Development and evaluation of the Communication over Language Barriers questionnaire (CoLB-q) in paediatric healthcare

Johanna Granhagen Jungner1,*, Elisabet Tiselius2,3, Marika Wenemark4,5, Klas Blomgren1,6, Kim Lützén3, Pernilla Pergert1,2

1 Childhood Cancer Research Unit, Department of Women’s and Children’s Health, Karolinska Institutet, Tomtebodavägen 18 A, Floor 5, SE-171 77 Stockholm, Sweden
2 Pediatric Oncology, Astrid Lindgren Children’s Hospital, Karolinska University Hospital, SE-171 76 Stockholm, Sweden
3 Department of Swedish Language and Multilingualism, Institute for Interpreting and Translation Studies, Stockholm University, SE-106 91 Stockholm, Sweden
4 Department of Medicine and Health Sciences, Division of Community Medicine, Linköping University, SE-581 83 Linköping, Sweden
5 Centre for Organisational Support and Development, Region Östergötland, SE-58185 Linköping, Sweden

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ABSTRACT

Objective: To develop a valid and reliable questionnaire addressing the experiences of healthcare personnel of communicating over language barriers and using interpreters in paediatric healthcare.

Methods: A multiple-methods approach to develop and evaluate the questionnaire, including focus groups, cognitive interviews, a pilot test and test-retest. The methods were chosen in accordance with questionnaire development methodology to ensure validity and reliability.

Results: The development procedure showed that the issues identified were highly relevant to paediatric healthcare personnel and resulted in a valid and reliable Communication over Language Barriers questionnaire (CoLB-q) with 27 questions.

Conclusion: The CoLB-q is perceived as relevant, important and easy to respond to by respondents and has satisfactory validity and reliability.

Practice implications: The CoLB-q can be used to map how healthcare personnel overcome language barriers through communication tools and to identify problems encountered in paediatric healthcare. Furthermore, the transparently described process could be used as a guide for developing similar questionnaires.

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1. Introduction

Dealing with language barriers and the use of interpreters in the healthcare sector is a growing challenge worldwide. The right to express oneself and receive information is proclaimed in article 19 of the Universal Declaration of Human Rights [1]. Furthermore, national legislations in countries such as Norway, Australia and Sweden [2–4] state that patients are entitled to individually adapted information to be able to participate in decisions concerning their care. Interpreters are thus crucial to meet the information needs of patients/families with limited language proficiency in the majority language. However, previous research shows that healthcare personnel perceive difficulties in using communication tools, such as interpreters, as well as a lack of knowledge and routines for overcoming linguistic and cultural barriers [5–7]. Presumably, the situation is even more delicate when it comes to communication over language barriers in paediatric healthcare. Children depend on their parents and on the communication between their parents and the healthcare personnel being satisfactory and not hindered by language barriers.

Previous research points to various problems related to the lack of a common language and the use of interpreters [8]. Healthcare personnel experience loss of control of information where there are cultural and language barriers and when they communicate through interpreters [9]. The interpreted encounter is also made difficult by the distraction that an interpreter adds to the consultation [10–14]. Research also identifies the risk for compact information, meaning that there is a tendency to give as much

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information as possible from many different healthcare professions when the interpreter is present [9,15]. Furthermore, nurses generally do not use interpreters but resort to other tools for communication [5]. Research also shows that there is a lack of experience and training in using interpreters among healthcare personnel, specifically among nurses [9,10]. There is also a lack of professionalism and training among interpreters consulted by the healthcare sector [16].

Furthermore, several qualitative studies have shown that there is a great need for improvement in communication over language barriers to be able to provide equitable healthcare [7,9,17–19]. However, results from qualitative studies in healthcare sciences in general are rarely implemented and used to make quality improvements, and they are not easily used in intervention studies [20]. Thus, there is a need for studies that develop quantitative measurements that can be used in intervention studies. There are a few questionnaires for exploring communication over language barriers and the use of interpreters among healthcare personnel. However, we have not been able to identify a transparent report on the validation process. In Norway, Kale and Syed [21] used a questionnaire developed in Italy by Tomassini [22], focusing on the use of interpreters rather than on communication over language barriers in the sense of using all types of communication tools (including interpreters). Hsieh, Pitaloka and Johnson’s [23] questionnaire assesses healthcare personnel’s evaluation of how important different interpreter functions are. Bischoff and Hudelson’s [10] questionnaire, which is pre-tested but not validated, covers issues concerning the impact of language barriers and interpreters on social integration in society. We would therefore argue there is a need for a questionnaire that focuses on both communication over language barriers and the use of interpreters within paediatric healthcare. It is also important that respondents find the questionnaire meaningful and trustworthy so as to increase their motivation to answer it truthfully and accurately [24]. There is therefore a need for a questionnaire with a development and validation process that is transparent and that takes the respondents’ perspective into consideration.

1.1. Objective

The objective of this project was to develop a valid and reliable questionnaire addressing the experiences of healthcare personnel of communicating over language barriers and the use of interpreters in paediatric healthcare.

2. Methods and results

This study uses a multiple-methods approach in the process of developing the questionnaire, as described by Broder, McGrath and Cisneros [25]. The development of the Communication over Language Barriers questionnaire (CoLB-q) was carried out in three phases. To improve readability, the methods and results are described consecutively for each phase of the development process.

2.1. Phase 1: initial development

Phase 1 included identification of an initial relevant pool of issues [26] found in the background literature and refining these issues into questions and items (Table 1).

2.1.1. Review committee: theme and question development

A review committee was set up, consisting of three researchers (co-authors of this article) with expertise in paediatric healthcare research (Granhagen Jungner and Pergert) and interpreting (Tiselius). The ten identified issues were discussed in the committee and certain themes where identified. The review

<table>
<thead>
<tr>
<th>Initial identified issues</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Experiences of communicating with a patient/family with low Swedish proficiency, e.g.</td>
<td>Experiences of language barriers and cultural difference</td>
</tr>
<tr>
<td>☑ cultural and language barriers to communication</td>
<td></td>
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<td>2. Different means of communication used, e.g.</td>
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<tr>
<td>☑ translated written information</td>
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<tr>
<td>☑ body language</td>
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<tr>
<td>3. Obstacles to ensure that the patient/family understands the information, e.g.</td>
<td></td>
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<tr>
<td>☑ loss of control of information</td>
<td></td>
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<tr>
<td>4. Experiences of needs for interpreters, e.g.</td>
<td></td>
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<tr>
<td>☑ interpreter as a tool but also an obstacle to communication</td>
<td></td>
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<tr>
<td>5. Practical problems to resolve needs for an interpreter, e.g.</td>
<td>The use of interpreters in healthcare encounters</td>
</tr>
<tr>
<td>☑ lack of time</td>
<td></td>
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<tr>
<td>☑ lack of control of time</td>
<td></td>
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<tr>
<td>6. General problems when using interpreters in medical encounters, e.g.</td>
<td></td>
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<tr>
<td>☑ triadic relationships</td>
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<tr>
<td>☑ compact information</td>
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<tr>
<td>☑ loss of control of information</td>
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<td>7. Nurse specific problems when using interpreters in healthcare encounters, e.g.</td>
<td></td>
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<tr>
<td>☑ lack of experience and training</td>
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<tr>
<td>☑ work routines</td>
<td></td>
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<tr>
<td>8. Frequency of interpreter use in general nursing, e.g.</td>
<td></td>
</tr>
<tr>
<td>☑ lack of use in inpatient care</td>
<td></td>
</tr>
<tr>
<td>9. Quality issues of healthcare interpreting services, e.g.</td>
<td>Interpreting services</td>
</tr>
<tr>
<td>☑ continuity</td>
<td></td>
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<tr>
<td>☑ availability of different languages</td>
<td></td>
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<td>☑ educational level of interpreters</td>
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<tr>
<td>10. Quality issues (professionalism) of a medical interpreter, e.g.</td>
<td>The professionalism of the interpreter</td>
</tr>
<tr>
<td>☑ language skills (including medical language)</td>
<td></td>
</tr>
<tr>
<td>☑ professionalism in relationships</td>
<td></td>
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</table>
committee developed specific questions and items within each theme. Decisions on the development of the questionnaire were made by consensus in the committee.

2.1.2. Results

Four themes were identified: 1) experiences of language barriers and cultural differences; 2) the use of interpreters in healthcare encounters; 3) interpreting services; and 4) the professionalism of the interpreter. These themes should be understood as general constructs rather than fixed themes, and therefore some of them will be renamed and others discarded. The initial issues and themes were used to develop questions and items as well as a first draft of the questionnaire (Fig. 1).

Demographic/background questions were also developed, regarding age, profession and active years. Likert scales, the most widely used scale measuring attitudes or experiences [27], were used to measure attitudes on the use of interpreters. This means that if a question is asked about frequency, the expected answer does not state the exact frequency, as in a number of times, but a perceived frequency, as in “this sometimes happens” or “this

Fig. 1. Flowchart of the methods, themes, actions and number of questions in the different phases of the development process.
always happens” (although “always” does not necessarily mean “every day”). During the question development, questions identified as difficult to formulate were singled out to be given extra attention in the focus group and cognitive interviews during the validation phase. The draft questionnaire after the first phase consisted of nine background questions, 36 Likert-type questions and three open questions (Fig. 1).

2.2. Phase 2: testing validity

Phase 2 established content validity [25] and face validity [28]. It included focus group interviews [29], cognitive interviews [28], a pilot test [30] and a review committee validation. During phase 2, the review committee was involved in the evaluation after each step.

2.2.1. Focus group interviews

A focus group interview is a qualitative research method used to gain knowledge about a certain phenomenon [29]. In our study, three focus group interviews were performed on a convenient sample of healthcare personnel with various academic, clinical and subject expertise. The total number of participants was 11, with three or four members per group, all female. The first focus group consisted of four specialist nurses with higher academic education and clinical experience in paediatric care (minimum eight years). The second focus group consisted of three nurses and one nurse assistant from a paediatric ward, and the third focus group consisted of three experts in transcultural healthcare with a background in sociology and nursing from the Stockholm County Council’s Transcultural Centre.

The focus group interviews were used to explore the questions and items in the questionnaire to establish content validity [29]. Participants were instructed not to answer the questions, but to refer to them during the discussion. They were encouraged to reflect on the relevance of the questions/items, how they understood them and also whether they wanted to add any questions/items. The first author moderated the focus groups and used open and probing questions. Interaction between participants was encouraged. The discussions lasted 30–45 min and were audio-recorded. The moderator took field notes in the questionnaire about the comments from the participants during the discussion. The field notes were elaborated with the help of the recordings immediately after the interviews. Results from the elaboration for each of the items were discussed in the review committee and used to refine the questions in the questionnaire. Examples from the field notes are given in Table 2.

2.2.2. Results

The focus group participants spontaneously expressed the opinion that the questionnaire felt very meaningful and that the questions/items were highly relevant. Their discussions helped the review committee refine the overarching themes of the use of interpreters in the healthcare sector and interpreting services. Some of the items were further clarified, for instance how to formulate the impact of the triadic relationship on communication, so that for example the item “The interpreter’s presence has a negative impact on my relationship with the family” became “The interpreter’s presence hinders my care relation with the family”. Changes were also made from past to present tense in the questions/items (Table 2).

2.2.3. Cognitive interviews

Cognitive interviewing is a method used to identify problems that may cause measurement errors when respondents try to understand the questionnaire, retrieve information or answer the questions [28]. To answer the questions, the first step of the cognitive process is to understand questions and concepts. To evaluate the cognitive response process, individual cognitive interviews were carried out with a convenient sample of five nurses and nurse assistants (n=5) working in specialized paediatric care. All the participants were asked to “think aloud” while answering the questionnaire and then, by using retrospective probes, to have a dialogue with the researcher on the clarity of the concepts and on their ability to understand and answer the questions. At the end of the session, they were asked about their overall impression of the questionnaire and the relevance of the items. Field notes were taken, and together with the participants’ notes from the questionnaire these were discussed with the review committee and used to further refine the questions.

2.2.4. Results

The cognitive interviews helped simplify the functional level of the questionnaire to facilitate the respondents’ cognitive process of answering the questions. An example in this case is the concept “interpreter”. Participants pointed out that, unless specifically framed, an interpreter could be anyone engaged in translating, including a family member, a colleague or a certified interpreter. These comments led to “interpreter” being defined explicitly in the questionnaire as “an interpreter booked through an interpreting agency (i.e. not a relative)”. Comments from the cognitive interviews also revealed that the item on language skills was unclear. The question was formulated as “Do you speak any

| Table 2 |
| Examples of notes from focus group interviews. |

| Confirmation of well-functioning questions |
| Informants endorse the background questions and confirm that they are ok and relevant (FG 1 & 3). |
| Informants strongly confirm that the topics of the questionnaire are highly relevant and important in paediatric healthcare (FG 1, 2 & 3). |

| Linguistic adjustments |
| Discussion about not using the concept “head nurse” (FG 2). |
| Discussion about the wording “negative impact” in regard to the triadic relationship in the communication with interpreters (FG 1). |

| Adjustments in terms of content |
| Informants suggest a question about the accessibility of interpreters (FG 1). |
| Informants suggest questions about the interpreter’s knowledge of medical terminology (FG 2). |
| Discussion about adding a question about the interpreter’s competence level (FG 2). |
| Discussion about the importance of stating who answers the questionnaire and that different professions should be reflected (FG 1). |
| Informants discuss if questions about the healthcare professional’s ethnicity and/or nationality should be included (FG 1). |
| Discussion about healthcare professionals’ proficiency in other languages of and which languages should be covered in the questionnaire (FG 1, 2 & 3). |
languages other than Swedish and English?”, and the participants responded, “Do you mean a second language or another mother tongue?” The review committee discussed different versions of the question, but because of its implicit lack of clarity, it was decided to remove it, at least temporarily. Finally, the various questions and items were more clearly divided into different themes depending on the construct they were representing.

During the focus groups and the cognitive interviews, it became clear that the themes “the professionalism of the interpreters” and “the interpreting services” could be merged into one. Furthermore, the theme “experience of language barriers and cultural differences” seemed to function better if divided into “interpreting in the healthcare sector” (together with “the use of interpreters in medical encounters”) and “cultural and religious differences affecting communication”. Before the pilot tests, the questionnaire consisted of 36 questions divided into three themes: 1) interpreting in the healthcare sector; 2) interpreting services; 3) cultural and religious differences affecting communication. There were also three open-ended questions, and background questions were reduced to eight after the removal of the question about other languages (Fig. 1).

2.2.5. Pilot test

Pilot testing is a method used to assess the feasibility of the questionnaire [30]. The pilot test was performed on a national sample of two different groups of nurses (n = 35) in different paediatric healthcare contexts. Respondents in the first group were nurses (n = 20) in continued advanced education. The respondents in the second group were nurses with a postgraduate diploma in specialist paediatric nursing (n = 15) and working in paediatric healthcare. Respondents were asked to make written comments when responding to the questionnaire about how they perceived certain questions or items, whether anything was missing, and how they perceived the questionnaire’s relevance, comprehensibility and ease of response. The answers from the closed questions were analysed using descriptive statistics. The answers from the open-ended questions, together with the written comments, were analysed from the perspective of the respondents’ understanding of the questions and suggestions for further improvements of the questionnaire.

2.2.6. Results

There were a few missing answers in the questionnaires, but they appeared randomly, and only one question was unanswered by more than one respondent (two). Three exemplified questions were identified where the answers supported the findings in the background literature, as well as re-enforced the underlying assumptions about the use of interpreters in paediatric healthcare, i.e. that the respondents often made use of language brokers (e.g. a relative or a child) and that they did not use interpreters very frequently for preparing and informing about procedures or for teaching patients and parents.

After the pilot test, it was decided to further specify some of the questions, such as the question about communication without an interpreter “Do you communicate through a language broker?”. The original question did not give any nuanced information. Furthermore, throughout the questionnaire, few respondents used the option “Always”.

2.2.7. Review committee: validation

At the end of the validation phase and before the reliability testing started, another review was performed by the committee. The discussions in the review committee were similar to the discussion during the items development, but with the focus on clarity and relevance for the users and with the addition to the committee of the third author (Wenemark), who is a statistician with expertise in survey methodology and respondent motivation.

2.2.8. Results

The review committee contributed to several changes. Items were organized into relevant matrix questions to improve both logic and effectiveness. Responses to the open questions about the use of qualified interpreters, the quality of the interpreter and training in the use of interpreters led to the addition of new items about these issues. The question on language skills (removed before the pilot test, see Fig. 1) was reintroduced in a clarified version as “Do you speak any languages other than Swedish fluently?”, as some of the respondents indicated that they used languages other than Swedish to communicate with the patients. The revised question about communication without an interpreter was divided into four items giving different examples of language brokers: “How often do you communicate without an interpreter the following way: using an adult relative/a child/a colleague/you know the language yourself?” The review committee decided to reduce the number of response alternatives by excluding the response option “Always” in the frequency scale. For several items “Always” was hardly an applicable option, as was also demonstrated in the results from the pilot study. For example, it is unlikely that communication is always carried out with a relative as translator (of the 35 respondents only one answered “always”). To avoid having two different frequency scales, it was therefore decided to use the four-graded scale (never/seldom/sometimes/often) for all items on frequency issues. A further advantage of the four-graded scale is that it reduces the risk of respondents misinterpreting the scale as a bipolar scale with a neutral middle alternative.

After the pilot test and the discussions in the review committee, the questionnaire consisted of 31 questions distributed among three themes: 1) communication over language barriers with or without an interpreter; 2) experiences of the use of interpreters; and 3) cultural and religious differences affecting communication (see Fig. 1).

2.3. Phase 3: testing reliability

Phase 3 included a test-retest to establish reliability [31] and a final revision of the questionnaire.

2.3.1. Test-retest

For the test-retest, 27 nurses in the educational programme in specialist nursing were invited to take the questionnaire, and 24 accepted. They were between 25 and 45 years old and had between three and 10 years of clinical working experience from various clinical contexts nationwide. A test-retest period of two to four weeks was chosen because it is a common time period for test-retest and because the use of interpreters can be assumed to have been fairly stable during that period. The nurses were back in their ordinary workplace during the interval between the tests but answered the questionnaire when attending the campus training. The dropout rate between test and retest was 25% (n = 6), and item non-response was low (<10%). The number of respondents for both questionnaires, test – retest, was 18.

The test-retest was analysed using descriptive statistics. As the group was small, statistical methods were chosen accordingly. We applied weighted Kappa [32,33] to evaluate reliability, since changes in one scale step in this ordinal scale – between test and retest – is more an issue of slight agreement than disagreement. For the weighted kappa we used the Cicchetti-Allison weighting matrix [34]. The Svensson method [35] for paired ordinal data was used to identify any systematic patterns of change at group level.
for example whether the respondents reported increased use of interpreters between test and retest.

2.3.2. Results

The results showed respondent consistency between test and retest with high agreement proportion (0.7059) (Fig. 2). The unweighted Kappa median value was 0.3700, and the weighted Kappa median value was even stronger (0.436), which is a satisfactory consistency between test and retest.

Despite the satisfying level of consistency, possible changes between test and retest were explored further. Svensson’s measure for relative position (RP) was applied to the data as ordinal scales were used in this questionnaire. The Svensson method identifies a systematic pattern of change at group level. In the Svensson method, differences in test-retest are reported by RP. RP lies between -1 and 1, where a positive value of RP indicates changes towards higher values on the ordinal scale, such as changing from “sometimes” to “often”. When applying the Svensson method, results showed only small movements between the scale steps. For three questions, though, the changes may not be explained by chance. For instance, in the question about whether respondents used translation tools to communicate with patients, 3 out of 13 changed their answer from “never” to “sometimes” (Table 3). In the case of the question about how often an authorized interpreter was booked, the relative position was negative, as four respondents changed their answers from “sometimes” to “never” (Table 3).

2.3.3. Review committee: finalization

Following the test-retest, the review committee was consulted again to finalize the questionnaire.

2.3.4. Results

The important decision was taken to jettison the theme of cultural and religious differences affecting communication. This was made to avoid respondent fatigue, as this theme included one question with 14 items. It was also important to focus the questionnaire only on the construct of communication over language barriers. The two remaining themes were subsequently re-labelled as 1) communication over language barriers and 2) the use of interpreters (Fig. 1). In addition, certain scales were changed as it was obvious from the distribution of the answers in the test-retest that the scale steps did not have sufficient discriminatory power [36]. It could be seen in the data that the three questions dealing with reporting the evaluation (orally, written and as feedback to the interpreting agency) of the work of the interpreters and the interpreting services had very little variation, with the respondents replying with the same answer on all three questions. To increase the motivation of the respondents, these three items were merged into one question. The test-retest showed consistency between a majority of answers. However, the answers to two specific questions, concerning whether healthcare personnel felt secure when it comes to correct information transfer and safe when using interpreters, showed a degree of inconsistency. The review committee interpreted the contradictory answers as the result of leading questions and removed them.

During the work on the questionnaire, it became clear that, with only minor changes, it had the potential to be used also for other professional groups in paediatric healthcare. For example, the item of arrival status concerned only the nurse profession and was complemented with arrival status/medical history to make it relevant also for physicians (Table 4).

The final questionnaire comprises questions about the respondents’ demographic/background information and two themes – 1) communication over language barriers, and 2) the use of interpreters – that contain questions about communicating with low Swedish-proficiency families, using interpreters in healthcare and using interpreting services. It contains a total of 27 questions, 10 demographic/background questions, 14 closed and three open (Fig. 1). Some questions consist of several items (Table 4).

3. Discussion and conclusion

3.1. Discussion

The focus of the study has been to develop a valid and reliable measurement of communication over language barriers as well as to provide a questionnaire perceived as important and easy to answer by respondents.

Communication over language barriers and the use of interpreters in healthcare is a challenge that needs to be further studied and addressed. When developing systematized questionnaires, we would argue for the importance of being transparent and of following rigorous methods in the development and in testing validity and reliability, as aimed for in this study. Studies on the use of interpreters have been performed using questionnaires without a transparent report on the validation process [10,21–23]. The CoLB-q includes questions about the interpreters’ function, the use of interpreters and the interpreters’ impact on the patients/families’ healthcare. The CoLB-q also covers other types of

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Table 3

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<thead>
<tr>
<th>Question</th>
<th>Estimate</th>
<th>SE</th>
<th>CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>How often do you use translation tools or apps to communicate without an interpreter?</td>
<td>0.1765</td>
<td>0.0897</td>
<td>0.0007 to 0.3523</td>
</tr>
<tr>
<td>How often do you inform about procedures and examinations with an interpreter?</td>
<td>-0.2622</td>
<td>0.1098</td>
<td>-0.4763 to -0.0481</td>
</tr>
<tr>
<td>How often do you inform about procedures and examinations with an interpreter?</td>
<td>-0.2422</td>
<td>0.1098</td>
<td>-0.4574 to -0.027</td>
</tr>
</tbody>
</table>

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communication over language barriers and other aspects of the use of interpreters, such as evaluation.

During the process, a review committee discussed the results and adjustments to the questionnaire. Expert review committees have previously been used in research on questionnaire development, though the compositions have varied [37,38]. In this study, the committee included expertise from the fields of healthcare science, questionnaire design and interpreting and communication science. We would argue that this inter-professional combination has been of great importance in the process of developing the CoLB-q. A key issue has also been the involvement of healthcare personnel in several steps of the process to produce a questionnaire that respondents perceive as relevant and important. Relevant and meaningful questions may increase the response rate, encourage thoughtful answers and provide healthcare personnel with a tool to highlight important issues in their workplace.

Questionnaires with an implementation effect may be difficult to validate by means of test and retest, although they may have a particular explanatory value. In our case this only applied to three out of 27 questions. Answering a questionnaire may generate a certain learning effect. Test-retest should not be expected to show a difference between the two tests, and for most of the questions it did not. For three questions, however, our results seem to indicate that some respondents had changed their behaviour, which we interpret as a possible learning effect between the test and the retest.

The validation so far has mainly involved female nurses and nurse assistants in paediatric healthcare. Furthermore, the number of the respondents in test-retest was low, which may have influenced the results. The questionnaire was mainly developed and evaluated in the paediatric healthcare context. However, we believe that after further adaptation and testing, the questionnaire is applicable in other clinical contexts and countries since the issues are universal in globalized healthcare.

3.2. Conclusion

We have aimed to develop a validated and reliable questionnaire investigating communication over language barriers and the use of interpreters. With regard to face and content validity, the cognitive interviews and the pilot test showed that the respondents understood the questions in the questionnaire and that the questions had sufficient clarity and readability. With regard to reliability, test-retest showed that results were stable, although three questions indicated a learning effect between test and retest. When further testing and validating the CoLB-q, other healthcare personnel such as physicians, phycologists and physiotherapists in different healthcare contexts should be included.

3.3. Practice implication

The CoLB-q may be used to explore how healthcare personnel overcome language barriers by means of communication tools, and to identify problems encountered in paediatric healthcare. Furthermore, the transparently described process of developing the CoLB-q could serve as an inspiration for the development of similar questionnaires.

Ethical considerations

Since this questionnaire has been developed to be used in highly specialized paediatric care, we applied for an ethical advisory statement from the Regional Ethical Review Board in Stockholm, Sweden. They responded in their advisory statement [2015/1783-31/5] that they did not see any ethical objections to the study.

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Contributors

Johanna Granhagen Jungner drafted the manuscript, wrote the first draft of the questionnaire, participated in the review committee and carried out the narrative literature review, focus groups, cognitive interviews, pilot test and test-retest. Elisabet Tiselius analysed the data, participated in the review committee, refined the questionnaire and drafted the manuscript together with Granhagen Jungner. Marika Wenemark analysed the data, contributed with statistical expertise, participated in the review committee, refined the questionnaire and critically revised the manuscript together with Klas Blomgren and Kim Lützén. Pernilla Perger supervised the work of Granhagen Jungner and Tiselius, participated in data collection in the pilot study, analysed the data, participated in the review committee, refined the questionnaire and critically revised the manuscript. All six authors have read and approved the final article.
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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.jpec.2018.04.007.

References