

# The health and lifestyles of adolescents with type 1 diabetes in Portugal

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## Introduction

This investigation resulted from a need identified during the 13-year career of the first author (MLS) as a nurse at the Portuguese Diabetes Association (APDP). Established in 1926, the APDP is thought to be the oldest diabetes clinic in the world and, in 2009, was recognised by the International Diabetes Federation as the first diabetes centre of education in the world. MLS works as part of a multidisciplinary team, comprising doctors, nurses, dietitians and psychologists, developing interdisciplinary work with adolescents with type 1 diabetes (T1DM). The adolescents and their parents attend periodic diabetes monitoring consultations, group consultations and summer camps organised by the APDP.

The importance of conducting research at this age is related to the need to improve knowledge of the situations of failure, including the reasons for lack of interest of some

## Summary

The changes during adolescence can affect adherence to diabetes treatment and the quality of life of adolescents with type 1 diabetes.

The aims of this study were to evaluate the behaviours and lifestyles, psychological adaptation and social support of adolescents with type 1 diabetes, and to compare the results with those of 'The Health of Portuguese Adolescents' study.

Study participants comprised 91 adolescents with type 1 diabetes, aged between 11 and 16 years, who were receiving diabetes monitoring consultations at the Portuguese Diabetes Association. Data were collected via a questionnaire consisting of 57 questions which were answered by the adolescents. This study used quantitative research methods with descriptive analysis, and comparative, correlational and inferential statistics.

The results showed that adolescents with diabetes have healthier eating habits and a more positive attitude towards their satisfaction with life, but their health perception is less positive than that of other adolescents. Body weight, height, and physical and leisure activities are similar in all of the adolescents. Youngsters show satisfactory adherence to insulin therapy, eating habits, physical exercise and glucose monitoring (59–92%). However, they present a high level of HbA<sub>1c</sub> (mean 9.9% [85mmol/mol]). The highest levels of HbA<sub>1c</sub> have been related to poor health perception ( $p < 0.01$ ) and less frequent blood glucose monitoring ( $p < 0.05$ ). The best representations and the best psychological adaptation to diabetes are positively correlated to regular physical exercise ( $p < 0.05$ ). Study participants reported that they have good social support from family, teachers, friends and their health care team (64–95%) and refer to the benefits of group sessions and summer camps with other youngsters with type 1 diabetes.

It was concluded that metabolic control in adolescents with type 1 diabetes is unsatisfactory, in spite of good adherence to diabetes treatment and a healthy lifestyle.

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## Key words

adolescents; type 1 diabetes; health; lifestyles; psychological adaptation

young people for treatment and, in some instances, poor self-care and diabetic control.

In adolescents with T1DM, the physical and psychological changes that occur during adolescence can affect adherence to various aspects of their treatment, diabetic control and quality of life. Adherence to ideal care in diabetes needs a great degree of self-management within a complex routine of insulin therapy, healthy nutrition, regular physical exercise and frequent glycaemic control. Adolescents with T1DM can perceive this routine as being imposed on them by their parents and the health care team during a developing phase when they need to separate from adults' authority. On the other hand, the benefits in

following this treatment are mainly to prevent late complications; however, youngsters live in the present and they usually do not worry about what happens in the future.<sup>1–4</sup>

According to the International Society for Pediatric and Adolescent Diabetes (ISPAD),<sup>5</sup> the targets of diabetes treatment for children and young people are promoting good growth and psycho-affective development, good control of diabetes, and prevention of late complications.

European research related to the Health Behaviour of School-aged Children (HBSC), sponsored by the World Health Organization (WHO), involves more than 30 countries. Portugal has been part of this project since 1995. The coordinator of this research in Portugal is Margarida

Gaspar de Matos, one of the authors of the present study. HBSC research in Portugal collects cross-national data every four years. The study questionnaires are filled in by 11- to 16-year-old adolescents from schools from all over the country; around 7000 adolescents participate in each study. This HBSC/WHO project aims to understand adolescents' behaviour with regard to health and health risks, their perceptions about their health, their lifestyles, their relationships with family, school and peers, and community resources. The coordinator of this project intended to apply the HBSC questionnaire to Portuguese adolescents with chronic disease in order to evaluate the differences. The first author (MLS) wanted to develop research with T1DM adolescents for a Masters Degree in Science of Education, and so we decided to plan the study based on the HBSC questionnaire, adapting it as described in the 'Data collection' section (below).

The study methodology included quantitative and qualitative research; these are complementary methods, and have been used with proven results by the Project Social Adventure & Health Studies team within the HBSC, related to the health of Portuguese adolescents.

The objectives of the quantitative study were to gain knowledge of the behaviours and lifestyles, quality of life and social support of adolescents with T1DM and to compare these results with those of the 2002 HBSC reference study, 'The Health of Portuguese Adolescents',<sup>6</sup> as well as the assessment of psychological adaptation, representations and behaviours of adolescents in relation to diabetes.

The qualitative study aimed to ascertain the views, perceptions and representations of adolescents in relation to their life in general and to their diabetes.

This paper presents the results of the quantitative study.

## Materials and methods

### *Study design and intervention*

This study uses cross-sectional quantitative research, developed with adolescents with T1DM, aged between 11 and 16 years, who attended periodic diabetes consultations at the APDP during 2003. The exclusion criteria were other chronic illness, mental illness and diagnosis of diabetes for less than six months. We talked with the adolescents and their parents, presenting written and oral information about the objectives of the study; those adolescents who agreed to participate filled in the questionnaire which took 20–30 minutes to complete.

### *Data collection instrument*

The data collection instrument was a 57-item questionnaire.

- Forty questions were based on the study questionnaire, 'The Health of Portuguese Adolescents',<sup>6</sup> and were related to physical characteristics and health behaviours, satisfaction with life, social support, affective relationships, leisure activities, and habits related to substances (e.g. tobacco/alcohol).
- Seventeen questions were related to diabetes, based on studies conducted at the APDP and on the Diabetes Quality of Life Measure (DQoL) questionnaire<sup>7</sup> and the Adjustment to Treatment (ATT 39) questionnaire.<sup>8</sup> These questions were about health and diabetes treatment, representations about diabetes and psychological adaptation to diabetes.
- Most of the questions had Likert scales – for instance, statements about diabetes representations and psychological adaptation to diabetes: '1 = strongly disagree', '2 = disagree', '3 = don't know', '4 = agree', '5 = strongly agree'; and satisfaction with life: from '1 = worst life' to '11 = best life'.
- Other questions are closed, with yes/no answers. A few others inquired about 'who?', 'what?' and 'how many?'.

Questionnaire assessment was done by a multidisciplinary panel of 15 APDP experts (five doctors, five nurses, three psychologists, one nutritionist and one dietitian) and by three teenagers, aged 17 years with T1DM, as well as three children aged 10, 11, and 12 years.

Data relating to HbA<sub>1c</sub>, weight and height were obtained on the same day on which the adolescents had a diabetes consultation and on which they completed the questionnaire; the adolescents themselves entered these data on the questionnaire.

### *Analysis methods and statistics*

This study used quantitative research methods with descriptive analysis, and comparative, correlational and inferential statistics. The statistical analysis was done with SPSS version 15.0 for Windows, using Student's *t*-test and chi-square, in order to compare groups (boys and girls [11–13 years old] and older adolescents [14–16 years old]). Spearman's test was used to correlate diabetes representations, psychological adaptation to diabetes, satisfaction with life and HbA<sub>1c</sub> levels, versus number of meals per day, number of hours of physical exercise, number of blood glucose measurements and number of administrations of insulin therapy. Pearson's test was used to correlate: diabetes representations with age, with age at diabetes diagnosis and with psychological adaptation to diabetes; psychological adaptation to diabetes with the age and the age at diabetes diagnosis; HbA<sub>1c</sub> with the age, the age at diabetes diagnosis and with psychological adaptation to diabetes.

Regression analysis models were also carried out. These analyses were related to the predictors of psychological adaptation to diabetes, diabetes representations and HbA<sub>1c</sub>.

### *Study population and ethical approval*

The sample consisted of 91 adolescents with T1DM attending diabetes

consultations at the APDP during 2003. Participants comprised 63 boys and 28 girls aged between 11 and 16 years, representing 60.7% of the population of that age attending APDP.

The study was approved by the APDP Ethics Committee. The individual information collected is confidential, has parental permission and informed consent.

The reference group, related to the results of 'The Health of Portuguese Adolescents' study,<sup>6</sup> comprised 7000 adolescents aged between 11 and 16 years old. The comparison with the results of this study was made only in terms of percentages, and the comparison concerning the similarities and differences between adolescents with and without chronic disease is presented in the 'Discussion' section (below).

## Results

### *Demographics and health behaviours*

The adolescents' mean weight was 53.38kg (range 30.20–81.00kg; SD 10.87). The mean height was 160cm (range 138–184cm; SD 0.10); 71% presented with normal weight relative to height, and 89% thought of their physical appearance as normal or good; 59% were not on a diet because they consider their weight to be good. More than a half of those with T1DM eat five to six meals a day (54%) and most of them eat fruit, vegetables, soup and milk at least once a day (63–92%). Sixty-five percent of the adolescents take physical exercise from three to seven days a week for at least one hour per day, and 35% play sport less than three days a week. The sleeping habits of 70–82% of the adolescents amounted to between 8 and 10 hours/24 hours.

### *Satisfaction with life*

The average display of satisfaction with life is 8 (in a scale from 1 [worst life] to 11 [best life]); 81% consider that they have a good life and 53–79% that they have good social skills.

Variable	Frequency	% of adolescents
Blood glucose measurements	3 times a day	59
	1 – 2 times a day	28
	3 – 4 times per week	13
Dietary intake	5 – 6 times a day	54
	7 – 8 times a day	29
	3 – 4 times a day	17
Balanced diet	Milk daily	92
	Fruit daily	69
	Soup daily	68
	Vegetables daily	63
Physical activity	≥3 days, at least 1 hour/day	65
	<3 days	35
Insulin therapy	3 – 4 administrations/day	69
	2 administrations/day	24
	5 administrations/day	7

**Table 1.** Adolescents' adherence to diabetes treatment

### *Social support and affective relationships*

Ninety-two percent of the youngsters consider that their family helps them whenever needed, and 89% report that their family is very concerned about diabetes. Eighty-one percent of the adolescents enjoy school and 94% feel safe at school; 90% consider that diabetes does not affect participation at school. Ninety-five percent report that their colleagues accept them and 82% that their colleagues are kind and concerned about them. Most of the adolescents (80–93%) consider that they have good communication with the diverse professionals of the diabetes team.

With regard to social support, it was found that adolescents feel they have good social support from their family, teachers, colleagues, friends and the health care team (64–95%), and experience ease in communicating with and relating to others. Most of the adolescents (66%) participated in group activities with other young people with diabetes and considered these experiences very positive. The group consultation and the summer

camp are valued as important experiences that help them not to feel different, allowing exchange of experiences, better management of diabetes, fun and fellowship. Forty-two percent of the adolescents report that they have never felt alone, while 14% have felt alone many times.

### *Leisure activities*

During leisure time 94% enjoy going to the beach, 88% like to be with friends, and 86% enjoy going to the cinema, musical performances and group sports practice.

### *Smoking, alcohol and recreational drugs*

In all, 17% have tried tobacco, but only 1.1% actually smoke; 26% have tasted alcohol and 10% drink it once a week or less; 3% have tried light drugs.

### *Health and diabetes treatment*

More than a half of the adolescents consider that they have reasonable health (52%), and 36% report having good health. In relation to insulin therapy, 69% self-administer three to four times a day; 46% report having lipodystrophies. Twenty-eight

Variable	Adolescents aged $\leq 13$ years	Adolescents aged $\geq 14$ years
Better eating habits	x	–
More surveys of blood glucose	x	–
More sedentary activities	–	x
Better relationship with family	x	–
Better relationship with teachers	x	–
Better academic achievement and safety at school	x	–
More satisfaction with the body	x	–
More satisfaction in life	x	–
Better perception of health	x	–

**Table 2.** Differences between younger and older adolescents that can affect diabetes control

percent evaluate glycaemia once- or twice-daily, and 59% evaluate this three or more times a day. Table 1 shows the adolescents' adherence to diabetes treatment.

The aspects of diabetes treatment that are considered more difficult for young people are self-management and nutrition (62%). HbA<sub>1c</sub> – the most widely used laboratory analysis to evaluate diabetes control, referring to the average of the last three months – is very high, with a mean level of 9.9% ([85mmol/mol]; range 5.8–15.8% [40–149mmol/mol]; SD 1.71). The highest values of HbA<sub>1c</sub> are correlated with poorer health perception ( $p < 0.01$ ) and less adherence to the evaluation of blood glucose ( $p < 0.05$ ). The younger adolescents (aged  $\leq 13$  years) have better control of their diabetes (average HbA<sub>1c</sub> 9.2% [77mmol/mol]) than the older ones (age  $\geq 14$  years, average HbA<sub>1c</sub> 10.4% [90mmol/mol];  $t = 3.161$ ;  $p < 0.01$ ), which is related to healthier nutrition, less sedentary activities, more satisfaction with the body, more social support, better perception of health and satisfaction in life. (Table 2.)

#### Representations about diabetes

Most of the young people agreed with the 10 positive representations made – namely, '*Being diabetic is being like all adolescents, socialising with friends and knowing their limits*'. The best representations about diabetes are positively correlated with better psychological adjustment to diabetes ( $r = 0.909$ ,  $p < 0.001$ ), better display of satisfaction in life ( $r^2 = 30.5\%$ ,  $p < 0.05$ ), better adherence to physical exercise ( $r = 0.164$ ,  $p < 0.05$ ) and young age at the onset of diabetes ( $r = 0.245$ ,  $p < 0.05$ ).

#### Psychological adaptation to diabetes

There have been some very positive results in matters related to the perception of capabilities of competence and autonomy; for example, '*Having diabetes means accepting responsibility for your own treatment*'. However, the results were not very satisfactory with regard to guilt, embarrassment and stress concerning diabetes – for example, '*I often think it's unfair to have diabetes when other people are so healthy*'. There was significant positive correlation between better psychological adaptation to diabetes and the

representations of diabetes ( $r^2 = 85.3\%$ ,  $p < 0.001$ ) and adherence to physical exercise ( $r = 0.241$ ,  $p < 0.05$ ).

#### Discussion

Since the HBSC study, 'The Health of Portuguese Adolescents',<sup>6</sup> is a reference study involving 7000 adolescents, representative of the national population, the comparison with the present study was done in terms of percentages. We found that the data relating to the Portuguese adolescents with T1DM in this study are consistent with the results of the Portuguese adolescents in the HBSC study<sup>6</sup> regarding: satisfaction with body weight and body image; physical activity; leisure activities; safety at school and academic achievement; sleeping habits; and representations of satisfaction in life in general.

The adolescents with T1DM have healthier eating habits than those adolescents without diabetes; this finding was possibly related to greater parental monitoring (as well as monitoring by health professionals), increased aid, and interest on the part of teachers (certainly due to the care taken in a chronic disease). The adolescents with T1DM also presented more positive perspectives on various aspects of satisfaction in life and social skills than other adolescents, probably because the chronic disease makes them more appreciative of life.

Those without diabetes feel lonely more often, probably because young people with a chronic disease are perhaps more supported, monitored and 'protected' by family and friends.

In the HBSC study,<sup>6</sup> more young people without diabetes reported using tobacco, alcohol and recreational drugs than those with T1DM; it is probable that parents and health care providers make young people with chronic diseases more aware of the dangers and risks related to these.

The non-diabetic adolescents have a more positive perception of health than those with diabetes,

which evidently seems to be because they do not have a chronic disease.

In spite of the difficulties reported about self-care and nutrition, most adolescents have satisfactory adherence to the various aspects of treatment – self-management, nutrition, physical activity and insulin therapy.

The high mean HbA<sub>1c</sub> (9.9% [85mmol/mol]) confirms the review of the literature: adolescence is the age group with more difficulty in obtaining good control of diabetes.<sup>5,9–11</sup> For adolescents, the ISPAD guidelines recommend a target HbA<sub>1c</sub> of <7.5% (58mmol/mol).<sup>11</sup> The highest values of HbA<sub>1c</sub> correlated with poorer health perception and less adherence to the evaluation of blood glucose, and this is also in agreement with the literature.<sup>11–14</sup> The younger adolescents (aged ≤13 years) have better diabetic control (average HbA<sub>1c</sub> 9.2% [77mmol/mol]) than older ones aged ≥14 years (average HbA<sub>1c</sub> 10.4% [90mmol/mol]). This is related to healthier nutrition, less sedentary activities, more satisfaction with the body, more social support, and better perception of health and satisfaction in life in younger adolescents; this is also in agreement with the literature.<sup>14–18</sup>

The best representations of the adolescents about diabetes are positively correlated with better psychological adjustment to diabetes and with a better display of satisfaction in life; this is also confirmed in the literature.<sup>14,16,17</sup> In general, adolescents consider themselves to have good social support, and this is an area that contributes greatly to satisfaction with life.<sup>10,19</sup>

Adolescents reported on the benefits of participating in group activities (group consultations and summer camps) with other adolescents with T1DM; they are seen as *'important experiences that help you not to feel different, allowing exchange of experiences, better management of diabetes, fun and fellowship'*. These points fall into

the Social Learning Theory, which analyses the benefits and advantages of group activities for adolescents with T1DM aiming for greater acceptance and adaptation to illness.<sup>20,21</sup>

### Conclusion

From the results presented, we conclude that adolescents with T1DM have weight–stature development, leisure and sedentary activities, social support and satisfaction in life similar to those adolescents without diabetes. Although adolescents with diabetes in this study show some healthier lifestyle habits than their non-diabetic peers in the HBSC study, and good adherence to treatments prescribed, the level of metabolic control is not satisfactory. More detailed studies are needed to evaluate this discrepancy.

The study samples were taken at the APDP where the participants' diabetes health care is provided, and this could affect the generalisation of the results. However, despite this limitation of the study, the findings are very important in helping us to know and better understand adolescents with T1DM and so target our work in accordance with their interests, needs and difficulties. The following opinion, given by an adolescent who participated in focus groups in the qualitative study, appears to be an excellent illustration of this work: *'It is a time of change, when we change our body, our tastes, our habits, everything changes and it is very complicated to control anything, above all, diabetes.'*

Following the study findings, the multidisciplinary health care team held meetings to reflect on the results. This was with a view to enabling new approaches to the motivation and education of adolescents and their families, with the use of new programmes mentioned in reference studies, such as motivational interviewing, developing skills, the educational programme and psychosocial intervention. In

this way, self-care skills, control of diabetes and the quality of life of adolescents and their families can be improved. We now have courses for parents of children and adolescents with T1DM, we have organised weekends for adolescents and young adults with insulin pumps, and we are organising web communication among adolescents and young adults. We are also developing a continuation of this research with a new study about 'The health and lifestyles of young adults (from 18 to 35 years old) with type 1 diabetes'.

The current study highlights the requirement for schools to address specific measures in order to meet adolescents' needs and wellbeing in school. These measures encompass teacher training, classroom debates about 'chronic health conditions' including diabetes, school–family reinforced links and access to facilities promoting healthier lifestyle choices (e.g. taking physical exercise, healthy eating). Our team is already developing intervention programmes at schools to help children and adolescents to live better with diabetes among their peers and school staff.

To our knowledge, this study is unique in Portugal regarding the lifestyles of adolescents with diabetes and comparing them to a control group. It is also related to the positive aspects of health promotion in these adolescents with T1DM, regarding nutrition and physical activities.

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### Declaration of interests

There are no conflicts of interest declared.

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