

Quality of life related to health of adolescents with dm1: an integrative review

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Abstract *This study aimed to analyze the scientific literature on health-related quality of life (HRQOL) of adolescents with type 1 diabetes mellitus. This is an integrative review whose inclusion criteria were full-text papers available online in Portuguese, English and Spanish; published and indexed in databases Lilacs, Medline, Adolec, BDENF, in the period 2003-2013 that reflected the theme HRQOL, Type 1 diabetes and adolescents. Twenty-two papers were analyzed, from which the following themes were retrieved: development and validation of tools to measure the HRQOL of diabetic adolescents; HRQOL of adolescents with diabetes; factors affecting the quality of life of adolescents with diabetes and resources used to assist adolescents in diabetes management. The HRQOL of adolescents with diabetes has been a widely studied and disseminated topic in international literature, but has poorly echoed in Brazil. Studies published in international journals in English predominated. Thus, we emphasize the importance of conducting research of this nature in Brazil, since the measurement of HRQOL of diabetic adolescents may help the multidisciplinary team in care planning.*

Key words *Quality of Life, Type 1 diabetes mellitus, Adolescent*

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Introduction

The concept of quality of life (QoL) has been the focus of many studies in the last decades, in different areas of knowledge, and has received different connotations depending on the time and context in which it has been used. Initially, this concept was related to the purchasing power and life conditions it provided. However, with the advancement of research, this approach became insufficient for such an evaluation¹.

Since the 1950s, with increased life expectancy of the population because of the progress of science and the survival of patients with chronic diseases, this concept was modified and expanded, and QoL began to be conceived by individuals in relation to their health condition, as well as to other realms of their life¹. In this context, the Quality of Life Group of the World Health Organization (WHO) conceptualizes quality of life as the individuals' perception of their own life condition, within their own context of culture and value system, considering their life goals, expectations and concerns².

Health-related quality of life (HRQoL) refers to individuals' perception of their life condition in the face of the disease and the consequences and treatments related to it, i.e. how the disease affects their life condition. Measuring this perception is very subjective, because of individuals' difficulty in relating their dysfunction to the multiple realms of their life³.

Chronic diseases affect the individuals' QoL the most, because they permanently interfere with their lifestyle and limit their productive capacity and worldview. In this context, diabetes mellitus (DM) is one of the diseases that impacts individuals' QoL the most, since therapy requires a radical change in their lifestyle and that of their family, due the need to maintain metabolic control in the ideal parameters. Thus, they must change their diet, physical activity, daily insulin injections and consultations with the endocrinologist to adjust the doses. This routine causes sadness, anxiety and frustration³.

When DM occurs in adolescence, the individual has to address age-related conflicts and must learn to deal with the disease, which is an extremely difficult task because it requires adolescents' discipline and change of habits. Thus, the need to change their lifestyle affects their physical, emotional, social condition and therefore their QoL. This problem has drawn the attention of scholars who sought to understand the experience of adolescents with DM¹⁴ and the re-

lationship between psychological well-being and the management of this disease⁵.

Thus, due to the relevance of this approach and the scarcity of studies in national journals, we asked: "What was produced in scientific journals from 2003 to 2013 in terms of HRQoL of adolescents with DM1? This study aimed to analyze the scientific production on health-related quality of life of adolescents with type 1 diabetes mellitus.

Methods

This is an integrative review, a method by which a phenomenon studied in previous research is analyzed, aiming to understand a certain theme. The study was developed from the following steps: identifying the theme and selecting the research question; establishing inclusion and exclusion criteria; identifying and selecting studies; categorizing selected studies; analyzing and interpreting the results and presenting the knowledge review/synthesis⁶.

The inclusion criteria previously established by the researchers were papers published from January 2003 to December 2013, available in full online in Portuguese, English and Spanish, published and indexed in Lilacs, Medline, BDNF databases, which portrayed the theme health-related quality of life, type 1 diabetes and adolescents. The exclusion criteria were papers that only had the abstract online, which included other chronic diseases in addition to type 1 diabetes and included other groups, such as children and/or adults and review papers.

Descriptors were also pre-established, starting with access to the Regional Medical Library of the Pan American Health Organization (PAHO/Bireme), Health Sciences Descriptors (DeCS) or Medical Subject Headings (MeSH).

The search for papers was conducted by two researchers between June and August 2014, who used the advanced search of the BVS, cross-referencing descriptors through the Boolean operation. In English, we used *Quality of Life AND Diabetes Mellitus AND Adolescent*; in Portuguese, *Qualidade de Vida AND Diabetes mellitus AND Adolescente*, and in Spanish, *Cualidad de Vida AND Diabetes Mellitus AND Adolescente*.

The first search was performed in the BVS with descriptor *Diabetes Mellitus* (302,349 papers), and the second one using the Boolean operation AND in the advanced search, cross-referencing descriptors in English *Quality of Life*

AND *Diabetes Mellitus* AND *Adolescent*, which returned 983 papers. In the third search, filters were used in order to comply with the inclusion criteria: full-text; database: MEDLINE, LILACS, IBECs, BDENF; main subject: type 1 diabetes mellitus, quality of life; limit: adolescent; languages: English, Spanish and Portuguese; years of publication: from 2003 to 2013; document type: paper, returning 294 papers.

In the advanced search, another search was made with the same descriptors in Spanish and later in Portuguese, which returned 766 and 783 papers, respectively. Next, the use of the same filters returned 245 papers in Spanish and 251 papers in Portuguese.

All findings were compared in order to find duplicated papers that appeared in all three languages and databases. Then, titles and abstracts were read and we excluded those with only abstracts online; those including other chronic diseases, in addition to type 1 diabetes; those including other groups, such as children and/or adults, and review papers, observing the exclusion criteria. Thus, by consensus among researchers and in compliance with the inclusion and exclusion criteria, 22 papers were selected and composed the sample.

In general, the BVS search process was shown briefly in Figure 1. We then proceeded to the critical reading of the studies that composed the sample, and with the help of a form prepared by the researchers themselves, we could extract

the most relevant information from the studies, shown in Chart 1.

In the analysis, the relevant data were identified and categorized, using the principles and guidelines of the Thematic Analysis⁷. Thus, initially, a free-floating reading of the collected data was made, considering its “homogeneity, relevance and pertinence”. Then, the significant expressions or words were sorted according to their content, and data were classified and aggregated, defining the empirical categories. Finally, data were interpreted and discussed with the relevant literature.

Results

Chart 1 shows the main data found in the papers that composed the sample, in the following aspects: database, language, type of approach, title, objectives, number of participants, age group, tool/technique to evaluate QoL and main conclusions.

Thus, the study showed that papers published in English (19), in English, Portuguese and Spanish (one), English and Spanish (one) and Portuguese (one) predominated. This proves the scarcity of studies in national journals whose object of study is the QoL of diabetic adolescents.

Most studies (21) adopted the quantitative approach; two of them were randomized, one with a control group, six were QoL tool con-

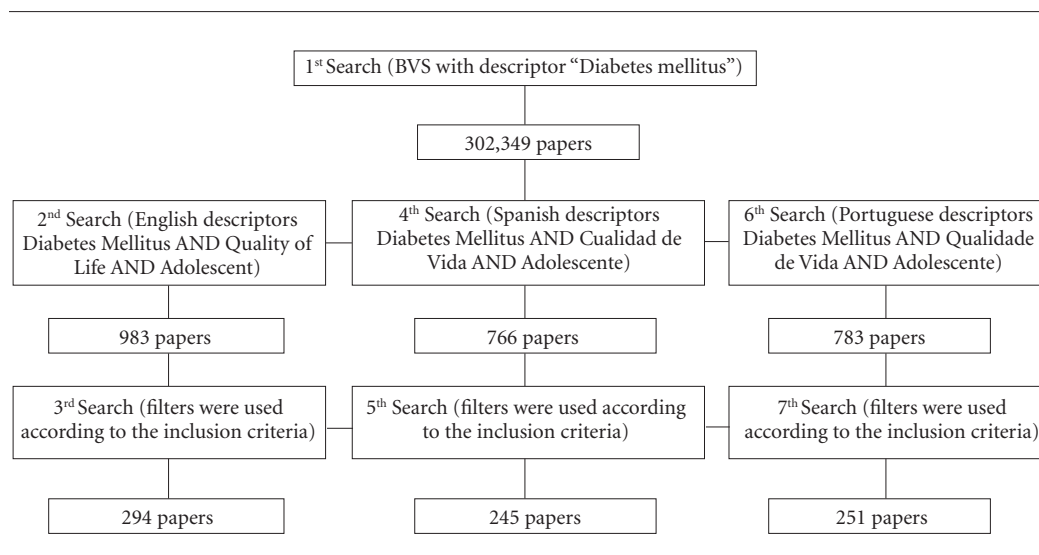


Figure 1. Summary of the search and selection stages of papers according to the inclusion criteria of the study.

Chart 1. Papers found in the Medline, Lilacs, BDNF and Adolec databases, in the period 2003-2013 with a QoL in adolescence approach.

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2004 MEDLINE ENGLISH QUANTI/ QUALITATIVE	The development of a new measure of quality of life for young people with diabetes mellitus: the ADDQoL-Teen ⁸	To assess the psychometric properties of ADDQoL-Teen, an innovative individualized, patient-centered questionnaire that measures the impact of diabetes mellitus on the quality of life (QOL) of adolescents.	23 adolescents	13-16 years	Semi-structured interviews; group discussion, ADDQoL-Teen	The ADDQoL-Teen is a new, perceived measure of the impact of diabetes and its treatment on adolescents' QOL, which will help health professionals and parents consider quality of life issues as well as medical outcomes when caring for young people with diabetes. It can be used in clinical trials and for routine clinical monitoring in the context of ongoing evaluation.
2007 LILACS/ BDNF PORT QUANTITATIVE	Quality of Life Tool for Young People with Diabetes (IQVJD) ⁹	To provide the Quality of Life Tool for Young People with Diabetes (IQVJD), from the American tool "Diabetes Quality of Life for Youths", in view of the lack of specific tools for assessing the Health-Related Quality of Life (HRQOL) of young people with Type 1 Diabetes Mellitus (DM) in Brazil.	124 adolescents with Type 1 DM	12-18 years	Quality of Life Tool for Young People with Diabetes (IQVJD)	It is believed that the dissemination of IQVJD for the implementation in Brazilian adolescents with type 1 DM can contribute to an effective improvement of the quality of care provided to these people.

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struction and/or validation and the others were cross-sectional.

Among data collection tools, the most used was the *Diabetes Quality of Life – Youth questionnaire (DQoLY)*, followed by its short form, the *Short Form of the Diabetes Quality of Life for Youth (DQLQY-SF)*. Attention is drawn to the *Quality of Life Tool for Young People with Diabetes (IQVJD)*, derived from Ingersoll and Marre-

ro's *Diabetes Quality of Life for Youths (DQOLY)*, adapted and validated for the Brazilian culture by Novato et al.⁹. This tool consists of 50 items, distributed in the following areas: "Satisfaction", with 17 items; "Impact", with 22; and "Concerns", with 11. Its use showed adequate psychometric properties to be used in our environment, and it was validated after it was tested in 124 young people with DM1. This is a reliable, valid and

Chart 1. continuation

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2007 MEDLINE ENGLISH QUANTITATIVE	Monitoring health-related quality of life in adolescents with diabetes: a review of measures ¹⁰	To identify and evaluate the use of generic (HRQoL) and diabetes-specific questionnaires for use in adolescents with type 1 diabetes.	-	-	Child Health Questionnaire-Child Form 87 (CHQ-CF87); Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0); Revidierter KINDer Lebensqualitätsfragebogen (KINDL-R); DISABKIDS chronic generic module; Diabetes Quality of Life-Youth questionnaire (DQOL-Youth); PedsQL-Diabetes Module (PedsQL-DM); KINDL-R-Diabetes Module (KINDL-R-DM); Audit of Diabetes Dependent Quality of Life-Teen version (ADDQoL-Teen); DISABKIDS-Diabetes Module (DISABKIDS-DM)	PedsQL and KINDL-R appear, at the time of the study, to be the most adequate tools to evaluate the quality of life of adolescents with DM1,
2008 LILACS/BDENF ENG/POR/SPA QUANTITATIVE	Cultural Adaptation and Validation of The “Diabetes Quality of Life for Youths” Measure of Ingersoll and Marrero into Brazilian Culture ¹¹	To adapt the “Diabetes Quality of Life for Youths (DQoLY)” measure to Brazilian culture and analyze its psychometric properties.	124 adolescents	12-18 years	Diabetes Quality of Life for Youths (DQoLY)	The translated version of DQoLY adapted to the Brazilian culture is a reliable and valid measure to be used in studies in Brazil
2008 MEDLINE ENGLISH QUANTITATIVE	Impact of clinical status and salivary conditions on xerostomia and oral health-related quality of life of adolescents with type 1 diabetes mellitus ¹²	To investigate the influence of clinical salivary conditions with the presence of xerostomia in adolescents with and without type 1 diabetes mellitus (DM1); and to investigate the influence of clinical status, salivary conditions and xerostomia on oral health-related quality of life (OHQoL) in patients with DM1	102 adolescents, 51 with diabetes and 51 without diabetes	-	Oral health-related quality of life (OHQoL)	DM1 was shown to be predictive of a high prevalence of xerostomia in adolescents. Caries and xerostomia were found to have a negative impact on the OHQoL of adolescents with DM1.

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Chart 1. continuation

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2008 MEDLINE ENGLISH QUANTITATIVE	Impact of family environment and support on adherence metabolic control, and quality of life in adolescents with diabetes ¹³	To determine the impact of family factors on diabetes, especially the influence of family support and family environment on adherence to treatment, quality of life and metabolic control in Portuguese adolescents with type 1 diabetes.	157 adolescents	-	Family Environment Scale; Self-Report Questionnaire on Adherence; Diabetes Family Behavior Scale;	The results confirmed that adherence was predicted by family support for women and lower-class patients, while metabolic control was predicted by family conflicts for upper-class patients. Quality of life was predicted by lack of family conflict and social support of the family for both males and females, as well as lower-class patients. The results highlight the importance of studying family variables in diabetes care of adolescents within the wider cultural factors that affect the patient.
2008 MEDLINE ENGLISH QUANTITATIVE	Pilot study of a novel educational programme for 11–16 year olds with type 1 diabetes mellitus: the KICK-OFF course ¹⁴	To implement and evaluate an educational program (Kick-off) for children and adolescents with DM1.	48 participants	11-16 years	Semi-structured interviews with children and parents	The Kick-off educational program was well received by children and parents, There were no changes in HbA1c levels, BMI or episodes of hypoglycemia, but was associated with improved quality of life.
2009 MEDLINE ENGLISH QUANTITATIVE	Impact of xerostomia on the quality of life of adolescents with type 1 diabetes mellitus ¹⁵	To assess the impact of xerostomia on the quality of life (QoL) of adolescents with type 1 diabetes mellitus (DM1).	51 adolescents		Quality of Life (QoL)	Xerostomia is frequent and has a negative impact on the quality of life of adolescents with DM1.

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specific measure to evaluate the quality of life of young Brazilian diabetics⁹.

Analysis and discussion

Sample data analysis resulted in the construction of the following themes: construction and valida-

Chart 1. continuation

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2009 MEDLINE ENGLISH QUANTITATIVE	Missed bolus doses: devastating for metabolic control in CSII-treated adolescents with type 1 diabetes ¹⁶	To investigate the management of continuous infusion of subcutaneous insulin (CSII) in adolescents with type 1 diabetes, including its administration of bolus doses and to study the relationships between insulin omission and metabolic control, body mass index, daily frequency of self-monitoring of blood glucose (SMBG) and bolus doses, quality of life (QoL), diabetes burden and treatment satisfaction.	90 adolescents	12-18 years	Health-Related Quality of Life (HRQoL)	Forgetfulness of insulin was common. Those who forgot the doses were less satisfied and perceived more impact with the treatment. Daily bolus and SMBG frequencies were associated with better metabolic control. Teams that work with diabetes require strategies to guide adolescents on how to avoid forgetting insulin.
2010 MEDLINE ENGLISH QUANTITATIVE	Correlates of glycemic control and quality of life outcomes in adolescents with type 1 diabetes ¹⁷	To investigate the factors associated with A1c and QoL using a methodology that considers these variables as simultaneous results	261 adolescents	13-18 years	Quality of Life (QoL)	Risk factors related to disease, management and personal characteristics that influence glycemic control and quality of life were observed. The findings may contribute to physicians' choice of more appropriate interventions that help adolescents achieve glycemic control without sacrificing quality of life.

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tion of tools to measure HRQoL of diabetic adolescents; measurement of the HRQoL of diabetic adolescents; factors that interfere in the QoL of diabetic adolescents and resources used to assist adolescents in managing diabetes.

Construction and validation of tools to measure the HRQoL of diabetic adolescents

The QoL cannot be reliably measured because it is a subjective concept. However, sev-

Chart 1. continuation

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2010 MEDLINE ENGLISH QUALITATIVE	Iranian diabetic adolescent girl's quality of life-perspectives on barriers ¹⁸	To explore prospects of Iranian diabetic adolescents so that they may have a good quality of life.	20 female adolescents with DM1	-	Semi-structured interview	Two effective barriers to good quality of life have been identified: (1) external barriers to good quality of life (family problems, social outlook on diabetes and school problems), (2) individual barriers to good QoL (negative feeling for treatment and care, negative effects of diabetes and uncertainty about the future).
2010 MEDLINE ENGLISH QUANTITATIVE	Quality of life and associated factors among Jordanian adolescents with type 1 diabetes mellitus ¹⁹	To evaluate the HRQoL of Jordanian adolescents with type 1 diabetes mellitus and its associated factors.	145 adolescents	-	Short form of the Diabetes Quality of Life for Youth (DQLQY-SF)	The HRQoL of Jordanian adolescents with type 1 diabetes was low. Improved glycemic control may contribute to improved quality of life.
2011 MEDLINE ENGLISH QUANTITATIVE	Chat line for adolescents with type 1 diabetes: a useful tool to improve coping with diabetes: a 2-year follow-up study ²⁰ .	To evaluate the impact of a 2-year-old chat line involving adolescents with type 1 diabetes in relation to quality of life and metabolic control.	193 adolescents	10-18 years	Diabetes Quality of Life for Youth Inventory (DQoLY)	A chat line is also a cheap and effective tool that helps to improve the diabetes alliance. The chat line can help the diabetes care team understand and treat their patients more comprehensively. In addition, it could help patients cope better with their daily lives.

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eral tools, such as the questionnaires have been elaborated with a view to ensuring reliable data. Self-reporting questionnaires can be selected in three categories: generic; specific realm for a particular disease and with specific realms. Generic questionnaires are used to measure QoL, regard-

less of any disease; the specific questionnaires for a particular disease are used to measure the consequences of a specific disease for the quality of life of the individual with that disease; and questionnaires with specific realms focus on certain quality of life realms, e.g. physical disabilities³⁰.

Chart 1. continuation

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2011 MEDLINE ENGLISH QUANTITATIVE	Coping and resilience in adolescents with type 1 diabetes ²¹	To use a sensitive coping development approach and explore how the use of particular coping strategies affect resilience (i.e. quality of life, competence and metabolic control) in adolescents with DM1.	33 adolescents and their mothers	10-16 years	Responses to Stress Questionnaire (RSQ)	The study results support the use of developmentally sensitive coping measures by researchers and physicians to determine the most effective coping strategies for adolescents with DM1.
2011 MEDLINE ENGLISH QUANTITATIVE	Factors influencing the quality of life of young patients with diabetes ²²	To evaluate the quality of life of young patients with diabetes, as well as the factors that affect it.	98 young patients	11-18 years	Diabetes Quality of Life for Youths Questionnaire (DQoLY)	The quality of life of young diabetics was influenced by demographic, somatometric and other characteristics of diabetes. Increased metabolic control, participation in sports activities and a greater number of insulin infusions resulted in a better quality of life. Increased patient age, duration of diabetes, HbA1c, BMI and the coexistence of various health problems, as well as the use of an insulin pump, decreased the quality of life.
2011 MEDLINE ENGLISH QUANTITATIVE	Influence of combined aerobic and resistance training on metabolic control, cardiovascular fitness and quality of life in adolescents with type 1 diabetes: a randomized controlled trial ²³	To evaluate the effect of physical training combined with metabolic control, physical fitness and quality of life in type 1 diabetic adolescents.	16 adolescents (8 from control group and 8 from the intervention group)	10-18 years	General Health Survey Short Form (SF-36)	Combined physical training seems to decrease daily insulin requirements and improve physical fitness along with better well-being.

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Chart 1. continuation

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2011 MEDLINE ENGLISH QUANTITATIVE	Short Form of the Chinese Version Diabetes Quality of Life for Youth Scale- A psychometric testing in Taiwanese adolescents with type 1 diabetes ²⁴	Test the psychometric properties of the short form of the Chinese tool for Quality of Life of Young People with Diabetes (C-DQOLY-SF).	371 adolescents	9-19 years	Short form of the Diabetes Quality of Life for Youth (DQLQY-SF)	The C-DQOLY-SF has satisfactory reliability and validity. C-DQOLY-SF can be conveniently used in clinical settings to assess the quality of life of adolescents with type 1 diabetes.
2012 MEDLINE ENGLISH QUANTITATIVE	A flexible diet using an insulin to carbohydrate ratio for adolescents with type 1 diabetes - a pilot study ³²	To assess glycemic control, weight status, and quality of life over 12 months in adolescents with type 1 diabetes, who initiated a flexible meal planning using an insulin proportional to carbohydrate counts.	28 adolescents		Diabetes Quality of Life -Youth questionnaire(DQoLY)	Glycemic control was impaired, but improved weight status and life satisfaction, both important aspects to adolescents.
2012 MEDLINE/ ENGLISH QUANTITATIVE	Assessing diabetes-related quality of life of youth with type 1 diabetes in routine clinical care: the MIND Youth Questionnaire (MY-Q) ²⁷	To describe developmental and psychometric assessment using the Monitoring Individual Needs in Diabetes Youth Questionnaire (MY-Q), a multi-dimensional HRQoLself-report questionnaire developed for the care of diabetes in pediatrics.	22 young people in the validation test + 84 young people with DM1	10-18 years	Monitoring Individual Needs in Diabetes Youth Questionnaire (MY-Q)	MY-Q is the first HRQoL questionnaire developed for use in clinical care, with acceptable measurement properties and that seems appropriate for routine care of adolescents with diabetes.

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The proliferation of tools that evaluate the HRQoL stems from the need to show the effectiveness of a particular care or treatment, aiming at a consensus, that is, a same vision around the disease or treatment, or beyond, in order to treat the patient holistically, incorporating the evaluated interventions into the care³¹. With this objective, studies^{8-11,24,26} that established, validated

and made available tools to evaluate the HRQoL of diabetic adolescents considering their cultures were found. This is a necessity because tools contain questions that assess relevant aspects that underpin one culture, but which may be very irrelevant in another.

When measuring the HRQoL of a given group, it is practical to use existing tools already validated

Chart 1. continuation

Year / Database / Language / Approach type	Title	Goal (s)	Number of participants	Age group	Tool / Technique to evaluate QOL	Main conclusions
2012 MEDLINE ENGLISH QUANTITATIVE	Coping, Self-Management, and Adaptation in Adolescents with Type 1 Diabetes ²⁹	To examine the relationship between reactivity and stress coping with self-management, quality of life and metabolic control in an ethnically diverse sample of adolescents with type 1 diabetes.	327 adolescents	11-14 years	Responses to Stress Questionnaire (RSQ); Self-Management in Adolescents with Diabetes questionnaire; Pediatric Quality of Life instrument	The results indicate differences in coping related to income and race/ethnicity and show the impact of coping on self-management and health outcomes in adolescents with type 1 diabetes.
2012 MEDLINE ENGLISH QUANTITATIVE	Health-Related Quality of Life Among German Youths With Early-Onset and Long-Duration Type 1 Diabetes ³⁰	To evaluate the self-report of children and adolescents and their parents about the general health status and the relationship of health with quality of life (QoL) in children and adolescents with type 1 diabetes of early and long-term onset compared to the general population in Germany.	629 subjects and their parents	11-17 years	Generic KINDL-R Questionnaire for Measuring Health-Related Quality of Life in Children and Adolescents	Compared to the general population, quality of life and overall health status were not impaired among those aged 11-17 years with the type of early onset DM1 despite the challenges of modern therapy.
2013 MEDLINE ENGLISH QUANTITATIVE	Diabetes self-management, depressive symptoms, quality of life and metabolic control in youth with type 1 diabetes in China ³¹	To assess diabetes self-management, depressive symptoms, quality of life and metabolic control in a cohort of young people with type 1 diabetes in mainland China.	136 young people	-	-	Chinese young people with DM1 report low self-management more than young people in the US and high depressive symptoms. Glycemic control and quality of life were below normal. There is an urgent need for more clinical consultations, treatment of high depressive symptoms and an intensive insulin regimen for young people with DM1 in China to improve self-management of diabetes and to help them adapt and live with the disease.

in another language. However, this is not the most appropriate procedure, since each country has its own culture and some items of a tool may not be adequate for evaluation in another country with a different culture. In addition, translating a tool from one language to another is a challenge, since a single word that has meaning in one language or another may not make the least sense. Thus, before being used, it must be adapted and validated in the language and culture of the country where the research will be conducted³².

Measuring the HRQoL of diabetic adolescents

Measuring the HRQoL of diabetic adolescents has been the concern of scholars in different cultures^{17,19,27-29}. In assessing the impact of the disease on the life of adolescents, interventions can be designed to help them adhere to treatment, reduce the possibility of complications and improve the QoL of these individuals.

A study²⁸ with young Germans compared the HRQoL of 11-to-17-year-old type 1 diabetic adolescents with their healthy peers and concluded that those who discovered the disease as early as childhood, when compared to their non-diabetic peers, did not show impaired QoL. This finding is probably due to the process of normalization, common in individuals with a chronic disease who have already experienced the adaptation process, become better acquainted with the disease and conceive it as normal, since it is part of their life and daily routine, so they do not feel different from their healthy peers³³.

The relationship between the values of glycatized hemoglobin (HbA1c) and the HRQoL of diabetic adolescents was the objective of studies^{17,19} that proved the relationship between the best level of HbA1c and the QoL of adolescents. The level of HbA1C is related to adolescent diabetes management, as well as to emotional factors, since stress is a risk factor for hyperglycemia due to the action of hormones that are produced in this condition. In addition, when the adolescent feels good about himself and others, he keeps his self-esteem and looks after himself. This is a way to improve his glycemic level³⁴.

In an ethnically diverse group of adolescents with DM1, the relationship between reactivity and coping with stress with self-management, quality of life and metabolic control²⁷ was examined. The research showed that there were no significant differences in coping with stress related to age, gender or type of treatment. Howev-

er, when comparing adolescents with an annual household income of US\$ 80,000 with those of lower annual income households of US\$ 40,000, the latter had significantly lower levels of primary coping control ($p < 0.001$) (for example, problem solving) and secondary coping control ($p < 0.01$) (for example, acceptance) and significantly higher levels of coping detachment ($p < 0.01$) (for example, avoidance). In addition, considering race/ethnicity in relation to coping, it was observed that minority youths reported significantly lower levels of primary coping control ($p < 0.001$) and secondary coping control ($p < 0.05$) and higher levels of coping detachment ($p < 0.05$) than non-Hispanic whites.

There were also differences in a multicenter study²⁹ performed with 135 Chinese youngsters with DM1, whose objective was to evaluate diabetes self-management, depressive symptoms, quality of life and metabolic control. Regarding glycemic control, it was worse in Chinese girls than in American girls, with 68% of them evidencing 9mg/dl glycatized hemoglobin.

A total of 17 (6%) Chinese girls reported high depressive symptoms, correlated with the household's annual income, school attendance, and peer-to-peer and father-child relationships. The overall mean satisfaction score on quality of life was 17.14 ± 3.58 . Thus, the Chinese girls had lower self-management of diabetes and quality of life when compared to American girls, and a higher level of depressive symptoms.

Therefore, assessing the HRQoL of diabetic adolescents is essential to help them manage the disease, and when the therapy is limited to metabolic control, without considering the disease's impact on the adolescent's life, psychosocial imbalances compromise adherence to treatment³⁵.

Factors that interfere in the QoL of diabetic adolescents

The QoL of diabetic adolescents is associated with several factors, so it is the focus of several studies^{12-16,18,22,23}. Adolescence is a stage characterized by conflicts, autonomy, immediacy, issues regarding the conduct of parents and other adults and the need to be accepted by the group, which probably hinders diabetic adolescents' coping with the disease and compromises their condition. Therefore, it is necessary to understand the factors that interfere in the management of DM1 and in the QoL of these adolescents.

In Iran, a survey¹⁸ carried out with female diabetic adolescents sought to understand the barriers

ers that interfere in the QoL of these adolescents. Among them, authors identified social barriers related to family issues, the social perspective on diabetes and school problems; and personal issues that involve negative feelings about treatment and care, the negative effects of diabetes and uncertainty about the future. In addition, the results of the same study indicate that the culture of that country imposes more control and limits on the life of girls, when compared to boys. This condition was an important negative factor on the quality of life of Iranian adolescent girls with DM1.

The perception about how the implications of DM1 may influence the QoL of adolescents seems to be differentiated between female and male. Studies related to the relationship between gender and QoL reveal that females tend to have the worst indicators of QoL when compared with males^{22,29,36,37}.

A study²² performed with Greek adolescents of both genders also observed that adolescent girls had a lower rate of satisfaction with their state, with a consequent decreased QoL, when compared with the adolescent boys. Insufficient diabetes control and increased BMI had a negative influence on QoL in this study as they generated emotional disturbances such as anxiety, distress, depression, low self-esteem, anorexia or bulimia, while adequate monitoring of capillary glycaemia and dietary flexibility were related to the highest levels of QoL.

Another study³⁸ has found similar results regarding anxiety as a common feature among adolescents, which may interfere with treatment adherence and QoL in adolescents with type 1 diabetes. Social stress, common in adolescence, may interfere with the adherence of young people to treatment, and those of less privileged social class are the most susceptible, since they have the worst metabolic control, highest number of hospitalizations and complications resulting from less adaptive coping strategies, therefore, they require more support to create and use them²¹. "The psychological stress can cause the immune destruction of beta cells of the pancreas, causing deficiency in the production of insulin by the organ, which, in this case, must be administered by the patient". In addition, diabetes is a risk factor for psychiatric disorders in this group³⁵.

Comparing the QoL of adolescent groups from different cultures was the objective of a multicenter study conducted with 136 Chinese youngsters, which revealed the difference in self-management of diabetes by this group compared to a similar group from the United States

of America. This finding was associated with the insulin treatment regimen, the treatment site, and the depressive and gender symptoms. The high rates (17.6%) of depressive symptoms found in the Chinese young girls were related to household income, school attendance, peer-to-peer and father-child relationships. The mean overall satisfaction score with the quality of life of these young girls was 17.14 ± 3.58 , and the mean HbA1c, 9.68%²⁴.

The family environment is an essential element in the support to adolescents in the management of diabetes, especially among the less favored social class, whereas metabolic control is more representative in adolescents of the more privileged class¹³.

In adolescence, it is common for adolescents to want to be independent from their parents. When it comes to those affected by diabetes, they feel frustrated and refuse to adhere to treatment. Thus, overprotection and parental control are related to worse QoL of adolescents, while those who provided positive emotional support with communication skills had better QoL. As can be seen, adolescents from families with less family conflicts report more well-being, and more understanding parents are related to children with better QoL than those with the highest number of authoritarians^{35,39}.

Investigating the management of continuous infusion of subcutaneous insulin (CSII) in adolescents with type 1 diabetes and its relationship with QoL and treatment satisfaction was the focus of a study²⁵ that revealed that a large percentage of adolescents (39%) forget to administer the bolus insulin doses. This fact is directly related to dissatisfaction with the treatment, which therefore affects their life. Therefore, the multi-professional team must empower adolescents and encourage them to use coping measures in the management of the disease.

An essential element in the treatment of diabetes, physical activity was analyzed in a randomized study²³, which evaluated the effect of physical training combined with metabolic control on physical fitness and QoL of adolescents with type 1 diabetes. At the onset of the study, none of the parameters (anthropometric indices, glycaemia and HbA1c) measured differed from the two groups, but the daily doses of injected insulin were significantly reduced in the training group (0.96 IU/kg/day pre- against 0.90 IU/kg/day post, $P < 0.05$), when compared with the control group. In addition, physical fitness greatly increased in the training group, and this has repercussions on

improving overall health, vitality and emotional function. Therefore, metabolic control combined with physical training appears to decrease daily insulin requirements and improve physical fitness and well-being. The study also investigated the relationship between one of the symptoms of diabetes, xerostomia and QoL, and concluded that it significantly interferes with the QoL of adolescents with DM1^{12,15}.

Resources used to help adolescents in the management of diabetes

The most diverse resources have been used with the objective of helping diabetic adolescents to live with the disease. Thus, a study²¹ aimed to identify which of the coping strategies used by adolescents have the greatest impact on their competence in dealing with diabetes. This study showed that the resolution of emotional problems was associated with higher QoL scores and better metabolic control, as well as the use of secondary strategies such as disease acceptance and distraction, better social competence, better QoL and better metabolic control. Researchers concluded that using effective coping strategies to help adolescents address DM1 is overly crucial.

In the UK, outpatient courses were offered to 48 adolescents aged 11 to 16 for three days to help them manage diabetes. Evaluations included glycemic control (HbA1c), body mass index (BMI) and hypoglycemia frequency before and after the course (three and six months post-intervention). QoL was assessed before the course and two weeks, three and six months after. The results showed that expectations of the pre-course group were met, and the educational evaluation was consistent. HbA1c and BMI indices did not change and there were no hypoglycemia episodes, but parents and adolescents reported improved QoL after the course¹⁴.

Another approach²⁰ that also aimed to support diabetic adolescents in the management of the disease evaluated the impact of an online chat for two years regarding the quality of life and metabolic control of 193 adolescents aged 10 to 18 years with type 1 diabetes. In this case, there was a significant improvement ($P=0.0001$) in those who participated in chat sessions, in addition to a decrease of 0.4% in HbA1c ($7.8 \pm 1.1\%$ vs. $7.4 \pm 0.5\%$, $P<0.0001$) compared to 0.1% of controls ($7.9 \pm 1.9\%$ vs. $7.8 \pm 1.8\%$, $P=0.668$). Authors concluded that this type of strategy is an inexpensive and effective tool that can be used by the team to assist adolescents in managing dia-

betes and their daily lives. Continuing education provided by professionals committed to the promotion and maintenance of care and self-care may contribute to healthy living and to improving QoL of diabetics⁴⁰.

A different approach was used in a study⁴ that aimed to evaluate glycemic control, weight status and quality of life over 12 months of adolescents with type 1 diabetes. Thus, a flexible plan of meals and the relationship between insulin and carbohydrate was used concomitantly. Nine months after using a flexible meal and insulin schedule, researchers noted that there was a decrease in mean BMI (Body Mass Index) of 0.15 ± 0.20 ; $P < 0.001$ and an increase in hemoglobin A1c ($0.7 \pm 0.83\%$, $P = 0.001$). Adolescents who participated in the study reported that there was no change in the impact or concern about diabetes. However, the mean life satisfaction scores increased (5.5 ± 9.5 ; $p = 0.008$). Authors suggest further investigations with such approaches, since studies with this public are scarce.

A study⁴⁰ with the same objective, also carried out with patients with type 1 diabetes, reached similar conclusions and mentioned the advantages for the diabetics in face of the flexibility in the choice of meals in this type of regimen, going as far as not being obliged to perform the six recommended meals in traditional schemes, thus translating into more acceptance of the disease and improvement of the quality of life. As in the previous study, it also recognized the need for randomized trials to compare different nutritional regimens and reach a more definitive conclusion.

All the efforts undertaken to help adolescents with DM1 to cope with the disease are valid. Living with this disease is a difficult experience for them and their family, hence the importance of the multidisciplinary team to support them, considering the unique therapeutic project, their culture, their convictions, their habits, their fears, their aspirations, in short, their experience in the family and social environment, as well as their difficulties with the disease.

Conclusion

The HRQoL of diabetic adolescents has been a subject studied and widely disseminated in the international literature, but with little repercussion at the national level. However, this does not diminish its relevance, since measuring the HRQoL of diabetic adolescents is a way of know-

ing their perceptions, needs, fears, aspirations and difficulties regarding self-care.

Many factors interfere with metabolic control, including anxiety and/or stress, fear of hypoglycemia, shame among peers, and others. However, the support of professionals and parents improves the performance of adolescents in relation to self-care and metabolic control.

In this context, measuring the HRQoL of diabetic adolescents and understanding which factors interfere is a way of helping the multi-professional team to design strategies that motivate them for self-care and minimize complications from the disease.

Collaborations

DSM Cruz worked on the design, outline, data analysis and interpretation and paper writing. N Collet worked on data analysis and interpretation, critical review and final writing. VM Nóbrega worked on the outline and data analysis and interpretation.

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