

Jørgensen L<sup>1</sup>, Terp Høyby M<sup>2</sup>, Jørgensen M<sup>3</sup>, Waldmann A<sup>3</sup>, Faust E<sup>4</sup>, Niesel A<sup>4</sup>, Lose G<sup>5</sup>, Rudnicki M<sup>6</sup>

*1. Department of Obstetrics and Gynecology, Roskilde University Hospital, Roskilde, Denmark, 2. National institute of public health, University of southern Denmark, Odense, Denmark, 3. Institute for Social Medicine and Epidemiology, University Hospital Schleswig-Holstein, Campus Luebeck, Luebeck, Germany, 4. Department of Obstetrics and Gynecology, Klinik Preetz, Ploen, Germany, 5. Dept. of Obst. & Gyn., Herlev University Hospital, Herlev, Denmark, 6. Department of Obstetrics and Gynecology, Odense University Hospital, Odense, Denmark*

## **URINARY INCONTINENT WOMEN'S HELP-SEEKING BEHAVIOR – DEVELOPMENT OF A QUESTIONNAIRE MIXED METHOD, EXPLORATORY DESIGN.**

### Hypothesis / aims of study

Urinary incontinence (UI) appears among women in all ages, although prevalence in recent studies differs according to their definition of UI, the populations on which it is based and the study design. UI is known to have a negative impact on women's health related quality of life (HQoL) and to be a subject of taboo. Many of the affected women do not seek medical help from their general practitioner (GP), even though clinical interventions are available. A small recent Danish report described that less than 55% seek help from their GP although suffering from severe UI.

([http://sundhedsstyrelsen.dk/publ/publ2010/EMM/Urininkontinens/Evaluering\\_urininkontinens\\_sammfatning.pdf](http://sundhedsstyrelsen.dk/publ/publ2010/EMM/Urininkontinens/Evaluering_urininkontinens_sammfatning.pdf)). Accordingly, a better understanding of women's help seeking behaviour is needed. Especially in low-income areas, this might be a severe problem. Region Fehmarnbelt represent such an area and currently we do not know much about these women's behaviour and need for help regarding UI.

The aim of this study is to create a questionnaire to be used for a survey regarding urinary incontinent women's help seeking behavior in the primary sector, and to understand what triggers and inhibitors influence the women to seek help. The project produced questions on this topic, based on reports from the UI women. The questionnaire is currently submitted to 8.000 women living in the above-mentioned region and their respective GP

### Study design, materials and methods

This study utilizes a multi method approach – exploratory sequential design. The study was initiated by qualitatively exploring the subject of urinary incontinent women's help seeking behavior through semi-structured focus group interviews. Participants were women, with urinary incontinence according to the IUGA/ICS joint terminology, which had or had not sought help from their GP regarding their incontinence symptoms. The participating women in the focus groups were recruited from the hospital ward, from an advert in a local paper or from the public. Inclusion criteria for participation were  $\geq 18$  years of age and suffered UI according to the IUGA/ICS terminology. A total of 8 focus groups were conducted both in Germany and Denmark, with 61 women, age ranging from 41-86 years of age. To achieve free-flowing conversation and heterogeneity, segmentation was used to compose the groups. An interview guide, with main topics was used to keep clarity and relevance. The interviews were qualitatively analyzed, with primary focus on the triggers and inhibitors regarding the women's help-seeking behavior in the primary sector. The main topics from the analysis were translated into questions. After this these questions were validated, which included two procedures testing the content validity and test-retest reliability. The content validity included 10 cognitive interviews, each including concurrent, scripted probing followed by retrospective probing. The test-retest reliability included 31 tests, with two weeks in between the tests.

### Results

The first milestone was analysis of the focus groups, with a main focus on the triggers and inhibitors of help-seeking behavior. Some women described as main inhibitors a barrier to contact their GP disregarding symptoms of UI, either because of a lack of confidence to the GP or a bad patient-physician relationship. They felt ashamed of their situation, and found it a subject of taboo. Furthermore, we observed that most women neglected their symptoms, or felt that their symptoms were not severe enough, although they felt inhibited in their daily chores, social life and/or physical activities. The women also mentioned that their symptoms were not related to a physical condition, and there was no effective treatment option. Triggers to contact their GP mentioned by the women were the experience of their symptoms getting worse and severely interfering with their daily lives. Furthermore, the women were worried about symptoms getting worse, because of awareness from their relatives or friends or from social medias. The result of the analysis was converted into 12 questions. Adjustments were made according to the content validation. The test-retest reliability showed a few questions with moderate reliability and most questions with good reliability, with a kappa value ranging from 0,63-1.

### Interpretation of results

The result of the qualitatively analysis gives a detailed description of the triggers and inhibitors of help seeking behavior among UI women, and shows that help seeking is influenced by multiple factors. Some influential factors mentioned are personally related factors, the severity of the symptoms and the influence on every day life, the awareness from friends and relatives, the health care system, etc. Unlike previous studies, where the triggers and inhibitors were based on assumption, our study has evaluated triggers and inhibitors in the target group, and consequently formulated questions based on their statements.

Even though this project gives a detailed qualitative description of women's help-seeking behavior, it does, not show which factors have the most influence on the women's help seeking. Despite the loss of detail, questions were formulated from the focus group data and the psychometric testing ensured that the most important factors were incorporated in the questions.

### Concluding message

Help seeking behavior is influenced by multiple factors. Our study describes which factors influence the women's behavior, but not which factors have the most influence. A quantitative analysis, using the questionnaire we produced is needed for this. This will be the next step in our procedure.

## References

1. [http://sundhedsstyrelsen.dk/publ/publ2010/EMM/Urininkontinens/Evaluering\\_urininkontinens\\_sammfatning.pdf](http://sundhedsstyrelsen.dk/publ/publ2010/EMM/Urininkontinens/Evaluering_urininkontinens_sammfatning.pdf)

## Disclosures

**Funding:** Interreg IVa, Region Fehmarnbelt **Clinical Trial:** No **Subjects:** HUMAN **Ethics Committee:** The German Ethic committee **Helsinki:** Yes **Informed Consent:** Yes