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Article / Review

AN INVESTIGATION OF THE RELATIONSHIP BETWEEN THE QUALITY OF LIFE OF THE CHILD PATIENT AND THE PARENT AFTER DESMOPRESSIN TREATMENT IN CHILDREN WITH PRIMARY NOCTURNAL ENURESIS

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Abstract. Our study aimed to assess the quality of life of both children with monosymptomatic enuresis and their parents during the enuresis period and through the process of cessation with desmopressin treatment. Materials and methods: The study assessed 78 children aged 6-18 with Monosymptomatic Nocturnal Enuresis (MEN) treated with desmopressin. Comprehensive evaluations, including physical exams and lab tests, were conducted. The surveys on the impact of enuresis on daily life and emotional well-being were evaluated. Results: The study observed 78 patients, averaging 10.6 years old, primarily treated for urinary incontinence with desmopressin. Patient demographics indicated 68% had education below high school, 74% were Turkish, and 26% Syrian. Familial data revealed an average of 3.87 siblings per patient. Key findings included a significant reduction in the number of incontinence days per week post-treatment (from 5.09 days to 2.59 days). Quality of Life (QOL) scores for both patients and parents showed significant improvement after treatment. The mean QOL for patients increased from 20 to 26.8, while for parents, it rose from 13 to 24.6. Overall, desmopressin demonstrated a positive impact on urinary incontinence and the associated quality of life. Conclusions: With treatment, there is a noticeable improvement in psychological, social, and emotional aspects among children with MEN and their parents. Therefore, it is essential to treat children experiencing MEN.

Key words. urinary incontinence, psychological emotinal, desmopressin, quality of life, children.

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Introduction

Nocturnal enuresis (NE) is the most commonly observed pediatric urological developmental disorder[1]. Primary monosymptomatic nocturnal enuresis (PMNE) manifests in children who have not previously exhibited any lower urinary system symptoms or a history of bladder dysfunction and have been dry for more than six months[2]. Despite nocturnal enuresis being a socially devastating and stressful condition, affecting approximately 15% to 20% of children by the age of 5, it generally has a favorable prognosis in children and boasts a high spontaneous remission rate[3,4]. Various interventions are employed for treatment, including pharmacological, psychological/behavioral approaches, bedwetting alarms, and traditional interventions like fluid restriction[3,4] Among the pharmacological treatments, tricyclic antidepressants, anticholinergics, and desmopressin are utilized. Desmopressin, acting as an antidiuretic, is used in the treatment of nocturnal enuresis in children[5]. Nocturnal enuresis is a multifactorial pathological condition. It has three main pathophysiological determinants: nocturnal polyuria, detrusor overactivity, and the inability to awaken in response to bladder sensations[6].The first-line drug therapy for patients with MNE associated with nocturnal polyuria and normal bladder function is desmopressin for a duration of three months. Desmopressin is associated with a response rate of approximately 40-60%, but its effects might not persist once the treatment is discontinued, and symptoms have been observed to recur in about 50-80% of cases post-discontinuation[7]. Desmopressin is available in various formulations, including intranasal solution, oral tablets, and oral lyophilized sublingual tablets (MELT).

Children with enuresis and their families can experience psychological and social challenges due to the condition[8]. It has been reported that children with enuresis often feel embarrassed, unhappy, and uneasy, displaying various behavioral issues[9]. Mothers tending to children with enuresis over time may experience feelings of helplessness, isolation, and weariness. As a result of limitations in their social lives and personal time, their quality of life deteriorates, leading to psychiatric symptoms[10]. Our study aimed to assess the quality of life of both children with monosymptomatic enuresis and their parents during the enuresis period and through the process of cessation with desmopressin treatment.

Materials and methods

The study included 91 children aged 6-18 who presented with complaints of nocturnal enuresis and were diagnosed with MEN (Monosymptomatic Enuresis Nocturnal). However, 7 patients who were non-compliant with treatment, 5 patients who did not attend the first month's check-up, and 1 child whose bladder capacity was calculated to be small for their age were excluded, resulting in a final sample of 78 patients (51 males, 27 females). In all cases, the presence of symptoms suggesting bladder dysfunction (such as daytime incontinence, dribbling, leg-crossing, urgent need to urinate, and inability to completely empty the bladder) was inquired. Additionally, the onset time of enuresis, frequency of urination, and the presence of constipation or encopresis were assessed. Children with urinary incontinence due to organic issues like meningomyelocele or neurogenic bladder, those with signs of bladder dysfunction, and those with diseases causing secondary enuresis such as urinary tract infection, parasitosis, and diabetes mellitus were not included in the study. Children from households with psychosocial issues, divorce, overcrowding, or caregivers with chronic illnesses or other health problems were also excluded.

Detailed physical examinations of the cases were conducted. All children's height and weight were measured. During the genital examination, in females, the presence of vulvitis, vaginitis, abnormal genitalia, and labial adhesion were checked, whereas in males, the presence of phimosis, epispadias, and hypospadias were observed. An evaluation of anal tone, sensation, and reflexes was conducted for neurological assessment. Moreover, the presence of sacral dimple, hair growth patterns, nevi, lipoma, and fecaloma were investigated. The number of siblings and the birth order of the child were inquired. Complete blood count, blood biochemistry (urea, creatinine, electrolytes, glucose), and a complete urine analysis were conducted. Ultrasonography was also performed to measure kidney sizes and to investigate the presence of bladder and post-void residual urine. Following comprehensive evaluations, 78 children diagnosed with Monosymptomatic Nocturnal Enuresis (MEN) were initiated on a 120mcg desmopressin treatment. Prior to the onset of treatment and at the first month, a novel scale was designed specifically for assessing nocturnal enuresis in children. This scale comprised of 7 questions:

1. Do you have difficulty waking up when you feel the urge to urinate? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
2. Does your mood deteriorate when you wet the bed? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
3. Does bedwetting reduce your daytime activities? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
4. Do you feel the urge to urinate at night? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
5. Do you feel sad when your family restricts fluid intake? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
6. Do you believe your parents change their attitude towards you when you wet the bed? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
7. How many days a week do you wet the bed? 1(1 point), 2-3(2 points), 4-5(3 points), 6(4 points), 7(5 points).

For parents, leveraging the Urinary Incontinence Quality of Life Scale (I-QOL), we designed a new survey to investigate changes in their quality of life. This survey required parents to provide information on their age, weight, height, the enuresis status of their child, and other factors related to the child's well-being. A consent section was appended to the bottom of the survey, which parents duly signed. This survey also consisted of 7 questions:

1. Do you feel despondent or depressed when your child wets the bed? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
2. Do you feel free enough to leave home for an extended period? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
3. Does your child's bedwetting constantly preoccupy your thoughts? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
4. Due to concerns about my child wetting the bed at night, I cannot sleep soundly. None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).
5. To what extent do you enjoy life when your child wets the bed at night? None(1

point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).

6. Do you feel compelled to monitor your child's fluid intake? None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).

7. Due to my child wetting the bed at night, I face difficulties in my intimate relationship with my partner. None(1 point), A little(2 points), Moderate(3 points), Quite a lot(4 points), Very much so(5 points).

Ethical approval

Ethical approval was obtained from Siirt University Local ethical committee (03.03.2023 / 69911).

Statistical analysis

The patient information was evaluated through various statistical techniques, such as producing descriptive stats, pinpointing frequencies, and examining factors in all categories. Quantitative figures were shown as mean±standard deviation. We verified the normality of continuous variables with Shapiro-Wilk and Kolmogorov-Smirnov tests. For data with normal distribution, we used the Student's T-test. Non-parametric methods were utilized for non-normally distributed data. Categorical data underwent the Chi-Square test. We gauged the data's sensitivity and specificity via ROC analysis. The analysis was done using SPSS Statistics for Windows, Version 26.0. A two-tailed p-value ≤ 0.05 marked statistical relevance.

Results

The study population comprised 78 patients with the following demographic and clinical characteristics: The average age was 10.6 years (SD = 2.51 years). The mean height of the patients was 142 cm with a standard deviation (SD) of 13 cm. The average weight was found to be 28.5 kg with an SD of 11.6 kg. Regarding the treatment specifics, the average dose of desmopressin administered to the patients was 130 mcg, with an SD of 56 mcg. Familial attributes showed that the mean number of siblings for each patient was 3.87 (SD = 1.78), and the average position of the patient in the sibling order (sibling row) was 2.73 with an SD of 1.38. The baseline urine density before any treatment intervention was recorded at a mean value of 1020 with an SD of 6.29. To evaluate the effectiveness of desmopressin treatment on urinary incontinence, we recorded the number of days of urinary incontinence per week for each patient before and after the treatment. Before commencing desmopressin treatment, patients reported an average of 5.09 days (SD = 1.74 days) of urinary incontinence per week. Following the desmopressin treatment, there was a notable reduction in the number of days patients experienced urinary incontinence, with an average of 2.59 days (SD = 2.15 days) per week. In terms of educational level, 53 patients (68%) had an educational level below high school and 25 patients (32%) had an educational level above high school. Out of the total patients, 58 (74%) were of Turkish nationality and 20 patients (26%) identified as Syrian **(Table 1)**.

Table 1: Demographic

Total patients (n=78)	n or mean	% or SD
Age	10,6	2.51
Gender (M)	51	65%
Height (cm)	142	13
Weight (kg)	28,5	11.6
Number of siblings	3,87	1.78
Siblings row	2,73	1.38
Urine density	1020	6.29
Number of days of urinary incontinence per week		
Before desmopressin treatment	5,09	1.74
After desmopression treatment	2,59	2.15
Educational level		
Below high school	53	68%
Above high school	25	32%
Nationality		
Turkish	58	74%
Syrian	20	26%

Before the initiation of desmopressin treatment, the mean QOL score was 20 with a standard deviation (SD) of 5.87 for patients. After undergoing desmopressin treatment, the mean QOL score showed an improvement, reaching 26.8 with an SD of 4.91 for patients. The observed difference in the QOL scores pre and post-treatment was statistically significant (p<0.001)

(Figure 1 and Table 2).

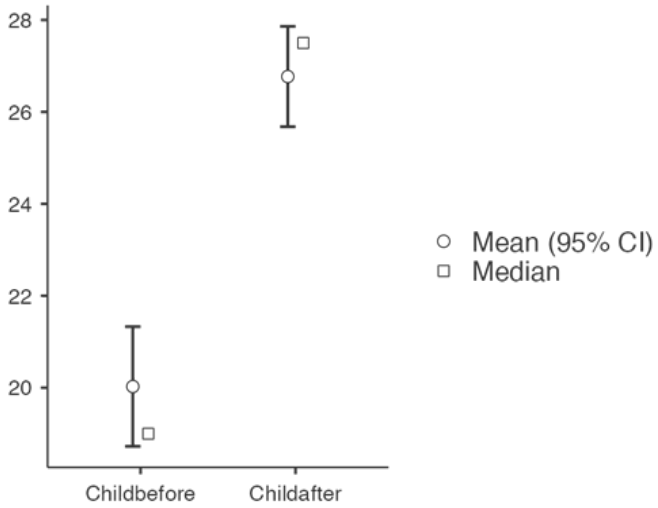

Figure 1: The patients results of QOL questionnaire before and after treatment with desmopressin

Prior to the desmopressin treatment, the mean QOL score for the parents was recorded as 13 with an SD of 2.93 for parents. Following the treatment, the mean QOL score for the parents significantly improved to 24.6 with an SD of 7.91 for parents. This change in the QOL scores before and after the treatment was also found to be statistically significant (p<0.001)

(Figure 2 and Table 2).

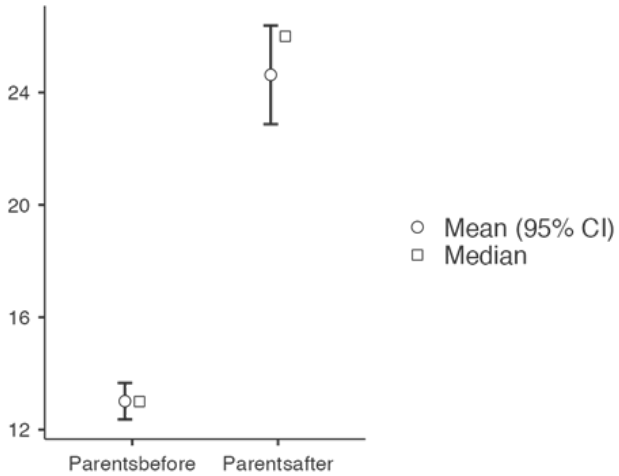

Figure 2: The parents results of QOL questionnaire before and after treatment with desmopressin

Prior to starting the treatment, patients reported urinary incontinence on an average of 5.09 days per week, with an SD of 1.74 days. After Desmopressin Treatment: Post-treatment, there was a substantial reduction in the reported average to 2.59 days per week, with an SD of 2.15 days. The marked decrease in the number of days patients experienced urinary incontinence after the treatment was statistically significant (p<0.001) (Table 2).

Table 2: Comparison of the QOL and number of days of urinary incontinence per week results after desmopressin treatment

	Mean	SD	p-value
QOL results for patients			<0.001
Before desmopressin treatment	20	5.87	
After desmopression treatment	26.8	4.91	
QOL results for patrents			<0.001
Before desmopressin treatment	13	2.93	
After desmopression treatment	24.6	7.91	
Number of days of urinary incontinence per week			<0.001
Before desmopressin treatment	5.09	1.74	
After desmopression treatment	2.59	2.15	

Discussion

While many studies have addressed the psychological changes in children with enuresis, there are scant investigations focusing on the mental state of parents with bedwetting children. The self-confidence acquired during this phase plays a crucial role in a child's growth and psychological development[11]. Enuresis can pose challenges not only for children but also for parents in social, psychological, and economic aspects. The World Health Organization (WHO) defines quality of life as the way an individual perceives their position in life, within the context of the culture and values in which they live, shaped by their goals, expectations, standards, and concerns[12]. In a study conducted by Safarinejad and colleagues, the prevalence of Monosymptomatic Nocturnal Enuresis (MEN) was reported as 18.6% in India, 3.8% in Italy, 9.2% in Korea, 8% in Malaysia, 5.5% in Taiwan, 4.2% in Thailand, 12.4% in Turkey, 18.9% in Australia, and 15% in another unspecified region[13]. In our study, out of the patients presenting with MEN, 55 (74%) were Turkish nationals, and 20 (26%) were Syrian nationals. In a study by Meydan and colleagues, the quality of life and stress levels of 60 mothers with MEN-affected children were compared with those of 90 mothers without affected children. A significant decrease was identified in the quality of life for the 60 mothers with enuretic children[14]. In a similar investigation by Naitoh et al., 139 parents of children with MEN were studied, revealing a meaningful improvement in their quality of life following MEN treatment[15]. Another study by Egemen and colleagues involved mothers of children with MEN (n=28) and those with healthy children (n=38). It was observed that the life quality scores of children with MEN were significantly lower[16]. In our research, a statistically significant improvement in the parents' quality of life was observed after treating MEN with desmopressin ($p<0.001$). In a study by Üçer et al.[17] the quality of life in 101 children with Monosymptomatic Nocturnal Enuresis (MEN) was found to be significantly lower than that of the control group. Furthermore, the same study revealed that children with MEN were unhappier compared to the control group. In our study, we did not have a control group; however, after the desmopressin treatment, there was a significant increase in the quality of life ($p<0.001$). Our study had several limitations worth noting. First, the sample size was limited to a specific geographical and cultural context, which may affect generalizability. Additionally, the utilization of a novel, non-validated QOL scale for nocturnal enuresis might introduce measurement biases. We also did not account for potential placebo effects or the long-term efficacy and sustainability of desmopressin treatment. Future studies with larger, diverse populations and standardized measurement tools are recommended.

Conclusions

Monosymptomatic nocturnal enuresis significantly adversely impacts the quality of life for both the affected children and their parents. With treatment, there is a noticeable improvement in psychological, social, and emotional aspects among children with MEN and their parents. Therefore, it is essential to treat children experiencing MEN.

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