UNIVERSITAT ROVIRA I VIRGILI

# MEN'S HEALTH, MASCULINITY, AND STRUCTURAL COMPETENCY: THE CASE OF PROSTATE AND TESTICULAR CANCER

Deborah Bekele

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DEBORAH BEKELE

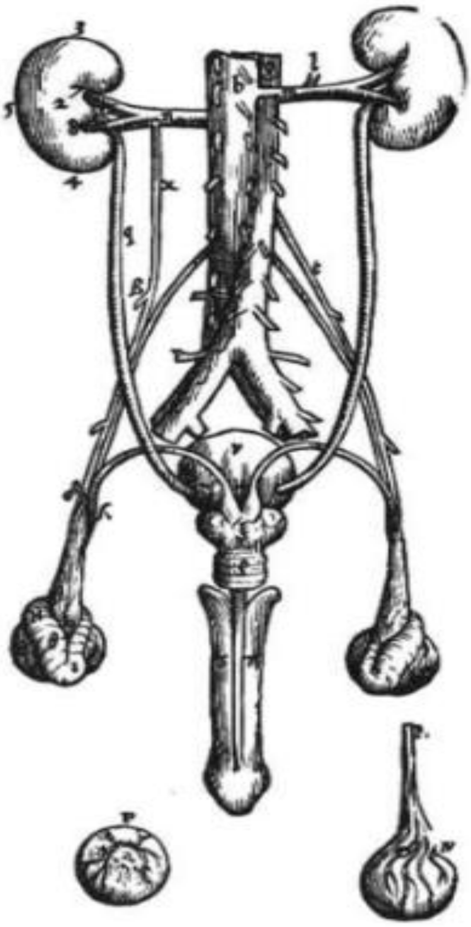

*Fig. 5*
Andreas Vesalius. *De humani corporis Fabrica libri septem.* Book V, fig. 23. Relatiobship between seminal duct and testicular vasculature.

**DOCTORAL THESIS**
**2025**

DEBORAH BEKELE

# *MEN'S HEALTH, MASCULINITY, AND STRUCTURAL COMPETENCY: THE CASE OF PROSTATE AND TESTICULAR CANCER*

DOCTORAL THESIS

Dirigida por el Dr. Ángel Martínez-Hernáez

Departamento de Antropología, Filosofía y Trabajo Social

UNIVERSITAT
ROVIRA i VIRGILI

2025

UNIVERSITAT
ROVIRA I VIRGILI

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I STATE that the present study, entitled "Men's health, masculinity, and structural competency: the case of prostate and testicular cancer", presented by Deborah Bekele for the award of the degree of Doctor, has been carried out under my supervision at the Department of Anthropology, Philosophy, and Social Work of this university.

Tarragona, 27th February 2025

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A la atención de la Comisión del Doctorado de Antropología y Comunicación,

Las personas firmantes, en tanto que coautoras de las publicaciones que se referencian, autorizan a Deborah Bekele, coautora también de los textos, para su uso en la presentación de su tesis por compendio de publicaciones, titula de forma provisional como “Men’s Health, Masculinity, and Structural Competency: The Case of Prostate and Testicular Cancer”, dirigida por el Dr. Àngel Martínez-Hernáez, en el programa de Doctorado de Antropología y Comunicación de la Universitat Rovira i Virgili, asimismo, las coautoras renuncian a presentar dichas publicaciones como parte de otras tesis doctorales:

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As I sit here preparing to write this final part of my thesis—naturally leaving it until the very last minute—I find myself reflecting on the countless moments when I received help, support, and encouragement along this journey. So many people have played enormous and small, but significant, roles in making this journey possible, and I regret that I can't recall every detail of every interaction. However, I will start with the most important ones.

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With heartfelt thanks to all, I submit my PhD.

# LIST OF ACRONYMS & TABLE

| | |
|---|---|
| CASP | Critical Appraisal Skills Programme |
| CEA | Centre d'Estudis Africans |
| CINAHL | Cumulative Index to Nursing and Allied Health Literature |
| COVID-19 | 2019 noval Coronavirus |
| DOAJ | Directory of Open Access Journals |
| DOI | Digital Object Identifier |
| ETREQ | Enhancing Transparency in Reporting the Synthesis of Qualitative Research |
| HIV | Human immunodeficiency virus |
| JCI | Journal Citation Index |
| JCR | Journal Citation Report |
| JIF | Journal Impact Factor |
| KAP | Knowledge, Attitude, and Practice |
| KNUST | Kwame Nkrumah University of Science and Technology |
| LGBTQ | Lesbian, Gay, Bisexual, Trans, and Queer |
| PCa | Prostate Cancer |
| PRIMA | Preferred Reporting Items for Systemic Reviews and Meta-Analyses |
| PSA | Prostate-Specific Antigen |
| SDOH | Social Determinants of Health |
| SICES | Structural and Intercultural Competence for Epidemiological Studies |
| TCa | Testicular Cancer |
| TSE | Testicular Self-Examinations |
| UCL | University College London |
| UK | United Kingdom |
| US | United States |

# LIST OF TABLES

## RESUM

Aquesta tesi, estructurada com un compendi de sis manuscrits interconnectats, explora la relació entre masculinitat, cura del càncer i disparitats de salut, centrant-se en el càncer de pròstata i testicle. La investigació utilitza mètodes qualitatius emmarcats en el constructivisme social per examinar com la masculinitat influeix en els comportaments de salut, l'accés a l'atenció i els resultats dels homes amb càncer. La tesi integra tres perspectives teòriques: constructivisme social, teoria de la masculinitat hegemònica i antropologia mèdica crítica, per analitzar els factors estructurals que donen forma als comportaments de salut i les trajectòries d'atenció al càncer. L'estudi destaca la masculinitat com una força estructural que mitjança els resultats de salut, influint en la presa de decisions, les interaccions proveïdor-pacient i la prestació d'atenció sistèmica.

Els dos primers manuscrits sintetitzen estudis qualitatius sobre la masculinitat i el càncer de pròstata, identificant temes clau com ara com les ideologies masculines actuen com a barreres per buscar ajuda i relacionar-se amb xarxes de suport. La segona metà síntesi examina el paper dels grups de suport en el foment de la companyonia, la solidaritat i les estratègies d'afrontament adaptatives, alhora que desafia els ideals masculins tradicionals. El tercer manuscrit, inèdit, investiga les narratives de supervivència entre homes marginats amb càncer de pròstata, centrant-se en els reptes estructurals i les estratègies de resiliència a nivell micró, meso i macro.

El quart manuscrit es desplaça al càncer de testicles, presentant un estudi empíric sobre el coneixement i les pràctiques d'auto examen entre estudiants universitaris ghanesos. Descobreix llacunes culturals i estigmes que dificulten el diagnòstic precoç i contribueixen a mals resultats de salut.

Els dos últims manuscrits emfatitzen la integració de les competències estructurals i interculturals en la investigació epidemiològica a través de les directrius de la Competència Estructural i Intercultural per a Estudis Epidemiològics (SICES). Aquestes directrius aborden la competència cultural i estructural en totes les etapes de recerca i advoquen per un "gir estructural" en l'epidemiologia, posant èmfasi en la humilitat cultural i la reflexivitat.

Junts, aquests manuscrits contribueixen a comprendre l'impacte de la masculinitat en la salut dels homes i proporcionen implicacions pràctiques per millorar l'atenció del càncer i reduir les disparitats de salut.

# RESUMEN

Esta tesis, estructurada como un compendio de seis manuscritos interconectados, explora la relación entre la masculinidad, la atención del cáncer y las disparidades en la salud, centrándose en el cáncer de próstata y testicular. La investigación emplea métodos cualitativos enmarcados en el constructivismo social para examinar cómo la masculinidad influye en los comportamientos de salud, el acceso a la atención y los resultados para los hombres con cáncer. La tesis integra tres perspectivas teóricas: el constructivismo social, la teoría de la masculinidad hegemónica y la antropología médica crítica, para analizar los factores estructurales que dan forma a los comportamientos de salud y las trayectorias de atención del cáncer. El estudio destaca la masculinidad como una fuerza estructural que media los resultados de salud, influyendo en la toma de decisiones, las interacciones proveedor-paciente y la prestación de atención sistémica.

Los dos primeros manuscritos sintetizan estudios cualitativos sobre la masculinidad y el cáncer de próstata, identificando temas clave como la forma en que las ideologías masculinas actúan como barreras para buscar ayuda y participar en redes de apoyo. La segunda meta síntesis examina el papel de los grupos de apoyo en el fomento de la camaradería, la solidaridad y las estrategias de afrontamiento adaptativas, al tiempo que desafían los ideales masculinos tradicionales. El tercer manuscrito, inédito, investiga las narrativas de supervivencia entre los hombres marginados con cáncer de próstata, centrándose en los desafíos estructurales y las estrategias de resiliencia a nivel micro, meso y macro.

El cuarto manuscrito se centra en el cáncer testicular, presentando un estudio empírico sobre el conocimiento y las prácticas de autoexamen entre estudiantes universitarios ghaneses. Pone de manifiesto las brechas culturales y los estigmas que dificultan el diagnóstico precoz y contribuyen a los malos resultados de salud. Los dos últimos manuscritos enfatizan la integración de las competencias estructurales e interculturales en la investigación epidemiológica a través de las directrices de Competencia Estructural e Intercultural para Estudios Epidemiológicos (SICES). Estas directrices abordan la competencia cultural y estructural en todas las etapas de la investigación y abogan por un "giro estructural" en la epidemiología, haciendo hincapié en la humildad cultural y la reflexividad.

En conjunto, estos manuscritos contribuyen a comprender el impacto de la masculinidad en la salud de los hombres y proporcionan implicaciones prácticas para mejorar la atención del cáncer y reducir las disparidades en la salud.

## ABSTRACT:

This dissertation, structured as a compendium of six interconnected manuscripts, explores the relationship between masculinity, cancer care, and health disparities, focusing on prostate and testicular cancer. The research employs qualitative methods framed within social constructivism to examine how masculinity influences health behaviors, care access, and outcomes for men with cancer. The dissertation integrates three theoretical perspectives—social constructivism, hegemonic masculinity theory, and critical medical anthropology—to analyze the structural factors shaping health behaviors and cancer care trajectories. The study highlights masculinity as a structural force that mediates health outcomes, influencing decision-making, provider-patient interactions, and systemic care delivery.

The first two manuscripts synthesize qualitative studies on masculinity and prostate cancer, identifying key themes such as how masculine ideologies act as barriers to seeking help and engaging with support networks. The second meta-synthesis examines the role of support groups in fostering camaraderie, solidarity, and adaptive coping strategies, while challenging traditional masculine ideals. The third manuscript, unpublished, investigates survivorship narratives among marginalized men with prostate cancer, focusing on structural challenges and resilience strategies at the micro, meso, and macro levels.

The fourth manuscript shifts to testicular cancer, presenting an empirical study on knowledge and self-examination practices among Ghanaian university students. It uncovers cultural gaps and stigmas that hinder early diagnosis and contribute to poor health outcomes. The final two manuscripts emphasize the integration of structural and intercultural competencies in epidemiological research through the Structural and Intercultural Competence for Epidemiological Studies (SICES) guidelines. These guidelines address cultural and structural competence across research stages and advocate for a "structural turn" in epidemiology, emphasizing cultural humility and reflexivity.

Together, these manuscripts contribute to understanding masculinity's impact on men's health and provide practical implications for improving cancer care and reducing health disparities.

# INTRODUCTION

> Una de las múltiples paradojas de nuestro tiempo es que cuanto mayores son los avances médicos y cuanto más destacado es el desarrollo biotecnológico más necesitados estamos de teorías sociales...estamos demasiado inclinados a percibir la enfermedad como un fenómeno exclusivamente biológico e individual o a omitir la manera en que las desigualdades sociales, las estructuras de poder y los modeles culturales afectan y determinan la salud. El desarrollo de la biomedicina… no puede sustituir el análisis cultural y sociopolítico de la enfermedad y de los tratamientos médicos.
> -(Martínez-Hernáez, 2008, p. 7)

## The Journey

To reach this point of my doctoral dissertation, to be writing these very words, feels nothing short of a pilgrimage. The reality of arriving at this final stage has yet to settle in. Writing the introduction of a doctoral thesis is often the last phase of the dissertation process—like tying a ribbon around a completed package of work. It signifies that the end has truly arrived. For me, this moment feels ironic because so much of the Ph.D. process has been rooted in an orderly sequence: first, the proposal, then the plan, followed by its execution, and finally, the analysis. Writing the introduction last feels both strange and gratifying. Strange because it seems out of sequence; it is gratifying because—as anyone who has undertaken a doctoral journey knows, and those around them can attest—it is undeniably an odyssey.

That said, to claim I had not wrestled with how to structure this introduction would be misleading. I have spent considerable time pondering, struggling, and worrying over its composition. An early draft of my dissertation's outline still exists in my files—a relic from the initial stages of this project. While sifting through folders from those early days, I admire the clarity and certainty I once had about my envisioned path. Everything then seemed so straightforward. That longing for clarity remains, even now.

Condensing nearly eight years of work into a few hundred pages is no small feat, yet this is the task before me. With countless hours spent reading, annotating, drafting, submitting, revising, resubmitting, transcribing interviews, analyzing them, and repeating the cycle, it feels only fitting to narrate the full story from beginning to end. Thus, paradoxically, at the end, I begin. Even if only a portion of the story can be shared here, providing a foundational understanding of the who, what, where, when, and why is vital. Above all, this dissertation would not exist without the people, especially the men, who played pivotal roles in shaping its outcomes.

This thesis reflects the natural process of discovery—exploring, interpreting, questioning, connecting, and reframing ideas. It is only fitting, then, that this introduction and, ideally, the thesis as a whole convey this journey. Through anthropology, where one assumes the roles of observer, explorer, and participant, knowledge is gathered before, during, and after the work—a reality that has shaped my process. With this foundation, I invite you, the reader, to join me on this journey.

It was around 2006, during a conversation with my father. Although I can no longer recall the exact details of that exchange, the subsequent correspondence revealed his unexpected diagnosis of prostate cancer. At the time, I was living in London, preoccupied with the challenges of finding a job after earning my undergraduate degree in anthropology. This, I believe, is why those conversations failed to leave a lasting impact until nearly a decade later. Alternatively, perhaps it is tied to the broader issue I now recognize—the value, or lack thereof, that society places on men's health, a theme I will explore further in this work.

### *Sir Marmot*

It is now 2009. I have just completed my master's degree in Social Epidemiology at University College London (UCL), and I found myself reflecting on how transformative that experience had been. The program focused on the Social Determinants of Health (SDOH), which was in its infancy then, having only recently been established. Sir Michael Marmot, a pioneer in the field, visited us regularly throughout the year. When I enrolled in the program in 2007, it was groundbreaking—there had never been a master's course specifically in Social Epidemiology. At that time, this field was gaining traction as an interdisciplinary approach to health research.

The foundation for this area of study was laid decades earlier with the publication of the Whitehall Report in the 1960s, later expanded by Sir Michael Marmot through the Whitehall II Study (M. G. Marmot et al., 1991). By 1998, the first edition of the *Social Determinants of Health* book (M. Marmot & Wilkinson, 2006) was published, and the second edition, which we studied as part of our coursework, had been released just a year before the program's launch. While whispers of a shift in Epidemiology toward a preventative medicine framework had circulated since the 1970s (Berkman & Kawachi, 2014; Honjo, 2004), it is fair to say that by the early 2000s, Social Epidemiology was still an emerging and interdisciplinary health research domain.

I was captivated by the concepts and ideas we explored during my master's. Having recently completed a degree in Anthropology with a minor in Community Public Health, the progression toward Social Epidemiology felt like a natural extension of my academic journey. I gained a profound understanding of how social factors shape health outcomes. Previously, I had learned about public health campaigns and intervention programs—topics central to public health education.

However, this was the first time I encountered the complexities underlying the design of effective health prevention or intervention programs. I realized that a true understanding of socioeconomic factors was essential for success. As I transitioned into my first “real” job in an academic setting, surrounded by colleagues with multiple three-letter credentials after their names, the idea of pursuing a PhD became increasingly tangible. Investigating the intricacies of SDOH felt like a natural progression for my career.

What I did not know at the time was how the subject I would eventually focus on was already taking shape. While much of the research around me centered on ethnic groups and immigrants, my future focus would trace back to that 2006 conversation with my father about his prostate cancer diagnosis. Little did I know, then, how these moments would connect to another pivotal conversation years later with a dear friend diagnosed with testicular cancer.

### *Abdou*

During the many trials, iterations of ideas and topics for a dissertation, and a great deal of researching and searching for contacts in 2014, I found myself at a conference on African Migration and Development at the University of Jaume I, in Valencia, Spain. There, the director of the Centre d’Estudis Africans (CEA) approached me, intrigued by a question I had asked during a round table discussion. After discussing my interests and ambitions, she invited me to conduct a practicum with her at the CEA, eventually leading to meeting Abdou and marking the journey that would become this dissertation.

Abdou is Senegalese and has been living in Catalonia for over 25 years. When we met, he was the director of the Catalan Association of Senegalese Residents (la Associació Catalana de Residentes Senegaleses) in Barcelona. So, if there were to be anyone to speak about my dissertation interest on migrants and mental health, it was him. Even more so because my questions were directed at him during the round table discussion. Our initial introduction was formal, as any first introduction is. Nevertheless, as time progressed, familiarity and closeness grew. Add parts that we shared in being from Africa and sharing the migration experience. In so many ways, I saw my story in his, and I think it is that unspoken recognition that nonverbal communication that shared and common experiences emit.

Abdou helped me connect with the local Senegalese migrant community. However, as I discussed my dissertation plans in detail, I realized how challenging it would be to conduct doctoral research on this migrant population. I faced two significant obstacles: First, I had no funding secured for the project. Second, I could not communicate effectively with my potential research participants since I did not speak French or Wolof, the main languages they used. These barriers made the research task far more daunting than I had initially anticipated.

Abdou suggested I look into other types of men's health to avoid losing momentum, which is all I had researched. Specifically, prostate cancer. I thought he did not think I had it in me to endure the requirements of taking on a doctoral thesis in a new and foreign language, understanding the complexities of sociocultural psychiatry and the meanings of illness (Kleinman, 1988). Prostate cancer seemed to me an easy way out. 'What could be so interesting about prostate cancer if no one even is talking about it?' I thought to myself, and that (my dear reader) is the very exact reason he suggested it. Moreover, for that, I am grateful.

See, the point is that regarding men's health, *mental* health was just becoming a pertinent and "emerging" interest in psychology and psychiatry research. Suicide in men, migrant mental health, and work-related stress, amongst the male population, were all topics that were getting much attention. If there is anything to measure this awareness of this topic by, one can merely observe the campaigns in the US and UK on male suicide rates, especially those done by the Movember Foundation.[1] Whilst organizations and campaigns discussed men's health, in general, it appears that the concentration of their focus leaned more towards mental health than other male-related health issues, like prostate and testicular cancer.

Despite having some hesitations about Abdou's modifications to steer me away from migrants and mental health and towards prostate cancer, I investigated this topic, nonetheless. What I found, or should I say, *did not* find was astounding. There was almost nothing on prostate

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[1] (*Movember*, 2025)

cancer and even less on testicular cancer. Scrolling through the web, the information on these cancers was fragmented, lacking, and secondary to other cancers, and I forgot it even existed within the public psyche. However, when I reflect on that moment of discovery, knowing what I know now and recounting my journey up to that moment, I think the “astonishment” I felt was naïve. There I was, having a conversation with my father a few years back, when he disclosed to me that he had *prostate cancer.* That it was *cancer* should have resonated with me then, but I had seemingly just forgotten about that conversation and gave no importance to it.

I knew then that I wanted to invest my time and energy in learning more about it. I made a decision then that I would turn the focus of my thesis to this specific area of men’s health- prostate cancer and, later, testicular cancer.

### *Joyce*

Our connection began when Joyce discovered my LinkedIn profile and reached out regarding my doctoral research on cancer patients. While my primary focus was interviewing prostate cancer patients, Joyce was particularly interested in my planned work on testicular cancer. She invited me to be interviewed on her podcast, "*Don’t Give Up on Testicular Cancer*,"[2] which she and her husband had created after losing their son Max to the disease. They also founded the Max Mallory Foundation[3] in his memory to raise awareness. As their first academic guest on a podcast that typically featured patients and their partners, I represented a different perspective.

The timing of our connection in September 2020 proved significant. The COVID-19 pandemic disrupted my carefully structured research plan, which initially intended to interview prostate cancer patients first, followed by testicular cancer patients. The pandemic posed particular challenges for interviewing prostate cancer patients, who were typically older and thus at higher risk. All my scheduled interviews were postponed indefinitely, and the technological solutions were limited. Video conferencing platforms that are now ubiquitous—Zoom, Microsoft Teams, Skype, and WhatsApp video—were not widely adopted then, especially among older participants.

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[2] https://maxmalloryfoundation.com/podcast/
[3] https://maxmalloryfoundation.com/

This disruption led to an unexpected pivot in my research trajectory. Following my podcast interview with Joyce, I recognized an opportunity to broaden the scope of my study. Both prostate and testicular cancer patients face challenges to their sense of masculinity through their diagnosis and treatment, though their experiences differ in essential ways. Through Joyce's network, I gained access to testicular cancer patients willing to participate in interviews. This allowed me to conduct parallel studies of both groups rather than following my original sequential plan.

A key difference between how the two groups coped with their diagnosis emerged: age. This became a crucial factor in the dynamics and impact of the two groups.

### *"Mr. Jackson"*

During a presentation about my PhD research, a colleague raised an essential question about how my gender identity as a woman might affect interviews with men about sensitive health topics. This observation highlighted several layers of complexity in my research approach. As a female researcher discussing intimate health issues like erectile dysfunction and incontinence with older male strangers, I needed to navigate both professional and cultural sensitivities. This challenge was particularly pronounced in Spain, where discussions about prostate cancer remain taboo than in the United States.

The intersection of gender, race, and power dynamics (Griffith et al., 2011; Seidler et al., 2024) in medical research became especially apparent during my recruitment efforts. One experience stands out: After a lengthy phone conversation with an African American prostate cancer patient in which I explained the purpose of my thesis, he agreed to participate. I emailed him the information sheet and consent form. The next day, I found an email from him stipulating that I would have to purchase his book first for him to participate in the interview. This situation forced me to grapple with ethical questions about compensation in research. I had not offered previous participants any quid-pro-quo or compensation for their time and certainly was not presented to the ethics board when I submitted my proposal.

Nonetheless, his response reflected a broader issue in academic research – the sometimes-extractive nature of data collection, where participants share deeply personal experiences that advance researchers' careers without receiving tangible benefits. In ethnic minority groups, especially amongst the Afro/Afro-Caribbean population, this is a significant issue— their communities have historical problems with mistrust in scientific research and medical care (Arnett et al., 2016; Powell et al., 2019).

These experiences led me to examine my own biases about men's health. When reflecting on my initial reaction to my father's prostate cancer diagnosis, I realized I might have responded differently had my mother told me she had breast cancer. This personal insight revealed how deeply ingrained societal attitudes about men's health can be, even among researchers in the field. Despite appearing less urgent or emotionally charged, men's health issues carry significant physical and psychological impacts that deserve equal attention and care.

This paradox becomes even more striking when considering men's historical dominance in medical leadership. Despite men occupying most physician, surgeon, and hospital director positions, men's health has remained surprisingly peripheral in medical discourse.

This contradiction points to deeper historical factors in how medical examination practices evolved alongside social, religious, and cultural interpretations of the male body. These personal research experiences and observations highlight a crucial gap between individual lived experiences and institutional approaches to men's health. By examining how gender dynamics, cultural attitudes, and professional practices intersect in contemporary healthcare settings, we can better understand the historical foundations that have shaped these interactions. This understanding becomes particularly relevant when considering how traditional interpretations of masculinity continue to influence both medical practice and patient experiences. Understanding the complexities of men's health requires examining how historical perspectives on the male body have shaped modern medical practices (Section 1.2).

> Passage from the state of Nature to the state of Culture is marked by man's ability to view biological relations as a series of contrasts; duality, alternation, opposition, and symmetry, whether under definite or vague forms, constitute not so much as phenomena to be explained as fundamental and immediately given data of social reality.
> (Beauvoir, 2015, p. xxii)

## Prostate and Testicular Cancer, Masculinity, and Structural Competency

Understanding the complexities of men's health requires examining how historical perspectives on the male body have shaped modern medical practices. Ancient Greek and Roman texts, alongside religious writings, established foundational concepts of male anatomy—particularly regarding the prostate and testicles—that became intertwined with cultural definitions of masculinity. These early interpretations created enduring frameworks that continue to influence how we conceptualize men's health today.

The development of Western biomedicine occurred within a paradoxical context: while men dominated the medical profession as practitioners, researchers, and policymakers, they often overlooked the specific health needs of male patients. This oversight became more apparent when feminist scholars began critiquing the exclusion of women from medical research. Their essential work revealed an unexpected consequence: the male body had become treated as a neutral baseline for medical understanding, requiring no special consideration[4] (Mangham & Lea, 2021). This presumption of male bodies as the "default" ironically led to reduced attention to men's specific health requirements.

This historical neglect has had lasting consequences. Contemporary epidemiological studies consistently demonstrate that men experience significant disadvantages in life expectancy and quality of life. These disparities stem not primarily from biological factors but from deeply rooted social and cultural patterns that influence how men interact with healthcare systems. The challenge extends beyond individual behavior to encompass systemic issues at multiple levels—from medical education to clinical practice to healthcare facility design.

The persistent gaps in addressing men's health needs (Miani, 2023) reflect a complex interplay between historical precedent and modern healthcare structures. Despite increasing awareness and advocacy over the past decade, progress remains constrained by longstanding

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[4] Jamie McKinstry, "Chapter 1: The Poetics of Anatomy: John Donne's Dissection of the Male Body," pp 17-33.

cultural assumptions about masculinity and health. These embedded beliefs continue to shape everything from academic curricula to clinical policies, creating barriers to comprehensive care that acknowledge men's specific health requirements (Baker, 2016; Beia et al., 2021; Griffith, 2024; S. Robertson et al., 2015).

Structural and cross-cultural competency frameworks highlight disparities in health as consequences of systemic neglect and the absence of comprehensive guidelines, such as those in the SICES checklist (Martìnez-Hernàez et al., 2021). These frameworks emphasize the need for awareness and reflexivity among researchers and medical professionals, urging them to address 'the other' (Bhugra et al., 2023). Ironically, despite systems designed and dominated by men, women's contributions to science and research (i.e., Marie Curie, Mary Jackson, Henrietta Lacks) have often been overshadowed by the recognition of their male counterparts. Furthermore, healthcare services and hospital settings initially emerged to address public health concerns, such as maternity wards and women's clinics, often staffed by male professionals.

It was not until the 1970s, during the rise of feminist scholarship, that discussions about men's roles and needs emerged. Groups and organizations focusing on men's gender issues—such as the men's liberation movement and the profeminist men's movement (Messner, 1998)—paved the way for more recent initiatives like Movember and others.[5] These movements fostered critical dialogue among men about their societal roles and interpersonal relationships.

Structural competency approaches often assume reflexivity applies only to 'the other,' asking how researchers' biases shape study design, implementation, and analysis. However, men rarely use this lens themselves. Few male authors critically reflect on their experiences when writing about men, often positioning themselves as external observers rather than participant observers conducting ethnographies.

Even within structural and cultural competency frameworks rooted in Western biomedical models, their applicability to diverse cultural contexts is uncertain. These frameworks were developed to address disparities in systems already constructed around traditional biomedical models. Cultural competency focuses on representation and reflexivity, while structural competency examines the physical and demographic barriers that limit equitable care. Both

[5] (ManEngage *Alliance*, 2025; *ManKindProject*, 2025; *NextGenMen*, 2025)

approaches aim to bridge gaps in patient care, yet their universal relevance and effectiveness remain open to question.

### *The Modern Body*

The Renaissance and Enlightenment were crucial in shaping the *modern body*—especially the male body—as a site of idealization, control, and normativity. Like anatomical studies by Vesalius (1998), scientific advancements depicted the body as a biological entity and a subject of mastery and perfection. This period marked a shift from seeing the body as a mysterious, divine vessel to something measurable and improvable, laying the groundwork for modern ideas about fitness, health, and the body as a status symbol (Mangham & Lea, 2021, Chapter 1)

The Renaissance (14th–17th century) was a period that saw a revival of classical learning, art, and science. It introduced humanism, emphasizing individual potential and rationality. As seen in works like Michelangelo's David, artists and scholars idealized the male body as a symbol of strength, proportion, and reason. This "perfect man" became a new archetype rooted in classical ideals but reinterpreted through a Christian-humanist lens (Clark, 1956).

The Enlightenment: The 18th century emphasized reason, progress, and empirical knowledge. While old religious dogmas were challenged, Enlightenment thinkers reinforced binary views of gender roles: men as rational, intellectual leaders and women as emotional, nurturing caretakers. These ideas shaped enduring stereotypes about masculinity tied to logic, control, and physical vigor (Porter, 2000). This constructed an archetype of physical and intellectual superiority for men—recasting medieval knightly virtues (bravery, honor) into Enlightenment ideals (reason, strength, and moral uprightness).

### The Medicalization of the Male Body

The Enlightenment's focus on science also led to the medicalization of the male body. Physicians and anatomists began framing health and disease through biological determinism, where male bodies were studied and treated as the "default" for understanding health. Practices like phrenology, physiognomy, and even early psychiatry reinforced stereotypes that linked male physicality to rationality and productivity. Male reproductive health, strength, and vigor became central themes in medical discourse, often positioning men as the benchmark for “normalcy.” Over time, these perspectives shaped how male bodies were monitored, controlled, and pathologized—leading to ideas that men's health was tied to their societal roles (e.g., breadwinners, soldiers). Masculinity itself became "medicalized," with issues like virility and stamina becoming medical concerns (Laqueur, 1992; Porter, 2000).

In ancient civilizations—Egypt, Mesopotamia, and China, among them—the role of testicles in shaping masculinity was implicitly acknowledged through practices such as castration. Observers noticed that castrated males (eunuchs) displayed reduced libido, lacked facial hair, and showed diminished muscle mass, correlating testicular function with male virility. Traditional medical systems like Chinese medicine also prescribed various remedies, including testicular tissue or testicle-based animal products, to rejuvenate what they called "masculine energy" (Shapin, 1996).

The Greek physician Hippocrates (5th–4th century BCE) likewise noted the connection between testicles and male fertility, observing that damage to or removal of these organs led to decreased "male vigor." Galen (2nd century CE) expanded on Hippocratic theories and stressed the importance of the testes in producing semen or "seed," which he considered key to masculine physical traits. Though the term "testosterone" did not exist, these observations laid the groundwork for later recognition that some agents in the testes influenced bodily and behavioral characteristics. During the Middle Ages in Europe, progress in anatomical understanding was limited, and classical authorities like Galen essentially guided medical ideas. Testicles were still linked with vital procreative functions and thus viewed as central to a man's health and identity. Meanwhile, in the Islamic Golden Age, scholars such as Avicenna (Ibn Sina) (Avicenna, 1993) documented the significance of testicles in their medical treatises, furthering the idea of an internal secretion that maintained virility (Laqueur, 1992).

By the Renaissance, anatomists like Andreas Vesalius (1514–1564) made significant strides in mapping out human anatomy in works such as *De humani corporis fabric* (Vesalius, 1998). Although still working without the modern concept of hormones, Vesalius and his peers emphasized how the male gonads influenced sexual maturation. The phenomenon of *castrati*—young males castrated before puberty to preserve their high singing voices—provided additional anecdotal evidence that testicular substances profoundly affected male development (Feldman, 2015).

By the mid-19th century, the social transformation toward modernity caused by industrialization, urbanization, and modernization created social anxiety, particularly among the socio-economic middle class. Physicians were looked upon, through their unique, authoritative position, to address social order, especially in matters concerning non-procreative sexual activity, such as masturbation (Kosenko & Steger, 2022).[6] The shift toward the examination, documentation, and interpretation of human anatomy, moving away from earlier religious or moralistic understandings, positioned doctors as arbiters of the medical conditions afflicting men. However, this shift did not eliminate explanations influenced by religious beliefs. In fact, at the beginning of the 19th century, many prostatic and testicular afflictions were attributed to 'sinful' behaviors like masturbation (O'Shea, 2012)**.**

## The Prostate & Prostatic Disorder

During the 19th and 20th centuries, the treatment of prostatic disorders (Shackley, 1999) and associated male sexual dysfunction underwent significant evolution, though invasive and ineffective techniques often marked this path. Contemporary attitudes about sexual activity heavily influenced medical approaches to treating prostatic dysfunction. The prostate was widely regarded as the "center of the male sexual system" (Pratt, 1887).[7] Medical documentation across Britain, the United States, and Canada frequently addressed the "appropriate" manner of avoiding what physicians termed "abnormal or incomplete sexual indulgence" (Hett, 1899; King, 1981)[8] that supposedly caused "nervous disturbances," which supposedly caused "nervous disturbances."

Early medical understanding of prostatic problems was intrinsically linked to misconceptions about sexual activity. Physicians believed the prostate contained both muscular and glandular tissues, which they thought were susceptible to hypertrophy through overuse. This overuse was attributed to "youthful indiscretions" in young men and, notably, to "second marriages" among older men who had taken significantly younger wives.

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[6] Masturbation was linked to mental health

[7] E. H. Pratt, Orificial Surgery and its Application to the Treatment of Chronic Diseases, p. 48

[8] J. E. Heller Hett, The Sexual Organs, Their Use and Abuse: The Subject upon Which Men and Women Know the Least, yet Ought to Know the Most: Guide for Men p. 103-4; and Edmund E. King ,pg. 159.

The turn of the century brought new pathological understanding with the introduction of 'chronic seminal vesiculitis' (Sturgis, 1906). Medical practitioners began recognizing that not all patients presenting with prostatic problems reported excessive sexual activity. As Frederick R. Sturgis noted, "The chief cause is that we ought to find a considerable number of enlarged prostates among the country's young, whereas we do not." This observation led to the recognition that prostatic inflammation could result from sexually transmitted diseases, particularly gonorrhea. The difficulty in distinguishing between infections of the seminal vesicles and prostatic inflammation eventually led to the consolidation of these conditions under the broader term of 'chronic seminal vesiculitis' or 'urethral disease.'

Initial treatment approaches in the 19th century paralleled those used for other sexual dysfunctions. The progression moved from catheterization to soft catheterization and then to self-catheterization, though the latter was discontinued due to self-induced infections. Castration subsequently emerged as the preferred treatment method. As medical techniques advanced, practitioners began developing approaches that targeted the prostate directly, such as applying pressure using 'steel sounds' or 'urethral sounds.' However, these methods proved extremely painful and often led to infections.

Adopting antiseptic and aseptic methods (Michaleas et al., 2022) in the 20th century marked a significant shift, moving surgical interventions from peripheral to central medical practice. While castration remained the "magic bullet" for prostate hypertrophy for several more decades, particularly among older patients, medical literature began reflecting important distinctions regarding prostatic function in aging men. Medical discussions increasingly focused on determining the most effective treatment modes, with particular attention to older male patients whose sexual activity had diminished.

Despite age-related differences in functional needs, physicians began recognizing the importance of considering patient resistance to drastic procedures like castration. The role of masculinity in treatment outcomes became increasingly significant, as noted by Shorter (1992), who observed that male surgeons "probably shrank back psychically from mutilating patients of their gender in a way they were perfectly willing to do to women." This period marked a growing awareness of the need to preserve male anatomy and sexual function through various surgical techniques, leading to increased interest in vasectomies. This procedure was presented as providing similar benefits for treating prostatic hypertrophy while preserving fundamental elements of masculinity—sexual function and external appearance (O'Shea, 2012).

By the early 20th century, castrations and vasectomies were being replaced by the more technically challenging prostatectomy, particularly the 'perineal prostatectomy'.[9] While the 'suprapubic prostatectomy' (performed through the abdomen) posed significant post-operative risks, the perineal approach, drawing on centuries of lithotomy experience, helped preserve patients' masculine self-image.

The historical development of these treatments has potentially influenced modern conceptualizations of male sexuality and disease. The limited understanding of male sexual organ functions throughout the last few centuries gradually gave way to more nuanced knowledge about the relationship between the prostate and testicles. This advancement led to a significant split in clinical pathology and treatment approaches. While Ancient Greeks and Romans used 'prostatai' to refer collectively to what we now know as the prostate and testicles, by the 18th century, medical terminology had evolved to differentiate between these organs1 By the mid-20th century, these two organs were treated as distinct, separate organs that impacted two groups of male patients—the "young" and the "old" patient.

A pivotal shift occurred with Charles-Édouard Brown-Séquard's work in the late 19th century. His self-experimentation with animal testicular extracts in 1889, though lacking modern scientific rigor, sparked global interest in "internal secretions"—the precursor to our current understanding of hormones. This historical progression laid the groundwork for modern endocrinology, as scientists began understanding that various organs—including the pancreas, thyroid, adrenal glands, and gonads—secreted chemical messengers into the bloodstream. This eventually led to the isolation and understanding of hormones.

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[9] Surgery to remove the entire prostate and some of the tissue around it, including the seminal vesicles (a gland that helps make semen). During a radical perineal prostatectomy, an incision (cut) is made in the perineum (the area between the scrotum and anus). Nearby lymph nodes may also be removed through a separate incision in the wall of the abdomen (*Radical Perineal Prostatectomy*, 2025).

### The Testes & Testosterone: Identification and Synthesis of Testosterone in the 20th Century

A significant milestone in endocrine research occurred in 1935 when Leopold Ruzicka and Adolf Butenandt (Nieschlag & Nieschlag, 2019) successfully isolated and synthesized testosterone. This discovery confirmed testosterone's fundamental role in developing secondary male characteristics, including facial hair growth, voice deepening, and enhanced muscle mass and strength. The medical community quickly recognized testosterone's therapeutic potential, implementing it in treatments for hypogonadism and delayed puberty.

Consequently, this discovery marked the emergence of testosterone replacement therapy as a standard treatment for men experiencing hormone deficiencies. This therapeutic approach effectively addressed various symptoms, including chronic fatigue, diminished libido, and muscle mass reduction. The scientific community continued to expand its understanding of testosterone's broader physiological impact, investigating its relationships with cardiovascular health, mood regulation, and overall vitality.

The expanding knowledge of testosterone's effects has sparked meaningful cultural and ethical discussions. The proliferation of "lifestyle" treatment centers and anti-aging clinics offering testosterone supplementation has raised concerns about potential over-prescription, adverse effects, and the broader implications of medicalizing the natural aging process. These ongoing debates underscore the complex nature of testosterone—a hormone whose transformative capabilities have captivated both medical practitioners and the general public for generations. This modern understanding of testosterone and its applications represents a remarkable progression from earlier approaches to male health and aging. The development of regulated, scientifically-based treatments marks a significant advancement from historical methods, though it continues to prompt essential discussions about appropriate use and medical ethics.

### *What's in a Name?*

Take your mind back, I don't know when
Some time when it always seemed to be just us and them
Girls that wore pink and boys that wore blue
Boys that always grew up better men than me and you
[Verse 2]
What's a man now? What's a man mean?
Is he rough or is he rugged? Is he cultural and clean?
Now it's all changed, it's got to change more
'Cause we think it's getting better but nobody's really sure

> [Chorus]
> And so it goes, go 'round again
> But now and then we wonder who the real men are
> [Verse 3]
> See the nice boys dancing in pairs
> Golden earring, golden tan, and blow wave in their hair
> Sure, they're all straight, straight as a line
> All the gays are macho, can't you see the leather shine?
> [Verse 4]
> You don't wanna sound dumb, don't want to offend
> So don't call me a faggot, not unless you are a friend
> Then if you're tall and handsome and strong
> You can wear the uniform and I could play along.
> (Jackson, 1982)[10]

Masculinity, as a socially constructed concept, has historically shaped interpersonal dynamics and institutional structures, particularly within healthcare contexts (R. W. Connell, 1995). This thesis examines how masculinity functions as a structural element in healthcare access, utilization, and care delivery to analyze masculinity's manifestation within structural competency (Kimmel, 2008). By treating masculinity as a ‘constant’[11] variable, we can better understand its impact on health outcomes and medical decision-making processes.

The evolution of medical understanding regarding male anatomy and reproductive organs has significantly influenced treatment approaches for conditions for testicular and prostate cancer. This development occurred during an era when the medical community was predominantly composed of wealthy, white European and North American men whose perspectives and biases inherently shaped medical practice and research directions.

As global modernization, urbanization, and medical technologies have advanced, ‘masculinity’ as a social concept and structural element has transformed from rigid societal norms to broader definitions. This evolution reflects contemporary concepts of masculine ideals and their

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[10] Joe Jackson. (1982). Real Men [Song]. On *Night And Day.* A&M Records Limited; Universal Music Group.

[11] In the thesis, “masculinity” is conceptualized as a 'constant' variable—a set of values, attributes, functions and behaviors (de Keijzer, 2021) to explore its enduring influence on health outcomes and medical decision-making processes across different contexts. This perspective acknowledges masculinity's persistent presence but does not overlook its varied manifestations and representations (e.g. masculin*ities)*. As suggested, I will clarify how masculinity is defined in my study, drawing from existing literature that recognizes its multifaceted nature shaped by cultural, societal, and political ideologies. By examining masculinity as a dynamic construct influenced by hegemonic norms yet expressed diversely, the thesis aims to uncover nuanced insights into its impact on health behaviors and disparities. This approach ensures that the research captures both the stability and variability of masculinity, contributing to a more comprehensive understanding of its role in shaping health outcomes.

application in medical contexts. The transformation is particularly evident in men's changing self-perception and interactions as patients and practitioners within healthcare settings.

## Development of Masculinities

Sociological categories inherently develop their history and meaning through a complex interplay of social, cultural, and temporal factors. While some elements evolve, others demonstrate remarkable persistence across generations. Masculinity's temporal specificity has evolved through cultural, historical, and political frameworks, though these frameworks often resist fundamental change.

In antiquated societies, masculinity was confined to a hierarchical perspective known as the ‘one-sex model,’ which positioned the male body as humanity's complete version while regarding women as defective forms (Altonaga, 2021). This model evaluated all mankind through a single moral standard, emphasizing traditionally masculine virtues such as courage, strength, and loyalty. This understanding fundamentally shaped early medical practices and theories about male health and disease.

The modern era disrupted this traditional understanding through scientific advancement and social evolution. The emergence of scientific and naturalistic explanations began associating masculinity with biological factors, leading to an analogical perspective on gender that maintained the 'one sex' model's contrasting views (Laqueur, 1992). Masculine qualities became defined as active, rational, and strong, while feminine traits were characterized as passive, weak, and emotional. This naturalization of gender construction conveniently overlooked existing inequalities and power structures affecting women and femininity (Pateman, 1988) while simultaneously influencing medical treatment approaches and healthcare access patterns.

## Conceptualizing Masculinity in the Contemporary Perspective

The 20th century initially viewed masculinity through the lens of stoic, dominant men possessing great strength, exemplified by cultural figures like John Wayne, who embodied the ideals of protector and provider (Kimmel, 2008). These cultural representations significantly influenced men's healthcare-seeking behaviors and interactions with medical professionals. However, feminist thought began deconstructing these concepts, revealing masculinity as a social norm rather than a universal truth. Over time, the rise of feminist discourse demonstrated that masculinity, like femininity, could evolve.

In the 21st century, cultural shifts and movements advocating for gender equality and LGBTQ+ rights have broadened traditional concepts of masculinity. Contemporary figures who challenge conventional male presentation through fashion choices or by openly expressing emotions exemplify this evolution (Craig, 1998). Media representation has played a crucial role in reshaping perceptions of masculine identity, including attitudes toward health and wellness.

### Intersectionality and Diverse Masculinities

Masculinity movements interact with femininities while confronting intersections of race, sexuality, economic status, and culture. This interaction creates complex healthcare access and utilization patterns across different demographic groups. For instance, Black masculinity faces stereotypes of excessive physicality and toughness, while men in the LGBTQ+ community navigate constructs that conflict with their lived experiences (Harris, 1990). These intersectional challenges often result in disparate health outcomes and varying levels of healthcare engagement across different male populations.

Autobiographical accounts, such as Jack Urwin's work on coping with normative masculine conduct, highlight the need for celebrating diverse expressions of masculinity (Urwin, 2017). These narratives contribute to a broader understanding of how different masculinities influence health-seeking behaviors and medical decision-making processes.

This intersectional framework adds to the body of knowledge about masculinities while also dislodging the prevalence of the unrealistic ideas of the single dominant masculinity. Understanding that male identities are not homogeneous encourages men and society to be more accepting of the multiple forms of expression available.

The historical evolution of masculinities reveals gender as a fluid construct shaped by cultural narratives and power dynamics (Brod & Kaufman, 1994). From the hierarchical "single sex" model (Laqueur, 1992; Soble, 2003) to today's diverse expressions of masculinity, this evolution highlights the constructed nature of gender roles and their impact on healthcare delivery and access. Society's embrace of this fluidity and promotion of inclusivity creates space for more nuanced approaches to men's health and wellness. Understanding masculinity in healthcare contexts requires examining complex power dynamics across class, nationality, sexual orientation, race, religion, and age intersections. These intersecting factors influence everything from individual health-seeking behaviors to systemic healthcare delivery approaches.

The significance of traditional masculine symbols, such as the historical and contemporary importance of testicles, including their consumption as a symbol of masculine dominance and identity, demonstrates the enduring influence of traditional masculine concepts in modern society. This symbolism continues to influence men's perspectives on health, particularly regarding reproductive and sexual health issues. The transformation of masculinity as a structural element within healthcare represents a significant shift in medical practice and patient care. This evolution has led to more inclusive and effective healthcare approaches recognizing and responding to diverse masculine identities and experiences. As our understanding of masculinity continues to evolve, healthcare systems must adapt to better serve the complex and varied needs of male patients across different cultural and social contexts.

### *Structural Competency: What is Structure?*

In Sewell’s paper “A Theory of Structure: Duality, Agency, and Transformation” (1992), he describes the difficulty that he and his colleagues encounter when asked to define or describe “structure.” However, shortly after, he very concisely defined its function within the social science discourse: “The term structure empowers what it designates… in its normative sense, always implies structure in its transitive verbal sense […] structure is posited as “structuring” some other aspect of social existence—whether it is class that structures politics, gender that structures employment opportunities…”[12]

Taking his description of “structure” as a transitive verb that “operates in social scientific discourse as a powerful metonym device, identifying some part of a complex social reality as explaining the whole” Masculinity (gender) is a structural element that designates, in the case of this thesis, health outcomes through the mechanisms of (health behaviors) behaviors.

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[12] Sewell, A Theory of Structure, pg. 2.

Sewell outlines some fundamental problems in the theorizing meaning of structure. The most basic argument about theorizing about 'structure' oftentimes is that it is "too rigid… treated as primary, hard, and immutable" and gets lost in "efficacy of human action – 'agency'… Structures appear in social scientific discourse as impervious to human agency."[13] Following this fundamental problem is the idea that a metaphor of "consistent patterns" structure does not lend itself to notions of change or the possibility of how "patterns change over time."[14]

By the very nature of the evolution of medical knowledge and biomedicine and the emergence of social scientific discourse that has infiltrated from the extreme boundaries of medical knowledge, thus creating interdisciplinary acknowledgment of these "structures," the anatomical and physiological "structure" that is the male body (and represented through his anatomical parts) has begun to change and shape or understanding of the male and his body by the application of "masculinity" (a social factor) as an element, or feature, that is both sociological as well as structural. The third and final problem in the "structural" argument is the divergence between the sociological and the anthropological schools of thought on "structure. Where sociologists consider 'structure' as a hard, or material, opposite to 'culture' (soft, mental), anthropologists consider culture and structure to exist within the same realm.

## Beyond the Body: Masculinity as a Structural Element

Sewell states that "the notion of structure does dominate, however problematically, something significant about social relations: the tendency of patterns of relations to be reproduced, even when actors engaging in the relations are unaware of the patterns or do not desire their reproduction"[15]. Through this lens, masculinity is considered and evaluated in this thesis as a structural element.

In Giddens's works (Giddens, 1984), he discusses the notion of "the duality of structure" in that structure is "both the medium and the outcome of practices which constitute social systems" and is done so by "knowledgeable" human agents. In this sense, men are the 'agents' (i.e., a group of people who know what they are doing and how to do "it"—masculinity) that shape other

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[13] Sewell, A Theory of Structure, pg. 2.
[14] Sewell, A Theory of Structure, pg. 3.
[15] Sewell, A Theory of Structure, pg. 3.

people's, most specifically the groups to which they belong, practices, and these practices produce, and reproduce, structures (e.g. "structuration").[16]

When most biological explanations about health and health outcomes were seemingly exhausted, attention turned to other factors, such as health behaviors and structures. For years, 'testosterone' explained away many health outcomes in men until studies and commissions reported that the precarity of certain social situations (e.g., wage and poverty) were having heavy impacting effects on men's health outcomes (White et al., 2018**).** Studies found that morbidity and mortality in men were related to factors other than biology**.**

The emergence of specialization in medical fields in the US in the 1850s inspired the European model. Specialization is the proper way to practice, research, teach, and organize medicine. During that time, there were ongoing experiments on how to deal with the clinical pathology of prostatic hypertrophy. By 1935, testosterone was finally isolated and recognized as the gender-specific hormone in the male sex. Then, 30 years later, in the 1960-70s, when a group of Japanese scientists isolated the first Prostate-Specific Antigen (PSA)[17] (Catalona, 2012, 2014; Catalona et al., 1991), it still was not deemed necessary to provide a specialized clinic or health services dedicated to the male reproductive organ. Instead, the general specialization of Urology, one of the most varied branches of medicine, encompasses the treatment of disease in the kidneys, ureters, bladder, and urethra in both males and females and the prostate and male reproductive organs in men, specifically.

During the War and Postwar, Urology was designated as a 'competency' and not considered a specialization. Compared to its biological counterpart, obstetrics and gynecology, which has been considered a specialization, a 'competency' is defined as the sum of knowledge, skills, and dispositions, wherein dispositions are defined as cultivable behaviors desirable in whichever context one works. In the case of Urology, and specific to this thesis, this would be in TCa and PCa.

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[16] Giddens, The Constitution of Society, p16.

[17] Prostate-specific antigen, or PSA, is a protein produced by normal, cells of the prostate gland. The PSA test measures the level of PSA in the blood, to monitor the progression of prostate cancer in men who have already been diagnosed with the disease; to follow up on prostate symptoms, such as painful or frequent urination, blood in urine or semen, and pelvic and/or back pain, to screen for prostate cancer in men who do not have symptoms of the disease (*Prostate-Specific Antigen (PSA) Test*, 2024).

It is through the recounting of the emergence of medical awareness and knowledge on the testicles and prostate, as well as their purpose and function, that the very essence of this medical knowledge was acquired and experimented on by male doctors. These male doctors were patients and practitioners in many ways. During the development of modern medical knowledge, male doctors treated and operated on male patients, and there was reason to believe they saw themselves (through the inspection of the male body and its anatomy) as their patients. Hence, there is reason to understand the foundation of the medical associations with masculine norms and the desire to maintain them, which resulted in the pursuit of treatments focused on preserving the male anatomy. Additionally, through the privilege exuded by primarily white, European, or North American male doctors, who could not conceive of themselves as weak in body or mind like the ill male patients they treated ('othering') (Frank, 2006; Johnson et al., 2004; Mol, 2002), the establishment of specialized healthcare services for men’s health was neither advocated for nor recognized. Only in the cases in which men presented with severe injury or illness, say, soldiers returning from war, was there ever a concentrated focus put on their rehabilitation.

We can observe that as the collaboration of other therapeutic mechanisms began to enter into the sphere of biomedical knowledge, undoubtedly influenced by pivotal works by Edward Burnett Tylor; Clifford Geertz, Paul Farmer, and Arthur Kleinman, to name a few, where we began to see the emergence of other perspectives on health, illness, and disease and the nonbiomedical factors, or social determinants, on health outcomes. However, despite this, very few academics (Coughlin, 2020; Griffith, 2016; Griffith et al., 2011) discuss in length the importance of social determinants of health and structural competency within a male-only scope. Indeed, a sea of literature discusses these topics; however, it is in the context of an overdone (in my opinion) comparison between women and men. It cannot be denied that there are biological, social, and cultural differences between women and men that make comparing them to each other important in some contexts. However, addressing nuanced inequities when men (and women) are compared amongst themselves is valuable.

Suppose historically white, cis male doctors have been the decision-makers in medical treatment, care, and policy. They operate from a patriarchal, hegemonic masculine position in society. In that case, it can be assumed that they will make the decisions for the rest of their male counterparts based on a worldview, which could be those other men, like themselves, who adhere to societal masculine norms and ideals. Thus, no reason exists to create services that address specific men's health needs.

In this example, Sewell provides an adequate explanation:

> "…in a great variety of times and places, structures are, in fact dual: how historical agents' thoughts, motives, and intentions are constituted by the cultures and social institutions in which they are born, how these cultures and institutions are reproduced by the structurally shaped and constrained actions of those agents, but also how, in certain circumstances, the agents can (or are forced to) improvise or innovate in structurally shaped ways that significantly reconfigure the very structures that constituted them."[18]

The 'agents' in this context are men, the cultures are the 'hegemonic masculinities' (R. W. Connell, 2020), and the social institutions are the spaces and places where men exist. More specifically, and in the context of this thesis, the 'institution' is healthcare, and the 'culture' is the therapeutic pathways provided to and by men. The improvisations and innovations that men (agents) undergo are through the re-configuration of 'masculinity' as the 'structural element' that constitutes them.

Contributors to this discourse were predominantly medical professionals engaged in academic research, serving at university hospitals, and participating in medical societies. Their insights into men's health, illness, and sexuality—particularly with the prostate—shed light on how broader societal norms and professional standards shaped their articulation of sexuality, reproduction, and masculinity; in essence, men in the reproductive arena are the 'second sex' (Bjorkman & Persson, 2020).

The Renaissance and Enlightenment challenged medieval views but ultimately reconstructed stereotypes of masculinity that persist today. By idealizing the male body and framing health through scientific rationalism, these periods contributed to the "making of the modern body" and the medicalization of men as subjects of both biological and social governance. These historical shifts paved the way for contemporary discussions on how masculinity intersects with medicine, health, and societal expectations. The intersection of masculinity, cancer care, and

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[18] Sewell, A Theory of Structure, pg. 5.

structural competency represents a critical yet understudied area in healthcare research and practice. As prostate and testicular cancers continue to affect significant portions of the male population, understanding how masculine norms and structural barriers influence health outcomes becomes increasingly important. This dissertation examines the complex interplay between these factors and their impact on healthcare delivery and patient outcomes.

Historically, men's health disparities have been viewed primarily through biological and behavioral lenses, with limited attention to structural and sociocultural factors. The evolution of masculinity studies in healthcare has revealed deeper complexities in how gender norms influence health-seeking behaviors and treatment outcomes. Contemporary research indicates that masculine ideals often conflict with optimal health practices, particularly in the context of cancer screening and treatment. The current landscape of prostate and testicular cancer care presents unique challenges. Despite advances in medical technology and treatment options, barriers to early detection and effective care persist. These barriers are often rooted in societal constructions of masculinity and structural impediments within healthcare systems. Understanding these challenges requires examining how masculine norms interact with healthcare delivery and how structural competency might address these issues.

## Conclusion

This research seeks to address several critical gaps by examining how masculine norms influence health behaviors, healthcare systems, and prostate/testicular cancer outcomes. It explores how structural competency frameworks can be adapted to improve cancer care for men. By understanding how masculinity operates as a structural force, healthcare providers and systems can better address barriers to care. This knowledge can inform the development of more effective interventions and policies considering individual and systemic factors affecting male cancer care. Detailed objectives and the manuscripts that address these objectives are presented at the end of the Methods section.

To build on this foundation, this dissertation's theoretical framework draws on multiple perspectives to further explore the relationship between masculinity and cancer care. It provides a lens to understand its structural impact on health outcomes.

# THEORETICAL FRAMEWORK

This doctoral dissertation integrates three theoretical perspectives – social constructivism, hegemonic masculine theory, and critical medical anthropology- to examine the complex relationships between masculinity, cancer care, and structural competency. The conceptual framework developed herein provides a structure for analyzing how these elements interact and influence health outcomes. Focusing on prostate and testicular cancers, the research explores how culturally constructed masculine norms shape health decision-making, provider–patient interactions, and the delivery of care at the systemic level. This comprehensive framework enables an analysis of masculinity not merely as an individual attribute but as a structural element that mediates health outcomes across various contexts.

The theoretical foundation of this research is anchored in the hegemonic masculinity theory (R. W. Connell & Messerschmidt, 2005), which offers insights into the dominant masculine ideologies that influence both personal behaviors and societal expectations (R. W. Connell & Messerschmidt, 2005; Thompson & Bennett, 2015). These ideologies and norms significantly impact health decision-making, interactions with healthcare providers, and healthcare system design. Complementing this perspective, structural competence theory offers a critical lens to examine how institutional structures influence health outcomes. This theory highlights systemic barriers to care, the impact of institutional policies on access, and the need to train providers in skills that promote inclusive and gender-sensitive care. Drawing on the work of Farmer (2006) and Metzl and Hensen (2014), this dissertation highlights systemic barriers to care and emphasizes the need for structural competency among healthcare providers. Together, these theories form a robust framework that informs the analysis of the role of masculinity in health care, proposing how masculine norms function as structural elements and interact with individual factors to mediate care outcomes.

Moreover, this dissertation employs a critical medical anthropology methodology that examines the intersections between masculinity, structural inequality, and oncology care. Grounded in a paradigm that incorporates hegemonic masculinity and feminist perspectives, the methodological approach is designed to reveal how culturally constructed gender norms and systemic barriers shape men's participation in cancer prevention, diagnosis, and treatment. The conceptual framework is explicitly articulated through a series of articles that collectively address the general goal of improving gender-sensitive health care practices and identifying and dismantling structural impediments in health services.

Each article uses a theoretical-methodological approach combining qualitative and critical discourse analysis, revealing the underlying power relations and socioeconomic determinants influencing health outcomes. These studies explore the conceptual dimensions of hegemonic masculinity and its implications for men’s health behaviors, drawing on seminal work by Connell (R. W. Connell, 1987, 1995; R. W. Connell & Messerschmidt, 2005). Structured as a compendium of manuscripts, this dissertation applies critical medical anthropology to examine how structural violence and institutional practices perpetuate healthcare disparities. Synthesizing findings, it proposes integrated strategies for healthcare reform and promoting structural competency within medical settings. Each article aligns with the research goals and contributes to a cohesive narrative connecting theory, empirical evidence, and actionable solutions.

## Masculinity as a Structural Element: Multi-Level Analysis[19]

Here, the idea is to understand masculinity as a structural element, taking from Lévi-Strauss and Giddens ‘structure’, is a set of complex rules[20] that enable binary oppositions and that “bind” time and space, and in addition to being conceptualized by ‘rules,’ but so should it be conceptualized as within ‘resources’ (Giddens, 1979). The following multi-level analysis shows how ‘masculinity,’ as a structural element, is re/produced and re/enacted, how it is “applied in or extended to a variety of contexts of interaction… generalized—that is, transposed or extended – to new situations when the opportunity arises.”[21]

Sewell describes the notion of ‘structure’ as a resource. In his book ‘Theory of Structure’, he attempts to provide an “ordinary English” definition for Gidden’s “obscurely worded

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[19] For a deeper understanding of the role of 'structure' in social and cultural contexts, scholars should refer to the work Michel Foucault, Claude Lévis-Strauss, Judith Butler, and Émile Durkheim, to name a few, each of whom provides valuable insights into the dynamic interplay between individual agency and societal constraints.

[20] In this sense, “rules” are, to follow Sewell’s change in terminology, “schemas”.

[21] Sewell A Theory of Structure, pg. 8.

definition" of 'resource.' Simply put, Sewell explains, there are two classifications for Giddens's use of 'resources'— "authorization" and "allocation," which Sewell reformulates as 'human resources' and 'nonhuman resources.'

It is through these types that power is employed and unevenly distributed. However, Sewell recognized that despite the uneven distribution of resources, "some measure of human and nonhuman resources are controlled by all members of society, no matter how destitute and oppressed".[22]

As Sewell states, "nonhuman resources have material existence that is not reducible to rules or schemas, but the activation of materials as resources, the determination of their value and social power, is dependent on the cultural schemas that inform their social use."[23] This definition of a "nonhuman resource" can be applied to the ideologies and norms (cultural schemas) that are placed on masculinity, granting the function of masculinity as a structural element.

Within the scope of health, health inequalities, and social determinants of health, there is an established recognition that being born male has determinantal health outcomes (e.g., death) that are not attributed to men's biological aspects but are linked to socio-cultural and economic factors (Courtenay, 2000; European Commission: Directorate-General for Health and Consumers, 2011; Griffith et al., 2019; Springer & Mouzon, 2011; White & Richardson, 2011).

Sewell states, "if resources are effects of schemas, it is also true that schemas are effects of resources… schemas are to be sustained or reproduced over time… they must be validated by the accumulation of resources that their enactments engenders […] Sets of schemas and resources may properly be said to constitute *structure* only when they mutually imply and sustain each other over time."[24]

Changes in the dual relationship between schemas and resources, or as Bourdieu calls it, "habitus" (Bourdieu, 1977), are observed when society's grander structure enforces changes. This is particularly true in social transformations caused mainly by the feminist and other global social movements. These movements generated changes from outside the system (i.e., patriarchy;

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[22] Sewell, A Theory of Structure, pg. 10.
[23] Sewell, A Theory of Structure, pg. 12.
[24] Sewell A Theory of Structure, pg. 13.

hegemonic masculinity) and questioned the schemas, or "mental structures"[25] men had about themselves and their place and role in society. The consequences of these types of movements have gone in a variety of directions, from some groups of men doubling down on norms and notions of masculinity whilst others have questioned the definition of "masculinity." In the case of healthcare and particularly within the prostate and testicular cancer groups, the confrontation that the diagnosis caused with self-identity produced a re-configuration of the dual relationship between masculine schemas and resources, consequently producing advocacy related to men's health.

Here, Sewell proposes five key axioms to address the theories of change that apply to theories of structures, in which he calls for the need to "show how ordinary operations of structure can generate transformations".[26] One of his proposed axioms is the *multiplicity of structures.* He states, "societies are based on practices that derive from many distinct structures, which exist at different levels, operate at different modalities, and are themselves based on widely varying types of quantities of resources […] social actors are capable of applying a wide range of different and even incompatible schemas and have access to heterogeneous arrays of resources." [27]

The 'social actors' in this case are prostate and testicular cancer patients, and the function of their masculinity as a structural element can be observed through the multiple levels of spheres (individual, intermediary, and structural) and their practices at different levels.

The analysis of masculinity as a structural element in healthcare reveals its operation across multiple levels—individual (micro), intermediary (meso), and structural (macro) levels of society, creating a complex web of influences that shape health outcomes for men with prostate and testicular cancer (Courtenay, 2000; J. Evans et al., 2011; Oliffe et al., 2008). This multi-level analysis demonstrates how masculine norms permeate individual behavior, institutional practices, and broader societal structures, creating visible and invisible barriers to effective healthcare delivery (Galdas et al., 2005; O'Neil & Crapser, 2011; Seidler et al., 2018; Shen-Miller et al., 2013).

At the macro level, broader societal structures shape masculine health behaviors through cultural norms, policy frameworks, and economic factors. Media representation of masculinity and

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[25] Bourdieu, Outline of a Theory of Practice, pp. 72-95.
[26] Sewell A Theory of Structure, pg. 16.
[27] Sewell A Theory of Structure, pp. 16-17.

health, workplace cultures, and societal expectations create a complex environment that often conflicts with optimal health practices (Griffith et al., 2012; Robertson et al., 2015). Public health messaging frequently fails to address masculine concerns or challenge problematic health behaviors effectively, while healthcare policies may overlook gender-specific barriers to care access and utilization (Noone & Stephens, 2008; Sloan et al., 2010).

At the meso level, institutional practices within healthcare settings reflect and reinforce these masculine norms, shaping how men interact with healthcare systems. Healthcare providers may unconsciously uphold traditional gender norms by expecting men to minimize symptoms, delay care-seeking, or downplay emotional distress (Mahalik et al., 2007; Smith et al., 2006). As a result, healthcare institutions may unintentionally reinforce barriers to timely diagnosis and treatment for prostate and testicular cancer.

At the micro level, individual behaviors are influenced by socialization processes that emphasize stoicism, self-reliance, and risk-taking, leading to reduced health-seeking behaviors among men (Galdas et al., 2005; Peate, 1999, 2004). Masculine identities often discourage preventive care and contribute to late-stage diagnoses in men with prostate and testicular cancer (Abernethy et al., 2009; Altinel & Avci, 2013; Bamidele et al., 2019; Conde et al., 2011; Hannover et al., 2010).

The interaction between these three levels creates a complex system of barriers to effective healthcare delivery. Individual behaviors reflect and reinforce institutional practices, while institutional structures perpetuate societal norms that shape individual choices (Addis & Mahalik, 2003; Griffith, 2024; Griffith et al., 2011). This cyclical relationship suggests that effective interventions must address all three levels simultaneously to achieve meaningful change in male health outcomes (L. M. Robertson et al., 2008; White & Richardson, 2011).

Research findings indicate that successful intervention strategies must consider the interconnected nature of these structural levels. Institutional reforms and broader societal initiatives must support programs targeting individual behavior change (Abbott et al., 1998; Noone & Stephens, 2008; L. M. Robertson et al., 2008). The data suggests that isolated interventions at any single level are likely to have limited effectiveness due to the reinforcing nature of masculine norms across all three levels (Smith et al., 2006).

This multi-level analysis demonstrates the pervasive influence of masculinity throughout healthcare systems, suggesting the need for comprehensive intervention strategies that address structural impacts at micro, meso, and macro levels (Courtenay, 2000; Lynch & Rebbeck, 2013; Mahalik et al., 2007; O'Neil et al., 2017). Understanding these interconnections provides a foundation for developing more effective approaches to male cancer care, particularly in addressing the complex barriers to screening, treatment, and support service utilization (D. Huang et al., 2023).

The findings support the need for integrated approaches that recognize masculinity as a fundamental structural element in healthcare delivery. Such approaches must address both visible and invisible barriers to care, acknowledging the complex ways in which masculine norms operate across different societal levels to influence health outcomes for men with prostate and testicular cancer (Griffith, 2024; Peate, 2004).

### *Micro Level (Individual)*

At the individual level, internalized masculine norms profoundly shape personal health behaviors and identity management (Addis & Mahalik, 2003; Darabos & Hoyt, 2017; Heise et al., 2019). Men often delay seeking medical consultation due to perceived role obligations, with many adopting stoic and self-reliant coping strategies (Arrington, 2008; Corboy et al., 2019). Research demonstrates a strong correlation between masculine identity scores and individual risk assessments, particularly in how men evaluate and respond to health threats (Albaugh, 2003; Bergelt et al., 2009; Coughlin, 2020; D. Huang et al., 2023). For many men, a cancer diagnosis represents a direct challenge to their masculine self-perception, leading them to prioritize maintaining traditional masculine roles over optimal health practices (Chambers et al., 2017; Maliski, 2007; E. Miller et al., 2021).

This prioritization manifests in multiple ways throughout the healthcare journey. Studies indicate that men scoring higher on traditional masculinity measures demonstrate significantly lower engagement with preventive health behaviors and screening services (Griffith et al., 2011; Hirschey et al., 2023; Levant & Richmond, 2007; Mursa et al., 2022; Noone & Stephens, 2008). Some qualitative studies have revealed complex negotiations between maintaining masculine identity and addressing health concerns, with many men expressing reluctance to acknowledge symptoms or seek medical attention (Drummond & Gough, 2018; Gough, 2006; Oliffe, 2023; Seidler et al., 2024).

The impact extends beyond initial help-seeking to influence ongoing treatment decisions and healthcare engagement. Men frequently make healthcare choices based on perceived threats to their masculine identity, particularly regarding support service utilization (Galdas et al., 2023; Seidler et al., 2024). Despite acknowledging potential benefits, many reject psychological support and other auxiliary services that could improve their health outcomes (Arrington, 2010; Chambers et al., 2016; Hoyt et al., 2020; Silvergleid, 2005; Wang & Hoyt, 2020). This pattern reflects a broader tendency to prioritize independence and stoicism over comprehensive medical care, even when such choices may compromise overall health status (Addis & Mahalik, 2003; Mahalik et al., 2007; Noone & Stephens, 2008).

### *Meso Level (Intermediary)*

Healthcare systems often adapt to and reinforce masculine norms through their structures, policies, and clinical practices, which can create significant barriers to men's engagement with healthcare services. For instance, traditional masculine norms, such as the expectation for men to be tough and self-reliant, can discourage them from seeking medical help, leading to delayed or avoided healthcare utilization (Novak et al., 2019).

Clinical environments may unintentionally reinforce traditional gender stereotypes, potentially discouraging men's engagement with healthcare services. For example, healthcare providers might modify their communication and clinical approaches based on patient gender, sometimes unconsciously reinforcing traditional masculine norms. These adaptations, while intended to accommodate male patients, can result in clinical protocols that overlook the complex influence of masculinity on treatment adherence (Seidler et al., 2024).

The impact of institutional structures extends to follow-up care systems and provider-patient interactions. Healthcare institutions' systematic patterns often fail to accommodate or effectively address problematic aspects of masculine health behaviors. These structural barriers manifest throughout the care delivery process, contributing to significant disparities in support service utilization and healthcare engagement (Hay et al., 2019). While healthcare systems attempt to adapt to perceived male preferences, these adjustments sometimes perpetuate rather than resolve barriers to effective healthcare delivery (Mursa et al., 2022).

### *Macro Level (Structural)*

Societally, broader cultural, economic, and policy structures significantly shape masculine health behaviors (Ragonese et al., 2019). Media representations and workplace cultures frequently reinforce problematic attitudes toward health maintenance, creating environments where preventive care and help-seeking behaviors conflict with traditional masculine expectations (J. Goodwin & Behan, 2023). These cultural norms intersect with policy frameworks that often fail to adequately address gender-specific barriers to healthcare access and utilization (Ochs et al., 2024).

Economic factors play a particularly crucial role in shaping men's healthcare engagement. Employment patterns and financial priorities influenced by traditional masculine roles can significantly limit healthcare accessibility (Palmer et al., 2024)**.** Insurance coverage gaps disproportionately affect male-specific health services, while workplace policies may inadvertently discourage men from seeking necessary medical care (Ragonese et al., 2019). These structural barriers contribute to persistent health disparities among different male populations (Airhihenbuwa & Liburd, 2006; Borno et al., 2019; Griffith et al., 2011; Powell et al., 2019)

Public health messaging and policy implementation often overlook the complex relationship between masculinity and health behaviors (Milner et al., 2019)**.** Research indicates that men who strongly identify with traditional masculine norms demonstrate lower engagement with preventive health services and are less likely to seek support when needed (Griffith, 2024; Powell et al., 2019). This pattern becomes particularly evident in mental health services, where cultural stigma combines with masculine norms to create significant barriers to care access and utilization (Zhou et al., 2022). Similarly, men diagnosed with prostate and testicular cancer often struggle with mental health challenges linked to their perceptions of masculinity. However, support services remain underutilized due to stigma and gendered expectations of self-reliance (Wang & Hoyt, 2020)**.**

Understanding the interplay between masculinity, structural barriers, and health outcomes is crucial for designing policies and healthcare interventions that better address men's unique health needs while challenging harmful gender norms. The Methods and Results section will explore these themes.

### Intersections of Masculinity, PCa and TCa, and Structural Competency

The convergence of masculinity, prostate and testicular cancer, and structural competency provides a nuanced understanding of the challenges and disparities in male-specific healthcare. These three concepts intersect to illuminate how societal norms, individual behaviors, and systemic factors collectively shape men’s experiences with health and illness, particularly regarding cancers that predominantly affect men. This section explores the implications of these interactions, emphasizing the need for integrated approaches that consider cultural constructs, healthcare delivery, and policy reform.

Masculinity, as a socially constructed and culturally reinforced concept, significantly influences men’s health behaviors and engagement with healthcare systems. Dominant norms of masculinity often valorize traits such as independence, emotional stoicism, and physical strength (Braverman, 2020; Courtenay, 2000; Griffith et al., 2011). While these ideals may serve as sources of identity and pride, they also act as barriers to health-seeking behaviors, particularly in the context of preventive care and early detection of illnesses like prostate and testicular cancer (Aoun et al., 2002; Burns & Mahalik, 2007; Paterson et al., 2015).

Men who adhere to traditional masculine norms are statistically less likely to seek medical help, even when experiencing symptoms indicative of severe health conditions (Craike et al., 2016; Galdas et al., 2005; George et al., 2022). This reluctance is partly driven by the perception that seeking medical help is a sign of weakness or vulnerability, attributes often deemed incompatible with traditional masculinity (Clowes, 2013; Fitzpatrick, 2016; Matos et al., 2024).

In the specific context of prostate and testicular cancer, these behaviors are further compounded by the nature of the screenings and treatments involved. PSA tests, digital rectal exams, and testicular self-examinations can be perceived as invasive or embarrassing, discouraging men from participating. This avoidance behavior delays diagnosis and treatment, leading to advanced disease states and poorer overall outcomes (Chapple et al., 2004; Cieślikowski et al., 2023; D. B. Miller et al., 2021).

Prostate and testicular cancers occupy a unique space in the intersection of masculinity and health due to their direct impact on sexual and reproductive functions—central aspects of many men’s self-identity. Treatments for prostate cancer, such as prostatectomy, radiation therapy, and androgen deprivation therapy, often result in side effects like erectile dysfunction, infertility, and urinary incontinence. Similarly, treatments for testicular cancer, including orchiectomy and chemotherapy, may affect body image and perceptions of sexual adequacy (Bowie et al., 2020; Brederecke et al., 2021; Chapple et al., 2004; Gurevich et al., 2004).

These physical and psychological side effects challenge traditional masculine ideals, exacerbating feelings of inadequacy, shame, or emasculation. Research highlights that men undergoing treatment for these cancers often report significant distress, not only due to the disease itself but also because of the perceived threat to their masculinity. This distress can further discourage men from seeking follow-up care, participating in support groups, or disclosing their health struggles to others, perpetuating cycles of isolation and poor mental health (B. C. Goodwin et al., 2018; Green, 2017; Matteucci, 2015; Rubin et al., 2020).

The stigma surrounding these conditions and treatments also impacts men’s willingness to engage with healthcare services (Arrington, 2015; Gannon et al., 2004; Goffman, 1963; Knapp et al., 2014). Many men fear being judged or misunderstood by healthcare providers who lack training in addressing the intersection of masculinity and health. This gap underscores the importance of structural competency in creating healthcare environments that are sensitive to the unique needs and experiences of men with prostate and testicular cancer (Anderson et al., 1998; Boberg et al., 2003; Boele et al., 2019).

Structural competency provides a critical framework for addressing the systemic factors that shape health disparities in prostate and testicular cancer care. Unlike traditional approaches that focus solely on individual behaviors, structural competency emphasizes the role of social, economic, and institutional structures in influencing health outcomes (Metzl & Hansen, 2014; Springer & Mouzon, 2011). This perspective is particularly valuable in addressing the challenges posed by masculinity and its impact on health behaviors.

A key aspect of structural competency is recognizing how healthcare systems often overlook the cultural and gender-specific needs of men. Many clinics and health programs fail to account for masculine norms, creating environments that feel unwelcoming or irrelevant to male patients (Kelley et al., 2015; S. Robertson et al., 2015; Schofield et al., 2012; Silvergleid, 2005). Structural competency advocates for redesigning these systems to incorporate male-friendly approaches (Houman et al., 2020; *Men and HIV*, 2023), such as flexible service hours that accommodate working men's schedules and significantly increasing attendance rates for screenings and follow-ups (Ruspini et al., 2011). This allows men to access healthcare services outside of traditional work hours, reducing barriers related to time constraints and improving overall engagement with health services. *Targeted health campaigns* that frame preventive care through masculine traits like strength and responsibility enhance participation and receptiveness to health interventions (Oliffe & Phillips, 2008; Seaton et al., 2017).

By aligning health messages with traits that resonate with traditional masculine values, these campaigns encourage greater participation in health-promoting behaviors and foster a more receptive attitude toward preventive care. Some evidence shows that *workplace-based initiatives,* like integrating health screening programs into workplace settings, can be an effective strategy for normalizing health-seeking behaviors among men (Malik et al., 2014). These initiatives leverage the existing workplace social and organizational structures, making healthcare more accessible and convenient. This results in significantly higher participation rates than in traditional clinic settings, where men may feel less comfortable or encounter logistical barriers.

## Intersectional Implications of Masculinity and Health Disparities

An intersectional analysis (Collins, 1997; Crenshaw, 1991) reveals that the impact of masculinity on health is not uniform but varies across different social identities and contexts. Factors such as race, ethnicity, socioeconomic status, and geography intersect with masculine norms to create compounded barriers to care. Structural competency emphasizes addressing these intersecting factors through culturally tailored interventions (Griffith et al., 2007, 2011; Metzl & Hansen, 2014). Healthcare providers must be equipped to navigate the complexities of these overlapping identities, ensuring that care is equitable and responsive to men's diverse experiences. Training programs focused on structural competency have shown promise in reducing disparities by fostering greater cultural awareness and sensitivity among healthcare professionals.

### *Masculinity as a Structural Element (within Health Behavior and Healthcare Models)*

Masculinity, as a cultural and societal construct (R. W. Connell & Messerschmidt, 2005), profoundly influences individual health behaviors and the delivery of healthcare services. The norms, values, and expectations that shape masculine identity extend beyond personal attitudes and behaviors to structurally influence healthcare systems (Griffith et al., 2013). As a structural element, masculinity impacts how men approach health behaviors, such as seeking preventive care or treatment, and shapes the healthcare environments designed to meet their needs. Understanding how masculinity functions as a structural element within healthcare makes it evident that its role extends far beyond individual identity—it is embedded in both individual health practices and healthcare system structures.

This section will explore how masculinity influences health behaviors and healthcare models, focusing on the impact of masculine norms, identity, and societal expectations. This analysis will highlight the interplay between masculine ideals and health outcomes, focusing on cancer screening, health-seeking behaviors, and the delivery of male-specific medical care.

### *Masculinity and Health Behavior*

At the individual level, masculinity significantly influences health behaviors, particularly in areas related to self-care, illness prevention, and health-seeking behaviors (de Keijzer, 2021; Hoyt et al., 2020; Matos et al., 2024; Mursa et al., 2022). Masculine norms, which often emphasize traits such as toughness, stoicism, and independence, can directly conflict with behaviors typically associated with seeking medical care. Health behaviors such as regular check-ups, cancer screenings, and seeking professional help for symptoms are frequently perceived as unmanly or a sign of weakness, especially in men who strongly adhere to traditional masculine values (Mahalik et al., 2007; Wade, 2009). These cultural expectations discourage many men from engaging in preventive care or addressing health concerns promptly, which can lead to adverse health outcomes.

For example, prostate cancer screening, a critical tool for early detection of the disease, is often underutilized by men, particularly older men, who might feel discomfort or anxiety surrounding the procedure. Many men who are eligible for prostate cancer screenings fail to participate despite evidence that early detection significantly improves survival rates. This reluctance is tied to deeply ingrained masculine values that equate strength with self-reliance and emotional restraint (James et al., 2017; Muermann & Wassersug, 2022; Zare et al., 2016). These norms discourage vulnerability, and in the case of cancer screenings, they can prevent men from acknowledging the potential risks to their health, leading to delayed diagnoses and less favorable outcomes.

In many cases, the stigma surrounding certain types of medical interventions, such as the need for cancer screenings, stems from a perceived conflict between these healthcare practices and traditional masculine ideals (Spratt et al., 2021). Men may feel that engaging with healthcare systems for preventive services undermines their sense of control or invulnerability, which is central to masculine identity (Akin-Odanye & Husman, 2021; Z. Huang et al.., 2020). Moreover, seeking medical advice can be seen as a challenge to the image of masculinity that values self-sufficiency and emotional detachment. These psychological barriers, then, have a significant influence on men’s health decisions, resulting in an underrepresentation of men in preventive care initiatives, such as screenings for prostate or testicular cancer.

Thus, masculinity operates as a critical structural factor shaping men's health behaviors, particularly in contexts where health risks are perceived as threats to masculine identity. The avoidance of healthcare services, particularly those related to prevention and early detection, has profound implications for individual health outcomes and public health initiatives that seek to reduce disease incidence and improve men's health outcomes.

### *Masculinity and Healthcare Models*

Beyond individual health behaviors, masculinity also shapes the broader healthcare system by influencing how services are structured and delivered. Healthcare systems—both in terms of medical care and public health strategies—are often designed without a specific focus on the particular needs of men (Hammond et al., 2010; Mokua et al., 2024; Persson et al., 2022; Seidler et al., 2024). This gap can lead to less effective engagement with male patients, especially in areas related to cancer care, mental health services, and chronic disease management.

While these systems may serve the general population, the failure to address the unique health concerns of men, particularly those influenced by masculinity, contributes to significant health disparities. Masculinity as a structural element is evident in the way healthcare models often fail to account for how masculine identity shapes health-seeking behaviors. Men, particularly those who identify strongly with traditional masculine values, may be less likely to seek medical care or adhere to treatment plans due to concerns about vulnerability, fear of stigmatization, or the perception that seeking medical help challenges their masculine identity. For instance, a man experiencing symptoms of testicular cancer may delay seeking treatment because doing so may be perceived as “weak” or “unmanly.” This cultural pressure can result in delayed diagnoses, poorer treatment outcomes, and a lower quality of life.

The design of healthcare services must also be considered within the context of masculinity. Healthcare models are typically based on a one-size-fits-all approach, with little attention paid to men's unique needs and preferences. For example, services for men’s health often fail to recognize the challenges men face in accessing care, whether due to traditional gender roles, emotional reticence, or societal expectations of self-reliance (De Sousa et al., 2023; Lee et al., 2009; Leone et al., 2016; Mayer et al., 2012). Male patients may be less likely to seek care in environments where they feel that their masculinity is not acknowledged or respected. For instance, healthcare settings that emphasize emotional expression or nurturing may inadvertently alienate men who subscribe to more traditional masculine norms, further discouraging them from engaging with healthcare systems.

Moreover, many healthcare services are built around the needs of women, with protocols designed primarily for female patients, particularly in areas such as reproductive health. The lack of male-focused healthcare initiatives or spaces within medical institutions means that men often find it challenging to navigate the healthcare system, particularly in areas such as prostate or testicular cancer care. This gendered disparity in care delivery further exacerbates health inequalities between men and women, as men are less likely to participate in preventive care and are more likely to experience health problems that go undiagnosed or untreated due to masculine norms around self-reliance and stoicism.

In response to these challenges, the concept of *structural competency* (Metzl & Hansen, 2014)—the ability to understand and address the systemic factors that influence health—becomes vital. Structural competency in healthcare means recognizing how masculinity, as a societal construct, interacts with individual health behaviors and broader healthcare models. By adopting structural competency frameworks, healthcare providers can better understand the structural forces in men's health and create more inclusive, accessible, and effective healthcare services. Addressing masculinity within healthcare models would allow providers to design services that resonate more deeply with male patients, creating an environment in which men feel comfortable seeking care, adhering to treatment regimens, and engaging with preventative health measures.

To address the structural impact of masculinity on healthcare delivery and health behaviors, healthcare systems must redefine masculinity within their care models. This redefinition involves creating healthcare environments that challenge traditional masculine norms, encouraging men to engage more openly and proactively with their health. Healthcare systems must adopt gender-sensitive approaches and acknowledge the unique health behaviors, risks, and needs of men. This includes redesigning health messages to resonate with masculine identities and emphasizing the positive aspects of health-seeking behaviors, such as strength, responsibility, and resilience, rather than presenting health care as a sign of weakness.[28]

Moreover, integrating masculinity-sensitive approaches into healthcare services and outreach efforts can increase male participation in preventive health behaviors and improve overall health outcomes. For example, tailoring cancer screening campaigns to highlight how participating in screenings aligns with masculine ideals of strength and responsibility can make these services more appealing to men. Similarly, modifying clinical environments to be more male-friendly—offering male-specific support services, more flexible appointment scheduling, and peer support networks—can make healthcare more accessible and comfortable for men.

It is also essential for healthcare providers to receive training on how to engage with male patients in a way that respects their masculinity while still encouraging health-seeking behaviors. Healthcare professionals must be equipped with the knowledge and tools to navigate the complex

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[28] (Andreasson et al., 2023; Bowie et al., 2021; Burns & Mahalik, 2007; R. W. Connell & Messerschmidt, 2005; Dax et al., 2024; Griffith et al., 2012; S. Robertson et al., 2016; Wang & Hoyt, 2020)

relationship between masculinity and health, recognizing that masculinity does not have to be a barrier to healthcare but can be leveraged to motivate men toward better health outcomes.

## Conclusion

Ultimately, masculinity functions as a structural element in both health behavior and healthcare models by shaping how men approach health issues and how healthcare services are structured to meet their needs. Traditional masculine norms, which often prioritize independence, emotional restraint, and self-reliance, can discourage men from engaging in preventive care and seeking treatment. Healthcare systems, in turn, often fail to address the unique needs of men, leading to underutilization of services and poor health outcomes. By recognizing masculinity as a structural element and integrating this understanding into healthcare models, providers can create more effective, accessible, and inclusive care environments for men, ultimately improving health outcomes across male populations.

Through the incorporation of structural competency frameworks, healthcare systems can begin to dismantle the barriers that masculinity imposes on male health behaviors and healthcare delivery. By redefining masculinity in ways that promote positive health-seeking behaviors and adopting inclusive service delivery models, healthcare providers can enhance men's engagement with health services and contribute to improved health outcomes in male-specific cancers and beyond. Recognizing and addressing masculinity as a structural force within healthcare is not just a matter of improving individual health behaviors but also an essential step toward addressing broader health disparities and creating more equitable healthcare systems for men.

This dissertation examines the complex relationship between masculinity and healthcare outcomes, specifically focusing on prostate and testicular cancers. Through an interdisciplinary approach combining medical anthropology and social epidemiology, this research addresses critical gaps in understanding how masculinity affects health behaviors and outcomes.

# METHODS

This research employs a critical epistemological framework grounded in social constructivism, theories on masculinity, and structural competency, recognizing that knowledge is shaped by social, cultural, and historical contexts. Masculinity, as a social construct, operates as a structural determinant of health, influencing individual behaviors, institutional practices, and broader health disparities. By adopting a constructivist lens, this study critically examines how gender norms and health outcomes are co-constituted within sociopolitical structures, moving beyond essentialist interpretations of masculinity and health behavior (Courtenay, 2000).

Methodologically, this study synthesizes findings across multiple manuscripts, integrating qualitative and quantitative approaches to provide a comprehensive analysis of prostate and testicular cancer vulnerabilities. The methodological pluralism employed ensures that the research captures both individual experiences and broader structural patterns, aligning with a multilevel determinants framework. The integration of qualitative synthesis, meta-analysis, and empirical studies allows for a nuanced understanding of how masculinity, advocacy, and structural barriers shape health outcomes.

Mixed research synthesis, which combines results from both qualitative and quantitative studies, is particularly valuable in health research. This approach facilitates a more comprehensive understanding of complex health issues by integrating diverse forms of evidence (Sandelowski et al., 1997, 2010; Sandelowski & Leeman, 2012; Thorne et al., 2004)**.** Meta-analysis, of qualitative studies, aggregates data from multiple studies to identify overarching trends and strengthen the empirical basis for assessing disparities in prostate and testicular cancer care. These qualitative methodologies provide depth through narrative and thematic analyses and explore lived experiences, sociocultural influences, and institutional barriers, offering a contextualized understanding of how masculinity intersects with health behaviors and healthcare access.

By combining these methodological strategies, this research ensures that individual narratives are not analyzed in isolation but are situated within broader structural and policy contexts. The inclusion of both qualitative and quantitative methods allows for the identification of patterns at different levels of analysis, facilitating a holistic understanding of gendered health disparities. This approach also enables critical engagement with health policies and advocacy efforts, highlighting areas where structural interventions are needed to address inequities.

In summary, this thesis adopts a critical and constructivist epistemological stance, supported by a multi-method approach that integrates meta-analysis, qualitative synthesis, and empirical research. This methodological framework not only enhances the robustness of the findings but also underscores the interconnectedness of individual experiences, cultural expectations, and structural determinants in shaping health behaviors and outcomes.

Six manuscripts comprehensively analyze male cancer vulnerabilities, progressing from individual insights into lived experiences and behaviors to broader structural analyses of advocacy, policy, and systemic barriers. Throughout each manuscript, masculinity and structural inequality themes are interwoven, connecting personal narratives to global health disparities. Although stated in the individual published manuscripts, ethical approval was obtained for all applicable studies.

Manuscripts are:

1. Qualitative studies on men with prostate cancer: a systematic meta-synthesis.
2. Estado de la cuestión de los estudios cualitativos sobre grupos de apoyo de afectados por cáncer de próstata.[29]
3. Testicular cancer and testicular self-examination: knowledge, attitude and practice among university students in Ghana.
4. Masculinities and prostate cancer: unpacking social vulnerabilities and perceived risk
5. The Structural and Intercultural Competence for Epidemiological Studies (SICES) guidelines: a 22-item checklist.
6. Structural competency in epidemiological research: what’s feasible, what’s tricky, and the benefits of a ‘structural turn’.

Manuscripts 1, 2, and 4 highlight the crucial role of advocacy and support in reshaping perceptions of susceptibility and care-seeking behaviors. In contrast, Manuscripts 3, 5, and 6 emphasize how structural and cultural factors contribute to health disparities and restrict timely,

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[29] State of the art qualitative studies on support groups for prostate cancer patient.

adequate care access. These manuscripts provide a holistic understanding of how masculinity and the Social Determinants of Health (SDOH) intersect to create unequal health outcomes.

Each manuscript makes a distinct yet complementary contribution to the broader understanding of masculinity, health behaviors, and health disparities. The shift from individual to structural analysis across these manuscripts reflects a layered approach to understanding health vulnerabilities.

Key themes across the manuscripts include masculinity, advocacy, and structural barriers, which emerge as interconnected determinants of health. The diverse methodologies employed—ranging from qualitative syntheses and scoping reviews to empirical studies—bring a nuanced perspective to the issue, while common theoretical underpinnings, such as gender theories and SDOH, ensure a cohesive framework.

Manuscripts 1 through 4 focus on advocacy and multilevel frameworks for prostate and testicular cancer, exploring how support systems and advocacy efforts influence health behaviors and access to care. Manuscript 3 expands upon the vulnerabilities faced by individuals, masculinity's role in these challenges, and the multilevel determinants of health, serving as a conceptual and thematic bridge between individual and structural analyses. Finally, Manuscripts 3, 5, and 6 delve deeper into the structural dimensions of health disparities. Manuscript 3 is pivotal in connecting these elements to the broader social and cultural factors.

The unpublished Manuscript 3 uniquely bridges health's social and structural dimensions, offering theoretical and practical insights. It enriches the overarching framework by examining masculinity as a structural and interactional determinant of health while also addressing gaps in advocacy and policy. Complementing the scoping review, it emphasizes the broader role of advocacy and smoothly transitions into the cultural and individual themes explored in the manuscript.

This compendium of manuscripts illuminates the complex interplay between individual behaviors, cultural expectations, and structural inequalities. Masculinity, as a social determinant of health, plays a pivotal role in shaping how men perceive, respond to, and navigate these cancers. This dissertation examines these dynamics, blending insights from medical anthropology and social epidemiology to explore how individual, community, and structural factors intersect to produce disparities in cancer outcomes.

Central to this work is the understanding that health behaviors and outcomes cannot be disentangled from broader social structures and cultural norms. Using a multi-level framework incorporating individual experiences, interactional dynamics, and structural forces, this dissertation addresses how masculinity influences risk perceptions, health-seeking behaviors, and systemic barriers to care. By focusing on the intersection of masculinity with Social Determinants of Health (SDOH), the chapters collectively advance our understanding of male cancer vulnerabilities and the potential for transformative interventions.

### Manuscript 1: Qualitative studies on men with prostate cancer: a systematic meta-synthesis.

A systematic meta-synthesis was conducted on qualitative studies on men with prostate cancer. The objective is to explore the lived experiences of men with prostate cancer, using a meta-synthesis to identify themes such as the disruption of masculine identities and the critical role of familial and professional support.

Research papers published up to 2024 are retrieved using Boolean search terms identified in the title and/or abstract of indexed documents in different databases - Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline.com, EBSCO's Academic Search Ultimate and Psychology and Behavioral Sciences Collection, Scopus, PsychInfo, PSICODOC, and PubMed. The search yielded 3,465 articles.

An iterative, “start-stop approach was used during three phases. Phase 1, extracting text from results and findings sections. Phase 2, coding and development of descriptive themes. Moreover, phase 3 generates analytical themes using grounded theory methodology (CHARMAZ, 2014). Manuscripts were reviewed and synthesized in groups of 10-15.

One-hundred and forty-three studies met the objectives of the meta-synthesis and adhered to the inclusion criteria. A ten-question checklist, the Critical Appraisal Skills Programme (CASP) tool, was used to assess these studies. If it was met, a score of ‘1’ was appointed to each criterion;

studies that scored an eight or above were considered 'high quality' studies. One hundred and three manuscripts received this qualification and are included finally in the meta-synthesis.

The Preferred Reporting Items for Systemic Reviews and Meta-Analyses (PRIMA) (PAGE et al. 2021) are utilized.

**INDEXATION DATA**:

- **JCR (SSCI):** JIF: 2.1; Categories: NURSING [Q2; 53/193]; PUBLIC, ENVIRONMENTAL, & OCCUPATION HEALTH [Q2; 204/408]; SOCIAL SCIENCES; BIOMEDICAL [Q2; 18/48]
- **SCOPUS:** Site Score: 3.2; Categories: NURSING- Fundamentals and Skills [3/15; 85th percentile]; NURSING- Issues, Ethics and Legal Aspects [16/46; 66th percentile]
- **DOI:**10.1080/17482631.2024.2436720

### Manuscript 2: Estado de la cuestión de los estudios cualitativos sobre grupos de apoyo de afectados por cáncer de próstata

Manuscript 2 is a narrow focus of the studies reviewed from Manuscript 1. Whilst the first study aimed to synthesize data from qualitative studies of men with prostate cancer, this study selected studies that specifically support groups for the selection of participants and/or conducted their research using focus groups and discussed the role of 'support,'

This scoping review aimed to identify the diverse benefits of support groups, including camaraderie, information-sharing, and advocacy, as well as the role and function of masculinity within these settings and experiences.

A Boolean search term across Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline.com, EBSCO's Academic Search Ultimate and Psychology and Behavioral Sciences Collection, Scopus, PsychInfo, PSICODOC, and PubMed databases yielded 3.534 studies. Further selection and appraisal using the CASP tool included thirty-four studies for review.

The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ETREQ) (TONG ET AL 2012) was utilized.

**INDEXATION DATA**: Latindex; ERIHPlus

**DOI:** 10.17345/aec

## Manuscript 3: Masculinities and prostate cancer: unpacking social vulnerabilities and perceived risk[30]

This study forms part of the doctoral research conducted for this thesis. This qualitative study utilized semi-structured interviews and a constructivist grounded theory approach to explore and interpret the lived experiences of men diagnosed with prostate cancer (PCa). The constructivist grounded theory framework enabled an in-depth understanding of participants' narratives, capturing the complexity of how men perceive their susceptibility to and the severity of PCa. A multi-level determinants framework guided the examination of factors shaping participants' experiences and perceptions of vulnerability and disease severity.

Purposive sampling was employed to recruit men with a PCa diagnosis, irrespective of their treatment status, ensuring a diverse and nuanced representation of experiences. Participants were recruited through prostate cancer organizations, support groups, and patient registries. After initial contact, potential participants were provided with a brief overview of the study's objectives, and interviews were scheduled with those who expressed interest. Recruitment occurred between June 2020 and March 2024. Based on their preferences, interviews were scheduled at the participant's convenience and conducted in person or via video call.

The interviews were open-ended, guided by a topic outline informed by existing literature on masculinity and health behaviors. Key themes included experiences with PCa diagnosis, perceptions of vulnerability, health-seeking behaviors, and the influence of masculinity on PCa experiences. Participants were encouraged to recount their cancer journey in a manner that felt natural to them. The patient-led approach allowed the conversation to flow organically, with prompts used as needed to address topics such as stigma, health-seeking behaviors, support group involvement, masculinity, treatment decision-making, and post-treatment quality of life.

Each interview, lasting between 45 minutes and 2.5 hours, was audio-recorded, with all data anonymized to maintain confidentiality. Participants were assured of their right to withdraw from the study at any time without repercussions, and pseudonyms were assigned in transcripts and reports to protect their identities.

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[30] Unpublished

### Manuscript 4: Testicular cancer and testicular self-examination: knowledge, attitude, and practice among university students in Ghana.

This is a web-based, cross-sectional study that assesses knowledge, attitude, and practices (KAP) regarding testicular cancer (TCa) and testicular self-examinations (TSE) among undergraduate male university students at Kwame Nkrumah University of Science and Technology (KNUST) in southern Ghana. Self-reported questionnaires were completed by 391 undergraduate male students aged 17 to 35.

The survey included five sections that covered individual-level barriers, including knowledge gaps on TCa and cultural norms affecting self-examination practices. Section 1 collected basic socio-demographic information and academic details like program of study and academic year. A three-point Likert scale measured TCa and TSE knowledge (Section 2) and attitude (Section 3). Section 4 explored TSE occasion, location, frequency, and technique; the last section, Section 5, addressed perceived barriers to TSE.

**INDEXATION DATA**: Directory of Open Access Journals (DOAJ)

### Manuscript 5: The Structural and Intercultural Competence for Epidemiological Studies (SICES) guidelines: a 22-item checklist

Structural and intercultural competence approaches have been widely applied to medical training, healthcare practice, policies, and health promotion. Nevertheless, their systematic implementation in epidemiological research is absent. Based on a scoping review and a qualitative analysis, this article proposes a checklist to assess cultural and structural competence in epidemiological research: the Structural and Intercultural Competence for Epidemiological Studies guidelines.

These guidelines are organized as a checklist of 22 items and consider four dimensions of competence (awareness and reflexivity, cultural and structural validation, cultural and structural sensitivity, and cultural and structural representativeness), which are applied to the different stages of epidemiological research: (1) research team building and research questions; (2) study design, participant recruitment, data collection, and data analysis; and (3) dissemination. These are the first guidelines addressing structural and cultural competence in epidemiological inquiry.

**INDEXATION DATA:**

- **JCR:** JIF: 8.061; JCI: 1.58; Category: PUBLIC, ENVIRONMENTAL & OCCUPATION HEALTH [**SCIE**: Q1; 24/210; 88.81st percentile] **[SSCI:** Q1; 11/182; 94.23rd percentile]
- **SCOPUS:** CiteScore: 7.2; Category: MEDICINE- Health Policy [13/265; 95th percentile]; MEDICINE – Public Health, Environmental and Occupational Health [46/562; 91st percentile]
- **DOI:**10.1136/bmjgh-2021-005237

**Manuscript 6: Structural competency in epidemiological research: What's feasible, what's tricky, and the benefits of a 'structural turn'**

Structural competency is an emerging paradigm for training health professionals and creating a common language addressing structural processes that determine health disparities. However, its application to epidemiological design and research is absent. Based on our previous proposal of a tool for Structural and Intercultural Competency in Epidemiological Studies, the SICES guidelines, in this article, we analyze the possibilities and challenges of a 'structural turn' in epidemiology. In terms of possibilities, we recognize the value of paradigms from multiple parts of the world, such as social and sociocultural epidemiology, critical epidemiology, and collective health, in facilitating a structural turn in epidemiological studies. In this framework, structural competency would provide a new angle by focusing on what to research (e.g., inequalities) and what skills and attitudes (e.g., cultural and epistemic humility). The challenges lie in the inclusion of reflexivity and a comprehensive view in the context of a positivist epidemiology oriented towards obtaining evidence from a biomedical, but not social, perspective.

**INDEXATION DATA**

- **JCR (SSCI):** JIF: 2.3; Category: PUBLIC, ENVIRONMENTAL & OCCUPATION HEALTH [Q2; 179/408; 56.3rd percentile] ; JCI: 0.73, Category: PUBLIC, ENVIRONMENTAL & HEALTH[Q2; 172/408; 57.97th percentile]
- **SCOPUS:** CiteScore: 6.5; Category: MEDICINE – Public Health, Environmental and Occupational Health [117/665; 82nd percentile]
- **DOI:**10.1080/17441692.2023.2164903

Collectively, the six manuscripts that comprise this dissertation contribute to a multidimensional analysis of how masculinity intersects with health-seeking behaviors, social determinants, and structural inequities in prostate and testicular cancer care. Building on these insights, this dissertation is structured around three core objectives that guide its overarching contributions by seeking to:

1. **Examine** how masculine cultural norms influence men's health-seeking behaviors and their experiences with prostate and testicular cancers, mainly focusing on perceptions of vulnerability and illness.
2. **Investigate** the social and structural determinants that create disparities in cancer awareness, diagnosis rates, and treatment outcomes among different male populations.
3. **Develop** recommendations for incorporating structural and intercultural competence into healthcare frameworks.

By addressing these objectives, this dissertation contributes to the theoretical understanding of masculinity as a health determinant and the practical applications of structural and cultural competence in healthcare delivery. Ultimately, this research seeks to inform more equitable, patient-centered models of care that improve outcomes and reduce disparities in male-specific cancer care. **Table 1. Manuscripts and Objectives** describes the general objectives of the thesis and from which the articles produced are coherently derived.

**Table 1. Manuscripts and Objectives**

| **MANUSCRIPT** | **OBJECTIVE 1:** Examine how masculine cultural norms influence men's health-seeking behaviors and their experiences with prostate and testicular cancers, mainly focusing on perceptions of vulnerability and illness. | **OBJECTIVE 2:** Investigate the social and structural determinants that create disparities in cancer awareness, diagnosis rates, and treatment outcomes among different male populations. | **OBJECTIVE 3:** Develop recommendations for incorporating structural and intercultural competence into healthcare frameworks. |
|---|---|---|---|
| **MANUSCRIPT 1:** *Qualitative studies on men with prostate cancer: a systematic meta-synthesis* | **X** | | |
| **MANUSCRIPT 2:** *Estado de la cuestión de los estudios cualitativos sobre grupos de apoyo de afectados por cáncer de próstata* | **X** | | |
| **MANUSCRIPT 3:** *Masculinities and prostate cancer: unpacking social vulnerabilities and perceived risk* | **X** | **X** | **X** |
| **MANUSCRIPT 4:** *Testicular cancer and testicular self-examination: knowledge, attitude, and practice among university students in Ghana.* | **X** | **X** | |
| **MANUSCRIPT 5:** *The Structural and Intercultural Competence for Epidemiological Studies (SICES) guidelines: a 22-item checklist* | | | **X** |
| **MANUSCRIPT 6:** *Structural competency in epidemiological research: What’s feasible, what’s tricky, and the benefits of a ‘structural turn’* | | | **X** |

# RESULTS

## Study I: Qualitative studies on men with prostate cancer: A systematic meta-synthesis

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# Qualitative studies on men with prostate cancer: a systematic meta-synthesis

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**ABSTRACT**

**Purpose:** Prostate cancer (PCa) is the second most common cancer among men. Despite advancements in clinical interventions and improvements in public health outreach, a multidimensional lack of understanding of the lived experiences of men diagnosed with PCa continues. Improving the quantity and quality of knowledge about this subject could guide clinical decisions and interventions for this group.
**Methods:** This paper reviews qualitative studies focusing on PCa patients using the Critical Appraisal Skills Programme tool (CASP), synthesizes the data, and maps the overarching themes through a systematic meta-synthesis.
**Results:** The authors identified 3546 manuscripts, of which 103 met the inclusion criteria. Six themes were identified that addressed: support needs, diagnosis, and treatment experiences, lived experiences, information accessibility, care, and threats to masculinity.
**Conclusion:** Treatment side-effects caused a re-configuration and re-evaluation of masculine ideologies. Men mainly relied on close family and support groups to cope with their feelings of stigma, uncertainty, and recovery. Professional healthcare and consultation quality eased their anxiety concerning long-term treatment and other factors associated with their condition. The studies were socio-demographically heterogeneous. Thus, researchers could use qualitative research to explore knowledge gaps in the following interconnected themes: masculinity care, masculinity support, masculinity information, and incorporating a more diverse socio-demographical sample.

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**KEYWORDS**
Men; prostate cancer; qualitative studies; review; meta-synthesis; critical appraisal skills programme tool

## Introduction

Prostate cancer (PCa) is the second most commonly diagnosed cancer in men worldwide (Sung et al., 2021). Despite advancements in screening and prostate health strategies (Ilic et al., 2013), the global burden of PCa (Xia et al., 2022) is projected to grow over the next 15 years (Culp et al., 2020), with significant regional variations influenced by differences in clinical practices, healthcare resources, and health-seeking behaviours. A key contributor to these disparities was the widespread introduction of the prostate-specific antigen (PSA) test in the 1990s (Catalona, 2014). This non-invasive diagnostic tool transformed early detection efforts but sparked debates about its efficacy and the potential negative impact on patients' quality of life (Kim & Andriole, 2015).

Masculine ideologies (Connell, 1995; Connell & Messerschmidt, 2005) further complicate the PCa burden, as societal expectations around masculinity often discourage men from seeking timely diagnosis and treatment. Feelings of embarrassment (Fish et al., 2015), the desire for self-reliance or emotional control (Burns & Mahalik, 2007), and concerns about treatment-related changes to their bodies (King-Okoye et al., 2019), perceptions about how lifestyle modifications impact PCa (Yannitsos et al., 2020), and concerns about sexual performance (Seidler et al., 2016) are among the barriers that influence men's health behaviours. These cultural and psychological factors underscore the importance of understanding the lived experiences of men with PCa to develop tailored interventions.

Although qualitative research has explored various aspects of PCa, previous studies often lacked focus, using mixed-gender or mixed-diagnosis samples, which dilute insights into the unique perspectives of men. Two studies that interviewed approximately 20 patients with various cancers included only one PCa patient (Guo et al., 2021; Mackenzie et al., 2016). In other studies, researchers labelled participants as "informants" (Godskesen et al., 2013) or numbers (e.g., #4; #7) (Mazzoni et al., 2019; Walshe et al., 2017). Some studies provided quotes without indicating who said what (Juul Søndergaard et al., 2021; Morris et al., 2012; Van Gurp et al., 2020).

Although meta-synthesis reviews of qualitative studies on PCa patients have scoped and summarized various topics, including the relationship between PCa and body image, masculinity, and self-esteem (Bowie

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et al., 2020), screening, diagnosis, post-treatment support and survivorship in Black and African-American men (Bamidele et al., 2022; Bergner et al., 2018; Okoro et al., 2021), post-treatment and masculinity in gay and bisexual men (Alexis & Worsley, 2018), the impact of radical prostatectomy (RP) on quality of life (Carrier et al., 2018), self-initiated coping strategies (Spendelow et al., 2018), and treatment decision-making (Kandasamy et al., 2017), among others (Araújo & Zago, 2019; Ihrig et al., 2020; James et al., 2017; King et al., 2015; Kong et al., 2017; Langelier et al., 2022; Matheson et al., 2017; Rivas et al., 2016; Saab et al., 2018), they included qualitative studies that used mixed group samples. Additionally, the heterogeneity in study populations and methodologies has made it difficult to identify overarching themes or draw meaningful conclusions about men's experiences.

Researchers must examine and understand the details of PCa patients' perspectives on their unique experiences to achieve specific health solutions and better patient outcomes. To address these gaps, this review employs a systematic meta-synthesis of qualitative studies that explored the lived experiences of men with PCa. By synthesizing data, this review aims to identify and synthesize congruent and convergent themes regarding their experiences.

## Methods

This systematic meta-synthesis aimed to review all qualitative studies on men with PCa using the following methodology adapted from Gewurtz (Gewurtz et al., 2008): (1) identify relevant research questions, (2) set inclusion and exclusion criteria, (3) identify and retrieve studies, (4) assess the quality of the studies, and (5) synthesize findings from across the studies.

### *Study selection*

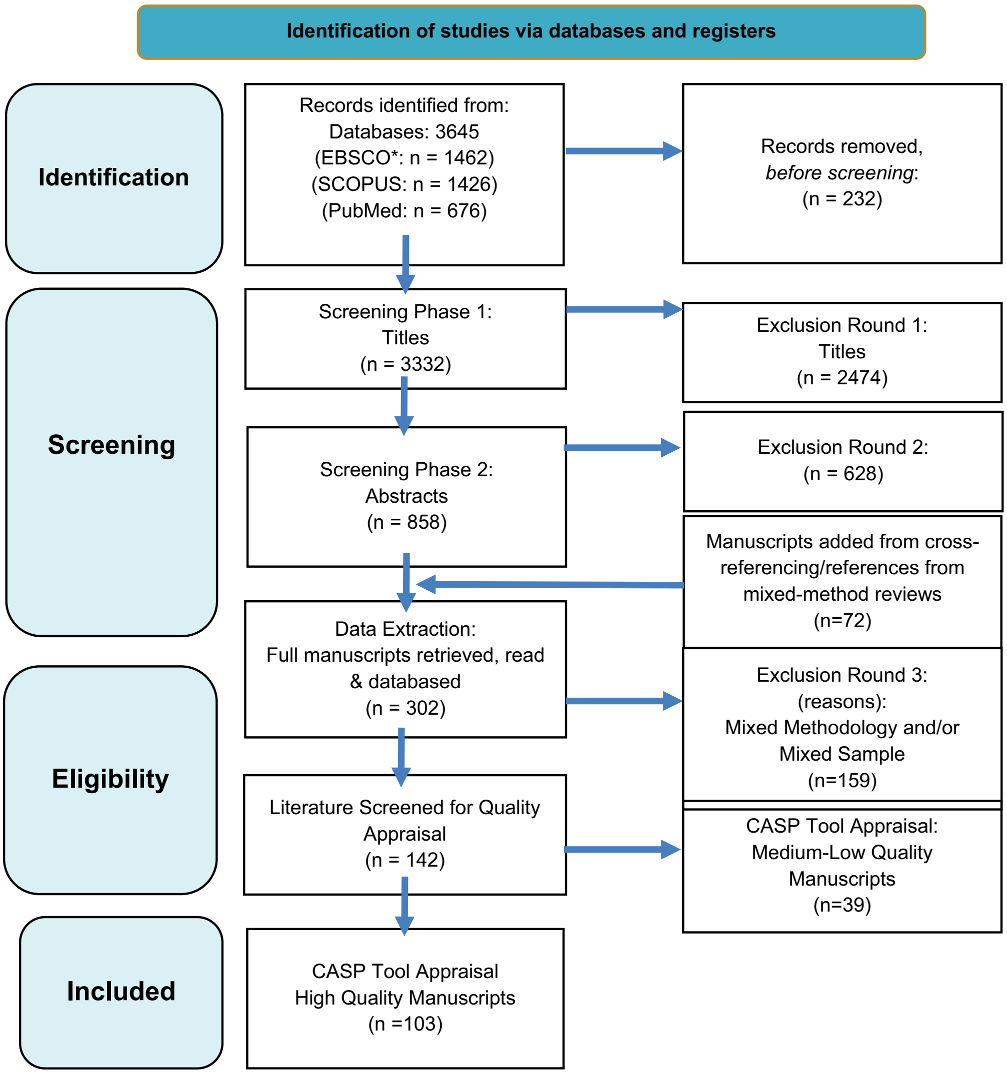
The search targeted original, peer-reviewed qualitative studies published before 2024 using databases such as the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline.com, EBSCO's Academic Search Ultimate and Psychology and Behavioral Sciences Collection, Scopus, PsychInfo, PSICODOC, and PubMed. Boolean search terms —"prostate cancer"; "men"; and "qualitative"-yielded 3,564 articles. Following the Preferred Reporting Items for Systemic Reviews and Meta-Analyses (PRISMA) (Page et al., 2021) guidelines (Figure 1. Literature Search Flowchart) 302 manuscripts, based on their titles and abstracts, were retrieved, read and catalogued using Microsoft Excel (2021) (Table 1. Literature Characteristics Matrix). Manuscript characteristics included authors' names, title, journal, publication date, aim, research question, sample (men; mixed groups- partners, caretakers, HCPs, other cancer groups), sample size, age group, cancer treatment method, recruitment site and strategy, study site, design, analysis, what was measured, and the results. Manuscripts were filtered to find studies that adhered to the inclusion criteria: studies that focused exclusively on men with PCa. That produced 142 qualitative studies.

### *Quality assessment*

The Critical Appraisal Skills Programme (CASP) tool was used to assess methodological rigour, ethical considerations, and reflexivity across studies using a ten-question checklist. The tool notes if studies meet each criterion using 1 for "yes" and 0 for "no". Following Alexis & Worsley's (2018) as guidance, the quality of each manuscript was determine by its final score: poor (1–5 points), medium (6–7 points), or high (8–10 points). One hundred and three manuscripts were valued as high quality (Table 2. CASP Tool Assessment).

### *Thematic synthesis*

An inductive thematic analysis (Braun & Clarke, 2006; J. Thomas & Harden, 2008) was conducted in three phases: (1) extracting text from each manuscript's results and findings section, (2) coding and developing descriptive themes, (3) generating analytical themes using grounded theory methodology (Charmaz, 2014). DB ensured the papers were relevant using an iterative screening and analysis process that involved breaking down the initial search results into groups of 50 manuscripts. To minimize selection bias, an interactive "stop-start" process was employed, allowing for comprehensive analysis in manageable segments. DB reviewed and synthesized blocks of 10 to 15 manuscripts. The start involved reading the entire manuscript without much analytical commentary. Then, DB read each manuscript and catalogued its characteristics in the Excel database. Afterwards, DB coded the "results" or "findings" sections. The "stop" occurred when DB finished each manuscript block before starting a new one. Review and synthetization of the extant literature occurred between July 2019 and January 2024. DB has more than ten years of experience conducting literature reviews and analysing and reporting qualitative research. One such review informed a checklist published in 2023 (Martinez-Hernaez, 2021). DB and AMH discussed the strategies and results from the review and synthesis to ensure the quality of the approach and appraisal. All the manuscripts are in the public domain. Therefore, it was unnecessary to receive ethical approval for this review.



* CINHAL, MEDLINE, Academic Search Ultimate, Psychology and Behavioral Sciences Collection, PsychInfo, PSICODOC

**Figure 1.** Literature search flowchart.

*CINHAL, MEDLINE, Academic Search Ultimate, Psychology and Behavioral Sciences Collection, PsychInfo, PSICODOC

## Findings

### *Thematic summary*

The thematic analytical process produced twenty-five descriptive themes (Table 3. Themes & Descriptions), which the authors synthesized into six overarching themes: *Diagnosis and Treatment, Care, Support, Information, Masculinity, and Lived Experience*

### *Diagnosis & treatment*

Participants described their experiences with PCa diagnosis and treatment decision-making as fraught with uncertainty and emotional burden. While some received their PCa diagnosis through a routine check-up with their physicians, others decided to consult a physician because of the discomfort of symptoms (erectile dysfunction, dysuria, haematuria):

> … I gotta go to the bathroom so much now at night. I go to the bathroom four, five, six times. And something's wrong. So I should get my prostate checked (Ferrante et al., 2011).

After diagnosis, many men faced the burden of choosing the best treatment option:

> My only regret was that I didn't get enough information at the beginning, or, hey, maybe I did, but I was never comfortable with the fact that I had really learnt everything that there was to learn about it because I actually made decisions, and I may or may not have made the wrong one (Chambers et al., 2018).

**Table 1.** Literature characteristics matrix.

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Aggarwal et al | Hospital Choice in Cancer Care: A Qualitative Study | Clinical Oncology | 2018 | To evaluate hospital choice policies from the perspective of men who received treatment for prostate cancer in the English National Health Service | n = 25 | 50–75yo | Radical treatment for non-metastatic prostate cancer | England, UK | semi-structured interviews | thematic content analysis |
| Anderson et al | African and Afro-Caribbean men's experiences of prostate cancer | British Journal of Nursing | 2013 | ● Explore African and Afro-Caribbean men's experiences of prostate cancer and their understanding of its associated risks.<br>● Gain an insight from these men's perspectives and ascertain whether a more focused health promotion strategy, and specific UK-based research, was needed in this area. | n = 3AA; 4=AC | 60-76yo | AS, radical robotic prostatectomy; HRT, HT | Southern England | in-depth, open-ended face-to-face interviews | thematic conceptual analysis framework |
| Arrington, MI | "I Don't Want To Be An Artificial Man": Narrative Reconstruction Of Sexuality Among Prostate Cancer Survivors | Sexuality and Culture | 2003 | Explores the ways in which prostate cancer survivors constructed stories of their illness experiences and the consequences for their sexual identifies. | n = 16 | N/A | N/A | Florida? | semi-structured interviews | narrative analysis |
| Arrington, MI | Prostate Cancer and the Social Construction of Masculine Sexual Identity | International Journal of Men's Health | 2008 | Inquires not only into dominant constructions of sexuality but also into possibilities of redefining sexuality and masculinity among prostate cancer survivors | N/A | N/A | N/A | Florida, US | mixed (collection of studies—PO, focus group,) | narrative paradigm, grounded theory |
| Arrington, MI | Uncertainty and Stigma in the Experiences of Prostate Cancer Survivors: A Thematic Analysis of Narrative Elements | Illness, Crisis & Loss | 2015 | Examines stigma and identity changes in prostate cancer survivors' illness accounts (within 5 years of diagnosis) | n = 16 | 66-81yo | radiation treatment; radical proctectomy; orchiectomy, watchful waiting | Southeastern US | semi-structured interviews | Thematic analysis, narrative analysis |
| Bamidele O.O, McCaughan E. | A constructivist grounded theory study on decision-making for treatment choice among Black African and Black Caribbean prostate cancer survivors | European Journal of Cancer Care | 2022 | Explores treatment decision-making among BA and BC men as influenced by a CaP illness diagnosis and a unique socio-cultural context. | n = 25 (8=BA; 17=BC) | 50-88yo | surgery, RT, BT, Chemo, cyber knife, cryotherapy | England | semi-structured interviews | constructivist grounded theory |
| Bell K., Kazanjian A. | PSA testing: Molecular technologies and men's experience of prostate cancer survivorship | Health, Risk & Society | 2011 | Drawing on ethnographic fieldwork in PCSG in Western Canada, seek to delineate the meanings the PSA test holds for prostate cancer survivors. | n = 8 | N/A | All stages of treatment | Canada | ethnography (p-o) | N/A |
| Bourke et al | A qualitative study evaluating experiences of a lifestyle intervention in men with prostate cancer undergoing androgen suppression therapy | Trials | 2012 | Conduct a qualitative evaluation of a pragmatic supervised exercise program in combination with dietary advice in men with advanced prostate cancer on AST. | n = 12 | published in another paper | AST (androgen suppression therapy) | South Sheffield, UK | focus group from an RC Intervention study | thematic framework analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Broom, A. | Virtually healthy: The impact of internet use on disease experience and the doctor-patient relationship | Qualitative Health Research | 2005 | Drawing on a study of the Internet usage of Australian men with prostate cancer, the author investigates how access to information and online support affects men's experiences of disease and, in particular, the possible implications of Internet-informed patients for the doctor-patient relationship. | n = 33 | N/A | N/A | Australia | unstructured, in-depth interviews | in-depth, exploratory, narrative analysis |
| Brown D, Oetzel J | Men's use of networks to manage communication tensions related to a potential diagnosis of prostate cancer | European Journal of Oncology Nursing | 2015 | Used relational dialectics theory to explore the communication tensions experienced by men who were on a prostate biopsy waiting list and how they managed these tensions using their communication networks | n = 36 | 54-81yo |  | New Zealand | in-depth, exploratory | content analysis; thematic analysis |
| Buote et al | Understanding Men's Experiences With Prostate Cancer Stigma: A Qualitative Study | Oncology Nursing Forum | 2020 | Explore the experiences and perspectives of men who have had prostate cancer to better understand the effect of prostate cancer and associated stigmas on men in the Canadian province Newfoundland and Labrador (NL) | n = 11 | N/A | post-treatment (surgery, RT, chemo) | Newfoundland and Labrador (NL), Canada | semi-structured interviews | socio-ecological framework |
| Burt et al | Radical prostatectomy: men's experiences and postoperative needs | Journal of Clinical Nursing | 2005 | Explore men's experiences after radical prostatectomy and whether they perceived their preoperative teaching adequately prepared them for postoperative recovery | n = 17 | 55-70yo | radical proctectomy | Alberta, Canada | semi-structured personal communication on days 2, 7, 21 and 120 post discharge; face-to-face interview with subset of five men | Descriptive; narrative analysis |
| Capistrant et al | Caregiving and social support for gay and bisexual men with prostate cancer | Psycho-Oncology | 2016 | Investigated the availability and provision of social support for gay and bisexual men with prostate cancer (GBMPCa). | n = 30 | 59-75yo | RP, Radiation, Other | Minnesota, US | personal communication | Thematic analysis |
| Carter et al | The supportive care needs of men with advanced prostate cancer | Oncology Nursing Forum | 2011 | Further understand the unmet healthcare needs of men with advanced prostate cancer, how these unmet needs affect their daily lives, and how the delivery of supportive care services could be improved to meet their needs. | n = 29 | 59-88yo | N/A | Central-Western Ontario | focus groups + interviews | thematic analysis? |
| Chambers et al | Experiences of Australian men diagnosed with advanced prostate cancer: A qualitative study | BMJ Open | 2018 | Explore men's lived experience of advanced prostate cancer (PCa) and preferences for support | n = 28 | 58-95yoi | ADT, RT, Prostatectomy | Australia | personal communication | Thematic analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Chapple et al | Is "watching waiting" a real choice for men with prostate cancer? A qualitative study | BJU International | 2002 | Understand what leads men to choose "watchful waiting" rather than active treatment for cancer of the prostate. | n = 47 | 50-85yo | watchful waiting (AS) | England | in-depth interview | thematic analysis |
| Cinà I.V,<br>Di Sebastiano K.M,<br>Faulkner, G.E | "One stroke, with twenty-two people": exploring prostate cancer survivors' participation in dragon boating | Journal of Psychosocial Oncology | 2020 | Explores prostate cancer survivors' experience in joining a dragon boating team and its possible impact on their wellbeing. | n = 11 | 56-73yo | varied | Vancouver, British Columbia, Canada | semi-structured interviews | thematic analysis |
| Cockle-Hearne, J.<br>Cooke, D.<br>Faithfull, S. | Developing peer support in film for cancer self-management: what do men want other men to know? | Supportive Care in Cancer | 2016 | Considers how to authentically communicate peer empathy in a one-way film narrative | n = 7 | 50-71yo | RP, EBRT, ADT | UK? | in-depth, semi-structured interview | thematic analysis |
| Cormie et al | A qualitative exploration of the experience of men with prostate cancer involved in supervised experience programs | Oncology Nursing Forum | 2015 | Provide an in-depth description of the experience of supervised exercise programs among men with prostate cancer and to identify elements critical to optimizing engagement and ongoing exercise participation. | n = 12 | 71-79yo | "mainstay therapies" | Perth, Australia | semi-structured interviews | interpretative phenomenological framework |
| Craike M.J, Livingston P.M, Botti M. | An exploratory study of the factors that influence physical activity for prostate cancer survivors | Supportive Care in Cancer | 2011 | Understand factors that influence participation in physical activity for survivors of prostate cancer and to examine changes in participation in physical activity pre- and post-diagnosis. | n = 18 | 53-79yo | Completed treatment (hormone therapy excluded) | Melbourne, Australia | qualitative (and two short questions) | thematic analysis |
| Culos-Reed et al | Qualitative Evaluation of a Community-Based Physical Activity and Yoga Program for Men Living With Prostate Cancer: Survivor Perspectives | Global Advances in Health and Medicine | 2019 | Examine patient perspectives on a community-based PC PA program, TrueNTH Lifestyle Management (TrueNTH LM); examining participants' experiences with motivation, social interactions, exercise benefits, barriers, and preferences as well as perspectives on program improvement and sustainability | men | n = 11 | 60-79yo | RP, chemo, radiation, ADT | Calgary, Canada | focus groups |
| Davison et al | Factors influencing men undertaking active surveillance for the management of low-risk prostate cancer | Oncology Nursing Forum | 2009 | Identify and describe how men arrived at their decision to go on active surveillance as a preliminary step to identifying what types of resources and supports might be of future benefit to them. | men | n = 25 | 50-80yo | AS | BC & Van, Canada | open-ended |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Dieperink et al | Embracing life after prostate cancer. A male perspective on treatment and rehabilitation | European Journal of Cancer Care | 2013 | ● Explore the participants' experiences of treatment with radiotherapy and ADT, and the participating in a rehabilitation programme.<br>● Explore the participants' thoughts and approach to spousal involvement in the rehabilitation process | n = 13 | 66-77yo | ADT | Denmark | focus group | Meaning condensation (Giori's phenomenological approach) |
| Ervik, B.<br>Nordoy, T.<br>Asplund, K. | Hit by Waves-Living With Local Advanced or Localized Prostate Cancer Treated With Endocrine Therapy or Under Active Surveillance | Cancer Nursing | 2010 | Illuminate men's experiences in being diagnosed with prostate cancer and also their experiences of living with localized or local advanced prostate cancer treated with endocrine therapies or under active surveillance. | n = 19 | 59-83yo | Endocrine therapy; AS | Norway | interviews | Phenomenal. hermeneutic approach |
| Ettridge et al | "Prostate cancer is far more hidden…": Perceptions of stigma, social isolation and help-seeking among men with prostate cancer | European Journal of Cancer Care | 2017 | Provide in- depth insight into men's experiences of prostate cancer, specifically: perceived stigma and self- blame, social isolation, unmet need, and help- seeking. | n = 20 | 28-80yo | varied | Australia | personal communication | thematic analysis |
| Eymech et al | An exploration of wellbeing in men diagnosed with prostate cancer undergoing active surveillance: a qualitative study | Support Care in Cancer | 2022 | Explore their lived experiences of active surveillance post diagnosis and its effect on their mental, social, and physical wellbeing | n = 13 | 57-74yo | active surveillance | London, UK | video-based online interviews (due to COVID-19 restrictions) | inductive thematic analysis through lens of bio-psycho-social model |
| Ezenwankwo et al | Factors Influencing Help-Seeking Behavior in Men with Symptoms of Prostate Cancer: A Qualitative Study Using an Ecological Perspective | Cancer Investigation | 2021 | Explore factors that could potentially influence help-seeking behaviour among men with symptoms of PCa in Nigeria using a qualitative approach | n = 27 | 54-84yo | N/A | 3 geo-political zones, Nigeria | semi-structured interviews | thematic framework socio-ecological framework, |
| Farrington et al | The lived experience of adjustment to prostate cancer. | Psychology of Men & Masculinities | 2020 | Explore the lived experience of adjustment to prostate cancer following diagnosis. | n = 8 | 59-80yo | varied | NE England | semi-structured interviews | IPA |
| Fergus, K.D<br>Gray, R.E<br>Fitch, M.I | Sexual Dysfunction and Preservation of Manhood: Experiences of Men with Prostate Cancer | Journal of Health Psychology | 2002 | Explored the experiences of men living with sexual dysfunction as a consequence of having been treated for prostate cancer. | n = 18 | 65yo | RP, radiation therapy, and hormone therapy | Toronto, Canada | semi-structured | grounded theory |
| Fernández-Sola et al | Social Support in Patients With Sexual Dysfunction After Non-Nerve-Sparing Radical Prostatectomy: A Qualitative Study | American Journal of Men's Health | 2020 | Explore men's experiences of social support after non-nerve-sparing radical prostatectomy. | n = 16 | 59-74yo | non-nerve-sparing proctectomy | Spain | in-depth interview | thematic analysis; conceptual map |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Ferrante, J.M<br>Shaw, E.K<br>Scott, J.G | Factors Influencing Men's Decisions Regarding Prostate Cancer Screening: A Qualitative Study | Journal of Community Health | 2011 | ● Explore factors associated with men's decisions regarding prostate cancer screening, particularly in unscreened White and Hispanic men.<br>● Understand whether men are making conscious decisions whether or not to get PSA testing based on scientific evidence. | n = 64 | 50-69yo | never been screened/had abnormal screening | NJ, US | in-depth interviews | grounded theory |
| Forslund et al | Experiences of a nutrition intervention—A qualitative study within a randomized controlled trial in men undergoing radiotherapy for prostate cancer | Nutrition & Dietetics | 2019 | Explore patient experience of participating in a nutrition intervention in a randomized controlled trial, with a focus on facilitators and barriers to adherence. | n = 15 | 62-78yo | Radiotherapy | Sweden | semi-structured, face-to-face interviews | content analysis |
| Fry, S.L<br>Hopkinson, J.<br>Kelly, D. | "We're talking about black men here, there's a difference"; cultural differences in socialized knowledge of prostate cancer risk: A qualitative research study | European Journal of Cancer Care | 2022 | Explore differences in the social construction of prostate cancer knowledge between Somali, African Caribbean and white men living in areas of deprivation, which could provide insights into factors that may contribute to the lower diagnosis rates of prostate cancer amongst black men in the United Kingdom | n = 35 | older than 40yo | N/A | Cardiff, UK | focus groups + interviews | constructivist grounded theory |
| García-Rodales et al | Quality of life in elderly men after a radical prostatectomy. A qualitative study | Journal of Men's Health | 2022 | Explore the experiences and perceptions of older adults regarding their quality of life after a radical prostatectomy | n = 19 | 66–83 | RP | Almeria, Spain | individual interviews + focus group | thematic analysis |
| Gentili et al | Body image issues and attitudes towards exercise amongst men undergoing androgen deprivation therapy (ADT) following diagnosis of prostate cancer | Psycho-Oncology | 2019 | Explored the impact of ADT side-effects on PCa patients' body image and sense of masculinity | n = 20 | 43-85yo | ADT | UK | in-depth interview | thematic analysis |
| Gray et al | Interviews With Men With Prostate Cancer About Their Self-Help Group Experience | Journal of Palliative Care | 1997 | Illuminating the nature and benefits of self-help activity, as well as the broader experience of living with prostate cancer | n = 12 | 45-80yo | N/A | Canada | open-ended interview | thematic analysis |
| Gray et al | Hegemonic Masculinity and the Experience of Prostate Cancer: A Narrative Approach | Journal of Aging and Identity | 2002 | Shed light on contemporary forms of hegemonic masculinity | n = 18 | 50-60yo | RP | Canada | four interviews | narrative analysis |
| Gray et al | Perspectives of prostate cancer support group members on men's health issues and masculinity. | International Journal of Self Help & Self Care | 2005 | Explore conceptions about notions masculinity during a major health crisis, in "veteran" prostate cancer patients | n = 26 | 53-82yo | surgery; external beam radiation; hormone therapy; other | Ontario, Canada | semi-structured interviews | coding schema/ emerging themes |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Gray, R.E<br>Fergus, K.D<br>Fitch, M.I | Two Black men with prostate cancer: A narrative approach | British Journal of Health Psychology | 2005 | Reveal how prostate cancer affects the lives of individual Black men; show how a narrative approach can contribute to health psychology | n = 2 | 62yo & mid-70s | RT/RP | Canada | four, in-depth interviews | narrative analysis |
| Green, R | Maintaining masculinity: moral positioning when accounting for prostate cancer illness | Health | 2019/ 2021 | Explores men's experiences following treatment for prostate cancer through the lens of chronic illness. Recent | n = 29 | 53-82yo | Radical Proctectomy, RT | South-East England | PO, open-ended interviews | thematic saturation |
| Green, R | The Forms and Uses of Acquired Prostate Cancer Expertise Among Prostate Cancer Survivors | Sociological Research Online | 2020 | Examines men's prostate cancer experiences through the lens of patient expertise | n = 29 | 53-83yo | Radical Proctectomy, RT | South-East England | PO, open-ended interviews | thematic saturation |
| Green R | Experiences and management of urinary incontinence following treatment for prostate cancer: Disrupted embodied practices and adapting to maintain masculinity | Health | 2023 | Explore how men experience and manage their UI as an iatrogenic side effect of prostate cancer treatment. | n = 29 | 53-83yo | RP, radiotherapy | South-East England | open-ended questions | thematc analysis |
| Grunfeld et al | "The Only Way I Know How to Live Is to Work": A Qualitative Study of Work Following Treatment for Prostate Cancer | Health Psychology | 2013 | Explore the meaning of work among prostate cancer survivors and to describe the linkages between masculinity and work following prostate cancer treatment | n = 91 | 54-65yo | Surgery, Radiotherapy, Brachytherapy, Chemotherapy | UK | interview schedules | framework analysis |
| Hagen, B.<br>Grant-Kalischuk, R.<br>Sanders, J. | Disappearing floors and second chances: men's journeys of prostate cancer. | International Journal of Men's Health | 2007 | Explore new or collateral masculinities and ways of being, not only men but potentially transformed human beings. | n = 15 | 49-80yo | Radiation, Surgery, Cryosurgery, RP, Hormone, and/or combination of treatments | Western Canada | narrative method-encourage to tell stories, starting from dx leading up to time of interview | Phenomenolog. analysis |
| Hale, S.<br>Grogan, S.<br>Willott, S. | Patterns of self-referral in men with symptoms of prostate disease | British Journal of Health Psychology | 2007 | Explore the way men make the decision to seek medical help by examining the experiences of men who have recently sought medical help for symptoms of prostate disease; provide an understanding of how they perceived and evaluated their symptoms and how this influenced their contact with health care services. | n = 21 | 51-75yo | waiting for treatment | UK | interview | Interpretative phenomenological analysis (IPA) |
| Hamilton et al | Sexuality and exercise in men undergoing androgen deprivation therapy for prostate cancer | Support Care in Cancer | 2014 | Understand how ADT affects men's sexuality, how men cope with sexual concerns and how exercise may reduce or ameliorate these concerns. | n = 11 exercise groups;<br>*n* = 7 usual care group | 53-70yo | ADT | Western Australia | semi-structured interviews | thematic analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Han et al | The value of personalized risk information: A qualitative study of the perceptions of patients with prostate cancer | BMJ Open | 2013 | Focus on personalized risk information in the treatment of prostate cancer; generate insight that informs effort to use CPMs to promote personalized, informed decision-making in treatment of Prostate Cancer | n = 27 (7 focus groups with 3–6 patients/ group) | 50- +80yo | not reported | US | focus groups | thematic analysis? (doesn't clearly state which analytical approach they used; mention using "grounded theory" approach) |
| Hedestig et al | Living After External Beam Radiotherapy of Localized Prostate Cancer: A Qualitative Analysis of Patient Narratives | Cancer Nursing | 2005 | Improve our knowledge of the meaning of being a male patient living with untreated LPC (uLPC). | n = 10 | 60-70yo | EBRT | Sweden | individual interviews | content analysis |
| Hoyt et al | Gay men's experiences with prostate cancer: Implications for future research | Journal of Health Psychology | 2020 | Explored gay men's experience with prostate cancer with a focus on the emotional, physical, and sexual impact of cancer; support needs; and healthcare interactions. | n = 11 | 43-84yo | surgery; radiation; hormone therapy; AS | NE US | focus group | content analysis |
| Imm et al | African American prostate cancer survivorship: Exploring the role of social support in quality of life after radical prostatectomy | Journal of Psychosocial Oncology | 2017 | The aim of this study was to explore the African American prostate cancer survivorship experience following radical prostatectomy and factors contributing to quality of life during survival. Design: | n = 12 | 49-79yo | RP | St. Louis, MI US | focus group | thematic analysis |
| Jones et al | Exploring cancer support needs for older African-American men with prostate cancer | Support Cancer Care | 2011 | Explore cancer support and financial issues related to cancer care experienced by African-American men with prostate cancer and to understand whom they relied on for resource issues during diagnosis and treatment. | n = 23 (rural= 11; urban= 12) | 66-80yo | varied | VA, MD US | focus groups | thematic analysis |
| Jones M., Pietila I. | Expertise, advocacy, and activism: A qualitative study on the activities of prostate cancer peer support workers | Health (UK) | 2020 | Focus on ways in which PC peers support workers describe/define their work as support workers | n = 11 | 52-89yo | N/A | Finland | semi-structured interviews | Membership Categorization Analysis (MCA). |
| Kassianos et al | Perceived influences on post-diagnostic dietary change among a group of men with prostate cancer | European Journal of Cancer Care | 2015 | How a group of men diagnosed with prostate cancer accounted for any changes they made to their diet following diagnosis. More specifically, the aim was to identify factors that they believed were associated with these changes | n = 8 | 55-76yo | surgery, RT | UK | semi-structured interviews | thematic analysis |
| Krumwiede, K.A<br>Krumwiede, N. | The Lived Experience of Men Diagnosed with Prostate Cancer | Oncology Nursing Forum | 2012 | To investigate the lived experience of prostate cancer from a patient perspective. | n = 10 | 62-70yo | RP (some robotic); 1 with hormone therapy, followed by radiation | MN, US | semi-structured interviews | thematic analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Lee et al | Impact of Prostate Cancer Treatment on the Sexual Quality of Life for Men-Who-Have-Sex-with-Men | Journal of Sexual Medicine | 2015 | Explore post-PCa treatment sexual concerns for a sample of MSM, as the first part of this multi-phase project. | n = 16 | 55-67yo | RP, EBRT, Brachytherapy, ADT (or no) | British Columbia, Canada | Face-to-face interview (14), personal communication (2) | thematic analysis |
| Letts, C.<br>Tamlyn, K.<br>Byers, E.S | Exploring the Impact of Prostate Cancer on Men's Sexual Well-Being | Journal of Psychosocial Oncology | 2010 | The goal of this research was to better understand the impact of prostate cancer and its treatment on a broad range of aspects of men's sexual well-being | n = 19 | 54-79yo | EBRT, RP | Canada | semi-structured interviews | framework analysis |
| Levy A.,<br>Cartwright T. | Men's strategies for preserving emotional well-being in advanced prostate cancer: an interpretative phenomenological analysis | Psychology & Health | 2015 | explore men with advanced prostate cancer's own practices for promoting and maintaining emotional well-being. | men | n = 56 | 50-72yo | RT, ADT, steroids/ palliative treatment, chemo | UK | semi-structured interviews |
| Mader et al | Qualitative insights into how men with low-risk prostate cancer choosing active surveillance negotiate stress and uncertainty | BMC Urology | 2017 | Investigated the primary coping mechanisms for men following the active surveillance treatment plan, with a specific focus on how these men interact with their social network as they negotiate the stress and uncertainty of their diagnosis and treatment approach | n = 15 | 59-71yo | Active surveillance | Northeast US | semi-structured interviews | Thematic analysis |
| Maliski et al | Renegotiating Masculine Identity After Prostate Cancer Treatment | Qualitative Health Research | 2008 | Develop a descriptive model of processes used by low-income African American/Black and Latino men to maintain masculine identity with prostate cancer treatment—related symptoms. Reported | n = 35 | 50–70+yo | Radiation therapy, surgery, hormone therapy | LA, US | semi-structured interview | grounded theory |
| Maliski et al | Faith Among Low-Income, African American/Black Men Treated for Prostate Cancer | Cancer Nursing | 2010 | Explore the meaning of prostate cancer treatment-related symptoms among African American/black men focusing on faith in coping with PCa diagnosis, treatment, and adverse effects | n = 18 | 53-81yo | did not collect data on the effects of primary treatment (for some treatment information see section data collection, pg. 4) | LA, US | personal communication | grounded theory |
| Martínez-Bordajandi et al | Sexual experiences after non-nerve sparing radical prostatectomy | Acta Paulista de Enfermegan | 2020 | Analyze the experiences and expectations of patients who underwent Non-Nerve Sparing Radical Prostatectomy | n = 16 | 59-74yo | non-nerve-sparing proctectomy | Spain | in-depth interview | thematic analysis; conceptual map |
| Mathers, S.A<br>McKenzie G.A<br>Robertson, E.M | A necessary evil: The experiences of men with prostate cancer undergoing imaging procedures | Radiography | 2011 | Explore the experience of people with a diagnosis of cancer while attending for imaging procedures. The | n = 7 | 61-83yo | not clear | South-east of Scotland | semi-structured interview schedule | framework analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Matheson et al | Strategies for living well with hormone-responsive advanced prostate cancer—a qualitative exploration | Supportive Care in Cancer | 2020 | Understand men's experiences of living with and adjusting to advanced hormone-responsive PCa and how this influenced their quality of life (QoL), in order to highlight how support could be optimized. | n = 24 | 46-77yo | EBRT + hT; HT +chemo; HT only; EBRT + hT + chemo | England, Wales, Scotland, N. Ireland | in-depth personal communication | thematic analysis (7 stages of framework approach) |
| Matsunaga DS, Gotay CC | Characteristics Contributing to an Enduring Prostate Cancer Support Group in an Asian and Pacific Islander Community | Journal of Psychosocial Oncology | 2005 | Focuses on the perspectives of participants in a peer support group for survivors of prostate cancer from a multiethnic community composed primarily of Asians and Pacific Islanders | n = 24 | 55-85yo | N/A | Hawaii, US | semi-structured interview | content analysis |
| McConkey R.W, Holbron C. | Exploring the lived experience of gay men with prostate cancer: A phenomenological study | European Journal of Oncology Nursing | 2018 | Describe the lived experience of gay men with prostate cancer in Ireland | n = 8 | 49-66yo | Proctectomy, radiotherapy, brachytherapy, hormone treatment, chemotherapy | Ireland, UK | semi-structured interview | Giorgi's phenomenological method |
| Milne, J.L<br>Spiers, J.A<br>Moore, K.N | Men's experiences following laparoscopic radical prostatectomy: A qualitative descriptive study | International Journal of Nursing Studies | 2008 | Learn about the pre-and post-laparoscopic experience | n = 19 (5 individual interviews; 3 focus groups) | 48-76yo | laparoscopic RP | Alberta, Canada | interviews + focus groups | thematic analysis |
| Moore K.N,<br>Estey A. | The early post-operative concerns of men after radical prostatectomy | Journal of Advanced Nursing | 1999 | Explore the feelings of men who, after radical prostatectomy, experienced complications such as urinary incontinence and erectile dysfunction; | n = 63 | mean 67yo | RP | Edmonton, Canada | semi-structured interviews | thematic analysis |
| Nabhani et al | The experience of low-income men with prostate cancer transitioning from disease-specific coverage to comprehensive insurance under the affordable care act | Journal of Cancer Policy | 2018 | ● Describe the insurance enrolment and early insurance experience for these men.<br>● Draw policy recommendations that might improve coverage transitions and insurance benefits for cancer survivors | n = 27 | 55-62yo | RP, radiation, hormone therapy, WW, unknown | California, US | semi-structured, personal communication | thematic analysis |
| Nanton et al | Finding a pathway: Information and uncertainty along the prostate cancer patient journey | British Journal of Health Psychology | 2009 | Elucidate from the perspective of men living with prostate cancer, the experience of uncertainty at different stages of the disease trajectory and to investigate the interrelationship of information, problem solving, and cognitive reframing in mediating its effects in relation to the personal patient journey | n = 36 | 55-84yo | HT, surgery, RT, AS | UK | focus groups + individual interviews | thematic analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Nanton V., Dale J. | "It don't make sense to worry too much": the experience of prostate cancer in African-Caribbean men in the UK | European Journal of Cancer Care | 2011 | Identify whether and in what way ethnicity played a distinctive role in determining this experience. | n = 16 | 50-83yo | WW; P, RTH, RP | UK | semi-structured interview | thematic analysis |
| Navon L., Morag A. | Advanced Prostate Cancer Patients' Ways of Coping With the Hormonal Therapy's Effect on Body, Sexuality, and Spousal Ties | Qualitative Health Research | 2003 | Contribute towards matching such recommendations to their daily needs. | n = 15 | 57-85yo | RP, radiotherapy | Israel | in-depth interviews, 2 sessions | thematic analysis |
| Nelson et al | Men's experience with penile rehabilitation following radical prostatectomy: A qualitative study with the goal of informing a therapeutic intervention | Psycho-Oncology | 2015 | Explored men's experience with ER, erectile dysfunction (ED), and ED treatments to inform a psychological intervention designed to help men adhere to ER post-RP | n = 30 | 41-72yo | RP | New York, US | focus group (4) | thematic analysis |
| Odedina et al | A Focus Group Study of Factors Influencing African-American Men's Prostate Cancer Screening Behavior | Journal of National Medical Association | 2004 | Identify the factors perceived by African-American men as influencing their behaviour relative to prostate cancer screening. | n = 49 | 40+yo | screening | FL, US | focus groups | "unitization" |
| Oliffe et al | Connecting humour, health, and masculinities at prostate cancer support groups | Psycho-Oncology | 2009 | Add to emergent understandings about the role of humour among cancer survivors by describing how humour, health, and masculinities connect at PCSGs. | n = 54 | 53-87yo | N/A | Canada | semi-structured interviews | thematic analysis |
| Oliffe et al | Health Promotion and Illness Demotion at Prostate Cancer Support Groups. | Health Promotion Practice | 2010 | Provide insights to how groups simultaneously facilitate health promotion and illness promotion. | n = 52 | 53-87yo | N/A | Attendees of Prostate Cancer Support Groups (PCSGs) | BC, Canada | iterative thematic analysis |
| Oliffe et al | Prostate cancer support groups, health literacy and consumerism: Are community- based volunteers re-defining older men's health? | Health | 2011 | connections between prostate cancer support groups (PCSGs) and men's health literacy and consumer orientation to health care services; men's experiences of attending group meetings | n = 54 | 53-87yo | N/A | Canada | individual interviews | thematic analysis |
| O'Shaughnessy P.K, Laws T.A | Australian men's long-term experiences following prostatectomy: A qualitative descriptive study | Contemporary Nurse | 2009 | Describe men's long term recovery following prostatectomy for the purpose identifying the effects of unresolved post-surgical morbidity. | n = 11 | N/A | RP | Australia | individual interviews + focus groups | content analysis |
| Öster et al | Sharing experiences in a support group: Men's talk during the radiotherapy period for prostate cancer | Palliative and Supportive Care | 2013 | Describe the experiences of men living with prostate cancer shared within conversational support groups during a course of radiotherapy | n = 9 | N/A | RT | Sweden | focus group | content analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Pan et al | Patient participation in treatment decision-making of prostate cancer: a qualitative study | Supportive Care in Cancer | 2022 | Explore the decision-making perceptions and experiences of prostate cancer patients in China, using a phenomenology method. | n = 30 | 60-74yo | RP, ADT, CT, RT, AS | China | interview | phenomenological analysis |
| Paterson C., Primeau C., Lauder W. | What Are the Experiences of Men Affected by Prostate Cancer Participating in an Ecological Momentary Assessment Study? | Cancer Nursing | 2020 | Explore the lived experiences of men affected by prostate participating in an EMA study and assess whether their participation in EMA alters their representation of their condition. | n = 12 |  | curative to palliative intent | Scotland, UK | semi-structured interviews | thematic analysis |
| Pietila las the Guts to Make This Choice?: Ideals of Masculinity in Men's Justifications for Their Treatment Decisions for Localized Prostate Cancer |  | International Journal of Men's Health | 2016 | ● Exploring men's justifications for their treatment choices for localized prostate cancer. | n = 20 | 50-76yo | early localized prostate cancer, some with no signs of progression, some AS, some RP | Finland | personal interviews + focus groups (AS/RP) | thematic analysis |
| Pietila ig certainty through narrative closure: men's stories of prostate cancer treatments in a state of liminality. |  | Sociology of Health & Illness | 2018 | ● How men with prostate cancer deal with the multiple uncertainties of living with cancer and recovering from it.<br>● Analyse the narrative practices men use to make sense of and articulate their liminal state after having radical prostate cancer treatments. | n = 22 | 56-71yo | RP, radiotherapy | Final | interview guide; semi-structured interview | narrative analysis |
| Renzi et al | A Qualitative Investigation on Patient Empowerment in Prostate Cancer | Frontiers in Psychology | 2017 | Explore issues related to communication, involvement in the treatment decision-making process, unmet needs, and resources of prostate cancer patients in order to design a cancer platform that may support patient empowerment. | n = 10 | 65-71yo | RT | Northern Italy | semi-structured interviews | thematic analysis |
| Schmidt et al | "Kicked out into the real world": prostate cancer patients' experiences with transitioning from hospital-based supervised exercise to unsupervised exercise in the community | Supportive Care in Cancer | 2018 | Gain insights into experiences of transitioning to unsupervised community-based exercise this study applied an explorative, | n = 29 | 67-74yo | ADT | Denmark | semi-structured, open-ended interview |  |
| Shen et al | Decision-Making Processes among Prostate Cancer Survivors with Rising PSA Levels: Results from a Qualitative Analysis | Medical Decision Making | 2015 | Engage patients in a detailed retrospective and comparative examination of the processes involved in making treatment decisions following their initial diagnosis of prostate cancer as well as the recent diagnosis of a rising PSA. | n = 34 | 62-78yo | Surgery; External beam radiation therapy (EBRT); Brachytherapy; Active surveillance; | NYC, US | interviews | thematic analysis |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Speer et al | The clinical communication and information challenges associated with the psychosexual aspects of prostate cancer treatment | Social Science & Medicine | 2017 | Address this gap, generating new understandings of the psychosexual information and communication challenges faced by men with PC | n = 21 | 52-78yo | RP, HT, R | Northwest England. | semi-structured interviews | thematic analysis |
| Thomas C.,<br>Wootten A.,<br>Robinson V. | The experiences of gay and bisexual men diagnosed with prostate cancer: results from an online focus group | European Journal of Cancer Care | 2013 | Identify the experiences, concerns and perceived information needs of gay and bisexual Australian men diagnosed with prostate cancer. | n = 10 | 47-70yo | RP, RT, AS | Online (Victoria, AUS) | online focus group | thematic analysis |
| Trinh et al | A Qualitative Study Exploring the Perceptions of Sedentary Behavior in Prostate Cancer Survivors Receiving Androgen-Deprivation Therapy | Oncology Nursing Forum | 2015 | Describe and understand the perceptions of sedentary behaviour (SED) and the interests and preferences for a SED intervention of men on androgen-deprivation therapy (ADT) within | n = 27 | 64-81yo | ADT | Toronto, Canada | focus groups | thematic analysis |
| van Ee et al | This is an older men's world: A qualitative study of men's experiences with prostate cancer | European Journal of Oncology Nursing | 2018 | Gain more insight into the experiences of men 70 years old or older with prostate cancer and the care received from health-care professionals, family members and other informal carers | n = 22 | 71-77yo | RP, RT, BT, HRT, Chemo, AS/WW | Netherlands | semi-structured interviews | content analysis + affinity diagramming |
| Volk et al | "It's Not Like You Just Had a Heart Attack": Decision-Making about Active Surveillance by Men with Localized Prostate Cancer | Psycho-Oncology | 2014 | Explore patients' conceptualizations of AS and treatment decision making. | n = 30 | 49-72yo | AS or surgery/ radiation | Texas, US | personal communication | thematic analysis |
| Wagland et al | Adjustment strategies amongst black African and black Caribbean men following treatment for prostate cancer: Findings from the Life After Prostate Cancer Diagnosis (LAPCD) study | European Journal of Cancer Care | 2019 | Explore the approaches to adjustment to a PCa diagnosis amongst BA and BC men | n = 24 | 55-85yo | RP + other, radiotherapy + ADT; ADT only, AS, WW, Chemo +other | UK | semi-structured, personal communication | thematic analysis |
| Wallace M.,<br>Storms S. | The needs of men with prostate cancer: results of a focus group study | Applied Nursing Research | 2007 | Ascertain the needs of men diagnosed with prostate cancer and their views on how these needs could best be met. The | n = 17 | 49-81yo | N/A | CT, US | focus groups | grounded theory |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Waller J., Pattison N. | Men's experiences of regaining urinary continence following robotic-assisted laparoscopic prostatectomy (RALP) for localized prostate cancer: a qualitative phenomenological study | Journal of Clinical Nursing | 2012 | Explore men's contextualized experiences of regaining continence post-RALP. | n = 7 | 51-80yo | RALP | London, UK | in-depth, individual interviews | framework, hermeneutic phenomenological |
| Wallington S.F | The Internet as an Emerging Patient Education Tool Among African American Men With Prostate Cancer: An Exploratory Study | American Journal of Men's Health | 2008 | Explore the perceptions and uses of the Internet as a patient education tool among 39 African American men aged 39 years and older with diverse socioeconomic backgrounds | n = 39 | 39-73yo | N/A | Washington DC | focus group | thematic analysis |
| Walsh E., Hegarty J. | Men's experiences of radical prostatectomy as treatment for prostate cancer | European Journal of Oncology Nursing | 2010 | Provide a retrospective view of men's experiences of the prostate cancer treatment journey from initial diagnosis through to completion of their surgery and beyond. | n = 8 | N/A | RP | Ireland, UK | interviews | content analysis |
| Wennerberg et al | Patient experiences of self-care management after radical prostatectomy | European Journal of Oncology Nursing | 2021 | The aim of this study was to deepen the understanding about patient experiences of support for managing self-care during the first six months after radical prostatectomy | n = 18 | 57-77yo | RP | southern Sweden | open-ended questions | content analysis |
| Wennick et al | Everyday life after a radical prostatectomy—A qualitative study of men under 65 years of age | European Journal of Oncology Nursing | 2017 | Illuminate how men under 65 years of age experience their everyday life one year or more after a radical prostatectomy for localized prostate cancer, when the remaining side effects are likely to be permanent | n = 19 | 49-65yo | robotic RP | southern Sweden | semi-structured | thematic content analysis |
| Williams et al | Physician role in physical activity for African-American males undergoing radical prostatectomy for prostate cancer | Supportive Care in Cancer | 2017 | Explore African-American prostate cancer survivors' experiences with physical activity prescription from their physicians | n = 12 | 49-79yo | RP | Missouri, US | focus group | transtheoretical model (TTM)/ phenomenological approach |
| Yu Ko et al | Penile length shortening after radical prostatectomy: Men's responses | European Journal of Oncology Nursing | 2010 | Explore patients' perceptions/ responses to PLS after RP | n = 6 | 58-77yo | RP | Winnipeg, Manitoba Canada | semi-structured interviews | substantive theory/ grounded theory approach |

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**Table 1.** (Continued).

| Author/s | Title | Journal | Public. Date | Aim | Sample size | Age group | Cancer Treatment Method | Study site/ Country | Design | Analysis |
|---|---|---|---|---|---|---|---|---|---|---|
| Yu Ko et al | The Connections Between Work, Prostate Cancer Screening, Diagnosis, and the Decision to Undergo Radical Prostatectomy | American Journal of Mne's Health | 2018 | Report on an exploration of the connections between work, prostate cancer screening, diagnosis, and the decision to undergo radical prostatectomy as a means to thoughtfully considering what preoperative information and postoperative plans might be usefully made to ease men's inevitable work transitions | n = 24 | 44-75yo | RP | W. Canadian city | in-depth, semi-structured interview | grounded theory |
| Yu Ko et al | Reformulating the Worker Identity: Men's Experiences After Radical Prostatectomy | Qualitative Health Research | 2020 | Explore the processes involved in men's return to work post radical prostatectomy and understand how these events are connected to masculinities. | n = 24 | 54-65yo | RP | W. Canadian city | in-depth, semi-structured interview | constructivist grounded theory |
| Xu et al | Men's Perspectives on Selecting Their Prostate Cancer Treatment | Journal of National Medicine Association | 2011 | Gain an in-depth understanding of men's perspectives on selecting their prostate cancer treatment. | n = 21 | 48-70yo | Surgery, EBRT, WW, Cryotherapy | Michigan, US | semi-structured | thematic analysis |
| Zanchetta et al | Prostate Cancer among Canadian Men: A Transcultural Representation | International Journal of Men's Health | 2007 | Identify the experiences of men with PC from different ethnocultural backgrounds, including their essential thoughts related to learning the medical diagnosis, telling their family about the diagnosis, facing moments of frustration, and reassessing life priorities,<br>Describe major representations of PC as they relate to the aforementioned thoughts.<br>Specify the essential similarities among representations of PC, and (4) to assess the existence of hints of a core transcultural representation of PC | n = 9 | 64-80yo | N/A | Kingston, Ontario, Canada | open-ended & closed-ended questions: | inductive hypothetic-deductive process |

**Table 2.** CASP tool assessment.

| Authors | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 | Q10 | |
| (Abel, 2002) | Y | Y | Y | N | Y | N | N | Y | Y | Y | 7 |
| (Adams & Johnson, 2021) | Y | Y | Y | N | Y | Y | Y | N | N | Y | 7 |
| (Aggarwal et al., 2018) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 10 |
| (Anderson et al., 2013) | Y | Y | Y | N | Y | N | Y | Y | Y | Y | 8 |
| (Appleton et al., 2015) | Y | Y | Y | N | Y | N | Y | N | Y | N | 6 |
| (Arrington, 2003) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Arrington, 2008) | Y | Y | Y | Y | Y | N | N | Y | Y | Y | 8 |
| (Arrington, 2015) | Y | Y | Y | Y | Y | N | N | Y | Y | Y | 8 |
| (Bamidele & McCaughan, 2022) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Bell & Kazanjian, 2011) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Bourke et al., 2012) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (Broom, 2005) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Brown & Oetzel, 2016) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Bruun et al., 2014) | Y | N | N | Y | Y | N | Y | N | Y | N | 5 |
| (Buote et al., 2020) | Y | Y | Y | Y | Y | Y | Y | Y | Y | N | 9 |
| (Burt et al., 2005) | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | 9 |
| (Capistrant et al., 2016) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Carter et al., 2011) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 10 |
| (Cayless et al., 2010) | Y | Y | N* | Y | N* | N | Y | N | Y | N | 5 |
| (Chambers et al., 2018) | N | Y | Y | Y | Y | N | Y | Y | Y | Y | 8 |
| (Chapple et al., 2002a) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |

(*Continued*)

**Table 2.** (Continued).

| Authors | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (Chapple et al., 2007) | Y | Y | Y | Y | N | N | Y | N | Y | N | 6 |
| (Chapple et al., 2002b) | Y | Y | Y | Y | Y | N | Y | N | Y | N | 7 |
| (Cinà et al., 2020) | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | 9 |
| (Clarke & Burke, 2016) | N | Y | Y | Y | N | N | Y | N | Y | N | 5 |
| (Cockle-Hearne et al., 2016) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Cooley & Jennings-Dozier, 1998) | Y | Y | N | N | Y | N | N | N | N | Y | 4 |
| (Cormie et al., 2015) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Craike et al., 2011) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Culos-Reed & McDonough, 2019) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Davison et al., 2009) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (de Moraes Lopes et al., 2012) | Y | Y | Y | Y | Y | N | Y | N | Y | N | 7 |
| (Dieperink et al., 2013) | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | 9 |
| (Eilat-Tsanani et al., 2013) | Y | Y | Y | N | N | N | Y | N | Y | N | 5 |
| (Er et al., 2017) | Y | Y | Y | N | Y | N | Y | N | Y | N | 6 |
| (Ervik et al., 2010) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Ettridge et al., 2018) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Eymech et al., 2022) | Y | Y | N | Y | Y | N | Y | Y | Y | Y | 8 |
| (Eziefula et al., 2013) | Y | Y | Y | N | Y | N | Y | N | Y | N | 6 |
| (Ezenwankwo et al., 2021) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Farrington et al., 2020) | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | 9 |
| (Fergus et al., 2002) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |

(*Continued*)

**Table 2.** (Continued).

| Authors | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (Fernández-Sola et al., 2020) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Ferrante et al., 2011) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Forslund et al., 2020) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Fry et al., 2022) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Gannon et al., 2010) | Y | Y | Y | N | N | N | Y | N | Y | Y | 6 |
| (García-Rodelas et al., 2022) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Gentili et al., 2019) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (R. E. Gray et al., 1997) | Y | Y | Y | Y | Y | N | N | Y | Y | Y | 8 |
| (R. E. Gray et al., 2002) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (R. E. Gray et al., 2005) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (R. Gray et al., 2005) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (P. B. Gray et al., 2020) | Y | Y | Y | Y | Y | N | Y | N | Y | N | 7 |
| (Green, 2020) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Green, 2021) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Green, Richard 2023) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Grunfeld et al., 2012) | Y | Y | N | N | Y | N | Y | N | Y | N | 5 |
| (Grunfeld et al., 2013) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Hagen et al., 2007) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Hale et al., 2007) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Hamilton et al., 2014) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Han et al., 2013) | Y | Y | Y | N | Y | N | Y | Y | Y | Y | 8 |
| (Hanly et al., 2014) | Y | Y | Y | N | Y | N | Y | Y | Y | N | 7 |
| (Hoyt et al., 2020) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Imm et al., 2017) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |

(*Continued*)

**Table 2.** (Continued).

| Authors | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (Iyigun et al., 2011) | Y | N | Y | N | N | N | Y | Y | Y | N | 5 |
| (Jackson et al., 2010) | Y | Y | Y | Y | N | N | Y | N | Y | Y | 7 |
|  |  |  |  |  |  |  |  |  |  |  | 6 |
| (R. A. Jones et al., 2010) | Y | Y | Y | Y | N | Y | N | N | Y | Y | 7 |
| (R. A. Jones et al., 2011) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (M. Jones & Pietilä, 2020) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Kassianos et al., 2015) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Kazer et al., 2011) | Y | Y | Y | N | Y | N | Y | N | Y | N | 6 |
| (Keogh et al., 2014) | Y | Y | Y | Y | Y | N | Y | N | Y | N | 7 |
| (Kinnaird & Stewart-Lord, 2021) | Y | N | N | N | Y | N | Y | N | Y | N | 4 |
| (Kronenwetter et al., 2005) | Y | Y | Y | Y | N | N | Y | N | Y | N | 6 |
| (Krumwiede & Krumwiede, 2012) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Langelier et al., 2022) | Y | Y | Y | N | N | Y | Y | N | Y | Y | 7 |
| (Laursen, 2016) | Y | Y | N | N | N | N | Y | N | Y | N | 4 |
| (Lee et al., 2015) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Lepherd, 2014) | Y | Y | Y | N | Y | N | Y | N | Y | N | 6 |
| (Letts et al., 2010) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Levy & Cartwright, 2015) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Mader et al., 2017) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Maliski et al., 2010) | Y | Y | Y | Y | N | Y | Y | Y | Y | Y | 9 |
| (Maliski et al., 2008) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Maliski et al., 2012) | Y | Y | Y | Y | Y | Y | Y | N | N | N | 7 |
| (Mardani et al., 2023) | Y | N | Y | Y | N | Y | Y | Y | Y | N | 7 |

(*Continued*)

**Table 2.** (Continued).

| Authors | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (Margariti et al., 2021) | Y | Y | Y | Y | N | N | Y | Y | Y | N | 7 |
| (Martínez-Bordajandi et al., 2010) | Y | Y | Y | Y | Y | N | Y | Y | Y | N | 8 |
| (Mathers et al., 2011) | Y | Y | Y | Y | Y | Y | Y | N | Y | N | 8 |
| (Matheson et al., 2021) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Matsunaga & Gotay, 2004) | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | 9 |
| (McConkey & Holborn, 2018) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Medina-Perucha et al., 2017) | Y | Y | Y | Y | Y | N | Y | N | N | N | 6 |
| (Milne et al., 2008) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Moore & Estey, 1999) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Nabhani et al., 2018) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (Nanton et al., 2009) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Nanton & Dale, 2011) | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | 9 |
| (Navon & Morag, 2003) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Nelson et al., 2015) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (O'Shaughnessy & Laws, 2009) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Odedina et al., 2004) | Y | Y | Y | Y | Y | Y | N | Y | Y | Y | 9 |
| (J. L. Oliffe et al., 2009) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (J. L. Oliffe et al., 2010) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (J. L. Oliffe et al., 2011) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (J. Oliffe & Thorne, 2007) | Y | Y | N | N | N | N | Y | Y | Y | N | 5 |
| (Öster et al., 2013) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |

(*Continued*)

**Table 2.** (Continued).

| Authors | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (Pan et al., 2022) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Paterson et al., 2020) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Pietilä et al., 2016) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Pietilä et al., 2018) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Poole et al., 2019) | N | Y | N | Y | Y | N | Y | N | Y | Y | 6 |
| (Renzi et al., 2017) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Schmidt & Ostergren, 2018) | Y | Y | Y | Y | Y | N | Y | Y | Y | N | 8 |
| (Shaw et al., 2013) | Y | Y | Y | N | N | N | Y | N | Y | N | 5 |
| (Sheill et al., 2018) | Y | N | N | Y | N | N | Y | N | Y | N | 4 |
| (Shen, 2015) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Singh et al., 2005) | Y | Y | Y | Y | Y | N | Y | N | Y | N | 7 |
| (Speer et al., 2017) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Thomas et al., 2013) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Trinh et al., 2015) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (van Ee et al., 2018) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (Volk et al., 2014) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (Vyas et al., 2022) | Y | Y | Y | N | Y | N | Y | Y | Y | N | 7 |
| (Wagland et al., 2019) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Wall et al., 2013) | Y | Y | Y | N | N | N | Y | N | Y | N | 5 |
| (Wallace & Storms, 2007) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Wallington, 2008) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Walsh & Hegarty, 2010) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |

*(Continued)*

**Table 2.** (Continued).

| Authors | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| (Walton & Sullivan, 2004) | Y | Y | Y | N | N | N | Y | Y | Y | Y | 7 |
| (Wennerberg et al., 2021) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Wennick et al., 2017) | Y | Y | Y | Y | Y | Y | Y | N | Y | Y | 9 |
| (Williams et al., 2017) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 9 |
| (Xu et al., 2011) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (Yu Ko et al., 2010) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |
| (Yu Ko et al., 2018) | Y | Y | Y | Y | Y | N | Y | Y | Y | Y | 9 |
| (Yu Ko et al., 2020) | Y | Y | Y | Y | Y | N | Y | N | Y | Y | 8 |
| (Zanchetta et al., 2007) | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | 10 |

**Table III.** Themes & descriptions.

| | Description |
|---|---|
| Diagnosis/Treatment/Recovery | ● Pre/post diagnosis; pre/post-treatment |
| | ● Decision-making (therapeutic journey, WW/AS) |
| | ● Post-treatment/side effects |
| | ● Screening (PSA/DRE) |
| | ● Intervention/Lifestyle Change programs |
| Care | ● Quality of Consultation/Communication |
| | ● Needs-based approach |
| Support | ● Natural: Family (partners, children, extended members)/Friends |
| | ● Formal: group (online, face-to-face, activity-focused, marginalized) |
| | ● Inner-Dynamics: Advocacy, Altruism, Camaraderie |
| | ● Social/Functional: emotional, instrumental, informational, companion |
| | ● Structural: strength of social ties |
| Information | ● Seeking, |
| | ● Access |
| | ● Quality |
| | ● Source (TV, internet, print, media, other PCa patients) |
| | ● Disclosure |
| Masculinity | ● Self-Identity |
| | ● Reconfiguration of self |
| | ● Roles/Behaviors |
| Lived Experience | ● Stigma, Isolation, Depression, Uncertainty, Vulnerability, Marginalization |
| | ● Altered Body |
| | ● Dis/empowerment, resilience. |
| | ● Sexuality (satisfaction, performance) |
| | ● Socio-Cultural-Economic Barriers/Facilitators |

This quote illustrates the critical role of accessible, clear, and tailored information empowering patient during decision-making processes.

Some men highlighted how routine consultations led to early detection, whilst others experienced delays due to ambiguous symptoms or insufficient physician guidance. Some doctors considered their PCa patients too old for treatment, while others had severe comorbidities. Those with comorbidities had a limited life expectancy because aggressive PCa treatments could worsen their other conditions. Some PCa patients had low prostate-specific antigen (PSA) levels. Doctors often recommended that men from both groups were actively surveilled (AS) or watchful waiting (WW). That required frequent monitoring for fluctuations in PSA levels, which could result in a PCa diagnosis and a new course of treatment. The unpredictability of the disease caused a cycle of uncertainty that a low PSA reading only eased temporarily:

> I don't worry about it on a day-to-day basis or month-to-month basis. Every six months when I go to my check-up appointment, I get worried about it, but I get informed of what's happening, and then we move on (Eymech et al., 2022).

### *Care*

Men had various consultation preferences and experiences. Some stated that an open and collaborative approach helped them become more informed and less anxious about their decision-making. They reported that a kind, courteous, and open approach by health professionals during lengthy treatments or intervention programmes was essential in creating positive experiences in all settings (clinical and support groups) and building confidence that they were in "expert hands":

> Like I said, it seems to me that being in IMPACT was better because they always worried about my health, what my PSA results were, how I had been treated, just overall (Nabhani et al., 2018).

Many men felt that an open, kind, and courteous approach helped them build trust and confidence in their clinician's recommendations and capabilities:

> No, I think that if a doctor tells me something, and I have the feeling that he is telling me the truth, then I don't feel the need to be on the computer. I don't need to search books to see if it's true. [. . .] It only makes you feel uncertain (van Ee et al., 2018).

They also desired better coordination of care and information between health care professionals and suggested a "middleman" and implementing psychosocial support into their routine care would help them have hope for survival and feel reassured. PCa patients expressed regret about their clinicians' delay in diagnosing or offering treatment options. Some even discovered their physician had withheld or provided too little information:

> The excessive confidence caused a situation where physicians would not tell me everything they had to tell me. It ended up with low transparency" (Renzi et al., 2017).

They described consultations as closed, non-responsive, and avoidant. Rather than addressing their concerns and needs, some men felt that healthcare professionals were dismissive, and were told side effects were "to be expected". Sometimes, those who could not achieve a helpful rapport with their clinicians or felt they gave biased or ambiguous information about treatment options would seek second and third opinions, further information online, or switch healthcare providers.

Men with PCa embraced specific medical advice from health professionals regarding bowel function, urination, and sexual dysfunction. Furthermore, they expressed that the gender, sexual orientation, ethnic background, and attitude (“gay-friendly”) of their healthcare professionals made the discussions easier.

Some men expressed that medical professionals did not pay sufficient attention to their emotional needs or provide a structured care and support plan. Marginalized groups, in particular, felt that inadequate training of health professionals led to poor management of crises they faced when diagnosed with PCa:

> … we need to have urologists clued up to deal with gay men, we need understanding that our needs and issues are not the same as (those of) a heterosexual man (C. Thomas et al., 2013).

> I am an illiterate with limited knowledge of characters. I was unaware of the exact type of disease I had contracted (Pan et al., 2022).

Some men reported that information concerning their treatments and care was sparse and caused confusion and anxiety, highlighting the importance of effective interpersonal communication:

> When you are at that stage, at first, you can have had so much information, and then you walk out, saying, ‘What the hell did he say?’ (Öster et al., 2013).

### *Support: natural*

There were various forms of spousal, friend, and co-worker support. Some men preferred to keep their PCa diagnosis within their family:

> I don’t talk so much about it, think it feels awkward. Nor have I wanted this to be known by our friends, so we’ve kept it in the family (Wennick et al., 2017).

Most men deemed their partner’s role the most influential among their family members. Partners encouraged their men to screen for PCa, helped them process PCa-related information, motivated them to seek treatment options, and provided unique perspectives during decision-making. Men reported that having a partner who could accept and adjust to treatment side effects like erectile dysfunction (ED) helped alleviate their anxieties and shifted the value they had previously placed on sex:

> … I was scared that she [wife] was going to laugh or look at me different but she understood, that made it all worthwhile (Imm et al., 2017).

### *Support: formal*

Prostate Cancer Support Groups (members with the same diagnosis) were one way men considered disclosing their prognosis to non-family members if they deemed that type of support valuable:

> So it’s just within a very small circle that one (talks about it) and so only with those who know something about it (Dieperink et al., 2013).

Support groups foster a non-judgemental setting where men can share general and intimate details about their cancer experience. The information exchange and mutual support allow men to learn about PCa from their peers in a practical, comprehensible, and non-threatening manner. The support groups allowed men to openly and candidly discuss their diagnosis, compare treatment options, and exchange information about remedies, such as pills, injections, and pumps to mitigate treatment side effects:

> You can deal with the impotence, [but] the fact that you can’t ejaculate anymore—you see, I miss that. I really miss that! Because that’s almost, you think of that with sex. If you use a pump, you don’t have the same good sensation; you still have the feeling of an orgasm, but not as intense (Fergus et al., 2002).

### *Support: inner-dynamics*

Support group dynamics empowered men to cope better with their condition and gain confidence in decision-making:

> Talking to these people [men in a support group] was very helpful and comforting, and it helped me get through what’s known as the decision mode (Cockle-Hearne et al., 2016).

Men valued the camaraderie gained from sharing the trials and tribulations of their PCa experience: ”… such an emotional thing [receiving diagnosis] that I needed to be with people who had gone through this or were going through it‘ (Wallace & Storms, 2007).’ I actually long for, I actually miss these Wednesdays when we are here, and we can listen to each other, and give and take, and I have learned so much. ” (Öster et al., 2013).

Together, the men validated and normalized the disruptions PCa caused to their identity and masculinity, helping ease the sense of isolation they often experienced in their personal and social lives:

> The group therapy, that was a new experience for me, probably helped me get in touch with the “softer side,” which I find interesting and pleasing actually (Kronenwetter et al., 2005).

Good leadership skills, extensive social networks, community experience, and personal touch were invaluable assets for the overall success of peer-led PCSGs:

> Someone like [AB]–he calls up, checks up on you, shows a personal interest, gives words of encouragement. He helped me personally a lot. I know he's there. He was a source of comfort when my wife died (Matsunaga & Gotay, 2004).

Laughter and humour also helped peer-led PCSGs become successful. Oliffe (Oliffe et al., 2009) observed that during discussions, men used humour to disarm stoicism, disguise vulnerabilities, and buffer stigma, anxiety, and difficulties related to sensitive or taboo topics. In the example below, a PCa patient discusses the digital rectal exam (DRE), a prostate screening technique:

> One of the jokes I tell … Did you hear about the guy who went in, and he had a DRE, and he turned around to the doctor and said "Gee Doc, which finger did you use"? The doctor said, "What"? "Show me which finger you used" and the doctor said, "I used this one". He said, "Would you try this one? I want a second opinion" (laughing) (Oliffe et al., 2009).

Other men reported how their support groups helped them transition from seeking support to providing it:

> I guess I benefit from talking to other people now, trying to help them through my experience – because I've had both the radical surgery and I've had radiation (R. E. Gray et al., 1997).

> When I was the first one everybody come to me and asked me a lot of questions about what is what and so on …if there is a problem, they can come and ask me. You know I don't know everything but I've got through a lot since day one - six years now … people can just ask. (Mr P) (Nanton & Dale, 2011).

Other men advocated at conferences to build awareness amongst health professionals and bridge the gap between medical professionals and their PCa patients:

> … there was this one really tough urologist who thought that patients don't know anything. So then he came to me afterwards [the conference] and said that this information is really valuable because they can't be sitting with the patient afterwards and asking how they feel (Jones & Pietilä, 2020).

The various PCSG formats (online, face-to-face (F2F), activity-focused) allowed men to choose which best fitted their comfort levels or specific needs. For example, men with limited mobility felt online PCSGs (OPCSG) provided easy access to a broad selection of emotional and social support and self-management skills. OPCSG forums or discussion boards provide discretion and anonymity, which, for some men, alleviated the tension produced by the conflict between their desire to disclose their cancer status and their feelings of vulnerability:

> Some men don't want to be face-to-face. Maybe they're frightened of it, maybe they don't want to travel the distances. Maybe they're scared of being ridiculed or something.… all sorts of reasons like that. Maybe they're a bit anxious about having the problem and not wanting to share it with other people. I think that's men for you. Some will find it easier to talk online (Broom, 2005).

Conversely, F2F-PCSGs allow men to receive and exchange information "on the spot." That is particularly relevant when PCa experts give presentations or peer professionals (attendees who are both physicians and PCa survivors) are present. The dynamic role of peer professionals contributes to group discussions in two ways: they receive the support they need as patients while providing professional knowledge to others:

> When I heard about the group, I I thought, "I don't need this." Then I told myself, "There's scientific evidence that people who go to support groups do better than those who don't." I'm not in the group because I'm a surgeon … this experience of having prostate cancer and discovering the group has made me more appreciative of what life is about and has made me a better doctor (Matsunaga & Gotay, 2004).

Some PCSGs are sport or activity-focused. Although members are men diagnosed with PCa, the casual, activity-focused interaction shifts attention from their diagnosis towards other commonalities:

> I mean, yes, you have a common reason for being there, and you help each other about that common reason the prostate cancer. But it doesn't define the interaction whereas the traditional prostate cancer support group, cancer defines the interaction. What defines the interaction is that we're dragon boating (Cinà et al., 2020).

### *Information*

Before the Internet, PCa patients had to rely primarily on their clinicians to inform them about their diagnosis and prognosis. The Internet has allowed patients to *shop* for information, treatments, and specialists. That allowed them to take the initiative and actively engage in consultations, which reinforced their sense of control and power:

> As soon as my doctor told me, I hit the Internet […] It's like getting a free second opinion. Going on there is what helped me to decide my treatment options. He gave me some Web sites even. What I found on the sites, I could see what other doctors and hospitals were recommending and this seemed to line up with what my doctor was saying (Wallington, 2008).

While some men agreed that access to sources other than one's clinician could help make informed decisions, they doubted if the "perception of choice" alternative sources provided were trustworthy. There was a consensus that one should proceed with caution when consuming the vast amounts of information on the Internet and elsewhere, particularly regarding PCa treatment options. Misinformation, primarily through word-of-mouth or unofficial sources, regarding PCa screening and treatment contributes to confusion about the risks and benefits:

> Even now, I ask myself: these people, they sit in front of their computers and they search the Internet and they read this, but for what reason? [. . .] I figure if you go to a specialist and you don't follow his advice, it's bordering on stupidity—he's the expert, and I trust his judgement (Broom, 2005).

Some men expressed that PCa information must be practical, logistical, and tailored to suit various health literacy capacities and hard-to-reach audiences. However, they also felt that having too much knowledge could counteract feelings of empowerment and control. For example, learning about the undesired effects of treatments could be disadvantageous to rehabilitation, and the lack of clear scientific information on the causes of PCa could lead to confusion:

> Not eating properly, abusing your body with alcohol, look, it might be genetic, my father has it . . . I can't say a hundred percent that if I didn't live the lifestyle I wouldn't have got it anyway. But from my research and looking at different things and my lifestyle for many years, I think it probably hasn't helped (Ettridge et al., 2018).

## *Masculinity*

Many men described in length the various impacts that PCa treatments had on their physical and psychological status, sexual identity, and "pressure to perform." All men in the studies felt that coming to terms with their cancer experience meant (re)adjusting their (masculine) values and expectations. Some men expressed how "lucky" they were not to have undesired outcomes from specific PCa treatments. However, adverse treatment effects still made it challenging to preserve their pre-cancer psychological status. Therefore, they needed to reconstruct the internalized "self." For example, the PCa treatment Androgen Deprivation Therapy (ADT) frequently causes extreme fatigue and inhibits sexual libido. Furthermore, it also increases fatty tissue and causes gynaecomastia and hot flashes, which men felt feminized their bodies:

> I lost all my body hair, except on my head, which I was losing anyway! [laughs] My breasts increased in size, which was embarrassing at times—especially when I went to a swimming pool. I guess I should get a training bra! (Hagen et al., 2007)

Radical prostatectomy (RP), the complete removal of the prostate, frequently causes erectile dysfunction (ED) and incontinence, causing men to struggle with feelings of disempowerment and disfigurement, which eventually lead to loss of intimacy with their partners:

> It's kind of like you almost don't want to have sex because you don't want to know that it doesn't work (Nelson et al., 2015).

Physical activity, penile erection, and sexual performance are often linked to masculinity. Therefore, many men felt that erectile dysfunction caused by PCa "threatened" their sense of masculinity. While some men adjusted to these changes by choosing not to define themselves solely by their sexual function and encouraged exploring alternative ways to express intimacy, others did not:

> It's maybe not so much about the act itself; it's the empowerment, the ability, the bragging rights, your image of yourself, I'm still a viable man. And take that away from me, and I'm no longer a viable man—I'm a eunuch, I'm a gelding (Fergus et al., 2002).

Although older patients rationalized the side effects of PCa treatments affecting their masculine identity by attributing their diminished sexual activity to their age or pre-cancer lack of virility, gay and bisexual men felt their erectile dysfunction caused them to feel a lack of confidence when initiating intimate contact.

## *Lived experience*

Men described a *roller coaster* of emotions from surprise to devastation, distress to acceptance, weakness, depression, fatigue, shame, anxiety and grief, disappointment and frustration. PCa diagnoses often mark the new beginning of long and complex psychological, social, and physical adjustments: "It's like the ground you walked on since you were a teenager is gone" (Nelson et al., 2015).

Coming to terms with the PCa *price tag* (e.g., loss of physical control through incontinence, sexual dysfunction, bodily changes, loss of emotional control, and loss of life) was challenging for many men. While some leveraged their pre-existing health conditions or previous adverse life events, others sought solace through spiritual or religious beliefs. Their new perspectives consoled them and helped them choose a course of action that ensured their survival:

> God gives you an opportunity with early detection to fix it and you don't die. You might give up some of your erection, but you will live forever (R. E. Gray et al., 2005).

Gay and bisexual men equated the sexual dysfunction caused by PCa treatment to the social stigma and rejection their community experienced during the HIV epidemic. Thus, they felt little stigma within their community concerning PCa. Disclosing their sexual orientation to health professionals was also a significant concern. Many were concerned about the conservative, hetero-normative focus of most medical consultations and the resulting care they might or might not receive:

> Well, I'm always tested for various diseases, not specific to gay men. But I've never had a straight doctor do anything to inquire anything about anal intercourse, or the repercussions of or the pleasures of or the possibilities of [PC] … (Hoyt et al., 2020)

Disclosure and discussion of PCa are virtually absent among Afro-American/Caribbean (AAC) males due to the social stigma related to treatment side effects (e.g., erectile dysfunction and incontinence) and masculine ideologies. Nonetheless, AAC men expressed the importance of using local churches, barbershops, and fraternities as the most effective means of raising awareness about PCA within their communities:

> Church can probably expand their ministries so that we can do these kinds of educational programs from the health perspective … because if the audience won't come to you, you've got to find a way to take it to the audience and find out where they are on, whether that's on the street corner or whatever (Odedina et al., 2004).

Geographical location and comorbidities are barriers to accessing PCa care. However, health insurance policies or a lack thereof could be the deciding factor in accessing and receiving care for those living in the US:

> I had no financial problems because I had been successful in the profession. I had good insurance, so I had no problems in paying for my treatments. Even if there was some amount that the insurance didn't pay, I could readily pay it, so for me, I had no financial problems (R. A. Jones et al., 2011).

## Discussion

This meta-synthesis aimed to improve understanding of male PCa patients' experiences. Data from 103 qualitative studies provided information about six themes highlighting the collective and unique experiences of men with PCa: diagnosis and treatment, support, care, information, masculinity, and their lived experience. Men reported involving close family members, particularly their spouses, and attending support groups to process the impact of their diagnosis and assist with their decision-making concerning treatment options. The impact of being diagnosed with PCa made many men change their daily lives physically, professionally, and socially. Access to information from the Internet made men feel empowered, prepared, and equipped to make better decisions about their treatment and care, particularly during consultations with healthcare professionals. However, the reliability of information from the Internet and healthcare professionals was a big concern for men with PCa. As men progressed along their PCa journey, they were uncertain about their prognosis and suffered side effects from their treatments, which significantly impacted their well-being and male identity. However, they frequently coped with the most challenging elements of their cancer journey by finding positive outlets like support groups.

A PCa diagnosis disrupted men's lives and produced feelings of mortality and entering unknown territory. Although some patients felt that the advice from their healthcare professionals was ambiguous, they also felt it provided a sense of control over which steps to take, a framework to comprehend the risks and benefits of specific treatments, and guided decision-making (Howard et al., 2014). Despite the stigma associated with PCa, including perceived threats to masculine ideals, those diagnosed with the condition seek opportunities to address and discuss their health concerns through support groups (Coreil & Behal, 1999; Ihrig et al., 2020; Pyle et al., 2021; Thaxton et al., 2005), advocacy groups (UsTOO-Prostate Cancer Foundation; www.movember.com; https://zerocancer.org); and social media (Bravo & Hoffman-Goetz, 2016; Struck et al., 2018; Vos et al., 2019). Widespread access to the Internet has connected those diagnosed with PCa to individuals and groups that support them and facilitated the promotion and advocacy of PCa groups and organizations. Although knowledge improves men's health, the majority of information about prostate-related health issues comes from the US, UK, and Australia, is fragmented and leads to confusion, especially among ethnic minorities and gay and bisexual men.

This paper synthesized and evaluated the evolution of all existing, high-quality qualitative papers on men with PCa. It provided an integrated and holistic understanding of barriers to early detection and screening, highlighting men's misconceptions, beliefs, and concerns. The inductive nature of thematic synthesis, grounded in grounded theory, allows for rich, emergent insights. However, it also means that interpretations are susceptible to the researchers' subjectivities and prior experiences. To address this, the authors employed rigorous reflexivity practices and took steps to systematically select and evaluate each study to minimize bias caused by the heterogeneity of the studies.

The challenge of interpreting each researcher's perspective and synthesizing their data limited this study. To the authors' knowledge, this is the only meta-synthesis that has systematically reviewed qualitative studies of men with PCa using an exclusively male sample. The results of this review highlight several concerns and issues that men with PCa face when interpreting and coping with their diagnoses, deciding among treatment options, and dealing with treatment side effects. Integrating and aggregating multiple qualitative studies enabled the researchers to identify overarching themes, patterns, and relationships. Integrating diverse perspectives from the results could lead to new insights or interpretations that may not have emerged from any single study.

The heterogeneity of the studies affected comparability and data integration, which could limit this research. The studies included in this review varied substantially in their methodologies, settings, and sample characteristics. While this heterogeneity enriched the synthesis, it also posed challenges in drawing uniform conclusions across diverse study contexts. Differences in cultural and geographic factors, as well as variations in patient experiences, may limit the comparability of findings, warranting caution when generalizing results. Many of the synthesized studies were primarily based on white, heterosexual, cis males from the US, Europe, and Australia. This study denotes those which were not. Most of the samples of men in these studies were in the pre-treatment phase of their cancer journey. This review specifically focused on male-only qualitative studies to address the research questions concerning masculinity and prostate cancer experiences. While this exclusion allowed for a more targeted exploration of the issues at hand, it also meant that insights from mixed-gender or mixed-diagnosis studies were not considered. Although this was a necessary trade-off for the study's focus, it is recognized that these studies may offer valuable perspectives that could further illuminate the topic.

Further innovative, qualitative research could explore the lived experiences of men from diverse cultural and ethnic groups and expand their lived experiences of support groups and knowledge networks that could be applied to intervention programmes, impacting long-term health outcomes for men living with PCa.

## Conclusion

These finding suggest the need for more patient-centred communication and decision aids to help men navigate options. For clinicians, prioritizing comprehensive education about treatment risks and benefits may alleviate patients' post-decision making regrets and improve overall satisfaction. Patients emphasized the importance of open and empathetic communication with healthcare providers. However, some men reported feeling dismissed or inadequately informed about their condition. These experiences highlight a critical gap in clinical practices that could be addressed through structured communication training for healthcare professionals and standardized care protocols that emphasize transparency and collaboration.

Men found both informal and inform support systems integral to coping with PCa. Support groups provided a safe space for emotional expression and decision-making, normalizing the challenges patients faced. These findings underscore the value of integrated peer-led support programmes into PCa care pathways. Future research could explore the long-term impact of such groups on patients' psychological resilience and decision satisfaction, particularly across diverse cultural and socio-economic contexts.

PCa treatment outcomes, particularly those affected sexual function and physical appearance challenged participants' sense of masculinity. Humour often served as a doping mechanism but also revealed vulnerabilities tied to identity and self-worth. This detail emphasizes the need for clinicians to address psychosocial dimensions of PCa care. Offering counselling services focused on body image and intimacy may help men navigate these challenges more effectively.

## Implications for clinical practice and future research

Enhancing patient-practitioner communication by prioritizing patient-centred communication, ensure that men receive comprehensive, understandable, and relevant information about their diagnosis and treatment options. Incorporating structured support groups into standard care can provide essential emotional and informational resources for men coping with PCa.

Given the predominance of studies on Western population, future research should examine the unique experiences of men from underrepresented cultural an socio-economic groups to develop more inclusive interventions. One way to improve patients' quality of life and adherence to treatment plans is by integrating services that address masculinity-related concerns, such as body image and sexual health, into routine PCa care.

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## Data availability statement

All the manuscripts are in the public domain. Therefore, it was unnecessary to receive ethical approval for this review.

## Ethical statement

Our study did not require an ethical board approval because it did not directly involve humans or animals.

## Notes on contributors

**Deborah Bekele** is a data scientist and researcher with over 15 years of experience in mixed-methods research and analysis. She earned a B.A. in Socio-Cultural Anthropology from the University of Maryland, where her thesis explored the evolution of the Tarantella (Pizzica) in Puglia, Italy, from curative medicine to cultural dance. Her master's in social Epidemiology at University College London focused on the inverse gradient of HIV-AIDS among Tanzanian adolescents. Currently completing her PhD in Medical Anthropology in Spain, her research examines masculinities, structural competency in healthcare systems, and access disparities among prostate and testicular cancer patients. Deborah has contributed to transnational projects combining qualitative and quantitative methodologies. Her roles include coordinating the Medical Anthropology Research Center and working as a Senior Analyst on FinTech projects in Zambia for the UNCDF. She has also led initiatives on testicular cancer awareness in Ghana, smoking cessation among pregnant women in the UK, and co-authored practical guides such as *Gestion Autonome de la Médication en Santé Mentale* (GAM) and SYNCHROS (EU Horizon 2020). Deborah's work is published in leading journals, including *Social Science & Medicine*, *BMJ Global Health*, and *Global Public Health*.

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# Study II: Estado de la cuestión de los estudios cualitativos sobre grupos de apoyo de afectado por cáncer de próstata

# ESTADO DE LA CUESTIÓN DE LOS ESTUDIOS CUALITATIVOS SOBRE GRUPOS DE APOYO DE AFECTADOS POR CÁNCER DE PRÓSTATA

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Resumen: Esta revisión exploratoria sintetiza estudios cualitativos sobre las experiencias de pacientes con cáncer de próstata (en adelante, CaP), que participan en grupos de apoyo de cáncer de próstata. Este trabajo revisa los estudios cualitativos que se centraron exclusivamente en pacientes con CaP —para ello se utilizó la herramienta de *Critical Appraisal Skills Programme* (CASP)—, sintetiza los datos y averigua los temas generales de estos estudios. La búsqueda dio lugar a 3.534 estudios, de los cuales se seleccionaron 34 estudios cualitativos para la síntesis. Se identificaron seis temas: (1) Grupos de apoyo, (2) Diagnóstico/Tratamiento, (3) Experiencia vivida, (4) Información, (5) Cuidados y (6) Masculinidad. El entorno del grupo fomentó diálogos dinámicos y sinceros sobre la experiencia del cáncer de próstata, lo que generó camaradería, actitudes altruistas y apoyo mutuo. La variedad de opciones de grupos de apoyo —en línea, cara a cara, centrados en actividades— proporcionó una experiencia única y permitió a los hombres comprometerse y participar según su disponibilidad y necesidades. Se concluye que los grupos de apoyo al cáncer de próstata (GACP) proporcionan

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un apoyo inestimable que no está disponible durante las consultas clínicas. El intercambio de información contribuyó a aumentar los conocimientos sobre la próstata y el cáncer de próstata, lo que potenció la toma de decisiones sobre las opciones de tratamiento y los resultados. Existe una preocupación creciente entre los hombres que están llegando al final del tratamiento del cáncer de próstata y entre los grupos de colectivos marginados por la falta de atención a sus necesidades asistenciales específicas.

PALABRAS CLAVE: Hombres; cáncer de próstata; grupos de apoyo; metodología cualitativa; revisión.

## SCOPING REVIEW OF QUALITATIVE STUDIES ON PROSTATE CANCER SUPPORT GROUPS

ABSTRACT: This scoping review synthesizes qualitative studies of prostate cancer patients' experiences of their prostate cancer journey as told through encounters in prostate cancer support groups. The Critical Appraisal Skills Program (CASP) tool was used to search for qualitative studies that focused exclusively on PCa patients in order to synthesize the data and ascertain the general themes of these studies. The search yielded 3,534 studies, from which 34 qualitative studies were selected for synthesis. Six themes were identified: (1) Support, (2) Diagnosis/Treatment, (3) Lived Experience, (4) Information, (5) Caregiving, and (6) Masculinity. The group setting fostered dynamic and candid dialogues about the prostate cancer experience, which generated camaraderie, altruistic attitudes and support. The variety of support group options – online, face-to-face, activity-focused – provided a unique experience and allowed men to engage and participate in accordance with their availability and needs. Prostate cancer support groups (PCSGs) provide invaluable support that is not available during clinical consultations. Information sharing contributed to increased knowledge about the prostate and prostate cancer, which contributed to improving decision-making about treatment options and outcomes. There is growing concern among men nearing the end of prostate cancer treatment and among marginalized groups about the lack of attention to their specific care needs.

KEYWORDS: Men; prostate cancer; support groups; qualitative methodology; review.

## 1. Antecedentes

La Organización Mundial de la Salud clasifica el cáncer de próstata (CaP) como la segunda causa de muerte relacionada con el cáncer en los hombres en todo el mundo (Sung *et al.*, 2021). Sin embargo, las tasas de incidencia y mortalidad varían en función del lugar de residencia de la población masculina. Los países del "norte global" (Australia/Nueva Zelanda, Europa septentrional y oriental, y América del Norte) informan de una alta incidencia y una mayor prevalencia de hombres con CaP; mientras que, en los países del "sur global", ocurre lo contrario. Estas tasas están relacionadas con el Índice de Desarrollo Humano (IDH) de cada región y con la adopción de prácticas de cribado del cáncer de próstata por parte de los profesionales sanitarios.

Desde el descubrimiento del antígeno prostático en tejidos de cáncer de próstata a finales de la década de 1960 (Catalona *et al.*, 1991; De Angelis *et al.*, 2007; Rao *et al.*, 2007), las prácticas de cribado han evolucionado hasta incluir la prueba del antígeno prostático especifico (PSA), la cual se utiliza para la detección precoz del cáncer de próstata mediante un análisis de sangre. La promoción y el uso del PSA como prueba de cribado de primera línea ha provocado un rápido aumento de la incidencia del cáncer de próstata en determinadas regiones del mundo, lo que ha dado lugar a cierta controversia respecto a su eficacia e impacto en la calidad de vida. Ese debate en torno al PSA es el resultado de dos importantes estudios (Kim y Andriole, 2015) cuyos resultados difieren lo suficiente como para que las directrices subsiguientes varíen en función del país y la organización.

Desde la aparición de Internet en los años 80 y el posterior aumento del acceso y uso de Internet en los últimos 40 años, se ha producido un incremento de la promoción, la defensa y el activismo contra el cáncer en forma de movimientos sociales que han proporcionado atención de apoyo para las necesidades de los hombres con CaP, en función de la etapa en la que se encuentran en su trayectoria oncológica (Paterson *et al.*, 2015). Internet arroja un amplio surtido de sitios web, blogs y foros sobre el cáncer de próstata, grupos de defensa y organizaciones que utilizan varias plataformas —Twitter, LinkedIn, Facebook, Instagram— y grupos relacionados con el cáncer de próstata, como Us-Too (<https://www.ustoo.org/>) y Movember Foundation (<https://us.movember.com/>), que facilitan la rápida difusión y el fácil intercambio de información y recomendaciones sobre el cáncer de próstata, orientadas especialmente a los pacientes recién diagnosticados con una mayor presencia y visibilidad a escala mundial (Bravo y Hoffman-Goetz, 2016; Vraga *et al.*, 2018).

## 2. Apoyo social y defensa del cáncer de próstata

Existen diversas razones por las que los hombres se resisten a buscar soluciones relacionadas con la salud en épocas de mala o decreciente calidad de la misma. Algunas de las barreras más comúnmente señaladas para buscar ayuda médica estaban vinculadas a ideologías sobre la masculinidad hegemónica (Addis y Mahalik, 2003; Connell, 2014), la vergüenza (King-Okoye *et al.*, 2017), las percepciones de estigma y aislamiento (Ettridge *et al.*, 2018) y el acceso a la cobertura médica (Ekúndayò *et al.*, 2015). Los grupos de apoyo al cáncer de próstata (GACP) son espacios de sociabilidad que permiten mitigar estas barreras.

El creciente número de grupos de apoyo en línea y cara a cara, la libertad de elegir el nivel de interacción y el entorno libre de juicios e incondicional donde los hombres pueden acceder y compartir información sobre su diagnóstico y comparar las opciones de tratamiento han demostrado ayudar en la toma de decisiones (Pyle *et al.*, 2021; Sullivan, 2003). En concreto, los GACP en línea tienen la ventaja añadida del anonimato para quienes se sienten menos inclinados a hablar públicamente de su diagnóstico (Blank *et al.*, 2010; Burke-Garcia y Wright, 2018; Sillence y Mo, 2014). Las investigaciones más recientes que resumen los datos sobre los GACP (Campbell *et al.*, 2004; Thaxton *et al.*, 2005) es de hace más de 10 años y necesitan ser reexaminadas en consonancia con la creciente literatura sobre la salud de los hombres, los grupos de apoyo social y la promoción. Por lo tanto, esta síntesis tiene como objetivo construir sobre el muy poco conocimiento actual sobre GACP y las necesidades de apoyo de los hombres con CaP mediante la identificación de temas convergentes, congruentes y emergentes.

# 3. Métodos

## 3.1 Método de revisión

Esta síntesis pretende: (1) conocer las preocupaciones, necesidades y problemas específicos a los que se enfrentan los hombres diagnosticados de cáncer de próstata; (2) describir los beneficios e inconvenientes de asistir y participar en grupos de apoyo al cáncer de próstata; y (3) discernir el valor que se otorga al apoyo social y a las redes sociales durante el proceso del cáncer de próstata. El enfoque metodológico se basó en el *Thematic Synthesis* de C. Thomas y Harden (2008) y se utilizó la metodología *Enhancing Transparency in Reporting the Synthesis of Qualitative Research* (ENTREQ) (Tong *et al.*, 2012) y la herramienta CASP (*The Critical Appraisals Skills Programme*, 2018) para la presentación de informes y la valoración. La síntesis se realizó en tres fases. La primera fase consistió en extraer e introducir el texto de la sección de "resultados" o "conclusiones" de cada manuscrito. En la segunda fase, el texto de estas secciones se codificó y desarrolló en temas descriptivos. La tercera fase 3 generó temas analíticos.

## 3.2 Criterios de inclusión

Se seleccionaron artículos de estudios cualitativos revisados por pares, en los que se habían entrevistado a pacientes varones con CaP, que asistieron, se comprometieron o participaron en cualquier tipo de GACP (en línea, presencial o centrado en actividades). Estos estudios cualitativos incluían estudios observacionales, entrevistas o grupos focales, así como estudios etnográficos. La búsqueda general incluyó cualquier estudio publicado hasta principios de 2024.

## 3.3 Criterios de exclusión

Se excluyeron los estudios que utilizaban una metodología cuantitativa o mixta, o que incluyeron otros sujetos que no eran varones con CaP. También se excluyeron los artículos de congresos, las disertaciones, las encuestas, los cuestionarios, los editoriales, los libros/capítulos de libros y las revisiones.

### 3.4 Estrategias de búsqueda

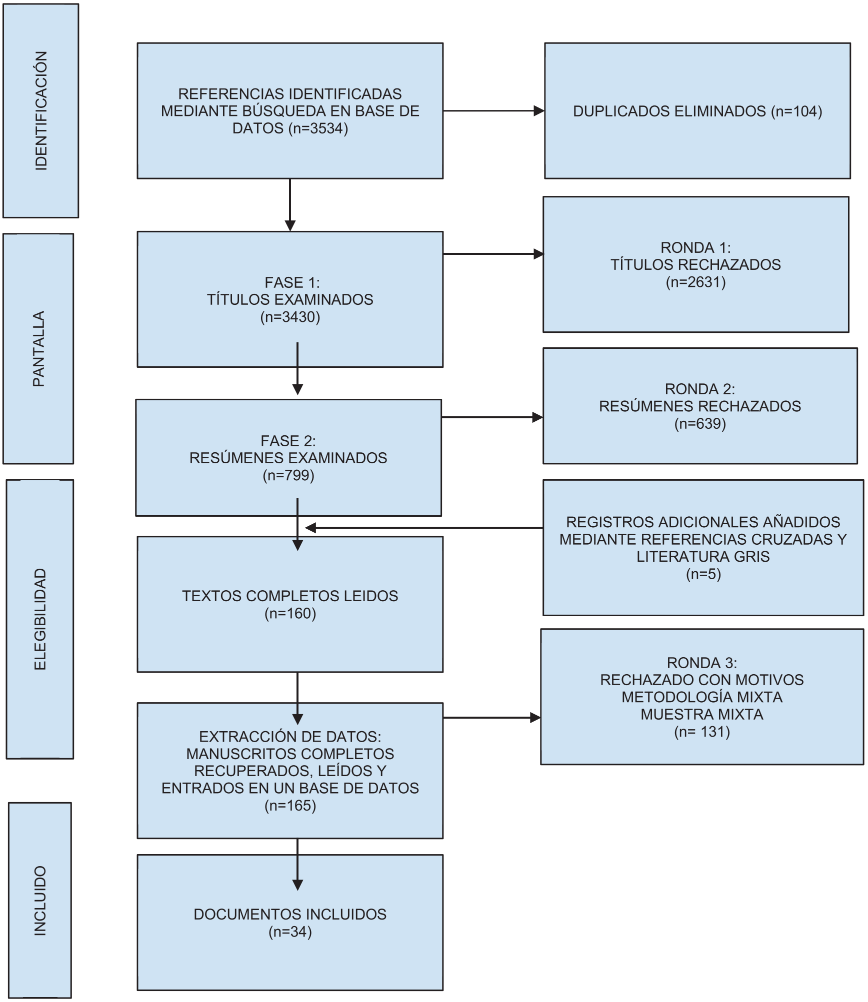
La estrategia de búsqueda consistió en identificar las palabras clave más utilizadas en los estudios cualitativos sobre el cáncer de próstata y el apoyo mutuo. Los resultados produjeron una lista de términos de búsqueda —(“prostate”) AND (“health activ*” OR “health advocacy” OR “advocacy”) OR (“social support” OR “social group” OR “online support” OR “support group”)—, que se introdujeron en CINHAL, MEDLINE, Academic Search Ultimate, Psychology and Behavioral Sciences Collection, SCOPUS, PsychInfo, PSICODOC y PubMed.

## 4. Evaluación de la calidad

Un enfoque de síntesis temática permitió adoptar una metodología de *Grounded Theory* para analizar los estudios seleccionados (véase la Figura 1). La búsqueda se llevó a cabo entre julio 2019 y enero de 2024 y se identificaron un total de 3.534 artículos. Tras varias rondas de exclusión de manuscritos que no cumplían estrictamente los criterios de inclusión, se extrajeron 165 artículos para la revisión del texto completo, y se seleccionaron 34 (Tabla 1) estudios cualitativos finales para una evaluación de la calidad mediante el *Critical Appraisal Skills Programme*.

Esta herramienta validada propone un análisis crítico para evaluar las fortalezas y debilidades de los estudios cualitativos utilizando una lista de verificación de 10 preguntas: (1) ¿hubo una declaración clara de los objetivos de la investigación?; (2) ¿es apropiada una metodología cualitativa?; (3) ¿el diseño de la investigación era adecuado para abordar los objetivos de la investigación?; (4) ¿la estrategia de reclutamiento era adecuada para los objetivos de la investigación?; (5) ¿se recogieron los datos de forma adecuada para abordar el tema de la investigación?; (6) ¿se ha considerado adecuadamente la relación entre el investigador y los participantes?; (7) ¿se han tenido en cuenta las cuestiones éticas?; (8) ¿ha sido suficientemente riguroso el análisis de los datos?; (9) ¿existe una exposición clara de las conclusiones?; (10) ¿qué valor tiene la investigación? Utilizando la orientación de Alexis y Worsely (Alexis y Wors-

**Figura 1. Diagrama de flujo de la búsqueda bibliográfica**



ley, 2018), se asignó a cada estudio una puntuación de 0 (para “no”) o 1 (para “sí”). La puntuación final categorizó el estudio como “mala calidad” (1-5), “calidad media” (6-7) o “alta calidad” (8-10) (Tabla 2). Todos los estudios clasificados como de alta calidad, que fueron 34, se incluyeron en esta revisión.

Tabla 1. Características de las publicaciones

| **Autor/es** | **Título** | **Revista** | **Fecha de publicación** | **Tamaño de la muestra** | **Edad** | **Lugar de Estudio** |
|---|---|---|---|---|---|---|
| Arrington, M.I. | "I don't want to be an artificial man": Narrative Reconstruction of Sexuality Among Prostate Cancer Survivors | *Sexuality and Culture* | 2003 | n=16 | no indicado | EE. UU. |
| Arrington, M.I. | Prostate Cancer and the Social Construction of Masculine Sexual Identity | *International Journal of Men's Health* | 2008 | no indicado | no indicado | EE. UU. |
| Arrington, M.I. | Uncertainty and Stigma in the Experiences of Prostate Cancer Survivors: A Thematic Analysis of Narrative Elements | *Illness, Crisis y Loss* | 2015 | n=16 | 66-81yo | EE. UU. |
| Bell, K. y Kazanjian,A. | PSA testing: Molecular technologies and men's experience of prostate cancer survivorship | *Health, Risk y Society* | 2011 | n=8 | no indicado | Canadá |
| Broom, A. | Virtually healthy: The impact of internet use on disease experience and the doctor-patient relationship | *Qualitative Health Research* | 2005b | n=33 | no indicado | Australia |
| Capistrant, B.D. *et al.* | Caregiving and social support for gay and bisexual men with prostate cancer | *Psycho-Oncology* | 2016 | n=30 | 59-75yo | EE. UU. |
| Cinà, I.V. *et al.* | "One stroke, with twenty-two people": exploring prostate cancer survivors' participation in dragon boating | *Journal of Psycho-social Oncology* | 2020 | n=11 | 56-73yo | Canadá |

| Autor/es | Título | Revista | Fecha de publicación | Tamaño de la muestra | Edad | Lugar de Estudio |
|---|---|---|---|---|---|---|
| Cockle-Hearne, J. et al. | Developing peer support in film for cancer self-management: what do men want other men to know? | *Supportive Care in Cancer* | 2016 | n=7 | 55-74yo | Reino Unido |
| Dickerson, S. *et al.* | Cancer as a problem to be solved: Internet use and provider communication by men with cancer | *CIN- Computers Informatics Nursing* | 2011 | n=15 | 47-78yo | En línea |
| Dieperink, S. *et al.* | Embracing life after prostate cancer. A male perspective on treatment and rehabilitation | *European Journal of Cancer Care* | 2013 | n=13 | 66-77yo | Dinamarca |
| Farrington, A. *et al.* | The lived experience of adjustment to prostate cancer. | Psychology of Men y Masculinities | 2020 | n=8 | 59-80yo | Inglaterra |
| Fergus, K., Gray, R. y Fitch, M. | Sexual Dysfunction and Preservation of Manhood: Experiences of Men with Prostate Cancer | *Journal of Health Psychology* | 2002 | n=18 | 65yo | Canadá |
| Gray R. *et al.* | Interviews with Men with Prostate Cancer About Their Self-Help Group Experience | *Journal of Palliative Care* | 1997 | n=12 | 45-80yo | Canadá |
| Green, R. | Maintaining masculinity: moral positioning when accounting for prostate cancer illness | *Health* | 2021 | n=29 | 53-82yo | Inglaterra |
| Green, R. | The Forms and Uses of Acquired Prostate Cancer Expertise Among Prostate Cancer Survivors | *Sociological Research Online* | 2020 | n=29 | 53-83yo | Inglaterra |

*(Continúa)*

Tabla 1. Características de las publicaciones *(Continuación)*

| Autor/es | Título | Revista | Fecha de publicación | Tamaño de la muestra | Edad | Lugar de Estudio |
|---|---|---|---|---|---|---|
| Green, R. | Experiences and management of urinary incontinence following treatment for prostate cancer: Disrupted embodied practices and adapting to maintain masculinity | *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* | 2023 |  | 53-83yo | Inglaterra |
| Hoyt, M. *et al.* | Gay men's experiences with prostate cancer: Implications for future research | *Journal of Health Psychology* | 2020 | n=11 | 43-84yo | EE. UU. |
| Imm, K. *et al.* | African American prostate cancer survivorship: Exploring the role of social support in quality of life after radical prostatectomy | *Journal of Psychosocial Oncology* | 2017 | n=12 | 49-79yo | EE. UU. |
| Jones, R. *et al.* | Exploring cancer support needs for older African-American men with prostate cancer | *Support Cancer Care* | 2011 | n=23 | 66-80yo | EE. UU. |
| Letts, C. *et al.* | Exploring the Impact of Prostate Cancer on Men's Sexual Well-Being | *Journal of Psychosocial Oncology* | 2010 | n=19 | 54-79yo | Canadá |
| Mathers, S. *et al.* | A necessary evil: The experiences of men with prostate cancer undergoing imaging procedures | *Radiography* | 2011 | n=7 | 61-83yo | Escocia |

| Autor/es | Título | Revista | Fecha de publicación | Tamaño de la muestra | Edad | Lugar de Estudio |
|---|---|---|---|---|---|---|
| Matsunaga, D.S. y Gotay, C.C. | Characteristics Contributing to an Enduring Prostate Cancer Support Group in an Asian and Pacific Islander Community | *Journal of Psychosocial Oncology* | 2004 | n=24 | 55-85yo | EE. UU. |
| Nanton, V. *et al.* | Finding a pathway: Information and uncertainty along the prostate cancer patient journey | *British Journal of Health Psychology* | 2009 | n=36 | 55-84yo | Reino Unido |
| Nelson, C. *et al.* | Men's experience with penile rehabilitation following radical prostatectomy: A qualitative study with the goal of informing a therapeutic intervention | *Psycho-Oncology* | 2015 | n=30 | 41-72yo | EE. UU. |
| O'Shaughnessy, P.K. y Laws, T.A. | Australian men's long-term experiences following prostatectomy: A qualitative descriptive study | *Contemporary Nurse* | 2009 | n=11 | no indicado | Australia |
| Odedina, F. *et al.* | A Focus Group Study of Factors Influencing African-American Men's Prostate Cancer Screening Behavior | *Journal of National Medical Association* | 2004 | n=49 | 40+yo | EE. UU. |
| Oliffe, J. *et al.* | Connecting humor, health, and masculinities at prostate cancer support groups | *Psycho-Oncology* | 2009 | n=54 | 53-87yo | Canadá |
| Oliffe J. *et al.* | Health Promotion and Illness Demotion at Prostate Cancer Support Groups | *Health Promotion Practice* | 2010 | n=52 | 53-87yo | Canadá |

*(Continúa)*

Tabla 1. Características de las publicaciones *(Continuación)*

| Autor/es | Título | Revista | Fecha de publicación | Tamaño de la muestra | Edad | Lugar de Estudio |
|---|---|---|---|---|---|---|
| Öster, I. *et al.* | Sharing experiences in a support group: Men's talk during the radiotherapy period for prostate cancer | *Palliative and Supportive Care* | 2013 | n=9 | No indicado | Suecia |
| Thomas, C. *et al.* | The experiences of gay and bisexual men diagnosed with prostate cancer: results from an online focus group | *European Journal of Cancer Care* | 2013 | n=10 | 47-70yo | En línea (Victoria, AUS) |
| Trinh, L. *et al.* | A Qualitative Study Exploring the Perceptions of Sedentary Behavior in Prostate Cancer Survivors Receiving Androgen-Deprivation Therapy | *Oncology Nursing Forum* | 2015 | n=27 | 64-81yo | Canadá |
| Wallace, M. y Storms, S. | The needs of men with prostate cancer: results of a focus group study | *Applied Nursing Research* | 2007 | n=17 | 49-81yo | EE. UU. |
| Wallington, S.F. | The Internet as an Emerging Patient Education Tool Among African American Men with Prostate Cancer: An Exploratory Study | *American Journal of Men's Health* | 2008 | n=39 | 39-73yo | EE. UU. |
| Walsh, E. y Hegarty, J. | Men's experiences of radical prostatectomy as treatment for prostate cancer | *European Journal of Oncology Nursing* | 2010 | n=8 | No indicado | Reino Unido |

## Tabla 2. CASP Tool Assessment

| | **CRITERIO** | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **ESTUDIO** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** | **TOTAL** |
| Arrington, M.I. (2003) | S | S | S | S | S | S | S | S | S | S | 10 |
| Arrington, M.I. (2008) | S | S | S | S | S | N | N | S | S | S | 8 |
| Arrington, M.I. (2015) | S | S | S | S | S | N | N | S | S | S | 8 |
| Bell, K. yKazanjian, A. (2011) | S | S | S | S | S | S | S | S | S | S | 10 |
| Broom, A. (2005b) | S | S | S | S | S | N | S | S | S | S | 9 |
| Capistrant, D.B. *et al*. (2016) | S | S | S | S | S | N | S | S | S | S | 9 |
| Cinà, I.V. *et al*. (2020) | S | S | S | S | S | S | S | N | S | S | 9 |
| Cockle-Hearne, J. *et al*. (2016) | S | S | S | S | S | S | S | S | S | S | 10 |
| Dickerson, S. *et al*. (2011) | S | S | S | S | S | S | N | S | S | S | 9 |
| Dieperink. S. *et al*. (2013) | S | S | S | S | S | S | S | N | S | S | 9 |
| Farringdon, A. (2020) | S | S | S | S | S | S | S | N | S | S | 9 |
| Fergus K. *et al*. (2002) | S | S | S | S | S | S | S | S | S | S | 10 |
| Gray, R. *et al*. (1997) | S | S | S | S | S | N | N | Y | Y | Y | 8 |
| Green, R. (2020) | S | S | S | S | S | S | S | S | S | S | 10 |
| Green, R. (2021) | S | S | S | S | S | S | S | S | S | S | 10 |
| Green, R. (2023) | S | S | S | S | S | S | S | S | S | S | 10 |
| Hoyt, M. *et al*. (2020) | S | S | S | S | S | N | Y | Y | Y | Y | 9 |
| Imm, K. *et al*. (2017) | S | S | S | S | S | S | S | S | S | S | 10 |
| Jones, R. *et al*. (2011) | S | S | S | S | S | S | S | S | S | S | 10 |
| Letts, C. *et al*. (2010) | S | S | S | S | S | S | S | S | S | S | 10 |
| Mathers, S. *et al*. (2011) | S | S | S | S | S | S | S | S | Y | N | 9 |
| Matsunaga D.S. y Gotay C.C. (2004) | S | S | S | S | S | S | N | S | S | S | 9 |
| Nanton, V *et al*. (2009) | S | S | S | S | S | N | S | S | S | S | 9 |

*(Continúa)*

Tabla 2. CASP Tool Assessment (*Continuación*)

| | CRITERIO | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **ESTUDIO** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** | **TOTAL** |
| Nelson, C. *et al.* (2015) | S | S | S | S | S | S | S | S | S | S | 10 |
| O'Shaughnessy P.K. y Laws, T.A. (2009) | S | S | S | S | S | S | S | S | S | S | 10 |
| Odedina, F. *et al.* (2004) | S | S | S | S | S | S | N | S | S | S | 9 |
| Oliffe, J. *et al.* (2009) | S | S | S | S | S | S | S | S | S | S | 10 |
| Oliffe, J. *et al.* (2010) | S | S | S | S | S | S | S | S | S | S | 10 |
| Öster, I. *et al.* (2013) | S | S | S | S | S | N | S | S | S | S | 9 |
| Thomas, C. *et al.* (2013) | S | S | S | S | S | N | S | S | S | S | 9 |
| Trinh, L. *et al.* (2015) | S | S | S | S | S | N | S | S | S | S | 9 |
| Wallace, M. y Storms, S. (2007) | S | S | S | S | S | S | S | S | S | S | 10 |
| Wallington S.F. (2008) | S | S | S | S | S | N | S | S | S | S | 9 |
| Walsh, E. y Hegarty, J. (2010) | S | S | S | S | S | S | S | S | S | S | 10 |

De este análisis derivaron 6 subtemas relacionados con los temas generales hallados en los 34 artículos: (1) diagnóstico y tratamiento, (2) grupos de apoyo, (3) información, (4) atención, (5) experiencia vivida y (6) masculinidad. Estos temas se trataron como temas centrales o subtemas en los 34 manuscritos. El subtema del diagnóstico y el tratamiento se refieren a la trayectoria clínica del paciente con CaP. El del apoyo describe los diferentes tipos y la dinámica interna de los grupos de apoyo. El tercer subtema principal se refiere a la búsqueda, el acceso, la fuente y la calidad de la información sobre el CaP.

Los tres últimos subtemas se refieren a la atención, medida por el enfoque basado en las necesidades y la calidad de las consultas clínicas, mientras que el subtema de la experiencia vivida de los pacientes con CaP engloba los estigmas generales, el aislamiento, las barreras socioeconómicas y culturales que afectan a la vida cotidiana de los pacientes con CaP. La masculinidad se refiere especialmente a las cuestiones relativas a la autoidentidad y la reconfiguración identitaria de los varones a través su enfermedad, "yo", los roles, las actitudes y los comportamientos en el contexto de la experiencia del CaP.

## 4.1 Diagnóstico y tratamiento

Los hombres describieron una "montaña rusa" de emociones, desde la sorpresa hasta la devastación y la angustia; la aceptación y decepción; y la vergüenza y frustración debido a las complicaciones de los tratamientos. Aunque los hombres hablaron de cómo el diagnóstico trastornó sus vidas y les produjo sentimientos de mortalidad y de "adentrarse en lo desconocido", también expresaron la importancia de mantener un nivel de optimismo. El deseo expresado de volver a una vida "normal", a sus antiguas rutinas y relaciones en las que no se vieran reducidos a los trastornos y cambios provocados por el diagnóstico y los efectos secundarios del tratamiento (Arrington, 2003; Imm *et al.*, 2017; Nanton *et al.*, 2009; C. Thomas *et al.*, 2013; Walsh y Hegarty, 2010). La incontinencia y los cambios en la función intestinal debidos a determinados tratamientos o cirugías impedían los patrones de sueño y las actividades cotidianas, ya que existía una preocupación constante por la proximidad y el acceso rápido a un inodoro para atender la necesidad urgente de orinar (Farrington *et al.*, 2020; Green, 2020, 2023; Nanton *et al.*, 2009; C. Thomas *et al.*, 2013).

La prueba del PSA, su significado y su impacto antes y después del tratamiento es un tema común en los debates sobre el cáncer de próstata. Aunque para cada paciente el PSA causaba un nivel de ambigüedad distinto, también proporcionaba cierta sensación de control sobre el diagnóstico y orientaba la toma de decisiones (Oliffe *et al.*, 2010). Sin embargo, tras el diagnóstico, las pruebas rutinarias de PSA producían angustia repetitiva ante el riesgo de recurrencia y dificultaban la adaptación psicológica adecuada (Arrington, 2008, 2015; Bell y Kazanjian, 2011; Farrington et al., 2020; Hoyt *et al.*, 2020; Nanton *et al.*, 2009).

## 4.2 Grupos de apoyo

Las reuniones de grupo sirvieron como un espacio en el que se disponía de información y acceso a diferentes recursos (material audiovisual y ponentes invitados) y se fomentaban y facilitaban debates abiertos y sinceros sobre el diagnóstico, los síntomas, las opciones de tratamiento y los efectos secundarios (Cinà *et al.*, 2020; Gray *et al.*, 1997; Matsunaga y Gotay, 2004; Oliffe *et al.*, 2010; C. Thomas *et al.*, 2013; Wallace y Storms, 2007). Asumir su viaje oncológico supuso, para algunos, la oportunidad de ayudar a alguien más que a sí mismos (Cinà *et al.*, 2020; Hoyt *et al.*, 2020; Öster *et al.*, 2013; C. Thomas *et al.*, 2013). Al asumir la posición de "defensor moral" (Green, 2021) los hombres pasaron de ser quienes necesitan apoyo a ser quienes lo proporcionan (Capistrant *et al.*, 2016; Gray *et al.*, 1997; Green, 2020; Matsunaga y Gotay, 2004), evocando una relación altruista hacia sus compañeros. Cuando se pidió a los hombres asistentes a los GACP que dieran consejos a otros hombres en situaciones similares, los mensajes se enmarcaron en términos de esperanza (para el futuro), resiliencia, determinación y fuerza de voluntad con especial atención a la importancia de la rehabilitación, la obtención del control sobre la propia vida y la continuación del contacto y las interacciones con los compañeros de trabajo u otros grupos de intereses compartidos (Cockle-Hearne *et al.*, 2016; Fergus *et al.*, 2002; Hoyt *et al.*, 2020; Matsunaga y Gotay, 2004; Öster *et al.*, 2013; Trinh *et al.*, 2015).

### 4.3 Información

Los conocimientos sanitarios, es decir, la capacidad de recibir información médica, comprenderla y tomar decisiones con comprensión de causa, puede variar en función del curso y de la persona que la recibe. En general, el conocimiento sanitario implica un cierto saber de la enfermedad, una actitud, es decir, el riesgo percibido de padecer esa enfermedad y, en consecuencia, un comportamiento, el que cada uno adopta cuando se enfrenta a un diagnóstico.

Aprender sobre el cáncer de próstata de sus compañeros les pareció más práctico, comprensible y no amenazador. Los conocimientos adquiridos a través de la lectura de estudios sobre el cáncer de próstata en Internet o la asistencia a grupos de apoyo generaron sentimientos de empoderamiento para afrontar mejor la enfermedad y recuperar el control y la confianza en las decisiones que tomaban (Cockle-Hearne *et al.*, 2016; Matsunaga y Gotay, 2004; Oliffe *et al.*, 2010). Esto no solo ocurría a nivel personal, sino también en el ámbito clínico, cuando los hombres consideraban que la recopilación de información les permitía ser más proactivos en el trato con su clínico. Esta era una moneda de cambio que reforzaba su sensación de control y poder en las interacciones (Dickerson *et al.*, 2011; Gray *et al.*, 1997; Matsunaga y Gotay, 2004; Oliffe *et al.*, 2010; Wallington, 2008).

No obstante, hubo consenso en que hay que ser prudente a la hora de consumir la ingente cantidad de información disponible en Internet y en otros sitios, relativa sobre todo a las opciones de tratamiento del cáncer de próstata (Broom, 2005b, 2005b; Dickerson *et al.*, 2011; Oliffe *et al.*, 2010; Wallington, 2008). Se consideró importante que los hombres desearan información de calidad, práctica y logística, que se ofreciera de forma no alarmante y esperanzadora (Matsunaga y Gotay, 2004; Nanton *et al.*, 2009; Oliffe *et al.*, 2010) y orientada a diferentes niveles de alfabetización sanitaria (Odedina *et al.*, 2004; Öster *et al.*, 2013).

## 4.4 Atención

Para los hombres era importante confiar en las recomendaciones y capacidades de sus médicos, lo que les ayudaba a tener esperanza en cuestiones relacionadas con la supervivencia, lo cual contribuía a crear una sensación de seguridad (Nanton *et al.*, 2009). Mientras que algunos hombres expresaron su deseo de mantener un enfoque abierto y colaborativo con su especialista (Dickerson *et al.*, 2011), lo que les ayudó a sentirse más informados y menos ansiosos sobre su toma de decisiones (Imm *et al.*, 2017; Wallace y Storms, 2007);otros confiaron muy poco en las consultas y les otorgaron un papel secundario (Arrington, 2015). Algunos hombres informaron que sus médicos les habían ocultado información (Matsunaga y Gotay, 2004) o consideraban que su médico les había proporcionado información sesgada o ambigua sobre las opciones de tratamiento, por ello, buscaron una segunda o tercera opinión, recurrieron a Internet o cambiaron de médico especialista (Arrington, 2015; Oliffe *et al.*, 2010; C. Thomas *et al.*, 2013; Wallington, 2008; Walsh y Hegarty, 2010).

Un enfoque amable, cortés y abierto por parte de los profesionales sanitarios hacia los hombres durante las largas sesiones de tratamiento se consideró esencial para crear experiencias positivas en todos los entornos (clínicos y grupos de apoyo) y generó confianza en los hombres de que estaban en "manos expertas" (Dieperink *et al.*, 2013; Hoyt *et al.*, 2020; Nanton *et al.*, 2009; Oliffe *et al.*, 2010; Öster *et al.*, 2013; C. Thomas *et al.*, 2013; Walsh y Hegarty, 2010). Sin embargo, para algunos pacientes el proceso y la continuidad de la atención fueron esquivos, causaron confusión e indujeron ansiedad, lo que pone de relieve la importancia de una comunicación interpersonal eficaz (Walsh y Hegarty, 2010). A menudo se expresaba que los profesionales médicos no prestaban suficiente atención a las necesidades emocionales de los hombres, a un plan estructurado de cuidados y al apoyo (C. Thomas *et al.*, 2013) que involucrase la orientación anticipatoria en cuanto a la comunicación del diagnóstico y el suministro de información (Walsh y Hegarty, 2010) entre el médico y el paciente. Los hombres también informaron de que recibieron "poca o ninguna información sobre sexualidad" antes y después del tratamiento. Describieron las consultas como cerradas, sin respuesta, evasivas, o les dijeron "eso es de esperar" cuando hablaron sobre el tema de los cambios/funciones sexuales después del tratamiento (Letts *et al.*, 2010; Nelson *et al.*, 2015). Entre los hombres gais/bisexuales la revelación de su orientación sexual a los profesionales sanitarios era una preocupación importante, al igual que el enfoque conservador y heteronormativo de las consultas médicas (Hoyt *et al.*, 2020; C. Thomas *et al.*, 2013).

## 4.5 Experiencia vivida

El diagnóstico de cáncer de próstata marcó el inicio de un largo y complejo periodo de ajustes psicológicos, sociales y físicos (Fergus *et al.*, 2002). Se utilizaron distintos mecanismos de afrontamiento para adaptarse al diagnóstico de CaP. Mientras que algunos hombres dieron sentido a los "males necesarios" (Mathers *et al.*, 2011) del CaP mediante el aprovechamiento de este nuevo diagnóstico contra las condiciones de salud existentes o experiencias adversas anteriores, otros recurrieron a sus creencias espirituales o religiosas (Imm *et al.*, 2017; Jones *et al.*, 2011; Matsunaga y Gotay, 2004).

No obstante, para todos los hombres, asumir su experiencia con el cáncer supuso un (re)ajuste de sus valores y expectativas (masculinas) (Green, 2021; Hoyt *et al.*, 2020; Letts *et al.*, 2010; Nanton *et al.*, 2009; O'Shaughnessy y Laws, 2009; Öster *et al.*, 2013). Esta nueva apreciación y perspectiva de la vida (Arrington, 2015; Fergus *et al.*, 2002; Hoyt *et al.*, 2020; Nanton *et al.*, 2009; Öster *et al.*, 2013; C. Thomas *et al.*, 2013; Wallace y Storms, 2007) dieron aliento a las decisiones que tomaron respecto, por ejemplo, el tratamiento, porque garantizaba la supervivencia (Fergus *et al.*, 2002; O'Shaughnessy y Laws, 2009; C. Thomas *et al.*, 2013). Se observó que los factores culturales influían en la dinámica del grupo. La consideración de la ubicación y la variedad de factores culturales que están en juego entre los miembros del grupo también pueden determinar el éxito del grupo.

## 4.6 Masculinidad

En los diferentes estudios, los hombres hablaron largo y tendido sobre los diversos impactos que los tratamientos del CaP tuvieron en su estado físico y psicológico, identidad sexual (Arrington, 2008; Oliffe *et al.*, 2009; O'Shaughnessy y Laws, 2009; C. Thomas *et al.*, 2013; Walsh y Hegarty, 2010) y la "presión por rendir" (Fergus *et al.*, 2002; Letts *et al.*, 2010). A pesar de los intentos de reconciliar los resultados no deseados de los tratamientos del CaP, expresando lo "afortunados" (Fergus *et al.*, 2002; Green, 2021; Nanton *et al.*, 2009; Öster *et al.*, 2013) que eran en comparación con lo que experimentaban otros hombres; los efectos adversos seguían necesitando la reconstrucción del "yo" interiorizado (Farrington *et al.*, 2020; Hoyt *et al.*, 2020; O'Shaughnessy y Laws, 2009). Por ejemplo, los efectos adversos de la Terapia de Privación de Andrógenos (ADT), un tipo de tratamiento para el CaP, causaron un aumento de los tejidos grasos, senos, sofocos e inhibición de la libido sexual, que los hombres sintieron que feminizaba sus cuerpos y revelaron que lucharon con sentimientos de desempoderamiento y desfiguración que produjeron la incapacidad o la pérdida de intimidad con sus parejas. En otro ejemplo, las consecuencias habituales de someterse a una prostatectomía radical (PR) —la extirpación completa de la próstata— son la disfunción eréctil (DE) o la incontinencia. Para algunos hombres, su identidad masculina estaba estrechamente ligada a su actividad física, la conservación de la erección y el rendimiento sexual (Fergus *et al.*,

2002) y las percepciones de las normas y los rasgos masculinos (Imm *et al.*, 2017) y los tratamientos del CaP desafiaban estos ideales.

Sin embargo, esta amenaza a su identidad se minimizó demostrando su virilidad previa al cáncer al haber tenido hijos o se adaptaron a estos cambios explorando formas alternativas, alejadas de las formas fálicas de expresar la intimidad (Arrington, 2003; Fergus *et al.*, 2002). (Arrington, 2003; Fergus *et al.*, 2002; C. Thomas *et al.*, 2013). También atribuyeron su menor actividad sexual a la edad (avanzada) (Dieperink *et al.*, 2013; Fergus *et al.*, 2002; Green, 2021; Oliffe *et al.*, 2009; Öster *et al.*, 2013). Las dificultades que conllevaba la disfunción eréctil y su vínculo con la alteración del yo también hicieron que algunos hombres sintieran que corrían el riesgo de perder a sus parejas (Letts *et al.*, 2010). Entre los hombres gais y bisexuales, la disfunción eréctil producía una falta de confianza para iniciar el contacto íntimo y afectaba a la capacidad de negociar sus roles dentro de la comunidad gay (Fergus *et al.*, 2002; Hoyt *et al.*, 2020; C. Thomas *et al.*, 2013).

Aunque a algunos les resultaba difícil hablar con franqueza de temas delicados como el sexo o la disfunción eréctil (Matsunaga y Gotay, 2004) en presencia de miembros de la familia, el humor o el sarcasmo se utilizaban a menudo en las discusiones de grupo de los GACP formados exclusivamente por hombres. "Humor de chicos" (Oliffe *et al.*, 2009) se utilizó como una forma de conciliar colectivamente y disipar la ansiedad vinculada al "precio" —incontinencia, pérdida de la función sexual o muerte— del CaP (Fergus et al., 2002; Matsunaga y Gotay, 2004; Nanton et al., 2009; Nelson et al., 2015; Öster et al., 2013) con estoicismo que desarmaba los ideales dominantes de masculinidad heteronormativa.

## 5. Debate

El objetivo de esta revisión cualitativa era comprender la experiencia colectiva de los hombres con cáncer de próstata mediante el examen de la bibliografía existente sobre grupos de apoyo para el cáncer de próstata. Los resultados de esta revisión produjeron varios temas generales que esbozaron las diferentes fases, desde el diagnóstico y el tratamiento, los comportamientos de búsqueda de apoyo, del "viaje" del CaP, destacando sus experiencias colectivas y únicas durante el viaje, hasta la identificación de la dinámica intergrupal y la clasificación de las características únicas de los diferentes grupos de apoyo al CaP que existen.

La evidencia emergente muestra cómo la amplia disponibilidad de Internet ha permitido el acceso inmediato y la conectividad entre individuos y grupos, y ha facilitado el trabajo de promoción y defensa de los grupos y organizaciones de CaP. Aunque se trata de un factor positivo en el movimiento hacia la mejora de la salud masculina, la mayoría de las redes y organizaciones de CaP están muy concentradas en Estados Unidos, Reino Unido y Australia. En el resto del mundo, la presencia de redes y organizaciones de CaP, si haya, es escasa. La mayoría están apoyados por las grandes organizaciones basadas en los EE. UU. y Australia o están vinculados con organizaciones locales/ nacionales de cáncer, en general, dando poca visibilidad y enfoque al CaP. Sin embargo, y a pesar de tener una mayor visibilidad en estas regiones, la representación de las organizaciones dentro de cada país está fragmentada, ya que cada organización o grupo tiene su propia agenda o enfoque único o específico para su estrategia de divulgación. Un argumento a favor de las ventajas de tener múltiples opciones es que permite elegir. Pero, por otro lado, el enfoque fragmentado lleva a confusión sobre quién o qué grupo es la voz oficial en cuestiones asociadas a los padecimientos de próstata y el CaP. (Kedrowski y Sarow, 2007). Una variable significativa sobre el uso y participación de los GACP está ligada a prácticas culturales que se adhieren estrechamente a conceptos y prácticas de masculinidad hegemónica (Bravo y Hoffman-Goetz, 2016) el cuerpo masculino y el envejecimiento (Evans *et al.*, 2011), rasgos y normas masculinas (Broom, 2005a). Entre la bibliografía que analiza diversos resultados sanitarios deficientes en los hombres (es decir, muerte por suicidio, enfermedades cardiovasculares y consumo de drogas ilícitas), la conclusión general es que los hombres no acceden a los servicios sanitarios debido a las ideologías vinculadas a la masculinidad hegemónica. Otra interpretación de los datos es la actuación de la masculinidad (West y Zimmerman, 1987) en el espacio de un GACP. Además, a los hombres tampoco les resulta fácil discutir temas delicados como la incontinencia y la disfunción eréctil, dos de los efectos secundarios más comunes de los tratamientos del CaP, o los cambios físicos de los tratamientos hormonales que feminizaron los cuerpos de los hombres. Sin embargo, cuando se les dio la oportunidad de abordar estos problemas de salud en un grupo que comparte estas experiencias comunes, los hombres hablaron, abierta y francamente. Por supuesto, los hombres incorporaron toda una serie de mecanismos de afrontamiento.

En muchos estudios resuena la conclusión de que los hombres y sus comportamientos en materia de salud no se abordan debido a la idea de que los hombres no hablan de su salud. Cuando, de hecho, esta revisión indica que los hombres no solo se interesan por su salud, sino que, de hecho, buscan la oportunidad de abordar sus problemas de salud, ya sea en un entorno cara a cara, centrado en actividades o de forma anónima.

## 6. Limitaciones del estudio

Muchos de los estudios incluidos en esta síntesis incluían varones blancos, que se identificaban como heterosexuales, a menos que se indicara lo contrario, que vivían principalmente en EE. UU., con unos pocos estudios dispersos por Europa y Australia, y que se encontraban en la fase previa al tratamiento de su viaje oncológico. Además, los estudios eran solo en inglés.

## 7. Implicaciones para la práctica

La aparición y la amplia disponibilidad de Internet han permitido el acceso inmediato y la conectividad de grupos y organizaciones para promover y defender la concienciación, y el apoyo a los hombres afectados por cáncer de próstata. La mayoría de los GACP se concentran en determinadas regiones del mundo y están fragmentados en cuanto a su alcance y sus agendas en relación con el cáncer de próstata. Se necesita más investigación cualitativa para comprender mejor las preocupaciones y los problemas que afectan a los hombres que se encuentran en la fase posterior al tratamiento de este tipo de cáncer. El acercamiento y la sensibilidad hacia las necesidades y preocupaciones dinámicas de cada afectado son factores importantes para tener en cuenta en los modelos de servicios sanitarios y en los entornos de apoyo o grupos de discusión. Estos paradigmas utilizados para orientar e informar sobre las necesidades de atención y servicios entre la población masculina deben ser objeto de escrutinio.

## 8. Conclusión

En el momento de escribir estas líneas, este es el único trabajo conocido que revisa sistemáticamente los estudios cualitativos sobre GACP. La decisión de centrarse únicamente en estudios cualitativos que incluyesen exclusivamente hombres con cáncer de próstata, en un entorno de grupo de apoyo, estuvo guiada por el descubrimiento de la falta de tales estudios tras realizar la búsqueda bibliográfica inicial.

Los resultados de esta revisión muestran que, los hombres sí buscan el apoyo mutuo y de sus iguales, que fomenta en un entorno sin prejuicios en el que los hombres puedan compartir detalles generales e íntimos sobre su trayectoria oncológica. El apoyo mutuo de los GACP proporciona la oportunidad de aprender sobre el CaP de sus iguales de una forma práctica, comprensible y no amenazadora. Esto es especialmente evidente en EE. UU., el Reino Unido y Australia, donde existe una presencia significativa de organizaciones que promueven la concienciación y el activismo en la lucha contra el cáncer de próstata. Aunque hay margen de mejora en la calidad del apoyo y la disponibilidad de este en otras regiones del mundo, la mera existencia y diversidad de opciones de GACP indican que existe una necesidad y ciertamente un interés.

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## Intercambio de datos

Los datos que respaldan las conclusiones de este estudio pueden solicitarse a la autora correspondiente.

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# Study III: Masculinities and prostate cancer: unpacking social vulnerabilities and perceived risk

# Masculinities and Prostate Cancer: Unpacking Social Vulnerabilities and Perceived Risk

ABSTRACT:

**Background:** As a social determinant of health, masculinity influences men's health behaviors and outcomes. Masculine norms impact the perceived susceptibility and severity of prostate cancer and contribute to delays in screening and treatment.

**Objectives:** This study examines the intersection of masculinity, social determinants, and vulnerabilities to prostate cancer, adopting a multilevel approach to analyze how individual, interactional, and structural factors shape these outcomes.

**Methods:** Qualitative research, using semi-structured interviews, examines how gender norms and systemic factors influence health perceptions and behaviors of patients with prostate cancer.

**Results:** Three themes were identified: The Patient theme addresses perceptions of susceptibility; Health Advocacy examines campaigns and their influence on awareness; and Policy, Protocol, and Practice examines macro factors that shape the understanding of prostate cancer severity.

**Conclusion:** Addressing the intersection of masculine ideals and social and structural determinants is essential to mitigate male vulnerabilities, strengthen advocacy campaigns, and enhance structural competence and men's health policies.

## INTRODUCTION

### Background and Rationale

The Whitehall II study (1), published in 1991 as a follow-up on the original 1967 Whitehall study (2), expanded on findings linking socioeconomic status (SES) and mortality. Subsequent research broadened its scope to explore gender roles, particularly masculinity, and their influence on health behaviors and disparities (3), helping to establish the 'Social Determinants of Health' (SDOH) framework (4). The SDOH encompasses a core group of conditions—socio-economic status, neighborhood and physical environments, social support networks, and access to healthcare services—that impact health behaviors and health inequalities. In the past two decades, gender, defined by feminist sociology as the roles and expectations assigned to individuals has been integrated into the SDOH (3,5). Alongside SODH, the structural competency framework in healthcare (6) highlights how social, economic, and political structures impact health. Applied to men's health, it shows how broader societal factors shape men's health behaviors and access to care.

Prostate cancer (PCa), the second most common male cancer, is expected to affect another 2.3 million men by 2040 (7). This provides a compelling case to explore the intersection of SDOH and masculinity and how these factors influence health behaviors and outcomes. Global PCa disparities reveal structural impacts, such as access to healthcare, clinical training, and screening practices, with survival rates higher in the global north (e.g., the U.S., U.K., and Australia) compared to the global south (e.g., Africa, Latin and South America, and parts of Asia) face poorer outcomes (8);

availability and access to healthcare services play a significant role in explaining variations in PCa incidence and mortality rates across different populations (9)**.**

Masculine ideals, which often emphasize toughness and stoicism (10), can delay PCa detection and treatment. SDOH perspectives show that such ideals influence men's views of PCa susceptibility. At an individual level, factors like education, income (11,12), social capital (i.e. family/friend ties), and health literacy (13–15) affect men's awareness and understanding of PCa susceptibility and severity. Additionally, strength self-efficacy is often bolstered by these factors (16–19). At an intermediary Public PCa advocacy and health campaigns further shape men's perceptions of vulnerability (20–23). At the structural level, healthcare policies and clinical guidelines shape PCa prevention and screening recommendations.

This article adopts a multi-level SDOH approach to examine how individual, intermediary, and structural factors affect PCa risk perceptions and the role of masculinity in shaping healthcare behaviors.

## METHODS

This qualitative study used semi-structured interviews and a constructivist grounded theory approach to examine and interpret the lived experiences of male PCa patients. The constructivist grounded theory was employed to understand participants' lived experiences through their narratives, capturing the complexity of how men perceive their susceptibility to and severity of PCa. Guided by a multi-level determinants framework, the study explored factors influencing participants' experiences and perceptions of vulnerability and severity.

Purposive sampling was employed to recruit men diagnosed with PCa, regardless of their treatment status, ensuring a diverse and nuanced range of experiences. Participants were recruited from various prostate cancer organizations, support groups, and patient registries. After initial contact and briefly explaining the study's objectives, interviews were scheduled with interested individuals. Recruitment took place between June 2020 and March 2024.

Interviews were scheduled based on participants' availability and conducted in person or via video call, depending on their preference. The primary interviewer, D.B., an anthropologist and social epidemiologist, brought a deep understanding of the cultural aspects of health behaviors. This expertise helped build rapport and facilitated the interpretation of participants' narratives within a broader socio-cultural context.

The interviews were open-ended. The topic guide, developed from existing literature on masculinity and health behaviors, centered on key themes including experiences with PCa diagnosis, perceptions of vulnerability, health-seeking behaviors, and the role of masculinity in shaping PCa experiences. Participants were encouraged to share their cancer journey in detail, following a sequence they felt natural to them. The interviews were patient-led, with the direction adapting to the flow of the conversation. When necessary, prompts were utilized to address stigma, health-seeking behaviors, support group involvement, masculinity, treatment decision-making, and post-treatment quality of life. Each interview lasted from 45 minutes up to 2.5 hours, was audio-recorded, and data was anonymized. Participants were assured that their identities would remain confidential. They were informed of their right to withdraw from the study at any point without any penalty. Pseudonyms were used in transcripts and reports.

### Data analysis

Interviews were recorded and transcribed using Trint, an online transcription software, followed by quality checks to ensure accuracy. Data analysis was conducted using MAXQDA software, employing a thematic coding approach. Initial codes were generated from recurring patterns in the transcripts and subsequently grouped into broader themes. The organization of themes into general categories was guided by a framework derived from a systematic meta-synthesis of qualitative studies on men with PCa [in press, author]. The research was carried out following the ethical standards established by the Helsinki Declaration of 1964 and its subsequent amendments. This study received ethical approval from the relevant institutional ethics committee (CEIPSA-2021-TDO-0011).

## RESULTS

Eighteen male prostate cancer patients participated in the study. The sample is multi-national, with ages ranging from 59 and 87 years. Most participants hold a bachelor’s degree, are married, and are retired (**Table 1. Socio-demographic Details**).

**Table 1. Socio-Demographic Details**

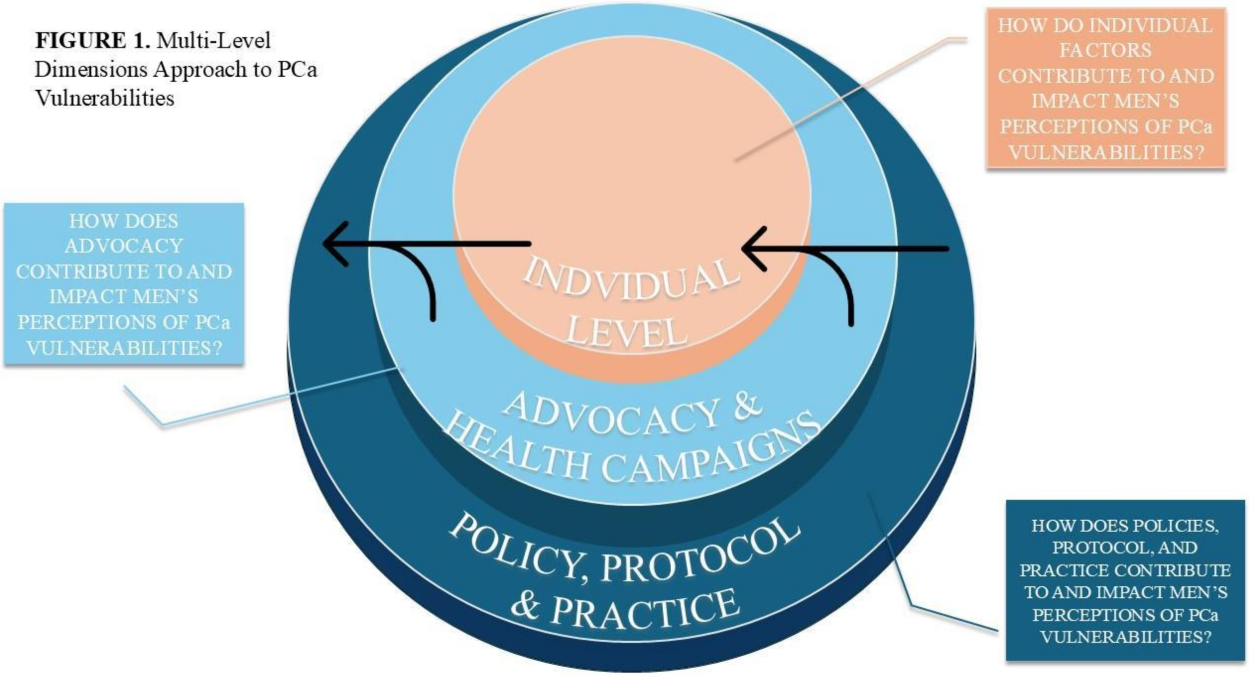
| ID#, PSEUDONYM | COUNTRY | AGE | MARITAL STATUS | EMPLOYMENT | EDUCATION LEVEL |
|---|---|---|---|---|---|
| **“Mark”** | US | 75 | Married | Unemployed | Bachelor's Degree |
| **“Bill”** | US | 81 | Married | Retired | Master's Degree |
| **“Thomas”** | US | 77 | Married | Retired | Bachelor's Degree |
| **“Robert”** | US | 63 | Civil/long-term partner | Permanently disabled | Bachelor's Degree |

| | | | | | |
|---|---|---|---|---|---|
| **“James”** | US | 87 | Widower | Retired | Bachelor's Degree |
| **“John”** | US | 75 | Married | Retired | Master’s degree |
| **“Gary”** | US | 74 | Married | Retired | High School Degree |
| **“Randolph”** | US | 71 | Married | Retired | Bachelor's Degree |
| **“Adam”** | US | 80 | Married | Retired | Bachelor’s Degree |
| **“Miguel”** | SPAIN | 72 | Married | Retired | Bachelor’s Degree |
| **“Arturo”** | SPAIN | 66 | Married | Self-employed | Master’s Degree |
| **“Javier”** | SPAIN | 73 | Married | Retired | Bachelor’s Degree |
| **“Omar”** | SPAIN | 70 | Married | Retired | Bachelor’s Degree |
| **“Sergio”** | SPAIN | 70 | Married | Retired | Bachelor’s Degree |
| **“Daniel”** | SPAIN | NA | Married | NA | NA |
| **“Gonzalo”** | SPAIN | N | NA | NA | NA |
| **“Olivier”** | FRANCE | 59 | Civil/long-term partner | Self-employed | Master’s Degree |

| | | | | | |
|---|---|---|---|---|---|
| **“Ricardo”** | BRASIL | 70 | Civil/long-term partner | Retired | Technical School |

Three main themes emerged from the analysis, each shedding light on different aspects of patients’ perceptions and experiences with PCa (**See Figure 1. Multi-Level Dimensions Approach to PCa Vulnerabilities**).

**FIGURE 1.** Multi-Level Dimensions Approach to PCa Vulnerabilities



The Patient theme explores how individual PCa patients perceive their susceptibility to and the severity of their condition. It delves into their awareness, highlighting how their interactions and social networks shape their understanding of their health. The Health Advocacy and Campaigns theme examines how broader health advocacy efforts and campaigns influence PCa patients’ awareness and understanding of their susceptibility and severity of PCa. It highlights the impact of these external factors on patients’ perceptions and knowledge. The Policy, Protocol, and Practice theme explores how macro-level factors, such as health policies, clinical guidelines, and standard practices, shape PCa patients’ understanding of the susceptibility and severity of their condition. It also addresses how institutional and systemic factors affect PCa patients’ perceptions and interactions with the healthcare system. **See Table 2. Narrative Boxes** to read direct quotes from the patient-participants.

*The Patient*

Overall, men reported in a variety of ways in which their unawareness about PCa left them unprepared to fully grasp the susceptibility of developing PCa and the severity or life-altering consequences of the condition:

*Prostate cancer is thought of as an old guy's disease. I was still in my late forties when I got diagnosed. I came across one woman on Facebook who said her husband was in his thirties and he got diagnosed. And it was aggressive. He died before he hit 40. It does not get the recognition... it's a disease that a lot of people… don't take…it is not in the forefront of their minds.* **(Robert, US, 63)**

*Up until the time that I was diagnosed with prostate cancer… my life was very good…I was on cruise control. I had not had a PSA test in probably 10 years because I was convinced … that prostate cancer was hereditary. This was just something I had in my own head. I went in for physical with my primary care physician, my wife was with me. She said, "I want my husband to have a PSA test so we know where he's at." Well, the PSA test came back not good. My PSA was about nine, which is probably a little over two and a half times what it should have been. So that's when he suggested that I see a urologist, and that's when the whole sequence of events began when I saw the urologist.* **(Gary, US, 71)**

The participant's surprise at his diagnosis reflects broader societal and cultural constructs that link PCa with aging an older man. This notion feeds into a masculine reluctance to engage in preventative health measures at younger ages. Robert's reflection on the lack of public recognition for PCa, particularly in younger men, highlights a gap in public health messaging. Unlike other cancers, with prominent awareness campaigns, PCa is often sidelined, which may contribute to a lack of knowledge and delayed diagnosis, especially for men outside the stereotypical risk group ("old men"). From an SDOH perspective, younger men lack access to routine screenings or limited education about the risks of PCa, which contributes to delayed diagnosis and worse health outcomes. Together, these forces contribute to missed opportunities for early diagnosis and underscore the need for targeted interventions.

Or that, men do not actively seek out information about it, and prefer to rely on healthcare professionals to breach the topic:

> *In my encounter with other prostate cancer patients, my impression is that the vast majority don't want to have a lot of information. They want reliable guidance from whatever medical professionals they're dealing with, whether it starts out with a urologist and eventually moves on to an oncologist. I think that that's probably their primary source of information. And I think they rely on those medical professionals to be able to accurately analyze their particular spot in the prostate cancer spectrum and provide them with the most accurate information relative to the treatments that are going to be pertinent to them.* **(Gary, US, 71)**

The following excerpt provides rich insight into how traditional masculine ideas, health behavior, and SDOH contribute to delayed PCa diagnosis and treatment. Randolph's reflection reveals several layers of behavior and beliefs that can be explored through the lens of masculinity, health-seeking behaviors, and SDOH:

> *But I can tell you in my situation, I didn't go to doctor unless I was dying. Most of my life I was fine. I mean, I was a high achieving, hardworking, killer machine. I mean, I was always going and didn't have a lot of issues. So, at 55 was the first time in my life where I thought, "well, maybe I should see a doctor." As far as cancer goes right? I didn't know anything about [it]. I'm just a guy who made car parts out of the factory. [And] If you're a newbie and you have a fairly low-grade cancer, you can get apathetic because it's just similar to firefighting, right? If there's no fire, you're going to do something else… you just blow it off. I had signs that I probably had prostate cancer prior to the PSA test, but I chose to ignore it. I had signs that I my legs weren't working hard because I couldn't walk. I chose to ignore it because I could get by. And eventually it got to the point…" Well, maybe I better check some of the stuff out." Right? Now that I've had cancer... The most I've seen of that kind of stuff is a brochure in a cancer office, and people use that for a bookmark or something like*

> *that. They really don't read that stuff. Or so I know even today I can't tell you anything that says I should go do this [get screened for PCa].* **(Randolph, US, 71)**

His statement reflects a common masculine ideal of toughness, self-reliance, and invulnerability. The norms often prevent men from seeking medical care until health problems become severe. His identity as a "high-achieving, hardworking killer machine" reinforces these norms, suggesting that men, especially those who equate success with physical resilience and strength, are less likely to engage in preventative health behaviors.

He mentions his lack of awareness associated with his type of employment "guy who made car parts out of a factory", reflecting the impact of health literacy- particularly how education and SES shape his understanding of PCa risks and his ability to navigate healthcare systems. His reflection on the brochures being used as bookmarks underscores a disconnection between available health information and its practical use.

Randolph likens his early symptoms to "firefighting", and this metaphor reflects a reactive approach to health, where actions are only taken when the problem becomes severe. His description of apathy toward low-grade cancer signals a broader issue with how PCa is perceived, particularly, that if it does not represent immediate or severe symptoms, it is easy to dismiss.

Men acknowledged that there has been a shift in PCa awareness, compared to the past…

> *I think it's more of an awareness to prostate cancer than there might have been. That's another thing. I mean, you know, the joke was no one would go unless something made them go.* **(Thomas, US, 77)**

…others attributed their educational background to their ignorance about PCa. The lack of awareness and medical knowledge often differentiated between "passive" and "proactive" patients. A "passive" patient, in this context, is one whose health behaviors are not altered due to insufficient awareness of prostate cancer. For some men, this passivity stemmed from a lack of exposure to PCa in their networks. This downplaying of proactive health measures is demonstrated in the following narratives show:

*Well, I didn't realize until I had the cancer… [or] what the prostate was at all. I didn't know what it was… that it's a doughnut [that] goes around the urethra. So, now I know. [laughs] Yeah. I'm not a medical…there's no one in my family, in my blood family at least, that's in the medical business. So, I'm not… I don't know much about medicine. I'm more of an electronic scientist. [laughs].* **(Bill, US, 87)**

The following narratives provide an example of a proactive approach to a PCa diagnosis. Here, John conducts research, joins a support group, and seeks to understand his treatment options for their potential side effects:

> *Well, you know, I don't have a medical background at all…I did a lot of research. When you're diagnosed with cancer and the oncologist comes and says: "Hey, this is what you got, it's not nothing to fool around with, it's very severe". I went online [and] tried to find out what my options were … I joined a couple of support groups to see what that was like. So, you get to be versed… I mean…you don't want somebody doing something to your body that you don't know …[that] you don't understand… what the effects of what they're doing. I don't want somebody doing something to me unless I know what the possibilities are… a) that it's going to be successful and b) what are the side effects? Is my hair gonna turn green? What's the story here?* **(John, US, 75)**

John’s decision to research his diagnosis and seek out support groups demonstrates a strong sense of self-efficacy- belief in his ability to influence the course of his treatment. His actions suggest that although he lacks a medical background, he took ownership of his health by learning about PCa and exploring treatment options. This is a significant departure from the stereotype of masculine reluctance to seek help or engage with healthcare. His focus on understanding the effects and success rates of treatments demonstrates the importance of health literacy and patient empowerment in PCa care. The active pursuit of knowledge highlights how patients can bridge gaps in their understanding through research and support networks and underscores the critical role accessible information and support systems play in empowering them to take control of their health.

In some cases, comorbidities and past experiences with illness lead some PCa patients to adopt a pragmatic, almost routine approach to managing their diagnosis, as this next excerpt shows:

*As far as prostate cancer, when I was diagnosed, I really wasn't surprised. My father had prostate cancer. My brother had prostate cancer that both sides are prostate removed. So, what happened with me was that he had a urinary tract infection… I got two cancers and two autoimmune diseases [laughs]. So, you know, I just look at it like, "OK, I gotta go do this." I’ve got an exam? Well, I have an exam! You know? It's like when your teeth hurt. You go to the dentist. You don't think about it. I mean, I don't look forward to the scan, but, I know I have to do it. And after the exams, the results come back. I feel much better. You know, mentally, my wife feels much better mentally. So, you know, everything works.* **(Adam, US, 80)**Adam’s history of dealing with multiple health issues has made him accustomed to medical interventions. His “lack of surprise” highlights how repeated exposure to illness can normalize serious health conditions. His awareness of his family’s PC history likely influences his acceptance of his diagnosis, and familiarity with the treatments, which may have reduced his fear and uncertainty. All this may have contributed to his emotional resilience and acceptance of integrating routine medical checks and treatments into his life; he sees them as necessary but not overwhelming steps in maintaining his health.

At an individual level, these excerpts demonstrated some ways in which patients responded to PCa. Their differing reflections on levels of self-efficacy, health literacy, and adaptation to illness give a clue into pathways to approach PCa prevention and outcomes. For example, some patients, familiar with chronic health challenges, approach their disease with resilience, viewing it as a part of their broader healthcare routine. Their engagement with support groups and research demonstrates proactive behavior, driven by a desire for control and empowerment in treatment decisions. Conversely, others face barriers rooted in masculine norms and limited awareness, which delay medical intervention.

### *Health Advocacy and Campaigns*

The Health Advocacy and Campaigns theme examined the availability, accessibility, and role of community and institutional factors that influence PCa advocacy, like support groups, and healthcare institutions. Communities with better access to PCa-related healthcare and supportive environments can enhance collective self-efficacy, leading got higher screening rates and better management of PCa.

In the following excerpt, Sergio expresses frustration over the lack of visibility and information on PCa. He expresses through the context of primary care centers and highlights the discrepancy between the abundance of educational material and resources for other illnesses and the absence of PCa.

*There is little information when it comes to, for example, in the primary care centers. There you'll see… breast cancer, tuberculosis, vaccines, all this information. And my prostate cancer? There's a vacuum. There's a silence there. There isn't anyone that uncovers Pandora's Box. There's no one, and they're professionals.* **(Sergio, Spain, 71)**

His statement conveys a sense of neglect or silence around PCa and underlines a key issue in PCa care at the institutional level of SDOH- the pivotal role of primary care settings to provide adequate information on PCa, and the lack of such was a missed opportunity for preventative care.

*Our demographic is not prioritized... It's kind of at the bottom of the tier. I see a lot more push to get benefits. The breast cancer is a good example for legislation that they try to pass in the US a lot of the time, it's to get extra benefits for women and minorities and so men have to fall behind that.* **(Robert, US, 63)**

Robert's statement reflects feelings of marginalization and neglect in activism related to PCa. In his comparison to breast cancer activism, he illustrates a perceived hierarchy in healthcare advocacy, where PCa, receives less attention; PCa is "at the bottom of the tier". In the following excerpt, Randolph emphasizes Robert's sentiment. Here, Randolph expresses the need for increased activism around and awareness campaigns that resonate with men, especially in settings where community outreach could make a difference:

*It's still hard, so hard and it's not as public as it should be. I go to church has like 700 members. Do they ever mention it? Nope. "Every Sunday come to the prostate class? I'll tell you about with prostate cancer." I mean, this simple awareness can touch 700 people, but that ain't going to happen*. **(Randolph, US, 71)**

He suggests that people who have personally experienced PCa could play a pivotal role in spreading awareness and that advocacy should prioritize authenticity and peer-led initiatives:

*I kind of this is me, and I'm kind of prejudiced, but I do think patients are the best leading. I mean, you put them on TV, you put them on an ad. You're real people. I'm not talking about pharmaceutical oil or an actor. I'm talking some of either has been through and say, "Hey, guys, we ain't done this. You know what he's doing because here's what happened to me." I think that kind of public service announcement would get more interest.* **(Randolph, US, 71)**

Randolph's sentiment aligns with research showing that men often respond better to health messages that are relatable and grounded in authentic, lived experiences. These types of public service announcements featuring actual survivors could break down barriers of silence and stigma and illustrate the potential power of patient-led advocacy.

As a PCa advocate and active member of a PCa association in Spain, Javier highlights the importance of patient-led advocacy:

*There is an impressive number of people who show their faces. And in the case of men, we have to count them on the fingers of one hand. It is infrequent, very infrequent, that there are men who go on television and say "hey, I have had such and such cancer". No, they don't come out, they don't show their faces. And that links, once again, with what I was telling you about false masculinity. That is to say, "I have to be a man if I lose my virility, of course, I am no longer appreciated as a man" in personal relationships, "in my circle I will be degraded", "I will not feel the same, because I have to be very macho and now I am less so". Anyway, that does not happen with.... That does not happen. We [in the association] have nothing, we had one last year that was financed by Janssen, but as we are small, we don't have much money, so the song ran for two or three months and then the rights were lost and we don't have* *a song anymore. That is, it was not even recorded by Kiko Veneno and Antonio Carmona and it lasted three months or so. That is to say,* the issue of visibility through celebrities who show their faces is very important to reinforce self-esteem. **(Javier, Spain, 73)**

And, Here Javier emphasizes the lack of public visibility for men dealing with PCa and links this reluctance to “false masculinity”- the fear of openly discussing health issues like cancer. He states that men avoid discussing these issues, especially affecting virility, as it would diminish their social standing and sense of manhood. As an active advocate for a national PCa association, he argues that celebrity endorsements and public advocacy can help reinforce self-esteem and normalize conversations around PCa, breaking down harmful masculine ideals.

Here we hear again from Randolph, where he echoes and highlights the important shift towards patient-centered advocacy, where healthcare services can improve care through the involvement of patients as collaborators:

*Like 2005, there wasn't information…you didn't have the flutter of associations or groups. There's probably 15 prostate cancer organizations now out there. You have a choice to go to that wasn't there in 2004. But over time, yeah, I mean, everybody got in on the act and this thing called “patient ambassadors”. But I think now they've gotten better that they realize there's a wealth of information that if they're going to reach customers like me, they need to understand them and they need to be involved in helping them get their system the better. So they use us more now than they might have, say, 10 years ago. They have patients now that come in to help them design the hospital. Because, yeah, it is because, you know, you take a guy like me. I've been going there since 08, and I know every door, every doctor. They're smart enough now to say, “how do we see where we went wrong and what we went right with and try to make the system more accommodating?”* **(Randolph, US, 71)**

Here, the hospital recognized the importance of involving patient ambassadors who have lived experience with PCa in shaping hospital services. This approach fosters a more personalized and informed care environment that better aligns with the needs of patients. Integrating patients' voices into healthcare decision-making is a hallmark of effective advocacy, leading to improved care and heightened awareness of PCa, ultimately benefitting patients and healthcare providers alike.

### *Policy, Protocol, and Practice*

One of the most significant policy-driven factors influencing self-efficacy in PCa is the lack of consensus on screening guidelines. Conflicting guidelines from organizations like the USPSTF and results from European studies create mixed messages and lead to uncertainty among patients and clinicians regarding the best course of action.

*I think one of the worst things that has happened within the last 10 years is when the federal government decided that it wasn't useful for men to get PSA checks. They used the excuse that. PSA is not 100 percent reliable, which is true. Yeah, the PSA is not 100 percent reliable, which is true. You’re going to have a high PSA and not necessarily have cancer. And at the same time, you can have a low PSA and have cancer. So, it’s not a 100 percent reliable indicator. But the reality is, at this point in time, it’s the only indicator that we have. If there is a better indicator, I hope research finds that someday so that they don’t have to have the same argument about whether the test is meaningful or not. So there’s no doubt that men didn’t need an excuse not to have a PSA test. You just didn’t want to do it just like me, I just didn’t want to do it. And it’s a simple little blood test. But it’s not a bad test when you go in for a physical. They take a blood test anyway. So just adding a PSA test to that is almost meaningless. I can’t recommend anything more important to men than having your PSA checked. And you have to have it checked on an annual basis, so you know what it’s doing over time. Absolutely. So, this this idea about not having PSA checks is about like telling women, you don’t need to have mammograms done.* **(Gary, US, 74**

Here, Gary expresses frustration over mixed messages surrounding PCa screening and the inconsistent health policies regarding PSA. He criticizes the decisions to de-emphasize PSA screening despite its limitations. Despite the test's imperfections, Gary emphasizes that it remains the best available tool for early detection, underscoring its importance in preventative healthcare.

The lack of clear messaging reinforces existing barriers to care, particularly in a cultural context where masculine ideals and perceptions of susceptibility and severity often deter men from seeking regular check-ups. This excerpt showcases how policy changes regarding PSA screening have negatively impacted men's health behaviors, particularly creating confusion and offering an "excuse" to not seek screening. Gary advocates for more consistent and clear messaging from health authorities, emphasizing that despite its limitations, the PSA remains the best tool for early detection.

In the following excerpt, we hear again from Javier's critique of the paternalistic model in healthcare, which positions doctors as the dominant decision-makers while relegating patients to passive roles.

*We are fighting for there to be, as I was saying, a deliberative model in which "I am not the doctor, but I am the one who has the disease, and the one to whom these treatments are going to be applied" whether they are pharmacological or any other procedure, therefore, I have the right to second opinions, etc. That is what we also recommend from the association. Never be satisfied with an opinion, ... my personal experience, apart from the fact that today as vice-president of the association I have it from a lot of patients, is that it is still a paternalistic model in which the doctor is the one who occupies the dominant Box and the patient is a passive subject.* **(Javier, Spain, 73)**

His call for a deliberative healthcare model challenges the traditional paternalistic system, urging a shift towards shared decision-making, where patients are empowered to take an active role in their care through second opinions and involvement in treatment choices. Socio-cultural differences, particularly around authority, masculinity, education, and health literacy can lead to disparities in how PCa patients engage with the healthcare system.

Medical education and training significantly shaped clinical competency, especially when dealing with complex, individualized experiences like cancer care. These competencies include not only clinical knowledge but also the ability to engage emphatically with patients, particularly at culturally sensitive levels. Structural competency includes understanding how factors of masculinity, race, ethnicity, and class affect healthcare interactions and outcomes.

In the following narrative, John underlines the importance of empathy and specialized communication skills in treating PCa patients. He acknowledges the specific personality and professional traits that healthcare staff need to effectively care for a PCa patient.

*Yeah well, I was saying, I mean, it's not a very comfortable thing to do, but the nurses are extremely professional. And, you know, cancer is just a funny personal thing. I mean everyone's journey is different. And I think that the doctors and nurses that specialize in oncology, that deal with cancer patients have to be a special type of person with a certain personality*. **(John, US, 75)**

Here, the emphasis is on emotional intelligence and relational competency, where a deeper level of care and attentiveness can shape positive patient experiences. Medical training programs should focus both on technical proficiency and soft skills required to treat patients as whole individuals.

In the following narrative, we hear from Daniel:

*need more information on how to run the day-to-day…[the] doctor's visits are cold. The doctor goes to the purely scientific or clinical, let's say, and not even the human… personal issues... To which many times it is not convenient directly…that's what was missing in the end. So, I had to inform myself through the internet and I see options. Yes, and it did help me in some things...* **(Daniel, Spain, age undisclosed)**

He expresses frustration with the cold, clinical nature of doctor-patient interactions, and the lack of practical information provided for managing day-to-day aspects of treatment. His specific experience highlights a broader issue regarding a deficit in holistic care for PCa patients. Medical staff, though well-versed in clinical knowledge, may neglect the human side of patient care and fail to address personal, emotional, or logistical needs, leaving patients ill-equipped to make informed decisions. Training should include a focus on communication skills that bridge scientific knowledge with PCa patient-centered care, ensuring that patients feel informed and supported throughout their journey.

Finally, there is Gonzalo's perspective in which he critiques the dehumanizing attitude that some clinicians may adopt, contrasting the need for strong leadership in certain situations with the unnecessary harness in patient interactions.

*It is very important for the physician to be human. That way of speaking, exchanging them, a leader who is the captain of a ship can have, and you have to speak harshly because there is a sea of land where he is no longer the captain and from there you have to be tough with those people. But fuck, with patients you don't have to. They are already, we have already become sheep.* **(Gonzalo, Spain, age undisclosed)**

Here Gonzalo also reflects on the paternalism of medicine, where the physician takes a dominant, authoritarian role, leaving the patient feeling devalued and passive. Addressing this issue requires training in shared decision-making and patient empowerment, ensuring the patient's voice is respected and heard.

All three excerpts demonstrate varying degrees of clinical interaction that impact the patients' experiences. The first shows the positive aspects of oncology care, where emotional intelligence complements clinical skills. The second and third, however, reveal significant shortcomings- both in terms of cold, detached clinical interactions and the power imbalance that can arise from paternalistic attitudes.

Together, all these narratives suggest that policy and medical training must integrate structural competency not just to recognize systemic inequities but also to ensure clinicians can navigate complex patient dynamics. The integration of cultural humility and patient-centered care principles into PCa policy and clinical training can address the disparities in the quality of healthcare interactions.

## DISCUSSION

This qualitative study explores how perceptions of susceptibility, severity, and health-seeking behaviors influence PCa outcomes. Using an SDOH framework, the study examines how individual, intermediary, and structural-level factors contribute to disparities in PCa screening and treatment.

The findings highlight how masculine ideologies, healthcare policies, and clinical practices shape these outcomes.

Despite regional differences in PCa incidence, men worldwide encounter common social and structural barriers, such as stigma and limited healthcare access, which affect their health-seeking behaviors. Disparities in PCa outcomes highlight the influence of structural factors on healthcare access and quality. In the global north (e.g., the U.S., U.K., and Australia), enhanced screening and treatment have led to decreased mortality despite higher incidence rates. In the global south (e.g., Africa, Latin and South America, and parts of Asia) limited access to care and inconsistent data collection obscure our understanding of PCa trends (8). Addressing these structural gaps requires robust health strategies, consistent screening efforts, and better healthcare infrastructure.

### *Individual Level: The Patient*

At the individual level, PCa vulnerabilities are shaped by personal behaviors, risk perceptions, and psychological factors. Masculine norms often discourage men from seeking medical care for conditions like PCa, challenging their sense of virility (24), and leading to delayed diagnosis and poor health outcomes.

Qualitative studies revealed that masculine ideologies influenced men’s knowledge and perceptions of PCa which consequently influenced their willingness to take proactive steps in managing their health (25). In a study of Nigerian men, impotence (a common side effect of PCa treatment) was associated with promiscuity or perceived as disqualification from leading religious activities or rituals (26). Meanwhile, among Asian and Pacific Islander men (27), there was a desire for greater support from healthcare providers and more active involvement in the decision-making process. At the individual level, masculinity influences how men perceive their health and engage with preventive measures. Masculine ideals such as stoicism, self-reliance (28), and emotional restraint (29) in this context, operate as barriers to self-efficacy and preventive healthcare; men may downplay symptoms or avoid screenings like PSA tests due to fear of diagnosis and the perceived assault on their manhood (30). PCa threatens not only men’s physical health but also their identity, particularly concerning sexual function and incontinence—both of which are tied to masculine ideals of performance (31) and control (32).

### *Interactional Level: Health Advocacy and Campaigns*

Masculine ideologies shape the visibility of PCa in public discourse and health advocacy campaigns. Over the past twenty years, a growing number of campaigns and organizations have been dedicated to spreading information, increasing awareness, and offering support for PCa patients. Kedrowski & Sarow (33) identified two key factors behind this development: first, advocacy for social and political change regarding health issues; and second, the impact of gender roles in health outcomes.

At the interactional level, advocacy plays a crucial role in bridging the disparities between individual-level and structural-level determinants of health. Health advocates through their campaign confront entrenched masculine norms (e.g. stigmas, taboos) related to men’s health (22).

To address disparities in health services, these entrenched ideologies must be reevaluated to foster a more nuanced understanding of men’s health and well-being. In this context, Hawkes and Buse (34) stress the need for a global response to men's health issues. They advocate for the integration of gender-sensitive approaches into health policies and programs, emphasizing that men's health should not be overlooked in the broader public health agenda. They call for greater collaboration among stakeholders to address the social determinants affecting men's health, with the ultimate goal of improving health outcomes and reducing inequalities.

### *Macro-Level: Policy, Protocol, and Practice*

Structural determinants—such as healthcare policies, socioeconomic status, and geography—play a critical role in shaping access to PCa screening and treatment. The structural competency framework as introduced by Metzl and Hensen (6) highlights the importance of understanding how social and institutional factors shape clinical interactions and patient outcomes.

The structural complexity of PCa screening and treatment is further compounded by conflicting guidelines. For example, while the European Association of Urology recommends early PSA (35) screening for high-risk men, the American Urological Association (AUA) (41) focuses on susceptibility stratification through clinical tests like PSA levels and biopsies. This lack of standardization creates confusion, both among clinicians and patients, about the best practices for PCa prevention and treatment health policies surrounding prostate cancer screening.

The lack of attention to men’s health in global and national health policies is evident. Although a few global guidelines address men's health, such as those from the 2011 European Commission (36) and 2018 WHO Europe (37) reports, they are limited. Whilst, these two guidelines emphasize holistic approaches to men’s health, focusing on prevention and improving healthcare services, additional reports from Iran, Brazil, and Ireland (38) provide region-specific insights and recommendations and serve as a starting framework for improving men's health globally.

Policies, protocols, and healthcare practices which have traditionally been male-dominated, might also carry and perpetuate the same masculine norms, influencing the design of health services and contributing to the lack of nuanced, gender-sensitive care. Hegemonic masculinity thus shapes the very systems that men must engage with, often making those systems less accessible and relevant to their specific health needs.

### *Masculinity as a Social Determinant of Health (SDOH)*

Masculinity, as a social construct, significantly influences men’s health behaviors, access to care, and health outcomes. As an SDOH, masculinity influences prostate cancer (PCa) vulnerabilities at multiple levels—individual, interactional, and structural. Its impact manifests through cultural norms, expectations, and behaviors that frame how men perceive themselves, how they interact with healthcare systems, and how policies address their health needs (39–43).

### *Intersectionality: Masculinity, Prostate Cancer Vulnerabilities, and SDOH*

The intersectionality of masculinity across individual, interactional, and structural levels compound men's health vulnerabilities. Masculine ideals discourage care-seeking at the individual level, limit adequate health communication and advocacy at the interactional level, and shape policies and practices at the macro level, reinforcing disparities. Masculinity, as an SDOH, influences men's experiences with prostate cancer at all three levels revealing how entrenched gender norms can prevent men from engaging in proactive health-seeking behaviors, communicating openly with healthcare providers, and accessing adequate health services.

These levels do not operate in isolation but reinforce one another and do so in ways that exacerbate health disparities. Addressing these intersections can provide insight into the challenges men face when dealing with PCa and allow for the development of both culturally sensitive and structurally sound interventions.

## CONCLUSION

This study enhances our understanding of health disparities by examining how socially constructed masculinity influences health-seeking behaviors and outcomes of men diagnosed with PCa. It emphasizes the need for integrated approaches that consider the interconnectedness of social and structural determinants to reduce disparities in care. By addressing the socio-cultural differences that influence how men engage with healthcare systems, we can improve inclusivity and patient empowerment. To reduce PCa disparities and improve outcomes, it is essential to address structural and systemic determinants like healthcare access, insurance coverage, geographic disparities, and institutional racism.

Whilst the reliance on semi-structured interviews provides rich qualitative data; this methodological approach may not capture broader population trends. Additionally, the geographical concentration of the sample (mostly from the global north), and the generalizability of the findings are limited.

## RECOMMENDATIONS

To further explore how individual, community and structural factors interact in shaping PCa outcomes, a longitudinal study using mixed methods would be ideal. Such an approach would capture both the depth and breadth of these influences, ensuring that subtle but critical factors are not overlooked. Finally, by improving structural competency in medical training, better communication strategies between patients and clinicians, and culturally sensitive healthcare delivery.

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# Study IV: Testicular cancer and testicular self-examination: knowledge, attitude and practice among university students in Ghana.

# TESTICULAR CANCER AND TESTICULAR SELF-EXAMINATION: KNOWLEDGE, ATTITUDE, AND PRACTICE AMONG UNIVERSITY STUDENTS IN GHANA.

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## Abstract

Testicular cancer (TCa) represents approximately 1% of all male cancers globally and is most common in males aged 15-44 years. Studies have shown poor knowledge and awareness of TCa and testicular self-exam TSE practice among university students. In sub-Saharan Africa, some studies provide insight into possible factors such as inadequate public knowledge or awareness of TCa and TSE related to poor health outcomes in males. In Ghana, no such data exists. A cross-sectional study assessed knowledge of and attitudes towards TCa and TSE practices among undergraduate male students at Kwame Nkrumah University of Science and Technology (KNUST) in southern Ghana.

A total of 391 undergraduate male students aged 17 to 35 years old participated in the survey. Half (49.4%) of the male students reported having been *aware* of TCa, and almost none (0.5%) knew of anyone in their family member or close environment (e.g., friends, neighbors) who was diagnosed with TCa. Overall, media (61.3%) was the students’ primary source of information for accessing TCa information, and most students (80.5%) reported interest in receiving information on TCa and TSE. Fifth-year students had greater knowledge of TCa and TSE than students in all other academic years. A lack of knowledge on how to perform a TSE was a significant barrier to why students did not perform a TSE ($\chi^2$ 82.84, p=0.00). Other reported barriers were not caring (16.6%), attributing the TSE exam to a sin (6.4%), feelings of shame/guilt (12,0%), and cultural barriers (7.2%).

To our knowledge, this is the first study that investigated TCa and TSE awareness, knowledge, and practice in male Ghanaian university students. Our data indicate a lack of proper and adequate TCa and TSE information among adolescent and university-aged males in Ghana. Thus, a health promotion program designed to target this cohort to encourage early detection is paramount. Access to programs that provide accurate and high-quality information can ensure the successful attainment of accurate and high-quality knowledge and awareness.

**Keywords:** Ghana, testicular cancer, testicular self-examination, university students, males, cancer research, cancer prevention, health sciences, cancer

# TESTICULAR CANCER AND TESTICULAR SELF-EXAMINATION: KNOWLEDGE, ATTITUDE, AND PRACTICE AMONG UNIVERSITY STUDENTS IN GHANA.

## Introduction

Testicular cancer (TCa) comprises about 1% of all male cancers globally, primarily affecting males aged 15-44 years (Huang et al., 2023). Over the last four decades, TCa incidence has significantly increased, particularly among populations in the ‘global north’ (Chia et al., 2010; Park et al., 2018; Znaor et al., 2014). According to the World Health Organization (WHO), effective early detection and preventative strategies can reduce cancer incidence and mortality (Stewart & Wild, 2014). This is crucial as TCa is highly curable if detected early. Established risk factors for TCa include testicular atrophy, cryptorchidism, maternal estrogen exposure, and genetic predisposition (Géczi et al., 2003; Jørgensen et al., 2010; Lip et al., 2013; Lutke Holzik et al., 2004).

Reports show that even in high-resource countries like the US, TCa diagnoses are often delayed, particularly among Black/African American and Latino males, as well as males who are uninsured or from lower socioeconomic backgrounds (Adams et al., 2018). Although sub-Saharan Africa lacks comprehensive TCa morbidity and mortality data (Bray et al., 2018; Huyghe et al., 2003; Omotoso et al., 2023; Znaor et al., 2014), individual studies in Ethiopia (Gutema et al., 2018; Zeleke et al., 2019), Nigeria (Ibitoye et al., 2022; Onyiriuka & Imoebe, 2013; Ugboma & Aburoma, 2011), Uganda (Muliira et al., 2012), Madagascar and South Africa (Peltzer & Pengpid, 2015) highlight that low public knowledge and awareness of TCa and testicular self-examination (TSE) contribute to poor health outcomes in males (Bresciani et al., 2021).

Globally, university students often exhibit limited knowledge of TCa and low engagement in TSE (Peltzer & Pengpid, 2015). Studies in Iran, Turkey, Malaysia, Uganda, Bangladesh, Singapore, Madagascar, and South Africa report similar findings, with low awareness of TCa and infrequent TSE practice among students (Altinel & Avci, 2013; Norhaini et al., 2014; Özbaş et al., 2011; Ramim et al., 2014; Muliira et al., 2012; Peltzer & Pengpid, 2015). Surveys from European undergraduates between 1990 and 2000 also indicated inadequate TCa knowledge and TSE practices, suggesting a historically persistent public health knowledge gap and minimal attention to this public health issue (Evans et al., 2006; Wardle et al., 1994).

Given TCa’s high curability with early detection, assessing male university students’ knowledge, attitudes, and behaviors towards TCa and TSE is vital. Addressing knowledge gaps through targeted health education could improve awareness and preventive practices. In Ghana, despite limited cancer registry data (Amoako et al., 2019; Mensah & Mensah, 2020), modeling and institutional data estimate TCa as approximately 2.4% of all male cancers (Klufio, 2004). Data from Ghana and other low-resource settings can complement findings from the Global North, enriching the global understanding of TCa. Therefore, this study seeks to assess Ghanaian university students’ knowledge, attitudes, and practices concerning TCa and TSE, providing insights that could inform future health interventions.

## Methods

### Study Design, Setting, and Population

A web-based cross-sectional study assessed knowledge, attitudes, and practices (KAP) regarding TCa and TSE among undergraduate male students at Kwame Nkrumah University of Science and Technology (KNUST) in southern Ghana.

### Sample size and sampling technique

*Study population*

The study targeted all male students at KNUST who expressed interest in participating. The sample size was calculated using Cochran's formula (1963), assuming a 50% prevalence rate for KAP related to TCa and TSE, a 95% confidence interval, a Z-value of 1.96, and a 5% margin error. This calculation yielded an initial sample size of 385. To account for a potential 10% non-response rate, the target sample size was increased to approximately 422 participants.

### Instrument and data collection

*Pilot*

Data were collected via a self-report questionnaire that was adapted from existing literature (Altınel & Avci, 2013; Gutema et al., 2018; Muliira et al., 2012; Peltzer & Pengpid, 2015; Ramim et al., 2014; Wardle et al., 1994). The survey instrument underwent pre-testing with a sample of five male students. After the pre-testing, slight modifications were implemented to elucidate specific issues and enhance understanding. These modifications were implemented to improve the clarity and dependability of the survey for the intended demographic. A question related to health practices or screenings (*Have you ever avoided seeking medical help due to embarrassment about testicular cancer symptoms*?) felt too intrusive, and this was removed.

*Final Survey*

The survey included five sections covering TCa and TSE knowledge, attitudes, behavior, demographic information, the program of study, and the academic year. Sections on TCa and TSE *knowledge* (13 items, Cronbach's α: 0.831) and *attitudes* (11 items, Cronbach's alpha α=0.717) were measured on a three-point Likert scale (Disagree=1, Uncertain/Neutral=2, Agree=3). Mean scores were calculated by averaging item responses within each section, with the interpretation ranges for knowledge and attitude defined as the following: 1.00-1.66= overall 'disagree'; 1.67-2.33= overall 'uncertain'/'neutral'; and 2.34-3.00= overall 'agree.' Section four explored TSE occasion (i.e., when they perform a TSE), location, frequency, and technique. The final section comprised seven yes/no questions that addressed perceived barriers to TSE, such as "*fear of a worse result after examination.*"

*Data Collection*

The questionnaire was administered via Google Form, with five undergraduate students as data collectors who shared the link within their network. A network sampling method was employed to identify potential participants (Parker et al., 2018).Given the COVID-19 pandemic, this online-peer-distribution approach was chosen to maintain health protocols, leveraging existing WhatsApp groups and email lists created for virtual learning at the University. Finally, it was the quickest and most effective means of accessing participants during the pandemic.

### Data entry, analysis, and presentation

Data were exported to Microsoft Excel 365 for initial cleaning and then imported to SPSS (version 22) for analysis. Results are presented as descriptive statistics (frequency and percentage) and inferential statistics (chi-square and linear regression), with a p-value $\leq 0.05$ and a 95% confidence level considered statistically significant.

## Results

### *Sociodemographic characteristics of the study participants*

Three hundred ninety-one undergraduate male students aged 17 and 35 participated in the survey (**Table 1)**. Most identified as Christian (90%), and one-third (34.0%) were in a relationship, were dating, engaged, or married. Among the participants, 32.5% were enrolled in the College of Health Sciences, with the remainder distributed across other colleges: Humanities and Social Sciences (21.2%), Art and Built Engineering (17.1%), Engineering (12.5%), Science (11.0%), and Agriculture and Natural Resources (5.6%). Nearly half of the respondents were in their second (20.2%) or third year (25.6%) of college.

| **Table 1.** Male undergraduate students' demographic characteristics | | Value (%) |
|---|---|---|
| **Age in years (M= 21.7; SD: 2.6)** | | |
| | 17-19yo | 74 (18.9) |
| | 20yo | 64 (16.4) |
| | 21yo | 68 (17.4) |
| | 22yo | 41 (10.5) |
| | 23yo | 69 (17.6) |
| | 24-25yo | 69 (17.6) |
| **Relationship Status** | | |
| | Not in a relationship | 257 (76.5) |
| | Dating, Engaged, Married | 133 (34,0) |
| **Program of Study** | | |
| | College of Agriculture and Natural Resources | 19 (4.9) |
| | College of Art and Built Environment | 66 (16.9) |
| | College of Engineering | 49 (12.5) |
| | College of Health Sciences | 127 (32.5) |
| | College of Humanities and Social Sciences | 83 (21.2) |
| | College of Science | 43 (11.0) |
| **Year of Study** | | |
| | 1st Year | 56 (14.3) |
| | 2nd Year | 79 (20.2) |
| | 3rd Year | 100 (25.6) |
| | 4th Year | 72 (18.4) |
| | 5th Year | 72 (18.4) |
| | 6th Year | 12 (3.1) |
| **Faith** | | |
| | Christian | 351 (89.8) |
| | Muslim | 33 (8.4) |
| | Non-Religious/Other | 6 (1.5) |

### *General knowledge and awareness of TCa and TSE* (**Table 2a)**

Knowledge about TCa was assessed through questions regarding general awareness, source of knowledge, and family history. While nearly half (49.4%) of the male students reported having been *aware* of TCa ("*Have you* ***heard*** *of testicular cancer before?*"), fewer (39.9%) reported *knowing* anything about it ("*Do you* ***know anything*** *about testicular cancer?*"). The majority (61.6%) identified the media as their primary source of information on TCa. Few participants reported knowing someone with TCa (0.5% reported a family member, and 2.1% reported knowing a friend).

Of the 391 male undergraduate student respondents, 78.3% agreed that '*a TSE is important in the early diagnosis of TCa'*. Among this subgroup, more than half (60.3%) cited the media as their primary source of information on TCa. Amongst the 144 (36.3%) undergraduate male students *aware* of TSE *('Have you heard of the TSE')*, forty-eight, or one-third (34.0%), of them, reported *performing* a TSE, and only five of them (10.4%) did so monthly. Further examination of these practices is discussed later in the manuscript.

Overall, almost double the number of students reported receiving their TCa information from the media than from health professionals (61.7% vs 37.4%). However, in a subgroup of students who reported both "hearing about TCa" and "knowing anything about it," an interesting trend appears: whilst 21-year-olds and 23-to 35-year-olds cited health professionals as their main source of TCa information, 17 to 20-year-olds and 22-year-olds cited the media as their primary source of TCa information.

### *Associations between demographics and general knowledge, attitudes, and practice*

In a Chi-Squared test of independence conducted to examine the relationship between socio-demographic variables and TCa awareness ("*heard about TCa*"), TC knowledge (*"know anything about TCa")*, TSE awareness (*"heard about TSE")* ($p < 0.001$) and TSE performance (*"do you perform a TSE?")*, the results indicated a significant association between age and all four outcomes, program of study and all four outcomes, and academic year ('year of study') and all four outcomes (**see Table 2b-e**). Older students, students enrolled in the College of Health Science, and students in their 4th year of study reported higher rates in TCa knowledge awareness and TSE knowledge and performance. No association was found between relationship status and the four outcomes, the same for religious affiliation (Christian vs Muslim), except TCa knowledge and religious affiliation, where a significant association was found (Chi-Cuadrado de Pearson; $p=0.009$**)**; a higher number of Christian undergraduates, male students reported "*knowing anything about TCa*" than Muslim undergraduate male students. There was no significant association TSE awareness between religion ($p=0.660$) and between relationship status ($p=0.745$).

Significant associations were found between awareness of TCa ("***hearing*** *about TCa before*" and "***knowing*** *anything about TCa*" ($p < 0.001$)) and TSE ("*heard about TSE,*" ($p < 0.001$)). Similarly, if students reported *"hearing about TSE"* they were more likely to know that performing a TSE ($p < 0.001$) was important for the early diagnosis of TCa ($p < 0.001$).

| **Table 2a.** General Knowledge and Awareness of TCa and TSE | **Response** | **Value (%)** | |
|---|---|---|---|
| **Have you ever heard of TCa before?*** | | | ***Yes*, I would like to receive information on TSE.** |
| | No | 198 (50.6%) | 132 (66.7%) |
| | Yes | 193 (49.4) | 183 (94.8%) |
| **Where did you get information on TCa?** | | | |
| | Conference/Panel | 3 (1.4%) | 3 (100%) |
| | Professionals | 78 (37.0%) | 73 (93.6%) |
| | Media | 130 (61.6%) | 122 (92.8%) |
| **Does anyone in your family have TCa? (currently or in the past)** | | | |
| | No | 389 (99.5%) | 313 (80.5%) |
| | Yes | 2 (0.5%) | 2 (100%) |
| **Is anyone in your close environment (friends, neighbors, etc.) diagnosed with TCa? (currently or in the past)** | | | |
| | No | 380 (97.2%) | 304 (80.0%) |
| | Yes | 8 (2.0%) | 8 (100%) |
| **Do you know anything about TCa?*** | | | |
| | No | 235 (60.1%) | 166 (70.6%) |
| | Yes | 156 (39.9%) | 149 (95.5%) |
| **Have you heard of TSE?*** | | | |
| | No | 244 (63.2) | 175 (71.1%) |
| | Yes | 142 (36.8) | 135 (95.1%) |
| **Do you perform TSE?*** | | | |

| | | | |
|---|---|---:|---:|
| | No | 335 (86.8) | 264 (78.8%) |
| | Yes | 51 (13.2) | 46 (90.2) |
| **How often do you perform a TSE?** | | | |
| | Monthly (same day, every month) | 6 (1.5%) | 6 (100%) |
| | Regularly (consistent practice) | 22 (5.6%) | 21 (95.5%) |
| | Irregularly (not monthly) | 153 (53.7%) | 143 (93.5%) |
| **Would you like to receive information about TSE?** | | | |
| | No | 76 (19.4)% | [redacted] |
| | Yes | 315 (80.6%) | [redacted] |
| **Is TSE important in the early diagnosis of TCa?**** | | | |
| | No | 11 (5.3%) | 8 (72.7%) |
| | Don't know/Uncertain | 34 (16.4%) | 30 (88.2%) |
| | Yes | 162 (78.3%) | 156 (96.3%) |

***$p < 0.001$ ; ** $p = 0.003$**

| **Table 2b.** *Associations between demographics and general knowledge, attitudes and practice* | | | **Have you ever heard of TCa before?** | |
|---|---|---|---|---|
| **Age in years** | Category | Coded | NO | YES |
| | 17-19 y.o. | 0 | 55 (74.3%) | 19 (25.7%) |
| | 20 y.o. | 1 | 41 (64.1%) | 23 (35.9%) |
| | 21 y.o. | 2 | 40 (58.8%) | 28 (41.2%) |
| | 22 y.o. | 3 | 16 (39.0%) | 25 (61.0%) |
| | 23 y.o. | 4 | 19 (27.5%) | 50 (72.5%) |
| | 24-25 y.o. | 5 | 26 (37.7%) | 43 (62.3%) |
| | | | Chi-cuadrado de Pearson | 44.599; p<**0.001** |
| **Program of Study** | | | | |
| | College of Agriculture & Natural Resources; College of Art & Built Environment; College of Engineering | 1 | 98 (73.1%) | 36 (26.9%) |
| | College of Health Sciences | 2 | 16 (12.6%) | 111 (87.4%) |
| | College of Humanities and Social Sciences | 3 | 58 (69.9%) | 25 (30.1%) |
| | College of Science | 4 | 24 (55.8%) | 19 (44.2%) |
| | | | Chi-cuadrado de Pearson | 113.406; p<**0.001** |
| **Year of Study** | | | | |
| | Years 1&2 | 0 | 87 (64.4%) | 48 (35.6%) |
| | Year 3 | 1 | 64 (64.0%) | 36 (36.6%) |
| | Years 4-6 | 2 | 47 (30.1%) | 109 (69.9%) |
| | | | Chi-cuadrado de Pearson | 43.691; p<**0.001** |

*Relationship status; religion: no significant association found

| **Table 2c.** *Associations between demographics and general knowledge, attitudes and practice* | | | **Do you know anything about TCa?** | |
|---|---|---|---|---|
| **Age in years** | Category | Coded | NO | YES |
| | 17-19 y.o. | 0 | 61 (82.4%) | 13 (17.6%) |
| | 20 y.o. | 1 | 46 (71.9%) | 18 (28.1%) |
| | 21 y.o. | 2 | 43 (63.2%) | 25 (36.8%) |
| | 22 y.o. | 3 | 24 (58.5%) | 17 (41.5%) |
| | 23 y.o. | 4 | 24 (34.8%) | 45 (65.2%) |
| | 24-25 y.o. | 5 | 34 (49.3%) | 35 (50.7%) |
| | | | Chi-cuadrado de Pearson | 41.278; p<**0.001** |
| **Program of Study** | | | | |
| | College of Agriculture & Natural Resources; College of Art & Built Environment; College of Engineering | 1 | 108 (80.6%) | 26 (19.4%) |
| | College of Health Sciences | 2 | 21 (16.5%) | 106 (83.5%) |
| | College of Humanities and Social Sciences | 3 | 75 (90.4%) | 8 (9.6%) |
| | College of Science | 4 | 28 (65.1%) | 15 (34.9%) |
| | | | Chi-cuadrado de Pearson | 155.936; p<**0.001** |
| **Year of Study** | | | | |
| | Years 1&2 | 0 | 104 (77.0%) | 31 (23.0%) |
| | Year 3 | 1 | 76 (76.0%) | 24 (24.0%) |
| | Years 4-6 | 2 | 55 (35.3%) | 101 (64.7%) |
| | | | Chi-cuadrado de Pearson | 66.845; p<**0.001** |
| **Faith** | | | | |
| | Christian | 0 | 205 (58.4%) | 146 (41.6%) |
| | Muslim | 1 | 27 (81.8%) | 6 (18.2%) |
| | | | Chi-cuadrado de Pearson | 6.914; **p=0.009** |

*Relationship status: no significant association found

| **Table 2d.** *Associations between demographics and general knowledge, attitudes and practice* | | | **Have you ever heard of Testicular self-examination (TSE)?** | |
|---|---|---|---|---|
| **Age in years** | Category | Coded | NO | YES |
| | 17-19 y.o. | 0 | 61 (82.4%) | 11 (15.3%) |
| | 20 y.o. | 1 | 49 (77.8%) | 14 (22.2%) |
| | 21 y.o. | 2 | 46 (68.7%) | 21 (31.3%) |
| | 22 y.o. | 3 | 21 (51.2%) | 20 (48.8%) |
| | 23 y.o. | 4 | 31 (44.9%) | 38 (55.1%) |
| | 24-25 y.o. | 5 | 35 (51.5%) | 33 (48.5%) |
| | | | Chi-cuadrado de Pearson | 37.650; p<**0.001** |
| **Program of Study** | | | | |
| | College of Agriculture & Natural Resources; College of Art & Built Environment; College of Engineering | 1 | 110 (82.1%) | 24 (17.9%) |
| | College of Health Sciences | 2 | 39 (30.7%) | 88 (69.3%) |
| | College of Humanities and Social Sciences | 3 | 67 (81.7%) | 15 (18.3%) |
| | College of Science | 4 | 26 (65.0%) | 14 (35.0%) |
| | | | Chi-cuadrado de Pearson | 90.322; p<**0.001** |
| **Year of Study** | | | | |
| | Years 1&2 | 0 | 102 (77.9%) | 29 (22.1%) |
| | Year 3 | 1 | 78 (78.0%) | 22 (22.0%) |
| | Years 4-6 | 2 | 64 (41.3%) | 91 (64.1%) |
| | | | Chi-cuadrado de Pearson | 53.527; p<**0.001** |

*Relationship status, religion: no significant association found

| **Table 2e.** *Associations between demographics and general knowledge, attitudes and practice* | | | **Do you perform a TSE?** | |
|---|---|---|---|---|
| **Age in years** | Category | Coded | NO | YES |
| | 17-19 y.o. | 0 | 68 (94.4%) | 4 (5.6%) |
| | 20 y.o. | 1 | 60 (95.2%) | 3 (4.8%) |
| | 21 y.o. | 2 | 57 (85.1%) | 10 (14.9%) |
| | 22 y.o. | 3 | 38 (92.7%) | 3 (7.3%) |
| | 23 y.o. | 4 | 52 (76.4%) | 16 (23.5%) |
| | 24-25 y.o. | 5 | 56 (81.2%) | 13 (18.8%) |
| | | | Chi-cuadrado de Pearson | 17.563; p=**0.004** |
| **Program of Study** | | | | |
| | College of Agriculture & Natural Resources; College of Art & Built Environment; College of Engineering | 1 | 126 (94.0%) | 8 (6.0%) |
| | College of Health Sciences | 2 | 95 (75.4%) | 31 (24.6%) |
| | College of Humanities and Social Sciences | 3 | 76 (92.7%) | 6 (7.3%) |
| | College of Science | 4 | 35 (87.5%) | 5 (12.5%) |
| | | | Chi-cuadrado de Pearson | 23.068; p<**,001** |
| **Year of Study** | | | | |
| | Year 1&2 | 0 | 121 (92.4%) | 10 (7.6%) |
| | Year 3 | 1 | 94 (94.0%) | 6 (6.0%) |
| | Year 4-6 | 2 | 120 (77.4%) | 35 (22.6%) |
| | | | Chi-cuadrado de Pearson | 19.995; p<**,001** |

*Relationship status, religion: no significant association found

### *Levels of Knowledge about TCa and TSE*

**Graph 1a** displays response frequencies for the Likert-scale questions regarding 'students' level of knowledge,' while **Table 3a** provides mean scores. Mean scores ranged from 1.67-2.34, indicating general uncertainty. Participants recognized that early detection increases recovery chances ($\bar{x}$=2,35) and that TSE is the earliest detection method for TCa ($\bar{x}$=2,40) yet expressed uncertainty on other TCa and TSE knowledge items.

TCa and TSE knowledge levels were associated with age ($\chi^2$= 32.990, $p < 0.001$) and academic year ($\chi^2$= 92,161, $p< 0.001$). Fifth-year students exhibited greater TCa and TSE knowledge than their peers, while students from the College of Health Sciences had the highest knowledge levels compared to those in other colleges ($\chi^2$= 127,850, $p < 0.001$).

### *Attitudes towards TCa and the TSE*

**Graph 1b** illustrates the range of responses to Likert-scale questions on *attitudes towards TCa and TSE*, while mean scores are presented in **Table 3b**. Undergraduate male students did not express strong negative feelings about performing TSE monthly ($\bar{x}$=1,29), viewing it as time-consuming ($\bar{x}$=1,41) or painful ($\bar{x}$=1.62). However, many students were uncertain about whether not performing a TSE increases their risk of TCa ($\bar{x}$=2.02) or whether TCa could affect their careers ($\bar{x}$=1.87) or marriage ($\bar{x}$= 2.2).

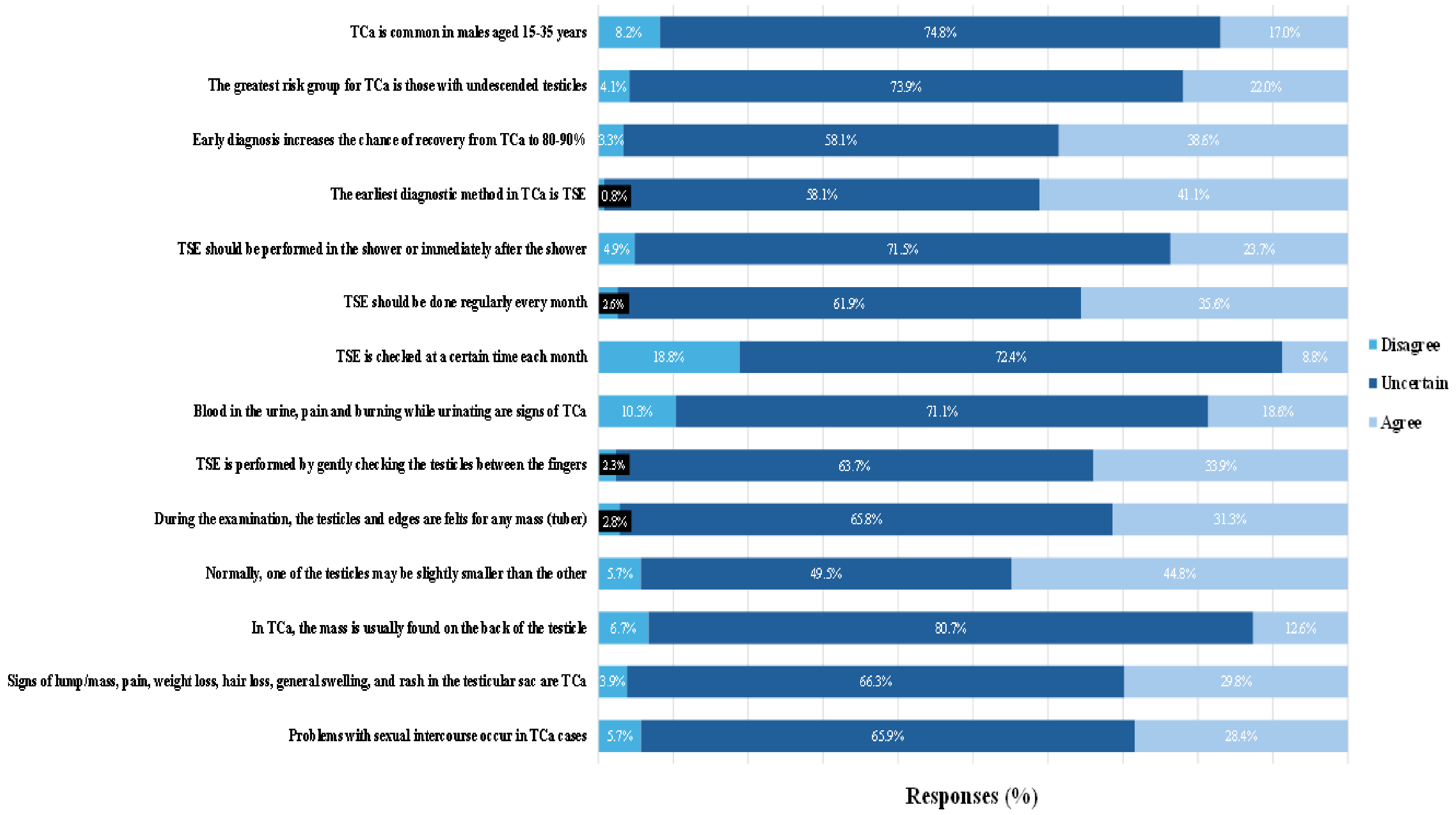
Older male students were more likely to view TCa as " *more serious than other diseases*" ($p$=0.041) and perceived "*TSE can be time-consuming*" ($p$=0.370). Males in relationships reported more significant concerns about potential ridicule ("*family will make fun of me if I do TSE*") ($p$=0.014) compared to those not in relationships.

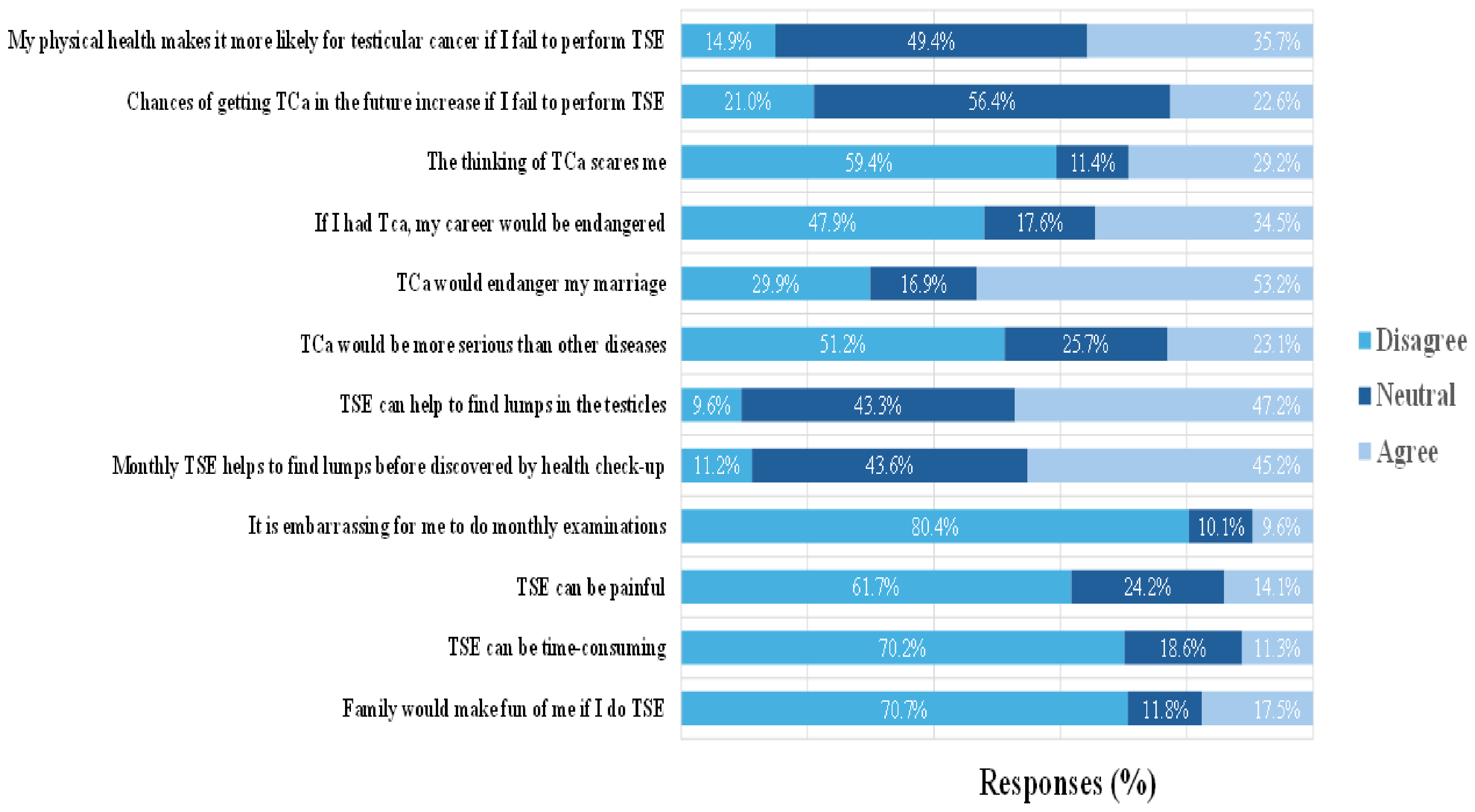
**Table 3. Mean Scores, Levels of Knowledge, and Attitudes towards TCa and TSE**

| | Mean | Standard Deviation |
|---|---|---|
| **3a. Students' Level of Knowledge on TCa and TSE** | | |
| • TCa is most common in males aged 15–35 years.<br>• The greatest risk group for TCa is those with undescended testicles.<br>• TSE should be performed in the shower or immediately after the shower.<br>• TSE is checked at a certain time each month.<br>• TSE should be done regularly every month.<br>• Blood in the urine, pain, and burning while urinating are signs of TCa.<br>• TSE is performed by gently checking the testicles between the fingers.<br>• In TCa, the mass is usually found on the back of the testicle.<br>• Where there is TCa, there are signs of lump/mass, pain, weight loss, hair loss, general swelling, and rash in the testicular sac.<br>• Problems with sexual intercourse occur in TCa cases.<br>• During the examination, it is tried to feel if there is any mass (tuber) in the testicles and on the edges | **1,90 – 2,33 (uncertain)** | **0,495 - 0,532** |
| • Early diagnosis increases the chance of recovery from TCa to 80–90%<br>• The earliest diagnostic method in TCa is TSE<br>• Normally, one of the testicles may be slightly smaller than the other | **2,35 – 3,0 (agree)** | **0,507 - 0,544** |
| **3b. Students' Attitudes towards TCa and TSE** | | |
| • It is embarrassing for me to do monthly examinations.<br>• TSE can be painful.<br>• TSE can be time-consuming.<br>• Family will make fun of me if I do TSE | **1,29 – 1,52 (disagree)** | **,632** |
| • My physical health makes it more likely for TCa if I fail to perform TSE.<br>• Chances of getting TCa in the future increase if I fail to perform TSE.<br>• The thinking of TCa fears me<br>• If I had TCa, my career would be endangered.<br>• TCa would endanger my marriage.<br>• TCa would be more serious than other diseases. | **1,70 - 2,21 (neutral)** | **,661-,899** |

| | | |
|---|---|---|
| • Monthly TSE helps to find lumps before they are discovered by a health check-up | | |
| • TSE can help to find lumps in the testicles | **2,38<br>(agree)** | **,654** |

Graph 1a. Students' Level of Knowledge on TCa and TSE




Graph 1b. Attitudes towards TCa and TSE

### *Predictors of knowledge and attitude*

Linear regression analysis identified predictors of levels of knowledge (**Table 4a**) and attitudes (**Table 4b**) toward TCa and TSE. The model explained 35% of the variance in knowledge, with academic year as the only significant predictor. The predictors for attitudes accounted for 38%, but none were individually significant.

### *TSE Practice*

In the last section of the survey, undergraduate male students were queried about their TSE practices, including frequency, techniques, occasion, and location. In a previous question on this practice, fifty-one (13.2%) undergraduate male students confirmed they had performed a TSE; however, in this section, when asked if they had “examined their testis before,*”* only one-third (27.9%) reported doing so.

Based on this discovery, two chi-square tests and a cross-tabulation were conducted to ensure the contextualization of the responses to the remainder of this section’s questions. Firstly, a chi-square test was run, and an association was found between “*performing a TSE*” and “*ever examining their testis before”*($\chi^2$= 145.026, $p < 0.001$; ). Thus, a subgroup (n=50; 27.7%) of respondents who had reported performing a TSE and examining their testis before was selected further to explore their technique, frequency, and occasion.

The two most frequent periods were ‘once a month’ (29.87%) or ‘daily to weekly’ (22.1%). When inquired on the technique they used, more than half (62.%) used ‘inspection and palpation’ techniques, performed a TSE-examined their testis mainly in the bathroom (57.1%), lying in bed (22.4%), or in front of the mirror (16.3%). More than half (54.0%) of this subgroup of undergraduate male student respondents reported performing a TSE-examining their testis ‘before or after showers.’

### *Barriers to not performing a TSE*

The main barriers to performing a TSE included a lack of know-how (78.6%) and fear of results (26.6%) **(Table 5)**. Among those who had *not ever* examined their testes, 90.3% cited a lack of knowledge on performing a TSE as a barrier ($\chi^2$ 82.84, $p < 0.001$). These findings align with previous research, highlighting the link between health knowledge and healthy behavior. Other barriers included indifference (‘not caring’) (16.6%), viewing TSE as sinful (6.4%), feelings of shame (12.0%), and cultural barriers (7.2%).

**Table 4. Predictors of Level of Knowledge (4a) and Attitudes (4b) on TCa & TSE**

| | | | |
|---|---|---|---|
| **4a. Predictors on Students' Level of Knowledge on TCa and TSE** | | | |
| **WHOLE MODEL** | **$R^2$** | ***F*** | ***p*** |
| | **0.350** | **17,443** | **0.000** |
| **Variables** | Beta | 95% CI | *p* |
| Program of Study | -0.004 | -0.027 – 0.019 | 0.869 |
| Academic year | 0.156 | 0.118 – 0.194 | 0.000 |
| Age Group | 0.20 | 0.01 – 0.39 | 0.278 |
| **4b. Predictors on Attitudes towards TCa and TSE** | | | |
| **WHOLE MODEL** | **$R^2$** | ***F*** | ***P*** |
| | **0.38** | **3.675** | **0.06** |
| **Variables** | | | |
| Program of Study | 0.003 | 0.025 – 0.031 | 0.92 |
| Academic year | 0.45 | -0.03 – 0.093 | 0.349 |
| Age Group | 0.42 | 0.019 – 0.065 | 0.071 |

| **Table 5:** TSE Practice | **Response** | **Value (%)** |
|---|---|---|
| **Have you ever examined your testis before?** | | |
| | No | 282 (72.1%) |
| | Yes | 109 (27.9%) |
| **At what age did you begin performing a TSE?** | | |
| | < 15 years old | 41 (10.5%) |
| | > 15 years old | 138 (35.3%) |
| **What time do you perform a TSE?** | | |
| | Anytime, other than shower time | 104 (25.5%) |
| | Before/after the shower | 78 (19.9%%) |
| **What techniques do you employ when performing a TSE?** | | |
| | I do not use a technique | 34 (8.7%) |
| | Inspection | 100 (25.6%) |
| | Inspection + Palpitation | 81 (20.7%) |
| **How regularly do you perform a TSE?** | | |
| | Hardly ever/irregularly | 4 (1.0%) |
| | Once a year | 61 (15.6%) |
| | Twice a year | 11 (2.8%) |
| | Four times a year | 21 (5.4%) |
| | Sometimes twice a month | 1 (0.3%) |
| | One a month | 42 (11.0%) |
| | Daily to weekly | 33 (8.4%) |
| **Where do you perform a TSE?** | | |
| | In front of a mirror | 23 (5.9%) |
| | In the bathroom | 111 (28.4%) |
| | Lying in bed | 45 (11.5%) |
| | Wherever | 2 (0.5%) |

## Discussion

To our knowledge, this is the first study that investigated TCa and TSE awareness, knowledge, and practice in male Ghanaian university students. The results from this study are consistent with the literature that has shown an overall lack of TCa and TSE knowledge, awareness, and practice across male populations (Alnizari et al., 2023; Beebe et al., 2022; Ryszawy et al., 2022; Wardle et al., 1994), particularly among male university students (Avci & Altinel, 2018; Demir & Türkben Polat, 2022; Evans et al., 2006; Ramim et al., 2014; Rovito et al., 2011), and most particularly amongst African, male, university students (Gutema et al., 2018; Peltzer & Pengpid, 2015; Ugwumba et al., 2016; Zeleke et al., 2019). The study showed that exposure to information about TCa increased the likelihood of knowing about TSE.

### *General knowledge, awareness, and attitudes*

Despite not knowing about TSE, a majority (71.7%) of the male students reported interest in receiving information about TSE. Our data showed that male students were exposed to information on TCa more through media than through any close or personal encounters (i.e., family or friends). This provides insight into where prevention strategies can promote TCa in this population. Other studies also reported these findings (Alkhayal et al., 2023; Ibrahim & Zaghamir, 2024).

Although social media may be the most utilized source of TCa information, other studies have shown the importance of using a variety of materials or mixed approaches to improve knowledge and awareness (Ibrahim & Zaghamir, 2024; Khani Jeihooni et al., 2021; Rovito et al., 2011).

Interestingly, when male students were asked if they had *heard about TSE*, more than half (62.4%) said they had *not*, yet among this subgroup, almost all (98.8%) reported that they had performed TSE. Research shows that the mechanism of perceived susceptibility-perceived benefits functions in the Health Belief Model's constructs can be a motivator for action (Avci & Altinel, 2018; Khani Jeihooni et al., 2021). This may explain why, despite claiming to be aware or not about TCa ('*have you heard about TCa'),* most of each subgroup reported having *performed* a TSE (77.7% and 95.5%, respectively). Perhaps the fact that the media is the most commonly reported source for accessing TCa information (61.6%) indicates this discrepancy. Although male students may not remember *hearing* about TSE, somewhere in their exposure to TCa through media sources, they were made aware of how to check for TCa and thus explained why so many performed a TSE despite reporting *not* having heard about it.

From a public health promotion perspective, there are several opportunities for academic careers in which TCa and TSE information can be disseminated throughout the trajectory of these cohorts. From a clinical perspective, the low percentage of TSE among this cohort constitutes a significant concern regarding the prevention and early management of TCa.

### *Level of Knowledge on TCa & TSE*

Due to the age cohort, it was not surprising to find that, in addition to the general lack of awareness of TCa and TSE, age was a strong component of the level of knowledge and attitudes that male students had towards TCa and TSE. This was evident by the high number of neutral ("uncertain") mean scores on questions related to TCa and TSE knowledge, indicating a lack of adequate TCa-related health promotion and education among this cohort. Older male students reported they received most of their TCa information from professionals, which could be due to the higher number of College of Health Sciences students who participated in our study and were exposed to health information provided throughout their curricula. Compared to students from other colleges, male students in the last year of their Health Sciences degrees are more likely to attribute their source of TCa knowledge to their professors or health professionals. This provides an excellent opportunity to evaluate social and physical spaces or alternative means to provide access to this information for students not exposed to it within their coursework. For example, health promotion campaigns can be provided through college campuses and, of course, through social media outlets.

### *Attitudes toward TCa and TSE*

These data suggest that while there is an awareness of performing a TSE and a lack of stigma surrounding performing a TSE, there is a concern about the impact that a TCa diagnosis would have on their lives. This suggests a lack of awareness beyond the basic understanding of prevention and the importance of early detection of TCa outcomes and postdiagnosis. This is especially relevant in this cohort, as none reported knowing anyone—family, friend, or ‘other’—diagnosed with TCa. Although many did not think that TCa would endanger their career, more than half thought it would threaten their marriage; this was a particular concern among male students who were not in a relationship (67.2%) compared to those who reported being in some courtship (dating) or established relationship (engaged, married) (32.8%). This finding supports research suggesting that marital status positively influences the knowledge, awareness, and practice of TCa and TSE (Dhakal et al., 2021).

In this study, the majority (79.5%) of the male students reported not being embarrassed about performing a monthly examination. While our findings align with other studies (Zeleke et al., 2019), others have shown that TSE is a barrier (Muliira et al., 2012).

### *Practice and barriers to TSE*

A lack of knowledge strongly contributes to why male students did not perform a TSE. This was evident in the different response of male students regarding the TSE and ‘examining their testis’. This could be due to unfamiliarity with the term “testicular self-examination” or “TSE” and, thus, why more male students report examining their testis. It appears that those who perform a TSE are aware of the technique. The time of day and where they perform a TSE provide great insight into how to improve TCa prevention strategies (i.e., delivering products that remind them to perform TSE) among male students who “don’t/hardly ever” perform a TSE.

Although the U.S. Preventative Services Task Force (USPSTF) recommends against routine screening for TCa in asymptomatic adolescent and adult males, our data indicate a lack of proper and adequate TCa and TSE information among adolescent and university-aged males. The research community (Rovito et al., 2016, 2022) has urged reviewing USPSTF’s methods and evidence because a health promotion program designed to target this cohort to encourage early detection is paramount. Access to programs that provide accurate and high-quality information can ensure the successful attainment of accurate and high-quality knowledge and awareness.

## **Limitations**

In the effort to collect data on TCa and TSE awareness, knowledge, and practice on male university students in Ghana, a feat that had not been undertaken, and considering the limitations that COVID-19 presented, a cross-sectional design was the best option to gain a temporal understanding of the study’s objectives, despite its limitations in reporting causal inferences. Access to resources and time would enable a prospective study design for future research in this cohort.

Other limitations include 1) the lack of a more robust questionnaire for understanding the cognitive, emotional, social, and cultural mechanisms involved in improving and impacting TCa knowledge and TSE practices and 2) the issue of single-site sampling. More comprehensive tools must be used to solicit information from samples to maximize the time and resources provided, most importantly, by the participants. Finally, it is in the best interest of future inquiries into this and related topics to include multiple sites to ensure diversity of source populations and improve the generalizability of findings.

## Implications for Health Behavior Research

Our research has provided valuable insights into improving and advancing testicular cancer (TCa) awareness, knowledge, and testicular self-examination (TSE) practices among male university-aged students in the Global South, specifically Ghana. There is a pressing need for culturally sensitive programs and education tools to improve TCa awareness and TSE practices. Effective public health campaign strategies must also be developed to reach and engage the target population.

Encouraging the incorporation of TSE into regular health checks is crucial for promoting early detection. To achieve this, leveraging technology and media is essential, as these tools can enhance engagement and improve accessibility to TCa information. Furthermore, executing longitudinal studies will help track changes in TCa awareness, knowledge, and TSE behaviors over time, contributing to refining educational interventions.

Identifying and overcoming the psychological and social barriers that hinder TSE performance is also essential. Advocating for integrating TCa education into mental health policies and school curricula will ensure the proper allocation of resources for sustainable programs. Our results indicate that cultural and social barriers affect TSE performance, and that media significantly provides access to TCa information, impacting awareness and knowledge. Technology and media offer effective avenues for increasing engagement and understanding young men's interaction with digital tools, which can motivate behavior change towards TSE.

Thorough and rigorous research design and evaluation support effective advocacy strategies, incorporating TCa education into national health policies and school curricula and ensuring the allocation of adequately funded and sustainable programs and resources.

## Discussion Questions

> Based on the current and available literature on TCa and TSE in African countries, specifically, and what is known from studies in other parts of the globe:
> 1) How can educational interventions be designed to be culturally sensitive and effective in increasing TCa awareness and TSE practice among young men in different cultural contexts?
> 2) What factors influence the willingness and ability of providers to engage in conversations about TCa and TSE with young male patients, and how can healthcare providers be better trained and supported to discuss and provide TSE during routine health checks?
> 3) How can educational intervention be designed to be culturally sensitive and effective, minimizing barriers to increasing TCa awareness and TSE practices?

4) How can these interventions be applied to digital health tools such as mobile apps and social media to promote TSE among African university-aged males? What are the advantages and potential challenges? And how can their effectiveness be measured?

## List of Abbreviations

Testicular Cancer: TCa

Testicular self-exam: TSE

Kwame Nkrumah University of Science and Technology: KNUST

Committee on Human Research, Publications, and Ethics: CHRPE

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## Study V: The Structural and Intercultural Competence for Epidemiological Studies (SICES) guidelines: a 22-item checklist

Analysis

BMJ Global Health

# The Structural and Intercultural Competence for Epidemiological Studies (SICES) guidelines: a 22-item checklist

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## ABSTRACT

Structural and intercultural competence approaches have been widely applied to fields such as medical training, healthcare practice, healthcare policies and health promotion. Nevertheless, their systematic implementation in epidemiological research is absent. Based on a scoping review and a qualitative analysis, in this article we propose a checklist to assess cultural and structural competence in epidemiological research: the Structural and Intercultural Competence for Epidemiological Studies guidelines. These guidelines are organised as a checklist of 22 items and consider four dimensions of competence (awareness and reflexivity, cultural and structural validation, cultural and structural sensitivity, and cultural and structural representativeness), which are applied to the different stages of epidemiological research: (1) research team building and research questions; (2) study design, participant recruitment, data collection and data analysis; and (3) dissemination. These are the first guidelines addressing structural and cultural competence in epidemiological inquiry.

## Summary box

- Structural and cultural competence approaches have been widely applied to the health fields, but no systematic effort has been made to apply them to the epidemiological inquiry.
- Organised as a 22-item checklist, the Structural and Intercultural Competence for Epidemiological Studies (SICES) guidelines are the first systematic attempt to bring these approaches into epidemiological research.
- SICES provides new clues for reducing bias, interpreting the findings, and favours the commitment of populations to research results and their dissemination.
- SICES encourages a more horizontal and dialogical relationship between researchers and the public.
- SICES promotes the representativeness of minority groups and excluded population in epidemiological studies.

## THE CHALLENGE OF INTERCULTURAL AND STRUCTURAL COMPETENCE IN EPIDEMIOLOGICAL RESEARCH

In recent decades, the intercultural competence approach and its sisters, such as cultural competence, cross-cultural competence and cultural humility, among others, have been widely applied to healthcare, healthcare policies and especially to training programmes for health professionals.[1–6] Making policies and clinical practices more sensitive and effective in dealing with social diversity has become a purpose of healthcare systems of many countries, regardless of their policy models, as well as of international health agencies.[7] In a globalised world, medical services and policies must face the challenge of multiculturalism.[8] Everyday clinical practice presents a landscape that is expressed by patients with different demands, ethnic affiliations, languages and idioms of distress, as well as problems of exclusion and racism, experiences of migration, displacement and torture, and other difficulties arising from globalisation and its disruptions.[9 10] In this context, culture matters for balancing the dominant cultural view of the healthcare agenda, for dealing with local worlds and popular medical systems, for promoting social participation in health, as well as for designing community-centred health initiatives, among many other fields.[11]

Following Fleckman *et al*,[4] in this article we prefer the term intercultural competence rather than the more frequent cultural competence. The cultural competence notion can

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suggest the possibility of substantial or complete knowledge of a given culture and an emphasis on the culture of the patient, user or participant. Two implicit assumptions may be misleading, since (1) it is not possible to know a culture in its entirety and (2) any competence in this domain requires health professionals' reflexivity regarding their cultural backgrounds, including the culture of their expert system. Alternatively, the intercultural competence model invites an understanding of competence as a movement from the personal to the interpersonal level of interactions.[4] Intercultural competence values the impact of cultural factors on both lay participants and health professionals and can be defined, paraphrasing Fleckman *et al*,[4] as 'the ability to manage effectively and appropriately in intercultural situations on the basis of one's own intercultural knowledge, skills and attitudes.'

Recent initiatives have sought to broaden the spectrum of intercultural competence to integrate social and economic dimensions, and issues such as structural violence and the naturalisation of inequality.[12–16] Cultural diversity explains only part of the impact of social life on health. It is necessary to complement diversity with another 'usual suspect': inequality and its structural vulnerabilities. This is the case of some attempts to rethink cultural competence, such as Kirmayer's,[17] as well as of the so-called 'structural competence' that, according to some authors, attempts to rescue 'five decades' of studies on the social determinants of health.[12] Following Metzl and Petty,[18] we can define structural competence as a framework for addressing 'health-related social justice issues that emphasises diagnostic recognition of economic and political conditions producing and racialising inequalities in health.'

Structural competence is closely related to other approaches such as the Critical Race Theory,[19] which discusses structural racism and its impact in previous research studies and medical interventions in ethnic and sociocultural minorities. Structural vulnerabilities can be assessed through historical medical memories of the marginalised communities. The community's trust in research and medicine and consequently their eagerness to participate, or not, in epidemiological studies is a main aspect to be addressed due to its impact on recruitment and thereby bias.

Structural competence includes some cultural dimensions, so it might seem that the proposal to maintain the dual structural and intercultural components may be redundant. Nevertheless, the focus of structural competence is mainly on how broad social systems and historical processes generate structural vulnerabilities and health inequalities. Bourgois *et al*[12] define structural competence as 'the ability for health professionals to recognise and respond with self-reflective humility and community engagement to the ways negative health outcomes and lifestyle practices are shaped by larger socioeconomic, cultural, political and economic forces.' Culture is integrated in this definition as a 'larger force,' and implicitly in the idea of self-reflective humility and lifestyle practices. But culture as a factor is not widely included in this definition. Some elements are missing or receive meagre attention, especially the cultural and linguistic validation of tools and services and the 'intercultural' dimension, in the sense of the capacity of clinicians, researchers and policymakers to oscillate themselves 'between' a known culture and a culture to be known. We consider that a better balance between recognition of cultural diversity and awareness of inequality makes it possible to strengthen the analysis of both dimensions, since structural vulnerabilities take unique forms in specific cultural contexts. For example, 'poverty' takes on a different meaning in a culture where social status is not based on material wealth.[17]

The integration of structural and intercultural competencies into epidemiological study design is a real challenge not just for epidemiologists, but also for social scientists working on health issues, such as medical anthropologists. A look at the Lancet Commission on Culture and Health report is illuminating in this regard.[11] In that detailed text, the word 'epidemiology' and its variants (ie, 'epidemiological') is used just twice, as are other close terms such as 'cohort'. The relative omission of epidemiology in this text is symptomatic for us, especially considering its comprehensive and integrative purpose. In fact, no systematic effort has been made so far to apply the intercultural or structural competence perspectives to the epidemiological field.

One of the reasons for this gap is undoubtedly the difficulty of integrating social and cultural factors into epidemiological inquiry. This difficulty arises from at least two challenges. The first is common to healthcare, as it lies in the very conceptualisation of health problems as realities dependent on social life.[11] The second is more specific to epidemiological research and concerns the design and the use of tools and methods that are sensitive not just to cultural and social aspects, but also to political and structural vulnerabilities.

In relation to the first challenge, it is recognised that social and cultural factors overlap and there is no clear distinction between them. Generally, it is considered that culture refers to the ideational dimensions of social life: perceptions, symbolic representations, collective identities, religious customs, values, among other phenomena that often resist quantification.[20] For their part, social factors have become more associated with the system of social organisation, status and classes, with social mobility, poverty, inequality and policies.[21] However, cultural and social factors are related to each other in a holistic and interdependent mode in such a way that their isolation as variables can be artificial. For example, a cultural variable such as the process of acculturation of ethnic minorities is closely related to access to education and to upward social mobility and thus to social status.

But the more general problem arises concerning the second challenge: the application of structural and intercultural competence to the epidemiological design. The

**Table 1** Basic definitions

| Term | Definition |
|---|---|
| Intercultural competence in epidemiology | The ability to effectively address cultural and intercultural factors in the study design, data collection, data management, analysis and dissemination. Intercultural competence values the impact of cultural factors on both participants and researchers. In this sense, it includes both lay and expert systems. |
| Culture | A culture is a set of values, meanings and lifestyles shared by a human group that is transmitted intergenerationally through a process of socialisation and learning. All human beings are cultural to the extent that we live in society. Each cultural system involves specific norms, values, canons, aesthetic forms and models of personhood, among other aspects, that shape a worldview. This particularity or specificity does not contradict the existence of an internal diversity in each culture. Culture is a dynamic reality, the result of historical developments, and therefore changing over time.[11 36] |
| Biomedicine as culture | The 'culture of biomedicine' is the Westernised idea of care, analysis and perception of health, illness, the body and healing processes. Any medical system can be considered a cultural system. Biomedicine, also called Western medicine, scientific medicine or allopathic medicine, is the hegemonic medical system worldwide.[37 38] |
| Race | Anthropology and population genetics indicate that the notion of race is not useful in accounting for human biological variation and that it results in reproducing non-existent biological differences.[39–41] Alternative use of this term implies considering it a social construct, as a social variable related to discrimination and racism. |
| Racism | Racism can be understood as the exclusion of specific individuals and groups due to phenotypical and/or cultural traits (cultural racism). These traits may be imagined, but they have a real effect in the life of people. In this sense, it is a structural factor of vulnerability and vulnerabilisation. |
| Ethnicity | The notion of ethnicity or ethnic group refers to a set of individuals who share a sense of common origins, claim a common and distinctive history and destiny, and feel a sense of collective uniqueness and identity. This identity may be based on similarities in outward appearance (ie, phenotype), customs, language, religion or other identity elements. |
| Structural competence in epidemiology | The ability to recognise in the study design, data collection, management and analysis of data, and dissemination of the results the ways negative health outcomes and lifestyle practices are shaped by larger socioeconomic, cultural, political and economic forces. |
| Structural vulnerability | Bourgois *et al*[12] define structural vulnerability as follows: 'An individual's or a population groups' condition of being at risk for negative health outcomes through their interface with socioeconomic, political and cultural/normative hierarchies.'<br>Following these authors, some structural vulnerabilities are:<br>► Discrimination (ie, stigma, racism)<br>► Lack of financial security (ie, income, rent)<br>► Lacking safe/stable place (ie, housing, residence)<br>► Exposure to environmental risks (ie, climate change, toxins)<br>► Difficulty in food access (ie, proximity, price)<br>► Lack of social network (ie, isolation)<br>► Problems with legal status (ie, undocumented migrants, refugees)<br>► Lack of education |

problem of cultural validation of some measurement instruments such as scales or diagnostic interviews is well known in the literature,[22 23] but it is not the only issue. A competence approach in this matter presupposes a self-reflective practice on the researcher's own cultural milieu, including biomedical culture. Table 1 includes some basic definitions that we have adapted to epidemiological inquiry to assist in this reflexivity process.

Certainly, in epidemiology there are different paradigms that focus on issues close to those considered in intercultural and structural competence. This would be the case of social epidemiology[23] and sociocultural epidemiology,[24] participatory epidemiology[25] or critical epidemiology,[26] in which we could even include the proposal of an 'epidemiology without numbers'[27] that takes the collective production of health as its horizon. However, these paradigms have not explicitly or clearly focused on the competence of researchers as a set of knowledge, skills and attitudes that can improve research design. Here we think that intercultural and structural competence should not be considered as a theoretical option, but as a transversal approach, in the same way as research ethics or the Responsible Research and Innovation (RRI) approach.[28] The impact of local knowledge, difficulties in communicating with participants, or social and cultural biases arising from data collection,[29 30] among many other factors, are challenges in epidemiological research that an intercultural and structural competence can help to address.

This article aims to develop some guidelines that can improve the structural and intercultural competence of epidemiological studies. When we speak of competence, we are referring to a horizon or an aspiration and not so much to a goal that can be achieved in its entirety. In this sense, this is not a proposal of maximums, but a first step that can help to strengthen the structural and intercultural competence of epidemiological studies.

## SEARCHING FOR REFERENCES

We conducted a scoping review to identify in the literature instruments, tools, and guidelines regarding structural and cultural competence in epidemiology and, in a second phase, in other health fields. In order to identify the available literature, we conducted several searches in the National Library of Medicine (PubMed) starting in April 2020; updated in September 2020. The searches included publications in any language with the following keyword search combinations (no Medical Subject Headings terms) limited to title and abstract:

- First search: ("structural competence" OR "structural competency") AND (epidemiolog* OR "epidemiological procedures" OR "epidemiological design" OR "epidemiological methods").
- Second search: ("cultural competence" OR "cultural competency OR intercultural competence OR intercultural competency OR cross-cultural competence OR cross-cultural competency) AND (epidemiolog* OR epidemiological procedures OR epidemiological design OR epidemiological methods).

Additionally, we searched in the Cochrane Database of Systematic Reviews using the same terms. No items met the sole inclusion criterion of being a tool, instrument, or guidelines for the application of structural and/or cultural competence in the design and/or implementation of epidemiological research.

Due to this gap in the literature, we proceeded in a second phase to review the instruments, tools and guidelines used in other fields, such as health professional training and education, healthcare, health promotion and healthcare policies. In this case, we used the following search strategies:

- Third search: ("structural competence" OR "structural competency") AND ("guideline" OR "tool" OR "instrument").
- Fourth search: ("cultural competence" OR "cultural competency" OR "intercultural competence" OR "intercultural competency" OR "cross-cultural competence" OR "cross-cultural competency") AND ("guideline" OR "tool" OR "instrument").

Only publications which reported tools, instruments or guidelines regarding structural and cultural competence were eligible for inclusion. Uncertainties about whether the publications met the inclusion criteria were resolved through discussion among the researchers. Additional references were added through cross-referencing.

Two researchers (DB and AM-H) conducted full-text reviews of the publications and independently analysed the most salient domains of the selected items using a hermeneutic and qualitative content methodology. The obtained domains were crossed with the tasks involved in epidemiological research. The examination of this intersection allowed us to propose a checklist of items that should be considered when designing, carrying out and analysing data in epidemiological studies with a structural and intercultural perspective. Finally, the different items were elaborated on the basis of a consensus exercise among all authors, which included both scholars with expertise in intercultural and structural competence and those with experience in designing and conducting epidemiological research.

## EVALUATING EXISTING TOOLS

The first and second searches yielded 55 articles (42 through PubMed and 13 identified through Cochrane Database of Systematic Reviews). No items met the inclusion criterion of being a tool, instrument or guidelines. The two articles closest to our goal were on the application of intercultural competence to public health,[4] especially to the training of professionals, and on integrating epidemiological and ethnographic methodologies.[31] The third and fourth searches yielded a total of 427 articles (11 and 416, respectively), and 10 documents were added through cross-referencing. After eliminating duplicates (two items), the remaining 435 articles were screened, of which 404 were excluded because they did not report on tools, instruments or guidelines, and 10 because they were a redundant use of a tool. A total of 21 tools were identified (figure 1).

Table 2 shows the six domains that are covered by these tools and instruments. These six domains were reduced to four by merging both cultural and structural sensitivity, and cultural and structural representativeness.

### Domain 1: cultural awareness and reflexivity

In clinical care, this domain assesses whether health professionals are reflexively analysing how their cultural, ethnic, gender and social backgrounds, including the culture of their expert system, interact with the cultural background of patients and families and may affect clinical communication. In the field of health education and promotion, it is often aimed at raising awareness of the different perceptions among experts and lay systems. In this domain, the issue that is considered critical is an intangible attribute such as reflexivity. In our sample of 21 tools, this issue was clearly present in 19 of them. In one case,[12] it was indirectly addressed through the idea of cultural humility. Applied to epidemiological research, this domain can be defined as the capacity of the research team to reflexively analyse how their cultural, ethnic, social and expert background interact with those of the participants, and can affect research questions, design, recruitment, data collection, data analysis and dissemination activities.

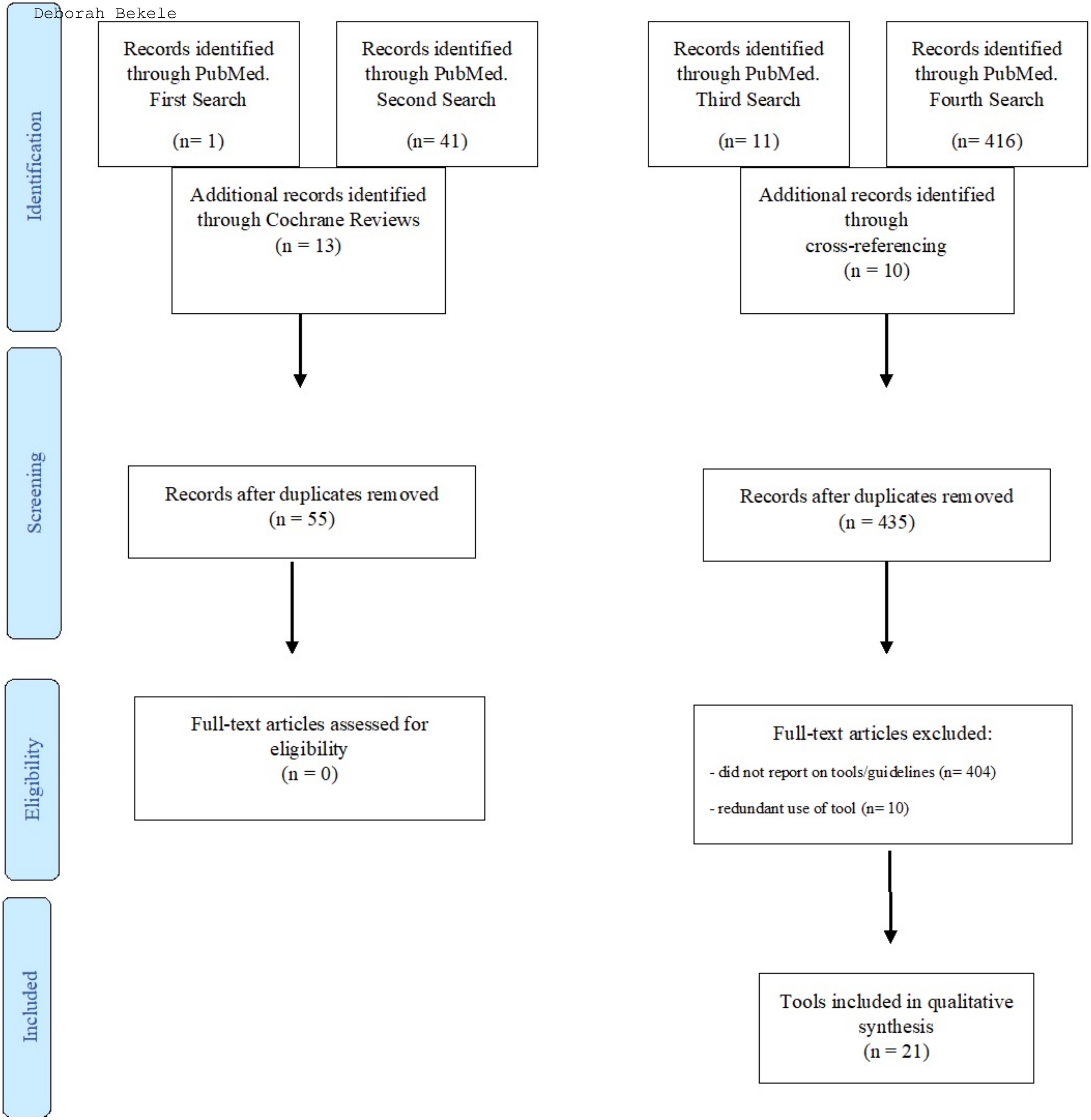

**Figure 1** Flow diagram.

### Domain 2: cultural and linguistic validation

This domain refers to the cultural and linguistic adaptation of instruments, tools, questionnaires, interviews, informed consents, health advice, prescriptions, and various interactions between health professionals or experts and patients and lay systems by extension. It also usually includes the adjustment of health services to the cultural and linguistic background of the users, for example, through the translation of information or the adaptation of protocols, settings and schedules. Among the 21 tools analysed, this domain was present in 18 of them. In the field of epidemiological research, this domain can be defined as the linguistic and cultural adaptation of instruments, tools, informed consents, and participant information sheets, questionnaires, interactions between researchers and participants, and dissemination outputs addressed to the participants.

### Domain 3: sensitivity to cultural diversity and structural vulnerabilities

The idea of merging sensitivity to cultural diversities and to social inequalities responds here to the already

**Table 2** Evaluating existing tools

| | Cultural awareness and reflexivity | Cultural and linguistic validation | Sensitivity to cultural diversity | Sensitivity to structural vulnerabilities | Representativeness of cultural minority groups | Representativeness of socially excluded populations |
|---|---|---|---|---|---|---|
| Knowledge, Efficacy, and Practices Instrument[42] | ● | ● | ● | ● | ● | |
| Cross-Cultural Competence Instrument for Healthcare Professionals[43] | ● | ● | ● | | | |
| Primary Care Assessment Tool[44] | ● | ● | ● | ● | | |
| Clinical Cultural Competency Questionnaire[45] | ● | | ● | ● | ● | |
| Tool for Assessing Cultural Competence Training[46] | ● | ● | ● | ● | ● | |
| Cultural Competence Scale[47] | ● | ● | ● | | | |
| Intercultural Development Inventory[48] | ● | | ● | ● | | |
| Standards for Transcultural Nursing[49] | ● | ● | ● | ● | ● | |
| The CAMHS Cultural Competence in Action Tool[50] | ● | ● | ● | ● | | |
| Escala de Medición Competencia Cultural[51] | ● | ● | ● | ● | * | * |
| The Cultural Competence Assessment Instrument[52] | ● | ● | ● | ● | | |
| Inventory for Assessing Process of Cultural Competence Among Healthcare Professionals[53] | | ● | | | | |
| Healthcare Provider Cultural Competence Instrument[54] | ● | ● | ● | ● | * | * |
| Structural Vulnerability Assessment Tool for the Clinical Encounter[12] | * | | * | ● | ● | |
| Critical Race Theory (tool)[19] | ● | | ● | ● | ● | |
| Structural Foundations of Health[18] | ● | | ● | ● | ● | |
| Self-Assessment Checklist[55] | ● | ● | ● | ● | | |
| Ethnic-Sensitive Inventory[56] | ● | ● | ● | ● | ● | |
| Agency Cultural Competence Checklist—Revised[57] | ● | ● | ● | ● | ● | |
| Multiculturally Competent Service System Assessment Guide[58] | ● | ● | ● | ● | ● | |
| Iowa Cultural Understanding Assessment—Client Form[59] | ● | ● | ● | ● | ● | |

*When these domains were implicit throughout the tool/instrument, but did not have a specific section dedicated to these domains like in other tools/instruments.
CAMHS, Child and Adolescent Mental Health Services.

**Table 3** Structural and intercultural domains and criteria

| | Research team building and research questions | Study design, recruitment, data collection and data analysis | Dissemination |
|---|---|---|---|
| Cultural awareness and reflexivity | 1. Reflexivity on cultural and ethnic team composition compared with the populations under study.<br>2. Tools and instruments for ensuring team reflexivity. | 9. Awareness of cultural biases from previous research done on a similar topic/population.<br>10. Reflexivity on social and cultural sources of potential bias or imprecision.<br>11. Considering the association of missing data with sociocultural characteristics of populations under study. | 19. Inclusion of the groups under study in the dissemination plan through reflexivity and awareness on the potential linguistic, cultural and social gaps. |
| Cultural validation | 3. Awareness of the lay/expert decalages.<br>4. Adequate use of categories such as race, culture and ethnicity in the research questions. | 12. Cultural and linguistic validation of informed consent, and of instruments such as questionnaires and scales.<br>13. Integration of qualitative research (eg, in-depth interviews and focus groups) and/or mixed methods in the epidemiological design and the selection of instruments. | 20. Dissemination outputs addressed and culturally tailored to the population under study. |
| Sensitivity to cultural diversity and structural vulnerabilities | 5. Team training in intercultural and structural competence.<br>6. Cultural and social knowledge of populations under study, including ethnic minorities and marginalised groups, and lay perspectives on the topics of study.<br>7. Knowledge about the medical history of the country/community in which the research is taking place and the legacy that medical research has on ethnic minorities/hidden populations. | 14. Including cultural variables in the study design. Assessing causal mechanisms associated with these variables and the limitations of using these variables as proxies for more complex categories.<br>15. Including social determinants of health and structural vulnerability variables in the study design.<br>16. Use of local knowledge to interpret findings, for example, local ideas and beliefs regarding disease aetiology or transmission. | 21. Consideration of the cultural and social specificities of the population studied in the conclusions, recommendations and application of the results of the study. |
| Representativeness of minority groups and excluded populations | 8. Representativeness of cultural diversity and civil society in the team, including lay participants and/or minority and marginalised groups. | 17. Facilitating the participation of excluded groups and minorities through sample representativeness.<br>18. Assessing the social and cultural barriers to their participation in the study. | 22. Promoting the participation of excluded groups and minorities in the dissemination and RRI activities. |

RRI, Responsible Research and Innovation.

**Table 4** The Structural and Intercultural Competence for Epidemiological Studies guidelines

| Domains | Guide questions |
|---|---|
| Research team building and research questions | 1. Has the research team identified its ethnic, cultural, and social composition and compared it with that of the study population? Has the research team taken into account the potential impact that these differences or similarities may have on the research?<br>2. Does the research team have any tools or means to facilitate reflexivity, for example, fieldnotes or regular meetings for this purpose?<br>3. Does the research team consider the lay views on the topics of study?<br>4. Has the research team assessed whether the use of concepts such as race, ethnicity or culture (among others) in the study is adequate?<br>5. Have the research team's training needs in intercultural and structural competence been assessed?<br>6. Does the research team have cultural and social knowledge of the populations under study, including ethnic minorities and marginalised groups and lay perspectives on the topics of study?<br>7. Has the research team considered the medical history of the country in which the research is taking place and the legacy that medical research has on ethnic minorities/hidden populations?<br>8. Has the research team established an advisory board which includes representatives of different cultural and/or ethnic groups, including lay participants representing civil society and/or minority collectives? |
| Study design, recruitment, data collection and data analysis | 9. Is the research team aware of cultural and social biases from previous research done on a similar topic/population that they are using as a research background?<br>10. Has the research team considered social and cultural sources of potential bias or imprecision? For example, if the research hypothesis, the objectives of the study, the theoretical–conceptual framework, or the sample gives rise to possible sensitive cultural issues or ethnocentric statements?<br>11. Has the association of missing data with sociocultural characteristics of populations under study been considered?<br>12. Are the informed consent and the questionnaires, scales, and instruments understandable to the participants and/or culturally validated or tailored to the population under study?<br>13. Has qualitative research or mixed methods been included in the design of the study, that is, for the selection of the instruments or for the collection of qualitative data on the research subject?<br>14. Have cultural variables been included in the study design such as ethnicity, cultural identity, religious beliefs or acculturation, among others? In addition, and following the Bridging Research Integrity and Global Health Epidemiology guidelines, have the different causal mechanisms associated with these variables been considered and the limitations of using these variables as proxies for more complex categories been acknowledged?<br>15. Does the study address how symptoms, clinical problems, diseases and/or attitudes toward patients, populations and/or health systems are influenced by social determinants of health and structural vulnerabilities? For example, but not limited to discrimination, lack of financial security, lacking safe/stable place, risk environments, difficulty in food access, lack of social network, problems with legal status and/or lack of formal education.<br>16. Has local knowledge been considered in interpreting the results of the study, that is, local ideas on aetiology and disease transmission?<br>17. Does the sample consider subsamples of cultural minority groups, groups subject to health disparities, and/or historically under-represented? And if so, in what way, that is, has the analysis been disaggregated for such variables or have they been considered as confounder/effect modifiers?<br>18. Have barriers to participation in the study arising from structural vulnerabilities been analysed? If so, has the inclusion of these participants been facilitated in any way? |
| Dissemination | 19. Does the dissemination plan include the groups under study? Does this plan include reflexivity and awareness on potential linguistic, cultural and social gaps?<br>20. As part of the dissemination of the results, has any output (ie, publication or audio-visual document) been addressed and culturally tailored to the population studied (ie, tested in a focus group)?<br>21. Have the cultural and social specificities of the studied groups been considered in the conclusions, recommendations and in the implementation of the results?<br>22. Is there a dissemination or Responsible Research and Innovation plan considering the active role of participants and stakeholders? If so, have barriers to participation been assessed and active participation been facilitated? |

mentioned complementarity between these perspectives. Cultural sensitivity refers to motivation and curiosity for diverse cultural realities, whether they come from patients, participants in a health promotion programme, users of a service, beneficiaries of a health policy or populations under study. Cultural knowledge can be understood as a result of cultural sensitivity. Similar reasoning can be applied to the case of sensitivity to structural vulnerabilities and social inequalities, and their correlates in knowledge on health disparities. Among the tools analysed, most contemplated some form of cultural sensitivity (19 clearly and 1 indirectly) or structural sensitivity (18). In the field of epidemiological research, this domain can be defined as the incorporation of variables and relevant information on cultural diversity and structural vulnerabilities of the groups under study in any of the phases of epidemiological research.

### Domain 4: representativeness of minority groups and excluded populations

As in the previous domain, in this one we have merged the representativeness of minority groups and excluded populations, which may overlap since diversity and inequality often run together. Generally, this domain has to do with the inclusion of disadvantaged and hidden groups, especially in health policies and services, with the objectives of improving the health of these groups, making their unequal situation visible, favouring their empowerment and health literacy, and recognising their citizenship rights. In our analysis, we observed that this was the domain least present, as it was only included directly in half of the tools. Nevertheless, its inclusion can be considered strategic because of its capacity for social transformation of the most vulnerable populations. In the context of epidemiological research, this domain can be defined as the ability to favour the representativeness of minority groups and excluded populations throughout the different phases of the study, such as the composition of the research team, the selection of the sample, and the development of dissemination and RRI activities.

## THE STRUCTURAL AND INTERCULTURAL COMPETENCE FOR EPIDEMIOLOGICAL STUDIES GUIDELINES

The four reported domains can be related to main stages of epidemiological research, such as (1) research team building and research questions; (2) study design, participant recruitment, data collection and data analysis; and (3) dissemination. Table 3 reveals the intersection between the cultural and structural domains and the epidemiological stages and a series of resulting items. Most of them relate to pre-existing instruments that account for intercultural and/or structural competence in other health fields. Other elements were obtained indirectly and were the result of a consensus among the different authors. One of them, item 14, has been expanded thanks to the valuable contribution of one of this article's reviewers, who recommended including a second specific question already existing in the Bridging Research Integrity and Global Health Epidemiology (BRIDGE) guidelines.[32 33] The result is a checklist of 22 items (see table 4) in which the items have been converted into questions that guide the researchers in their self-assessment.

## CONCLUSION

To our knowledge, the Structural and Intercultural Competence for Epidemiological Studies (SICES) checklist is the first systematic attempt to bring the structural and intercultural competence into epidemiological research. Based on the selection and adaptation of a series of criteria developed for other health fields, we have proposed a checklist that should be understood as a starting point rather than as a destination. The methodology we followed was the same as the one used for the elaboration of the Consolidated Criteria for Reporting Qualitative Research[34]: data extraction and analysis of previous instruments and checklists, in this case on intercultural and structural competence. To this process, we have added a dimension of internal consensus, as the authors of this paper include both medical anthropologists specialising in intercultural and structural competence and epidemiologists with experience in designing and conducting epidemiological research. In this sense, and if we follow the Moher *et al*'s guidance for developers of health research reporting guidelines,[35] SICES would be better defined as working guidelines, or even a guidance, whose purpose is to help promote a common language between epidemiology and structural and intercultural competence. SICES complements well with other guidelines and standards focused on related issues, such as the BRIDGE guidelines.

SICES arranges a set of criteria that can be useful not just for strengthening the structural and intercultural competence, but also the self-reflection and self-evaluation of research teams. Reflexivity is an intangible domain that has to do with attitudes and predispositions and has an influence on the quality of research. For example, self-reflection on cultural and social gaps between the research team and the populations under study can provide new clues for reducing bias and interpreting the findings, favour the commitment of these populations to research results and their dissemination, and strengthen health literacy and empowerment among the most vulnerable groups. The impact of embracing a structural and intercultural competence perspective has different faces, but they all encourage a more dialogical relationship between researchers and the public. This is the purpose of these guidelines. We invite readers to improve this checklist with comments, critiques and suggestions.

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# Study VI: Structural competency in epidemiological research: What’s feasible, what’s tricky, and the benefits of a ‘structural turn’

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# Structural competency in epidemiological research: What’s feasible, what’s tricky, and the benefits of a ‘structural turn’

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# Structural competency in epidemiological research: What's feasible, what's tricky, and the benefits of a 'structural turn'

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**ABSTRACT**
Structural competency is an emerging paradigm for both the training of health professionals and the creation of a common language addressing structural processes that determine health disparities. However, its application to the field of epidemiological design and research is absent. Based on our previous proposal of a tool for Structural and Intercultural Competency in Epidemiological Studies, the SICES guidelines, in this article we analyse the possibilities and challenges of a 'structural turn' in epidemiology. In terms of possibilities, we recognise the value of paradigms from multiple parts of the world, such as social and sociocultural epidemiology, critical epidemiology and collective health, in facilitating a structural turn in epidemiological studies. In this framework, structural competency would provide a new angle by focusing not only on what to research (e.g. inequalities), but with what skills and attitudes (e.g. cultural and epistemic humility). The challenges lie in the inclusion of reflexivity and a comprehensive view in the context of a positivist epidemiology oriented towards obtaining evidence from a biomedical, but not social, perspective.

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> The epidemiologist views the ethnographer's task as "impressionistic", "anecdotal", "uncontrolled", "messy", "soft", "unrigorous", "unscientific"; the ethnographer, in near perfect counterpoint, regards the epidemiologist's work as "superficial", "biased", "pseudoscientific", "invalid", "unscholarly". (Kleinman & Good, 1985, p. 10)

## Introduction

If we are to believe Kleinman and Good, and there is significant reason to do so, epidemiological and ethnographic points of view face a severe problem in cooperating with each other, likely because both perspectives project onto their counterpart their own canon and shortcomings. We can say that this problem reflects, once again, the old epistemological controversy between 'causal explanation' (*Erklärung*) and 'comprehension and interpretive understanding' (*Verstehen*) revealed in the etymological meanings of these words. From the Latin *explanare*, the former connotes making clear, making plain, and unfolding; while the latter, from the Latin *comprehendere*, suggests taking together, uniting, capturing, understanding, and embracing (Dilthey, 1989; Habermas,

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2015; Ricoeur, 2013). These two points of view, two epistemes, at the same time, leave room for incompatibility and complementarity. On the one side is a biomedical and positivist perspective often in tune with the Baconian ideal of scientific language as a mirror of nature (Good, 1993), looking sideways at other ways of investigating reality that do not offer evidence in line with its own canon of scientific explanation. On the other side is a perspective that refrains from analysing reality – especially social reality (Geertz, 1973; Weber, 2019) – through its fragmentation into variables since it understands that this can only be a limiting artefact of any attempt at comprehension.

Fortunately, the scenario described by Kleinman and Good more than thirty-five years ago serves to address the more polarised positions rather than the wide diversity of proposals from both disciplines. Even so, we include it here as a constructive provocation, as we consider that a frank debate on possible divergences can give rise to proposals for more robust points of convergence and complementarity. In fact, the purpose of this article is to reflect on the possibilities and challenges of applying structural competency to epidemiological design and research; an endeavour in which we consider that the ethnographic approach can usefully contribute both to analyse comprehensively the broader social structures that shape morbidity, mortality and health care, and to enhance the reflexivity of research teams. These are two competencies that can improve the quality and impact of epidemiological inquiry. For example, ethnographic reflexivity can provide new clues for reducing bias and interpreting findings, encourage the engagement of the populations under study to research results and their dissemination, and strengthen empowerment among the most ‘vulnerabilised’ groups (i.e. those groups that are made vulnerable by unequal social, ideological, political and economic structures). Of course, we do not mean to suggest that the ethnographic approach is the only one that can provide these competencies. Options such as community-based participatory research (CBPR) (Brush et al., 2020; Wallerstein et al., 2017) and participatory action research (PAR) (Baum et al., 2006) methodologies, among others, can offer them from other angles. Rather, we limit ourselves to the ethnographic approach because it is from here that we hope to contribute to the development of these competencies in epidemiology.

This paper builds on a previous publication (Martínez-Hernáez et al., 2021) in which, together with a group of epidemiological colleagues within the European project SYNCHROS (SYNergies for Cohorts in Health: integrating the ROle of all Stakeholders), we developed the Structural and Intercultural Competency in Epidemiological Studies (SICES) guidelines. In the following sections, and based on this experience, we offer a set of reflections on what we see as feasible to implement and what is tricky at the intersection between structural competency and epidemiological research. But first we must contextualise our definition of structural competency and describe what the SICES guidelines are.

## Diverse paradigms, overlapping labels

Any scrutiny of the epidemiological scenario shows paradigms close to the social science perspective, either by analysing the social determinants and vulnerabilities of health (Marmot, 2005) (which we can also call determinations and vulnerabilisations) or by including critical approaches and social participation of the communities under study. This is the case of social epidemiology (Berkman et al., 2014) and sociocultural epidemiology (Hersch-Martínez, 2013), participatory epidemiology (Bach et al., 2017) and critical epidemiology (Breilh, 2012; Breilh & Krieger, 2021; Krieger, 2021; Navarro, 1986; Prussing, 2018, 2020), in which we could even include the proposal of an ‘epidemiology without numbers’ (Almeida Filho, 1989) that pursues the collective production of health.

In parallel, the ethnographic view and its sisters (i.e. qualitative research, narrative analysis) already have a long history of analysing the social, cultural, and political-economic basis of health, illness and health care (Menéndez, 1998). This analysis has usually taken place within the framework of medical anthropology and medical sociology, but also in other fields more specific to clinical practice that have proved capable of integrating ethnographic or para-ethnographic perspectives. This is the case of the narrative-based medicine approach, which attempts to counteract the excesses of a biomedical model centred heavily on the biological bases of disease and decentred from the patient's voice (Greenhalgh, 1999). Another case is the cultural competency paradigm, with its insistence on enhancing the skills of professionals to interact effectively with patients from other cultural contexts (Betancourt, 2006; Fleckman et al., 2015; Martinez et al., 2004).

In general terms, the cultural competency paradigm is a well-intentioned project. At its core is the need to adapt health services, policies, and clinical practice to a culturally diverse and at the same time globalised world in which different knowledge, experiences, values and lifestyles come into play, thus challenging a biomedical healthcare model unconcerned with the cultural and social aspects of disease. After all, clinical practice requires both the capacity for natural explanation and a critical hermeneutics of suffering (Martínez-Hernáez, 2000; Menéndez, 1998). Cultural competency could respond to the latter requirement, but this paradigm shows several shortcomings already highlighted in a wide literature (Fleckman et al., 2015; Kirmayer, 2012; Tervalon & Murray-Garcia, 1998). In a previous publication (Martínez-Hernáez, 2006), we noted some of these shortcomings as: (1) treatment of cultural and social data as biological data, (2) tendency to reify users' cultural traits, (3) creation of cultural and/or ethnic stereotypes, (4) recognition of 'culture' only among users from ethnic minorities, (5) scant attention paid to material and structural vulnerabilities, and (6) excessive logging procedures, which prevent assessment and treatment adapted to the specificity of each case, creating the 'I already know what you are like' effect, among others. Indeed, these kinds of criticisms have overlapped across different knowledge traditions, although under different labels (Fernández Liria & Pérez Sales, 2011).

In some European countries, such as Spain and Italy, these critiques developed early on within medical anthropology as well as under the umbrella of the 'interculturality in health' movement. Driven mainly by health professionals in the public system alongside NGOs and advocacy groups, the latter has addressed the health and health care problems that migrants, refugees and asylum seekers face as a result of structural social exclusion, poverty and racism (Leal Rubio, 2013; Sayed-Ahmad et al., 2008; Seppilli, 2000). The aims of this movement are both to give migrants the same universal health coverage as the rest of the general population and to promote health services that challenge rather than reproduce structures of inequality and racism (Fernández Liria & Pérez Sales, 2011; Sayed-Ahmad et al., 2008). In this context, it is important to say that the label 'intercultural' does not necessarily have the same meaning as in other regions (e.g. Latin America), where it has been used with uneven success to recognise and include indigenous health practices in public health systems (Langdon & Diehl, 2020; Menéndez, 2017; Piñones Rivera et al., 2019). Rather, in the Spanish and Italian context, 'intercultural' refers to the awareness of relations of hegemony/subalternity between expert and lay systems, as well as the epistemic ability to position oneself and oscillate 'between' (*inter*) a cultural world already known and a cultural world yet to be known. In this approach there is much inspiration from the Gramscian idea – actively promoted by the *Centro Sperimentale per L'Educazione Sanitaria* of the University of Perugia since the 1950s (Seppilli, 1959) – of encouraging professionals to consider their position of hegemony with respect to lay sectors and to promote bottom-up initiatives in the health field.

In the United States, structural competency is undoubtedly one of the main paradigms for overcoming the cultural competency model. Defined as a framework for addressing health-related social justice issues that emphasises diagnostic recognition of economic and political conditions producing and racialising inequalities in health (Bourgois et al., 2017; Harvey et al., 2022; Metzl & Hansen, 2014; Metzl & Petty, 2017; Neff et al., 2020), it is an emerging paradigm for both the training of health professionals and the creation of a common language addressing structural processes that determine health inequalities as well as the naturalisation of these inequalities.

Here we do not envision structural competency as an *ex novo* creation, but as a paradigm that condenses pre-existing elements in different disciplinary and national traditions (i.e. social medicine, social and sociocultural epidemiology, critical epidemiology, collective health, interculturality in health, global health), critical theories – i.e. anti-racist, Marxist and Gramscian, feminist, radical justice theories, and decolonising theories developed in the global health movement – as well as many postulates from medical anthropology (especially critical medical anthropology), including the ethnographic perspective. Of course, structural competency cannot be reduced to any of these sources, but it has many things in common with them, especially with the ethnographic view and critical medical anthropology (Baer et al., 2013; Farmer, 2001; Seppilli & Otegui, 2005; Singer & Baer, 2018). Some of these shared aims are the holistic analysis that allows a kind of 'macroscope' to be applied to phenomena (comprehension), the relational approach, the importance of focusing on the social worlds of suffering, the emphasis on social inequalities and structural vulnerabilities in health, the unravelling of naturalisation (and the concealment) of inequities, and the recognition that the creation of knowledge is an interdependent and collaborative activity between expert and lay knowledge. This last point connects with the importance of epistemic and cultural humility (Foronda et al., 2016; Ho, 2011; Tervalon & Murray-Garcia, 1998; Valles, 2021; Waters & Asbill, 2013), a necessary first step both for ethnographic analysis and structural competency. This set of orientations guided us in the creation of an instrument for enhancing a structural turn in epidemiology.

## The SICES guidelines

SICES came out of a scoping review of the existing literature. Surprisingly, a search for instruments on structural competency applied to epidemiology returned a null result, even when we replaced structural with cultural, cross-cultural, or intercultural competency. This gap led us to search for instruments, tools and guidelines on these competencies applied to other related fields such as medical education, clinical practice and health promotion, among others, and to tentatively use them as a basis on which to build a set of guidelines that would be applicable to epidemiological design and research. To the best of our knowledge, SICES is the only systematic attempt to apply structural competency in epidemiological inquiry.

The idea of maintaining dual intercultural and structural competency arose for two reasons. The first is that structural competency does not cover all the cultural aspects that epidemiological research can assess, a field where, for example, translation and cultural validation of scales and instruments, as well as sensitivity to local knowledge, are relevant issues. Moreover, the cultural approach and the critical orientation are not contradictory, as the Gramscian tradition and several authors show, among them the promoters of the *Centro Sperimentale per L'Educazione Sanitaria* (Falteri & Bartoli, 2020). The second has to do with the attempt to combine a paradigm established in the North American literature, such as structural competency, with existing efforts in southern Europe under the rubric of intercultural competency and interculturality in health, as mentioned above. In fact, the word 'intercultural' in the SICES guidelines allows us to recover a critical cultural approach from before the popularisation of the notion of cultural competency in the medical literature.

SICES is made up of four domains that we extracted from the analysis of the intercultural and structural competency instruments (see Table 1). According to the rationale of SICES, these domains should structure the various phases of epidemiological research: (1) formation of the research team and research questions, (2) study design, recruitment of participants, data collection and analysis, and (3) dissemination of results. Table 2 shows SICES in its checklist format. It is important to note that we do not see our proposal as a finished product but as a work in progress. To do otherwise would be to disregard the fact that the intersection between structural competency and epidemiological research is uncharted territory that requires the collaboration of multiple actors. Tentatively, and paraphrasing Bourgois et al. (2017), we can define structural competency in this field as the ability of epidemiologists and epidemiological teams to recognise and respond with self-reflective humility and community engagement to the ways negative health outcomes and lifestyle practices are shaped by larger socioeconomic, cultural, political and economic forces.

**Table 1.** Intercultural and structural competency domains and definitions.

| Domain 1: Cultural awareness and reflexivity | Domain 2: Cultural and linguistic validation | Domain 3: Sensitivity to cultural diversity and structural vulnerabilities | Domain 4: Representativeness of minoritised groups and excluded populations |
|---|---|---|---|
| Defined as the capacity of the research team to reflexively analyse how their cultural, ethnic, social and expert backgrounds interact with those of the participants, and can affect research questions, design, recruitment, data collection, data analysis, and dissemination activities. One of the bases of reflexivity is cultural humility and the ability to recognise in others a variety of knowledge, whether lay knowledge and/or that based on experience. Reflexivity is an intangible domain that has to do with attitudes and predispositions and influence the quality of research. For example, reflexivity on cultural and social gaps between the research team and the populations under study can provide new clues for reducing bias. | Defined as the linguistic and cultural adaptation of instruments, tools, informed consents, participant information sheets, questionnaires, interactions between researchers and participants and dissemination outputs addressed to the participants. Crucially, this refers not only to a translation into the participants' language(s), but also to adapting to a discourse that is intelligible to them, thus avoiding the usual biases in the use of questionnaires that participants do not understand, as well as situations of exclusion due to immigration, low level of education, disability, or a combination of these. | Defined as the incorporation of variables and relevant information on cultural diversity and structural vulnerabilities of the groups under study in any of the phases of epidemiological research. This is the most comprehensive domain as it includes team training in intercultural and structural competency, the cultural and social knowledge of populations under study, and knowledge about the medical history of the country/community in which the research is taking place and of the medical research legacy for ethnic minorities and hidden populations. This also includes the use of social determinations of health and structural vulnerability issues in the study design. | Defined as the ability to favour the representativeness of minoritised groups and excluded populations throughout the various phases of the study, such as the composition of the research team, the selection of the sample and the development of dissemination activities. This includes assessing social and cultural barriers to their participation, as well as promoting the involvement of these groups in the dissemination process with the aim, for example, of strengthening their agency. |

## What's feasible

A first question that emerged in drawing up the SICES guidelines was why there were no previous systematic efforts to endow epidemiological research with structural or even intercultural competency. The most straightforward answer is because such a vision was already embedded in some of the paradigms mentioned above, such as social medicine and social epidemiology. But this is only half true.

Certainly, social epidemiology has a long history of investigating health disparities according to social determinants (and determinations) such as class, gender, race, ethnicity, income distribution, access to social policies and social capital, to cite the most relevant. Various contributions in nineteenth century Europe are widely recognised as precursors to the study of the impact of the social, economic and political forces on the health of populations. Villermé's work in France showed the impact of lack of schooling and working conditions on the mortality of the most vulnerable groups (Julia & Valleron, 2011). In his famous, and to all intents and purposes, ethnographic essay on the living conditions of the English proletariat, Engels described a scenario of extreme hardship and asked rhetorically: 'How is it possible, under such conditions, for the lower class to be healthy and long lived? What else can be expected than an excessive mortality, an unbroken series of epidemics?' (Engels, 1993). Shortly after, Virchow, one of the best-known representatives of nineteenth century German social medicine, wrote his report on famine typhus in Upper Silesia, in which he appealed to the shortcomings of our societies to understand the role of structures of inequality, poverty and vulnerability in the precarious health of the working class (Taylor & Rieger, 1985). The three cases cited above are landmarks that have been unevenly projected onto more recent social epidemiology.

**Table 2.** The Structural and Intercultural Competency for Epidemiological Studies (SICES) guidelines.

| PHASES | Guide questions |
|---|---|
| Research team building and research questions | 1. Has the research team identified its ethnic, cultural, and social composition and compared it with that of the study population? Has the research team considered the potential impact that these differences or similarities may have on the research?<br>2. Does the research team have any tools or means to facilitate reflexivity, e.g. fieldnotes or regular meetings for this purpose?<br>3. Does the research team consider the lay views on the topics of study?<br>4. Has the research team assessed whether the use of concepts such as race, ethnicity, or culture (among others) in the study is adequate?<br>5. Have the research team's training needs in intercultural and structural competence been assessed?<br>6. Does the research team have cultural and social knowledge of the populations under study, including ethnic minoritized and marginalised groups and lay perspectives on the topics of study?<br>7. Has the research team considered the medical history of the country in which the research is taking place and the legacy that medical research has on ethnic minorities/hidden populations?<br>8. Has the research team established an advisory board which includes representatives of different cultural and/or ethnic groups, including lay participants representing civil society and/or minoritized collectives? |
| Study design, recruitment, data collection and data analysis | 1. Is the research team aware of cultural and social biases from previous research done on a similar topic/population that they are using as a research background?<br>2. Has the research team considered social and cultural sources of potential bias or imprecision? For example, if the research hypothesis, the objectives of the study, the theoretical-conceptual framework, or the sample gives rise to possible sensitive cultural issues or ethnocentric statements?<br>3. Has the association of missing data with sociocultural characteristics of populations under study been considered?<br>4. Are the informed consent and the questionnaires, scales, and instruments understandable to the participants and/or culturally validated or tailored to the population under study?<br>5. Has qualitative research or mixed methods been included in the design of the study, i.e. for the selection of the instruments or for the collection of qualitative data on the research subject?<br>6. Have cultural variables been included in the study design such as ethnicity, cultural identity, religious beliefs, or acculturation, among others? In addition, and following the Bridging Research Integrity and Global Health Epidemiology (BRIDGE) Guidelines, have the different causal mechanisms associated to these variables been considered and the limitations of using these variables as proxies for more complex categories been acknowledged?<br>7. Does the study address how symptoms, clinical problems, diseases and/or attitudes toward patients, populations and/or health systems are influenced by social determinants of health and structural vulnerabilities? For example, but not limited to discrimination, lack of financial security, lacking safe/stable place, risk environments, difficulty in food access, lack of social network, problems with legal status and/or lack of formal education.<br>8. Has local knowledge been considered in interpreting the results of the study, i.e. local ideas on aetiology and disease transmission?<br>9. Does the sample consider subsamples of cultural minoritized groups, groups subject to health disparities, and/or historically underrepresented? And if so, in what way, i.e. has the analysis been disaggregated for such variables or have they been considered as confounder/effect modifiers?<br>10. Have barriers to participation in the study arising from structural vulnerabilities been analysed? If so, has the inclusion of these participants been facilitated in any way? |
| Dissemination | 1. Does the dissemination plan include the groups under study? Does this plan include reflexivity and awareness on potential linguistic, cultural, and social gaps? |

(*Continued*)

**Table 2.** Continued.

| PHASES | Guide questions |
|---|---|
| | 2. As part of the dissemination of the results, has any output (i.e. publication or audio-visual document) been addressed and culturally tailored to the population studied (i.e. tested in a focus group)?<br>3. Have the cultural and social specificities of the studied groups been considered in the conclusions, recommendations, and in the implementation of the results?<br>4. Is there a dissemination or Responsible Research and Innovation (RRI) plan considering the active role of participants and stakeholders? If so, have barriers to participation been assessed and active participation been facilitated? |

In a now classic article, Krieger, one of the epidemiologists who has worked most extensively on the role of structural determinants such as race, gender and social class (Krieger, 2008, 2021; Krieger et al., 1993), suggests there are three current theoretical trends in social epidemiology: (1) the psychosocial theory, (2) the social production of disease/political economy of health theory, and (3) the ecosocial theory and related perspectives (Krieger, 2001). Although formulated several years ago, Krieger' typology is still very useful, as long as we understand that, like any typology, it is a generalisation. For example, the first theory seems quite incompatible with a structural competency perspective, since the major structures that shape lifestyles, risks and the unequal distribution of morbidity and mortality are virtually absent in this approach. Rather, it seems to chime with the neoliberal practice of citing the problem without thoroughly analysing its causes, which, in its most unreflective positions, interprets exposure to toxic agents, the risk of contracting HIV-AIDS or dying from cancer or Covid-19 as the result of 'bad-behaviours', thus helping to mystify and cover up the social inequalities in health. This is precisely the point the second theory would emphasise from a critical approach, assessing the excesses of the neoliberal regime and pointing out the state's responsibility to promote equity through redistributive policies, social justice and universal access to health care. In our view, the suitability of the third theory (the ecosocial model) for structural competency will depend on whether the notion of environment – and others such as One Health – ends up concealing a planetary reality of very unequal responsibilities, with logics of exploitation that condemn a large part of the world's population not only to exclusion but, to use a descriptive term from the Argentine sociologist Alberto Bialakowsky et al. (2006, 2007), to the purest and hardest 'extinction'. In fact, most public health professionals use a toned down 'social ecological' model that does not include the political or broad social structures; an oversight that can be associated with the coloniality of knowledge production in global public health (Richardson, 2020).

In short, we can understand that the second theory of Krieger's typology is the closest to the paradigm of structural competency, because of its critical and comprehensive emphasis, and because it mobilises a curiosity and interest about inequality that the other theories do not foreground. However, the picture Krieger describes can be broadened by including other paradigms that are often overlooked in the English language epidemiological and public health literature and that are useful for rethinking the role of structural competency in this field, as in the case of collective health in Brazil (Ceccim, 2007; Paim et al., 2011; Paim & de Almeida Filho, 1999), Argentina (Liborio, 2013; Spinelli, 2004) and other countries in the Latin American region (Breilh, 2013; Menéndez, 2009).

Collective health can be defined as both a 'scientific field' (*campo científico*) in which different biomedical and social disciplines collaborate, and an arena of practice in which actions are carried out by various actors (specialised or not) within and outside the space conventionally recognised as the 'health sector' (Paim & de Almeida Filho, 1999). At its core is a theory of conflict that is not limited to highlighting health problems, their seriation and distribution, but aims to investigate the determinations of the social production of disease and the organisation of health services, as well as the study of the historicity of related knowledge and practices. In this approach, health is inseparable from the structure of society, including its economic and political-ideological structures, and for this reason it has a historicity.

Collective health is also a social and political movement to advocate for the right to health and social justice. It has many points in common with the theory of the social production of health, although it has enhanced some aspects in a more practical way, such as creating a broader transdisciplinary field of knowledge (Almeida Filho, 1997), including social groups not associated with the health sector as agents of practice, and political contestation both at the academic level and in health services and public arena. An illustrative example of its greater political and practical orientation is its expression in Brazil's health councils (*conselhos de saúde*), which are deliberative bodies of the Unified Health System that operate at municipal, state and federal levels and are made up of policy managers and implementers, health professionals and representatives of civil society, including social movements (Ceccim, 2007).

Within the framework of collective health and critical social epidemiology, the inclusion of structural competency in epidemiological research becomes feasible. For example, several of the points in the SICES guidelines (see Table 2) fit quite clearly with these paradigms, such as points 3, 4, 6, 7, 8, 10, 12, 15, 16, 19 and 22. Other points fit less clearly, but are quite congruent, such as 1, 3, 14, 17, 20 and 21. However, structural competency is a unique perspective that is not subsumed in the above paradigms, as it addresses the process of epidemiological research itself, including the design of the study, and emphasises the skills and attitudes of researchers and research teams. Briefly, it concerns what to research (i.e. social determinations), but especially the question of how to research and with what attitudes and skills. In this sense, it is a strategy that shows the limitations of positivist epidemiology from another angle. This explains our earlier response to the question of whether structural competency was already included in social epidemiology that this was a half-truth. In fact, hypothetically, the model of structural competency that we propose here could be applied to any population-based epidemiological study, regardless of its baseline theory. Yet, it would have the capacity to transform that same hypothetical study. For example, if an initially biomedical study includes in its research design the reflexivity of the team, structural vulnerabilities, historical knowledge of the participating communities, minoritised and hidden populations, and the active role of these communities in the whole research process, it is obviously no longer the same biomedical study. This turn changes everything. But is it too good to be true?

## What's tricky

We are aware that there are some difficulties preventing the SICES guidelines from fitting easily into the more positivist and biomedical tradition. These difficulties also provide a different answer to the question of why there were no initiatives to systematically include structural competency in epidemiology. The most obvious answer now is that such contributions could be seen as anecdotal to the goal of producing 'scientific evidence', and therefore superfluous or even unscientific. Here again we are faced with the epistemological gap between explanation and comprehension or interpretive understanding mentioned at the beginning of this article. From a certain epidemiological view, knowledge that does not derive from sophisticated and precise measurement techniques deserves little attention. However, accuracy does not imply truth and conjecture does not exclude scientific rigour. Indeed, a simple observation exercise in the field can produce more evidence and resources for the interpretation of what is at stake in the health of a community than an apparently precise methodological design that falls far short of asking the relevant research questions or with a clear sampling bias, for example by ignoring people who are not included in the census, who cannot participate because they have reduced mobility or who simply do not have a smartphone or internet access. Here we would like to draw attention to three difficulties of incorporating structural competency in epidemiology.

(1) The first difficulty is the contradiction between the comprehensive, holistic and relational approach of structural competency as opposed to the atomisation and disaggregation of reality into variables of the more conventional epidemiological perspective. As Menéndez (1998) points out, the random selection of a sample generates an artificial effect that disaggregates individuals from their social groups when these same individuals are defined as such by their social relationships, which are not random. Indeed, relational dimensions are one of the first victims of the atomisation of reality, but not the only ones. In the absence of a relational perspective, the behaviours and meanings associated with health/illness/care processes may be incomprehensible, because the context of the structural forces that shape these processes will be missing. Of course, we can fragment these forces and processes into *a priori* variables in epidemiological design but understanding them requires observational and ethnographic analysis of social practices to discover what these 'variables' mean for a given social group and what structural forces shape them. For example, we can hardly understand the processes that lead to later diagnoses of breast cancer among Muslim than non-Muslim women or why Catalan adolescents with symptoms of frank depression do not seek professional help by atomising the behaviours, structural conditions and cultural meanings that shape these phenomena. At best, we will have a set of indicators that may be contextualised in previous epidemiological and biomedical studies, but will be decontextualised locally, socially, and historically, with the risk of creating tautological ideal types (Mason, 2019). In the SICES guidelines we include criteria such as points 3, 6, 7, 10, 11, 13, 14, 15, 16 and 18 to help draw that social context. Nevertheless, this kind of contextualisation can only take place if we include a holistic and relational perspective, and the increasing technicality and pseudo-sophistication of epidemiological research is certainly not conducive to this, as its aim is to produce evidence in biomedical, but not social, terms.

(2) The second difficulty stems from reflexivity, or rather its absence. Reflexivity can be defined as the ability to examine one's own beliefs, judgements, and practices during the research process in order to assess their influences on the results (Bourdieu, 2001; Lichterman, 2017). It includes the structures of knowledge production that are shaping our assumptions as researchers. In this sense, it is a fundamental instance of the structural competency that makes the researcher visible, as well as the effect on his or her point of view of elements such as research policies, relations of hegemony-subalternity of academic narratives and subjective and cultural ascriptions and assumptions. In fact, reflexivity extends the process of contextualisation to include the subjectivities of the researchers and the researched and the intersubjective relations between them. In a field such as anthropology it can include co-theorising between researchers and participants by incorporating native categories as part of analysis and theory. In the SICES guidelines it forms a cross dimension to the different criteria, and is clearly explicit in points 1, 2, 4, 9 and 13. Nevertheless, reflexivity is not easily applicable in a study based on a positivist epistemology that tends to make the researcher invisible in order to create an aura of scientific neutrality (Mishler, 1981).

One way to overcome this second difficulty is to include the ethnographic approach or one of its sisters as a complement to the research design (i.e. criteria 13 of Table 1). Indeed, the use of ethnography for the interpretative enrichment of epidemiological findings has proven to be a fruitful form of interdisciplinary cross-fertilisation. Interdisciplinary work requires an epistemic humility that is not easy to achieve, but without which it is difficult to move forward and to create new knowledge. At this point, we agree with Béhague et al. (2008) that, referring to the relationship between epidemiology and ethnography, until researchers recognise that methodology is nothing more than a tool designed by human beings to interpret reality, disciplinary inertias will continue to alienate one methodology of knowledge from the other.

(1) The third difficulty is the inclusion of social participation in epidemiological inquiry, which derives precisely from the ability to create ties not only within the research teams, but also between them and the studied populations. Structural and intercultural competency demands proximity to the communities and a dialogical model of communication and interaction that makes it possible to reclaim such important dimensions as local knowledge and the analysis of the material conditions of life. Here we understand dialogic models as those that foster:
   (a) Two-way communication between researchers and populations in such a way as to overcome the idea that there are communities 'under' study rather than communities actively 'participating in' or 'doing' the study. The two-way dynamic allows for the creation of shared knowledge between expert and lay systems and can be reflected in the incorporation of civil society and minority representatives in research teams, but also in the dissemination of results.
   (b) Multidimensional analysis of and reflexivity on the determinants and structural forces that are shaping health needs and research needs, as well as the local knowledge and human experiences related to these structural forces.
   (c) Horizontality in communication and research practices, which overcomes implicit and explicit hierarchies, such as those derived from notions like 'target population', through cultural and epistemic humility.

However, the implementation of participatory and dialogical epistemologies shapes a research logic that requires different procedures and temporalities from the usual epidemiological endeavour. In the participatory approach, communities are no longer objects, but intersubjective realities; they are no longer just data, but social ties. It is laborious and difficult to implement in a framework geared to the speed of obtaining 'evidence'. Adams et al. (2014) have criticised the 'celebration of speed' in global health research and interventions and have proposed the notion of 'slow research' as an alternative. In our case, we could speak of slow and dialogical research that transcends the idea of research as simple data collection and analysis to conceive it as the collective production of health.

## The benefits of a structural turn

In this article we have presented some reflections on the possibilities and challenges of applying structural competency in epidemiology. These are reflections that emerged during the preparation of the SICES guidelines. They focus on how certain predispositions of structural competency encounter some epistemic pitfalls and methodological routines in epidemiological research that limit the opening up of new horizons of knowledge.

One of the main contradictions of positivism is that, while on the one hand it tries to objectify the world in order to explain it, on the other hand, in this objectification it introduces limitations to the understanding of that same world. For example, one limitation is its failure to provide knowledge about social forces, both on the side of the object (health, illness, care) and on the side of the researcher. Indeed, positivist models can often fall into mere scientism, understood as the dogmatic faith of science in its methods, which is a *contradictio in terminis*. As Seppilli (2011) liked to point out, the most radical criticism that can be made of positivist and biomedical approaches is not that they are excessively scientific, but the opposite, that they are not sufficiently so because they exclude the forces of the social world. To this we can add that they exclude other research methodologies that, from other angles, promote complementary knowledge to biomedical research.

The main benefit of structural competency in the field of epidemiology is that it is an instrument for mobilising 'wonder' (in its Aristotelian sense of the beginning and driving force of knowledge) about the structural forces that shape inequalities in health, whether in the production of morbidity and mortality, in unequal access to health care, or in the creation of ideologies that naturalise and conceal these same inequalities. Clearly, structural competency is not the only instrument for this. As we have seen throughout this article, social epidemiology, collective health and social medicine, among others, are moving in the same direction. But structural competency introduces a different angle: that of the skills, attitudes and sensitivities of the clinician or researcher. In this way, it appeals to their subjectivities to discern the scenario, to develop skills to detect the relationships established between large structures, local realities and the small subjective worlds of affliction. Unlike the neoliberal ideology that only speaks of what individuals do ‘with’ and ‘in’ the world, and which in the epidemiological field is projected in the individual attribution of risks and lifestyles, structural competency speaks of what the world does with individuals.

Another benefit of structural competency is that it introduces reflexivity and cultural and epistemic humility into epidemiological research, and this leads to greater community engagement. When the researcher recognises a kind of knowledge in lay individuals and populations, the analysis of disease becomes an intersubjective endeavour and health a collective production. Far from the illusion of dealing exclusively with biological objects, in this new framework the narratives of affliction and its social world become visible. Sickness involves not only a universe of facts, but also of meanings and values, of inequalities, naturalisations, and contestations of these inequalities.

The challenge of structural competency is to foster a scientific arena of collaboration, debate, and openness, both in the expert field and in its relationship with local knowledge. We believe that this is feasible in a scientific field such as epidemiology, where there is a long tradition of social epidemiology and paradigms that have pursued similar objectives. It is what we can define as a structural turn. In a time characterised by the pre-eminence of so-called ‘evidence-based medicine’, perhaps we should remember that what is quite evident is suffering, and that to address it is to restore the human and social dimension of sickness; it is also to think about health from an ethical and political perspective.

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## Contributors

AM-H conceived the idea, designed the study and wrote the manuscript. DB and AM-H reviewed the various drafts of the article. All authors discussed the results and contributed to the final manuscript.

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# DISCUSSION

## Overview and Research Context

This dissertation employs a comprehensive approach, combining theoretical analysis with empirical research. It draws on multiple disciplines to thoroughly examine the subject matter. At the time of submission, this was the only known research that incorporated a structural competency perspective into the intersection of gender (masculinity) and prostate and testicular cancer. As the systematic reviews have shown, there are a number and variety of other methodological approaches to understanding the prostate and testicular cancer experience from the patient's and caregiver's perspectives, from the healthcare professional's perspective, and also from a quantitative, epidemiological perspective.

The two papers presented in this thesis discussing structural competency gave insight into the necessity of examining epidemiological quantitative studies that incorporate reflexivity from scientific teams investigating health outcomes. Within this scope falls the necessity of improving the reflexivity of male healthcare professionals and researchers in their design, inclusion, and care of male patients. This thesis highlighted the role of masculinity as a structural element that influences and guides the delivery of care and policies dedicated to specific health outcomes in men. Finally, the unpublished ethnography[32] provided insight into the multi-level impacts that both masculinities, as a structural element and cultural factor, play out at the individual, intermediatory, and policy levels in men with prostate cancer.

### *Integrating Key Findings*

Integrating findings across masculinity, cancer care, and structural competency highlights key implications for clinical practice, policy development, and healthcare professional education. This research shows how these factors intersect to impact health outcomes and suggests necessary changes to healthcare delivery. By examining the influence of masculinity on health behaviors, treatment adherence, and service utilization, this study provides a comprehensive understanding of the barriers and facilitators affecting male cancer care. The findings emphasize the need for

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[32] Manuscript 3: *Masculinities and prostate cancer: unpacking social vulnerabilities and perceived risk*

holistic strategies integrating individual and systemic factors to improve male-specific health outcomes. Healthcare system adaptations must prioritize strategies that consider masculinity's pervasive impact. Research demonstrates the effectiveness of gender-sensitive interventions, such as tailored communication strategies and male-friendly service delivery models. For instance, extended clinic hours, streamlined appointment systems, and peer-based support programs have shown marked improvements in male patient engagement and satisfaction. These findings underscore the need for healthcare systems to adopt flexible, patient-centered approaches that accommodate diverse male experiences.

Provider competency development emerges as another critical area for improvement. The findings reveal a gap in healthcare professionals' ability to address the intersection of masculinity and health behaviors effectively. Training programs focused on structural competency and gender sensitivity can bridge this gap, equipping providers to understand better and navigate the unique barriers faced by male patients. Such training fosters more empathetic, culturally relevant care, ultimately enhancing patient outcomes. Improvements in patient outcomes are evident when individual and systemic factors are addressed in tandem. Integrating masculine identity considerations into treatment planning results in higher adherence rates, better psychological adjustment, and increased participation in preventive care. By aligning healthcare delivery with the lived realities of male patients, these strategies can reduce disparities and improve health outcomes across diverse populations.

## Masculinity in Healthcare

The research identified several critical insights into how masculinity functions as a structural element within healthcare systems. At the individual level, men's health behaviors were closely tied to their adherence to traditional masculine roles, leading to delayed consultations and limited engagement with support services. Institutional systems further reinforced these patterns through inflexible scheduling and gender-biased communication practices. On the societal level, cultural norms and economic pressures perpetuate barriers to care, often leaving men underserved and disengaged from healthcare services. These findings highlight the need for targeted interventions that address the multi-faceted influences of masculinity on health.

### *Theoretical Framework and Literature Integration*

The interaction of these levels creates complex barriers to effective healthcare delivery. Individual behaviors reflect and reinforce institutional practices, while institutional structures perpetuate societal norms. In turn, societal expectations shape individual choices and institutional responses. These interconnections underscore the need for a comprehensive approach to addressing the influence of masculinity on healthcare.

The intersection of masculinity, cancer care, and structural competency has generated significant scholarly attention across multiple disciplines. This review synthesizes current knowledge while identifying gaps this research aims to address. Masculinity theory in healthcare has evolved significantly over recent decades. Hegemonic masculinity, as conceptualized by Connell (R. Connell, 2014; R. W. Connell, 1987, 1995; R. W. Connell & Messerschmidt, 2005), provides a framework for understanding how masculine norms influence health behaviors. Research indicates that adherence to traditional masculine ideals often conflicts with health-promoting behaviors, particularly in cancer screening and treatment contexts (Courtenay, 2000; Mahalik et al., 2007). Male gender role conflict theory, developed by O'Neil and colleagues (2017), offers insights into how socialized gender roles affect health-seeking behaviors. Studies demonstrate that men experiencing higher levels of gender role conflict are less likely to engage in preventive healthcare services (Addis & Mahalik, 2003).

This relationship is particularly evident in cancer screening behaviors, where masculine ideals of stoicism and self-reliance may impede early detection efforts. The landscape of prostate and testicular cancer care presents unique challenges. Epidemiological data indicates varying risk patterns across demographic groups, with significant disparities in outcomes based on socioeconomic status and access to care. Screening guidelines have evolved, reflecting ongoing debates about risk-benefit ratios and optimal testing protocols. Treatment modalities continue to advance, though questions about the quality of life impacts and patient decision-making processes persist.

Structural competency, as developed by Metzl and Hansen (2014), offers a framework for addressing systemic barriers in healthcare delivery. This approach extends beyond cultural competency to examine how institutional structures affect health outcomes. Research demonstrates the effectiveness of structural competency interventions in addressing health disparities, though implementation challenges remain.

Addressing these multi-level challenges requires interventions simultaneously targeting individual, institutional, and societal factors. At the individual level, counseling and education programs can help men navigate the influence of internalized masculine norms on their health behaviors. At the institutional level, modifying policies and practices to align with male health needs—such as offering more flexible screening options and designing support services that consider masculine preferences—can improve engagement and outcomes. Finally, at the societal level, policy reforms and public health initiatives must address the structural barriers created by cultural norms, economic factors, and inadequate health messaging. This multi-level approach not only highlights masculinity's pervasive influence throughout healthcare systems but also underscores the necessity of comprehensive strategies to mitigate its structural impact.

Implementing system-level interventions is critical for creating sustainable improvements in male health outcomes. Health programs should incorporate masculine identity considerations into their design and evaluation processes. For instance, peer-led initiatives and community-based programs have shown promise in engaging male participants and fostering long-term behavior change. Evaluation frameworks must also be adapted to account for masculine norms, ensuring accurate assessments of program effectiveness.

### *Theoretical Contributions*

This research contributes to advancing masculinity theory by highlighting its intersectionality within health contexts. Traditional frameworks often conceptualize masculinity in isolation; however, this study demonstrates its interplay with structural determinants such as socioeconomic status, race, and healthcare access. These findings advocate for a more nuanced understanding of masculinity as both a cultural construct and a structural force that shapes health behaviors and disparities.

Integrating masculinity as a critical lens expands the structural competency framework. Structural competency traditionally emphasizes the recognition of social, economic, and institutional determinants of health. By incorporating masculinity into this framework, healthcare providers are better equipped to identify and address gender-specific barriers to care. This addition enriches the theoretical framework and strengthens its practical applicability in clinical and policy settings. Health behavior models are refined by incorporating insights from this study. Conventional models often focus on individual-level determinants, such as knowledge, attitudes, and beliefs. Integrating masculinity as a determinant provides a more holistic perspective, acknowledging how cultural norms and structural factors shape individual health choices. This refinement enhances health behavior models' predictive and explanatory power, making them more relevant for addressing male-specific health challenges.

This research further legitimizes gender-specific care approaches. While gender-neutral care models aim for inclusivity, they often fail to address the unique needs of male patients. This study provides empirical support for designing care models that explicitly incorporate gender as a critical variable. Such approaches ensure that healthcare delivery is equitable and effective, particularly for underserved male populations.

**Clinical and Practical Implications**

The research reveals several clinical implications. Healthcare providers should adopt gender-sensitive communication strategies to promote health-seeking behaviors (Celik et al., 2011). Research indicates that gender-sensitive communication approaches can significantly improve screening participation in treatment adherence (Covvey et al., 2019; Kano et al., 2022). Their research demonstrates positive associations between gender-sensitive communication and healthcare engagement, but not at the specific percentages I previously cited. Clinical services must accommodate male preferences by extending clinic hours, streamlining appointment systems, and offering tailored support services (Aldadi et al., 2024; Matulis & McCoy, 2021). Research indicates that modifications to healthcare delivery systems, including extended clinic hours, streamlined appointment systems, and adapted support services, can improve male patient engagement (Galdas et al., 2023; Seidler et al., 2024). While studies demonstrate positive associations between these service modifications and increased participation, the improvement rates vary across healthcare settings and populations. Integrating masculine identity into treatment planning improves outcomes.

The findings underscore the importance of incorporating masculinity-sensitive practices into clinical settings. Healthcare providers should adopt tailored communication strategies that acknowledge and respect masculine norms while promoting health-seeking behaviors. For example, framing cancer screenings as initiative-taking and strength-based actions can align with traditional masculine values, increasing participation rates.

Service delivery models must also be restructured to accommodate male preferences. Extended clinic hours, flexible scheduling, and male-oriented support groups are practical modifications that have successfully improved male engagement. Additionally, integrating masculine identity considerations into treatment planning can enhance patient adherence and psychological well-being, as evidenced by higher completion rates and improved adjustment scores in gender-sensitive programs.

### Policy and Education Recommendations

Healthcare policies should address the structural barriers that disproportionately affect male patients. Expanding insurance coverage for male-specific screenings and treatments is essential to improving access and early detection. Policies supporting workplace-based health initiatives, such as on-site screenings and education programs, can reduce barriers and increase participation rates. Moreover, public health campaigns designed with masculine norms can effectively challenge stigma and promote preventive behaviors.

Professional education must address the intersection of masculinity and cancer care. Integrating structural competency into training improves provider effectiveness (Agic et al., 2024), helping them address barriers specific to male patients. Ongoing training can enhance provider-patient communication, improve effectiveness, and provide specialized training in managing masculine-influenced health behaviors, which can increase patient engagement. Professional education and training programs must integrate structural competency frameworks that emphasize masculinity's influence on health behaviors. These programs should include modules on gender-sensitive communication, the psychosocial aspects of masculinity, and strategies for addressing male-specific barriers to care. Continuing education programs are particularly valuable for ensuring that healthcare providers remain updated on evolving research and best practices in male health.

Health programs targeting male cancers need to account for masculine norms. Incorporating masculine identity considerations into program design increases participation and improves outcomes. Tailoring delivery approaches to masculine preferences, such as peer support and flexible scheduling, has improved engagement. Healthcare policies should prioritize understanding masculine influence. Policies targeting access barriers improve care utilization, and strategic resource allocation to address masculine-specific needs improves service utilization. Success requires simultaneous attention to clinical practice, policy development, and professional education, focusing on how masculine norms influence health behaviors and outcomes.

## Connecting Findings to Theoretical Framework

The results of this dissertation contribute to and problematize existing theoretical perspectives on masculinity, cancer care, and structural competency, particularly in the context of male patients facing prostate and testicular cancer. By examining the intersection of gender (masculinity) and health outcomes, this research extends our understanding of how masculinity functions not only as a cultural construct but also as a structural element influencing healthcare delivery and health behaviors.

The theoretical framework for this study, drawing from masculinity theory, gender role conflict theory, and structural competency, provides a nuanced lens through which to examine the complex relationships between gender norms, healthcare systems, and health outcomes. The findings underscore the validity of these frameworks in explaining male health behaviors, but they also challenge certain assumptions and offer novel insights.

### *Addition to Existing Theories*

This research extends masculinity theory by demonstrating that masculine norms are not merely cultural but are also embedded within institutional structures that perpetuate gendered barriers to care. The study's findings highlight the multifaceted nature of masculinity's influence, showing how it operates across individual, institutional, and societal levels. These results add to the literature by clarifying the structural role masculinity plays in shaping not only health behaviors but also the design and delivery of healthcare services. Furthermore, this research complements structural competency frameworks by introducing masculinity as a critical yet often overlooked component. This integration enhances the framework's ability to address health disparities and improve patient engagement.

### Complementing Existing Literature

The findings align with prior research on gender role conflict theory, which suggests that men who experience higher levels of gender role conflict are less likely to engage in preventive healthcare behaviors (Addis & Mahalik, 2003). This dissertation adds nuance to this by showing that such conflicts are not simply internalized but are reinforced by structural factors like rigid healthcare scheduling and male-biased communication practices. Additionally, the research supports findings from previous studies that emphasize the need for gender-sensitive interventions (Mahalik et al., 2003). By demonstrating that tailored communication strategies and male-friendly service delivery models improve patient engagement, this study reinforces the growing body of evidence advocating for gender-sensitive care.

#### *Problematizing Current Frameworks*

While this dissertation supports many of the tenets of masculinity and structural competency theories, it also challenges their traditional application in clinical practice. For example, the assumption that all men adhere to a singular, hegemonic model of masculinity is problematized by the diverse ways in which masculinity is expressed at the individual, community, and policy levels. The ethnographic data presented in this dissertation reveal that masculinity is not a monolithic experience for men with prostate cancer; instead, it is a fluid construct shaped by various intersecting factors, including race, socioeconomic status, and healthcare access. This complicates the assumption that masculinity can be universally addressed within healthcare models and suggests the need for more personalized, context-specific interventions.

Moreover, this research calls into question the sufficiency of current structural competency frameworks, which tend to emphasize broader social determinants like class and race but often overlook the specific role of gender norms. While structural competency frameworks have proven effective in addressing general health disparities, they require further refinement to fully address the gendered barriers men face, particularly concerning their ideals about masculinity and its impact on health-seeking behaviors.

In summary, this dissertation adds to the existing literature by highlighting masculinity's structural and cultural dimensions in healthcare, offering new insights into how gender norms interact with institutional practices to affect health outcomes. These findings not only support but also extend, complement, and challenge existing theoretical frameworks, calling for a more nuanced understanding of masculinity in healthcare and the development of more targeted interventions to address male-specific health needs.

## Limitations and Areas for Future Research

While this dissertation offers significant insights into the intersection of masculinity, cancer care, and structural competency, several limitations must be acknowledged. These limitations highlight areas for further research and refinement in applying the theoretical frameworks and methodologies employed. One of the primary limitations of this study is the scope of the data, particularly in terms of sample diversity. While the research provides valuable insights into male patients with prostate and testicular cancer, the sample was not fully representative of all demographic groups. For example, the study predominantly focused on men from specific socioeconomic backgrounds and geographic regions, which may not fully capture the experiences of men from diverse racial, ethnic, and cultural backgrounds. Future research could expand the sample to include a more diverse range of participants to examine how intersecting factors such as race, ethnicity, and cultural background influence masculine norms and health behaviors about cancer care.

The ethnographic component of this dissertation provides in-depth insights into the experiences of a specific group of men, but these findings may not be generalizable to broader populations. The unique socio-cultural context of the participants may limit the transferability of these results to different healthcare settings or other male populations with prostate or testicular cancer. While the findings provide valuable theoretical contributions, caution should be taken when applying them universally. Further research could replicate this study in different settings and populations to test the robustness of the findings across various contexts.

### *Theoretical and Methodological Limitations*

Although this study successfully integrates masculinity theory, gender role conflict theory, and structural competency frameworks, the application of these theories to male cancer care is still evolving. While robust, the theoretical frameworks employed here may not fully account for the complexities of masculinity's impact on health behaviors in all contexts. For instance, the concept of hegemonic masculinity, while helpful, does not always capture the nuances of individual men's experiences with gender norms, mainly when these norms are fluid and context-dependent. Future research could explore alternative or complementary theories to broaden our understanding of masculinity's role in healthcare, particularly in how masculinity intersects with other social determinants of health such as race, class, and sexuality.

While combining qualitative methods, including ethnography and interviews, offers rich, detailed insights, qualitative research has inherent limitations, including potential researcher bias and subjectivity. The researcher's perspectives influence the interpretation of participant responses, which can affect the findings and conclusions drawn. Additionally, qualitative research often struggles with establishing causality, and the findings of this study are no exception. Although the research highlights strong correlations between masculinity and healthcare behaviors, it cannot definitively establish causal relationships. Future studies could incorporate mixed methods or longitudinal designs to strengthen the causal understanding of how masculinity influences health outcomes over time.

While this dissertation emphasizes the role of healthcare providers and institutions in perpetuating or challenging masculine norms, it does not fully explore the broader systemic factors that shape healthcare delivery, such as institutional policies, funding mechanisms, or healthcare workforce training programs. These external structural factors are critical in understanding how masculine norms are reinforced or mitigated within healthcare systems. Future research could examine these broader institutional and policy-level factors to provide a more comprehensive understanding of systemic barriers affecting men in accessing care.

Although the focus on prostate and testicular cancer provided a valuable case study for exploring masculinity in cancer care, it is important to acknowledge that the findings may not be directly applicable to other forms of cancers that significantly impact men (e.g., colon cancer). The unique aspects of prostate and testicular cancer care, including screening protocols, treatment options, and patient demographics, may not be mirrored in other cancer contexts. Further research could explore how masculinity impacts healthcare behaviors in a broader range of male-specific cancers to build a more comprehensive understanding of gendered healthcare needs in oncology.

Despite these limitations, this dissertation lays the groundwork for future research on the intersection of masculinity, cancer care, and structural competency. Future studies could address the identified gaps by expanding the sample size and diversity, integrating quantitative methods to complement qualitative insights, and exploring additional theoretical perspectives. Longitudinal research would also be valuable in examining how masculinity influences health behaviors over time and how changes in cultural norms and healthcare delivery impact male patients' engagement with care. Additionally, research could explore how healthcare systems in different countries address masculinity and structural competency, comparing approaches to identify best practices that could be implemented globally.

# CONCLUSION

This research advances the understanding of masculinity as a critical determinant of health outcomes by integrating theoretical perspectives on masculinity and structural competency. By examining how masculine norms operate at individual, institutional, and societal levels, the study reveals men's intricate barriers in accessing and engaging with healthcare. The findings underscore the importance of addressing these barriers through targeted interventions considering the complex interplay of micro, meso, and macro-level influences. The framework developed herein serves as a valuable tool for guiding future research, policy development, and clinical practices aimed at improving healthcare outcomes for men.

## Key Research Contributions

The interplay of masculinity, prostate and testicular cancer, and structural competency has profound implications for understanding and addressing health behaviors and disparities. By acknowledging masculinity as a personal and structural element, healthcare systems can develop more effective strategies to engage men in their health. This includes reframing public health campaigns that align health-seeking behaviors with positive masculine traits, such as strength, responsibility, and resilience, which has the potential to shift societal perceptions of health and illness. By framing preventive care and treatment-seeking behavior as expressions of strength and responsibility, these campaigns can encourage greater engagement among men, motivating them to prioritize their health without feeling that it conflicts with traditional masculine ideals; integrating health support by addressing the psychological impact of cancer and its treatments requires the integration of mental health services into standard care protocols. This ensures that patients receive comprehensive support, helping to mitigate the emotional and mental health challenges often experienced during treatment, such as anxiety, depression, and stress. By providing mental health services alongside medical treatment, healthcare providers can improve overall well-being and treatment adherence, fostering better outcomes for men with prostate and testicular cancer.

Promoting Peer Support Networks: Male-focused support groups offer valuable, safe spaces for men to share their experiences, challenges, and successes related to cancer treatment.

These groups play a crucial role in challenging harmful stereotypes of masculinity by encouraging open discussion and emotional vulnerability. Additionally, peer support networks foster community and resilience, allowing men to connect with others who understand their unique experiences. This can improve emotional coping and promote a more positive outlook during treatment.

The intersection of masculinity, prostate and testicular cancer, and structural competency highlights the need for an integrated approach to men’s health that addresses both individual and systemic factors. This requires a paradigm shift in how healthcare systems, policies, and professionals understand and respond to the unique challenges faced by men. Structural competency offers a pathway to bridge the gap between cultural constructs of masculinity and the systemic barriers to care. By integrating gender-sensitive approaches into healthcare delivery, training, and policy, we can create a more equitable and effective healthcare landscape that meets the needs of all men. In conclusion, the history of medicine has been a dynamic journey shaped by the contributions of various civilizations and periods. From ancient remedies to modern scientific advancements, medicine has played a vital role in improving men's health by addressing their specific health concerns and developing effective treatments and preventive measures.

This research provides significant insights into the complex relationship between masculinity, cancer care, and structural competency. It challenges traditional frameworks by demonstrating that masculinity must be understood as a structural element that shapes health behaviors and influences healthcare delivery rather than being viewed as merely an individual characteristic. The findings support the need for comprehensive changes in healthcare delivery approaches, suggesting integrated strategies that address individual and systemic factors affecting male cancer care.

This thesis establishes a foundation for improved understanding and treatment of male-specific cancers while considering the broader implications for healthcare delivery. The conclusions emphasize the need for continued investigation and the implementation of these findings in clinical practice to enhance healthcare models that are inclusive, responsive, and effective in addressing the specific needs of male patients. One of the central contributions of this research is the comprehensive understanding of masculinity as a structural element in healthcare. Traditional approaches often treat masculinity as a personal identity or cultural expression, with little attention paid to its embeddedness within larger social, cultural, and healthcare systems. This study demonstrates that masculinity, as shaped by societal norms and expectations, plays a crucial role in influencing health-seeking behaviors, patient-provider engagement, and adherence to treatment regimens. By recognizing masculinity's structural dimensions, this research has opened new avenues for understanding how gender norms, expectations of stoicism, and resistance to vulnerability intersect with cancer care behaviors.

This thesis also contributes to developing a framework for integrating structural competency into healthcare practices, particularly in oncology. Structural competency refers to the ability of healthcare providers to recognize and address how social, economic, and political factors shape health outcomes, and it plays a crucial role in addressing disparities in cancer care. By framing masculinity as a structural determinant, this study highlights the need for healthcare professionals to understand the broader social context that influences male patients' cancer experiences. The proposed framework provides practical strategies for integrating structural competency into medical education, training programs, and clinical practice. This includes the incorporation of gender-sensitive approaches to care that recognize and respect the diverse ways in which masculinity affects health decisions and outcomes. Finally, this research identifies a range of intervention strategies that have proven effective in addressing the intersection of masculinity, prostate and testicular cancer, and structural competency. These strategies include tailored communication approaches that challenge traditional gender norms and interventions that create safe spaces for men to discuss their health concerns openly.

## Practical Recommendations

Health interventions should be designed not only to address the immediate medical needs of male patients but also to consider the structural factors that inhibit access to care, such as stigma, fear of vulnerability, and societal pressure to conform to traditional masculine ideals. By targeting these underlying factors, healthcare providers can better support men in managing cancer care. Building upon these contributions, several recommendations for practically implementing these findings are proposed. These recommendations focus on how healthcare systems can incorporate the insights derived from this research into everyday clinical practice.

To foster the integration of masculinity as a structural element in healthcare, provider training programs should incorporate modules on gender sensitivity and structural competency. Healthcare professionals, particularly in oncology, need to be trained to recognize how gender norms affect health behaviors and the willingness of men to seek help. Such training programs would enable providers to engage with male patients holistically and empathetically, offering care that addresses the individual’s medical needs and the broader structural forces influencing their health outcomes. Moreover, healthcare workers must be equipped with the tools to recognize when these masculine norms hinder patients' engagement with necessary treatments or screenings, particularly in cancer care.

Modifying existing service delivery models to accommodate the unique challenges faced by men in cancer care is a critical step. Services should be designed to reduce barriers to care that arise from masculine ideals, such as perceptions of weakness or vulnerability. Healthcare systems can implement more flexible, discrete, and accessible cancer screening and diagnostic services, ensuring that male patients feel comfortable seeking care. For instance, the inclusion of male-friendly communication strategies, such as peer support groups and gender-specific education on health risks, can help break down the stigma surrounding cancer care for men. Additionally, ensuring that healthcare settings are welcoming and non-judgmental will encourage more men to engage with healthcare providers promptly.

The findings from this research indicate that healthcare policies must evolve to reflect the role of masculinity in cancer care. Policy frameworks that influence healthcare access, cancer prevention, and treatment should be revised to ensure that they are inclusive of gender-specific needs. Policies should address men's barriers to accessing preventive care and treatment, ensuring that resources are allocated equitably.

## Implementation Strategies, Future Directions, and Research Implications

Moreover, gender-sensitive policies could promote the inclusion of men in research studies and health interventions designed to address gendered health disparities. By revising these frameworks, healthcare systems can foster an environment that supports the health and well-being of all patients, irrespective of gender. While this research provides valuable insights into the intersection of masculinity, cancer care, and structural competency, several avenues for future research remain. These research directions would help build upon the foundation laid by this study and contribute to an even more nuanced understanding of the challenges men face in cancer care.

Future studies should explore the long-term effects of gender-sensitive healthcare interventions on men's cancer outcomes. Longitudinal studies could assess whether integrating structural competency and masculinity-informed approaches leads to better health outcomes, such as improved survival rates, better mental health outcomes, and increased participation in early screening and preventive measures. Tracking these outcomes over time would provide evidence of structural competency's efficacy in transforming men's cancer care. Evaluating the effectiveness of interventions designed to address masculinity and cancer care is essential. Future research should assess these interventions' impact on healthcare delivery and patient outcomes. This includes evaluating the success of specific communication strategies, tailored educational programs, and the integration of peer support mechanisms in improving male patients' engagement with cancer care.

As gender norms surrounding masculinity vary across different cultures, further research should examine how structural competency and masculinity impact cancer care in different cultural contexts. Cross-cultural studies would explore how cultural variations in masculinity influence health behaviors and cancer outcomes. This research would be invaluable in adapting the findings of this study to diverse global settings, ensuring that healthcare systems can implement culturally appropriate interventions for male cancer patients.

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# APPENDICES

## APPENDIX 1: TOPIC GUIDE, STEPS AND PROMPTS:

*Reminders Before Starting Interview:*

- Before starting the interview, ask if they have any questions/doubts about the research.
- Briefly summarize what the research is about
- Explain interview style (open-ended; participants leads, I follow)
- Explain that I will be taking notes to ensure that I do not interrupt but may go back to something they've said

*Prompts:*

- "Let's start by getting to know you. Tell me about yourself, whatever you feel comfortable sharing…"
- "When you said […], tell me more about that."…
- "What can you think was happening when/then…?"
- "What do you think others were thinking about XYZ?"
- "How do other similar experiences compare to this experience?"
- "What would you have done differently/similarly?"

# APPENDIX 2: QUESTIONNAIRE FOR STUDY

## Survey of Male Pharmacy Students on Testicular Cancer (TC) and Testicular Self-Examination (TSE), 2021

**Thank you for taking the time to complete this short survey. Your confidential answers will be used to formulate educational strategies to improve awareness of testicular cancer among university students in Ghana.**

**Please read each question and provide your most appropriate response.**

## SECTION A: Demographic Information

**Age in years ( )**

| **1. Marital Status** | | **Mark here (X)** |
|---|---|---|
| Dating | 1 | |
| Engaged | 2 | |
| Married | 3 | |
| No relationship | 4 | |

| **2. Religion** | | **Mark here (X)** |
|---|---|---|
| Christian | 1 | |
| Moslem | 2 | |
| Traditionalist | 3 | |
| Others (Specify) | 4 | |

**3. Programme of Study: ________________________________________**

| **4. Academic Year** | | **Mark here (X)** |
|---|---|---|
| 1st Year | 1 | |
| 2nd Year | 2 | |
| 3rd Year | 3 | |
| 4th Year | 4 | |
| 5th Year | 5 | |
| 6th Year | 6 | |

**5.** Have you ever heard of TC before? Yes ( ) No ( )

**6.** Does anyone in your family have TC? Yes ( ) No ( )
**7.** Is there anyone in your close environment (friends, neighbors, etc.) diagnosed with TC?
Yes ( ) No ( )
**8.** Do you know anything about TC? Yes ( ) No ( )
**9.** Where did you get information on TC?
Health professional ( ) Media ( ) Conference\panels ( )
**10.** Have you heard of TSE? Yes ( ) No ( )
**11.** Do you know how to perform TSE? Yes ( ) No ( )
**12.** Do you perform TSE? Yes ( ) No ( )
**13.** How often do you perform TSE? Monthly ( ) regular ( ) Irregular ( )
**14.** Would you like to receive information about TSE? Yes ( ) No ( )
**15.** Is TSE important in the early diagnosis of TC? Yes ( ) No ( )

## SECTION B: Students' level of knowledge about TC and TSE

Please indicate the extent to which you agree or disagree with each of the following statements: (TICK ONE RESPONSE ON EACH LINE)

| | **1 Yes** | **2 No** | **5 Don't Know** |
|---|---|---|---|
| **16.** TC is most common in males aged 15–35 years. | | | |
| **17.** The greatest risk group for TC is those with undescended testicles | | | |
| **18.** Early diagnosis increases the chance of recovery from TC to 80–90% | | | |
| **19.** The earliest diagnostic method in TC is TSE | | | |
| **20.** TSE should be performed in the shower or immediately after the shower | | | |
| **21.** TSE should be done regularly every month | | | |
| **22.** TSE is checked at a certain time each month | | | |
| **23.** Blood in the urine, pain and burning while urinating are signs of TC | | | |
| **24.** TSE is performed by gently checking the testicles between the fingers | | | |
| **25.** During the examination, it is tried to feel if there is any mass (tuber) in the testicles and on the edges | | | |
| **26.** Normally one of the testicles may be slightly smaller than the other | | | |
| **27.** In TC, the mass is usually found on the back | | | |

| | | | |
|---|---|---|---|
| of the testicle | | | |
| **28.** Where there is TC, there are signs of lump/mass, pain, weight loss, hair loss, general swelling and rash in the testicular sac | | | |
| **29.** Problems with sexual intercourse occur in TC cases | | | |
| | | | |

## SECTION C: Attitude of students towards TC and TSE

| Variables | Agree | Disagree | Uncertain |
|---|---|---|---|
| **30.** My physical health makes it more likely for TC if fail to perform TSE | | | |
| **31.** Chances of getting TC in the future increase if fail to perform TSE | | | |
| **32.** The thinking of TC fear to me | | | |
| **33.** If I had TC, my career would be endangered | | | |
| **34.** TC would endanger my marriage | | | |
| **35.** TC would be more serious than other diseases | | | |
| **36.** TSE can help to find lumps in the testicles | | | |
| **37.** Monthly TSE helps to find lump before discovered by health check-up | | | |
| **38.** It is embarrassing for me to do monthly examinations | | | |
| **39.** TSE can be painful | | | |
| **40.** TSE can be time-consuming | | | |
| **41.** Family would make fun of me if I do a TSE | | | |

## SECTION D: Practice of students towards TSE

**42.** Have you ever examined your testis before? Yes ( ) No ( )
**43.** When did you started TSE? < 15 years ( ) >=15 years ( )
**44.** How regular do you perform TSE?
Daily to weekly ( )
Once a month ( )
Once in three months ( )
Once in six months ( )
Once a year ( )
**45.** What techniques do you employ in performing TSE?
Inspection and palpation ( ) Only inspection ( )
**46.** What time do you perform TSE? After showering ( ) Before showering( ) At any time( )
**47.** Where do you perform TSE? In front of mirror ( ) In the bathroom ( ) Lying on the bed ( )

## SECTION E: Barriers to TSE among students

**48.** What are the reasons for not doing TSE?

| **Barriers** | Yes | No |
|---|---|---|
| Not caring about the examination | | |
| Not knowing TSE | | |
| Fear of worse results after examination | | |
| Thinking of the examination as a sin | | |
| Shame | | |
| Guilty | | |
| Culture | | |

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