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GATHERING LONG-TERM FOLLOW UP AFTER ENURESIS TREATMENT: MORE DIFFICULT THAN IT SEEMS

Hypothesis / aims of study
To study the presence of nocturia in patients formerly treated for enuresis, as enuresis and nocturia share etiological factors, but little is known about their association. We however experienced problems with response. We focus on this and possible solutions for this field of research.

Study design, materials and methods
Cross-sectional questionnaire (ICIQ M/FLUTS and LUTSqol) study in 553 patients ≥18 years, treated between 2005-2011 by adapted Dry Bed Training. Invitations were sent in three, sequential, steps: initial invitation (9% response), subset called (15% response), random subset, n=50, offered reward (42% response). Due to these low response rates, we decided to focus on comparing patient characteristics according to invitational phases, instead of comparing prevalence of nocturia between initial success-of-treatment-groups.

Results
Of the 76 responders, median age was 23 [IQR 20-25], 41 were men. ICIQ and bother scores were all low. Nocturia (≥1x) was present in 55% (men) and 72% (women); clinically relevant nocturia (≥2x) in 8% (men) and 25% (women). Ten men (30%) and 9 women (28%) had enuresis (≥1/28 nights). In the different invitation phases, patient characteristics were not significantly different, although the reward-group had slightly lower bother scores and nocturia prevalence.

Interpretation of results
We faced serious problems in successful patient recruitment in studying long-term follow-up of treatment for enuresis. Comparable studies have experienced response rates of approximately 40%. The possibility of digital completion of the questionnaires was presumed to increase the response rate, as we approached a young, digitally active, group of patients.

Several different explanations for the problems in patient recruitment can be assigned:
The increasing amount of questionnaire to evaluate services or products resulting in a lower willingness to participate in all separate evaluations. Aside, our questionnaire was rather large and patients had been asked to fill in a very short questionnaire before. The lack of an active treatment relation with our center can also have lowered response rates. Additionally, enuresis is often felt as a shameful problem; former patients want to let this topic rest if the enuresis is gone, or do not want to talk about it if it is still present. A high proportion of the responders had a full treatment response (ICCS terms) six months after the initial adapted DBT (80%), whereas this was 66% for the total invited population. Apparently, cured patients were more willing to respond to this evaluating questionnaire.

We used four different strategies to include patients. Our analyses showed differences in outcomes between these groups. Those patients that responded to the invitation with a reward differed with respect to the treatment response compared to the telephone group and the initial response on paper group. Although not statistically significant, a slightly lower proportion had nocturia. Of course, due to the low numbers, it is unclear whether this group or the other groups represent the whole population best. The initial responders could be eager to respond because they still have LUTS and are hindered by it. The responders to the reward-invitation are mainly those not experiencing any bother of their LUTS. Possibly, their main reason for participation is the reward. Overall, we think it to be worthwhile to improve inclusion of patients by offering them a reward, as the response rate increased to above 40%, in which case additional analyses can be performed to interpret the data.

Concluding message
We faced serious problems in successful patient recruitment in studying long-term follow-up of adapted DBT for enuresis. Although others have faced this as well, we did analyse this specific problem and we doubt if long long-term follow-up is feasible in this patient group suffering a shameful disease. When gathering long-term follow-up in a retrospective study, we recommend to offer a reward to increase response rates and thus interpretability of results.

Disclosures
Funding: Isala innovation and research fund **Clinical Trial:** No **Subjects:** HUMAN **Ethics Committee:** Zwolle Medicall Ethical Committee **Helsinki:** Yes **Informed Consent:** Yes