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The Family and the Wet Bed

The parents' perspective and the child's treatment

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Abstract

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The focus of this thesis is nocturnal enuresis in the primary care setting. Three aspects have been central: 1) the parental perspective, 2) differences between children with enuresis of varying severity, and 3) to explore whether the universally recommended basic bladder advice have any therapeutic effect.

Study I built on qualitative data from interviews with 13 parents of children with enuresis, focusing on family impact and coping strategies. A common consensus among the participants was that they felt frustrated about the perceived lack of information and help they received from the healthcare system. In study II anamnestic data and voiding chart parameters – reflecting renal and bladder function – were compared between 54 children with enuresis of varying frequency. No measurable differences were found. Study III was a randomised controlled study. Forty children with previously untreated enuresis were recruited and randomised to receive either first bladder advice for one month and then alarm therapy (n=20) or just the alarm therapy (n=20). The bladder advice did neither result in a significant reduction in the number of wet nights, nor improve the effect of subsequent alarm therapy. Study IV was a cross-sectional questionnaire study of 52 parents, including comparison with normative data and with validated instruments evaluating intra-parental stress and satisfaction. The results showed no significant differences between the parents studied and normative data.

Study I and IV were the first to look at the parents, as opposed to children with enuresis. The results can be used by healthcare professionals when counselling families about strategies to use and attitudes to avoid. Study II aimed at filling a glaring blank in the field of knowledge: we do not know how children with infrequent enuresis differ from those who wet their beds often or every single night. The fact that no differences in bladder or kidney function was found indicates that they may differ in the way they sleep. Study III will probably have the greatest impact on how we should treat children with enuresis. The recommendation that all of them be given bladder training as a first-line therapy can no longer be supported.

Keywords: Nocturnal Enuresis, Parents, Children, Treatment, Nursing

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*To my children Philip, Carl and
Alexander*

List of Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I Cederblad, M., Nevéus, T., Åhman, A., Österlund Efraimsson, E., Sarkadi, A. (2013) “Nobody Asked Us if We Needed Help”. Swedish parents experiences of enuresis. *J Pediatr Urol*, 10:74-9
- II Cederblad, M., Sarkadi, A., Engvall, G., Nevéus, T. (2014) Infrequent enuresis, the uninvestigated majority – comparisons between children with enuresis of varying severity. *J Pediatr Urol*, 1477-513(14)00257-5
- III Cederblad, M., Sarkadi, A., Engvall, G., Nevéus, T. (2015) No effect of basic bladder advice in enuresis. – a randomized controlled trial. *J Pediatr Urol*. (In press)
- IV Cederblad, M., Engsheden, N., Ghadari, A., Enebrink, P., Nevéus, T., Sarkadi, A. (2015) No difference in relationship satisfaction between parents of children with enuresis and normative data. (Submitted manuscript)

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Abbreviations

ADHD	Attention deficit-hyperactivity disorder
BBA	Basic bladder advice
CE	Constant enuresis
DO	Detrusor overactivity
EBC	Expected bladder capacity
EEG	Electroencephalography
FFC	Family centred care
FE	Frequent enuresis
IE	Infrequent enuresis
ICCS	International Children's Continence Society
LC	Locus coeruleus
LUT	Lower urinary tract
PMC	Pontine micturition centre
RAS	Reticular activation system
REM	Rapid eye movement
ODD	Oppositional defiant disorder

Preface

During the ten years that I have been working as a nurse in a paediatric out-patient clinic, I have met many children with enuresis and their parents. Almost from the start I was struck by the intense frustration of the parents, who demanded a quick and effective treatment for their children. They wanted them to become dry *now*. Thoughts about how to optimize the treatment for these children in primary care and how to describe more closely the emotions of their parents grew, and when, in November 2010, it was suggested to me that I become a PhD student in this field of knowledge I jumped at the opportunity.

Introduction

Enuresis: definitions and epidemiology

The scientific word for bedwetting is enuresis (or nocturnal enuresis for extra clarity), which is defined as involuntary emptying of the bladder during sleep, occurring at the age of five or more. There is a distinction between primary enuresis, which means that the child has never been dry at night, and secondary enuresis, when the child has had a dry period of at least 6 months. Enuresis is also subdivided into monosymptomatic and non-monosymptomatic types. Children with monosymptomatic enuresis have no symptoms of bladder dysfunction during daytime, such as daytime incontinence, urgency symptoms, voiding difficulties or abnormal voiding frequency, whereas children with nonmonosymptomatic enuresis do have such additional symptoms [1]. The pathogenesis probably differs between these two types of enuresis and they often require different treatment.

Nocturnal enuresis is common among children, and to a certain extent also teenagers and young adults. It occurs in 10% of all 6 year-olds, and 0.5-1% of teenagers and young adults, and is 1.5-2 times more common in boys than girls [2, 3]. The condition is to a large extent hereditary [4]. Children with enuresis can either be affected by the problem every night or more sporadically, but the problem can be perceived as major even for the latter group. According to the International Children's Continence Society (ICCS) frequent enuresis (FE) is defined as bedwetting occurring four or more times per week, whereas infrequent enuresis (IE) affects the child less often. Although IE is more prevalent than FE, very little is known about what differentiates these groups, apart from the observation that the long-term prognosis is worse for children with FE [5-7]. It is, for instance, unclear whether the children differ pathogenically or if they require different therapies in order to become dry.

Physiological background

The pathogenesis behind enuresis is complex and involves lower urinary tract function, regulation of urine production as well as sleep and arousal mechanisms.

Lower urinary tract function

The lower urinary tract (LUT) consists of the bladder, urethra and sphincter. During the filling phase of the micturition cycle the internal sphincter is tonically contracted, whereas the detrusor, i.e. the smooth muscle layer of the bladder wall, is relaxed in order to protect the kidneys from harmful pressure and to avoid the voiding of the bladder at inopportune occasions. During the voiding phase, which only starts when it is socially acceptable and on prompting from higher cortical centres, the sphincter relaxes and the detrusor contracts until the bladder is completely emptied. These opposing actions of the sphincter and detrusor during the filling and voiding phases need to be closely coordinated [8].

The bladder of the newborn child can hold approximately 30 ml, a volume that will increase with approximately 30 ml per year as the child grows. In the lower teens the bladder has reached its adult capacity of around 400 ml. Consequently, the expected bladder capacity (EBC), or the amount of urine the bladder of a child with normal LUT function can be expected to hold, can be calculated using the following formula: $EBC = 30 + (age \times 30)$ ml [8].

The bladder and the sphincter are unique organs in that the volitional activities of micturition or urine storage are effectuated by smooth muscles and the autonomous (non-volitional) nervous system. These processes must thus be indirectly controlled through spinal reflexes, which, in turn, are coordinated by the pontine micturition centre (PMC). The PMC receives instructions from the cerebral cortex (the conscious impulse to urinate) and integrates somatic input and signals from the sympathetic and parasympathetic branches of the autonomous nervous system [9]. The parasympathetic activity makes sure that the detrusor muscle is relaxed and the internal sphincter contracted during the filling phase. The sympathetic nervous system will ensure that the opposite happens during the voiding phase [10].

Nerve endings in the bladder wall detect bladder distension or detrusor contraction. These sensory signals go through peripheral nerves and spinal pathways and give a conscious sensory impression (the feeling of urgency or bladder fullness) via the frontal and temporal lobes of the cerebral cortex. During bladder filling inhibitory input from the cerebral cortex to the PMC will make sure the micturition reflex is not activated. This inhibition is also responsible for continence while asleep [10].

If detrusor contractions, or the full micturition reflex, occurs during the filling phase, we speak about detrusor overactivity (DO) [1]. The subjective hallmark of DO is the experience of urgency – i.e. a sudden urge to urinate. Many, but not all, patients with DO also suffer from daytime incontinence, and when completing a bladder diary it is often found that they have an increased micturition frequency and have voided volumes far lower than the EBC. DO can be primary, but also secondary to constipation, since the blad-

der and the bowel are anatomically close and the distended rectum applies pressure on the bladder from behind [11].

Urine production

The usual urine production for a school-aged child is typically 500-1500 ml/day. A median value for a child aged seven is 700 ml/d and for a 16-year old about 1800 ml/d [12]. The regulation of urine production by the kidneys is a complex process involving several hormones, local renal factors and the autonomous nervous system. Under normal circumstances, urine production is reduced during the night, allowing for uninterrupted sleep. The central (but not only) factor behind the decreased urine production during sleep is the pituitary hormone vasopressin, or antidiuretic hormone [13]. Vasopressin is produced by neuron groups in the hypothalamus from where it is transported to the posterior pituitary and secreted. Increased levels of vasopressin acts by stimulating reabsorption of water from the distal nephron, thus making the urine more concentrated [13].

Sleep and arousal

Human sleep consists of rapid eye movement (REM) sleep and non-REM sleep [14], the latter of which can be split into four stages. Stage 1 is a transitory phase between awakesness and sleep. The person is then easily aroused and has difficulty in determining if he or she has slept at all. When falling asleep, stage 1 is usually very soon followed by stage 2 sleep when the rhythms of the electroencephalogram (EEG) is slower and arousal thresholds are slightly higher. After 10-20 minutes in stage 2 delta sleep, or stage 3 and 4 of non-REM sleep, is usually reached. During delta sleep considerable effort is needed if the person is to be awakened. The delta sleep will usually continue for 15-40 minutes, whereafter 5-20 minutes of REM sleep will follow. The intermittent rapid eye movements that can be observed during REM sleep illustrate that this is the stage when dreaming is taking place. The night's sleep will be spent cycling through these REM and non-REM sleep phases. The delta sleep periods are longer and more stable during the first part of the night, whilst the REM sleep periods are longer and the non-REM sleep less profound towards the morning. Consequently, the sleeper is most difficult to arouse during the first hours of sleep [14, 15].

The child's sleep differs from that of the adult. The younger the child is, the more time is spent in REM sleep and more of the non-REM sleep is delta sleep. The infant dreams around half of the time it is sleeping whilst the adult spends 15% of the night in REM sleep. Children also need more sleep than adults do [16].

To be able to wake up from sleep activation of the brainstem reticular activating system (RAS) is needed. The RAS is a diffuse network of neurons, which has its uppermost terminus in the locus coeruleus (LC) in the upper pons. Arousal is also connected to powerful activity of the central nervous system part of the sympathetic nervous system, which also has the LC as a major component. Arousal from sleep means that the sensory signals, elicited by an alarm clock or a distended bladder for instance, activate RAS and LC which leads to increased sympathetic tone (with increased heart rate and a rise in blood pressure as the result) and activation of the cerebral cortex, making the person aware of the circumstances and prepared for whatever may come [17].

Pathophysiology of enuresis

Arousal thresholds are crucial in enuresis [18]. Almost all parents of bedwetting children can attest to the child being difficult to wake up. Indeed, the factor almost all children with enuresis share is that they are difficult to arouse and therefore sleep through the signals from the bladder [19]. Why the child does not wake up to the extended or contracting bladder has not yet been conclusively determined, but some research suggests that the child may suffer from a disturbance in the vicinity of the LC [18, 20, 21]. There are also studies suggesting that although the bedwetting children are difficult to wake up and thus sleep “deeply”, they might in fact have a poor sleep quality [22, 23]. The repeated arousal stimuli from the bladder could make the child paradoxically difficult to wake up. The phenomenon can be illustrated by the metaphor that if someone constantly rang the doorbell you would probably end up having it disconnected in order to get some sleep.

The second factor which is present in many of the children is that they have nocturnal polyuria due to a lack of vasopressin [24]. This means that at night the child produces comparatively large amounts of diluted urine, and hence the bladder fills to capacity before the night is over. However, it turns out that not all children with enuresis have nocturnal polyuria, and not all children with polyuria are vasopressin deficient [25].

The third common pathogenetic factor is detrusor overactivity [26], i.e. the bladder has a tendency to contract unexpectedly without being full. This, in turn, may often be combined with constipation, with or without bowel-related symptoms [11]. Except for the link to constipation, not much is known about why some children with enuresis – and most children with daytime incontinence – have detrusor overactivity.

Thus, children with enuresis usually have either nocturnal polyuria, and/or detrusor overactivity – which may be combined with constipation – and they are difficult to arouse from sleep. This is further illustrated in Figure 1

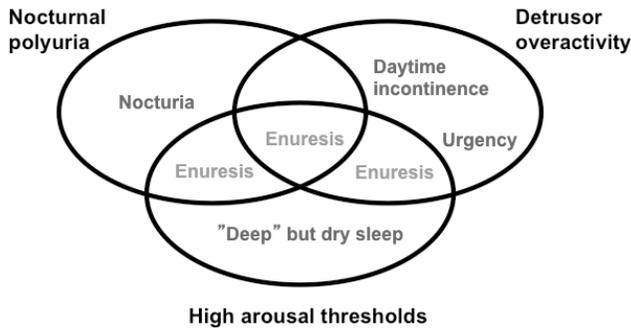


Figure 1. The overlapping pathogenetic factors in children with enuresis

Psychosocial aspects

Sigmund Freud, the father of psychoanalysis, is reputed to have said that "every nocturnal micturition corresponds to an ejaculation and is caused by frustrated sexuality" [27]. Accordingly, bedwetting children were previously usually treated with psychoanalysis, other psychiatric therapies or not at all, and both the children and their parents were given the impression that the condition was in some way their fault. It took time for the scientific community to realize that this attitude was misplaced and most of the treatment ineffective. The revolutionary change came in the eighties when researchers in Aarhus, Denmark, found the existence of a somatic cause behind enuresis [28].

Today it is known that bedwetting is mainly a somatic condition. On the other hand, it has been shown that enuresis can cause poor self-esteem with a risk for secondary psychological problems; a fact which underlines the importance of getting the children dry [29]. Recent research has also confirmed that enuresis is overrepresented among children with neuropsychiatric disturbances such as attention deficit-hyperactivity disorder (ADHD) or oppositional defiant disorder (ODD), although the cause behind this link is unclear [30].

Many parents show understanding and tolerance towards the bedwetting child, but some parents, usually those with older children and mothers, feel both depression and stress, and can make this affect the child [31, 32]. Parents have many strategies to deal with the enuresis of their child, such as setting an alarm to take the child to the bathroom in the middle of the night

or using various rewards or punishments [33]. Even though a child's enuresis affects the whole family not much research has been done regarding the parental experience. We don't know much about how it is to live with a child suffering from enuresis and what kind of help and support these parents receive, or wish to receive, from society [33-35].

Treatment

First-line treatment of enuresis can be divided into basic bladder advice and active treatment with the enuresis alarm or desmopressin. For several reasons the active treatment alternatives should not be utilised before the age of six. Besides the fact that the group of children with enuresis below that age is very large, they do not seem to be much bothered by their condition and may be difficult to motivate for treatment [36]. Before treatment starts, constipation must be looked for and, if present, treated [11].

The enuresis alarm

Alarm treatment is often recommended, at least if the family is well motivated. The principle behind the alarm, which emits a powerful noise when the child wets the bed, is, supposedly, that the child learns to either wake up and go to the toilet or to suppress the detrusor contractions in a semi-conscious state and thereafter go back to sleep. The exact therapeutic mechanism of the alarm is actually somewhat unclear, but the method is successful for around 2/3 of the children, provided the family is motivated and receives proper instructions from the caregiver. A big advantage with this method is that the successfully treated child is often permanently cured. The disadvantage is that the method is labour-intensive for the child as well as for the parents who will have to help the child to wake up [36, 37].

Desmopressin

Desmopressin is a synthetic vasopressin analogue which possesses the hormone's antidiuretic effect. The medicine is taken in the evening, and the decreased urine production hopefully leads to a dry night by preventing the bladder from filling to capacity before the morning. This works well for 1/3 of the children, while 1/3 have a partial success and the last third see no effect at all [38].

Basic bladder advice

In addition to the therapies described above, many authorities, including the expert panel behind the current ICCS guidelines, suggest that all children with enuresis receive basic bladder advice (BBA) prior to active therapy with the alarm or desmopressin [36]. The rationale for recommending this daytime therapy to children with nocturnal enuresis is that detrusor overactivity is recognized as a pathogenetic factor in enuresis [26] and urotherapy is known to be quite effective against daytime incontinence due to detrusor overactivity [39]

BBA can be regarded as a simplified version of urotherapy that can be provided by any healthcare professional. In accordance with the ICCS guidelines it can be summarized as follows [36]:

1. *Information and demystification.* The child and family are informed that enuresis is very common and that it is not the child's fault. Explanations regarding the pathogenesis are also given.
2. *Regular voidings during the day,* i.e. in the morning, twice during the school day, after school, at dinnertime, and before going to bed.
3. *Sound drinking habits,* i.e. liberal fluid intake in the morning, at lunch and early afternoon, but in the evening only enough to quench thirst.
4. *Good voiding posture.* Children are asked to sit on the toilet in an optimal position to relax the pelvic floor muscles.
5. *Physical activities encouraged.*
6. *Discontinuation of ineffective therapies,* such as scheduled waking of the child at night.

As mentioned above, bladder training or urotherapy is probably useful in daytime incontinence [40]. The evidence behind its efficacy in enuresis is, however, much more meagre. Hagstroem *et al.* could in their study show that timed voidings, with or without the addition of a wrist-watch timer, had a good effect against daytime incontinence, but did nothing to improve the bedwetting of children with concomitant enuresis [41]. There have been only a small number of studies specifically addressing the effect of urotherapeutic advice against enuresis and they have shown only a modest effect [42-45]. Furthermore, these studies have been afflicted with other flaws: either a large number of children dropping out from the therapy has not been taken into account or the children have used desmopressin and/or the alarm at the same time as the urotherapy. This means that the effect of BBA on its own cannot be determined. None of the studies mentioned included a control group. Still, it is recommended globally that BBA should be the first part of the treatment of children with enuresis.

Prognostic variables; which treatment works for whom?

It is now known that children with nocturnal polyuria and normal voided volumes during the day have a good chance to become dry with desmopressin therapy [46]. These data are easily acquired with the use of a so-called bladder diary, in which the child, together with his/her parents, records voided volumes at each micturition and assesses nocturnal urine production by weighing the diapers or sheet covers. There are some studies suggesting that children with smaller daytime voided volumes may respond better to the alarm, while children with nocturnal polyuria and small voided volumes possibly respond best to a combination of desmopressin and alarm [47]. These prognostic indicators are, however, less secure than those for desmopressin therapy. The best prognostic indicator for the alarm is the level of motivation of the family and the child [48].

Nursing science aspects

Salutogenic theory

According to the salutogenic theory “sense of coherence”, has a positive influence on health. A person’s sense of coherence explains why he or she may stay well in stressful situations and possibly even be able to improve his/her health. Sense of coherence includes the concepts of *comprehensibility, manageability and meaningfulness* [49].

Comprehensibility denotes the degree to which a person experiences information and knowledge about a situation as orderly, coherent, structured and clear. *Manageability* describes an understanding of which resources are available to assist the individual in coping with his/her current situation. The kinds of available resources are highly individual and can be anything from family members and caregivers to religious beliefs. *Meaningfulness* represents the degree to which people perceive meaning in their life despite everyday demands and adversity. This helps people view everyday life as part of something bigger with an overarching meaning, and challenges thus become worth tackling [49].

Family Centred Care

Different models can be applied in the care of the child and his/her family. Family centred care (FCC) is based on the patient empowerment literature and has also gained inspiration from salutogenic and systems theory [50, 51]. FCC promotes a relationship based on partnership between the nurse and the family, who in turn are viewed as an interconnected system where processes affecting one member spill over to other members. FCC also re-

gards the family system as the focus of intervention, rather than the individual child. In doing so it is the nurse's responsibility to discuss with the family how much they wish to participate in the care and what goals they wish to set. This kind of partnership implies an autonomy-promoting attitude from the nurse, meaning that he/she supports the reaching of treatment goals, rather than setting them. This approach is especially useful in chronic conditions and to support behavioral change processes.

FCC in relation to children with chronic conditions implies that the information to the family about the child's condition should be honest, unbiased and given in a way the family finds useful and affirming, so that they may effectively participate in the care and decision-making process. Information for children and families should be available in the range of cultural and linguistic diversity in the community and take into account health literacy. The ultimate goal of FCC is to recognize and build on the strengths of individual children and families by empowering them to discover their own strengths, build confidence and participate in making choices and decisions about their health care [52, 53].

Rationale for the thesis

Children with enuresis can either be affected by the problem every night or more sporadically, and the condition can be very bothersome even for the latter group. As mentioned above, almost all studies on children with enuresis have focused on the subgroup who suffer from FE, even though IE is more common. And apart from the observation that the long-term prognosis is worse for children with FE, and that alarm therapy is unsuitable for children with IE [54], we know very little about what differentiates these groups. With more knowledge we may be able to individualize therapy based on the child's enuresis frequency.

Although the rationale behind the widespread recommendation to provide BBA as a first-line therapy to all children with enuresis is logical, given the role of urotherapy as a mainstay in the treatment of daytime incontinence due to detrusor overactivity, there is, as yet, no firm evidence that bladder training is useful against nocturnal enuresis. This situation is highly unsatisfactory. Before global recommendations are given we should have evidence supporting these recommendations.

Many studies have been performed evaluating the situation of the children with enuresis [55-57]. Although, as FCC teaches us, the enuresis of the child affects the whole family, only little research has been done on the parents. We don't know much about how it is to live with a child suffering from enuresis and what kind of help and support these parents receive, or wish to receive, from society.

Overall and specific aims

As seen above, there are several areas where we lack crucial knowledge. Thus, the overall aims of this thesis were 1) to study the problem of enuresis from a parental perspective, 2) to get a more detailed description of the group of children with infrequent enuresis, and 3) to find out if daytime BBA has any effect against nocturnal enuresis. The specific aims of the four papers are stated below.

Study I

To explore the everyday dilemmas of parents living with a child with enuresis, and their support needs in relation to healthcare professionals.

Study II

To compare children with FE and children with IE using anamnestic data and variables related to bladder and kidney function. The hypothesis was that children with IE, as a group, have a less overactive bladder and/or less nocturnal polyuria than those with FE. Another aim was to look at the group of children who wet their beds every single night, a phenomenon we chose to call constant enuresis (CE).

Study III

To see whether the general recommendation to treat all children suffering from enuresis with BBA could be supported by evidence. We wanted to test both if the treatment is useful as a stand-alone therapy and/or if it increases the chances of success of subsequent alarm therapy.

Study IV

To evaluate how parents of children with enuresis rated their relationship satisfaction compared with normative data. A secondary aim was to investigate the potential differences in psychological symptoms, feeling of incompetence in the parenting role, and parental conflict between parents of children with the various subtypes of enuresis: IE, FE and CE.

Subjects and methods

An overview of the methodology and participants of the studies is presented in table 1.

Table 1. Overview of studies I-IV

Study	Design	Participants	Data analysis
I	Qualitative study based on semi-structured interviews	13 parents (10 mothers, 3 fathers) to children with enuresis	Thematic analysis with systematic text condensation
II	Comparative study	54 children with enuresis (16 girls, 38 boys)	Chi-square and Fisher exact test, ANOVA
III	Randomised, controlled intervention study	40 children with enuresis (11 girls, 29 boys)	t-test, Kruskal-Wallis, Mann-Whitney U test, Chi-square test
IV	Cross-sectional questionnaire study, comparisons with normative data	52 parents (34 mothers, 18 fathers) to children with enuresis	t-test and one-way ANOVA

Study I

This study built on qualitative data from parental interviews, analyzed using systematic text condensation as described by Malterud [58]. Interviews were made with parents of children with enuresis, focusing on family impact and coping strategies. Parents were invited to participate when they contacted the paediatric outpatient clinic because of their child's enuresis for the first time. Recruitment continued until information saturation was reached.

Individual semi-structured interviews were conducted and recorded at a place of the parents' own choice. Before the interview was started demographic data were obtained from the parents. The interviews lasted between

35 and 90 minutes. An interview guide was used and the participants were asked questions that covered the following areas:

- The experience of being a parent of a child with enuresis
- Any challenges or difficulties that parents may have encountered
- What strategies parents use in their daily life
- What support they received, or would like to receive, from healthcare providers

All interviews were recorded and transcribed verbatim by the interviewer. The material was then analyzed using systematic text condensation [58], (Table 2).

The analysis proceeded through the following stages: 1) reading and re-reading all the material to obtain an overall impression while making an effort to bracket previous preconceptions; 2) identifying all units of meaning, representing different aspects of parental dilemmas and experience in their everyday lives, and coding for these; 3) condensing and abstracting the meaning within each of the coded groups/categories; and 4) summarizing the contents of each category to generalized descriptions and concepts reflecting the most important aspects of dilemmas and experiences.

Table 2. The four steps of the analysis process in systematic text condensation according to Malterud [58]

Steps in data analysis	An example from the data
1 Total impression of the data:	Parents felt disappointed by the child health centre (CHC), especially by the health nurse, because of the lack of help and information about enuresis.
→ Finding Themes	Preliminary Theme: The Help
2 Identify and sorting relevant text units – meaning units	<ul style="list-style-type: none"> • Text units: <i>“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?”</i> • <i>“No one asked if we needed help”</i>
→ from Themes to Codes.	Code group: Lack of information

3	Condense the meaning in each code group as if it were a story told by a parent	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?
	→ from code to meaning through abstraction	Abstraction: Parents felt frustrated and disappointed that the topic of enuresis was not raised routinely and professionally at the CHC.
4	Summarize the essence of each code group - Synthesizing	Essence: Openness and support from health care providers would have helped.
	→ Validate the result by re-reading transcripts.	Re-reading transcripts, we found that the code group matched statements in the interviews and that the theme recurred in most of the interviews.

Study II

This was a comparative study, looking at anamnestic data and voiding chart parameters in children with FE and IE. We also chose to look separately at the children who wet their beds every single night. The eligible children were at least six years old, with enuresis but no daytime incontinence. They did not have any concurrent disorders or handicaps and had not been previously treated with the enuresis alarm or second-line antienuresis therapies, such as anticholinergics or antidepressants. They were recruited from two paediatric outpatient clinics in Uppsala, Sweden, between 2011 and 2013.

A paediatrician examined the child and a noninvasive urodynamic investigation, consisting of uroflowmetry and residual urine assessment, was performed. The family was then interviewed in a structured way, and the following anamnestic items were recorded: heredity, previous daytime incontinence, faecal incontinence, subjective arousal thresholds and finally constipation, defined according to the Rome III diagnostic criteria [59]. Thereafter, the child and the parents were asked to complete a voiding chart over a two-week period, recording wet and dry nights and daytime lower urinary tract symptoms. During this time, parents were also asked to measure daytime voided volumes and nocturnal urine production (by recording diaper weight) during 48 hours. The following data were obtained from the voiding charts: daytime micturition frequency, enuresis volume (the amount of urine voided

in the bed), nocturnal urine production during wet nights (including the first morning void), average daytime voided volume (with and without the first morning micturition included), maximum daytime voided volume (with and without the first morning micturition included) and 24 hour urine production. Daytime voided volumes, enuresis volume and nocturnal urine production were expressed as percentages of EBC. Constipation, if present, was treated. According to the results of the voiding chart the children could be divided into three groups; children who recorded seven wet nights or less during two weeks were assigned to the infrequent enuresis (IE) group and children who had between 8 and 13 wet nights were sorted into the frequent enuresis (FE) group. In a further subdivision, children with no dry nights formed the constant enuresis group (CE). The anamnestic and voiding chart data were compared between these three groups.

Study III

A randomized controlled study, exploring the possible antienuretic effects of BBA. Children with previously untreated enuresis were recruited and randomized to receive either first BBA for one month and then alarm therapy or just the alarm therapy. Prognostic indicators were gathered from the case history and voiding chart data.

The inclusion criteria were the same as in study II, except that in study III only children with an enuresis frequency of at least 8 nights out of 14 were included. The initial assessment of the children – including physical examination, noninvasive urodynamics, anamnesis and the completion of a 14 day voiding chart – was identical to that described above under study II.

After initial assessment the children were randomly assigned to two groups. Group A was treated with BBA according to the ICCS guidelines [36] (see above) during one month, recording wet and dry nights again during the last two weeks. After this, if the child still suffered from enuresis, alarm therapy was given for 8 weeks. Once again, wet and dry nights were documented during the last two weeks of treatment. The children in group B were only given alarm therapy during 8 weeks, without preceding BBA, and wet and dry nights were recorded during the last two weeks. The design is illustrated in Figure 2.

The reduction of wet nights between baseline and the end of the alarm treatment was thereafter compared between the two groups. Within group A, paired comparisons of the number of wet nights before and after BBA were also made.

Based on earlier studies in similar populations, it was assumed that the number of wet nights out of 14 (± 1 SD) without treatment was approximately 11.5 ± 2.7 . With a statistical power of 0.9 and a significance level of 5 % ($p = 0.05$), at least 15 children were needed in each treatment group to avoid missing a true difference in the treatment efficacy of three wet nights out of 14.

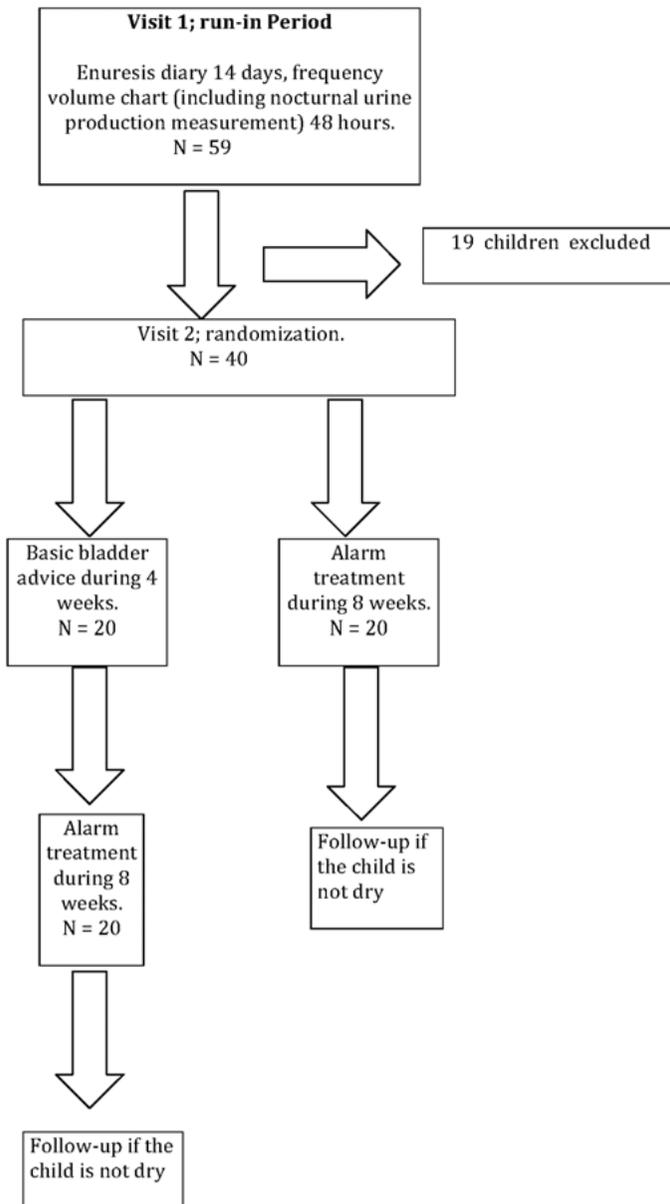


Figure 2. Study design and patient numbers in study III

Study IV

A cross-sectional questionnaire study, which also included comparisons with normative data. The validated instruments used focused on intra-parental stress and satisfaction. We examined how parents of children with enuresis

rated their relationship satisfaction compared with normative data. The potential differences between parents of children with FE, IE and CE as regards psychological symptoms, feeling of incompetence in the parenting role, and parental conflict were also assessed.

Participating families were recruited from two community paediatric outpatient clinics between April 2012 and April 2014 (see study II and III). Data were gathered using an electronic questionnaire distributed through Easyresearch®. If the questionnaire was not returned in two weeks, a reminder was sent.

Normative data from Björnsdotter *et al* were used to provide an age- and gender-stratified sample, with adequate distribution and representation of both sexes and all ages. This sample consisted of families of 2800 children aged 6-9 years and 1411 children aged 10-13 years [60].

The questionnaire consisted of five components: 1) Demographic background questions, 2) The Dyadic Adjustment Scale, 3) The Swedish Parent Stress Questionnaire, 4) The Parent Problem Checklist, and 5) The Depression, Anxiety, and Stress Scale.

Demographic background questions

Apart from questions regarding parents' age, education, civic status, and number of children one question was posed regarding family income, with four possible answers: *not enough*, *hardly enough*, *enough*, and *more than enough*.

1 The Dyadic Adjustment Scale (DAS)

Parents' relationship quality [61] was measured with an abbreviated version of the DAS, using four questions [62]:

1. "How often do you discuss or consider divorce, separation, or termination of your relationship?"
2. "In general, how often do you think that things between you and your partner are going well?"
3. "Do you confide in your partner?"
4. "Please, circle the dot which best describes the degree of happiness, all things considered, in your relationship"

This abbreviated version has shown a good stability over time and general effectiveness in identifying clinically distressed couples.

2 The Swedish Parent Stress Questionnaire

Parents' feeling of incompetence in their parenting role [63] was measured using nine statements [64], which were evaluated on a 5-grade scale from 1 = not at all true to 5 = very much true.

3 The Parent Problem Checklist (PPC)

This instrument is used to assess parents' ability to cooperate in child rearing. On a list of 16 possible problems the parents are asked to indicate whether those are present in their family or not; a typical problem can for example be "arguments about child care", "parents undermining each other's authority", or "inconsistency between parents" [65].

4 The Depression, Anxiety, and Stress Scale (DASS-21)

This standardized instrument, widely used in both research and clinical settings, consists of 21 questions, used to measure psychological symptoms [66].

Ethical considerations

The research included in this thesis was conducted according to the principles of the Declaration of Helsinki and was approved by the Ethical Review Board of the Medical Faculty of Uppsala University (dnr 2010/336). All children and parents were provided with written and oral information and gave written consent. It was clearly stated that participation was voluntary and that participants could withdraw from the study at any time if they so decided. The parents and children were also informed that their decision would not affect the care they received.

Results

Study I

A total of three fathers and ten mothers to 13 unique and unrelated children consented to participate in the study. No parent declined to participate. The children were between six and nine years old. They were all born in Sweden except for one, who was from Southern Europe. The parents were 29-53 years of age, married or cohabiting and living both in the rural and urban catchment areas of the clinic. Their educational level ranged from high school to university degrees. Three of the parents had themselves suffered from nocturnal enuresis in childhood. See Table 3

Table 3. Demographic information of the participants in Study I

Parent demographics	Parents	Fathers	Mothers
N	13	3	10
Mean age (years)	39.5	47	37.3
Age range (years)	29-53	40-53	29-43
University education	11	3	8
High School graduate	13	3	10
Enuresis in childhood	3	0	3
Lives in the rural area	3	1	2
Lives in the city	10	2	8

Six themes emerged during the analysis: 1) Enuresis is socially stigmatising and handicapping, 2) All practices and home remedies are tested, 3) It creates frustration in the family, 4) “It is my duty to protect my child”, 5) Support from health care providers would have helped, 6) “It’s something we just have to live with”.

1 Enuresis is socially stigmatizing and handicapping

Some parents were ashamed that the child wet his or her bed, and avoided speaking to others about it so that the child should not be perceived as having a disability. Sometimes the family avoided spending the night at a friend's house or in a hotel. Some parents avoided seeking professional help, thinking that the old "freudian" view of enuresis still prevailed.

2 All practices and home remedies are tested

Parents were willing to test all remedies which they had heard of from relatives and friends or read about on the Internet, such as waking the child once or twice per night, using diapers or instructing the child to pee at regular intervals during the day. The strategies could also include praise and disapproval. The constant search for new methods were induced by the feeling that the child was not faring well in his or her present situation, thus creating parental anxiety.

3 It creates frustration in the family

All the extra work with laundry and changing linen could make one of the parents annoyed at the other, especially if he/she did not adhere to the implicit rules, such as limiting the child's fluid intake in the evening.

"Then I ask my husband: did you give him something to drink, or why did this happen otherwise?" (Mother of 7 year old boy).

Being repeatedly awakened by the child at night disturbed the sleep of the entire family. If one of the parents had been a bedwetter him/herself, he or she felt guilty that the child had inherited this trait. Other parents, who had no such family history, could wonder "what did we do wrong?". Some families were concerned that the child felt no remorse or worry that the bed was wet, which the parents thought was provocative.

4 It is my duty to protect my child

Some parents stated that it was important that the enuresis should not limit the daily activities of the family. Enuresis was felt to be a problem that should be addressed by the whole family. There was a need to protect the child from being teased. Bedwetting was a very personal matter and not something to be discussed with outsiders. Even so, some parents chose to speak about the condition to close relatives and carefully selected friends. The family developed different strategies to prevent the child from being subjected to awkward situations during school trips or when sleeping over

with friends. These strategies could include smuggling a diaper into a large pyjamas which concealed it. It could also include the use of "white lies" to excuse the child from joining school trips.

5 Support from health care providers would have helped

All parents felt that support from the healthcare system was completely lacking. This included information about the condition, the treatment options available and the fact that diapers and sheet covers can be prescribed free of charge. Parents would have wanted the primary care nurse to be more active and ask if the child was a bedwetter. Many parents believed that if this had been the case they would not have been so frustrated about their situation.

6 It is something we just have to live with

These parents tried to work as a team. They had common rules about how to deal with the situation, but did not hesitate to seek professional help, especially when the child him/herself requested it. When one parent felt tired then the other took over.

"We team up, when one of us goes to the bathroom with...the other changes the bed linen superquickly and puts the wet ones in the washing machine. Yes we are a good team" (Father of 9 year old boy)

Synthesis

The main finding was that there are two types of parents in families with children suffering from enuresis: those who do not think that the enuresis affects the daily life of the family, and those who consider it anxiety-inducing and shameful (see Table 4). A consensus among the interviewed parents was that they all felt frustrated about the perceived lack of information and help they received from the healthcare system. The frustration could at times lead to unnecessary conflicts between the parents, or between the parents and the child. The parents gathered information by themselves and tried to invent their own strategies to make the child dry.

Table 4. Summary of themes and main patterns identified in the analysis

Themes	Main patterns
Enuresis is socially stigmatizing and handicapping	“Anxious night-launderers”
To protect the child from gossip or teasing	
“It’s something we just have to live with”	“Unworried wet bed-fixers”
It creates frustration in the family	Themes describing living with a child with enuresis
All practices and home remedies are tested	
Support from health care providers would have helped	

Study II

The total number of participants was 54 (age 6-11 years, median 6). Of these, 16 were girls and 38 boys. The number of investigated children with IE, FE and CE were 14, 18 and 22, respectively. No statistically significant differences in kidney and bladder parameters were found between the groups, and the only significant anamnestic difference was that children with IE had previously had daytime incontinence to a somewhat larger extent than those with FE (see Table 5). The most likely explanation for the lack of renal and urodynamic differences may be that the sleep and arousal of the groups are different, although this was not measured in the study.

Table 5. Anamnestic variables; comparisons between children of varying enuresis severity

	Infrequent enuresis	Frequent enuresis	Constant enuresis	p-value
	Proportion (%)	Proportion (%)	Proportion (%)	
Heredity*	7/12 (58.3%)	10/17 (58.8%)	14/22 (63.6%)	0.036
Urgency	6/14 (42.9%)	5/18 (27.8%)	8/22 (36.4%)	0.668
Previous daytime incontinence	7/14 (50.0%)	2/18 (11.1%)	2/22 (9.1%)	0.006
Faecal incontinence	3/14 (21.4%)	4/18 (22.2%)	3/22 (13.6%)	0.745
Constipation	2/14 (14.3%)	3/18 (16.7%)	2/22 (9.1%)	0.766

* Three of the children were adopted

Study III

Fifty-nine children were recruited. Of them, 19 were excluded because 14 of them wet their bed less than 50% in two weeks and five did not comply with the study protocol. This left 40 children, 11 girls and 29 boys, for the final analysis. Twenty children were included in each treatment arm.

The number of wet nights (out of 14) before and during the study can be seen in Table 6 and are further illustrated in Figure 3. There was no statistically significant reduction of wet nights during BBA ($p=0.089$) and the groups did not differ regarding the final outcome ($p=0.74$). Only four children in group A had a partial or full treatment response to BBA, but three of them relapsed immediately during alarm therapy. Thus, BBA did neither help on its own, nor improve the success rate of subsequent alarm therapy.

Table 6. The number of wet nights out of 14 before and after the interventions. Numbers within parentheses are mean \pm 1 SD.

	Run-in	After bladder advice	After alarm treatment
Group A (n = 20)	8-14, median 14 (11.9 \pm 2.5)	0-14, median 13.5 (10.5 \pm 4.8)	0-14, median 4.5 (5.6 \pm 5.36)
Group B (n = 20)	8-14, median 14 (12.6 \pm 2.3)		0-14, median 2.5 (4.8 \pm 5.38)

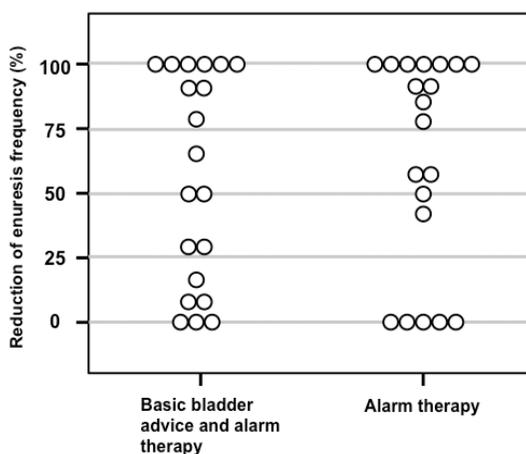


Figure 3 Reduction of enuresis frequency (%)

Study IV

Out of 110 eligible parents, 82 agreed to participate. Of these 82, 52 completed the questionnaires. Of the participating parents, 34 were mothers and 18 fathers; in 11 of the cases both parents answered the questionnaire. Most of the parents were married (77 %), whereas seven (13.4%) were cohabitant, two (3.8 %) were single parents, one (1.9 %) was living apart from the other parent, and two (3.8 %) indicated "another type of the relationship". These 52 parents represented 41 children with enuresis, aged between 6 and 12 years (mean and median = 7 years, $SD = 1.4$). Twenty-nine (71 %) of the children were boys and 12 (29 %) girls. Concerning the frequency of enuresis, 10 children (24 %) were categorized as IE, 13 children (32 %) as FE, and 18 children (44 %) as CE.

No significant differences were found between the parents studied and normative data. Furthermore, there were no differences between groups of parents to children with different enuresis frequency (IE, FE, CE). Finally, mothers and fathers had similar scores on relationship satisfaction, a finding that stands in contrast to previous general findings in the parenting literature [67].

Discussion

The findings presented in this thesis may have considerable impact on children with enuresis and their families. Study I and IV were the first to look at the parents, as opposed to children with enuresis. Valuable insights as to how families cope were gained. The results can be used by healthcare professionals when counseling families about strategies to use and attitudes to avoid. Study II aimed at filling a glaring blank in the field of knowledge: we do not know how children with infrequent enuresis (the majority) differ from those who wet their beds often or every single night. Now we know that the children do probably *not* differ as regards two of the three crucial pathogenetic factors: nocturnal polyuria and nocturnal detrusor overactivity. This will help in tailoring treatment strategies for the two groups of children. Study III, finally, will probably have the greatest impact on how we will treat children with enuresis. As the first study ever to evaluate, in a prospective, randomized, controlled manner, the value of daytime basic bladder training as a treatment of children with nocturnal enuresis, it has given grounds for changing the international guidelines. The recommendation that all children with enuresis be given bladder training as a first-line therapy can no longer be supported.

Study I showed that there were two groups of parents to bedwetting children, one who did not feel that their child's condition had a major impact on the family's everyday life, and another group who felt burdened by anxiety and shame. Common for all interviewed parents was that they expressed disappointment over the, as they saw it, virtually non-existent information and support they received from the healthcare system. The nurse is knowledgeable in nursing science and can develop a deeper understanding of the family dynamics, and the effect this has on the child's experience of the situation and *vice versa*. By doing this the nurse can develop his/her role as a mediator for planned and structured nursing with focus on the entire family. How this is accomplished depends largely on his/her 1) preconceptions of the families, 2) professional role and 3) attitude towards family involvement in the care. The general idea of FCC [50] is to perceive the entire family in the nursing care based on the needs expressed by the family. In this context one sees assets rather than shortcomings, and especially assets within the family. The relationship between the nurse and the family should be characterised

by partnership, so that the nurse contributes with information and support, and the family makes and executes decisions. Study I shows a failure in this respect as the parents thought that information about the child's enuresis should have been offered by the primary care nurse and paediatrician. This lack of information and support caused frustration, which, in turn, could lead to less useful coping strategies and unnecessary conflicts as well as extra costs for the families affected. Parents expressed that there seemed to be a lack of knowledge and involvement by health professionals, given that enuresis does not inflict any physical harm to the child. They also expressed the taboo nature of enuresis and were disappointed to find that their paediatric nurses never raised the subject. In their mind, if these nurses, who see children and their families on a daily basis, do not talk about enuresis as something common and treatable – who will?

Despite the stresses of living with enuresis, Study IV showed that concern for the child and the lack of information did not affect the parents' relationship or their perception of being "good parents", compared to the general Swedish population. Parents of both sexes had basically the same result and this could possibly reflect the fact that Swedish society encourages equal responsibility in the care of the child. Another explanation can be that most of the parents were married, cohabiting with high education and income level.

These apparently contradictory results do, however, show the complexity regarding families with a child with enuresis: on the one hand the enuresis does not affect relationship and role satisfaction in the family. On the other hand, the bedwetting and its practical and emotional consequences do affect the family and may possibly lead to conflicts and a sense of shame or of doing something wrong. As mentioned earlier, enuresis is both a big problem for the child and family and, due to the high prevalence of the condition, a source of big costs for the healthcare system, since effective treatment often demands several visits and/or phonecalls from the healthcare professional. It is of crucial importance that the allocations of healthcare resources be optimised to give the largest possible number of families effective help to the lowest possible cost. In study I we have shown that due to a perceived lack of information from the healthcare professionals the parents gather their own information and try their own home remedies since the wish to get the child dry is so pressing. In Sweden, the age when parents are allowed to seek professional help for their child with enuresis is usually six years, and help is usually sought via primary care or a paediatric out-patient ward. It is then important that the family get access to effective treatment since the child will soon start school and activities involving camps or sleep-overs with friends will become increasingly relevant.

At the start of study II we identified a group of children who, just by visiting the study nurse and being asked to complete a bladder diary during two weeks, decreased their presumed enuresis frequency to less than 50% of the nights. That this group with infrequent enuresis exists is of course well-known, but there has been very little research about how these children differ from those with more frequent enuresis. Every healthcare professional involved in the care of children with enuresis is familiar with the story of children who wet their beds most nights at home but stay dry whenever they sleep at grandma's house, only to start wetting again when they get home. By looking at anamnestic data and voiding chart parameters we found no indication that children with varying enuresis severity differ regarding two of the crucial pathogenetic factors, namely bladder function and nocturnal urine production. Remains the third factor: sleep and arousal. It is logical to assume that what differs when a child sleeps away from home is not related to renal or bladder function but to the child's sleep. Strengthened by the results of this pilot study, we can speculate that what makes some nights dry and some wet for children who do not wet their beds every night is the quality of their sleep. This is also in line with the observation that the enuresis alarm, which obviously acts via effects on sleep and arousal, works best in children with frequent or constant enuresis [54].

According to global expert recommendations, including the ICCS guidelines [1], active antienuretic therapy with the enuresis alarm or desmopressin should be preceded by bladder training, i.e. BBA. This is quite remarkable, given the almost total lack of evidence that such treatment is effective. The available evidence only gives support for its use in daytime incontinence [39]. It is equally remarkable that so few studies have addressed this lack of knowledge: the efficacy of BBA in enuresis has just been taken for granted, just as in an earlier era the prevailing notion that psychotherapy or counselling was the treatment of choice was never seriously questioned. The few investigations in which the role of BBA or urotherapy in enuresis have been examined have been hampered by either not taking the drop-outs into account [42-45] or not differentiating between active therapy and urotherapy, and none of them have been randomised and controlled. In our prospective, randomised and sufficiently powered study we could find no evidence that the treatment was effective. Only four children responded to therapy and for three of those the response was partial and temporary. We can not be at all sure that the dryness of the single child who actually became consistently dry after BBA was due to the advice given, it could just as well have been a case of spontaneous remission or a placebo effect: earlier research has shown that the mere documentation of wet and dry nights can have some therapeutic effect [68].

Limitations of the studies

Study I differs from the others in having a qualitative approach. Within qualitative research, three concepts are used to judge quality: 1) *credibility*, which refers to the amount of confidence one has to the truth of the data in relation to the research question; 2) *dependability*, which refers to the stability of the data and describes the extent to which results can be corroborated or confirmed by others; and 3) *transferability*, which refers to the extent to which the findings can be transferred to other settings or contexts [69].

Credibility was strengthened by the use of an interview guide with open questions, ensuring that the same areas would be covered in all interviews. Dependability was enhanced by leaving a clear “decision trail” throughout the entire process of analysis (Table 2). Dependability was further strengthened by the fact that three authors with different backgrounds (physician, midwife and paediatric nurse) analyzed the data individually and then discussed their findings on several occasions. Transferability was promoted by paying careful attention to describing the sampling procedure and the background characteristics of participants, as well as presenting both typical and atypical views expressed by the parents. Limitations to transferability include the lack of non-Swedish speaking parents and that few fathers and parents with a low educational level were represented. Despite these limitations, we believe that the findings can add valuable knowledge about parents of children with enuresis. It would be of value to do future research in another area in Sweden with other types of income and education levels than Uppsala.

The main limitation of study II was that it was not planned in advance and that no power calculations could be done prior to patient recruitment. Thus, the fact that we did not find any differences between the groups does not preclude that there may, in fact, be small differences that would have been found had we looked at a bigger sample. Still, we thought this was an interesting group to look at separately, as a pilot project.

Arguably, the main limitations of study III are that we did not give the treatment long enough and did not ensure compliance with the therapeutic regimen using frequent follow-up visits. That would, however, have disqualified the results since the treatment that was evaluated was *basic* bladder advice – i.e. the simple, easy-to-follow instructions that can be given by any healthcare professional – not full-blown urotherapy. We wanted to test the value of a therapy that is supposed to be indicated as a first-line therapy for standard patients in primary care. Intensive urotherapy for, say, two months, including time-consuming efforts of the nurse, may possibly help more children with enuresis to become dry, but is not cost-effective to use before the evidence-based treatments, i.e. the alarm and desmopressin, have failed.

In study IV parents from Uppsala County were invited. Limitations to the study were that most of the parents were native Swedes with both higher

educational level and economic standard compared to the normal population. Furthermore, the number of participants was small, especially for fathers, and we cannot exclude that small differences would have been found if we had looked at a larger sample.

Conclusions

The results of paper I add to the knowledge that having a child with enuresis influences all family members and can be stressful for the parents. Parents may display different ways of coping with the situation, but Study IV showed that enuresis doesn't influence the parents' relationship as a couple or their sense of competence as parents. Paper II indicates that the "unexplored majority" of the children with enuresis, who do not wet their beds every night probably do not differ from children with more frequent enuresis regarding bladder and kidney function, but may be more easy to arouse from sleep. Finally, as paper III shows, daytime bladder training does not reduce the frequency of wet nights in children with enuresis.

Clinical implications

Given that 10% of all 6-year olds are affected by enuresis, our results imply that the general level of knowledge about the condition needs to be raised in the healthcare system, both regarding treatment options and how the condition can affect the family. Since the treatment of enuresis largely depends on involvement of the parents it is vital to employ models of care that best make use of their resources and capabilities. One crucial implication of our results is that daytime bladder training should probably not be recommended as a first-line therapy in enuresis. Instead, these children should start alarm or desmopressin therapy straight away. A change of strategy in line with the implications of our research would save time for the family and child as well as for the healthcare professional involved, since BBA is time-consuming. This way, the limited healthcare resources could be used in an optimized way.

Knowledge gained about parents' perceptions can be used when healthcare professionals are counselling families about strategies to use and attitudes to avoid. Probably, an approach according to FCC could be useful to apply to facilitate the family's decisions about treatment options and to support them in reaching their goals.

Populärvetenskaplig sammanfattning på svenska

Det vetenskapliga namnet på sömnavbrott är enures. Det är mycket vanligt i den tidiga skolåldern men kan ibland finnas kvar långt upp i tonåren eller till och med i vuxen ålder. Bakom enuresen finns tre centrala orsaksfaktorer. Den faktor som de flesta barn med nattväta har gemensamt är att de är svåra att väcka när de sover. Den andra faktorn som är aktuell hos en del av barnen är att de utsöndrar för lite av hormonet vasopressin, som minskar urinproduktionen under natten. Detta innebär att barnet under natten producerar förhållandevis stora mängder urin och att urinblåsan därigenom blir full innan natten är slut. Den tredje faktorn som ibland finns med är att urinblåsan kan ha en benägenhet att dra ihop sig utan förvarning och utan att den är full.

Barn med enures kan endera drabbas av problemet varje natt eller mer sällan. En del barn kan till exempel vara torra under utlandsresor eller när de sover över hos mormor, men sedan börja kissa i sängen igen. Vi vet inte mycket om vad som skiljer dessa barn från dem som kissar i sängen varje natt.

Det finns två bevisat effektiva behandlingar mot enures; enureslarmet och läkemedlet desmopressin. Enureslarmet är en apparat som har en urindetektor i barnets underbyxor kopplad till ett larm, som då barnet kissar på sig ger en kraftig ljudsignal. Tanken är att barnet vaknar av signalen och därigenom gradvis lär sig att koppla kissnödighet under sömn till att vakna eller knipa istället för att kissa i sängen. Desmopressin har samma effekt som hormonet vasopressin och ser alltså till att njurarna inte producerar så mycket urin under natten. Förutom dessa behandlingar menar många experter att alla barn med enures också skall träna sin urinblåsa dagtid genom att följa ett antal enkla blåsråd. I korthet går instruktionerna ut på att lära barnet kissa regelbundet och i rätt kroppsställning samt att tömma blåsan fullständigt.

Tidigare ansågs enures vara en psykisk störning. Sigmund Freud menade att ”varje nattlig blåstömning motsvarar en sädesuttömning och beror på frustrerad sexualitet”, men idag vet man att nattväta är ett huvudsakligen kroppsligt problem. Att det däremot kan ge upphov till bristande självkänsla och därigenom sekundära psykologiska problem är väl känt och huvudskälet till att man bör få barnen torra.

Många föräldrar visar förståelse och tolerans gentemot sitt sömnavbrottande barn, men en del känner både nedstämdhet och stress, och kan låta detta gå

ut över barnet. Föräldrar kan ha många typer av strategier för att hantera sitt barns enures, som att ställa klockan och ta upp barnet på natten eller genomdriva olika former av belöningar eller straff. Trots att ett barns enures drabbar familjen i stort vet vi väldigt lite om hur dessa föräldrar upplever vardagen samt vilken hjälp och stöd de får från vården.

Syftet med denna avhandling var att ta reda på om blåsträning har någon effekt vid enures samt att studera hur det är att vara förälder till ett barn med enures. Dessutom ville vi titta närmare på den grupp av barn som har enures men inte drabbas varje natt.

I delstudie I intervjuades 13 föräldrar till barn med enures. Studien visade att det fanns två grupper av föräldrar: de som inte tyckte att enures var något som påverkade vardagen för familjen, trots en massa extraarbete med nattliga sängombyten och tvättar, samt de som tyckte att enures var något mycket ångestladdat och skambelagt. Gemensamt för alla de intervjuade föräldrarna var att de kände ett stort missnöje över den – som de upplevde det – näst intill obefintliga information och hjälp de fått från sjukvården. Framför allt menade man att denna information borde ha kommit från BVC-sjuksköterskan. Denna avsaknad av information och hjälp skapade frustration hos föräldrarna; en frustration som ibland ledde till onödiga konflikter mellan föräldrarna eller mellan föräldern och barnet. Föräldrarna påpekade att det verkar finnas en brist på kunskap och engagemang från sjukvårdens sida, eftersom enures inte ses som en åkomma som kan innebära fara för barnet rent fysiskt. Föräldrarna sökte egen information och försökte sig på olika egensnickrade behandlingar eftersom önskan att få barnet torrt var så stor.

I studie II valde vi att jämföra grupper av barn med enures som drabbas av sitt problem olika ofta. Vi fann inga tydliga skillnader i njur- och blåsfunktionen. Slutsatsen är att det sannolikt är sömnen och uppvaknandet som skiljer de olika barnen åt.

I studie III fick två grupper om vardera 20 barn med enures olika behandlingar. Den ena gruppen fick genomgå blåsträning under en månad och sedan – om de fortfarande kissade i sängen – behandling med enureslarmet. Den andra gruppen fick behandling med larmet redan från början. Blåsträningen gjorde inte barnen torrare. Däremot hjälpte enureslarmet bra.

I delstudie IV ville vi närmare se om barnets enures påverkade föräldrarnas parrelation samt stress i föräldrarollen. Femtiosex föräldrar till barn med enures fick fylla i en enkät innehållande olika frågor gällande depression, ångest och stress, samt frågor som rör föräldraskapet och relationen mellan föräldrarna. Resultaten jämfördes med en stor grupp föräldrar ur befolkningen i stort och resultatet visade att föräldrarna till barn med enures inte skilde sig från resten av befolkningen.

De resultat som presenteras i denna avhandling kan ha betydande inverkan på barn med enures och deras familjer. Studie I och IV har gett värdefulla insikter hur föräldrarna mår och resultaten kan användas av sjukvårdspersonal för att underlätta för dessa familjer. Studie II syftade till att fylla den okunskap som vi har om barn med olika typer av enures och där vi nu vet vi att de olika typerna inte skiljer sig åt. Detta kan komma att bidra till att vi mer kan skräddarsy behandlingsstrategier för dessa grupper. Studie III har nog den största betydelsen eftersom den visar att de nu gällande internationella rekommendationerna att ge alla barn med enures blåsträning bör ändras. Behandlingen bör börja direkt med enureslarmet eller medicinering.

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