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Development of a Bilingual Questionnaire about General Practitioners' Handling of Female Urinary Incontinence

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Abstract: Background: Urinary incontinence is a prevalent symptom among women. In a Danish-German study, the barriers experienced by general practitioners regarding communication about urinary incontinence are identified using a newly developed questionnaire. Objectives: Description of the development and validation of a questionnaire for general practitioners on the topic urinary incontinence. Methods: Investigation of literature and instruments and conduction of qualitative interviews. Development of an initial questionnaire in English language, which was then translated into the target languages, Danish and German. The questionnaire was verified in cognitive interviews, revised and tested for its retest-reliability and linguistic validity. Results: The analysis of the qualitative interviews allowed identification of general practitioners' barriers and insecurities on this topic. Cognitive testing led to a change in 14 questions or answering categories. The evaluation of the retest-reliability showed good or moderate absolute concordance or correlation of 98% of the items. Conclusion: The process of the development of a questionnaire which must suit the different languages and cultural and structural differences of two countries is very complex and time-consuming. Initial results showed a high acceptance of the questionnaire.

Keywords: Ouestionnaire design; Reliability and validity; Methodology; Oualitative research; Urinary incontinence.

1. Introduction

Temporary or permanent urinary incontinence [urinary incontinence (UI)] is a common symptom among women. Prevalence rates given in the literature range from 17% to 50% [1-4] and depend on study design, age groups and the definition of UI. Studies showed that UI causes multiple psychosocial effects, such as impairment of quality of life, social isolation, anxiety disorders, and depression. [5-10] Despite these impairments, only a minority of affected women talked to their GP about their UI. [3, 11, 12] The reasons for this are manifold and include women's interpretation of UI as a "natural fact" of aging, feelings of shame, and lack of confidence in physicians.

Welz-Barth and colleagues [13] described the situation in the following way: "Physicians don't ask and patients don't tell." This description suggests that barriers to communication exist not only on the part of women patients. Until now, knowledge about the relevance that GPs give the topic of UI, communication barriers and GPs' handling of UI has been sparse. There are no validated questionnaires regarding these topics currently available.

To learn more about the situation of affected women and GPs' handling of UI, a German-Danish study was conducted between 2012 and 2015 in the Fehmarnbelt-region. The study addressed both women and GPs, and the main aim was to improve the medical treatment of women with UI.

The development and validation of a questionnaire for GPs, which is suitable for both countries, was the central part of the study and is presented in this article.

2. Methods

The development of the questionnaire was carried out in several steps, including qualitative as well as quantitative methods. A central challenge was that the English language had to be used for all communication between the project partners – a foreign language for all staff members.

2.1. Preliminary Studies

The first step comprised a search of relevant literature and instruments. The aim was to identify the central subject areas and factors which influence GPs' handling of female UI and to identify validated instruments.

The search of instruments showed no standardized and validated instruments suiting our research questions. The literature search revealed a multitude of topics and factors which are supposed to influence GPs' habits regarding UI and their ways of dealing with the subject. These topics and factors were discussed in the binational and multiprofessional team to find those factors which were expected to play a relevant role in both countries. The following central topics were determined:

- GPs' estimation about the relevance of UI: Do they think that UI is a significant problem among women? Is UI a common topic in their everyday work?
- Handling of UI: Communication with affected women and barriers regarding communication about the topic. Who should address UI?
- Management of UI: Who should be responsible for the management of UI?
 Satisfaction with the management offered by their own practice.
- Influence of medical guidelines on diagnosis and treatment of UI.

2.2. Steps of the Questionnaire's Development

Figures 1 and 2 illustrate the process of the questionnaire's development.

2.2.1. Development of an Interview Guideline and Conducting Interviews

The aim of this qualitative and explorative part of the study was to gain information about GP's attitudes regarding UI among women, barriers that keep them from addressing the topic and their experiences with UI in their everyday work.

Study participants were recruited in different ways:

- Contact by telephone
- Presentation of the project in a quality circle of GPs; members of the quality circle received information materials to pass on to colleagues
- Individual contact with personally known GPs

Participating GPs gained an allowance of 50€.

The interviews were based on a semi-structured guideline including the central topics which emerged from the preliminary studies (see above). Interviewers were allowed to tailor the questions to the specific context and to be responsive to the interviewee's responses.

The questions were intended to induce narrations about concrete situations: In which situations did GPs address the topic of UI? How did women react if they were asked about UI? What happened when women told the GP that they had UI symptoms?

The one-to-one interviews were conducted by a staff member (SE or MJ) and the focus group interview by both staff members together. Each interview was audio taped and transcribed verbatim. Names and other individual data allowing the identification of individuals were anonymized.

The analysis of the interviews was conducted according to the content analysis method of Mayring [14].

To include the experiences and attitudes of Danish GPs in the development of the questionnaire, qualitative interviews (two focus groups and one individual interview) were also conducted in Denmark.

2.2.2. Development of an English Version of the Questionnaire

Based on the results of the interviews, questions focusing each of the central topics were formulated.

The formulation of questions, selection of answering categories, and scales were discussed and revised in multiple steps, first among the German team and afterwards among the whole team. The central aim of all revisions was to generate questions which suited both the German and the Danish cultural and structural contexts. Another aim was to keep the questionnaire as short as possible to increase GPs' motivation to complete it. Due to this it was decided to exclude most questions about GPs' management of UI.

The result of this developmental step was an English version of the questionnaire which was agreed upon by the whole team.

2.2.3. Translation of the Questionnaire in the Target Languages

In accordance with the experts of the GESIS – Leibnitz Institute for the Social Sciences the Team Translation Model (TRAPD) was chosen for the translation of the English version (developed by foreign speakers) into the two target languages (see Figure 2). This approach was considered to be the most adequate for intercultural comparative studies.[15, 16].

At the beginning of the translation process, two translations of the English questionnaire for each target language were completed independently by team members. This step resulted in four versions of the questionnaire (two German, two Danish) which provided the basis for a "translation meeting" in which the whole team participated and which was moderated by a professional translator. In this meeting, the two German and two Danish versions of the questionnaire were merged into one for each language. Ambiguities regarding formulations were discussed within the team. With the assistance of the translator, one valid translation for each target language was developed. The translation followed to a lesser extent the aim of identical wording but more so the conceptual equivalence of terms and the cultural and lingual adaptation.

2.2.4. Cognitive Interviews

The now available German questionnaire for GPs was tested for comprehensibility and usability. The aim was not so much to test for functionality of skip instructions or the like but to gain insight into the cognitive processes during the responses to the questions. Different techniques of questioning were used [17].

- Comprehension Probing: Questions about the comprehensibility of the whole question or single elements: Do the respondents understand the question? Do they understand the question how it was meant? How do they understand the specific terms used?
 - Example: How did you interpret the word "treatment"? What does the term include for you in this context?
- Category Selection Probing: How did the respondents chose an answering category or the point on a numerous scale? Were the answering categories understandable/ appropriate/ complete? Were the scales too detailed or too imprecise?
 - Example: Why did you chose answer XY?
 - You made a cross at the scale at "4": Can you please explain why you chose this value?
- Confidence Rating: Rating of the degree of reliance of an answer.
 - Example: How precise is your answer? Is it more an estimation or are you sure?
- Paraphrasing: Interviewees are asked to repeat the question in their own words. Using this technique, it is possible to understand in which way they interpreted the question.
- Thinking aloud: Interviewees are asked to speak out loud what they are thinking when answering the question.

Before conducting the interviews, the technique to be used for each question was determined. In cases where it became obvious that interviewees did not accept one of the techniques, changes were allowed.

At the end of the interview, interviewes were asked about their overall impression: Does the questionnaire includes questions which they were reluctant to answer (for example, because they were too private)? Is the questionnaire too long/ detailed/ cursory? Are the questions relevant? Is something important missing?

Participants were recruited in different ways:

- Presentation of the project in a quality circle of GPs; members of the quality circle were provided with information materials to pass on to colleagues
- Individual contact with GPs who were known from earlier studies conducted by the Institute for Social Medicine and Epidemiology in Lübeck

GPs gained an allowance of 50€ for participating in the cognitive interview.

Questions and direct answers of the cognitive interviews were transcribed verbatim, with digressions omitted. Striking reactions such as laughter or groaning were also documented. Each interview was treated as a discrete unit of analysis for which the questions of the interviewer and the answers of interviewee were documented in a table. In a first analytical step, each interview was analyzed for a universal pattern which may have exerted an influence on the answers: For example, one interviewee did not like the scales from zero to ten. This was documented for all equal scales even if the person did not repeat their critique for every scale of this format.

In a second step, a cross-sectional testing of each question of the questionnaire was conducted: For this reason, the answers of all interviewees were compiled, which allowed the identification of congruent misinterpretations of the questions as wholes or specific words.

After the analysis, the team discussed the required revisions of the questionnaire.

2.2.5. Analysis of the Retest-Reliability

To evaluate the retest-reliability of the questionnaire, it was administered to GPs twice with an interval of four weeks.

Because the questionnaire does not allow calculating scales, the retest-reliability was determined for each single item. The retest-reliability was assessed using Pearson's correlation in metric data and the absolute accordance and Cohen's Kappa in metric data.

2.2.6. Linguistic Validation

Finally, the present German version of the questionnaire was translated into the Danish language by a professional translator. This translation was tested by interviewing two Danish GPs for linguistic adequacy and cultural adaptation.

3. Results

As described previously, the development of the questionnaire followed several steps. The results of the qualitative and quantitative parts of the study are presented here.

3.1. Development of an Interview Guideline and Conducting Interviews with GPs

The German study team conducted eleven (three females and eight males) one-to-one interviews and one focus group interview with GPs (three females and four males). Participants were between 40 and 65 years old. Seven of them worked within a single practice, six in a practice with one partner and four in a practice together with more than one partner.

Results showed that for the GPs female urinary incontinence is a topic with relatively low relevance, even if they are aware that it is a problem for many women. In contrast to our expectations, GPs talked frankly about their uncertainties concerning treatment options and the management of UI. Moreover, it became obvious that the GPs regarded specialists (particularly gynecologists) as primarily responsible for the diagnosis and treatment of female UI.

3.2. Cognitive Interviews

Nine GPs (four females and five males) aged 30 to 60 years old took part in the cognitive interviews. The interviews lasted between 45 and 80 minutes.

The first two cognitive interviews showed that the interviewees did not accept the think-aloud technique; as such, it was not used in the following interviews.

The questionnaire was revised according to the results of the interviews: 14 questions and answering categories were reformulated, the sequence of two questions was changed and in one question the sequence of the answering categories was modified. In one question two new answering categories were added. Further, two questions about the total number of patients, and age and gender distribution were added. One question about the use of medical guidelines was deleted because the interviewees regarded the question as a form of criticism which may reduce the GPs' motivation to answer the questionnaire.

3.3. Analysis of the Retest-Reliability

GPs' motivation to take part in the retest study was very low. Altogether, 16 GPs (nine females and seven males, aged 37 to 60 yrs old) participated. Three of them worked in a single practice, eight in a double practice and five in a practice with more than one partner.

Results showed a good absolute accordance or correlation with 61% of the items and a moderate absolute accordance or correlation with 37% of the items. Cohen's Kappa was at medium range for most of the items; however, in several cases Cohen's Kappa could not be determined because of the low numbers of cases in the contingency tables. The results regarding the retest reliability provide the indication for the change of only one question of questionnaire (for detailed information see [18]).

3.4. Linguistic Validation

The linguistic adequacy and cultural adaptation of the Danish version of the questionnaire was finally tested in interviews with two GPs. As a result, some small modifications in wordings were made, especially in relation to specific medical terms.

At the end of this last step in the questionnaire development, we had a tested questionnaire in both target languages (available at www.fehmarnbelt-luts.eu), which included 28 questions on the following topics:

- Relevance of the topic of female urinary incontinence in the everyday work of the GP
- Communication about UI and barriers in relation to communication about it
- GPs' management of UI and barriers regarding the management
- Personal data of the GPs and the structure of the practice

4. Discussion

The aim of the study was to examine GPs' experiences with female urinary incontinence and to identify resources and barriers that influence the GPs in dealing with this topic. Since no questionnaires suiting these research questions were available, we developed and tested a new questionnaire. The steps of questionnaire development are subject of this article.

The process of questionnaire development included several steps using different methods. After a preliminary search of literature and instruments, qualitative interviews were conducted. The methodology used for the qualitative interviews assessed subjective perspectives and evaluations of the interviewees in order to ascertain their individual experiences. In addition to this, the qualitative approach enabled the collation of information about the terms and phrases they use in the field of UI. This knowledge was essential for the development of the questionnaire.

To benefit from both interview techniques, we used focus group interviews and one-to-one interviews. Focus group interviews have the advantage of allowing the researcher to assess the interpretations and perspectives of individual participants as well as the interpretations and perspectives resulting from group interactions. [19, 20] Note that, more so than in one-to-one interviews, participants of a focus group interview have to phrase their ideas and perspectives as clearly as possible to be understood and recognized by the other interviewees. Also, the statements of the other participants function as a catalyst to rethink the own positions and discover new aspects of the topic under discussion. [19, 20]

Compared to focus group interviews, one-to-one interviews have the advantage that the interviewee will be more likely to address individual insecurities or barriers, especially with regard to delicate topics. The risk of answers biased by anticipated social desirability is lower than in group interviews. Also, the method of face-to-face interviewing offers more space for each participant, which makes it possible to go into more detail.

The disadvantage of a qualitative approach lies in its time-consuming nature, which only allows relatively small sample sizes. This disadvantage can be partly compensated by an attentive sampling that strives to maximize the heterogeneity of the sample. Nevertheless, the existence of a recruiting bias has to be considered, and especially in case of studies with recruitment problems such as ours.

The recruitment of GPs for our study was difficult, particularly with regard to the testing of the retest reliability. The plan to involve 50 GPs in the retest failed because of the low motivation of the GPs and limited time resources. In general, it became obvious that UI is a topic of only minor interest to many GPs.

A particular challenge of the project was to cope with the cultural, structural and linguistic differences of both participating countries, and to develop a questionnaire which was feasible in both countries and which generated comparable data. For this reason, the question about the adequate translation process was highly important. In contrast to the widely-used procedure of backward and forward translation (English-German, German-English and English-Danish, Danish-English) which nowadays is seen to guarantee only limited quality in cases where more than one target language exists, we chose the TARP Team Translation Model [15, 16] (Fig. 2). This procedure allows verification during several steps of the translation process if the versions of the target languages coincide regarding content and concept and respect cultural and linguistic differences.

5. Conclusion

We developed a questionnaire which was used in a survey including all GPs in the Fehmarnbelt-region (N=929). Since the region covers sections of Germany and Denmark, two versions of the questionnaire were developed.

The development of a questionnaire to be used in different countries is complex and very time consuming, a fact that should be seriously considered when planning such a project. Another problem with our project was the difficulty of recruiting as many GPs as planned within the given time limit. Due to the small sample size for some steps of the questionnaire development process - especially the testing of retest-reliability - these results should be interpreted with caution.

Despite this limitation, initial results from the survey showed that the questionnaire was widely accepted and that a majority of GPs completed the questionnaire without missing values or problems.

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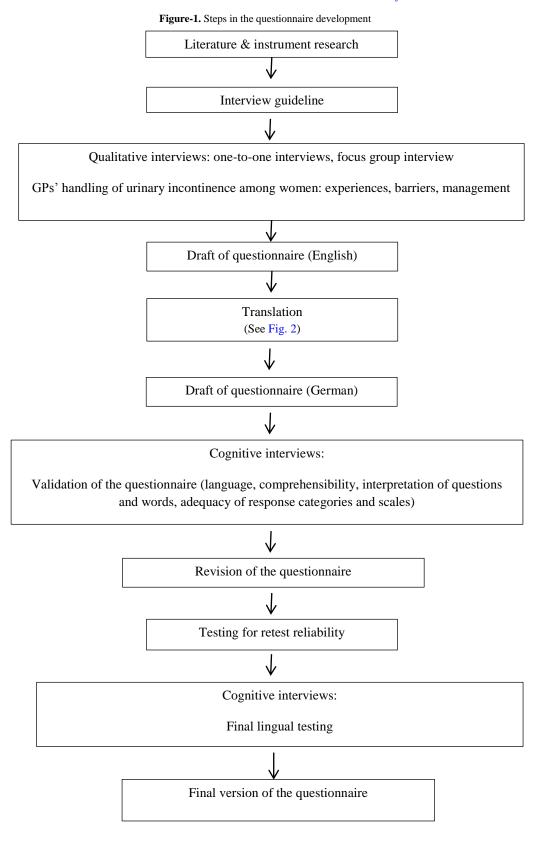


Figure-2. Translation procedure

