

Impact on the quality of life of adolescents with diabetes mellitus type 1

Impacto en la calidad de vida de los adolescentes con diabetes mellitus tipo 1

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What do we know about the subject matter of this study?

Some studies show the alterations that Type 1 Diabetes Mellitus causes in the physical health of adolescents, but there is a lack of studies on the impact of this chronic pathology on the quality of life of this age group.

What does this study contribute to what is already known?

This study provides information on the bidirectional impact of glycosylated hemoglobin levels on the quality of life of the adolescent with Type 1 Diabetes Mellitus.

Abstract

Introduction: Type 1 diabetes mellitus (DM1) is a chronic disease. **Objective:** To identify scientific evidence on the impact of DM1 on the quality of life of adolescents with this disease. **Method:** Systematic review in the bibliographic databases MEDLINE, LILACS, CINAHL, and ScIELO, using the following descriptors: "Adolescent **", "Teen **", "Diabetes Mellitus, Type1", "Diabetes, type 1", "Type 1 diabetes", "Quality of life", "Health related quality of life", "Life quality", "Health impact assessment", "Health impact", "Impact assessment, health", "Diabetes Impact Measurement Scales", "PedsQL", "Glycated Hemoglobin A1c", "Glycosylated Hemoglobin A1c", and "HbA1c". Out of 679 articles identified, 25 were included in the analysis. Some studies were national and international multicenter. The most widely used instruments related to quality of life measurements were the Pediatric Quality of Life Questionnaire (PedsQL) in its generic version and the diabetes module. **Results:** The quality of life assessed by the adolescent with DM1 using Quality of Life Scales is significantly and inversely associated with HbA1c values. This association includes a significant correlation between the total generic quality of life scores and HbA1c but does not have the same impact on specific scores. **Conclusions:** Metabolic control appears to be the cornerstone that influences the impact on the bidirectional relationship between DM1 and quality of life, however, there is no absolute consensus on the types of factors and degrees that would influence metabolic control.

Keywords:

Adolescent;
Type 1 Diabetes Mellitus;
Quality of life;
Health Impact Assessment;
Glycated Hemoglobin A1c

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Introduction

Type 1 diabetes mellitus (DM) is the most common chronic non-communicable disease in children and adolescents, with a prevalence ranging from 0.8 to 4.6/1,000 inhabitants worldwide, where the age group with the highest incidence is 10 to 14 years old¹. According to the International Diabetes Federation, these estimates are increasing every year².

In this sense, Chile is the only Latin American country that has an incidence study of the entire population in the public health system, which represents 80% of the general population. Data from the mandatory reporting of type 1 DM from the Explicit Healthcare Guarantees (GES) program show that the average annual incidence has increased significantly from 10.2 in 2006 to 13.8 in 2014, with the highest rate in the 10-14 year age group (16.8/100,000)³.

Since this is a chronic pathology and requires strict metabolic control, it affects the different stages of the life cycle of those who suffer from it⁴. Adolescence is especially affected, which involves the transition between childhood and adulthood, and *'is characterized by profound biological, psychological, and social transformations, many of which generate crises, conflicts, and contradictions'*⁵.

Pathological and biopsychosocial changes of these individuals can impact their quality of life, defined by the World Health Organization (WHO) as *'the individual's perception of her/his position in life in the culture and value systems in which she/he lives and in relation to her/his objectives, expectations, standards, and concerns'*⁶. Specifically, the concept of quality of life-related to health is defined *'as the level of well-being based on the evaluation that the individual makes in diverse domains of her/his life, considering the impact that her/his health status has on these'*⁷.

According to the above, the objective of this study was to identify scientific evidence about the impact of type 1 DM on the quality of life of adolescents who suffer from this disease.

Method

Systematic review of the literature related to type 1 DM and adolescents, according to the stages recommended by the Cochrane Collaboration, which are (I) research question formulation, (II) establishment of inclusion and exclusion criteria, (III) location of articles, (IV) application of methodological quality criteria, (V) data collection, analysis, and (VI) presentation of results^{8,9}.

We conducted this review according to the question 'What scientific evidence is there about the im-

pact of type 1 DM on the quality of life of adolescent carriers of this disease?' This question is based on the PICO strategy, which stands for: Patient - adolescent carrier of type 1 DM; Intervention - factors or behaviors that intervene in type 1 DM and are related to the adolescents' quality of life; Comparison - not applicable in this review; Outcomes/Results - evaluation of the impact of type 1 DM on adolescent health as measured by the quality of life scales.

For this search strategy, in December 2019 we reviewed the databases Medical Literature Analysis and Retrieval System (MEDLINE), Cumulative Index to Nursing and Allied Health Literature (CINAHL), Latin American and Caribbean Health Sciences Literature (LILACS), and Scientific Electronic Library Online (SciELO).

In English, we used selected descriptors from the Medical Subject Headings (MeSH), in Spanish and Portuguese, the Health Sciences Descriptors (DeCS) along with Boolean operators (AND and OR). The following MedLine search strategy was used and then adapted to the other databases: *Search (((((Adolescent*) OR Teen*)) AND (((Diabetes Mellitus, Type1) OR Diabetes, type 1) OR Type 1 diabetes)) AND (((Quality of life) OR Health related quality of life) OR Life quality)) AND (((((((Health impact assessment) OR Health impact) OR Impact assessment, health) OR Diabetes Impact Measurement Scales) OR PedsQL) OR Glycated Hemoglobin A1c) OR Glycosylated Hemoglobin A1c) OR HbA1c) OR Glycemic Control).*

The inclusion and exclusion criteria were then applied to this search. The inclusion criteria were research articles, systematic reviews, and meta-analyses published between 2010 and 2019 in Spanish, English, and Portuguese. Among the particular characteristics of the subject under study were adolescents (10 to 18 years old) with type 1 DM. The exclusion criteria were narrative reviews, clinical guidelines, letters to the editor, opinion articles, experience reports, clinical cases, books, conference presentations, studies where the measurement method of the variable under study was not clear, and articles that did not answer the research question. Among the particular characteristics, adolescents suffering from type 2 DM or other chronic diseases and institutionalized diabetic patients were excluded, in addition to those who had other diseases associated with type 1 DM.

Once we identified the articles in the databases, the duplicate records were eliminated using EndNoteBasic software, Thomson Reuters, USA. Then, in order to further refine the search strategy, two phases of record elimination were executed; the first one, through reading titles and abstracts, and the second one, reading the full text.

The criteria for evaluating the methodological qua-

lity of the studies were applied to the selected articles in full text using the AMSTAR scale (Assessment of Multiple Systematic Reviews) for systematic reviews and the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) list for observational studies^{10,11}. As a last stage, the articles that scored less than 80% were eliminated, obtaining the articles included for review. This entire process of identifying, selecting, and evaluating the eligibility of the articles was carried out using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) protocol¹².

Three authors independently analyzed the selected articles for review and the divergences were resolved through consensus, after a new review of the article or articles in disagreement. This analysis was carried out through a descriptive and analytical review of the results found in the reading of the full-text articles.

Using a summary table, the results were presented and evaluated regarding their applicability or answer to the research question, which considers the following aspects: article identification, source country, year of the study, sample size, participants' age, type of study, inclusion criteria of the study participants, evaluation scales, and the contribution to the research question.

Regarding the ethical aspects, we respected the integrity of the articles, making no changes to their contents.

Results

679 studies were identified using the search strategy in the Medline, LILACS, CINAHL, and Scielo databases. Figure 1 shows the identification, selection, eligibility, and inclusion process of the selected studies.

The articles included in the study for analysis were 25¹³⁻³⁷ (table 1 and 2), most of them were obtained from the MEDLINE bibliographic database. English was the predominant language^{13-22,24-35} and most of them were published in 2018 (7 - 28%)³⁰⁻³⁶. Pediatric Diabetes was the most widely used academic journal for publishing articles^{15,26,31,33}.

There were research in 4 continents, 9 publications in Europe^{14,15,17,19,22,25,29-31}; 4 publications in Asia^{13,18,20,24}; 1 publication in Africa²⁸, and 11 publications in the Americas^{16,19,21,23,26,32-37}. In addition, there was one publication covering all five continents²⁷.

In this diversity of countries, we observed that most of the studies were carried out in the United States (5 - 20%)^{16,19,26,33,34}, and in South America, Brazil^{21,32,37} and Chile^{23,36} stand out. Also, 2 narrative review studies^{16, 36}, and 1 with meta-analysis²³ were found; the rest were descriptive cross-sectional studies and, in some cases, comparative studies of two or more co-

horts^{14,15,17,20-22,24-37}. Finally, some studies had characteristics of national^{17,19,31} and international²⁷ multicenter studies. These latter studies were those with the largest study population, such as the TEEN study that was one of the world's largest studies conducted between 2012 and 2013 in more than 20 countries and 219 centers worldwide with 5,887 children or young people between the ages of 8 and 25; which considered topics such as the management of type 1 DM and the impact on the psychosocial parameters of these patients.

The hypothesis tested in this cross-sectional observational study was the existence of a linear relationship between quality of life and HbA1c levels and that, according to its authors, it is probably a two-way relationship; however, a causal relationship cannot be established since it is a cross-sectional study²⁷.

Regarding the three national studies, there is a first multicenter study carried out in Norway with a population base. It evaluated the quality of life of 937 children and adolescents with type 1 DM regarding the insulin administration system. The results showed no significant differences in the scores between users of an insulin pump and those under multiple-dose insulin injection therapy¹⁷.

The second national multi-center study was a 4-year longitudinal observational follow-up of a sample of 1,151 adolescents from the U.S. SEARCH for Diabetes in Youth project. The objective was to compare the quality of life of a type 1 DM versus a type 2 DM cohort. The results show that adolescents with type 1 DM had higher PedsQL (better quality of life) scores that were related to parents with further education, greater physical activity, and lower HbA1c levels compared with adolescents with type 2 DM¹⁹.

Finally, the third multicenter study was quantitative correlational to evaluate the quality of life of 229 adolescents with type 1 DM mainly from the behavioral point of view, observing a significant association between quality of life and resilience³¹.

Regarding the particular characteristics of the study subjects, in the studies that had these data, the age of the participants varied from 2 to 25 years^{30,33} and the average age ranges from 10.8³⁴ to 16.3 years^{30,33}; however, there are 3 studies in which children and adolescents were included^{13,14,22}.

The study population consisted of 11,720 participants; the smallest sample was 30 adolescents, who were participating in a diabetes camp²⁴ and the largest one was 2,846 adolescents²⁷ from the TEENs study, which covers 20 countries.

The most common inclusion criterion to participate in the study was that adolescents should have type 1 DM at least 1 year since diagnosis^{18,20,21,23,27,28,29,31,32,34}. The most widely used instrument, relating to the quality of life measurements, was the Pediatric Quality of

Life Questionnaire (PedsQL)^{13,14,18-20,22-25,27,29,31,33,34}. The PedsQL 3.2 Diabetes Module is a measurement instrument used to evaluate the quality of life of pediatric patients (2 to 18 years) with DM. It consists of five dimensions that measure the symptoms of diabetes (15 items), treatment barriers (5 items), adherence to treatment (6 items), concern (3 items), and communication (4 items). It has an excellent construct validity and reliability that gives it the capacity to evaluate the symptoms and management of DM according to the impact on the patient's daily life. In addition, it standardizes the results in scientific research⁴⁵.

Discussion

The scientific evidence analyzed shows that type 1 DM is present on all continents, as confirmed by studies conducted on adolescents with type 1 DM in different countries¹⁷⁻³⁷. The international study TEENs, which covered a global sample of 2,846 adolescents from the 5 continents, aimed at characterizing the type 1 DM-related quality of life, used multivariate linear regression analysis and concluded that quality of life was closely related to HbA1c levels, meaning that the lower the HbA1c values, the better the health-related quality of life (HRQoL)²⁷. In this study, 71% of the adolescents had HbA1c values ≥ 7 , similar to 12 other studies in this review that show average HbA1c³¹ values from 7.1%²⁷ to 10.3%.

These percentages are far from the cut-off point determined by the American Diabetes Association (ADA) and the International Society for Pediatric and Adolescent Diabetes (ISPAD), which establishes HbA1c values $\leq 7\%$ as an ideal goal for diabetic patients under treatment^{38,46}. However, several cohorts of these studies are above these HbA1c values, thus these adolescents have a moderate metabolic decompensation^{18,33,34,35,37} and, in other cases, a severe one^{31,32}.

Linked to this level of metabolic involvement, the high prevalence of metabolic decompensation is confirmed, as shown by the 4.5-years follow-up retrospective study conducted in Chile with children and adolescents who had strict nutritional management and an insulin therapy scheme, which showed that only 20% of the cases had a metabolic control according to ADA standards⁴⁷. Therefore, due to the relevance of this blood test defined as a *gold standard* for monitoring metabolic control, it is included in the evaluation of clinical aspects of HRQoL³⁸.

Other aspects that go along with the quality of life evaluation are the psychosocial ones of the adolescent who suffers from type 1 DM. According to Riaño, the adolescent with type 1 DM sees all areas of her/his life affected, especially the psychological one³⁹. As stated by Barroso et al. the most complex step in these chroni-

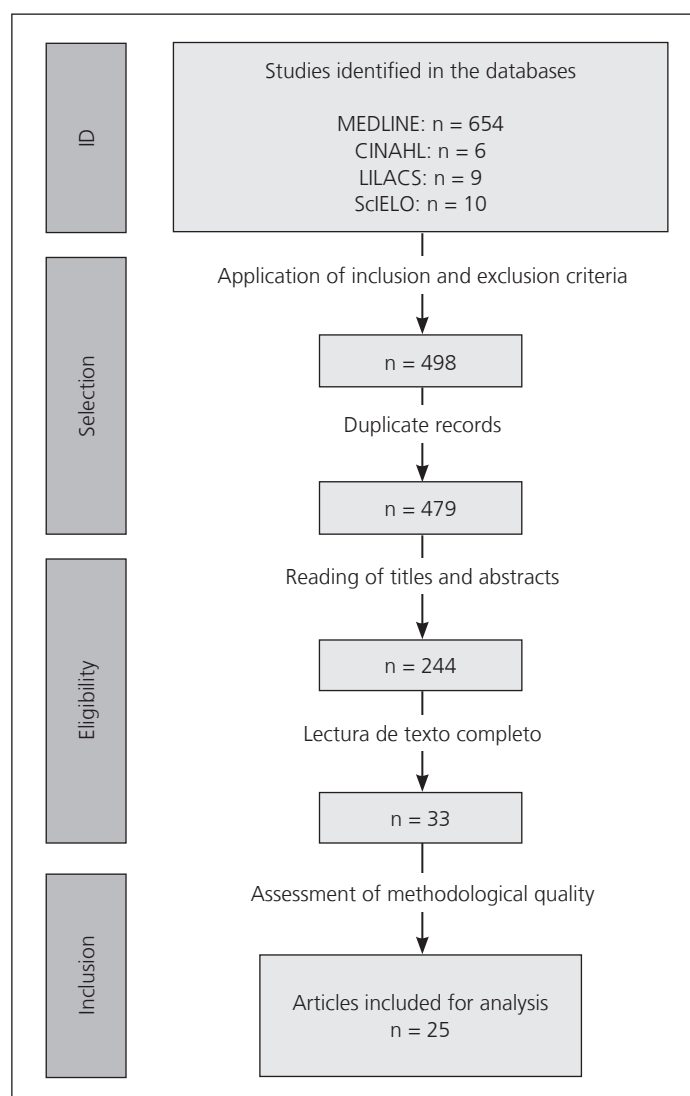


Figure 1. Study identification, selection, eligibility and inclusion flowchart. Santiago Chile, 2020

cally ill adolescents is the acceptance and adaptation to this pathological situation^{2,5,40}. The importance of these psychological alterations is such that their management is considered within the recommendations of the ISPAD Clinical Guidelines for Psychological Care⁴⁸. Therefore, living with type 1 DM is a challenge for the adolescent.

To evaluate the above aspects, there is the PedsQL in generic version and with the diabetes module that assesses HRQoL, which is widely used and has been validated in several languages^{16,41,42}. Both scales range from 0 to 100, with higher scores indicating better quality of life or fewer diabetes-related symptoms^{42,43}.

In this literature review, the generic or specific PedsQL was used in 14 of 25 studies^{13,14,18-20,22-25,27,29,31,33,34}, where 9 of them are cross-sectional studies^{20,22,24,25,27,29,31,33,34} and 5 case-control ones^{13,14,17,18,25}.

Table 1. Characterization of studies on Type 1 Diabetes Mellitus and quality of life of adolescents - Santiago, Chile, 2020

Article ID	Country of study and year of study	Sample size	Age of participants	Type of study	Study entry characteristics of the participants
Jafari et al., 2011 ¹³	Iran Does not refer	94 children or adolescents (study cohort) and 200 healthy children or adolescents (control group) from tertiary care clinics.	8 to 18 years	Study of 2 randomized cohorts.	Participants must be at least 3 months after diagnosis of DM1
Tahirović et al., 2012 ¹⁴	Bosnia and Herzegovina 2008	65 children or adolescents from the Regional Center for Diabetes	5 to 18 years	Cross-sectional study of 2 cohorts: 1st group HbA1c <8% (n = 21) 2nd group HbA1c > 8% (n = 44)	With more than 6 months of diagnosed DM1
De Wit et al., 2012 ¹⁵	Holland Does not refer	84 participants with DM1 The women are 44 and the men 40	10 to 18 years X = 14.4 years	Psychometric evaluation of the Individual Needs Monitoring Questionnaire in Juvenile Diabetes (MY-Q)	Adolescents with T1D from two pediatric outpatient clinics in the Netherlands.
Hirose et al., 2012 ¹⁶	USA 2012	Author does not refer, but there are 113 bibliographic references in the article	Author does not refer, but the references are from the last 2 decades	Narrative bibliographic review	-----
Frøisland et al., 2013 ¹⁷	Norway 2010 to 2011	Two cohorts of adolescents with DM1: 923 adolescents (study cohort) from the Pediatric Control and 1029 (non-participating cohort) from the Norwegian Childhood Diabetes Registry	8 to 19 years X = 13.3 years (study cohort) versus X = 14.3 years (non-participant)	Population comparative cohort study of 21 pediatric centers	In intensive treatment with continuous subcutaneous insulin infusion (CSII)
Abdul-Rasoul et al., 2013 ¹⁸	Kuwait Does not refer	188 adolescents with DM1 from 6 hospitals and diabetes centers	Adolescent (13 to 18 years)	Case-control study with 2 study cohorts: 97 adolescents with DM1 (case group) and 91 without DM1 (control group)	With time of diagnosis of DM1 ≥ 1 years
Naughton et al., 2014 ¹⁹	USA Does not refer	910 participants with DM1 and 241 with DM2	10 to 22 years X = 13.6 years (DM1) X = 15.2 years (DM2) 52.8% (DM1) and 38.2% (DM2) are men	Longitudinal, 4-year follow-up observation of 2 cohorts (DM1 and DM2) of the SEARCH National Multicenter Study	It excludes young people with gestational diabetes.
Al-Hayek et al., 2014 ²⁰	Saudi Arabia 2013	214 adolescents from the Diabetes Treatment Center.	13 to 18 years X = 15.2 years	Cross	No chronic diseases and with at least 1 year of follow-up at the Center.
Costa LM et al., 2015 ²¹	Brazil 2014	96 adolescents in control at the Endocrinology Center	Adolescents from 10 to 19 years old	Cross	With a minimum of 1 year after the diagnosis of DM1.
Boogerd et al., 2015 ²²	Netherlands 2009	110 children with DM1, with their parents and health professionals.	4 to 16 years	Cross	-----
Higueta-Gutiérrez et al., 2015 ²³	Chile 2015	Composed of 10 articles that included a population with 6,841 adolescents with DM1, 941 with DM2, 835 with overweight and 291 with obesity	Adolescents from 10 to 19 years old with DM1, 56 women and 42 men	Systematic review with meta-analysis	At least 1 year after the diagnosis of DM1
Boo et al., 2016 ²⁴	South Korea 2012 to 2013	30 teenagers from a diabetes camp.	8 to 18 years X = 13.3 years	Cross	Excluding participants who have had hospitalizations.

Table 1. Characterization of studies on Type 1 Diabetes Mellitus and quality of life of adolescents - Santiago, Chile, 2020 (continuation)

Article ID	Country of study and year of study	Sample size	Age of participants	Type of study	Study entry characteristics of the participants
Samardzic et al., 2016 ²⁵	Montenegro 2013 to 2014	165 children or adolescents with DM1 from the Endocrinology Clinic	87 adolescents from 13 to 18 years old X = 12.6 years	Cross-sectional with 4 cohorts: 3 cohorts according to HbA1c levels (165 children or adolescents case group) and a group of 163 without DM1 (control group)	They should have been diagnosed with DM1 for more than 6 months
Huston, et al., 2016 ²⁶	USA	246 adolescents with DM1	11 to 16 years X = 13.2 years 64.3% were women	Not specified, but transverse type is inferred	-----
Anderson et al., 2017 ²⁷	Clinical offices in 20 countries on 5 continents	5,887 children or young people from 8 to 25 years old The group of adolescents was 2,846 (13 to 18 years old)	Divided into 3 groups according to age. The group from 13 to 18 years old (X = 15.3 years)	International cross-sectional (TEENS study)	With time of diagnosis of DM1 greater than 1 year
Hassan et al., 2017 ²⁸	Egypt Does not refer	150 adolescents from the Pediatric Diabetes Unit	10 to 18 years X = 12.3 years	Cross	With a time of diagnosis of DM1 of at least 1 year
Mozzillo et al., 2017 ²⁹	Italy 2014 to 2015	242 adolescents from 3 pediatric diabetes centers	13 to 19 years	Cross	With time of diagnosis of DM1 ≥ 2 years
Bächle et al., 2018 ³⁰	Germany 2009-2010	839 adolescents, 425 being men and 414 women	Adolescents from 11 to 21 years old. X = 16.3 years	Analysis of the national survey "Clinical Course of Type 1 Diabetes in Children, Adolescents and Young Adults with Disease Onset in Preschool Age "	-----
Lukács et al., 2018 ³¹	Hungary Does not refer	229 adolescents with DM1.	X = 15.35 years, 51.2% were men	Multicenter quantitative correlational design study	Diagnosed with DM1 for at least 1 year and without mental disorders that impede the development of the test
Martins et al., 2018 ³²	Brazil 2013	59 teens	Adolescents from 9 to 16 years X = 13.6 years 57.6% were women.	Cross	Adolescents with a diagnosis of DM1 less than 1 year old and other pathologies are excluded.
Varni et al., 2018 ³³	USA 2015 to 2017	418 adolescents and young adults from 10 clinics	13 to 25 years X = 16.3 years	Cross	DM1 should be a primary diagnosis.
Saoji et al., 2018 ³⁴	USA Does not refer	132 adolescents from two multidisciplinary diabetes clinics	13 to 16 years X = 15.0 years	Cross	Diagnosis of DM1 at least 1 year
Guerrero-Ramirez et al., 2018 ³⁵	Puerto Rico 2018	51 Latino adolescents (29 girls) accompanied by 1 caregiver each	12 to 17 years X = 14.7 years	Data from a parent project whose name is not specified	--
Henríquez-Tejo et al., 2018 ³⁶	Chile 2018	The article has 49 bibliographical references	--	Narrative review	--
Souza et al., 2019 ³⁷	Brazil 2014	92 adolescents with DM1 in health control for DM	X = 14.6 years SD = 2.9	Cross	--

Table 2. Assessment scales of the quality of life of adolescents with type 1 Diabetes Mellitus, results of the studies and contributions to the research question, Santiago, Chile, 2020

Study identification	Assessment scales	Contributions to the research question
Jafari et al., 2011 ¹³	Generic PedsQL™ 4.0 Core Scales	The total scores on the PedsQL 4.0 scale were 67.98 ± 14.03 (DM1 cohort) and 78.21 ± 13.23 (healthy cohort). For PedsQL 3.0 the domain barriers to treatment was the lowest score (58.38 ± 21.51) and the highest was the communication domain with 61.08 ± 27.34 .
Tahirović et al., 2012 ¹⁴	PedsQL™ 3.0 Diabetes Module Pediatric Quality of Life Questionnaire:	Group 1 (HbA1c <8%) had better Health-related Quality of Life (HRQOL) scores in the domains of diabetes symptoms, barriers to treatment, adherence to treatment, and concern, compared to Group 2 (HbA1c > 8%).
	Generic PedsQL™ 4.0 Core Scales	There is a significant correlation between the generic total HRQOL and HbA1c scores, indicating that poor glycemic control is associated with lower generic and specific HRQL scores, that is, poorer quality of life.
	PedsQL™ 3.0 Diabetes Module	
De Wit et al., 2012 ¹⁵	Juvenile Diabetes Individual Needs Monitoring Questionnaire (MY-Q)	The MY-Q questionnaire obtained a Cronbach's alpha of 0.80, that is, a good internal consistency. Furthermore, strong correlations between total MY-Q and PedsQL diabetes module and generic scores confirmed concurrent validity.
		The study indicates that at a younger age there is a greater management of the pathology. A higher HbA1c was associated with a lower perception of diabetes control.
Hirose et al., 2012 ¹⁶	Not applicable, but this review discusses the impact of new technologies on the quality of life in children and families with DM1	It is presented for the management of insulin therapy, insulin pump and continuous glucose monitoring, evaluating the impact of these therapies on HRQL
		Insulin pump therapy improves meal times, bolus infusion patterns, and hourly basal insulin, which in turn increases flexibility in everyday life for children and families. But, these promising findings need more and better-designed studies to confirm the impact of insulin pump therapy on the quality of life of children with DM1
Frøisland et al., 2013 ¹⁷	Chronic Generic Module DISABKIDS DCGM-37 Questionnaires	Average duration of DM1 = 4.9 years (study cohort) 5.9 years (non-participant)
	Diabetes Specific Module DDM-10	The mean HbA1c values were 8.5% (study cohort) and 8.8% (non-participant)
		Lower scores on the DDM-10 Scale were significantly associated with being female and with a higher HbA1c. Quality of life was related to better metabolic control and gender, but not to the mode of treatment
Abdul-Rasoul et al., 2013 ¹⁸	PedsQL 3.0 Diabetes Module	Average HbA1c values were 8.9%
		The HRQL of adolescents with DM1 was consistently lower than controls, as higher HbA1c values were associated with lower quality of life scores (total, emotional and social domain)
		HRQoL was higher among those with DM1 versus DM2
Naughton et al., 2014 ¹⁹	Pediatric Quality of Life Questionnaire (PedsQL)	Among the DM1 participants, the highest (best) total PedsQL scores were related to greater parental education, lower HbA1c values, and greater physical activity during the last 7 days
		The girls' HRQL remained stable or decreased over time, while the men's HRQL increased, indicating that the effects of diabetes on HRQL differ by sex
		79.9% of the adolescents had HbA1c > 7%
		The average time of diagnosis was 8.7 years ago.
Al-Hayek et al., 2014 ²⁰	Pediatric Quality of Life Questionnaire (PedsQL 3.0 DM)	Age, type of treatment (multiple daily injection), diabetic ketoacidosis, and HbA1c > 7 were independent influencing factors for the diabetes symptoms subscale. HbA1c > 7 was the independent influencing factor for treatment barriers and HRQL in general. Diabetic ketoacidosis was the independent influencing factor for the worry subscale and female gender was the independent influencing factor for the communication subscale

Table 2. Assessment scales of the quality of life of adolescents with type 1 Diabetes Mellitus, results of the studies and contributions to the research question, Santiago, Chile, 2020 (continuation)

Study identification	Assessment scales	Contributions to the research question
Costa LM et al., 2015 ²¹	Quality of Life of Jovens com Diabetes (IQVJD)	81% of the adolescents had decompensated DM (HbA1c ≥ 7) The average and minimum and maximum values of the IQVJD instrument are: satisfaction domain, 35 (17-62); impact domain, 51 (26-73) and concern domain 26 (11-44) The quality of life of the adolescents was evaluated as good or excellent (74%). But, there are specific factors that reduce it, such as being treated in a public service, having a diagnosis of DM1 for more than 3 years, not practicing physical activity and working in addition to studying No statistically significant associations were found between clinical factors (time to diagnosis, type of insulin, hypoglycemia, physical activity and nutritional status) and the items in the impact domain Children with DM1 showed more psychosocial problems and a lower HRQoL compared to their healthy peers. Professionals seem to tend to overestimate psychosocial problems
Boogerd et al., 2015 ²²	Strengths and difficulties questionnaire Pediatric quality of life questionnaire (PedsQL)	In DM1, the average physical health was 85.0; psychosocial health 78.4; emotional state 74.9; social relations 86.0 and school domain 74.1 The HRQL of adolescents with DM1, DM2, overweight and obesity do not present significant differences from a clinical point of view, it also reflects that in the four diseases the domains related to emotional and school health are affected to a greater extent than physical health
Higueta-Gutiérrez et al., 2015 ²³	Pediatric Quality of Life Questionnaire (PedsQL)	Average duration of DM1 = 4 years The average HbA1c was 8.8%
Boo et al., 2016 ²⁴	PedsQL™ 3.2 Diabetes Module	PedsQL diabetes ranged from 46.1 to 93.8 with a mean of 69.2 ± 14.1 The average of the PedsQL Scale was 69.2 with a range of 46.1 to 93.8 Older, masculine and less depressed adolescents were more likely to have a better quality of life Children and adolescents with T1D had lower HRQoL in the domain "Psychosocial health" and "School functioning" compared to healthy adolescents. Lower HbA1c values were associated with fewer worries and better quality of life
Samardzic et al., 2016 ²⁵	PedsQL 4.0 Generic Core Scales (GCS) PedsQL 3.0 Diabetes Module	Scales were proposed for the evaluation of different points. It is concluded that the greatest problem for patients is not being able to carry out the activities that they enjoyed with their friends due to diabetes, considering that the best accepted point was the adaptation of the user with diabetes related to physical and recreational activities
Huston, et al., 2016 ²⁶	Average time of DM1 = 8.2 years Coping Scale, Seeking Benefits Scale, Negative Diabetes Emotion Scale, Emotion Processing and Expression of Emotions Scale, Acceptance Scale, and Diabetes Adaptation and Comfort Scale	71% of adolescents had HbA1c ≥ 7 There is a significant linear relationship between quality of life and HbA1c. Adolescents with HbA1c < 7.5% have the best quality of life in relation to higher HbA1c values There are 3 diabetes control behaviors that were significantly associated with improved quality of life: advanced methods used to measure food intake, more frequent daily blood glucose monitoring, and more days per week of physical activity
Anderson et al., 2017 ²⁷	PedsQL 3.0 Diabetes Module	

Table 2. Assessment scales of the quality of life of adolescents with type 1 Diabetes Mellitus, results of the studies and contributions to the research question, Santiago, Chile, 2020 (continuation)

Study identification	Assessment scales	Contributions to the research question
Hassan et al., 2017 ²⁸	Diabetes Attitudes, Wishes and Needs (DAWN) Diabetes Quality of life for Youth	43.33% of the adolescents had a good perception of their health Better metabolic control was associated with better quality of life Quality of life had a significant association with gender, residence, educational level, and metabolic control of adolescents. But, the duration of diabetes and body mass index did not have a statistically significant effect on quality of life
Mozzillo et al., 2017 ²⁹	PedsQL 3.0 Diabetes Module KIDMED (Mediterranean diet evaluation)	15 (6.2%) adolescents fulfilled the set of 3 healthy lifestyle habits; 62 (25.6%) had 1 unhealthy lifestyle habit and 165 (68.2%) had ≥ 2 The grouping of unhealthy lifestyle habits is associated with a reduction in HRQL in adolescents with DM1 High PedsQL was significantly associated with being male, living in southern Italy, having lower mean HbA1c levels, and adherence to healthy lifestyle habits
Bächle et al., 2018 ³⁰	HRQL surveys KINDL-R generic, DISABKIDS (DCGM-12) chronic generic module DISABKID diabetes specific module with impact and treatment scales	Average HbA1c values were 8.3% The mean quality of life scores were for the KINDL-R (73.2); for DCGM-12 (76.1); for the impact of diabetes (66.2) and for the treatment of diabetes (56.4) (DISABKIDS) Although both the quality of life results and the HbA1c level improved with increasing individual socioeconomic status, no association was observed between deprivation at the area level (income, education, employment, environment, municipal income, social capital, security) and none of the results
Lukács et al., 2018 ³¹	Diabetes 3.0 Module of the Pediatric Quality of Life Questionnaire (PedsQL DM) Resilience Scale (RS) version 15	Average HbA1c level = 10.3% The total mean HRQL score of the patients was 71.57 No problems with compliance with treatment (82.07) Problems with the presence of symptoms of diabetes (63.45) A significant association between HRQL and Resilience can be observed. Supposedly, a higher level of physical activity promotes a higher level of Resilience, which in turn helps to increase HRQL in adolescents with DM1. Treatment with insulin pump therapy, too, promotes better HRQL
Martins et al., 2018 ³²	Quality of Life of Young People with Diabetes (IQVID)	The average HbA1c the previous year was 10% The results showed a good quality of life in 71% of the adolescents. When performing a domain analysis, height Z score, lower HbA1c, physical activity practice, pen use, fewer hospitalizations, and residence in a rural area were associated with better HRQL
Varni et al., 2018 ³³	PedsQL Diabetes Module 3.2 Scale	The average HbA1c is 8.9% Average PedsQL = 82.33 SD = 13.53 Diabetes demographic, clinical, symptoms, and treatment variables significantly accounted for 53% of the variance in generic HRQL, demonstrating a large effect size on quality of life Patient health communication and social shame had direct effects on the barriers to adherence to treatment perceived by the patient and HRQL
Saoji et al., 2018 ³⁴	PedsQL Diabetes Module Scale PedsQL Family Impact Module	The average HbA1c was 9.0% Average duration of DM1 was 6.1 years The average quality of life was 67.2 Diabetes-specific quality of life was strongly associated with the "pain and discomfort regimen" for adolescents

Table 2. Assessment scales of the quality of life of adolescents with type 1 Diabetes Mellitus, results of the studies and contributions to the research question, Santiago, Chile, 2020 (continuation)

Study identification	Assessment scales	Contributions to the research question
Guerrero-Ramírez et al., 2018 ³⁵	Suicidal Ideation Questionnaire-Junior (SIQ-Jr) Diabetes Quality of Life Questionnaire for Youth (DQOLY) Diabetes Self-efficacy Scale (SED) Barriers to Adhesion Questionnaire (BAQ) Child Behavior Checklist (CBCL)	The average HbA1c was 9.14% The factors associated with suicidal ideation were depression, somatic complaints, and perceived family emotional support (they explain 46% of the variance) The factors associated with HRQOL were cognitive alterations, barriers to adherence, perceived family emotional support, and diabetes self-efficacy (they explain 61 % of the variance)
Henríquez-Tejo et al., 2018 ³⁶	Clinical and epidemiological aspects Personal and social costs Current treatment of DM1 in Chile Psychosocial repercussions Adolescence and psychosocial problems. Psychosocial care	Education has not had a great impact on glycemic control Family factors and peer support have a greater impact than drug treatment He refers that adolescent girls have poorer control of DM, due to hormonal changes and a lower level of physical activity than men, which results in lower scores in quality of life evaluations It stands out that the educational programs (TEENCOPE, CASCADE and Managing Diabetes) have had better results in glycemic control
Souza et al., 2019 ³⁷	Diabetes Quality of Life Questionnaire for Youth (DQOLY)	Average time since DM1 diagnosis = 6.8 years Age of onset of symptoms = 7.6 years Without other pathologies (96.7%) With chronic complications (87%) 59.8% use 4 or more doses of insulin/day 18.5% had controlled HbA1c The mean HbA1c value was 9.59% Total HRQL is high (117.5) in all domains except for the "impact" domain, which has an average value of 53, which indicates a low HRQL. The most altered item was the impact domain (parents' overprotective attitude and excessive concern for their children's glycemic control). In the sociodemographic variables, it was found that the economic class showed statistically significant differences between the scores for HRQOL and the "impact" domain. In the clinical variables, the complications of DM1 showed statistically significant differences for the total HRQL score and the "impact" domain. These results indicate a greater deterioration in total HRQOL and a greater impact on the lives of adolescents with complications associated with the disease

When measuring with that scale, it was identified that the younger the age, the greater the management of the pathology¹⁵, and when comparing by sex, being a woman was significantly associated with lower scores, that is, worse quality of life^{17,19,24,29,36}.

The emotional and social domains of this generic PedsQL scale, when associated with higher HbA1c levels, had the lowest scores, as was the case in case-control studies, where the diabetic cohorts had lower scores in the emotional, social, and school domains of the PedsQL scale when compared with the healthy cohorts^{13,18,22,25}.

Authors such as Higuaita-Gutiérrez et al. confirm the above in their systematic review and meta-analysis, where they state that the emotional health and school domains are affected far more than physical health²³. This is an important finding since an emotional state associated with higher levels of stress generates higher levels of cortisol that interfere with insulin metabolism and, thus, metabolic control²³. In addition, by confirming that higher HbA1c levels were associated with a lower perceived control of diabetes, these psychological aspects are related to physical health¹⁵. These results lead to studies that reaffirm that high HbA1c levels are associated with a lower HRQoL score^{14,17,18,20,25,27-29,32}. These studies showed that this pathology requires daily self-control on the part of the adolescent, which is the cornerstone of care for this entity.

The PedsQL Diabetes Scale aims at evaluating the specific domains of this pathology which, in some studies, shows that the best scores in the domains of diabetes symptoms, barriers to treatment, adherence to treatment, and concern, are associated with better glycemic control^{14,25,33,35}. A case-control study comparing 2 groups of adolescents with type 1 DM who had different average levels of metabolic control (7.3% and 8.8% of HbA1c) reaffirmed these results and confirmed the trend of previous results, meaning that adolescents with better metabolic control have better scores in the PedsQL scale diabetes dimensions, except in the "communication" one¹⁴. However, authors such as Frøisland et al. did not obtain the same findings in their research, since they found that quality of life was not related to adherence to treatment¹⁷.

When using other scales, such as the Diabetes Quality of Life Questionnaire for Youth (DQOLY), the most altered aspect was the impact domain (overprotective attitude of parents and their excessive concern for their children's glycemic control)³⁷. A different result was obtained with the same scale, in which between the impact domain and clinical factors (such as type of insulin, hypoglycemia, physical activity, and nutritional status) there was no statistically significant association²¹.

Other studies, such as the one by Souza et al., found

that clinical variables showed statistically significant differences in the total HRQoL score and the impact domain³⁷. In this scale, the results indicated a greater deterioration of the total HRQoL and that the greatest impact on the lives of adolescents is the complications associated with the disease secondary to poor management of metabolic control³⁷.

Related to the previous hypotheses, Anderson et al., refer that one of the three most relevant behaviors for the control of diabetes, which was significantly related to a better quality of life, is the daily monitoring of blood glucose²⁷, therefore, the treatment with an insulin pump would help this fact. Lukács et al., who found that the insulin pump promotes better HRQoL³¹, also share this idea. However, Hirose et al. did not support this view, who through a narrative review, reported that studies with insulin pump therapy technology have poor methodological designs and, therefore, their evaluations are inconsistent with quality of life. Thus, the author states that they limit the power to claim that there is a strong association between the benefits of insulin pump therapy and quality of life¹⁶.

Regarding other behaviors, such as lifestyles, it can be observed that the highest total PedsQL scores were related to lower HbA1c values and greater physical activity^{19,27,29,31,32,36}.

This statement was also presented when comparing a group of adolescents with type 1 DM with another one with type 2 DM, demonstrating that a better HRQoL in type 1 DM is related to more physical activity, parents with further education, and lower HbA1c values¹⁹. However, other studies report that both the quality of life and the HbA1c level improved with an increase in the individual's socioeconomic level, but there was no association with a decrease in income, education, employment, social capital, and security, among other aspects³⁰.

Another important aspect of the life cycle of these adolescents with type 1 DM is the transition from pediatric to adult health care. In order to learn about this process, an interesting study was conducted in Chile to evaluate the effectiveness of a "transition program" with two study groups; one with comprehensive health care team interventions and the other one without it. The results showed that adolescents with such intervention had better adherence indicators for maintaining or improving HbA1c levels. (60% versus 30%), however, this was not significant⁴⁹. These studies were published in specific scientific journals on the subject such as *Pediatric Diabetes*^{15,26,31,33}, *Journal of Pediatric Endocrinology and Metabolism*^{25,28}, *Current Diabetes Reports*¹⁶, and *Diabetes Care*²⁷.

The review and analysis carried out shows the existence of great concern of the scientific community to help face this disease, which represents support from

science that contributes to answering the research question posed in this work.

In conclusion, quality of life measured by diabetic adolescents is significantly associated with HbA1c values, in other words, the higher the level of this indicator, the lower the HRQoL score. This link extends to a significant correlation between the total generic HRQoL scores and HbA1c levels, but it does not have the same impact on the specific HRQoL scores, due to the existence of controversies in some dimensions of this scale.

Thus, the metabolic control is established as the cornerstone that affects the impact on the relationship between type 1 DM and quality of life; a link that is seen as bidirectional, although there is no absolute consensus on the types of factors and degrees that would influence the metabolic control.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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