

ORIGINAL RESEARCH—ONCOLOGY

Examining Sexual Dysfunction in Non-Muscle-Invasive Bladder Cancer: Results of Cross-Sectional Mixed-Methods Research

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ABSTRACT

Introduction. More than 70,000 new cases of bladder cancer are diagnosed in the United States annually; with 75% being non-muscle-invasive (NMIBC). Research examining sexual dysfunction in bladder cancer survivors is limited, and previous studies have focused on cystectomy patients.

Aims. To evaluate the impact of sexual dysfunction on NMIBC survivors.

Methods. Mixed-methods data collection integrated a quantitative survey (Study 1; n = 117) and semi-structured qualitative interviews (Study 2; n = 26) from a non-overlapping sample of NMIBC survivors. We performed descriptive and classification and regression tree (CART) analyses of survey data and qualitative analysis of interviews.

Main Outcome Measures. Self-reported sexual activity, interest in sex, and physiologic symptoms (e.g., male erectile/ejaculatory difficulties, female vaginal dryness) over the previous 4 weeks; partner communication about sexuality; contamination concerns; illness intrusiveness.

Results. Participants in these studies averaged 65 years of age (mean and median) and were male (77%), white (91%), and married (75%). Survey (Study 1) results linked NMIBC treatment to sexual symptoms and relationship issues. Many participants reported sexual inactivity (38.8%). Sexually active participants reported erectile difficulties (60.0%), vaginal dryness (62.5%), and worry about contaminating partner with treatment agents (23.2%). While almost one-half reported the usefulness of talking with partners about sexual function, only one-fifth of participants reported sharing all concerns with their partners. CART analysis supported the importance of communication.

One-half of interviewees (Study 2) reported sexual dysfunction. Two-thirds reported negative impacts on their relationships, including perceived loss of intimacy and divorce; over one-third were sexually inactive for fear of contaminating their partner or spreading NMIBC.

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Conclusions. Survivors' sexual symptoms may result from NMIBC, comorbidities, or both. These results inform literature and practice by raising awareness about the frequency of symptoms and the impact on NMIBC survivors' intimate relationships. Further work is needed to design symptom management education programs to dispel misinformation about contamination post-treatment and improve quality of life. **Kowalkowski MA, Chandrashekar A, Amiel GE, Lerner SP, Wittmann DA, Latini DM, and Goltz HH. Examining sexual dysfunction in non-muscle-invasive bladder cancer: Results of cross-sectional mixed-methods research. Sex Med 2014;2:141–151.**

Key Words. Urinary Bladder Cancer; Sexual Dysfunction; Cancer Survivorship; Partner Communication; Calmette-Guerin Bacillus

Introduction

Bladder cancer (BlCa) is the 4th most common form of cancer in the United States with over 70,000 new cases diagnosed annually [1]. Any malignancy of the pelvis, including BlCa, may lead to sexual dysfunction among men or women, defined as a decrease in sexual desire or variability of the sexual response cycle (i.e., excitement, plateau, orgasm, resolution) due to psychogenic or organic causes. Previous studies have demonstrated that radical cystectomy and urinary diversion, mainstays of surgical management for muscle-invasive bladder cancer, result in increased incidence of sexual dysfunction [2]. However, non-muscle-invasive bladder cancer (NMIBC) accounts for approximately 75% of incident bladder cancers [3]. Sexual dysfunction has not been well-studied among NMIBC survivors, who frequently undergo surveillance and various intravesical therapies.

Most treatments for BlCa cause substantial side effects that increase as treatments become more invasive and may persist. For example, Bacillus Calmette–Guérin (BCG) treatment may cause pain, dysuria, and urinary frequency [4,5]. Men may also experience erectile difficulties, which may resolve after BCG therapy ends [5]. Since BlCa is primarily a male disease, the limited literature does not include data on sexual dysfunction in women receiving BCG therapy. However, while sexual dysfunction has traditionally been perceived as predominately affecting men, more recent data suggests that a larger percentage of women (43% vs. 31% of men) are affected by sexual dysfunction (e.g., decreased vaginal lubrication, dyspareunia, diminished arousal, or difficulty achieving orgasm) [6].

Transurethral cystoscopy with either rigid or flexible instruments is currently the most common

method of monitoring for bladder cancer recurrence and progression. Rigid cystoscopy has been shown to cause transient impairment of sexual function and temporary decrease in libido among sexually-active patients [7]. Yet, the long-term effects of repeated surveillance cystoscopy have not been fully evaluated.

Quality of life (QOL) is critical to consider when discussing both the direct effects of cancer and those associated with subsequent treatment. Increasingly, sexual dysfunction has become an important component of QOL measurement, particularly in the evaluation of genitourinary malignancies [8]. Among men, sexual dysfunction, specifically ED, represents a significant cost to the healthcare system [9]. However, existing QOL measures do not fully account for the detrimental psychological effects of sexual dysfunction experienced by men and women (e.g., poor self-image, diminished self-esteem, depression mental stress and negative effects on personal relationships). This is particularly true when considering the acute onset of sexual dysfunction secondary to cancer or its treatment. One study using focus groups of men who had undergone definitive therapy for localized prostate cancer showed that physiologic sexual dysfunction impacted the quality of sexual intimacy, everyday interactions with women, sexual imagining and fantasy life, and self-perceptions of masculinity [10].

Aim

The literature on psychological burden of disease among bladder cancer survivors is limited and focuses primarily on muscle-invasive disease survivors. The few existing studies of NMIBC survivors focus primarily on male survivors. Thus, the goal of the present study is to examine the impact of

sexual dysfunction on NMIBC survivors and to describe psychosocial characteristics of persons with differing reported sexual functioning. Given that three-quarters of new bladder cancer diagnoses are *de novo* NMIBC, these survivors represent a significant population that has been largely neglected with respect to the effects of cancer and its treatment on sexual function as a critical component in QOL measurement. Furthermore, we hope to identify specific points of intervention that may help reduce the impact of sexual dysfunction in this group of individuals.

Methods

The current project employed a mixed-methods design combining an initial quantitative survey and subsequent qualitative semi-structured interviews. For the quantitative study, a convenience sample of participants ($N = 117$) was recruited over two phases. In the first phase, veterans from a large, urban VA tumor registry and patients from an academic urology clinic patient list were contacted and screened using an opt-out letter. Study staff called patients who did not opt out until (i) potential participants were contacted, or (ii) ten contact attempts were made. In the second phase, participants were recruited by posting an ad on bladder cancer survivorship websites (e.g., Bladder Cancer Advocacy Network) asking potential respondents to contact study staff. Potential participants were screened for study eligibility and eligible participants were scheduled for a follow-up telephone interview. To be eligible for inclusion in the study, participants had to have been diagnosed with NMIBC within 4 years of study entry date.

Participants gave informed consent and were asked to complete a 45-minute telephone survey administered by trained interviewers consisting of several validated measurement tools. Measures included a validated disease-specific health-related quality of life (European Organization for Research and Treatment of Cancer Quality-of-Life Questionnaire Bladder Cancer—Superficial—24 [BLS-24]) [11]. The measure has a 7 item sub-scale for urinary symptoms and 3 item sub-scale for survivors' future perspective on their illness. Sexual function and related concerns were evaluated over the 4-week period preceding survey completion using the 8 sexual activity questions included in the BLS-24. Questions captured level of interest in sex, frequency of sexual activity, degree of enjoyment, sexual arousal difficulties, intimacy concerns, and

partner contamination concerns related to bladder cancer treatment. Responses were collected on a 4-point scale (i.e., Not at all, A little, Quite a bit, Very much). Survivors' perceptions of their cancer's disruption of their life was measured by the Illness Intrusiveness Rating Scale (IIRS) [12], a 13-item measure used in a number of studies of cancer and chronic disease. The effects of intrusiveness stem from the reduction of positive outcomes from participating in valued life activities and of the patient's sense of control over the ability to obtain positive outcomes or avoid negative ones. Psychological distress was measured with the Brief Symptom Index-18 (BSI-18), which includes a total score and subscales for somatization, depression, and anxiety [13], and has been widely used in studies of cancer survivorship. An assessment of partner communication about cancer-related concerns was performed using a previously validated 10-item measure adapted from Porter [14].

Descriptive analyses of the survey results were carried out using SAS v9.2 (SAS Institute, Cary, NC). Chi-square tests were used to examine differences in respondent characteristics stratified by level of sexual interest. In addition, Classification and Regression Tree (CART) methodology was implemented to classify groups with similar characteristics. A total of 85 patients with complete covariate information were used to identify groups of similar individuals and explore relationships with sexual activity. CART decision tree methodology permits the evaluation of unique interactions between subsets of covariates and offers a visual representation of these relationships. CART analysis was performed using CART v6.4 software (Salford Systems, San Diego, CA).

To gain a greater understanding of issues identified in the survey, participants for the qualitative study were recruited from the same VA tumor registry and urology clinic ($N = 26$). Individuals were sent opt-out letters, contacted, and screened using similar eligibility criteria to the quantitative study. While participation in the quantitative study was not part of the exclusion criteria, no qualitative participants reported enrollment in the quantitative study. Study participants gave informed consent and were asked to complete a semi-structured interview administered by a trained qualitative interviewer (HHG) consisting of diagnosis, treatment, monitoring, symptoms and management, relationships and sexuality, and patient navigation. Interviews were audiotaped and averaged one hour and six minutes in length, with a range of 48 to 120 minutes.

Recordings were transcribed verbatim by a professional transcription service and analyzed using holistic-content and constant comparative analyses. Two co-authors independently read each transcript line-by-line and developed codes and patterns located in the qualitative data (open coding). These co-authors then conducted several meetings validating these codes, before jointly synthesizing related codes into themes. A third co-author reviewed the thematic coding scheme, as well as supporting codes and data, in order to affirm the final themes. Related to the current study, initial codes related to participant statements concerning complete or partial erectile dysfunction, difficulty with vaginal lubrication, and other aspects of sexual dysfunction post-treatment. The resulting final theme was noted as “experiences of sexual dysfunction among NMIBC survivors” and exemplifying quotes to illustrate the findings were selected and discussed until 100% consensus was reached.

Based on these qualitative analyses, participants were placed along a nonlinear scale of sexual function from least to most affected. Select excerpts from the interviews were also retrospectively mapped to the corresponding terminal nodes of the CART analysis of survey respondents to further match specific individual experiences with their appropriate levels of sexual interest, disease intrusiveness, arousal dysfunction, and partner communication.

Both studies were approved by BCM Institutional Review Board, and participants provided informed consent.

Results

Table 1 shows the demographic and clinical characteristics of the individuals participating in the quantitative and qualitative portions of the study. There were more men (72.6% and 84.6%) than women, more white participants (94.0% and 80.8%) than other ethnicities, and respondents were generally older in both arms of the study, likely due to the epidemiological distribution of bladder cancer as a disease predominantly affecting men, whites, and older adults. The majority of participants in the two studies were married (74.4% and 73.2%). Participant level of education was well-represented across both quantitative and qualitative studies. Finally, individuals had been diagnosed with various tumor stages of non-muscle-invasive bladder cancer (T_a, T_{is}, and T₁).

Table 1 Demographic and clinical characteristics across quantitative and qualitative study samples

	Quantitative survey	Qualitative survey
Age (Mean [SD])	64.6 (9.50)	69.1 (9.40)
	N (%)	N (%)
Gender		
Male	85 (72.6)	22 (84.6)
Female	32 (27.4)	4 (13.4)
Race/ethnicity		
White	110 (94.0)	21 (80.8)
Black or African American	2 (1.7)	4 (15.4)
Other	5 (4.3)	1 (3.8)
Marital Status		
Married	87 (74.4)	19 (73.2)
Single, never married	3 (2.6)	3 (11.5)
Separated/divorced	17 (14.5)	1 (3.8)
Widowed	10 (8.5)	3 (11.5)
Education		
Less than high school	0 (0.0)	2 (7.7)
High school graduate	18 (15.4)	7 (26.9)
Some college	43 (36.8)	8 (30.8)
Bachelor's degree	32 (27.4)	8 (30.8)
Postgraduate degree	24 (20.4)	0 (0.0)
Unknown	0 (0.0)	1 (3.8)
Tumor stage		
T _a	37 (31.6)	8 (30.8)
T _{is}	15 (12.8)	2 (7.8)
T ₁	35 (29.9)	5 (19.2)
Did not know/unknown	30 (25.6)	11 (58.2)

Quantitative Survey

Greater than one-half (55.3%) of respondents reported NMIBC or its treatment had interfered with their relationship with their spouse or partner. Over one-third (38.8%) of respondents reported no sexual activity over the 4 weeks prior to the survey. The percentage of sexually-inactive survivors was higher among females than males (56.0% vs. 31.3%; $P = 0.04$) but was not different between survivors diagnosed with T_{is} compared to T_a or T₁ bladder tumors ($P = 0.86$). For those individuals who were sexually active, 60.0% of males experienced difficulty gaining or maintaining an erection and 43.1% of males had problems with ejaculation (Table 2). Among sexually-active females, 62.5% experienced problems including vaginal dryness.

Contamination from bladder cancer treatment was a significant concern among both male and female respondents that inhibited sexual activity with their partner. Almost one-quarter (23.2%) of participants reported some degree of concern over transmitting disease to their partners. While only 20% of the individuals surveyed reported sharing all concerns about sexual function with their partners, nearly 50% of participants reported that it was very helpful to discuss concerns about sexual function with their partners, with a similar

Table 2 Patient characteristics stratified by level of sexual interest

	No interest in sex (N = 17) (Mean [SD])	At least some interest in sex (N = 76) (Mean [SD])	P
Age (years)	65.1 (10.0)	62.5 (8.4)	0.36
Time since diagnosis (months)	16.7 (10.7)	25.4 (14.1)	0.02
	n (%)	n (%)	
Gender			0.07
Male	9 (13.2)	59 (86.8)	
Female	8 (32.0)	17 (68.0)	
Education			0.42
High school diploma	4 (23.5)	8 (10.5)	
Some college	6 (35.3)	28 (36.8)	
Bachelor's degree	3 (17.7)	24 (31.6)	
Graduate school	4 (23.5)	16 (21.1)	
Relationship status			0.17
Married	12 (70.6)	64 (84.2)	
Not married	5 (29.4)	12 (15.8)	
Smoking status			0.45
Current smoker	3 (17.7)	9 (11.8)	
Nonsmoker	14 (82.3)	67 (88.2)	
Stage of disease			0.76
T0	0 (0.0)	3 (4.3)	
Ta	4 (26.7)	23 (32.9)	
Tis	2 (13.3)	9 (12.9)	
T1	4 (26.7)	22 (31.4)	
Unknown/missing	5 (33.3)	13 (18.5)	

percentage of male and female respondents indicating discussion was helpful ($P = 24$).

There was a significant difference ($P = 0.02$) in the time since diagnosis as measured in months between those surveyed who endorsed at least some interest in sex (25.4 months) and those

who reported no interest in sex (16.7 months). However, no other demographic variables were associated with level of sexual interest, including relationship status ($P = 0.17$). Between these two groups, the difference in the amount of communication regarding concerns over sexual function approached significance ($P = 0.09$) based on responses on a five-point Likert-type scale (data not shown). On the other hand, neither degree of illness intrusiveness ($P = 0.47$) nor arousal dysfunction ($P = 0.64$ for men, $P = 0.26$ for women) exhibited a significant difference between those who had no interest in sex and those who had at least some interest in sex.

Survey data were used to formulate a decision tree with seven terminal nodes in order to group individuals according to their interest in sexual activity, level of disease intrusiveness, degree of arousal dysfunction, and strength of partner communication (see Figure 1). This analysis further demonstrated that there were two subsets of NMIBC survivors who reported the least sexual activity: (i) survivors indicating any interest in sex, mild illness intrusiveness, and moderate-to-severe arousal dysfunction, and (ii) survivors indicating any interest in sex, severe illness intrusiveness and poor communication with their spouse/partner regarding concerns about sexual function. Both subsets describe clinically modifiable intervention points where sexual medicine physicians and sex therapists could potentially intervene.

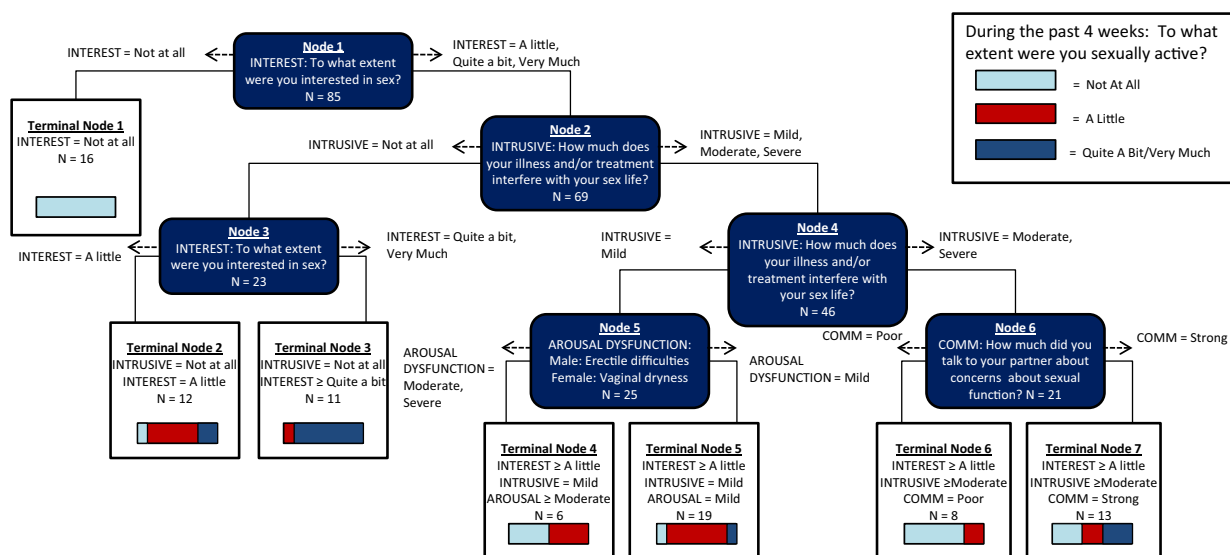


Figure 1 CART analysis demonstrates relationship between NMIBC survivor characteristics and level of sexual activity.

Conversely, the decision tree illustrated two groups of NMIBC survivors reporting the most sexual activity were those who (i) indicated little to no illness intrusiveness and at least quite a bit of interest in sex, and (ii) indicated any interest in sex, severe illness intrusiveness, and strong communication with their spouse/partner regarding concerns about sexual function.

Description of CART Terminal Nodes and Sexual Activity among Grouped Individuals

Terminal Nodes 1, 2, and 3 explored the intersection of sexual interest, illness intrusiveness, and sexual activity within the previous 4-week period. Survey participants whose response patterns indicated that they were “not at all interested in sex” ($n = 16$) were also “not at all” sexually active within the 4-week period preceding their telephone interview. In contrast, survey participants who reported having some degree of interest in sex and no illness intrusiveness varied in terms of their sexual activity in the previous four weeks. The majority of survey participants whose response patterns indicated “a little interest” in sex and no illness intrusiveness (Terminal Node 2, $n = 12$) reported being sexually active “a little” or “quite a bit/very much” in the last month. Most survey participants indicating “quite a bit” or “very much” in sex and no illness intrusiveness (Terminal Node 3, $n = 11$) reported being sexually active “quite a bit/very much” in the last month. No Terminal Node 3 participants reported sexual inactivity in the month prior to completing the survey.

New trends emerged when survey responses were analyzed in terms of the impact of sexual interest, illness intrusiveness, and arousal dysfunction on sexual activity in the previous 4-week period. Only one half of survey participants who reported having some degree of interest in sex, mild illness intrusiveness, and moderate-to-severe erectile difficulties or vaginal dryness (Terminal Node 4, $n = 6$) were “a little” sexually active over the past 4 weeks. The other half of these respondents were “not at all” sexually active. Alternatively, the majority of survey respondents who reported some degree of interest in sex, but experiencing both mild intrusiveness and arousal dysfunction were sexually active “a little” or “quite a bit/very much” in the last month (Terminal Node 5, $n = 19$). Only a small number of survey participants whose responses corresponded to Terminal Node 5 reported sexual inactivity in the past month.

Like the arousal dysfunction variable, communication between partners affected sexual activity in the previous 4-week period. Among those survey respondents with some degree of interest in sex, but who were experiencing moderate-to-severe illness intrusiveness, communication was instrumental in determining their degree of sexual activity. Participants who reported “poor” communication with their partners or spouses (Terminal Node 6, $n = 8$) were primarily sexually inactive within the month preceding the survey. These findings were in sharp contrast with survey participants who reported “strong” communication with partners or spouses. Survey participants’ responses corresponding with Terminal Node 7 ($n = 13$) were those who remained interested in sexual activity, in spite experiencing moderate-to-severe illness intrusiveness, and communicated frequently and comprehensively with partners about their concerns about sexual functioning. Terminal Node 7 participants varied in terms of their sexual activity in the previous 4 weeks. However, the majority were “a little” or “quite a bit/very much” active.

Qualitative Study

The information gathered through qualitative study interview transcripts was used to report sexual dysfunction and level of affectedness among NMIBC survivors on a linear scale. A scaled view of how sexual dysfunction affects NMIBC survivors is presented in Figure 2.

The qualitative data showed that 50% of participants interviewed reported physical symptoms of sexual dysfunction. In addition, greater than 40% of the individuals endorsed a negative impact on their primary relationships, including perceived loss of intimacy and divorce. Similar to the quantitative study, over 30% of those interviewed refrained from sexual activity due to a fear of contaminating their partner with treatment-related agents or spreading NMIBC.

Several themes related to sexual dysfunction and partner interaction that were observed in CART analysis of quantitative survey participants were reinforced by responses from the qualitative survey. Table 3 displays quotations extracted from the transcripts of qualitative surveys as mapped onto the CART terminal nodes from survey respondents. Excerpts from qualitative participants revealed that individuals with strong partner communication re-established a sexual relationship after bladder cancer diagnosis and treatment.

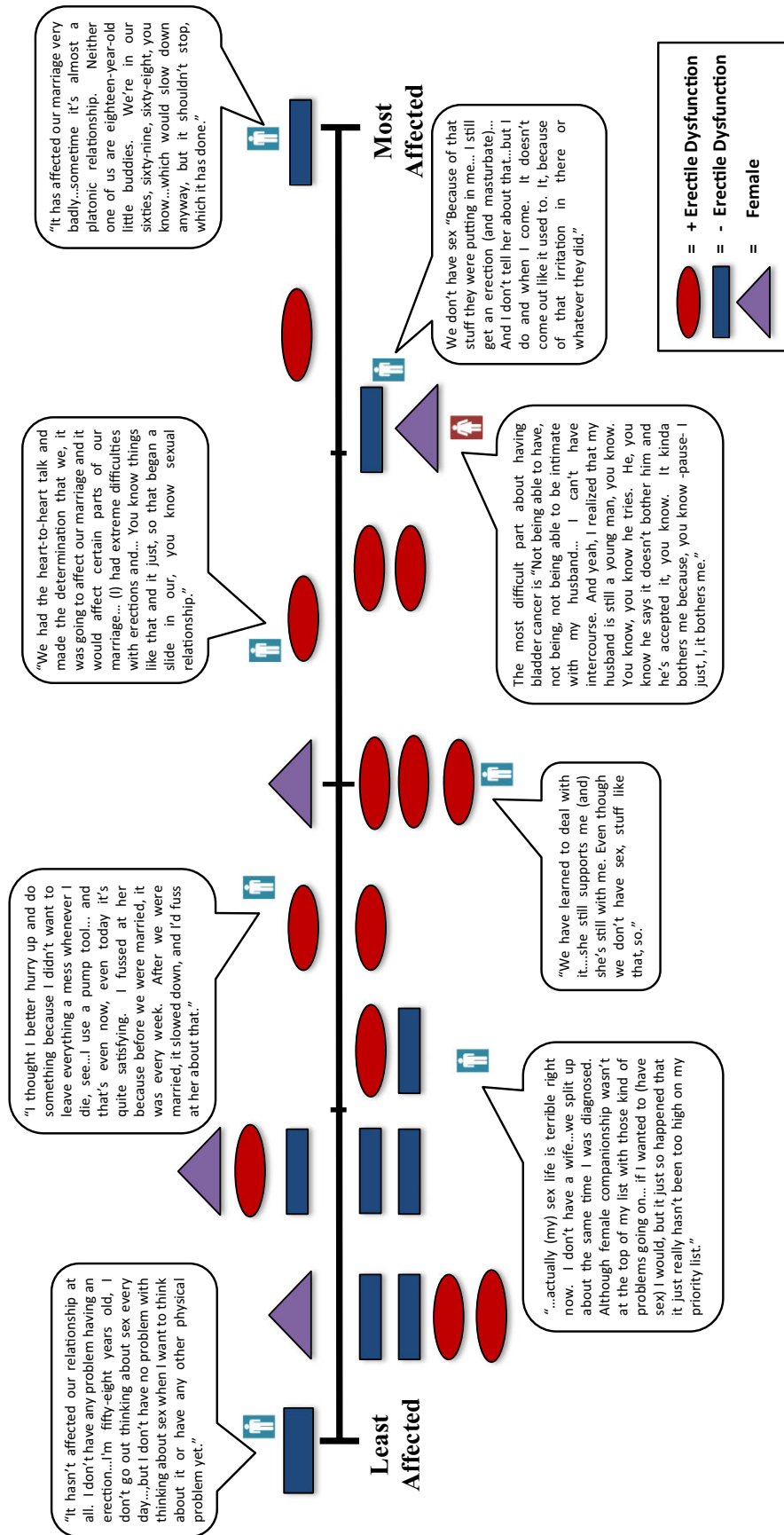


Figure 2 A scaled view of sexual dysfunction among a sample of NMIBC survivors.

Table 3 Qualitative interview excerpts mapped onto CART terminal nodes from survey respondents

Terminal node	Feeder node concepts	Outcome: Sexual activity during previous month*	Exemplar quotes from qualitative study
1	"Not at all" interested in sex	"Not at all" sexually active	"... actually [my] sex life is terrible right now. I don't have a wife ... we split up about the same time I was diagnosed. Although female companionship wasn't at the top of my list with those kind of problems going on ... if I wanted to [have sex] I would, but it just so happened that it just really hasn't been too high on my priority list." (VA 017)
2	"A little" interested in sex; No illness intrusiveness	"A little" or "Quite a bit/Very much" sexually active	"It hasn't affected our relationship at all. I don't have any problem having an erection. ... I'm [in my late fifties], I don't go out thinking about sex every day ... but I don't have no problem with thinking about sex when I want to think about it or have any other physical problem yet." (VA008)
3	"Quite a bit/Very much" interested in sex; No illness intrusiveness	"Quite a bit/Very much" sexually active; None reported sexual inactivity	"... We still have the same sexual relationship and quite active ... a couple times a week ... there's no liquid or anything. But you still have the same sensation and like I said she's not missing any orgasms at all, so ... we got, you know all these aids and pumps and different things we've tried, but we still, we've got, we could write a book on that so that's not really a problem. We just get it on and been doing that for, since [the sixties] ... Sometimes we use [a pump], sometimes we don't. And like I say we still have fun and achieve satisfaction in both parties. ... There's, like I said I'm still got that drive and I'm always aggravating her [for sex]." (BCM015)
4	"Quite a bit/Very much" interested in sex; "Moderate-to-severe" arousal difficulties; Mild illness intrusiveness	"A little" or "Not at all" sexually active	"Well obviously for sex it's different. ... As far as the marriage goes, it really made it stronger. Like I say she was there for me the whole time. And I think we bonded a little closer even. We've been married for [over two decades], so it's, I mean we were pretty close before that. And obviously [bladder cancer] changed our sex life a little bit. We still have sex, but it's a little different now. ... It's, well obviously it's different for me. Since I can't have normal intercourse, but other than that, I mean for me it's a lot of foreplay, but I enjoy that too. It's, you know I, if you'd have told me before this that I would've still enjoyed sex, I might've not known it. But it's still, I mean it's okay. It's not as good as it was before, but it's still pretty good. ... And also now, I guess I can say it, [I] bought a vibrator so. ... She can still have orgasms, which it's, it changed the dynamics of sex a little bit for me though, it's. You know now it's more to make sure that she has an orgasm. ... Cause I can't, so now it's my enjoyment for her to have one. But I still enjoy sex, so it's not like I don't want to do it." (VA010)
5	"A little/Quite a bit/Very much" interested in sex; "Mild" arousal difficulties; Mild illness intrusiveness	"A little" or "Quite a bit/Very much" sexually active in; Only 3 reported sexual inactivity	"I can't tell that [bladder cancer treatment] made any difference [in our sex lives]. I wouldn't say that there's been any change ... There's no change that I can tell ... I more or less abstained [from sex] for about six weeks. It was a couple weeks after the completion of [BCG] treatment. I was leery of having had that chemical in there not knowing what it was. I think it was just voluntarily that we suspended intercourse during the period of treatment for a couple weeks thereafter and then resumed it ... there's no difference now." (BCM011)
6	"A little/Quite a bit/Very much" interested in sex; "Moderate-to-severe" illness intrusiveness; "Poor" communication	Primarily sexually inactive; Only 2 reported "A little" sexual activity	"The most difficult part about having bladder cancer is not being able to have, not being, not being able to be intimate with my husband. ... I can't have intercourse [post-radical cystectomy]. And yeah, I realized that my husband is still a young man, you know. You know, you know he tries. He, you know he says it doesn't bother him and he's accepted it, you know. It kinda bothers me because, you know [pause] I just, I, it bothers me." (VA022) "It has affected our marriage very badly ... sometime it's almost a platonic relationship. Neither one of us are eighteen-year-old little buddies. We're in our sixties, sixty-nine, sixty-eight, you know ... which would slow down anyway, but it shouldn't stop, which it has done." (VA004)
7	"A little/Quite a bit/Very much" interested in sex; "Moderate-to-severe" illness intrusiveness; "Strong" communication	Majority reported "A little" or "Quite a bit/Very much" sexual activity	"I thought I better hurry up and do something because I didn't want to leave everything a mess whenever I die, see ... I use a pump tool ... and that's even now, even today it's quite satisfying. I fussed at her because before we were married, it was every week. After we were married, it slowed down, and I'd fuss at her about that." (VA002) "Well I have already told you about the respect that I have gained for my husband and his attention and so on, and our [sexual] relations are not what they were, but they still are [happening], and so [my urologist] laughed at us. My daughter was in there with us and he sent her out so he could talk about sex [with us]. Hahaha. And so [my urologist] said it wasn't very many of my patients that are ... still concerned about sex. I said well, to each his own. Hahaha. [We have sex] weekly. ... It's more careful now. ... I make sure that I have on a fresh pad so I have plenty of room if I should squirt. ... In fact, [my husband is] kind of amused with the whole thing sometimes. I say oh ... I think I'm leaking. Hahaha. He says well you sprung a leak." (BCM016)

*Outcomes reported by quantitative study participants.

Discussion

The data on sexual dysfunction, psychological burden of disease, and the relationship between the two, among bladder cancer patients are limited. Most studies of sexual dysfunction and other aspects of HRQOL focus on cystectomy patients. The present study is the first to employ a mixed-methods approach to examine sexual dysfunction and its psychosocial correlates among a sample of NMIBC survivors, the largest group of new bladder cancer diagnoses. Results revealed the frequency of sexual dysfunction was considerable. First, the physical manifestation of sexual dysfunction, e.g., ED and ejaculatory problems among men and vaginal dryness among women, was reported in more than one-half of sexually-active NMIBC survivors. Study findings also demonstrated significant psychological and emotional burden. Responses from the two studies indicate that participants viewed their NMIBC diagnoses and treatment-related sequelae as negatively impacting their relationship with their partner, including loss of intimacy. Additionally, participants in both study arms reported worrying about harming their partner through sexual contact following NMIBC treatment. Lastly, results from CART analysis underlined the importance of effective partner communication in modifying and maintaining sexual intimacy in the relationship, particularly among those that perceived NMIBC and its treatment as intrusive in their sex life. With our cross-sectional, small convenience sample approach, these results may not represent the wider population of bladder cancer survivors. However, our results suggest these issues are worthy of further exploration in the clinic and in population-based studies of survivors.

Sexual Dysfunction and Bladder Cancer

In a nationally representative sample of 1,550 women and 1,455 men aged 57–85, an age group similar to the study population, physical symptoms of sexual dysfunction (e.g., difficulty achieving orgasm) were reported by approximately 35% of individuals surveyed [15]. Previous research also suggests that NMIBC treatment is associated with at least transient sexual dysfunction [5,7]. Results from the present study support previous findings detailing sexual dysfunction and its etiology in this population. The study participants in the quantitative study reported limited sexual activity. Consistent with previous findings, nearly 40% of respondents reported not engaging in any sexual contact over the 4 weeks preceding survey comple-

tion [16]. Additionally, in both quantitative and qualitative studies, over one-half of sexually-active individuals experienced some degree of sexual dysfunction.

In these two study samples, co-morbid conditions, the natural effects of aging, and NMIBC treatment and monitoring impact sexual functioning and intimacy in relationships. The cancer continuum model introduced by Flynn exemplifies the physical, emotional and psychological difficulties that arise in conjunction with ongoing management of this complex disease process [17]. Given the multifaceted biopsychosocial issues that impact sexual functioning in this population, the question remains how best to address each of the aforementioned issues surrounding sexual activity in the face of NMIBC. Discussion of sexual side-effects and management strategies should be incorporated into pre-treatment, patient-provider communication, and continue throughout treatment and monitoring.

Women's Issues

Women's experiences are especially underreported in the scientific literature. Female NMIBC survivors may have differing needs following their diagnosis and throughout subsequent surveillance and treatment for their disease process. Research has previously noted that women tend to report decreased sexual activity when compared to men across all ages, and more likely that they do not value penetrative sex as much as men. However, sexual health continues to play a significant role in female QOL issues [18,19].

Both physical and emotional factors, such as a decrease in sexual attractiveness, may influence sexual life among women. Zippe et al. surveyed women who underwent radical cystectomy for muscle-invasive bladder cancer and demonstrated that 48% of subjects reported sexual dysfunction due to physical inability, and 30% expressed a decreased desire for sexual activity due to apprehension related to "imperfection" (i.e., urostomy) [20]. While women suffering from NMIBC may not experience the level of invasiveness associated with radical cystectomy and reconstruction, they continue to undergo procedures that may contribute to physical and emotional responses affecting ongoing sexual activity.

As mentioned previously, ED and vaginal dryness may precipitate an "identity dilemma." However, psychosocial and emotional responses related to this shift in self-perception require skilled navigation in order to find new ways of being

sexual. Wittmann et al. reviews the various physiologic therapies that are available to aid men's sexual function [19]. Common ED treatments include pharmacologic (e.g., Phosphodiesterase Type-5 inhibitors and Alprostadil), mechanical (e.g., vacuum devices), and prosthetic aids, or some combination of these therapies. Fewer resources are available to women with cancer [21], although since bladder cancer is not a hormonally driven cancer, hormone replacement therapy consultation with a gynecologist may be valuable.

Despite the variety of options available for the physiologic treatment of sexual dysfunction as a result of NMIBC, the psychological implications may represent even more of a conundrum. The loss of a man's erections or prematurely developed vaginal dryness may be painful and confusing resulting in grief and mourning. The psychological defenses typically used to fend off feelings of grief tend to generalize and subdue other emotions (e.g., sexual desire). If men and women with NMIBC feel safe and can share their vulnerability and grief with their partners, they will be in a better position to stay in touch with their sexual feelings. The ability to replace longing for spontaneity with intentional sexual activity will reduce anxiety and result in greater experience of pleasure [19]. In our sample, participants who reported at least some interest in sex were farther removed from their initial NMIBC diagnosis than those reporting no interest. We hypothesize that the participants with greater interest in sex might have been farther along in their grief process as described in Wittmann's model of sexual rehabilitation.

Given the physiological and psychological complexity associated with sexual health amongst cancer survivors, it is necessary to consider multidisciplinary care. Social workers are trained to facilitate grief and can provide additional guidance with case management, health information, and patient navigation necessary to address the array of sexual health concerns found in our sample. While it is valuable to alert patients about the sexual side-effects of treatment and the options for regaining sexual activity, patients may wish to address their sexual concerns at some distance from diagnosis when they have come to terms with the changes brought about by treatment and wish to become sexually active again.

Partner Communication and Maintaining Sexual Health in NMIBC Survivors

Our quantitative survey, CART analysis, and subsequent qualitative study all reinforce the impor-

tance of strong communication in maintaining sexual health between the patient and his/her partner. Open discussion may often overcome the effects of illness intrusiveness and physiologic dysfunction to promote ongoing sexual activity. Unfortunately, our findings demonstrate that participants rarely disclosed all of their sexual-health-related concerns to their partners.

Previous research indicates cancer survivors may be uncomfortable with or not understand how to discuss their sexual functioning with their partners [22,23]. Education about the effect of treatment on sexuality and encouragement of communication about sexual concerns should be provided as a part of usual care. Sex therapy may also help survivors adjust to new sexual realities and allow survivors to expand their sexual repertoire to include non-penetrative sex when penetration is no longer an option. Accurate information about the non-transmissibility of toxic treatment agents from partner to partner through sex should be provided so that couples can feel reassured and not avoid sexual activity.

Conclusions

Non-muscle-invasive bladder cancer, its treatment or both, as well as comorbid conditions may result in sexual problems. The cross-sectional nature of our data does not permit comparisons of sexual functioning or psychological status before and after diagnosis bladder cancer. However, the dearth of information about sexual functioning among NMIBC survivors, particularly women, heightens the utility of our data for generating hypotheses for further work. The findings of the present study inform the scientific literature and clinical practice about the pervasiveness of these symptoms and their impact on NMIBC survivors' sexual and romantic relationships. Further work is needed to design symptom management and educational programs to dispel misinformation about contamination by treatment agents and to encourage greater communication between partners and with health care providers about sexual concerns. Interventions that address sexuality after treatment should be developed to improve this important and often ignored aspect of quality of life of NMIBC survivors.

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