Children with myelomeningocele (MMC) / spina bifida and bladder emptying using clean intermittent catheterisation.

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Background

There are born approximately 15-20 children with MMC in Norway per year. (Numbers based on information from the Medical health register received from TRS (a National resource center for this diagnosegroup.) In 90 % of the children with MMC/spina bifida the nerve impulses to the bladder are affected. There can be highly complex combinations of effects regarding both the filling and the emptying phase. Detrusor –sphinkter dyssynergia and high intravesical pressure are most dangerous for the renal function. (Backhaus et al 2002). The effects of sufficient and adequate treatment are important to avoid severe renal damage, UTIs and urinary leakage.

Most of patients with MMC empty their bladder with clean intermittent catheterisation (CIC), an established method proven to be safe and effective with few complications. (Bakke 1993, Lindehall 2007).

In Norway children with MMC are being urodynamically investigated in 4 regional hospitals. Our unit in Rikshospitalet HF, the National Hospital, is performing most of these, approx 150 investigations per year on patients between 3 months and 18 years old.

Importance of the problem

We experience that a part of our patients performing CIC still have residual urine directly after the procedure. Others have confirmed this for adult patients with spinal cord injury. (Jensen et al. 1993). The prevalence and the amount of residual urine after CIC for children and the consequences are not much described in the literature. Residual urine is connected with bacteriuria and UTI, an unpleasant smell of the urine and urinary leakage.()

Patients with MMC often have reduced sensibility in the genital area related to their condition, as most of them having paraplegia. The implication is commonly reduced ability to recognize bladder filling, urge/need to empty the bladder, regular symptoms of UTI and urinary leakage.

Cognitive problems in various degrees are seen in these patients (Persson et al.2007). 90% have been shown to have hydrocephalus (Lindquist et al 2005). Probably hydrocephalus is one of the reasons for cognitive problems. Our experience is that unpleasant urinary smell is not always detected by the patient him/herself. This gives implications to social acceptance. A connection between urinary leakage and a negative self-esteem is documented (Moore et al 2004).

The impact of the cognitive function are special needs for information, education and follow up as the aim is independence and optimal care for own health and social functioning.

Objectives

In our planned study we want to measure to which degree our patients who emptying their bladder with CIC still have residual urine. We are routinely registering the prevalence of UTI, urinary leakage, max bladder capacity, bladder medication, catheter-size (ch)/length and radiological status of the upper tract. In this study we want to see if there is a possible correlation between these factors and amount of residual urine directly after performed CIC. Factors like special problems with CIC, ability to recognize signals from the bladder and smell of urine, and age of start performing CIC independently are also of relevance.

The hypothesis is that there is residual urine after CIC for a major part of the patients. If the hypothesis is confirmed the effect can be attention to the problem, possible solutions and improved education to the patients and their parents.

Short literature review; summary of the present knowledge

The list of literature about MMC patients and their urological situation is long. On the other hand documentation on residual urine after CIC in this group or other groups is not much described. CIC as procedure is described several times. In Norway the clean technique started in the aprox 1982 and has since then become the most usual method for bladder emptying. The disputation of A. Bakke on this subject in 1993 was an important factor.

I found one (small) study from 1993, were 12 patients (adults) with SCI were examinated. Residual urine after 25 of 36 catheterisations (70%) was measured with ultrasonography. The patients were being catheterised by staff and were laying flat during the procedure. They were catheterised for 5 minutes without external bladder manipulation or being elevated in the late phase of catheterisation. The conclusion was that catheterisation in a laying position is not optimal and that even small amounts of residual urine can be disposing for UTI. (Jensen et al 1993)

In our study we want the patients to do the catheterisation themselves while we catheterise and scan with portable ultrasound directly after CIC.
In 2007 a study including 24 adult females with neurogenic bladder using Speedicath compact (short catheters, 7 cm) found 0-20 ml residual urine. (Biering-Sørensen et al 2007).

Urotheraphist/RN Birgitta Lindehall has in her disputation investigated teenagers and young adults with myelomeningocele and clean intermittent catheterisation-urological and psychososcial aspects.

Relevance to urology nursing

Urological nurses/urotherapists are usually the teachers in CIC for paediatric urological patients and their parents. The aim of the teaching and treatment will be to reduce the risk factors of developing kidney failure, UTIs and urinary leakage. To enlighten factors that might be of importance for improving the techniques is of great importance for the patients and the field of nevro-urology.

Methodology

Design

Prospective, descriptive study where the patients are coming to an already planned visit.

Cross-sectional analyse with a representative, unbiased sample of the population of MMC - patients. The mix of gender is supposed to be even. The age can vary from 6 till 18 years old.

There are no new elements for the patients than in an ordinary consultation. For this reason there will be no pilotstudy. Totally 100 patients are planned to be included.

The reason for choosing this design is because this is a method which gives information about prevalence and problems in a population of patients with the same diagnose. The patients are not chosen by the investigators, but are invited by a patient coordinator.

Inclusions criteria

Patients who are performing CIC independently (meaning inserting the catheter into the bladder themselves). Patients, who are referred to urodynamic investigation and together with their parents given their written approval to participate in the study.

Exclusion criteria

Patients, who are not for any reason performing CIC independently or have not, with their parents, given their written approval to participate in the study.

Possible weaknesses of the registration.

Physical explanations to RU after CIC can be bladder diverticula's. If the patient have developed diverticula's they can be filled with urine during the filling phase. When the patient have emptied the bladder the diverticula's might empty after a while. Micturation cystograpy can reveal this factor, but since that is not done routinely for our patients this can be a weekness in the registration. Our patients will have urinary ultrasound yearly.

Another possible factor is variation in the ADH (antidiuretichormone) -production in our population related to the effect of hydrocephalus. This implicates that during a short time the patient might produce more urine than usual. (Ferrara et al.2002)

It is also possible that "the busy-patients" are using a longer time to empty their bladder and maybe get another result than the other days, but this has to be a factor when children are involved. Whether it has a consequence is not known.

Ethical considerations

Performing a study where children are involved demands strong ethical standards and information suitable and adequate for the age of the patient.

The patients and parents will receive written study information and a consent formula based on the Helsinki declaration enclosed with the time- notice of the visit in our ward.

Oral information will be given before the investigation with the same insurance that it is not influencing the treatment/care if they don't want to participate. The patients/parents who want to be enrolled sign the consent formulary.

In this information it will be informed about the fact that there will be no difference in treatment and care whether the patient/parents want to participate or not.

Study procedures
The patients/parents who want to participate in the study get oral information and sign the written consent.

The patient performs CIC as usual in the wards bathroom after his usual procedure before the investigation.
The patient will come directly to the investigation-room were we will scan the bladder with an ultrasonographic scan and then catheterise the bladder for residual urine into a pre-weighed incontinence pad.
Outcome measures and relevant urological information will be obtained with the doctor and registered. (See attachment 1)

Statistical analysis
Quantitative, descriptive analyse performed with SPSS guided by a statistic analytical employed at Rikshospitalet. Look at statistical correlations between demographic, equipments, medical status, and medical consequences and the response variables (1.prevalence of patients having residual urine after CIC and 2.the amount).

Sample size
100 patients will be enrolled in this descriptive study. Whether the sample size is enough for statistic significance is not known.
Possibly this will be a hypothesis generating study for other elements as well that can be a focus for further investigations.

Feasibility
To do this registration is possible because the procedure is basically like the ordinary investigation. The registration and the study related factors (consents, information and applications) come in addition.

Timetable

August 07 Inform ward responsible leaders
Sept-Dec 2007 Writing the project plan.
Nov:07 Find medical cooperates. Discuss with a statistical employee.
Dec: start to write the registration formulas, consents and patient information.
Dec 1th: send the plan to EAUN.
Des 07 meeting with the cooperates.

Dec 07-Febr 08 Work more with the theoretical part – literature revue and further searching.
January/February: Finish registration formulas
February –March 08 Apply Internal approvals
March 08 Maybe/hopefully EAUN guidance
April: Apply to the Regional ethical committee. After acceptance: start the project.
May 08 Start the project
May 09 Estimated End. Statistical analyses and report writing.

Budget:

What are you going to use the EAUN budget for, and where will you find more funding (if needed) to complete your project?

My wish is to get more formal knowledge about doing research. If I win that is what I want to spend the prizemoney on.
The project will be a low-cost, because it is a part of what we are already doing.

Conclusions / Relevance

This is important both for the neuro-urological field and the knowledge of MMC and possible factors for complications with residual urine. The practical effect might be better education to the patients with neurogenic bladder dysfunction and maybe even reduction in the risk of complications from residual urine after CIC.
There are many possibilities for further researches for nurses on this area as this can absolutely be a hypothesis -generating study needing more research both for nurses and doctors.

References

Words for searching
Urinary Catheterization, urinary tract infection, bacteriuria, residual, residual urine, urinary bladder, urine, urinary leakage, urinary leakage, meningomyelocele, myelomeningocele, spina bifida, ultrasonography depressive, selfesteem.

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