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Need for Public Health Messaging Related to Bladder Health from Adolescence to Advanced Age

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Abstract

Objective: The purpose of this analysis was to explore adolescent and adult women's interest in public health messaging around bladder health and perceptions of its usefulness.

Materials and Methods: Directed content analysis of focus group data from the Study of Habits, Attitudes, Realities, and Experiences, which explored adolescent and adult women's experiences, perceptions, beliefs, knowledge, and behaviors related to bladder health across the life course. This article reports an analysis of the "Public Health Messaging" code, which included participants' desire or need for information about bladder health and recommendations for appropriate priority audiences.

Results: Forty-four focus groups were conducted with 360 participants organized into six age groups (11–93 years). There was consensus across age groups that more information about the bladder is wanted and needed throughout the life course, as there is currently a lack of reliable educational resources. Information on bladder health was seen as useful and important because it enables people to anticipate negative changes in bladder health and act to prevent these. Several priority audiences were identified based on their risk of developing symptoms, but participants also saw value in educating the general public regardless of risk status. They also recommended education for parents and teachers who are in positions to control bathroom access.

Conclusions: Results indicate a uniform desire for information on women's bladder health and a need for more research to develop individual prevention strategies and public health messaging for women of all ages, as well as guidance for organizations with a role in supporting bladder health.

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Introduction

AN ESSENTIAL PUBLIC health service is to “communicate effectively to inform and educate people about health, factors that influence it, and how to improve.”¹ Effective messaging can motivate individuals to change their behavior and communities to adopt policies to promote positive health behaviors and shift social norms. Bladder health is an important component of individuals’ overall health, yet its role is not fully appreciated by most health care professionals or the general public.²

Lower urinary tract symptoms (LUTS), such as urinary incontinence and overactive bladder, are highly prevalent among women in the United States, with considerable cost and negative impact on quality of life.^{3,4} Effective treatments exist, but many women with LUTS do not seek treatment or delay care for years.^{5–11}

In recent years, LUTS research has expanded beyond the traditional paradigm of disease mechanisms and treatment to include a focus on prevention, including elucidating risk and protective factors.¹² As evidence emerges on how to reduce the risk for LUTS, effective public health and clinical messaging will be a priority for population-based primary prevention strategies to promote healthy bladder habits. Increasing awareness about bladder health would help promote secondary prevention through earlier treatment seeking before progression to severe LUTS. Often public health messages are developed by health care professionals with limited input from intended audiences,^{13,14} leaving a gap in the literature regarding women’s desire or need for bladder health related information and preferences around public health messaging.

The purpose of this analysis was to explore adolescent and adult women’s interest in public health messaging around bladder health using focus group data from the qualitative Study of Habits, Attitudes, Realities, and Experiences (SHARE),¹⁵ which explored the perspectives of a diverse sample of women across a broad age range recruited at seven U.S. sites.

Materials and Methods

Overview

We conducted a directed content analysis of qualitative data from the SHARE focus group study. SHARE is a qualitative study of the Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium, a transdisciplinary network established to expand research related to the prevention of LUTS and the promotion of bladder health in adolescents and adult women.¹²

The SHARE study used focus group methodology to explore adolescents’ and adult women’s experiences, perceptions, beliefs, knowledge, and behaviors related to bladder health and function across the life course. The full protocol has been published elsewhere.¹⁵ This article reports an analysis of two subcodes of the “Public Health Messaging” code, “participants’ desire or need for information about bladder health” and “appropriate priority audiences.”

Participants

Participants ($N=360$) were adolescent and adult women recruited from the communities surrounding each of the seven PLUS centers using a variety of methods, including flyers, social media, email, and referral by community partners. Applying a life course perspective,¹⁶ participants were organized into six age categories: 11–14, 15–17, 18–25, 26–44, 45–64, and 65+ years. Participants were included without regard to LUTS status.

The study was approved by the University of Pennsylvania Institutional Review Board (IRB), the central review board for six of the seven centers, and a local university IRB at the remaining site. All participants provided informed consent.

Procedures

Forty-four focus groups were conducted between July 2017 and April 2018. Sessions were facilitated by female moderators with standardized training in qualitative research principles and the SHARE study protocol.¹⁷ Each session followed a semistructured focus group guide informed by the PLUS conceptual framework, based on the social ecological model.¹⁸ The guide covered the following domains: healthy bladder beliefs/attitudes, bladder knowledge acquisition, LUTS experience and care seeking, terminology, and public health messaging. The focus group sessions were audio-recorded and transcribed verbatim.

Data Analysis and interpretation

Focus group transcripts and field notes were entered into Dedoose.¹⁹ Guided by a four-member interdisciplinary team, the iterative analysis process used consensus building, involving (1) memoing transcripts,²⁰ (2) using directed content analysis to formulate *a priori* deductive codes derived from the focus group guide, and (3) identifying emergent inductive codes.

For the current article, a second layer of data analysis and interpretation was conducted using the “Public Health Messaging” code, derived from discussions in response to the following questions: “We are thinking of developing some programs to inform the public about bladder health. Do you think people will be interested in this type of information? Would the information be useful?”

The directed content analysis was conducted by the authors using a transdisciplinary lens. Following a life course approach, excerpts were organized into the six designated age groups. Initially, the lead author identified and categorized emerging subcodes, which were reviewed and consensus reached by the investigative team. Working independently of one another, pairs of investigators used a deductive process to assign segments of text to the appropriate subcode within each age category. The coding was reviewed by a third coder who reconciled discrepancies and produced the final body of excerpts for each subcode. At the conclusion of the analysis phase, the investigators used a life course perspective to characterize and contextualize participants’ views. This article reports on results from two subcodes, desire for information and target audiences.

Results

Characteristics of the sample

The 360 participants ranged in age from 11 to 93, with a mean of 45.8 years (Table 1). The sample was diverse with respect to race and ethnicity. The majority (69.5%) were urban dwellers while 17.3% were suburban, and 13.2% were rural. Regarding LUTS status, 76.4% reported at least one symptom.²¹

Desire for information on bladder health

Across the life course, participants uniformly endorsed the view that more information on bladder health is wanted and needed, noting a lack of information and education on the topic. They perceived that most people do not have much knowledge about the bladder and have not received guidance on what is considered healthy. (Summary of excerpts in Table 2)

*I think yes (information is needed) because **I don't think a lot of people know what happens to your bladder** when it is affected, or how your bladder can get affected or how to keep your bladder healthy. So, it would be useful for, to know about your bladder. (11–14yrs)*

*Well, I would say nobody tells us it's all kind of things about how to keep our bodies in good shape when we get older, **nobody tells how to keep our bladders in good shape** (group in agreement). (45–64yrs)*

TABLE 1. CHARACTERISTICS OF PARTICIPANTS (N=360)

Age years, mean (SD)	45.8 (21.6)
Age years, range	(11–93)
Race, n (%) ^a	
White/Caucasian	145 (40.3)
Black/African American	114 (31.7)
Asian	5 (1.4)
Some other Race/Ethnicity	75 (20.8)
Participant did not answer	23 (6.4)
Ethnicity, n (%)	
Hispanic, Latina, Spanish	117 (32.5)
Geographic, n (%)	
Rural	45 (13.2)
Suburban	59 (17.3)
Urban	237 (69.5)
Missing ²	19
Language spoken at home, n (%)	
English	280 (77.8)
Spanish	75 (20.8)
Another language	5 (1.4)
Lower urinary tract symptoms, n (%)	
Frequency	100 (27.8)
Nocturia	85 (23.6)
Incontinence	81 (22.5)
UTI	187 (51.9)
Any LUTS ^c	275 (76.4)

Source: Williams et al.²¹

^aThe question about race allowed participants to denote multiple races, such that the percentages do not always sum up to 100.

^bBased on responses to individual items of the LUTS Tool questionnaire (for adults) and the ICIQ CLUTS Survey (for adolescents).

^cAny LUTS was defined as endorsement of any of the four LUTS items (frequency, nocturia, incontinence, and UTI).

LUTS, lower urinary tract symptoms; UTI, urinary tract infection.

Participants noted that traditionally, conversations about bladder issues rarely occur between parent and child.

*A lot of parents don't talk to their kids about you know bladder health. I don't remember my mom sitting me down. **Dear, let's talk about bladder health.** (45–64yrs)*

*Unfortunately, we had more mothers who were very reserved, and until this date they were reserved, died being reserved and **never communicated** information with us, for example the bladder. (65+yrs)*

Personal experience was often described as a primary source of knowledge about bladder health. The lack of information seems pervasive unless an individual has a problem with her bladder and seeks input—“Until it happens to me.”

*I didn't know any of these things could happen **until they happened to me** and now, I heard other people's stories. (26–44yrs)*

*I feel like you get all your potty training in when you're younger and then you don't really get much information until you make it to your 20s, where you either have a new kid or **you have your first UTI, you have like some sort of problem** and then you get an education. (26–44yrs)*

While information is available about a variety of other health topics, information on bladder health is seen as lacking, even in encounters with health care providers.

*If you think about it, there is a lot of information about every other major organ in your body like the brain, heart... most of your organs there's like a lot of research done and studied, like, preventative care, to prevent like certain things about it. And **for the bladder we don't have that... you don't really know how to keep your bladder healthy.** (18–25yrs)*

*I don't recall a doctor and I go yearly or more often since I've had a birthday this year, but **I don't remember a doctor ever discussing bladder health, what to do.** I don't recall ever having even discussed bladder. (65+yrs)*

Participants cited a lack of accurate, fact-based, comprehensive educational resources about bladder health and articulated limited awareness of where such reliable resources would be available.

*I feel like a lot of us have heard this or that from this person or that person and there's **not really been just like a main source** of you learn this from your school or from your doctor; you know it's just kind of a piecemeal on where you find all your information... I don't think any of us are 100% certain on the information that we have if it's really correct or not. (26–44yrs)*

*Growing up it would have been nice if someone had said, hey listen, if you do have something, you do have some issues, **here's a great resource** because sometimes we're doing web and Internet searches and things that aren't, they're, they're not fact-based, they're just, they're inaccurate and they're blogs and things like that. (26–44yrs)*

Participants expressed reasons for needing bladder health information, such as having the ability to anticipate changes in bladder health, being prepared for the potential for bladder problems, and knowing how to take action to prevent them. It is “better to learn before something happens,” and “knowledge is power.”

***The more aware you are of the information, you'll recognize the signs** before something becomes too terrible. ...you can kind of, **you can catch those problems before they would occur.** (26–44yrs)*

TABLE 2. DESIRE FOR INFORMATION BY THEME AND AGE GROUP

Lack of Information, Education, and Communication: People Don't Know Much About the Bladder

Ages 11–14

*I think yes (information is needed) because **I don't think a lot of people know what happens to your bladder** when it is affected, or how your bladder can get affected or how to keep your bladder healthy. So, it would be useful for, to know about your bladder.

Ages 15–17

Like I said, it, this like bladder, **bladder control and like bladder problems should be taught like at a certain age** and I know in a lot of high schools like PE class, **they don't teach that stuff**.

In my school...the only people really learning about things that go inside, of your body are the medical majors and I'm not a medical major so **how am I supposed to get that information?** Like I'm not going to track down a medical major and be like **what do I need to do to have my bladder healthy, like tell me now**. So, like I feel like **there's just no concern in schools to have it taught**.

Ages 18–25

*If you think about it, there is a lot of information about every other major organ in your body like the brain, heart... most of your organs there's like a lot of research done and studied, like, preventative care, to prevent like certain things about it. And **for the bladder we don't have that... you don't really know how to keep your bladder healthy**.

If I saw a pamphlet, I'd probably pick it up because **you never see any with bladder health, so I'd be like oh, this is interesting**. I don't know enough about it. I would pick it up.

Like in the context of like health class, like sexual, like understanding your sexual health, understanding your bladder health, you know it kind of like hangs together and makes sense. **That would have been a nice time to learn about that**.

Ages 26–44

I think that we've all kind of agreed that like **none of us really learned why bladder health does matter really**, you know?

... we talk to the girls about sex. We talk about menstrual cycles. We talk about dating, **but we don't talk about bladders**.

It's about like shaving and your menstrual cycle and you know things like that, **but I don't recall ever seeing anything about bladder health**.

One of the benefits when you're putting things out there on websites or whatever would be that **there isn't a lot of information on bladder health**. So, if you decide that you want to make your website, there won't be a lot of places... you can become the definitive source that people would go to.

They have not talked about this topic (in workshops at school), they have never...

I don't recall ever seeing anything about bladder health, anything like that because I bought my daughter one of those books, but it didn't have anything like that in there. It'll be nice to add something like this to one of those kind of books.

*I feel like a lot of us have heard this or that from this person or that person and **there's not really been just like a main source** of you learn this from your school or from your doctor, or from; you know it's just kind of a piecemeal on where you find all your information from and we don't, I don't think any of us are 100% certain on the information that we have if it's really correct or not.

*Growing up it would have been nice if someone had said hey listen, if you do have something, you do have some issues, **here's a great resource** because sometimes we're doing web and Internet searches and **things that aren't, they're, they're not fact-based**, they're just, they're inaccurate and they're blogs and things like that.

*As we all have acknowledged that **there's kind of fuzziness about what could happen except with our own personal experiences**. Like I didn't know any of these things could happen **until they happened to me** and now, I heard other people's stories.

I would also like it if there were programs, where to go and learn what the bladder is, and how we should know more about it; because as it is, well, no, **none of us have knowledge about that** and how she said it, where do we go to learn?

Ages 45–64

Well, I would say nobody tells us it's all kind of things about how to keep our, our bodies in good shape when we get older, **nobody tells how to keep our bladders in good shape** (group in agreement).

As you can tell, **nobody's talking to us about it**. we're all saying nobody's mentioning our bladder, no matter what we say on the questionnaires for health and that's coming back about our bladder.

There's no health class in high school anymore and a lot of **parents don't talk to their kids about you know bladder health**. I don't remember my mom sitting me down. Dear, let's talk about bladder health. No.

I go to internal medicine doctor and **I don't see**, I see more stuff about arthritis and those kind of things because you know I'm 57 so it's more elderly you know but if I go to my GYN doctor, she's still you know, still woman of baby bearing age, I see a lot of stuff there about bladder and you know anything but when I go my internal medicine, it's usually arthritis, memory, stuff like that, you know.

(continued)

TABLE 2. (CONTINUED)

*Lack of Information, Education, and Communication: People Don't Know Much About the Bladder***Ages 65+**

*Unfortunately, we had more mothers who were very reserved, and until this date they were reserved, died being reserved and **never communicated** information with us, for example the bladder.

*I don't recall a doctor and I go yearly or more often since I've had a birthday this year, but **I don't remember a doctor ever discussing bladder health, what to do.** I don't recall ever having even discussed bladder.

I was brought up we didn't like go to the bathroom. You didn't say pee or anything like that. [One other in agreement.]

You just were not allowed to talk about it.

We don't have the knowledge of it. It's not discussed unless you're going to a urologist or you're doing some really having an issue you're not aware of it.

We're still sitting back all these years later and **we're not talking about bladder issues**, which obviously I'm beginning to think the vast majority of women end up with some way or the other.

*Information on Bladder Health is Wanted, Needed, and Important***Ages 11-14**

I agree with everything that she said (that information about bladder would be useful), because **some people don't know**, like, when it happens to you, so and then they have, that **would be a good thing for people.**

Ages 15-17

Maybe we should have like a lesson in school on it maybe because the way we learned about it, it's just another organ, but **we need to go deeper into it** so maybe other people can understand other people's needs.

I think this type of thing would go into school... like **to make people more concerned** about it, **I think it would be beneficial.** Like this but condensed into a class period time would be **very beneficial.**

Ages 18-25

I think knowing the difference between a healthy and unhealthy bladder... just raising awareness of what to look for because like I said earlier, I take it for granted that I'm healthy, so I think ... **that would be helpful.**

I think it would be a good idea, like, for me when I had my first UTI, I realized I needed to go to the doctor because I Googled it and like that's not healthy and like my roommate's like I've, like, told them about it and now they like know when they need to go to the doctor. But **that shouldn't be how information is distributed.** Like it should be coming from like a reliable source.

Like for us, **I think UTIs would be great to have information** that's very easy to remember and like straightforward. **There should be posters about bladder**, like how many times you should use the bathroom or signs of something that something is wrong, how many cups of water we should drink a day and just important facts about it **I think would be helpful.**

I think just sort of a **general bathroom health would be comprehensive and helpful.**

A poster in the bathroom about your bladder when I'm drying my hands would be **so helpful.**

I can't speak for everyone, but I feel like **a lot of people I know would kind of write off** that kind of program as something that's **not really targeted to them...** that's you know just for old people or whatever.

I know it's not true but my gut reaction or my emotional reaction to that term thinks of older people and like Depends and pantyliners, so and **it's easy to write it off because thinking about bladder health is kind of scary sometimes, so it's not my problem**, it's someone else's problem and I don't have to worry about it.

Ages 26-44

Women do want more information about bladder health.

Teach us the harms obviously of, like, what process to hold it or what are the process if you don't take care of your bladder?... I'm sure I **would be interested to learn about.** Like I'm still kind of **not sure what happens** to the bladder, so.

I think that just basics like you were saying just like basic dos and don'ts, so of bladder health would be **really, really useful for most women.**

Oh, my gosh. But we need to, that's the thing. **We need to talk about it.** That's the only way we can **break the stigma** is where we have open and honest conversations about it and we won't let people shut us up.

I would **like it if they could talk to us** about, um, everything. From how to take care of it and what are the first symptoms when one is not doing well and all of that, **so one can know and take care, take care of our kids.**

I would like it if they offered workshops like this one, very similar, as you are seeing, listening and learning because questions come out and, do you know? It happened to me, I know somebody.

I would like [to have] a workshop like the one we are in, sharing, right? From the experiences of all and, [get] a little bit more of deep information.

This is why I think that it is **necessary that somebody comes who could give us answers** to the questions.

I think it would be interesting to develop a program **to get the word out.** I think people don't really think about it or don't really talk about it until it is a problem.

You got to keep this and you got to (give) **more information the better**, so don't, we should not always assume that oh, their parent's going to tell them... So I think **more information the better** and when it's presented, it will cause a lot of you know you'll be more aware of instead of waiting till it gets ...

Some people are going to, that have problems, are going to probably go full force, but some **people that don't have problems and, they're not gonna feel like they have any reason to go to one of those.** They're going to be reluctant because it's something that's just like hush hush. But I think **it's very much needed.**

(continued)

TABLE 2. (CONTINUED)

Information on Bladder Health is Wanted, Needed, and Important

But I would say that in general, there are **very few ways that you could advertise it that would make the average person who does not have a problem interested in that kind of information.**

Just let everybody know generally how important it is to have a healthy function of a bladder because... I think, awareness and all that general good information on a lot of different topics associated **would be really good** but, you know, some kind of way breaking the ice, because like I said, I've seen it work with people. They are so reluctant when it comes to that.

People may feel reluctant if people don't have problems, it's "hush hush"; it's not on people's "radar" to care about it right now but **education is needed.**

Yes. I think, I think people who are in need of the information will find it useful and ... that people who think that it doesn't apply to them may at least **know that the information is out there**, so once it does apply to them, it then becomes useful.

Ages 45–64

I think **people want to know more** and I think where it triggers is after you have a child. I think that's where we all are like whoa, **nobody told us this was going to happen.** I think that's where we all start to think, saying **we need to find out more information** about this, even though people haven't shared it with us.

I think we need more of it but the problem is getting us out to something.

But I think that there **obviously needs to be more education across many different levels.**

Ages 65+

I think they (people) would (be interested in learning about bladder health), especially if they have a problem...

But **I think that it is so important to know about the bladder**

I think it **definitely should be in the curriculum in health.**

We're... not talking about bladder issues... So, it's like hello, people, wake up, it's the 21st century.

Speaker 2: Exactly.

Speaker 1: **Let's get it out there.**

Speaker 3: **Let me hear about it.**

It is so **important to know about the bladder...**

Why It Is Important to Have Information on Bladder Health: Preparation, Prevention, and Helping Others

Ages 11–14

I mean, yeah, because it's **really important** part because you have all the dirt, and the bladder helps you release that dirt that's in your body? ...So helps you like have a relief and like feel healthy.

Ages 15–17

How can I make my body healthy? What can I do? Like what fruits and stuff can I eat to make my body healthy?

Ages 18–25

I think another important thing with getting information out there and making sure that people have access to resources is kinda getting rid of rumors or **misinformation.**

Ages 26–44

I would like it if they could talk to us about everything. From how to take care of it and what are the first symptoms when one is not doing well and all of that, **so one can know and take care, take care of our kids.**

Well, I think as they are saying that it is good that the kids receive education at school regarding this, but also us, as adults, because that way **we could take care of them** and be paying attention to what they are also doing. Because when we don't know, they say, this is normal.

because ...it affects everything. Like you can't do anything if your bladder's not right, you know, you might not have a problem with it today but it's not to say you might not have, **might have a problem tomorrow.**

***The more aware you are of the information, you'll recognize the signs** before something becomes too terrible. ... you can kind of, **you can catch those problems before they would occur.**

So that might be something to tailor toward the girls and say, you know, this is something, it's more "normal." I know it happens to a lot of people and talk about what it might feel like and what girls can expect and **so that they're not afraid**, like you said, when you had your first one and you had no idea that was even possible.

...very basic information that **can be preventative**, as opposed to treating the problem, but I think a lot of women would benefit from.

Ages 45–64

We all go, right? We all got to pee. **And this is why it's important** because it's - I think it's just kind of like this invisible thing that we just do and don't pay attention to.

You know we're talking about you know menopause and leaking and incontinency. I went through early menopause.

I didn't have that information. I was 47. I've been going through this for quite some time now. You know so it's just **good to have that information** you never know what new medical information comes along. That's just good to have it, I think.

I just think that you know the more we know and the more we **share with even younger women** ... the more we know and the more we share and not be embarrassed to share, it'll **help other people.**

(continued)

TABLE 2. (CONTINUED)

Why It Is Important to Have Information on Bladder Health: Preparation, Prevention, and Helping Others

Ages 65+

If you have the knowledge of that and you prevent it, what you can do to help the situation I think most people would take advantage of that. We don't have the knowledge of it.

I would say just be more aware of taking care of your bladder... I think we can maybe with, with having the awareness that we can maybe help some others along the way, and that's what life's all about is helping others.

It (workshop) could be at the schools or the high schools, like that, so they take care of their bladder and they know everything before they get to our age. Maybe we have suffered many things because we did not know anything, right? ...how is it going to help me? Well, it's going to help me because I'm going to, know when my bladder burns is because I'm not doing this, this, and that.

I just think that knowledge is power and the fact that you put the information out there, whoever wants to is going to read it, and those who don't want to are going to know it's available when they finally get hit in the head with it. So, you know, I think anything that you can do to enlighten people, because it's almost been like, you know, that unspoken problem that we females have.

You don't wait until you're 40 or, or 60 to suddenly discover the problem. Prepare yourself and start protecting yourself, just like now everybody knows about the nefarious effects of salt, you know?

*Indicates quote included in the text.

You don't wait until you're 40 or 60 to suddenly discover the problem. Prepare yourself and start protecting yourself... you know? (65+ yrs)

We know we have problems sometimes, but we don't know what makes it (the bladder) tick, what makes it do this or that. If you have the knowledge of that and you prevent it, what you can do to help the situation I think most people would take advantage of that. (65+ yrs)

Priority audiences for bladder health messaging

Participants identified a broad range of population groups as potential recipients of bladder health education. They articulated a desire for age relevant information and expressed a need for education directed to individuals in other life stages. There was an overarching emphasis on disseminating bladder health information to individuals at both ends of the life course—older adults and young people.

Older adults were perceived as having a higher frequency of bladder problems, representing a population of women who potentially would welcome and use the information (Summary of excerpts in Table 3).

This tends to happen a lot when people get, tend to get elderly, they tend to lose the ability, like, they can't control their bladder anymore and it just comes out. So it happens also in elderly people not just, you know, teens or kids or adults. (26–44 yrs)

I think they (people) would (be interested in learning about bladder health), because especially the seniors because as we get older, we wasn't taught that, we weren't taught at a younger age about bladder... (65+ yrs)

Participants also suggested directing information to individuals who serve in caregiving roles for older adults, where being informed can foster their sensitivity to the bladder health needs of care recipients.

I always felt that a caregiver should be trained a little bit more also in taking care of elderly people and maybe you know through the program as a caregiver to get that information when they going to be trained to do caregiver about the body and the bladder. (65+ yrs)

Across age groups, a dominant theme was that young women, adolescents, and children should be taught about

bladder health. Younger age groups were considered priority audiences because they are in formative stages of development, and having the information early could potentially prevent future bladder health problems.

I think that we must start with, with the youth, with the young girls, with the girls so they speak up, they speak up if they have something wrong, what is happening to them and all of that, right? (65+ yrs)

Why don't they organize workshops for the kids, the youth? That girls who are twelve, thirteen years old. ...so they take care of their bladder, and they know everything before they get to our age. Maybe we have suffered many things because we did not know anything, right? (65+ yrs)

Adolescents were considered an important audience for bladder health information, in part, because of the risks they may face related to sexual activity and urinary tract infections.

...when you're 10, 11, or 12, but you know it so that way down the line when you are becoming sexually active, (26–44 yrs)

...it would be really beneficial to get more information out when you're like 14 and 15. So then you're more informed, you kind of know what's going on, right? Before you have something go wrong. (26–44 yrs)

Other priority audiences were identified because they are situated in positions to convey the information to children and adolescents. Participants thought that parents should be informed, so that they could teach their children and grandchildren about the bladder.

I think it would be great to start especially with like the younger group, educating the parents along with the children. (45–64 yrs)

To please... provide resources to educate parents on how to talk to their children about the bladder. (26–44 yrs)

There was a pronounced desire among adolescents and young adults for those in supervisory and/or gate keeping roles to be informed about bladder health issues to sensitize them to students' needs for access to school bathrooms.

I think our teachers really need to know about the bladder and stuff, because they don't really know how, like, it can affect you. (11–14 yrs)

TABLE 3. PRIORITY AUDIENCES BY THEME AND AGE GROUP

Across the Life Course: From Childhood to Older Adulthood

Ages 11–14

Like tweets and stuff like that for like **little kids**, like, you could have like this little fun little toy that give it to them and like it has a note and it says like fun fact.

And then when they like touch the little pad, they gives out facts and some kids do read it, some kids don't because they don't like to read. But yeah, you can like give out little facts, like, on a little screen or something like that. And **then the kids would know**, like, you can do such and such to help yourself, and like good hygiene stuff like that

I think that like **kids my age** like phones ... So then it's like, it's like forcing you to learn more about your bladder, but at the same times it's like so you can get a picture.

It should be like on social media since **teenagers** these days use social media so much.

Ages 15–17

Teach me how I can make my body healthy besides running around playing kickball... A lot of kids don't know so they don't want to make it better.

Ages 18–25

You could easily develop an app or something that you could, also more with like bladder.... And then it **targets like our age group and like even people that are younger**.

Also, like health **programming in schools**, that's a decent way. It's probably not super complicated stuff, so you could probably hear about it as a **15-year-old** and like retain it then just now, and that's not gendered.

One of the other things to consider is for more of the long-term, incorporating it into sex ed and kind of **health classes** as well. 'Cause you're already learning about your reproductive system and all these other health aspects with your body and it kinda just makes sense to incorporate the bladder as well.

... with **older people** you may be trying to target more like incontinence and stuff and there would be different ways to administer that information to them or us, like, it would be beneficial to have like an article or like through social media or something like that.

Ages 26–44

Like start **teaching children when they were little**.

*...when you're **10, 11, or 12**, but you know it so that way down the line when you are becoming **sexually active**...

Yeah, I think **kids in schools** could be really powerful way.

I think it's important, especially if you're in a, I think your idea is super, but that **pre-teen**, like that age group I think is really powerful. But I think at that age, you have to make it fun.

Put it on social media. That's going to **reach the young folks**. That's going to, every, they're all on social media. Yeah, actually, I can't knock it because that's how I found out about this group but I think the, **the younger** we can reach them, the better.

*I feel like you get all your potty training in when you're younger and then you don't really get much information until you make it to your 20s, where you either have a new kid or you have your first UTI, you have like some sort of problem and then you get an education, then it would be **really beneficial to get more information out when you're like 14 and 15**. So then you're more informed, you kind of know what's going on, right? Before you have something go wrong.

Most of the women in my family don't have children for reasons we won't get into but we all suffer from stress incontinence. I think it's important to get this information out at **younger ages** like when we learn, like **health class** in junior high. Do they even do that anymore? ...but I think we need to get the information out at a **younger age**.

I think the way to go would be through social media whenever they have those like pop up ads about like something you don't necessarily care about but looks cool. I think that would be like easy for **like young people** to click on, especially **like girls who haven't even started going to the OB yet**. Like I got my first umm UTI before I even got my period. So I didn't even go to the OB at that time. I talked to my mom about the UTI...

I mean, whether that would be something that we could do for kids who are you **know junior high like puberty or if you're pregnant** and this is a resource that maybe is on a pamphlet when you're at the **gynecologist or prenatal care**.

For me, I met <her> at a **hospital new moms group** and so I would start there because you have a bunch of women who are **probably experiencing bladder control issues** and they're, at that point, willing to hear and discuss their problems in a safe hospital setting.

Well **now you've got your baby** and oh, by the way, here's this class that's free of charge from whatever hospital that you're at.

*This tends to happen a lot when people get, tend to get elderly, they tend to lose the ability, like, they can't control their bladder anymore and it just comes out. So it happens **also in elderly people** not just, you know, teens or kids or adults. you would have to add, in my opinion, for the **older generation**... **But** I mean I would think you would need to talk to the **older generation** to kind of, I don't know how they get their information, I mean do newspapers still exist? You know what I'm saying?

Ages 45–64

Talking to someone about what's going on with your bladder is, is a good thing to, and also, **when you have girls, teach your girls**. You must teach, teach your girls from little coming up not to hold yourself you know.

The **teenagers** and the **young women**. Yes, it would be important [to have] a meeting like this one for them, so it is explained to them as well how important it is to take care of the bladder.

(continued)

TABLE 3. (CONTINUED)

Across the Life Course: From Childhood to Older Adulthood

*I think that it should be part of what you are told **when you are pregnant**. From the **moment you get pregnant**, you should be told that this is a potential problem, is gonna be a potential problem for you so you can start doing those exercises early so that all the tissue doesn't relax and then you have the problem. So, if you start with the exercises early, you shouldn't have that problem afterward.

*I didn't realize that this was gonna happen to me, you know, **as soon as I gave birth** and this was gonna be, you know, something that happened to me afterward. But I think most people, my impression is **most people have a high chance of this happening to them**. And so I agree with you, **this should be part of the pregnancy**.

Ages 65*

...how to pass on the information to our **children, to our grandkids**, so they are prepared for life. Because it is a preparation for life for them, so, we are a bit behind but, well, there we go [laughs].

To have, an open conversation with the, **children and grandchildren**, to be able to have more information to give them and even if we don't have it, well, us be able to... teach them.

*I think that we must start with, with **the youth, with the young girls**, with the girls so they speak up, they speak up if they have something wrong, what is happening to them and all of that, right?

*Why don't they organize workshops for the **kids, the youth**? That girls who are **twelve, thirteen years old**, who easily pick up an infection because they are not careful when going to the restroom, or "other," right? To have it explained to them very well.

Yes, it should be. So that maybe the children know when someone speaks to them about it. Oh, I, I remember hearing that. I think it **definitely should be in the curriculum in health**.

And I think **young women** ... who are **pregnant** should be immediately - - You don't wait until you're 40 or, or 60 to suddenly discover the problem.

*I think they (people) would (be interested in learning about bladder health) because **especially the seniors** because as we get older, we wasn't taught that, **we weren't taught at a younger age about bladder**, but now we was not taught, so I think never too late to learn and I think majority of us in here have a problem with our bladder.

Parents, Teachers and Caregivers, Health Professionals

Ages 11-14

*I think our teachers really need to know about the bladder and stuff, because **they don't really know how, like, it can affect you**.

Like, or like just calling people, or like meeting up with them someplace, I don't know, or like sending information to **their parents or to their doctors** and being like Ella's having a problem with this, can you talk to her about it or something?

Ages 15-17

I think **teachers don't understand** that (we need to use the bathroom)...like they really need to be more lenient and more understanding of our health and what we actually need to do to maintain a good healthy body.

Ages 18-25

I mean if I'm in like lecture hall at school and, like, you know, if we're having, like, a long lecture about important topic if my professor sees that you're getting up (to visit the restroom), he'll call you out. He'll be like where are you going? **They don't understand**.

Ages 26-44

*To please ... provide resources to educate **parents on how to talk to their children** about the bladder.

I would like it if they were to give a class to the girls, **including a teacher** from, from pre-kinder to eighth grade...when they are 8, 9 years old, because they hold it in, in that, in that if they raise the hand, or they say, 'I need to go to the restroom'...they don't, don't take you into account or they say, 'that is what the recess is for,' or things like that and the **girls are very much harmed**...

I think that I like what her **parents** did to her, like, they made her a routine for her, so that would be really nice. Like, now that I think about it, like, I would do that with my girls, my little girl. Make her routine about going to go pee - -

Moderator: So we'd need to **teach the parents** what to teach the kids?

Yes.

Well, I think as they are saying that it is good that the kids receive education at school regarding this, but **also us, as adults**, because that way we could take care of them and be paying attention to what they are also doing. Because when we don't know, they say, this is normal.

I think that is a good way to get it out as well as you know **parents and the health person**, They're like when you wipe, wipe front to back.

I don't know. It's been a long time for me but and, of course, **gynecologists and midwives**. Anyone who deals with women's health.

Ages 45-64

*I think it would be great to start especially with like the younger group, educating the **parents along with the children**, but I think there should be a tiered kind of level.

I think the **primary care doctor should be trained more** to bring up that issue because they do ask you about bowel movements but never about your bladder, so I don't see; that's just one small step. You know if they're already, already asking you that question, why don't they ask you about your bladder?

(continued)

TABLE 3. (CONTINUED)

Parents, Teachers and Caregivers, Health Professionals

Ages 65+

If you ... **send it to the parents** for them to have the obligation to talk to them too, enroll the parents, enroll them. I think educating the **parents** first ... **if a parent knows**, and let's talk about this a little bit so that when if it does happen to you, this is what you can do it but let's, let's try to get not to, not to happen to you. So I think, I think in communities, we call it go ahead and educate the **parent**.

*I always felt that a **caregiver** should be trained a little bit more also in taking care of **elderly people** and maybe you know through the program as a caregiver to get that information when they going to be trained to do caregiver about the body and the bladder.

...so this is a good way to get the information out there, do the study, talk with maybe whoever their **caregivers** are, and keep them encouraged, motivated, and let them know hey, it's going to happen to all of us, that we do have accidents, and don't make yourself feel bad

All Women and the General Public

Ages 11–14

Just like through school and social media because a lot of people just use social media.

Ages 15–17

*I think that people may secretly want to know, so it would be helpful for those that like don't want to mention it but are curious.

Ages 18–25

*... but it's an issue for everybody. You know, **everybody has a bladder**, so if they did come up with something, you know, promoting bladder health that it needs to be **universal** for both genders and it needs to be made more normalized... You know, make it more prominent and more relatable to everybody.

I think it could also be something that like during a **yearly physical** that a doctor could bring up and say as opposed to like asking questions that may relate to bladder health, but you don't necessarily know that they relate to bladder health, like clearly saying like and how is your bladder health and kind of explaining various things that you know could be educational for them.

Maybe there should be **more health campaigns** on bladder health because like we do see a lot of you know campaigns, I guess try to **educate the public** about cancer or about like STDs, things like that, but nobody really ever thinks about bladder health. So if there was more initiatives like for the **community health initiatives** to target.

I was about to say radio, too... and I think podcasts would actually be a really good place, too, because you're **targeting a population** that's most likely listening to something because they want to learn already, and so they're already open to hearing about that.

Ages 26–44

*I'd make it; most young women who are healthy people, **healthy women** will go to a gynecologist every year, so that could be a way just to educate or have like posters or brochures in the waiting room for that in that office.

I know that there's a lot of good information out there for people, **whether or not that they have problems**.

*I think people who are in need of the information will find it useful and similar to <her> point that **people who think that it doesn't apply to them** may at least know that the information is out there, so once it does apply to them, it then becomes useful.

Every single runner that I've ever come into contact with at least talks about bladder issues directly related to running, so I think that would be a good space to, to reach people who would be affected by bladder issues.

I would say signage inside bathrooms at state fairs would be a pretty good route because everyone, you know it's like how do you reach a **variety of demographics** something like that that it's not just hitting one type of group? You want to hit people of **different socioeconomic** income levels and everything.

The **more people** we can reach, the better...

Ages 45–64

Yes, to inform **restaurants and stores** when they don't let us go in [to their bathroom], that it could also happen to them. They're in their own business, but if they go elsewhere, I don't think they'll go back to their business to go to their bathroom, right? So, inform them that it's a necessity;..

I just attended a back-to-school event... and they had a **medical van** where you can have physicals and vaccinations...

And I think using that kind of as a community benchmark to get with **both the young set and the adults**, so you're kind of hitting two nails with one hammer, ...and ultimately I think **community events**. ...but I do think community events really, really work and they, they get a **lot of population**.

You know it would be great if **every doctor could change their practice** and make sure that they were communicating that to **all of their patients**,

Ages 65+

*You know, **every young woman** at some point has her first female exam....You know, either by her primary care or who, OB, and I think that's the ideal place to start. ... You know? And now you're a woman, let's look at this whole picture, you know?

*Indicates quote included in the text.

For adult women, the emphasis was on the need for bladder health information for pregnant and postpartum women, because they are more likely to experience symptoms and it may be the first time young women experience changes in bladder function.

*From the moment you get **pregnant**, you should be told that **this is a potential problem**, is gonna be a potential problem for you so you can start doing those exercises early so that all the tissue doesn't relax and then you have the problem. (45–64yrs)*

*I didn't realize that this was gonna happen to me, you know, **as soon as I gave birth** and this was gonna be, you know, something that happened to me afterwards. But I think most people, my impression is **most people have a high chance of this happening to them**. And so I agree with you, **this should be part of the pregnancy**. (45–64yrs)*

Although participants spoke of particular groups that could use bladder health education because they were at risk for experiencing symptoms, there was also a desire for healthy, asymptomatic women to receive information during routine health care visits, for example, yearly physical examinations, pap smears.

*I'd make it; **most young women** who are healthy people, healthy women will go to a gynecologist every year, so that could be a way just to educate or have like posters or brochures in the waiting room for that in that office. (26–44yrs)*

*You know, **every young woman** at some point has her first female exam. You know, either by her primary care or who, OB, and I think that's the ideal place to start... (65+yrs)*

Some participants took a more universal perspective that included bladder health education for men, as well as women, all age groups, and all demographics, regardless of whether they are experiencing bladder symptoms, noting “Everybody has a bladder.” They saw benefit in educating the general public through community events and health campaigns and reaching people who would not otherwise seek information on bladder health.

*... but it's an issue for everybody. You know, **everybody has a bladder** so if they did come up with something, you know, promoting bladder health that it needs to be **universal for both genders** and, it needs to be made more normalized... (18–25yrs)*

*I think that people may secretly want to know, so it would be helpful for **those that like don't want to mention it** but are curious. (15–17yrs)*

While acknowledging that some women may not be interested or receptive to education on bladder health, participants thought it was still important for them to know that information is available when they need it and where to find it.

*Yes. I think, I think people who are in need of the information will find it useful and... that people who think that it doesn't apply to them may at least **know that the information is out there**, so once it does apply to them, it then becomes useful. (26–44yrs)*

Discussion

In this study, we explored interest in public health messaging around bladder health among participants spanning early adolescence to advanced age. Across the life course,

participants uniformly expressed the belief that more information on bladder health is wanted and needed and would be useful in preventing bladder problems. They perceived that most people do not know much about the bladder due to a lack of accurate, fact-based, comprehensive educational resources and limited awareness of where to obtain reliable resources. While information is readily available on many other women's health topics, information on bladder health is seen as lacking, even in encounters with health care providers. For many, the primary source of knowledge about bladder health was personal experience.

While participants wanted information for themselves, many also took a broader perspective, expressing concern for other women and other generations. Younger women noted that the elderly are likely to have bladder problems and the older participants articulated a need to educate girls about the bladder when they are young. Some participants saw benefit in educating the general public to reach many individuals who would not otherwise seek information on bladder health.

Although participants lacked information on bladder health, they were aware, through personal experience and observation, of problems that can occur with the bladder. Their desire for information seemed driven by wanting to anticipate changes in bladder health, to be prepared for bladder symptoms, and be empowered to prevent them. Noteworthy was a clear desire among adolescents and young adults for those in supervisory and gate keeping roles to be informed about bladder health issues, not only so that they can convey information but also so that they can be sensitized to students' needs. As described elsewhere, based on analysis of SHARE data, some participants thought that teachers did not understand students' need to use the bathroom.²² Study participants felt that if teachers were more knowledgeable about bladder health, they would implement more bladder-friendly policies in the classroom and allow adequate bathroom access.

One reason for a relative lack of information in this area may be the stigma associated with some bladder conditions.²³ For example, there is a substantial body of literature documenting the embarrassment women experience with incontinence, the extent to which they hide their condition, and their reluctance to broach the topic with providers.^{23–26} Our finding that parents did not teach their daughters about the bladder beyond the stage of toilet training may reflect not only a lack of knowledge but also the private and sensitive nature of the condition even within the family. As with other sensitive topics, bladder health may be considered a personal matter to be handled quietly by the individual. Thus, stigma and embarrassment may deter open discussion and widespread recognition of bladder conditions by the public.

Another reason for the lack of emphasis on bladder health may be that most LUTS tend to be seen as chronic and not life threatening, despite well-established evidence of their progressive nature and associated morbidity in terms of anxiety, depression, and functional status. Thus, bladder issues may not be prioritized by busy health care providers unless brought to the clinician's attention.^{5,6,9} This is consistent with participants' reports that they lack information unless they have a problem. Unfortunately, the literature reveals that the majority of women with urinary incontinence do not even mention it to their provider.^{5–11} They often live with it sometimes for many years in the belief that it is a normal part

of being a woman or of aging and do not seek help in the mistaken belief that treatments are not available.^{24–29}

In addition to these individual-level factors, institution-level barriers exist, including lack of knowledgeable providers with expertise to treat bladder symptoms, limited professional training opportunities, provider attitudes and discomfort, time constraints, and competing work priorities.^{25,30–34} When health care providers don't ask and patients don't tell, there is a lost opportunity to exchange useful information.

While information is available to the public through online resources (*e.g.*, National Institutes of Health, National Association for Continence), and bladder awareness initiatives such as Bladder Health Month supported by the American Urological Association,³⁵ participants viewed bladder health programs as much less available and accessible than those for other health conditions. This may be because the bulk of publicly available information focuses on LUTS and their treatment rather than on prevention, a major reason that participants gave for wanting information. However, there is currently a lack of evidence to support public health recommendations around promoting bladder health. While there is considerable publicly available evidence on risk factors for more lethal conditions such as heart disease, less is known about behaviors to maintain bladder health.

The large epidemiological literature on risk factors for incontinence identifies factors such as age, pregnancy, parity, and comorbid conditions.³⁶ But there is less evidence on the role of individual-level behaviors that may contribute to the development of LUTS and what constitute healthy bladder behaviors. Multiple clinical trials have demonstrated the benefit of pelvic floor muscle exercise for reducing incontinence during pregnancy and postpartum.^{37,38} There is growing evidence that maintaining normal body weight helps prevent bladder problems.^{38–42} But meager evidence exists for the effects of other behavioral domains, such as voiding frequency, delaying voiding, toileting practices, dietary factors, fluid intake, general physical exercise, or other bladder habits that could potentially be modified or adopted.⁴³

As research on prevention of LUTS is conducted by the NIDDK PLUS Consortium and others, more information will emerge that can be used to develop evidence-based public health interventions. Findings from the current study provide a compelling argument for more research focusing on the role of potentially modifiable risk factors, including individual behaviors that could promote bladder health. Although not specifically described by participants, the findings have implications for bladder health promotion through interventions at other levels of the social ecological model. Research is needed to understand the role of institutional and environmental barriers to bladder health, as well as the effects of interventions to address these barriers, such as promoting bladder health in the health care system, providing bladder health education and training to medical professionals, improving school and workplace policies, and modifying the built environment to improve bathroom quality and increase access.

Such work is needed to lay the foundation for the development of prevention interventions, including public health messaging that educates women across the life course about how to keep their bladders healthy and informs organizations, health care providers, policy makers, and communities about their role in providing a responsive health care system and environments that support bladder health.

A strength of this study is the large number of focus groups across a wide age range and geographic distribution, including urban and rural communities and inclusion of women from diverse racial and ethnic identities. A limitation of this analysis is that it was based on a single domain of a larger focus group guide, such that there was limited time for discussion and probes for more in-depth information.

Conclusion

The consensus across age groups was that women desire more information about the bladder throughout the life course. Findings indicate a need for more research to understand individual- and institutional-level factors associated with bladder health, inform development of prevention interventions, and support broad ranging public health messaging to individuals of all ages and organizations with a role in supporting bladder health.

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