


Challenges Faced by Women With Neuromuscular Diseases When Having to Urinate Away From Home

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Abstract

The aim of this study was to investigate the challenges women with neuromuscular disease face when having to urinate when away from home. The design for this study was qualitative using the interpretive description methodology and the Sense of Coherence theory. The method was three semi-structured focus group interviews with 12 women (3 ambulant and 9 non-ambulant) with neuromuscular diseases at a specialized rehabilitation hospital. We found that physical and functional barriers hampered the opportunity to urinate when away from home due to lack of accessibility and impaired physical functioning. Psychosocial impacts were related to inconvenience and dependency on relatives, fear of stigmatization and impacted dignity, and the constant social sacrifices. The challenge of access to adequate and equitable sanitation for women with neuromuscular diseases is not always met in society, and these women consequently often must resort to repressing the fundamental need to urinate.

Keywords

nursing care, healthcare professionals, communication, bladder health, urinate, Denmark

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Introduction

Neuromuscular diseases (NMDs) are characterized as a group of hereditary, degenerative disorders that affect muscle strength and function—either directly in the muscle itself or indirectly through the motor neurons in the spinal cord, the peripheral nerves, or the neuromuscular junction (Emery, 1999). As a group, NMDs can be regarded as a set of common characteristics in relation to disease mechanisms and epidemiology (Deenen et al., 2015). There is a wide range of functioning levels among people with NMDs; some never achieve ambulation, some lose ambulation, while others are ambulant throughout their lives. Everyone with a NMD, however, experiences gradual loss of muscle strength at varying speed, which affects their functional level such as the ability to sit down and/or stand up, and therefore women with NMD (ambulant or non-ambulant) often experience difficulties in urinating when away from home. Consequently, women with NMDs who experienced an impaired function are more prone to having challenges with going to the bathroom to urinate, especially when away from home. Thus,

they are in risk of not emptying their bladder throughout the day, thereby risking complications such as incontinence due to overflow from an overdistended bladder, repeated urinary tract infections, or sensory affection because of reduced or no intake of fluids during the day (Averbeck & Madersbacher, 2015; Nishi et al., 2023). In addition to health risks, women with NMDs are at high risk of becoming socially impaired because the inadequate access to bathroom facilities hampers their possibilities to participate in everyday activities (United Nations, 2010).

This study was based on the clinical experience that women with NMD who have impaired function experience

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difficulties in urinating when away from home since they (unlike most men) cannot use a urine bottle. The inability of women to urinate when needed and hence miss out on social participation may have a negative effect on their quality of life (Blok, 2020; Handberg et al., 2021). Moreover, the Convention on the Rights of Persons with Disabilities states that women and girls with disabilities are subject to multiple discrimination, and emphasizes that States parties shall take suitable measures to ensure that persons with disabilities have access to facilities on an equal basis with others (United Nations, 2010). Research investigating the challenges for women with NMDs to urinate when away from home is sparse. Only one recent study describes problems related to urinating in persons with a NMD, and only from a biomedical point of view (Roth et al., 2020). Therefore, the aim of this study was to investigate the challenges women with NMDs face when having to urinate when away from home.

Methods

Design

The design for this study was qualitative using the interpretive description methodology (Handberg & Jensen, 2021; Thorne, 2016) and the Sense of Coherence (SOC) theory by Antonovsky (1979, 1987). Interpretive description is an inductive qualitative applied research methodology that aims to gain insight into clinical challenges and bring back the research founded knowledge back into practice (Handberg & Jensen, 2021; Thorne, 2016). Interpretive description allows for a choice of methods that fit the research aim. The data were analyzed through the theoretical lens of the SOC theory, where Antonovsky described health as a movement on a continuum of ease and disease (Antonovsky, 1979, 1987). Antonovsky described how humans through life are being exposed to stressors that life inevitably offers through for instance illness, work, etc. The ability to cope with stressors is described by Antonovsky as the SOC, which is a global orientation that helps people perceive life as comprehensive, manageable, and meaningful (Antonovsky, 1979, 1987). This theoretical lens is relevant when seeking to understand the challenges women with NMDs encounter when having to urinate when they are away from home to gain insight into their ways of coping with these challenges in relation to comprehensibility, meaningfulness, and manageability.

Sampling and Recruitment

This study was conducted at the National Rehabilitation Center for Neuromuscular Diseases (RCFM), a highly specialized neuromuscular rehabilitation hospital at which around 3,500 people with NMD are registered—most of the people with NMDs living in Denmark (Handberg & Werlauff, 2022; RCFM, 2017, 2024). Participants were recruited from

Table 1. Sample Characteristics (n = 12).

Characteristics	n (%)
Age, mean (range)	40 (30-57years)
Diagnosis	
Atrophies	n = 3 (25%)
Dystrophies	n = 5 (42%)
Neuropathies	n = 3 (25%)
Myopathies	n = 1 (8%)
Mobility	
Ambulant	n = 3 (25%)
Non-ambulant	n = 9 (75%)
Employment	
Working full-time	n = 1 (8%)
Working part-time	n = 8 (67%)
Disability pension	n = 3 (25%)

RCFM's patient register by a purposive sampling (Thorne, 2016). To identify appropriate participants and ensure experience with the research question, a list of all female patients ≥ 18 years was reviewed by four healthcare professionals from RCFM to identify women who were either non-ambulant or ambulant with impaired gait function. Patients with ALS (amyotrophic lateral sclerosis) were excluded due to the rapid progression of the disease as were patients with myotonic dystrophy type 1 due to the cognitive element of the disease that could influence participation in a focus group interview.

Participants

In all, 73 women (57 ambulant and 16 non-ambulant) were invited to the study through a secure digital mailbox (e-Boks) or by email. Reminders were sent twice to the non-ambulant women and three times to the ambulant. Twelve women, four ambulant, and eight non-ambulant, accepted the invitation (Table 1). The reasons for opting out were: did not have a problem with urinating when away from home, did not have time to participate, did not respond to the invitation, or found it too difficult to participate. Twelve women participated (Table 1); 50% of the non-ambulant invitees participated, whereas only 7% of the ambulant women participated.

Data Collection

The method applied for the study was focus group interviews which was used to obtain knowledge and data from the participating women on their experienced challenges when trying to urinate when away from home either as ambulant or non-ambulant. The form of focus groups interviews made it possible for the women, based on questions from the researchers to interact and discuss their challenges (Casey et al., 2015; Gill & Baillie, 2018). Through the method of focus group interviews we sought to benefit from the

Table 2. Semi-Structured Interview Guide.

Key interview questions in relation to study aim—inspired by the Sense of Coherence theory

“How do you experience that your diagnosis and functioning affect your everyday life?”

“How often do you urinate during the day (home versus away)?”

“How does urinating away from home differ from being at home?”

“In what way do the possibilities to urinate when away from home affect your choice to leave your home?”

“How do you usually manage to urinate when away from home?”

“If you refrain from urinating when away from home, what are your benefits/downsides?”

“What practical solutions or means do you use to urinate when away from home?”

“On a scale of 1–10, 1 being no problem and 10 being a serious problem—how big a problem is it for you to urinate when away from home on an average day?”

“How could urinating away from home be made easier?”

Follow-up questions were related to:

Roles, concerns, challenges, comprehensibility, meaningfulness, manageability, and counseling.

Elaborative questions were used during the entire interview:

What happened in that episode? What do you think that means? Can you tell us more about it?

How do you think it influences the interaction? What made you make that choice?

Now we’ve talked about. . . , what other things do you think have an influence on this?

Concluding questions:

Is there anything you would like to add or elaborate on from what you have already said?

May we contact you again and ask you to elaborate on your explanations if there are any ambiguities?

participants spontaneous answers to statements from other participants and from the synergy and snowball effect from the group dynamic.

Three semi-structured focus group interviews were conducted on the online Teams platform. We conducted two focus group interviews with non-ambulant women and one focus group interview with ambulant women. Two of the focus group interviews were conducted by CH and BK and one by CH and UW. Two women from the author group participated in one focus group interview each as informants on equal terms as the other participants. The interviewers were experienced and ensured room for all the participants’ perspectives to be unfolded equally. The interview guide was developed in the light of the SOC theory and related to understanding the challenges women with NMDs face when having to urinate when they are away from home (Table 2; Antonovsky, 1979, 1987). The guide was developed based on existing evidence on NMDs, expertise from the women with NMDs who co-authored the paper, and expertise from the healthcare professionals at the rehabilitation hospital. All focus group interviews were recorded and transcribed verbatim by a student assistant. The focus group interviews lasted between 1 hr and 19 min and 1 hr and 27 min. During the interview, the participants were asked to rate their experience of the problem of urinating when being away from home on an average day on a standard visual analog scale of 1 to 10 (1 = no problem, 10 = serious problem; Table 2).

Data Analysis

The data were analyzed inductively inspired by the SOC theory. We worked in an inductive manner and did therefore not apply questions specifically relating to Antonovsky’s

three components comprehensibility, meaningfulness, manageability, but mainly used the theory as an inspiration (Antonovsky, 1979, 1987). The data were analyzed inductively using the four-step interpretive description analysis process (Handberg & Jensen, 2021; Thorne, 2016): (1) the interview data were transcribed and uploaded to NVivo™12, and an initial content and analysis coding was conducted in collaboration with the whole author group in relation to the study aim, (2) the transcriptions were re-read by the whole group of authors and specific patterns identified through constant comparison in a process of thorough investigation of specific elements, (3) all authors conducted a critical appraisal of the relationships within the data and the relevance of thematic options and this led to primary categorizations and interpretations, and (4) the main messages and key insights identified were extracted (Table 3; Handberg & Jensen, 2021; Thorne, 2016).

The study (idea, planning, analysis, and writing up the article) was carried out as a collaborative endeavor by the whole author group, which consisted of three women with NMD (SG, AVP, JS), two senior researchers respectively a registered nurse and a physiotherapist from RCFM and specializing in NMD (CH/UW), one senior researcher and registered nurse from the Department of Urology at Aarhus University Hospital (BT), and one physiotherapist (BK) specializing in NMD. The composition of the research group ensured that various nuances and perspectives were brought forward in the planning of the study and in the analysis of the findings.

Ethical Considerations

This study was conducted in accordance with the Helsinki Declaration of 1975 (The World Medical Association, 2016).

Table 3. Illustration of the Inductive Analysis and Coding Process Leading Up to the Final Categorical Themes—Guided by the Interpretive Description Methodology and the Theoretical Lens of Aaron Antonovsky’s Sense of Coherence Theory.

Contents	First analytical step	Second analytical step	Third analytical step	Fourth analytical step
Description of the content and process of the four analytical steps in regard to interpretive description	A process of discernment of particular circumstances and generalized patterns in relation to study aim	A critical appraisal of relationships within data and relevance of thematic options leading to the primary categorization	Extraction of main messages arising from key insights within the data captured in the form of a final categorization structure	A model illustrating the hierarchy and relations of the themes and displaying the final findings reported in the findings section
Inspired by Aaron Antonovsky’s Sense of Coherence theory	Sense of Coherence: Comprehensibility Manageability Meaningfulness	Sense of Coherence: Comprehensibility Manageability Meaningfulness	Sense of Coherence: Comprehensibility Manageability Meaningfulness	
Codes and subthemes leading up to the final categorical themes	Affected physical functioning Physical barriers hampering urinating Contextual/physical barriers Physical consequences of refraining from urinating Dependency on relatives Feeling being an inconvenient to relatives Planning in relation to bathroom facilities Constant negotiations and calculations Giving up on or missing out on social events Psychological impact of missing out Fearing stigmatization and reduced dignity	Impaired physical functioning and contextual factors Bodily consequences of refraining from urinating Inconvenience and dependency on close relatives Stigmatization and impacted dignity Unavoidable social sacrifices Inner negotiations and “Pee math” Obsessive planning ahead	Physical and functional barriers hampering the opportunity to urinate when away from home Psychosocial impacts related to not being able to urinate when away from home	

According to the Central Denmark Region Committees on Biomedical Research Ethics, the project was not liable to notification (Request 166/2020 case citation: 1-10-72-1-20). All participants were informed about the project by oral and written information and were guaranteed anonymity. Written and oral consent was obtained from all participants. The present study adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007).

Results

The challenges women with neuromuscular disease face when having to urinate when away from home were clearly evident in the data. On standard visual analog scale (VAS) from 1 to 10 (1=no problem, 10=serious problem) the non-ambulant participants rated the problem of not being able to urinate when being away from home on an average day to be 8, and the ambulant women rated the problem to be 5.5. In addition, the women’s narratives provided detailed descriptions of the physical and functional barriers that hampered their opportunity to urinate when away from

home due to impaired physical functioning as well as the bodily consequences from refraining from urinating too long (see Figure 1). Psychosocial impacts were related to inconvenience and dependency on relatives, fear of stigmatization and impacted dignity, and the constant social sacrifices of giving up or missing out on participating in social events, entailing obsessive planning ahead, inner negotiations, and “pee math.” The physical and functional barriers and the psychosocial impacts had a negative effect on the participants’ SOC. The women had specific suggestions for initiatives and solutions that could ease some of the challenges faced by women with NMDs when urinating away from home (Table 4).

Physical and Functional Barriers Hampering the Opportunity to Urinate When Away From Home

Impaired Physical Functioning and Contextual Factors. The participants explained that physical conditions, either as such or their effect on function, could hamper their opportunity to urinate when away from home. The ambulant participants had difficulties getting on and off the toilet due to their

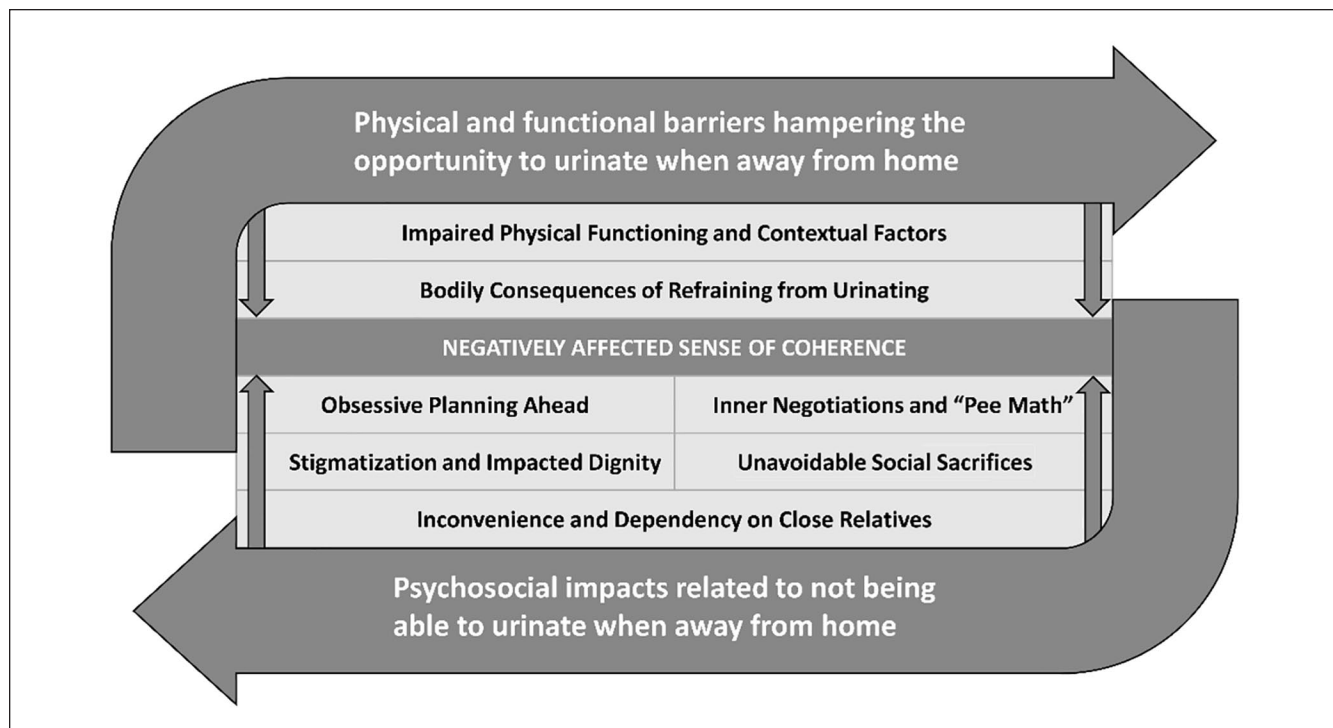


Figure 1. Understanding challenges women with NMDs encounter when having to urinate when they are away from home.

weakened leg muscles. Additionally, some of the ambulant participants also described difficulties due to balance problems, and/or had impaired function of their arms, hands, and/or fingers, whereas the non-ambulant women had difficulties due to sitting on their urethral opening.

I sometimes manage to sink down and sit on the toilet and think ‘Okay, you shouldn’t have sat here, you’ll never get up again’. It is as if, when the desperation increases and becomes great enough, I occasionally find a solution to get up. . . sometimes, but then I manage to push myself up sometimes. . . I can’t get up. I don’t have the strength in my arms for that. (ID10: Ambulant woman, Myopathy)

In addition, they mentioned that locks on toilet doors could be a problem as could getting their underpants or trousers on and off or zippers up and down due to their reduced hand and arm function and affected sense of touch. Bathrooms with too much space could also be difficult for women who struggled with reduced balance because they had no walls to lean on.

I can stand up, but I have balance problems, so I need something to hold on to when I have to get up and go to the toilet. Of course, it depends on how the toilets are designed. I also have to find out where can I place my wheelchair and what can I hold on to, how can I bend over, and things like that. I must think it all over, and then there’s something else, the toilet cannot be too low, because if it is a low toilet, I struggle with getting up again, so these are all things I must figure out quickly. (ID3: Non-ambulant woman, Neuropathy)

Another problem was that toilets often have heavy doors and/or are placed in the basement of buildings, meaning that stairs must be climbed for instance during school hours or restaurant visits, and this can take up a lot of energy. For the non-ambulant women, the COVID-19 pandemic had been a relief in some ways since they could stay at home and use their own bathrooms and assistive devices. The impaired physical functioning had a negative effect on the participants’ manageability of their everyday challenges. The women had learned to adjust to the ongoing difficulties and struggles related to urinating when away from home; however, they affected their quality of life negatively.

Bodily Consequences of Refraining from Urinating. The participating women revealed that they would refrain from urinating when away from home to avoid challenges related to toilet visits and that sometimes they would refrain from urinating for many hours.

I think my record is 27 hours, once in connection with an overnight stay but also in connection with long flights, and at the moment I’m really good at keeping up, I can do that, so I don’t have problems with. . . , but it’s more than that, in order to cope, you do pee math, where you drink less and adjust your fluid intake so you can hold your urine longer, and that actually makes you feel bad. You become dehydrated and uncomfortable and use of a ventilator also makes your mucus become really thick, so I can’t, that is, my body can’t tolerate that kind of dehydration that I suffered from a lot when I was younger. (ID2: Non-ambulant woman, Dystrophy)

Table 4. Initiatives and Solutions Suggested During the Focus Group Interviews That Would Ease Some of the Problems Faced by Women With NMDs When Urinating Away From Home.

Suggested solutions or devices to bring along when away from home

- Disposable bags that absorb urine
- Stand-to-pee devices made of plastic, silicone, or cardboard
- Period pants to prevent leakage
- Sanitary towels
- Diapers
- Trousers or dresses with elastic bands
- A urine collection system with a female external catheter
- Spray to prevent and neutralize smell of urine
- Urine bags with a plastic ring
- Urine flasks
- Portable urine bags
- Salty diets

Stationary solutions when away from home

- Use accessible bathrooms at nursing homes, hospitals, restaurants, etc.
- Person hoist in the car and a bucket
- Person hoist and bed in the car
- Accessible large bathrooms

Wishes for and thoughts about future initiatives

- An online list of accessible disability bathrooms across the country
- Bathrooms with person hoists
- Bathrooms with beds
- Toilets with height-adjustable seats
- A wheelchair with split seat that can be drawn forward
- Consider insertion of a urinary top catheter
- Consider performance of a Mitrofanoff procedure
- Toilet facilities in which lifting and moving is not necessary
- Legal requirement for accessible disability toilets
- Mapping of available disability bathrooms
- More support from local authorities

The women mentioned a range of bodily consequences resulting from refraining from urinating when away from home. Some of these consequences gave rise to bladder problems, especially in the non-ambulant women, like urge incontinence, overflow incontinence causing leakage of urine on clothes and in the wheelchair, frequent urinary tract infections, or bladder spasms. The participants explained that they managed these challenges by using menstrual underwear or a diaper to avoid leakage.

I've done like [name], and refrained from urinating as much as I could, and drunk less. . . , but I've actually also started to wear a diaper once in a while. . . , and not many people know that. Luckily when you sit down, people can't see it, but it serves as a means to allow myself to have just a little to drink and. . . , because it can take a while. . . I'm not able to hold my pee for a whole day, I'm unable to do that for a whole day like [name], and then a diaper might help a little, . . . it allows me to go out to a café or something, without having to go home straight away, or makes it impossible for me to drink a coke, so this has been my sort of solution. (ID4: Non-ambulant woman, Dystrophy)

Moreover, according to the women one of the ways to avoid urinating was to refrain from drinking, but this resulted in dehydration and they feared consequences for their heart, liver, and kidneys, which might lead to a reduced life expectancy. Of less importance was that the women could experience feeling faint and/or if they were on a ventilator having viscous saliva that made breathing and coughing difficult. The overall lack of meaning in having to resort to living with bodily consequences from refraining to urinate because of their disability resulted in less SOC for the participants, especially since they had to resort to managing and living with these consequences on their own.

Psychosocial Impacts Related to Not Being Able to Urinate When Away From Home

Inconvenience and Dependency on Close Relatives. The ambulant and non-ambulant participants stressed that being dependent on personal assistance when going to the bathroom when away from home entailed feelings of being a nuisance or an inconvenience for their relatives or their personal assistants. They explained that they constantly had a bad conscience about being a bother to others or being nervous about being lifted and moved in unfamiliar surroundings.

I am also getting heavier and heavier and find it difficult to keep my weight down, and I find it harder and harder to "help" my personal assistants when I go to the bathroom. In other words, it can both hurt my back and the backs of others if the lifting is done incorrectly. Of course, my husband and I have a routine that we follow, and it works for both of us, but as soon as other people help, it's just really. . . Firstly, it's really annoying to have to ask for help. I'm not that good at it, and I also think it's embarrassing, which is really mind-boggling, because that's just the way reality is. (ID10: Ambulant woman, Myopathy)

The women described that they worried about their constant loss of functioning due to their progressive diseases and about the increasing need for help as a result; the ambulant women especially worried about losing ambulation, leading to an increased need for help. Being dependent on their partners could be straining for the relationship, and the participants described a constant worry about interrupting or taking time from others.

I didn't have a personal assistant as a child, and my parents had to help if I had to pee, and it was annoying to others, even if they didn't say so, I could hear them sighing because I came and said that I had to pee. . . They would say things like: "Couldn't you have said that before I started this thriller," . . . but I didn't know you were starting a thriller. . . , in that way it is deeply rooted in my mind that having to pee is something you feel a little guilty about, and not something you can accept as a natural need. (ID2: Non-ambulant woman, Dystrophy)

Moreover, the need to bring one's partner or a personal assistant along when going out with friends could be awkward and take up a lot of energy. To always be dependent on others

and experience being an inconvenience affected the women's overall SOC and coping negatively. The women had difficulties comprehending why there was an overall lack of options for them to urinate when away from home when there actually were possible solutions out there; why were they not available or only present in very few places.

Stigmatization and Impacted Dignity. The participants described that they often felt stigmatized or that their dignity was impacted negatively due to circumstances related to not being able to urinate when having to. The non-ambulant women told stories about urinating in a bucket while being hoisted into their disability car or that they smelled of urine due to leakage because of refraining for too many hours.

Smelling of urine has a huge social impact. The other day, I could smell that I smelled like pee, so I asked my personal assistant. . . I have a crazy "dog nose," I can smell everything, and my assistant said: "You don't smell, relax." I said, "I need to be hoisted up so that I'm able to check out the seat cover of my wheelchair." We took the cover off, and it seriously stank, and luckily, we had an extra pillow that absorbs everything and there are some holes in it so that I could get some air to my crotch, and the cover needs be washed. So now it's fine, but the fact that I'm constantly aware of whether I smell, and I feel like I smell sometimes even when I don't, it all adds up to maybe 10 (on a VAS scale) socially if I feel that I've been drinking and stuff and some can smell it. (ID1: Non-ambulant woman, Dystrophy)

When having to refrain from urinating for many hours, some of the non-ambulant women resorted to wearing a diaper to avoid or prevent leaking onto the wheelchair even though they explained feeling degraded and humiliated by doing this. Others refused to wear a diaper for the same reasons and argued that it made them feel like a baby.

I haven't used a diaper, using a diaper provokes me, when I have to go, I really have to go and a lot comes out, it's not just that it leaks a little, it's more like a liter because I have such a big bladder. (ID8: Non-ambulant woman, Myopathy)

The ambulant women explained that they had tended to accept the problem of not being able to urinate when in need but leading up to the interview or during the interview, they realized how much this repressed fundamental need affected their lives negatively. They explained that they felt discriminated against and that their dignity was impinged upon. All the women described that having to always plan and think so much about the conditions of the bathrooms when they were away from home was stigmatizing and induced a constant feeling of being degraded, humiliated, and deemed worthless. They explained that the whole subject of having to urinate was tabooed to a degree where the participants would not even discuss their worries with family and friends for fear of being stigmatized or humiliated. This had a negative effect on their overall SOC and made them less resilient to challenges in their everyday lives.

Unavoidable Social Sacrifices. The participants explained that their participation in either work life or social life was limited due to troublesome bathroom conditions when they were away from home. They often missed out on various events due to either difficult or impossible bathroom conditions, and some of the non-ambulant women talked about missing out on educational lectures, social events, or job opportunities due to the lack of usable bathroom facilities for people living with a disability. The participants emphasized that bathrooms located far away from an event meant that a bathroom visit was time consuming and that they would therefore miss out on things like conversations, education, sequences in movies, etc. Some of the women explained that at social events (especially when they were young), they would feel a social pressure to drink the same amount of alcohol as everyone else, well-knowing that the consequences would be a need to go to the bathroom afterwards.

Well, at times it takes up all your energy, energy that should have been used at the party you would attend, or the friends you should have seen, right. It may well be that the toilet is there, and I can use it, but the design is so low, so I use up all my strength to get back up from the toilet the few times that I must go. Then I end up going to bed early or go home early because, well, there's just no more energy left. (ID12: Ambulant woman, Neuropathy)

Additionally, the women mentioned how difficult it was to have a conversation with a teacher, doctor, or friend if all you could think of was the need to go to the bathroom. The women often resorted to opting out of social events or having people over to their homes, preferring to work in the convenience of their own home—which they explained was tedious in the long run for everyone. Leaving parties or events early to go home to urinate was something all the participants were familiar with.

I have like [name] says, driven out to places where I knew they had a disability bathroom, and sometimes with the result that I have gone home before the party was over, and people at the party have gone on into town. . . In that way it has meant many losses socially, also regarding alcohol, I have refrained from alcohol for a long time, or only drunk a little to avoid having to pee, so in that way it has limited my social life. (ID5: Non-ambulant woman, Atrophy)

The women explained that it was difficult and painful to always be the one missing out on conversations, possibilities, or events due to having to go home and urinate and how this had a negative effect on their overall wellbeing and sense of participation in life. The lack of meaning also adversely affected their manageability and coping strategies and often resulted in withdrawal and isolation, which meant missing out even more.

Inner Negotiations and Pee Math. The women explained that they constantly had to conduct inner negotiations and do pee

math on either where to find a fit bathroom or refrain from urinating for hours. Spontaneity was not possible because there was always the issue of pee math, like how long was it possible to refrain from urinating, how little could they drink, how much did they have to dehydrate themselves to be able to stay for the whole event. The women described that this problem was humiliating and that they often did not share it with anyone, not even family.

Well, the problem is that I don't have anything to lie on, in most public toilets there is nothing to lie on, I'm not that big, but a changing table is much too small, and then I have to resort to the floor and it's quite disgusting, and in addition that's a bad working posture for my personal assistant, but yes, that's sort of the biggest problem, I'd say. Therefore, my solution has always been to refrain, and I'm extremely good at that and can do it for a whole day without actually having to pee. (ID6: Non-ambulant woman, Atrophy)

They would simply resort to drinking and eating less, which led to discomfort like dizziness, headaches, urinary tract infections, obstipation, and reduced energy and concentration. Some of the women had even not taken diuretics prescribed for their heart condition because of the risk of having to urinate more. Moreover, they were strategic around what fluids they drank at parties; for example, avoiding soda or beer, which increased the need to urinate much more than strong liquor, or they would increase their salt intake to retain fluids. In general, the women only urinated around three times during the day and sometimes refrained for many hours—one woman up to 27 hr.

My focus is always on how long I need to refrain [. . .]. I'm extremely good at refraining and can withhold for ages and I've been on airplanes for long trips and managed to refrain for up to 10 hours without a problem, but I'm dehydrated of course, and I get tired. I also think that at my age after menopause, . . . it's probably combined with dry mucous membranes, but I've actually got problems with incontinence and with refraining to the same extent as I used to, . . . be careful with that. . . it has consequences in the long run, . . . it probably has, but I have the incontinence part pretty much under control, I think. (ID11: Ambulant woman, Neuropathy)

The ongoing inner negotiations and pee math were exhausting for the women and affected them socially because they were not able to participate in everyday life on equal terms with everyone else. The women's SOC was affected immensely because it took large amounts of energy to constantly plan ahead in order to manage the challenges of having to urinate when away from home.

Obsessive Planning Ahead. Planning was, according to the women, essential but time-consuming and exhausting. They explained that they always had to think about the conditions of the bathroom before they could look forward to going out.

They would, for instance, call restaurants, cafes, or hotels to ask if bathroom facilities were accessible.

When I have to go to the toilet, I need a hoist and to lie down to take off my trousers, . . . so there are very few places I can use, but I gradually I have gotten to know the few places I can use what works. At my parent's house I can go to the toilet, and then there is [name], which is a good place. If you are going to [name], you can make a stop and borrow their bathroom, but in that way, it takes a lot of planning, and mental energy . . . always planning ahead and investigating where there are usable bathrooms. (ID7: Non-ambulant woman, Atrophy)

Obsessive planning was necessary for every event they attended or place they visited. For the ambulant people, the distance to the bathroom or low toilets mattered, and the possibility that there might be stairs also mattered for the non-ambulant women, who had to bring their wheelchair. Every little detail needed to be checked out beforehand, and in addition, the women also had to plan what they would wear and how much they ate and drank. For instance, wearing clothes that were easy to get off in the bathroom could be essential for the opportunity to be able to urinate when having to. Also important was knowing they had someone with them who could guard the bathroom door if they were not able to lock the door due to impaired function of their hands and arms. The risk of not being able to go to the bathroom was always at the back of their minds, hence the obsessive planning that affected any chance of being spontaneous.

I can still stand up, and it has saved me many times, because I can pee in a small container I've found, I can even hold my pee, but otherwise it is still quite limited. . . I know all about dehydrating myself, and planning ahead, and not being able to go to the bathroom, because even though I can stand up, I can't get up and sit down unless there's a chair that can move up and down, so I know those limitations well, and I can move via the sliding board, which also helps, but then you have to think a lot about what clothes you're wearing, so that you can take them off, when you sit down and things like that, so it's a constant challenge for me. (ID9: Non-ambulant woman, Dystrophy)

The obsessive planning in relation to all events during everyday life took a lot of energy, and the constant struggle to cope in relation to something as basic as urinating when away from home negatively affected their overall SOC.

Discussion

To our knowledge this is the first study that investigates the challenges for women with NMD to urinate when away from home. The results illustrated that the physical and functional barriers hampered the opportunity to urinate when away from home due to impaired physical functioning and the bodily consequences from refraining from urinating too long. Psychosocial impacts were related to inconvenience

and dependency on relatives, fear of stigmatization and impacted dignity, the constant social sacrifices of giving up or missing out on participating, and obsessive planning ahead, inner negotiations, and pee math.

Physical Consequences

Literature has shown that holding back urine can have various health consequences especially lower urinary tract symptoms (Chapple et al., 2008). Lower urinary tract symptoms are a global term that encompasses all urinary symptoms, including storage, voiding, and postmicturition symptoms. The symptoms are not always related to the underlying pathophysiology (Averbeck & Madersbacher, 2015; Blok, 2020; Chapple et al., 2008; Jagtap et al., 2022). This is in line with the present study, where the non-ambulant women experienced lower urinary tract symptoms due to holding their urine for long periods of time, and as a result their bladders were affected giving rise to urge incontinence, overflow incontinence entailing leaking urine in the wheelchair, frequent urinary tract infections, or bladder spasms.

The best possible preservation of upper and lower urinary tract function in relation to the individual woman with a NMD is important in neuro-urological management (Averbeck & Madersbacher, 2015). Research has shown that holding urine for long periods of time is an important risk factor for lower urinary tract symptoms and leads to a high frequency of self-reported urinary tract infections (Jagtap et al., 2022). These symptoms have also been related to refraining from urinating, especially in women due to behavioral features and attitudes (Averbeck & Madersbacher, 2015; Blok, 2020; Jagtap et al., 2022). Godfrey et al. (2012) found that older people refrained from drinking to promote social interaction. Similarly, our findings illustrate that to be able to participate socially, the women would drink less and/or dehydrate themselves to avoid urinating, making them prone to the abovementioned health conditions. The participants in the present study had a NMD, resulting in impaired physical functioning that made them even more exposed to barriers that prevented them from going to the bathroom.

In a Danish study on a random sample of the Danish population, 8,700 elderly males and 1,000 females above 50 years, only 8.2% of the women had been to a physician within the last 2 years because of voiding problems, even if the problems were moderate or severe (Nørby et al., 2005). Moreover, some people consider lower urinary tract symptoms as a normal consequence of aging or disease, and due to this misconception they may avoid help-seeking behavior (Palmer et al., 2012). This is an unfortunate pattern that we could also recognize in the women in the present study, who stated that they tried to solve their voiding problems themselves and avoided discussing them with their family and friends.

Nishi et al. (2023) showed in a 2-year follow-up study that poor hydration status can be associated with a decline in

cognitive function especially in older adults (aged 55–75) who suffer from metabolic syndrome and are overweight. These findings, even though related to metabolic syndrome and overweight, are unfortunate for the women with NMD. The participants in the present study explained that they often had to resort to dehydrating themselves to avoid or postpone the need to void, hence being at risk of possible cognitive decline over time. In addition to these physical consequences from not being able to urinate when away from home, the participants in our study also experienced psychosocial impacts.

Psychosocial Consequences and Quality of Life

Research has shown that increasing lower urinary tract symptom severity has a negative effect on voiding, quality of life, and general health (Boyle et al., 2003; Girman et al., 1998; Nørby et al., 2005). It has also been shown that an older person's general health could be affected negatively by multiple conditions that cause lower urinary tract symptoms (Nørby et al., 2005). This is also supported by the findings in the present study. The participants experienced a negative impact on their quality of life in relation to being an inconvenience and dependent on others. They felt stigmatized and experienced a loss of dignity; they constantly made social sacrifices (like staying at home or leaving social events early) and engaged in obsessive planning ahead that entailed inner negotiations and doing pee math. Bladder health may be affected by sociocultural and environmental factors that influence voiding behavior, and additionally, bladder dysfunctions and lower urinary tract symptoms are known to be underreported, underdiagnosed, and undertreated (Palmer et al., 2012). Such misunderstandings involving lower urinary tract symptoms and the lack of the comprehension of their importance for overall health may contribute to this global public health issue (Palmer et al., 2012).

Physical Barriers in Society

There has been little attention in the field of public health on the provision of public toilets, and research underscores the need to recognize this issue (Stanwell-Smith, 2010). So far, there has been little awareness of the difficulties encountered by women with NMDs when they have to urinate when they are not at home and the consequent biopsychosocial negative impact. The literature in this area is sparse despite this being a serious problem that effects the overall quality of life of these women. The participants in our study often faced biopsychosocial challenges related to urinating when away from home. Their impaired physical functioning, the bodily consequences from refraining from urinating, and what women with NMD encounter on a daily basis are ongoing. Public health initiatives designed to promote bladder health and foster recognition of its importance around the world may raise the overall level of health and promote beliefs and attitudes

regarding bladder health as well as sociocultural and environmental factors (Palmer et al., 2012). The negative impact of the lack of opportunities to urinate when away from home makes it immensely important to create awareness and knowledge of the problem that women with NMDs and other disabilities are likely to experience because they both face the same physical challenges and consequences related to urinating and voiding.

There is a need to find solutions that make it possible for women with NMD to live independently and allow them to remain active and participate in all aspects of life and not have to depend on adequate toilet facilities and/or assistance from others. The present study has shed light on some of the challenges and consequences women encounter when having to refrain from urinating. We can conclude that the needs of the women in our study were not met in Danish society and that the women constantly repressed the fundamental need to urinate. The women in the present study experienced constant physical and functional barriers hampering their opportunity to urinate when away from home due to a lack of assistive devices or public accessible disability bathrooms. Even though the findings bring forward possible solutions, more knowledge is needed. Therefore, the findings will be used in a national survey aimed at revealing the extent of the problems women with NMD face when having to urinate away from home.

Methodological Considerations

In all, 73 women were invited to participate in the study, 16 non-ambulant women and 57 ambulant women. The women that were invited to participate were selected by purposive sampling based on their functioning. The large percentage of women who did not answer the invitation to participate (especially the ambulant women) might be because the problem of urinating when away is less prominent in this group than in the non-ambulant women. The fact that so many ambulant women opted out of participating might have biased the results because the ambulant women who chose to participate might have been those with specific challenges related to urinating when away from home. Another important factor for not enrolling might be that the topic is associated with severe stigmatization, hence the possibility for individual interviews might have increased the number of participants.

The representation of participants and data, however, ensured a nuanced and broad data set that supported the results well, and those who participated were the ones experiencing challenges in urinating when away from home and were therefore able to elaborate extensively on these challenges. Whilst working inductively, the theoretical lens of SOC provided us with the means to unfold data and analyze it in the light of comprehensibility, manageability, and meaningfulness (Antonovsky, 1979, 1987). The use of SOC as the theoretical lens provided an insight into the daily challenges that the women in the present study experienced when

needing to urinate when away from home. The structure in society hampered their possibility for activity and participation in daily life negatively (Schiøler & Dahl, 2012). The SOC theory furthermore provided the possibility to gain insight into how the women managed a basic human need like urinating when away from home and provided insight into how the women's biopsychosocial sacrifices repeatedly affected their SOC negatively.

The research group consisted of seven people with different experiences and educational backgrounds, ensuring that various perspectives were brought forward. Moreover, these various perspectives on the field under study (inside and outside perspectives) reduced the risk of preunderstandings and enhanced the possibility to ensure potential rigor and trustworthiness (Thorne, 2016). We ensured transferability by working systematically in accordance with the interpretive description analysis process and by visualizing our coding process in a table (Thorne, 2016). In the interpretive description analysis, saturation is not an endpoint based on a belief that it is impossible to identify a specific point in time at which saturation is achieved (Saunders et al., 2018; Thorne, 2016). This approach builds on an assumption of never knowing what the next participant will say (Thorne, 2016). Even though the sample in the present study was rather small, the information provided by the sample was highly relevant for the study and contained satisfactory informative power to gain new knowledge regarding the study aim (Malterud et al., 2015)

The findings in the present study are relevant for women with NMD but also for many other women who live with a disability affecting their functioning to an extent where using normal bathroom facilities when away from home is difficult. In future research, it would be relevant to conduct a national survey to investigate the scope of the problem of refraining from urinating that includes any possible impact on social activities, education, and working life. The survey should also map out to what extent those who refrain from urinating experience urination problems, such as urinary tract infections and incontinence, and how these are addressed in the clinical setting. Moreover, there is a need to investigate further solutions that will allow the women with NMDs to live independently, remain active, and participate in all aspects of life without having to depend on adequate toilet facilities and/or assistance from others.

Conclusion

The study findings detail the challenges women with NMD face when having to urinate when away from home. Access to adequate and equitable sanitation was a constant challenge for the participants in our study, and their needs were not met by society. Together the physical and functional barriers and the psychosocial impacts had the potential to negatively influence participants' SOC. These challenges might be similar for other women with NMD and other disabilities who

have difficulties in voiding outside their homes. The findings will be used to target future rehabilitation counseling. Because of the clinical and practical implications for women with NMDs, it is important to raise political awareness on ensuring accessible public disability bathrooms. Nurses and other healthcare professionals play a central role in targeting future health professional knowledge and counseling on bladder health and knowledge of possible ways by which women with NMDs and impaired functioning can urinate when away from home. Nurses and other healthcare professionals can ensure that accessible communication and online information on devices to assist voiding is available, and they can compile information on available and accessible public disability bathrooms.

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Author Contributions

All authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content; (3) final approval of the version to be submitted.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Declaration of Conflicting Interests

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