

## DISABKIDS® in Brazil: advances and future perspectives for the production of scientific knowledge\*

Viviane Romeiro<sup>1</sup>

 <https://orcid.org/0000-0002-5244-627X>

Monika Bullinger<sup>2</sup>

 <https://orcid.org/0000-0001-8876-0159>

Maria Helena Palucci Marziale<sup>1</sup>

 <https://orcid.org/0000-0003-2790-3333>

Claudia Fegadolli<sup>3</sup>

 <https://orcid.org/0000-0002-2991-0206>

Roberta Alvarenga Reis<sup>4,5</sup>

 <https://orcid.org/0000-0003-3286-6071>

Renata Cristina de Campos Pereira Silveira<sup>1</sup>

 <https://orcid.org/0000-0002-2883-3640>

Moacyr Lobo da Costa-Júnior<sup>1</sup>

 <https://orcid.org/0000-0002-4216-0243>

Fátima Aparecida Emm Faleiros Sousa<sup>1</sup>

 <https://orcid.org/0000-0002-9796-5954>

Valéria Sousa de Andrade<sup>6</sup>

 <https://orcid.org/0000-0002-7961-6558>

Beatriz Juliana Conacci<sup>1,5</sup>

 <https://orcid.org/0000-0003-2034-230X>

Fernanda Karla Nascimento<sup>1,5</sup>

 <https://orcid.org/0000-0003-1620-1387>

Claudia Benedita dos Santos<sup>1,7</sup>

 <https://orcid.org/0000-0001-7241-7508>

\* Paper extracted from master's thesis "DISABKIDS® in Brazil: advances and future perspectives in the production of scientific knowledge", presented to Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto, PAHO/WHO Collaborating Centre for Nursing Research Development, Ribeirão Preto, SP, Brazil. Supported by Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), Grant # 130226/2017-3, Brazil.

<sup>1</sup> Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto, PAHO/WHO Collaborating Centre for Nursing Research Development, Ribeirão Preto, SP, Brazil.

<sup>2</sup> University Medical Center Hamburg-Eppendorf, Instituto de Medicina Psicológica, Hamburgo, HB, Germany.

<sup>3</sup> Universidade Federal de São Paulo, Instituto de Ciências Ambientais, Químicas e Farmacêuticas, São Paulo, SP, Brazil.

<sup>4</sup> Universidade Federal do Rio Grande do Sul, Faculdade de Odontologia, Porto Alegre, RS, Brazil.

<sup>5</sup> Scholarship holder at the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES), Brazil.

<sup>6</sup> Universidade Federal do Triângulo Mineiro, Departamento de Terapia Ocupacional, Uberaba, MG, Brazil.

<sup>7</sup> Scholarship holder at the Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), Grant # 311289/2017-7, Brazil.

Objective: to map the Brazilian scientific production related to the stages of the methodological process for the use of DISABKIDS® instruments and/or forms adapted to Brazil. Method: scoping review, with searches conducted on 10 electronic databases, plus Google Scholar and contacts with researchers, without restriction of period or language. Results: the mapping identified 90 scientific studies involving 46 instruments. Of these, 11 (23.9%) included the elaboration and/or cultural adaptation of the DISABKIDS® instruments to measure the Quality of Life of children or adolescents with chronic conditions and 35 (76.1%) used the Generic Measures and/or Specific Modules for the semantic validation of other instruments. Conclusion: this scoping review allowed a comprehensive evaluation of the use of the DISABKIDS® instrument and forms, in relation to the validation of the instrument adapted to Brazil, presenting a positive advance in the scenario with the development of academic/scientific projects in the country, incorporating the method recommended by the literature for the elaboration, cultural adaptation and validation of instruments and for the systematized and standardized recording of the perception and understanding of the target population about the measure of interest, using DISABKIDS® forms adapted for this purpose.

Descriptors: Cross-Cultural Comparison; Validation Studies as Topic; Surveys and Questionnaires; Psychometrics; Quality of Life; Review.

### How to cite this article

Romeiro V, Bullinger M, Marziale MHP, Fegadolli C, Reis RA, Silveira RCCP, Costa-Júnior ML, Sousa FAEF, Conacci BJ, Nascimento FK, Santos CB. DISABKIDS® in Brazil: advances and future perspectives for the production of scientific knowledge. Rev. Latino-Am. Enfermagem. 2020;28:e3257. [Access    ]; Available in:  . DOI: <http://dx.doi.org/10.1590/1518-8345.3003.3257>.

month day year

URL

## Introduction

The area of health constantly requires valid and reliable measures, with instruments that are calibrated to measure constructs applied according to standards. Instruments used for research and care assess mental, social and physical aspects and are aimed at achieving good health and making decisions about care and health policies(1-2).

It is important to develop instruments to measure morbidity or physical aspects; however, this process is less complex than the elaboration of instruments that evaluate constructs or characteristics related to human behavior. This fact has motivated the adaptation of previously constructed instruments that are appropriate to the socio-demographic or clinical specificities of the study population<sup>(3-5)</sup>.

In order to obtain reliable conclusions, studies that aim to measure subjective conditions with constructed or adapted instruments should have high methodological quality, both in the definition and in the measurement of the construct of interest<sup>(6)</sup>. They should provide clinically useful, meaningful and interpretable results, and psychometric properties such as validity, reliability and responsiveness should be assessed<sup>(1,7-8)</sup>.

In Brazil, the number of adaptations of instruments elaborated and validated in other cultures and the number of constructions of new questionnaires have been increasing. As a result, researchers have been doing this with the collaboration of international educational institutions and funding from government agencies<sup>(9-16)</sup>.

The project DISABKIDS<sup>®</sup>, from the European group DISABKIDS<sup>®</sup>, is a collaboration of seven European countries with the main objective of voicing the concerns of children and adolescents with chronic health conditions, as well as of their parents and caregivers. The project has constructed and refined tests of a system of instruments called DISABKIDS<sup>®</sup> questionnaires<sup>(17)</sup>, translated into Brazilian Portuguese as *Instrumentos DISABKIDS<sup>®</sup>*. Among these, there are instruments that help the semantic validation process, referred in Brazilian Portuguese as *Formulário DISABKIDS<sup>®</sup> de Impressão Geral* (DISABKIDS<sup>®</sup> Chronic Generic Measure).and *Folha DISABKIDS<sup>®</sup> Específica* (DISABKIDS<sup>®</sup> Specific Modules).

DISABKIDS<sup>®</sup> instruments are valid, reliable and sensitive, as well as fast to fill and easy to score and interpret<sup>(18)</sup>.

The objective of this study was to map the Brazilian scientific production related to the stages of

the methodological process for the use of DISABKIDS<sup>®</sup> instruments and/or forms adapted to Brazil.

## Method

The scoping review<sup>(19)</sup> method, used in this study, has become popular in health research in recent years, as it does not restrict the parameters of the review to randomized controlled trials nor it requires quality evaluation of the studies included in the review<sup>(20-21)</sup>. The process is interactive and requires researchers to be involved in each step and, when necessary, to redo steps to ensure that the literature is comprehensively surveyed<sup>(19,21)</sup>.

According to the systematization proposed for scoping review studies, there are five mandatory stages and one optional stage: (1) identification of the research question; (2) identification of relevant studies; (3) selection of studies; (4) data mapping; (5) grouping, analysis and summary of data; and (6) contact with researchers (optional)<sup>(19-20)</sup>.

These stages guided this study, which also included considerations from other authors<sup>(21-22)</sup>. The research question must be designed to ensure comprehensiveness and depth<sup>(19)</sup>, and, in addition, it should be well structured, and contain information such as definition of concepts, target population, among others<sup>(21)</sup>. In addition, the question must be associated with the objective of the study<sup>(22)</sup>.

In the first stage, the research question was elaborated using the PICO strategy [acronym for patient (ou population), intervention, comparison, outcomes]. The use of this strategy directs the study and allows identifying keywords related to the theme. This helps the process of constructing the search strategy to find relevant studies in electronic databases, so that the best available scientific evidence can be located<sup>(23)</sup>. According to this strategy, P: DISABKIDS<sup>®</sup> Instruments/Forms adapted for Brazil, I: the stages of the methodological process for the release of instruments, C: not applicable, as there are no comparisons in this study, and O: advances and perspectives of scientific knowledge in Brazil. Thus, the guiding question of this research was: "What are the advances and perspectives of scientific knowledge regarding the phases of the methodological process for releasing instruments according to the use of DISABKIDS<sup>®</sup> instruments/forms adapted to Brazil?"

To ensure the identification of relevant studies in the second stage, the search strategy occurred according to two processes. Initially, the researchers were consulted by two different means of communication.

The first one was Facebook, a free online public social network that is an important space for interaction and enables the sharing of questionnaires and transmission of information<sup>(24)</sup>. The Facebook profile called "DISABKIDS no Brasil" was used to invite all researchers to answer the research form, which had the objectives of collecting information regarding the use of DISABKIDS® instruments/forms in research and to provide access to these research for the collection of information.

The second mean was an e-mail sent to all professors, undergraduate and graduate students, and active nurses linked to a public Brazilian higher education institution. They were asked to respond to the research form.

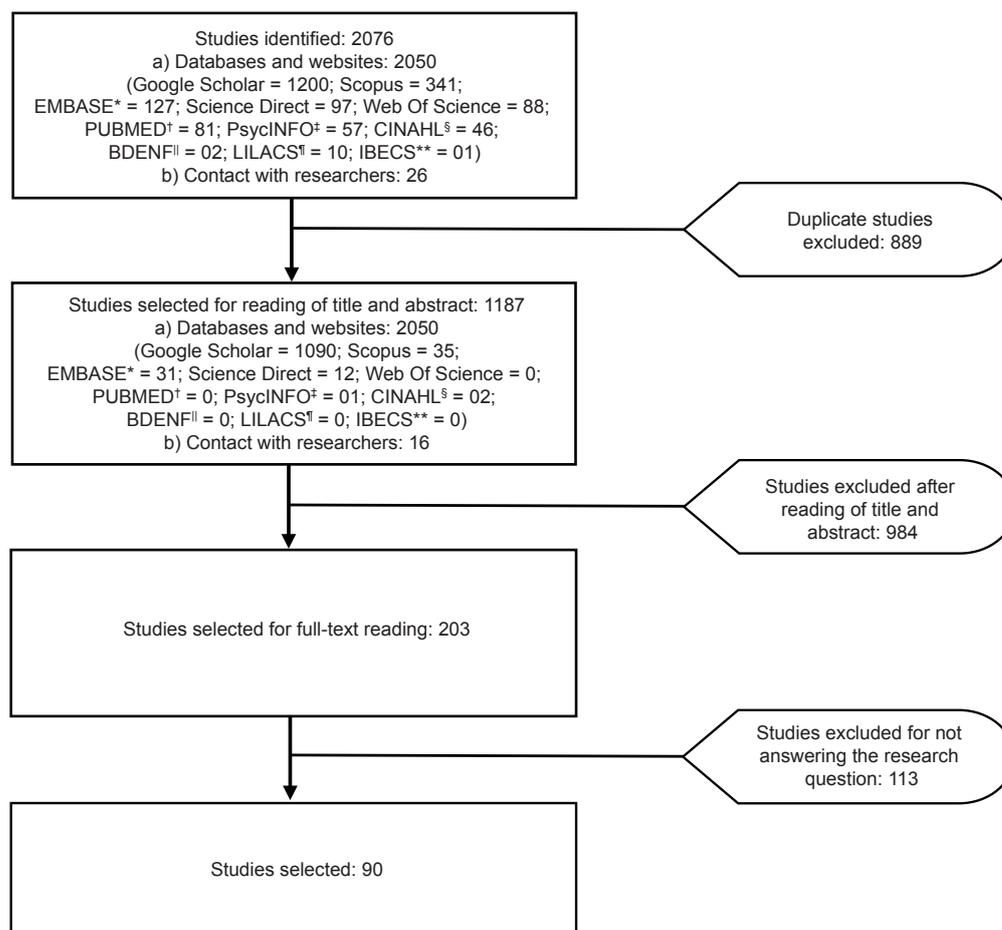
Then, in December 2017, ten electronic databases were consulted: US National Library of Medicine National Institutes of Health (PUBMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), American Psychological Association (PsycINFO), Excerpta Medica dataBASE (EMBASE), Scopus, Web Of Science, Science Direct, Latin American and Caribbean Health Sciences Literature (LILACS), Brazilian Nursing Database (BDENF),

Índice Bibliográfico Español en Ciencias de la Salud (IBECS) and the search engine Google Scholar (<https://scholar.google.com.br/>). Additionally, the bibliographic references of the studies included were contacted with specialists to check if there were any studies that were not included in the electronic search.

The search in the electronic databases did not limit period of publication nor language, and the only term used was "DISABKIDS". Repeated studies were considered only once.

In the third stage, studies conducted in Brazil using DISABKIDS® instruments/forms adapted to Brazil in the development of research, in part or in full, were included, regardless of the language of publication. Systematic or integrative reviews, opinion articles, comments, editorials or response letters were excluded.

The studies were divided into two equal parts, and reviewed by two pairs independently. Each pair had a PhD researcher and all had expertise in methodological studies. The disagreements were settled by a third researcher, who was an associate professor, with vast and recognized experience in this process (Figure 1).



\*EMBASE = Excerpta Medica dataBASE; †PUBMED = US National Library of Medicine National Institutes of Health; ‡PsycINFO = American Psychological Association; §CINAHL = Cumulative Index to Nursing and Allied Health Literature; ¶BDENF = Brazilian Nursing Database; ¶LILACS = Latin American and Caribbean Health Sciences Literature; \*\*IBECS = Índice Bibliográfico Español en Ciencias de la Salud

Figure 1 – Flowchart of the study selection process - Ribeirão Preto, SP, Brazil, 2017

The fourth stage is mapping of relevant information for synthesis and interpretation of data. To answer the research question, data were extracted and mapped according to the variables: (1) ID (identification of the study); (2) title; (3) authors; (4) year of publication; (5) objectives; (6) population/participants (number of participants as reported in the document published by the author of each study included in the review), (7) chronic condition/functionality; (8) study type/design (as published by the study author); (9) study category (thesis, dissertation, article, annals, scientific initiation or final paper); and (10) means of publication.

To group and summarize the data collected according to the fifth stage, the following processes were identified: (1) elaboration of new instruments; (2) cultural adaptation of instruments; (3) validation of instrument (complete or pilot study); (4) application of the instruments; (5) use of the DISABKIDS® structured questionnaire for focus groups; (6) use of the DISABKIDS® structured questionnaire for focus group adapted for expert interviews; (7) use of the DISABKIDS® Chronic Generic Measure; and (8) application of the DISABKIDS® Specific Modules.

The studies were divided into two groups to identify the stages of the methodological process for the release of instruments: Group A, which included studies with elaboration and/or cultural adaptation processes of the DISABKIDS® Instruments to measure Quality of Life of children or adolescents with chronic conditions; and Group B, in which the Generic Measure Forms and/or Specific Modules were used for the semantic validation of other instruments.

When verifying the release of instruments and the use of DISABKIDS® forms, the stages were described according to groups of studies defined by "mother" projects, with the objective of avoiding duplicate information collection (Figure 2, Figure 3).

To address the last stage of this review, aspects related to the means of dissemination of results, opportunities for knowledge sharing, and exchanges with those interested in the field studied should be included<sup>(20)</sup>.

In accordance with the resolution of the National Health Council, the project was approved by the Research Ethics Committee of the Ribeirão Preto College of Nursing, University of São Paulo (CAAE: 59431916.6.0000.5393). Before the beginning of data collection consisting of contact of researchers through an online questionnaire, the researchers received information about the project and had access to the Informed Consent Form (TCLE). They were informed that answering the questionnaire would imply signing the consent form.

## Results

Ninety scientific studies involving 46 different instruments that used DISABKIDS® forms/instruments adapted to Brazil were mapped.

Among the 90 studies selected, 39 (43.3%) are directly related to DISABKIDS® instruments that measure the quality of life of children and adolescents with chronic conditions - Group A (Figure 2); and the other 51 (56.7%) are studies that used DISABKIDS® in the semantic validation stage of their research - Group B (Figure 3).

Most studies, 82 (91.1%), were conducted in the State of São Paulo, followed by three (3.3%) in Minas Gerais, two (2.2%) in the Federal District, one (1.1%) in Bahia, one in Rio Grande do Norte and one in Sergipe.

Among these studies, 29 (32.2%) are articles, 24 (26.7%) are thesis, 16 (17.8%) are dissertations, 11 (12.2%) are papers presented at scientific events, nine (10%) are undergraduate studies presented as final papers and one (1.1%) is a thesis of an Associate Professor.

A significant part (44.4%) of these studies were published in the format of scientific articles or in the annals of national or international conferences. Among the 29 articles published in scientific journals, 11 (37.9%) had international co-authorship, with at least one international author.

The impact factor of the journals ranged from 0.446 to 2.768. As for the Qualis CAPES (Higher Education Personnel Improvement Coordination) classification for Nursing, the publications are in journals with classifications A1 (5; 17.24%), A2 (13; 44.83%) and B1 (11; 37.93%).

In the stages of elaboration and cultural adaptation, there is a larger number of studies that opted for the process of cultural adaptation. Ten (17.9%) are "mother" projects, among the 56, related to the elaboration of instruments and 45 (80.4%) are related to the cultural adaptation stage (Table 1).

The validation process occurred in 31 (55.4%) studies, of which 14 (45.2%) performed the validation of the initial psychometric properties of the instrument studied and 17 (54.8%) were related to the conclusion of the validation process for Brazil - three of which concerned elaboration and the others concerned adaptation.

Among the studies found, 21 (37.5%) did not include any stage of the validation process, which may be directly associated with the increased understanding of the complexity of the process of validation of instruments for construct measurement. This fact occurs because these studies are inserted in the measurement

"Mother" Project	Instrument	Category
1	DISABKIDS® Chronic Generic Measure	<i>Livre Docência</i> <sup>(25)</sup> ; thesis <sup>(26)</sup> ; article <sup>(14)</sup>
2		Thesis <sup>(27)</sup> ; congress <sup>(28-29)</sup>
3		Dissertation <sup>(30)</sup> ; congress <sup>(31)</sup>
4	DISABKIDS® Module - Living with Hearing Impairment	Thesis <sup>(32)</sup>
5	DISABKIDS® - Cerebral Palsy	SI*Final paper <sup>(33)</sup>
6	DISABKIDS® - Cystic Fibrosis Module	Dissertation <sup>(34)</sup> ; congress <sup>(35-36)</sup> ; article <sup>(11)</sup>
7		Thesis <sup>(37)</sup> ; congress <sup>(38)</sup> ; article <sup>(12)</sup>
8	DISABKIDS® - Atopic Dermatitis Module	Dissertation <sup>(39)</sup> ; article <sup>(13,40)</sup>
9		Thesis <sup>(41)</sup>
10	DISABKIDS® - Asthma Module	SI*Final paper <sup>(42)</sup>
11		SI*Final paper <sup>(43)</sup>
12		SI*Final paper <sup>(44)</sup>
13	DISABKIDS® - Arthritis Module	SI*Final paper <sup>(45)</sup>
14		SI*Final paper <sup>(46)</sup>
15	DISABKIDS® - Epilepsy Module	SI*Final paper <sup>(47)</sup>
16		SI*Final paper <sup>(48)</sup>
17	DISABKIDS® - Living with HIV <sup>1</sup> Module	Congress <sup>(49-50)</sup> ; thesis <sup>(51)</sup>
18		Dissertation <sup>(52)</sup> ; congress <sup>(53)</sup>
19	DISABKIDS® - Chronic Kidney Disease Module	Congress <sup>(54-55)</sup> ; thesis <sup>(56)</sup> ; article <sup>(9-10)</sup>
20	DISABKIDS® - Obesity Module	SI*Final paper <sup>(57)</sup>

\*SI = Scientific Initiation; <sup>1</sup>HIV = Human Immunodeficiency Virus

Figure 2 – Distribution of studies belonging to Group A, according to the "mother" project, instrument and category. Ribeirão Preto, SP, Brazil

"Mother" project	Instrument	Category
01	Duke Anticoagulation Satisfaction Scale	Dissertation <sup>(58)</sup>
02	Adolescent Pediatric Pain Tool	Dissertation <sup>(59)</sup>
03	Cardiac Patients Learning Needs Inventory	Article <sup>(60)</sup>
04	Body Image Quality Of Life Inventory	Dissertation <sup>(61)</sup> ; article <sup>(62)</sup>
05	Palliative Outcome Scale	Dissertation <sup>(63)</sup>
06	<i>Identificação da Prática de Enfermeiros nas Radiodermatites</i>	Dissertation <sup>(64)</sup> ; article <sup>(65-66)</sup>
07	Appraisal of Self Care Agency Scale-Revised	Thesis <sup>(67)</sup> ; article <sup>(68)</sup>
08	Patient Assessment of Chronic Illness Care	Thesis <sup>(69)</sup>
09	<i>Tecnologia educacional para a avaliação clínica de recém-nascidos prematuros</i>	Article <sup>(70)</sup>
10	Questionnaires for knowledge and Compliance with Standard Precaution	Article <sup>(71)</sup> ; Thesis <sup>(72)</sup>
11	<i>Coordenação das redes de atenção à saúde pela Atenção Primária à Saúde</i>	Thesis <sup>(73)</sup> ; article <sup>(74-75)</sup>
12	<i>Intervenção Educativa sobre a Medida Indireta da Pressão Arterial por profissionais de enfermagem</i>	Thesis <sup>(76)</sup>
13	Costs of caring for children with câncer	Article <sup>(77)</sup>
14		Dissertation <sup>(78)</sup>
15	Pain Assessment in Advanced Dementia	Dissertation <sup>(79)</sup> ; article <sup>(80)</sup>
16	Comply with post-exposure management among health care workers	Thesis <sup>(81)</sup> ; article <sup>(82-83)</sup>
17	United States Pharmacopeia Dispensing Information	Article <sup>(84)</sup>
18	<i>Mandala de avaliação</i>	Dissertation <sup>(85)</sup>
19	Food Choice Questionnaire	Article <sup>(86)</sup>
20	<i>Avaliação da Transferência do Tratamento diretamente observado</i>	Article <sup>(87)</sup> ; Thesis <sup>(88)</sup>
21		Thesis <sup>(89)</sup>
22	Perceived Stigmatization Questionnaire e Social Comfort Questionnaire	Article <sup>(90)</sup> ; Thesis <sup>(91)</sup>
23	Tuberculosis Related Stigma	Thesis <sup>(92)</sup> ; article <sup>(93-94)</sup>
24	Patient Activation Measure	Thesis <sup>(95)</sup>
25	Quality Of recovery – 40 item	Thesis <sup>(96)</sup> ; article <sup>(97)</sup>
26	<i>Cartões da Qualidade da Dor</i>	Dissertation <sup>(98)</sup>
27	<i>Avaliação do impacto da capacitação dos Agentes Comunitários de Saúde em doenças sexualmente transmissíveis</i>	Thesis <sup>(99)</sup>
28	Genetic Counseling Outcome Scale	Dissertation <sup>(100)</sup>
29	Needs of Parents Questionnaire	Dissertation <sup>(101)</sup>
30	<i>Avaliação da necessidade de saúde de pessoas com deficiência física, auditiva e visual</i>	Thesis <sup>(102)</sup>
31	<i>Programa educativo sobre registro da pressão arterial em serviço hospitalar de emergência</i>	Thesis <sup>(103)</sup>
32	<i>Inventário de integração a vida universitária</i>	Thesis <sup>(104)</sup>
33	Diabetes Management Self-efficacy Scale	Article <sup>(15)</sup>
34	Test Oral Anticoagulation Knowledge	Article <sup>(16)</sup>
35	Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being	Thesis <sup>(105)</sup>
36	<i>Questionário de conhecimentos sobre Práticas Forenses</i>	Dissertation <sup>(106)</sup>

Figure 3 – Distribution of studies belonging to Group B, according to the "mother" project, instrument and category. Ribeirão Preto, SP, Brazil, 2017

theory. Therefore, all psychometric assumptions to support their validity and reliability should be verified before its use<sup>(6-8,107)</sup>.

Considering the application of instruments elaborated, adapted and validated for Brazil, it was observed that they were applied in only one study in Group A and five studies in Group B.

Among the studies that used DISABKIDS® forms adapted for Brazil, 39 (69.6%) corresponded to the Generic Measure and 44 (78.6%) to the Specific Modules. Group A included 11 (55%) and 12 (60%) projects, respectively. Group B, in turn, included 28 (77.8%) and 32 (88.9%) projects (Table 2).

Table 1 - Distribution of "mother" projects belonging to Groups A (n = 20) and B (n = 36) according to the stages of the methodological process for the release of instruments (n = 56) - Ribeirão Preto, SP, Brazil, 2017

Group	Elaboration	Cultural Adaptation	Validation	Application	
	n (%)	n (%)	n (%)	n (%)	
A	Yes	4 (7.1)	12 (21.4)	11 (19.6)	1 (1.8)
	No	16 (28.6)	8 (14.3)	9 (16.1)	19 (33.9)
B	Yes	6 (10.7)	33 (58.9)	20 (35.7)	5 (8.9)
	No	30 (53.6)	3 (5.4)	16 (28.6)	31 (55.4)

Table 2 - Distribution of "mother" projects belonging to Groups A (n = 20) and B (n = 36) according to the use of DISABKIDS Forms adapted for Brazil (n = 56). Ribeirão Preto, SP, Brazil, 2017

	DISABKIDS® Structured Questionnaire for Focus Groups	DISABKIDS® Structured Questionnaire for Focus Group adapted for expert interviews	DISABKIDS® Chronic Generic Measure	DISABKIDS® Specific Modules	
	n (%)	n (%)	n (%)	n (%)	
A	Yes	4 (7.1)	2 (3.6)	11 (19.6)	12 (21.4)
	No	16 (28.6)	18 (32.1)	9 (16.1)	8 (14.3)
B	Yes	0 (0.0)	0 (0.0)	28 (50.0)	32 (57.1)
	No	36 (64.3)	36 (64.3)	8 (14.3)	4 (7.1)

## Discussion

The results showed that ever since the introduction of the stages of elaboration, translation, cultural adaptation and validation of DISABKIDS® instruments and forms in Brazil, 90 studies that presented at least one of the systematized methods were developed.

The studies were developed by researchers affiliated to recognized higher education institutions in Brazil and had products derived from scientific work, showing that the process addressed allows access to knowledge and training of researchers at different levels<sup>(108)</sup> (Figure 1, Figure 2). The studies involved 46 different instruments that can be made available as valid and reliable measurement tools for use in various sectors in Brazil, such as health and education<sup>(12,67,71)</sup>.

Regarding the stages of elaboration and cultural adaptation, there is a larger number of studies that performed cultural adaptation, corroborating the recommendations of the scientific literature on these aspect<sup>(15-16,38,95,97)</sup>. In fact, the complexity and slowness of the process of elaborating an instrument for measuring subjective constructs have motivated the search and adaptation of previously constructed instruments<sup>(5,109)</sup>.

The process of inclusion of DISABKIDS® adapted forms in the semantic validation stage shows that researchers are concerned not only with the translation of the items of an instrument, but also want these items to be relevant and comprehensible for the target population in the process of cultural adaptation<sup>(5,109)</sup>.

This result reinforces the understanding of the Brazilian scientific community, which advocates the use of a standardized method for the cultural adaptation of the items, giving voice to the participant, which contributes to the validity and reliability of the instrument, regardless of the culture<sup>(5,9-10,12-14,40,110-111)</sup>.

Giving voice to the participants has been a decision-making strategy in studies on Patient Reported Outcomes (PRO)<sup>(112-113)</sup>. In these studies, in addition to discussing the importance of the participation of patients for the quality of care, there is also concern with their literacy and with management strategies<sup>(14,109)</sup>.

The projects developed in Group B began two years after the implementation of the process for Brazil, with populations and contexts different from Group A, which included cardiac patients, coordination of health care networks, tuberculosis stigma, blood pressure, educational technology, among others. This indicates that the method was quickly incorporated

and understood, and easily applied by the scientific community (Figure 3).

Attention to these details allows comparing, in different national and international scenarios, the impact of a condition and/or its management on people's lives, in a standardized way, in multicenter tests or outcome evaluations<sup>(5,114)</sup>.

The application of these measures can help improving the quality of care provided to the general population. These measures related to planning can be driven by: (i) attributes measured individually, through instruments that assess certain processes, such as mental, physical and social aspects, and coping with various situations; or (ii) interventions tested through clinical trials or quasi-experimental studies, using scores derived from these instruments to compare results in different groups<sup>(9,83,115)</sup>.

Additionally, the use of these measures is relevant, as health is still strongly based on the biomedical model and focused mostly on the disease, and not on a biopsychosocial approach, which would incorporate health components at body and social levels, taking into account their functionality<sup>(3)</sup>.

As found in this scoping review, the fact that most studies were developed in the state of São Paulo may be associated with the lack of dissemination of the method to other educational institutions in the country. Another gap found refers to the scarcity of use of the instruments in clinical practice.

## Conclusion

This scoping review answers the guiding question of the research, as it presents a positive advance of the scenario of development of academic/scientific projects that include the method recommended by the literature for the elaboration, cultural adaptation and validation of instruments and for the systematic and standardized recording of the perception and understanding of the target population about the measure of interest, using DISABKIDS® forms adapted for this purpose.

The results also show perspectives regarding the dissemination of the method throughout the country, which will allow the release of valid and reliable instruments that can be used in clinical practice, aiming at reaching a biopsychosocial approach, associated with improving the quality of health care provided to the population.

The results presented show a broad use of DISABKIDS® instruments/forms adapted to Brazil, facilitating the complex and thorough process of adaptation or elaboration of instruments within the practice of researchers.

## References

1. Cano SJ, Hobart JC. The problem with health measurement. *Patient Prefer Adherence*. 2011; 5: 279-90. doi: <https://doi.org/10.2147/PPA.S14399>
2. Coluci MZO, Alexandre NMC, Milani D. Construction of measurement instruments in the area of health. *Cienc Saúde Coletiva*. 2015;20(3):925-36. doi: <http://dx.doi.org/10.1590/1413-81232015203.04332013>
3. Fleck MPA. The World Health Organization instrument to evaluate quality of life (WHOQOL-100): characteristics and perspectives. *Cienc Saúde Coletiva*. 2000;5(1):33-8. doi: <http://dx.doi.org/10.1590/S1413-8123200000100004>
4. Curado MAS, Teles J, Marôco J. Analysis of variables that are not directly observable: Influence on decision-making during the research process. *Rev Esc Enferm USP*. 2014;48(1):146-52. doi: <http://dx.doi.org/10.1590/S0080-623420140000100019>
5. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. *J Clin Epidemiol*. 1993 Dec;6(12):1417-32. doi: [https://doi.org/10.1016/0895-4356\(93\)90142-N](https://doi.org/10.1016/0895-4356(93)90142-N)
6. Mokkink LB, Terwee CB, Knol DL, Stratford PW, Alonso J, Patrick DL, et al. The COSMIN checklist for evaluating the methodological quality of studies on measurement properties: A clarification of its content. *BMC Med Res Methodol*. 2010 Dec 18;10(1):22. doi: <https://doi.org/10.1186/1471-2288-10-22>
7. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. The COSMIN checklist for assessing the methodological quality of studies on measurement properties of health status measurement instruments: an international Delphi study. *Qual Life Res*. 2010 May;19(4):539-49. doi: <https://doi.org/10.1007/s11136-010-9606-8>
8. Pasquali L. Psychometrics. *Rev Esc Enferm USP*. 2009 Dec 1;43(spe):992-9. doi: <http://dx.doi.org/10.1590/S0080-62342009000500002>
9. Abreu IS, Nascimento LC, Lima RAG, Santos CB, Abreu IS, Nascimento LC, et al. Children and adolescents with chronic kidney disease in haemodialysis: perception of professionals. *Rev Bras Enferm*. 2015 Dec;68(6):1020-6. doi: <http://dx.doi.org/10.1590/0034-7167.2015680604i>
10. Abreu IS, Kourrouski MFC, Santos DMSS, Bullinger M, Nascimento LC, Lima RAG, et al. Children and adolescents on hemodialysis: Attributes associated with quality of life. *Rev Esc Enferm USP*. 2014;48(4):602-9. doi: <http://dx.doi.org/10.1590/S0080-623420140000400005>
11. Santos DMSS, Deon KC, Fegadolli C, Reis RA, Torres LAGMM, Bullinger M, et al. Adaptação

- cultural e propriedades psicométricas iniciais do instrumento DISABKIDS® – Cystic Fibrosis Module – versão brasileira. *Rev Esc Enferm USP*. 2013 Dec 1;47(6):1311–7. doi: <http://dx.doi.org/10.1590/S0080-623420130000600009>
12. Santos DMSS, Deon KC, Bullinger M, Santos CB. Validity of the DISABKIDS® - Cystic Fibrosis Module for Brazilian children and adolescents. *Rev. Latino-Am. Enfermagem*. 2014 Oct; 22(5):819-25. doi: <http://dx.doi.org/10.1590/0104-1169.3450.2485>
13. Deon KC, Santos DMSS, Bullinger M, Santos CB. Preliminary psychometric assessment of the Brazilian version of the DISABKIDS® Atopic Dermatitis Module. *Rev Saúde Pública*. 2011 Dec;45(6):1072–8. doi: <http://dx.doi.org/10.1590/S0034-89102011005000067>
14. Fegadolli C, Reis RA, Martins STA, Bullinger M, Santos CB. Adaptation of the generic DISABKIDS® module for Brazilian children and adolescents with chronic disorders. *Rev Bras Saúde Matern Infant*. 2010;10(1):95–105. doi: <http://dx.doi.org/10.1590/S1519-38292010000100010>
15. Pace AE, Gomes LC, Bertolin DC, Loureiro HMAM, Bijl JVD, Shortridge-Baggett LM. Adaptation and validation of the Diabetes Management Self-Efficacy Scale to Brazilian Portuguese. *Rev. Latino-Am. Enfermagem*. [Internet]. 2017; 25 [cited Oct 3, 2019], e2861. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-11692017000100335&lng=en&nrm=iso](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692017000100335&lng=en&nrm=iso). Epub May 22, 2017. ISSN 0104-1169. <http://dx.doi.org/10.1590/1518-8345.1543.2861>.
16. Praxedes MFS, Abreu MHNG, Ribeiro DD, Marcolino MS, Paiva SM, Martins MAP. Cross-cultural Adaptation of the Oral Anticoagulation Knowledge Test to the Brazilian Portuguese. *Cienc Saúde Coletiva*. [Internet]. 2017; [cited Oct 3, 2019];22(5):1615–29. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1413-81232017002501615&lng=pt&nrm=iso&lng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232017002501615&lng=pt&nrm=iso&lng=en)
17. Baars RM, Atherton CI, Koopman HM, Bullinger M, Power M, DISABKIDS group the D. The European DISABKIDS project: development of seven condition-specific modules to measure health related quality of life in children and adolescents. *Health Qual Life Outcomes*. 2005 Nov 13;3:70. doi: <https://doi.org/10.1186/1477-7525-3-70>
18. Group TD. Summary of the DISABKIDS Instruments. [Internet]. 2018 [cited Jul 11, 2018]. Available from: <https://www.disabkids.org/disabkids-project/instruments/>
19. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol*. 2005 Feb;8(1):19–32. doi: <https://doi.org/10.1080/1364557032000119616>
20. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci*. 2010 Sep 20;5:69. doi: <https://doi.org/10.1186/1748-5908-5-69>
21. O'Brien KK, Colquhoun H, Levac D, Baxter L, Tricco AC, Straus S, et al. Advancing scoping study methodology: a web-based survey and consultation of perceptions on terminology, definition and methodological steps. *BMC Health Serv Res*. 2016 Dec 26;16(1):305. doi: <https://doi.org/10.1186/s12913-016-1579-z>
22. Daudt HML, Van Mossel C, Scott SJ. Enhancing the scoping study methodology: A large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Med Res Methodol*. 2013;13(1):1–9. doi: <https://doi.org/10.1186/1471-2288-13-48>
23. Santos CMC, Pimenta CAM, Nobre MRC. The PICO strategy for the research question construction and evidence search. *Rev. Latino-Am. Enfermagem*. [Internet]. 2007 June [cited Oct 3, 2019] ; 15(3): 508-11. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-11692007000300023&lng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692007000300023&lng=en). <http://dx.doi.org/10.1590/S0104-11692007000300023>.
24. Queiroz AAFLN, Sousa AFL. PrEP Forum: an on-line debate on pre-exposure prophylaxis in Brazil. *Cad Saúde Pública*. [Internet]. 2017 Nov [cited Oct 3, 2019] 33(11):e00112516. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0102-311X2017001105007&lng=pt](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-311X2017001105007&lng=pt)
25. Santos CB. Processo de adaptação transcultural e validação de instrumentos de qualidade de vida para crianças e adolescentes com condições crônicas desenvolvidos pelo grupo DISABKIDS [Livro Docência]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2007.
26. Fegadolli C. Transcultural adaptation and validation of instrument DISABKIDS-37 for Brazilian children and adolescents with chronic conditions: phase I [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2008. doi:10.11606/T.22.2008.tde-17032009-161916
27. Nunes SPH. Validation of the DISABKIDS®-37 instrument for Brazilian children and adolescents with chronic conditions [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014. doi:10.11606/T.22.2014.tde-30032015-185317
28. Nunes SPH, Silva JK., Anjos FM, Fegadolli C, Bullinger M, dos Santos CB. The DISABKIDS®-37 questionnaire for Brazilian children and adolescents with chronic conditions showed cross-cultural Brazilian regions validity. In: 22TH International Society for Quality of Life Research (ISOQOL). Vancouver, Canada; 2015. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-015-1078-4>

29. Fegadolli C, Nunes SPH, Reis RA, Silva JK, Anjos FM, Bullinger M, et al. Validation of the DISABKIDS®-37 questionnaire for Brazilian children and adolescents with chronic conditions. In: 23<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Copenhagen, Denmark; 2016. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-016-1390-7>
30. Monteiro SNC. Quality of Life: perceptions of ostomy children and adolescents and their parents and/or guardians [dissertação]. Brasília: Universidade de Brasília; 2013. Available from: <http://repositorio.unb.br/handle/10482/15346>
31. Monteiro, SNC, Melo MC, Santos JS, Kamada I. Percepção de criança e adolescente estomizados acerca da autonomia do cuidado. In: XI Congresso Brasileiro de Estomaterapia. 2015. [cited Oct 3, 2019]. Available from: <http://sobest.org.br/arquivos/CBEAULAS/dia2/13H30%20-%20SANDRA%20NAZARE%20-%207.pdf>
32. Reis RA. Specific Module of the Health-Related Quality of Life Assessment for Children and Adolescents Living with Hearing Impairment - ViDA [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2009. doi:10.11606/T.22.2009.tde-19022009-140912
33. Toller G. Tradução e adaptação cultural do módulo específico paralisia cerebral do DISABKIDS Cerebral Palsy Module® (DISABKIDS - CPM®) para crianças e adolescentes brasileiros [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2009.
34. Santos DMSS. Cultural adaptation and validation of DISABKIDS - Cystic Fibrosis Module® to Health related Quality of Life's measurement of Brazilian children and adolescents: Fase I. [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2010. doi:10.11606/D.22.2010.tde-09032010-164502
35. Santos DMSS, Deon KC, Fegadolli C, Reis RA, Bullinger M, Santos CB. Initial Psychometric Properties of the DISABKIDS® - Cystic Fibrosis Module to Measure the Health-Related Quality of Life for Brazilian Children and Adolescent. In: 18<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Denver, United States; 2011. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-011-0097-z>
36. Santos DMSS, Deon KC, Fegadolli C, Reis RA, Bullinger M, Santos CB. Translation and Semantic Validation for the Brazilian Culture of the Health-Related Questionnaire DISABKIDS® - Cystic Fibrosis Module for children and Adolescent. In: 18<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Denver, United States; 2011. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-011-0097-z>
37. Santos DMSS. Validation DISABKIDS® - Cystic Fibrosis Module instrument for Brazilian children and adolescents [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2013. doi:10.11606/T.22.2013.tde-11072014-092749
38. Santos DMSS, Deon KC, Kourrouski MFC, Bullinger M, Santos CB. Validation for Brazil of DISABKIDS® - cystic fibrosis module, proxy version, for parents or caregivers of children and adolescents with cystic fibrosis. In: 21<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Germany, Berlin; 2014. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-014-0769-6>
39. Deon KC. Cultural adaptation and validation of the Atopic Dermatitis Module from the instrument of measurement of children and adolescents Health Related Quality of Life DISABKIDS®-MDA - preliminary results [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2009. doi:10.11606/D.22.2009.tde-29102009-143802
40. Deon KC, Santos DMSS, Reis RA, Fegadolli C, Bullinger M, Santos CB. Translation and cultural adaptation of the Brazilian version of DISABKIDS® Atopic Dermatitis Module (ADM). Rev Esc Enferm USP. 2011;45(2):450-7. doi: <http://dx.doi.org/10.1590/S0080-62342011000200021>
41. Deon KC. Validation for Brazilian children and adolescents of the instrument for measuring Health-related Quality of Life-DISABKIDS® - Atopic Dermatitis. [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2013. doi:10.11606/T.22.2013.tde-07012014-152509
42. Galiano C. Adaptação cultural, para o Brasil, do módulo específico Asma, do instrumento de avaliação da Qualidade de Vida Relacionada à Saúde de crianças e adolescentes - DISABKIDS®. [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2011.
43. Barros LA. Validação do instrumento DISABKIDS® - Módulo Asma para crianças e adolescentes brasileiros, versão "self". [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2015.
44. Santos LTF. Validação do instrumento DISABKIDS® - Módulo Asma para crianças e adolescentes brasileiros, versão "proxy". [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2015.
45. Andrade AB. Adaptação cultural, para o Brasil, do módulo específico Artrite, do instrumento de avaliação da Qualidade de Vida Relacionada à Saúde de crianças e adolescentes - DISABKIDS®. [Iniciação Científica].

- Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2011.
46. Caroni RC. Propriedades psicométricas do instrumento DISABKIDS® - Módulo Artrite reumatoide para crianças e adolescentes brasileiros. [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014.
47. Santoro JVN. Adaptação cultural, para o Brasil, do módulo específico Epilepsia, do instrumento de avaliação da Qualidade de Vida Relacionada à Saúde de crianças e adolescentes - DISABKIDS®. [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2013.
48. Mendes JFL. Propriedades psicométricas do DISABKIDS® - Epilepsy Module para crianças e adolescentes brasileiros, versão "proxy". [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014.
49. Kourrouski MFC, Abreu IS, Oliveira ACGM, Santos DMSS, Deon KC, Cervi MC, et al. Brazilian children and adolescents infected with HIV: the initial stage of development an instrument of health-related quality of life-DISABKIDS Group. In: 19<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Hungary, Budapest; 2012. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-012-0248-x>
50. Santos CB, Kourrouski MFC, Bullinger M, Collet N, Deon KC, Nascimento LC, et al. Development of a specific module of the DISABKIDS® to measure the health-related quality of life of children and adolescents living with HIV/AIDS. In: 21<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Germany, Berlin; 2014. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-014-0769-6>
51. Kourrouski MFC. Specific module of the instrument DISABKIDS® of life quality evaluation related to the health of Brazilian children and adolescents living with HIV [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014. doi:10.11606/T.22.2014.tde-22052014-162104
52. Oliveira ACGM. Quality of life related to health tool for Brazilian children and adolescents: specific module validation HIV-DISABKIDS® [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2016. doi:10.11606/D.22.2016.tde-06052016-155337
53. Oliveira ACGM, Kourrouski MFC, Nascimento LC, Santos CB, Cervi MC, Collet N, et al. Health-related quality of life of children and adolescents: construction and validation of the DISABKIDS-HIV Module. In: 23<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Copenhagen, Denmark; 2016. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-016-1390-7>
54. Abreu IS, Santos DMSS, Deon KC, Lima RAG, Kourrouski MFC, Reis RA, et al. Dimensions of quality of life of Brazilian children and adolescents in hemodialysis. In: 19<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Hungary, Budapest; 2012. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-012-0248-x>
55. Abreu IS, Kourrouski MFC, Nascimento LC, Lima RAG, Bullinger M, Santos CB. Quality of life of children and adolescents with chronic kidney failure undergoing hemodialysis: construction of the Specific DISABKIDS® Module. In: 21<sup>th</sup> International Society For Quality Of Life Research (ISOQOL). Germany, Berlin; 2014. [cited Oct 14, 2019]. Available from: <https://link.springer.com/article/10.1007/s11136-014-0769-6>
56. Abreu IS. Quality of life of children and adolescents with chronic kidney failure undergoing hemodialysis: construction of the Specific DISABKIDS® Module [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014. doi:10.11606/T.22.2014.tde-07012015-145618
57. Mendes MFT. Construção do módulo específico DISABKIDS® para crianças e adolescentes brasileiros com obesidade. Fase 1: identificação dos atributos impactantes na qualidade de vida. [Iniciação Científica]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2016.
58. Pelegrino FM. Cultural adaptation and the instrument Duke Anticoagulation Satisfaction Scale (DASS) validity: version for brazilian patients undergoing oral anticoagulant therapy [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2009. doi:10.11606/D.22.2009.tde-08062009-113803
59. Bortoli PS. Cross-cultural adaptation of the Adolescent Pediatric Pain Tool (APPT) for Brazilian children and adolescents with cancer. [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2011. doi:10.11606/D.22.2011.tde-31102011-084625
60. Galdeano LE, Furuya RK, Delacio MCB, Dantas RAS, Rossi LA. Semantic validation of Cardiac Patients Learning Needs Inventory for Brazilian and Portuguese. Rev Gaúcha Enferm. 2011;32(3):602-10. doi: <http://dx.doi.org/10.1590/S1983-14472011000300024>
61. Assunção FFO. Body Image Quality of Life Inventory-BIQLI: Adaptation to portuguese and validation for brazilian burn-victim patients [dissertação]. Ribeirão Preto: Escola de Enfermagem

- de Ribeirão Preto da Universidade de São Paulo; 2011. doi:10.11606/D.22.2011.tde-28112011-162411
62. Assunção FFO, Dantas RAS, Ciol MA, Gonçalves N, Farina JA, Rossi LA. Reliability and validity of the body image quality of life inventory: Version for Brazilian burn victims. *Res Nurs Health*. 2013;36(3):299–310. doi: <https://doi.org/10.1002/nur.21538>
63. Correia FR. Translation, cultural adaptation, and initial validation of the Palliative Outcome Scale (POS) [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2012. doi:10.11606/D.22.2012.tde-27032012-153946
64. Fuzissaki MA. Elaboration and validation of na instrument for identification of the practice of nurses to handling and prevention of radiodermatitis [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2012. doi:10.11606/D.22.2012.tde-06062012-160850
65. Fuzissaki MA, Clapis MJ, Santos CB, Oliveira GT. Development of an instrument to identify nurses' practice in radiodermatitis. *Rev Enferm UERJ*. [Internet]. 2015 Aug [cited Jul 5, 2018];23(6):747–53. Available from: <http://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/12677>
66. Fuzissaki MA, Santos CB, Almeida AM, Gozzo TO, Clapis MJ. Semantic validation of an instrument to identify the nursing practice in the management of radiodermatitis. *Rev Eletrônica Enferm*. [Internet]. 2016 Mar 31 [cited Jul 5, 2018];18(0). Available from: <https://revistas.ufg.br/fen/article/view/35164>
67. Stacciarini TSG. Adaptation and validation of the scale to evaluate the self-care capacity Appraisal of Self Care Agency Scale - Revised for Brazil [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2012. doi:10.11606/T.22.2012.tde-16012013-111537
68. Stacciarini TSG, Pace AE. Translation, adaptation and validation of a self-care scale for type 2 diabetes patients using insulin. *Acta Paul Enferm*. [Internet]. 2014 [cited Jul 5, 2018]. 27(3):221–9. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0103-21002014000300221&lng=pt&nrm=iso&tlng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002014000300221&lng=pt&nrm=iso&tlng=en)
69. Landim CAP. Cultural adaptation of the Brazilian and Portuguese version of Patient Assessment of Chronic Illness Care (PACIC) [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2012. doi:10.11606/T.22.2012.tde-17042013-144940
70. Fonseca LMM, Aredes ND, Leite AM, Santos CB, Lima RAG, Scochi CGS. Evaluation of an educational technology regarding clinical evaluation of preterm newborns. *Rev Latino-Am. Enfermagem*. [Internet]. 2013 Feb [cited Jul 5, 2018];21(1):363–70. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-11692013000100011&lng=en&tlng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692013000100011&lng=en&tlng=en)
71. Valim MD, Marziale MHP. Cultural adaptation of the "Questionnaires For Knowledge and Compliance With Standard Precaution" to Brazilian portuguese. *Rev Gaúcha Enferm*. [Internet]. 2013 Dec [cited Jul 9, 2018];34(4):28–36. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1983-14472013000400004&lng=pt&nrm=iso&tlng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-14472013000400004&lng=pt&nrm=iso&tlng=en)
72. Valim MD. Cultural adaptation and validation of the Questionnaires for knowledge and compliance with standard precaution for Brazilian nurses [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014. doi:10.11606/T.22.2014.tde-09012015-114413
73. Rodrigues LBB. Adaptation and validation of scale to assess the coordination of health care networks by the primary care: preliminary results [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014. doi:10.11606/T.22.2014.tde-20052014-201509
74. Rodrigues LBB, Leite AC, Yamamura M, Deon KC, Arcêncio RA. Coordination of primary healthcare networks: semantic validation of an adapted instrument. *Cad Saúde Pública* [Internet]. 2014 Jul [cited 2018 Jul 9];30(7):1385–90. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0102-311X2014000701385&lng=pt&tlng=pt](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-311X2014000701385&lng=pt&tlng=pt)
75. Rodrigues LBB, Santos CB, Goyatá SLT, Popolin MP, Yamamura M, Deon KC, et al. Assessment of the coordination of integrated health service delivery networks by the primary health care: COPAS questionnaire validation in the Brazilian context. *BMC Fam Pract*. [Internet]. 2015 Dec [cited Jul 9, 2018];16(1):87. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26198100>
76. Machado JP. Educational Intervention On Indirect Blood Pressure Measurement By Nursing Professionals: a proposition for patient safety [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2014. doi:10.11606/T.22.2014.tde-20052014-194718
77. Pan R, Marques AR, Santos BD, Jacob E, Santos CB, Nascimento LC, et al. Cultural adaptation to Brazil of the questionnaire Costs of caring for children with cancer. *Rev Latino-Am. Enfermagem*. [Internet]. 2014 Aug [cited Jul 9, 2018];22(4):591–7. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-11692014000400591&lng=en&tlng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692014000400591&lng=en&tlng=en)
78. Marques-Camargo AR. Financial experience of families in the care of children and adolescents with cancer [dissertação]. Ribeirão Preto: Escola de Enfermagem

- de Ribeirão Preto da Universidade de São Paulo; 2014. doi:10.11606/D.22.2014.tde-30032015-134544
79. Valera GG. Tradução e adaptação cultural para o Brasil da escala Pain Assessment in Advanced Dementia PAINAD [Dissertação]. Universidade Federal de São Carlos. [Internet]; 2014 Feb [cited Jul 9, 2018]; Available from: <https://repositorio.ufscar.br/handle/ufscar/3269?show=full>
80. Valera GG, Carezzato NL, Vale FAC, Hortense P. Cultural adaptation of the scale Pain Assessment in Advanced Dementia - PAINAD to Brazil. *Rev Esc Enferm USP*. [internet]. 2014 [cited Jul 9, 2018];48(3):462. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0080-62342014000300462&lng=en&nrm=iso&tlng=en&ORIGINALLANG=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342014000300462&lng=en&nrm=iso&tlng=en&ORIGINALLANG=en)
81. Jansen AC. Cultural adaptation and validation for Brazil of the instrument Comply with post-exposure management among health care workers for nursing professionals. [thesis]. São Paulo: Escola de Enfermagem da Universidade de São Paulo; 2014. doi:10.11606/T.83.2014.tde-08012015-152822
82. Jansen AC, Marziale MHP, Santos CB, Dantas RAS, Santos DMSS. Assessment of adherence to post-exposure conducts among health workers: translation and cultural adaptation of an instrument. [Internet]. *Texto Contexto - Enferm*. 2015[cited Jul 5, 2018];24(3):670-9. Available from: <http://www.index-f.com/textocontexto/2015/r24670.php>
83. Jansen AC, Helena M, Marziale P, Santos CB, Spadotti RA. Validation of the Comply with Post-Exposure Management Among Health Care Workers Instrument for Brazil. *Rev Esc Enferm USP*. [Internet]. 2016 Nov/Dec [cited Jul 5, 2018];50(6):973-81. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0080-62342016000600973](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0080-62342016000600973)
84. Barros IMC, Alcantara TS, Santos ACO, Paixao FP, Araujo GG, Lyra-Junior DP. Semantic validation of subtitles and analysis of understanding of pictograms taken from the United States Pharmacopeia Dispensing Information (USP-DI). *African J Pharm Pharmacol*. [Internet]. *Academic J*. 2015 Jan; [cited Jul 5, 2018];9(1):6-11. Available from: <http://www.academicjournals.org/journal/AJPP/article-abstract/70052F249742>
85. Barros IMDC. Mandala de avaliação: pistas para avaliação, integração e produção de diálogo no cotidiano do trabalho [dissertação]. Feira de Santana: Universidade Estadual de Feira de Santana; [internet]. 2015. [cited Oct 19, 2018]. Available from: <http://tede2.uefs.br:8080/handle/tede/716>
86. Heitor SFD, Estima CCP, Neves FJ, Aguiar AS, Castro SS, Ferreira JES. Translation and cultural adaptation of the questionnaire on the reason for food choices (Food Choice Questionnaire - FCQ) into Portuguese. *Cienc Saúde Coletiva*. [Internet]. 2015 Aug [cited Jul 5, 2018];20(8):2339-46. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1413-81232015000802339&lng=pt&tlng=pt](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232015000802339&lng=pt&tlng=pt)
87. Silva LMC, Andrade CS, Sicsú AN, Mitano F, Almeida JN, Santos CB, et al. Design and semantic validation of a new instrument to assess policy transfer of directly observed treatment for tuberculosis. *Rev Panam Salud Publica*. [Internet]. 2015 May[cited Jul 5, 2018];38(2):129-35. Available from: <https://www.scielosp.org/article/rpsp/2015.v38n2/129-135/>
88. Silva LMC. Development and validation of an evaluation tool of Directly Observed Therapy of tuberculosis transfer from the perspective of mid and high-level health professionals (ATP-IINFOC-TB) [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2016. doi:10.11606/T.22.2016.tde-05052016-211603
89. Peruhype RC. The planning and transfer of the Directly Observed Treatment of Tuberculosis policy in the municipality of Porto Alegre - RS [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2015. doi:10.11606/T.22.2015.tde-16062015-184557
90. Freitas NO, Caltran MP, Dantas RAS, Rossi LA. Translation and cultural adaptation of the perceived stigmatization questionnaire for burn victims in Brazil. *Rev da Esc Enferm*. [Internet]. 2014 [cited Jul 9, 2018];48(1):25-33. Available From: <http://dx.doi.org/10.1590/S0080-623420140000100003>
91. Freitas NDEO. Cross-cultural adaptation and validation of the Perceived Stigmatization Questionnaire (PSQ) and Social Comfort Questionnaire (SCQ) for Brazilians who suffered burn [thesis]. São Paulo: Escola de Enfermagem da Universidade de São Paulo; 2016. doi:10.11606/T.83.2017.tde-30012017-093634
92. Crispim JA. Cultural adaptation and validation of the Tuberculosis-Related Stigma Scale to Brazil - Phase I [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo;2016. doi:10.11606/T.22.2017.tde-24012017-155753
93. Crispim JA, Touse MM, Yamamura M, Popolin MP, Garcia MCC, Santos CB, et al. Cultural adaptation of the Tuberculosis-related stigma scale to Brazil. *Cienc Saúde Coletiva*. [Internet]. 2016 [cited Oct 3, 2019];21(7):2233-42. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1413-81232016000702233&lng=pt&nrm=iso&tlng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232016000702233&lng=pt&nrm=iso&tlng=en)
94. Crispim JA, Silva LMC, Yamamura M, Popolin MP, Ramos ACV, Arroyo LH, et al. Validity and reliability of the tuberculosis-related stigma scale version for Brazilian Portuguese. *BMC Infect Dis*. [Internet]; 2017 [cited Oct 3, 2019];17(1):1-8. Available from: <https://>

- bmcinfectdis.biomedcentral.com/articles/10.1186/s12879-017-2615-2
95. Cunha CM. Patient Activation Measure (PAM): Adaptation and validation of the versions of 22 and 13 items in a sample of Brazilian patients with chronic diseases [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2016. doi:10.11606/T.22.2016.tde-11102016-152746
96. Eduardo AHA. Psychometric properties of the Brazilian version of the questionnaire Quality of recovery - 40 item [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2015. doi:10.11606/T.22.2015.tde-23112015-194016
97. Eduardo AHA, Santos CB, Carvalho AMP, Carvalho EC. Validation of the Brazilian version of the Quality of Recovery - 40 Item questionnaire. *Acta Paul Enferm.* [Internet]. 2016. [cited Oct 3, 2019 ];29(3):253–9. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0103-21002016000300253&lng=pt&nrm=iso&lng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002016000300253&lng=pt&nrm=iso&lng=en)
98. Guedes DMB. Children Pain Assessment: A Semantic Validation of Pain Quality Cards [dissertação]. São Paulo: Escola de Enfermagem da Universidade de São Paulo; 2016. doi:10.11606/D.7.2017.tde-10052017-121608
99. Neves JPP. The impact assessment of the Community Health Agents' training in relation to sexually transmitted diseases, in São Sebastião do Paraíso - MG [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2016. doi:10.11606/T.22.2016.tde-11102016-153801
100. Ribeiro MS. Genetic Counseling Outcome Scale (GCOS-24): cultural adaptation and validation to Brazilians in process of Genetic Counseling [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2016. doi:10.11606/D.22.2017.tde-25012017-104528
101. Andrade RC. Cultural adaptation and reliability assessment of the Needs of Parents Questionnaire (NPQ) for use in Brazil [dissertação]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2016. doi:10.11606/D.22.2017.tde-26012017-173255
102. Belmiro SDR. Evidência de validação do instrumento de avaliação da necessidade de saúde de pessoas com deficiência física auditiva e visual [thesis]. Repositório Institucional da Universidade Federal do Rio Grande do Norte. [Internet] 2016 [Acesso 9 jul 2018]; Disponível em: <https://repositorio.ufrn.br/jspui/handle/123456789/21616>
103. Daniel ACQG. Educational program concerning blood pressure documentation in emergency department: an intervention study [thesis]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2017. [cited Oct 14, 2019]; 29(3): 253–9. Available from: <https://www.teses.usp.br/teses/disponiveis/22/22132/tde-08082019-150438/pt-br.php>
104. Carleto CT. Transcultural adaptation and evidences of validity of the Brazilian version of the Integration into college life inventory (I-IVU) [thesis]. Biblioteca Digital de Teses e Dissertações da Universidade Federal do Triângulo Mineiro. [Internet] 2017 [cited Jul 9, 2018]; Available from: <http://bdted.ufm.edu.br/handle/tede/475>
105. Alvarenga WA. FACIT-Sp-12 Spiritual Well-Being Scale: adaptation for Brazilian adolescents with chronic disease, development of the parental version, and their validations [thesi]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo; 2017. doi: <https://doi.org/10.11606/T.22.2019.tde-29032018-161556>
106. Felipe HR. Validation of the Knowledge Questionnaire over Forensics Nursing Practices [dissertação]. Ribeirão Preto: Universidade de São Paulo, Escola de Enfermagem de Ribeirão Preto; 2018 [cited Oct 3, 2019]. Available from: <http://www.teses.usp.br/teses/disponiveis/22/22132/tde-29052018-161705/pt-br.php>
107. Terwee CB, Bot SDM, Boer MR, van-der-Windt DA, Knol DL, Dekker J, et al. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol.* [Internet]. 2007 Jan [cited Jul 9, 2018];60(1):34–42. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17161752>
108. Beaton DE, Bombardier C, Guillemin F, Ferraz MB. Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine.* 2000 Dec; 25(24): 3186–91. doi: 10.1097/00007632-200012150-00014
109. Gamba NCR, Martinez MR, García JC. Cross-cultural validation of the "DISABKIDS" questionnaire for quality of life among Colombian children with chronic diseases. *Rev. Latino-Am. Enfermagem.* [Internet]. 2018 [cited Sep 18, 2019]; 26: e3020. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S0104-11692018000100336&lng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-11692018000100336&lng=en)
110. Barros RS, Pereira MJB, Santos CB. Assessment mandala: supply of an instrument to conduct evaluative processes in institutional support. *Interface.* (Botucatu) [Internet]. 2018; [cited Oct 3, 2019]. 22( 66 ): 827-40. doi: <http://dx.doi.org/10.1590/1807-57622016.0787>
111. Schmidt S, Bullinger M. Current issues in cross-cultural quality of life instrument development. *Arch Phys Med Rehabil.* [Internet]. 2003 Apr [cited Jul 9, 2018];84(4 Suppl 2):S29–34. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12692769>
112. Bullinger M, Quitmann J. Quality of life as patient-reported outcomes: principles of assessment. *Dialogues*

- Clin Neurosci. [Internet]. 2014 [cited Sep 18, 2019];16(2):137-45. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4140508/>
113. Bullinger M, Globe D, Wasserman J, Young NL, Mackensen SV. Challenges of patient-reported outcome assessment in hemophilia care—a state of the art review. Value Health. [Internet]. 2009 [cited Sep 18, 2019 ]; 12: 808– 20. Available from: [https://www.valueinhealthjournal.com/article/S1098-3015\(10\)60744-9/abstract](https://www.valueinhealthjournal.com/article/S1098-3015(10)60744-9/abstract)
114. Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQoL instruments: the universalist approach. Qual Life Res. [Internet]. 1998 May [cited Jul 5, 2018];7(4): 323–35. Available from: <https://bura.brunel.ac.uk/bitstream/2438/10007/1/Fulltext.pdf>
115. Daniel ACQG, Machado JP, Veiga EV. Blood pressure documentation in the emergency department. Einstein (São Paulo). [Internet]. 2017 [cited Sep 18, 2019];15(1):29–33. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1679-45082017000100029&lng=en&tlng=en](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1679-45082017000100029&lng=en&tlng=en)

Received: Jul 19<sup>th</sup> 2018

Accepted: Jan 09<sup>th</sup> 2019

---

Corresponding author:

Viviane Romeiro

E-mail: [viviane.rom@gmail.com](mailto:viviane.rom@gmail.com)

 <https://orcid.org/0000-0002-5244-627X>

**Copyright © 2020 Revista Latino-Americana de Enfermagem**

This is an Open Access article distributed under the terms of the Creative Commons (CC BY).

This license lets others distribute, remix, tweak, and build upon your work, even commercially, as long as they credit you for the original creation. This is the most accommodating of licenses offered. Recommended for maximum dissemination and use of licensed materials.