Trends in Referral to a Single Encopresis Clinic Over 20 Years

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ABSTRACT. *Objective.* **To compare the characteristics of children with encopresis referred to a single encopresis clinic over the course of 20 years, including symptoms, previous diagnostic and therapeutic interventions, and parental attitudes.**

Methods. **A retrospective study was conducted of an encopresis clinic at a tertiary care pediatric hospital. Questionnaires at initial evaluation elicited information about bowel habits, soiling, previous evaluations, previous treatments, and parental attitudes.**

Results. **In 503 children with encopresis, the average age of referral dropped from 115 months during the earliest 5 years to 77 months during the most recent 5 years. Children who had soiling for >3 years before referral decreased from 63% to 12%. The use of barium enema before referral decreased from 14% to 5%, as did psychological evaluation, from 25% to 14%. Previous therapy with enemas decreased from 45% to 27%. Mineral oil use remained at approximately 50%, and 20% of children had no previous treatment. Symptoms at referral and parental attitudes did not change across the years.**

Conclusions. **Children are now referred at an earlier age to our tertiary encopresis clinic. The number of invasive and psychological evaluations has decreased before referral. However, treatment by many primary care providers before the referral has not changed. These data may suggest that pediatricians have increased awareness of encopresis and greater appreciation of its primarily physical rather than psychological nature. Additional studies will be needed to determine how these factors affect outcome.** *Pediatrics* **2003;111:e604–e607. URL: http://www.pediatrics.org/cgi/content/full/111/5/e604;** ***toilet training, encopresis, constipation, children.***

Encopresis remains a significant problem in children. It is estimated to afflict 1% to 3% of the general pediatric population.[1–3] In 1975, Levine[4] wrote a classic paper outlining the descriptive characteristics of 102 children with encopresis seen at Children's Hospital in Boston. He described age of onset, type and timing of fecal accidents, and patient demographics. These data helped to corroborate his formulation of a relatively new approach to encopresis, using disimpaction, training, and education as treatment for this disorder. Although his approach is now widely used[5–10] and his descriptions of a typical child with encopresis are often quoted, there has been little reevaluation of his findings.[1,2,11–16]

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We examined the characteristics of 503 children who over the next 20 years attended the encopresis clinic that Levine founded to determine whether the classic descriptions still were valid. We also wanted to explore whether there were changes in the age of referral, type and duration of symptoms, and parental attitudes about encopresis. Furthermore, we looked at the evaluations and treatments that the children had undergone before referral as an indirect reflection of primary care practice at that time.

METHODS

The study population consisted of children who were older than 4 years and referred to the encopresis clinic known as the Pains and Incontinence Program at Children's Hospital, Boston, between 1980 and 1999. A full medical history and physical examination were performed on every child, and those who were found to have an organic cause for defecation problems (Hirschsprung's, tethered spinal cord, hypothyroidism, imperforate anus, etc) were excluded. A detailed parent questionnaire developed by Levine was used in its original format between 1980 and 1999.[17] This questionnaire was completed by the family at home before the first visit and was reviewed with a staff physician at the time of the initial consultation. The questionnaire included inquiries about the characteristics of current and past bowel habits, previous diagnostic procedures, and previous therapeutics used. The questionnaire also solicited parental attitudes about the bowel problems.

Encopresis was defined as the repeated passage of feces into inappropriate places (eg, underwear, pajamas), whether involuntary or intentional, after age 4 years.[18] Primary encopresis was defined as uninterrupted soiling.[17]

An analysis of the questionnaire results was compiled. Comparisons were made between children who were seen in 1982–1986 (group 1), 1987–1991 (group 2), 1992–1995 (group 3), and 1996–1999 (group 4). All tables also show the numbers reported in the original Levine paper.[4] These numbers are not used for any statistical comparison.

The analysis was compiled using SPSS for Windows (SPSS Inc, Chicago, IL). The tables report percentages, based on the total number of positive answers divided by the total number of responses to the question. Comparison of categorical values across groups was made using the Mantel-Haenszel trend test. Continuous variables were compared using the Kruskal-Wallis for independent samples. P values were considered significant at $P < .05$.

RESULTS

Levine's patients in his original report were an average age of 88 months. However, children older than 13 years (156 months) were excluded from his clinic at that time. In the encopresis clinic, which followed, children were seen through adolescence; thus, the range seen was 48 to 215 months. The mean age in this study overall was 100 months (standard deviation: 40). If only children younger than 13 years are considered, to compare with Levine's population, then the mean is 91 months (standard deviation: 32). As is evident from Table 1, the age at referral decreases over time ($P = .001$). Children are also re-

TABLE 1. Demographics*

	Levine[4] (1972–1974)	Group 1 (1982–1986)	Group 2 (1987–1991)	Group 3 (1992–1995)	Group 4 (1996–1999)	*P*
N	102	136	101	173	92	
Mean age†	88‡	116 (43)	112 (38)	92 (34)	78 (33)	
% Male	85%	74%	79%	71%	71%	NS
Duration of problem						
>1 y		86%	76%	86%	93%	NS
>3 y		63%	52%	65%	12%	.059
>5 y		14%	17%	11%	6%	NS
Primary encopresis	39%	45%	48%	56%	71%	.003
Current enuresis	31%	25%	30%	38%	41%	.005

* The percentages are based on the total number of positive answers divided by the total number of responses to the question. NS indicates not significant ($P > .05$).
† Mean age expressed in months (standard deviation in months).
‡ Includes only ages 48 to 156 months.

ferred earlier after the onset of the encopresis. The majority of children in the 1980s and early 1990s had symptoms for 4 to 5 years, whereas in the late 1990s, the majority experienced symptoms for <3 years before referral ($P = .059$, not significant). There is a significant increase in the proportion of children with primary encopresis ($P = .003$) and with enuresis ($P = .005$).

The vast majority of the children who were referred for encopresis had evidence of current constipation based on hard, large or infrequent stools or painful or difficult defecation. The proportion with constipation did not change significantly over the years (Table 2). The soiling patterns also do not seem to change over the years, with respect to both type of soiling and timing. It is interesting that more than half of the children soiled daily, most soiled in school, and between 38% and 58% soiled at night in their sleep.

Evaluation of the child with encopresis before the referral to this clinic shifted with fewer barium enemas done (14%–5%; $P = .021$) and fewer mental health evaluations (25%–14%, $P = .032$; Table 3). Rectal biopsy rate remained low at 2% to 3%. Although rectal manometry initially decreased from 9% to 4%, in the late 1990s the rate suddenly climbed to 14%.

Treatment of encopresis before referral has not changed substantially (Table 3). There has been a decrease in the proportion of children who were given enemas (45%–27%; $P = .001$). However, the use of mineral oil, laxatives, suppositories, toilet sitting, and even psychological therapy has not substantially changed. Approximately 20% of children received no treatment, according to parental report, before referral. Mineral oil remained the mainstay of therapy, with >50% receiving this intervention.

The attitudes toward encopresis, on the part of both child and parent, were generally similar when compared over time (Table 4). Parents who are asked to identify all contributing factors to their child's encopresis continue to blame behavioral aspects to a large extent. Laziness (in 33%–43%), carelessness (in 21%–25%), and emotional problems (in 27%–38%) were blamed, although some (30%–36%) suspected an organic problem as well. Although children continue to deny the problem (in 46%–53%), there has been a shift in that fewer children hide their soiled underwear ($P = .001$). Isolation continues to be common for children with encopresis: only 11% to 18% of children and 24% to 33% of parents know of another child with similar symptoms.

DISCUSSION

We found that over the past 20 years, the average age at referral to the encopresis clinic has fallen from 116 months (9.7 years) to 78 months (6.5 years). The factors underlying this shift have not been well elucidated. Perhaps patients or families are more likely to report encopresis, or physicians are more likely to ask about this symptom. Although one could postulate that previously more physicians had chosen to treat patients on their own before referral, the lack of change in previous treatments experienced by the children make this less likely. Additional studies should be done to determine whether earlier referral

TABLE 2. Characteristics of Stooling and Soiling Patterns*

	Levine[4] (1972–1974)	Group 1 (1982–1986)	Group 2 (1987–1991)	Group 3 (1992–1995)	Group 4 (1996–1999)	*P*
Infrequent BM (<2/wk)		48%	37%	47%	65%	.017
Hard BM		71%	75%	68%	70%	NS
Huge BM	57%	54%	51%	47%	52%	NS
Strains		70%	70%	69%	70%	NS
Painful BM		59%	61%	61%	60%	NS
Blood on BM		7%	12%	8%	11%	NS
Soils >daily		57%	58%	70%	50%	NS
Soils asleep	58%	44%	38%	54%	52%	.062
Soils at school	79%	74%	76%	72%	78%	NS

BM indicates bowel movement.
* The percentages are based on the total number of positive answers divided by the total number of responses to the question.

TABLE 3. Previous Evaluation and Treatment Practices*

	Group 1 1982–1986	Group 2 1987–1991	Group 3 1992–1995	Group 4 1996–1999	*P*
MD check	78%	77%	74%	71%	NS
Barium enema	14%	11%	8%	5%	.021
Rectal biopsy	3%	2%	3%	2%	NS
Manometry	9%	5%	4%	14%	NS
Psychological evaluation	25%	16%	16%	14%	.032
None	20%	19%	18%	23%	NS
Enema	45%	39%	27%	27%	.001
Suppository	33%	36%	27%	30%	NS
Mineral oil	45%	51%	52%	52%	NS
Laxative	48%	54%	55%	57%	NS
Regular sit	47%	52%	42%	48%	NS
Diet	31%	26%	25%	19%	.043
Psychological treatment	16%	18%	12%	17%	NS

* The percentages are based on the total number of positive answers divided by the total number of responses to the question.

TABLE 4. Perception of Encopresis*

	Group 1 1982–1986	Group 2 1987–1991	Group 3 1992–1995	Group 4 1996–1999	*P*
Child					
Denies problem	46%	47%	53%	48%	NS
Hides underwear	62%	71%	52%	40%	.000
Is unaware of urge	69%	67%	72%	68%	NS
Parents suspect					
Organic problem	32%	30%	36%	33%	NS
Emotional problem	31%	38%	31%	27%	NS
Toilet training problem	8%	6%	9%	12%	NS
Home problem	9%	8%	5%	3%	.049
Laziness	43%	37%	41%	33%	NS
Carelessness	22%	25%	21%	21%	NS
Child wants attention	21%	20%	15%	13%	NS
Child wants to aggravate them	14%	12%	9%	6%	.050
Food related	21%	27%	16%	19%	NS
Child is stubborn	27%	33%	44%	52%	.000
Child knows others with this problem	12%	18%	11%	14%	NS
Parent knows others	24%	25%	27%	33%	NS

* The percentages are based on the total number of positive answers divided by the total number of responses to the question.

has an impact on length of treatment required or eventual outcome. One would expect that early intervention might at least improve the child's sense of confidence or self-esteem.

As one might expect, the stooling patterns of children with encopresis have not changed over the years.[8–10] The majority have features of constipation. Infrequent stooling is the only characteristic that has changed over the years, with 48% originally and now 65% affected ($P = .017$). Frequent soiling, nocturnal soiling, and soiling in school continue to occur often. The larger proportion of primary encopresis and enuresis may result from a younger referral population.[13]

Evaluation before referral became less invasive as the rate of barium enemas dropped from 14% to 5%; however, the rate of rectal biopsy (also done to rule out Hirschsprung's disease) stayed steady at 2% to 3%. Anorectal manometry initially dropped from 9% to 4% but then rose in the past 5 years. It is unclear whether this was attributable to the availability of skilled manometry or increased recognition of its diagnostic usefulness in other conditions such as tethered cord or anismus.[6,14] Psychological and psychiatric evaluation before referral has dropped significantly from 25% to 14%. Does this represent increasing recognition of the smaller role played by emotional and behavioral factors in the cause and treatment of encopresis,[1,7] or does it simply represent economic constraints? The largest decline occurred in the mid-1980s, which may indicate that the change in theory may be more important than economics.

There has been no significant change in the treatment of children with encopresis before referral over the past 20 years at our center. Mineral oil continued to be the mainstay, with 45% to 52% receiving this intervention.[1,2,7–10] Regular sitting times are also used extensively (in 47%–52%).[1,7–9] However, 18% to 23% of patients report no treatment before referral. This observation deserves additional exploration in future studies. Do these patients bypass their primary care provider and self-refer directly? Do they misperceive, ignore, or forget suggestions made by their provider? Do providers lack the knowledge or confidence to treat these children? Future studies will address these questions.

Parental attitudes toward encopresis have not shifted much.[4,11,12] Although a decreasing trend of "wants to aggravate parents" may indicate a more sympathetic view, it is countered by a rising percentage who blame the stubbornness of the child. It would be interesting to determine whether parental attitude correlated with compliance with medical regimens or recovery rates. There is scant informa-

tion in the literature on parental attitudes toward encopresis.[9]

There are a number of limitations to this study. First, our encopresis clinic is a referral clinic and thus will reflect the changing patterns of referral in the community and within the hospital. However, there were few changes in the hospital milieu or the referring community to Children's Hospital during this study period. Second, this study does not evaluate children with encopresis who were successfully treated in the primary care setting or children who were referred to other specialists.

We found that children were referred at a younger age to a referral encopresis clinic and had fewer invasive tests and mental health evaluations before the referral. In contrast, children with encopresis seem to present with the same clinical picture and parents seem to have the same reaction. We are hopeful that the earlier referral pattern reflects an improved knowledge of the cause and treatment of encopresis as a result of an educational initiative begun by Levine and continued by developmental pediatricians and gastroenterologists.

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