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Research Needs to Understand Self-Management of Lower Urinary Tract Symptoms: Summary of NIDDK Workshop

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IN men lower urinary tract symptoms (LUTS) have traditionally been attributed to an enlarged prostate, described as benign prostatic hyperplasia (BPH). However, understanding the etiology of LUTS has begun to expand to encompass potential contributors including obesity, diabetes, physical activity and diet among others.[1] Medical and surgical treatments for LUTS have potential limitations. Fewer than a third of men prescribed medication still take them after 1 year,[2] many men wish to avoid the risks associated with surgery, and mismatches between patient treatment goals and outcomes decrease patient satisfaction.

Patient self-management, defined as "an individual's ability, in conjunction with family, community and the appropriate healthcare professionals, to successfully manage the symptoms, treatment, physical, psychosocial, cultural and spiritual consequences, and inherent lifestyle changes required for living with a chronic disease,"[3] may not only enable successful implementation of behavioral treatments in LUTS, but may also support adherence to and satisfaction with medical and surgical therapies. Self-management is effective for improving treatment outcomes for numerous chronic conditions, and yet a paucity of evidence exists on using specific self-management skills, such as goal setting, self-monitoring and problem solving in men with LUTS.

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To address this gap, the NIDDK (National Institute of Diabetes and Digestive and Kidney Disease) convened the "How to Help Men with LUTS Help Themselves" meeting (www.niddk.nih.gov/news/events-calendar/Pages/How-To-Help-Men-With-LUTS-Help-Themselves.aspx) in September 2016. After reviewing self-management approaches for chronic conditions and current knowledge of their application in LUTS, participants identified key research needs to advance self-management science for this condition.

APPLICATION OF SELF-MANAGEMENT STRATEGIES

Like most chronic conditions, LUTS share features amenable to self-management, including multivariate causation; gradual onset; uncertain prognosis; no cure; an emotionally, socially and professionally challenging nature; and a need for patient involvement in management.[4] Patient participation in LUTS self-management may be motivated by the perceived bother and significant quality of life (QoL) burden, the potential for immediate positive reinforcement through symptom relief, and the interest from many patients in avoiding medical and surgical interventions.

Initial studies of self-management of LUTS have had promising results. In a randomized controlled trial (RCT) of nearly 140 men with uncomplicated LUTS a self-management program combined with standard care improved QoL, ameliorated symptoms, slowed symptom progression and reduced treatment failure compared to standard treatment alone.[5] The program included 3 nurse-led small group sessions that focused on bothersome symptoms, tracking through frequency volume charts, problem solving and goal setting.

Self-management research of patients with diabetes and asthma may serve as useful examples of how to develop self-management therapies for LUTS. Given that LUTS are a common complication of diabetes and the advanced state of diabetes self-management programs, incorporating LUTS into diabetes programs is a reasonable starting point. Asthma self-management focuses on preventing exacerbation of symptoms by understanding and avoiding triggers, which may translate to LUTS.

RESEARCH NEEDS TO INFORM SELF-MANAGEMENT

Meeting participants concluded that before embarking on a RCT to assess self-management approaches to the treatment of LUTS in men, key questions must first be addressed:

Better Understanding of LUTS, Comorbidities and Current Treatments

Relationships between LUTS and associated diseases.—LUTS are associated with numerous conditions, including depression, cardiovascular disease, erectile dysfunction and sleep disturbances, among others. However, potential causal relationships that might characterize these associations have yet to be determined. Understanding these relationships might inform research and treatment of LUTS and associated diseases, including self-management trials for LUTS.

Symptoms most bothersome.—Because symptom severity and bother correlate with self-management participation for other chronic conditions,[6] understanding which LUTS are

most bothersome to men may help identify the most appropriate symptoms to target for self-management. In a population based study men and women reported urgency urinary incontinence (UI) as the most bothersome LUTS, although urgency and nocturia were more common and also identified as bothersome.[7] Building on existing work assessing factors (eg symptom severity and frequency, age, poverty) that contribute to perceived bother[8] may be beneficial.

Factors that encourage men to seek health care.—Only about a third of men with LUTS seek treatment.[9] However, the factors that affect decisions to seek care are not fully understood. While symptom severity and bother are associated with seeking treatment, they do not fully explain treatment seeking patterns. Other factors reported to affect seeking care for LUTS are knowledge and misperceptions about LUTS, social determinants (eg socioeconomic status, health care access), age and embarrassment. Community based education to reduce stigma and improve knowledge about LUTS may encourage care seeking but optimal methods and channels for education have yet to be determined. Men with than those without a spouse may be more likely to seek care, perhaps because a spouse is likely to motivate his or her partner to do so. The effect of spousal relationships on treatment seeking for men with LUTS should be explored further.

Individualizing treatment.—Despite growth in available treatments for LUTS in recent decades, existing therapies do not work consistently for all men with LUTS. Interest is growing in developing a better understanding of potential factors that might influence therapeutic success in order to better target treatments and personalize approaches to care. Such research will likely require a comprehensive approach with consideration of biological, behavioral, cognitive and social factors.[10] A series of NIDDK meetings is focused on identifying and promoting research opportunities to advance individualized treatment for men and women with UI (https://www.niddk.nih.gov/news/events-calendar/Pages/Individualizing-Treatment-Broadening-the-Framework-for-Urinary-Incontinence-Research.aspx).

Determining which Patients Will Benefit Most from Self-Management and which Components of Self-Management are Most Effective

Factors that influence the likelihood of engaging in and responding to self-management.—Certain groups of men with LUTS might be more amenable to participating in or more likely to respond to self-management approaches. A broad array of factors may influence self-management participation and response, including symptom bother, type and severity; age; cultural background; marital status; access to social support; cognitive abilities; level of self-efficacy; and sociodemographic factors among others. Determining which factors influence uptake of self-management practices may help to target such treatments to the patients most likely to benefit. Alternatively, a deeper understanding of these factors may help identify individuals who need a greater or lesser degree of support to successfully engage in and respond to self-management strategies. Potential factors influential in LUTS may be identified from self-management research in other disease contexts.

The neurobiology that enables self-management behavior.—Engaging in positive health behavior change is notoriously challenging, even when individuals face dire consequences under the status quo. Our understanding of the contributions of neurobiology to human behavior is growing, and might inform the development of effective self-management strategies for LUTS and other chronic conditions.

Effectiveness of various elements of self-management for LUTS.—Self-management programs often include a variety of interventions to support desired behaviors. Because it would be nearly impossible to study each component of self-management individually, much research to date has focused on multiple interventions. Greater understanding of the effect of individual interventions might enable the eventual development of personalized or optimized self-management therapies. Such understanding may be achieved via factorial experiments that manipulate 2 or more independent variables to yield insights into the effectiveness of individual components. Importantly, specific self-management components may have variable effectiveness in different subgroups of men with LUTS. Therefore, the effectiveness of self-management components should be explored in men with different profiles of LUTS, personality traits, ages and cognitive skill sets from multiple backgrounds, locales and socioeconomic status groups.

Best Settings and Systems to Support Implementation of Self-Management

Ideal composition and organization of a LUTS self-management support team.—Central to successful self-management of chronic conditions is the support of a care team, including clinicians, health educators and community health workers among others. Although urologists are well suited to manage pharmacologic and surgical interventions for LUTS, we must identify appropriate clinical teams to effectively implement self-management strategies into urology practice. Importantly, Medicare reimburses diabetes self-management training provided by a qualified clinician, which has likely facilitated uptake of self-management support for diabetes and encouraged growth of the diabetes educator profession. Similar personnel might be needed to support implementation of self-management programs in urology practices, especially in the United States where current reimbursement models may not incentivize urologist participation.

Development of remote technologies for self-management.—Remote self-management intervention approaches (eg telephone, Internet etc) have been successful for other chronic conditions and may facilitate broader implementation in LUTS. Innovative use of digital technology should be explored as potentially cost-effective platforms for implementation of self-management plans for LUTS. A web and video based self-management program targeting more than 250,000 men with LUTS in Kaiser Permanente Southern California is currently being evaluated.

Potential negative impact of delaying medical or surgical management.—While self-management strategies may be implemented alongside medical or surgical therapies, debate persists about contributions of self-management to watchful waiting and causing delay of medical or surgical therapies, which may result in negative consequences,

especially for men with worsening symptoms. Research is needed to determine how self-management may best be implemented in the context of medical and/or surgical treatments.

REFERENCES

1. Warren K, Burden H and Abrams P: Lower urinary tract symptom: still too much focus on the prostate? Curr Opin Urol 2014; 24: 3. [PubMed: 24280652]
2. Cindolo L, Pirozzi L, Sountoulides P et al. : Patient's adherence on pharmacological therapy for benign prostatic hyperplasia (BPH)-associated lower urinary tract symptoms (LUTS) is different: is combination therapy better than mono-therapy? BMC Urol 2015; 15: 96. [PubMed: 26391357]
3. Wilkinson A and Whitehead L: Evolution of the concept of self-care and implications for nurses: a literature review. Int J Nurs Stud 2009; 46: 1143. [PubMed: 19200992]
4. Lorig KR and Holman H: Self-management education: history, definition, outcomes, and mechanisms. Ann Behav Med 2003; 26: 1. [PubMed: 12867348]
5. Brown CT, Yap T, Cromwell DA et al. : Self management for men with lower urinary tract symptoms: randomised controlled trial. BMJ 2007; 334: 25. [PubMed: 17118949]
6. Richardson J, Loyola-Sanchez A, Sinclair S et al. : Self-management interventions for chronic disease: a systematic scoping review. Clin Rehab 2014; 28: 1067.
7. Agarwal A, Eryuzlu LN, Cartwright R et al. : What is the most bothersome lower urinary tract symptom? Individual- and population-level perspectives for both men and women. Eur Urol 2014; 65: 1211. [PubMed: 24486308]
8. Sarma AV, Jacobsen SJ, Girman CJ et al. : Concomitant longitudinal changes in frequency of and bother from lower urinary tract symptoms in community dwelling men. J Urol 2002; 168: 1446. [PubMed: 12352415]
9. Kaplan SA, Roehrborn CG, Chapple CR et al. : Implications of recent epidemiology studies for the clinical management of lower urinary tract symptoms. BJU Int, suppl, 2009; 103: 8.
10. Bavendam TG, Norton JM, Kirkali Z et al. : Advancing a comprehensive approach to the study of lower urinary tract symptoms. J Urol 2016; 196: 1342. [PubMed: 27341750]