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Importance and Assessment of Quality of Life in Children and Adolescents with Diabetes

The concept of health-related quality of life (HRQoL) stems from the World Health Organization's (WHO) 1947 definition of health as a state of complete physical, mental, and social well-being, and not merely the absence of disease. Specifically, HRQoL is defined as the perceived state of health and reflects the impact of a disease on various aspects of life—whether physical, emotional, or social—making it a multidimensional and dynamic concept that must be adapted to different cultures. Evaluation is obtained from the patient—or caregivers in the case of minors—through Patient-Reported Outcomes (PROs), which allow for the measurement of subjective factors related to a disease or treatment.[1]

Type 1 diabetes (T1DM) is one of the most common chronic diseases in childhood and has seen a significant increase in incidence in recent years. Beyond its health impact, T1DM imposes a substantial economic and social burden, as well as a considerable personal and familial strain, since it requires a high degree of self-care, greatly affecting daily life. Advances in treatment intensification and technology over recent decades have led to a reduction in diabetes-related morbidity, albeit at the cost of a notable sacrifice in the patient's and family's quality of life (QoL), which is not always measurable with objective parameters.

A better HRQoL predicts improved adherence to treatment, better self-care, and more effective metabolic control. For this reason, the latest clinical practice guidelines from the International Society for Pediatric and Adolescent Diabetes (ISPAD) recommend the routine implementation of tools in clinical practice to assess and discuss the psychosocial well-being and QoL of all young people with diabetes (recommendation grade A) (2).

The Diabetes Control and Complications Trial (DCCT) and later the Epidemiology of Diabetes Interventions and Complications (EDIC) were the first studies in T1DM to evaluate other concepts, such as cost and HRQoL, in addition to the risk of complications based on metabolic control. Shortly thereafter, the international Hvidoere Study Group was established—a multicenter study conducted across 23 countries to analyze strategies for improving the quality of care in pediatric patients with T1D and, consequently, improve adult outcomes.

When analyzing **factors that influence HRQoL**, it is known that chronic illnesses impact individuals differently depending on their developmental stage. Generally, older children report poorer HRQoL, particularly during adolescence, which brings significant biological and psychological changes that alter daily routines and self-care practices. Psychological well-being is one of the most affected dimensions during puberty, directly impacting HRQoL. In terms of gender, boys generally report better health and fewer symptoms than girls, both in healthy and sick populations. Socioeconomically, children from families with lower educational levels, limited income, or single-parent households tend to report worse perceived health. Regarding diabetes-related technologies, their use is generally associated with significant improvements in QoL. Finally, mental health has been described as one of the factors most strongly influencing HRQoL, in both adults and children/adolescents.

Based on this, we can deduce that various factors influence disease control and HRQoL—such as age, sex, and specific family characteristics—forming a bidirectional relationship, since better HRQoL predicts better disease outcomes, and vice versa.

However, despite recommendations for assessing HRQoL in clinical practice for children with T1DM, practical experience remains limited. In 2012, a systematic review of 17 highly heterogeneous and mostly descriptive studies on HRQoL in children with T1DM was published. Most studies found no significant differences in HRQoL domains between patients and healthy controls, although some disease-specific issues were identified. Most studies suggest that younger children report better HRQoL.

The SEARCH study, a large observational follow-up of more than 2,500 American youths with diabetes, showed that poor HRQoL was associated with worse diabetes outcomes, low socioeconomic status, higher levels of depressive symptoms, and significant ageand gender-related differences.

A French longitudinal study collected data from more than 4,000 children with T1DM and found that glycated hemoglobin (HbA1c) was more closely related to perceived health status than the type of insulin therapy used.

The most extensive population-based study to date evaluating HRQoL in pediatric and young adult patients with T1DM across 5 continents is the TEENs Study (3). Conducted with a global sample of 2,846 adolescents, it found a direct relationship between HRQoL and metabolic control. It also highlighted that family conflicts are very common in T1DM and appear frequently among patients with low HRQoL. The study identified 3 specific behaviors linked to better HRQoL: carbohydrate counting, frequent glucose monitoring, and regular physical activity—behaviors that may serve as potential intervention points in clinical practice. The study

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BETTER HEALTH-RELATED QUALITY OF LIFE PREDICTS BETTER TREATMENT ADHERENCE, SELF-CARE, AND METABOLIC CONTROL

INSTRUMENT	TYPE	COUNTRY OF ORIGIN	AGE (YEARS)	NO. OF ITEMS	ADAPTED TO SPANISH
DISABKIDS-DM	Specific to chronic disease (short version) and T1D-specific module	European	8-18	10–37	Yes
DQOLY	Specific	International	10-18	35–52	Yes
EQ-5D-Y	Generic	European	8-18	5	Yes
KIDSCREEN-52 (27 or 10)	Generic	European	8-18	52 (or 27 or 10)	Yes
KINDL-R-DM	Generic with T1D-specific module	European	7-13	17–24	Yes
MIND-Y	Specific	European	10-25	36	Yes
PedsQL v.3.2	Generic with T1D-specific module	United States	2-18	23–28	Yes

TABLE 1. Instruments for Measuring Quality of Life in Pediatrics.

DISABKIDS: European Quality of Life for Chronic Health Problems; DQOLY: Diabetes Quality of Life for Youth; EQ-5D-Y: EuroQol-5D Youth version; IDI: Impact of Diabetes on Interpersonal Relations; KIDSCREEN: Health-Related Quality of Life Questionnaire for Children and Young People and Their Parents; KINDL-R: Revised KINDer Lebensqualitätsfragebogen (Children's Quality of Life Questionnaire); MIND-Y: Monitoring Individual Needs in Diabetes Youth Questionnaire; PedsQL: Pediatric Quality of Life Inventory;
T1DM: type 1 diabetes mellitus.

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concluded that QoL was significantly associated with HbA1c levels.

Nevertheless, the systematic and continuous use of HRQoL measurement tools in routine clinical practice for pediatric T1DM patients remains limited, and few studies have been published. Those available show that these tools are useful for improving the care process and patient satisfaction by bringing up specific issues during consultations that might otherwise go unaddressed. However, these improvements tend to persist only while HRQoL assessments are actively being performed and disappear once the evaluation stops (4–5). This demonstrates the importance of doctor-patient communication at all ages and the need to involve patients in self-care decision-making.

TYPES OF HRQOL QUESTIONNAIRES

HRQoL measurement instruments or questionnaires are classified as **generic**, which cover all dimensions of HRQoL and can be used with both healthy and chronically ill individuals, or **disease-specific,** which focus on a particular illness, symptom, or condition. Compared to generic tools, disease-specific questionnaires are generally more sensitive to change and better at detecting treatment effects.

To measure HRQoL, it is necessary to use an appropriate and reliable tool that can be administered quickly and easily, and that yields valid and reproducible results. To be considered **valid**, an instrument must be age-, language-, and culture-appropriate and must possess adequate psychometric properties to be usable in clinical practice. Most questionnaires include physical (e.g., activities of daily living, physical symptoms), psychological (e.g., mood, worries), and social (e.g., relationships with family, friends, and school) dimensions, though the structure and content of these dimensions vary greatly between instruments.

In recent years, the number of new HRQoL instruments has increased exponentially, including in pediatrics. Most have been developed in English-speaking countries, and only a few have been adapted for use in Spain. The minimum age for use varies between 7 and 9 years, with caregiver reporting used for younger children.

MAIN INSTRUMENTS (Table 1):

Euro-Qol-5D Youths (EQ-5D-Y):

A generic econometric HRQoL tool for children, validated in Spanish. It consists of 5 dimensions with 1 item each and a visual analog scale (VAS) describing general health status (6).

KIDSCREEN-52

A generic HRQoL instrument for children up to 18 years, developed as part of a European project. The KIDSCREEN family has 3 versions (52 items, 27 items, and

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» the KIDSCREEN-10 Index). It is adapted to Spanish and available in both digital and paper formats. The 27-item version is designed for clinical studies (7).

Pediatric Quality of Life Inventory (PedsQL):

A generic HRQoL instrument for children aged 2–18 years, designed for both parents and children. It includes a general questionnaire and a disease-specific module for T1D. It is quick and easy to apply, with versions structured by developmental stage (2–4, 5–7, 8–12 years, and adolescents up to 18). A limitation of the specific module is its lack of depth on 2 key daily life aspects: diet and physical activity (8).

DISABKIDS

A generic HRQoL tool for children, developed by a European project aimed at improving QoL and independence for children with chronic illnesses and their families. It allows for both general HRQoL evaluation and assessment of specific chronic diseases, including T1DM. It has recently been adapted into Spanish (9).

MIND-Youth

A disease-specific HRQoL tool designed for routine clinical practice with pediatric and adolescent patients with T1DM, used in the DAWN-MIND-Youth program *(Diabetes Attitudes, Wishes and Needs – Monitoring of Individual Needs in Diabetes)*. This initiative aims to implement computerized HRQoL evaluation and discussion during annual checkups. Designed in the Netherlands for children aged 10 and older with T1D, it has recently been validated in Spanish (10). **D**

CONCLUSIONS

HRQoL is a multidimensional concept and one of the main health indicators that should be regularly assessed. In T1DM, as a chronic disease that profoundly affects the daily lives of patients and their families, HRQoL measurement is essential. However, it is important to have validated questionnaires that are culturally and linguistically adapted to our context to perform assessments systematically, following the latest clinical practice guideline recommendations. This approach allows for the evaluation not only of biometric parameters but also of the patient's perspective, enabling the early identification of problems in various areas and the establishment of individualized interventions to optimize outcomes.

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