Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium
Overview

• **Primary goal of the Prevention of Lower Urinary Tract Symptoms (PLUS) Consortium**
  – A multi-center network funded by the NIH/NIDDK
  – Prevention of LUTS in women and girls by advancing bladder health

• **Transdisciplinary members**
  – Includes physicians, nurses, psychologists, sociologists, public health and prevention scientists, epidemiologists, and biostatisticians

• **Consortium work**
  – Provide an overview of the PLUS consortium, including ongoing efforts to define and measure bladder health
Prevalence of LUTS

• Boston Area Community Health 2002-2005
• Gaps in urologic epidemiologic data
  – Population based prevalence
  – Age specific prevalence/incidence
  – Disparities in conditions
  – Changes in symptoms
  – Gender differences
The Urologic Iceberg

- 20% women 30 yrs and older have moderate-severe symptoms
- 73% community dwelling women report at least 1 symptom

Iceberg concept adapted from Last (1963; 2001)
Kupelian et al, JAMA 2006
Hall et al, BJUI, 2008
LUTS impact

• Economic
  – OAB costs alone estimated at $66 billion in 2006
  – Recurrent UTIs $2 billion annually
  – LUTS associated with decreased work productivity

• Morbidity/health
  – Depression, weight gain, obesity, decreased physical activity, and diabetes linked to LUTS
  – LUTS independently predict increased ED visits when controlled for comorbidities, age, and race
Reframing LUTS: Important Medical Condition with Quality of Life Impact

LUTS → Decreased Physical Activity → Depression → Decreased Work Productivity

Priority, Costly Medical Conditions:
- Obesity
- Diabetes risk
- Cardiovascular risk
- Musculoskeletal risk
- Falls and Fractures
- Cancer risk
- Depression
Opportunities Provided by a Bladder Health and LUTS Prevention Strategy

People With Bladders

Educate about bladder function, healthy behaviors and abnormal symptoms and spectrum of treatment options

More sufferers recognize their situation as abnormal and treatable

More sufferers seek evaluation and treatment with basic understanding of problem, treatment options and their role in treatment

Opportunity to change unhealthy behaviors and incorporate behaviors that promote healthy bladder function

IMPROVE OVERALL HEALTH
Opportunities Provided by a Bladder Health and LUTS Prevention Strategy

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**IMPROVE OVERALL HEALTH**
PLUS Research Consortium Investigator Specialties

- Clinical Psychologist/Behavioral Medicine
- Community Health Scientist
- Health Comm Researchers
- Women's Health Advocate
- Epidemiologists
- Biostatisticians Researchers
- Health Psychologist Ped Urol Nurse Practitioner
- Urogynecologists
- Developmental Pediatrician Reproductive Health
- Peripartum Health
- Behavioral Interventionist Physiatrist
- Social Welfare
- Behavioral Neuroendocrinologist
- Prevention Scientists
- Geriatricians Medical Sociologist
- Adolescent Health Infectious Disease Nurse Midwife
- Female Urologists
- Geriatric Nurse Practitioner
NIH “Bladder/Pelvic Floor” Networks

NIDDK

PLUS
Define Bladder Health and LUTS Risk Factors

MAPP
DEEP PHENOTYPING UCPPS

LURN
DEEP PHENOTYPING LUTS

PRO

Urinary Incontinence

NICHID

PFDN
Pelvic Organ Prolapse
Anal Incontinence
The GOAL

• To obtain the necessary information to plan future interventions to promote bladder health and prevent LUTS
What is a prevention science approach?

• **What do prevention scientists do?**
  – Conduct etiologic studies to identify risk and protective factors
  – Develop and test prevention interventions aimed at modifying risk and protective factors
    • **Goal is to promote health and prevent major dysfunction before onset of a disease or disorder**

• **Prevention science applies a life course developmental perspective**
  – Dissemination of findings are expected to impact health promotion programs, practices, and policies, and in turn, the health of populations across the life course

(Coie et al., 1993; Heller, 1996; Society for Prevention Research, 2013)
Social Ecological Model

- Interactions between social context and biology
- Health behaviors are determined by multiple factors outside of the individual
- Biologic, psychosocial, behavioral, cultural, environmental factors
Social Ecological Model
(McLeroy, Bibeau, Steckler, & Glanz, 1988)
Individual Level

• Mind/Behavior
  – Knowledge
  – Beliefs / Perceptions
  – Attitudes
  – Personality Traits
  – Behavior

• Biological Systems
  – Genetics
  – Physiology
Interpersonal Level

- Interpersonal processes within primary groups may influence behavior
- Primary groups shape an individual’s social identity, define an individual’s role, and provide support to the individual
  - Family
  - Friendship networks
  - Colleague / Peer networks
  - Intimate partners
  - Patient/provider relationship

Theory at a Glance (National Cancer Institute, 2005)
Institutional Level

- Organizational or institutional culture, informal structure, rules, regulations, and policies may promote or constrain specific behaviors

- Organizations and institutions have a formal identity and may be comprised of an individual’s primary group members
  - Schools
  - Worksites
  - Churches
  - Clinics

Theory at a Glance (National Cancer Institute, 2005)
Community/Societal Level

• Extended social networks and their norms, whether formal or informal, may influence behavior

• Communities may be comprised of individuals, primary groups, and organizations/institutions

• Local, state, and federal policies and laws may regulate or support healthy behavior

Theory at a Glance (National Cancer Institute, 2005)
Categorizing risk and protective factors for bladder health / LUTS

**EcoLOGICAL SYSTEMS**

- Societal/Community
  - Factors that broadly influence the health of populations and communities
- Institutional
  - Characteristics that vary across workplaces, schools, clinics, and other institutions
- Interpersonal
  - Characteristics that vary across families, friendships, and other close relationships
- Individual (Mind/Behavior)
  - Cognitive, affective, psychosocial, and behavioral factors that vary across individuals

**BiOLOGICAL SYSTEMS**

- Individual (Biology/Body)
  - Co-morbid medical conditions and biologic function/dysfunction
- Multi-organ systems
  - Microbiome/host response, tissue injury/inflammation
- Cellular function
  - Hormonal environment, exposure to medications
- Molecular function
  - Genetics that vary across individuals
- Genomic substrate
PLUS CONSORTIUM
Research Themes

Bladder Health

- Hormonal Status Across Lifespan
- Infections and Microbiome
- Stress and Mental Health
- Lifestyle Behaviors (e.g., Fluid Intake, Hydration Management, Dietary Factors, Smoking, Sexual Behaviors)
- Toileting Environment/Access/Habits/Techniques
- Personal Physical Health/Medical Conditions
- Pregnancy and Childbirth
- Musculoskeletal Function/Pelvic Floor Health/Muscle Awareness
Gaps- some examples

• **Toileting environment – Access to toilets**
  – School (students and teachers)
  – Workplace via occupation
  – Public spaces

• **Musculoskeletal Function**
  – Low back pain
  – Prior lumbar/sacral surgery

• **Stress and Mental Health**
  – Anxiety
  – Children/adolescents
What is bladder health?
“In modern medicine, we have a name for everything, but a cure for nothing.”
Charles F. Glassman
Definitions – LUTS Terminology
Current uses of “bladder health”

November is Bladder Health Month

This month serves as a reminder to get the facts about common bladder health problems and to take an active role in your health. During November, the Urology Care Foundation will highlight a different bladder health theme and related resources.

- **Week 1 Theme: Incontinence, OAB and SUI**
  November 1-5

- **Week 2 Theme: Nocturia and Bedwetting**
  November 6 - 12

- **Week 3 Theme: Bladder Cancer**
  November 13 - 19

- **Week 4 Theme: Bladder Infection/UTI**
  November 20 - 26

- **Week 5 Theme: Interstitial Cystitis (IC) and Neurogenic Bladder**
  November 27 - 30
Definitions – Why Bladder Health?

• While there are effective *treatment* options for LUTS, *few* *prevention* programs studied
  – In part due to no definition of Bladder Health

• A standardized Bladder Health definition can aid in identifying:
  – factors to promote health
  – factors to modify to prevent LUTS
Bladder Health: More than the absence of LUTS

• Working definition
  – *A complete state of physical, mental, and social well-being related to bladder function, and not merely the absence of LUTS*
  – *Function that permits daily activities, adapts to short term physical or environmental stressors, and allows optimal well-being (e.g. travel, exercise, social, occupational activities)*

• Functions of the bladder
  – Storage
  – Emptying
  – *NEW Bioregulatory (protection from infection, inflammation, etc.)*

• QoL/functional status
  – Function does not impact activities on a routine basis, is adaptable to short term physical or environmental stressors, and allows optimal well-being (e.g. travel, exercise, social, occupational activities)
Next Steps-The Map

Create PLUS Measurement Toolbox

- Conduct PLUS FOUNDATIONAL STUDY (Cross-sectional & Longitudinal)
- Develop and Implement Prevention Intervention for Bladder Health Promotion
- Develop and Validate Measures of Risk and Protective Factors
- Develop and Validate Measure of Bladder Health
Bladder Health Measurement Roadmap

What components should we include?

Determine Components of Bladder Health

Conceptualize Bladder Health
Conceptualize Bladder Health

What components should we include?

Bladder Health Measurement Roadmap

1. Determine Components of Bladder Health
2. Determine How to Measure Components
3. Select/Develop Measurement Approach
4. Develop and Validate Measure of Bladder Health

What components should we include?
Bladder Health Measurement Roadmap

- Conceptualize Bladder Health
- What components should we include?
- Determine Components of Bladder Health
- Determine How to Measure Components
- Select/Develop Measurement Approach
- Validate Measures
- Administer Measurement Tool

Develop and Validate Measure of Bladder Health
Bladder Health Measurement Roadmap

- Conceptualize Bladder Health
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Develop and Validate Measure of Bladder Health

- Develop and Validate Measure of Bladder Health
Study of Habits, Attitudes, Realities and Experiences (SHARE)

- **Purpose:** To explore women and girls’ experiences, perceptions, knowledge, and behaviors related to bladder health across the life course and to inform development of a Bladder Health Instrument
- **44 Focus groups across 7 PLUS sites, 6 in Spanish**
- **360 Community dwelling women and adolescents**
- **Life Course Approach**
  - Early adolescents 11-14
  - Adolescents 15-17
  - Young adult women 18-25
  - Adult women 26-44
  - Middle aged women 45-64
  - Older women 65+
- **Diversity: Racial, Ethnic, Geographic**
Study of Habits, Attitudes, Realities and Experiences (SHARE)

• Coding & Multilevel Content Analysis
• Interpretation <-> Community Engagement <-> Feedback
• Prioritized topics:
  Terminology & Lay Discourse: Exploring lay discourse about bladder health and function
  Bladder Monitoring: The social processes of monitoring bladder behavior across social ecologies and throughout the life course
  Bladder Navigation: Female adult and adolescent experiences accessing toilets in public spaces, workplaces and schools
  Healthy Bladder: Women’s and adolescents perceptions of healthy bladder
Background

Research about lay terminology and discourse can provide insight into women’s and adolescents’ perspectives on bladder health and function. Lay language for bladder function and urinary symptoms often does not coincide with scientific medical terminology. The lay public does not have a recognized shared repository of terminology or a common arena for discourse about bladder health. There is a need to develop a consensus on terminology for bladder function to facilitate lay-medical conversations and to inform public health initiatives.

Objectives:
1. To characterize the attributes of lay language and terminology related to bladder function
2. To describe the landscape of lay discourse
3. To identify common terms associated with bladder health and function

Methods

Focus group sessions conducted by trained moderators
Semi-structured guide based on the PLUS conceptual framework
Sessions audio-recorded, transcribed, and entered into Dedoose
Field note scribe observed the sessions for nonverbal communication, group dynamics, and articulating emerging insights.
Multilevel content analysis conducted by trained coders using deductive approach to develop code book.
4-member transdisciplinary interpretation team used inductive approach for data interpretation of the "lay terminology" code
Multiple cycles of data immersion and consensus building
Insights validated by 11-member community engagement panel comprised of adolescents and women and additional participants from public service communities.

Results

Lay Terminology: A Repertoire of Terms

Lay expressions for bladder reflect a cumulative and generational process associated with developmentally related exposures. Across age, race, ethnic and rural/urban settings, adolescents and women have a repertoire of terms for bladder function in general, and passing urine, in particular:

- Informal functional terms such as "pee," "piss" and " urine"
- Formal terms such as "void" and "urinate" (not often used)
- Polite euphemistic terms as "going to the ladies room" or "being excused"
- Cultural and regional metaphors and idioms such as "pining up the water" or "throwing the waters"

Lay Terminology: Social-Historical Context

Lay terminology is embedded in a social-historical context, with terms coming in and out of vogue due to changing social norms, practices, and sensibilities. Additional terms and colloquialisms include:

- My mother-in-law used to always say I went to get to the little girl’s room. . . What about when mothers used to say they’re going to powder their nose? . . . In the bathroom
- I always say I have to go to the restroom, and I have a friend that she says I need to pee. In front of me! It’s so weird you’re telling me, for me, it doesn’t sound good.
- Boys, I know boys be like I got to take a piss. . . Ooohhh (cringes) Yeah, that’s so gross. . . I hate when boys say that!
- Sometimes I’ll say it out loud, like what I have to do. Some people with be like, they share their business too much. So you just gotta keep it to yourself.

Lay Discourse: Family and Friend Narratives

Conversations about bladder function occur predominantly among family members and friends and typically take the form of storytelling, anecdotes and cautionary tales. Additional examples include:

- My mother-in-law talked more in my younger adult years, telling me about what she was experiencing, and that’s when I became more alert. She said, "hey, as you grow older, . . . When you laugh, you tinkle, when you sneeze you tinkle.
- If you are having straining or difficult voiding to generation since my grandmother, my great-grandmother, also my mother with bladder problems. . . For that reason, the bladder for us, has not been taboo. That is talked about in the household without hesitation.
- My mother used to tell me. . . The queen never misses an opportunity. Whenever there’s an opportunity to pee, you take it because keeping things coming out is a good thing.
- This friend group of mine, whenever we go out drinking, it’s like don’t break the seal. Because as soon as you break the seal, you’re just going to have to keep going back to the bathroom.

Conclusions

Lay discourse and terminology for bladder health and function:

- is shaped by historical and life course influences
- is influenced by contemporary norms and practices
- is embedded in social and interpersonal contexts
- illustrates a preference for diminishing emotional impact and culpability
- reveals an underlying social process of definitional discordance between medical and lay views

Relies heavily on personal anecdotes shared with family and friends.

Do not exhibit language for translating stories of personal troubles into issues of public health.

Public health educational programs can foster bladder health literacy by targeting family-peer networks; integrating lay perspectives; messaging about health-promoting behaviors rather than clinical conditions.

Contact: Beverly Rosa Williams, PhD: Beverlywilliams@uabmc.edu
Innovative Bladder Health Measurement

• Developing a smartphone bladder application for discovery & dissemination of information
  – Assess behaviors, adaptations, bladder measures, risk/protective factors
  – Utilize ecological momentary assessment (EMA) so events are recorded close in time to experience
Clarification of Language, Evaluation And Refinement of questions

• Develop instrument to measure bladder health components
  – Storage, emptying, bioregulatory, QoL/functional
• Identified existing items and developed novel questions
• Cognitive evaluation
Bladder Health Measurement Roadmap

1. Conceptualize Bladder Health
2. Determine Components of Bladder Health
3. Determine How to Measure Components
4. Select/Develop Measurement Approach
5. Validate Measures
6. Administer Measurement Tool
7. Future Directions
8. Conceptualize Bladder Health
9. Determine Components of Bladder Health
10. Validate Measures
11. Administer Measurement Tool
• Develop and establish internal and external validity of a bladder health instrument (BHI) for use in:
  – Population-based research
  – Clinical research population
  – Post-partum population

Link to ClinicalTrials.gov site:
https://clinicaltrials.gov/ct2/show/NCT04016298?term=VIEW%2C+Luts&rank=1
Large observational study of bladder health

• Determine distribution of bladder health in a national representative sample

• Use in person visits recruited through regional sampling around our 7 research centers for physical assessments and laboratory assessment

• Obtain the necessary information to plan future interventions to promote bladder health and prevent LUTS
Observational Study Aims

1. Determine the distribution of bladder health (BH) status.

2. Identify BH trajectories over time and across the life-course.

3. Determine the distributions of knowledge, attitudes, beliefs; and toileting behaviors.
4. Evaluate associations of various candidate risk and protective factors with BH at baseline (based on surveys, clinical assessments and biological specimens, as appropriate).

5. Evaluate associations of various candidate risk and protective factors with changes in BH over time.
Planned Impact

• Development and testing of evidence-based prevention interventions
  – Broad dissemination to the public
  – Integration into health care systems
  – Shaping of health-promoting policies within schools, workplaces, public spaces, and public health agencies

• Promoting the overall well-being of girls and women