

Quality of life and self-esteem of adolescents with diabetes mellitus*

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Calidad de vida y autoestima de adolescentes con diabetes mellitus

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ABSTRACT

Objective: To evaluate the quality of life related to health (QLRH) and self-esteem (SE) of adolescents with Diabetes Mellitus type 1 (DM1) and analyze the relations between these constructs in this population. **Methods:** 124 adolescents with DM1, aged 12 to 18, answered the instruments validated for Brazil about Self-Esteem and Diabetes Quality of Life for Youths while they waited for their medical appointments. **Results:** The adolescents evaluated their quality of life and self-esteem positively. The concepts of quality of life and self-esteem were positively related. **Conclusions:** The study participants' QLRH and SE were considered good, overall. The SE and QLRH concepts were related, i.e., the higher the self-esteem, the better the quality of life of adolescents with DM1.

Keywords: Diabetes mellitus, tipo 1; Self concept; Quality of life; Adolescent

RESUMO

Objetivos: Avaliar a qualidade de vida relacionada à saúde (QVRS) e a auto-estima (AE) de adolescentes com Diabetes Mellitus tipo 1 (DM1) e analisar a relação entre estes construtos nessa população. **Métodos:** Cento e vinte quatro adolescentes com DM1, com idades entre 12 e 18 anos, responderam aos instrumentos, validados para o Brasil, de Auto-Estima e de Qualidade de Vida Para Jovens com Diabetes enquanto aguardavam a consulta médica. **Resultados:** Os jovens avaliaram a qualidade de vida e a auto-estima positivamente. Os conceitos de qualidade de vida e auto-estima estiveram relacionados positivamente. **Conclusões:** A QVRS e a AE dos participantes do estudo, de maneira geral, foram consideradas boas. Os conceitos de AE e QVRS estiveram relacionados, ou seja, quanto mais elevada a auto-estima melhor a qualidade de vida dos adolescentes com DM1.

Descritores: Diabetes mellitus tipo 1; Auto-imagem; Qualidade de vida; Adolescente

RESUMEN

Objetivos: Evaluar la calidad de vida relacionada a la salud (CVRS) y la autoestima (AE) de adolescentes con Diabetes Mellitus tipo 1 (DM1) y analizar la relación entre éstos en esa población. **Métodos:** Participaron en el estudio 124 adolescentes con DM1, con edades comprendidas entre 12 y 18 años, los cuales respondieron a los instrumentos, validados para el Brasil, de Autoestima y de calidad de Vida Para Jóvenes con Diabetes, mientras aguardaban la consulta médica. **Resultados:** Los jóvenes evaluaron la calidad de vida y la autoestima positivamente. Los conceptos de calidad de vida y de autoestima estuvieron relacionados positivamente. **Conclusiones:** La CVRS y la AE de los participantes del estudio, de manera general, fueron consideradas buenas. Los conceptos de AE y QVRS estuvieron relacionados, o sea, cuanto más elevada la autoestima mejor era la calidad de vida de los adolescentes con DM1.

Descriptor: Diabetes mellitus tipo 1; Autoimagen; Calidad de vida; Adolescente

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INTRODUCTION

Diabetes mellitus (DM) is a chronic disease, present in every country regardless of their stage of development, and afflicts people in all socio-economic classes.

The Diabetes Control and Complications Trial – DCCT⁽¹⁾ was the most important prospective and multi-centric study, which followed 1,441 individuals with diabetes mellitus type 1 (DM1) aged 13 to 39, for an average 6.5 years.

This study proved that intensive treatment, monitory capillary glycemia three to four times a day, multiple daily doses of insulin, dieting and physical exercise, besides having more frequent contact with the diabetes-specialized multiprofessional team can reduce significantly the incidence, progression and severity of long-term complications of this disease⁽¹⁾.

This intensive treatment implies in important transformations in the behavior of people with diabetes. In clinical practice, these necessary changes are reportedly not always easily incorporated, especially during adolescence, a phase when physiological changes can reflect in the psychological function⁽²⁾.

DM is one of the most common chronic diseases in this phase and requires special self-care behaviors throughout life⁽³⁾. The sudden onset of the disease and the treatment required to control glycemia, as well as stress factors, cause sudden changes in the young person's lifestyle and interfere in their self-image and quality of life⁽⁴⁻⁵⁾.

The stigma of having a chronic disease, the necessity of submitting oneself to control procedures in public places and the risk of hypoglycemia, to which one is exposed by the therapy or by being careless about it, reinforce the condition of being different and can cause feelings of inferiority on the adolescent⁽⁵⁾.

Besides, in this period of transition between childhood and adulthood, the multiprofessional team and the family tend to encourage the adolescent's independence regarding the handling of the disease. However, this sudden transition can result in personal and family conflicts, since the adolescent may possibly not be mature enough to assume such responsibilities⁽⁶⁾. Stress and frustration caused on the adolescent, by not being able to meet the goals expected by the team and the family, contribute to metabolic instability⁽⁵⁾.

Based on such considerations found in literature, diabetes interferes significantly on the adolescent's physiological and psychosocial function⁽⁷⁾. Several studies have been developed to explain the impact of diabetes in the adolescents' development⁽⁸⁾. The evaluation of certain aspects such as quality of life (QL) and self-esteem (SE) is an important tool for the comprehension of such impact.

As the repercussions of the chronic condition can be evaluated, in the adolescent's perspective, it is believed that it is possible to develop more effective interventions, with the possibility of improving their SE and QL, favoring compliance with the treatment.

A growing number of studies have focused on studying the influence of DM, its complications and the handling of the individuals' QL. For some authors, QL has been as important a variable as metabolic control⁽⁹⁻¹⁰⁾. Besides, it is believed that adolescents with DM are less susceptible to develop psychiatric disorders⁽¹¹⁾, with low SE among them.

There are several definitions about the expression of QL and there is no consensus about its meaning. Aspects such as happiness, satisfaction, well-being and achieving goals in life have been focused on, either implicitly or explicitly in their conception⁽¹²⁾.

The World Health Organization defines QL as "the perception of the individuals about their place in life, in the context of the culture and system of values in which they live and in relation to their goals, expectancies, standards and concerns"⁽¹³⁾.

The concept was directed to the health field, being named quality of life related to health (QLRH)⁽¹⁴⁾, incorporating aspects such as the health state, damages, symptoms and incapability⁽¹⁵⁾.

Instruments have been developed and adapted to measure the QLRH dimensions, detecting changes in the health status over time, evaluating the prognostics and estimating the consequences and benefits of an intervention⁽¹⁶⁾.

Like QL, there is no universal definition for what SE is. One of the definitions of this concept is reported as the evaluation of the individuals about themselves, how capable and important they feel through their approval and disapproval behaviors. The development of SE is a process that lasts throughout life, and is related to the interactions that the individuals have with their families and people that are significant to them⁽¹⁷⁾.

Given the importance of the concepts presented herein and their possible repercussions on the treatment, the present study had the purpose the evaluation of the QLRH and SE of adolescents with diabetes mellitus type 1 and analyzing the relation between these constructs in this population.

METHODS

This is a cross-sectional, correlational and non-experimental study. The studied population consisted of all patients with DM1 registered in the services: Diabetes Outpatient Clinic at Instituto da Criança da Faculdade de Medicina da Universidade de São Paulo (FMUSP), Diabetes Outpatient Clinic at Hospital das Clínicas-HCFMUSP and at Liga de Controle do Diabetes, part

of the Endocrinology course of HCFMUSP. These are reference centers for diabetes treatment.

The inclusion criteria were: being between 12 and 18 years old, since this is the age range that corresponds to adolescence in Brazil⁽¹⁸⁾; having cognitive ability to answer the questions in the research instruments and agreeing to take part in the study.

The sample size was calculated with the formula proposed by Bolfarine and Bussab⁽¹⁹⁾. This formula considers the standard deviation used in a similar study, in this case, the study performed for the divulgation of *Diabetes Quality of Life for Youths*⁽²⁰⁾. For this calculation, the maximum error of the estimate was assumed as 2, and the adopted level of significance was 0.05. The sample was made up of 124 adolescents. It should be noted that all the adolescents contacted agreed to take part in the study.

The instrument adopted for the QLRH evaluation in youths with DM1 was the Brazilian version of *Diabetes Quality of Life for Youths* (DQOLY)⁽²⁰⁾, a specific instrument publicized by Ingersoll and Marrero in 1991. In order to be used in Brazil, DQOLY was adapted and validated, respecting the methodological recommendations found in literature. The Brazilian version, named *Instrumento de Qualidade de Vida para Jovens com Diabetes (IQVJD)*, showed adequate psychometric properties that made its utilization possible in our midst⁽²¹⁾.

IQVJD consists of 50 questions, divided in three domains: A – Satisfaction (17 questions); B – Impact (22 questions); C – Concerns (11 questions). The American instrument contains one more item in the Impact domain, regarding the utilization of motor vehicles. In the Brazilian version, this item was shown to be inconsistent, since it is not related to the everyday activity of the Brazilian adolescents, and was excluded from the instrument.

The questions have five possible answers each, varying from “very satisfied” to “very dissatisfied” in the Satisfaction domain, and from “never” to “always” in the Impact and Concerns domains. Lower scores correspond to a better QL, except for one of the questions of the Impact domain, whose values are inverted.

In order to facilitate the interpretation of the data obtained by the application of IQVJD, we chose to transform the scores to a scale of 0 to 100⁽²²⁾, similar to the multi-centric study *Hvidore Study Group on Childhood Diabetes*⁽²³⁾. Lower values indicate better quality of life.

To evaluate self-esteem, Rosenberg’s Self-Esteem Instrument was used, adapted and validated for the Brazilian culture⁽²⁴⁾. This instrument consists of ten statements, which can either be agreed or disagreed with. The individual has four answer choices varying from “totally agree” to “totally disagree”. In items 1, 3, 4, 7 and 10, the answer choice “totally agree” refers to the

highest SE, while this option points to the lowest SE in items 2, 5, 6, 8 and 9.

The IQVJD and Rosenberg’s SE were self-applied. The adolescents answered the questionnaires individually, being mindful to avoid the influence of their accompanying partners in the answers. The sociodemographic and clinical data were collected through interviewing and consulting the medical records. The patients were addressed in the waiting rooms of the selected services before their medical appointments.

The study was approved by the Review Board at Escola de Enfermagem da Universidade de São Paulo, file #311/13/2003. The term of consent was signed by the adolescents themselves or by the legal guardians of those younger than 18 years old. They were granted anonymity, secrecy of information and the possibility of abandoning the study if they wished to.

The SPSS for Windows software v. 10.0 – Statistical Package for the Social Sciences – was used for the statistical calculations.

Cronbach’s Alpha coefficient was used to analyze the internal consistence of the IQVJD and SE instruments. For the remaining analysis, Kolmogorov-Smirnov’s test was used to verify the normalcy of data distribution. Pearson’s correlation coefficient was used to compare the average scores of the IQVJD and SE instruments.

RESULTS

The clinical and sociodemographic characteristics of the studied sample are shown in Table 1.

The sample consisted of adolescents of both genders, with average age 14.74 (\pm 2.11), being mostly made up by students with 7.60 (\pm 2.24) years of education. These adolescents have had DM1 for a considerable amount of time, being submitted to 2.94 (\pm 0.93) daily applications of insulin.

Evaluation of QLRH and SE of adolescents with DM1

The results of the application of IQVJD and Rosenberg’s SE instrument in the studied sample, as well as Cronbach’s Alpha are shown in Table 2.

The data in this table show that, overall, QL was evaluated positively, considering a total average score of 29.95. The Concerns domain presented the highest value (32.44), indicating that its evaluation was worse than the others.

Regarding SE, the scores were converted so that the lowest values correspond to the best scores. Considering that the maximum value that could possibly correspond to the worst SE is 40, the average value of the sample is below the average score of the instrument.

Cronbach’s Alpha coefficient show that the IQVJD

and the SE instrument were highly consistent internally when applied to the studied sample.

Table 1 – Clinical and sociodemographic characteristics of the studied sample. São Paulo, 2004

Characteristics	n
Gender (n=124)	
Female	65 (52.4%)
Male	59 (47.6%)
Age (n=124)	
Average (SD)	14.74 (2.11)
Median/ Variation	15.00/ 12.00-18.00
Education in years (n=124)	
Average (SD)	7.60 (2.24)
Median/ Variation	8.00/ 3.00-12.00
Occupation (n=124)	
Studies	97 (78.2%)
Works	9 (7.3%)
Studies and works	13 (10.5%)
None	5 (4%)
Time with diabetes in years (n=124)	
Average (SD)	6.2 (3.93)
Median/ Variation	6.0/ 1.00-16.00
Number of insulin injections / day (n=122)	
Average (SD)	2.94 (0.93)
Median/ Variation	3.00/1.00-6.00
Home monitoring (n=108)	
Average (SD)	2.85 (1.56)
Median/ Variation	3.00/ 1.00-8.00
Glycosylated hemoglobin (n=124)	
Average (SD)	9.70(2.79)
Median/ Variation	9.02/ 5.00-18.50

Relations between QLRH and SE in adolescents with DM1

The results of the correlations between the IQVJD and the SE instrument are shown in Table 3.

All correlations between the IQVJD scores with the SE instrument scores were positive and statistically significance, with a moderate magnitude (0.42 to 0.59). The Concerns domain had the lowest correlation with the SE scale.

Table 2 – Descriptive statistics and Cronbach's Alpha coefficients for IQVJD and Rosenberg's SE instrument applied to the studied sample. São Paulo, 2004

IQVJD Total/Domains	Average	Median	Standard deviation	Minimum/ maximum	Cronbach's Alpha
Total	29.95	27.60	14.37	2.08/ 69.27	0.93
Satisfaction	26.59	25.74	14.65	0.00/ 73.53	0.87
Impact	31.44	30.00	15.54	3.75/ 81.25	0.86
Concerns	32.44	27.27	20.89	0.00/ 86.36	0.84
Self-esteem	17.26	17.00	5.23	11.00/32.00	0.88

IQVJD = *Instrumento Qualidade de Vida para Jovens com Diabetes* (Diabetes Quality of Life for Youths (DQOLY)); SE = Self-esteem

Table 3 – Correlations between IQVJD and the SE instrument - São Paulo, 2004

IQVJD Total/ Domains	Self-Esteem Pearson's Correlation	p-value
Total	0.59	< 0.001*
Satisfaction	0.54	< 0.001*
Impact	0.56	< 0.001*
Concerns	0.42	< 0.001*

* Statistically significant

IQVJD = *Instrumento Qualidade de Vida para Jovens com Diabetes* (Diabetes Quality of Life for Youths (DQOLY)); SE = Self-Esteem

DISCUSSION

Adolescence is a phase marked by intense biopsychosocial transformations. Adolescents who are carriers of a chronic disease, such as DM1, have to face the demands that stem from the disease and the treatment in addition to dealing with the usual aspects of this phase.

In this period of physical and emotional vulnerability, it is likely that there will be more difficulties for the incorporation of behaviors of compliance with the treatment, and consequently, the metabolic control is likelier to deteriorate.

As such, the comprehension of the impact of DM1 and its handling in the adolescents' daily routine become more and more important. It is believed that psychosocial factors can influence the compliance with the treatment⁽¹⁾.

The individuals in the present study were uniformly distributed according to gender. The average age of the researched youths, 14 years old, and the average time with DM1, of 6 years, indicate that it is diagnosed during childhood. These data suggest that these individuals have undergone the many acute situations of the disease, such as diabetic ketoacidosis and episodes of hypoglycemia. They have also been submitted to long-term treatment periods and are probably adapted to it.

The average number of insulin applications and daily monitoring followed the recommendations of the DCCT Research Group⁽¹⁾ for the maintenance of an adequate metabolic control. In spite of that, the average value of glycohemoglobin was above the acceptable values of 7%,

showing an inadequate metabolic control.

The instruments used in this study to measure QL and SE had adequate Cronbach's Alpha values, being therefore considered reliable measurements for this goal.

The IQVJD analysis showed that all the values obtained from the studied sample were below 50, suggesting that QL was overall seen as good.

However, when the results of the present study are compared with those obtained by *Hvidore Study Group on Childhood Diabetes*⁽²³⁾, it is observed that the studied sample showed worse QL levels in all domains of the instrument. In that study, the results were as follows: Satisfaction domain 25 (18), Impact 25 (± 11) and Concerns 19 (± 16). Therefore, the adolescents in the present study are seen to present higher averages in all three domains (worse QL), with the highest difference lying in the Concerns domain (32.44 ± 20.89) and lowest difference in the Satisfaction domain (26.59 ± 14.65).

As for SE, it is possible to infer that the adolescents, overall, evaluated the construct positively, since the average sample score (17.26 ± 5.23) is under the average score of the instrument, which is 20.

When the scores of these instruments were correlated, the domain scores and the total IQVJD scores presented positive and significant correlations with the SE instrument ($p < 0.001$), showing that the better the QL, the better the SE. The strongest correlation occurred between the SE scores and the Impact domain, i.e., the higher the perceived impact, the worse the SE. This result can be explained because this domain contains items related to leisure, school, handling the disease in public and social life with friends and family, aspects that are related with the social interactions that are fundamental in adolescence.

Positive and significant correlations between QL and SE were also found in another study, which compared the DQOLY scores with the SE instrument OSEI (*Offer Self Esteem Inventory*) in 77 adolescents with DM1⁽²⁵⁾. In another study⁽²⁶⁾, performed with 2941 French adolescents of the general population, the converging validity of a QL instrument named VSP-A (*Vécu et Santé Perçue de*

l'Adolescent) was confirmed by the positive and significant correlation with the SE instrument, *Echelle Toulousaine d'Estime de Soi – ETES*. These studies confirm that the QL and SE concepts are related.

CONCLUSIONS

The participants' QLRH and SE were considered good. The SE and QL concepts were related, i.e., the higher the self-esteem, the better the quality of life of the adolescents with DM1.

FINAL CONSIDERATIONS

The evaluation of the psychosocial function of the adolescents becomes increasingly more essential. The central focus on the metabolic control, without an evaluation of the impact of treatment, new technologies, handling the disease related to the adolescents' QL and SE can result in psychosocial disorders and jeopardize compliance with the treatment. Therefore, the results of this study contribute for the improvement of knowledge, with the purpose of promoting the publication of articles about this topic, consolidating them so that this type of evaluation can become a part of the nursing clinical practice in the future, in the quest for psychosocial strategies that promote welfare and influence in the compliance with the therapeutic proposals.

The difficulty to compare the data obtained with others published before is characterized as a limitation of this study, since there are few studies focusing the concepts involved here. Most of them focus on populations with different characteristics, either due to the age range analyzed or due to no specificity related to DM1.

The results of this study cannot be generalized for all the adolescents with DM1 in Brazil, since the services where the research was performed can present different specific characteristics from others in the country. Performing studies like this one is necessary in order to confront these concepts, so that the generalization (or not) of these concepts can be made possible.

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