

**MESTRADO EM**  
PSICOLOGIA CLÍNICA E DA SAÚDE

# **Sexual Health After Prostate Cancer Treatments: Challenges and Unmet Sexual Needs of Survivors**

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of Survivors**

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## Resumo

**Introdução:** O cancro da próstata (CP) é o segundo tipo de cancro mais diagnosticado em todo o mundo e a sua incidência aumenta com a idade. Os efeitos secundários dos tratamentos são frequentes e afetam significativamente a saúde sexual, o bem-estar geral e a qualidade de vida das pessoas doentes. Apesar deste impacto, tem sido dada pouca atenção às necessidades sexuais das pessoas sobreviventes.

**Objetivo:** O principal objetivo deste estudo é identificar as necessidades sexuais não satisfeitas de sobreviventes de CP. Pretende-se compreender a) o impacto dos tratamentos médicos na qualidade de vida das pessoas sobreviventes, b) os principais desafios na prossecução de uma vida sexual satisfatória e saudável após os tratamentos e necessidades sexuais específicas não satisfeitas.

**Método:** De acordo com os princípios do *Patient and Public Involvement* (PPI), foram convidados 2 sobreviventes de CP a integrar a equipa de investigação. Estes co-investigadores foram envolvidos em várias atividades de investigação a fim de recolher informação junto de diferentes *stakeholders* através de entrevistas individuais para a identificação de necessidades sexuais não atendidas nos sobreviventes de CP. Os resultados foram analisados sob uma análise temática de conteúdo.

**Resultados e conclusões:** A disfunção erétil e incontinência urinária surgiram como principais consequências físicas dos tratamentos. As principais necessidades não atendidas identificadas prenderam-se com a necessidade de 1) reforço de recursos de saúde, 2) literacia em saúde sexual, e 3) apoio psicológico. Os dados deste estudo oferecem um contributo importante para informar o desenvolvimento futuro de programas psicoeducativos com vista ao aumento da literacia em saúde sexual e à melhoria da sexualidade de sobreviventes de CP.

**Palavras-chave:** Cancro da próstata; Necessidades não atendidas; Saúde sexual; Envolvimento do público.

## Abstract

**Introduction:** Prostate cancer (PC) is the second most diagnosed cancer worldwide and its incidence increases with age. Side effects of treatments are frequent and significantly affect the sexual health, general well-being, and quality of life of sick people. Despite this impact, little attention has been paid to the sexual needs of surviving people.

**Objective:** The main objective of this study is to identify the unmet sexual needs of PC survivors. It is intended to understand a) the impact of medical treatments on the quality of life of survivors, b) the main challenges in pursuing a satisfactory and healthy sexual life after treatments and specific unmet sexual needs.

**Method:** According to the principles of Patient and Public Involvement (PPI), two PC survivors were invited to join the research team. These co-researchers were involved in multiple research activities in order to collect information from different stakeholders through individual interviews for the identification of unmet sexual needs in PC survivors. The results were analyzed under a thematic content analysis.

**Results and conclusions:** Erectile dysfunction (ED) and urinary incontinence emerged as the main physical consequences of treatments. The main unmet needs identified were related to the need for 1) reinforcing health resources, 2) sexual health literacy, and 3) psychological support. The data of this study provide an important contribution to inform the future development of psychoeducational programs aimed at increasing sexual health literacy and improving the sexuality of PC survivors.

**Keywords:** Prostate cancer; Unmet needs; Sexual health; Public involvement.

## Résumé

**Introduction:** Le cancer de la prostate (CP) est le deuxième cancer le plus diagnostiqué au monde et son incidence augmente avec l'âge. Les effets secondaires des traitements sont fréquents et affectent considérablement la santé sexuelle, le bien-être général et la qualité de vie des personnes malades. Malgré cet impact, peu d'attention a été donnée aux besoins sexuels des personnes survivantes.

**Objectif:** L'objectif principal de cette étude est d'identifier les besoins sexuels non satisfaits des survivantes de PC. Il vise à comprendre a) l'impact des traitements médicaux sur la qualité de vie des survivants; b) leurs principaux défis dans la poursuite d'une vie sexuelle satisfaisante et saine après les traitements spécifiques et les besoins sexuels non satisfaits.

**Méthode:** Selon les principes de la participation des patients et du public (PPI), deux survivants de CP ont été invités à se joindre à l'équipe de recherche. Ces chercheurs ont participé à diverses activités de recherche afin de recueillir des renseignements auprès de différents intervenants au moyen d'entrevues individuelles en vue de déterminer les besoins sexuels non comblés chez les survivantes de CP. Les résultats ont été analysés dans le cadre d'une analyse de contenu thématique.

**Résultats et conclusions:** La dysfonction érectile et l'incontinence urinaire sont apparues comme les principales conséquences physiques des traitements. Les principaux besoins non satisfaits identifiés étaient liés à la nécessité de 1) renforcer les ressources en santé, 2) la littératie en santé sexuelle et 3) le soutien psychologique. Les données de cette étude fournissent une contribution importante pour éclairer l'élaboration future de programmes psychoéducatifs visant à accroître la littératie en matière de santé sexuelle et à améliorer la sexualité des survivantes de CP.

**Mots-clés :** Cancer de la prostate; Besoins non satisfaits; Santé sexuelle; Participation du public.

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## **List of Abbreviations**

ED - Erectile Dysfunction

GRIPP - Guidance for Reporting Involvement of Patients and the Public, Version 2

PC - Prostate Cancer

PCs - Prostate Cancer survivors

PSA - Prostate-Specific Antigen

PPI - Public and Patient Involvement

QoL - Quality of Life

WHO - World Health Organization

## Introduction

Prostate Cancer (PC) is the second most diagnosed cancer in men worldwide with an estimated 1.414.259 new cancer cases in 2020 and an estimated number of prevalent cases (5-year) of 4.956.901. In Portugal, 6.759 new cases were diagnosed in 2020, representing the second most diagnosed cancer among Portuguese men (Globocan, 2021). PC is associated with increasing age, affecting one in 52 men aged 50 and 59, and only one out of 350 males under the age of 50. Men over the age of 65 account for nearly 60% of all cases (Rawla, 2019).

There are several treatment modalities available for PC, depending on the characteristics of the tumor: 1) local therapy, focusing on a certain area to be treated, can include surgery and radiation therapy; 2) systemic therapy, that works throughout the body and includes hormone therapy, chemotherapy, or other treatments designed to maintain or improve patient's QoL (see Appendix A for more details). Depending on the type of treatment, several side effects may be experienced by the patients. Studies have shown that urinary incontinence, pain, and fatigue are common complications after treatment for PC (NCCN, 2023). In addition, patients frequently experience significant levels of emotional distress (e.g., anxiety, depression, low self-esteem) and negative sexual consequences such as erectile and orgasm dysfunction, lack of sexual desire, and overall sexual distress (Chung, 2021; Watts et al. 2014). In general, treatments for PC have been associated with negative effects on patients' mental and sexual health, contributing to significant emotional, sexual, and relational distress (Maggi et al. 2018; Quinta-Gomes et al. 2018), and to decreased QoL (Chambers et al. 2017).

A qualitative study conducted by Schantz Laursen (2016) aimed to explore patient's perceptions about changes in sexuality after surgical treatment for PC. Findings indicated that most of the patients found sex to be "no longer spontaneous" and a perception of lack of control over their sexual lives, which impacted their sense of masculinity, self-esteem, and libido, was reported. In addition, patients reported the need to adjust their sexual expression and behavior after losing their ability to have spontaneous erections. Given the significant alterations associated to penile length and sexual response (e.g., alterations on orgasmic response, lack of erection, and loss of ejaculation) patients were no longer able to see themselves as "genuine men", which significantly affected their overall self-image and self-esteem. According to the authors of the study, the need of redefining sexuality by integrating new forms of sexual stimulation in the current sexual interactions

(e.g., petting, rubbing instead of focusing on sexual penetration), was perceived as very demanding for some patients, but recognized as needed in order to adjust to a changing life circumstance. As suggested by Wassersug et al. (2017), PCs' adjustment to post treatment may be different from patient to patient, as for some men it may be an opportunity to explore new forms of sexual stimulation, while to others with the need of great focus in intercourse, the sense of masculinity will be threatened, and a cascade of sexual difficulties and associated distress may be experienced.

### **1. Unmet Supportive Care Needs in Patients with PC**

Supportive care is characterized as a person-centered approach for delivering the essential services to patients impacted by cancer (Rahman et al. 2022). The concept of unmet supportive care needs arises when this support provision is insufficient, and the patients see themselves unable to access quality care when needed. This can arise for various reasons, including barriers related to the availability, accessibility, and acceptability of services (Rahman et al. 2022).

In a systematic review conducted by Paterson et al. (2015), several unmet supportive care needs have been identified by men living with and after PC. According to the authors these needs can be divided in ten different domains (for a detailed description, see Appendix B). According to the same authors, intimacy, informational, physical, and psychological needs were the most frequently reported needs among patients with PC. Authors highlighted the importance of healthcare professionals to be aware of patients and their partners specific supportive care needs and the need of conducting more studies to understand how these care needs evolve over the cancer trajectory.

Despite the recognized importance of sexual adjustment of PCs and their partners, there are still few psychotherapeutic interventions available addressing patient's specific unmet supportive care needs. In order to accomplish this goal, it is important to identify first the main challenges associated with sexuality in this population, by collecting information from different stakeholders, in order to further develop programs aimed at meeting such emotional and sexual unmet needs and contribute to the increase of sexual literacy and sexual health and well-being in PCs (Alexis & Worsley, 2018).

### **2. PPI on Prostate Cancer Research**

As a topic where it is so important to consider patients' voices and needs, involving patients in research and service design seems entirely appropriate, and has grown in

popularity over the last decade. Public and Patient Involvement (PPI) in research is defined by INVOLVE, an English national advisory organization, as "*research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*" (INVOLVE, 2012). This approach differs from prior research and treatment techniques in which healthcare practitioners believed themselves to be the only experts in making decisions (Nissen et al., 2018). According to the same authors, PPI brings a different perspective than those marked by only researchers and clinicians. As a result, it can help determine the research relevance at all phases, improve the applicability of information material for study participants, and improve the quality of implementation. Furthermore, participants report feeling valued and expressing personal benefits, while researchers report obtaining more insight into their research topic and a stronger relationship with the community. PPI processes in research are time-consuming and costly; also, it requires a certain degree of project flexibility to allow for change and avoid a tokenistic engagement of patients.

Following the principles of PPI in research, Brett et al. (2022) conducted a study on the impact of PPI on Life After Prostate Cancer Diagnosis. The study used a mixed methods design (online surveys and semi-structured interviews), and GRIPP2 reporting guidelines. Patients were involved in several phases, including the definition of the study design and materials, implementation of the survey, topic guide, and data analysis. The authors concluded that including PPI maximized the program's effectiveness and impact.

Gordon et al. (2017) aimed to explore the inclusion of PPI in a qualitative study on the experiences of men with PC regarding information in radiotherapy. Authors decided on an early phase of the design and development of the research to 'ask the experts', i.e., a selection of patients who had been diagnosed with PC and underwent radiotherapy, to inform about the research design and materials to be implemented, and to be involved in the research group for advising the researcher's during the design process. The authors concluded that the contribution of PPI to this study was beneficial to the development and evaluation of the study design since the researchers were informed about methodological issues that would not otherwise have been considered. The self-worth of the reference group participants demonstrates that the value of PPI in health research should not be underestimated. Involvement of PPI should be seen as standard practice to both ensure and support well-designed, robust research processes.

As sexuality and intimacy remain important dimensions of overall well-being and QoL of PCs (and their partners) and are deeply affected by the side-effects of treatments,

the use of PPI in research to identify sexual health needs will contribute to an accurate identification of such needs that require specialized healthcare provision, to be further addressed in future psychotherapeutic programs designed to improve sexual health literacy for PCs.

### **3. Objectives of the Study**

Considering the well-known long-term impact and sequela of treatments for PC on mental and sexual health of survivors, it is important to understand the patients and health professionals' perspectives on these topics and how to contribute to an effective sexual healthcare provision for the patients. Therefore, the aim of the present study is to explore the specific unmet sexual needs of PCs that are preventing them from experiencing a satisfactory sex life after treatments. This study sought to answer the following research question: "What are the unmet sexual health needs of PC patients and survivors?". In order to accomplish this objective, we described and analyzed: a) the impact of medical treatments in the QoL of PCs after treatments, b) the main challenges of PCs in pursuing a fulfilling and healthy sex life after treatments, and specific unmet sexual needs. The information collected will be used to inform the development of a future psychological intervention program aimed at promoting a fulfilling and healthy sex life of PCs. Given the exploratory nature of this investigation, no research hypotheses were formulated. PPI approach was followed to better capture stakeholder's (e.g., patients, healthcare providers, representatives of patient's associations) experiences regarding the impact of PC treatments in the patient's sexual health and QoL, and to explore information regarding unmet sexual health needs.

### **Method**

The present study was part of a larger research project entitled "SexHealth & ProstateCancer - Biopsychological Determinants of Sexual Health in Men with Prostate Cancer", developed by the Research Group in Human Sexuality of the Center of Psychology at the University of Porto. This project aims to identify the main protective and risk factors for PC adjustment and to develop and test the efficacy of a digital intervention to promote sexual health of PCs. Considering the importance of developing a program targeting users unmet sexual needs to increase future adherence and acceptance of the program, this study preceded the development of the digital program. The current

study is a work of citizen science, which intended to consult the near ecosystem of PCs, about the needs and priorities of intervention and support, starting from the (few) needs and priorities that have already been identified in previous investigations. Therefore, sexual health unmet care needs were explored among different stakeholders (patients, healthcare providers, representatives of patient’s associations) to further inform the content of the program. This qualitative study was approved by the ethical committee of the Faculty of Psychology and Educational Sciences of the University of Porto (Ref.<sup>a</sup> 2022/07-02b).

The long form of GRIPP2 (Staniszewska et al., 2017), the first international guidance for reporting of PPI in health and social care research, was used in this study. As mentioned before, PPI involves research method that includes actively planning, managing, designing, and carrying out research in collaboration with patients and members of the public (Hoddinott et al. 2018). In the present study, 2 experts by experience (male; PCs) were invited to join the research team as co-researchers.

## 1. Participants

Four women (n= 4) aged between 29 and 36 years old (M= 33; DP= 2.94) and five men (n= 5) aged between 30 and 84 (M= 53; DP= 22.65) were contacted to participate in this study. Participants were Portuguese and currently working in the field of PC. Four of the participants were urologists and oncologists (44.4%), four participants were nurses working in the field of oncology and urology (44.4%), and one participant was the president of a prostate patient association and a PCs (completed brachytherapy 9 years ago; 11.2%). All participants had a university degree. Table 1 displays participant’s sociodemographic characteristics.

**Table 1**

*Participants' sociodemographic characteristics*

Identification	Self-reported gender	Age	Nationality	Education	Occupation
I1	Male	No data	Portuguese	No data	Urology Nurse Hospital São João



I2	Male	30 years	Portuguese	Masters in Medicine	Doctor
I3	Female	29 years	Portuguese	Masters in Medicine	Doctor
I4	Male	No data	Portuguese	No data	Doctor
I5	Female	No data	Portuguese	No data	Nurse
I6	Male	46 years	Portuguese	Degree in Nursing	Urology Nurse IPO
I7	Female	36 years	Portuguese	Masters in Oncology Nursing	Nurse specialized in Oncology Champalimaund Foundation
I8	Female	34 years	Portuguese	Masters in Medicine	Radio-Oncologist IPO Porto
I9	Male	84 years	Portuguese	Degree in Social Sciences	Retired

*Note:* The data missing was requested but not provided by participants.

## 2. Procedures

The study was structured in five phases. In phase 1, a literature review was conducted with the aim of understanding what already existed in the literature regarding unmet sexual needs in PCs. After collecting this information, an entire session was reserved to discuss the findings with the co-researchers and a list of six unmet needs was achieved (see Appendix C). During phase 2, an interview script was developed in collaboration with the co-researchers, based on the findings of phase 1. In this phase, associations and institutions were also identified in order to be contacted for the interviews. In phase 3, the interviews were conducted and recorded by telephone to the available professionals of the identified associations/institutions. Inclusion criteria were: 1) ability to provide informed consent; 2) healthcare providers currently working in the field of urology/oncology and with regular contact with PC patients; 3) PCs (no longer under

treatment). Participants were provided with information regarding anonymity and confidentiality of their responses and data protection and provided their informed consent. Sample size was determined after theoretical saturation was achieved (Fontanella et al. 2008). The interviews were transcribed verbatim, and a thematic analysis was performed to identify the main themes and needs identified by the respondents. In phase 4, a final meeting was scheduled with the co-researchers for interview feedback and discussion of the findings (see Appendix D). Finally, in phase 5, the findings were organized and shared with the research team of the global project to inform about the topics to be included in the program to be developed for promoting sexual health in PCs.

According to *The Research with Patient and Public Involvement: a Realistic evaluation (RAPPORT)*, six salient actions are required for effective PPI: a clear purpose and structure for PPI; ensuring diversity; whole research team engaged with PPI; mutual understanding and trust between the researchers and lay representatives; ensuring opportunities for PPI throughout the research process; and reflecting on, appraising, and evaluating PPI within a research study (Brett et al. 2022). These parameters were followed throughout the present study.

### **3. Instruments**

#### *Sociodemographic questionnaire.*

A sociodemographic questionnaire was used to collect information on sociodemographic variables, such as age, education, marital status, and current professional occupation (Appendix E).

#### *Interview script for assessing unmet sexual needs.*

An interview script was developed and focused on questions assessing the impact of treatments on the QoL of PCs, the main challenges in having a satisfactory sex life after treatments, and the identification of the main unmet needs (Appendix F).

### **4. Data Analysis**

Descriptive statistics were calculated for characterization of the sample (means, standard variations, range, and percentages for categorial variables).

Thematic analysis (inductive method) was performed. According to Braun & Clarke (2006), thematic analysis is a method for identifying, analyzing, and reporting patterns or themes within data. It minimally organizes and describes the data set in detail. The

inductive logic was followed and derived from the fact that categories emerged from the collected data, that is, information was gathered from the interview content to induce categories. This process was not linear, but rather a constant movement back and forth between the different phases of the analysis: 1) familiarization with the data, 2) generation of initial categories, 3) category search, 4) review of categories, 5) definition and naming of categories, and 6) report production.

## Results

After several readings of the interview transcripts and analysis of the interview notes, 2 first-level categories, 4 second-level subcategories, and 2 third-level subcategories emerged. Data is summarized in Table 2.

**Table 2**

*Categorical analysis with illustrative examples*

Category/Subcategory	Operational Definition	Examples
1. Physical Impact of Treatments	Physical consequences after PC treatment.	I6: "Sexual function is highly compromised. It stops being spontaneous and when we do manage to restore some function, it always has to be with a provoked response."  I9: "In the urinary area, it was only about 2/3 years ago that I started to have some urinary retention problems, but very simple ones, which I manage to live with some intervention I've done."
2. Unmet Needs		
2.1 Sexual Health Literacy	Lack of sufficient literacy/training for both professionals and patients regarding sexual health after PC treatment.	I1: "We don't have a very well-informed population, don't we? And so many of them take it without knowing what's happening to them."  I7: "If all the professionals involved in their illness were really trained to talk about it, half of people's problems would be solved."
2.2 Need of Health Resources	Inability to provide better support for patients after treatment due to a lack of	I2: "Referral does exist, but it's not always very easy and it's not always very frequent, but it does exist."

	resources at the oncologic clinics/hospitals.	I5: "Tell me about a hospital that has a multidisciplinary team. There may be one, but I never heard about it, and that includes everyone (doctor, nurse, physiotherapist, psychologist)."
2.3 Intimate Needs		
2.3.1 Main Barriers	Barrier's patients face in pursuing a healthy sex life after treatments related to feelings of shame, the age of the patient and their state of health.	<p>I7: "(...) and at the same time, I still see shame among the patients, shame in broaching the subject (sexuality)."</p> <p>I3: "Since basic sexual function also greatly predicts what the impact on the patients will be and whether they accept taking medication, there are patients who don't make it a priority for them to treat sexual dysfunction, they prefer to treat the oncological part, and only once they have stabilized do they accept treatment."</p>
2.3.2 Redefine Sexuality	Redefining sexuality considering the changes caused by treatments. Giving new meaning to the word "intimacy".	I8: "Decentralize sexuality from penetration. Because no matter how much medication they take or treatment they undergo, it can be difficult to regain an erection like they had before, so you have to manage expectations, you have to do psychoeducation."
2.4 Psychological Needs	Importance of having access to psychological support in an attempt to have a satisfactory sex life after treatment.	<p>I5: "In those cases where we're not able to make the medication effective I think they [specialized therapies] would make a difference, because they would work on everything else and there's nothing better than a person in the field of sex therapy to help them, because they would effectively help the patients much more than we would with other strategies, it's very important."</p> <p>I1: "In the dialog we have with the patients we don't know what's going on inside, because many of them don't express their feelings with us. If there was a continuity of other types of consultation, for example psychological follow-up, they would also slowly fit in and then be able to question the doctor about certain types of things."</p>

## **Analysis and Discussion of the Results**

This section presents the analysis and discussion of the results and follows the categorical and sub categorical logic, guided by the conceptual lines that comprise a thematic analysis of inductive nature. The writing process arises from the interconnection between the aim of the study - to explore the specific unmet sexual needs of PCs that are preventing them from having a satisfactory sex life after treatment -, a presentation of the results, and their sustained interpretation and discussion.

### **1. Physical Impact of Treatments**

This category arises from the thematic analysis under the explanation that in order to identify the challenges faced by PCs when it comes to having a satisfactory sex life after treatments, as well as the unmet sexual needs, it seems important to go to the heart of the problem and understand the extent of the impact of treatments on patients.

As mentioned in the introduction section, PC treatments can have long-term side effects that greatly impact patients' QoL (Davis et al. 2014). Some evident and common aspects in the interviewees' discourses was the fact that the type of treatment has an influence on the type of changes the patients will undergo. It should be also noted that although the significant impact of sexual consequences associated with treatment for PC, they appear more frequently in some cases than in others. Sometimes they may never arise, although this is unlikely to happen. In addition, these consequences may vary in time, severity, and can be transitory or permanent (Dias, n.d.).

*“The impact of treatments will depend a lot on the stage of the disease. If we're talking about localized disease, localized prostate disease and where the treatment is curative, which mostly involves surgery or radiotherapy, the impact on QoL is mainly in terms of sexual function and urinary function, and it can still be an important impact, especially in the first 2/3 years after treatment, when the changes are more marked, then there can be some recovery or in most of them there is a great recovery in terms of sexual function and, above all, urinary function. If, on the other hand, we're talking about advanced disease, metastatic disease in which the treatments are systematic, the impact on QoL can be greater due to the systemic symptoms of the medication, sometimes even the chemotherapy, and then the impact will be more marked, not just in terms of sexual and urinary function, but in terms of the body as a whole, so to speak. The main challenge is the loss of erectile function itself, so objectively it's because the treatments, especially for localized disease, prostate surgery or radiotherapy have a very big impact on erectile function in the first 1 or 2 years.” (I4)*

Taking this into account, when identifying the greatest impact of treatments, ED and urinary incontinence are on the top of the list. Additionally, alterations on penile length and on sexual response (e.g., alterations on orgasmic response, lack of erection, and loss of ejaculation) are also common (Schantz Laursen, 2016). However, ED is still the most usual and challenging side effect of both surgical removal of the prostate, radiotherapy, and hormone therapy, and configure the main cause of concern among patients. The incidence of ED has been reported as high as 79-88% after radical prostatectomy, despite advances in nerve sparing surgical techniques, and 67-72% after external beam radiation. It is less common after brachytherapy but can still occur with this technique. ED impacts QoL, with the majority of men reporting QoL as either severely or moderately affected by this condition (Albaugh et al. 2017).

## **2. Unmet Needs**

### **2.1 Sexual Health Literacy**

According to the WHO definition, the term “health literacy” refers to “*the cognitive and social skills which determine the motivation and ability of individuals to gain access to, use and understand information, in ways which promote and maintain good health*” (Goodwin et al. 2018). Low health literacy hinders following health professional instructions, medication prescriptions, and appointment schedules, and understanding the healthcare system to receive necessary services (*Measuring Literacy in a Health Context*, n.d.). If we consider specific changes in sexual function, the literature indicates that encouraging sexual health literacy promotes well-being and health, with an important impact on higher QoL and relationship satisfaction (Mota, 2018).

When analyzing the content of the interviews, one thing that was reiterated in stakeholders’ discourses was the lack of knowledge of patients, as well as the lack of training of professionals regarding sexual health. This decreased health literacy, particularly with regards to sexual health, compromises PCs’ access to services for sexual health rehabilitation after treatments. When it comes to the patients this is the overall health care’s perspective:

*“We [Portuguese population] don’t have a very well-informed population and so many of them take it [cancer] without knowing what’s happening to them.” (I1)*

*"Patients aren't very prepared and it's a shame, most of them don't even know that they can have an orgasm without having an erection. There's an abysmal lack of sexual culture." (I5)*

*"They look for [help to recover sexual function], but they never look for what they should be looking for. They look for illegal unauthorized medication a lot, I hear really bizarre stories of things they try. They try anything and everything, but usually it's never anything legal. It's always their friend's friend who's got some pills, and the help is never professional, and they're led to do some stupid things." (I5)*

Despite the growing attention given to health literacy and the evidence that poor health literacy contributes to poorer general health status (Pinela, 2019), there is still a lack of literacy in patients. According to Parker et al. (2000), what contributes to poor health literacy is not only the education system, but also healthcare providers who assume that users should take full responsibility for their own selfcare. For this purpose, it seems important that healthcare providers could step in and address the topic of sexual health in a regular and open manner with the patients.

*"People are doing a specific treatment and professionals are the most qualified people to know what those treatments can entail in people's lives. If the professionals themselves are trained and feel free to talk about sexuality the same way they for example talk about food, this literacy will reach the patients. While a patient may be very capable, but then doesn't know what to do with this information, what can or cannot do depending on the treatment he's undergoing, whether he can have sex, whether he cannot have sex, if only three months later, if not..." (I7)*

*"There are doctors who are very open and very explanatory, to the point of explaining the smallest detail, what's happening to the patient, and I think that's a good thing. At the opposite end of the spectrum is the doctor who has the patient in front of him, looks at the tests the patient has had, makes some kind of physical observation depending on the type of illness, of course, or palpates some part of the body or something and then sits down at the computer and writes out the prescription or the medication and how many times he has to take it and says "come back in 6 months". This is the invasive doctor. It's important for the doctor to explain in detail to the patient what they actually have and what is going to be done, and this doesn't always happen. The information part, as I see it, involves a lot of this." (I9)*

To overcome these obstacles and understand which setting best promotes health literacy, Goodwin et al. (2018) stated that patient's skills in navigating health care systems and engaging with different forms of support were moderately associated with mental health related QoL, and the strongest association was between active engagement with

providers and mental health status. Educating and assisting men to seek and engage effectively with appropriate health services may facilitate improvements in emotional distress, social connections, and interpersonal relationships often negatively impacted by PC treatment. According to respondents, promoting sexual health literacy in both patients and healthcare providers is relevant and can be achieved in a variety of ways:

*“Using the mediation that we have available today. For example, here at IPO were elaborated podcasts and one was directed to sexuality in PCs. I think one of the means is this, and then in person in the moments we have here with people, we can’t give up. Maybe normalize the theme more. Integrate in our everyday conversation, trivialize sexuality as we trivialize other subjects.” (I6)*

*“In places of much movement there should be posters or some kind of information. Ex: metro stations where there are automatically controlled boards that can promote certain type of information not only about the subway. Put this type of information in places that involves a lot of movement. Train, airports, parish councils that always have many habitants daily. There should be more publicity about the need for men to seek information about the prostate. For example, in relation to Facebook I do not know anymore, between 40 and 65 years there is a nucleus in which the internet and tv still work, but outside this age I feel that ceases to interest.” (I9)*

To sum up, the interviewees' perspectives and the complementary literature suggest that the full impact of inadequate health literacy is unknown and often goes unrecognized. However, interventions that acknowledge and address the issue of health literacy offer an important opportunity to achieve cancer control objectives (Davis et al. 2002). Clear and transparent communication between patients and healthcare professionals with specific training and scientific knowledge, are crucial for a PCs to be informed about the new condition and to accomplish a satisfactory sex life after PC treatment.

## **2.2 Need of Health Resources**

The need for health resources was unanimously pointed out by respondents as a topic that impairs communication and the ability to give the most adequate follow-up to patients who want to improve their sex life after treatments. The short amount of time that the doctors have for consultation results in the fact that only issues objectively related to the disease and treatment are addressed, leaving behind the opportunity to approach other topics of patient’s interests, as sexuality after treatments.

*“And so, I think that in such a quick medical consultation, the doctor can’t explain everything either. The doctor can’t read what your comprehension skills are in order to*



*guide you better, to explain better, because appointments are so fast that I don't know, this is something I doubt about appointment times, isn't it? The appointments are so short that even if the doctor takes a little longer, the patient can never explain all the doubts they have that day, because the doubts will only appear later.” (11)*

According to Elmore et al. (2016) longer consultations may be required to achieve clinical effectiveness and patient safety. However, the problem of reduced consultation time is a problem of the availability of health system resources. To overcome this issue, the discourse analysis of the interviewees highlighted two hypotheses: 1) the existence of a multidisciplinary team in more health contexts:

*“Because sometimes they question us [nurses] and we have a hard time explaining things to them, because we don't know what happened during the consultation. So, we can't go too far either, can we? Because we can't contradict the doctor, can we? And it makes it very difficult for us to be able to help patients in this respect. If there was a professional from a consultation next door on another day, but close by, maybe we'd win.” (11)*

*“I think we should have an andrology consultation, but a multidisciplinary one, so that we're all on the same page when it comes to working with these patients, because there are still so many of them.” (15)*

*“Tell me about a hospital that has a multidisciplinary team. There may be one, but I never heard about it, and that includes everyone (doctor, nurse, physiotherapist, psychologist).” (15)*

2) An improvement in the way consultation time is used:

*“There's a lot that isn't passed on and isn't talked about. When you give the patient a diagnosis (...) I'd say that 80% of what follows they don't hear.” (15)*

*“I think that sometimes health professionals aren't available to answer these questions [related to challenges of having a satisfactory sex life after treatment] and they [the patients] only come here twice a year, so they have few opportunities to ask for help.” (18)*

Multidisciplinary team working is the global "gold standard" for cancer care delivery across the world (Soukup et al. 2018). The existence of a multidisciplinary team is crucial in oncologic services, so when time is reduced with one professional, another one (i.e., psychologist, physiotherapist, occupational therapist) could be available to answer the remaining questions. Effective multidisciplinary team driven care involves inputs (i.e.,

teams, environment, patients), processes (i.e., interactions, tests) and outputs (i.e., patient experience, outcomes), which taken together are aspired to achieve high-quality and efficient care for patients (Soukup et al. 2018). By focusing on the needs of patients, the team is able to take care of those with different levels of complexity (Comité Técnico Asap, 2021).

Improvement of healthcare providers' communication skills is also a requirement. The most important communication skills during a consultation are understanding how to listen to the patient; using ordinary language and supporting healthy behavior; advising and educating the patient by clarify doubts and summarize the information provided by the patients; give concise information and understandable explanations. That is, even if the consultation time is reduced, when these criteria are met the time will be profitable and the patient will have the opportunity to address and clarify specific concerns (Alves, 2011).

Therefore, the reduced consultation time with the doctors could be minimized, ideally, through 1) the replication of multidisciplinary teams operating in oncologic health facilities, 2) transparent, clear, and objective communication also focused on the patient's priorities during the time available for the consultation.

## **2.3. Intimate Needs**

### **2.3.1 Main Barriers**

Regarding the intimate needs, a subcategory intitled *Main Barriers* emerged during the analysis. This subcategory depicts the circumstances that may contribute to patient's abandonment of a satisfactory sex life after treatments: patient's age and health status, and anticipation of stigma when addressing the topic of sexuality.

Based on data analysis and existing literature, the expectation of patient's absent or reduced sexual activity prior to the diagnosis of cancer may constitute a barrier to address sexual health:

*"Although these patients also often have reduced sexual function due to their age." (I3)*

*"Most of them didn't have great erections before, let's be honest. The vast majority of patients were over 60 when they were diagnosed, so most of them weren't super healthy at that point." (I5)*

PC incidence is higher in men over 65 years old and in that age, a number of limitations associated with "sexuality in the elderly" is assumed. As Vilar and Gomes (2016) have

stated *"sexual desire is part of the life of the elderly, although the clairvoyance of physical limitations is quite evident, but it is not an insurmountable barrier, but an obstacle that must be circumvented"*. Being an obstacle to overcome, it is to be expected that only few patients are willing to move forward, making it difficult to tackle the topic with them.

Additionally, the likelihood of developing health problems increases as people age (Besdine, 2019), and this is particularly evident in patients with cancer, to whom it is assumed sexual health is not a priority.

*"It depends on the age of the man. Until he's in his 60s or 70s, if possible, from the point of view of prostate health, a man will try to maintain a certain relationship, whether it's with his wife, partner, whoever. From the age of 70-something onwards, the man is probably already involved with other types of illnesses that have nothing to do with the urinary tract or the prostate, but rather the heart, the lungs, all of that, and so his attention is very much diverted away from the sexual relationship factor."* (I9)

Finally, the impact of an oncological diagnosis on patient's emotional and physical health, contributes to a certain level of patient's conformity to the situation:

*"A certain resignation, because once they become cancer patients, they think that just being able to survive is enough and then everything else takes a back seat and they switch off. And then, sometimes in the couple's own life context, it's something that's more underestimated. There isn't a large percentage of people who, as much as they say they have a sex life with so much need, want to seek help."* (I6)

The diagnosis of cancer is not socially neutral as the word "cancer" reminds the individual about his/her finitude (Neves, 2002). It is, therefore, understandable that some survivors focus on their state of health after treatment, feeling grateful to be alive, leaving behind the search for a satisfying sex life. In addition to the age and the diagnosis of PC, the anticipation of stigma when addressing sexual health (and associated emotions of guilt and shame) is also a barrier when seeking specialized care for sexual difficulties associated with treatments (Larkin et al. 2022). Among the perceptions gathered, the following stood out:

*"(...) [the patients] are always amazed when we say that most men over 60 need our help. But it's taboo for them to talk about this subject [sexuality], they're such studs. I often tell men that I know they were all supermen, but even to the superman they saw what happened."* (I5)

*"We found it very interesting that at these meetings [of the PC patients' association] the men were accompanied by women (partners or girlfriends) and so the intimate part here*

*has a lot to do with it, and that when it came to the questions and answers they were more active than the patients themselves. We noticed that in an assembly of 50/70 people, about a third were women accompanying men. At a certain point we realized that it was the man who told the person he was with to ask this or that, and it was she who asked the question, and the same thing over the phone. You can see that men has someone by their side who is suggesting the questions, issues and doubts they have. It's hard to understand, why isn't the man asking the question?" (I9)*

According to Chambers et al. (2017), men are encouraged to keep specific experiences to themselves, especially experiences that might call their masculinity into question. In addition to the issue of masculinity and having a cancer diagnosis, losing the ability to have and maintain an erection, which will consequently affect the sexual relationship with the partner, is a concern for these patients.

*"From my experience, one of the most difficult problems to deal with and one that comes with a cultural issue is ED. For men, culturally, having an erection and ejaculation are the signs that their sex life is working properly." (I7)*

This change causes pressure on PCs to continue to prove their virility and a feeling of diminished masculinity, leading them to consider that they are not "as men as" before and are not able to sexually satisfy their partner anymore, as a result of dysfunctional sexual beliefs associated with sexuality (Nobre, 2010). In addition, feelings of shame, embarrassment, and reduced self-worth are also frequently experienced (Chambers et al., 2017; Martins & Nascimento, 2020).

### **2.3.2 Redefine Sexuality**

Male sexual beliefs are characterized by ideas that the individual holds about himself and the others regarding sexuality, influencing the interpretation of certain events and, consequently, their sexual response (Nobre & Pinto-Gouveia, 2006). This subcategory results from healthcare professionals' perceptions on patient's beliefs about the primacy of coitus in sexual interaction. Under that restrictive view of sexuality, a satisfactory sex life after treatments becomes even more difficult for these patients, especially in cases where the mechanical dimension of sexual response is impaired.

*"From the point of view of the sexual sphere I would say that most of our patients would like to have an erection again." (I4)*

*"They [patients] usually try to follow a staircase from the simplest to the most complex. First, they would like the sexual sphere to be resolved without any kind of help. When*

*necessary, they naturally prefer the oral pharmacological route to the injectable pharmacological route. Therefore, the patient will usually prefer an approach from less complex to more complex.” (I4)*

*“(…) they still have much associated sexual intercourse with penetration.” (I5)*

Regarding the perspective of the professionals themselves on this topic, it appears that they understand sexuality through its comprehensive concept, in the sense that it is present in the five senses that can be expressed through the body, mind, affections, understanding (Costa & Neto, 2010). This conception of sexuality thus meets the statement of Manuel Costa (2017:103) when the author states that *"sexuality does not mean only genitality, it is not restricted to the sexual impulse, but understands the interaction of these aspects with affectivity and interpersonal relationship"*.

*“When the treatments involve, for example, the man no longer ejaculating, it's a lot about sexual health education to explain and make them understand that ejaculation is not the same as orgasm, and that even though they don't ejaculate, they can still have an orgasm. When we talk about the issue of ED, we have to demystify the fact (for heterosexual men) that most women don't even orgasm vaginally, and therefore devalue the penetrative effect that an erect penis has on women, and so the fact that we do all this sexual health education generally helps to greatly reduce the low self-esteem that these changes cause in well-being and in the experience of sexuality. At the same time this helps men, who in my opinion are very culturally emasculated to live in a very fixed way to sexuality, to really broaden their view of sexuality and explore other erogenous areas of themselves and their partner.” (I7)*

Subjects who have dysfunctional sexual beliefs associated with sexual performance and women's sexual satisfaction, such as "a true man must be able to endure the time necessary to satisfy the woman" or "a man who does not satisfy the woman is a failure" are more susceptible to the development of catastrophic ideas about the consequences of unsuccessful sexual activity (Nobre 2010; Zilbergeld, 1999). Consequently, these men develop and maintain negative and dysfunctional ideas about themselves and as sexual partners (negative self-concepts as "I am a sexual failure"; "I will never be able to solve this problem; Nobre, 2006) that interferes with overall sexual response and sense of well-being. For this reason, it is of utmost importance to provide specialized and personalized sexual care for these patients in order to educate them on alternative and more appropriate and adaptive strategies for promoting their sexual life and satisfaction.

## 2.4 Psychological Needs

According to Gabinete de Estudos OPP (2018), Psychology currently plays a key role in the prevention, treatment, and management of oncological diseases. The high comorbidity among oncological diseases and psychological health problems have been estimated to be higher than 47%, which is considerably higher than the incidence in the general population (Gabinete de Estudos OPP, 2018). Some of the most common psychological problems contributing to patient's morbidity and with profound consequences on their QoL, are depression, anxiety, post-traumatic stress disorder, sexual dysfunctions, body image problems, cognitive disorders, and suicidal ideation.

*"The impact [of post-treatment] is giant and despite being oncologically treated there is great frustration at not returning to what they were before the treatments." (I2)*

*"The psychological part matters because that's where all the other parts come from and it's not being taken care of at the moment. The hospitals, not all of them, are trying to cover the other parts, now the psychological part isn't. They [PCs] need more than anything to be listened to and cared for, and above all to realize that they're not the only ones. If you treat the mind, if we treat the psychological, half the problems disappear." (I5)*

Psychological and emotional aspects cannot be separated from sexuality; no matter the specificity of one's practice, an ability to understand what sex and sexual dysfunction mean to a patient is critical (Shindel & Lue, 2021). Any situation altering physical appearance can cause dramatic loss of self-esteem, leading to an additional loss of sexual confidence. If someone feels physically unattractive, they will subconsciously protect themselves against emotional hurt by developing a barrier towards intimate contact, leading to a loss of libido (Carr, 2007).

It has been evident throughout the results analysis how important it is for patients to recover at least part of their sexual function. As evidenced by Carr (2007), when patients with PC were asked to evaluate the potential length of survival concerning sexual function, 68% were willing to sacrifice a 10% increase in the chances of 5-year survival to maintain sexual function (Singer et al., 1991). For this reason, it seems important to focus on sexual health, when necessary, especially with professionals capable of responding to this need, such as sex therapists or oncosexology professionals.

*"When we can't get the medication to be effective, it's very important because we have caverjet (...) even vacuum pumps, and if they don't have that then I think it [specialized interventions] would make a difference, because it would work on everything else and*

*there's nothing better than a sex therapist to help them, because they would effectively help the patients much more than we would with other strategies, it's very important. But maybe 2/3 months later, because rehabilitation time is more or less 4 months and if they don't get help at the end of that period, they give up and consider themselves unhappy and make the people around them unhappy, because when there is no love, in whatever form, there is no QoL. Sexuality is an indicator of QoL.” (15)*

*“I would say that any time that there is evidence that the change that the person is experiencing is causing suffering, targeted support and more specific strategies associated with treatments are needed.” (17)*

As mentioned before, doctors and nurses also identify some barriers in discussing sexual implications of PC, such as lack of time, lack of knowledge, privacy, and personal comfort levels (Schwartz & Plawecki, 2002). An often-cited reason for avoiding the topic is lack of referral pathways when a sexual problem is identified (Carr, 2007). The lack of information available and the lack of opportunity for the patient to discuss sexual matters with the medical team has been widely reported (e.g., Krouwel et al. 2019). A recent study showed that health professionals, even when addressing sexuality with the patient, often offer limited information regarding the physical aspects of sexuality, such as erection alterations and fertility issues, whilst not providing any information on the emotional aspects (Paterson et al. 2015). From the content analysis presented, the first step to solve this is not necessarily to be an expert on the topic but leaving an "open door" so that the patient feels that this support exists, if needed, and mention the topic without fear or shame.

*“We know how much this [quality of sex life] influences well-being and QoL and consequently the way in which the person will experience the process in a lighter way or not. Therefore, it's part of our role as health professionals to refer and respond and open the door to talk about the subject. If the person wants to talk about it, fine, if not, they already know that if they knock on the door, they'll get answers and there's someone there to help, so we're following that path. Now, on the part of the professionals, I still find it very difficult to approach certain strategies.” (17)*

Although non-specialists' healthcare providers can play an important role in addressing the topic of sexual health with the patients, there is still a need for a specialized provision of psychosexual support to help the patients in a more effective and personalized way (Humphrey & Nazareth, 2001). Sexual and relationship therapists are trained to help overcome emotional issues associated with the loss of libido and intimacy,

which may be either directly linked to or triggered by the cancer. For this reason, a clinical background, or some education about the aspects of cancer and its treatments are needed in order to better understand what the patient has been experiencing, before working with the client about their sexual problem (Carr, 2007).

The long-term effects and distress associated to the negative side-effects of treatments highlight the importance of providing patients with accessible specialized support and care on mental and sexual health, and the need of incorporating personalized strategies to restore sexual intimacy and emotional well-being in overall patient's oncological care to ensure patient's QoL (Wei et al. 2002). From this perspective, psychologists and psychology services in cancer care configure an emerging need, not only at post-treatment but throughout the process and trajectory of the cancer and associated treatments, as they can provide adequate assessment, intervention, and support to individuals with cancer.

### **Conclusion**

The present study aimed to explore the specific unmet sexual needs of PCs that may prevent them from having a satisfactory sex life after treatments. To accomplish this objective, individual interviews were conducted, followed by a qualitative approach using a thematic analysis of inductive nature. A PPI approach was followed in the different phases of the study and contributed to better capture stakeholder's experiences regarding the impact of PC treatments in the patients' sexual health and QoL, and to explore information regarding unmet sexual health needs. PPI contribution allowed us to obtain a unique perspective on the subject, a broader interpretation of the data collected, and a dissemination of results tailored to the needs felt by PCs. In this section the main conclusions of the study will be presented.

The impact of PC is notorious at all levels of the human body and mind. Regardless of the treatment, the individual is not the same before and after the treatments, however, certain treatments cause a more marked impact than others on patient's overall emotional, physical, and relational dimensions. The most visible and recognized changes happen at the physical level, however, changes associated with sexual function and intimacy also have an emotional impact on patient's life and are often minimized and underestimated.

Changes in sexual function motivates most PCs to seek alternatives that enable them to pursue a satisfactory sex life after treatments. Nonetheless, a number of associated challenges and unmet needs configure significant obstacles/barriers. Considering the existing literature and the findings from our study it became clear that the first challenges



in pursuing a satisfactory sexual life after the treatments were the need of reinforced health resources, the need for sexual health literacy, and the need to increase the duration of medical consultation. The circumstances compromising the necessary time for the medical appointments prevent patients to address the topics they also feel as important for them. In addition, the low level of literacy on sexual health in both healthcare professionals and the patients, results in a significant failure to address information on sexual health. The lack of knowledge and training of the healthcare professionals is also a well-known barrier for providing patients with the most suitable strategies for adjusting to their new sexual life. The existence of a multidisciplinary team in oncological facilities was strongly suggested as an important way to reduce the barriers identified in addressing sexual health with PCs.

Regarding the intimate needs, it is consensual that sexuality is surrounded by taboos among men and women, particularly relevant when it is expressed in the scope of cancer associated with advanced age. The shame associated with sexuality and the comorbidity of other health problems were found to be an obstacle in pursuing a satisfactory sex life after the treatments. The feeling of relief and gratitude for being a PCs proved to be sufficient to leave the search for a satisfying sex life in the background. In addition, PC appears mainly in an age group in which the level of sexual life may be already biologically reduced prior to the disease, and therefore this condition remains an anticipated aspect. These factors highlight the importance of providing education to patients and the partners regarding the importance of sexual health, above and beyond PC. Therefore, the need for psychological support in the form of psychotherapy for emotional problems or sexual problems (i.e., sex therapy or oncosexology) are of utmost importance in the oncological context of care provision.

It is believed that the present study sprouted useful information for the development of future psychoeducational programs to increase sexual health literacy and improve the sexuality of patients, more adjusted to their new reality.

### **Limitations of the study and future direction**

Despite the considerable contributions of this study, some limitations should be highlighted. First, the interviews conducted for the study did may not represent the general reality of the topic under study, and only allows to present the perceptions of the selected participants, according to the objective of the study. However, the research

values the direct relation between empirical results and grounded theoretical contributions. We also anticipated to include the contribution of PCs and their partners, but several constraints interfered with their participation (e.g., difficulty in interviewing those participants in time for analysis and data presentation of the study). Finally, regarding the PPI, despite the enriching contribution, in a future study, to avoid dubiety between the co-researcher's role and the participant's role, it is recommended to provide an in-depth overview of the researcher's responsibilities in the study.

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## Appendixes

### Appendix A - Types of Treatment

Types of Treatment		
Observation	Involves monitoring the PC and watching for symptoms. The goal is to prevent them before they are likely to start. Treatment focused on palliation or symptom relief than to cure the cancer.	
Active Surveillance	Is a term used to describe a plan that closely watches the condition. During this the patient will have tests on a regular basis to look for changes in tumor growth.	
Surgery	Open Surgery	Removes the prostate through one large cut or incision.
	Minimally Invasive Surgery (Laparoscopic or Robotic Surgery)	Uses several small incisions or cuts. Laparoscope is a long tube with a camera at the end to see the prostate and other tissues inside the body. Laparoscopic surgery can also be done using robotic arms to control the surgical tools.
	Radical Prostatectomy (Retropubic or Perineal)	Removes the entire prostate, seminal vesicles, and some nearby tissue. Pelvic lymph may be removed.
	Pelvic lymph node dissection	Is an operation to remove lymph nodes from the pelvis.
Radiation Therapy (EBRT or Internal radiation)	Can be used as the main or primary treatment instead of surgery. RT uses high-energy radiation from x-rays, gamma rays, and other sources to kill cancer cells and shrink tumors.	EBRT uses a machine outside of the body to aim radiation at the tumor(s).  Internal Radiation is placed inside the body as a solid like seeds. This is called brachytherapy.
Hormone Therapy	Hormones can cause PC to grow. Hormone therapy is a treatment that adds, blocks, or removes hormones from the body.	
Bone Targeted Therapy	Medicine that targets bones may be given to help relieve bone pain or reduce the risk of bone problems. Some treatments for PC, like hormone therapy, can cause bone loss, which put the patient at increased risk of fractures.	
Clinical Trials	Type of research study that tests new methods of screening, prevention, diagnosis, or treatment of a disease.	

*Appendix B – Unmet Supportive Care Needs in Patients with PC (Paterson et al. 2015)*

<b>Unmet Need</b>	<b>Description</b>
Physical Needs	Resulting from urinary symptoms, hot flushes, enduring bowel symptoms, fatigue, weight gain, and breast soreness.
Psychological/Emotional Needs	Anxiety about the uncertainty of exam results (e.g., PSA), uncertainty about the future, fear of the cancer returning or spreading, anger, sadness, frustration, regret, and concerns about the worries of the relatives.
Family Related Needs	Lack of support to carers/partners making them have to conceal and suppress their own emotional support needs to protect the patients.
Social Needs	Experienced by men due to living with a decreased functional ability that significantly reduce their social activities and also a sense of loneliness when it comes to dealing with their illness with lack of social support.
Interpersonal/Intimacy Needs	As a result of the impact of sexual dysfunction.
Practical Needs	As financial support, travel insurance, supplies of incontinence pads and easy parking facilities.
Daily Living Needs	In cases where the treatment has been more aggressive, and therefore the day-to-day symptoms are more noticeable.
Spiritual Needs	Possibility of death, doubts about the prognosis of the disease, and uncertainty about the future.
Health System/Information Needs	Related to problems with the provision of information about treatment modalities and post-treatment, contradictory statements, lack of information on the practical aspects of incontinence management.
Patient-Clinician Communication Needs	Such as reduced consultation time, lack of follow-up appointments, lack of emotional support due a focus on physical aspects, and lack of factual information on patient's condition.

*Appendix C – List of Unmet Needs Achieved on Phase 1*

Unmet Need	Description
Physical Needs	Changes caused by treatment. Resulting in ED, urinary symptoms, hot flushes, enduring bowel symptoms, fatigue, weight gain, and breast soreness.
Psychological Needs	Anxiety about exam results (i.e., PSA); uncertainty about the future; fear of the cancer returning or spreading; anger, sadness, frustration, regret; concerns about the worries of the relatives; and lack of emotional support due a focus on physical aspects that results in a need for psychological support that is not suggested.
Social Needs	Decreased functional ability that significantly reduce survivors' social activities and also a sense of loneliness when it comes to dealing with their illness with lack of social support. Need to create support groups due to the tendency that men show in hiding the problem and need to talk to someone who has gone through the same.
Intimacy Needs	As a result of the impact of sexual dysfunction. Lack of strategies suggested by health professionals, who end up focusing on the positive side of being alive and neglect the patient's will to continue their sex life.
Practical Needs	As financial support, travel insurance, supplies of incontinence pads, easy parking facilities, anticipation of returning to work. Too much bureaucracy in handling these matters.
Information Needs	Related to problems with the provision of information about post-treatment; contradictory statements; lack of information on the practical aspects of incontinence management; reduced consultation time; lack of follow-up appointments; lack of factual information on patient's condition; and lack of a multidisciplinary team.

## Appendix D – Meeting with Co-researchers (Interview Feedback and Discussion of the Findings)

*"I was waiting for these results. The needs found fit into what is the reality of today and reflect all the challenges and lack of support that we feel, and that deep down leads us men to enter a little into deprivation and take refuge in ourselves, because we feel more comfortable. We see this mirrored in society in relation to health. We do not have that answer and there is a long way to go, but this work will succeed, because it contributes to change in this direction." (Member of the Research Team – Co-researcher)*

*"The study was well directed taking into account the objectives and I think it was possible to identify the points that are fundamental and extremely important within the state of the disease that is the PC. Namely, the point of need for sexual health literacy which, for me, is one of the biggest deficits I've ever seen. There's clearly a flaw in follow-up after treatments, and sometimes it is counterproductive how information is transmitted about their consequences in sexual life. This deficit mainly concerns the psychological accompaniment, as it was verified, because the physical is being attended. We are still a conservative society, and as mentioned, not all 60/70-year-olds have a mental openness to look for alternatives. In this sense, monitoring in relation to following a satisfactory sexual life after the treatments should be structured at the level of health professionals, and it should be the urologist himself to refer. Even if it is not a mandatory support, because there are men who want, men who do not want, or men who do not want initially and then change their mind, it is important to inform the person in this sense, to inform that support exists, and also include the partners in these consultations to make it easier. If there is no such opening, shame and ideals like "instead of being happy to be alive you are worried about sex life" will be perpetuated. The approach should be natural for health professionals and the important thing now is that these conclusions are properly taken into account and put into practice as soon as possible." (Member of the Research Team - Co-researcher)*

## Appendix E – Sociodemographic Questionnaire

### Questionário Sociodemográfico

1. Idade: \_\_\_\_\_
2. Género: \_\_\_\_\_
3. Nacionalidade: \_\_\_\_\_
4. Habilitações literárias (último ano de ensino concluído): \_\_\_\_\_
5. Profissão atual: \_\_\_\_\_
6. Especialização: \_\_\_\_\_

*Nota: As questões 7, 8 e 9 são questões direcionadas a pacientes.*

7. Situação relacional (ex.: solteiro, casado, em união de facto, etc.): \_\_\_\_\_
8. Data do término dos tratamentos: \_\_\_\_\_
9. Tratamentos efetuados: \_\_\_\_\_

## *Appendix F - Interview Script*

### **Guião de Entrevista**

1. Qual o impacto que os tratamentos têm na qualidade de vida dos sobreviventes?
  2. Na sua opinião, quais os principais desafios em ter uma vida sexual satisfatória, após os tratamentos?
  3. De que forma considera que os sobreviventes de CP procuram melhorar a sua saúde sexual após os tratamentos?
  4. Em que momento do curso da doença considera que seria importante os doentes receberem apoio psicológico?
  5. Em que momento do curso da doença considera que seria importante os doentes receberem apoio especializado (ex. terapia sexual, oncosexologia, medicina sexual) para dificuldades sentidas relativamente à sua saúde sexual?
  6. Na sua opinião, quais são as três principais necessidades não atendidas que considera mais importantes, e porquê?
    - a. Necessidades Físicas
    - b. Necessidades Psicológicas
    - c. Necessidades Sociais
    - d. Necessidades Íntimas
    - e. Necessidades Práticas (ex.: obter estacionamento prioritário, acesso a fraldas, apoio no regresso ao trabalho, etc.)
    - f. Necessidades de Informação (ex.: comunicação médico/paciente, acesso limitado a informação, tempo muito reduzido de consulta, etc.)
-