Sexual health care in prostate cancer for men and their partners

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Chapter 3

Discrepancy between expectations and experiences after prostate cancer treatment: a Dutch multicenter study

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Introduction

Men who have undergone prostate cancer (PCa) treatment may have unrealistic expectations about sexual side effects they may develop after treatment. A great number of men treated with laparoscopic prostatectomy expect to recover to their baseline erectile function, whilst erectile complaints have been described in 75% of these patients (1,2). Whenever treatment-related expectations do not match the actual outcomes, a decrease in quality of life may occur, as it is defined as the gap between patients' expectations of health and their experience of health (3). Expectation management as to possible treatment-related side effects plays a crucial role when it comes to enhancing quality of life after PCa treatment. In order to set more realistic expectations, patients could benefit from receiving adequate information regarding the possible side effects of the treatment. To our knowledge, we are the first to assess throughout a multicenter, cross-sectional survey possible discrepancies between patients' expectations and experiences concerning sexual side effects after PCa treatment. The aim is to investigate if expectations and developed sexual side effects are related to demographic characteristics, clinical components, comorbidity, or hospital where treated. Furthermore, to investigate if certain aspects of the obtained information (eg, given by whom and in which manner) are associated with the discrepancies between patients' expectations and sexual side effects. Moreover, to evaluate if sexual side effects have an influence on the patients' relationship.

Material and methods

Study population

For this multicenter, cross-sectional survey lists of eligible patients who were under active surveillance (AS), who received prostatectomy, brachytherapy, external-beam radiotherapy (EBRT), and/or hormonal therapy (HT) for PCa between 2013 and 2015 were obtained from Leiden University Medical Center (LUMC), Reinier de Graaf Gasthuis and Sint Antonius Hospital. Eligible patients also consisted of men who had started (additional) treatment between 2013 and 2015, but were diagnosed prior to 2013. Men under AS or diagnosed before 2000 were excluded. Patients' date of birth, year of diagnosis, prostate-specific antigen (PSA) level, tumor, nodes and metastasis (TNM) staging, Gleason grading and type(s) of received treatment were obtained from the oncology registry and the hospitals' electronic medical records. An information letter and consent form were sent by mail. With affirmative consent, questionnaires were sent.

Questionnaire design

The questionnaire was pilot tested among members of the Dutch PCa foundation. Erectile complaints before and after treatment were determined through a 3-point Likert scale ranging from "no erectile complaints" to "major erectile complaints." Multiple option questions were used to determine sexual activity (defined as sexual intercourse and masturbation), providers of information prior to treatment, methods of information provision, sources used for self-gathered information and reasons for (not) being satisfied with information provision. Multiple choice questions were used to inquire information about the influence of sexual side effects on the patients' relationship, satisfaction about information provision, and whether sexual side effects developed after treatment were in accordance with their expectations.

Statistical analysis

Demographic characteristics and clinical variables were analyzed using frequency tables. Numerical variables (age of participants, years between diagnosis and completing questionnaire, age at diagnosis, and PSA level at diagnosis) were described using mean (SD) or median (min. - max.). Categorical variables (relational status, occupation, education level, year of diagnosis, TNM staging, Gleason grading, and type of treatment) were described with number (%). Discrepancies between patients' expectations and developed sexual side effects reported not as bad or same as expected, were merged into "sexual side effects not as bad as expected" and compared to "sexual side effects worse than expected." Associations between numerical variables and discrepancies between patients' expectations and developed sexual side effects were calculated using unpaired t tests or Mann-Whitney U tests. Associations between categorical variables and discrepancies between patients' expectations and developed sexual side effects were calculated using Pearson Chi-Square test or Fisher's Exact test. Associations between paired categorical variables (sexual activity and erectile complaints before and after treatment) were calculated using McNemar's test. To analyze if age of participants was correlated with TNM staging, the Kruskal Wallis test was used. The One-way ANOVA test was used to calculate associations between age of participants and Gleason grading together with discrepancies between patients' expectations and developed sexual side effects and PSA level at diagnosis. Associations between age of participants and PSA level at diagnosis were analyzed with Spearman's correlation. Two-sided p values $<.05$ were considered statistically significant.

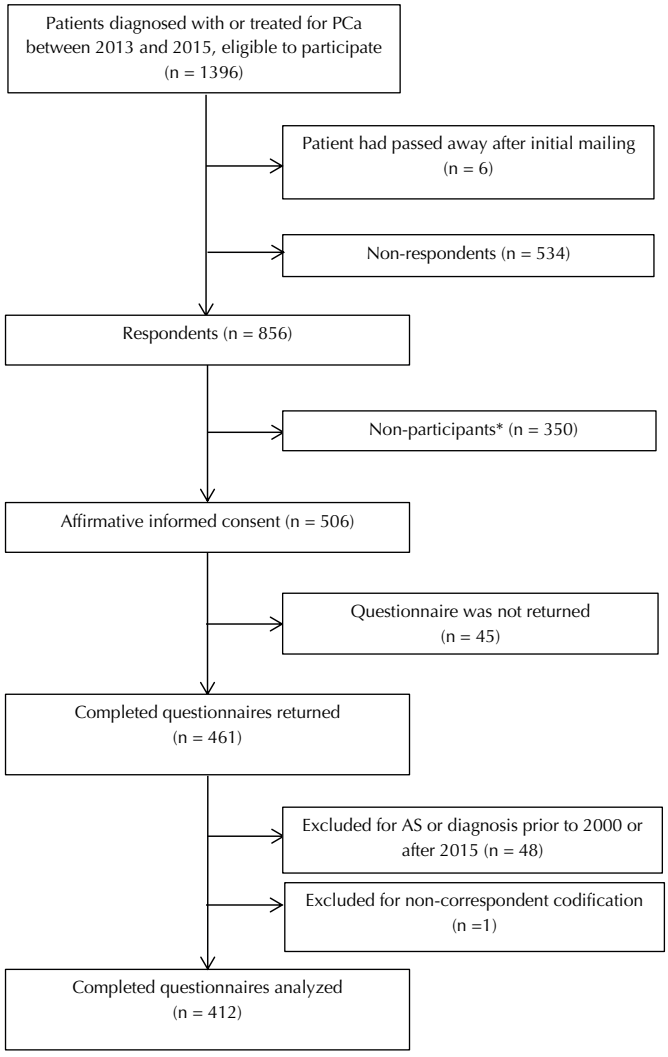
Ethics

Protocol for this study was approved by the Institutional Review Board at Leiden University Medical Center.

Results

Overall, 461 participants returned a completed questionnaire out of 1396 eligible men (response rate 33.0%). Forty-nine patients were excluded: men under AS (n = 41), diagnosed with PCa before 2000 (n = 6) or in 2016 (n = 1) and due to noncorresponding codification between data and questionnaire (n = 1). In total, 412 questionnaires were analyzed (Fig. 1).

Figure 1. Flow-chart of patient inclusion in the study.



* Most named reasons were non-interest (n = 114), questions being too personal (n = 63) and irrelevance regarding improvement in this area (n = 61)

Sociodemographic and clinical characteristics

The average patient age was 70.2 years (SD 6.8). The most named comorbidities were hypertension (n = 143), hypercholesterolemia (n = 81) and cardiovascular disease (n = 70). Thirty percent had no comorbidities (n = 122). The majority of the participants were diagnosed with localized disease (88.8%, n = 366) and a third was treated with prostatectomy (33.5%, n = 138). Seventy-eight percent of men completed the questionnaire 1 up to 5 years after diagnosis (78.7%, n = 324). Details are described in Table 1.

Table 1. Sociodemographic and clinical characteristics.

	n (%)
Age (years)	
Mean 70.2 (SD 6.8)	412 (100.0)
Relational status	
In a relationship	363 (88.1)
Unknown	1 (0.2)
Occupation	
Employed	61 (14.8)
Unemployed	10 (2.4)
Retired, employed	116 (28.2)
Retired, unemployed	223 (54.1)
Unknown	2 (0.5)
Education level	
Low educated	139 (33.8)
Secondary educated	138 (33.5)
High educated	132 (32.0)
Unknown	3 (0.7)
Year of diagnosis	
2000-2005	13 (3.2)
2006-2010	56 (13.6)
2011-2015	343 (83.2)
Years between diagnosis and completing questionnaire	
Median 3.4 (min. 0.5 - max. 19.7)	
<1 year	
1 – 2 years	3 (0.7)
3 – 5 years	154 (37.4)
6 – 10 years	170 (41.3)
11 – 15 years	73 (17.7)
>15 years	8 (1.9)
	4 (1.0)
Age at diagnosis (years)	
Mean 66.4 (SD 6.7)	412 (100.0)
Tumor, nodes and metastasis (TNM) staging at diagnosis	
T – Local stage tumor	366 (88.8)

Table 1. Sociodemographic and clinical characteristics.

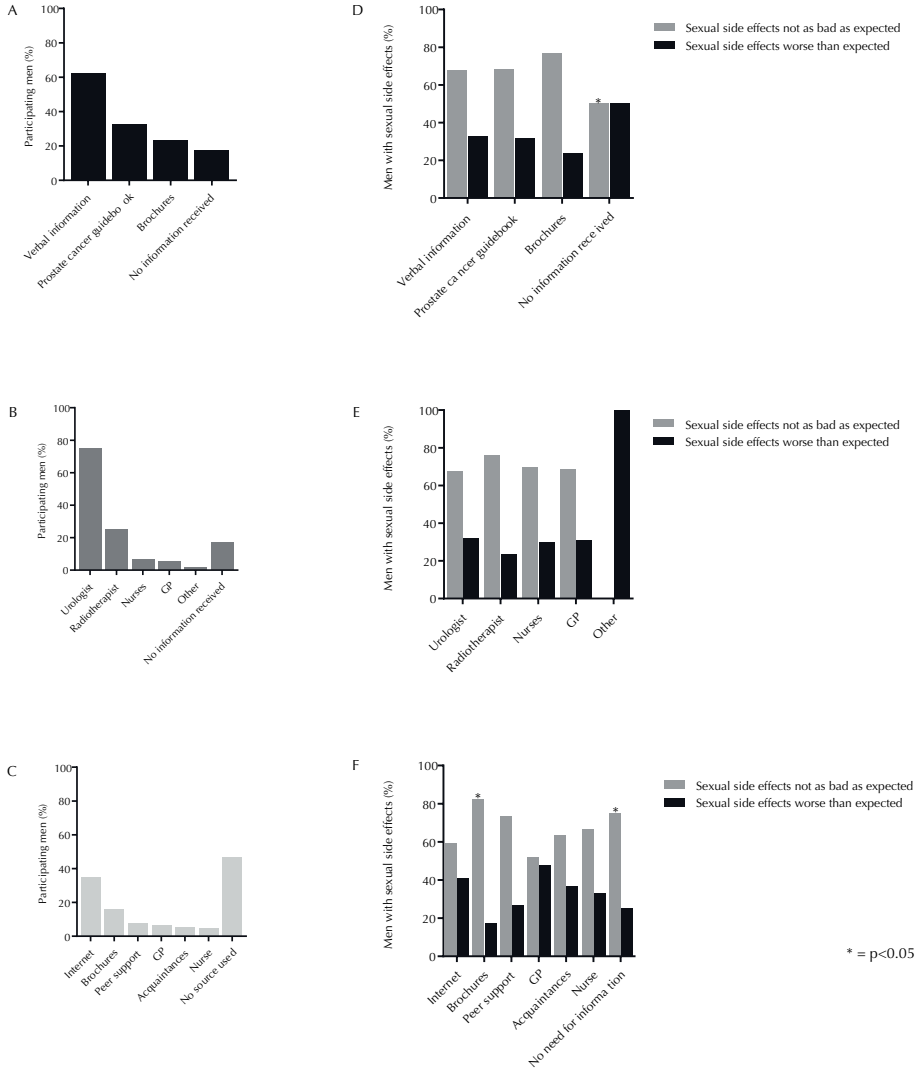
	n (%)
N – Regional stage tumor	26 (6.3)
M – Distant stage tumor	19 (4.6)
TNM staging unknown	1 (0.3)
Prostate-specific antigen at diagnosis	
Median 11.0 (min. 2.0 - max. 1090.0)	404 (97.8)
Gleason grading at diagnosis	
≤ Gleason 5	7 (1.7)
Gleason 6	158 (38.3)
Gleason 7	156 (37.9)
Gleason 8	41 (10.0)
Gleason 9	35 (8.5)
Gleason 10	5 (1.2)
Unknown	10 (2.4)
Type of treatment	
Prostatectomy[a]	138 (33.5)
Brachytherapy (BT)[b]	57 (13.8)
External beam radiotherapy (EBRT)[c]	80 (19.4)
Hormonal therapy (HT)[e]	31 (7.5)
Radiotherapy combined with HT[d]	104 (25.3)
Other[f]	2 (0.5)

PLND, > : pelvic lymph node dissection, TURP, > : transurethral resection of the prostate.
a. Including LRP (n = 67), RALP (n = 45), ORP (n = 1), LRP combined with EBRT (n = 5), LRP combined with EBRT and PLND (n=2), LRP combined with PLND (n = 2), LRP combined with HT (n=1), ORP combined with EBRT (n = 3), ORP combined with HT (n=1), ORP combined with PLND and HT (n = 1), RALP combined with EBRT (n = 4), RALP combined with EBRT and PLND (n=3), RALP combined with PLND (n = 3) and RALP combined with HT (n=1).
b. Including BT combined with TURP (n = 1) and BT combined with PLND (n = 1).
c. Including EBRT combined with PLND (n = 3)
d. Including EBRT combined with HT (n = 94), BT combined with HT (n = 10), EBRT combined with HT and PLND (n = 29), EBRT combined with HT and TURP (n = 2), EBRT combined with ORP and HT (n = 1), LRP combined with EBRT and HT (n = 1), LRP combined with PLND, EBRT and HT (n = 1)
e. Including surgical castration (n = 1), PLND combined with HT (n = 4) and TURP combined with HT (n = 1)
f. PLND (n = 1), cysto-prostatectomy (n = 1) and unknown due to referral to different hospital for treatment (n = 1)

Information provision prior to treatment

Information was most commonly received verbally (62.1%, n = 252) and from a urologist (74.9%, n = 301). The internet was most frequently used as a source for self-gathered information concerning sexual side effects (34.7%, n = 140). Further details on information provision are described in Figure 2A-C. Almost half of men (46.5%, n = 188) had no desire to search for additional information, eg if they already had received sufficient information (20.2%, n = 38).

Figure 2. Information provision prior to treatment among all participating men: (A) methods of information provision, (B) type of healthcare professional and (C) sources of self-gathered information. Information provision prior to treatment among men with sexual side effects: (D) methods of information provision, (E) type of healthcare professional and (F) sources of self-gathered information.



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2. Histogram A – C: descriptive.

Histogram D: percentages of men with sexual side effects per method of information provision; each method of information provision was compared to all other methods of information provision to determine possible significant association .

Histogram E: percentages of men with sexual side effects per type of healthcare professional; each type of healthcare professional was compared to all other type of healthcare professionals to determine possible significant association.

Histogram F: percentages of men with sexual side effects per source of self-gathered information; each source of self-gathered information was compared to all other sources of self-gathered information to determine possible significant association.

Satisfaction concerning information provision

Twenty-four percent (n = 99) reported to have received insufficient information prior to treatment concerning sexual side effects after treatment, whilst 63.5% (n = 261) stated they had received sufficient information. Furthermore, a small group (12.4%, n = 51) had no desire to obtain any information and did not receive it either. Two in three (65.6%, n = 246) were satisfied about information provision. However, 24.8% (n = 93) stated content and quantity of received information were insufficient. Incorrect timing of information provision was reported by 9.6% (n = 36).

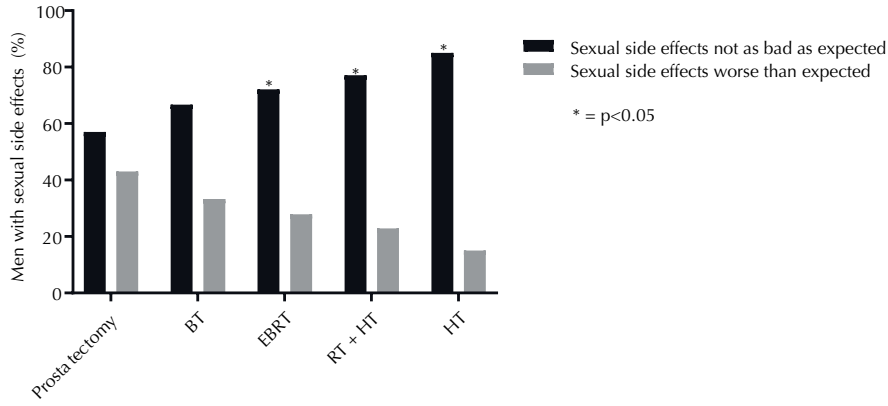
Sexual functioning after treatment

Almost all men reported to have been sexually active prior to treatment (95.1%, n = 389). Significantly fewer men reported to be sexually active after treatment (47.7%, n = 193; $p < .001$). Significantly more men reported moderate to severe erectile complaints after treatment than prior to treatment (82.8% vs 28.2%, $p < .001$). A total of 293 men (73.3%) experienced an increase in their erectile complaints after treatment. Thirty percent (n = 107) reported that the sexual side effects had had a negative effect on their relationship.

Discrepancies between patients' expectations and developed sexual side effects

Of men with sexual side effects after treatment, 1 in 3 reported them as worse than expected, based on the received information before treatment (32.5%, n = 109). Sixty percent reported no discrepancies between their expectations and developed sexual side effects (n = 199). A small group reported their sexual side effects as less severe than expected (8.1%, n = 27). No significant associations existed between degree of accordance in expected and developed sexual side effects and age ($p = .629$), age at diagnosis ($p = .759$), year of diagnosis ($p = .821$), educational level ($p = .390$), employment ($p = .704$), relationship status ($p = .555$), comorbidities ($p = .443$) or hospital where treated ($p = .644$). Having had erectile complaints prior to treatment and discrepancies between expectations and developed sexual side effects after treatment was not significantly associated ($p = .476$). Men who had undergone prostatectomy reported their sexual side effects as worse than expected more often than men who were nonsurgically treated (43.0% vs 26.1%, $p = .001$). Compared to men who had undergone prostatectomy, significantly less men who had undergone EBRT ($p = .046$), HT ($p = .017$), and RT combined with HT ($p = .003$) reported discrepancies. No significant difference between prostatectomy and brachytherapy was reported ($p = .270$) (Fig. 3). Men who had received RT combined with HT reported their sexual side effects as not as bad as expected than patients treated otherwise ($p = .031$).

Figure 3. Men with sexual side effects reporting discrepancies per treatment type compared to men who had undergone prostatectomy.



Of all tumor stages, men with a local stage tumor reported their sexual side effects most frequently as worse than expected (p = .005). Men with sexual side effects worse than expected had a significantly lower PSA level at diagnosis (17.4 vs 33.3 ng/mL, p = .046). Both PSA level and Gleason grading were not significantly associated with age (respectively p = .075, p = .173), whereas younger men were diagnosed more often with a local stage tumor (p = .018).

Men who reported to have received insufficient information prior to treatment, described their sexual side effects significantly more often as worse than expected than men who had received sufficient information (60.7% vs 22.6%, p < .001). Men who had used brochures for self-gathered information, reported their sexual side effects less often as worse than expected than men who had used other sources of information (17.5% vs 46.9%, p < .001). Men who used internet as source for self-gathered information (40.9%, n = 54), reported their sexual side effects more often as worse than expected than men who had used other sources (p = .110). Further details on aspects of information provision are described in Figure 2D-F.

Comment

Our study indicated that PCa patients may not always be able to accurately foresee sexual side effects they may develop after treatment based on the information received prior to treatment. Moreover, men who experienced these sexual side effects believe to have received insufficient information and were not satisfied regarding content and quantity of information provision. Expectations regarding sexual outcomes least closely reflect the actual outcomes in comparison with nonsexual outcomes (4). Van Stam et al. stated that most PCa patients poorly understand the different risks of treatment, with

61% having inaccurate perceptions of the risks on ED after prostatectomy compared to other treatments. Provision of treatment information by a radiotherapist or a clinical nurse is seen as a positive predictor of better understanding the risk differences between treatments (5). In our study, information provision was mostly given by a urologist and around a quarter received their information from a radiotherapist. We did not find significant discrepancies between expectations and developed sexual side effects based on type of health professional. However, the portion of participants who had received information from a nurse was small, probably leading to a lack of power for adequately evaluating information provision by nurses. Men who indicated to not have been in need for self-gathered information, reported sexual side effects as not as bad as expected. Since men who do not experience sexual complaints are less likely to have addressed this need after treatment, this could represent a form of recall bias.

Men who retrospectively reported to have received insufficient information prior to treatment, reported discrepancies between expectations and sexual side effects significantly more often than men who reported to have received sufficient information. This may indicate that expectations on the development of sexual side effects are more accurate when adequate information is provided. In our study, a quarter of men reported to have received insufficient information concerning possible side effects. Nevertheless, a possible influence of emotions accompanying the diagnosis may cause inability to accurately absorb crucial elements of the verbal information. Moreover, 40%-80% of medical information is immediately forgotten by patients (6). The extent to which patients are able to adequately absorb information, is at least as important as the fact whether any information was provided.

Having undergone prostatectomy, having been diagnosed with a local stage tumor and a lower PSA level at diagnosis were significantly associated with more discrepancies between expectations and sexual side effects. Generally, local stage tumors are treated with curative intent, as is the case for surgical treatment (7). Understandably, both patient and health professional will primarily focus on eliminating the tumor. Consequently, sexual and other side effects will have a lower priority in counseling. This may possibly lead to less accurate expectations due to lack of information provision since sexuality is ought to be discussed less. Meanwhile, patients with the perspective of curation, will have to deal with these, possibly lasting, sexual side effects for a much longer period. Considering men who were diagnosed with local stage tumor were significantly younger, discussing feasible sexual side effects becomes of an even greater importance.

Patients who had undergone RT combined with HT had a significantly higher accordance

between expectations and developed sexual side effects. As the vast majority of men receiving HT develop sexual side effects, prospects of sexual functioning are generally poor (8). Consequently, provided information will describe more conclusive and modest outcomes, which may possibly lead to more accurate expectations. Furthermore, men treated with HT often gradually lose interest in sexuality as a result of this treatment (8). This could possibly lessen their expectations in hindsight, leading to a greater extent of recall bias. However, a study by Walker et al. showed that men treated with HT who are given an educational intervention as to managing sexual side effects report a better sexual relationship than men who did not receive this educational intervention (9). Therefore, developing such interventions could be of great value for this group of men in order to enhance their sexual health despite HT.

Furthermore, men who had undergone RT combined with HT, HT and EBRT reported less discrepancies between expectations and developed sexual side effects compared to men who received prostatectomy. Men treated surgically have very low proportions as to regaining their baseline sexual function scores compared to men treated with RT (10). Overall, men treated with prostatectomy, experience a higher negative impact on their sexual functioning compared to men treated with EBRT (11). This finding emphasizes the need to further aid this group of patients in order to improve their understandings concerning possible treatment-related side effects. A study performed by Paich et al. evaluated the use of a preoperative psychoeducational seminar for patients and partners. It showed that almost all participants experienced the seminar as informative and the majority did not encounter discomfort as to the group setting of the seminar (12). Thus, for men who are treated surgically, this kind of informative method could prevent unrealistic expectations as to sexual function after prostatectomy.

The internet was the most often used source for self-gathered information, yet men who had used the internet reported discrepancies between expectations and sexual side effects more frequently. Our study shows that men who have used brochures as an information source reported accordance in expected and developed sexual side effects most frequently. As brochures are often made by health professionals and patient associations, correctness of information is likely to be of higher quality than information provided on unregulated websites. Moreover, provision of written information materials enables patients to read the information again at a later moment.

Improvement of written information provision as to possible sexual side effects after treatment is one of the important steps that should be taken. For patients, it is challenging to absorb verbal information completely and accurately, especially after being diagnosed with PCa. As our study shows, the use of brochures is associated with better accordance

between patients' expectations and sexual side effects. Therefore, it is recommended that health professionals extend their focus towards providing brochures with broad information about possible effects of treatment on sexuality, as an addition to verbal information. The brochures should contain information about the risks of developing sexual side effects, ED treatments, possible relational problems, sexual counseling options and if desired, contact details for reference to an appropriate health professional (13). Especially for patients with low-stage tumors, low PSA levels and for whom surgical treatment is an option, further clarification is recommended. Since men tend to use the internet as primary information source, it is also recommended to develop and further improve websites designed by hospitals, foundations and patient associations.

The main strength of this study is that even though it involved an intimate topic, a large cohort of men participated. It concerned a multicenter survey; both academic and peripheral hospitals. Clinical data were obtained through an oncology registration and electronic medical records, which led to highly accurate and reliable data. Limitations include the design, as patients had to retrospectively report their experiences from a course of time both before and after treatment. Clinical and sociodemographic data from nonparticipating patients could not be obtained, so no evaluation of possible extent of response bias could be performed. Although reasons for nonparticipation were inquired, participation bias may have resulted in an altered outcome, considering it possible that patients who are less satisfied after treatment have a greater wish to participate in this study. No validated questionnaires were used, however, a pilot study to evaluate the questionnaire was performed among members of the Dutch PCa foundation in order to enhance readability and comprehensibility. In the questionnaire, the term "sexual activity" was defined as masturbation and sexual intercourse. The definition could have been more extensive so that further sexual activities were represented as well. In the future, a longitudinal study design, with the use of validated questionnaires to evaluate sexual side effects, information provision, and expectations, could further enhance accuracy of the outcomes.

Conclusion

A discrepancy between expectations and sexual side effects after PCa treatment was found in a third of men, based on the obtained information prior to treatment. Moreover, 1 in 4 men reported to have received insufficient information as to possible development of sexual side effects. Of all treatments, RT combined with HT was associated with better accordance, whereas treated with prostatectomy, low-stage tumors and low PSA levels were associated with more discrepancy. It is recommended that health professionals provide brochures additionally to verbal information in order to improve patients' understanding of possible sexual side effects and to enhance the accuracy of patients' expectations.

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