

Multidimensional study on quality of life in children with type 1 diabetes

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Abstract. – Aim: To study the Health Related Quality of Life (HRQoL) and metabolic assessment in 33 children affected with type 1 diabetes (18 males, 15 females; mean age 10.3 years).

Methods and Results: We used the Child Health Questionnaire - Parental Form 50 items (CHQ-PF50), measurements of metabolic control and we related them to patient management and family status. Quality of life (QoL) in diabetic children was worse than in the healthy sample. Interestingly, mean and last glycosylated hemoglobin (mean HbA1c $r: -.4410$ $p < .01$ and last HbA1c $r: -.4012$ $p < .01$), age of patients ($r: -.4428$; $p < .009$) and number of glycaemia controls ($r: -.37$, $p < .03$) were the most important parameters related to HRQoL parameters.

Conclusion: This multidimensional study stressed that HRQoL is influenced by the metabolic assessment. Moreover, the report examined the parental perception of QoL in children with chronic diseases. Higher number of glycaemia controls/day, better metabolic control, lower age of children and earlier onset of diabetes produced better physical and psychological aspects of QoL. In comparison with adolescent patients, in children with diabetes, factors as number of insulin injections and daily snacks, and the level of education of the mother were not so important to influence QoL. Unexpectedly, in this sample, life habits, family features, and anthropometric parameters did not correlate with specific domains of QoL.

Key Words:

Type 1 diabetes, CHQ-PF50, Quality of life, Children.

and in their family^{1,2}. In the last decades, the management of type 1 diabetes has improved, with better metabolic control and reduction of diabetic complications. In order to keep a good metabolic control it is important to determine a burden on the lifestyle of patients and their family.

Little is known about how children with diabetes and their parents consider their overall physical and psychological health, and how this differs from children without diabetes³. Diabetic care requires many injections of insulin per day, multiple daily glycaemic controls and a specific diet in order to obtain a satisfactory metabolic control with an impact on the daily physical, emotional, and social well-being of patients and their parents.

In order to assess the QoL in young diabetic patients and to correlate it with the clinical picture and the metabolic control, we performed a prospective multidimensional study, according to the outcome research roles, by employing the most used general health status questionnaire for children (the Child Health Questionnaire-CHQ)⁴. The results examine the relationship between metabolic control, family habits, clinical aspects of an Italian sample of children with type 1 diabetes and their quality of life as reported by parents. The aim of this study was to describe the health of children with diabetes in comparison with a normative sample of Italian children matched for sex and age and to evaluate which factors may influence the QoL.

Introduction

Many literature reports have shown the importance of Health Related Quality of Life (HRQoL) in children and adolescent with chronic illness

Materials and Methods

Thirty-three consecutive outpatients affected by type 1 diabetes (18 males, 15 females; mean

age 10.3 years, range 6-14 years; mean BMI 19.2, range 14-25, mean duration of diabetes 6.2 years, range 1-11 years) followed in the Diabetic Center of the Pediatric Department of Catholic University in Rome, Italy, participated in this study. Normative health population was composed by 50 children (29 males, 21 females; mean age 11.3 years, range 5-15 years; mean BMI 18.4, range 14.5-24.5).

For each patient, a thorough assessment of the pathology was obtained through a parent-, physician-, and metabolic-oriented evaluation, as follows.

Patient-Oriented Evaluation

The Child Health Questionnaire (CHQ-PF50), is a generic health-related quality-of-life (HRQoL) tool that measures the physical and psychosocial well-being of children since the age of 5 years with or without disability and consists of domains representing the most essential components of a child's HRQoL. The CHQ-PF50 is a parent-completed questionnaire. The official, cross-culturally adapted, and validated Italian version of the CHQ-PF50 was given to the patient's parents in accordance with standardized methodologies⁵.

CHQ-PF50 is a disease-specific measure that consists of 50 items covering the general health status of patients with the purpose of being a quick and easy HRQoL measure used together with other more functionally-based outcome measures, to assess the effects of medical care. This questionnaire provides 15 specific categories of physical and emotional scores (four specific categories concern patient's parents: Parental Impact-Time – PT, Parental Impact-Emotional – PE, Family Activities – FA, Family Cohesion-FC. The others concern the child: Physical Functioning-PF, Role/Social-Physical – RP, Bodily Pain – BP, General Health – GH, Change in Health – CH, Role Emotional Behaviour – REB, Behaviour Emotional – BE, Mental Health – MH, Global Behaviour Emotional – GBE, Self Emotional-SE) summarised into two main scores: Physical Score (PhS) and Psychosocial Score (PsS). Very low scores for PhS indicate severe physical dysfunction, distressful bodily pain, frequent tiredness and unfavourable evaluation of the health status. Very low scores for PsS indicate frequent psychological distress, and severe social and role disability due to emotional problems. High CHQ-PF50 scores (0-100) in-

dicate good health status. For patient-oriented assessment, PhS and PsS were considered main measurements. In some cases we also reported the subscore results to better assess the main physical and mental patterns. With regard to the subscores, RP and RE were found to be very important in this study. Therefore, we have specified the difference between RE, which assesses limitations of various kinds in everyday role activities *due to emotional problems*, and RP, which assesses similar limitations *due to physical health problems*.

Note that CHQ-PF50 is normally used in patients aged between 5-14 years of age⁷.

Historical Data

For each patient, informations were collected in a schedule and data about clinical history were obtained (age, sex, diabetes duration, associated diseases); auxologic data (weight, height, body mass index); metabolic control (daily glycaemia, daily injections of insulin, total daily dose units of insulin, mild, moderate and severe hypoglycaemia events, HbA1c); food intake (number of daily meals, snacks); neuropathic signs (numbness or prickling sensation in the feet; deep or burning pains in the legs; inability to distinguish cold and hot water sensation; touch hypersensitivity in the feet, etc); other diabetic complications (retinopathy, nephropathy, etc); daily activities (school hours, sport); socio-economic conditions (educational level of the patient and of the parents).

Metabolic-Serological Assessment

Data on glycosylated haemoglobin (HbA1c) of each patient were gathered from the medical records. Two values of HbA1c were taken into consideration: (1) the mean HbA1c of the last two years (M-HbA1c) and (2) the last HbA1c value (L-HbA1c).

Statistical Analysis

Statistical analysis was performed by the STAT-SOFT (Tusla, OK, USA) package. Because of ordinal or nominal scale values were used, non-parametric analysis of the correlation was assessed by the Spearman's R test and the comparison of the groups was assessed by the U-Mann Whitney test. The values are mean \pm SD.

Comparison between the current sample of patients and the Italian healthy subject population was assessed through one sample t-Test.

Results

The number of daily glycaemic detections was different: 3 children used three detections/day; 18 patients used four detections/day; 12 patients, five detections/day. The number of injections of insulin per day was: 3 injections for four children, 4 injections for twenty-nine children. Twenty-three patients self-administered insulin, while ten patients had insulin administered by their parents. The mean of insulin units/kg/day was 0.84 (range: 0.2-1.4 units/kg/day). The mean value of HbA1c in children studied was 8% (range 5.8-12%, SD 1.1), while the mean value of the last HbA1c was 8.1% (range 6.2-10, SD 0.9).

With regard to the clinical picture, one patient had an associated disease (coeliac disease).

Twenty-seven patients reported mild hypoglycaemic episodes (tremors, hunger, tiredness, sweating), nobody reported severe hypoglycaemic events (i.e., convulsions or unconsciousness).

Nineteen patients followed a dietary regimen.

Two patients used to have three daily meals, ten used to have four meals and twenty-one five meals. Thirty-one children used to have snacks: twenty-one had two snacks per day, ten had one snack per day.

No patients were affected by neuropathy.

As for sports activity, only eight children didn't use to play sport, while twenty-five used to play sport on a regular basis.

All patients had good socio-economical behaviour. The level of education of the father was elevated for seven patients, intermediate for eight-teen, low for eight patients. The education level of the mother was elevated for seven patients, intermediate for six-teen, low for ten patients. The relationship between their parents was rated "good" for twenty-seven children and "bad" for six children. Table I shows scores and subscores in 33 diabetes children affected compared with the Italian healthy subjects population and statistical significance between these samples.

We observed that HRQoL is deteriorated from both the physical and the psychosocial perspective comparing to an healthy Italian sample.

In particular, Tot Physical Score (TOT-PhS) which is a sum of all the subscores concerning children's physical aspect (PF, RP, GH, BP, and partly PT and PE) showed significantly lower value ($p < .0000$) in comparison with the Italian

norms. Finally, Tot TOT-PsS, which is a sum of all the subscores concerning children's psychosocial aspect (PT, PE, REB, SE, MH, BE) showed significantly lower values ($p < .0000$) in comparison with the Italian norms.

Patient-Oriented Evaluation Versus Metabolic Assessment

No significant relationship was observed between metabolic assessment (M-HbA1c and L-HbA1c) and Total-Physical score (ToT-PhS) and Total-Psychosocial score (ToT-PsS).

Analyzing the single domain scores, we observed that general health (GH) is inversely related to both glycosylated hemoglobin parameters (mean HbA1c $r: -.4410$ $p < .01$ and last HbA1c $r: -.4012$ $p < .01$). In other words, patients with lower HbA1c reported perception of better GH (Figure 1). No correlation was observed between BMI, hypoglycaemia symptoms and CHQ-PF50 domains. The Parental Impact – Emotional score is inversely related with age ($r: -.4428$; $p < .009$) (Figure 2). No other significant correlations or differences were noted.

Patient-Oriented Evaluation Versus Therapy

No correlations between therapy (number of daily injections of insulin, insulin-units/kg, number of daily glycaemia controls) and Total-Physical score (ToT-PhS) and Total-Psychosocial score (ToT-PsS) were found.

Analyzing the single domain scores related to therapeutic patterns it was observed that higher number of daily glycaemia controls is associated with better GBE ($r: -.37$, $p < .03$) and SE ($r: -.35$, $p < .04$).

No correlations were found between the number of daily injections of insulin, insulin-units/kg, snacks and CHQ-PF50 domains.

Patient-Oriented Evaluation Versus Lifestyle and Environment

No correlations between lifestyle and ToT-PhS and ToT-PsS were found.

Analyzing the single domain scores, we observed that the education level of patients was positively related with the Parental Impact-Time score (PT) ($r: .34$ $p < .04$): parents of patients with higher level of education state spend more time for themselves.

Table I. CHQ-PF50 scores and subscores in children with diabetes.

Concepts	Deteriorated*	Normal	P
GGH and GH (Global health, General health perceptions)	In children suffering from diabetes general health is usually compromised		$p < .000$
PF (Physical Functioning)		Physical function is not limited in children affected by diabetes; they can perform all physical activities, including the most vigorous.	NS
REB (Role Emotional Behaviour)		Behavioural problems do not limit children in their school work or in other daily activities, such as activities with friends.	NS
RP (Role Physical)		Physical health doesn't cause limitations in school activities or in the activities with friends.	NS
BP (Bodily Pain)		Pain doesn't cause limitation in everyday life.	NS
GBE (Global Behaviour)		Children never show signs of violent, immature or criminal behaviour.	NS
BE (Behaviour Emotional)	Children's emotional behaviour is deteriorated by diabetes.		$p < .0006$
MH (Mental Health)	Children's mental health may greatly change, from anxiety and depression to happiness and calmness.		$p < .003$
SE (Self Esteem)		Children affected by diabetes are satisfied with abilities, looks, family/peer relationships and life overall.	NS
CH (Change in Health)	Children strongly perceive that their health has worsened with respect to one year before.		$p < .0000$
PE (Parental impact – Emotional)	Parents suffer from their perception of their children's physical and/or psychosocial health		$p < .001$
PT (Parental impact – Time)		Parents don't experience limitations in time with respect to Italian norms due to the cares they have to dedicate to their children because of their impaired physical and/or psychosocial health	NS
FA (Family Activity)		Children's health neither limits family activities nor is a source of family worry (the pattern is similar to that of the Italian norms).	NS
FC (Family Cohesion)		Family's ability to get along is rated "excellent" and it is even significantly higher than in Italian norms	$p < .0000$

*With respect to the Italian norms.

Discussion

The relationship between HRQoL and diabetes was previously analyzed in adult diabetic patients⁶⁻¹². However, few studies reported HRQoL in young diabetic patients: some had underlined that in adolescents a better metabolic control is

associated with a better QoL¹³ and others had emphasized the relationship between socio-economic characteristics and quality of life related to metabolic control, underlining that diabetic patients in poor metabolic control had a lower educational level^{14,15}. As far as we know, in the literature very few studies regarding children

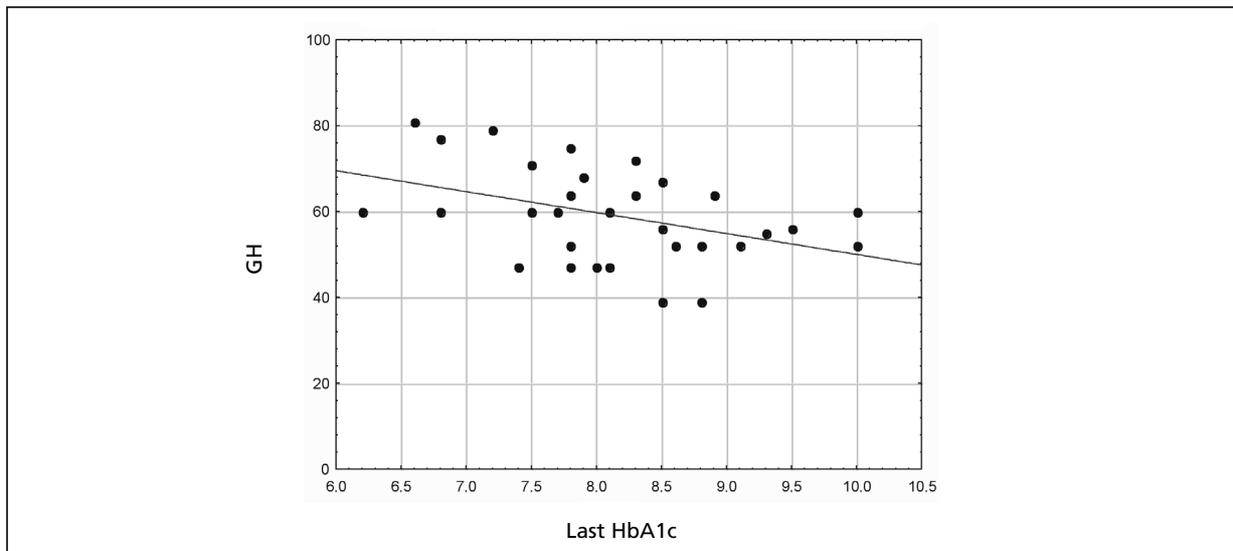


Figure 1. Relationship between metabolic assessment and General Health (CHQ score).

population¹⁶⁻²⁴ and no studies about the Italian population are present.

We performed a study to assess QoL in children with diabetes and to correlate it with their clinical picture and social behaviour. We performed a prospective multidimensional assessment that, through both traditional assessment of diabetes and validated measurements of parents' perspective on diabetic children (6-14 yrs), evaluates the patient's QoL.

As we described previously²⁵, also in diabetic children QoL is influenced by the metabolic pic-

ture: both the last and the mean lower HbA1c are related with better general health. These results underline the crucial role of metabolic control in diabetic assessment confirming the previous results^{21,25}.

Comparing the current sample of diabetic children to an healthy Italian sample we observed that globally QoL of patients, according to the parents perspective, is deteriorated only in some aspects namely: general health, emotional behaviour and worsening of health as time goes by.

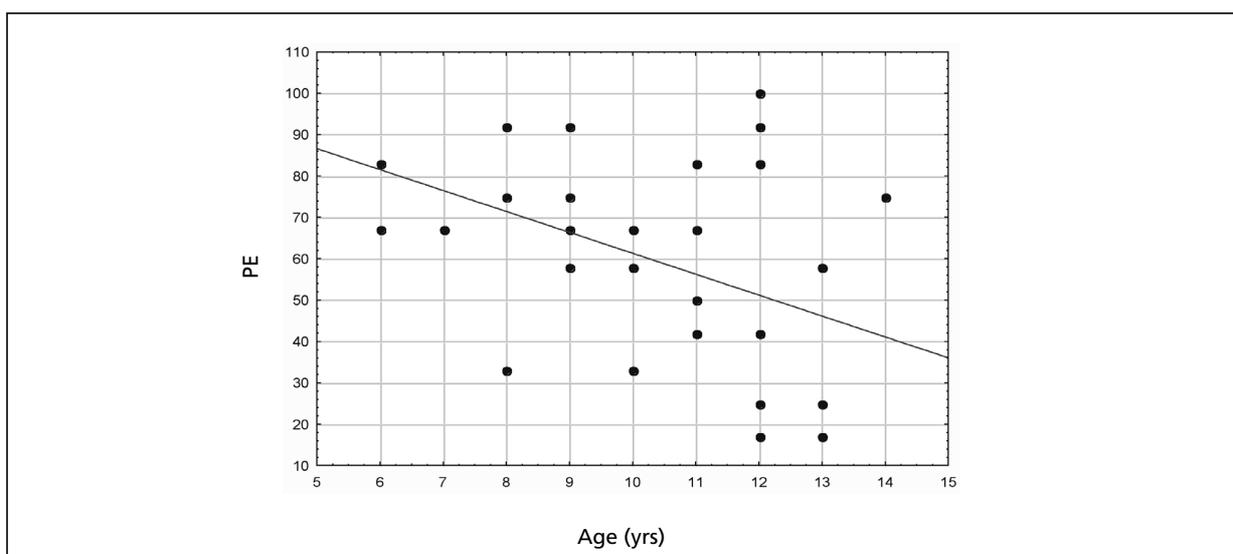


Figure 2. Relationship between Parental Emotional Score and age of patients.

Conversely, it is important to underline that physical function is not limited in children affected by diabetes, similarly either emotional and physical aspects or bodily pain do not limit daily activity. Hence these results suggest that children with diabetes usually may have a daily life as healthy peer. Moreover, we would like to confirm that even self-esteem is not deteriorated in diabetic children²¹. Finally the current sample of diabetic children never shows signs of violent, immature or criminal behaviour.

With regard to the relationship between QoL and metabolic control, we observed that higher number of daily glycaemic controls is associated with better emotional aspects of QoL. This is the opposite we previously observed in adolescents where increased frequency of glycaemic controls were associated with lower physical function. Probably this difference is due to the fact that, in current sample, QoL is evaluated by parents and because social life is crucial in adolescents and higher number of metabolic control may influence the social activity. Similarly, in adolescents we previously noted that higher number of insulin injections were related with a deterioration of daily activity, conversely in children higher frequency is not related, according to the parents, with deterioration of QoL,

By using a parental form we observed also data not related with the aim of the current study. In fact we acquired also data about patients' parents: for example it interesting to note that emotional pattern of parents is more deteriorated in parents with older patients. We are not able to explain these findings. We think that further study focused on the QoL of parents of diabetic patients should be performed.

In conclusion, our data provided useful information for clinical practice underlying that also if diabetes can be rightly considered a chronic disease with a very strong impact in both children and their parents. Nevertheless it can be managed very well, and does not limit children's physical and social activities.

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