Impact of pre-treatment counselling on decisional regret of prostate cancer survivors: Cross-sectional analysis of patient-reported experience following diagnosis or treatment

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ABSTRACT

Introduction: Prostate cancer (PCa) impacts patient lives beyond oncologic concerns alone. PCa survivorship entails all impacts of PCa, from time of diagnosis to end of life. This may include decision regret (DR). We aimed to determine survivor experiences from a functional perspective throughout survivorship.

Methods: Our cross-sectional survey was circulated to all members of the Manitoba Prostate Cancer Support Group. Questions explored patient understanding of functional impacts concerning treatment. Survey items included binary and Likert scale questions, and an open-answered question asking how care may be improved. Responses were used to identify predictors of DR.

Results: A total of 514 patients received our survey with a response rate of 23.7% (n=122). Most survivors were offered radical prostatectomy (RP) or radiation therapy, at 73.0% and 63.9%,

KEY MESSAGES

- Prostate cancer survivors identified that common side effects of treatment, such as ED and urinary incontinence, are thoroughly discussed prior to treatment, while others, like climacteria and penile shortening, are poorly understood by patients and require more discussion.
- Predictors of decision regret among prostate cancer survivors after treatment included treatment with a radical prostatectomy and low pre-treatment understanding of potential ED and urinary incontinence
- Virtual followup did not impact rates of decision regret.
- Prostate cancer survivors are motivated to learn about their condition and frequently request more information on treatments, side effects, and local support groups.

respectively; 14.9% reported lacking understanding of treatment impact on erections. Similarly, 11.5% reported lacking understanding of treatment on urinary continence. Predictors of DR included treatment with RP and low pre-treatment understanding of potential erectile dysfunction (ED) and urinary incontinence.

Conclusions: PCa survivors are at high risk of DR, particularly those who undergo treatment with RP and those who identify as having low pre-treatment understanding of potential ED and urinary incontinence. Virtual care did not impact DR. Results highlight the importance of thorough counselling on functional aspects of PCa management prior to treatment.

INTRODUCTION

The optimal detection and management of prostate cancer (PCa) is a rapidly growing topic in urology. Although PCa is a highly prevalent disease, given its overall high survival rates, results in a high number of PCa survivors.[1] Despite advancements in our understanding of the detection and management of PCa, optimal management of PCa is an area of ongoing research. Historically, radical prostatectomy (RP) or radiotherapy were preferred treatment modalities for men presenting with localized PCa, however contemporary long-term series have shown comparable survival whether patients undergo treatment or active surveillance.[2–4] In addition, treatment of PCa can result in significant impairment in urinary and sexual function affecting patient's quality of life.[5] Due to these factors, approximately 20% of PCa survivors will report regret in their treatment decision.[6]

Survivorship strategies for PCa remains an area for ongoing improvement, with decision regret (DR) reported at a higher rate than other malignancies such as breast and colon.[7,8] Pre-treatment counselling can be a crucial period in limiting DR in PCa patients, as deciding on a treatment option can be a process plagued with uncertainty for the patient. Improved knowledge transfer and patient participation in the decision-making process has been shown to reduce DR, however the quality of evidence around this topic remains limited.[6,9] Despite uncertainties in current literature, a relationship between increased DR and decreased subjective well-being has been identified.[10] Furthermore, this negative relationship may be mitigated through shared decision making. With the COVID-19 pandemic, delivery of health care took a dramatic shift toward virtual care that has persisted. Although conducting clinic visits virtually has certain advantages, some patients report feeling rushed during their virtual visit which may contribute to DR.[11,12] Despite the growing research to identify prognostic factors of DR, the impact of counselling on potential urinary and sexual dysfunction, and virtual care has yet to be fully determined.

Our objective was to describe the local experiences and perspectives of PCa survivors regarding their functional outcomes at both the pre- and post-treatment level. Additionally, we sought to investigate the relationship between patients' understanding of sexual and urinary side effects of treatment as well as modality of care delivery (i.e., virtual or in person) and development of treatment DR.

METHODS

Participants and setting

Our online survey was sent out to all members of the Manitoba Prostate Cancer Support group, which included 514 patients at the time of the study. The support group is a non-profit charitable organization that holds monthly meetings created with the mission to provide prostate cancer awareness, education, and support to the community. Monthly, they host meetings with medical guest speakers, and distribute newsletters with current articles on research, treatments, new drugs, and clinical trials. Participation is voluntary, and all members are individuals who were diagnosed and/or treated for PCa in Manitoba, Canada. More information about the support group can be found on their website: www.manpros.org. Data collection was performed between May and July of 2023. This study received ethics approval by the University of Manitoba Health Research Ethics Board (HS26019).

Instruments

We designed a 31-item online survey focused on PCa survivorship using Google Forms. The initial survey was drafted by two urology resident doctors. Next, the survey items were reviewed by two local urologists with fellowships in urologic oncology, and a local urologist with a fellowship in andrology. All three urologists have a background in research focused on diagnosis and/or treatment of urologic cancers. Following this review items were modified based on feedback, reviewed by the urologists once more, and the survey was distributed to PCa survivors. Items included patient demographics, and experiences prior to, during, and after being diagnosed and/or treated for PCa. Topics included ED, penile shortening, urinary incontinence, and patient understanding throughout their journey. Participants were asked to rate specific items using a 5-point Likert rating scale from 1 (strongly agree) to 5 (strongly disagree). Additionally, some items requested selection of answers that related to patient experience such as methods of treatment offered for incontinence or ED, as well as nominal data regarding demographics. Our final item was an open-ended question asking how patients felt we could improve the quality of PCa survivorship care. Responses were kept anonymous, participation was voluntary, and completion indicated consent to participate in the study. The survey was designed to gain insight on current PCa survivor experiences to build on and add strength to current research on PCa survivorship care. As this data set was created to capture overall patient reported experiences of PCa survivorship instead of only focusing on DR, this variable was simply included as a binary yes-no question.

Data analysis

Descriptive statistics were used to: (a) identify how important patients felt their sexual health was, (b) evaluate patient understanding of treatments, treatment risks and side effects, and management of such side effects prior to, during, and after treatment, (c) summarize how often specific treatment options were offered or received, (d) how often specific treatment side effects were experienced or discussed, and (e) if follow up care included virtual delivery. Mean demographics such as age at time of diagnosis and treatment, as well as location of follow-up care were calculated using the entire sample. Univariate logistic regression analysis was performed using SPSS (Version 29.0.2) to assess the predictive value of pre-treatment understanding of functional side effects, virtual method of care delivery, and PCa treatment received. Two-sided statistical significance was set at p = 0.05.

RESULTS

From May to July of 2023, our survey was administered to a total of 514 patients, with 122 completed responses for a response rate of 23.7%. Table 1 describes demographics for all participants as well as treatments offered and received. Participants had median age of 65.2 years at time of diagnosis and 65.9 years at time of treatment. Participant were most frequently offered RP at 73.0%, radiation therapy at 63.9%, and androgen deprivation therapy (ADT) at 36.9%. Similarly, treatments received were most frequently RP at 63.9%, radiation therapy at 54.1%, and ADT at 36.1%. Patients frequently receive multiple treatment modalities, which is reflected in Table 1 total number of treatments being received (221) outnumbering total number of participants (122). Participant reported importance of sexual health was measured by rating overall importance on a 4-point Likert scale, ranging from “1” indicating “very important” to “4” indicating “not important at all”. 71.9% reported sexual health to be very or somewhat important. 71.9% reported sexual health to be very (37.2%) or somewhat important (34.7%), while 28.1% reported sexual health to be not very important (23.1%) or not important at all (5.0%).

Patient reported experiences prior to treatment

Table 2 displays PCa survivor experiences of initial treatment counselling on potential side effects, and treatment options to address potential adverse effects. Participants frequently reported receiving discussion regarding potential urinary incontinence (72.7%) and ED (72.1%). However, few participants reported receiving discussion on the risks of male infertility (39.2%), penile shortening (23.1%), and climacturia (5.0%). Similarly, future family planning options, penile rehabilitation, or referral to a sexual health specialist was offered only to 7.6%, 8.2%, and 18.3% of participants respectively. Potential options offered to treat post-treatment ED included oral phosphodiesterase inhibitors at 40.2%, by penile injections (17.9%), sexual health psychiatric counselling (10.3%), and penile prosthesis (1.8%). 31.3% of participants selected “other” as an option, of which 23.2% indicated they were not offered treatment, and 8.0% indicated they were not interested in treatment. Potential options offered to treat post-treatment urinary incontinence included pelvic floor physiotherapy at 57.9%, followed by chronic indwelling foley catheter (3.2%), and clean intermittent catheterization (1.1%). 38.9% of participants selected “other” as an option, of which 1.1% indicated they were offered a sling procedure, and 1.1% indicated they were offered an artificial urinary sphincter. Figure 1 displays participant understanding regarding risks and impact of treatment using a 5-point Likert scale ranging from “1” indicating “strongly disagree” to “5” indicating “strongly agree”. The right side of the divergent point indicates some form of agreement, either as “somewhat agree” or “strongly agree”. Left of the divergent point indicates participant responses that “neither agree or disagree”, “somewhat disagree”, or “strongly disagree”. 84.4%, 71.1%, and 75.4% of participants showed some degree of understanding for impact of treatment on erections, impact of treatment on ability to control urination, and overall treatment risks respectively.

Patient reported experiences during and after treatment

32.5% of participants reported receiving follow-up in the form of a virtual appointment via telephone communication. Patient reported outcomes regarding counselling during and after treatment around urinary incontinence and ED are shown in Table 3. 16% of participants reported discussion regarding urinary incontinence at every appointment and 21.8% reported frequent discussion. 27.7% and 34.5% of participants reported infrequent or non-existent discussion surrounding urinary incontinence respectively. 6.6% and 12.3% of participants reported discussion regarding post-treatment ED at either every appointment, or frequently. Majority of patients reported minimal discussion of potential ED, as 35.2% and 45.9% of participants reported either infrequent or non-existent discussion of sexual function. Only 35.2% and 23.6% of participants indicated they were offered treatment for ED or urinary incontinence respectively.

Predictors of decision regret

Table 4 displays results of our univariate logistic regression analysis identifying predictors of DR. Delivery of virtual care was not found to be a significant predictor of DR (OR 0.813 (p=0.661; 0.322-2.052)). In terms of patient understanding of sexual side effects of treatment, participants reported pre-treatment discussion of penile shortening (OR 1.480 (p=0.422; 0.586-3.855)) and of penile rehabilitation (OR 0.350 (p=0.329; 0.042-2.888)) were not significant predictors of DR. However, worse pre-treatment understanding of potential ED (OR 1.496 (p=0.018; 1.071-2.090)) and urinary incontinence (OR 1.595(p=0.014; 1.098-2.316)) were significant predictors of DR. Finally, participants who underwent RP were more likely to endorse DR (OR 3.262 (p=0.027; 1.141-9.326)).

Qualitative responses

Results of the open-ended question asking patients “How do you feel we can improve the quality of prostate cancer survivorship care” revealed three emerging themes: (1) participants desired improved counselling on treatment options and potential side effects prior to receiving any form of treatment, (2) valued counselling among other survivors with shared experiences through participation in support groups, and (3) expressed that side effects including urinary incontinence, ED, penile shortening, climacturia, and costs associated with treatments like phosphodiesterase inhibitors are often poorly understood by patients and warrant further discussion.

DISCUSSION

PCa despite being a highly prevalent disease, given its overall high survival rates, results in a high number of PCa survivors.[1] PCa survivorship has been an area of growing interest, given that one in five survivors will express DR in their treatment decision.[6] Patient understanding of treatment related side effects as well as active participation in decision making has been implicated as predictors of DR.[13–15] However, the impact of pre-treatment counselling and patient understanding regarding sexual and urinary dysfunction remains poorly understood. Our study demonstrated that (1) improved understanding regarding pre-treatment urinary and sexual side effects are associated with less DR, (2) Climacturia and penile shortening are infrequently included in pre-treatment counselling, and (3) virtual delivery of care does not appear to be associated with DR.

A recent systematic review and meta-analysis by Fanshawe et al. (2023) demonstrated there is a possible association between post-treatment urinary and sexual dysfunction with DR.[6] A meta-analysis was not performed given the heterogeneity of the data reporting; however, it did appear that there is conflicting evidence in the literature. In our study, presence of sexual and urinary dysfunction post treatment was not significantly associated with DR, however perceived lack of understanding of these side effects pre-treatment was found to be a significant predictor of DR. Previous studies have demonstrated the importance of proper pre-treatment counselling of treatment options in preventing DR.[16,17] The setting in which pre-treatment information is given likely impacts patient understanding. In a study that looked at patient recall 1-3 days after initial disclosure of a cancer diagnosis Gabrijel et. al (2008) found that patients were only able to retain about half of the information provided.[18] Furthermore, the source of information appears to impact DR. Patients who obtained most of their information from Internet-based resources were significantly more likely to have DR.[14] Although clinicians and other health care providers should be expected to provide more accurate information, some patients may find this information to be insufficient.[19] It is important to recognize that more information may not equate to improved patient understanding, as patients may find this overwhelming again leading to increased DR.[20]

The use of decision aids has also been explored to aid in patient education and improving rates of DR. However, a recent meta-analysis found that the use of decision aids had no significant impact on DR.[21] Interestingly, tailoring decision aids to patient cultural preferences were found to be more impactful.[22] To promote improved perceived understanding of patients, clinicians should consider the setting of discussion, patient preferences, health literacy, and culture to provide comprehensive counselling.[23]

Although ongoing improvements are required in the education of sexual dysfunction with PCa treatment, erectile dysfunction is now a widely known and discussed side effect of RP. However, other components of sexual function that may be affected after RP such as climacturia and penile shortening are less understood. The incidence of orgasm associated incontinence has been reported as high as 47% in one series, however given the lack of data, the true incidence remains unknown.[24] In our cohort, only 5% of patients reported receiving counselling on potential post-treatment climacturia. Given the low rate of counselling around this complication in our cohort, we were unable to assess whether this variable is a predictor of DR. Although further research is required in this area, clinicians should consider discussing potential climacturia as part of their pre-treatment counselling, as patients suffering from this complication have been shown to have significantly higher rates of low self-esteem, depressed mood and anxiety.[25] Additionally, clinicians should attempt to elucidate this potential complication in routine follow-up and offer potential management strategies such as pelvic floor rehabilitation, penile loops, or even surgical therapies.[26] Similarly, counselling regarding potential penile shortening post RP was not routinely discussed in our cohort, however lack of counselling around this topic was not associated with DR. Future research is required to assess its impact on post-treatment DR.

Virtual care has continued to be a mainstay in everyday clinical practice since the COVID-19 pandemic. Despite having multiple benefits, the association between virtual delivery of care and DR in PCa remains poorly understood. In our study, virtual follow-up was not a significant predictor of DR. This finding is in keeping with a recent systematic review and meta-analysis assessing the psychosocial impact of virtual cancer care. Of the 4434 subjects included, virtual delivery of care did not appear to negatively influence patient's psychosocial health and was associated with improvements in QoL and anxiety related scores.[27] A potential explanation for these findings is that virtual care may provide easier access to providers, as well as allowing patients to receive care in the familiarity of their home. Clinicians however should remain cognisant of the length and thoroughness of virtual appointments, as some patients have reported feeling rushed during virtual encounters.[11] Although time pressure is present in any clinical practice, it is important to be aware of perceived time pressure by patients when deciding on treatment plan, as this has been implicated as a predictor of DR.[12] Receiving a cancer diagnosis can be associated with significant psychosocial impact, therefore emphasizing patient understanding with comprehensive counselling are of utmost importance, regardless of care delivery method.

There are several limitations to this study. A relatively low response rates of 23.7% was seen, limiting our sample size. Additionally, response bias may be present, as unhappier patients may be more likely to participate in the survey to voice their experiences. However, the rate of decision regret seen in our study of 23.5% was in keeping with published literature, indicating that our cohort is representative of the PCa survivor population. Another limitation is the use of a non-validated questionnaire. To ameliorate potential bias, questionnaire was reviewed by local urologists and researchers with additional fellowship training in urologic oncology and andrology. Through this review, questions were examined for relevance to the study. Additionally, wording was modified to reduce leading questions, loaded questions, and medical jargon to improve understanding by patients and limit potential bias. Furthermore, the population selected for our study was chosen due to its inclusion of PCa survivors living in urban, rural, and remote communities. By distributing our survey to all Manitoba, Canada, PCa survivors we aimed to improve generalizability of results across survivor demographics. As DR was examined by a binary yes-no response, this may represent another potential limitation to our study as it forces a stringent answer from respondents. DR may exist on a spectrum with some survivors regretting their choices completely, and others regretting the circumstances their decision was made under but ultimately believing their final decision would remain the same. Although validated DR scales exist, which further examine these nuanced responses, our questionnaire was initially designed to broadly examine PCa survivorship experiences and DR was not the initial focal point.[28] Thus, we did not use validated questionnaires designed to measure decisional regret. However, we feel that even as a binary variable, important inferences can be made. We were also not able to capture and record duration of post-treatment follow-up at time of questionnaire completion, frequency of follow-up, and frequency of follow-up by location. DR may be more evident in patients who are earlier on in the follow-up, as patients post prostatectomy are likely to have more pronounced urinary incontinence and sexual dysfunction in the earlier time periods. Additionally, we are unable capture what proportion of post-treatment follow up consisted of virtual care, which may be a confounding variable. We were further limited by our sample size, limiting our ability to perform multivariate logistic regression analysis for predictors of decision regret. Further maturation of our database will allow for more robust analysis to control for potential confounders. Finally, our study included patients who received any treatment for PCa (RP, radiation, watchful waiting, active surveillance, etc…). Some elements of the questionnaire may not be applicable for each treatment modality; however, pre-treatment counselling should include all the available treatment options as well as their respective pros and cons. Future research may involve survey modifications to address these limitations and allow for testing of the survey's reliability and validity. Despite these limitations, this study highlights pre-treatment understanding of potential sexual and urinary complications are associated with DR. Additionally the presence of virtual follow-up care does not appear to increase DR in PCa survivors, however future prospective studies are required the impact of virtual care in this population.

This study identifies low, prior to therapy, patient understanding of PCa treatment impacts on urinary incontinence and ED as significant predictors to DR. Additionally, individuals who undergo RP were also at higher risk for DR. Although a single method of pre-treatment counselling has yet to be identified which would minimize DR, by understanding risks associated with DR, Urologists caring for patients with newly diagnosed PCa may tailor their counselling to address these predictors. Future studies may explore different pre-treatment counselling protocols that target patient understanding of treatment effects. Such protocols should measure patient understanding at various time-points prior to treatment and evaluate which counselling methods provided the highest level of improvement in patient knowledge. Longitudinal data should examine whether these counselling methods correlate with reduced DR.

CONCLUSIONS

Counselling patients about treatment options should include discussion of treatment side effects, as well as treatment for such. Many patients expressed poor understanding of less known side effects such as penile shortening and climacturia. Clinicians should prioritize promoting patient understanding of potential sexual and urinary dysfunction with PCa treatment, as this was found to be an independent predictor of decision regret.

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FIGURES AND TABLES

Figure 1. Pre-treatment understanding of quality-of-life impact and risk of prostate cancer survivors.

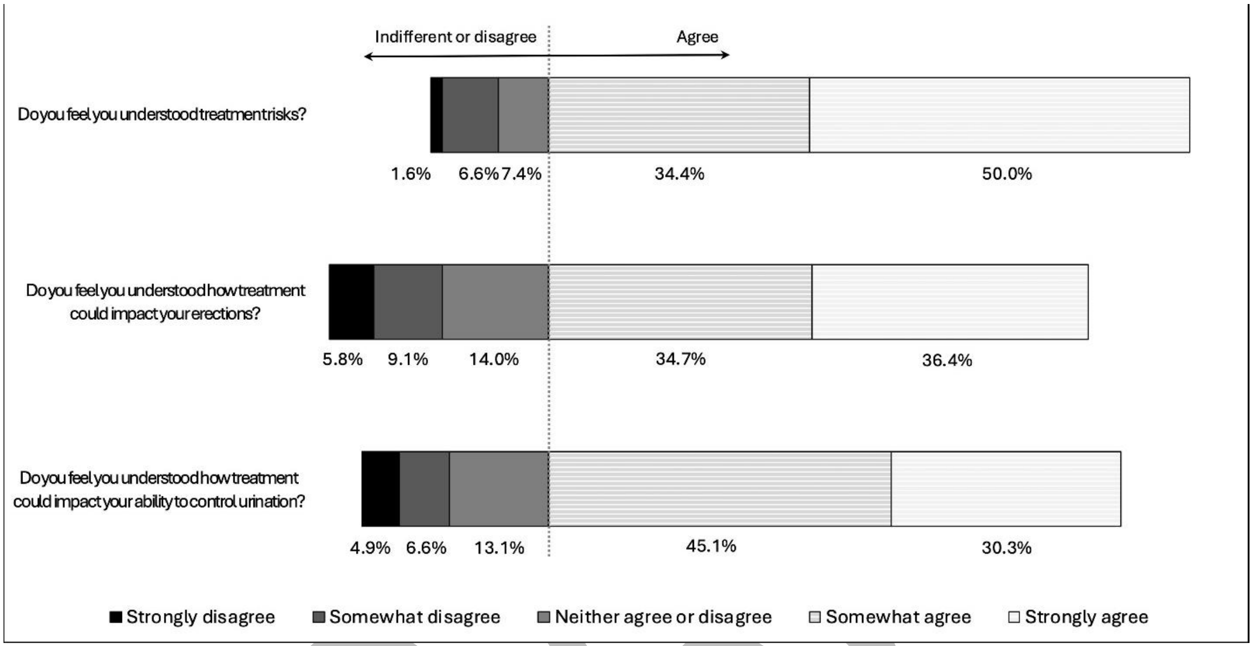

Table 1. Demographics of prostate cancer survivors in Manitoba, Canada, and treatments offered/received	
N= 122	**Mean/median (SD)**
Age at diagnosis (years)	65.2/65.9 (7.4)
Age at treatment (years)	65. /66.0 (7.8)
Treatments offered	Total/average (%)
Radical prostatectomy	89/73.0
Radiation therapy	78/63.9
Androgen deprivation therapy	45/36.9
Active surveillance	27/22.1
Watchful waiting	24/19.7
Cryotherapy	7/5.7
Chemotherapy	2/1.6
Treatments received	Total/average (%)
Radical prostatectomy	78/63.9
Radiation therapy	66/54.1
Androgen deprivation therapy	44/36.1

Active surveillance	19/15.6
Watchful waiting	13/10.7
Cryotherapy	1/0.8
Chemotherapy	0/0

SD: standard deviation.

Table 2. Prostate cancer survivor survey responses regarding patient experiences and care provided prior to treatment for prostate cancer

"Did you receive discussion about the risk of…"	**"Yes" response**
Urinary leakage (incontinence)	72.7%
Erectile dysfunction	72.1%
Male infertility	39.2%
Penile shortening	23.1%
Climacturia	5.0%
Side effect mitigation and treatment related questions	"Yes" response
Was a referral to a sexual health specialist offered?	18.3%
Was penile rehabilitation discussed?	8.2%
Were options for future family planning offered?	7.6%
"What treatment options were offered for…"	Frequency
Erectile dysfunction	
Oral medications	40.2%
Penile injections	17.9%
Penile prosthesis	1.8%
Sexual health psychiatric counselling	10.7%
Other[*]	31.3%
Urinary incontinence	
Chronic indwelling foley catheter	3.2%
Clean intermittent catheterization	1.1%
Pelvic floor physiotherapy	57.9%
Suprapubic catheterization	0.0%
Other[*]	38.9%

[*] Selection of other allowed for typed in responses; for breakdown of responses see results section.

Table 3. Prostate cancer survivor survey responses regarding patient experiences during and after treatment for prostate cancer	
Question regarding followup care	**Response rate**
How frequently was sexual dysfunction (ED) discussed?	
At every appointment	6.6%
Frequently	12.3%
Infrequently	35.2%
Never	45.9%
How frequently was urinary incontinence discussed?	
At every appointment	16.0%
Frequently	21.8%
Infrequently	27.7%
Never	34.5%
Questions related to treatment for side effects	“Yes” response
Were you offered treatment for ED?	35.2%
Where you offered treatment for urinary incontinence?	23.6%
Location of follow-up care	Response rate
Doctor’s clinic (hospital)	65.8%
Doctor’s stand-alone clinic	35.8%
Virtual appointment (telephone)	32.5%

ED: erectile dysfunction.

Table 4. Univariate logistic regression analysis for predictors of decision regret		
Variable	**Odds ratio**	**p**
Virtual care	0.813 CI (0.322–2.052)	0.661
Pre-treatment penile shortening discussed	1.480 CI (0.586–3.855)	0.422
Pre-treatment penile rehabilitation discussed / implemented	0.350 CI (0.042–2.888)	0.329
Pre-treatment ED understanding	1.496 CI (1.071–2.090)	**0.018***[*]
Pre-treatment incontinence understanding	1.595 CI (1.098–2.316)	**0.014**[*]
Radical prostatectomy performed	3.262 CI (1.141–9.326)	**0.027**[*]

[*] $p<0.05$ was used to measure statistical significance. CI: confidence interval; ED: erectile dysfunction.