

HAP-PEE - study I

Challenges faced by women with neuromuscular diseases when having to urinate away from home – Study I



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Results

Twelve women with neuromuscular diseases (NMD) participated in 3 focus group interviews. The qualitative analysis showed that physical and functional barriers hampered the possibility to urinate when away from home due to impaired physical functioning.

Prolonged refraining from urinating had bodily consequences and psychosocial impacts related to inconvenience and dependency on relatives, fear of stigmatization and impacted dignity, and constant social sacrifices when giving up or missing out on participation. This entailed obsessive planning ahead, inner negotiations, and 'pee math' (Figure 1 + Table 1).

The participants offered specific suggestions for solutions which could ease some of the challenges in urinating when away from home (Table 2).

Design and methods

The design was a qualitative interview study guided by the interpretive description methodology and Aaron Anotnovsky's theory of Sense of Coherence.

The study was developed by four researchers and three women with NMD.

Aim

To investigate challenges of women with NMD when having to urinate when away from home to gain knowledge to target future counselling and to qualify the development of a questionnaire survey.

Conclusion

We found that the challenge of access to adequate and equitable sanitation for women with NMDs are not at all met in society and that the women consequently often have to resort to repressing the fundamental need of peeing. The findings will be used in a national survey aimed to unfold the problems women with NMDs face.

Figure 1

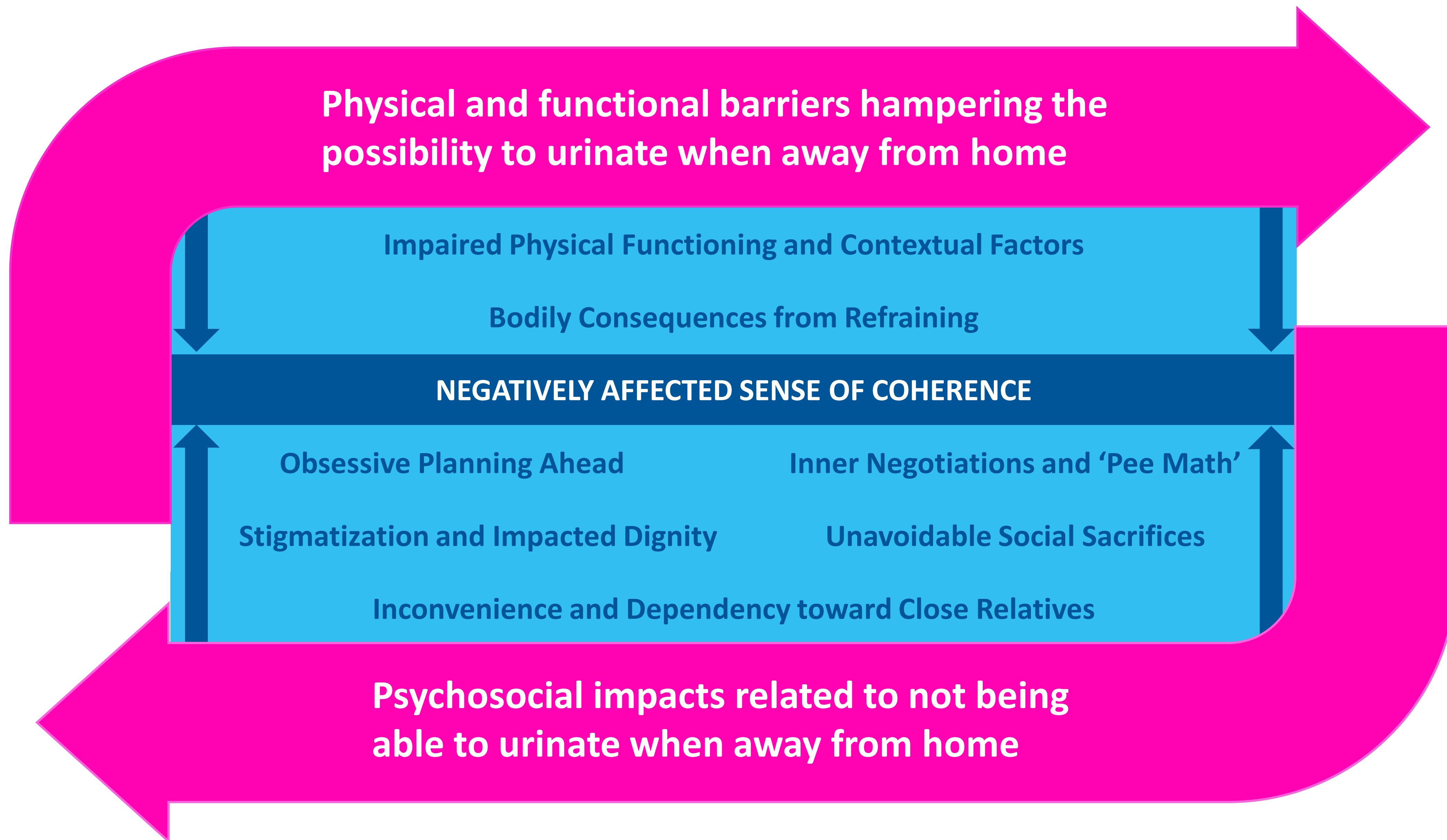


Table 1 Characteristics of participants

	Participants (N=12) (%)
Sex	Female (n=12) (100)
Age (mean (range))	Atrophies (n=3) (25) Dystrophies (n=4) (33,5) Neuropathies (n=4) (33,5) Myopathies (n=1) (8)
Diagnosis	Ambulant (n=3) (25) Non-ambulant (n=9) (75)
Mobility	Working full-time (n=1) (8) Working part-time (n=8) (67) Disability pension (n=3) (25)
Employment	Working full-time (n=1) (8) Working part-time (n=8) (67) Disability pension (n=3) (25)
Self-rated experience of the problem on VAS, mean (ambulation)*	5,5 (ambulant) 8 (non-ambulant)

*On a standard visual analog scale (VAS scale) of 1 to 10 (1 being the least problematic and 10 the most problematic) the participants were asked to rate their experience of the problem of urinating when being away from home on an average day.

Table 2 Solutions suggested during interviews

Solutions to bring along when away from home
<ul style="list-style-type: none"> • Disposable urine absorbing bags • Stand-to-pee devices (cardboard or silicone) • Female external catheter • Urine bags or urine flasks • Period pants • Sanitary towels • Diapers • Clothes with elastic waistbands • Spray to neutralize smell of urine • Salty diets
Stationary solutions when away from home
<ul style="list-style-type: none"> • Use accessible bathrooms at nursing homes, hospitals, etc. • Hoist, bucket and bed in the car • Sizeable bathrooms
Wishes for and thoughts about solutions for the future
<ul style="list-style-type: none"> • A guide to disability bathrooms across the country • Bathrooms with beds and/or hoists • Toilets where the seat can be raised • A wheelchair seat that can split or be pushed forward • Top catheter • Mitrofanoff procedure • Legal requirement for accessible disability toilets • More support from local authorities and politicians

Clinical and patient implications

<ol style="list-style-type: none"> 1. Raise political awareness on ensuring accessible public disability bathrooms 2. Healthcare professionals play a central role in targeting future health professional knowledge and counselling on bladder health and possible solutions 3. Healthcare professionals can ensure available and accessible communication and online information on possible assistive devices to help voiding 4. The findings will be used to qualify a national questionnaire survey aimed to unfold the problems among women with NMD and to further test possible solutions to help women urinate when being away from home regardless of level of functioning (please see poster with study II)
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