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Sexual health care in prostate cancer for men and their partners

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Part I

Sexual health care
in prostate cancer:
Men

Chapter 2



Suitable sexual health care according to men with prostate cancer and their partners

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Background

Prostate cancer (PCa) is the most common cancer among men in the Western world, with approximately 11.000 cases diagnosed in the Netherlands each year (1). Increased public awareness and prostate-specific antigen testing partially explain the raise of PCa detection (2). Treatment method is primarily selected according to disease stage and where applicable, to the patient's preference. Early detection and improvement of therapies have led to an increase in survival outcomes, meaning PCa therapy may be curative or life prolonging.

Nevertheless, can PCa treatment affect quality of life (QoL) majorly (3). Among other treatment-related side effects, such as incontinence of urine, sexual dysfunction (SD) is one of the most prevalent consequences of PCa treatment with erectile dysfunction (ED) as primary complaint (4). Five years after diagnosis, 79% of men treated with radical prostatectomy (RP) experience ED and 64% of men treated with radiotherapy (5). Seventy-two percent of men treated with RP experience significant loss of QoL due to ED (6). At present, common ED treatment options consist of PDE5 inhibitors, intra-urethral medications, intracavernous injections, vacuum therapy and penile prostheses (7). Despite PDE5 inhibitors are considered as first-line treatment, alprostadil or tadalafil in comparison to placebo does not always show significant improvement in RP-related ED (8, 9). Accordingly, it is important to initiate penile rehabilitation after PCa treatment as soon as possible in order to encounter which treatment suits best.

Alterations in sexual health do not only affect men, but their partners as well. Partners report higher levels of anxiety, not only as a result of coping with the disease, but also due to changes in their sexual relationship (10). Thirty-eight percent stated to be unsatisfied with the sexual relationship with their partner (11). Moreover, changes in a sexual relationship can negatively affect the overall relationship (12). A study performed among couples facing PCa showed that both men and partners suffered from the impact of the treatment-related side effects on their psychological wellbeing as well as on their romantic relationship (13).

Nevertheless, limited research has been performed to investigate adequate management of sexual side effects of PCa treatment (14). There are limited opportunities for men and partners to address the impact of the treatment-related side effects on their sexual health during follow-up consultations, since priority is given to disease control (15). Consequently, psychological wellbeing of men and their partners may be impaired, leading to a decrease in QoL (16).

Hence, we aimed to evaluate the current situation of sexual health care and satisfaction of treatment options provided to men experiencing treatment-related SD. Furthermore, we aimed to investigate which healthcare provider is preferred and what timing is considered as most suitable for sexual counseling after PCa treatment according to the point of view of men and their partners

Methods

Study population

For this cross-sectional study, patients were recruited throughout the oncology registration of Leiden University Medical Center. Based on the hospital's declaration code for PCa, a list was obtained with patients diagnosed with or treated for PCa between 2013 and 2015. Subsequently, the list also comprised patients who were diagnosed with or treated for PCa before 2013 and had received an (additional) treatment between 2013 and 2015. Patients under active surveillance (AS) or treated (after AS) with laparoscopic radical prostatectomy (LRP), brachytherapy (BT), intensity-modulated radiotherapy (IMRT) and/or hormonal therapy (HT) were included. Additional patient data obtained from the oncology registration included age, PCa staging and type of obtained treatment(s). Using the registration of the municipal personal records database, patients who deceased or moved abroad were refined. This process led to a total of 590 eligible men. In June 2015, an information letter and a consent form for patient and/or their partner were sent by mail. Reason to not participate, could be indicated on the consent form. With affirmative consent, questionnaires were sent in separate, post-paid envelopes to warranty privacy of patients and their partners.

Materials

Questionnaire design

The questionnaires were designed by the authors, based on the study aim and review of literature. The questionnaire developed for patients treated after diagnosis or after AS, consisted of 47 items assessing topics such as sociodemographic-factors, sexual function (SF) before and after treatment, experience and satisfaction regarding current sexual health care and desired sexual health management. A similar questionnaire was developed for patients who were under AS where questions around received treatment were withdrawn. The questionnaire developed for partners consisted of 14 items including sociodemographic factors, sexuality throughout their partner's treatment and whether counseling in sexuality and/or relational matters would be appreciated.

In February 2015, a pilot test was performed among five members of the Dutch

PCa Foundation to improve suitability and comprehensiveness of the questionnaire. Adjustments were made to the content, phrasing of questions and additions to answer possibilities were performed. Due to an incorrect question-answer combination with regard to the question what timing was found to be suitable for sexual counseling, part of the answers lapsed. Responses from the participants who had interpreted the question correctly, were described in the results.

Statistical analysis

Quantitative data were analyzed using IBM SPSS Statistics, version 23.0. Descriptive statistics were used to analyze demographic and clinical variables. Numerical variables were described with mean (SD), categorical variables with number (%). Associations between preferred healthcare provider and clinical data were analyzed using the Pearson's Chi-Square test. Associations in clinical data were calculated using the McNemar test. Two-sided p values <0.05 were considered statistically significant.

Ethics

The protocol for this study was approved by the Institutional Review Board at Leiden University Medical Center in June 2015. Consent was essential, since it concerned a survey with sensitive questions and confidentiality of the participants had to be guaranteed.

Results

A total of 584 men were eligible to participate in this study (in hindsight six men were considered ineligible to participate, due to death after start of the study). Among men who did not want to participate in the study ($n = 168$), most named reasons were non-interest ($n = 49$), irrelevance regarding improvement in this area ($n = 33$) and questions being too personal ($n = 29$). A remaining group of 134 men who were approached, did not respond throughout the consent form. A group of 29 men gave their consent, yet did not return the questionnaire. Consequently, a total of 253 men participated in our study.

Sociodemographic characteristics

The average age of men was 69.3 years (SD 6.9, range 45–89), the majority (78.6%, $n = 198$) was retired. Almost 78.0% ($n = 196$) was married, with an average duration of the relationship of 40.3 years (SD 14.1, range 2–64). PCa was diagnosed at an average age of 66.2 years (SD 6.7, range 42–86) and most participants (91.7%, $n = 232$) had localized disease at the time of diagnosis. IMRT combined with HT was the most common type of treatment received (28.1%, $n = 71$), followed by LRP (25.3%, $n = 64$) and IMRT (23.7%, $n = 60$). Further details on demographic and clinical characteristics are shown in Table 1.

Table 1. Demographic and clinical characteristics of participating men.

	n (%)
Age (years)	
Mean 69.3 (SD 6.9, range 45 – 89)	253 (100.0)
Occupation	
Employed	47 (18.6)
Unemployed	7 (2.8)
Retired, employed	69 (27.3)
Retired, unemployed	129 (50.9)
Unknown	1 (0.4)
Education	
No qualification/elementary school	16 (6.3)
Lower vocational education	65 (25.7)
Intermediate vocational education	56 (22.1)
Higher secondary education	33 (13.1)
Higher education	81 (32.0)
Unknown	2 (0.8)
Marital status	
Unmarried	18 (7.1)
Married	196 (77.5)
Common law	11 (4.3)
Widowed	13 (5.1)
Other	14 (5.5)
Unknown	1 (0.5)
Duration of relationship	
Mean 40.3 (SD 14.1, range 2 – 64)	217 (85.8)
Age at diagnosis (years)	
Mean 66.2 years (SD 6.7, range 42 – 86)	253 (100)
TNM staging	
T – Primary tumor	232 (91.7)
N – Regional lymph nodes	11 (4.3)
M – Metastatic disease	8 (3.2)
TNM staging unknown ^a	2 (0.8)
Type of treatment	
Active surveillance (AS)	17 (6.7)
Laparoscopic radical prostatectomy (LRP) ^b	64 (25.3)
Brachytherapy (BT)	25 (9.9)
Intensity-modulated radiotherapy (IMRT)	60 (23.7)
IMRT combined with HT ^c	71 (28.1)
Hormonal therapy (HT)	15 (5.9)
Other ^d	1 (0.4)

a. Clinical diagnosis, no TNM staging available

b. Including LRP combined with IMRT (n = 5) and LRP combined with HT (n = 1)

c. Including BT combined with HT (n = 8) and IMRT combined with LRP and HT (n = 4)

d. Pelvic lymph node dissection (n = 1)

Sexual function throughout treatment

Prior to treatment, 34.6% out of 250 participating men had moderate to severe ED. After treatment a significant difference in ED was found: 80.5% suffered from moderate to severe treatment-related ED ($p < 0.001$). Half of the participants (50.0%, $n = 124$) was no longer sexually active due to treatment and 78.2% ($n = 190$) reported deteriorated SF. Erectile complaints were experienced immediately after treatment mostly by men treated with LRP (93.8%, $n = 60$) followed by men treated with IMRT combined with HT (77.9%, $n = 53$). In Table 2, presence of ED before and after treatment is displayed for the different types of treatment, with the greatest increase of percentage points in men treated with LRP and in men treated with IMRT combined with HT by 62.5% ($p < 0.001$) and 53.3% ($p < 0.001$) respectively.

Table 2. Moderate to severe ED before and after treatment.

Type of treatment	ED prior to treatment n (%)	ED after treatment n (%)	Percent difference (%)	<i>p-value</i> ^c
Active surveillance (AS)	5 (29.4)	6 (35.3)	5.9	NS (1.000)
Laparoscopic radical prostatectomy (LRP) ^a	20 (31.3)	60 (93.8)	62.5	< 0.001
Brachytherapy (BT)	14 (56.0)	22 (88.0)	32.0	0.021
Intensity-modulated radiotherapy (IMRT)	26 (43.3)	46 (81.0)	37.7	< 0.001
IMRT combined with HT ^b	17 (24.6)	53 (77.9)	53.3	< 0.001
Hormonal therapy (HT)	5 (33.3)	11 (73.3)	40.0	NS (0.070)
Other ^c	-	-	-	-

NS: Not significant

a. Including LRP combined with IMRT ($n = 5$) and LRP combined with HT ($n = 1$)

b. Including BT combined with HT ($n = 8$) and IMRT combined with LRP and HT ($n = 4$)

c. McNemar test

ED treatment options

Participants were asked to report which types of ED treatment options were offered by their healthcare provider. Out of available ED treatment options, PDE5 inhibitors were offered the most (50.0%, $n = 94$), followed by a single consultation to discuss sexual health (12.8%, $n = 24$), intra-urethral medications (11.2%, $n = 21$), intracavernosal injections (6.9%, $n = 13$), and vacuum therapy (5.4%, $n = 10$). One out of seven men (14.4%, $n = 27$) indicated their health provider never offered an ED treatment option. Out of 101 men, a third indicated “partial satisfaction” (30.7%) up to “no satisfaction” (25.7%) regarding treatment for their erectile complaints. Reasons for dissatisfaction consisted of limited results (54.8%, $n = 17$), discomfort (6.5%, $n = 2$), and high costs (3.2%, $n = 1$). Six participants (19.4%) indicated to be unable to report results concerning the effect of ED treatment, as they had not used the prescribed medication yet. Despite preceding results, only a third of men with ED (31.2%, $n = 58$) were offered the possibility to discuss sexuality with a specialized healthcare provider, such as a sexologist.

Partners

A total of 174 partners of men with PCa participated in this study, among them 171 women and 3 men. The average age was 65.5 years (SD 7.6, range 45–86) and the majority (65.6%, $n = 114$) was retired. Further details on demographic and clinical characteristics are shown in Table 3.

Table 3. Demographic and clinical characteristics of the partners.

	n (%)
Age (years)	
Mean 65.5 (SD 7.5, range 45 – 86)	174 (100.0)
Gender	
Female	171 (98.3)
Male	3 (1.7)
Occupation	
Employed	46 (26.4)
Unemployed	14 (8.1)
Retired, employed	19 (10.9)
Retired, unemployed	95 (54.6)
Education	
No qualification/elementary school	12 (6.9)
Lower vocational education	79 (45.4)
Intermediate vocational education	33 (19.0)
Higher secondary education	17 (9.7)
Higher education	33 (19.0)
Marital status^a	
Unmarried	4 (2.3)
Married	146 (83.9)
Common law	7 (4.0)
Widowed	1 (0.6)
Other	4 (2.3)
Unknown ^b	12 (6.9)
Comorbidities^c	
Hypertension	54 (18.4)
Hypercholesterolemia	45 (15.3)
Rheumatic and joints disease	45 (15.3)
Obesity	20 (6.8)
Chronic inflammatory lung disease	16 (5.4)
Diabetes mellitus	15 (5.1)
Psychological disease	13 (4.4)
Heart and coronary artery disease	9 (3.1)
Thyroid disease	7 (2.4)
Cerebrovascular accident	5 (1.7)
Other	15 (5.1)
No comorbidities	50 (17.0)

a. Data obtained by correlating partners with corresponding patients

b. Partners of patients who did not participate

c. Comorbidities are displayed in number of frequencies

Half of the partners (50.6%, $n = 81$) reported to have experienced difficulties handling the altered situation regarding sexuality. Fifty-one percent ($n = 85$) reported to have faced moderate to severe problems concerning sexuality subsequent to treatment of their partner. As regards to other treatment-related side effects, such as urinary incontinence, 61.6% ($n = 101$) mentioned to have not experienced difficulties dealing with it. Nevertheless, the majority of the partners (69.3%, $n = 115$) mentioned these changes in intimacy have not influenced their romantic relationship.

Regardless the fact that almost half of the partners reported difficulties around sexuality with their partner, 86.9% ($n = 93$) indicated to not be in need of additional support for sexual health and/or relational issues. A few partners (11.5%, $n = 6$) indicated that a long-term relationship should be capable of overcoming these kind of obstacles, and although a sexual relationship is no longer existent, being intimate in another way is considered satisfactory as well. Several partners (25.0%, $n = 13$) reported to have accepted the new situation around sexuality and experienced improved communication within their relationship due to this alteration. Still, a greater part of the partners (29.8%, $n = 36$), who did not feel the necessity to obtain additional support, reported to have experienced difficulties with their sexuality and relationship. Lack of intimacy (33.3%, $n = 12$), loss of their sexual relationship (27.8%, $n = 10$), coping with frustrations of their partner, and coming from dealing with ED as well as the feeling of loss of masculinity (25.0%, $n = 9$) and increased tension in their relationship (13.9%, $n = 5$) were the most named reasons.

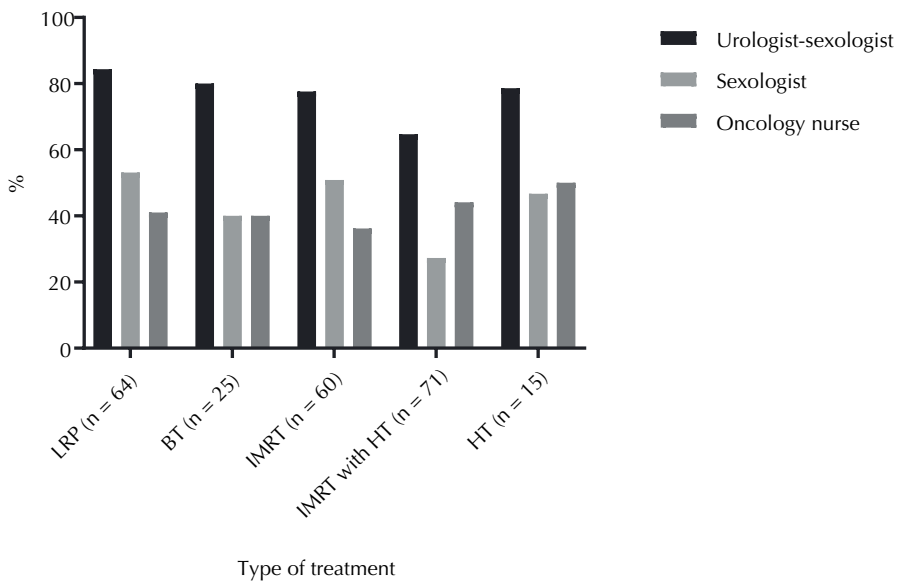
Preferred sexual health care

We asked the participants whether they would appreciate it to discuss treatment-related SD and relational matters with certain healthcare providers. On the assumption this would take place with a urologist-sexologist, the majority (74.7%, $n = 183$) answered positively. In case that would concern a sexologist, 43.0% ($n = 104$) agreed and if these subjects would be discussed with an oncology nurse, 40.5% ($n = 98$) conceded. Around one fourth of participating men (24.4%, $n = 60$) indicated such a consultation should only occur on patients' initiative. Two men preferred to discuss these personal matters with their general practitioner.

Preferences for certain healthcare providers depending on received type of treatment were analyzed (see Fig. 1). Out of all men who preferred the urologist-sexologist, this healthcare provider was named the most by men who had undergone surgical treatment (84.4%, $n = 54$). When comparing the group by whom the urologist-sexologist was named the least, namely men who received IMRT combined with HT (64.7%, $n = 64$), a significant difference was found ($p = 0.01$). Again, the group of men who received

IMRT combined with HT was in the minority as to when the sexologist was suggested as a suited healthcare provider (27.3%, $n = 19$). When comparing the group of men treated with IMRT combined with HT with the LRP treatment group as well as with all other types of treatments, a significant difference in preference as to the sexologist as most suited healthcare provider was found ($p < 0.05$ and $p < 0.05$). With regard to the preference for the oncology nurse, no significant difference was found when the group of men who received IMRT was compared to the HT treatment group nor to all other types of treatments ($p = 0.38$ and $p = 0.34$).

Figure 1. Preferences for various healthcare providers per treatment.



Subsequently, participants were inquired to determine the most suitable timing for sexual counseling. Almost half of the participants (47.6%, $n = 49$) considered 3 months after treatment as best suited. A third (33.0%, $n = 34$) preferred as soon as possible; meaning the first visit attending their urologist; around 4 weeks after treatment. A minority (11.6%, $n = 12$) mentioned a period of 6 to 9 months after treatment as convenient, followed by a group who considered 1 year after treatment as most suited (7.8%, $n = 8$).

As to which extent involvement of partners is important when sexuality is discussed, 67.9% ($n = 144$) of participating men determined involvement of their partner as crucial. A small part (20.3%, $n = 43$) indicated to not feel concerned whether their partner is involved or not and 11.8% ($n = 25$) preferred to discuss intimate issues without the presence of their partner.

Discussion

Key results

This study shows current sexual health care is not conclusive according to men experiencing SD due to PCa treatment. Significant loss of erectile function (EF) is experienced by the majority of men treated for PCa. Several ED treatment options are available, for what PDE5 inhibitors were prescribed the most. However, more than half of the participants were not satisfied with the ED treatment results. A standard consultation with a urologist-sexologist 3 months after treatment is preferred by the majority of the participants. The same consultation performed by a sexologist or an oncology nurse is considered preferable as well. Men who have received surgical treatment have a preference for a urologist-sexologist compared to men who have received IMRT combined with HT, whom prefer a urologist-sexologist the least. When it comes to a consultation with a sexologist, the group of men treated with IMRT combined with HT preferred the sexologist the least, whereas the group of men who were treated with IMRT preferred the sexologist the most. When the consultation would take place with an oncology nurse, among all types of treatments, no significant difference was found. Regarding the partners, half of them encountered issues concerning altered sexuality. However, dealing with other treatment-related side effects, such as urinary incontinence, were not experienced as a problem by a great number of partners. Moreover, the majority of the participating men indicated presence of their partner as crucial during such consultations, whilst a minority stated to prefer consultations in a private setting.

Comparison with literature

Although an overall high satisfaction is found concerning supportive care after treatment, men treated for PCa reported that physical problems are addressed more often than psychosocial-related issues (4). SD as a result of PCa treatment comprises several components, including ED. Gandaglia et al. investigated whether penile rehabilitation is effective after nerve-sparing RP (17). Penile rehabilitation was defined in this study as implementation of any intervention in the context of obtaining erections sufficient for sexual intercourse, and preferably to obtain EF back to its preoperative state. Clinical studies reported inconsistent results as to long-term effects on EF. The authors concluded that an optimal recovery program for men treated with RP is still a subject in need of further investigation. Regarding SF subsequent to RT, Incrocci performed a study to investigate post-radiation ED in men treated for PCa (18). The investigators stated post-radiation ED is a multi-factorial problem. Consequently, PDE5 inhibitors seem to be efficacious in only half of men treated with radiation therapy. In consonance with our study, men who used PDE5 inhibitors reported dissatisfaction due to lack of efficacy, high costs and side effects.

Importance of psychosexual care

Current Western health care has gained more focus on improving QoL throughout enhanced disease management, especially in oncology treatments, considering its great impact to psychological health and wellbeing (19). Nevertheless, psychosexual care is still found to be a great unmet need among the majority of men treated for PCa, since psychosocial and relational problems are unaddressed in comparison to physical problems (4). Despite the fact sexual health issues may concern an important topic to them, they experience difficulties in disclosing their complaints with healthcare providers or their partners (20). Moreover, many tools are available to provide proper guidance to men experiencing SD; however, great part of them are hardly ever used (21).

Noteworthy to mention is the lack of need of the partners to obtain supportive care around sexuality and/or relational issues. Despite the imposing difference between the two genders, it has been described in the literature previously (11). This study described a group of men and their partners where, comparable to our study group, men were more interested to obtain supportive care around altered sexuality whereas almost half of the partners reported to not be interested in receiving support for changes in their intimate relationship. Several types of reasons therefore were named by partners within our study group. Part of them considered these issues as an obstacle apparent to overcome within their long-term relationship, whilst others accepted the altered situation and even encountered improved communication with their partner. However, an important number of partners experienced several sexual issues, and are still not in need of additional support. Wittmann et al. studied partners of men surgically treated for PCa and found that several partners did not attempt to initiate sexual activities in order to not pressure their partner to perform (22). Although partners may experience high unmet sexual needs, they tend to emphasize other elements of the relationship rather than the sexual part to not let their partners feel insecure about their sexual performance (23). Thereupon, men reported to be unaware of their partners' sexual needs. So despite the fact that partners report to not be in need of sexual support, they may not be neglected when sexual recovery for men treated for PCa is considered, since they may disguise their own sexual needs to prevail upon their partner's anxiety.

Strengths and limitations

One of the strengths of this study consists of its large cohort of men obtained from an academical cancer registry center, emphasizing the use of accurate and reliable data. Throughout this study, we were able to identify the unmet needs of men treated for PCa and to determine their preference by means of their received treatment. Moreover, we were able to address the supportive care needs of their partners as well.

Limitations include the cross-sectional research design, which implies participants presented their experiences retrospectively. Longitudinal evaluation of intervention outcomes designed according to received treatment and the patient's preference are key focus for future research.

Clinical implications

We were able to inventory to what extent ED treatment options were offered within our department and to which degree men were satisfied. Based on the study results, a patient-specific intervention can be developed and implemented. The outcomes showed that men have the preference to discuss sexual health issues with a urologist-sexologist the most, followed by a sexologist and an oncology nurse. Within the groups of men who received various treatments, preferences concerning the adequate healthcare provider differed. Accordingly, the person who will discuss sexual matters with men and their partners can be correlated throughout the received treatment. Content of these consultations can vary from discussing altered sexuality, methods as in how to experience intimacy in a different way to specific sexual education, and therapy interventions, based on the level of treatment-related SD and the patient's and his partner's preference. It is recommended to implement this standard consultation 3 months after treatment. The intervention will not only provide the necessary space for men to mention their sexual complaints, in addition, it will aid to improve the physician-patient relationship as well, enhancing health-related QoL (24). If the health care department is unable to provide such consultations with the suggested healthcare provider, it becomes fundamental to identify sexual and/or relational problems in good time so referral can take place properly. Accordingly, referral systems within corresponding hospital or clinic should be well-established.

Conclusions

PCa treatment has important consequences for the psychosexual health and for the relationship between men and their partners. Unfortunately, it has become an underexposed aspect during follow-up consultations, leading to a decrease in QoL. PDE5 inhibitors are considered as the most common ED treatment option, although unsatisfactory results are reported. A great number of men would rather obtain supportive care provided by a urologist-sexologist with regard to sexual health issues and relational matters. Three months after treatment is considered the most suitable timing. In addition, the majority prefers their partner to be present during these consultations. It is therefore recommended to schedule an additional consultation or to refer a patient to a urologist-sexologist in case altered sexuality is experienced as a result of PCa treatment.

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