National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

WORKSHOP ON BEHAVIORAL AND PSYCHOSOCIAL FACTORS IN WOMEN WITH URINARY INCONTINENCE

6707 Democracy Boulevard
Bethesda, MD

Monday, March 30, 2015

Meeting Summary

Meeting Introduction

Opening Remarks

Robert Star, MD, NIDDK
Dr. Star welcomed the meeting participants and brought greetings from Dr. Griffin Rogers, director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), who was unable to attend. He also thanked Dr. Tamara Bavendam and the other organizers of the workshop.

Dr. Star began by acknowledging that the Institute has a large and varied research portfolio in urinary incontinence, including clinical trials as well as basic and translational research. Much of NIDDK's clinical research, including the Urinary Incontinence Treatment Network (UITN), has focused on highly symptomatic women who sought treatment. UITN set the bar for conducting clinical research in benign urology, aided by strong collaboration between urologists and urogynecologists. Treatments evaluated in the UITN studies were standard of care, based on the current understanding of the pelvic organs and how they work. Dr. Star added that NIDDK also supports basic and translational studies to help us understand the underlying mechanisms of disease. In these studies, organs are generally studied at the cellular and subcellular levels rather than as whole units.

Dr. Star emphasized that both clinical and basic research is important to improve the lives of women with urinary incontinence. He noted that over the years, studies have shown that many treatments can be effective, although the duration of improvement may be shorter than desired. However, based on the biologic and demographic information captured in current studies, it is not possible to identify the women who may be best suited for the available treatments. Dr. Star acknowledged that NIDDK is about to begin the Path to Prevention of Lower Urinary Tract Symptoms Initiative, through which we will learn about women at an earlier stage in their symptom evolution. We hope this work will help us identify subgroups for specific treatment pathways.

Dr. Star quoted William Osler, who said, "It is much more important to know what sort of a patient has a disease than what sort of disease a patient has." Dr. Star noted that over the past century—since the days of William Osler—advancing technology has enabled us to study humans and diseases on an increasingly minute scale: from the whole patient, to organs, to cells, to organelles. However, he cautioned that perhaps a strictly reductionist approach—at the exclusion of thinking about the patient as a whole—has not always served patients well. Dr. Star explained that NIDDK aims to maintain a broad focus. He noted that today's meeting brings us to uncharted territory and is a first step in exploring the potential value of research to understand how behavioral and psychosocial factors affect women with urinary incontinence. He added that each participant at today's workshop brings a unique perspective to apply to these issues and expressed enthusiasm for the stimulating discussions ahead.

Setting the Stage

Tamara Bavendam, MD, MS, NIDDK
Dr. Bavendam thanked Dr. Star for his introduction and expressed her excitement about the meeting. She also acknowledged the people involved in planning the meeting and summarized the meeting agenda and format.

Dr. Bavendam began by setting a framework for the breadth of lower urinary tract conditions women can experience. These conditions include frequency/urgency (sometimes called overactive bladder), bladder infections, interstitial cystitis/painful bladder syndrome/chronic pelvic pain syndrome, trouble urinating, and urinary incontinence. She noted that even though behavioral and psychosocial factors could apply to all of these conditions, the day's discussion would center on urinary incontinence (UI) in order to focus the discussion and capture some of the unique barriers to women seeking care for UI.

Dr. Bavendam outlined the path a women with UI must follow to achieve better outcomes. When a woman experiences symptoms, she must first acknowledge those symptoms and then choose to discuss them with her clinician. Then, the clinician must acknowledge her condition, evaluate the condition, and work with the woman to choose a treatment that will hopefully yield a satisfactory outcome. Dr. Bavendam noted that barriers exist at every point along the way and that the day's goal is to identify the non-biologic pieces of the puzzle, such as beliefs and values, cognitive function, knowledge, cultural influences, societal influences, behaviors, psychosocial concerns, resiliency, and personality.

Dr. Bavendam encouraged participants to think broadly and raise all non-biologic factors (NBF), regardless of whether they seem actionable under the current healthcare system. She noted that the meeting is a think-tank and encouraged participants to assume that all ideas and identified NBFs will advance our thinking in this area. She also encouraged participants to concentrate on the pathway for women with UI rather than the constraints of the health care system, such as the limited time clinicians have with patients. Once we identify and prioritize the NBFs, we can determine how to use the information to minimize the impact of UI on the lives of women along the continuum from self-care to clinician-directed care.

Participant Self-introductions

Dr. Bavendam invited participants to introduce themselves:

- Kathryn Burgio, PhD, behavioral psychology and uropsychology
- Helen L. Coons, PhD, ABPP, clinical health psychology, women's health and mental health
- Jennifer Dodson, MD, PhD, pediatric urology and surgery
- Andrea Fairman, PhD, OTR/L, CPRP, occupational therapy
- Judy Fried-Siegel, MD, pediatric and women's urology and surgery
- Ziya Kirkali, MD, urology
- John Kusek, MD, epidemiology of urologic and kidney diseases
- Marva Moxey-Mims, MD, pediatric pathology
- Diane Newman, DNP, ANP-BC, FAAN, adult urology and surgery
- Jenna Norton, MPH, kidney and urologic science translation
- Neil Resnick, MD, geriatric medicine
- Leslie Rickey, MD, MPH, female pelvic medicine and surgery
- Rebecca Rogers, MD, urogynecology and female pelvic medicine
- Silvia Sörensen, PhD, psychiatry, gerontology, and human development
- Marian Tanofsky-Kraff, PhD, clinical psychology and pediatric obesity
- Kevin Weinfurt, PhD, experimental psychology and behavioral science
- Gail Wyatt, PhD [via telephone], clinical psychology, psychiatry, and behavioral science
- Andrew Zabel, PhD, ABPP, neuropsychology

Introductory Presentations

Urinary Incontinence in Women

Leslie M. Rickey, MD, MPH, Yale School of Medicine, New Haven, CT

Dr. Rickey provided an overview of UI in women for participants new to urology. She acknowledged that the bladder has two functions—to store urine and to empty urine—and explained that as people develop from infants to adults, they develop higher order pathways to make decisions—such as determining when it is socially acceptable to urinate and controlling the emptying of the bladder—about autonomic bladder function. She suggested that dysfunction may occur within these higher order pathways and that when bladder storage is compromised and urine leakage occurs, the patient experiences the situation as a loss of bladder control. Dr. Rickey commented that clinicians hear the same anecdotes from patients about UI, such as leaking after exercise, laughing, or coughing; having to leave a meeting several times to use the bathroom; being unable to find a bathroom quickly enough; or wearing dark clothes to hide leaking. She explained that UI plays into social, emotional, and physical fears and emphasized that understanding the experience of bother and the impact on quality of life is an important area for consideration.

Dr. Rickey noted that UI is a common problem and the most common pelvic floor disorder, with 25 to 50% of women reporting UI. She highlighted the many risk factors and comorbidities associated with UI, including elevated body mass index (BMI), increased parity (including vaginal childbirth and pregnancy), smoking, asthma, and age. Because symptom frequency and severity increase with age, she emphasized that UI prevalence will likely increase as the U.S. population continues to age. However, she stressed that only about half of women who experience daily or weekly incontinence seek treatment and noted that although embarrassment and lack of access to health care are barriers to seeking care, it is likely that other factors also play a role.

Dr. Rickey highlighted UI's severe negative impact on quality of life across genders and all age groups older than 12 years. Those impacts may be insidious and affect physical function and emotional well-being. She also emphasized the potential impact of UI on health. For example, a woman who knows she needs to lose weight but who leaks during physical activity may be much less likely to exercise. Additionally, Dr. Rickey addressed cost and work productivity issues related to UI. Among employed American women, 37% reported urine loss in the past 30 days.

Dr. Rickey reviewed the three main types of UI: (1) stress incontinence, which is leakage with exertion or activity; (2) urgency incontinence, which is leakage accompanied by urgency that may occur during the day or at night (nocturia); and (3) mixed incontinence, which is a combination of stress and urgency incontinence. Less common types include overflow incontinence, in which bladder muscles do not contract and the bladder continues to store urine until it overflows. Dr. Rickey explained that stress UI may result from a weakened urethral sphincter or decreased pelvic floor support and ability to contract, whereas urgency UI may involve bladder neuromuscular dysfunction, which could originate in the bladder, spinal cord, or central nervous system.

Dr. Rickey also covered treatment options by type of UI. Stress UI treatment focuses on weight loss and ways to increase bladder resistance, such as pelvic floor muscle exercises, incontinence rings (or pessaries), office procedures (e.g., bulking agents), and surgery (e.g., sling procedures). Primary urgency UI treatment includes behavior changes, such as managing fluid intake, timed voiding, and urge suppression with pelvic muscle contraction as well as medication. Second-line therapies for urgency UI include Botox injection into the bladder or neuromodulation such as InterStim surgery or peripheral nerve stimulation. Dr. Rickey noted that behavioral therapy can work with urgency UI, but it requires time; second-line therapies are used if the other treatments do not work. Additionally, she stressed that developing a treatment plan involves a considerable amount of patient education.

Barriers to treatment begin with patients' misconceptions and fears. Dr. Rickey noted that many patients may feel that incontinence is part of normal aging, is not severe or frequent enough to treat, is too embarrassing to discuss, or will not be improved with treatment. Moreover, patients fear invasive procedures, and both patients and clinicians lack knowledge about treatment options. Additionally, primary care providers have many competing demands that may make focusing on UI challenging.

Dr. Rickey acknowledged the complexity of treating UI, which requires identifying the type of incontinence, recognizing how treatments may exacerbate other conditions (e.g., overactive bladder medications may cause constipation), understanding patient behaviors and the driving factors behind them (e.g., frequency may be due to pain, urgency, or fear of leaking), learning the psychosocial and cultural environment of the patient, and considering individual patients' expectations regarding treatment.

Dr. Rickey closed by reviewing the concept of the urologic iceberg, which suggests that observed cases of urologic conditions (the part of the iceberg above the water) accounts for only a small portion of people who have symptoms. Most research has been done on symptomatic people who seek treatment and receive a diagnosis, but many people with symptoms (who are represented by the submerged portion of the iceberg) seek care but are not diagnosed, acknowledge symptoms but do not seek treatment, or neither acknowledge symptoms nor seek care. Many studies have relied on International Classification of Diseases, 9th Revision (ICD-9) codes, but studies comparing prevalence based on ICD-9 codes and other administrative data with prevalence based on survey reporting suggest that administrative data significantly underestimate true prevalence.

Discussion

A participant underscored the lack of correlation found in epidemiology research between the amount and frequency of UI in a patient and the amount of bother that patient experiences. When asked how much bother patients experience, 20% of patients who leaked only a few drops reported significant bother, whereas only about 60% of patients who leaked significant amounts reported significant bother.

Another participant cautioned that the perception of bother may be based on what the patient perceives as normal. Because many women believe that UI is normal, we need to provide more education about healthy bladder function and teach women what is normal. She added that many healthy women with no or few symptoms are eager to participate in education programs and learn about their bodies.

Behavioral and Psychosocial Factors in Women across the Life Span with Urinary Incontinence

Helen L. Coons, PhD, ABPP, Women's Mental Health Associates, Denver, CO

Dr. Coons opened with a review of several UI cases, including a 36-year-old woman pregnant with her fifth child who has experienced UI since her fourth delivery, a 58-year-old woman with a 6-year history of UI who has ceased physical and sexual activity and has not sought care, and a 73-year-old woman with multiple chronic conditions and routine incontinence who has stopped going to church and has not sought care. She continued by acknowledging the broad range of psychosocial and behavioral factors that may affect care-seeking and the impact of UI on these women, including social withdrawal, body image, sexual health, dating/relationships, beliefs, UI diagnosis, treatment procedures, quality of life, functional roles, insomnia, distress, depression, employment, and economic impact. She called out the coexisting or preexisting behavioral health conditions, psychosocial stressors, and socioeconomic/sociocultural factors that set the context in which women acknowledge UI and make treatment decisions, which includes a host of health beliefs about UI and the health system based on prior experiences.

Specifically with regard to seeking care and reporting symptoms to providers, Dr. Coons reviewed several relevant behavioral, psychosocial, and sociocultural factors, including the patient's age, available time (e.g., work schedule, competing demands, stress, and priority placed on health), lack of health insurance, limited money for co-pays, shame/embarrassment/stigma, beliefs and knowledge about UI and diagnostic and treatment options, uncertainty about which provider to ask, fear of the provider's response, level of social support, and prior negative experience or marginalization in the health system. She also acknowledged the nonlinear relationship between seeking care and the type, impact, severity, and duration of UI that a participant had previously highlighted.

Dr. Coons emphasized the importance of considering the larger contextual issues that affect women's health and well-being in the United States and constitute barriers to care. More than 50% of women in the United States are single, and many are overwhelmed by multiple roles and stresses. U.S. women are coping with co-occurring and preexisting conditions, including medical diagnoses, mental health and substance abuse issues, depression, and preexisting issues with body image, sexual health, and relationships. Additionally, women disproportionately experience emotional, physical, and sexual trauma across the life span, which is a significant pathway to physical and mental health issues.

Finally, women have preexisting beliefs and experiences with the health system related to prior care.

Dr. Coons added that UI often leads to significant psychological distress, in part through decreased functional status and quality of life. For example, women with UI may stop going to religious gatherings or work, avoid visiting friends, and/or limit travel or physical activity. She noted that—similar to other chronic conditions such as breast cancer—younger women with UI report a higher rate of psychological distress, even though UI is more common among older women.

Dr. Coons noted that nondisclosure of UI places women at increased risk for adverse physical, psychosocial, behavioral, cognitive, and relational outcomes. Nondisclosure increases the likelihood that women will remain uninformed and unprepared about diagnostic and treatment options for UI, inhibits opportunities for educating and empowering women about their general health, and decreases opportunities to provide evidence-based care for a broad range of conditions beyond UI (e.g., insomnia, depression, body image, sexual issues, social isolation).

Dr. Coons closed with recommendations for a behavioral and psychosocial research agenda relating to women with UI. She suggested that research include identifying effective methods for disseminating accurate information, increasing social support, enabling assertive communication about health issues, supporting self-efficacy and control, and enhancing health-related problem-solving skills among women with UI. She added that research should yield insight into helping women with UI become partners in their care to improve physical, behavioral and psychosocial outcomes.

Discussion

A participant wondered whether women might prefer to take care of UI symptoms by themselves (if, for example, pessaries were easily available over-the-counter), rather than partnering with health care providers. She added that increasing availability and high sales of adult diapers and pads suggest many people do address symptoms outside of the health care system.

Dr. Coons agreed that there is probably a subset of women with the appropriate health knowledge, comfort level, and self-efficacy who would benefit from over-the-counter access to pessaries and other UI treatment. However, she noted there are likely others who may have cultural, knowledge, and comfort barriers to acquiring and inserting their own pessaries. For example, the patient would have to know what a pessary is, how to use it, and be comfortable touching herself. She added that a skilled clinician may be able to open this dialogue to determine what course of action might be acceptable to the woman and her sense of self as well as her cultural/religious beliefs.

The group agreed that although many women do self-manage UI outside of the health care setting (through use of pads, fluid restriction, etc.), an opportunity exists to educate these women about more effective solutions for treating UI rather than simply coping with symptoms. The group also noted that significant costs and barriers are associated with purchasing pads and that women may prefer this coping mechanism over seeking care only because of significant barriers to accessing the health care system (e.g., feeling unwelcome, costs, lack of provider diversity).

Dr. Bavendam commented that we frame UI in the context of people who come to health providers for care because we interact with and have data on this population, but those who do not come in for care may be a bigger piece of the population and may have different self-management preferences from those who do seek care. She cautioned against framing efforts based only on the population we see because we do not know much about the people who do not seek treatment.

A participant noted that, according to a report from the Institute of Medicine, providers often fail to provide the same level of care to underserved populations (e.g., minorities, obese women). This disparity in care delivery may be due to a combination of beliefs and unconscious biases that perpetuate lack of adequate care. She suggested that efforts should focus both on educating and informing clinicians in addition to focusing on women.

Another participant suggested that the fact that women have UI in the context of many other issues can be both a challenge (in terms of competing priorities) but can also provide an opportunity to educate women about UI when they seek care for a related condition. For example, because so many people with kidney disease also have diabetes, NIDDK has found success delivering kidney health messages through diabetes programs. A similar opportunity might exist regarding UI education.

Dr. Coons remarked that one such opportunity may be to engage primary care providers (including general gynecologists and pediatricians) in routine screening for UI. She added that messages may need to reach an audience broader than women with UI and clinicians in urology/urogynecology and suggested that the group should engage in a conversation about extended target audiences for messaging.

A participant highlighted an epidemiology study that found two key predictors of treatment-seeking in UI: (1) symptom severity and (2) a regular pattern of clinician visits.

Another participant commented on the parallels with eye care messaging. She noted that her practice conducts telehealth screenings in primary care for diabetic retinopathy, which has been very successful in identifying patients who need additional care. The practice also provides in-person education sessions and is exploring use of telehealth methods to educate patients. She suggested this approach may be successful in raising awareness of UI and its treatment options. The group agreed that UI messaging needs to happen interprofessionally at all levels, at the community level, and via the media to raise awareness of treatment options and what is normal in terms of bladder function.

Disinhibited Eating: Utility for Elucidation of Obesity Phenotypes and Intervention

Marian Tanofsky-Kraff, PhD, Uniformed Services University of the Health Sciences, Bethesda, MD

Dr. Tanofsky-Kraff opened by noting the similarities between UI and obesity. Like obesity, UI is associated with a host of other health issues (e.g., low self-esteem, poor quality of life). In addition, both obese people and people with UI may be reluctant or ashamed to go to the doctor. However, Dr. Tanofsky-Kraff acknowledged that the obesity research community has made more progress than the UI community in understanding and addressing behavioral and psychosocial issues. She noted that obesity-related efforts may suggest a potential pathway for moving forward in UI.

Dr. Tanofsky-Kraff stated that the obesity community has moved away from a one-size-fits-all approach to treatment and is seeking ways to subtype obesity to target interventions and achieve better treatment outcomes. To provide some background, Dr. Tanofsky-Kraff reviewed the energy balance model of obesity, which suggests that obesity results from an imbalance of energy intake and expenditure. However, she emphasized that weight control is much more complex than making healthy food choices and getting exercise.

Even though energy intake and expenditure both play an important role in obesity, Dr. Tanofsky-Kraff noted that her discussion would focus on energy intake. She defined disinhibited eating as behaviors and traits that involve a lack of healthy restraint over eating, thus promoting obesity. She noted that disinhibited eating is studied around the globe, but different terminology (e.g., food addiction, emotional eating, binge eating, etc.) is used in different locations. In her work, Dr. Tanofsky-Kraff has used the term “loss of control (LOC) eating,” defined as the experience of being unable to stop eating or control what or how much is being eaten regardless of the amount of food consumed. Dr. Tanofsky-Kraff explained that prevalence of pediatric LOC is 50% or more among obese treatment-seeking adolescents, and the condition predicts excess weight and fat gain, adverse metabolic states, binge eating disorder, and symptoms of depression and anxiety.

Dr. Tanofsky-Kraff highlighted the genetic underpinnings of LOC eating. LOC eating has been shown to aggregate in families and is associated with the common single nucleotide polymorphism (SNP) rs99396090 in the first intron of the FTO gene. Additionally, phenotyping reveals that pediatric LOC eating is associated with changes in observable behavior.

Dr. Tanofsky-Kraff reviewed a study of energy intake in which 177 youths were exposed to two test meals on 2 separate days. In one test meal, participants were told to eat as much as they would at a normal meal. In the other test meal, participants were told to let go and eat as much as they wanted. Participants were randomized to one of two groups. One group received the normal meal instruction first, and the second group received the binge meal instruction first. Participants with LOC reported experiencing a greater degree of negative emotions (including confusion, depression, fatigue, and tension) immediately before eating and consumed more highly palatable foods (e.g., cookies, candies) and fewer lunch-type foods. Additionally, overweight girls with LOC eating consumed more at binge meals than those without LOC eating. Dr. Tanofsky-Kraff stated that negative emotions may be a potential driver of LOC eating.

Dr. Tanofsky-Kraff noted that findings are mixed regarding the relationship between obesity and attention bias to food in children. However, her research has shown a significant positive relationship between attention bias to highly palatable foods and BMI-z (the measures of relative weight adjusted for child age and sex) only among youth with LOC. Because of these data and because attention biases have been linked to both genetic and neurologic underpinnings, efforts in endophenotyping (parsing behavioral symptoms into more stable phenotypes with a clear genetic connection) LOC eating are underway. Endophenotyping pediatric LOC eating revealed alterations in physiology, including a higher level of fasting leptin among youth with LOC eating, which suggests that LOC eating involves alterations in the hypothalamus. Additionally, research using ecological momentary assessment (EMA) showed a physiologic stress response (increased heart rate variability) before LOC eating episodes.

To review the potential effect of social stress on LOC eating, Dr. Tanofsky-Kraff reviewed a recent pilot study in which participants were given access to a test meal following exposure to a social stress task. The stress task required participants to identify peers with whom they wanted to chat and then learn which peers were (or were not) interested in chatting with them. fMRI scans during the stress task showed that negative peer feedback elicited diminished engagement in the ventromedial prefrontal cortex in girls with LOC eating. Additionally, bilateral fusiform face area activity was positively associated with intake during the test meal. These findings suggest social cues may be involved in eliciting negative affect, which in turn may result in LOC eating.

Dr. Tanofsky-Kraff continued by reviewing how these research findings are being implemented in targeted obesity interventions focused on prevention of LOC eating. One intervention, interpersonal psychotherapy (IPT), is based on the theory that improved interpersonal functioning will decrease negative affect, thereby reducing LOC eating and preventing excess weight gain. To test the hypothesis that IPT will be more effective than standard-of-care health education in reducing the presence of LOC eating and classic binge eating, as well as preventing excess weight gain in adolescent girls at high risk for adult obesity, Dr. Tanofsky-Kraff randomized 113 girls to either IPT or standard health education. She reported that both the standard health education group and the IPT group reduced LOC eating and both reduced BMI-z scores by 1 year. Some initial data suggest that in certain subgroups, IPT may lead to improved outcomes, which suggests that more narrow targeting of interventions may be necessary.

To improve the efficacy of obesity and LOC eating interventions, Dr. Tanofsky-Kraff suggested developing more targeted therapies based on more precise endophenotypes; working more collaboratively by speaking the same language and acknowledging overlap in terminology (e.g., we may all be studying different aspects of a few constructs or a continuum of disinhibited eating); and considering multiple behaviors and traits that may be tied to specific biological functions (e.g., impulse control, negative drive, and reward drive may interact). She noted that the soon-to-be-launched Children's Growth and Behavior Study may provide additional insight into endophenotypes by evaluating biopsychosocial factors involved in the onset and maintenance of childhood disinhibited eating behavior and excessive weight gain among healthy adolescents.

Dr. Tanofsky Kraff concluded by reiterating that one size does not fit all in obesity—or UI—interventions, and suggested that identification of endophenotypes may be useful in both fields. She added that we must think like psychologists when it comes to intervention and determine "what treatment, delivered by whom, is most effective for what problem, under which set of circumstances."

Discussion

A participant commented on the success of IPT in specific high-risk subgroups and emphasized that varied results across subgroups speak to the importance of more narrowly focusing interventions.

Dr. Tanofsky-Kraff agreed and added that cognitive behavior therapy in the eating disorders field has focused on the restraint model, which assumes patients go through binge/restraint cycles. However, she emphasized that this model does not appear to apply to African American girls, who may experience LOC eating because of social stress. To test whether IPT may be more effective in people who experience severe stress, Dr. Tanofsky-Kraff will be conducting a study among military dependents.

A participant asked whether the IPT study included both low- and middle-income African Americans and Latinos, and Dr. Tanofsky-Kraff clarified that both were included in the study but the data have not yet been analyzed based on income level.

A participant queried whether Dr. Tanofsky-Kraff has conducted interventions to assess brain imaging outcomes. Dr. Tanofsky-Kraff responded that she is currently seeking funding to do so.

A participant asked whether the IPT analysis included history of sexual trauma and emphasized the importance of including this variable, noting that many African American girls overeat to make themselves less attractive to avoid sexual abuse. Dr. Tanofsky-Kraff acknowledged the importance of including sexual trauma, but noted that the Uniformed Services University Institution Review Board has concerns about this line of questioning in children.

A participant commented on Dr. Tanofsky-Kraff's use of ecological momentary assessment (EMA) and suggested it may be valuable in understanding UI. Currently, clinicians may not get accurate information from patients about frequency of UI and may not understand the context of the UI episode. Especially when linked to mobile devices that many patients already have, EMA may enable clinicians to better capture more complete UI data.

Non-biologic Factors That Influence Urinary Incontinence—Disease Experience and Case Examples

Rebecca G. Rogers, MD, University of New Mexico, Albuquerque

Dr. Rogers began by noting that her practice of urogynecology is largely influenced by her location in New Mexico, a minority-majority state, where she sees a significant number of Hispanic and Native American patients. To inform the development of cases for the group to review, she queried colleagues and patients to get input on what the cases should cover. Dr. Rogers acknowledged that much of treatment research in UI has focused on upper- or middle-class Caucasian women.

Dr. Rogers reviewed three key components of research: design, analysis, and measurement. She noted that figuring out what to measure and how to measure it is a critical component because the way we define outcome influences study results. Dr. Rogers noted that UI might be measured by physical exam, imaging, urodynamics, neurophysiologic testing, and patient-reported outcomes, but she emphasized that patient-reported outcomes must be validated in diverse populations. She noted that the goal of the day's meeting could be framed as refocusing research from variations in treatments to variations among individuals, which implies defining subgroups.

As the first case study, Dr. Rogers introduced SA, a healthy 65-year-old woman with a history of five full-term pregnancies who leaks with activity and urgency. She takes care of her grandchildren and a husband with early-onset dementia. She feels that too much time would be involved in seeking treatment, does not believe pelvic floor muscle exercises work, and cannot remember to complete them. Dr. Rogers noted that the case reflects some of the barriers to seeking care for UI, which include fear of treatment, lack of knowledge of treatment, communication issues, provider barriers, avoidance/denial, normative thinking, competing health priorities, and limited access to care.

As the second case study, Dr. Rogers introduced a 42-year-old woman with a history of two full-term pregnancies who is married and leaks during intercourse. The husband is urging her to seek treatment and will not have sex with her because she leaks. She also leaks rarely with activity, coughing, laughing, and sneezing. The woman is not bothered by her leaking. She is seeking surgery on her husband's urging. The group noted the patient's goal in this case is ultimately to stop her husband from pestering her, which is not what surgery is designed to do. Dr. Rogers emphasized the importance of considering the patient's treatment goals and expectations because they play a major role in satisfaction. Dissatisfaction with treatment outcomes often results from a mismatch between expectations and results. For example, the SISTr trial found that, despite counseling that slings would not improve overactive bladder (OAB) symptoms, many women continued to believe their OAB symptoms would improve with a sling and were disappointed when they did not.

Dr. Rogers cautioned that UI does not exist in a vacuum and emphasized that it cannot be separated from the context of life. In one study, patient-reported goals varied from symptom relief, to quality-of-life improvement, to other very broad goals (e.g., “live happy life”) that may not be possible to effect through treatment.

As a third case study, Dr. Rogers introduced a 42-year-old women with a history of two full-term pregnancies who leaks with coughing, laughing, and sneezing and has urgency symptoms. She has had two prior midurethral sling surgeries and has done pelvic floor muscle exercises and behavioral therapy without mild improvement. She wears a pad daily. Given the options of continuing current therapy, using a pessary, or having another surgery, she chose surgery. Noting that risk-takers may be more likely to choose surgery, Dr. Rogers reviewed a study that assessed treatment choices in 152 women and found unmeasured predictor variables, such as patients’ attitudes, beliefs, and values toward each treatment choice, that affect those choices. Dr. Rogers also reviewed a study of 316 women who were categorized based on life orientation (31% pessimists, 38% optimists), which found that optimistic women had fewer goals than pessimistic women and were less likely to choose surgical treatment.

Dr. Rogers introduced cases four and five together, presenting AG and SC, two patients seeking care for urgency UI who both received an antimuscarinic drug, pelvic floor exercises, and behavioral therapy. Both patients improved, but AG was completely satisfied after dropping from five leaks to one leak per day, whereas SC was only somewhat satisfied after dropping from two leaks to one leak per day. Dr. Rogers noted that satisfaction is highly subjective. If expectations are low, the person may be satisfied with poor outcomes. Satisfaction is linked to expectations.

Dr. Rogers presented a sixth case, in which AG went on to receive surgery to implant a midurethral sling for stress UI. The surgery was uncomplicated, except that she had temporary voiding dysfunction and constipation postoperatively. Even though the stress UI resolved, the patient was not satisfied. Dr. Rogers noted that most outcome measures are created by physicians for physicians and do not consider outcomes that may be important to the patient. She also emphasized the importance of managing patient treatment expectations in order to improve satisfaction.

Dr. Rogers presented a final case, introducing HG, who leaks with urgency and coughing, laughing, and sneezing. She wears a pad and is bothered by her symptoms but is reluctant to seek care because she believes the problem was ordained by a higher power, which necessitates talking to a spiritual leader about whether to pursue therapy. Dr. Rogers noted that she often hears this concern from patients.

Dr. Rogers closed by highlighting three concepts that emerged from fecal incontinence research regarding treatment options, which physicians did not identify but which patients felt were important: (1) hope for improvement, (2) responsibility and personal effort to control symptoms, and (3) encouragement to go on living life fully.

Discussion

A participant reiterated that beliefs about health conditions being preordained can inhibit action, noting that she has seen this situation in people with obesity and diabetes as well. In a similar vein, a participant noted that with an increasing immigrant population, clinicians may be treating more women of various ages who rely on spouses or family members to make health decisions for them. Previously, this situation was usually seen only with the elderly and the frail.

A participant noted that some patients may lack the cognitive or executive skills to make health decisions and may have a guardian who serves as the health decision-maker. Additionally, some patients may have undiagnosed deficits in cognitive/executive function or problem-solving skills (e.g., dementia, frailty).

A participant asked about the relationship between developmental neurocognitive conditions that may compromise urinary/bowel function in children and available treatment options. Another participant responded that many children without neurological issues come in with voiding dysfunction and noted that the International Children’s Continence Society provides guidelines about treatment with biofeedback and behavioral management.

It was noted that cognitive function and bladder control are related because competent executive function is required to sense the urge to urinate. fMRI scans show that many parts of the brain are involved in sensing and regulating the need to urinate. Additionally, bladder control occurs relatively late in the developmental pathway—not until after children learn to walk, talk, and feed themselves—suggesting that higher order pathways are involved. However, a participant emphasized the distinction between cognitive deficits and the spectrum of cognitive skill level in people with normal cognitive function. A patient may be cognitively normal but his/her executive function may be overwhelmed with competing concerns or he/she may lack teachable skills (e.g., problem-solving, prospective memory), which could make seeking or adhering to treatment more challenging. Another participant noted that nonhabitual behaviors may place a greater burden on cognitive/executive function; therefore, when executive function is overwhelmed, people are more likely to revert to habitual behaviors. For example, because grocery shopping may be a habitual behavior, an overwhelmed person may be more likely to purchase pads while grocery shopping than to take the nonhabitual action of seeking treatment.

Although physical issues do underlie UI in many cases, a participant suggested that because of the complex neurology involved in bladder control, some UI may result from psychological issues (e.g., depression, anxiety, or post-traumatic stress disorder). Another participant noted that the sometimes transient nature of UI is more consistent with psychological than physical conditions. Epidemiologic data correlate psychological and bladder control issues; however, prospective data to demonstrate causality are limited. One longitudinal cohort study by Melville did show that depression predicts onset of UI in women.

Multiple participants noted the importance of health literacy in communicating about UI, particularly because of the complexity regarding type of UI and corresponding treatments. Messages must be communicated clearly in language used by patients, especially given the high rate of UI among people with cognitive impairment.

A participant reiterated the importance to patient motivation of having hope that things will change and added that positive feedback also plays a significant role in motivation. Both hope and feedback that demonstrates progress should be components of any interventions.

Non-biologic Factors That Impact the Treatment Pathway

Group Discussion

The group acknowledged that NBFs may affect decisions along the entire treatment pathway, including the patient’s experience of and response to the condition, acknowledgement of the condition, decision to seek care, treatment choice, treatment adherence, and perceptions of satisfaction with care. The group listed the following factors but noted that different factors will apply to different points along the treatment pathway. Additionally, the group agreed that the relevance of each factor may vary according to the patient’s age (e.g., adolescents involved in high-impact sports versus elderly women).

- Who is bothered (e.g., the patient versus a family member)
- Trauma across the lifespan
- Knowledge of bladder function/disease
- Competing priorities—where UI fits in regarding overall wellness/ life
- Social support
- Relationship status
- Socioeconomic status
- Access to care (distance, insurance, cost, clinician diversity)
- Resource constraints (limited time, money, cognitive capacity)
- Knowledge of treatment options
- Therapeutic alliance between the patient and clinician
- Marginalization by the health care system
- Positive feedback from providers
- Depression, anxiety and post-traumatic stress disorder
- Duration of symptoms
- Level of bother
- Belief systems
- Spirituality

Culture

- Pessimism/optimism
- Expectations of bladder function (e.g., ageism)
- Normative thinking (i.e., level of bladder control the women considers normal for her age)
- Hope
- Self-efficacy
- Shame/embarrassment
- Stigma (clinical, caregiver, society)
- Power/control
- Fear
- Sense of responsibility
- Limited cognitive resources/cognitive burden
- Neuroticism
- Openness
- Extraversion
- Conscientiousness
- Agreeableness
- Risk seeking/avoiding personality
- Health literacy
- Willingness to engage in new behavior
- Medical mistrust
- Private/reserved nature
- Proactive/reactive tendencies
- Problem-solving skills
- Prospective memory skills
- Decision-making skills
- Resiliency
- Readiness to acknowledge issue/seek treatment
- Avoidance
- Coping
- Body image and sexual functioning
- Illness related anxiety

Conducting Research on the Impact of Non-biologic Factors in UI

Group Discussion

The group raised several issues that should be considered in planning interventions and research on NBFs and UI. The group agreed that some factors may be addressed through patient intervention whereas other factors may require changes in how clinicians communicate with patients and/or target therapies. Still other factors may not be amenable to intervention at all.

The group raised several considerations regarding communication strategies and behavior change interventions targeting women with or at risk for UI:

- For many women, UI is one more thing on a long list of responsibilities and concerns. UI interventions must be considered in the context of the whole women.
- Motivational interviewing may be an effective method for increasing knowledge/encouraging behavior change among women with UI.
- Women may be more receptive to educational efforts and/or may be more motivated to change behavior pre-partum, due to concern about the health of their child.
- Women tend not to want to pathologize their bodies, yet viewing UI as normal may inhibit action around UI treatment. Communication strategies must clarify that UI is not normal without making women feel pathologized.

There is a need to create a safe harbor for patients to report symptoms and outcomes.

Regarding engaging primary care clinicians in UI screening and care, the group highlighted several barriers:

- For busy primary care clinicians, UI is one more condition on a long list under their purview. Discussing UI in the context of multiple chronic conditions may increase its relevance.
- The lack of a current procedural terminology (CPT) code for preventive care in urology inhibits prevention-focused treatment in UI.
- The limited number and low value of relative value units (RVU) relating to UI reduce clinician attention to UI.
- UI performance measures in the Healthcare Effectiveness Data and Information Set (HEDIS)—a tool used by more than 90% of America's health plans to measure performance—are based only on checking a box that presence of UI was queried. The measures do not incentivize action regarding UI.

The group noted that many NBFs lack validated measurement tools. Such tools must be developed and validated across populations and age groups in order to conduct research on NBFs. Tools currently exist to measure only a few NBFs (e.g., problem-solving skills can be measured through the Barkley Deficits in Executive Function Scale, the Behavior Rating Inventory of Executive Function scale, and/or possibly through a scale developed by Nezu and Nezu; personality can be measured through the 10-item personality inventory). The Agency for Healthcare Research and Quality and the Patient-Centered Outcomes Research Institute (PCORI) may have additional tools.

Planning the Next Steps

Group Discussion

The group agreed that pursuing the following activities could help advance knowledge and facilitate research on the potential role of non-biologic factors (NBFs) in UI:

- Increasing our understanding of the UI disease course and women's experience with UI through NIDDK's recently launched Prevention of Lower Urinary Tract Symptoms in Women (PLUS) consortium. The group suggested PLUS may be able to accomplish the following goals:
- Support a health survey among a diverse population to better understand symptoms, burden, bother, and treatment-seeking barriers or motivations. This survey could yield insight into the extent to which coping with UI (e.g., using pads instead of seeking care) is occurring in the general population.
- Generate prospective data to show what conditions or factors (e.g., trauma, anxiety, depression, obesity, etc.) predict onset of UI.
- Clarify the role of physical and psychological issues in the development of UI.
- Increase understanding of the costs of not treating UI.
- Conducting additional meetings and calls to categorize the NBFs raised during the day's discussion and prioritize them for research. The group agreed that
- Problem-solving skills are a priority factor for research.
- Involving Barbara Anderson, PhD, of Ohio State University and Christine M. Nezu, Ph.D., ABPP, Drexel University may be helpful to future discussions.
- Developing tools to measure priority NBFs, potentially through PCORI or R21 grants, once factors are categorized and prioritized.
- Raising awareness and knowledge of UI among women and empowering them to seek care when they experience symptoms.
- Raising awareness of UI among primary care clinicians and increasing their knowledge and preparedness to manage patients with UI.

Thanks and Summary of Meeting

Tamara Bavendam, MD, MS; Robert Star, MD; Jenna Norton, MPH, NIDDK

Dr. Bavendam thanked the participants for their contributions to the meeting and noted a consensus among the group regarding the value of pursuing research on the role of NBFs in UI. She stated that consideration of non-biologic factors must be incorporated into how we think about UI across the disease course.

Dr. Star noted that the meeting highlighted the complexity of non-biologic factors and the potential role they may play in UI treatment outcomes. He suggested that there may be significant overlap and interaction between biologic and non-biologic factors in the development of UI and added that we still have much to learn about the biology involved in UI. Ms. Norton provided a brief summary of the day’s discussion. She noted that the wealth of potentially relevant non-biologic factors raised throughout the day’s discussion must be prioritized for research and that tools must be developed to measure those priority factors. She highlighted two separate efforts raised in discussion: (1) increasing awareness and knowledge of UI among patients and clinicians with the limited evidence-based information that exists and (2) researching potentially effective interventions related to non-biologic factors in UI.

Adjournment

Dr. Bavendam reported that the meeting summary will be posted on the NIDDK Web site after participants have reviewed it. If participants are interested in authoring a manuscript detailing the meeting findings and recommendations, she will establish a writing group. She thanked participants again for their participation and adjourned the meeting.