

PSYCHOMETRICS

Development of a Sexual Quality of Life Questionnaire for Men-Who-Have-Sex-With-Men With Prostate Cancer



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ABSTRACT

Background: Prostate cancer (PCa) is often diagnosed early with prolonged survival, which makes sexual quality of life (QoL) an increasingly important treatment consideration, but existing QoL questionnaires have limited applicability for men who-have-sex-with-men (MSM) beyond penile erections and penetrative sex.

Aim: We aimed to create a validated survey instrument for assessing a variety of sexual activities beyond penile insertive sex for MSM after PCa treatment.

Methods: Based on our previously published survey findings, we have generated a prototype questionnaire with 13 different domains, reviewed by both healthy MSM and pilot-tested by MSM treated for PCa.

Outcomes: We report here on progress in developing the questionnaire and demonstrate the complexity of MSM sexual side effects resulting from PCa treatment(s).

Results: Statistical analysis of 204 responses from MSM treated for PCa showed that each domain performed well individually (Cronbach's alpha coefficients ranged from 0.80 to 0.95; item-total correlations ranged from 0.16 to 0.89), with many significant intercorrelations between the domains (ranged from -0.048 to 0.93).

Clinical Implications: The questionnaire can contribute to clinical diagnosis and treatment decisions that best fit the preferred sexual practices of individual MSM.

Strengths & Limitations: The current questionnaire considers a much broader repertoire of MSM's sexual practices and preferences than other currently available questionnaires. The high intercorrelations between the many parameters demonstrate that problems in one domain can affect other domains. This preliminary analysis warrants further exploration with a larger sample size.

Conclusions: Once validated our questionnaire should help develop tailored psychosocial supports for MSM experiencing sexual dysfunction after PCa treatment and help newly diagnosed MSM with PCa make treatment decisions informed by their preferred sexual practices. **Wibowo E, Dowsett GW, Nelson CJ, et al. Development of a Sexual Quality of Life Questionnaire for Men-Who-Have-Sex-With-Men With Prostate Cancer. Sex Med 2022;10:100480.**

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INTRODUCTION

According to the Surveillance, Epidemiology, and End Results (SEER) program of the National Cancer Institute (NCI), over 3 million men were living with prostate cancer (PCa) in the USA in 2018. The number of new cases in 2021 was over 240,000. Assuming 5% of the male population are men-who-have-sex-with-men (MSM)—a conservative estimate—this translates into a possible annual incidence in the USA of over 9,500 and prevalence of over 158,516.^{1,2}

Research on MSM sexual quality of life (QoL) after PCa treatment has been challenging because of the lack of a validated questionnaire to assess the breadth of their sexual practices and concerns and to capture clinically relevant and reliable data.³ Ongoing barriers to accessing healthcare for MSM, patient's fears of discrimination upon disclosure of sexual identities and/or practices, and perceived discomfort with such disclosures on the part of healthcare professionals^{4–7} are all obstacles in creating a validated questionnaire for this population. Another problem is the sole focus on erectile function for penile insertive sex without addressing other ways that PCa treatment can affect sexual function. These include loss of ejaculation, climacturia, reduced sexual desires, and how these changes affect the receptive versus penetrative roles in anal sex.^{5–9}

Three of the more commonly used questionnaires for assessing sexual function for PCa patients are the Expanded Prostate Cancer Index Composite (EPIC),¹⁰ Male Sexual Health Questionnaire (MSHQ),^{11,12} and The International Index of Erectile Function-MSM (IIEF-MSM).^{13,14} The majority of participants during the development phases of those questionnaires have been heterosexual men, which limits the validity of those measures beyond penile erections and penile insertive sex.¹⁵ IIEF has been modified to IIEF-MSM for the HIV-positive MSM subpopulation.¹⁴ While it contains questions on different sexual practices such as insertive and receptive anal intercourse, oral sex, and masturbation, the main focus remains on erectile function. It has not been validated for use with PCa patients, who typically suffer from post-PCa treatment sexual side effects and differ from the HIV population. Furthermore, by focusing on HIV-positive MSM only, it neglects those in the heterosexual population that may also practice receptive anal intercourse.^{16,17}

Considering these limitations, we planned to derive, pilot test, and validate a sexual QoL assessment instrument for MSM facing PCa treatment inclusive of the breadth of MSM sexual practices. The instrument we envisioned would independently assess different sexual practices. As a first step in developing this instrument, we undertook semi-structured qualitative interviews with a sample of MSM.¹⁸ Findings from those interviews led to the first draft of a comprehensive sexual QoL questionnaire. Here we report on our next steps, which were to refine the wording in the questionnaire prototype and then pilot test it. The resultant questionnaire provides a new and broad perspective on MSM sexual QoL. The results of the pilot test, however, suggest that

the negative impact of PCa treatments on MSM sexual QoL crosses many domains underscoring the need for tailored interventions.

In summary, the primary goal of this research is to develop a questionnaire to assess the sexual needs of MSM diagnosed with PCa. As a hypothesis we wish to know, “Can an instrument that captures the breadth of sexual concerns for MSM taking into consideration the diversity of their preferred sexual roles be created for clinical and research settings?”

METHODS

Procedure

Detailed methods for our semi-structured interviews are documented in Lee et al (2015).¹⁸ By using the findings from those interviews plus other validated questionnaires—notably the sexual domains of the EPIC, MSHQ, and IIEF-MSM—we created a questionnaire prototype that covered a breadth of MSM sexual practices. [Figure 1](#) summarizes the steps in the development of our questionnaire. Ethics approval was obtained from the University of British Columbia, BC Cancer Research Ethics Boards (REB number H19-00791).

Comprehensive Questionnaire Prototype Wordings Assessment

In order to ensure the language was accessible and the questions were relevant to the MSM population, 56 MSM between 18 and 75 years of age from a local gay community organization, with education levels ranging from high school to post-graduate, were recruited between December 2016 and February 2017 through an email blast and website presentation to assess draft questions. A guaranteed 1,250 CAD donation to a non-profit charity and a raffle of one gift card of 25 CAD for every 10 participants were offered as incentives. After giving consent, each participant filled in a short demographic questionnaire and was then directed to the list of questions. Participation was anonymous.

The focus at this stage was on the wording of the questions. Participants were asked to comment on how well the questions were worded, including whether they could clearly understand what the questions were asking and, if not, how the wording could be improved. In some cases there were multiple versions of questions that asked about similar issues. We then asked participants to select the wording they preferred. There were also open-ended questions to collect participants' feedback on the questions' overall quality and value.

Reviewing the draft document took each participant approximately 60 minutes. Four of the authors (B.L., E.W., R.W., G.D.) reviewed the collected responses, paying attention to participants' preferences for wording and incorporating their feedback into the next version of the questionnaire. This yielded our concise questionnaire prototype.

Description of the Concise Questionnaire Prototype

The demographics section of the draft questionnaire captured information on age, country of residence, ethnicity, sexual orientation, education level, employment status, relationship status, sexual role, sexual function before PCa treatment, and information on PCa diagnosis and treatment. In this section, a number of questions were included to detect fraudulent answers by ensuring participants' current age, years since PCa diagnosis, and age at the time of PCa diagnosis matched.

The main part of the questionnaire consisted of 13 sets of questions that independently covered domains including sex drive (3 questions), ejaculation (9 questions), erection (14 questions), orgasm (9 questions), general sexual questions that were not related to specific sexual practices (7 questions), receptive anal intercourse (11 questions), insertive anal intercourse (7 questions), solo masturbation (9 questions), receiving masturbation (4 questions), receiving oral sex (7 questions), sex with regular partner(s) (15 questions), sex with casual partner(s) (9 questions), and urinary incontinence (7 questions). Each question was scored using 4 to 6 point Likert scales, included questions on sexual frequency, satisfaction, and bother from limitations in function. Because the questions for the different domains were designed to function independently and there were different numbers of question for the domains, no total score was calculated for the questionnaire built from the separate sets of questions.

The comprehensive questionnaire was designed to minimize participation fatigue with conditional pathways that reduced the number of questions based on previous answers. For example, if a participant has answered "no difficulty with erection", the question on whether the lack of erection was bothersome did not appear. Each domain ended with open-ended questions on whether the participant found the questions upsetting and a place for participants to provide additional feedback.

Pilot Testing of the Concise Questionnaire Prototype

MSM with a history of PCa pilot-tested the complete questionnaire prototype online hosted on the Demographix survey platform. The goal at this stage was to test the acceptability and quality of the questions prior to making refinements to questions based on statistical analyses. Eligibility criteria for this pilot testing included being 75 years of age or under, a history of having sex with men, and a history of non-metastatic PCa treated with curative intent, which included radical prostatectomy, external beam radiation, and brachytherapy with or without androgen deprivation therapy.

Recruitment took place online through Facebook and Malecare (<https://malecare.org/>). Organizers of PCa support groups internationally were also approached through emails and phone

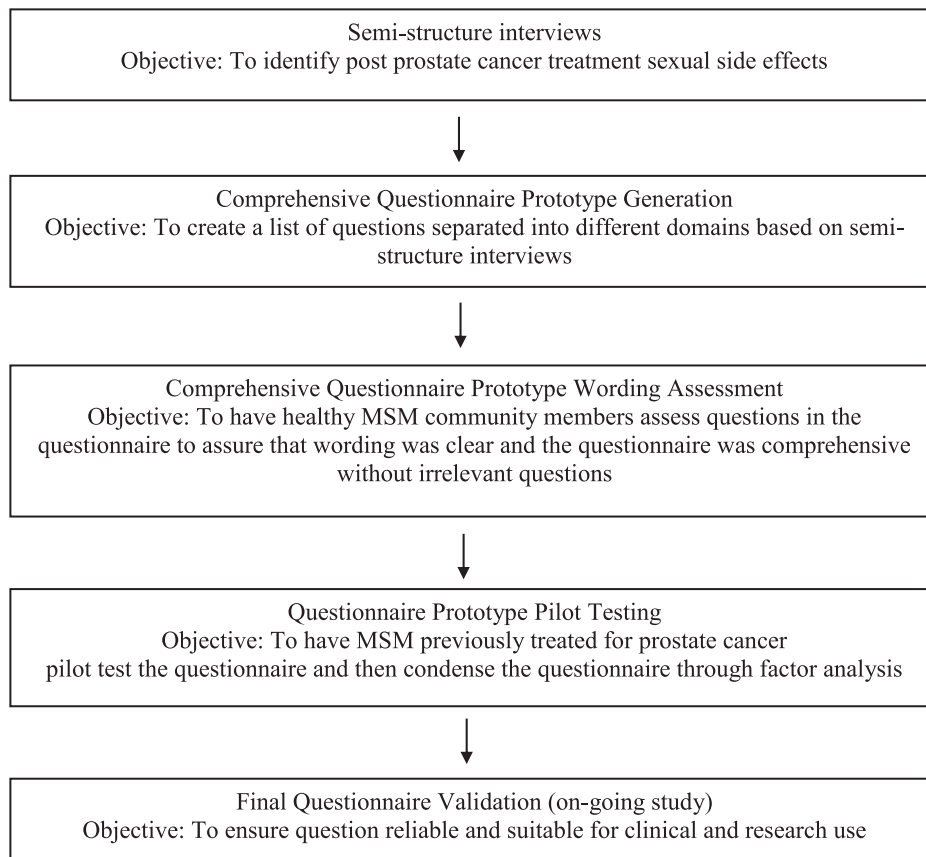


Figure 1. Summary of the steps developing the MSM and PCa sexuality questionnaire.

calls to promote the study through their membership lists. The incentive to participate was in the form of a raffle for a 50 USD gift card for one in every ten participants.

Statistical Analyses of the Concise Questionnaire Prototype

Each response was checked for eligibility and the response was excluded from analysis if there was more than a 5 years discrepancy based on participant age, years since PCa diagnosis and age at time of PCa diagnosis. Where appropriate Likert scale responses were inverted so that higher scores indicating better sexual functioning and less sexual bother or difficulty.

All statistical analysis was conducted using SPSS version 25. The main goal of the statistical analysis at this stage was to consolidate the questions and streamline the questionnaire using a factor analysis. The Cronbach's alpha coefficient for each domain was calculated to evaluate the consistency of the questions within the domain. The factor analyses utilized principal axis factoring as the extraction method and the promax rotation method (an oblique rotation method, chosen to permit factors to correlate). Unidimensionality was evaluated based on eigenvalues and inspection of the scree-plot. This analysis explored how well the domains matched each other. In other words, this analysis helped determine whether participants, who revealed a low score for one domain had a low score in another domain. The analysis yielded loading scores ranging from 0 to 1, with higher scores suggesting a correlation between domains. Items with loadings of 0.35–0.4 and above were considered to load on a given factor.

RESULTS

Data Analyses

Two hundred and twenty-five individuals completed the survey between November 2017 and September 2019. Responses were eliminated from participants who: (i) did not meet eligibility criteria; (ii) did not provide information related to PCa or treatment; (iii) completed the survey in less than 10 minutes; (iv) were extreme outliers in age, for example, under 30 years old; and (v) showed inconsistencies between age, age of diagnosis, and length of treatment with discrepancy of >2 years. After exclusions, there were 204 completed surveys available for analysis.

The mean age of participants was 62 +/- 7.99. Their age at PCa diagnosis was 57 +/- 6.59, which is younger than the median age for diagnosis found in the SEER database.¹ The majority of the participants had attained university or higher education qualifications (74%). The time from PCa treatment to when participants filled in the questionnaire ranged from 0 to 21 years (mean = 5.32, standard deviation = 4.97). Treatment modalities included radical prostatectomy (n = 143, 70%), brachytherapy (n = 38, 19%), external beam radiation (n = 59, 29%), and androgen deprivation therapy (n = 37, 18%). Eighty-eight percent of participants identified as gay/homosexual, 9% as

bisexual, and 3% as others or did not answer, which might include transgender or non-binary individuals. Thirty-seven percent of participants were single, 43% were in monogamous relationships, and 19% were in non-monogamous relationships. More details on participants' characteristics can be found in Tables 1 and 2.

To assess the initial psychometric properties of our questionnaires, we focused on reliability statistics (Cronbach's coefficient alphas; item-total correlations) and factor analyses for each of the 13 proposed domains. In general, all domains and a majority of questions performed well, with questions in each domain following similar scoring patterns in individual participants. Two questions—one from the “Sex with Casual Partners” domain: “Over the past 4 weeks, how often have you taken the initiative to have sex with casual sexual partner(s)?”, and one from the “Insertive Anal Intercourse” domain: “Over the past 4 weeks, how often have you used any medications (eg, Viagra, Cialis, penile injection) or aids (eg, penis pump) for insertive anal intercourse?”

Table 1. Participants demographics (n = 204)

	N	%
Country of Origin		
USA	156	76.4
Canada	16	7.8
Australia	5	2.4
UK	13	6.3
New Zealand	3	1.4
Other	11	5.4
Race		
White/Caucasian	189	92.6
Black/African	6	2.9
Latino/Hispanic/Mexican-American	6	2.9
Other	2	1.0
Sexual Orientation		
Gay or Homosexual	180	88.2
Bisexual	18	8.8
Other or did not answer	6	2.9
Relationship Status		
Living with spouse(s) or partner(s), in a monogamous relationship	81	39.7
Living with spouse(s) or partner(s), in a non-monogamous relationship	37	18.1
In a significant, monogamous relationship, not living together	7	3.4
In a significant, non-monogamous relationship, not living together	3	1.5
Single	75	36.8
Preferred Sexual Role		
Bottom	45	22.1
Bottom/Versatile	26	12.7
Versatile	42	20.6
Top/Versatile	40	19.6
Top	27	13.2
Other	24	11.8

Table 2. Participants PCa parameters (n = 204)

	N	%
Gleason Score (52 missing data)		
6	40	19.6
7	83	40.7
8	13	6.4
9	15	7.4
10	1	0.5
PSA (54 missing data)		
<10	112	54.9
10–20	26	12.7
>20	12	5.9
T Stage (115 missing data)		
T1	25	12.3
T2a/b	17	8.3
T2c	18	8.8
T3	23	11.3
T4	6	2.9
Treatment received		
Radical Prostatectomy	143	70.1
External Beam Radiation	59	28.9
Brachytherapy	38	18.6
Androgen Deprivation Therapy	37	18.1

were excluded because of item-total correlations being near zero. With these questions removed, coefficient alphas for the 13 domains ranged from 0.80 to 0.95, and questions in each domain exhibited item-total correlations in the expected directions (Table 3).

Next, we examined intercorrelations between the domains. Most domains were positively correlated with each other. Correlations between domains are described in Table 4.

Finally, we entered each of the 13 domains into an exploratory factor analysis (principal axis factoring with promax rotation) to examine their structure. The “Ejaculation”, “Receptive Anal Intercourse”, “Insertive Anal Intercourse”, and “Sex with Casual Partner(s)” domains were excluded because the sizes of the subgroups endorsing questions on these domains were insufficient ($n_s < 50$). For the remaining domains, a one-factor solution emerged (eigenvalue = 6.75) accounting for 75.0% of the total variance. When examining other possible factor structures, no other eigenvalues exceeded 1.3, so the one-factor solution was retained. All domains entered into the analysis loaded on this single factor, with loadings ranging from 0.81 to 0.97, with one exception: the “Urinary Incontinence” domain had a loading of 0.28, below the traditional cut-off of 0.4.

Discussion

The adverse effects of PCa treatment on men’s sexual function have been studied primarily in heterosexual men with a focus on penile rigidity firm enough for penile-vaginal

Table 3. Coefficient alphas for individual scale performance in internal consistency

Domain	n	Alpha	Item-total correlations
Sex Drive	201	0.80	0.50–0.73
Ejaculation	44	0.89	0.47–0.77
Erection	134	0.95	0.25–0.89
Orgasm	154	0.90	0.32–0.82
General Sexual Questions	199	0.92	0.70–0.81
Receptive Anal Intercourse	50	0.94	0.49–0.88
Insertive Anal Intercourse	31	0.84	0.16–0.89
Solo Masturbation	169	0.87	0.30–0.77
Receiving Masturbation	57	0.87	0.32–0.88
Urinary Incontinence	139	0.86	0.54–0.74
Receiving Oral Sex	8	0.83	0.29–0.83
Sex with Regular Partner(s)	73	0.90	0.18–0.84
Sex with Casual Partner(s)	5	0.86	0.24–0.82

intercourse. Compared with heterosexual PCa populations,^{19–23} few studies have addressed sexual quality of life (QoL) among MSM post-PCa treatment. Some studies have shown that MSM with PCa, compared with their heterosexual counterparts, may have different and potentially poorer sexual QoL after treatment.^{24–30} For example, erectile and bowel dysfunction can impair insertive and receptive anal sex, especially for MSM.^{8,27,31} Furthermore, erectile dysfunction can contribute to feelings of sexual disqualification, exclusion from the gay sexual community, and challenges to masculine and gay identities.^{9,32}

Receptive anal sex after PCa treatment may be affected by rectal damage or changes in prostate sensation. Changes in sexual practice, for example, from an insertive to receptive role, may seem to be an option but, in reality, may be undesirable both physically and psychologically for many men.^{4,32–35} Sexual changes often lead to a higher rate of psychological distress and isolation for MSM with PCa compared with heterosexual men.^{26,36} This evidence indicates a need for targeted interventions specific for MSM PCa patients.

Our research team and others have recognized that this ignores the variety of sexual and relationship challenges that many MSM face as a result of PCa treatments.^{6,9,37,38} In order to study and monitor sexual QoL for MSM with PCa, we aimed to develop a comprehensive and validated sexual assessment questionnaire.

Post-treatment sexual dysfunction represents the main treatment regret for men with PCa.³⁹ Our data are a step toward having a validated assessment instrument that considers MSM’s sexual practices and preferences beyond just penile insertive sex. The data our questionnaire captures, once fully validated, may

Table 4. Intercorrelations among all domains

Scale	Sex drive	Ejaculation	Erection	Orgasm	General sexual questions	Receptive anal intercourse	Insertive anal intercourse	Solo masturbation	Receiving masturbation	Urinary incontinence	Receiving oral sex	Sex with regular partner(s)	Sex with casual partner(s)
Sex Drive	r 1	0.74	0.47	0.45	0.58	0.88	0.61	0.44	0.23	0.24	0.39	0.59	0.40
	<i>P</i>	<.001	<.001	<.001	<.001	<.001	<.001	<.001	.091	.005	<.001	<.001	.004
Ejaculation	r	1	0.70	0.83	0.74	0.75	0.84	0.74	0.61	0.52	0.71	0.65	0.81
	<i>P</i>		<.001	<.001	<.001	.001	.004	<.001	.011	.013	<.001	.003	.008
Erection	r		1	0.54	0.78	0.80	0.84	0.76	0.84	0.33	0.78	0.60	0.53
	<i>P</i>			<.001	<.001	<.001	<.001	<.001	<.001	.002	<.001	<.001	.001
Orgasm	r			1	0.58	0.88	0.63	0.67	0.50	0.11	0.37	0.57	0.41
	<i>P</i>				<.001	<.001	<.001	<.001	<.001	.29	.002	<.001	.01
General Sexual Questions	r				1	0.73	0.68	0.79	0.69	0.31	0.67	0.78	0.66
	<i>P</i>					.002	<.001	<.001	<.001	<.001	<.001	<.001	<.001
Receptive Anal Intercourse	r					1	0.93	0.83	0.80	0.44	0.84	0.89	0.74
	<i>P</i>						.003	<.001	.01	.20	<.001	.001	.06
Insertive Anal Intercourse	r						1	0.53	0.29	0.39	0.32	0.61	0.55
	<i>P</i>							.008	.24	.082	.088	.005	.009
Solo Masturbation	r							1	0.82	0.25	0.72	0.61	0.55
	<i>P</i>								<.001	.006	<.001	<.001	<.001
Receiving Masturbation	r								1	-0.048	0.86	0.41	0.32
	<i>P</i>									.77	<.001	.023	.11
Urinary Incontinence	r									1	0.30	0.23	0.36
	<i>P</i>										.028	.091	.029
Receiving Oral Sex	r										1	0.52	0.42
	<i>P</i>											<.001	.009
Sex with Regular Partner(s)	r											1	0.80
	<i>P</i>												<.001
Sex with Casual Partner(s)	r												1
	<i>P</i>												

facilitate treatment decision-making by physicians and MSM men with PCa taking into consideration a much broader repertoire of sexual activities than are assessed in commonly used questionnaires.

During our initial interviews with MSM, many participants expressed concerns that discussions with healthcare providers about sexual function predominantly focused on presumption of penile-vaginal sex as the “gold standard” for men’s sexual practices.¹⁸ As such, those discussions did not always address the sexual experiences and desires of MSM nor the QoL implications. The original IIEF, for example, was designed for the heterosexual population and does not explore side effects that might negatively impact MSM in the receptive role.¹³ The IIEF-MSM questionnaire, which was developed to explore HIV risk in the MSM population, also focuses on erectile function.¹⁴ As such it similarly did not explore equally the capacity of men to perform both insertive and receptive anal sex roles.

Several of the domains explored in our questionnaire, such as those pertaining to erectile function, orgasm, urinary incontinence and ejaculation, are shared by heterosexual and MSM populations. As such, we built our questionnaire on existing validated questionnaires with adjustments and expansions to specifically serve the MSM population. As a first step in the development, the questions and their wording were confirmed to be relevant and appropriate through assessment by 56 healthy MSM from the community. That helped us refine the wording for the comprehensive questionnaire prototype that was investigated later with MSM diagnosed and treated for PCa.

The number of participants, who pilot-tested our questionnaire prototype was substantial; that is, over 200 MSM with PCa. Over 90% of the participants met the eligibility criteria for validity, presumably because we did not offer a direct financial reward for participation, which has been shown by others to attract fraudulent participation.⁴⁰ The mean age of diagnosis of our participants was 57, which is younger than median age of 67 according to SEERS database.¹ This reflects the potential earlier prostate cancer screening and detection in MSM population, and further amplifies the importance of sexual function for MSM with prostate cancer.^{41,42} Overall, the questionnaire performed well in terms of Cronbach's alphas for the sets of questions on individual domains, with only 2 questions being excluded because of low correlations with other questions on the first axis of the principal component analysis.

The results of the factor analysis, though preliminary, raises a concern that needs to be further explored with a larger sample size. This is related to the high intercorrelations between the many parameters that we measured, where problems in one domain is associated with other domains. This suggests that erectile function has a primacy for men in terms of their masculine self-esteem.²⁹ This may be true regardless of whether MSM perform strictly in the receptive role during partnered sex where an erection is not essential. At the same time, the change in satisfaction and performance in other

domains may also negatively affect erection. In this situation, addressing other sexual concerns in addition to restoring erection may prove to be more effective for maintaining sexual intimacy. Other past research in PCa patients in general have supported the notion that retaining sexual intimacy in the broad sense rather than focusing on penetrative sex may be crucial for sexual rehabilitation of PCa patients.^{43–45}

The questionnaire prototype now needs to be validated with a formal test-retest procedure. Such a validation exercise is underway. We look forward to assessing the questionnaire in the clinical setting and with a larger sample of MSM facing or already impacted by PCa treatments.

The main limitation of this study was the fact that all data were collected online. As such, some feedback and comments that participants provided when filling in the questionnaire deserved dialog, but could not be followed up on because the data were anonymized. PCa diagnosis and treatment history data were collected retrospectively and prone to recall bias in the absence of medical record verification. Because validation of our questionnaire has not been completed, we have not attempted to analyze sexual QoL based on treatment modalities.

It was difficult to recruit large samples of MSM with PCa. As a result, there was not adequate power for an item-level factor analysis across all domains, although such an analysis could help explore the overall structure of the sexual problems reported by MSM with PCa. We hope this will be examined in future survey research that recruits a larger sample of MSM with PCa.

Lastly for this study, we followed the Centres for Disease Control and Prevention definition of MSM, which focuses on sexual behavior alone, without accounting for sexual orientation and gender identity.⁴⁶ As such participants who identified as transgender or non-binary, as well as heterosexual identified men, who have sexual engagement with men, were not excluded from the survey. The only group excluded was heterosexual men who practiced receptive anal intercourse with women. Once fully validated our survey instrument may be applicable to research with these other populations and for patients beyond just those diagnosed with PCa. This remains uncharted territory for future sexuality research.

CONCLUSION

According to the SEER 2013–2017 database, the median age of diagnosis for PCa diagnosis is 66 years-old when many men are still sexually active. We anticipate that the questionnaire introduced here, once validated, will be useful in both clinical and research settings to generate long-term, sexual side effects data. Such data may help MSM patients in deciding on treatments based on the sexual practices that are most important to them. It may also help health professionals to advise and manage expectation prior to treatment, and develop post-treatment targeted interventions.

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