Mending Gaps in Knowledge
Collaborations in Neurogenic Bladder Research

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KEYWORDS

• Neurogenic bladder • Spinal cord injury • Complication • Incontinence
• Patient-reported outcomes

KEY POINTS

- Patient-reported outcomes need to be incorporated into the study design of neurogenic bladder trials.
- Prospective studies around neurogenic bladder management need to be guided by clinical outcomes and patient preferences.
- Multi-institutional collaborative groups are essential in neurogenic bladder research due to the rarity of many causes of neurogenic bladder, and due to potential institutional and individual surgeon biases that arise from single-center studies.
- A large prospective observational study of bladder-related quality of life after spinal cord injury has been initiated by the Neurogenic Bladder Research Group.

BACKGROUND

Neurogenic bladder (NGB) is a nonspecific term that encompasses many different patterns of bladder dysfunction. The term implies an underlying neurologic condition leading to bladder dysfunction, but these underlying disease states span hugely disparate conditions from elderly diabetic patients with peripheral neuropathy to childhood spinal cord problems, such as myelomeningocele. In addition, bladder dysfunction from NGB also has a huge range of clinical manifestations from benign urinary retention to high bladder storage pressures leading to complications such as renal failure, urosepsis, and death.

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Given the heterogeneity of disease processes causing NGB and its clinical presentations it is difficult to define best management recommendations and treatment guidelines. Two important components of research in NGB are first to define patient preferences for management via patient-reported outcome measures (PROMs) and then use this information to target these preferences with high-quality prospective studies of innovative strategies oriented to improving the clinical outcomes and quality of life (QoL) associated with the treatments. For instance, if patients within a given NGB population generally prefer indwelling catheters, efforts to try to keep them doing intermittent catheterization are futile and research should instead be focused on making indwelling catheters safer and minimizing complications, such as serious urinary tract infections (UTIs) and renal dysfunction.

Because the causes of NGB are so varied, many subpopulations of patients are rarely encountered by clinicians outside of specialty centers. For instance, although spinal cord injury (SCI) is among the leading causes of NGB, it is estimated that SCI affects fewer than 1 out of 1000 people in the United States.[1] Other causes, such as myelomeningocele, cerebral palsy, and bladder exstrophy have an even lower prevalence compared to SCI. Over the last several decades, a major step forward in the study of SCI has been establishment of several large national and international databases. Perhaps the best known of these databases is the Model System for SCI care in the United States.[2,3] The Model System of SCI treatment centers contribute to a large database, which collects longitudinal information about the incidence, prevalence, cause, bladder and bowel management, and complications associated with SCI. However, PROMs within this database are limited to general health-related QoL and are not specific to urinary incontinence or bladder-related QoL. The rarity of patients with NGB and lack of specific data about bladder-related QoL emphasizes the importance of study through collaborative multi-institutional groups.

Collaborations in Reconstructive Urology

The Neurogenic Bladder Research Group (NBRG; NBRG.org), was formed in 2015. A founding principle was to address gaps in knowledge in the treatment of NGB and provide a platform for high-quality patient-centered prospective studies. The group is currently composed of 8 high-volume centers in North America with urologists that specialize in reconstructive urology or neurourology. The impetus for the formation of NBRG was to address limitations in the study of NGB to date. First, it addressed the lack of prospective well-designed studies in NGB. In the literature, retrospective, single-center studies predominate. These studies often report patient outcomes over huge spans of time, include surgical techniques that may not be reproducible by others, and focus on surgeon-defined outcomes. These studies may be prone to bias and under-reporting of adverse effects on QoL. Second, it addressed the need to establish a framework to evaluate patient-reported outcomes, which requires sampling of a large diverse population because of the heterogeneity of NGB patient populations.

The Trauma and Urologic Reconstruction Network of Surgeons (TURNS) is an analogous group that focuses on outcomes research in trauma, urethral strictures, and male incontinence. This group was established in 2009 and served as the conceptual framework for establishment of NBRG. Universities of Utah and Minnesota are active members of TURNS, and experience gained and the lessons learned with this group were critical in the formation of NBRG. There are important design considerations in a collaborative group. First, an administrative structure for sharing clinical data in a safe way across multiple health care systems must be established. TURNS accomplished this with a centralized database, which now functions on the Research Electronic Data Capture (REDCap) platform and is housed at a participating institution. Shared databases on these types of platforms can allow patient identifiers to be removed from view other than the institution entering the data. They also allow scheduled questionnaires to be sent electronically through email to patients for longitudinal follow-up. Questionnaires can be custom-generated or standardized questionnaires can be designated from a large library housed in REDCap. Multi-institutional databases have been increasingly recognized, in many fields, as critical tools for pushing clinical outcomes research forward.[4,5] Second, full buy-in from all collaborators with commitment of time, resources, energy, and ideas is necessary. In forming collaborative research groups, many active surgeons or clinicians express interest in contributing; however, it is helpful to have clear thresholds defining active participation in the group. These requirements can include active ongoing entry of data, participation in planning and completion of studies, article preparation, and administrative tasks (ie, Web site design, budgetary considerations, and promotion of the group). Third, there must be adequate support from a participating institution. Data entry is time-consuming, as well as tracking