

Meeting the Needs of Parents and Pediatric Patients: Results of a Survey on Primary Nocturnal Enuresis

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Summary: Primary nocturnal enuresis (PNE) affects about 7 million children and adolescents in the United States. A telephone survey of 745 parents/guardians of children aged 3 to 14 years was conducted to determine their knowledge and attitudes about PNE. Most did not know that PNE is a physical problem. Although 82% would want healthcare providers to discuss PNE with them if their child older than 6 years wet the bed, most would be uncomfortable initiating the dialogue. According to parents, healthcare providers either never or rarely discuss PNE. For the benefit of their young patients, healthcare providers must initiate discussion about PNE.

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Introduction

Primary nocturnal enuresis (PNE) is the involuntary voiding of urine during sleep in a child who has never achieved sustained nighttime continence.¹ Nocturnal enuresis is considered primary when it occurs at an age when bladder control is expected (usually by 5 years old), and secondary if it follows a dry period of at least 6 months.²

PNE was described as early as 1935 by Frary.³ In the 1950s, PNE

was presumed to be a psychiatric problem and was treated (often unsuccessfully) with psychotherapy. The etiology of PNE is now considered multifactorial, including diminished functional bladder capacity,⁴ inadequate production of antidiuretic hormone (ADH) at night,⁵ and/or an arousal disorder (lack of awareness of a full bladder during sleep),⁶ but not a pathologic process. Recent studies report an association between enuresis and obstructive sleep apnea and ade-

notonsillar hypertrophy.⁷ This association appears to be infrequent and needs to be explored via additional clinical trials. Constipation might also be a contributing factor and should be relieved when present.⁸ Urinary tract infection and specific psychosocial events (e.g., acrimonious divorce) are more common etiologic factors in secondary enuresis.²

An estimated 5 to 7 million children and adolescents in the United States are affected by PNE,⁹ although the true prevalence of enuresis is unknown owing to underreporting. There is a strong hereditary component. The prevalence of enuresis in children who have 1 or both parents with a history of childhood enuresis is 3-fold and 5-fold higher, respectively, as compared to the prevalence in children of

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parents with a negative history.² Results of twin and molecular genetics studies also support a genetic basis for PNE.¹⁰ A spontaneous, 15%-per-annum resolution rate of enuresis supports a developmental component. This resolution rate continues into adulthood,¹¹ when the prevalence of bedwetting remains at approximately 1% to 2%.²

Although PNE typically is not associated with medical sequelae, there is often a significant psychosocial impact on affected children and their families. Enuretic children experience embarrassment, social isolation, behavioral problems, and low self-esteem,¹²⁻¹⁴ with the impact of bedwetting increasing and expanding to all family members as children age. In a questionnaire-based study conducted by van Tijen and coworkers,¹⁵ children and adolescents with PNE ranked it as the third most stressful life event, after parental divorce and fighting, and more stressful than pressure for academic attainment or being teased.¹⁵ Enuresis can be a source of great frustration and stress within families and has been implicated as a trigger in child abuse.¹⁶

Despite the prevalence of PNE, our clinical experience suggests parents know little about PNE, and healthcare providers spend very little time discussing it with their pediatric patients. To further understanding of PNE with objective evidence, the National Association of Pediatric Nurse Practitioners (NAPNP) sponsored a survey to assess parental knowledge, attitudes, and concerns about PNE, as well as parents' expectations vis-à-vis their healthcare provider's role in discussing, diagnosing, and treating PNE. The results of this survey are presented in this paper.

Methods

Survey Population

A telephone survey was conducted using a national probability sample of 4,163 adults over age 18 years living in private households in the continental United States. This yielded 745 useable survey responses (n=745). An unrestricted random sampling procedure that controls for serial bias found in systematic sampling was used to generate a random-digital sample. The sample was fully replicated and stratified by region of the country. The anonymity of all respondents was maintained. Responses of the 745 adults who identified themselves as parents or guardians of children age 3–14 years were included in this survey.

Survey Questions

An initial question was asked to identify the target audience for the survey (as described above). Adults who met the inclusion criteria were asked questions about the following: their knowledge of bedwetting, their response if 1 of their children over age 6 years suffered from bedwetting, and the role of healthcare workers in the management of bedwetting.

The survey was administered to every individual in a standardized fashion. The interviewers followed a script, asking identical questions and presenting identical answer options to every study participant.

Data Collection and Analysis

The interviews were conducted by employees of Opinion Research Corporation International (Princeton, NJ) and were completed during April and May 2003. All interviewers had previously completed intensive training and were supervised and monitored to maintain high-quality

interview standards. Interviews were conducted using a computer-assisted telephone interviewing system, which provides an accurate form of data entry. Only 1 interview was conducted per household. Up to 4 attempts per sample telephone number were permitted to complete the interview.

The results of the completed interviews were weighted by 4 variables: age, sex, geographic region, and race, to ensure reliable and accurate representation of the total adult population. The raw data were weighted by a custom-designed program that automatically develops a weighting factor for each respondent. The survey margin of error was $\pm 4\%$.

Respondents were categorized by the following: sex (male or female), parent age in years (18–24, 25–34, 35–44, 45–54, 55–64, ≥ 65 years), residence in metropolitan vs nonmetropolitan area, race (Black, Caucasian, Hispanic), annual household income (< \$15K, \$15K to < \$25K, \$25K to < \$35K, \$35K to < \$50K, \geq \$50K), age of children in household (3 to < 12 years old and 12–17 years old), and educational status (high school incomplete, high school graduate, college incomplete, college graduate). A 95% confidence interval was computed for the differences between categories of each demographic characteristic.

Results

In total, 745 respondents met the inclusion criteria for the survey. The survey population was equally represented by sex (45% males), and the majority (75%) was Caucasian. Mean age was 39 years, mean annual household income was \$52K, and just over half had either entered but not completed (22%) or graduated (37%)

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from college. Most (82%) had children under 12 years old. Respondents were living in the Northeastern (19%), North Central (22%), Southern (39%), or Western (20%) regions of the United States.

Half (50%) of surveyed parents reported someone who continued to wet the bed from the age of 6 years and older. Eighteen percent had a child, 21% had another family member, and 27% knew a friend or child of a friend who suffered from bedwetting. Seven percent remembered they themselves had wet the bed. Mothers and those in the lowest income category were significantly more likely to admit knowing someone who had nocturnal enuresis during childhood. When informed about the published prevalence of bedwetting by age, 57% claimed to be “not surprised,” 16% said they were “very

surprised,” and 26% were “somewhat surprised” by the facts.

Despite their knowledge about the prevalence of PNE, only 38% of survey respondents correctly identified bedwetting as a health problem (defined as, “the child cannot control it because of a physical problem”). Many considered it either a psychological problem (26%) or a behavioral problem that the child can control (13%). Females (46% vs 28% of males) and those residing in nonmetropolitan areas (47% vs 35% in metropolitan areas) were significantly more likely to know bedwetting is a health problem. Responses (lack of parental knowledge) were generally consistent across all parental income levels and ages.

Parents were also questioned about their need for information about PNE. If their child age 6 years or older continued to wet

the bed, parents expressed the most interest in knowing the causes ($p < 0.05$ in the low-income group vs higher income categories), followed by available treatment options, the effect PNE has on their child, and how to discuss the disorder with their child (Figure 1).

Parents' primary concern, in regard to the effect of PNE on their child, was its negative impact on the child's self-esteem (Figure 2). Other concerns (in decreasing incidence) included fewer opportunities for overnight family visits, stress in the home, and conflict between themselves and their child. Fathers and mothers were equally concerned about the effect of bedwetting.

Perhaps a reflection of the long-standing stigma associated with bedwetting, 64% of parents expressed discomfort (“not too” or “not at all” comfortable) with

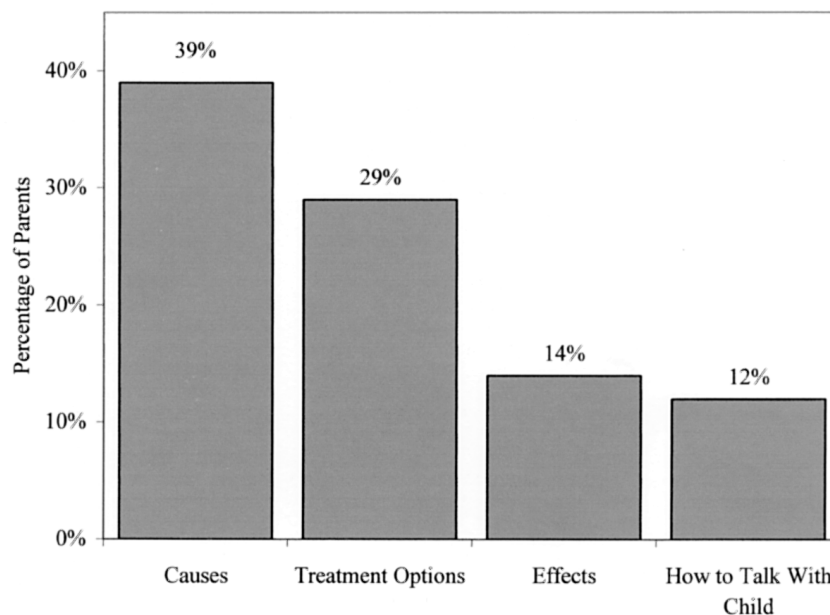


Figure 1. Information needs among parents of children with primary nocturnal enuresis.

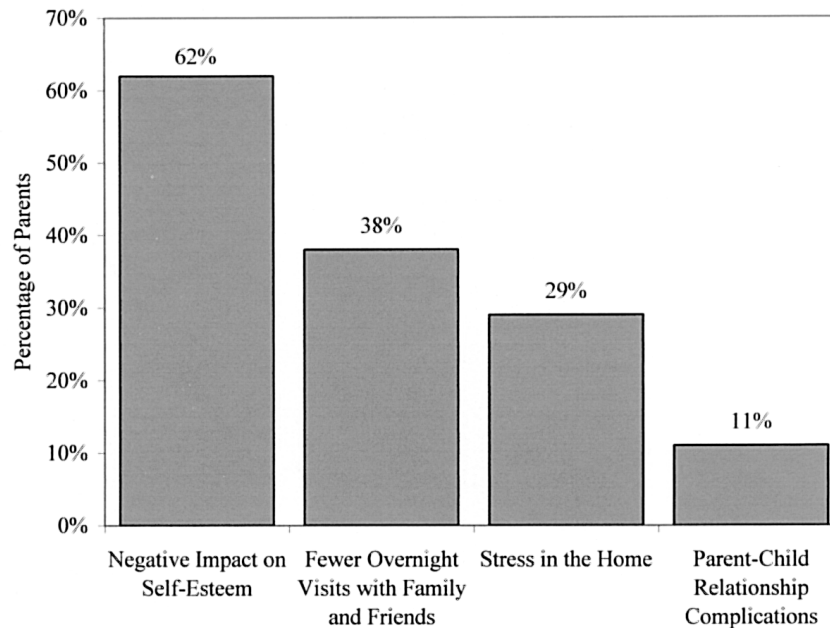


Figure 2. Parental concerns if their child had primary nocturnal enuresis.

their child's friends or parents knowing about their child's bedwetting. In contrast to the privacy they desired with family and friends, the majority of parents (82%) expressed an interest ("definitely or probably") in discussing PNE with a healthcare provider if bedwetting should be an issue with 1 of their children (Figure 3). Fathers and middle to upper income respondents were significantly more reluctant to discuss the problem.

Despite the fact that 82% of parents expressed an interest in discussing PNE with a healthcare provider, only about half (56%) would take the initiative to contact their healthcare provider if their child wet the bed. Mothers were significantly more likely to contact a healthcare provider about bedwetting (61% vs 50% of fathers, $p < 0.05$). Furthermore, parents expressed discomfort in initiating the dialogue about PNE, with many preferring that

the healthcare provider bring up the subject. More than a third (35%) of respondents thought healthcare providers need to more frequently screen children for PNE. Each of these opinions was held by significantly more ($p < 0.05$) mothers than fathers and low-income and noncollege graduate respondents.

A finding most important to clinical practice was the parents' perception that healthcare providers do not adequately address PNE. Two thirds (68%) of parents said their children's pediatrician or primary care provider has never addressed bedwetting during a routine visit, regardless of the child's age.

Discussion

The results of this survey underscore the imperative for healthcare providers to take the lead in opening discussions about

PNE. Most parents remain unaware that PNE is a health problem. While they are reluctant to initiate conversations about it with healthcare providers, parents want healthcare providers to discuss PNE with them.

A complete review of the diagnosis and management of PNE is beyond the scope of this article. Given the stigma of the condition and the tremendous psychosocial impact that it can have on the child and the family, the responsibility for identification and discussion of PNE rests with the clinician. Once the condition is diagnosed, the clinician can reassure the parent and child that PNE is a common childhood condition, of neither behavioral nor psychological origin, and that it is "no one's" fault. It can be successfully managed, thereby reducing the related discomfort and embarrassment.

Treatment decisions depend on many factors, including the

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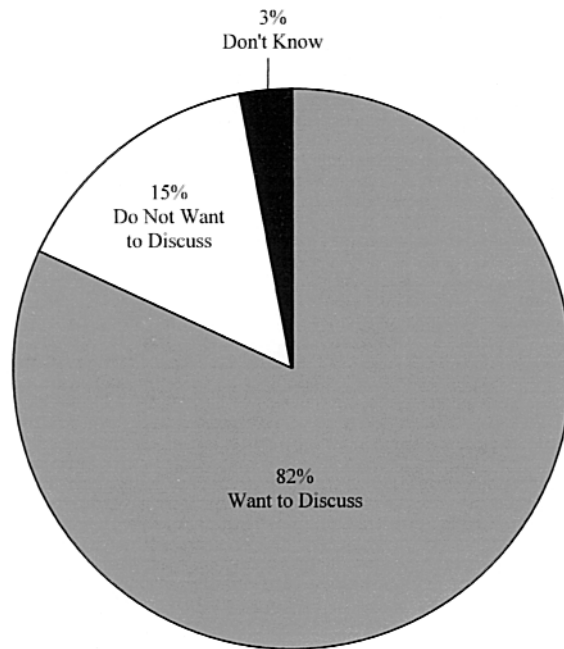


Figure 3. Parents' desire to discuss primary nocturnal enuresis with a healthcare provider.*

*If their child wet the bed from the age of 6 and older.

age of the child, the severity or perceived severity of the bedwetting problem, its impact on the family, and the family social structure (2-household families, multiple caregivers, etc). Treatment must be individualized and attention paid to lifestyle issues. Various treatments and the advantages and limitations of each should be presented as options. Effective treatment significantly improves the self-esteem of children with nocturnal enuresis.¹⁴

First-line treatment options can include nonpharmacologic (behavioral conditioning) or pharmacologic intervention. Behavioral conditioning is based on the use of a moisture-activated alarm, which emits either an auditory or vibratory signal when activated. Initially, the alarm acts as an unconditioned stimulus, wak-

ing the child when urination occurs and prompting the child to get out of bed, go to the bathroom, and complete voiding. Over time, the alarm creates a conditioned response in which the same physiologic stimuli that preceded urination wake the child and inhibit voiding. With good compliance, up to 70% of children using an alarm system become dry,^{17,18} with about half getting up during the night to void and the other half sleeping through the night dry. Studies document dropout rates up to 30%⁹ and personal experience suggests this rate may be as high as 50%. Parents of a "heavy sleeper" should be advised that the alarm will probably awake them rather than the child. They may well need to go wake the child. They should expect 2–3

weeks of use before the child responds. When a child has been wetting at night for 6 years, results with an alarm should not be expected in just a few days.

Desmopressin (DDAVP), a synthetic analogue of the antidiuretic hormone 8-arginine vasopressin, is the most commonly used pharmacotherapy in the United States for the treatment of PNE.¹⁹ It has a rapid onset of action (around 1 hour) following oral administration. Short-term and long-term efficacy and safety in the treatment of nocturnal enuresis have been established with desmopressin. In a clinical study by Snajderova and colleagues,²⁰ the response rate with desmopressin was 73%, 71%, and 62% at the end of each of 3 successive years. Similar results were observed in the Swedish Enuresis

Trial (SWEET).²¹ The highest response rates are observed in older children and those with adequate functional bladder capacity.²² The rate of adverse events with desmopressin has been shown comparable to that of placebo.²³⁻²⁵ Desmopressin is available in tablet and nasal spray form. The tablet form allows for discreet administration, which makes the child's condition less apparent to others, a concern among survey parents. The nasal form must be refrigerated, which tends to decrease compliance and increase visibility of the problem. Hogg and colleagues²⁶ recommend starting children at a dosage of 20 µg spray or 0.2 mg tablet. If the child's bedwetting does not improve within a few days, the dose should be gradually increased to 40 µg or 0.6 mg, respectively.

The tricyclic antidepressant, imipramine, is also approved for treatment of PNE. Its use has declined owing to the potential for clinically significant side effects, including dysfunctional voiding, personality changes, sleep disorders, nausea, and nervousness.²⁷ Imipramine overdose can be fatal.²⁸ The unfavorable side effect profile and the introduction of desmopressin have made imipramine a less desirable treatment option. Clinical response with imipramine correlates with plasma concentrations.²⁹ Consider obtaining drug plasma concentrations periodically to optimize efficacy and monitor safety.

Combination therapy may be helpful in patients with PNE refractory to behavioral and pharmacotherapy.³⁰ The combination of desmopressin and alarm resulted in better response than with either agent alone.^{31,32} Some clinicians recommend initial treatment with combination therapy to achieve rapid initial success

and then gradually reduce the use of medication over time.

Restricted intake of caffeinated beverages (owing to presumed diuretic properties of caffeine) and a redistribution of daily fluid intake (only 20% of total intake in the evenings) are also recommended by some clinicians.² In the author's experience, many children obtain the majority of their fluid intake between 3 P.M. and 9 P.M. Intake is self-restricted to milk on the morning cereal, the obligatory carton of chocolate milk at lunch, and a few sips from the water fountain at school. They arrive home thirsty and drink large quantities starting after school hours. Motivational therapy (e.g., reward system for a certain number of dry nights in a row), as an adjunct to other approaches, may also play a role in the multicomponent treatment of enuresis. The relapse rate is high with motivational therapy alone, resulting in only a slightly higher cure rate than that of spontaneous resolution.³³

Conclusions

The prevalence of PNE clearly indicates that every pediatric practice includes children with PNE. The medical condition has significant psychosocial implications on children, parents, and extended families. Children often feel there is something wrong with them, and many parents believe the condition is a reflection of poor parenting skills, resulting in shame and embarrassment for all. Survey results indicate that parents and children want and need information about PNE but don't know how to ask for it. Healthcare providers must be proactive in addressing the topic with their patients and the chil-

dren's parents. A question about bedwetting should become a standard part of the history and physical of every child from the kindergarten physical through adolescence.

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