Paediatric Enuresis Excellence Group

PEE

Promoting quality in continence care

Bladder & Bowel UK

Supporting people with bladder and bowel problems

part of Disabled Living

Enuresis Update

Welcome to the Autumn 2018 edition of 'Enuresis Update'

'Enuresis Update' aims to be a resource for clinicians involved with caring for children and young people with bedwetting problems, that promotes excellence in practice.

In this edition we have included reviews of published papers on multidisciplinary assessment and treatment, optimizing response to desmopressin, the impact of bladder capacity, the role of sleep-disordered breathing on enuresis and an article about the importance of empowering families. We hope you find them interesting and useful.

We welcome ideas and comments, as well as suggestions about what you would like to see included. We would also be happy to share any updates about your services' development.

Please do get in touch with us at email: bladderandboweluk@disabledliving.co.uk with your contributions. We look forward to hearing from you.

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Empowering Families

Previous work identified the benefits of empowering families to self manage a range of paediatric continence problems such as constipation and bedwetting (Rogers 2012). In the majority of cases, it is what families do at home that can make the difference between success and failure of treatment and management interventions. If families have a good understanding of the problem their child is experiencing and have the appropriate information to self manage that problem, within clear prescribed treatment packages, they are more likely to support their children throughout the process resulting in improved outcomes.

A number of studies have explored the use of social media and online information to help educate patients regarding their condition. Housel et al (2014) carried out a review looking at the benefits and challenges of empowering patients via social media. They concluded that such technology holds promise for improving patient engagement and empowerment and community building. They felt that social media has a future in healthcare, especially with regard to patient engagement and empowerment. However, they were cautious regarding several challenges, particularly around misinformation, that had to be overcome before the technology could achieve its full potential.

Clerici et al. (2012) reported several benefits to using digital social media and noted that online videos are a more effective way of sharing health information than written text. They also reported that it was easier for patients to describe their experiences and first hand impressions, relating to their disease, using videos they had seen on YouTube.

Li et al (2012) also discussed the advantages of digital media to deliver specifically targeted videos to population groups, who find that using this information and resources is easier than with written text. They felt that if the viewers are emotionally involved they are more likely to make behavioural changes in response to the story they see in the video. The authors also noted that for those with poor literacy skills, video provides a more user-friendly approach to sharing and understanding health information. Additionally, videos, especially ones using animation, can help reach ethnic population groups.

Thielst (2011) also reported that social media can help patients find information when they are diagnosed with a condition that requires ongoing treatment and management. The author noted that social media technologies can be used to reduce the utilization of health services and improve both patient responsibility and acceptance. Other benefits of social media found by Thielst were that using social media based videos rather than

text interventions can have increased impact on patient empowerment and patient engagement, for a variety of health behaviours.

Within children's continence, the changing role of school nurses and health visitors has led to a reduction of level 1 intervention. Consequently, many families are not receiving timely, appropriate information and advice. We therefore considered how we could help families, affected by bedwetting, to have access to the most appropriate information and decided to look at developing a range of online videos to help educate and empower families in the causes and treatment of children and young people with this condition.

Ferring Pharmaceuticals created the website www.stopbedwetting.org as a resource providing information and support materials to help empower families affected by bedwetting. Working with Ferring Pharmaceuticals Ltd and a creative and medical education agency Bladder and Bowel UK supported development of a range of short online videos to explain, the causes of bedwetting, what parents/carers can do to help improve bedwetting and the treatments that are available. These videos will all be uploaded over the next few months. The website will be continually reviewed so that it remains educational and informative.

Many parents/carers contacting the Bladder and Bowel UK helpline reported that they had been told that their child would 'grow out' of the bedwetting, or that treatments were not available until the child was 7 years old. This was worrying because it meant the child was not being assessed, with potential underlying problems, such as constipation, being missed. We wanted to be able to provide families with the appropriate information increase their confidence when they spoke with a healthcare professional about their child's bedwetting.

The Stopbedwetting website is an ideal platform for families to gain an insight into the causes and treatment of bedwetting but also, by using the online tools, to feel more confident about managing their child's bedwetting.

References

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Research Reviews

Monosymptomatic Nocturnal Enuresis in Pediatric Patients: Multidisciplinary Assessment and Effects of Therapeutic Intervention.

Simone N Fagundes, Adrienne Surri Lebi, Leticia Azevedo Soster, Guilherme Jorge Sousa de Silva, Edwiges Ferreira de Mattos Silvares

Pediatr Nephrol (2017) 32:843-851

Abstract

This was a prospective Study of MNE (Monosymptomatic Nocturnal Enuresis), in patients aged 6-16 years. The Author's view was there were few studies about managing patients with isolated MNE with multidisciplinary evaluation and pre and long-term post intervention monitoring.

The study was conducted by a multidisciplinary team, involving nephrology, sleep physiology and behavioural therapy units. Assessment was expert and detailed. It considered a wide range of possible contributory factors in Nocturnal Enuresis and included investigations at the end of the first visit of blood and urine analysis, kidney and urinary tract ultrasound and polysomnography with additional investigations including 24 hr calcium or MSSU as indicated. Diaries were requested of bladder bowel habit for 7 days and wetting incidents and sleep habits for a month. Evaluation was used to differentiate MNE, Non MNE and Enuresis associated with chronic disease. Assessment also included pre and post intervention questionnaires using the Children's Behaviour Checklist and the Pediatric Quality of Life Index.

There were 140 initial applicants with a mean age of 9.5 years. 75.6 % were males and 85% had Primary Enuresis. 64% had Enuresis more than four times per week. Further analysis of the applicants showed them to be similar to those used in other studies. First assessment of potential participants led to exclusions for the following reasons; Non MNE (27), Hypercalciuria (4), Nephropathy (3) and ADHD (1) and 17 children failed to complete the first assessment.

A diagnosis of MNE was made in 88 patients, one of whom resolved spontaneously. The 88 children then had polysomnography, which identified 40% of children to have mild to moderate apnoea. Six children had severe sleep apnoea so they were referred to specialist services and excluded from the study.

82 children continued on to the treatment phase. All children were offered Urotherapy (awareness of micturition and bowel habit, dietary modifications and water restriction at night) and constipation management if required (81%). This led to remission in 7 patients.

The remaining 75 patients were randomized into three treatment groups of Desmopressin (20 patients), alarm (30 patients) and a combination of alarm and Desmopressin (25 patients). Success was measured as partial (>50% improvement) or complete (100% dry nights). Alarm was discontinued after 14 consecutive dry nights.

During therapy 14 dropped out (mainly from the alarm group). Initial Response (during treatment, complete or partial) was 56.6% alarm, 70.0 % Desmopressin and 100% combined. Children who were dry then underwent 'overlearning'; drinking a variable amount of water, according to age, at bedtime after alarm treatment was successful (>14 dry nights) and Desmopressin was discontinued.

The children were followed up at 12 months. Recurrence rate was 15.0% Alarm, 5.2% desmopressin, 0% combined. Continued dryness in the remainder was 71.4% alarm, 84.2% Desmopressin and 100% combined.

The study analysed several other aspects of this group of children: Clinical risk factors for the severity of enuresis (only significant for prematurity) and improvement of response (association with a normal voiding frequency of between 4-7 voids per day.) All drop outs were interviewed and were associated with a pre-treatment desire to progress more quickly and post treatment with treatment failure.

Implications for Practice

This study focused on the treatment of MNE and followed on from a previous paper giving looking at the results of detailed multidisciplinary specialist assessment and included investigations not often carried in children with Nocturnal Enuresis. The authors emphasised the value of assessment in defining the children and clarifying the treatment group that they wished to evaluate. They did not however demonstrate that these assessments were necessary in all children with MNE as good history taking should identify which children may need further assessment. We should already be aware of such conditions e.g. polyuria secondary to renal conditions and obstructive sleep apnoea and we will already have established routes of referral if we have concerns about specific conditions.

Assessment was comprehensive and included investigations not often considered in children with Nocturnal Enuresis. These are not usually accessible to community clinics and are probably not warranted. However, good history taking will help identify conditions we should be aware of, such as sleep apnoea and constipation. The authors emphasised the value of assessment in defining the children and clarifying a treatment group.

There was a high prevalence of constipation, which is consistent with experience although NE resolved in only 8.5% following effective management of constipation with urotherapy alone. Treatment success was more strongly associated with a normal voiding frequency emphasising the role for diaries and urotherapy as a part of all treatment plans.

This study was randomised and the majority of drop-outs were in the alarm group. There was a similar response rate for alarm and Desmopressin. Alarm treatment is effective but onerous so the drop-out rate may have been lower had there been informed choice. Combined treatment resulted in a rapid response and combined treatment was more effective than single treatment. Furthermore, relapse was higher in the alarm than in desmopressin (14.3% relapsed with alarm and only 5.3% with desmopressin)

There was improvement in child behaviour and quality of life scores. Close management and effective follow-up was a factor in both the initial and the sustained improvement. There were greater improvements in parent/caregiver scores compared to child scores on quality of life assessment demonstrating we are treating the whole family and highlighting the need for emotional support for patients and families throughout the process**.**

Optimizing response to desmopressin in patients with monosymptomatic nocturnal enuresis

Konstantinos Kamperis & Charlotte Van Herzeele & Soren Rittig & Johan Vande Walle
Pediatric Nephrology 2017 32, 217-226 DOI 10.1007/s00467-016-3376-7

Abstract

In light of a research paper citing that one third of children referred to a specialist centre became dry on desmopressin, having previously not responded to the desmopressin, together with the associated impact of prolonged bedwetting, the article considered best practice for desmopressin in monosymptomatic nocturnal enuresis (MNE).

It is considered that nocturnal polyuria in most children with MNE is as a result of insufficient secretion of arginine vasopressin at night, although other factors may be involved.

The paper highlights that desmopressin is twice as likely to be effective in children who have mean voided volume (MVV) >70% of expected for age compared to children with reduced MVV. Desmopressin was also more efficacious in older children partially because younger children were more likely to be affected by food ingestion near bedtime negatively affecting desmopressin tablet absorption and action.

Implications for Practice

Kamperis et al make several recommendations for practice:

Oral lyophilisate (melt) may offer improved response in some children due to: 1. ease of administration (being preferred by children under 12 years) 2.not requiring water for administration (reducing evening fluid intake and diuresis) 3. reduced interaction with food, particularly for younger children who have a short interval between their evening meal and bedtime 4. the pharmacokinetics of the oral lyophilisate is more predictable than the tablet, which may give greater consistency to antidiuretic effect in individuals.

Desmopressin has best effect when taken one hour before bedtime and two hours after the evening meal. This is not practical for many young children and therefore the oral lyophilisate may be more effective if it is not possible to optimise timing of administration.

Eating protein and sodium (salt) in the evening can increase osmotic excretion overnight as can low daytime fluid intake. Avoiding high salt and high protein foods before bed and ensuring adequate daytime fluid intake may help resolve NE for some children

Ensuring fluid restriction for an hour before and eight hours after desmopressin administration optimises treatment response as well as reducing the risk of hyponatremia.

There is a wide variety in the time taken to reach maximum antidiuretic effect of desmopressin and in the duration of the action of desmopressin in children with NE. Increasing the dose is likely to increase the duration of the antidiuretic effect.

Adherence to treatment is required for effectiveness. Studies have shown more than 30% do not adhere to treatment for chronic conditions after 3 months. Families need to understand the importance of continuing treatment as recommended

For children who do achieve dryness there may be some benefit to structured withdrawal programmes over several weeks to reduce relapse. However, not all studies demonstrated this effect.

Some children only have a low bladder capacity at night i.e. there are no daytime bladder symptoms. If nocturnal polyuria is confirmed (by measuring overnight voided volumes combined with the volume of the first void of the morning) addition of an anticholinergic in a specialist clinic may be warranted.

If the child fails to respond to desmopressin despite good adherence consideration should be given to combination therapy or different treatments.

Evidence of reduced bladder capacity during night time in children with monosymptomatic nocturnal enuresis

Borg B, Kamperis K, Olsen L.H, Rittig S.
Journal of Pediatric Urology (2018) 14, 160.e1-160.e6

Abstract

Introduction and objective: Daytime frequency volume charts are used to estimate bladder capacity but it is well known that nocturnal bladder capacity may not be the same. The authors aimed to assess nocturnal bladder capacity in children with monosymptomatic nocturnal enuresis (MNE) with normal daytime bladder capacities equated with their maximum voided volume (MVV).

Methods: 103 children (mean age 8.9 +/-1.7 years, 38% girls) with MNE and normal MVV (>65% EBC) attending a tertiary centre recorded their overnight nocturnal urine production NUP (weight of wet nappy/g-wt of dry nappy/g + 1st void of am) for 2 weeks and the NUPs on wet nights were used as a surrogate for estimated nocturnal bladder capacity (eNBC). It was considered reduced if it was less than MVV for that patient. The recordings were also made for 2 weeks on desmopressin treatment for comparison.

Results: 82% of children had an episode of NE associated with reduced eNBC. The mean percentage of wet nights with reduced eNBC (<MVV) was 49% and 23% (<EBC). Children who had frequently reduced eNBC at night responded less well to desmopressin.

Limitations: Biased sample from a tertiary hospital and assumption that the bladder is only emptied once during the night with complete emptying, which the authors acknowledge is often known to not be the case.

Implications for practice

Children with monosymptomatic nocturnal enuresis and normal MVV by day often have reduced nocturnal bladder capacity and storage function at night. This will not be shown in a daytime frequency-volume chart alone but is evident on night-time recordings of nocturnal urine production on wet nights. Night-time bladder capacities are very variable

but if there is frequent reduction in nocturnal bladder capacity then response to desmopressin is poor. This may give an explanation as to why a child with MNE and normal daytime bladder capacities does not respond to desmopressin treatment and possible alternative strategies to increase nocturnal bladder capacity include the use of the enuresis alarm and anticholinergics.

Obstructive sleep-disordered breathing, enuresis and combined disorders in children: chance or related association?

Zaffanello M, Piacentini G, Lippi G, Fanos V, Gasperi E, Nosetti L.
Swiss Medical Weekly 2017; 147:w14400

Abstract

Both bedwetting and obstructive sleep-disordered breathing (SDB) are common problems in childhood that coexist and occur during sleep. SDB, which features snoring and/or increased effort to breathe includes obstructive sleep apnoea syndrome (OSAS) – observable apnoea, unrefreshing sleep and daytime tiredness. OSA, like enuresis, is complex and multifactorial. It occurs in 0.7 – 3% of children and both conditions are underpinned by sleep disturbance, sleep fragmentation and changed sleep arousal.

The authors aimed to elucidate whether there was a link between enuresis and upper respiratory obstruction, the frequency of OSAS in children with enuresis, why OSAS increased the risk of enuresis and whether treatment of OSAS cured enuresis.

There were a number of limitations to the 17 studies reviewed and the strength of the evidence was not high, with most being at level 2c . However the reported findings from the studies included the following:

- The prevalence of enuresis was not related directly to severity of OSAS
- Snoring was related to increased frequency of enuresis
- Snoring and monosymptomatic enuresis are related to increased risk of behaviour and psychosocial problems and impaired health-related quality of life
- 8-47% of children with enuresis were reported to have obstructive SDB
- Enuresis has resolved in 31-76% of children surgically treated for OSAS
- Diastolic BP and urinary excretion of sodium increase in line with increased severity of obstructive SDP, resulting in increased urine production, which resolves on treatment of OSAS
- SDB can increase secretion of atrial natriuretic peptide (a small peptide secreted by the heart upon atrial stretch and high systemic blood pressure. The acute effects of this potent, short-lived peptide include increased glomerular filtration and increased renal excretion of sodium and water) and reduce secretion of vasopressin, as well as increase systemic blood pressure and intra-abdominal pressure. All of which combine to increase overnight urine production. These resolved after treatment for OSAS

• Adenotonsillectomy did improve the health related quality of life scores for all children in the studies, regardless of impact on enuresis

The authors concluded that, as their findings came from mostly observational studies there is a need to further explore these correlations in controlled studies, to improve the quality of the evidence.

Implications for practice

All children and families should be asked about symptoms of obstructive sleep apnoea syndrome (OSAS) when they present with enuresis. These include snoring, sleep apnoea and restless sleep.

Where these present or there is confirmed sleep disordered breathing (SDB) children with enuresis should be referred for investigation and treatment
If enuresis persists after treatment for SDB children should be assessed and treated for enuresis in the normal way.

World Bedwetting Day 2019

Tuesday 28th May

Enuresis Award Winner 2018
Children's Continence Team West Sussex

The Children's Continence Team from West Sussex were worthy winners of the 2018 BBUK Enuresis Award. Their entry highlighted their determination to improve the care of children and young people with bedwetting. An overview of their project is below.

Improving Enuresis service and outcomes for children and young people by provision of single person use enuresis alarm

The key aim was to improve outcomes and service delivery for Children and Young People (CYP) by providing single person use enuresis alarm at an initial clinic appointment.

Historically, if an alarm was recommended by the nurse, the CYP were allocated to a waiting list, until an alarm was available, with some waiting more than two years. Management of the waiting list, collection and redistribution of reusable alarms was time consuming, making the nurse less accessible to patients requiring support.

There were a number of challenges to overcome, but changing to single person use alarms significantly improved patient experience. CYP have the option of two treatment pathways to manage enuresis, in line with NICE Guidance. They are provided with an enuresis alarm at the point of highest CYP motivation – at their nurse-led clinic appointment.

Costs to the NHS Healthcare Trust for alarms are are no greater, but significant savings have been made in nurse hours, resulting in improved patient contact and flow through the service. This has facilitated increased training to other professionals and a new continence champion role within each of the tier one healthy child teams. The referral process was changed to ensure operation as a tier two continence service, with improved assessment of need, patient compliance and earlier treatment intervention.

Resources

Enuresis

Information leaflets are available from: **Bladder and Bowel UK at:**
https://www.bbuk.org.uk/children-young-people/children-resources/

Children's continence special interest group

To join email bladderandboweluk@disabledliving.co.uk Members receive email newsletters and information about training, developments and issues related to continence.

Pathways

Bladder and Bowel UK have published new pathways for Children's Continence at Level 1 and Level 2 with supporting information and assessments for Level 1. These are available to download and print from:
https://www.bbuk.org.uk/professionals/professionals-resources/

Training

For more information about bespoke training email:
bladderandboweluk@disabledliving.co.uk

Bladder and Bowel UK annual National Symposium
6th March 2019, Bolton Arena Information available at:
https://www.bbuk.org.uk/professionals/professionals-training/training-symposium/

Bladder and Bowel UK Paediatric Special Interest Group Education Day
17 October 2019, Manchester. Information available from:
https://www.bbuk.org.uk/professionals/professionals-training/training-paediatric-continence-promotion-day/

Sharing Best Practice

In future editions we would like to have a section in the Enuresis Update for you to share comments, concerns and local approaches to best practice.

We will publish your letters, comments, questions, ideas and descriptions of things you have done that have improved care for children and families in your area, or anything you feel might help others.

Let us know what you think of this newsletter and if there is anything you would particularly like to see in future editions. Email us at bladderandboweluk@disabledliving.co.uk