

# SYSTEMATIC OR INTEGRATIVE REVIEW

## INSTRUMENTS FOR THE EVALUATION OF THE QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH DIABETES MELLITUS

### INSTRUMENTOS PARA AVALIAÇÃO DA QUALIDADE DE VIDA EM CRIANÇAS E ADOLESCENTES COM DIABETES MELLITUS

### HERRAMIENTAS PARA EVALUAR LA CALIDAD DE VIDA DE NIÑOS Y ADOLESCENTES CON DIABETES MELLITUS

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## ABSTRACT

**Objective:** to review the literature on existing instruments to evaluate the quality of life in children and adolescents with diabetes mellitus, adapted and validated for use in Brazil. **Methodology:** this was an integrative review study with the guiding question: “what are the existing instruments in the national literature that can be used to evaluate the quality of life in diabetic children and adolescents?” The PICO strategy was used: “patient, intervention, comparison, and outcomes.” The analysis of the instruments found was performed using the JBI QARI instrument (Joanna Briggs Institute – Qualitative Assessment and Review Instrument) for the evaluation of systematic reviews. Scientific publications indexed in databases were evaluated. **Results:** four instruments were identified. They are: Quality of Life Instrument for Young People with Diabetes (IQVJD), DISABKIDS Generic Module, Pediatric Quality of Life Inventory™ version 4.0 (PedsQLTM 4.0), and KIDSCREEN-52. The classification, according to the JBI QARI instrument, showed positive results for eight out of 10 items evaluated in all analyzed studies. The dissemination and incorporation of these instruments in the clinical practice can help the development of care plans tailored to each patient.

**Keywords:** Diabetes Mellitus; Quality of Life; Pediatrics; Child; Adolescent.

## RESUMO

**Objetivo:** revisar a literatura sobre instrumentos existentes para avaliar a qualidade de vida em crianças e adolescentes com diabetes mellitus, adaptados e validados para uso no Brasil. **Metodologia:** estudo de revisão integrativa, com a questão norteadora: “quais são os instrumentos existentes na literatura nacional que podem ser utilizados para avaliar a qualidade de vida em crianças e adolescentes diabéticos?” Utilizou-se a estratégia PICO: “paciente, intervenção, comparação e outcomes (desfecho)”. A análise dos instrumentos encontrados foi realizada por meio do instrumento JBI QARI (Joanna Briggs Institute – Qualitative Assessment and Review Instrument) para avaliação de revisões sistemáticas. Foram avaliadas publicações científicas indexadas em bases de dados. **Resultados:** foram encontrados quatro instrumentos. São eles: Instrumento de Qualidade de Vida para Jovens com Diabetes (IQVJD), Módulo Genérico DISABKIDS, Pediatric Quality of Life Inventory™ versão 4.0 (PedsQLTM 4.0) e o KIDSCREEN-52. A classificação, segundo o instrumento JBI QARI, obteve resultado positivo para oito dos 10 itens avaliados em todos os estudos analisados. A divulgação e a incorporação desses instrumentos na prática clínica podem auxiliar a elaboração de planos de cuidado adequados a cada paciente.

**Palavras-chave:** Diabetes Mellitus; Qualidade de Vida; Pediatria; Criança; Adolescente.

## RESUMEN

El objetivo de la presente investigación fue buscar en la literatura herramientas adaptadas y validadas en Brasil para evaluar la calidad de vida de niños y adolescentes con diabetes mellitus. Se trata de un estudio de revisión integradora con la pregunta guía: “¿Qué herramientas de la literatura nacional sirven para evaluar la calidad de vida de niños y adolescentes con diabetes?” Se utilizó la estrategia PICO: “Paciente, Intervención, Comparación y Outcomes (resultados)”. El análisis de las herramientas se realizó con el software JBI QARI, Joanna Briggs Institute – Qualitative Assessment and Review Instrument) para evaluar las revisiones sistemáticas. Se analizaron las publicaciones científicas indexadas en las bases de datos. Se encontraron los cuatro instrumentos siguientes: Instrumento de Calidad de la Vida para Jóvenes con Diabetes (IQVJD), Módulo Genérico DISABKIDS, Pediatric Quality of Life Inventory™ versión 4.0 (PedsQLTM 4.0) y el KIDSCREEN-52. La clasificación, según el JBI QARI, obtuvo un resultado positivo para 8 de los 10 puntos evaluados en todos los estudios analizados. La divulgación y la incorporación de estas herramientas en la práctica clínica podría ayudar a elaborar planes de atención adecuados para cada paciente.

**Palabras clave:** Diabetes mellitus; Calidad de Vida; Pediatria; Niño; Adolescente.

## INTRODUCTION

Diabetes *mellitus* (DM) is a chronic disease causing numerous comorbidities that directly affect the quality of life of patients. It is the second most common chronic disease in childhood and adolescence, with the great impact on economic, social, and psychoemotional order.<sup>1</sup> It is defined as a group of metabolic diseases characterized by hyperglycemia resulting from lack of insulin secretion and/or inability of insulin to act properly. The characteristic symptoms are: polydipsia, polyuria, blurred vision, and weight loss.<sup>2</sup>

It is a disease whose treatment and control require behavioral changes in the diet, taking medications, and lifestyle, i.e., changes that can compromise the quality of life (QV).<sup>3</sup> The sudden disease onset and needed treatment to control blood glucose cause abrupt changes in the lifestyle of the young and interfere with their self-image and, consequently, in their quality of life.<sup>4</sup> In addition, being a chronic disease carrier causes a stigma that can have negative effects on teenage life because it strengthens the idea of being "different", often involving restrictions that can make the person feel excluded before others.<sup>5</sup>

Due to the scope and complexity of the concept, there are still limitations and difficulties in defining QV. There is no consensus in the scientific community, which determines clearly its meaning, however, QV has been defined as an individual's perception of his position in life in the context of culture and value system in which he lives and in relation to his goals, expectations, standards, and concerns. The health-related QV concept focuses on the aspects influenced by the disease and/or treatment.<sup>6</sup> Therefore, there is a need to create a way to evaluate it. For this, instruments are used to measure QV providing information on how the disease process interferes with the individual's well-being in several areas of life. Such data can support the development of health policies and create new ways of understanding and caring for patients by promoting a more humanized care among health professionals, focused on patients' needs.<sup>7</sup>

Although the chronic complications of DM are not yet present in children, some acute decompensation can occur, which triggers changes in their daily life, and therefore, lies the need to assess the impact of changes in the lives of these patients.<sup>7,8</sup>

Although the number of studies related to QV is increasing, the scientific production in Brazil is still scarce, especially for the studied population. Evaluating the quality of life of children with chronic diseases is of utmost importance because their life expectancy has increased with technological advances, however, without assessing its impact on QV.<sup>8</sup> By studying this population specifically, we attempted to identify the different degrees of perception that these developing individuals have about themselves and the world where they live because they have peculiar characteristics related to the stage where they are, which makes such issues even more conflicting.<sup>9</sup>

Considering the epidemiological magnitude of DM, its implications in the lives of patients, and the need to develop individualized care plans, this study aimed to identify in the literature the appropriate and validated instruments, for the Brazilian culture, used to measure QV in children and adolescents.

## MATERIAL AND METHOD

This study it is an integrative review, a methodological approach that includes experimental and non-experimental studies for a complete understanding of the analyzed phenomenon. The integrative review combines data from the theoretical and empirical literature while incorporating a wide range of purposes: definition of concepts, theories, and evidence reviews, and analysis of methodological problems of a particular topic.<sup>10</sup>

The following steps guided the study: theme identification and selection of the guiding research question; establishment of criteria for inclusion and exclusion of studies (sample selection); definition of information to be extracted from selected articles; evaluation of the studies included in the review; analysis and interpretation of results and review presentation.

The following guiding question was formulated to guide the review: what are the existing instruments in the national literature that can be used to evaluate the quality of life in diabetic children and adolescents? The PICO strategy was used in drafting the question and searching for evidence, which is an acronym that has the following meaning: "P" for patient or population; "I" for intervention or indicator; "C" for comparison or control; and "O" for outcome, which in English means clinical outcome, or result, or even the answer expected in scientific studies.<sup>11,12</sup> This strategy allows locating specifically scientific information (evidences) about the issues in the investigation.

Scientific publications indexed in the following databases were researched through online access: Latin American and Caribbean Literature in Health Sciences (LILACS); *Scientific Electronic Library Online* (SciELO); National Database of Nursing (BDENF); *Cumulative Index to Nursing and Allied Health Literature* (CINAHL); Scopus; Web of Science; *US National Library of Medicine National Institutes of Health* (PubMed Central), and *Cochrane Library*. Descriptors in Health Sciences (DeCS) and *Medical Subject Headings* (MeSH) were used: "quality of life", "diabetes *mellitus*", "validation studies", "pediatrics", "quality of life", "pediatric" "validation studies", "calidad de vida", "pediatría", "estudios de validación validation studios."

The inclusion criteria were: published between 2000 and 2013; studies whose instruments have been subjected to a cross-cultural validation process for the Brazilian population in addition to being related to DM type 1 and 2, and whose age range include children and adolescents. Theses and dissertations that did not have their results published as an article were excluded.

In addition, to improve the analysis of the instruments found, the *Joanna Briggs Institute has been applied – Qualitative Assessment and Review Instrument (JBI QARI)*<sup>13</sup>, a software that evaluates systematic reviews and aims to determine the level of evidence considering feasibility, practicality, adequacy, intervention adjustment, and significance of the study was applied.

## RESULTS

This integrative review found four studies that met the inclusion criteria and were published in the following journals: *Revista Paulista de Pediatria*; *Jornal de Pediatria*; *Revista Brasileira de Saúde Materno-Infantil*; and *Revista Latino-Americana de Enfermagem*. Although the search was carried out in the aforementioned relevant databases, all validation studies included were found in one single database, SciELO.

The area of work of the authors in these articles were Biochemistry, Dentistry, Nursing, Medicine, and Physical Education. The publication period was from 2007 to 2011. Table 1 presents a summary of the selected articles.

The description of the four instruments that make up the study is presented below:

- **Quality of Life Instrument for Young Diabetics (IQVJD):**<sup>14</sup> this is a specific instrument to evaluate the quality of life in young patients with DM type I, which comes from the *Diabetes Quality of Life for Youths (DQOLY)*, which in turn was based on the *Diabetes Quality of Life measure (DQOL)*. The instrument underwent a cultural adaptation to suit the psychometric variables in the studied population. The final version was made up of 50 items, distributed among the following domains: satisfaction (17 items), impacts (22), and concerns (11). The responses are mea-

sured through a Likert-type questionnaire, with scores ranging from one to five. The lower the final score, the better the QV. The study for the validation of this instrument in Brazil used a sample of 124 adolescents with type I DM, aged 12-18 years. The reliability analysis showed satisfactory result given by the Cronbach's alpha coefficient: 0.87 in the satisfaction domain; 0.86 in the impact domain; 0.84 in the concerns domain; and 0.93 for total items.

- **DISABKIDS<sup>15</sup> Generic Module for Brazilian children and adolescents with chronic conditions:** it is a generic instrument used to evaluate QV in children/adolescents with chronic conditions (CC). It was originated from the *Disabkinds Chronic Generic Measure long form 37 (DCGM-37)*, developed by the European group DISABKIDS (Kids with Disabilities).<sup>8</sup> It consists of 37 items distributed into three areas: a) mental domain (independence and emotional); b) social domain (inclusion and exclusion); c) physical domain (limitation and treatment). The answers are classified using a Likert-type scale: the lowest answered value (1) indicates high health condition negative impact on the QV of children/adolescents, while the highest value (6) means low impact. The instrument was applied to Brazilian outpatient children and adolescents, aged between eight and 18 years, and diagnosed with asthma or diabetes. The questions were answered by them and their parents, independently, to avoid influence on answers. In all, there were 118 children/adolescents and their parents. The version of the instrument to be used in children and adolescents as self-administered was named *self* and the version used for parents, *proxy*. The reliability analysis showed a high degree of internal consistency according to Cronbach's alpha coefficient: 0.92 for the total score of the *self* and 0.93 for *proxy* versions.

Table 1 - Distribution of existing instruments to evaluate the quality of life of Brazilian children and adolescents, according to the studied population, domains, number of items, and objectives

Author/Year / Database	Title/Instrument	Objectives	Type/ Items and Domains
Novato et al., 2007 <sup>14</sup> SciELO	Quality of Life Instrument for Young People with Diabetes (IQVJD)	Evaluate the quality of life in young people with diabetes type I	Specific* 50 items 3 Domains
Fegadolli et al., 2010 <sup>15</sup> SciELO	Quality of life of children and adolescents in São Paulo: reliability and validity of the Brazilian version of the generic questionnaire Pediatric Quality of life InventortyTM version 4.0/PedsQLTM 4.0	To assess pediatric QV	Generic** 23 items 4 Domains
Klatchoian et al., 2008 <sup>16</sup> SciELO	Adaptation of the DISABKIDS generic module for Brazilian children and adolescents with chronic conditions	Measuring QV for children/adolescents with chronic conditions	Generic** 37 items 6 Domains
Guedes and Guedes, 2011 <sup>17</sup> SciELO	Translation, cultural adaptation, and psychometric properties of KIDSCREEN-52 for the Brazilian population	To provide practical measures to clinicians and researchers to assess the well-being and subjective health of children and adolescents, healthy or with chronic conditions	Generic** 52 items 10 Domains

\*Specific: destined to the studied population with DM type I. \*\*Generic: destined to the studied population with chronic health disorders.

- **Pediatric Quality of Life Inventory™, version 4.0 (PedsQL™ 4.0) – Brazil:**<sup>16</sup> the questionnaire was developed for a self-assessment of QV in children and adolescents between five and 18 years old. The same questionnaire can be applied to parents to measure the QV of children and adolescents with chronic health disorders between two and 18 years old. It consists of 23 items covering the domains: a) physical (eight items); b) emotional (five items); c) social (five items); d) school (five items). The estimated time for completing the instrument is five minutes. The self-assessment by children was divided according to age groups: five to seven years; eight to 12; and 13 to 18. For parents, the questionnaire was divided into the following age groups: two to four years old; five to seven; eight to 12; and 13 to 18.

In this instrument, the extent of each problem during the last month is investigated and respondents use a five-level scale to answer: “zero” to “it was never a problem” to “four”, “it was almost always a problem.” For the validation and cultural adaptation process, 105 children and adolescents aged two to 18 years and with a diagnosis of rheumatic disease were selected. Parents were also included. However, their questionnaire was administered separately. The reliability analysis for the total score was 0.88 for children and parents according to the Chronbach’s alpha coefficient indicating excellent reliability in internal consistency.
- **The Brazilian version of the KIDSCREEN-52 instrument:**<sup>17</sup> the questionnaire has a general nature, and can be used by both healthy children and those with chronic health conditions. It is for the age group between eight and 18 years old, consisting of 52 questions divided into 10 domains: health and physical activity; feelings; emotional state; self-awareness; autonomy and free time; family/home environment; financial aspects; friends and social support; school environment; and provocation/bullying. Responses are measured on a Likert-type scale of five points. There is also a version for parents/guardians. The validation process took place in the city of Londrina-PR with children and adolescents from two schools: one public and one private. According to the Chronbach’s alpha coefficient, all domains, except “feelings,” had the same range of variation of the original instrument, suggesting good reliability in the Brazilian version. According to the classification made by the JBI QARI instrument, a satisfactory result was obtained in eight out of the ten items evaluated in the four analyzed studies.

## DISCUSSION

A reduced number of instruments that are validated in Brazil and applicable to children/adolescents with DM was identified in this study. Out of the four instruments, only one is intended exclu-

sively for DM carriers. Another, although not specific, was validated with diabetics indicating good applicability for this population.

A careful analysis of each instrument showed advantages and disadvantages regarding the use of these questionnaires. The use of one specific instrument is defended by the fact that it explores more precisely the characteristics related to a particular disease. However, authors question this approach based on hindrance on a broader view of the problems posed by the disorder in question. They advocate the use of generic tools or evaluations that link different instruments.<sup>18</sup>

The IQVJD<sup>14</sup> was the only specific instrument found to assess QV in diabetic children/adolescents. This instrument, in the Portuguese version, can assist in the elaboration of a plan of care based on specific interventions, according to the needs highlighted in the questionnaire results, allowing health professionals to conduct a targeted assistance.

Compared to the DCGM-37,<sup>15</sup> the adaptation and cultural validation of psychometric variables showed that it is a reliable instrument to evaluate QV. In that study, diabetic children were included. However, other studies in which it had been used again for this population after the process of cultural adaptation were not found, as with the KIDSCREEN-52.<sup>17</sup> In general, these instruments need to be tested for reliability, applicability, and validity in different Brazilian socio-cultural contexts; hence, the importance of disseminating them.

The PedsQL 4.0<sup>16</sup> instrument was used in another study, whose aim was to describe the QV of children with type I DM under outpatient follow-up. It was observed that the total scores were higher for patients than those obtained from parents, showing that the impact of disease is higher in the perspective of children than of caregivers – a finding opposite to that reported in the instrument validation study of children with rheumatic diseases.<sup>14</sup> Overall, the PedsQL 4.0<sup>16</sup> was considered of easy application. As for the age groups included in the validation studies, the instrument with the most comprehensive coverage was PedsQL4.0,<sup>16</sup> involving children aged two to 18 years old. In this study, the evaluation took place via an instrument applied to parents of children from two to four years old. This information can be of great benefit to health care professionals, who will develop a plan of care, because the sooner there are actions in place decreasing the greatest impact of problems in the lives of these children, the fewer consequences and long-term complications there will be.

About the items covered by each instrument, those with the highest number of items were IQVJD<sup>14</sup> and KIDSCREEN-52,<sup>17</sup> both with 50 items each. However, studies state that these are easily applied questionnaires.

It was verified that none of the instruments was created specifically for the Brazilian population; they were all from international organizations. Although the process of adaptation and validation is detailed, populations have characteristics that



are inherent to socioeconomic and cultural realities of each country or region where they live. Thus, it is necessary to evaluate the context in which the population is inserted, especially in societies that are strongly marked by social inequalities such as in Brazil. In the case of QV, a concept characterized by inaccuracies, such contextualization further increases the difficulty to find a way to quantify it accurately.<sup>19</sup>

In general, these instruments are potential tools to be used by health professionals to direct the approach to patients with DM aiming to minimize, as much as possible, the negative impacts that the disease brings. Therefore, such strategies should be put in practice for children and adolescents, which is a population marked by specific characteristics related to the growth and development of human beings.

Not only the patient, but the family needs to have their QV evaluated and a reference team or even a support network to provide information and support in this process, which requires a number of changes in various aspects of the life of those involved. Among health professionals, nurses have a special role in health care, which in general have the control of the clinical picture taking into account the social, economic, family, and developmental conditions of the child as their main objective.<sup>20</sup> Sports practices, theater, and dance are examples of activities that nurses can incorporate in the care plan and that have a direct impact on the QV of their patients. These activities usually lessen stress and allow moments of distraction. Other possibilities include the use of therapeutic play and inclusion in youth groups in religious institutions or even NGOs.

## FINAL CONSIDERATIONS

Four studies about instruments to evaluate the QV in children and adolescents were identified in this integrative review. Of these, only one is specific to children with diabetes, the other three are generic. The instrument with the most comprehensive content was IQVJD (specific). As for age range, the instrument with the widest coverage was PedsQL4.0 (generic), and the one with the highest number of evaluated domains was KISCREEN-52 (generic).

All instruments analyzed in this study have scientific evidence according to the classification using the JBI QARI instrument.

The number of instruments found was reduced and they need to be more applied in populations with DM since this is a chronic degenerative disease with high incidence in children and adolescents, which requires daily care and strict controls. Thus, it is necessary to evaluate the impact of these situations in the life of these patients because these conditions make them exposed to factors that can significantly impair QV. It is important to disseminate that there are instruments to evaluate QV in children and adolescents, which may be tested, improved, and

become tools to be used not only by nurses but other health professionals in developing a plan of individualized care.

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