Factors associated to the quality of life of adolescents with type 1 diabetes mellitus

FATORES ASSOCIADOS À QUALIDADE DE VIDA DE JOVENS COM DIABETES MELLITUS DO TIPO 1

FACTORES ASOCIADOS A LA CALIDAD DE VIDA DE JÓVENES CON DIABETES MELLITUS TIPO 1

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ABSTRACT

The objective of this study was to perform a literature review of the factors that may influence the Health Related Quality of Life (HRQL) of adolescents with type 1 diabetes mellitus using the PICO strategy. PubMed/ MEDLINE, ISI Web of Knowledge and EMBASE were the databases used. A larger survey of articles was possible by combining standardized and non-standardized descriptors. Though HRQL is a specific construct used to evaluate aspects related to the repercussions of health, illness, and treatment, it appears that sociodemographic, psychosocial, and family-related aspects have a significant effect on HRQL.

DESCRIPTORS
Quality of life
Adolescent
Diabetes mellitus, type 1
Review

RESUMO

O objetivo deste estudo foi realizar a revisão bibliográfica acerca dos fatores que podem influenciar a Qualidade de Vida Relacionada à Saúde (QV) dos adolescentes com diabetes mellitus tipo 1, por meio da estratégia de PICO. As bases de dados utilizadas foram PubMed/MEDLINE, ISI Web of Knowledge e EMBASE. O maior levantamento dos artigos foi possível com a combinação de descritores padronizados e não padronizados. Apesar da QV ser um construto específico de avaliação dos aspectos relacionados às repercussões da saúde, doença e tratamento, os fatores sócio-demográficos, psicossociais e relacionados à família parecem influenciar de forma significativa na QV.

DESCRITORES
Qualidade de vida
Adolescente
Diabetes mellitus tipo 1
Revisão

RESUMEN

El objetivo de este estudio fue realizar la revisión bibliográfica acerca de los factores que puedan influenciar la Calidad de Vida Relacionada a la Salud (QV) de adolescentes con diabetes mellitus tipo 1, mediante la estrategia de PICO. Se utilizaron las bases de datos PubMed/MEDLINE, ISI Web of Knowledge y EMBASE. La mayor captación de artículos se posibilitó combinando descriptores estandarizados y no estandarizados. A pesar de que la QV es un constructo específico de evaluación de aspectos relacionados a las repercusiones de salud, enfermedad y tratamiento, los factores socio-demográficos, psicosociales y relacionados a la familia parecen influir en ella de forma significativa.

DESCRIPTORES
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Revisión

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INTRODUCTION

Diabetes Mellitus (DM) is one of the most prevalent chronic illnesses nowadays and reaches epidemic proportions all over the world[1]. Type 1 DM (T1T1DM) is not the most incident type in the global population, but it is one of the most prevalent illnesses in childhood and adolescence. The disease entails an important social impact, as it affects young people and prolonged exposure to hyperglycemia anticipates the development of chronic complications in economically active individuals.

The (DCCT) was the most important longitudinal study, which proved that intensive treatment, including capillary glucose monitoring three or four times per day, multiple daily insulin doses, diet, physical exercise and more frequent contact with the multiprofessional team specialized in diabetes can reduce the incidence and progression of retinopathy, nephropathy, neuropathy and cardiovascular illnesses[2-3].

Despite the proven efficacy of intensive treatment, questions about the barriers faced for its application have been reported in research and clinical practice[4]. New habits and behaviors, needed to put intensive treatment in practice, are not always easily incorporated, especially during adolescence. Therefore, studies have been accomplished to determine the psychosocial aspects that can interfere in treatment adherence among young people.

A widely investigated aspect in literature is Quality of Life (QoL), defined as *an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*[5]. QoL assessment permits assessing the impact of T1DM and treatment strategies that will service to support disease management and therapy compliance[6]. Surveying factors that can influence the QoL of adolescents with T1DM has provided support for a better understanding of and access to the mechanisms involved in treatment compliance, with a view to greater wellbeing and adequate metabolic control. Therefore, the goal of this study was to accomplish a bibliographic review on the factors that can influence the QoL of adolescents with T1DM, through the PICO strategy.

> Quality of Life of adolescents with Type 1 Diabetes Mellitus has provided support for a better understanding of and access to the mechanisms involved in treatment compliance...

LITERATURE REVIEW STRATEGY

The PICO strategy was used for the literature search, a tool used to seek evidence in electronic databases. PICO is the acronym of P= patient, I= intervention, C=control or comparison and O=outcome[7]. The papers were located through descriptors, combined with Boolean operators. The following databases were used: EMBASE, PubMed/MEDLINE and ISI (Web of Knowledge). No minimum period was delimited for the publications, and the surveyed papers had been published until January 2008.

In a first search, standardized DeCS descriptors were selected, then inserted in the databases, using the PICO strategy as follows:

P= (quality of life OR life style) AND (diabetes mellitus, type 1) AND (adolescent) AND (self concept OR gender identity OR age factors OR diet OR diet, carbohydrate-restricted OR hemoglobin A, glycosylated OR Blood Glucose Self-Monitoring OR exercise OR insulin OR insulin, long acting factors OR health education OR hypoglycemia OR hyperglycemia).

O= (correlation OR association OR prediction OR review).

Not many papers were surveyed through this combination. The hypothesis that authors frequently use non-standardized descriptors led to a second search, including non-standardized synonymous descriptors that are commonly cited in important publications, as presented next.

P= (quality of life OR life style OR health-related quality of life OR well-being) AND (diabetes mellitus, type 1 OR insulin-dependent diabetes mellitus OR type 1 diabetes OR diabetes insulin-dependent) AND (adolescent OR youth OR youths OR adolescents) AND (self-concept OR self-esteem OR gender identity OR gender OR age factors OR age OR diet OR diet, carbohydrate-restricted OR carbohydrate counting OR hemoglobin A, glycosylated OR glycosylated hemoglobin OR metabolic control OR glycemic control OR glycated hemoglobin OR exercise OR physical activity OR insulin OR continuous subcutaneous insulin infusion OR insulin, long acting OR multiple daily injections OR intensified insulin therapy OR insulin, short acting OR insulin, rapid-acting OR insulin, Intermediate-acting OR regular insulin OR health education OR diabetes education OR hypoglycemia OR hyperglycemia OR Blood Glucose Self-Monitoring OR self-monitoring of blood glucose).

O= (correlation OR association OR prediction OR review OR relation OR impact OR influence).

Through this second search, a larger number of papers could be recovered. It should be highlighted, however, that the authors' use of non-standardized terms leads to the loss of studies and the accomplishment of systematic reviews. Table 1 shows the search results.

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Table 1 - Aspects related to QoL of young people with T1DM in the studies surveyed through the PICO strategy - São Paulo - 2008

Descriptors	EMBASE	PubMed/MEDLINE	ISI (Web of Knowledge)	Total
DeCS	132	98	5	235
DeCS + non standardized	540	715*	224	1480

*Limit - research involving human beings

As more papers could be located through the use of standardized and non-standardized descriptors, the survey of factors related to the QoL of young people with diabetes was based on this second search.

Criteria for including the surveyed papers were established before reading the 1480 abstracts. The selected studies were published in Portuguese, English or Spanish, with samples of adolescents with T1DM and actual assessment of their QoL.

The following abstracts complied with the inclusion criteria: 68 in EMBASE, 51 in PubMed/MEDLINE and 39 in ISI (Web of Knowledge), totaling 158 papers. Eighty-two of them were repeated, so that the final survey included 76 articles. Through the reading of these papers, the aspects most commonly related with the QoL of young people with T1DM could be identified, displayed in Chart 1.

Chart 1 - Aspects related to QoL of young people with T1DM in the studies surveyed through the PICO strategy - São Paulo - 2008

General Aspect	Specific Aspect
Socio-demographic factors	Socioeconomic profile, gender, ethnics, age
Psychosocial aspects	Coping, educational and motivational strategies; depression, anxiety, health condition and self-esteem
Diabetes Mellitus Treatment	Insulin scheme, capillary glucose and carbohydrate counting
Relation with the family	Protection, emotional support, communication skills and family conflicts
Metabolic control	Glycated hemoglobin
Hypoglycemia	Impact of episodes

QoL and socio-demographic factors

The investigation of the relation between QoL and socioeconomic status was the target of an American study that involved 222 young people and their families. The educational level and caregivers' type of work defined the socioeconomic profile. The following instruments were used:: PedsQL 4.0 and 3.0, besides the Hollingshead Four-Factor Index of Social Status. Individuals from better socioeconomic classes showed a better QoL and worse metabolic control (p<0.002)[8].

T1DM and its implications seem to influence the QoL of male and female individuals differently. Publications that explored the related between QoL and gender have demonstrated that female adolescents tend to report more impaired QoL in comparison to males. These studies were accomplished with different QoL instruments, such as the Diabetes Quality of Life for Youths (DQOLY) and the Child Health Questionnaire[9-19]. Based on the difference between genders, found in most studies, it can be inferred, in general, that adolescents' QoL tends to be assessed worse among female adolescents.

The most deteriorated QoL has been appointed among adolescents from ethnic minorities. A study has demonstrated that self-assessed health was better among white adolescents (p<0.012)[18]. Caucasian youths obtained better scores in the Impact and Worries domains (p< 0.05)[19].

Studies that assessed the impact of diabetes and its repercussions on QoL among young people of different ages have presented different results. The worst assessment of QoL among older adolescents was demonstrated in the largest study[12-13,18,20]. Nevertheless, opposite results have also been found in literature[9,21].

Another prospective study that aimed to assess the repercussions on QoL over the years investigated 117 adolescents for 5 years. Despite the harm caused for metabolic control, QoL did not change over time, at a 95% confidence interval[22].

QoL and psychosocial aspects:

Many studies focus on the repercussions of psychosocial interventions for the QoL of young people with T1DM. Interest in this theme seems to be related with the hypothesis that, in a way, these aspects are related with wellbeing and affect metabolic control.

Five publications looked at the efficacy of training regarding coping skills. This training aims to reinforce people's sense of competency, stimulating positive behaviors, particularly learning how to deal with the daily problems that emerge, instead of focusing solely on diabetes management. All of these studies were longitudinal and took between 3 and 12 months. Experimental groups were constituted, including young people who received training and control groups that received educational orientations. QoL, assessed through the DQOLY, was reported better in the experimental group in all studies[23-27].

Two publications studied the relation between coping strategies and QoL. Mental and behavioral detachment, aggressive coping and self-complaint were negatively correlated with all QoL aspects in a study of 116 young people between 13 and 18 years of age (r=-0.22 and – 0.49)[28]. Another publication, however, demonstrated there was no relation between coping and wellbeing in 70 subjects between 11 and 18 years old, using the multiple regression model[29].

Other experimental studies have investigated the repercussions of educational and motivational strategies, including the discussion of QoL, telephone contact, behavioral counseling, relaxation and responsibility sharing for QoL, which was generally reported better among adolescents from the experimental group[30-36].

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Cross-sectional and longitudinal studies have investigated existing relations between QoL, depression and anxiety in young people with T1DM. The results showed a direct relation between these variables, that is, the presence of depression and anxiety worsened QoL, assessed through the Well- Being Questionnaire and DQOLY[10,37-38].

The relation between the perceived health condition and QoL has been disclosed in literature. Adolescents who assessed their health best also displayed the best QoL assessment[9,19,39-41].

Positive correlations between QoL and the self-esteem of young people with T1DM indicate that these concepts are related[42-43]. The Brazilian study confirmed this finding through the application of the Quality of Life Instrument for Young People with Diabetes and the Rosenberg Self-Esteem Scale to 124 adolescents (r=0.42 to 0.59; p<0.001)[42].

QoL and Diabetes Mellitus treatment

Since the DCCT's publication on the importance of intensive treatment in diabetes control, many studies have assessed the impact of these strategies in people's daily lives. The sole study that compared adolescents, randomly divided in a conventional and an intensive group (at least three insulin applications/day, frequent verification of capillary glucose, monthly consults, frequent telephone contacts), demonstrate that younger adolescents, under intensive treatment, reported worse results in their satisfaction with school[44].

The impact of insulin therapy was the most investigated treatment aspect in young people's QoL. In two studies, young people using lispro insulin reported better QoL assessments in comparison with regular insulin users[45-46]. The repercussions of using the continuous insulin infusion device for QoL have been assessed in cross-sectional, longitudinal and comparative studies. Most of these studies demonstrated that using the device not only improved metabolic control, but also affected QoL positively, as assessed through different generic and specific instruments[15,47-52].

An Italian study of 33 young people demonstrated that, the more frequent the capillary glucose measurements, the better the emotional aspect of the Children Health Questionnaire (r=-0.37, p< 0.03)[53]. The influence of carbohydrate counts on young people's QoL, using slow-acting insulin, was assessed in a longitudinal study that involved 38 subjects, allocated in an experimental group (traditional diet) and control (counting). At the end of the study, subjects who counted carbohydrates showed better scores in the Worries domain of the DQOLY (p=0.05)[54].

QoL and relation with the family

Adolescence is a period of vulnerability, in which family support can influence treatment success. The number of studies on the family's role demonstrates the importance of this aspect for these young people's QoL.

Parents' overprotection and greater control deteriorated young people's QoL in two studies[55-56]. On the other hand, adolescents inserted in families who mentioned positive emotional support and communication skills presented better QoL assessments (p<0.008)[57]. Lesser family conflicts were related with better wellbeing in another study (p<0.05)[14]. Parents assessed as more comprehensive have children with a more adequate QoL than more authoritarian parents (p=0.04)[58].

QoL and metabolic control

Professionals and research presuppose that young people with better metabolic control (glycated hemoglobin) present a better QoL. This hypothesis is confirmed in many studies[8,11-12,15,18-19,39,41-42,53]. A large number of publications, however, appoint that no relations exist between these variables[9-10,31,40,56-57]. Frequent research on the relation between metabolic control and QoL demonstrates the need for knowledge on the impact of physiological on psychosocial aspects in the scientific context. In the only Brazilian study, higher glycated hemoglobin levels were related with worse assessment on the Quality of Life Instrument for Young People with Diabetes (p<0,009)[39].

QoL and hypoglycemia episodes

The negative impact of severe hypoglycemia episodes on the QoL of young people was demonstrated in three studies, which involves samples ranging from less than 100 to more than 2000 young people[19,59-60].

CONCLUSION

This bibliographic review aimed to assess the main aspects intervening in the QoL of adolescents with T1DM published in literature. Although the article search strategy permitted the identification of many papers, the authors' use of non-standardized keywords may have enhanced the non-identification of all papers available in databases on the theme.

The identified papers demonstrated that QoL has been widely investigated in literature and that many factors interfere in its assessment. Although QoL is a specific construct to assess aspects related to the repercussions of health, disease and treatment from the young people's perspective, socio-demographic, psychosocial and family-related factors seem to influence QoL. These results are important because they evidence the need to put in practice treatment that affects not only the biological but also the psychosocial sphere, with a view to treatment compliance and wellbeing.

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