

# Lower Urinary Tract Symptoms in Women With Female Genital Mutilation

Julia Geynisman-Tan, MD,\* Andrew Milewski, PhD,† Carly Dahl, MD,\* Sarah Collins, MD,\* Margaret Mueller, MD,\* Kimberly Kenton, MD, MS,\* and Christina Lewicky-Gaupp, MD\*

**Objective:** This study aimed to describe symptom prevalence and quality of life impact from lower urinary tract symptoms (LUTS) in women living with female genital mutilation (FGM) in the United States.

**Methods:** A convenience sample of English-speaking women with FGM were invited to complete an anonymous survey including the Female Lower Urinary Tract Symptoms questionnaire to assess symptom prevalence and bother and the Pelvic Floor Impact Questionnaire-7 to assess quality of life impact from pelvic floor disorders. Data are reported as median (interquartile range). Correlations were calculated using Spearman  $\rho$ .

**Results:** Thirty women with an age of 29 (24–40) years were included. Sixty-seven percent self-identified as black/African and 77% were Muslim. Women reported being circumcised between ages 1 week and 16 years (median, 6 years). Forty percent reported type I circumcision, 23% reported type II, 23% reported type III, and 13% were unsure. Fifty percent were vaginally parous. Seventy-three percent of women reported the presence of LUTS. Twenty-seven percent voided at least 9 times per day, and 60% had nocturia at least 2 times. Bothersome voiding symptoms were commonly reported: urinary hesitancy (40%), strained urine flow (30%), and intermittent urine stream (47%). Fifty-three percent reported urgency urinary incontinence and 43% reported stress urinary incontinence. Symptom prevalence and bother were correlated for all 12 items ( $\rho = 0.51$ – $0.90$ ,  $P < 0.001$ ). Median Pelvic Floor Impact Questionnaire-7 score was 102 (8–144), with 63% reporting urinary symptoms having “moderate” or “quite a bit of” impact on their activities, relationships, or feelings.

**Conclusion:** Lower urinary tract symptoms are common and bothersome in women with FGM. Providers caring for patients with FGM should inquire about LUTS.

**Key Words:** female genital mutilation, urinary incontinence, urinary urgency, voiding dysfunction

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As defined by the World Health Organization, female genital mutilation (FGM) involves the partial or total removal of the external female genitalia.<sup>1</sup> Female genital mutilation is further categorized into 4 types, clitoridectomy (type 1), clitoridectomy and excision of the labia minora (type 2), infibulation of the introitus with or without clitoridectomy (type 3), and other (type 4). The practice of FGM is prevalent among some ethnic or tribal groups in Africa, Asia, the Middle East, the Pacific Islands, and South America.<sup>1</sup> As a result of global migration, women and girls with FGM now also live in the United State and Europe.<sup>1</sup> The number of women living with FGM in the United States is rising,

with estimates of 513,000 American women and girls either cut or at risk of being cut in 2012.<sup>2</sup> Estimates suggest that 130 million women and girls are living with FGM globally.<sup>3</sup> Female genital mutilation is illegal in many countries and has been condemned by the World Health Organization, the United Nations, the International Federation of Gynecology and Obstetrics, and many national governments.<sup>4</sup>

Female genital mutilation has no known health benefits but does have many immediate and long-term risks: hemorrhage, local infection, tetanus, sepsis, hematometra, dysmenorrhea, dyspareunia, obstructed labor, severe obstetric lacerations, fistulas, and even death.<sup>5,6</sup> Although the psychological and obstetric consequences of FGM are well documented, there are few studies on the urogynecologic complications of FGM.<sup>7,8</sup> One recent study suggested that FGM is associated with urinary retention, urinary urgency, hesitancy, and incontinence.<sup>9</sup> However, the women enrolled in this study were presenting for care to a urogynecology clinic and therefore may not reflect prevalence rates in the overall FGM population. In addition, the population of women in the study was from a homogenous ethnic group and may not be generalizable to all women living with FGM in the United States.

Therefore, given the significant number of women with FGM in the United States and the paucity of data on the effects of FGM on the urinary system, the aim of our study is to describe the prevalence of both voiding and storage lower urinary tract symptoms (LUTS) in women living with FGM in the United States.

## METHODS

This is a cross-sectional study of a convenience sample of English-speaking women living with FGM in the United States. Women were invited to complete research questionnaires through partnerships with case workers, immigration lawyers, and physician asylum evaluators (physicians who provide pro bono physical or mental health evaluations to document evidence of torture and other human rights abuses for immigrants fleeing persecution in their home countries). Participants were from a variety of urban and rural communities across the United States and from numerous countries of origin. All but one of the women were immigrants to the United States. Patient recruitment to the study occurred primarily in New York, Boston, Chicago, Minneapolis, and San Francisco. All participants had to have sufficient proficiency in English to independently read and complete the questionnaires. Advertisements for the study and the consent form were in English, and case workers were asked not to assist patients in survey completion. Participants were not compensated for completing the survey and did not receive medical care from the investigators. Surveys could be completed online from the participant’s telephone or computer. All participants completed the survey in its entirety. The study was approved by the Northwestern University Institutional Review Board.

Participants completed an anonymous online questionnaire including demographic questions, questions regarding the timing and type of FGM (with pictorial aids), and validated assessments of LUTS<sup>1</sup>: Female Lower Urinary Tract Symptoms questionnaire (FLUTS) to assess symptom prevalence and bother and<sup>2</sup> Pelvic

From the \*Division of Female Pelvic Medicine and Reconstructive Surgery, Northwestern University, Chicago, IL; and †New York-Presbyterian/Weill Cornell Medical Center, New York, NY.

Correspondence: Julia Geynisman-Tan, MD, 250 E Superior St, Suite 03-2302, Chicago, IL. E-mail: Julia.Geynisman-Tan@nm.org.

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**TABLE 1.** Prevalence of LUTS as Assessed by the FLUTS

Score	Urgency	Bladder Pain	Hesitancy	Strained Flow	Intermittent Flow	SUI	UII	Insensate UI	Enuresis
0 (never)	4 (13%)	9 (30%)	12 (40%)	10 (33%)	7 (23%)	6 (20%)	8 (27%)	15 (50%)	15 (50%)
1 (occasionally)	8 (27%)	7 (23%)	6 (20%)	10 (33%)	9 (30%)	11 (37%)	6 (20%)	6 (20%)	8 (27%)
2 (sometimes)	10 (33%)	8 (27%)	0 (0%)	8 (27%)	6 (20%)	9 (30%)	12 (40%)	8 (27%)	7 (23%)
3 (most of the time)	5 (17%)	6 (20%)	8 (27%)	2 (7%)	6 (20%)	3 (10%)	2 (7%)	1 (3%)	0 (0%)
4 (all the time)	3 (10%)	0 (0%)	4 (13%)	0 (0%)	2 (7%)	1 (3%)	2 (7%)	0 (0%)	0 (0%)
>0 (any symptoms)	26 (87%)	21 (70%)	18 (60%)	20 (67%)	23 (77%)	24 (80%)	22 (73%)	15 (50%)	15 (50%)
≥2 (at least sometimes)	18 (60%)	14 (47%)	12 (40%)	10 (33%)	14 (47%)	13 (43%)	16 (53%)	9 (30%)	7 (23%)

All metrics are listed in n (%).

UI, urinary incontinence.

Floor Impact Questionnaire-7 (PFIQ) to assess quality of life impact from pelvic floor disorders.<sup>10,11</sup> The FLUTS has 12 items, each asking for the prevalence (never, 0; occasionally, 1; sometimes, 2; most of the time, 3; always, 4) and bother of a symptom (not at all [0] to a great deal [10]). We considered a prevalence score of at least 2 (at least sometimes) as *positive* for having the symptom. Total FLUTS symptom scores range from 0 to 48. The PFIQ, on the other hand, has 7 items assessing impact of pelvic floor symptoms on quality of life. Items are scored from 0 being not at all to 3 being quite a bit bothered. Total scores range from 0 to 300, with each subscale (urinary, prolapse, and fecal) score ranging from 0 to 100. The total score and the urinary incontinence subscale score are analyzed and reported here. SPSS version 24 (Chicago, Illinois) was used for data analysis. Data are reported as median (interquartile range). Correlations were calculated using Spearman  $\rho$ .

## RESULTS

Thirty women with a mean (interquartile range) age of 29 (24–40) years were included in this cohort. Sixty-seven percent (20/30) self-identified as black/African; 23% (7/30), East Asian; 7% (2/30), white; and 3% (1/30), South Asian. Seventy-seven percent (20/30) were Muslim, and 23% (7/30) were Christian. Women reported being circumcised between ages 1 week and 16 years (median, 6 years). Forty percent (12/30) reported type I circumcision, 23% reported type II (7/30), 23% (7/30) reported

type III, and 13% (4/30) were unsure. Fifty percent (15/30) were vaginally parous; 33% (10/30) of these women reported that they tore into their urethra at delivery. A history of urinary tract infections (UTIs) was common in the cohort: 46% (14/30) reported having at least 1 infection since circumcision, 26% (8/30) in the last year and 10% (3/30) reported more than 3 UTIs in last year.

Seventy-three percent (22/30) of the cohort were found to be positive for at least 1 LUTS (score  $\geq 2$  on the FLUTS), although many were positive for multiple symptoms (Table 1). Twenty-seven percent (8/30) of women voided at least 9 times per day, and 60% (18/30) had nocturia at least 2 times per night. Bother-some voiding symptoms were common: urinary hesitancy (40%; 12/30), strained urine flow (30%; 10/30), and intermittent urine stream (47%; 14/30) were often reported. Fifty-three percent (16/30) reported urgency urinary incontinence (UUI), and 43% (13/30) reported stress urinary incontinence (SUI). The median total FLUTS score for the cohort was 19 (9–25). There was no difference in the FLUTS scores of nulliparous and parous women or of women with various types of circumcision. Median FLUTS bother score was 5.5 (3.7–7.5). Symptom prevalence and bother were moderately or strongly correlated for all 12 items ( $\rho = 0.51$ – $0.90$ ,  $P < 0.001$ ) with a strong correlation each ( $\rho > 0.7$ ,  $P = 0.001$ ) specifically for bladder pain, urgency, strained urine flow, SUI, UUI, and enuresis. The median total PFIQ score was 102 (8–144), and the median score on the urinary subscale (Urinary Impact Questionnaire [UIQ]) was 72 (34–89; Table 2). Using the UIQ, 63% (19/30)

**TABLE 2.** PFIQ and UIQ Subscale

UIQ Subscale, Median (Range)	POPIQ Subscale, Median (Range)	CRAIQ Subscale, Median (Range)	PFIQ Total Score, Median (Range)
72 (34–89)	36 (12–62)	17 (0–33)	102 (8–144)
			<b>n (%) of Participants Reporting Moderate or “Quite a Bit” Impact</b>
UIQ Subscale Questions			
How do symptoms or conditions in your bladder or urine usually affect your:			
Ability to do household chores (cooking, laundry housecleaning)?			9 (30)
Ability to do physical activities such as walking, swimming, or other exercise?			9 (30)
Entertainment activities such as going to a movie or concert?			12 (40)
Ability to travel by car or bus for a distance greater than 30 min away from home?			15 (50)
Participating in social activities outside your home?			11 (37)
Emotional health (nervousness, depression, etc)?			13 (43)
Feeling frustrated?			14 (47)
Any one of the above questions answered as moderate or “quite a bit” of impact			19 (63)

CRAIQ, Colorectal Anal Impact Questionnaire; POPIQ, Pelvic Organ Prolapse Impact Questionnaire.

of women reported that their urinary symptoms have “moderate” or “quite a bit” of impact on their activities, relationships, or feelings.

## DISCUSSION

Our study suggest that LUTS are present in most women with FGM in the United States and cause them significant bother. Urgency was the most commonly reported LUTS (60%; 18/30) followed by UUI (53%; 16/30). Given the median age of our cohort, the rate of LUTS in our cohort is significantly higher than has been previously reported for premenopausal women.<sup>12,13</sup> Using the definition of FLUTS prevalence score of at least 2 (at least sometimes) as *positive*, a study of otherwise healthy nulligravid women aged 18 to 30 years found the prevalence of urgency to be 14.5% (compared with 60% [18/30] in our cohort), straining to be 6% (compared with 33% [10/30] in our cohort), and enuresis to be 0% (compared with 23% [7/30] in our cohort).<sup>13</sup> Instead, the prevalence of LUTS in our cohort more closely resembled that of a cohort of healthy young Nigerian women aged 18 to 30 years, in which the authors reported a prevalence of LUTS of 55%, with 15% reporting urinary incontinence and 14% reporting voiding symptoms.<sup>14</sup> The authors do not mention the presence of FGM in their study population, but the published prevalence of FGM in Nigeria is 41%, with some communities reporting rates of 76%.<sup>15</sup> Therefore, it is likely that many of the survey respondents had experienced FGM, thereby increasing the prevalence of LUTS in their cohort. In a study of women in Egypt presenting to a urogynecology office, those with FGM were 2 to 4 times more likely to report LUTS compared with women without FGM.<sup>9</sup>

The connection between FGM and LUTS can be understood from the literature on childhood sexual assault and LUTS. Most women who experience FGM recall fear, pain, and helplessness.<sup>16</sup> Like sexual assault, FGM is known to cause posttraumatic stress disorder, somatization, depression, and anxiety.<sup>17,18</sup> These psychologic effects manifest as somatic symptoms. In studies of children not exposed to sexual abuse, the rates of LUTS range from 2% to 9%.<sup>19</sup> In comparison, children who have experienced sexual assault have a 13% to 18% prevalence of enuresis and 38% prevalence of dysuria.<sup>20,21</sup> The traumatic imprinting acquired in childhood persists into adult years. In a study of adult women with overactive bladder, 30% had experienced childhood trauma compared with 6% of controls without overactive bladder.<sup>22</sup> There is a neurobiological basis for this imprinting. Studies in animal models show that stress and anxiety at a young age have a direct chemical effect on the micturition reflex and can cause upregulation of pain receptors in the bladder.<sup>23–25</sup> In addition, the impact of sexual trauma on pelvic floor musculature has been well described.<sup>26</sup> Women who experience genital trauma often respond with involuntary contraction of the pelvic floor, which can develop into nonrelaxing pelvic floor dysfunction and subsequent urinary hesitancy, strained flow, retention, bladder pain, and overflow incontinence.<sup>27</sup>

Our study was not powered to find a difference in symptoms between women with different types of FGM or ages of cutting, as it was purely descriptive. Prior studies have reported a relationship between the type of FGM and the degree of symptoms.<sup>9</sup> In addition, our study relies on patient reporting of FGM type, obstetric complications, UTI rates, and LUTS. No physical examinations or urinary studies were performed in our study to corroborate patient-reported histories. However, the recall bias of this population would seem to be minimal, as only 13% were “unsure” of the type of circumcision done. In addition, our study was designed using an observational approach in which no defined comparator group was included. Because of the wide variety of cultural and

ethnic groups within which FGM occurs, we believe that finding an accurate comparison group would be ultimately unachievable. In addition, as sexual and psychological trauma symptoms have also been associated with LUTS and many women with FGM have experienced trauma, this would have to be controlled for in each group to establish a true causal relationship between FGM and LUTS. Finally, this study was limited to English-speaking women with FGM, which represents the minority of women living with FGM in the United States. Therefore, this cohort may not be generalizable to the symptoms of non-English-speaking women living with FGM in the United States.

Although this study describes a small cohort of women with FGM, it is the first to describe the prevalence of LUTS in women living with FGM in the United States. Our data show that LUTS are extremely common and very bothersome to the social and psychological well-being of patients with FGM. Patients with FGM do not always disclose this history to their providers and may not be aware of the connection between their FGM and their bladder symptoms. Therefore, providers caring for patients with FGM or seeing patients for clitoral restoration should inquire about and offer treatment of LUTS.

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