Received: 13 November 2022 | Revised: 14 December 2022 | Accepted: 15 December 2022

DOI: 10.1111/apa.16634

ACTA PÆDIATRICA NURTURING THE CHILD WILEY

ORIGINAL ARTICLE

Can enuresis alarm therapy be managed by the families without the support of a nurse? A prospective study of a real-world sample

Jens Larsson[1] | Malin Borgström[2,3] | Birgitta Karanikas[3] | Tryggve Nevéus[3]

[1]Urotherapy Unit, Section for Pediatric Surgery, Skåne University Hospital, Lund, Sweden

[2]Center for Clinical Research Dalarna, Falun, Sweden

[3]Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden

Correspondence
Tryggve Nevéus, Depatment of Women's and Children's Health, Uppsala University Children's hospital, 751 85 Uppsala, Sweden.
Email: tryggve.neveus@kbh.uu.se

Funding information
VINNOVA, Grant/Award Number: 2020-04131

Abstract

Aim: The alarm is the first-line treatment of nocturnal enuresis. However, the therapy is labour-intensive for both families and healthcare providers. Our aim was to see whether the treatment could be successfully used by the families, without support from healthcare providers.

Methods: An alarm linked to an application on a parent's smartphone was used. The app recorded enuretic events and gave instructions. Group A were children supported by a nurse. Group B were patients whose families had bought the alarm and downloaded the app independently.

Results: There were 196 children in group A and 202 in group B. The percentages of full responders, partial responders, non-responders and dropouts were 18.4%, 20.4%, 22.4% and 38.8% in group A and 13.4%, 11.4%, 14.9% and 60.4% in group B. The risk for dropping out of therapy was higher in group B ($p < 0.001$), whereas the chance for adherent children to become dry did not differ between the groups ($p = 0.905$).

Conclusion: For families who are able to adhere to alarm therapy the chance of success is just as good when managed independently as when supported by a nurse. But the latter children will have a greater chance of adhering to the full treatment.

KEYWORDS
adherence, application, enuresis, enuresis alarm, nurse

1 | INTRODUCTION

Enuresis is common, socially distressing and does not always disappear by itself. Five to ten percent of 7-year-olds are affected[1] and even among adults, the prevalence is 0.5%–2%.[2,3] Many families, and maybe adults, do not seek help from healthcare professionals.[4] The initial evaluation of the enuretic child is fairly straightforward and does not involve blood tests or invasive investigations.[5] The only pressing concern, prior to starting treatment, is to find the (very few) children with enuresis due to an underlying medical condition such as diabetes, polyuric renal failure or bladder outlet obstruction.

The enuresis alarm is a well-established first-line treatment, that is in contrast to pharmacological alternatives, potentially curative.[6] One of the problems with the enuresis alarm, wherever it is used according to instructions, is the workload, both for the family and for the healthcare professionals. The sleep of the child – and possibly

Abbreviations: ICCS, international children's continence society; IR, intermediate responders; NR, non-responders; R, responders.

the rest of the family – will be severely disrupted, at least one parent needs to attend to the child every single night for possibly several months. And the supporting healthcare professional needs to explain and demonstrate the device as well as provide frequent follow-ups at least by telephone. Another problem is availability, in many countries or regions, the alarm is hardly ever used and desmopressin is given routinely as a first-line treatment. In Sweden, for instance, general practitioners and community nurses do not usually provide alarm therapy but leave this to specialised paediatric outpatient wards. This is, at least from an economic perspective, not optimal.[7]

If there was a way to transfer the responsibility of the enuresis alarm treatment to the families themselves, without the help of healthcare professionals, the nurses and physicians could focus on the children who do not respond to alarm treatment and society saves money. Also, more children could become dry and would not need to take medications. This scenario would be ideal, provided it did not put the children at any risk.

Consequently, the aim of this study was to see if families can manage the alarm treatment by themselves without the support of healthcare professionals.

Key Notes

- The enuresis alarm is often curative but incurs a heavy workload for both affected families and supporting healthcare providers, furthermore, in many regions, the alarm is not available through primary care.
- We found that families could manage alarm therapy themselves via an online app but that the support of a nurse increased adherence to the instructions.
- With further development, alarm therapy could be individualised and healthcare resources more effectively used.

2 | SUBJECTS AND METHODS

2.1 | The alarm device

The enuresis alarm used in this study was a body-worn alarm produced by Pjama Inc. that was wirelessly attached to an application downloaded to a parent's smartphone or tablet. When the families downloaded the app, they had to provide the age and sex of the child and answer questions about usual enuresis frequency (wet nights per week), perceived arousal thresholds, urgency, daytime incontinence, previous desmopressin use and previous alarm use. Furthermore, questions regarding warning signs such as excessive thirst and a need to strain to pass urine were asked, and the families were instructed to seek medical attention if these signs were present. In order to optimise adherence, the families were not asked to complete a voiding diary or measure nocturnal urine production.

During the treatment, the parents were asked to record the time when the child went to bed and the alarm was activated. The enuretic event was automatically recorded by the application, and in the morning, the parents were asked to document if the child woke by itself or had to be helped by a parent and if, during dry nights, there had been nocturia.

The app instructed the families according to ICCS international guidelines on enuresis alarm treatment[5]:

- The child should be helped by parents/guardians to wake up when the alarm goes off.
- Only one alarm per night is enough.
- The alarm should be used consistently, every night, for at least 8 weeks in a row or until 14 consecutive dry nights are achieved.
- If 8 weeks have passed, and the child is improved but not completely dry, the treatment should be continued for another 4 weeks.

2.2 | Group 1: Children supported by a nurse

These were children with enuresis who had been in contact with any of the nine paediatric outpatient wards in Sweden, and the alarm treatment was started after a recommendation from a nurse. They received the same instructions from the nurse as the app gave, listed above. The families were contacted by phone after 2–3 weeks of therapy, for encouragement and problem-solving, and then again at the end of the alarm treatment. The children were unselected insofar as they were included in the study if they did not have any symptoms of the underlying disease and the parents gave informed consent. Current daytime incontinence was not an exclusion criterion if the enuresis was the main complaint.

2.3 | Group 2: Independent patients

This group consisted of subjects who started treatment without support from healthcare professionals. The families had purchased the alarm device and downloaded the app by themselves (either via the purchase of a Pjama bedwetting alarm from one of the company's distributors or by searching the web). These persons were recruited from all over Europe and were known to the researchers only by the names and (sometimes incomplete) data entered in the app.

2.4 | Calculations

Only subjects whose enuresis frequency could be calculated during the first 2 weeks of treatment were included. That means at least three registered nights during the first week or at least six nights during the first 2 weeks.

The study subjects were grouped according to the treatment response after a maximum of 12 weeks of therapy, in line with ICCS recommendations[8], into the following groups:

- Responders (R): the achievement of 14 consecutive dry nights
- Intermediate responders (IR): reduction of enuresis frequency by at least 50%, comparing the last 2 weeks with the first 2 weeks of recording

- Non-responders (NR): less than 50% reduction of wet nights after a minimum of 8 weeks, comparing the last 2 weeks with the first 2 weeks of recording
- Dropout: discontinuation of therapy before 8 weeks, without the achievement of 14 consecutive dry nights
- Dry at the start: first two recorded weeks completely dry

However, since not all families followed the instructions to discontinue therapy after 14 consecutive dry nights or a maximum of 12 weeks of therapy, subjects were also grouped into final outcome categories, comparing the actual last 2 weeks of therapy with the first 2 weeks.

When looking for predictors of treatment response, the subjects were dichotomised into those with favourable (R or IR) and unfavourable (NR) responses. Comparison between two groups was made with T tests or non-parametric alternatives and chi-square test used for categorical data. A statistical significance level of 95% ($p < 0.05$) was chosen.

2.5 | Ethical considerations

The study was performed according to the Helsinki Declaration and approved by the Swedish Regional Ethics Authority (2021-00206). The use of the data entered by the patients' guardians in the application was cleared according to the General Data Protection Regulation. Only the patients' treating nurse had access to the identities and patient files for the nurse-supported group. The identities of the subjects in the independent group were unknown to the researchers.

3 | RESULTS

3.1 | Study population

The population consisted of, in total, 398 subjects, 196 children in the nurse-supported group and 202 patients in the independent group. The overall sex distribution was 105/293 female/male (49/147 in the nurse-supported and 56/180 in the independent groups; $p = 0.54$).

There was a difference in age between the groups. The subjects of the independent group were generally older than the nurse-supported children (9.4 ± 5.1 and 8.3 ± 2.0 years, respectively, $p = 0.006$). In the former group, there were also 25 children under 6 years of age as well as 14 adults older than 18 years.

The mean estimated enuresis frequency per week was 5.4 ± 1.8 nights per week in the nurse-supported and 5.2 ± 2.0 in the independent group ($p = 0.26$). The other baseline characteristics of the groups are presented in Table 1. As can be seen, the nurse-supported group had previously tried desmopressin or the alarm to a larger extent than the independents.

3.2 | Treatment outcome

Treatment parameters in the two groups are listed in Table 2.

As can be seen in the table, treatment length in the independent group was shorter than among the nurse-supported children, but they also included some families who continued the treatment far longer than recommended (maximum 539 nights).

TABLE 1 Dichotomised baseline characteristics of the two groups

	Nurse-supported		Independents		
	n	Proportion	*n*	Proportion	*p*
Difficult to arouse from sleep	186	128 (68.8%)	170	110 (64.7%)	0.41
Urgency symptoms	196	94 (48.0%)	180	74 (41.1%)	0.18
Daytime incontinence	196	33 (16.8%)	180	27 (15.0%)	0.63
Previous desmopressin use	196	129 (65.8%)	180	61 (33.9%)	<0.001
Previous alarm attempt	196	67 (34.2%)	180	43 (23.9%)	=0.028

Note: When *n* is below the number of subjects in the group (196 nurse-supported and 202 independents) that means either that the families have failed to provide that data or stated that they do not know.

TABLE 2 Treatment parameters

	Nurse-supported		Independents		
	n	Mean ± 1 SD	*n*	Mean ± 1 SD	*p*
Treatment duration (days)	196	68.7 ± 57.0	201	54.3 ± 59.7	0.015
Adherence (% nights with alarm use)	196	95.3 ± 10.3	201	87.8 ± 18.1	<0.001
Enuresis reduction at 8–12 weeks (%)	121	56.3 ± 55.2	78	35.6 ± 89.2	0.069
Enuresis reduction at the actual end of treatment (%)	117	55.4 ± 52.3	80	46.3 ± 68.6	0.32
Days until dryness in responders	63	50.8 ± 45.4	39	57.8 ± 45.6	0.45
Proportion of nights with technical problems (%)	193	6.9 ± 10.3	201	7.3 ± 13.5	0.77
Days until relapse after 14 dry nights (if known)	38	18.9 ± 6.6	23	27.8 ± 16.0	0.018

The chart below (Table 3) shows outcomes categorised into two ways described in the Methods section above. Twenty-two subjects who had achieved 14 consecutive dry nights continued registration and had a relapse of enuresis and 15 patients who were non-responders after 12 weeks became drier (R or IR) when continuing therapy.

The nurse-supported group had a more favourable final effect of the alarm in total ($p = 0.003$) but not if the dropouts were taken out of the comparison. In the latter case, there was no difference in response ($p = 0.905$). The dropout rate for the independent group was much higher than among the nurse-supported children ($p < 0.001$). This difference was still valid when the adult patients, who had an extra high dropout rate, were taken out of the calculation. And the significances were similar regardless of whether the response was assessed after maximum of 12 weeks or at the actual end of treatment.

The nurse-supported children and the (lack of) predictors of treatment response among them are reported in a separate article.[9]

Looking for predictors of non-completion of the full-treatment course within the independent group, the risk of dropout was not affected by baseline enuresis frequency, daytime incontinence, urgency, previous alarm treatment or technical problems with the alarm. But subjects dropping out tended to be older (10.1 ± 5.8 vs. 8.4 ± 3.8 years, $p = 0.024$), were more likely to have previously tried desmopressin therapy (43% vs. 20%, $p = 0.001$) and had poorer adherence during the course of treatment (85% ± 20% vs. 92% ± 15%, $p = 0.009$).

As mentioned above, the adult patients had an extra high risk of dropping out, in fact, 11/14 did not complete therapy, and they also usually had not received any previous treatment with the alarm or desmopressin.

4 | DISCUSSION

The main finding of this study is that there is a high risk of discontinuing enuresis alarm therapy if the families manage the treatment independently via an app, without support from a nurse, but for those who do continue the treatment, the chance of success is similar in the two groups.

We do not want to overstate the success of the treatment given. It should be noted that the majority of users of the alarm – independent or nurse-supported – did not become completely dry. This stands in contrast to the much better results of the large Australian retrospective evaluation of Apos et al.[10] We have no reason to believe that the alarm used was inferior or the nurses less motivated. We think that the poor response is due to (1) an unusually unselected patient population and (2) that the documentation of both dry/wet nights and actual alarm use were done by the app, not by the families. We hope that this reflects clinical reality better than if we had, for instance demanded voiding charts to be completed before initiation of therapy.

The main asset of this study is that the central question – whether enuresis alarm therapy guidance can be moved from the healthcare professional to the families themselves – has not been assessed before. And the app used in this study is a new method, with potentially great benefits for many children. Furthermore, the app lowers the risk for recall bias or false information from the families, thus giving a truer assessment of treatment adherence and treatment success than previous studies. One downside of this study is that we do not have much background information about the subjects who used the app independently. And neither group was required to provide voiding chart data or measurements of nocturnal urine production.

Why did so many of the independent users' dropout of therapy? We suspect that the human contact with the nurse makes the families more committed to continue therapy and embarrassed about dropping out. The non-human interface with an app is much easier to ignore. Another explanation could be the lack of knowledge among the independent users about what to expect from the treatment; perhaps, these patients expected the therapy to provide a quick cure and when this did not happen they felt less motivated to continue. We also know nothing about possible differences in socio-economic circumstances or education levels of the two groups, factors that may influence adherence. Finally, it was possible for the users to quit the application and just use the alarm without online guidance. We consider it unlikely that many of the dropouts used this strategy because they would gain nothing from this and most of these families had already before discontinuing shown patchy adherence.

But if the families continued the treatment alone, then the results were just as good as if they had been led by a nurse. This means that the treatment instructions can just as well be given by messages in the app. Here there are potential benefits to be gained for society, as the burden of instruction and guidance at the first alarm treatment attempt can be shifted from the healthcare professional to the families, and the former can then focus on supporting the non-responders. And if the app could be modified, taking the knowledge gained from this pilot investigation into account, maybe the adherence could increase, and more children (and adults) be helped. Also, predictors of treatment non-response and/or dropout, gained during the first few weeks of therapy, could make the app advise

TABLE 3 Outcome according to response categories

	Nurse-supported $n = 196$	Independents $n = 202$
Response after 8–12 weeks		
Full response	51 (26.0%)	25 (12.4%)
Intermediate response	28 (14.3%)	21 (10.4%)
Non-response	42 (21.4%)	32 (15.8%)
Dropout	72 (36.7%)	122 (60.4%)
Dry at start	3 (1.5%)	2 (1.0%)
Response at end of treatment		
Full response	36 (18.4%)	27 (13.4%)
Intermediate response	40 (20.4%)	23 (11.4%)
Non-response	44 (22.4%)	30 (14.9%)
Dropout	76 (38.8%)	122 (60.4%)

the families to discontinue treatment if the outlook is bleak, thereby sparing the patient and families much frustration. Such modifications are presently being planned via the use of machine-learning algorithms.

The discovery of a substantial subgroup of adult patients was a surprise. Many of them had not been treated before. They had a very high dropout rate, presumably either because there was nobody available to help them wake up from the alarm or because the treatment was difficult to reconcile with the demands of daily life. Furthermore, the fact that for several adult subjects, a parent's name was also registered on the app suggests that some of them were, due to disabilities, still cared for by their parents. Regardless of this, adults with enuresis constitute a group of patients who risk being neglected. Therefore, plans are underway to make the app more adapted to adults.

If the treatment continued longer than recommended, that is beyond 14 consecutive dry nights and/or beyond 12 weeks, the response rate changed. Some patients relapsed after more than 14 dry nights and some of the patients who were not completely dry after 8–12 weeks became dry if they continued the treatment longer. This was a chance finding that we had not expected, or indeed looked for. As far as we know, the 14 dry nights limit recommendation has not been tested in a prospective way. We have all just assumed that a child who has achieved two consecutive dry weeks is cured.

In analyses of the nurse-supported group published separately,[9] we have found that good predictors of both treatment response and treatment adherence can be found during the first few weeks of therapy (but not at baseline). Those findings made us suggest that it would be beneficial for the individual patient if the alarm treatment were reassessed after 4 weeks and that patients with a high risk of non-response or non-adherence could then be advised to interrupt therapy and seek other help. This reassessment could be made by the app as well as the nurse. Based on the results of the present study, we can add the recommendation not to stop treatment after 14 consecutive dry nights but 28.

We think that the app, if further developed, may be beneficial to both the patients and the healthcare system because some patients can be treated without the involvement of healthcare professionals, who can focus on the patients who really need their help. And the inclusion of the questions regarding warning signs in the app reduces the risk that children with enuresis due to serious underlying conditions are missed. We are not sure that all physicians or nurses involved in the first-line evaluation of enuretic children remember to ask these questions, but the app will not forget.

5 | CONCLUSIONS

Enuresis alarm treatment can be managed by the families themselves at home with the support of an app, but with a high risk of discontinuing therapy before completion. The central role of the nurses supporting the families seems to be to encourage them not to quit the treatment in advance.

AUTHOR CONTRIBUTIONS

Jens Larsson took part in the design of the study, collected data and took part in all stages of data analysis and writing of the manuscript. *Malin Borgström* took part in the design of the study, collected data and took part in all stages of data analysis and writing of the manuscript. *Birgitta Karanikas* took part in the design of the study, collected data and took part in all stages of data analysis and writing of the manuscript. Tryggve Nevéus conceptualised and designed the study, supervised data collection and analysis and actively participated in the production of the manuscript at all stages. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

ACKNOWLEDGEMENTS

This study was supported by a grant from Sweden's Innovation Agency (2020-04131). The alarm unit, including the application, was provided by Pjama® Inc. The researchers did not receive any compensation from the company and none of the researchers have any economic interest in the company.

FUNDING INFORMATION

The work was supported by a grant from Sweden's Innovation Agency (2020-04131).

CONFLICT OF INTEREST

No author has any conflict of interest to declare. None of the researchers has any financial interests or ownership conflicts vis-à-vis Pjama Inc.

DATA AVAILABILITY STATEMENT

The authors are happy to, on reasonable request, provide data on a group level that could due to space limitations fit into the article.

ORCID

Tryggve Nevéus https://orcid.org/0000-0002-4590-4957

REFERENCES

1. Järvelin MR, Vikeväinen-Tervonen L, Moilanen I, Huttunen N-P. Enuresis in seven-year-old children. Acta Paediatr Scand. 1988;77:148-153.
2. Baek M, Park KH, Lee HE, et al. A nationwide epidemiological study of nocturnal enuresis in korean adolescents and adults: population based cross sectional study. J Korean Med Sci. 2013;28:1065-1070.
3. Hirasing RA, van Leerdam FJ, Bolk-Bennink L, Janknegt RA. Enuresis nocturna in adults. Scand J Urol Nephrol. 1997;31(6):533-536.
4. Schlomer B, Rodriguez E, Weiss D, Copp H. Parental beliefs about nocturnal enuresis causes, treatments, and the need to seek professional medical care. J Pediatr Urol. 2013;9(6 pt B):1043-1048.
5. Nevéus T, Fonseca E, Franco I, et al. Management and treatment of nocturnal enuresis – an updated standardization document from the international Children's continence society. J Ped Urol. 2020;16:10-19.
6. Keten T, Aslan Y, Balci M, et al. Comparison of the efficacy of desmopressin fast-melting formulation and enuretic alarm in the treatment of monosymptomatic nocturnal enuresis. J Pediatr Urol. 2020;16(5):645.e1-645.e7.

7. Perrin N, Sayer L, While A. The efficacy of alarm therapy versus desmopressin therapy in the treatment of primary mono-symptomatic nocturnal enuresis: a systematic review. Prim Health Care Res Dev. 2015;16(1):21-31.
8. Austin P, Bauer S, Bower W, et al. The standardization of terminology of lower urinary tract function in children and adolescents: update report from the standardization committee of the international Children's continence society. J Urol. 2014;191(6):1863-1865.
9. Larsson J, Borgström M, Karanikas B, Nevéus T. The value of case history and early treatment data as predictors of enuresis alarm therapy response. J Ped Urol. 2022. doi:10.1016/j.jpurol.2022.11.003. Online ahead of print.
10. Apos E, Schuster S, Reece J, et al. Enuresis management in children: retrospective clinical audit of 2861 cases treated with practitioner-assisted bell-and-pad alarm. J Pediatr. 2018;193:211-216.

How to cite this article: Larsson J, Borgström M, Karanikas B, Nevéus T. Can enuresis alarm therapy be managed by the families without the support of a nurse? A prospective study of a real-world sample. Acta Paediatr. 2023;112:537–542. https://doi.org/10.1111/apa.16634