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Cross-cultural adaptation of the Swedish version of Endometriosis Health Profile-30

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ABSTRACT
The Endometriosis Health Profile-30 (EHP-30) is focusing on the effect of endometriosis symptoms upon health-related quality of life. The aim of this study was to pre-test and culturally adapt the Swedish version of EHP-30. Eighteen Swedish-speaking women with laparoscopically verified diagnosis of endometriosis answered the questionnaire and 17 were interviewed regarding their interpretations of the questionnaire. Demographics, distribution of answers, roof-ceiling effects and missing answers were analysed. The interviews were analysed using the qualitative approach proposed by Beaton et al. The Swedish version of EHP-30 was experienced as accessible with 100% data completeness and a roof effect (11%) in one dimension. Some women had difficulties with the instructions and one word should be replaced in order to culturally adapt the questionnaire. In conclusion, the Swedish version of EHP-30 is a useful and well-accepted questionnaire for women with endometriosis in Sweden, but a minor change of wording is recommended.

IMPLICATION STATEMENT
• What is already known on this subject? Cross-cultural adaptation and psychometric testing are crucial when introducing translated questionnaires. Cross-cultural adaptation is a process that looks at both translational and cultural issues when a questionnaire is being prepared for use in another country than the original. EHP-30 has been translated into Swedish but has not yet been cross-culturally adapted.
• What do the results of this study add? The Swedish version of EHP-30 was experienced as a useful and well-accepted questionnaire for women with endometriosis, but a minor change of wording is recommended in one question to make the questionnaire convergent with the original version.
• What are the implications of these findings for clinical practice and/or further research? The Swedish version of EHP-30 is user friendly and can be used in clinical practice after a minor change of wording. Then, it should also undergo psychometric testing.

Introduction
Endometriosis is a chronic gynaecological disease affecting approximately 10% of women of reproductive age (Adamson et al. 2010). Common symptoms are dysmenorrhoea, non-menstrual pelvic pain, dyspareunia and subfertility (Dunselman et al. 2014), and the disease often leads to impaired physical, mental and social wellbeing (Culley et al. 2013).

Health-related quality of life (HRQoL) is a multidimensional concept including physical, psychological and social aspects of living with a disease or treatment (Guyatt et al. 1993). The negative effect of endometriosis upon HRQoL is well documented (Jia et al. 2012; Bourdel et al. 2019). Most studies involve The Short Form Health Survey (SF-36) (McHorney et al. 1994). However, the use of generic questionnaires to evaluate HRQoL in women with complex conditions such as endometriosis has been criticised for lacking sensitivity, and such questionnaires may not cover aspects of life that are unique to endometriosis (Neelakantan et al. 2004). As a result, the 30-item Endometriosis Health Profile (EHP-30) was presented in 2001 (Jones et al. 2001). It was derived from in-depth interviews of patients with endometriosis, and is currently the most reliable and most comprehensively validated questionnaire for HRQoL measurement in women with endometriosis. EHP-30 is recommended by the American Society for Reproductive Medicine and the European Society of Human Reproduction and Embryology (Vincent et al. 2010). Use of EHP-30 is also recommended in the Swedish National Guidelines for Endometriosis Care (National Board of Health and Welfare 2018).

With the increasing numbers of multinational and multicultural studies, adequate translation, cross-cultural adaptation and psychometric testing are crucial when introducing questionnaires in new countries. According to Beaton, ‘cross-cultural adaptation’ is a process that looks at both translational and cultural issues when a questionnaire is being
prepared for use in another country (Beaton et al. 2000). EHP-30 has been translated into several languages and has been psychometrically tested with mainly good results (Nojomi et al. 2011; van de Burgt et al. 2011; Maiorana et al. 2012; Jia et al. 2013; Nogueira-Silva et al. 2015; Chauvet et al. 2017; Verket et al. 2018).

The Swedish version of EHP-30 recently showed responsiveness to change in pain intensity after perturbation treatment (Wickstrom et al. 2017). However, to the best of our knowledge, evaluation of usefulness and cross-cultural adaptation has not yet been done. Thus, the aim of the study was to pre-test and culturally adapt the Swedish version of EHP-30.

Material and methods

Participants

Women with laparoscopically verified endometriosis who had made an endometriosis-related appointment with a gynaecologist at Uppsala University Hospital during the previous 12 months were randomly invited. Inclusion criteria were endometriosis symptoms during the last four months, and being Swedish-speaking. The women received a letter with information about the study, followed by a telephone call where they were asked about participation. Out of 51 invited women, 10 did not answer the call, and 13 declined participation. Twenty-four women fulfilled the inclusion criteria and were scheduled for participation. Six women did not show up for the scheduled appointment, leaving 18 women answering the questionnaire. One woman was excluded from the interview because of a language barrier.

The study was approved by the regional ethics committee in Uppsala (2010-06-29, ref. no. 2011/220).

Data collection

The pre-test was inspired by the method described by Beaton et al. According to Beaton, the translation and cross-cultural adaptation of a questionnaire should follow a multistep model including a) translation b) synthesis c) back-translation d) an expert committee and e) a pre-test with participant interviews (Beaton et al. 2000). For the Swedish version of EHP-30 steps a–d had been conducted earlier (Oxford University Innovation 2016).

The pre-test was conducted within two weeks of invitation. All participants (n = 18) responded to questions on demographic data and answered the questionnaire. The time to complete the questionnaire was clocked. Afterwards, 17 of the 18 women were interviewed. The interviews were conducted using a structured interview guide including women’s interpretations of the questions and answers (Table 1). Three pilot interviews were conducted and resulted in a few modulated questions. The pilot interviews were included in the analysis.

EHP-30 consists of five core subscales: pain (11 items), control and powerlessness (six items), emotional well-being (six items), social support (four items) and self-image (three items). Women are asked to report their endometriosis-related symptoms within the previous four weeks. Answers are given on a 0–4-point scale graded as never–rarely-sometimes–often–always. Each item is scored from zero to 100, with higher scores indicating worse health status (Jones et al. 2001).

Data analysis

Demographics, roof-ceiling effects and missing answers were analysed using the Statistical Package for the Social Sciences 20.

Content validity was ensured by calculation of roof-ceiling effects. If >15% of the answers reach the highest or lowest scores, this is considered to be a threat against content validity (McHorney and Tarlov 1995).

The interviews were transcribed and analysed using a method inspired by content analysis and described by Beaton et al (2000). Answers from all interviews were marked, grouped and condensed. A conclusion was drawn from the condensed answers. In the results section, quotes are used to illustrate the findings.

Results

Data completeness was 100%, as all women answered all of the questions. The mean time required to answer the questionnaire was 3 min and 33 s (minimum 1 min, 21 s; maximum 8 min, 20 s). The distribution of dimension points is visualised in Figure 1. A roof effect (i.e. best health status) was apparent

<table>
<thead>
<tr>
<th>Table 1. The structured interview guide.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can you please describe, in your own words, how you perceived the instructions for the questionnaire?</td>
</tr>
<tr>
<td>Can you please describe, in your own words, how you perceived the questionnaire?</td>
</tr>
<tr>
<td>Was there anything unclear to you in the questionnaire? What?</td>
</tr>
<tr>
<td>Was there anything that you did not understand in the questionnaire? What?</td>
</tr>
<tr>
<td>Was there any word that you found unclear or did not understand?</td>
</tr>
<tr>
<td>Was there any question that you did not answer? Why?</td>
</tr>
<tr>
<td>Was there any question that you found offensive or too private?</td>
</tr>
<tr>
<td>Did you miss any question important to describe your life with endometriosis?</td>
</tr>
<tr>
<td>Was there any unnecessary question? Which one and why?</td>
</tr>
</tbody>
</table>

Figure 1. Spreading of dimension points.
in two women (11.1%) in the self-image dimension. Table 2 shows demographic characteristics of the participants.

The women found the questionnaire instructions clear and easy to understand. The majority of women answered the questions according to what they had experienced during the specified period. However, some women found it hard to distinguish between endometriosis symptoms, symptoms of other conditions and side effects of medical treatments. These women chose different strategies to overcome the difficulties. Three women chose only to focus on the disease itself and neglect side effects of treatment. ‘Sometimes it can be quite hard to make sure it is only due to the endometriosis’ (A1012). ‘The questions make you think… is it related to the endometriosis and at the same time I thought about the amount of medicine I take’ (A1008). Four women reported difficulties in separating the endometriosis symptoms from those of other conditions [Irritable bowel syndrome, rheumatism] or their general health, ‘I also have irritable bowel syndrome; it’s difficult to know what is what’ (A1015). ‘I probably think about general health’ (A1008). Some women also found it difficult to answer in relation to the previous four weeks. ‘I want to demonstrate how it is at its worst’ (A1010). ‘Since it comes and goes you know how it usually is and then you chose something in between’ (A1016).

The questionnaire was described as understandable, with relevant questions regarding vital aspects of living with endometriosis. The women reported no difficulties with questions or words. ‘Good questions, exactly what I experience, they were the right questions’ (A1016). ‘It embraced a lot of questions that I think are common to many endometriosis patients’ (A1007). Only one woman found some parts somewhat difficult to assess. ‘Mostly I found it understandable, but some [questions] were maybe a little bit cryptic’ (A1009).

All women answered all of the questions. No questions were experienced as unnecessary to the women, except for one woman who had never reflected upon which clothes she was unable to wear. ‘The one with the clothes I didn’t really understand, but maybe that’s just me… I have never even thought about it’ (A1020). While one woman reported some overlapping questions (A1026), others wished for even more questions. ‘It’s always better to ask twice…’ (A1015).

The possible answers were easy to understand and given in steps that conformed to the questions. However, some women wished to have the possibility to answer ‘I don’t know’ (A1015) and ‘Not applicable’ (A1021). One woman found the possible answers too blunt (A1104). There was also a need to mark the space between the answers. ‘Because answering “Always” does not feel right since it’s not twenty-four seven, but “Often” isn’t right either’ (A1019). Sometimes the women had to think carefully if the right answer was never or always. In addition, the meaning of always/often/sometimes/rarely was described as too much a matter of interpretation. The women had suggestions for other rankings of answers, such as a scale from a little to a lot (A1004), an even number of possible answers (A1015), and more alternative answers (A1019).

Generally, the women agreed that the EHP-30 score reflected the experience of living with endometriosis. However, there were concerns regarding the lack of questions on important aspects of life such as relationships, family and the work situation. ‘There were several missing aspects, such as family relations, how the children are affected, working life and so on’ (A1009). Several women pointed at the lack of questions on sexual aspects. ‘However, I was surprised to find no questions about sexual aspects since I know that is a common problem’ (A1024); ‘Well, those issues about sex life, that is often a huge part I think’ (A1016); ‘I think the part on sexual relationships should be given more attention, since it has such a big effect on your life’ (A1020); ‘Yes, sex’ (A1023). There were also missing questions on infertility (A1013, A1012), stress (A1015) and bodily symptoms such as intestinal or urinary problems (A1010, A1012, A1015, A1018, A1021).

One woman asked for questions on weariness (lack of energy), loss of focus and concentration loss (A1015). Because of the many missing aspects in the questionnaire, it was experienced as somewhat general (A1004). Open-ended questions giving women the opportunity to tell their stories and describe their experiences of treatments and surgery were also desired. ‘What treatments you are on, that is so important. The foundations of medication, types of surgery and all that you have gone through’ (A1010).

At question 18, ‘Felt depressed’, several women noticed that the word ‘depression’ is a diagnosis and that the phrase should be replaced. Some women also noticed that violence and aggression (question 23) were not applicable to endometriosis, and they did not identify with the concept.

Discussion

The Swedish version of EHP-30 was found useful and was not experienced as offensive. The pre-test showed a high level of user-friendliness, since the women found it clear and comprehensible, with relevant questions and no difficult or ambiguous words. The 100% data completeness and the relatively short filling-in time further support its usefulness in a clinical setting. The difficulties that a few women had to fill
in the questionnaire were considered as representing a general problem when understanding and filling in questionnaires, not related to the EHP-30 or the Swedish translation.

The qualitative analysis revealed some limitations of the Swedish translation. The most evident one was that many women had different definitions of ‘because of endometriosis’ in the instructions. For example, Irritable bowel syndrome is common in women with endometriosis (Viganò et al. 2018), and the symptoms are often overlapping. Some women in this study chose to include Irritable bowel syndrome symptoms, while others did not. This may be a validity problem in the use of EHP-30 in small comparative studies, but less problematic when using it in individual evaluations of treatments. To overcome the definition problem, Nojomi et al. (2011) excluded women with conditions other than endometriosis that may have an impact on HRQoL in their validation of the Persian version of EHP-30 (Nojomi et al. 2011). Since the exclusion of women with other symptoms is not possible in routine clinical use, clarification of the meaning of ‘because of endometriosis’ could be useful in the instructions.

In this study, women expressed a desire to describe their whole-life situation and not only report the experiences of the previous four weeks. This might result in lower health status scores and affect individual evaluations and follow-up. According to the findings in this study, question 19 (‘Felt depressed’) should be re-formulated. The Swedish word for ‘depressed’ is associated with the diagnosis of depression and is therefore not comparable to the English meaning.

A majority of the aspects of life that women felt were missing in the EHP-30 are covered in the modular part, which comprises 23 items divided into six areas: work, relationship with children, sexual intercourse, medical profession, treatment and infertility. There is a Swedish version of the modular questions but it has not yet been cross-culturally adopted or psychometrically tested.

Intestinal and urinary problems such as periodic bloating, diarrhoea or constipation are common problems among women with endometriosis, but often not well recognised. Many women also experience difficulties during defaecation and urination (Ballard et al. 2008; Dunselman et al. 2014). Surprisingly, none of these problems are included in EHP-30 or among the modular questions.

Many women with endometriosis experience problems with communicating their problems, and feelings of exposure, normalisation and trivialisation are common (Young et al. 2015; Grundström et al. 2018). Having a validated questionnaire for HRQoL specific for endometriosis could be one way for women to visualise their hidden condition. It may also be an important instrument for healthcare professionals within the field, as it enables objective comparisons of outcomes of treatments both between groups and over time within the same individual.

If the focus is experiences of healthcare, EHP-30 could be used in combination with the ENDOCARE questionnaire (Dancet et al. 2011), or with the Endometriosis Treatment Satisfaction Questionnaire (Deal et al. 2010), which has its emphasis on satisfaction with treatment. When using these types of patient-reported instruments, cross-cultural adaptations are important to minimise the risks of cultural or linguistic miss-interpretations (Beaton et al. 2000; Wild et al. 2005). Some translations of EHP-30 have been criticised for not being adapted and translated appropriately: the Italian version lacked reliability and construct validity (Maiorana et al. 2012), and the Norwegian version showed a lack of cross-cultural validity in one domain (Verket et al. 2018).

There were some limitations of this study. First, as many as 67% of the women stated university as their highest education level, which is higher than in the average population. Secondly, Beaton et al. (2000) recommend a larger study group, so the study population in this pre-test was small. However, we reached theoretical saturation after 13 interviews, meaning that no new answers were obtained in the last four interviews. Furthermore, EHP-30 is a relatively simple and short questionnaire, and thereby we argue that our study population was large enough to give us trustworthy results.

The quantitative measures such as roof-ceiling effects should be interpreted with caution due to the limited numbers of participants. The questionnaire is in need of further psychometric testing for internal consistency, construct validity, test–retest reliability, and floor and ceiling effects in a larger study population.

Conclusion
The Swedish version of EHP-30 is a useful and well-accepted questionnaire for measuring HRQoL in women with endometriosis in Sweden. A minor change of words is recommended to make it convergent with the original version. The translated questionnaire should undergo further psychometric testing in a larger study population.

Disclosure statement
The authors report no conflicts of interest.

References


