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ORIGINAL CONTRIBUTION

Quality of life of adolescents with autism spectrum disorders: comparison to adolescents with diabetes

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Abstract Relationships are of great importance during adolescence. Because of their social, communication and behavioral impairments, adolescents with Asperger's syndrome (AS) or high functioning autism (HFA) probably suffer from considerable impairment of their quality of life when facing their peers in school. Nevertheless, only one recent study has been published on this subject, indicating a lower health-related quality of life in children and adolescents with autism spectrum disorders (ASD) than in healthy controls. The goals of our study were to clarify the consequences of autistic disorder without mental retardation on such adolescents' daily lives, and to consider them in comparison with the impact of a chronic somatic disease (diabetes) and with the period of adolescence itself, using the VSP-A questionnaire. Adolescents with diabetes were chosen as a comparison group because of the encumbrance of having a constant need for insulin supplementation, to be assimilated to the constant need for communicative adjustments in teenagers with ASD, and the consequences in daily life. The effects of social skill training and social support on quality of life and the appropriateness of using the VSP-A in this population were also studied. Twenty-six adolescents with AS and HFA, 44 diabetic adolescents, and 250 controls completed a self-administered and validated questionnaire on quality of life, the VSP-A. Scores for adolescents with ASD were significantly lower than those of the control and the diabetic adolescents, especially for friendships, leisure time, and affective and sexual relationships. On the other hand, better scores were obtained for the relationships with parents and teachers and for self-image. Social parameters affected the quality of life of subjects with ASD, such as having friends, regularly participating in a sport, and having the support of a school carer. For subjects with autistic spectrum disorders and without mental retardation, impairment of quality of life is significant in adolescence and young adulthood. Such adolescents are dissatisfied with their relationships, although they often have real motivation to succeed with them. Relevance of VSP-A questionnaire in these special individuals is discussed.

Keywords Quality of life · Asperger's syndrome · High functioning autism · Pervasive developmental disorders · Diabetes · Adolescence

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Introduction

Autism is a complex developmental disorder [3, 22, 28] and an impairment in social relationships, communication,

and behavior impact significantly on the functional life of those affected [2, 10, 12, 27, 29]. Asperger's syndrome (AS) and high functioning autism (HFA) are parts of autism spectrum disorders (ASD) [8, 11], and persons with these diagnoses do not have mental retardation. Intellectual abilities, though often heterogeneous, are within normal limits [1]. These young patients mostly attend general educational establishments, faced with their peers on a daily basis and their own developmental characteristics [7, 16].

The period of adolescence is a phase of life in which social relations are pressing and fundamental, and the difficulties in social area can thereby be increased [5, 6, 14, 15, 17, 24]. Studies have been conducted in populations of young healthy controls [8, 25, 28]. These teenagers often suffer from asthenia, physical pain, symptoms of depression, and suicidal ideas. Adolescent girls report lower levels of psychological and physical well-being and energy levels than boys, and a poorer self-image. Moreover, quality of life declines as the young person becomes older.

In children and adolescents with ASD without mental retardation, only one recent study [19] has been conducted on the quality of life of 42 subjects (mean age 12.7 ± 2.6 years), using a generic tool for assessment of quality of life, with self and proxy report. Kamp-Becker et al. indicated a lower health-related quality of life (HRQOL) than controls, but better than in other psychiatric disorders. In adults with autism and without cognitive impairment, three studies have been undertaken. Jennes-Coussens et al. [18] studied quality of life in 12 young adults with AS, aged 18–21 years. These young men reported a poorer quality of life than controls, mainly in the areas of physical health (pain, discomfort, dependence on medical treatment, daily activities, ability to work, energy and fatigue, mobility, sleep, and rest) and social life (affective and working life). Kamp-Becker et al. [20] also reported a lower health-related quality of life using a self-report HRQOL questionnaire in 26 adolescents and young adults (mean age 21.6, range 17–28 years), specifically in the domains "physical health," "psychological health," and "social relationships". When comparing to HRQOL of individuals with schizophrenia spectrum disorder, subjects with ASD displayed a better quality of life. Renty et al. [26] conducted a study in 58 young men with pervasive developmental disorders (PDD) without mental retardation, with an average age of 28 years. This study showed no significant effects of characteristics such as age, sex, educational level, lifestyle, or intimate relationships on their quality of life. The two parameters that had a substantial influence were the subject's daily activities and perceived social support. Focusing on HRQOL of children with ASD without mental retardation, very few studies have been undertaken. Bastiaansen et al. [4] found that children with PDD ($n = 28$, mean age 9.7 ± 2.4 years) had a poorer HRQOL than children in other psychiatric disorders groups including children with attention-deficit and disruptive behavior disorders, anxiety disorders, and mood disorders from the perspective of the clinician working with the child and parents. We can suppose that children with PDD displayed no cognitive impairment as they were able to complete a QOL questionnaire but still, IQ scores of children with PDD are not mentioned in the article. Finally, Limbers et al. [23] studied the appropriateness of using PedsQL in a population of school-aged children with Asperger's syndrome. They demonstrated the severity of impairments in HRQOL and cognitive functioning in these patients from the perspective of 22 parents of children ages 6–12 years.

We present here one of the first studies exploring the quality of life of adolescents with ASD, and comparing their quality of life with that of healthy adolescents, and that of adolescents with chronic somatic disease (diabetes), with a generic, self-administered and validated questionnaire on quality of life, the VSP-A [28]. Adolescents with ASD and without mental retardation were included in the study, in order to focus on the impact of autistic disorder and to avoid the consequences of mental retardation on quality of life. Patients with comorbidity were not included, knowing that adolescents without any further comorbidity are probably the ones who would assess their health-related quality of life considerably better than the large amount of patients with ASD who suffer from another condition. Adolescents with diabetes were chosen to be a comparison group because of the constant need for insulin supplementation, to be assimilated to the constant need for social and communicative adjustments for the adolescents with ASD, and the consequences for both groups on their everyday life. Disorders in both groups did not stop these young subjects from leading a life quite similar to their peers (attending the same schools, using the same means of transport, having fun with the same games, same leisure, etc.). Quality of life was expected to be worse in teenagers with ASD and with diabetes than in the control group. The differences between the teenagers with ASD and with diabetes were expected in the area of social relationships with friends, parents, and teachers, in which adolescents with ASD would be more disabled than adolescents with diabetes or healthy teenagers. Consequences in the field of psychological well-being and of physical well-being were expected in adolescents with ASD and adolescents with diabetes. Among the teenagers with ASD, the second aim of the study was to evaluate the potential positive impact of social skill training and social support on their quality of life. Finally, the appropriateness of using the VSP-A in a population of adolescents with ASD was explored.

Methods

Participants

Three hundred and twenty adolescents participated in this study: 26 subjects with AS or HFA, 44 with diabetes and 250 controls. The average age in each group was 15.0 ± 2.5, 14.3 ± 1.7, and 14.8 ± 2.2 years, respectively, ranging from 10 years 2 months to 20 years 2 months.

Adolescents with ASD ($n = 26$) were recruited through consultations and assessments made in a University Center of Child and Adolescent Psychiatry between 2006 and 2009. Thirty-two teenagers had been seen during the time period, and six declined to participate. All adolescents involved had been diagnosed by a child psychiatrist specialising in ASD, and fulfilled the international diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM) IV edition and the International Classification of Diseases (ICD) 10th edition, for typical or atypical autism ($n = 8$) or Asperger's syndrome ($n = 18$). The range of total IQ in these adolescents was [71–137] (mean = 100.3, SD = 18.1). All participants were receiving normal education in state or private middle or high schools, except for two teenagers, one of whom was attending an educational treatment center, and the other who was enrolled at a National Centre for Distance Learning.

Two hundred and fifty controls were recruited from schools, 143 being middle school students and 107 high school students. Adolescents with diabetes were recruited from the medical outpatient clinic at Pediatric University Hospital. They all had type 1 diabetes of more than 6 months duration. Twenty patients were being treated with an insulin pump and 22 by four subcutaneous injections of insulin per day. The average hemoglobin A1C value (glycated hemoglobin, measured to identify the average plasma glucose concentration over the last 3 months) in this group was 8.2%. All adolescents with diabetes were attending normal schools.

The exclusion criterion for this study was the existence of another disabling medical, surgical, or psychiatric disorder. Comorbidity, such as attention deficit/hyperactivity disorder, anxiety disorders, major depressive disorders, or oppositional defiant disorder/conduct disorder, was excluded by diagnosis of the child psychiatrist, through parent interview and association to child characteristics, based on the international diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM) IV edition and the International Classification of Diseases (ICD) 10th edition.

Informed consent for participation in the study was obtained after providing a full explanation of the protocol to each adolescent, and to the parents of sick adolescents and of younger controls (and parent signature for the latter). Anonymity of data was guaranteed.

Measures

To assess quality of life, all 320 adolescents completed the VSP-A ("Experience and Perceived Health" for adolescents), a self-administered generic questionnaire in French, validated and published by Sapin et al. [28], investigating quality of life in relation to health. The VSP-A questionnaire was chosen for its good reliability and validity, though no specific quality of life measure currently exists for adolescents with ASD. This assessment tool includes 39 items grouped in 11 dimensions: energy, psychological well-being, relationships with friends, leisure, relationships with parents, physical well-being, relationships with teachers, school work, self-Image, relationships with medical staff and paramedics, and affective and sexual relationships. Each item is given a score on a 5 point Likert scale, ranging from 1 "not at all/never" to 5 "always/very much". The adolescent was required to answer questions on the basis of the last 4 weeks. The score for each dimension corresponds to the average of the items constituting the dimension, and can be calculated only when the subject has responded to at least half of the items. All scores are then transformed linearly to obtain a score between 0 and 100, "0" indicating the poorest quality of life and "100" the best.

The teenagers had to complete the questionnaire by themselves, requesting the help of their parents only when they did not understand the meaning of a question for instance.

Participants also completed a form that included questions on social skill training and social support, including parameters like "having friends or not," "participating in sport or not," or "having the support of a school carer or not."

Finally, there were nine additional questions to study the appropriateness of using the VSP-A in a population of adolescents with ASD. The interpretation of some items, especially those about desire for social relationships, can be questioned in this group of patients. The 320 adolescents were asked to rate (between 0 and 10) how much activities dealing with relationships with their friends and relatives, e.g., "meeting up with a group of friends" or "Speaking freely, giving your opinion to your parents," mattered in their everyday lives.

Statistical analysis

Statistical analyses were performed using Student's t tests and ANOVAs with Newman–Keuls post hoc tests. For ANOVAs, effect size is also measured using partial eta squared (η_p^2). Statistica V8 software was used.

Table 1 Social, familial and school characteristics of groups

	Adolescents with ASD	Adolescents with diabetes	Controls
Total subjects	26	44	250
Average age (years ± SD)	15.0 ± 2.5	14.3 ± 1.7	14.8 ± 2.2
Youngest age	10 years 7 months	11 years 1 months	10 years 2 months
Oldest age	19 years 2 months	17 years 4 months	20 years 2 months
Sex ratio (boys/girls) (%)	92/8	52/48	42/58
School (state/private) (%)	46/27	84/11	100/0
SPC[a]			
Executives, academic professions (%)	50	21	22
Intermediate professions (%)	31	27	29
Employees (%)	11	25	31
Artisans, merchants, business executives (%)	8	16	13
Farmers, manual workers (%)	0	9	3
Area of residence (urban/rural) (%)	58/42	25/75	68/31
Parents' situation (together/separated) (%)	81/19	70/30	64/34
Only child (%)	19	0	9
Having the support of a school carer (%)	58	0	0
Regularly participating in sport (%)	54	50	65
Having friends (%)	69	100	99

[a] SPC: Higher socio-professional category of the two parents

Results

Description of population

There was no statistically significant difference between the average ages of the three population samples ($F(2,317) = 0.92$, ns). There was a high preponderance of males in the ASD group (as already recognised), compared with the diabetic group and the controls. The distribution of parents' occupational status (the highest professional status of both parents was selected) revealed more executives and academic professions in the group of adolescents with ASD, compared with the diabetic group and the controls, and a lower proportion of artisans, merchants and business executives, employees, and manual workers. Adolescents with ASD were more often only children compared to the other groups, and their parents were less often separated or divorced. Three quarters of the teenagers in the diabetic group lived in rural areas, compared with a little over two-thirds in the control group and a little over half in the ASD sample (Table 1).

Comparison of quality of life between the three groups of adolescents (Fig. 1)

Adolescents with ASD had a significantly lower level of quality of life compared to the other two groups, mainly in the areas of relationships with friends ($F(2,317) = 25.84$, $p < 0.001$, $\eta_p^2 = 0.14$), leisure ($F(2,317) = 29.93$, $p < 0.001$, $\eta_p^2 = 0.16$), and affective and sexual relationships ($F(2,217) = 4.78$, $p < 0.001$, $\eta_p^2 = 0.04$). On the other hand, adolescents with ASD reported greater satisfaction in their relationships with their parents ($F(2,317) = 3.59$, $p = 0.028$, $\eta_p^2 = 0.02$) and with their teachers ($F(2,309) = 8.48$, $p < 0.001$, $\eta_p^2 = 0.05$), compared to the other two groups. Moreover, there was no significant difference between groups for the dimensions of psychological well-being, physical well-being, or energy. In terms of self-image, adolescents with ASD had significantly higher scores than the other two groups ($F(2,316) = 4.55$, $p = 0.011$, $\eta_p^2 = 0.03$). Finally, there was no significant difference between groups with ASD or diabetes for relationships with medical staff and paramedics.

Impact of social skill training and social support on quality of life in adolescents with ASD

Quality of life in adolescents with ASD depended on age, and they showed greater satisfaction regarding their school work before the age of 15 years ($t(23) = 2.12$, $p = 0.042$). In contrast, the quality of their relationships with friends improved with increasing age, with significantly better results in this dimension for students in the last year of middle school and higher levels ($t(21) = -2.14$, $p = 0.039$). Teenagers who had the support of a school carer reported a higher level of energy ($t(22) = 2.75$,

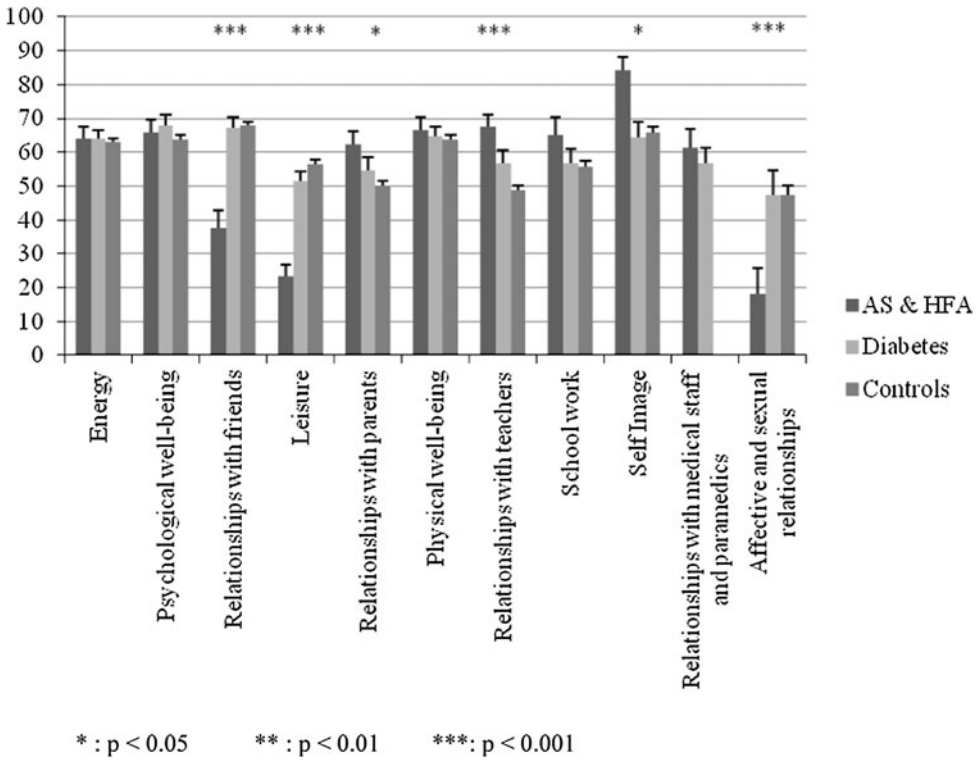

Fig. 1 Comparison of quality of life in the three groups of adolescents (mean and SEM)

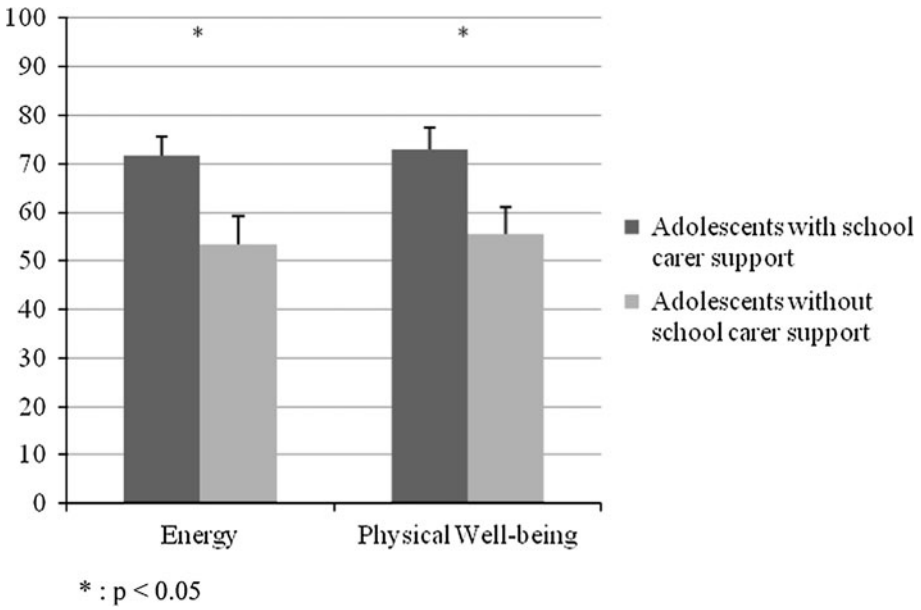

Fig. 2 Impact of school carer support on quality of life (mean and SEM)

$p = 0.009$) and greater physical well-being ($t(23) = 2.42$, $p = 0.022$) (Fig. 2).

Among spare-time activities, regularly participating in sport enabled the teenager to achieve better relationships with teachers ($t(22) = 2.16$, $p = 0.043$). Adolescents with ASD who had friends were more satisfied with their leisure time ($t(21) = -2.54$, $p = 0.018$) and with their relationships with friends ($t(21) = -2.68$, $p = 0.012$). Conversely, they scored lower for satisfaction with their school work than adolescents who had no friends ($t(20) = 2.18$, $p = 0.038$).

Relevance of VSP-A questionnaire in a group of adolescents with ASD

The results showed statistically significant differences between the three groups. Adolescents with ASD attributed less importance to activities in connection with their peers,

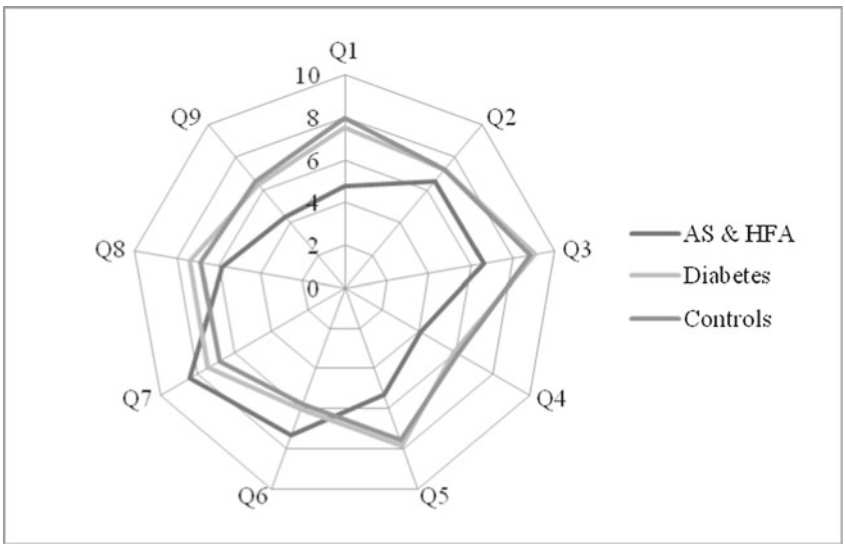

Fig. 3 Level of importance attached to social activities described in VSP-A by the three adolescent groups *Q*1 "meeting up with a group of friends" *Q*2 "going out (to town, cinema, etc.)" *Q*3 "talking with your friends" *Q*4 "confiding in, talking about your problems with your friends" *Q*5 "expressing yourself freely, giving your opinion to friends" *Q*6 "confiding in, talking about your problems with your parents" *Q*7 "expressing yourself freely, giving your opinion to your parents" *Q*8 "visiting your friends" *Q*9 "playing outside with your friends (cycling, football, roller skating, etc.)"

such as "meeting up with a group of friends" ($F(2,290) = 17.85$, $p < 0.001$, $\eta_p^2 = 0.11$), "talking with your friends" ($F(2,290) = 15.39$, $p < 0.001$, $\eta_p^2 = 0.10$), "confiding in, talking about your problems with your friends" ($F(2,290) = 4.17$, $p = 0.016$, $\eta_p^2 = 0.03$), "expressing yourself freely, giving your opinion to friends" ($F(2,291) = 8.96$, $p = 0.001$, $\eta_p^2 = 0.06$), and "playing outside with your friends (cycling, football, roller skating, etc.)" ($F(2,288) = 4.32$, $p = 0.012$, $\eta_p^2 = 0.03$) than the other two groups. In contrast, statistical analysis showed that subjects with ASD attached increased importance to activities with their parents: "speaking freely, expressing your opinion to your parents" ($F(2,291) = 3.86$, $p = 0.019$, $\eta_p^2 = 0.03$) (Fig. 3).

Discussion

This study confirms that the level of quality of life of adolescents with ASD is much lower than that of the control group, mainly in the fields of friendships, leisure, and affective and sexual relationships. This is in line with the only other study including adolescents with ASD without cognitive impairment [19]. The impact of this neurodevelopmental disorder on adolescents' everyday life is also significantly more severe than the impact of a somatic disorder on those with diabetes. These latter subjects display no impairment on their level of quality of life related to their chronic illness, compared to healthy teenagers, findings in agreement with the studies from Laffel et al. [21] and de Wit et al. [9].

The results of the VSP-A questionnaire were "heterogeneous" in the ASD population. Indeed, the scores were very low in the areas mentioned above, and higher than in the other two groups for the areas of relationships with parents, teachers, and self-image. In the controls and diabetic adolescents, the results were more homogeneous across the different areas studied. These results highlight the difficulties inherent in autistic disorder, i.e., the functional impact of their social and communication impairments on their daily lives. It is also of note that there are benefits for these young people from having a network of friends (for 16 of them) in terms of the quality of friendship and leisure. In contrast, adolescents who have no friends seem to be those who overinvest in school work and in knowledge in general. Furthermore, probably due to the less pronounced mental changes related to adolescence in patients with ASD, relationships with their parents and teachers and self-image are less a source of difficulty for them. The fact that there is more variation in quality of life ratings in persons with ASD than in the other two groups could also be due to the smaller sample size. Finally, and surprisingly, the levels of psychological and physical well-being and the energy levels were not significantly different between the three groups of adolescents in this study. One explanation could be that there were some levels of depression in all the adolescents involved. Choquet [8] highlighted the prevalence of depressive symptoms and suicidal ideas among all adolescents. Ghaziuddin and Whitehouse [13, 32] showed a heavy preponderance of depressive symptoms among subjects with autism.

Some parameters in this study had a noticeable effect on quality of life of adolescents with AS or HFA, although these results should be interpreted cautiously because of the low level of significance of statistical tests. Adolescents' quality of life was related to age, with relationships with friends improving as these young people grew older. According to Attwood [1], it is not until the age of thirty that subjects with AS genuinely embrace the different facets of real relationships with friends. This study

highlighted the importance for these young students of having the support of a school carer, with a potential positive impact on energy levels and physical well-being. Finally, in the field of leisure, regularly participating in sport was associated with better relationships with their teachers, despite their frequent motor and coordination disabilities.

Using the VSP-A questionnaire, a generic tool for assessment of quality of life, in a population of adolescents with ASD, provided an initial assessment of their quality of life, and such a study has previously been undertaken only once [19]. No specific quality of life questionnaire currently exists for young people with ASD. Our results call into question the appropriateness of using this tool in this population. On the one hand, the importance attached to peer relationships appeared to be greater among controls compared to those with ASD. On the other hand, the latter attributed greater importance to being able to confide in their parents than controls. However, other factors may also need to be included to assess in detail their quality of life such as hypersensitivity to noise and motor clumsiness, which can have a real impact on the everyday lives of these teenagers [17, 30, 31]. Moreover, adolescents with ASD often present a disorder in theory of mind and undoubted alexithymia, and a potentially limited ability of these individuals to rate their own HRQOL adequately can therefore be discussed. Further studies are required, involving evaluation of the adolescent's quality of life by himself/herself, the parents, and professional care providers.

However, quality of life is a concept which is currently of great interest to clinicians. Its assessment is particularly relevant in populations of adolescents with ASD without mental retardation, a population in which there is a high prevalence of mood disorders. The impact of their relational disabilities on the functional aspects of their daily lives is high. Assessing quality of life might allow clinicians to better comprehend the patient's quality of life, and the effectiveness of treatment proposed.

Conflict of interest The authors declare that they have no conflict of interest.

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