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Current Practice Patterns Among Members of the American Urological Association for Male Genitourinary Lichen Sclerosus

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Abstract

Objective—To determine the practice patterns of urologists who treat male genitourinary lichen sclerosus (MGU-LS) via a national web-based survey distributed to American Urological Association members.

Methods—A 20-question survey was collected from a random sample of American Urological Association members. Respondents answered questions on their practice patterns for MGU-LS diagnosis, treatment of symptomatic urethral stricture disease, surveillance, and follow-up.

Results—In total, 309 urologists completed the survey. The majority of respondents reported practicing more than 20+ years (37.5%) within an academic (31.7%) or group practice (31.1%) setting. The majority of respondents saw 3-5 men with MGU-LS per year (32.7%). The most common locations of MGU-LS involvement included the glans penis (66.2%), foreskin (26.3%), and/or the urethra (5.8%). Respondent first-line treatment for urethral stricture disease was direct visual internal urethrotomy (26.6%) and second-line treatment was referral to subspecialist (38.4%). After controlling for the number of patients evaluated with MGU-LS per year, those with reconstructive training were more likely to perform a primary urethroplasty for men with symptomatic urethral stricture disease (adjusted odds ratio 13.1, 95% confidence interval 5.1-33.8, $P < .001$). They were also more likely to counsel men on the associated penile cancer risks (adjusted odds ratio 4.6, 95% confidence interval 1.7-12.5, $P < .01$).

Conclusion—Reconstructive urologists evaluate the most number of patients with MGU-LS and are more likely to perform primary urethroplasty for urethral stricture disease. Men with MGU-LS should be referred to a reconstructive urologist to understand the full gamut of treatment options.

Male genitourinary lichen sclerosus (MGU-LS) or balanitis xerotica obliterans (BXO) is a chronic inflammatory dermatological condition of unknown origin and pathogenesis.[1] The true incidence and prevalence of MGU-LS are difficult to quantify, as a multitude of specialists are responsible for its diagnosis and treatment including urologists, dermatologists, and primary care physicians.[2] MGU-LS causes destructive scaring and

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fibrosis of the glans, foreskin, and/or urethra.[3] Prolonged inflammation secondary to MGU-LS may lead to a decline in male urinary and sexual function.[2] Symptoms of MGU-LS include a worsening urinary stream, hesitancy, incomplete emptying, erectile dysfunction, urinary retention, and/or ejaculatory dysfunction.[1,4,5] Due to the chronic, recalcitrant nature of MGU-LS, many men will require lifelong surveillance of disease progression and repeated surgical interventions.[6] Furthermore, MGU-LS is associated with an increased risk of penile squamous cell carcinoma[7] and other comorbid conditions such as hypertension, obesity, and diabetes.[8]

Physicians utilize a multitude of conservative measures to temporize and treat MGU-LS including topical steroid creams, photodynamic light, or topical calcineurin inhibitors (eg, tacrolimus).[1] As the disease progresses, urologists may offer surgical interventions such as circumcision or urethroplasty to treat worsening phimosis or urethral stricture disease, respectively.[9] Intervention and treatment recommendations for MGU-LS along its disease spectrum are subject to debate.[6] Little is known about how urologists diagnose, treat, and survey MGU-LS and whether differences exist among providers who often treat MGU-LS compared to low-volume urologists. MGU-LS presents considerable challenges to the reconstructive urologist as these strictures are more likely to recur after urethroplasty than non-MGU-LS cases.[9,10] Furthermore, MGU-LS is associated with a worse quality of life and sexual dysfunction compared to non-MGU-LS.[1]

To characterize the current practice patterns for the diagnosis, treatment, and surveillance of MGU-LS, we conducted a national survey of American Urological Association (AUA) members. Our primary aim is to address a knowledge gap in understanding how urologists treat and counsel patients with MGU-LS. To date, no prior survey has investigated how urologists treat this challenging disease. Determination of how urologists nationwide treat MGU-LS may help lead to promotion of standard practices of diagnosis, treatment, and surveillance.

Methods

Survey

We developed a survey directed to members of the AUA directory. The survey itself was composed of 20 questions targeting surveillance, follow-up, diagnosis, and treatment of symptomatic urethral stricture disease secondary to lichen sclerosus. We pilot-tested our survey on a sample of 5 urologists and finalized the wording and organization of the 20 questions pending feedback. Respondents were motivated with the opportunity to win a $100 Amazon Gift Card following completion of the survey. The survey instrument used was not validated by prior literature. (See website for full survey: https://urology.ucsf.edu/research/Breyer/Lichen_Sclerosis.)

Questionnaire Administration

The final survey instrument was electronically delivered via RedCap (Nashville, TN) to 5283 AUA members listed in the 2012-2013 Membership Directory. The survey was active for respondent accrual from October 2015 to November 2015. Each eligible respondent was

e-mailed a cover letter with a hyperlink to the electronic survey. Nonresponders were e-mailed a reminder cover letter every week for 2 successive waves over the 4-week accrual period. At the conclusion of the survey, 320 members selected the hyperlink to start the survey and 309 members fully completed all questions. We found that 12% (634) of surveys bounced back due to inactive member e-mail addresses. Our data were maintained and organized by the RedCap's proprietary software. Any respondent identifiers were removed prior to analysis. The institutional review board at the first author's institution approved this study.

Statistical Analysis

All data were extracted and exported to STATA Software v14 (College Station, TX). Respondent frequencies and percentages were calculated for all questions. Baseline demographic characteristics and practice patterns were reported with descriptive statistics. Bivariate associations of practice patterns and demographics were calculated using a Pearson chi-square test. We used Fisher's exact test when expected values were less than 5. Multivariate logistic regression was then performed to detect significant predictors and odds of various demographics and practice patterns. We adjusted for the reported number of patients with MGU-LS seen per year. All tests were two sided and statistical significance for all cases was defined as $P < .05$.

Results

Of the 320 AUA members who initiated our survey, 309 members fully completed the survey and are included for analysis.

Demographic and Baseline Characteristics of Respondents

The majority of respondents practiced clinical urology for more than 20 years (37.5%) compared to 11 to 20 years (24.6%) and 5 to 10 years (16.8%). Most practiced clinical urology within an academic (31.7%) or group practice (31.1%) setting. The majority of respondents completed a fellowship (41.4%). The most common fellowships completed were pediatrics (21.9%) or male reconstruction and/or trauma (21.1%) (Table 1).

Clinical Features of MGU-LS

The majority of respondents saw 3-5 men with MGU-LS per year (32.7%). The majority of urologists (69.9%) relied upon physical examination alone to make a diagnosis of MGU-LS. The most common locations of MGU-LS involvement included the glans (66.2%), foreskin (26.3%) and/or urethra (5.8%) (Table 2). Roughly 21% of respondents had diagnosed a case of penile cancer following a previous diagnosis of MGU-LS. Roughly 48.9% of AUA members reported counseling men on the associated risks of penile cancer following MGU-LS diagnosis. Following diagnosis, 40.4% reported they would not continue to survey men for cancer.

Treatment Patterns of AUA Members for MGU-LS

Steroid creams were the most common first-line treatment used by respondents for MGU-LS of the foreskin (52.6%) or meatus (47.1%). Direct vision internal urethrostomy (26.6%) was

the most common first-line treatment used for MGU-LS of the urethra causing a stricture. Common second-line treatments for MGU-LS of the foreskin were circumcision (53.6%) and meatoplasty (34.1%) for meatal stenosis. Should internal urethrotomy fail and a urethral stricture recurs, only 38.4% of urologists would refer men to another urologist (Table 3). Respondents often preferred a dorsal approach for buccal graft placement when either an onlay substitution urethroplasty (10.1%) or an augmented anastomotic urethroplasty (11.1%) was performed compared to ventral placement (5.5%). The most common tools independently utilized by urologist for routine surveillance of disease recurrence included physical examination alone (70.5%), urinary flow rate (51.0%), and postvoid residual (44.2%).

Comparative Analysis

We found that reconstructive urologists evaluated significantly more men (>11 per year) with MGU-LS compared to those without reconstructive training (59.3% vs 13.9%, $P < .01$) (Table 4). As the disease progressed anatomically from the foreskin, to the meatus, and then to the urethra, respondents were more likely to refer their patients to a subspecialist in reconstructive urology (8.9%, 16.8%, and 41.9%, respectively, $P < .01$) (Table 4). The most common first-line treatment offered by reconstructive urologists compared to those without reconstructive training was urethroplasty (76% vs 13.3%, $P < .01$). Internal urethrotomy was significantly less likely to be offered by reconstructive urologists compared to those without reconstructive fellowship training (8% vs 34.9%, $P < .01$).

On multivariate analysis after controlling for the number of MGU-LS patients evaluated per year, those with reconstructive training were more likely to perform first-line urethroplasty for men with symptomatic urethral stricture disease (adjusted odds ratio (aOR) 13.1, 95% confidence interval (CI) 5.1-33.8, $P < .001$). They were also more likely to counsel men on the associated cancer risks (aOR 4.6, 95% CI 1.7-12.5, $P < .01$). Similarly, respondents were more likely to continue surveillance for penile cancer following MGU-LS if they had previously diagnosed a case of penile cancer (aOR 6.7, 95% CI 3-15, $P < .01$).

Discussion

Little is known on how urologists counsel patients and dispense clinical recommendations following a diagnosis MGU-LS. To date, no guidelines, practice statements, policy statements, nor position statements are put forth by any urologic association. We sought to better characterize AUA member practice patterns for MGU-LS utilizing a national web-based survey to a random sample of urologists.

In our survey, we found that the majority of respondents see between 3 and 5 patients with MGU-LS per year. Most commonly, the initial diagnosis is made by physical examination alone. On subsequent follow-up visits, urologists also most commonly performed a physical examination alone to survey men. Respondents most commonly recommend a topical steroid followed by circumcision for MGU-LS involving the foreskin. When the disease affects the glans, respondents most commonly prescribe topical steroids for first-line treatment and subsequent meatoplasty when this fails. For urethral involvement, respondents most

commonly performed cold-knife internal urethrotomy followed by referral to another urologist if the stricture recurred.

To date, it is unclear why MGU-LU affects solely the glans penis in some whereas in others the entire penile urethra is affected.[1] Survey respondents report the most common location of MGU-LS involvement to be the glans (66.2%), followed by the penile foreskin (26.3%). This is consistent with prior reports noting that MGU-LS most commonly affects the foreskin and glans in 57%-100% of cases.[5] We found that as the disease progressed anatomically from the foreskin, to the meatus, and then to the urethra, respondents were more likely to refer their patients to a reconstructive subspecialist.

It is estimated that the incidence of penile cancer in men with MGU-LS is between 2.3% and 8.4%.[7,11] The European Association of Urology guidelines identify MGU-LS as a strong risk factor for penile cancer.[12] Despite the aforementioned incidence and recommendation, only 48.9% of AUA members reported counseling men on the associated risks of cancer following MGU-LS diagnosis. In fact, 40.4% of respondents reported they would not survey men for cancer after a diagnosis of MGU-LS. Respondents were more likely to survey for penile cancer and counsel men on its associated risks only after previously diagnosing a case of penile cancer. Completion of a Urologic Oncology fellowship did not increase likelihood for continual surveillance of penile cancer following MGU-LS diagnosis. These statistics reinforce the notion that awareness of MGU-LS is necessary and continual surveillance of penile cancer is warranted.

There is no surgical gold-standard treatment for MGU-LS. Respondents preferred a dorsal approach for buccal graft placement when either a substitution or an augmented anastomotic urethroplasty is performed. This is consistent with prior literature whereby a dorsally placed buccal mucosal graft was utilized twice as often in a retrospective series of bulbar strictures secondary to MGU-LS.[13] We found that only 2% of respondents performed a perineal urethrostomy as a surgical urethral reconstructive option for men. It has been reported that perineal urethrostomy is associated with improved quality of life for men with recalcitrant strictures secondary to MGU-LS.[4] This option should not be forgotten for men devastated by the disease. Reconstructive urologists are most fit to deal with the complexities of this disease.

In one of the few manuscripts highlighting stricture recurrence following urethroplasty for MGU-LS, Levine et al reported a success rate of 81%.[13] Men may require tertiary or quaternary procedures for this challenging and complex disease.[1] As a result of such complexities associated with MGU-LS, we found that reconstructive urologists evaluated significantly more men with MGU-LS per year compared to those without reconstructive training. Similarly, urologists with reconstructive training were more likely to offer a urethroplasty as their first-line intervention. Unfortunately, less than 39% of men were referred to a subspecialist if their first-line treatment had failed for either MGU-LS affecting the meatus or the urethra. In addition, reconstructive urologists were four times more likely to counsel men about the associated risks of penile cancer. Continual referral to reconstructive specialists will allow men to understand the full gamut of treatment options and associated risks of such a complex disease. Experienced urologists who regularly treat

MGU-LS understand that upfront aggressive, early intervention may prevent disease progression, especially for the foreskin and meatus.[14]

There are several limitations to this study. Roughly 5% of the surveyed pool responded to the 20-question survey, which is lower than recently published mail surveys.[15,16] This low response rate may induce a nonresponse bias; however, current data support that response rate does not correlate with response bias.[17] We feel that this response rate was due to the 10% bounce-back of e-mails and spam-filtering. As a result, the true denominator of our surveyed cohort is difficult to determine. Roughly 21% of our sample completed a reconstruction and/or trauma fellowship, which is larger than previous reports.[18] It is likely that oversampling was based on exposure alone (reconstruction fellowship) and not based on outcomes in our study (such as cancer surveillance, or counseling). Thus, our measures of association are not likely due to sampling bias. Although residual confounding is possible, all measures of association were adjusted for the number of MGU-LS patients evaluated per year. We did not query respondents on surgical outcomes nor success rates; therefore, defining superiority of any one treatment is not feasible. Similarly, we did not substratify respondents on their treatment of pediatric MGU-LS and the impact of Pediatric fellowship on treatments rendered. Lastly, as with any survey-based study, recall bias is inherent. Despite these limitations, this study provides the first description of how American urologists diagnose, treat, survey, and counsel patients with MGU-LS.

Conclusion

Reconstructive urologists evaluate the most number of patients with MGU-LS, are more likely to perform first-line urethroplasty, and perform surveillance for penile cancer. Continual investigation and research in all facets of MGU-LS are necessary to unravel what remains a challenging and complex disease.

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Table 1
Demographic and baseline characteristics of survey respondents

	N = 309 (%)
Practice duration	
Still in training	30 (9.7)
Less than 1 year	9 (2.9)
1 to 4 years	26 (8.4)
5 to 10 years	52 (16.8)
11 to 20 years	76 (24.6)
More than 20 years	116 (37.5)
Urethroplasties performed per year	
None	154 (49.8)
1 to 4	81 (26.2)
5 to 10	17 (5.5)
11 to 20	11 (3.6)
Greater than 20	46 (14.9)
Practice type	
Academic medical center	98 (31.7)
Solo private practice	37 (12.0)
Single urology group practice	96 (31.1)
Multispecialty group	61 (19.7)
Fellowship completed	
Yes	128 (41.4)
No	157 (50.8)
Type of Fellowship completed	
Urologic Oncology	25 (19.5)
Endourology/Stone Disease	19 (14.8)
Female Pelvic Medicine and Reconstructive Surgery	16 (12.5)
Infertility/Andrology/Erectile Dysfunction	12 (9.4)
Male Reconstruction/Trauma	27 (21.1)
Pediatrics	28 (21.9)
Transplant	1 (0.8)

Table 2

Reported clinical features of MGU-LS

	N (%)
Number of patients seen/year with MGU-LS	
None	15 (4.9)
1 to 2	75 (24.3)
3 to 5	101 (32.7)
6 to 8	39 (12.6)
9 to 10	23 (7.4)
Greater than 11	56 (18.1)
Diagnosis of MGU-LS made by	
Physical examination alone	215 (69.6)
Shave biopsy	8 (2.6)
Punch biopsy	19 (6.1)
Excisional biopsy	52 (16.8)
I am not the physician making the diagnosis	15 (4.9)
Most common location for MGU-LS	
Glans penis	204 (66.2)
Foreskin	81 (26.3)
Male urethra	18 (5.8)
Penile shaft	2 (0.6)

MGU-LS, male genitourinary lichen sclerosus.

Table 3

Frequencies of treatments rendered by survey respondents for MGU-LS involving the foreskin, meatus, and urethra

	N (%)
First-line treatment of foreskin MGU-LS	
Topical steroid	162 (52.6)
Topical tacrolimus	2 (0.6)
Topical retinoid	2 (0.6)
Photodynamic therapy	1 (0.3)
Circumcision	124 (40.3)
Referral to another urologist	9 (2.9)
Second-line treatment of foreskin MGU-LS	
Topical steroid	86 (27.9)
Topical tacrolimus	11 (3.6)
Topical retinoid	7 (2.3)
Photodynamic therapy	0 (0.0)
Circumcision	165 (53.6)
Referral to another urologist	26 (8.4)
First-line treatment of glanular meatal stenosis from MGU-LS	
Topical steroid	145 (47.1)
Topical tacrolimus	2 (0.6)
Topical retinoid	2 (0.6)
Photodynamic therapy	1 (0.3)
Circumcision	25 (8.1)
Meatoplasty	56 (18.2)
Urethral dilation	48 (15.6)
Urethroplasty	7 (2.3)
Referral to another urologist	20 (6.5)
Second-line treatment of glanular meatal stenosis from MGU-LS	
Topical steroid	27 (8.8)
Topical tacrolimus	6 (1.9)
Topical retinoid	3 (1.0)
Photodynamic therapy	1 (0.3)
Circumcision	20 (6.5)
Meatoplasty	105 (34.1)
Urethral dilation	46 (14.9)
Urethroplasty	44 (14.3)
Referral to another urologist	47 (15.3)
First-line treatment of urethral stricture from MGU-LS	
Topical steroid	13 (4.2)
Urethral dilation	71 (23.1)
Direct vision internal urethrotomy	82 (26.6)

	N (%)
Direct vision internal urethrotomy plus injection	11 (3.6)
Urethroplasty	53 (17.2)
Referral to another urologist	65 (21.1)
Second-line treatment of urethral stricture from MGU-LS	
Topical steroid	2 (0.7)
Urethral dilation	20 (6.5)
Direct vision internal urethrotomy	37 (12.1)
Direct vision internal urethrotomy plus injection	15 (4.9)
Endourethral stent	3 (1.0)
Urethroplasty	91 (29.6)
Referral to another urologist	118 (38.4)

Abbreviation as in Table 2.

Table 4

The impact of reconstructive fellowship training on the evaluation, management, and referral patterns for MGU-LS

	No Reconstructive Fellowship N = 282 (%)	Reconstructive Fellowship N = 27 (%)	*P* Value
First-line treatment offered for urethral MGU-LS			<.01 *
Dilation	67 (26.3)	4 (16.0)	
Internal urethrotomy	89 (34.9)	2 (8.0)	
Urethroplasty	34 (13.3)	19 (76.0)	
Referral	65 (25.5)	0	
Number of patients with MGU-LS seen/year			
None	15 (5.3)	0	<.01 *
1 to 2	75 (26.7)	0	
3 to 5	97 (34.5)	4 (14.8)	
6 to 8	34 (12.1)	5 (18.5)	
9 to 10	21 (7.5)	2 (7.4)	
Greater than 11	39 (13.9)	16 (59.3)	
Referral patterns following treatment failure of MGU-LS			
Treatment failure of foreskin	25 (8.9)	1 (3.7)	.35 †
Treatment failure of meatal stenosis	47 (16.8)	0	.02 †
Treatment failure of urethral stricture	117 (41.9)	0	<.01 †

Abbreviation as in Table 2.

* Fisher's exact test.

† Test of proportions.