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“Nobody Asked Us if We Needed Help”: Swedish parents experiences of enuresis

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Abstract *Objective:* To explore the everyday dilemmas of parents living with a child with nocturnal enuresis and to describe their support needs in relation to healthcare professionals. *Subjects and methods:* The study was conducted in 2011 in Uppsala County, Sweden. Parents of 13 children with enuresis, 10 mothers and three fathers, participated in qualitative semi-structured in-depth interviews, which were analysed using systematic text condensation.

Results: The analysis of the material resulted in six themes: enuresis is socially stigmatising and handicapping; all practices and home remedies are tested; it creates frustration in the family; protecting the child from gossip or teasing; support from healthcare providers would have helped; it's something we just have to live with. Two patterns of coping were identified: the *Unworried wet-bed-fixers* and the *Anxious night-launders*.

Conclusion: Having a child with enuresis can be stressful for parents, although they tried hard not to blame their child. Because parents can feel reluctant to bring up enuresis themselves, they want child health nurses to routinely raise the issue of bedwetting at the yearly check-up. Parents' information needs included causes of and available treatment options for enuresis as well as access to aids and other support for affected families.

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Introduction

Nocturnal enuresis (NE) is defined as involuntary voiding of urine during sleep at the age of 5 years or older [1–3]. Second to allergic disorders, bedwetting is the most common chronic condition among children aged 6–7 years, afflicting 10% of all 6 year olds, 5% of all 10 year olds, and 0.5–1% of teenagers or young adults [4]. There is a 15%

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annual spontaneous cure rate [1]. There is often a hereditary factor, and bedwetting is 1.5–2 times more common in boys than in girls [5]. Active treatment involves the enuresis alarm or pharmacotherapy and commonly starts at approximately age 6 years [1].

Previously, NE was considered a psychiatric disorder but in professional circles today it is regarded as an essentially somatic problem in which psychological factors play a marginal role, whereas parents sometimes still see it as an emotional problem [6]. In an American telephone survey, many parents reported that they believed that NE was *not* a somatic disorder and that they wanted healthcare providers to more actively seek out the causes of their child's symptoms [7]. Parents of bedwetting children also tend to believe that bedwetting is uncontrollable and look for causal medical and psychological explanations [8,9].

Quantitative studies show that parents of bedwetting children often experience feelings of helplessness regarding their child's condition and are more anxious and concerned than other parents [10,11]. Butler et al. [12] showed that most parents understood that their child could not help wetting the bed, but as the child grew older some mothers were found to be less tolerant. For some parents, enuresis can lead to frustration and has been implicated as a trigger to child abuse [13]. Studies have also shown that enuresis may cause low self-esteem and social isolation for the child [14,15].

Parents use several strategies and practices to try and prevent or cope with enuresis of their children. These practices include waking the child to urinate before the parents' bedtime, limiting the child's fluid intake in the evening, making use of reward systems, punishing or showing displeasure, and using diapers and mattress covers [8].

Although a small number of quantitative [6–9,13,14] and even fewer qualitative studies [10,11] have been published on the subject, there is a clear lack of in-depth knowledge about parents' perceptions of having a child with enuresis. This knowledge is crucial for healthcare providers' ability to give adequate support and advice to the families. The aim of this study was therefore to explore the everyday dilemmas of parents living with a child with enuresis and their support needs in relation to healthcare professionals.

Methods

A qualitative, semi-structured in-depth interview study was conducted and the interviews were analysed using systematic text condensation (STC). STC is a descriptive and explorative method, the goal of which is to find common themes in the experiences of participants, as expressed by them, rather than interpreting these experiences [16,17].

Participants

Eligible for inclusion was parents of children between 6 and 9 years with primary enuresis and for whom medical attention had been sought. Consecutive parents contacting either of two paediatric outpatient clinics for their child's enuresis were invited to participate in the study. To

establish the severity of enuresis, the children's frequency of voiding, volumes produced and "wet nights" were registered using a diary for 14 days prior to treatment commencement.

The parents ($N = 13$, 3 fathers and 10 mothers representing 13 unique and unrelated children), were 29–53 years of age, married or cohabiting, living in both rural and urban catchment areas of the paediatric outpatient clinics. The parents' educational level ranged from high school to university degrees. They were all born in Sweden except for one, who was from southern Europe. Three of the mothers had themselves suffered from nocturnal enuresis in childhood (Table 1).

The interviews

The first author (MC) carried out all the interviews between January 2011 and July 2011. The parents could choose where they would be interviewed. An interview guide was developed using literature [1–3] and the first author's experience of caring for families with children with enuresis as a paediatric nurse. No parent declined to participate, and the interviews, lasting between 35 and 90 min, were recorded. The questions covered the experience of everyday dilemmas of parents living with a child with enuresis and their perceived support from healthcare professionals.

When the first nine interviews were conducted they were transcribed and read through in order to make a primary analysis of the data. An additional four interviews were then conducted whereupon it was found that no new pertinent data was obtained and thus saturation was reached. The material was judged to have reached saturation when it was rich in details of parents' personal descriptions of their situations, also referred to as "thick description", with considerable variation in the kinds of experiences described, but also clear common themes therein.

Data analysis

All interviews were transcribed verbatim by the interviewer (MC) and then STC was applied [16,17]. This procedure is completed in four stages: in the first stage preliminary themes are found through reading and re-reading of the data. In the second stage new themes are discovered by searching only the data that directly impact the research

Table 1 Demographic information.

Parent demographics	Parents	Fathers	Mothers
<i>N</i>	13	3	10
Mean age (years)	39.5	47	37.3
Age range (years)	29–53	40–53	29–43
University	11	3	8
High school graduate	13	3	10
Nocturnal enuresis in childhood	3	0	3
Rural areas	3	1	2
Urban areas	10	2	8

question, called meaning units (i.e. quotations that are relevant to the research question). At this stage, if parts of the transcript are not relevant to the research question, then they are removed from the analysis and the remaining text units are sorted into code groups within each theme. The third stage consists of decontextualising the code groups into a condensate, which is an imagined narrative based on the meaning units within the code group in order to tell a story in the first person. The researcher thereafter writes an abstraction by describing the essence of the narrative, without searching for any underlying meaning. In the final stage the condensate is used to reconceptualise the data and create an analytic text, and relevant quotations are added in for demonstration purposes. Additionally, the original transcripts are re-read in order to determine the goodness of fit with the final set of themes and code groups.

To increase reliability in the analysis (referred to as dependability in qualitative methods), three researchers conducted the analysis (MC, AA, AS). Independent analysis was done in the first and last steps of the procedure, whereas the team of analysts met several times and worked through the findings together in the second step to determine the code groups.

In terms of subjective influences on the researchers' part, the first author had a preconception those parents of children with enuresis seemed somewhat ashamed when they presented the child's problems to her as a paediatric nurse. Her clinical experience also influenced the kinds of questions she asked about the practicalities of living with a child who has enuresis. The other analysts were medical professionals without personal or professional experience of enuresis.

Ethical aspects

The study was conducted according to the principles of the Declaration of Helsinki and was approved by the Regional Ethics Committee at Uppsala University, Document no. 2010/336. Informed written consent was obtained from the participants, it was clearly stated that participation was voluntary and that they could withdraw from the study at any time if they so decided. The parents were also informed that their decision to participate would not affect the care they receive, and that, if needed; they could contact the researcher at any time. To guarantee non-violation of the integrity of parents and children, only the researchers had access to the recordings and the transcribed interviews. Any names mentioned and geographical references were carefully removed at transcription to keep the data confidential and make recognition of individual subjects impossible.

Results

The analysis revealed six themes: (1) enuresis is socially stigmatising and handicapping, (2) all practices and home remedies are tested, (3) it creates frustration in the family, (4) protecting the child from gossip or teasing, (5) support from healthcare providers would have helped, (6) it is something we just have to live with.

(1) Enuresis is socially stigmatising and handicapping

Sometimes parents felt ashamed to have a bedwetting child. They feared that others in the community would know and maybe gossip about the child's condition. They often felt lonely and left out and did not dare to talk to people outside the family about their child's problem. Families sometimes avoided visits with overnight stays.

"It has been a bit limited, this with travelling and staying overnight ... you don't want to feel ashamed ... you especially don't want your child to happen to pee in someone else's bed" (Mother of a boy 8 years old)

There was concern about what others would think if they found out about their child's enuresis. Would they believe that their child had a developmental disability? Parents also described how their child compared him/herself with other children of similar age and felt immature. To wear nappies at night was considered by parents to be developmentally inappropriate for older children.

Fear and mistrust of the medical care system were also expressed, parents described uncertainty about whether old "Freudian" theories on sexual frustration or other psychological problems still influenced professional views about the cause of enuresis. This view was something that kept a father from accessing services for his son for a long time.

"I was unsure of what medical services thought this kind of thing was caused by. So maybe this would be considered to be part of psychiatric care rather than medical." (Father of a boy 9 years old)

(2) Protecting the child from gossip or teasing

Parents saw it as their duty to protect their child. This included protection from the wider family and other relatives as well as school friends and neighbours. They wanted to spare the child from embarrassing situations and so had adopted different strategies such as hiding nappies or providing "white lies" to avoid sleepovers.

"So we help him in this, we are his buddies in this, we help him and protect him from others" (Mother of a boy 7 years old)

Bedwetting was perceived as a very personal matter, and talking about it in front of others was perceived as violating the child's privacy. Parents took some care in how and to whom they talked about enuresis. Some of these parents were not so secretive with relatives or friends, whereas others emphasised that they only talked about the child's enuresis with carefully selected people, such as grandparents or close friends, as well as healthcare providers. Another issue that was mentioned by these parents was worry about the future. Would the child's self-esteem be hurt? Parents also worried about what might happen in the future if the child should continue to wet the bed. Would they be able to find a partner and enjoy a close relationship?

(3) It's something we just have to live with

These parents tried to have a shared understanding with their partner of how to relate to their enuretic child and

tried to manage everyday work together, as a team. They supported each other and could agree on their respective roles in solving different situations, such as who picks up and washes the child and who changes the sheets at night. They accepted each other's differences, tried to help out when the other parent was tired and often discussed how to solve things together.

"Teamwork is the cornerstone" (Father of a boy 9 years old)

These parents felt that it helped to discuss their child's problem with people they trusted.

Once the child him/herself had expressed concerns about bedwetting, parents did not hesitate to seek medical help. They contacted providers, such as the school nurse, a paediatrician, or primary care physician. They also used websites, Internet communities, or read information leaflets to get information and obtain advice.

Although enuresis was perceived as a social stigma in this group as well and parents sometimes worked hard to conceal its signs and consequences, many of them also showed great fighting spirit. They wished their child's life to be as normal as possible. They viewed enuresis as a practical problem to be solved: these parents were very clear about not giving in to enuresis.

"For this will not stop us in any way, will not stop us from living our lives, we'll work this out!" (Mother of a girl 8 years old)

(4) All practices and home remedies are tested

Parents tried different methods to keep the child dry. It could be waking the child once or twice a night using an alarm clock or taking them to the toilet when the parents went to bed. Parents also used nappies for their children, and protective covers for beds, in order to reduce the amount of laundry. Sometimes they asked the child to void regularly with fixed intervals during daytime. Also, the use of psychological methods such as threats, showing anger, or using reward systems were described. Sometimes it was just a reminder of the child's problematic condition:

"... 'If you want to sleep in my bed you need to pee before'... and then he is very co-operative because he thinks it's so nice to sleep with mommy." (Mother of a boy 6 years old)

Sometimes parents felt that the child was ashamed of his/her bedwetting. This, in turn, created guilt for the parent:

"He woke up and came in and said 'I wet myself, I am sorry'... and that hurt, really, really hurt, but that was of course the result of him feeling that I thought it was a drag" (Mother of a boy 7 years old)

(5) It creates frustration in the family

The child's enuresis resulted in many additional hours of work for the parents. All the extra laundry was a source of frustration and parents became irritated with each other. Fluid intake during the evening was often restricted for these children and if rules regarding this decided by one of

the parents had not been abided to by the other, and the child in fact had wet the bed, irritation and conflict was the result. The disrupted nocturnal sleep made both the parents and the child constantly tired.

Sometimes the child, or the other parent who had the same problems in childhood, was blamed. Parents felt frustration and irritation with the child and were ashamed of these feelings afterwards. Many asked themselves if they had done something wrong or if they could have done something different.

"Have we done everything right, thinking back like that? Should we be doing something differently?" (Father of a boy 6 years old)

Parents sometimes also expressed frustration with the child's apparent lack of motivation to become "dry". Much time and energy was spent nagging and reminding the child to pee before bedtime or not to drink so much in the evening. Sometimes the parents thought that the child should take more responsibility for trying to be dry.

"We're trying to help but he doesn't care!" (Mother of a boy 7 years old)

(6) Support from healthcare providers would have helped

The parents felt that they did not get the help they needed from the Child Health Centre (CHC). There was a lack of information about what causes enuresis, at what age to start treatment and how common it is.

"Nobody ever asked us if we needed help" (Mother of a boy 8 years old)

When parents asked the child health nurse about enuresis they perceived that they were not taken seriously and no information about how to take care of the problem was given. Parents also felt that the nurse did not feel comfortable talking about enuresis. Criticism was also directed at the primary care nurses and paediatricians for not informing families about incontinence aids that they were entitled to without extra cost. Families ended up paying, as they were not informed about these benefits. Parents expressed that a good time to inform about enuresis would be at the regular CHC pre-school check-up at age 5 years.

"Why didn't we receive any information at the CHC about how common this is and where to turn ... There must be a reason why they don't talk about it ... is it a taboo?" (Mother of a girl 7 years old)

Two main patterns identified

As a whole, the interviews revealed a picture of parents that differed in how well they succeeded in dealing with the situation and how much stress they experienced related to the child's bedwetting. Two main patterns were identified relating to the six resulting themes. Parents who expressed enuresis are socially stigmatising and handicapping; protecting the child from gossip or teasing were designated *Anxious night-launderers*. Parents who expressed it's something we just have to live with were

termed *Unworried wet-bed-fixers*. The themes it creates frustration in the family, all practices and home remedies are tested and support from healthcare providers would have helped were relevant to both groups even if they were expressed in somewhat different ways (Table 2).

Discussion

Methodological considerations

Credibility was strengthened by the use of an interview guide with open questions ensuring that the same areas would be covered in all interviews. Having a clear decision trail throughout the entire analysis process enhanced dependability (Table 3). The trustworthiness was strengthened by the fact that three authors (MC, AS, and AÅ) analysed the data individually and then discussed their findings on several occasions during the analysis. Transferability was promoted by paying careful attention to describing both typical and atypical views expressed by the informants and looking for patterns both inside and outside the designated themes. However, a limitation to transferability is that more mothers than fathers participated and all parents had at least a high school degree, with several having a university degree. Nonetheless, parents were recruited from both urban and rural areas of the county. However, the results may not be transferable to low-income and marginalised segments of the population or to families with different cultural backgrounds living in Sweden.

Two main patterns identified

Being a *Unworried wet-bed-fixer* or *Anxious night-lauderer* had consequences for how parents perceived the

Table 3 Summary of themes and main patterns identified in the analysis.

Themes	Main patterns
1. Enuresis is socially stigmatising and handicapping	"Anxious night-lauderers"
2. To protect the child from gossip or teasing	
3. "It's something we just have to live with"	"Unworried wet-bed-fixers"
4. It creates frustration in the family	Themes describing living with a child who has enuresis
5. All practices and home remedies are tested	
6. Support from healthcare providers would have helped	

present situation as well as what thoughts they had about the future. For *Anxious night-lauderers*, talking about their child's enuresis with people outside the private sphere was almost unthinkable since others might think that their child had psychological problems. These feelings and beliefs that NE is not a somatic disorder are similar to what has been described by Dunlop [7]. *Anxious night-lauderers* were also concerned about the child's future and wondered if enuresis would be a limiting factor in their child's possibilities to live a meaningful and whole life.

The *Unworried wet-bed-fixers*, on the other hand, were confident that their child would manage with or without enuresis later on and had no problem in seeing enuresis as a relatively unimportant, albeit hassle-intensive, part of their family lives.

Table 2 The four steps of the analysis process in systematic text condensation according to Malterud, with an example from the data [16,17].

Steps in data analysis	An example from the data
1 Total impression of the data: → Finding themes	Parents felt disappointed by the child health centre (CHC), especially by the health nurse because of the lack of help and information about enuresis. Preliminary theme: The Help
2 Identify and sorting relevant text units – meaning units → From themes to Codes.	Text units: "Why didn't we receive any information at the CHC about how common this is and where to turn... There must be a reason why they don't talk about it... is it a taboo?" "No one asked if we needed help" Code group: Lack of information
3 Condense the meaning in each code group as if it were a story told by a parent → From code to meaning through abstraction/interpretation	The CHC nurse never raised the issue of enuresis, it felt like it was taboo so I didn't ask her about it. But I feel that if we don't get adequate information at the CHC, where are we supposed to turn as parents? Abstraction: Parents felt frustrated and disappointed that the topic of enuresis was not raised routinely and professionally at the CHC.
4 Summarise the essence of each code group - Synthesizing → Validate the result by re-reading transcripts.	Essence: Openness and support from Healthcare providers would have helped. Re-reading transcripts, we found that the code group matched statements in the interviews and that the theme recurred in most of the interviews.

The patterns of mothers' and fathers' answers were similar, although no specific analysis was conducted to determine this. Some fathers seemed worried about social reactions to their child's enuresis, whereas some mothers were confident that their child would do just fine. There were also examples of the opposite reactions in both sexes. There were three mothers who had enuresis as a child, but we could not see any difference in the responses between parents with or without a history of enuresis.

It would have been interesting to look at tensions between parents and/or siblings linked to the issue of bed-wetting. This strategy would, however, have required longer time and the presence of the whole family, and will thus have to be left to future studies.

Healthcare may play a major role in eliminating the taboo

Irrespective of whether the parents could be described as *Unworried wet-bed-fixer* or *Anxious night-launderers*, many of them frequently used words like "shame", "taboo", and "blame". The disappointment and frustration described by parents in this study about the perceived absence of support from healthcare, and from the community paediatric nurse in particular, is echoed by the findings of others [4]. Healthcare professionals' attitudes may signal that they lack the interest, knowledge, or the courage to talk about enuresis, thus discouraging the discussion of the topic and the related feelings of shame and blame.

There was no evidence of physical violence against the children in this study, as opposed to that of Can et al. [13]. Even so, parental frustration and anger are to be expected at times of fatigue and stress and should be allowed to be discussed openly during consultation with the CHC nurse.

Conclusions and implications for healthcare

The main findings of this study illustrate that parents of children suffering from nocturnal enuresis often express feelings of frustration and shame even if they generally cope well and are not very worried about the condition. They want healthcare providers, especially child health nurses, to give more information both to parents at regular meetings and more specifically to parents with children who have nocturnal enuresis.

The hard work of adapting to everyday life and developing coping strategies are daily experiences for these parents. This study shows that, despite seemingly more enlightened societal attitudes, many parents continue to feel ashamed and worried about the possible causes and social consequences of their child's enuresis. Our recommendation based on our results is that questions about enuresis should be posed routinely to all families at child health surveillance visits. To reduce the stigma associated with nocturnal enuresis, relevant information about the condition, its (somatic) causes, available treatment options, and rights to aids and other support should be provided to affected families.

Conflict of interest

None.

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