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## **Sexual health care in prostate cancer for men and their partners**

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# Chapter 1



# General introduction and outline of the thesis



## GENERAL INTRODUCTION

Prostate cancer is one of the most common types of cancer among men (1). In 2022, more than 14,000 Dutch men were diagnosed with prostate cancer (2). As a result of enhanced awareness, many men engage into early prostate cancer screening. Consequently, the number of annual diagnoses has increased over the past years (3).

Most men diagnosed with prostate cancer are treated with curative intent. Several treatments exist for prostate cancer, depending on disease stage and preference of the patient. Prostate cancer can be generally treated by means of radical prostatectomy, brachytherapy, external radiotherapy and a combination of radiotherapy and hormone therapy (4). Hormone therapy solely and chemotherapy are mostly used in case of metastasized disease (5). Conversely, active surveillance can be chosen in case of localized disease and contingent upon choice of the patient (6).

### **Sexual dysfunction after prostate cancer treatment**

Indisputably, each treatment can be accompanied by several side effects adversely affecting sexual function. Prostate cancer treatment can affect loss of libido, shortness of penile length, and ejaculatory changes (7). Yet, most men treated for prostate cancer experience an important loss in sexual function, mainly due to erectile dysfunction. On average, 85% of men encounter erectile dysfunction after a laparoscopic radical prostatectomy; whereas robot-assisted radical prostatectomies show a lower, yet considerable percentage of men with erectile dysfunction, namely 67% (8, 9). In general, brachytherapy is one of the treatments that causes the least amount of sexual side effects. After brachytherapy, about 32% of men experience erectile dysfunction (10). Notwithstanding its lower percentage of erectile dysfunction after treatment, men treated with brachytherapy have declared to endure changes in their sexuality, which have negatively influenced their overall quality of life (11). After one year, around 30% of men who have undergone external beam radiotherapy treatment still encountered alterations in erectile function (12). When treated for metastasized disease, 80% of men experience loss of libido, erectile, and orgasmic dysfunction leading to important changes in sexual function (13).

### **Expectations concerning sexual side effects**

As abovementioned, experiencing sexual dysfunction after prostate cancer treatment has major consequences for men and their sexuality. Great part of men declares to regret their treatment due to the sexual problems it has caused (14). Therefore, it is utterly important that men, who have to undergo prostate cancer treatment, are well aware of the potential side effects. In order to meet adequate expectation management,

information provision becomes a key element. Adding written information material is therefore of great importance. Kessels has shown that 40 up to 80% of the verbal information is forgotten when provided in a consultation setting (15). Moreover, studies have shown that adding written information material increases patient's satisfaction concerning overall treatment (16, 17). Nevertheless, men may still prefer other types of information material, for instance websites or videos; especially when also considering those who have a low level of literacy (18). Yet, healthcare providers should be aware of the fact that not all web resources may meet the intended standards and so professional web resources should be further explored or should preferably be generated by healthcare providers themselves together with patient associations if possible.

### **Partners**

Prostate cancer diagnosis and treatment does not only affect men, yet also their partners. Emotional distress, trying to keep harmony between concerns about their own health, and their husband's wellbeing together with possible deficiency of communication within their relationship may lead to problems which are currently underestimated by health physicians (19). Studies reveal that around a third of female partners declared to not have experienced sexual problems and that they are helpful towards the new situation as a result of sexual dysfunction (20, 21). Still, partners may feel that their sexual needs are not sufficiently highlighted since all attention is mostly around men dealing with their changed sexual function (22). Around half of the partners report to have experienced difficulties dealing with sexual side effects of prostate cancer treatment (23). In some cases men perceive their erectile function and sexual performance higher than their partners (24). Moreover, partners may experience more distress than men and so sexual side effects have a rather important influence on couples (24). Partners who endure more general depression, also endure more sexual dissatisfaction and diminished sexual esteem. The level of depression among partners regarding their sex lives is significantly correlated with the level of relationship satisfaction among men; thus, the higher the level of depression, the poorer the quality of communication about their sexual relationship (22). Partners with an unsatisfactory sexual relationship, do not often approach their loved ones concerning this subject since they do not want to let them feel pressured (25). Moreover, communication becomes a crucial element in assessing changes in sexual function after prostate cancer treatment. Unfortunately, literature reveals that not all couples feel properly guided and unmet needs are present when it comes to supportive therapy (26, 27).

### **Adequate healthcare provision**

In order to provide suitable guidance regarding sexual dysfunction after prostate cancer treatment, it is utterly relevant to further improve healthcare provision. The European

Association of Urology (EAU) Guidelines stated that nurse led multi-disciplinary rehabilitation has beneficial outcomes as regards to sexual function (28). Giesler et al. described nurse led multi-disciplinary rehabilitation as a form of recovery in the matter of sexual function and relationship issues (29).

As to urologists and urology residents, the EAU Sexual and Reproductive Health Guidelines reported an altered method to treat erectile dysfunction (30). Contrary to the prior step-wise approach as to ED management, i.e. PDE-5 inhibitors, intra-urethral medication, intracavernosal injections, vacuum devices, shock wave therapy, and implantation of penile prostheses, Burnett et al. suggested that men should be given all options at once so they may make a decision that suits them best together with their treating healthcare provider (31).

Urologists, urology residents, radiotherapists, and oncology professionals are considered eligible to execute proper consultation for men and their partners for treatment concerning the expected side effects and adequate supportive care afterwards. Several factors (i.e. kind of information and timing) contribute to proper healthcare provision and preference may vary per type of patient and their partner (23). Nevertheless, in the interest of administering appropriate health care, training, and education of healthcare providers becomes crucial. In Europe most healthcare providers involved in sexual health care, especially after oncological treatment, have reported to not feel sufficiently competent (32). As to urology residents who treat men with prostate cancer, almost 70% declared to be in need of more education and training in order to consult patients experiencing sexual dysfunction more adequately (33). Hence, further melioration of education programs are needed as well as suitable counseling for couples dealing with obstacles after prostate cancer diagnosis and/or treatment.

## **OUTLINE OF THE THESIS**

The aim is to obtain a valuable impression concerning current sexual health care in prostate cancer and determine possible lacks and assess necessities of all involved parties. The aim of research is whether the provision of current sexual health care is sufficiently adequate to guide men with prostate cancer and their partners when encountering issues around altered sexuality after treatment and anxiety as to disease recurrence or progression. This thesis comprises three parts reporting the results of a patient study evaluating sexual health care from the patient's point of view, a study among partners defining sexual side effects and studies regarding information provision and the sexual health care system from the perspective of healthcare providers.

Part I describes results of two studies among men with prostate cancer. The first study (Chapter 2) examines what type of counseling and which moment during treatment is considered most suitable to discuss altered sexual function. The second study (Chapter 3), a multicenter patient study, explores the discrepancy between expectations and the experienced consequences of prostate cancer treatment as to sexual side effects based on information provision.

Information provision given by urological and radiotherapeutical department have been compared in Chapter 4 of Part II.

In Chapter 5 of Part III sexual side effects from the partner's point of view are reported with an analysis of the impact on the relationship and possible associations with demographic and clinical characteristics.

Part IV consists of several studies, which investigate sexual health care from the health professional's perspective. A study establishing level of knowledge and competence among urology residents together with their possible needs for additional education and training is described in Chapter 6. Furthermore, in Chapter 7 knowledge, competence and general practice of healthcare providers was evaluated at a symposium concerning sexual health care in prostate cancer and six months afterwards. Additionally, Chapter 8 outlines a letter to the editor regarding current sexual healthcare education whereas not only sexual health training should be meliorated, yet also management of outpatient clinics and availability of referral possibilities and information provision.

PartV involves the general discussion defining the main findings with recommendations for future research and the conclusion of this thesis.



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