## Mass General Brigham

# #642: The subjective experience of underactive bladder: Key findings from concept elicitation interviews in patients with urodynamically-confirmed detrusor underactivity

## Introduction

Detrusor underactivity (DU) can result in symptoms of underactive bladder (UAB). UAB research has been limited by the absence of a sensitive and reliable measure to capture patient symptoms and experiences.

Following federal guidelines for patient reported outcome measures (PROM) development and validation, we implemented a 5-stage study design, including sequential qualitative and quantitative assessments, and in-depth investigation of the subjective experience of patients with urodynamically-confirmed DU. We present here key findings from the concept elicitation.

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## **Methods**

interviews were performed using a semi-structured discussion guide with open-ended questions to elicit patient experiences in their own words to allow for the emergence of unanticipated symptoms.

Domains included symptoms (e.g., storage, voiding, postvoiding) and impacts (e.g., activities of daily life, burden, quality of life).

Interviews were were audio recorded and transcribed.

Data were systematically analyzed using standard methods of qualitative analysis and examined to assess concepts of interest and determine specific language relevant to patients.

## **Results**

-Frequency (85%), urgency incontinence (66%), nocturia (94%) and urgency (81%) were the most prevalent symptoms. A

->50% participants reported impacts on physical activity, sleep, social life and/or sex life.

-All participants reported some degree of bother associated with their urinary symptoms ranging minor annoyance to a consuming stress.

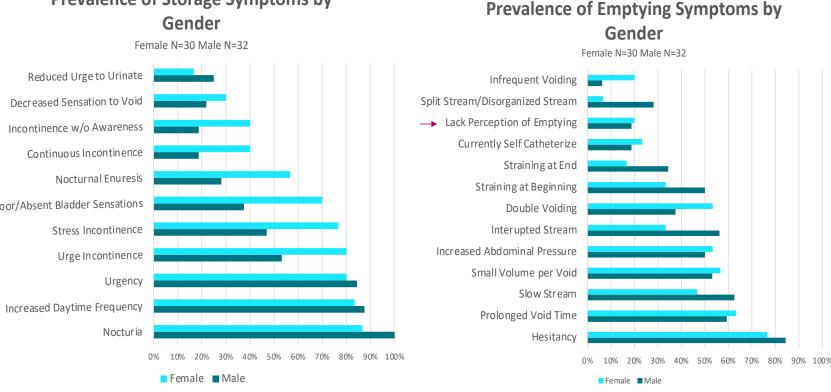
-Frequency, hesitancy, and self-catheterization were most bothersome 94% plan their life around toilet visits and 84% reported stress/anxiety due to their urinary symptoms

-Participants reported that stress and anxiety associated with UAB took a major toll on their well-being.

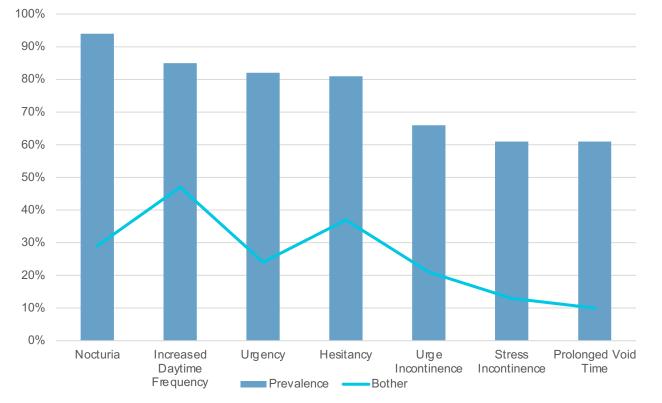
-Many participants, 40%, associated or dismissed the symptoms at first as part of the natural aging process

		Total	Male	Female
			(N=32)	(N=30)
Gender	Male	52% (32)		
	Female	48% (30)		
Age	40-49 years	3% (2)	3% (1)	3% (1)
	50-59 years	21% (13)	10% (3)	33% (10
	60-69 years	29% (18)	34% (11)	24% (7)
	70-79 years	31% (19)	34% (11)	27% (8)
	80-89 years	13% (8)	13% (4)	13% (4)
	90-99 years	3% (2)	6% (2)	0% (0)
Race/Ethnicity	Hispanic/Latino	3% (2)	3% (1)	3% (1)
	American Indian or Alaska Native	0% (0)	0% (0)	0% (0)
	Asian	0% (0)	0% (0)	0% (0)
	Black or African American	2% (1)	0% (0)	3% (1)
	Native Hawaiian/Pacific Islander	0% (0)	0% (0)	0% (0)
	White or Caucasian	93% (58)	94% (30)	94% (28
	Unknown	2% (1)	3% (1)	0% (0)

#### Prevalence of Storage Symptoms by



### Chart 1. Symptoms Prevalence & Bother

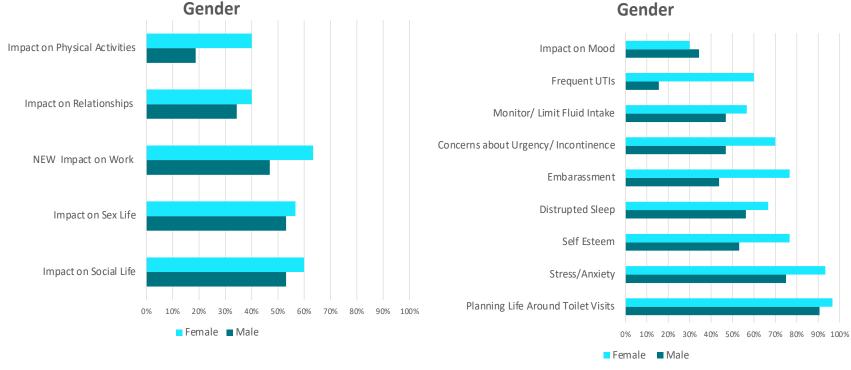


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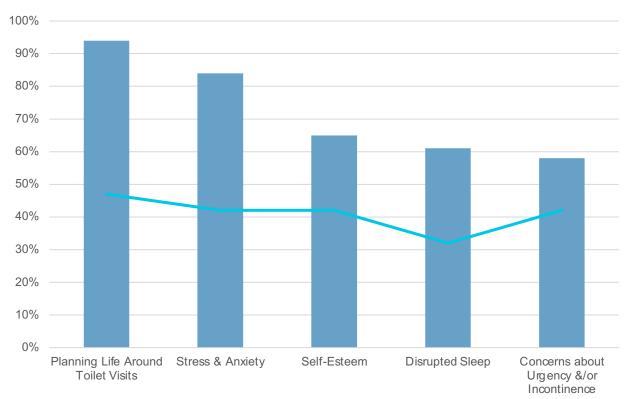
Table 2. Participant Medical History (N=62)					
		Total	Male (N=32)	Female (N=30)	
Prior Pelvic Surgery	Yes	34% (21)	22% (7)	47% (14)	
	No	66% (41)	78% (25)	53% (16)	
	Hypertension	60% (37)	63% (20)	57% (17)	
	Spinal Stenosis	5% (3)	3% (1)	7% (2)	
Medical	Hyperlipidemia	35% (22)	47% (15)	23% (7)	
Comorbidities	Sleep Apnea	8% (5)	3% (1)	13% (4)	
	Prostatitis	2% (1)	3% (1)	0% (0)	
	Hypothyroidism	8% (5)	6% (2)	10% (3)	
			•		
	0	90% (56)	91% (29)	91% (27)	
	1	3% (2)	3% (1)	3% (1)	
	2	2% (1)	0% (0)	3% (1)	
Self-Catheterization Frequency, per day	3	2% (1)	3% (1)	0% (0)	
	4	0% (0)	0% (0)	0% (0)	
Ī	5	0% (0)	0% (0)	0% (0)	
ſ	6	3% (2)	3% (1)	3% (1)	
Alpha Blocker	Yes	6% (4)	9% (3)	3% (1)	
Medications	No	94% (58)	91% (29)	97% (29)	

Individuals with underactive bladder report symptoms of impaired storage along with impaired emptying. These symptoms negatively impact emotional well-being, activities of daily living, and quality of life. Individuals express some hesitancy to come forward about their symptoms at first which may lead to delayed diagnosis and or treatment

Prevalence of Impacts on Activities by







Prevalence —Bother



## Discussion

### References

1.Smith PP, et al014. Neurourol Urodyn. 2016 Feb;35(2):312-7. 2. Yu YD et al.Urol. 2017 Dec;58(Suppl 2):S68-S74. doi: 10.4111/icu.2017.58.S2.S68. Epub 2017 Nov 13. 3.Aldamanhori R, et al. t Curr Opin Urol. 2017 May;27(3):293-299.

#### Prevalence of Quality of Life Impact by