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Parents' expectations of the outpatient care for daytime urinary incontinence in children: A qualitative study

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Summary

Introduction

Daytime urinary incontinence (UI) can have an enormous impact on a child's life, lowering both self-esteem and quality of life. Although most children start therapy after their first visit to our outpatient clinic, no studies have reported on parents' or patients' expectations of care for daytime UI in this setting.

Objective

We aimed to explore the expectations of the parents of children referred to an outpatient clinic for daytime UI.

Study design

This was a qualitative study that involved performing semi-structured interviews with the parents of children who had been referred for daytime UI (with or without nocturnal enuresis). Interviews took place between July 2018 and October 2018 and continued until saturation was reached. The results were transcribed verbatim and analyzed according to Giorgi's strategy of phenomenological data analysis.

Results

Nine parents of children, aged 5–12 years old, were interviewed, revealing "(Experienced) Health," "Self-management," and "Social Impact" as the main themes that influenced parental expectations. All parents wanted to know if there was a medical explanation for UI, some were satisfied when

diagnostics revealed no underlying condition, and others wanted treatment. Parents expressed no preferences about diagnostics or the content and duration of treatment, but they hoped that any previously attempted ineffective steps would not be repeated. Some parents defined treatment success as their child becoming completely dry, but most stated that learning coping strategies was more important.

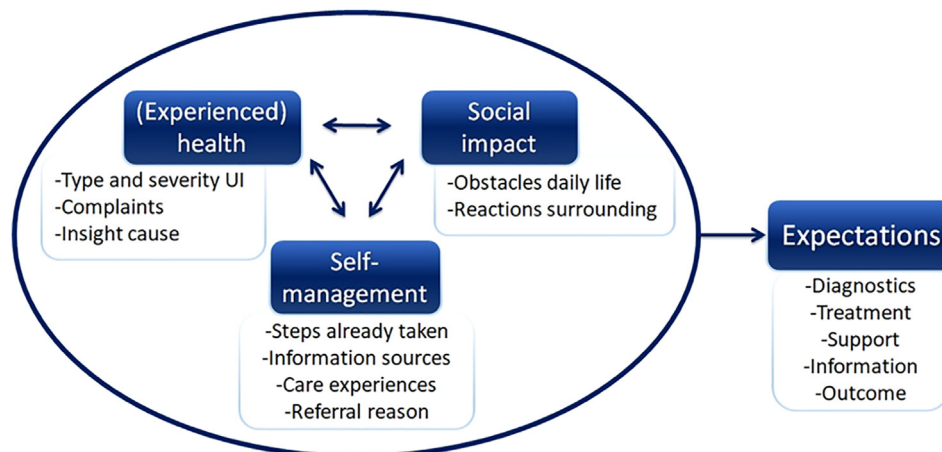
Discussion

This is the first study to explore the expectations of parents when attending outpatient care for children with daytime UI. We employed a strong theoretical framework with a clear interview guide. The main limitations are that we only interviewed parents and that this was a qualitative study, precluding the drawing of firm conclusions. Nevertheless, our results point to the need for quantitative evaluation.

Conclusion

Expectations seem to be influenced by (experienced) health, efforts at self-management, and the social impact of UI, making it critical that these themes are addressed. It was interesting to note that parents do not always attend outpatient departments with the goal of completely resolving daytime UI. Instead, some only want to know if there is an underlying medical condition or want to reduce the social impact by learning coping mechanisms. Excluding underlying medical conditions may therefore stimulate acceptance of watchful waiting without the need to start treatment.

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Theoretical model showing three main themes influencing expectations of parents concerning the assessment of daytime urinary incontinence. The (experienced) health, social impact and self-management of parents influence each other and together form the expectations of on the assessment of daytime urinary incontinence.

Introduction

Daytime urinary incontinence (UI) is a common condition that can lower both self-esteem and quality of life [1]. As the child ages, daytime UI poses a greater burden and more often leads to them being bullied, resulting in social withdrawal and even aggression [2]. Daytime UI can be diagnosed from 5 years old and requires multidisciplinary treatment [3] by general practitioners (GPs), urologists, and pediatricians in the Netherlands. However, whereas the Dutch associations of pediatricians and urologists have composed a joint guideline for managing UI [4], none exists for Dutch GPs. In the joint guideline, urotherapy is initially advocated after excluding anatomical and neurological deficits. This involves explaining urinary tract function and giving instructions about micturition, but may include treatment of constipation and infection as well as the use of cognitive therapy, behavioral therapy, and physical therapy. When an overactive bladder is diagnosed, antimuscarinic medication can be prescribed [5].

In the Netherlands the GP is the first doctor a patient turns to. It is not possible to consult a pediatrician nor urologist without a referral, except in case of a medical emergency. When GPs decide to refer a child with daytime UI, they can choose to refer to the pediatrician or urologist. In our hospital, we treat some 130 children with daytime UI at the outpatient clinics annually. Although most start therapy after their first visit with the goal of completely resolving symptoms, there has been no structured analysis as to whether parents share this goal in such settings. This need rectifying given that the role of shared decision making has grown in importance in recent decades. Gaining information on children's expectations is relevant in this context, and meeting these has been shown to correlate with overall satisfaction [6]. Positive expectations in adults have similarly been associated with better health outcomes, underlining the need to discuss these expectations [7]. However, we are aware of no studies on what care parents or patients expect for daytime UI. Studies of

nocturnal enuresis indicate that enuresis can be stressful for parents, indicating the need for not only information on the causes and available treatment options but also access to aids and support [8,9].

In this study, we aimed to explore the expectations of parents whose children were referred to our hospital with daytime UI.

Material and methods

Study design

We conducted a qualitative study with semi-structured interviews among the parents of children with daytime UI who were referred to the outpatient departments of pediatrics or urology of our hospital. The Medical Ethics Committee of our hospital approved the study in March 2018 (METC number 180333) and all participants provided written informed consent.

Sample selection

We selected children aged 4–18 years referred for daytime UI, regardless of the presence of nocturnal enuresis or other lower urinary tract symptoms. The selection was made based on information in the referral letter from the referrer. Exclusion criteria were insufficient mastery of the Dutch language, nocturnal enuresis without daytime UI, or urinary tract infections as the explanation for UI. We approached parents before their first visit to explain the study and invited them to participate. Written information about the study was then sent to their home addresses, and after two weeks, parents were called again to check their willingness to participate.

Data collection

We developed an interview guide based on research questions, clinical experiences, and literature review ([Appendix](#)

A) [10–13]. The guide was used to initiate the interview and stimulate discussion. All interviews took place between July 2018 and October 2018 and were conducted in-person before the first visit at the outpatient clinic. The interviewer (JML) was independent, had no connections with the parents or children, and audio-recorded the interviews. The children were present during the interview and could participate in the discussion when they wanted.

Interviews were transcribed verbatim by an external company. Recruitment and interviewing continued until saturation was achieved (meaning that further interviews revealed no new findings or opinions). We also collected demographic variables from children's medical records (gender, age, type of incontinence, period in life without urine loss, medical history). All data collection and analysis took place concurrently, and during the analysis, the research team met to discuss the ideas emerging from the data.

Data analysis

Data were coded and analyzed in duplicate based on Giorgi's strategy of phenomenological analysis [14], using ATLAS.ti 8.3.1 (ATLAS.ti Scientific Software Development GmbH). After open coding of the first two interviews, matching codes were merged and differences were discussed (Table 1). The third interview was then coded and the research group met to discuss the emerging codes and themes until consensus was reached. Subsequent interviews were coded accordingly. The research group was

multidisciplinary including a GP, (pediatric) urologists, pediatricians, nurse practitioners, epidemiologists and an independent researcher. An extensive description of the data analysis is given in appendix B.

Results

Saturation was reached after nine interviews with parents of patients recruited from the Department of Pediatrics. Each interview lasted 15–30 min, only mothers participated, and all included children were unrelated. There were no new referrals to the urology outpatient department during the study period. Table 2 shows an overview of the participant characteristics. Three main themes emerged from the interviews: (1) "(Experienced) Health," (2) "Self-management," and (3) "Social Impact." The themes influenced each other, and together, influenced parental expectations, as illustrated in Fig. 1.

(Experienced) health

The type and severity of UI, insight into the cause of UI, and the experiences of parents and children to date were included in the (experienced) health theme. Parents expressed that the UI and its lack of predictability was a burden.

Quote 1: "The question is not if it's going to go wrong, but when." (P5)

Table 1 Example of the coding process.

Quote	Open coding by separate researcher		Codes after combining	Theme
"She's trying to hide it a little" (P9)	<p>Researcher 1 Feelings of shame Bothersome moments Reaction of the child</p> <p>Researcher 2 Effect on social life Reaction on urine loss</p>	Merging matching codes + discussing differences	Reaction of the child on urine loss Social burden/bothersome accidents	Social impact

Table 2 Participant characteristics.

ID no.	Child's gender	Child's age (years)	Type of incontinence	Period in life without urine loss	Relevant medical history
P1	Boy	6	Day and night	No	Fatigue
P2	Boy	11	Day and night	Yes	Attention-deficit/hyperactivity disorder
P3	Girl	6	Daytime	Yes	None
P4	Boy	5	Day and night	No	None
P5	Boy	6	Day and night	No	None
P6	Boy	8	Daytime	No	None
P7	Boy	5	Day and night	No	None
P8	Girl	7	Daytime	No	Anxiety disorder
P9	Girl	5	Day and night	No	Developmental delay, language and speech disorder

A total of 14 children was selected. Two parents could not be reached by telephone and three refused participation. Four of these children were aged 4–7 years old, one child was 12 years old.

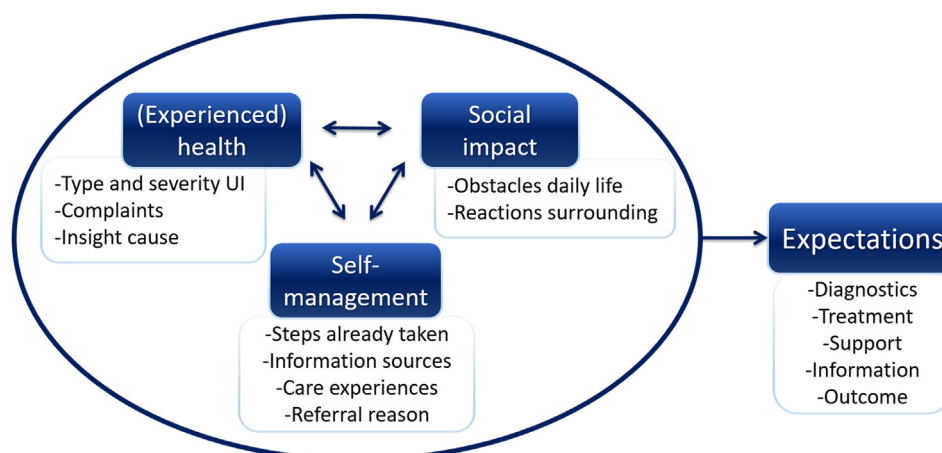


Fig. 1 Theoretical model showing three main themes influencing expectations of parents concerning the assessment of daytime urinary incontinence. *The (experienced) health, social impact and self-management of parents influence each other and together form the expectations of on the assessment of daytime urinary incontinence.*

Not knowing why the loss occurs intermittently also raised questions and doubts, but most parents acknowledged that multiple factors contribute to the urine loss.

Quote 2: "I'm very busy with everything, except for what counts" (P5)

Quote 3: "It just needs its time. The one child is faster than the other." (P4)

From age 5–6 years, some parents experienced UI as an increasing problem, but others reported having reached a sustainable situation.

Quote 4: "He has been in school for two years now. In the first period we still thought something like, well not everyone is super potty-trained at this point, so it doesn't matter. But in the past year and a half we did start to feel like, well ..." (P1)

Quote 5: "You know, it is handleable at the moment. I am not constantly occupied with making sure it doesn't go wrong" (P3)

Self-management

Self-management involved steps already taken by parents to minimize or stop UI, the information sources used, prior experience with treatments and caregivers, and the reason for the current referral.

Parents wanted support when UI persisted. Most had started on the internet, searching for tips, advice, and the experiences of other parents. Relatives were also asked for help. However, some parents avoided searching because they feared it could make them unnecessarily worried.

Quote 6: "My brother and my two nephews also wet their beds for a long time. So, I had, of course, already discussed that with my mom and aunts like, how did you two deal with all of that." (P1)

Quote 7: "Interviewer: Did you also look up information yourself? Mother: No, that only makes you worry." (P9)

Parents also reported that they felt that they had failed when, despite their efforts, the UI did not improve. They mentioned that it affected daily life and the relationship with their child.

Social impact

The third main theme concerned the social impact of UI on daily life, which related to the reactions of others, interactions with peers, and experiences at school. Parents expressed that UI was an obstacle to the social development of their child. For example, peers noticed wet spots and the smell of urine, often commenting, and parents recognized that this made contact with classmates harder. Children also omitted certain activities to hide their UI, such as sleepovers or playdates.

Quote 8: Question: "Do you refrain from doing things because of this?" Child: "Sometimes, sleepovers, for example." Mother: "Oh, yes. School camp ... that was quite a thing." (P2).

Many schools have a policy of not changing the clothes of children, forcing the child to handle UI without assistance. Some schools even demand that the child is continent before they are welcome. Parents therefore experienced little support from schools. In addition, support from family members varied between participants.

Quote 9: "The teachers at school don't do anything about that anymore because it isn't included in their job responsibilities. He thus has to be able to do it completely by himself, he doesn't even get small inclinations like, go to the toilet, anymore. Another example is that, when he is wet, he has to be able to redress himself. So, it's a lot different now compared to what I was used to, going to school back in my day." (P4)

The social impact was also reported to increase as the child aged. In particular, parents expressed concerns that the child would be bullied and excluded from social groups because of the UI.

Expectations on the outpatient care

The three main themes influenced parental expectations of outpatient care. These concerned not only the overall care trajectory but also the specific components, such as diagnostics, treatment, support, information, and treatment outcomes.

All parents wanted to know if a medical condition caused the UI. Parents expected that diagnostic tests would be performed to exclude pathology, but they did not have a clear idea on what diagnostics would be used. Some parents only wanted to know if there was a physical abnormality, and if reassured, they stated that they would be satisfied with no further treatment or support.

Quote 10: "See, if anything is found, you'll be busy for a year before you know it. But if they find nothing, yeah well that's it and we'll undertake action at home. I don't require any further assistance in that case." (P3)

Most parents found it hard to say what they expected of the treatment because they did not know the cause of the UI. However, they did not want to repeat steps that had been tried and found to be of no benefit.

Quote 11: "I don't really know, because I'm not sure whether it's behavior or something physical, so to speak. I really expect that if it is behavioral, he'll have to start practicing. A sort of physical therapy, specifically for this." (P6)

Quote 12: "That the child is being checked, not that every child is being treated the same, that is the starting point. That someone checks what all is going on, so that you don't have to return with the thought 'wow this could all have gone so much faster.'" (P4)

Parents wanted accessible information about the cause of the UI, the diagnostic tests, and the treatment to be provided (both orally and in writing). Some mentioned they would prefer informational videos to re-watch at home, and some mentioned that this information was necessary for others involved in their care, such as grandparents or school staff. A number wanted child-centered support, expecting that efforts would be made by practitioners to involve the child in the consultation, providing tailored advice and tips.

It was hoped that hospitals would consider the schedules of children when making appointments to avoid their child needing to attend hospital during school time. This was because the child often did not want to miss fun activities, feel different to their peers, or explain their absence.

Although all parents were confident that outpatient treatment would be successful, the definition of success varied. Some parents defined success as becoming totally dry, but most stated that their main goals were to learn coping strategies and to reduce the social impact.

Quote 13: *Mother: "a success, or actually: just being helped to a point where she can be dry during the day."*
Child: "If everything, really everything, is over." (P6)

Quote 14: "Success is him not wearing soaking wet pants during the day anymore. A few drops are fine. But not everything from his socks to his pants. So that other children at least don't see him standing around with wet pants anymore. So that he has that self-confidence of 'hey, I go to the toilet in time; I can hold it in.' For me, that's a real goal: it not being a problem that others see; it being handleable." (P4)

Quote 15: *Well, I never really have many expectations. I just go in with an open mindset and hope that a solution is found. But I also know that may not be possible and that it maybe just needs time (...) I at least hope to find out if there is something medical going on. And for the rest, possibly, get some tips on how to deal with it (...) I have tried everything at this point, and we really do not know anymore. (P9).*

Parents responded differently about whether they wanted to meet other parents to discuss their problems. Some only wanted to speak to other parents if there was something medically wrong. Others said they had enough friends and family to ask for help and tips, and that they did not feel the need to talk to a stranger about UI.

Quote 16: "Possibly, for him, it is depending on the cause. What the origin of this? Is it something physical? Is it just something psychological? Is it something ... a lack of interest on his part? Or ... ? (...) If there is a physical cause, I think you would talk with other parents about it: how do you manage this? (...) If this is something time will resolve, then I don't know." (P4)

Discussion

We are aware of no prior research evaluating the expectations of parents before attending outpatient care for children with daytime UI. We showed that expectations were affected by the (experienced) health, self-management, and social impact of UI. Most parents worry about the health and social development of their child when potty training is unsuccessful, typically only seeking help when self-help strategies do not resolve the problem. The main goal of parents is not always to achieve complete symptom resolution, however, with some only wanting to know if there is a medical cause or how to reduce the social impact by learning coping mechanisms. They do not want to repeat steps or treatments if they have previously been unsuccessful.

It was noteworthy that some parents expressed that they would be satisfied if diagnostic testing showed that there was no physical abnormality causing the UI. These parents stated that they had already acquired the necessary coping strategies to handle the condition and did not want immediate treatment if it was unnecessary. We believe that this is a remarkable finding because, in daily practice, it has been our experience that most health care professionals assume that therapy is necessary and start it

from the first visit. Given that the prevalence of UI is known to decrease with age [15], overtreatment may be a problem in some children, particularly the young and/or those with potentially self-limiting conditions. If the expectations of these parents and children are addressed at the first visit, confirming the absence of a physical abnormality could encourage watchful waiting. Indeed, this may allow discharge from outpatient follow-up, meaning fewer hospital visits, fewer unnecessary treatments, and a reduction in health care cost. We believe that it is likely that this happens in other hospitals and in other countries, though confirmatory studies will be needed.

We were unable to find comparable studies concerning the expectations of the parents of children with daytime UI, but we did find two similar studies about nocturnal enuresis [8,9]. First, Cederblad et al. reported that Swedish parents wanted more information and to protect their child from gossip or teasing [9]. Similarly, parents in our study expressed that they had sought further help because they were afraid that, as their child aged, they would become a victim of bullying from classmates. Another parallel is that parents mentioned that they had already exhausted all self-help options and that they sometimes felt guilty [9]. However, among parents of children with nocturnal enuresis in America, Dunlop reported that fewer than half wanted to know more about the causes and that fewer than one-third wanted to know about available treatment options [8]. By contrast, our results showed that most parents wanted information on the cause of UI. Another difference is that a surprisingly few parents (12%) in Dunlop's study expressed interest in knowing how to discuss enuresis with their child. This contrasts starkly with our finding that parents wanted to know more about coping mechanisms for their child and themselves. Nevertheless, these differences could be explained by the fact that the studies were performed in different populations. Dunlop included a national probability sample, while we selected parents attending an outpatient clinic after seeking help for UI in their child. Only half of all parents in Dunlop's study reported that they would take the initiative to contact their healthcare provider if their child experienced nocturnal enuresis. It is possible that the parents in our study had suffered more from the experience of dealing with their child's UI, which could explain the need for information and coping strategies.

Finally, parents in our study mentioned that they felt little support from the teachers of their children, consistent with statements by children in a previous study [16]. This may explain why parents in our study stated that information should not only target themselves but also those in their wider environments.

Strengths and limitations of this study

The main strengths of this qualitative study are that we employed a strong theoretical framework with a clear interview guide based on current literature and clinical experience. Interviews were carried out by only one interviewer who was familiar with the subject and not involved in the treatment. This gave parents the freedom to speak without affecting the care trajectory. We also

continued to interview until we reached saturation, and the results were discussed extensively among a multidisciplinary research team during analysis, ensuring the input of different professional perspectives.

A limitation of this study is, that despite the age range for inclusion of 4–18 years old, we only enrolled children between 5 and 11 years old. Therefore, our studied population may not fully cover the population of our clinic. In another study we performed [unpublished data], we noted that the vast majority of our population consists of young children (median age 6). It might be possible that teenagers have other expectations. Following the current study, we developed a questionnaire, which will be sent to the older children as well to also explore their expectations. However, it is possible that not all aspects that older children experience are included in the questionnaire and that teenagers have other expectations.

Another limitation could be that we only interviewed parents and, because of their young age, did not interview children. However, we did ask parents about their child's expectations, and they often mentioned that their child did not know what to expect from the hospital. We therefore feel that the impact of this limitation is small, not least because children typically do not initiate referrals and only attend on the instruction of a parent or GP. In older children, some mothers did involve their child in the interview, but most of the time, the child had no clear opinion or simply agreed with the mother. A study on treatment expectations revealed that half of adolescents aged 13–18 years with chronic musculoskeletal pain agreed with their parents [12]. Given that we had younger children in our group (all were aged ≤ 12 years), we expect a much higher level of agreement in our study.

All children in our study were referred to a pediatrician, with no referrals to the urologist during the inclusion period. This is in line with the findings of an observational study in our hospital, which revealed that 85% of new referrals for daytime UI were to pediatricians [unpublished data]. We believe that there would be no major differences in parental expectations before their first visit to the pediatrician or urologist, because they have not been seen by either specialist. From one of our other studies, we know that parents (and children) are not actively involved in choosing to which specialist they are referred [unpublished data]. We assume that the knowledge of the parents about the differences between the pediatrician and urologist is limited, and therefore this will not influence the experience. Our study focusses on the expectations regarding solving the UI and this problem is the same between the two groups. Another limitation was that all participants in the current study were mothers. This is consistent with our experiences at the outpatient clinic, where the vast majority of children is accompanied by their mother, but we do not know if mothers have different expectations from fathers. It could be possible that there are differences. However, although Dunlop found that mothers were more likely to contact a healthcare professional about bedwetting, parents were reported to be equally concerned about the effect of nocturnal enuresis [8]. Similarly, Cederblad et al. reported that the patterns of the answers were comparable between fathers and mothers [9].

Conclusion

The expectations of parents with daytime UI are influenced by the (experienced) health, self-management, and social impact of UI. However, our data indicate that it may not be appropriate to strive for the complete resolution of UI for all patients from the first appointment. Of equal or greater importance to many parents was that they wanted to learn how to cope with UI. Indeed, excluding underlying medical conditions meant that many parents could accept watchful waiting. We therefore recommend addressing the expectations of parents and children at the first outpatient visit and to be aware that each person's experienced health, their self-management efforts, and the social impact of UI each influences expectations. If approached correctly, addressing these could avoid unnecessary treatment, result in fewer visits to hospital, and reduce the costs of health care. However, the qualitative and exploratory nature of this study means that further research is needed. As such, we have developed a questionnaire based on the current data to quantify our findings and to expand our knowledge of parental expectations when children with daytime UI are referred to a specialist outpatient department. We plan to administer this to newly referred patients over the coming years and will publish the results in due course. This questionnaire will be sent to older children as well, which enables to generalize the findings to a wider population.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jpuro.2021.05.026>.