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Development, psychometric evaluation, and factor analysis of an instrument measuring quality of life in autistic preschoolers

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Abstract

Introduction: Early interventions for autistic children should target their quality of life (QoL) but require adapted measures. The association of a child's temperament and parental characteristics with the QoL of autistic children remains unknown.

Methods: We constructed an autism module based on a thematic analysis, a Delphi survey with experts, and a pre-test with parents to be completed alongside the proxy version of the PedsQL 4.0. We explored compliance, responsiveness, internal consistency, convergent validity, and factor structure with 157 parents of autistic preschool children. We examined the association between child and parental characteristics with the QoL of autistic children using correlation analysis, principal component analysis, hierarchical ascending classification, and linear regression. Sociodemographic information was collected via multiple choice questions, autism severity via Autism Diagnostic Observation Schedule (ADOS) scores, and parental

acceptance and child's temperament via the Acceptance and Action Questionnaire and the Emotionality, Activity, and Sociability.

Results: An autism module comprised of 27 items emerged. Psychometric evaluation resulted in a 24-item autism module with good internal consistency and significant convergent validity. ADOS total score was not significantly related to QoL, contrary to children's sleep issues, children's emotionality, and parental acceptance.

Conclusions: The autism module is a reliable QoL proxy measure for autistic preschool children. Results suggest parental interventions targeting children's QoL.

KEYWORDS

acceptance, autism spectrum disorder, preschoolers, psychometric validation, quality of life, temperament

1 | INTRODUCTION

Early interventions in autism have targeted diagnostic signs or related symptoms such as language, adaptative, and challenging behaviors (APA, 2013), with only modest effects (Sandbank et al., 2020). Some researchers have therefore suggested that interventions should also target other outcomes, such as quality of life (QoL), a core measure in health research (Provenzani et al., 2019). Quality of life is a multidimensional and subjective concept (Schalock, 2004), conceptualized as the individual's perspective among several dimensions, including physical, social, and psychological functioning (World Health Organization [WHO], 1946). Quality of life is, therefore, similar to well-being, but the latter tends to be included in the broader and encompassing concept of QoL (Gasper, 2010).

Quality of life is lower in autistic children than in typically developing children (Ikeda et al., 2014). However, few studies have focused on the QoL of autistic children under the age of six (Lichtlé et al., 2021). While the number and variety of early interventions are increasing (French & Kennedy, 2018), their effects on children's QoL are unknown (Reichow et al., 2018). Furthermore, previous studies investigating the QoL of autistic preschool children have used generic measures not tailored to autism (Erez & Gal, 2020). For example, the time allotted to autistic children to enjoy their special interests is not found in generic measures (Tavernor et al., 2013). Thus, developing a QoL measure tailored to these children is a priority (McConachie et al., 2015).

Studies investigating the factors associated with autistic preschoolers' QoL have typically focused on sociodemographic or child-related factors (Lichtlé et al., 2021). Critically, autism symptoms do not predict QoL (Van Heijst & Geurts, 2015), contrary to the presence of challenging behaviors (Kuhlthau et al., 2018) or comorbidities (Mazefsky & White, 2014). The latter are attributed to temperamental difficulties rather than to the intensity of autism symptoms (Korbut et al., 2020). Factors associated with autistic preschoolers' QoL also include caregiver characteristics, notably parenting stress (Chuang et al., 2014). The stress management strategies used by parents of autistic children—such as experiential avoidance/acceptance considered on a continuum (Hayes et al., 2012)—would, therefore, be associated with their children's QoL (Catalano

et al., 2018). Acceptance refers to a general openness to emotions (Hayes et al., 2004), while experiential avoidance is associated with stress in parents of typically developing children (Kashdan & Rottenberg, 2010). Experiential avoidance is also associated with stress in parents of autistic children, which can negatively impact their child's QoL (Hastings et al., 2005).

1.1 | Study aims

This research aimed to develop a quality-of-life measure for autistic preschool children (Study 1), to investigate its reliability and validity (Study 2), and to examine the association between sociodemographic factors, autism signs, children's temperament, and their parents' acceptance skills with the QoL of their children (Study 3).

2 | STUDY 1: DEVELOPMENT OF AUTISM MODULE ITEMS

2.1 | Measures

The Pediatric Quality of Life Inventory Version 4.0 (PedsQL 4.0) assesses the QoL of individuals aged 2–25 years (Varni et al., 2001). While additional modules have been developed to assess specific conditions in addition to the generic scale (Varni et al., 2019), no module for preschool-aged children has been developed for autism. The 2- to 4-year-old version of the PedsQL 4.0 is only available for proxy reports, measuring the parents' perceptions of the QoL of the child; its French version has been validated with French parents (Lichtlé et al., 2023).

2.2 | Construction of the autism module

We extracted a bank of simple, short, and unambiguous items written in the same format as those of the PedsQL 4.0 (Sprangers et al., 1998) from a thematic analysis of interviews with 10 autistic

adults (Lichtlé et al., 2021). Any items not unanimously agreed upon were eliminated or revised using an online two-round Delphi survey (Letrilliart & Vanmeerbeek, 2011). Thirteen autistic and non-autistic experts working in the field of autism were also asked to provide information on their activity, length of service, and, for the autistic experts, how they obtain their diagnoses. They first judged each item's importance level on a Likert scale (from 1 = not important to 5 = extremely important), then answered the yes/no question: "Is this item clearly formulated?" They were also allowed to suggest rewordings, suggest further items, or identify possible redundancies. Items below the consensus threshold (i.e., 80% of the experts judging the item as very or extremely important and clearly formulated) and those reworded through the experts' comments were presented in a second round of evaluation of their importance and clarity. Items that remained below the consensus threshold (80%) were eliminated. We then pre-tested the selected items with a sample of 10 parents from the target population, aged 30–44, who completed the PedsQL 4.0 and the newly developed module. To be included, the parents were required to have a child under the age of six who had been diagnosed with autism according to DSM-5 criteria and to be proficient in the French language. The criteria studied were response time and compliance (Boeije & Willis, 2013). The parents could also indicate when an item was unclear, redundant, or upsetting.

2.3 | Results

After removing three items similar to items already present in PedsQL 4.0, we generated 44 items, which were subdivided into five dimensions based on the results of the thematic analysis (Lichtlé et al., 2021): "activities and interests," "communication," "social interactions," "sensory features," and "habits and predictability" (Appendix Table S1). Of the 22 experts approached, five did not respond, one explicitly declined to participate in the study, and three did not complete the process. Thirteen out of the 22 solicited experts participated in the Delphi survey: three autistic women and one autistic man (a peer helper, a director, and two special needs teachers), and six non-autistic women and three non-autistic men (seven psychologists, a psychology researcher, and a psychomotor therapist). In round one of the Delphi survey, 14 items obtained a consensus of over 80% for their level of importance and the quality of their formulation. These items were, therefore, not presented in the second round. Eleven items did not achieve consensus for their level of importance but did for the quality of their formulation. One of these items was eliminated for redundancy, and the remaining 10 were presented in the second round without any improvement in their wording. Finally, 19 items did not achieve consensus either for their level of importance or the quality of their formulation. Seven of these items were eliminated for redundancy. The remaining 12 items were presented in the second round with improved wording. Five novel items suggested by the experts were also added to the list for Round 2. In total, 27 items were presented to the experts in Round 2. Fourteen items obtained a consensus of more than 80%. Thirteen

items did not obtain a consensus for their level of importance or the quality of their formulation. Overall, 28 items were retained after the survey.

The pre-test had an average completion time of 12 min (min. = 6.5, max. = 18) with a compliance rate of 98.6%; two of the parents refused to answer one item, and one parent refused to answer two items. Furthermore, one item from the "activities and interests" dimension was deleted because we (and one of the parents) concluded that the item was redundant with another item of this dimension. Five items were modified (two from the "activities and interests" dimension and three from the "social interactions" dimension). The final module included 27 items (Appendix Table S2).

3 | STUDY 2: PSYCHOMETRIC EVALUATION

3.1 | Measures

The PedsQL 4.0 (the 2- to 4-years-old version) includes 21 items divided into four domains (i.e., physical, emotional, social, and school), resulting in the calculation of four subscores (Cronbach's alpha between 0.75 and 0.88) and a total score (Cronbach's alpha = 0.90) ranging between 0 and 100 (Varni et al., 2001). The higher the scores, the better the QoL. The "Family Information Form" provides demographic information about the child and parents and calculates the Hollingshead Four-Factor Index of Socioeconomic Status (Varni et al., 2001).

3.2 | Method

One hundred and fifty-seven parents (141 mothers) participated in this study ($M = 37.4$; range 24–71; $SD = 6.8$); 59% resided in the Paris region. The inclusion criteria were similar to the pre-test of Study 1. The mean age of the children was 56.2 months (range 28–72; $SD = 10.9$); 21% were girls, which is somewhat reflective of the male-to-female sex ratio of 3:1 in autism (Loomes et al., 2017). Compared with the general population (according to the National Institute of Statistics and Economic Studies, 2020), blue-collar workers were underrepresented (2.6% vs. 19.2%), whereas participants without occupation were overrepresented (27.4% vs. 10.3%).

The participants completed the PedsQL 4.0, its "Family Information Form," and the autism module developed in Study 1. The autism module includes a 5-point Likert-type response scale, similar to the PedsQL 4.0 (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Items were reverse-scored and transformed to a 0–100 scale as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0. The average total scores or subscores for both the PedsQL 4.0 and autism module were obtained by summing the items over the number of items answered. We used RStudio, Stata (version 14), and Mplus (version 8.2) to perform the analyses, and we explored the compliance and responsiveness of the PedsQL 4.0 and the module. We

assessed internal consistency using Cronbach's alpha and used Exploratory Structural Equation Modeling to determine factor structure (Asparouhov & Muthén, 2009). Convergent validity of the module was assessed via correlation analyses with PedsQL 4.0 scores.

3.3 | Results

We retained 125 and 139 questionnaires, respectively, for analysis of the PedsQL 4.0 and the autism module (some questionnaires were excluded due to missing data). Missing values were mainly associated with the items addressing the "school" dimension of the PedsQL 4.0 (6.4% of the parents did not answer more than half of the items for this dimension). For other dimensions, the proportion of participants who did not answer more than half of the items ranged between 0% and 3.8%. No floor (i.e., score = 0) or ceiling (i.e., score = 100) effects were observed for the PedsQL 4.0 and autism module total scores, while small floor and/or ceiling effects were found for all subscores (<5%).

The Cronbach's alpha was 0.86 for the PedsQL 4.0 total score. All items except item 16 correlated positively (at least 0.40) with the total score. Cronbach's alpha did not increase after removing each item one by one. Cronbach's alphas for the four subscores were 0.73 (physical), 0.72 (emotional), 0.71 (social), and 0.50 (school). The Cronbach's alpha for the total autism module score was 0.91. All items correlated positively (at least 0.38) with the total score. Cronbach's alpha did not increase after removing each item. Cronbach's alpha for the subscores were 0.60 (activities and interests), 0.83 (communication), 0.86 (social interactions), 0.79 (sensory features), and 0.88 (habits and predictability).

For the PedsQL 4.0, we explored four factorial solutions (five-, four-, three- and two-factor). The exploratory factor analysis of the original study identified four dimensions (Varni et al., 2001), but other studies chose to select another solution (two dimensions, according to Amedro et al., 2021; five dimensions, according to Reinfjell et al., 2006). Hence, we decided to explore several factorial solutions in order to determine which one would be the best fit to the data. A solution with one more factor and another with one fewer factor enabled us to obtain elements of comparison on the goodness-of-fit indices. The goodness-of-fit of the ESEMs was assessed regarding the Tucker-Lexis Index (TLI), the Comparative Fit Index (CFI), and the Root Mean Square Error of Approximation (RMSEA) index (Table 1). The five-factor solution indicated excellent fit (CFI and TLI >0.95), and every solution except for the two-factor solution had RMSEA values demonstrating good fit (Marsh et al., 2010). The saturation analysis did not recover the original four-factor structure of PedsQL 4.0 (Appendix Table S3).

For the autism module, four factorial solutions were explored (six-, five-, four- and three-factor). All solutions had an RMSEA index reflecting a reasonable fit (Table 1). The three-factor solution was found to be the most appropriate (Table 2). We chose the three-factor over the four-factor solution because it was more readable and parsimonious; the four-factor solution subdivides the "social interactions" dimension, unlike the three-factor solution. For this solution, items 4–7 saturated on the factor corresponding to the initial "communication" dimension. Items 9–15 saturated on a second factor belonging to the initial "social interactions" dimension and referred to interactions with adults. Items 2 and 16–27 saturated on a third factor. Item 2 ("Not having access to favorite activities") belonged to the initial "activities and interests" dimension, while items 16–27 corresponded to the two initial "sensory features" and "habits and predictability" dimensions. These 13 items referred to the adaptation of a child to their environment. In this three-factor solution, items 1 and 3 ("Devote time to his/her favorite activities" and "Doing activities different from his/her favorite activities"), as well as item 8 ("Other children are not interested in him/her"), were below the 0.3 saturation criterion, while items 3 and 8 saturated on two factors.

TABLE 1 PedsQL[TM] 4.0 and autism module fit indexes for each factorial solution.

PedsQL[TM] 4.0 fit indexes for each factorial solution									
	CFI	TLI	RMSEA	SRMR	AIC	BIC	X^2	df	Sig.
2 factors	0.74	0.68	0.093	0.071	23,635	23,859	316	151	<0.0001
3 factors	0.91	0.88	0.058	0.054	23,540	23,815	830	130	<0.0001
4 factors	0.93	0.89	0.055	0.045	23,529	23,852	160	116	0.0041
5 factors	0.97	0.95	0.036	0.034	23,520	23,887	116	100	0.1264
Autism module fit indexes for each factorial solution									
	CFI	TLI	RMSEA	SRMR	AIC	BIC	X^2	df	Sig.
3 factors	0.82	0.77	0.082	0.058	34,860	35,247	529	273	<0.0001
4 factors	0.85	0.78	0.081	0.051	34,810	35,268	474	249	<0.0001
5 factors	0.86	0.78	0.081	0.043	34,781	35,306	432	226	<0.0001
6 factors	0.88	0.79	0.079	0.037	34,763	35,353	380	204	<0.0001
3 factors (without items 1, 3 and 8)	0.86	0.81	0.080	0.054	30,964	31,308	390	207	<0.0001

TABLE 2 Module item saturations greater than 0.30 (bold) or between 0.20 and 0.30 (underlined).

Dimensions	Item	6 factors #1	#2	#3	#4	#5	#6	5 factors #1	#2	#3	#4	#5	4 factors #1	#2	#3	#4	3 factors #1	#2	#3	3 factors (without items 1, 3, and 8) #1	#2	#3
Activities and interests	I01	_0.27_							**0.34**				_0.22_	**0.33**			_0.27_					
	I02		**0.44**						**0.39**					**0.39**	**0.37**			_0.29_	**0.41**	**0.30**	**0.44**	
	I03	_0.20_		_0.23_		_0.28_				_0.21_	**0.36**		_0.26_		_0.27_	_0.23_	_0.23_		_0.27_			
Communication	I04	**0.62**						**0.65**					**0.66**				**0.67**			**0.68**		
	I05	**0.77**						**0.81**					**0.81**				**0.84**			**0.83**		
	I06	**0.63**	_0.22_					**0.62**			_0.21_		**0.67**				**0.71**			**0.71**		
	I07	**0.69**						**0.68**					**0.71**		_0.21_		**0.69**		_0.23_	**0.70**		_0.23_
Social interactions	I08				**0.47**				**0.50**					**0.52**			_0.22_	_0.26_				
	I09				**0.90**				**0.50**					**0.52**			_0.21_	**0.32**		**0.41**	_0.28_	
	I10		_0.26_	**0.54**	_0.23_				**0.46**	**0.47**				**0.46**		**0.48**		**0.76**		_0.24_	**0.30**	
	I11		**0.37**	_0.29_	**0.31**				**0.63**					**0.63**				**0.53**			**0.73**	
	I12		**0.50**	**0.59**					**0.50**	**0.49**				**0.49**		**0.52**		**0.84**		_0.20_	**0.50**	
	I13			**0.79**						**0.74**						**0.74**		**0.82**			**0.80**	
	I14			**1.1**						**0.98**						**0.96**		**0.85**			**0.79**	
	I15			**0.38**	_0.24_				_0.26_	**0.35**			_0.23_	_0.27_		**0.33**		**0.46**			**0.82**	
Sensory features	I16					**0.59**					**0.65**		_0.20_		**0.56**				**0.57**			**0.57**
	I17					**0.63**					**0.58**				**0.37**				**0.39**			**0.39**
	I18					**0.47**				_0.20_	**0.36**	_0.21_			**0.45**				**0.48**			**0.48**
	I19					**0.65**					**0.62**				**0.38**				**0.37**			**0.37**
	I20					**0.58**					**0.51**	_0.22_			**0.56**				**0.58**			**0.57**
	I21					**0.34**					**0.37**				_0.29_				**0.30**			**0.30**
	I22		_0.29_			**0.43**			_0.22_		**0.54**		_0.20_	_0.22_	**0.40**		_0.21_	_0.24_	**0.43**	_0.23_	_0.23_	**0.44**
Habits and predictability	I23						**0.85**					**0.83**			**0.82**				**0.83**			**0.82**
	I24						**0.71**					**0.71**			**0.80**				**0.83**			**0.83**
	I25						**0.77**		_0.27_			**0.77**		_0.25_	**0.69**				**0.74**			**0.74**
	I26						**0.84**					**0.84**			**0.86**				**0.86**			**0.86**
	I27	_0.24_					**0.49**	_0.23_				**0.48**	_0.24_		**0.61**		_0.20_		**0.61**			**0.61**

These results invited the removal of items 1, 3, and 8. They allowed us to consider the module in three dimensions composed, respectively, of items 4–7 ("communication" dimension), items 9–15 (renamed "adult relationships" dimension), and items 2 and 16–27 (renamed "environmental adaptation" dimension). The means for the total score and the "communication," "adult relationships," and "environmental adaptation" dimensions were 57.3 ($SD = 16.7$), 44.8 ($SD = 24.4$), 63.1 ($SD = 22.7$), and 58 ($SD = 19.5$), respectively. The Cronbach's alpha was 0.90 for the total score. All items correlated positively (at least 0.39) with the total score. Removing items individually did not increase the alpha. Cronbach's alphas for the "communication," "adult relationships," and "environmental adaptation" dimensions were 0.83, 0.86, and 0.89, respectively. The RMSEA index of this solution reflected a reasonable fit (Table 1). Item 2 ("not having access to favorite activities") no longer saturated on factor 3 but on factors 1 ("communication") and 2 ("adult relationships") (Table 2). However, item 2 remained better suited to the "environmental adaptation" dimension. The correlation of the total score on the reconfigured module with the total score on the PedsQL 4.0 was significantly positive ($r = 0.71$, (t (112) = 10.57, $p < 0.0001$, 95% confidence interval = [0.62; 0.90]).

4 | STUDY 3: FACTORS ASSOCIATED WITH QUALITY OF LIFE OF AUTISTIC PRESCHOOL CHILDREN

4.1 | Measures

The 157 participants of Study 2 also completed the Emotionality, Activity, and Sociability (EAS) survey, which assesses child temperament across four dimensions (emotionality, sociability, activity, and shyness; Buss & Plomin, 1984). Cronbach's alphas of the EAS validated with French children aged 2–5 years ranged from 0.62 (for "sociability") to 0.80 (for "emotionality"; Rouxel et al., 2013). The scores range between 1 and 5 (the higher the score, the greater the temperament dimension). The participants also completed the Acceptance and Action Questionnaire (AAQ-II) to assess the constructs referred to as acceptance, experiential avoidance, and psychological inflexibility (Bond et al., 2011); this questionnaire was previously validated in French (Cronbach's alpha = 0.82; Monestès et al., 2009). The scores ranged between 10 and 70 (the lower the score, the lower the acceptance).

Finally, the parents were asked to indicate—via open or multiple choice questions—whether they had any health problems or disabilities and to provide the following information about their child: date of diagnosis, medication treatments, difficulty falling asleep, waking up at night, eating habits, comorbidities (i.e., epilepsy, chronic illnesses, and gastrointestinal symptoms), special interventions, schooling, enrollment in sports or leisure clubs, and siblings (gender, age, and whether any other children in the sibling group were autistic). Autism severity was collected retrospectively via the Autism

Diagnostic Observation Schedule (ADOS) calibrated severity score (Lord et al., 2000), which is stable over time (Bieleninik et al., 2017).

4.2 | Method

We examined the association between sociodemographic data and child and parental characteristics with the QoL of autistic children using correlation analysis, principal component analysis (PCA), hierarchical ascending classification (HAC), and linear regression. All analyses were performed using SPAD.neXt software (release 9.2; www.coheris.com).

4.3 | Results

Characteristics of the children and parents are presented in Table 3. The most critical correlations with the PedsQL 4.0 and autism module scores relate to the AAQ-II ($r = 0.398$, $p < 0.001$), EAS ($r = -0.488$, $p < 0.001$), and sleep issues scores ($r = -0.511$, $p < 0.001$) (Appendix Table S4). Our results also revealed non-significant correlations between ADOS scores and the PedsQL 4.0 ($r = -0.229$, N.S.) and autism module scores ($r = -0.177$, N.S.). These results call for caution, given that the analysis was only performed on 71 participants and we found a significant difference in QoL scores between participants for whom we had obtained ADOS scores and those for whom we had not ($M_{withADOS} = 62.62$, $M_{withoutADOS} = 55.04$, $p = 0.002$).

The five QoL variables were highly correlated inter-correlated (Appendix Table S5); they can be summarized by the first two dimensions of the PCA, and account for 81% of the total variance of the five variables (Appendix Table S6). The first dimension can be considered as a QoL axis (explaining 67% of the variance). The second, less influential dimension (14% of the variance) consists of two subscores of the autism module: communication and adult relationship. *These two variables were clearly differentiated (opposite) on this second dimension.* Although significant, their correlation was the lowest of those between the five variables.

We then performed the HAC of the participants by taking their coordinates in the space constituted by the two selected dimensions. We considered three classes, of which the between-variance rate (η^2) was 63%. We plotted the classes in the plane of the first two dimensions retained from the PCA, with their respective concentration ellipses (Figure 1). Class 1 ($N = 39$) comprised individuals whose QoL averages were lower than the general averages (Table 4). Class 2 ($N = 105$) was an intermediate class of individuals whose QoL averages were slightly above the general averages. Class 3 ($N = 13$) contained those with the best QoL. All observed differences were significant at the 0.05 level (corrected for multiple comparisons).

Characterizing the classes according to the EAS and AAQ-II, Class 1 had higher averages for "emotionality" and "shyness" but lower averages for "sociability"; it was also characterized by a lower average AAQ-II score (Table 4). Class 2 had averages close to the

TABLE 3 Children's and parents' characteristics.

Measures	n	M	SD
Children's characteristics			
Age at diagnosis (months)	154	38.4	11.9
Length of time since diagnosis (months)	154	17.4	12
ADOS score	71	6.9	1.9
Temperament	157		
Emotionality		3.3	0.9
Activity		3.9	0.8
Sociability		2.5	0.9
Shyness		3.2	0.9
Sleep issues (difficulty falling asleep/waking up at night)			
2	40		
3	22		
4	41		
5	17		
6	35		
Gastrointestinal symptoms			
0	3		
1	134		
2 or 3	20		
Chronic illnesses (including epilepsy)			
Yes	31		
No	126		
Eats a variety of foods			
Never or rarely	58		
Occasionally, frequently or always	97		
Treatment			
Yes	47		
No	110		
Schooling			
Yes	136		
No	19		
Schooling in a regular class	115		
Non-regular schooling	21		
Full-time schooling	60		
Part-time schooling	76		
School support (full/part)	54/52		
No school support	30		
Number of special interventions			
0	7		
1	39		
2	56		

TABLE 3 (Continued)

Measures	n	M	SD
3	38		
4 or 5	17		
Enrollment in sports or leisure clubs			
Yes	49		
No	106		
Sociodemographic data			
Hollingshead index	157	42.4	15.1
Siblings			
No autistic siblings			
0	42		
1 or more	115		
Autistic siblings			
0	135		
1 or more	22		
Parents' characteristics			
Health problems or disabilities			
Yes	35		
No	122		
AAQ-II score	157	46.2	10.7

Abbreviations: AAQ, Acceptance and Action Questionnaire; ADOS, Autism Diagnostic Observation Schedule.

general averages for these same variables. Class 3 had averages for "shyness" and "emotionality" that were well below the general averages and an average for "sociability" that was above the general average; it was also characterized by a higher average AAQ-II score. All of the observed differences were significant at the 0.05 level.

For the categorical variables, we compared the frequency of the category in each class to that of the overall sample. If the difference between the two frequencies was greater than 5%, we performed a test, and if the test was significant, we considered the modality to be characteristic of the class (Table 4). Class 3 appeared to be characterized by not taking treatment and a level 2 rating for sleep disorders (i.e., rarely having difficulty falling asleep and rarely waking up at night). On the other hand, Class 1 was characterized by taking treatment and a level 6 rating for sleep disorders (i.e., often having difficulty falling asleep and often waking up at night). In our sample, melatonin was the most commonly given treatment. Class 2 was characterized by school support. All of the observed differences were significant at the 0.05 level.

Moving to the "emotionality," "shyness," and "sociability" dimensions and the AAQ-II scores, we performed a multiple regression using the dimensions of these three EAS as predictor variables, and then we added the AAQ-II scores (Table 5). By regressing QoL with "shyness" and "emotionality," we obtained a significant coefficient and goodness-of-fit of 20% and 18%, respectively. After introducing
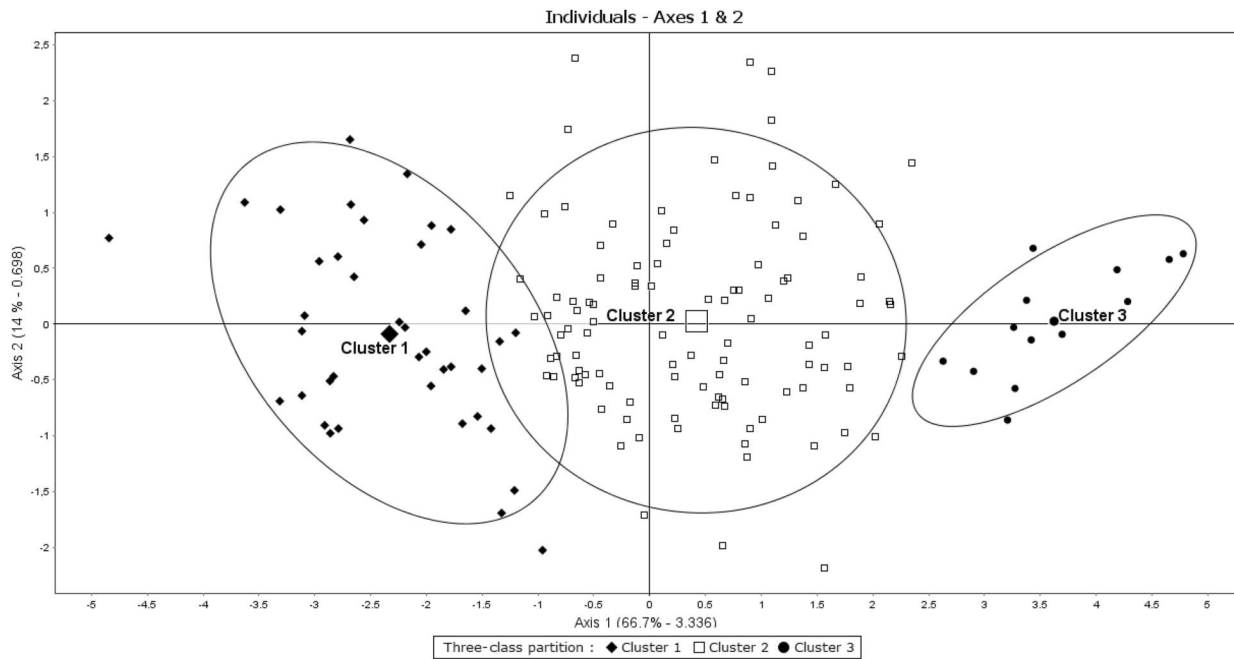
FIGURE 1 Cloud of individuals in the plane of the first 2 dimensions of the principal component analysis (PCA) and projection of the hierarchical ascending classification (HAC) classes with their concentration ellipses.

TABLE 4 Quality of life (QoL), quantitative and qualitative variables characterizing classes.

Quantitative variables characterizing classes (means and std deviations)[a]			
Characteristic variable	**Average for class 1 (n = 39)**	**Average for class 2 (n = 105)**	**Average for class 3 (n = 13)**	**Overall average**
PedsQL 4.0 total score	**42.10** (8.80)	**61.05** (10.28)	**86.12** (7.59)	58.51 (15.14)
Autism module total score	**33.61** (9.70)	**60.04** (9.75)	**88.47** (5.24)	55.97 (17.61)
Environmental adaptation subscore	**34.35** (13.89)	**61.36** (14.38)	**88.49** (6.81)	57.18 (20.21)
Communication subscore	**19.77** (16.64)	**48.21** (20.04)	**76.92** (17.57)	43.52 (24.70)
Adult relationships subscore	**41.24** (19.24)	**64.41** (19.72)	**95.22** (4.72)	61.39 (23.60)
Emotionality	**3.90** (0.71)	**3.20** (0.87)	**2.66** (0.46)	3.33 (0.88)
Shyness	**3.75** (0.68)	**3.08** (0.80)	**2.26** (0.75)	3.18 (0.86)
Sociability	**2.02** (0.70)	2.58 (0.94)	**3.42** (0.71)	2.51 (0.94)
AAQ-II	40.64 (10.32)	47.35 (10.07)	53.31 (8.86)	46.18 (10.65)
Qualitative variables characterizing classes (percentages)[a]			
	% of modality in the class 1	**% of modality in the class 2**	**% of modality in the class 3**	**% of modality in the sample**
Taking treatment	**48.7**	26.7	0.0	29.9
Parent with health problems or disabilities	**35.9**	19.0	7.7	22.3
Sleep issues level 6	**35.9**	20.0	0.0	22.3
School support	46.2	**75.2**	69.2	67.5
Full-time schooling	25.6	38.1	**76.9**	38.2
Not taking treatment	51.3	73.3	**100.0**	70.1
Sleep issues level 2	2.6	30.5	**53.8**	25.5

[a]Bolded values are characteristic of a class. Non-characteristic values of a class are in italics.

TABLE 5 Results of quality of life (QoL) regression on emotionality, shyness, sociability, and Acceptance and Action Questionnaire (AAQ-II) score.

QoL	β	p	R²
Emotionality	−0.420	0.000	0.176
Emotionality	−0.349	0.000	0.238
AAQ-II	0.257	0.001	
Shyness	−0.445	0.000	0.198
Shyness	−0.417	0.000	0.297
AAQ-II	0.316	0.001	
Sociability	0.313	0.000	0.098
Sociability	0.324	0.000	0.213
AAQ-II	0.363	0.001	

AAQ-II as another predictor, we found the coefficients to be significant, with an improvement of the R^2 to 30% and 24%, respectively.

5 | DISCUSSION

5.1 | Summary of findings

This study allowed us to create and validate a measure of the parents' perceptions of the QoL of their child, which is dedicated to autistic preschool-aged children. The measure is composed of 24 items divided into three dimensions. The module can also be used in conjunction with the PedsQL 4.0, but for optimal use of the PedsQL 4.0 with French autistic children, we suggest retaining only the total score. This study shows that autistic children's temperament and sleep issues are associated with their QoL; it also confirms the importance of the parents' characteristics.

5.2 | Psychometric study

The total score items, as well as the physical, emotional, social, and school subscores of the PedsQL 4.0, showed satisfactory homogeneity. These results are comparable to those from Limbers et al.'s (2009) study of autistic school-aged children living in the United States. However, as with that study, the homogeneity of the "school" functioning in the current study was weak. This dimension could, indeed, measure two constructs (Varni et al., 2001). As with Viecili and Weiss's (2015) study of Canadian autistic children and adolescents, our factor analysis did not confirm the original four-factor structure suggested by Varni et al. (2001), which suggests an evaluation of the same construct, although this is difficult to rule out due to our modest sample size.

Our results show excellent internal consistency for the total module score and good internal consistency for four of the five subscores. Only the Cronbach's alpha for the "activities and

interests" dimension did not reach the recommended threshold (Nunnally, 1978), which can be explained by a weakness in face validity for two items in this dimension. The factor analysis of the module led us to exclude three items and to consider it across three dimensions: "communication" (four items), "adult relationships" (seven items), and "adaptation to the environment" (13 items). These had good internal consistency.

Compared to the version of the module before its psychometric evaluation, the "communication" dimension was the only one that remained unchanged. This dimension assessed problems related to receptive and expressive language. Meanwhile, the items in the "adult relationships" dimension referred to the children's social relationships with adults. Indeed, young autistic children are more likely to interact with adults than with their peers (Hume et al., 2019). Items in the "adaptation to the environment" dimension assessed difficulties autistic children have with adjusting to their environments (APA, 2013). The results of the correlation between the total score of the reconfigured module and the PedsQL 4.0 show a good convergent validity, which supports the meaning given to the QoL concept as assessed by this module. Nevertheless, both tools have different factor structures since they are complementary. The PedsQL 4.0 and the autism module form a "modular scale," combining the advantages of a generic scale and a tool dedicated to autism (Varni et al., 2001).

5.3 | Factors associated with quality of life

Our participants' QoL was not related to the severity of their autism (as measured on the ADOS), consistent with data collected from older autistic individuals (Kim & Bottema-Beutel, 2019). This suggests that the prototypicality of autistic presentation, of which the ADOS total score represents a proxy, should be conceptually separated from an individual's ability to function with the symptoms identified by their ADOS score (Mottron & Gagnon, 2023; Szatmari et al., 2015).

Temperament characteristics (e.g., high intensity of emotionally driven reactions in autistic preschool children) are negatively related to QoL (Chuang et al., 2014). Consistent with this previous finding, the emotionality scores measured on the EAS in the current study were negatively and significantly associated with PedsQL 4.0 and module scores. Compared to typically developing children, autistic children have higher levels of emotionality (Omelańczuk & Pisula, 2020); the literature also highlights the difficulties autistic children have with emotion regulation (Cai et al., 2018). Emotion dysregulation is thought to negatively impact the mental health of autistic individuals (Conner et al., 2021) and their behaviors, regardless of their intelligence (Berkovits et al., 2017). Ultimately, high emotionality and emotion dysregulation would predispose autistic children to poorer QoL (Menezes & Mazurek, 2021). Furthermore, there could be common neurobiological processes that affect emotional dysregulation and sleep disorders (Gadow et al., 2015) that may provide us with a deeper understanding of the associations between our participants' QoL scores and sleep issues.

Finally, regarding the association between receiving treatment and the QoL of our participants, data from the literature do not allow for a valid study of the relationship between pharmacological interventions and the QoL of autistic individuals (Bertelli et al., 2013).

Chuang et al. (2014) highlighted the importance of parenting variables on the QoL of autistic preschool children. Our results follow this trend, revealing that the AAQ-II scores were positively and significantly associated with the PedsQL 4.0 and module scores. This suggests that the lower the level of acceptance exhibited by the parent of an autistic child, the greater the child's risk of poor QoL. Greater acceptance skills of parents are associated with better emotion regulation in typically developing children (Morris et al., 2007), and parents' improved emotion management would help autistic children to regulate their emotions better (Chetcuti et al., 2021) and reduce behavioral problems (Wilson et al., 2013). A bidirectional association also exists between parents' psychological distress and their children's emotional difficulties (Yorke et al., 2018). Acceptance is one of the processes of Acceptance and Commitment Therapy (ACT; Hayes et al., 2016). ACT may, therefore, be of benefit to the parents of autistic children (Juvin et al., 2021; Lichtlé et al., 2020), and to the children themselves, by changing parental perceptions (Lord et al., 2021).

5.4 | Limitations and perspectives

The current diagnosis of autism promotes heterogeneity (Mottron & Bzdok, 2020). Therefore, our module certainly cannot be generalized to all children with autism. In this study, the children's temperaments were assessed by their parents, which may have biased the assessment (Chetcuti et al., 2021); however, it nonetheless informs the quality of the parent-child relationship (Duthu et al., 2008). A similar limitation relates to measuring the children's QoL, as it only measures the parents' perceptions. Nonetheless, the parent's view of their child's QoL may directly affect the child (Cappe et al., 2018). A physiological proxy (e.g., heart rate variability) may provide a more direct, complementary assessment of the child's experience (Hufnagel et al., 2017) independently of their parents' perception and judgment. It might also be of interest to estimate the reliability of the tool independently of the subjectivity of the rater by interviewing both parents. In addition, we cannot conclude that the autism QoL module we developed and evaluated is generalizable to all autism subgroups. Information processing patterns differ depending on whether or not the autistic child has a speech delay (Samson et al., 2015), which could impact the determinants of QoL according to these two groups. Furthermore, syndromic and nonsyndromic autistic children may differ in their QoL (Bolbocean et al., 2021).

Meanwhile, the AAQ-II has been criticized for its lack of discriminant validity (Tyndall et al., 2019). Furthermore, according to ACT, measuring only acceptance does not recognize the complexity of coping skills. The latter are part of the concept of psychological flexibility, a meta-process responsible for psychological difficulties (Monestès & Baeyens, 2016). We also cannot rule out recruitment

bias (Fletcher-Watson et al., 2019). In addition, the participants were predominantly mothers, and we do not know the impact of the non-responding parent's characteristics on their child.

This research is limited to the study of a French population. Validation outside of the French-speaking context and culture is recommended. Our data encourage future research to assess the stability of the factor structure of the autism module on an independent sample. Furthermore, the discriminant validity of the autism module should be assessed to verify that it does not relate to constructs that it should not relate to theoretically. Our results also invite future research to target the emotional competencies of young autistic children through an increase in parents' psychological flexibility. We also encourage the study of the associations of parenting interventions, such as ACT, with the QoL of these children. Finally, these findings require replication in a larger, independent sample.

AUTHOR CONTRIBUTIONS

JL: Principal investigator of the study; developed the research protocol; established the research collaborations with partner clinical services; participated in recruiting participants, collecting data, data processing, and analyzing; wrote and proofread the article. ED: Participated in analyzing Study 2's data and proofreading the article. IZD: Participated in analyzing Study 3's data. JLM: Participated in proofreading the article. LM: Co-scientific leader of the study; participated in establishing the research collaborations with partner clinical services, writing, and proofreading the article. EC: Scientific leader of the study; participated in developing the research protocol, establishing the research collaborations with partner clinical services, analyzing the data, writing, and proofreading the article. The other authors participated in recruiting participants. We confirm that all named authors provided substantial contributions to this study and have reviewed and approved the final version of this manuscript. We all agreed to the listing order for authors.

CONFLICT OF INTEREST STATEMENT
The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data supporting this study's findings are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

All procedures performed in studies involving human participants were approved by the *Comité d'Ethique pour les Recherches Comportementales et En Santé* of the *Université Paris Descartes* (2018/n°2018–27).

PATIENT CONSENT STATEMENT

All participants signed an informed consent form before participating in the study.

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