Family compliance with the use of alarm devices in the treatment of monosymptomatic nocturnal enuresis

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ABSTRACT

Objective: In the treatment of monosymptomatic nocturnal enuresis (MNE), enuretic alarm devices (EADs) are the first recommended treatment option. This study aimed to evaluate parental and child compliance with EAD treatment.

Material and methods: Fifty patients for whom EAD therapy was recommended were included in this study. The mean age of the patients was 10.4 years (5-16). All the patients were nursery or school children. Patients who did not return for their follow-up visits were called by phone, and verbal information were gathered about the use and performance success of the device. We documented the patients who used, and did not use the EAD with their reasons.

Results: Nineteen (36%) patients were able to use the EAD without any problems. Eight of the remaining 31 patients didn’t return for control, and they could not be get in touch with, either. Of the 23 (46%) families whom we could get a contact, 4 families did not purchase EAD due to a decrease in the number of wet nights, 4 families due to compensatory payment, and 3 families due to reluctance of one of the parents. One family reported that they gave up the EAD treatment because of the disturbing loud volume of the device. Four families reported that their children refused to use the EAD. Four families said that they could not use the EAD regularly because the device frequently did not work properly. In this study, we could not keep in touch with 16% of the patients, and 46% of the patients stopped using or did not receive this therapy.

Conclusion: Although EAD has been the priorly recommended alternative with its relatively higher success, and lower recurrence rates, our study demonstrated that the compliance of families with this treatment is below the expected level.

Key words: Alarm treatment; family compliance; monosymptomatic nocturnal enuresis.

Introduction

Monosymptomatic nocturnal enuresis (MNE) is one of the most frequently seen conditions during childhood. Regional studies conducted in Turkey, reported its prevalence as 9-25.9 percent. Although it demonstrated regional differences, its overall prevalence changes with age (5 yrs, 15%; 8 yrs, 7%; 10 yrs, 3-5%; 12 yrs, 2-3%, and 14 yrs, 1%). With advanced age, annual incidence of its spontaneous resolution is 15 percent. Therefore it can be considered as a benign condition. However, in nearly 7% of 7-year-old children complaining of bedwetting at night, enuresis persists during adulthood. In chronic MNE cases, family compliance decreases with time which interferes with adherence to the treatment protocol. In this study, we aimed to evaluate compliance of the families to therapy in patients who started to use enuretic alarm device (EAD) with the indication of MNE.

Material and methods

Fifty children who consulted to our outpatient clinic within the previous two years with the diagnosis of MNE were included in our study. These children had obtained medical board reports approving use of EAD. Mean age of these children was 10.4 years (5-16 yrs.), and they were kindergarten or school children. All children were evaluated with the collaboration of at least one parent. Information about the present condition, progression, and treatment alternatives of the disease was provided, and expectations of the families were evaluated. The children, and their families were requested
to keep daily records in order to motivate the child, integrate him/her in the treatment protocol, and evaluate pretreatment condition of the patient, and response to treatment. Following recommendations about balancing daily fluid intake and motivating motivation, all patients were called for a control visit.

In the guidelines of European Association of Urology (EAU) although EAD is the priorly recommended treatment alternative especially in children who experience difficulties in arousal from sleep at night, expectation of the family, child’s desire, and social position (staying in a youth hostel etc) were taken into consideration in the selection of the treatment. Medical treatment (desmopressin) or alarm therapy is initiated in patients whose motivation, and supportive therapy proved to be insufficient. The families were informed about the difficulties encountered in compliance to the therapy, and EAC therapy was started with the informed consent of the families. All families were called for monthly controls, and asked them to bring the diaries kept by their children. Data of the patients who attended to their control visits without delay were retrospectively analyzed, and families lost to the follow-up were contacted with phone calls. During these phone calls they were asked if they had used the device, and the reason for not using EAD. Private verbal consents of the families were documented. Compliance of the families to EAD use was assessed. This study was started after approval of the ethics committee of Keçiören Training and Research Hospital with the decree # 302 dated 06.26.2013.

**Results**

Nineteen (38%) out of 50 families included in the study used the device without encountering any problem, and regularly complied with prescribed routine controls. However, 8 (16%) out of remaining 31 (62%) families never attended to control visits, and any phone contact could not be achieved. Twenty-three (46%) families indicated that they didn’t or couldn’t use EAD for various reasons.

These 23 families stated that they had never purchased the device for various reasons as follows: decrease in the complaints of bedwetting at night (n=4; 17.4%), price gap to be compensated (n=4; 17.4%), reluctance of the other parent (n=3; 13.1%), and negative feedback of their neighbour (n=1; 4.3%). One parent (4.3%) didn’t use the device, because it didn’t alarm the child before bedwetting episode. One family (4.3%) abandoned EAD use, because they were disturbed by the noise it produced. One family (4.3%) declined to use the device, because they did not know how to use it, and 4 (17.4%) families didn’t want to use EAD in compliant with their children’s will. Four families (17.4%) couldn’t use the device because of frequent breakdowns they were encountered (Table 1).

Although, we requested from the families to seek medical help in case they had experienced difficulties in compliance to the EAD use, and be insistent on maintaining therapy, 17 (17/23; 73.9%) families didn’t use the device, in addition they didn’t consult to our polyclinic or another hospital. We had got information about the device through phone contact.

**Discussion**

Though as a globally widespread problem in the world, MNE is a benign condition, it still has a potential to be a source of stress in children, and their parents. Nowadays, genetic transfer is an obvious phenomenon, and MNE is thought to be a multifactorial problem. The most important etiologic factor is difficulty in arousal from a sound sleep. However this definition is not an essentially correct description of nocturnal enuresis. Indeed not only enuretic children, but also nonuretic children have a difficulty in awakening from a deep sleep. Besides, nighttime bedwetting

<table>
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<th>Table 1. Parents’ compliance to the recommended enuretic alarm devices, and influential factors on adherence</th>
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<td>No. (%)</td>
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<td>EAD users who regularly adhere to their control visits without any problem</td>
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<td>Enuretics who didn’t/couldn’t use their EADs</td>
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<td>Decrease in the bedwetting episodes at night</td>
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<td>The device did not alarm the child before bedwetting</td>
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<td>Disturbing noise of the device</td>
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<td>Don’t know how to use the device</td>
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frequently occurs during light phases of the sleep. The problem in these children has been associated with inability of the central nervous system (CNS) to perceive vesical strain, and contractions of the bladder wall during sleep. Delay in maturation process of the bladder, and CNS is blamed for enuretic episodes, and these children are expected to benefit from alarm therapy.[7]

Even though motivation therapy per se is not frequently sufficient to solve the problem, it constitutes the first phase of a combination therapy. In monosymptomatic nocturnal enuresis, following motivation therapy, treatment alternatives are medical treatment, and alarm therapy. In medical therapy “imipramine” used to be widely prescribed, after reports of cardiotoxicity, and death, 2013 EAU guidelines discourages its use (evidence, and recommendation level 1C).[1] Desmopressin is the most prevalently used popular drug therapy. Although cure rates climb to 86% in different publications, cessation of the therapy results in extremely higher recurrence rates (90%).[3] Alarm therapy is another treatment alternative, it is the first-line therapy especially in children experiencing difficulties in arousal from a deep sleep.[10] In the alarm therapy, success rates climb to 76%, recurrence rates are relatively lower in comparison to the drug therapy (34.1%).[2] Besides, its use, and compliance of the family to the therapy are relatively challenging. Indeed, with every moment of bedwetting, parents also awaken, change soaked underwears of their children, and replace the device properly. Compliance of the family to the alarm therapy weakens with time.

An annual 15% chance of spontaneous resolution, decrease in its prevalence with age, and concerns of the families about adverse effects of medications prevent families from searching treatment options during the early phase of the disease. However, when the school years of the child begins, and the child builds his/her social environment, the families concern about their children, and need medical support.[7] Bedwetting leads to feelings of embarrassment, and loss of child’s self-esteem. Frequent washings, and home dependency during during night hours trigger development of emotional stress in parents.[8] Tolerability levels of especially working parents decrease in parallel with poorer sleep quality. A 35% of the families with enuretic children believe that their children should be punished for bedwetting.[7] In a study performed by Schlomer et al.[9] the authors indicated that 2% of the families consider, and implement punishment as a treatment alternative. In the same study, only 27% of the families believe that this condition can be successfully treated by a physician. Another striking point in Schlomer’s study is that families with higher educational level more frequently seeked medical help.

Some of the families who receive medical support lose their motivations, and abandon their physicians if they don’t get an early response from the treatment. Alarm therapy has a higher success, and lower recurrence rates compared to desmopressin, and the families confront difficulties during their application. During EAD therapy sleeping patterns of the children, and their families are deranged (level 1A recommendation, and evidence). Since minimal duration of therapy is at least 6-8 weeks, families’ compliance to treatment decreases with time.[10]

Evans et al.[11] prospectively evaluated data of 251 patients from 29 clinics, and compared desmopressin with EAD. This study analyzed data gathered from centers in England, France, and Denmark, and adherence to EAD was defined as usage of the device longer than 75% of the treatment period. Sufficient amount of data was not collected for 19 (32%) of 59 patients, and in 50-78% of all patients with complete follow-up data adhered to the prescribed EAD use. In our series, 54.8% of 42 families which we established full contact, compliance with the EAD use appeared to be 54.8 percent. Our study results resembles to those of the study performed by Evans et al.[11] which indicated patient’s preference as the most important reason for early termination of the alarm therapy. Underlying causes of this phenomenon were as follows: cables, and pads of the device which complicate adherence to alarm therapy, repeated episodes of awakenings, and lack of active involvement of the parents in the treatment process. Another striking data of this study is the impact of EAD on the sleep duration. Especially during the initial phases of the treatment, the first stages of the sleep terminated an average of three hours earlier in the alarm group relative to desmopressin group. This study which encompassed patients from 29 clinics in three countries, detailed information about cultural, and socieconomical factors potentially influential on EAD device use by the families were not provided.

Vandersteen et al.[12] evaluated 29 MNE patients aged 18-33 years, and used EAD in 27 patients with recurrent episodes refractory to desmopressin, and 56% of these patients did not continue their treatments. In a study performed by Nappo et al.[13] 107 adolescents aged 13-23 years were evaluated, and the investigators indicated that 25 (23%) patients declined the treatment from the beginning. However in this article, any information about treatment alternatives recommended for these 25 patients was not provided. In the same study, EAD was recommended only for 8 patients, and two of them were compelled to abandon the treatment. As a justification of their cessation of the treatment, one patient stated that the noise produced by the alarm device was not loud enough to waken their children, and the other patient expressed the distress he felt from the cables of the device. The most important reason for reluctance expressed by adolescents was feeling of embarrassment towards other family members. Especially during the camping seasons or for children staying in hostels this phenomenon carries utmost importance. Besides, children in this age group, and their parents look for quicker, and more practical solutions, and thus in this group medical treatment has a critical importance. Also in our study, 4 children aged ≥12 years rejected EAD use before starting therapy or shortly after its initiation.
In the literature because of the abovementioned difficulties in EAD usage, lower rates of EAD application have been cited, however despite this finding, a detailed study concerning the patients, and their families has not been performed so far, and the question “How do we overcome the difficulties concerning EAD usage?” has remained unsolved. Because of aforementioned difficulties, after a while, some families either have given up the treatment or searched for other treatment modalities. As a more attractive alternative, especially, parents working hard all day long prefer to give their children an oral medicine before they go to sleep. In our study, although challenging treatment hardships have been told to families before initiation of the treatment, only 38% of them used the device without any problem, and adhered to return visits consistently. While 16% of them never consulted to us for a control, and we couldn’t get in touch with them. Besides, 46% of them never used or failed to use EAD for various reasons.

Although children, and their parents should be considered as a whole, motivations of the parents of little children are in the foreground, while adolescents are relatively more motivated to use EADs than their parents. Therefore, before starting on the therapy, the burden of EAD application should be told to the parents in detail, and in case of need their willingness to long-term use of this device should be guaranteed. Besides age of the children, and their expectations from the treatment should be taken into consideration, and they should be motivated to use enuretic alarm device. We think that, with respect to the long-term adherence to EAD therapy by the children, and their parents, as motivating factors, their treatment should be monitored by the same physician, easy accessibility to the medical centers, and reservation of sufficient amount of time for them in the outpatient clinics should be provided.

The most important limitations of this study are its retrospective design of the study, and restricted number of participants. Besides, socioeconomic, and cultural background of the families were not scrutinized. Whereas, we think that this study will be a guiding light in that it is the first study performed in Turkey which reveals the problems of compliance experienced by the families who use alarm devices. We think that larger scale prospective studies will enable us to reach more sound conclusions on this issue.

In conclusion, despite higher success, and lower recurrence rates achieved by enuretic alarm devices, families either do not initiate treatment or lose their motivation and abandon therapy. During the selection process of the treatment modality, compliance issues should be discuss with the families in detail, their expectations, and life styles should be analyzed, and appropriate decision for therapy should be made in collaboration with the family, and the child.

**Informed Consent:** Written informed consent was obtained from patients who participated in this study.

**Peer-review:** Externally peer-reviewed.


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