



Patient Decision-making and Predictors of Genital Satisfaction Associated With Testicular Prostheses After Radical Orchiectomy: A Questionnaire-based Study of Men With Germ Cell Tumors of the Testicle

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OBJECTIVE	To better understand patient decision-making and genital satisfaction associated with postorchietomy testicular prosthesis (TP) implantation in patients with germ cell tumors of the testicle.
MATERIALS AND METHODS	An electronic survey to assess TP decision-making and genital satisfaction was distributed to patients via an institutional database ($n = 70$) and social media outlets ($n = 167$). Statistical analyses were performed using chi-square tests for categorical variables, Wilcoxon-Mann-Whitney tests for continuous variables, and multivariate regression analyses to identify independent predictors of receiving a prosthesis, genital satisfaction, and prosthesis satisfaction.
RESULTS	24.9% of respondents elected to receive a TP, but 42% of men without a prosthesis reported never being offered one. Identifying as a heterosexual man (2.86) and receiving a TP (odds ratio = 3.29) were both positive predictors of overall genital satisfaction. Having the orchiectomy performed at an academic institution (odds ratio = 2.87) was a positive predictor of testicular prosthesis TP placement. 89.8% of TP recipients were satisfied with the look of their prosthetic, but only 59.3% of respondents were satisfied with prosthetic feel.
CONCLUSION	There are high levels of genital satisfaction in those who elect to receive a TP postorchietomy. Associations between TP placement, genital satisfaction, and sexuality merit further investigation. Our results also indicate that patients who pursue an orchiectomy at an academic institution are more likely to receive a TP. The use of social media to recruit study participants in urology should be explored further. UROLOGY 124: 276–281, 2019. © 2018 Elsevier Inc.

Radical inguinal orchiectomy is considered the gold-standard therapeutic intervention for testicular cancer.¹ Given the young age and long life expectancy of the testicular cancer patient population, there is considerable focus placed on maintaining patient physiological and psychological quality of life postorchietomy. However, men who undergo orchiectomy to treat testicular cancer report a negative change in body image and quality of life associated with having the procedure.^{2,3}

The use of a testicular prosthesis (TP) to restore the cosmetic appearance of a patient's scrotum postorchietomy was first described in 1941.⁴ Since then, a limited number of studies have shown high rates of overall TP satisfaction and improved self-esteem in patients who elected to receive a TP.⁵⁻⁷ However, there have been few studies to date that have examined predictors of genital satisfaction in testicular cancer survivors postorchietomy or characteristics associated with a patient electing to receive a TP and no studies have included both patients with a TP and without a TP to determine predictors of genital satisfaction. Moreover, respondents in previous studies have always been recruited directly from academic centers or registries associated with a single academic institution.

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With these deficiencies in the literature in mind, the goals of this study are to utilize social media in addition to a traditional patient registry to recruit a diverse, international testicular cancer patient population to complete a questionnaire regarding TP and genital satisfaction. Based on patients' responses, we can determine characteristics that are predictive of a patient choosing to receive a TP, predictors of TP satisfaction, and predictors of overall genital satisfaction postorchietomy within the United States and abroad.

MATERIALS AND METHODS

An electronic survey was developed to assess patient characteristics associated with the decision to get a TP and genital satisfaction in 3 domains—cosmetics, psychosocial, and sexual well-being—regardless of TP status (survey in Appendix 1). Patient-reported outcome surveys from the field of plastic surgery were used to guide the development of our survey.^{8,9} However, our survey was not independently validated. For those who received a TP, additional questions concerning satisfaction with the prosthetic were asked.

Questionnaire respondents were recruited via 2 separate processes as part of a research protocol approved by the Johns

Hopkins Institutional Review Board. Study data from patients enrolled in the Johns Hopkins Testicular Cancer Program were collected and managed using REDCap electronic data capture tools hosted at Johns Hopkins.¹⁰ Patients from outside our institutional database were recruited using social media posts on Twitter, Reddit, and Facebook that included a link to our electronic questionnaire generated using Qualtrics software, Version November 2017. Qualtrics software was also used to manage the social media respondent data.

Level of satisfaction with TP was measured using a 4-point Likert scale with 1 corresponding to “very dissatisfied” and 4 corresponding to “definitely satisfied.” Comparisons were made between patient groups using chi-square test for categorical variables and Wilcoxon-Mann-Whitney test for continuous variables. Multivariate logistic regression models were run to identify independent predictors of receiving a prosthesis, satisfaction with genitals, and overall satisfaction. Patients were considered to be satisfied with the appearance of genitals if reported at least “Somewhat satisfied” to the question “In the past 2 weeks, how satisfied or dissatisfied have you been with how your genital area looks now compared to before you had surgery?”. Patients were considered to be overall satisfied with their prostheses if they reported being at least “Somewhat satisfied” to all 5 questions regarding prosthetic satisfaction. Analysis was performed using statistical software package SAS, Version 9.3 (SAS Institute Inc., Cary, NC).

Table 1. Demographics of respondents recruited from social media vs institutional database

	Social Media Respondents	Institutional Respondents	All Patients	P Value
Years from diagnosis	6.6 (0-43)	2.5 (0-16)	5.2 (0-43)	<.01
Age at diagnosis	31.7 (14-63)	34.6 (16-60)	32.5 (14-63)	.16
Race				<.01
Asian	3 (1.8)	3 (4.5)	6 (2.5)	
Black	0 (0)	5 (7.5)	5 (2.1)	
Latino	0 (0)	3 (4.5)	3 (1.3)	
White	153 (90)	56 (83.6)	209 (88.2)	
Other	14 (8.2)	0 (0)	14 (5.9)	
Marital status				.56
Married	97 (57.1)	41 (61.2)	138 (58.2)	
Nonmarried	73 (42.9)	26 (38.8)	99 (41.8)	
Sexually active				.97
Yes	150 (88.2)	59 (88.1)	209 (88.2)	
No	20 (11.8)	8 (11.9)	28 (11.8)	
Sexual orientation				.04
Heterosexual	141 (82.9)	63 (94)	204 (86.1)	
Nonhetero	25 (14.7)	2 (3)	27 (11.4)	
Unknown	4 (2.4)	2 (3)	6 (2.5)	
Location of orchiectomy				<.01
United States	124 (72.9)	63 (94)	187 (78.9)	
Outside of the United States	41 (24.1)	0 (0)	41 (17.3)	
Unknown	5 (2.9)	4 (6)	9 (3.8)	
Institution of orchiectomy				<.01
Academic	52 (30.6)	49 (73.1)	101 (42.6)	
Nonacademic	102 (60)	16 (23.9)	118 (49.8)	
Unknown	16 (9.4)	2 (3)	18 (7.6)	
Postorchietomy treatment				.03
Yes	128 (75.3)	41 (61.2)	169 (71.3)	
No	42 (24.7)	26 (38.8)	68 (28.7)	
Prosthesis				.27
Yes	39 (22.9)	20 (29.9)	59 (24.9)	
No	131 (77.1)	47 (70.2)	178 (75.1)	

Bolded values correspond to clinically significant p values.

Table 2. Comparisons of patients that elected to receive a TP vs those who did not receive a TP

	Prosthesis	No Prosthesis	P Value
Years from diagnosis			0.03
≥5	22 (37.3)	36 (20.2)	
<5	27 (45.8)	102 (57.3)	
Unknown	10 (16.9)	40 (22.5)	
Age at diagnosis			0.22
≥30	29 (49.2)	76 (42.7)	
<30	29 (49.2)	102 (57.3)	
Unknown	1 (1.7)	0 (0.0)	
Race			0.17
White	55 (93.2)	154 (86.5)	
Nonwhite	4 (6.8)	24 (13.5)	
Marital status			0.18
Married	30 (50.9)	108 (60.7)	
Nonmarried	29 (49.1)	70 (39.3)	
Sexually active			0.65
Yes	53 (89.8)	156 (87.6)	
No	6 (10.2)	22 (12.4)	
Sexual orientation			0.04
Heterosexual	45 (76.3)	159 (89.3)	
Nonhetero	12 (20.3)	15 (8.4)	
Unknown	2 (3.4)	4 (2.3)	
Location of orchiectomy			0.25
United States	42 (71.2)	145 (81.5)	
Outside of the United States	14 (23.7)	27 (15.2)	
Unknown	3 (5.1)	6 (3.4)	
Institution of orchiectomy			0.02
Academic	33 (55.9)	68 (38.2)	
Nonacademic	20 (33.9)	98 (55.1)	
Unknown	6 (10.2)	12 (6.7)	
Postorchiectomy treatment			0.18
Yes	38 (64.4)	131 (73.6)	
No	21 (35.6)	47 (26.4)	

TP, testicular prosthesis.

RESULTS

A total of 237 respondents were included in this study. Seventy respondents were recruited from the Johns Hopkins Testis Cancer Program (response rate 56.5%) and 167 respondents were recruited using social media. Demographics between the 2 groups were statistically different in reference to race, sexual orientation, location of orchiectomy (United States vs elsewhere), years since diagnosis, institution of orchiectomy (academic vs nonacademic), and utilization of postorchiectomy treatment (Table 1). Fifty-nine total respondents received a TP and 178 respondents did not receive a prosthesis. Differences in patient characteristics between those who received a prosthesis and those who did not are shown in Table 2. Respondents who received prosthetics were more likely to have been diagnosed with testicular cancer more than 5 years prior to responding to the questionnaire (37.3%), have received treatment at an academic institution (55.9%) and identify as nonheterosexual (20.3%).

Table 3 reports patient characteristics that were predictive of a patient electing to receive a TP on multivariate analysis. Age greater than or equal to 35 at the time of the questionnaire (odds ratio [OR] = 2.69; 95% confidence interval [CI] 1.24-5.85) and having the orchiectomy performed at an academic institution (OR = 2.87; 95% CI 1.42-5.81) were both positive predictors of a patient electing to receive a TP. Predictors of overall genital satisfaction on multivariate analysis

are outlined in Table 4. Of note, receiving a TP (OR = 3.29; 95% CI 1.49-7.27) and identifying as heterosexual

Table 3. Multivariate regression for predictors of being a TP recipient

	Odds Ratio	95% CI	P Value
Age			
>35	2.69	(1.24–5.85)	0.04
≤35	Ref		
Race			0.06
White	3.08	(0.95–10.05)	
Nonwhite	Ref		
Marital status			0.07
Married	0.50	(0.23–1.05)	
Nonmarried	Ref		
Sexually active			0.20
Yes	2.30	(0.64–8.36)	
No	Ref		
Sexual orientation			0.12
Heterosexual	0.37	(0.15–0.96)	
Nonhetero	Ref		
Institution of Orchiectomy			<0.01
Academic	2.87	(1.42–5.81)	
Nonacademic	Ref		

Table 4. Multivariate regression for predictors of overall genital satisfaction

	Odds Ratio	95% CI	P Value
Age at diagnosis			
≥30	1.1	(0.59–2.07)	0.77
<30	Ref		
Years from diagnosis			
≥5	0.688	(0.33–1.43)	0.32
<5	Ref		
Race			
White	0.783	(0.3–2.02)	0.61
Nonwhite	Ref		
Marital status			
Married	0.719	(0.35–1.47)	0.37
Nonmarried	Ref		
Sexually active			
Yes	1.899	(0.66–5.47)	0.24
No	Ref		
Sexual orientation			
Heterosexual	2.857	(1.11–7.36)	0.03
Nonheterosexual	Ref		
Institution of orchiectomy			
Academic	1.147	(0.59–2.22)	0.68
Nonacademic	Ref		
Postorchiectomy treatment			
Yes	0.741	(0.36–1.51)	0.41
No	Ref		
Prosthesis			
Yes	3.29	(1.49–7.27)	<0.01
No	Ref		

(OR = 2.86; 95% CI 1.11-7.36) were both positive predictors of overall genital satisfaction.

Most respondents (86.4%) who elected to receive a prosthesis agreed that their desire to have a normal looking scrotum contributed to their prosthesis decision. Respondents that chose to receive a TP were more likely than respondents who did not receive a TP to report having one (or no) testicle would affect their sex life (61.0% vs 19.3%, $P < .01$) and having one (or no) testicle would be noticeable when unclothed (76.3% vs 42.6% $P < .01$). Those who received a TP were also more likely to report scrotal pain at least some of the time (49.1% vs 30.5%; $P = .01$), but also report greater satisfaction with postsurgical genital appearance than those who did not receive a prosthesis (79.7% vs 60.2%; $P = 0.02$).

Over half of respondents (52.2%) without a TP indicated that they were concerned with TP side effects. Nearly a quarter of respondents without a TP (73.9%) also indicated that their sex life was unaffected by their scrotal appearance. Of note, 42.0% of patients who did not receive a TP report that they were never offered a TP.

Figure S1. depicts subjective evaluations of prosthetic look, location, size, and feel in those respondents that elected to receive a TP. Respondents reported the highest levels of satisfaction associated with the natural look of their prosthetic (89.8%), while only 59.3% of respondents were satisfied with the feel of their prosthetic.

DISCUSSION

In our cohort, both sexual orientation and institution of orchiectomy were associated with respondents receiving a

TP. However, when considering the decision-making process of men electing to get a TP, it is important to consider that our data showed 42% of men without a TP were not offered a TP. This figure is higher than the 33% of testicular cancer survivors that reported not being offered a TP in previous research.¹¹ One reason why we may have found a higher rate of men not being offered a TP is due to the inclusion of large number of men who underwent their orchiectomy at a nonacademic institution (50% of respondents). Interestingly, over a third of men without a TP who received an orchiectomy at a nonacademic center reported not being offered a TP while only 12% of men without a TP who underwent their orchiectomy at an academic hospital were not offered a TP. Considering the minimal risks associated with TP placement,¹²⁻¹⁴ further research should be done to better understand why urologists at nonacademic centers are not offering a TP to their patients at the same rates as their academic counterparts.

When evaluating genital satisfaction, we found a significantly greater percentage of respondents (79.7%) with a TP to be somewhat or definitely satisfied with their genitals postsurgery than those who did not receive a TP (60.2% somewhat or definitely satisfied). The higher rate of overall genital satisfaction in the TP cohort is similar to levels of genital satisfaction seen in the general male population. In studies examining genital satisfaction in the general population, Gaither et al report 85.6% of men to be satisfied with their genitals¹⁵ while Herbenick et al report 87.3% of men to be satisfied with their genitals.¹⁶

This similarity between genital satisfaction in patients with a TP compared to genital satisfaction in the general population highlights the utility of TP in restoring genital satisfaction to near normal levels.

Another factor that was associated with a respondent being satisfied with their genitals postorchiectomy was heterosexuality. Nonheterosexual men were significantly less likely to be satisfied with their genitals postorchiectomy than men that identified as heterosexual. Previous studies that have examined genital satisfaction in men who identify as homosexual or bisexual present conflicting results regarding heightened genital dissatisfaction. In the study by Gaither et al mentioned previously, there was no statistical difference in genital satisfaction between men who identified as heterosexual vs nonheterosexual—although the authors noted that there was a nonstatistically significant trend toward nonheterosexual men having higher rates of genital dissatisfaction. However, in the Herbenick et al study, the authors found nonheterosexual men to report significantly lower rates of satisfaction with their genitals and a study by Veale et al showed men who identified as homosexual or bisexual to have a higher likelihood of reporting dissatisfaction with their genitals in regards to size.¹⁷ Our study did not elicit why nonheterosexual testicular cancer survivors are more likely to be dissatisfied with their genitals postorchiectomy or whether genital dissatisfaction in nonheterosexual testicular cancer survivors is heightened when compared to nonheterosexual men without testicular cancer. However, it is important for clinicians to be aware of the fact that genital dissatisfaction is more prevalent among this subpopulation of testicular cancer survivors because male genital image has been shown to impact sexual satisfaction, medical decisions, and sexual health outcomes.¹⁸

The subjective satisfaction levels reported by patients who received a TP in our cohort were consistent with satisfaction levels demonstrated in previous studies.⁵⁻⁷ The vast majority of patients were satisfied with the look, size, and location of their prosthesis, but dissatisfaction with prosthetic feel continues to be an issue for TP recipients. In recent studies by Clifford et al and Dieckmann et al, 44.0% and 52.4% of TP recipients noted that their TP was too firm.^{5, 7} Although we did not directly ask participants about TP firmness, multiple respondents who indicated that they were dissatisfied with the prosthesis feel made note of the excessive firmness of their TP in the free text section of the questionnaire. TP manufacturers should be made aware of patients' dissatisfaction with prosthesis feel and alter their products accordingly. In the meantime, urologists may try to use the softest TP model available to provide patients with optimal comfort and counsel their patients regarding TP firmness prior to implantation.

In this study we also showed the feasibility and benefits of using social media sites such as Twitter, Facebook, and Reddit to recruit questionnaire respondents. By utilizing social media to recruit respondents, we were able to

greatly improve our study's power while recruiting directly from our target demographic. Previous studies outside the field of urology have suggested social media recruitment to be a feasible and effective way to reach individuals with specific diseases (ie, testicular cancer) and individuals who regularly use social media.¹⁹⁻²¹ In regards to our patient population, the average age at which an individual is diagnosed with testicular cancer is 33.²² Today, most of our target demographic is plugged into social media with 78% of 30 to 49-year-old adults and 88% of 18 to 29-year-old adults in the United States reporting that they use at least 1 social media site regularly.^{20,21,23} By posting links to our questionnaire on social media sites we were able to better target a robust international cohort of testicular cancer survivors for recruitment that was not available within our institutional registry. Furthermore, our results demonstrate social media respondents to be more geographically diverse, more likely to report being nonheterosexual, more likely to have received postorchiectomy treatment and more likely to have received their orchiectomy at a nonacademic institution than respondents recruited from our registry. Whether the demographics of these respondents better reflect the testicular cancer community at-large than the respondents we recruited via our institutional registry is unknown. Therefore, further research should determine whether social media respondents better represent the general population of testicular cancer survivors.

While there were many benefits to our study, it is not without limitations. As with any questionnaire-based study, our results are subject to respondent bias. Particularly in regards to our social media cohort, we have no records on patients who reviewed the questionnaire and declined to participate. Additionally, we could not independently verify that all social media respondents were testicular cancer survivors. However, we did exclusively market to the testicular cancer community—utilizing testicular cancer support groups and testicular cancer survivors to promote the study. Other biases that may have affected our results include recall bias and selection bias. Lastly, the questionnaire we utilized for this study has not been independently validated. Future studies may benefit from the development of a validated questionnaire to assess the impact and effectiveness of TP implantation within the testicular cancer community.

CONCLUSION

Our study suggests high levels of overall genital and TP satisfaction in testicular cancer survivors who elect to receive a TP postorchiectomy. Our results also indicate that patients who pursue an orchiectomy at an academic institution are more likely to receive a TP. Associations between TP placement, genital satisfaction, and sexuality merit further investigation. In addition, the use of social media to recruit study participants in urology should be

explored further as a way to increase patient diversity and improve research participation rates.

Supplementary Figure 1. Patient satisfaction with testicular prosthesis characteristics.

SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.urology.2018.09.021>.

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