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Original Article

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Danish translation and qualitative validation of the Measure Yourself Medical Outcome Profile and the Measure Yourself Concerns and Wellbeing

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ABSTRACT

Introduction. Patients may experience late complications following surgical treatment for colorectal and anal cancer, and we need instruments in Danish to plan treatment and person-centred follow-up treatment approaches. For this purpose, we chose the Measure Yourself Medical Outcome Profile (MYMOP) and Measure Yourself Concerns and Wellbeing (MYCaW). The aim of this study was to translate the two instruments into Danish and conduct a subsequent qualitative validation.

Methods. The translation process consists of five stages: forward translation, synthesis, back translation, expert panel review and pretesting. Qualitative validation included interview with target audience representatives, testing of face-validity and evaluation by lay persons.

Results. Through the translation process and qualitative validation, we produced Danish versions of the MYMOP and the MYCaW.

Conclusions. The Danish versions of the two questionnaires are now ready for use in clinical practice and research after individual licensing consultation with the copyright holders.

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A major challenge when designing treatment courses and treatment options is to integrate patients' experiences of living with symptoms and the burden of the symptom in everyday life, and take into consideration the concerns they experience. Within surgery and gastroenterology, shared decision making has been explored in a few studies, and establishment of good rapport between patient and surgeon [1] and also active patient participation have been proposed by patients to be important elements [2]. So far, patient-reported outcome measures (PROMs) have been suggested to increase the identification of symptoms that should be treated [3], but patients should also be prompted to prioritise the symptoms that they assess to be the most burdensome. Using the patient-centred outcome measure approach, i.e. by employing the Measure Yourself Medical Outcome Profile (MYMOP) and Measure Yourself Concerns and Wellbeing (MYCaW), supports patients in determining the important and relevant issues themselves [4].

The MYMOP was developed in Great Britain [5], and it was accredited for use within the National Health Service (NHS) and in primary care it has been applied in various clinical settings [6]. The MYMOP became available once the initial paper was published in the BMJ in 1996 [5], and was revised to the MYMOP2 in 1999 by adding some follow-up questions [7]. The tool identifies what patients consider to be the two most important symptoms related to their specific health issue and establishes which parts of daily living are affected by these symptoms. Moreover, the MYMOP also monitors general patient wellbeing, symptom duration and whether the patient has used any medication and if such medication had any effect. The MYMOP may be used to identify and rank symptoms and may be administered in subsequent consultations to evaluate treatment effects. Symptoms, activity and general wellbeing are scored on a seven-point Likert scale following the instructions for administration [7].

The MYCaW was designed to measure outcomes in cancer support care [4], and it combines qualitative and quantitative data analysis methods [8]. The instrument identifies the primary concerns of the patient and records the patient's overall wellbeing. Furthermore, the MYCaW has been used by carers [9] and in various different cancer populations and is recommended for clinical use and research [10]. The MYCaW produces quantitative data, which may be analysed accordingly. Furthermore, the qualitative data may be analysed using content analysis or thematic analysis. Like the MYMOP, the MYCaW has been accredited for use within the NHS in England.

In 2020, Meaningful Measures Ltd assumed the management of the tools, which are now trademarked and licensed. In 2021, both tools were accredited for use within personalized care pathways by NHS England & NHS Improvement owing to their brevity, ease of use and patient-centred design. Both the MYMOP and the MYCaW are validated in the original language [5, 11] and have been formally translated into many languages; however, not yet into Danish.

These tools help clinicians to understand what unmet needs a patient has. As such, the subjective perception of patients' health should, if possible, form part of the evaluation of any treatment offered by health professionals [8]. To support this, we decided to translate, validate and implement the MYMOP and MYCaW, which are two patient-centred questionnaires designed to include data with relevance for the patient [5, 10]. The questionnaires may be used in the clinical setting as a consultation aid for the clinician to promote active patient participation and provide a structure for systematically involving patients in prioritising their most important concerns or symptoms. By using these tools, we expect that we may identify concerns and symptoms that are not usually discussed in the clinical community within colorectal cancer surgery. Previous data analysis of the MYCaW concerns of people with cancer has identified several non-clinical categories that patients prioritised and furthermore categories that were not included in standard health-related quality of life outcome measures for patients with cancer [10, 11]. We also anticipate that implementing the tools may enable patients to become more engaged in their treatment and rehabilitation.

Translation of patient questionnaires for use in a local language comprises various phases [12]. The present paper reports the results of the translation phases of the MYMOP and the MYCaW including forward/backward translation by professional translators, translators with the same mother tongue as the target audience, and review by expert panels. The qualitative validation results will include an interview with the target audience, testing of face-validity and evaluation by lay persons. Thus, the aim of this study was to translate and perform a qualitative validation of the MYMOP and the MYCaW into Danish, using established qualitative methods.

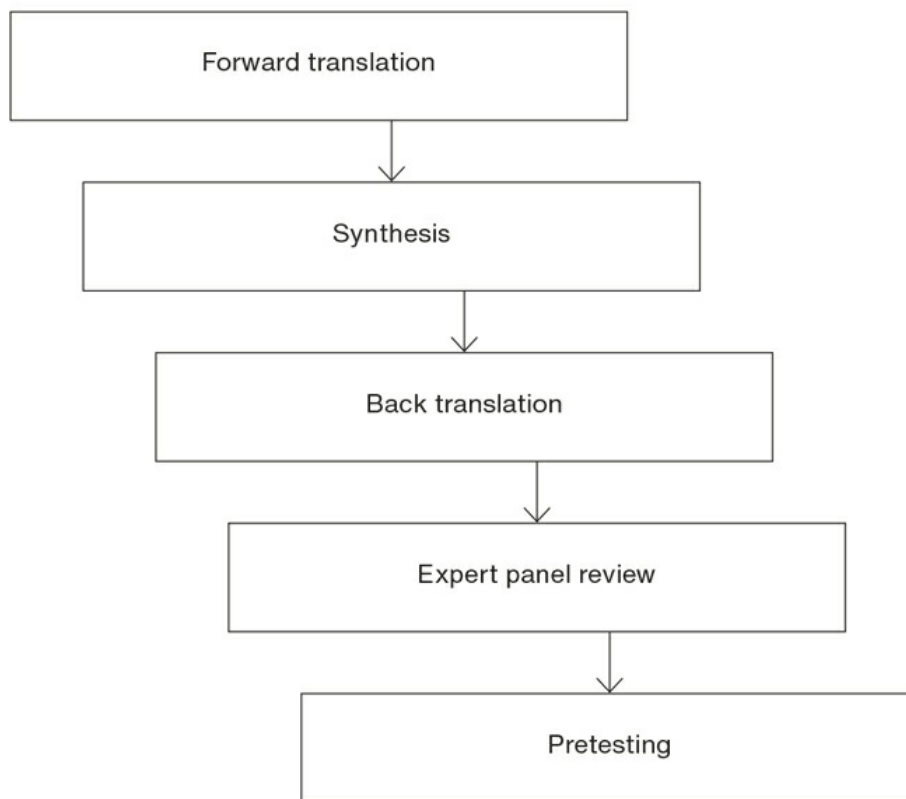
METHODS

No specific reporting guideline is available for this type of study [13], so we chose to report our design and

results along the lines established by other similar studies. The tools for this trial were the MYMOP [5, 14] and the MYCaW [4, 15].

After obtaining permission for the translations, the English versions of the MYMOP and the MYCaW were translated into Danish according to WHO recommendations for translation and cross-cultural adaption of instruments [16], a slight modification of the recommendations from the European Organisation for Research and Treatment of Cancer (EORTC) [17], and the guidelines by Beaton et al. [18]. According to these guidelines, the translation process may consist of five stages: forward translation, synthesis, back translation, expert panel review and pretesting (Figure 1).

FIGURE 1 Overview of the translation and validation process.



For the MYMOP, a forward translation was performed by one person, a professional translator whose mother tongue was Danish and who was knowledgeable about the English-speaking culture. This translation was reviewed by an expert panel consisting of the forward translator and two medical doctors, and a consensus version was constructed. Finally, another professional translator whose mother tongue was English and who was naïve to the original version performed a back translation. No further adaption was needed after additional expert panel review. For the MYCaW, forward translation from English into Danish was done by two translators of Danish mother tongue. One of the translators was had a professional background within cancer surgery to ensure awareness of all the concepts that MYCaW measures. The other translator was a person without professional insights. After synthesis of a version based on these two translations, an expert panel consisting of specialised doctors, nurses within the field and scientists with expertise in translation of instruments for use in healthcare evaluated and approved the new version. The Danish version underwent backward translation by a translator of English mother tongue who was naïve to the original English versions, and no further adaption was needed.

The qualitative validation included interviews with a target audience, testing of face validity and evaluation by lay persons. Once the Danish versions were available, we tested the versions on the target population of patients with late complications after treatment for colorectal and anal cancer. The qualitative validation was done systematically from an interview guide, and every question was reviewed after which patients were asked: Is the question difficult to answer?, Is the question confusing?, Is the question difficult to understand?, Is the question offensive or shocking? Pilot-testing for face validity and understandability was achieved by cognitive interviewing of ten persons in the target group [19]. Based on these interviews, the final Danish wording was determined. The final versions were then evaluated by lay persons belonging to the Danish Cancer Society and the Society for Late Complications in Denmark.

As we did not collect and store individual patient data, the study did not require permission from the Danish Data Protection Agency. Likewise, the study was exempt from ethical committee evaluation and approval. Permission to translate the questionnaires was granted by the copyright holders of the original versions.

Trial registration: not relevant.

RESULTS

The in-depth analysis revealed no significant linguistic or cultural issues with the Danish versions of the MYMOP and the MYCaW. The Danish versions from the forward translations had only few corrections after the subsequent synthesis, backward translations and qualitative validation. One of these corrections was that "I forløbet hos os, hvad har så været de vigtigste aspekter for dig?" which was changed to: "I forløbet hos os, hvad har så været den vigtigste hjælp, du har fået?".

No large discrepancies were recorded after backward translations from the original versions of the MYMOP and the MYCaW, and the final products of the linguistic validation were therefore accepted as the final Danish versions for clinical use (Figure 2). The expert panel evaluations by specialised doctors, nurses and lay persons from patient organisations also did not change the Danish versions as the feedback simply indicated that it was easy to use and fully understandable. As such, we expect a high degree of acceptability on the part of health professionals and patients alike when using the questionnaires in clinical practice.

FIGURE 2 The final Danish versions of the Measure Yourself Medical Outcome Profile (MYMOP) 2 and the Measure Yourself Concerns and Wellbeing (MYCaW). Full versions and licenses may be obtained from Meaningful Measures Ltd.



DISCUSSION

When caring for patients with late complications to surgical treatment, in this case following surgery for colorectal and anal cancer, it is important to be attentive to patient wishes and expectations and not to focus solely on what we, as healthcare providers, believe to be the most important areas of concern. Therefore, the MYMOP and MYCaW questionnaires are excellent tools in this clinical setting as they focus on patients' needs. These tools are gaining widespread acceptance within numerous clinical fields and were recently accredited for use in the NHS in England; hence, we chose to produce validated Danish versions for use in daily clinical practice and research.

The phases of the validation process may be discussed, and numerous methods (and opinions) exist for this. We previously reported discrepancies in the literature with respect to methodology in studies reporting on the translation and validation of local-language questionnaires [12]. The most commonly used methods depend on the setting and include translation (translation guide, forward/backward translation, professional translators, translators with mother tongue the same as the target audience, review by an expert panel), qualitative validation (interview of target audience, testing of face-validity, lay persons) and quantitative validation (internal validity, reliability, criterion validity, construct validity) [12]. Although recommendations are in place to use professional translators, these are often replaced by expert panels. As numerous ways exist to translate and validate questionnaires into local languages, we chose to follow the recommendations proposed by the WHO [16], the EORTC [17] and the guidelines by Beaton et al. [18].

The translation of the MYMOP and MYCaW tools was done in collaboration between two university hospitals in Denmark, Aarhus and Herlev. Aarhus translated the MYMOP and Herlev translated the MYCaW. We used two different ways of forward translation because of local customs at each hospital, and both types are described in the recommendations from the WHO [16] and the EORTC [17]. The present study used qualitative validation

since such validation of these two widely used questionnaires was performed in British patients. As British patients are presumably similar to Danish patients with respect to these two simple questionnaires concerning patients' wellbeing, we expect that the results from British patients may be generalised to Danish patients. However, to confirm this hypothesis and to explore the validity of the tools further in a Danish setting, a psychometric validation study among Danish patients with rectal cancer is currently being conducted.

Surprisingly, the use of a formal focus on patients' needs and wishes in healthcare has only recently become part of good clinical practice. Thus, PROMs are gaining widespread use and are in these years being developed and tested in many patient populations either as simple PROMs [20] or as core outcome sets. In terms of terminology, the MYCaW and the MYMOP are person-centred outcome measures, which are a subclass of PROMs, and in this context the MYMOP and the MYCaW are optimal. The MYMOP is an individualised problem-specific outcome measure, which identifies and measures the outcome(s) that people consider most important from their health consultation. The MYMOP is a validated patient-reported outcome measurement tool, which is helpful in identifying whether certain aspects of their health status change over time.

The MYCaW is an individualised outcome measure used for evaluating holistic and person-centred approaches to supporting people, and it is a short validated tool that may be routinely incorporated into a consultation to see where a person most wants support. These instruments are used not only for prioritizing problems but may also be used to measure changes in quality of life in a manner that may make more sense to patients than the contents that may be fitted into a standardized quality of life form. These two instruments are free of any illness-specific words or emotional words since the patient's own words and the patient's own experience of symptoms are measured by the instruments. Therefore, the translation from English to Danish was not a complicated translation process.

CONCLUSIONS

This study was the first translation and qualitative validation of the MYMOP and the MYCaW into Danish. The Danish versions are now ready for widespread use after individual consultation with the developers [7] regarding licensing terms.

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Conflicts of interest Potential conflicts of interest have been declared. Disclosure forms provided by the authors are available with the article at ugeskriftet.dk/dmj

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