

# How to Measure Quality-of-Life Concerns in Patients with Neurogenic Lower Urinary Tract Dysfunction

Darshan P. Patel, MD, Jeremy B. Myers, MD,  
Sara M. Lenherr, MD, MS\*

## KEYWORDS

- Urinary bladder • Neurogenic • Patient-reported outcome measures • Health-related quality of life
- Urinary incontinence

## KEY POINTS

- Patient-reported outcomes measurements are an important method of assessing bladder-specific quality of life in patients with neurogenic bladder.
- Recent instruments validated specifically in patients with neurogenic bladder allows more precise assessment of priorities pertinent to this population.
- Prospective utilization of patient-reported outcome measures will benefit further understanding of patient priorities as clinicians continue try to improve care of patients with chronic neurogenic bladder.

## INTRODUCTION

Neurogenic lower urinary tract dysfunction, also classically described as neurogenic bladder (NGB), is a term used to describe lower urinary tract problems arising secondary to damage to the central nervous system, peripheral nervous system, and/or autonomic nervous system. Some causes include spinal cord injury (SCI), multiple sclerosis (MS), traumatic brain injury, cerebrovascular accident, spina bifida, cerebral palsy, and transverse myelitis.<sup>1</sup> There are many severe health long-term complications associated with NGB, including urinary tract infections, sepsis, and renal failure. Additionally, urinary symptoms have a

significant impact on quality of life (QoL) in these patients.<sup>2–4</sup>

Globally, there is a growing interest in patient-reported outcomes and in patients' perspective on health and QoL. However, most assessments are validated for the general patient population and not for neurogenic patients specifically. For example, at the health care system level, the Centers for Medicare and Medicaid Services and the Agency for Healthcare Research and Quality developed the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS).<sup>5</sup> HCAHPS is a 27-question survey administered to patients at the time of discharge from the hospital to gather critical aspects of the patient's hospital

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Division of Urology, Department of Surgery, University of Utah, 30 North, 1900 East, Room 3B420, Salt Lake City, UT 84132, USA

\* Corresponding author. 30 North, 1900 East, Salt Lake City, UT 84132.

E-mail address: [sara.lenherr@hsc.utah.edu](mailto:sara.lenherr@hsc.utah.edu)

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experience. In 2010, passage of the Patient Protection and Affordable Care Act of 2010 included HCAHPS as a critical measure to calculate value-based incentive payments in the Hospital Value-Based Purchasing program. Although health care systems and providers are using these tools, they do not accurately report the health outcomes that result from an NGB.

There is an evolving role for health-related QoL (HRQoL) measures and patient-reported outcome measures (PROM) in the evaluation of NGB in both clinical and research settings.<sup>6</sup> These self-reported data are highly applicable to a specific patient and provide an accurate assessment of the patients' perception of their symptoms. Obtaining HRQoL measures initially can help trend the longitudinal impact of treatment. Traditionally, there has been a focus on clinical outcomes for interventions associated with NGB. Because many interventions for NGB are directed at QoL improvement, it is surprising that PROMs have not played a larger role. This is particularly of interest when there is a discordance between clinical and patient-reported outcomes in the evaluation of interventions.<sup>7</sup> Additionally, HRQoL and PROMs provide valuable information regarding the patient perspective and can be used to improve the quality of care received by this population.

A distinction should be made between PROMs and HRQoL measures. They are intimately related and have high correlation; however, they are different in several key areas. PROMs is a collective term used to represent the action of asking patients their perspective on a multitude of issues, including symptoms, functionality, health status, HRQoL, and perceptions of health care. For NGB, generally PROMs assess symptoms such as "how many times do you urinate in a day?" HRQoL is another subtype of PROM, and is a multidomain concept representing the patient's global perception of his or her condition on various aspects of life (eg, physical, mental, social). For example, an HRQoL item may ask "if you had to live with your bladder the way it is right now for the rest of your life, how much would it bother you?"

In this article, we review various bladder-specific and general HRQoL instruments used as PROMs for NGB. A strong conceptual framework is needed for incorporating various PROMs and HRQoL measures in NGB research.

## PATIENT-REPORTED OUTCOME MEASURES

Measuring patient perceptions, preferences, and outcomes is done with PROMs, which are generally validated questionnaires or item banks. Validation of questionnaires is a complex epidemiologic

science first involving the generation of questions with "face validity," usually with focus groups composed of patients and sometimes clinicians. Psychometric testing is then used to test the statistical validity of these questions, their ability to test for the desired measurements within a given population of patients, and reproducibility. Finally, psychometric testing determines whether differences can be detected for patients with a range of disease states which the instrument is measuring.<sup>8</sup> A well-designed instrument has a normal bell-curve distribution around the mean and will differentiate patients with minimal impact from a given disease as well as those who are very affected by their disease. If the questionnaire instead measures accurately at only one end of the spectrum of disease (ie, very healthy or very ill), it is said to have either a floor or ceiling effect. **Table 1** summarizes several validated PROMs that have been used in QoL and clinical outcome studies in patients with NGB.

## GENERAL HEALTH-RELATED QUALITY-OF-LIFE QUESTIONNAIRES AND NEUROGENIC BLADDER POPULATIONS

There are many general HRQoL PROMs that have been used in patients with NGB. Some of the more common examples of these are the Satisfaction With Life Survey (SWLS), and the Medical Outcomes Study Short Form 36-Item or 12-Item (SF-36, SF-12).<sup>9-12</sup> These PROMs ask about general HRQoL issues, such as physical and mental health perceptions as well as activity limitations. However, these instruments are designed for patients who have the capacity to ambulate. For example, the SF-12 questionnaire asks "[How does your health limit you in]... climbing several flights of stairs?" An equivalent physical activity such as walking or wheeling yourself 2 blocks or up a hill may not be a problem for a paraplegic patient with SCI but the question is not phrased this way. Nonvalidated versions of the SF-12 are used by some researchers to enable use of this tool in patients with SCI, but this limits comparison with validated populations.

Despite the limitations, previous studies have tried to use these general HRQoL tools in patients with NGB using different bladder management strategies. The largest application of these broad QoL measures using the SWLS was in more than 7000 patients with SCI followed by the National SCI Model System Centers.<sup>13</sup> Analysis showed no difference in HRQoL among patients using indwelling catheters, intermittent catheterization, or condom catheters, despite there being a higher rate of multiple complications in patients with

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