatment.

Ethical Clearance to Conduct the Study

This study has obtained full ethical clearance.

This study registration is BREC/00000478/2019.

If you have any concerns, you are welcome to contact the research office at: BIOMEDICAL RESEARCH ETHICS ADMINISTRATION, Research Office, Westville Campus, Govan Mbeki Building, Private Bag X 54001, Durban, 4000, KwaZulu-Natal, SOUTH AFRICA, Tel: 27 31 2604769 - Fax: 27 31 2604609. Email: BREC@ukzn.ac.za

STUDY INCLUSION CRITERIA

Inclusion Criteria: Participants who qualify for inclusion in this study will meet the following criteria.

1. Participants must have undergone treatment for Prostate Cancer consisting of radical prostate surgery (Prostatectomy) or prostate radiation (Brachytherapy or External Beam Radiation) in the last 1-5 years.
2. Participants must be aged between 45 and 75 years.
3. Participants must be South African, and have had their treatment in South Africa.
4. Patients must be able to understand, read and write in English.
5. Participants must be otherwise medically stable.
6. Participants must consent to partake in the study.
7. Participants must not have any of the exclusion criteria.

STUDY EXCLUSION CRITERIA

Exclusion Criteria- Participants who are ELIGIBLE to participate **MUST NOT** have had any of the following ·

1. Erectile dysfunction due to other conditions before being diagnosed with Prostate Cancer.
2. Incontinence due to other conditions before being diagnosed with Prostate Cancer.
3. Previous nerve conditions of the lower spine causing any pelvic pain, incontinence or erectile dysfunction.
4. Previous pelvic trauma/fractures.
5. Other cancers of the spine, vital organs and or pelvis.
6. Undergoing treatment for any other type of cancer.

With reference to the inclusion and exclusion criteria, please assess if you meet the requirements and continue with the survey. If you do not meet the criteria to continue as a participant, then we wish you well in your recovery and thank you for your willingness to help us.

Consent

By completing this questionnaire, you consent to participate in this study. You understand that you may withdraw at any point, and you understand that you will not be compensated for your participation in this

study. You understand that the information provided in this survey is anonymous, but the collective results may be used as part of an academic publication in a medical journal.

Who is completing this questionnaire? *

- You are completing this questionnaire by yourself
- You are completing this questionnaire with your partner/spouse
- You are completing this questionnaire on behalf of your partner, based on their experience. (Please complete the information based on your partner.)

PART A: Demographic Information

* Please complete the details for the patient in the rest of the survey if you are completing this on behalf of someone else.

Email: Please note that the only reason for requesting your email details is for us to differentiate between different participants and to identify duplicate surveys. *

example@example.com

Date of Birth *

Month Day Year

Race *

- White
- Black
- Indian
- Coloured
- Asian
- Other

In which province did you receive your Prostate Cancer treatment? *

- ☐ Gauteng
- ☐ Western Cape

- ☐ KwaZulu Natal
- ☐ Free State
- ☐ Limpopo
- ☐ North West
- ☐ Eastern Cape
- ☐ Northern Cape
- ☐ Mpumalanga

Did you receive your Prostate Cancer treatment in the private or government sector? *

Private sector
Government Sector
Both Private and Government Sector (Please elaborate)

Please elaborate if you had your treatment in both the private and government sector.

Indicate the type of treatment you have received and indicate how long ago the treatment was done *

- ☐ Robotic Prostatectomy
- ☐ Laparoscopic Prostatectomy
- ☐ Open Prostatectomy
- ☐ Radiation (External Beam Radiation)
- ☐ Radiation (Brachytherapy)
- ☐ Other/ Combination of Treatments

How long ago did you receive your treatment? *

What was the stage of your Prostate Cancer and your Gleason Score immediately before you received your treatment? (if you are unsure leave blank)

What was the confirmed stage of your Prostate Cancer and your Gleason Score after you received your treatment? (if you are unsure leave blank)

Are you currently on medication to treat Hypertension? *

- Yes
- No

If YES, please specify the name of the medication/s and the dosage/s

Are you currently on medication to treat Depression? *

- Yes
- No

If YES, please specify the name of the medication/s and the dosage/s

Are you on medication to treat Diabetes? *

- Yes
- No

If YES, please specify the name of the medication/s and the dosage/s

Other- Please specify

Were you Sexually Active before your treatment for Prostate Cancer started? *

- Yes, with a partner
- Yes, but without a partner
- Yes, with a partner and without a partner
- No, not at all

If YES, did you require any of the following

- ☐ Medication to help an erection (Viagra/Cialis or other)
- ☐ A Vacuum Erection Device (penis pump)
- ☐ Penile Injections
- ☐ Other
- ☐ No, I did not use/need anything

Other-Please specify

Are you currently Sexually Active *

- Yes, with a partner
- Yes, but without a partner
- Yes, with a partner and without a partner
- No, not at all

Have you used medication before to treat Erectile Dysfunction after your treatment? *

- Yes
- No

Are you currently on medication to treat Erectile Dysfunction (Viagra/Cialis, other etc) ? *

Yes
No

If YES, please specify the name of the medication/s and the dosage/s

What is your perceived effectiveness of the above mention drug/drugs if applicable (choose one)?

Not Effective
Somewhat Effective
Effective
Very Effective
Extremely Effective

Have you ever used a vacuum erectile device (penis pump) after your treatment for Prostate Cancer? *

Yes
No

Are you currently using a vacuum erectile device? *

Yes
No

If YES, what is your perceived effectiveness of the vacuum erectile device if applicable (penis pump)?

Not Effective
Somewhat Effective
Effective
Very Effective
Extremely Effective

Are you currently using Penile Injections ? *

Yes
No

If YES, what is your perceived effectiveness of the Penile Injections (if applicable)?

Somewhat Effective
Effective
Very Effective
Extremely Effective

Are you currently using a Penile Prosthesis? *

Yes
No

If YES, what is your perceived effectiveness of the Penile Prosthesis (if applicable)?

Not Effective
Somewhat Effective
Effective
Very Effective
Extremely Effective

Have you had any involvement (participated) in support groups after your Prostate Cancer treatment?

Yes
No

Have you had any treatment sessions with a Psychologist after your Prostate Cancer treatment to help you with your recovery?

Yes
No

Part B: The Neglected Sexual Side Effects After Prostate Cancer Screening Tool

Think about the last 3 months a, and answer the following questions.

Leaking Urine with Sexual Arousal

Have you experienced any involuntary leaking of urine associated with sexual arousal (besides during an orgasm)? *Arousal can be defined as the state of being sexually excited with or without ejaculation, and with or without a partner. *

- Yes
- No
- I am currently unable to experience any sexual arousal

If YES, how problematic is this when you engage in sexual activity?

- Never
- Seldom
- Sometimes
- Often
- Always

Achieving an Orgasm

Have you been able to achieve an orgasm? (*An orgasm may be achieved with or without ejaculating) *

- Yes
- No
- I am currently unable to achieve an orgasm

If YES, how problematic is it to achieve an orgasm when you engage in sexual activity?

- Never
- Seldom
- Sometimes
- Often
- Always

Leaking Urine During an Orgasm

Have you experienced any involuntary leaking of urine during an orgasm? (*An orgasm may be achieved with or without ejaculating) *

- Yes
- No
- I am currently unable to achieve an orgasm

If YES, how problematic is this when you engage in sexual activity?

- Never

Seldom
Sometimes
Often
Always

Pain During an Orgasm

Have you experienced pain during an orgasm? (*An orgasm may be achieved with or without ejaculating) *

Yes
No
I am currently unable to achieve an orgasm

If YES, how problematic is this when you engage in sexual activity?

Never
Seldom
Sometimes
Often
Always

Ejaculate Volume

When you ejaculate, has the volume of ejaculatory fluid decreased? *

Yes
No
I have had a prostatectomy and do not ejaculate anymore

If YES, how problematic is this when you engage in sexual activity?

Never
Seldom
Sometimes
Often
Always

Penile Sensory Changes:

Have you experienced any sensory changes in your penis ? *

Yes

No

If YES, how problematic is this when you engage in sexual activity?

Never
Seldom
Sometimes
Often
Always

Penile Length

Has your penis become shorter in length? *

Yes
No

If YES, how problematic is this when you engage in sexual activity?

Never
Seldom
Sometimes
Often
Always

Penile Curve

Has your penis developed any new curvatures or bends? *

Yes
No

If YES, how problematic is this when you engage in sexual activity?

Never
Seldom
Sometimes
Often
Always

PART C

Please answer the following 3 questions in your own words.

Please describe your journey with sexual dysfunction after Prostate Cancer treatment. *

How has sexual dysfunction impacted your life after your Prostate Cancer treatment. *

Do you think that there is anything else that other people who are going through Prostate Cancer treatment should know? *

Thank you for taking the time to help us with our important research.

Would you be willing to participate in a follow up online questionnaire in a few days that should only take 5 minutes of your time.

Yes

No

Submit