

European Society of Paediatric Urology Nurse group, ESPUN

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Workshop report: Disposables, chaired by:

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The first 30 minutes Hanny Cobussen-Boekhorst presented a review of the literature on disposables. After that the audience was divided into groups of about 10 persons from different countries. All groups received two case-reports and some questions. After each participant had written down the answers the group discussed the questions. Before moving to the next question the participants had to write down if they had learned something new from their colleagues. After 45 minutes the groups also evaluated the workshop.

Thirty-three members participated in the workshop; they were divided in four groups and 23 answers were collected afterwards. Eight countries were represented: Sweden (4 persons), China (1 person), The Netherlands (6 persons), Belgium (4 persons), UK (3 persons), Germany (1 person), New Zealand (1 person), Denmark (2 persons) and one was unknown.

First question was to inform the other about ones own work:

1. Do you advice and/or prescribe disposables?

Sixteen persons answered yes and 7, no. The no answers stated that they advice disposables, but are not allowed to describe (3 persons of Belgium, 1 of NZ and 2 of the Netherlands and one unknown)

Case-report I:

Sarah's parents have made an appointment with you. Sarah is 9 years old and has spina bifida and is wheelchair dependent. Her mental development is of a child age 7 years and she is obese. Because of high leak point pressures she got a vesicostomy when she was 2 years old. Her bowel problems have been solved by enemas. For her urinary output she has to wear diapers. The urologist has suggested that the next step in her urological treatment could be a bladder augmentation with a Mitrofanoff.

Now Sarah's parents want to discuss this option with you. Sarah has problems with her diapers, the absorption capacity is insufficient and the skin around her vesicostomy is irritated. Her parents are worried, because Sarah is not able to perform clean intermittent catheterization, CIC, independently. At the moment there are several people who change Sarah's diapers but most of them are not willing to perform CIC. Sarah's intellectual understanding is too limited to understand the consequences of the suggested option.

The questions to discuss:

- **Would you advice Sarah and her parents a bladder augmentation with a Mitrofanoff?**

Answers: Advice Sarah and her parents to do a bladder augmentation with a Mitrofanoff.?

- **Discuss the advantages and disadvantages of a bladder augmentation with a Mitrofanoff for Sarah.**

Answers:

Advantages: no more diapers, no skin problems, becoming continent, socially independent, increased self esteem, doing CIC by herself, easy to catheterise, self-supporting, easier for others to help. Lower bladder pressure, enlarge capacity. It can only be better, not worse.

Disadvantages: Parents worried about CIC, too young to do CIC, obese is a risk factor for surgery, surgery has complications (leakage, stricture, stone, mucus, dependent of CIC, regime) , what does the child wants? She has to learn CIC by herself, risk with major surgery, small risk for cancer, eventually need to flush the bladder, electrolyte disturbances (depending on type of augmentation). More dependent because of intellectual understanding, parents or caretakers need to supervise. Long time in hospital after surgery, no assurance that the patient will be continent, not to operate age younger than 5, psychological acceptance.

Note: tell everything, also the disadvantage.

- **What would you advise *at this moment* in expectation of further medical care?**

Answers: Advantage: Solving the skin problem with protections (barrier crème, cavilon, hydrocolloid systemic antifungal, yoghurt granuflex) and see what causes the problem. Change the diapers regularly or more often, better/ different nappies, communication with the care-takers, so that everybody does the same, observation of the skin, no appliance for a while. Practice CIC via vesicostomy at this moment as to prepare for further care.

Is there an infection? Education and discussion with child and family about CIC, voiding/ drinking pattern and social services. Try a stoma bag.

Disadvantage: time-consuming

- **Did the discussion bring up something new for you?**

Yes: 13 persons, No: 9 person.

Case-report II:

The paediatric nephrologist has referred Mike, 4 years old and his family to you. Mike's underlying disease is dysplastic kidneys. Because of his kidney problem he suffers from polyuria. His mother is desperate. Every night she changes diapers at 23.00 and at 2.00 o'clock in the morning, but despite all her efforts Mike's bed and pyjamas are wet in the morning. To lower the costs Mike's mother buys cheap diapers from the supermarket. Mike's mother tells you, she doesn't like big diapers. In daytime he is potty-trained.

The questions to discuss:

- **What would be your advice to Mike and his parents?**

Answers: Advices: More absorbent nappies, bed protection, help for mother, bigger/ better nappies, medication? Changing nappies before parent goes to bed. Wake child up after couple of hours to change diaper. Nefrologist? Education about the problem, penile sheet, urotherapy, insurance.

- **Did the discussion bring up something new for you?**

Yes: 4 persons. No: 8 persons.

Other questions (which not all the groups/participants answered):

2. Which information, in your opinion, do you absolutely need to give when advising about disposables?

Answers: Insurance of the parents - will insurance pay for it? Financial position of parents, needs of parents at this moment, options of child, information to parents to control always the necessity after some time, depending on the diagnosis, diapers are the last option, find a product that fits the child's need, keep close contact, economic support, prize versus quality, extensive knowledge of available products, what does the child wants? (disposable/washable)

3. Which criterions are you using for yourself?

Answers: Financial position of parents, what do they really need, child possibility to be dry, child's option, adequate information to the parents and to the child as well, training, new things, diagnosis, dryness? Less burden/ visible, skin irritation, what is the best, has the child the possibility to be dry? If it is possible to train do that first, medical indication, age of the child, Absorption capacity, fit, motivation of the child (does it wants to be dry?)- then you can try with different disposables

4. Did the discussion bring up something new for you?

Yes: 3 person, No: 14.

5. Are you working according to any guidelines for prescribing disposables?

Yes: 3 persons, (Sweden, HK and Belgium) No: 14 persons.

6. Would you like to work according a guideline for prescribing disposables?

Yes: 8 persons, No: 4 persons

7. Discuss the advantage and disadvantage of such a guideline.

*Answers: Advantages: easier to describe disposables, have standards to prescribe disposables by different nurses, washable product for Denmark, gives inside in absorption capacity, gives inside in costs, it can be a good idea to have an overview over the products
Disadvantages: It depends on the prescription system in each country*

8. Did the discussion bring up something new for you?

Yes: 3 persons, No: 3 persons.

9. Which problems remain difficult to solve in your daily practice?

Answers: To find a good product for all children, financial situation of different families, difficult to find the best product, there are so many nappies for children of 7-12 years old. Nappies for children > 25 kg.

10. Did the discussion bring up something new for you?

Yes: 1 person, No: 1 person

11. Do you have your own nursing consulting hours?

Yes: 11 persons, No: 5 persons

12. How much time do you have for your patient per consultation?

Half an hour: 2 persons, 1 hour: 4 persons, Half an hour to 1 hour: 4 persons

Remarks: Now we only see patients who are going to have an appendectovesiostomy. We like to have more hours.

13. Does your institution/hospital make recommendation for your choice of material and advices?

Yes: 9 persons

No : 7 persons

14. Does insurances influence the choice for material and advices?

Yes: 10 persons

No: 7 persons

Remarks: for catheters

15. Do you feel that your patients' choices are restricted by the rules of the insurance?

Yes: 6 persons.

No: 10 persons

Sometimes: 1 person

Remarks: not a wide range of products, mostly adult's products

16. Does the insurance pay for your consultation?

Yes: 2 persons

No: 12 persons

17. Are you involved in research concerning this subject?

Yes: 1 person (Sweden)

No: 15 persons)

Evaluation of the workshop:

In general the comments were positive, but:

- *The room must be better, the members wanted to sit more quiet.*
- *There were to much question for the time given*
- *The list with questions should be given a few hours before the workshop, so that the members already can read and think about the questions.*
- *For some members the concept of 'disposables' wasn't clear.*

Wishes for future workshops:

- *Role-play when a person pretends to be a patient and the audience asks questions.*
- *When doing a workshop about devices, bring the devices.*
- *Create a CORE-group, with a delegation from each country, who can make a guideline or make recommendations.*
- *Make groups by countries and discuss later the differences between the countries.*

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