

Translation of the quality of life questionnaire for primary ciliary dyskinesia (QOL-PCD) into Hebrew: The Israeli experience

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Abstract

Background: Patients with primary ciliary dyskinesia (PCD) have chronic morbidities affecting their quality of life (QOL). Health-related QOL (HRQOL) has been recognized as an important tool for assessing the burden of PCD on patients and their families. A PCD-specific HRQOL questionnaire (QOL-PCD) was developed and validated for the English-speaking populations. Still, it has not yet been translated into Hebrew or adapted for Israeli PCD patients.

Methods: This describes our translation of the original English version of QOL-PCD into a Hebrew version. The process involved forward translation by independent translators, construction of a consensus version, back-translation into the original English version, analysis by the expert committee, and a pretest. The pretest was administered to 20 participants with PCD (the patients and the parents of minor patients) to assess the feasibility and practicality of the tool. Scale and item indices (scale-level content validity index [S-CVI] and item-level content validity index [I-CVI]) were calculated for content validity.

Results: All study participants understood the final Hebrew version that the expert committee had approved with no difficulty. The instrument had satisfactory (>0.80) content validity, with S-CVI indexes of 0.99 for the adult version, 0.86 for the parental version, 0.95 for the adolescent version, and 1.00 for the child version.

Conclusion: The English version of a QOL-PCD was translated into Hebrew and adapted in Israel. This translation is a valid instrument to assess HRQOL in Hebrew-speaking patients with PCD and their family members. It may be helpful for PCD patient management and research in Israel.

KEYWORDS

primary ciliary dyskinesia, quality of life, surveys and questionnaires

Abbreviations: ATS, American Thoracic Society; ERS, European Respiratory Society; FDA, Food and Drug Administration; HRQOL, health-related quality of life; I-CVI, item-level content validity index; PCD, primary ciliary dyskinesia; S-CVI, scale-level content validity index.

Ronen Bar-Yoseph and Moran Lavie are equal last authors.

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1 | BACKGROUND

Primary ciliary dyskinesia (PCD) is a rare, genetically heterogeneous, multiorgan disorder caused by impaired structure and/or function of motile cilia. Clinical manifestations of PCD are diverse and include recurrent and chronic infections in the lung, ear, nose, and sinuses, as well as the involvement of other systems, such as cardiovascular (congenital heart diseases and laterality defects, such as situs inversus totalis) and reproductive systems (infertility).¹

Chronic diseases, such as PCD, are strongly associated with stress and anxiety related to managing the disease while maintaining the usual daily living activities. The burden of care, concern, missed school, work, fears about relationships, and disease progression can contribute to psychosocial health challenges among patients and their family members.²

Health-related quality of life (HRQOL) measures have become a vital and necessary component of patient-reported outcomes in the setting of chronic diseases.³ The US Food and Drug Administration (FDA) defines HRQOL as the patient's perception of how they "survive, feel and function."⁴ There is general agreement that assessment of HRQOL should encompass, at the least, physical, social, and emotional well-being, as well as multidimensional and systematic measurements of how the illness and its treatment impact symptoms and other domains of functioning. A reliable HRQOL patient-reported outcome measure for PCD is significant, given that physiological measures, such as plethysmography, lung clearance index, and high-resolution computed tomography (HRCT), are neither sensitive nor suitable for repeated testing.

Researchers from the UK and North America^{5,6} have developed age-specific QOL questionnaires (QOL-PCD) for children, adolescents, parents of young children, and adults with PCD using FDA and European Agency for the Evaluation of Medicinal Products guidance.^{7,8} The questionnaires were developed through individual and group interviews with specialists, adult patients with PCD, and parents of pediatric PCD patients. They were refined following cognitive interviews. The English-language version of the QOL-PCD measures has been validated, representing an essential step for its use in research and clinical practice.^{2,9} The instrument contains 37, 43, 41, and 48 items in its child, adolescent, caregiver, and adult versions. It includes physical, emotional, and social functioning, treatment burden, role functioning, vitality, and others. This instrument is specific to PCD patients and includes questions on associated rhino sinus and ear symptoms, not to be confused with disease-specific HRQOL measures for adults with cystic fibrosis (CF) or non-CF bronchiectasis,^{2,3} which do not contain these symptoms.

Israel has one of the largest populations of patients with PCD, and it was recently ranked among the countries with the highest prevalence of PCD worldwide.^{10,11} This may be related to the high number of consanguineous marriage family clusters in Israel.^{10,12} The high prevalence of PCD in Israel, clearly establishes the need for a Hebrew-language assessment of QOL-PCD for application in clinical care and research. The purpose of this paper, therefore, was to

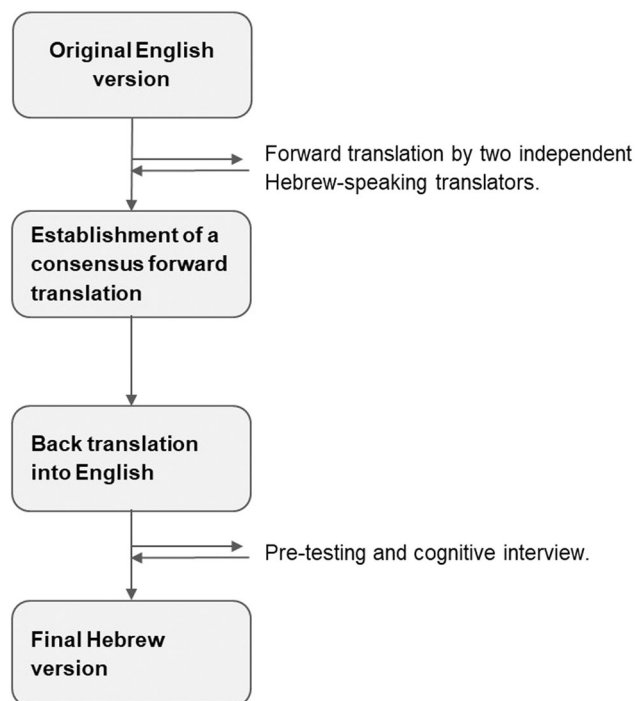


FIGURE 1 The development of the Hebrew-language version of the quality-of-life questionnaire for patients with primary ciliary dyskinesia

describe the process by which the original English instruments were translated into Hebrew and validated according to a standardized, well-established procedure.^{13,14}

2 | METHODS

A flowchart of the development of the Hebrew language assessment of QOL-PCD is depicted in Figure 1. Forward translation, back translation, and cultural adaptation were completed, and a draft version was created in Hebrew in the first phase. In the second phase, the instrument prototype was pretested by means of a cross-sectional survey among patients and parents of patients with PCD. A validation assessment of the content was also performed.

2.1 | Translation and adaptation

The initial step was the translation of the English version of the QOL-PCD child, adolescent, parent-proxy, and adult to Hebrew. The forward translation was completed by two independent translators (IA, NBS) who are native Hebrew speakers fluent in English and have good knowledge of PCD disease. A third translator (RBY), also a native Hebrew speaker fluent in English and knowledgeable in PCD disease, translated the Hebrew forward translation version back into English (back-translation). The latter researcher had not seen the original English version of the instrument. We then compared the

back-translated versions of the Hebrew questionnaires with the original English version of the questionnaire to check for differences.

2.2 | Validation

Content validity of a measurement scale or a questionnaire relates to the degree to which a specific scale (PCD in this case) adequately represents the construct of interest (quality of life in patients with PCD).¹⁵ The scale-level content validity index (S-CVI) and item-level content validity index (I-CVI) were used to quantitatively test the content validity of the Hebrew version of the QOL-PCD instrument. The three PCD experts on the team (IA, RBY, and ML), each with at least 10 years experience in treating PCD patients, were asked to rate the relevance of each item, on a 4-point scale as follows: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, and 4 = highly relevant. Then, for each item, the I-CVI is computed as the number of experts giving a rating of either 3 or 4, divided by the number of experts—that is, the proportion in agreement about relevance. For example, an item rated as “quite” or “highly” relevant by four out of five judges would have an I-CVI of 0.80. Examples of qualitative questions for the experts were “whether each item was clearly expressed” and “whether there was difficulty in understanding due to cultural differences.” The scale-level CVI (S-CVI) for the overall scale (i.e., the sum of all items on the I-CVI divided by the total number of items) was based on that value.¹⁶ Figure 2 illustrates the method for calculating content validity. The content was regarded as adequate when the S-CVI was >0.8.¹⁶

2.3 | Pretest

The final revision of the QOL-PCD was administered to 20 participants (the patients and the parents of minor patients) to assess the feasibility and practicality of the tool. Patients had been diagnosed as having PCD according to standard ERS/ATS criteria at least 1 year before study entry. These criteria included compatible clinical phenotype + genetic confirmation and/or ciliary ultrastructural defects on electron microscopy.¹⁷ After completing the questionnaire, the participants completed an individual cognitive debriefing interview whose elements queried the participants on how they interpreted the question, whether they could

repeat the question in their own words, and what came to mind when they heard the question. After rating the item, they were asked why they chose their answer and what made them choose an alternative answer. This process was repeated for each item. Respondents were asked what they thought of the question and whether there were any words they did not understand or if any important content or impacts of PCD on their QOL were absent. The feedback was recorded and used for further revision by the experts.

3 | RESULTS

Forward-translation, back translation, and cultural adaptation were conducted. The researchers first discussed the translation among themselves and then with the British researchers from the referral center for PCD at the University of Southampton, United Kingdom who were the developers of the original QOL-PCD. The meaning of the Hebrew version of each question was discussed and compared with the original meaning in English. Any controversy regarding statements of ambiguity related to the wording was resolved, and a “consensus” forward/backward translation version was finalized. Minor cultural differences were addressed and discussed, and any remaining discrepancies were resolved by consensus.

Based on the original English version, four prototype Hebrew QOL-PCD questionnaires were developed, one for each target population: children, adolescents, adults, and parents of children with PCD. For evaluation of the content's validity, all of the experts reviewed the items of the Hebrew prototype version and compared them to the original version. They rated each item of the instrument concerning semantic/idiomatic, cultural, and conceptual domains and scored each item from 1 (entirely irrelevant) to 4 (highly relevant). The S-CVI for each questionnaire was calculated as previously described, and the results were: adults = 0.99, parents = 0.86, adolescents = 0.95 and children = 1.00 (See Table 1).

Five adults with PCD, five adolescents with PCD, five children with PCD, and five parents of children with PCD were included in the pre-test and cognitive interview. Overall, the specific items of the translated version were easily understood by patients and parents of minors. Only a few specific words were difficult to understand or

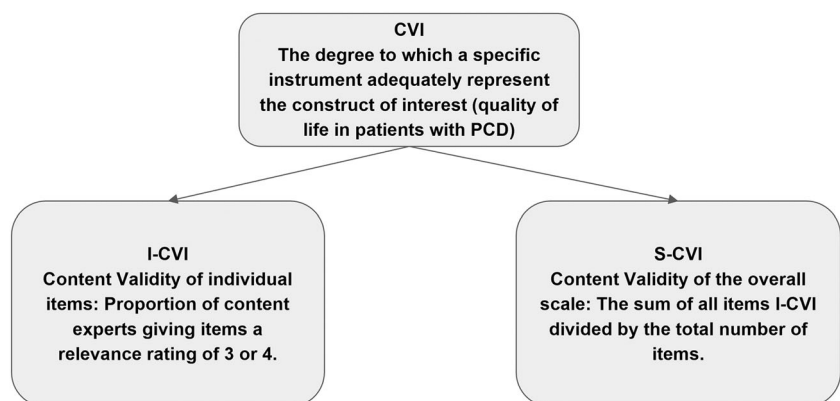


FIGURE 2 Content validity index (CVI) method

Questionnaire	Item	Expert 1	Expert 2	Expert 3	Experts in agreement	Item CVI
Children	1	Yes	Yes	Yes	3	1
	2	Yes	Yes	Yes	3	1
	3	Yes	Yes	Yes	3	1
	4	Yes	Yes	Yes	3	1
	5	Yes	Yes	Yes	3	1
	6	Yes	Yes	Yes	3	1
	7	Yes	Yes	Yes	3	1
	8	Yes	Yes	Yes	3	1
	9	Yes	Yes	Yes	3	1
	10	Yes	Yes	Yes	3	1
	11	Yes	Yes	Yes	3	1
	12	Yes	Yes	Yes	3	1
	13	Yes	Yes	Yes	3	1
	14	Yes	Yes	Yes	3	1
	15	Yes	Yes	Yes	3	1
	16	Yes	Yes	Yes	3	1
	17	Yes	Yes	Yes	3	1
	18	Yes	Yes	Yes	3	1
	19	Yes	Yes	Yes	3	1
	20	Yes	Yes	Yes	3	1
	21	Yes	Yes	Yes	3	1
Adolescents	1	Yes	Yes	Yes	3	1
	2	Yes	Yes	Yes	3	1
	3	Yes	Yes	Yes	3	1
	4	Yes	Yes	Yes	3	1
	5	Yes	Yes	Yes	3	1
	6	Yes	Yes	Yes	3	1
	7	Yes	Yes	Yes	3	1
	8	Yes	Yes	Yes	3	1
	9	Yes	Yes	No	2	0.67
	10	Yes	Yes	No	2	0.67
	11	Yes	Yes	Yes	3	1
	12	Yes	Yes	Yes	3	1
	13	Yes	Yes	Yes	3	1
	14	Yes	Yes	Yes	3	1
	15	Yes	Yes	Yes	3	1
	16	Yes	Yes	Yes	3	1
	17	Yes	Yes	Yes	3	1
	18	Yes	Yes	Yes	3	1
	19	Yes	Yes	Yes	3	1

TABLE 1 Content validity index (CVI) for the PCD-QOL questionnaire: Children, adolescents, adults, and parents

Questionnaire	Item	Expert 1	Expert 2	Expert 3	Experts in agreement	Item CVI
	20	Yes	Yes	Yes	3	1
	21	Yes	Yes	Yes	3	1
	22	Yes	Yes	Yes	3	1
	23	Yes	Yes	Yes	3	1
	24	Yes	Yes	Yes	3	1
	25	Yes	Yes	Yes	3	1
	26	Yes	Yes	Yes	3	1
	27	Yes	Yes	Yes	3	1
	28	Yes	Yes	Yes	3	1
	29	Yes	Yes	Yes	3	1
	30	Yes	Yes	Yes	3	1
	31	Yes	Yes	Yes	3	1
	32	Yes	Yes	Yes	3	1
	33	Yes	Yes	Yes	3	1
	34	Yes	Yes	Yes	3	1
	35	Yes	Yes	Yes	3	1
	36	Yes	Yes	Yes	3	1
	37	Yes	Yes	Yes	3	1
	38	Yes	Yes	Yes	3	1
Adults	1	Yes	Yes	Yes	3	1
	2	Yes	Yes	Yes	3	1
	3	Yes	Yes	Yes	3	1
	4	Yes	Yes	Yes	3	1
	5	Yes	Yes	Yes	3	1
	6	Yes	Yes	Yes	3	1
	7	Yes	Yes	Yes	3	1
	8	Yes	Yes	Yes	3	1
	9	Yes	Yes	Yes	3	1
	10	Yes	Yes	Yes	3	1
	11	Yes	Yes	Yes	3	1
	12	Yes	Yes	Yes	3	1
	13	Yes	Yes	Yes	3	1
	14	Yes	Yes	Yes	3	1
	15	Yes	Yes	Yes	3	1
	16	Yes	Yes	Yes	3	1
	17	Yes	Yes	No	2	0.67
	18	Yes	Yes	Yes	3	1
	19	Yes	Yes	Yes	3	1
	20	Yes	Yes	Yes	3	1
	21	Yes	Yes	Yes	3	1

(Continues)

TABLE 1 (Continued)

Questionnaire	Item	Expert 1	Expert 2	Expert 3	Experts in agreement	Item CVI
	22	Yes	Yes	Yes	3	1
	23	Yes	Yes	Yes	3	1
	24	Yes	Yes	Yes	3	1
	25	Yes	Yes	Yes	3	1
	26	Yes	Yes	Yes	3	1
	27	Yes	Yes	Yes	3	1
	28	Yes	Yes	Yes	3	1
	29	Yes	Yes	Yes	3	1
	30	Yes	Yes	Yes	3	1
	31	Yes	Yes	Yes	3	1
	32	Yes	Yes	Yes	3	1
	33	Yes	Yes	Yes	3	1
	34	Yes	Yes	Yes	3	1
	35	Yes	Yes	Yes	3	1
	36	Yes	Yes	Yes	3	1
	37	Yes	Yes	Yes	3	1
	38	Yes	Yes	Yes	3	1
	39	Yes	Yes	Yes	3	1
	40	Yes	Yes	Yes	3	1
Parents	1	Yes	Yes	Yes	3	1
	2	Yes	Yes	Yes	3	1
	3	Yes	Yes	Yes	3	1
	4	Yes	Yes	Yes	3	1
	5	Yes	Yes	Yes	3	1
	6	Yes	Yes	Yes	3	1
	7	Yes	Yes	No	2	0.67
	8	Yes	Yes	Yes	3	1
	9	Yes	Yes	Yes	3	1
	10	Yes	Yes	Yes	3	1
	11	Yes	Yes	Yes	3	1
	12	Yes	Yes	Yes	3	1
	13	No	Yes	No	1	0.33
	14	Yes	Yes	Yes	3	1
	15	Yes	Yes	Yes	3	1
	16	No	Yes	Yes	2	0.67
	17	No	Yes	Yes	2	0.67
	18	Yes	Yes	Yes	3	1
	19	Yes	Yes	Yes	3	1
	20	Yes	Yes	Yes	3	1
	21	Yes	Yes	Yes	3	1

Questionnaire	Item	Expert 1	Expert 2	Expert 3	Experts in agreement	Item CVI
	22	Yes	Yes	Yes	3	1
	23	Yes	Yes	Yes	3	1
	24	Yes	Yes	Yes	3	1
	25	Yes	Yes	Yes	3	1
	26	Yes	Yes	Yes	3	1
	27	Yes	Yes	Yes	3	1
	28	Yes	Yes	Yes	3	1
	29	Yes	Yes	Yes	3	1
	30	Yes	Yes	Yes	3	1
	31	Yes	Yes	Yes	3	1
	32	Yes	Yes	Yes	3	1
	33	Yes	Yes	Yes	3	1
	34	Yes	Yes	Yes	3	1
	35	Yes	Yes	Yes	3	1

Abbreviation: PCD-QOL, primary ciliary dyskinesia-quality of life.

interpret. These words were addressed by the expert committee and were revised to clarify their meaning. Of note is that following the 5th interview in each group, the authors noted no new comments or additional revisions required.

The final cross-culturally adapted, Hebrew version of the QOL-PCD questionnaire preserved the main features of the original English questionnaire. Minor changes to spelling and punctuation were performed with standardization of format and layout (uppercase and lowercase, and bold), as in the original questionnaire.

4 | DISCUSSION

The present study reports the successful translation and cultural adaptation of the original English version of a QOL-PCD into a Hebrew version for use among Israeli PCD patients and parents. A recent systematic review² on the psychosocial impact of PCD identified 14 studies conducted in the United States and in several European countries and showed that QOL decreases in patients with PCD over time. It also highlighted the disorder's having significant effects on the physical aspects of QOL (e.g., limitations in activities of daily living), as well as on its emotional (frustration, anxiety, and stress) and social aspects (stigmatization).² Little information has been available on these aspects of PCD, and QOL had been traditionally assessed with generic non-PCD specific HRQoL tools such as the St. George's Respiratory Questionnaire (SGRQ) and the SF-36 questionnaire.¹⁸ The first specific QOL-PCD questionnaires were subsequently developed and validated in English as part of the BESTCILIA FP7 project.^{2,5,19-21}

This important QOL assessment tool has now been translated into German/Swiss German, Danish, Dutch, Flemish, French, Spanish, Polish, Norwegian, Swedish, Portuguese (Brazilian), Czech, Greek, and Turkish. The present study was the first attempt to translate it into

Hebrew. The multistep method of translation and cultural adaptation used in this study was based on similar ones related to PCD in other languages. While a key element of the translation process is ensuring the translated questionnaires are conceptually, technically, and semantically equivalent to the original English version, it is important that translation should not be exclusively linguistic, but it must be culturally adapted to maintain the same measurement properties. This was ensured firstly in the translation process where the translations were completed by PCD clinicians. At each stage of the translation process, discussions were held to determine which equivalent phrases would be acceptable and easily understood by patients within each age group; this often related to equivalent commonly used terms for daily treatments (such as physiotherapy and medicine), expressions for emotions (such as grumpy and frustrated) or symptoms (runny nose, stuffy nose, post-nasal drip). The consensus was reached before moving to the next stage of the translation process. Cognitive interviews completed with 5 patients from each age group also ensured the questionnaire is culturally acceptable, comprehensive, and readable.

Some limitations, however, bear mention. The sample size we used for the pre-test step was relatively small, and that factor may have affected the results to some extent. We were precluded from applying more formal psychometric evaluations (e.g., Cronbach alpha or factor analysis) since they require a much larger sample size. The combined impact of COVID-19 on potential participants attending the clinic, PCD being a rare disease, and time constraints, limited the number of pre-test patients. In conclusion, translation and cultural adaptation of the English language QOL-PCD questionnaire into Hebrew was successfully carried out and revealed its utility as an important tool for assessing HRQoL in PCD patients in Israel. Our results demonstrated that the Hebrew version of the QOL-PCD tool is equivalent to the original tool in English. The translated version was easily understood by patients and parents of minor

patients and successfully adapted to the Israeli culture. It is hoped that this newly available tool will facilitate a better understanding of QOL among Israeli PCD patients and help clinicians and researchers in evaluating negative QOL changes and traits in a timely manner as well as develop strategies to manage such changes. It may also serve as a measure of outcome in studies of interventions for PCD in Israel. Finally, it will provide a standardized validated measure for Israeli clinicians and researchers to apply in conducting national and international clinical trials.

The final version of the Hebrew version can be retrieved at (Appendix 1, <https://drive.google.com/drive/folders/1zYoaij0nMXz4rp2XCSliCx4-Tb0gVxQr?usp=sharing>).



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CONFLICTS OF INTEREST

The authors declare no conflicts of interests.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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