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Women's Knowledge of Bladder Health: What We Have Learned in the Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium

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Abstract

Purpose of Review—The goal of this manuscript is to review the current literature on bladder health education, summarize *P*revention of *L*ower *U*rinary Tract *S*ymptoms (PLUS) [50] findings on environmental factors that influence knowledge and beliefs about toileting and bladder function, and describe how PLUS work will contribute to improved understanding of women's bladder-related knowledge and inform prevention intervention strategies.

Recent Findings—Analysis of focus group transcripts revealed the various ways women view, experience, and describe bladder function. In the absence of formal bladder health educational platforms, women appear to develop knowledge of normal and abnormal bladder function from a variety of social processes including environmental cues and interpersonal sources. Importantly, focus group participants expressed frustration with the absence of structured bladder education to inform knowledge and practices.

Summary—There is a lack of bladder health educational programming in the USA, and it is unknown to what degree women's knowledge, attitudes, and beliefs influence their risk of developing lower urinary tract symptoms (LUTS). The PLUS Consortium RISE FOR HEALTH study will estimate the prevalence of bladder health in adult women and assess risk and protective factors. A Knowledge, Attitudes, and Beliefs (KAB) questionnaire will be administered to determine KAB around bladder function, toileting, and bladder-related behaviors, and examine the relationship of KAB to bladder health and LUTS. The data generated from PLUS studies will identify opportunities for educational strategies to improve bladder health promotion and well-being across the life course.

Keywords

Bladder health; Bladder education; Incontinence prevention; Women's health; Bladder knowledge; Toileting

Introduction

Lower urinary tract symptoms (LUTS) are highly prevalent among women in the USA, with profound health, social, and economic implications [1, 2]. In community samples, almost 20% of women who are 30 years and older report moderate-to-severe LUTS [3]. Prevalence and severity of symptoms increase as people age, with 65% of women over 60 years of age reporting a bladder control problem [4]. The cost to society for overactive bladder (OAB) alone has been estimated at over $65 billion per year, with the majority of costs borne by community-dwelling adults [5]. Furthermore, the total annual loss of productivity in the

USA due to OAB is estimated to be $1.38 billion [5]. Lower urinary tract symptoms are expected to affect more than 43 million women over the next 30 years; [6] therefore, LUTS impose considerable individual and societal costs that will continue to rise as the population ages.

The majority of LUTS research and clinical practice has focused on treatment of the most affected subsets of women presenting for care and lacks a well-developed evidence base for prevention. Increased awareness of the public health impact of LUTS has highlighted the need for research to inform public health education, bladder health promotion strategies, and primary prevention initiatives [7–9]. The *P*revention of *L*ower *U*rinary Tract *S*ymptoms (PLUS) Research Consortium, established by the National Institutes of Health (NIH)/ National Institutes of Diabetes and Digestive and Kidney Diseases (NIDDK) in 2015, is an example of LUTS research expansion to focus on prevention. PLUS scientists, who represent a wide range of disciplines, are tasked with using a transdisciplinary approach to inform strategies for the prevention of LUTS and the promotion of bladder health in adolescent and adult women across the life span [10••]. PLUS seeks to identify risk and protective factors associated with LUTS and bladder health to inform strategies for future prevention efforts.

As a foundational step, the PLUS Research Consortium developed the following definition of bladder health: “A complete state of physical, mental, and social well-being related to bladder function and not merely the absence of LUTS. Healthy bladder function permits daily activities, adapts to short-term physical or environmental stressors, and allows optimal well-being (e.g., travel, exercise, social, occupational, or other activities) [11••].” This definition broadens the features of health, consistent with the World Health Organization, in recognition that absence of symptoms alone does not constitute health [11••, 12]. Grounded in this definition of bladder health, this paper reviews the literature on bladder health education and knowledge, describes current and ongoing PLUS studies in this area, and articulates PLUS’s vision for future research.

Current Literature on Bladder Health Education

Sparse research exists on the development and implementation of primary prevention education interventions that aim to optimize bladder health in asymptomatic women. Education initiatives delivered by professional and consumer organizations largely focus on secondary or tertiary prevention related to the management of LUTS and bladder conditions (e.g., overactive bladder and incontinence). Evidence to support these strategies has been drawn from systematic reviews or studies which focus on self-management interventions among older women with LUTS and pelvic floor muscle exercises in antenatal and postpartum women [13–18]. For example, an early study with a predominantly older female sample found that a 1-h class led to behavioral changes and bladder function improvements [17]. The class provided education on myths, bladder function and symptoms, causes of urinary incontinence, and self-management strategies (e.g., cognitive strategies for managing urgency, pelvic floor muscle exercises, use of absorbent products). The Translating Unique Learning for Incontinence Prevention (TULIP) trial found that both a 2-h group class and viewing a 20-min video on anatomy, incontinence, pelvic floor muscle exercises, and fluid/

dietary topics were equally effective in preventing urinary incontinence among women aged 55 and over [18].

Several trials have examined the effect of group-based bladder health education or pelvic floor fitness programs on LUTS improvement in symptomatic older women [16, 18–24]. The Group Learning Achieves Decreased Incidents of Lower Urinary Symptoms (GLADIOLUS) trial found that women aged 55 and over with LUTS who participated in a 2-h bladder health and self-management session had significant improvement in ICIQ-SF scores as compared to a control group [16]. In a randomized controlled trial of women 60 years and older with incontinence at least once weekly, a continence promotion workshop in combination with self-management strategies related to weight, pelvic floor strength, caffeine intake, smoking, and constipation was more effective in improving LUTS than either intervention alone [23]. A trial of a 6-week toileting behavior education program that addressed urinary tract anatomy, micturition, and healthy toileting behaviors in a predominantly female population with OAB and type 2 diabetes resulted in a higher adoption of healthy toileting behaviors and improvement of urinary symptoms 6 months post-intervention compared to routine care alone [24]. Taken together, these studies demonstrate the potential role for larger scale education programs on bladder function and bladder-related behaviors in both primary prevention and treatment of LUTS.

To be optimally effective, primary prevention interventions should be delivered to younger, asymptomatic women. There are very few studies examining educational strategies for adolescent girls. A novel 6-week pelvic health curriculum delivered in US urban schools to adolescent females covered topics such as cultural views of the female pelvis, pelvic anatomy and function, the importance of pelvic health, pelvic hygiene, LUTS, and help-seeking [25]. Knowledge deficits measured by the Adolescent Bladder and Pelvic Health Questionnaire were reduced as a result of the intervention [25]. The adolescent girls were initially reticent to talk about bladder health issues but opened up quickly with tools like Pelvic Health Bingo that introduced content using levity and game-based learning [26]. Additionally, discussions were robust when it was clear the environment was confidential and safe for any related questions [26].

Globally, there are common challenges related to bladder education that may provide learning opportunities for shared intervention strategies. Menstrual health and hygiene is a key area for introducing LUTS education among adolescent girls and young women worldwide, as this is a life stage where young women become more aware of toilet availability and infrastructure [27, 28]. There are unique aspects influencing bladder health in low and middle income countries (LMICs) including inadequate sanitation and lack of privacy, making toileting inherently stressful for adolescent girls in these environments [29–32]. Incontinence related to childbirth, including obstetric fistula, can be highly stigmatizing for women in LMICs, which may present a barrier to bladder health and LUTS education, although more recent literature suggests that treatment and knowledge is increasing in some communities [33, 34]. There is a small collection of literature describing the ways in which *w*ater, *s*anitation, and *h*ygiene programs (commonly abbreviated as “WASH”) would benefit from a gendered approach, as cisgender girls and women have different toileting needs

than cisgender boys and men that must be considered in the construction and location of latrines/toilets [35–39].

In summary, little research to date has focused on primary prevention of LUTS and the promotion of bladder health. As a first step to building prevention strategies and impactful educational programming, it is essential to know what women know. Throughout the life course, a crucial source of knowledge is experience; therefore, it is important to understand women's lived experience of bladder function. It is equally important to explore women's views of bladder health and their perceptions of what constitutes barriers to healthy behaviors. Understanding women's experiences and perspectives will help us identify the context of bladder health and bladder risk behaviors and select appropriate strategies and channels for achieving behavior change. In the next sections, we will describe what we have learned in PLUS about women's perceptions and experiences with bladder health and LUTS. We will also describe ongoing work within PLUS that aims to better understand women's knowledge, attitudes, and beliefs around bladder health; sources of bladder education; and desired bladder health education content and platforms.

PLUS and LURN Qualitative Studies: Perception and Beliefs About Bladder Function

PLUS and the Symptoms of Lower Urinary Tract Dysfunction Research Network (LURN) are both NIDDK-sponsored research networks that were established to reduce the burden of LUTS and advance the understanding of individual experiences related to bladder function [40]. However, while PLUS focuses on bladder health and LUTS prevention among women, LURN goals include improved measurement of patient experiences of LUTS and identifying important subtypes of LUTS in women and men.

The first study launched by PLUS was the Study of Habits, Attitudes, Realities and Experiences (SHARE), which examined perceptions of the bladder among adolescent and adult women without recognized LUTS or history of LUTS treatment. SHARE was a multi-site qualitative focus group study that included 360 participants ranging in age from 11 to 93 years [41••]. Analyses of focus groups transcripts from the SHARE study and individual interviews conducted within the LURN network have revealed the various ways women view, experience, and describe bladder function. In the absence of formal bladder health educational platforms, women appear to develop knowledge of normal and abnormal bladder function from a variety of social processes including environmental cues and interpersonal sources. Key among these are the processes of *conversing with others* about bladder practices [42], *observing* bladder behavior [43], *navigating* the toileting environment [44], and *delineating what constitutes normal bladder function* [45].

The social process of *conversing* with others about bladder function primarily occurs within family and friendship groups and focuses on exchanging information about perceived normal function and providing advice about abnormal bladder function. Such conversations can become mechanisms for normalizing LUTS. Across the life course, conversations about bladder function vary by topic. Adolescents and young adult women often share information about the impact of sexual behavior, pregnancy, or childbirth on bladder health, while

middle-aged and older adult women talk about the effect of menopause and the aging process on bladder function [42]. For example, women discussed the belief that urinating after sex will prevent UTIs as well as their perceptions of the causal relationship between reproductive processes and bladder health. However, dissemination of lay theories about bladder function runs the risk of spreading information about symptoms and treatments without a scientific evidence base and may also serve to normalize negative outcomes (e.g., incontinence after childbirth).

The social cognitive process of observing bladder behavior consists of three overlapping practices that inform community-dwelling women's knowledge and understanding of bladder function and practices: self-observation, observation of others, and being aware of being observed by others [43]. Observing one's own bladder behavior facilitates women's understanding of what is normal for them and alerts them to changes in bladder function that may indicate a problem (e.g., more frequent urination, darker urine). Observing others' bladder practices in educational, occupational, social, and home settings exposes girls and women to social expectations about bladder function and influences their perception of what is normative and appropriate. The perception of being observed by others can lead to increased awareness of one's toileting practices and engender behavior changes as a form of self-regulation to better fit within social norms or expectations. In school classrooms or occupational settings, voiding norms that discourage "voiding on urge" can be harmful if they lead to restricted hydration or delayed voiding (holding). Conversely, in a family environment with healthy voiding practices, young people can benefit from the exposure that will shape their toileting behaviors overall.

Women learn about bladder health through their experiences *navigating* toilet access in a variety of environments. A secondary analysis of individual interviews of women with LUTS conducted by the LURN found that accessing public toilet facilities imposes temporal constraints on toileting practices and shapes women's assumptions about normal bladder function outside of the home environment [44]. Accessing toilets in schools, workplaces, and public spaces also affects toileting knowledge among asymptomatic women. SHARE found that across settings and age groups, toilet access in the USA was restricted by "gatekeepers" (i.e., individuals who control access to toilets). For adolescent women, gatekeepers were almost universally present in schools, whereas adult women had variable experiences with gatekeepers in workplaces or public settings. Teachers, managers, and store employees were identified as gatekeepers. As a result of this gatekeeping, adolescent and adult women described how it was considered normative that they are expected to hold urine when they are in public spaces. Other factors which led to intentional delayed voiding included internalized norms to prioritize school and job responsibilities over voiding, and lack of cleanliness in public toilets. Participants noted disparities in the ease of accessing toilets between men and women, including longer lines for women related to their menstruation needs, clothing differences, and increased experience of LUTS.

The PLUS-supported study, SHARE-MORE (Sexual and Gender Minority Opinions, Realities and Experience), found additional disparities in toilet access between cisgender and sexual and gender minority individuals. An analysis of 6 focus groups with 36 individuals from SHARE-MORE found that sexual and gender minority individuals feel

the gendered bathroom culture and infrastructure is restrictive and anxiety-inducing [46]. Both gender norms and structural policies limit the individual's ability to void when needed. Furthermore, bathrooms can be sites of discrimination and violence for trans individuals [46, 47].

Women *define what constitutes normal bladder function* based on their experiences and perceptions. The SHARE focus group participants often identified normal bladder function and bladder health as the absence of symptoms. Initial responses to the question "What is a healthy bladder?" consisted primarily of descriptions of symptoms of an unhealthy bladder (urinary tract infections, leakage) [48]. Participants described the concept of a healthy bladder as one you did not need to think about, but that did require effort to maintain. Exemplars of what was necessary to maintain bladder health included fluid intake (too much or too little), frequency of voiding (either voiding too frequently or "holding" too often), and being able to generally participate in age-related activities. Participants were frustrated by the lack of systematic information to guide their understanding of what was "right" and what constituted healthy habits to optimize bladder function.

An analysis of LURN individual interviews of adult women with LUTS explored women's understanding of what constitutes normal bladder function [49]. Participant views of "normal" were based on several aspects of bladder function. A key theme was that voiding should occur as a seamless process, beginning with an urge sensation, followed by voiding with ease and to completion, and then "being done." Features of normal bladder function also included voiding regularity, which constituted voiding frequency, intervals, and patterns during the day and night. The notion of having control in terms of not leaking urine, as well as the ability to hold urine and defer urination also figured into the perception of normal bladder function. Similar to the SHARE study on healthy bladder, interviews conducted by the LURN offered views of normal bladder function that encompassed both the absence of symptoms and the positive impact of being symptom-free in day-to-day life, including not having to think about or worry about the bladder or limit daily activities.

These large-scale qualitative studies conducted by the PLUS Consortium and LURN not only offer insights into women's knowledge, attitudes, and beliefs concerning bladder health, but also identify gaps in both scientific and popular understanding of what constitutes a healthy bladder and how LUTS may be prevented.

Current PLUS Studies: Examining Women's Bladder Health Knowledge and Education

Knowledge, Attitudes, and Beliefs (KAB) Measurement Development

Building upon work from SHARE and LURN, a current focus within the PLUS Research Consortium is developing an instrument to evaluate bladder health KAB in adult women across the life course. These beliefs likely influence daily toileting and bladder-related behaviors across the lifespan, and therefore have potential to significantly impact bladder health and risk of LUTS. Initial instrument development included (1) identifying peer-reviewed research articles that assessed KAB about bladder health or LUTS; (2) extracting

KAB questions that were asked of female participants; and (3) cataloging articles for the presence of PLUS KAB research priorities (pelvic floor musculature, pregnancy and childbirth, influence of others on KAB, beliefs about toileting practices), bladder function (storage, emptying, bioregulatory processes), constructs from the Theory of Planned Behavior (attitudes, perceived norms, perceived control), and other conceptual constructs (knowledge, beliefs). Based on these initial activities, the study team concluded that there was not an available validated questionnaire to measure bladder health KAB.

The team then went on to build an inventory of items for a KAB questionnaire that includes the following domains: overall bladder health knowledge (e.g., basic anatomy), pregnancy and childbirth (e.g., impact on bladder function, LUTS prevention strategies), pelvic floor (e.g., pelvic muscle and Kegel exercises), and Theory of Planned Behavior-informed attitudes and beliefs about specific behaviors (e.g., fluid intake, voiding in relation to urge). For the initial core module, q-sort methodology and e-panel assessment were used to reduce relevant items for a 17-item KAB instrument that was then further evaluated through cognitive interviewing. Final refinement was achieved through content-expert review, community-member feedback, and cross-cultural assessment. Additional items developed by the KAB work group for its inventory are being further developed, evaluated, and included in subsequent PLUS data collection efforts.

Bladder Health and Public Health Messaging

Women’s recommendations for public health messaging including approaches, formats, and context are currently being analyzed from SHARE focus group data. Areas of opportunity being explored include bladder health educational content in K-12 school curricula and preferred strategies for bladder health promotion programming across the life course and during specific developmental phases (e.g., puberty, pregnancy). Women’s suggestions for locations of bladder health campaigns as well as use of social medial platforms are also being reviewed from the focus group transcripts.

Conclusions and Future Directions for PLUS Research

Additional studies are critical to advance the bladder health knowledge and education scientific literature. Findings from past PLUS studies have informed the design and planning of the “RISE FOR HEALTH” study, which aims to estimate the prevalence of bladder health in adult women and assess risk and protective factors for bladder health. Including KAB measures alongside other sociodemographic variables will allow for more tailored educational strategies that consider socio-contextual factors. Novel associations between women’s bladder knowledge and beliefs and their bladder health will be examined in this study, providing a foundation for future interventions. The data generated from PLUS studies will expand the evidence base concerning knowledge about bladder health among women in the USA, offering new opportunities to improve health and well-being across the life course.

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