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ARTICLE

Development of a social and professional stress scale for parents of children with autism spectrum disorder[1]

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Abstract

Parents of children with Autism Spectrum Disorder (ASD) may experience increased stress in their social and professional activities due to the challenges of raising a child with ASD. The present study developed a scale to measure the Social and Professional Stress (SPS) experienced daily by these parents. The study sample consisted of 255 parents residing in Brazil aged between 21 and 61 years (mean = 38, SD = 6.0). Item Response Theory (IRT) was used to develop the SPS-Scale, which showed good psychometric properties. Our findings indicated a higher level of SPS among mothers who are primary caregivers and who have children with symptoms of ASD at medium or severe levels. The child's age and the interviewee's marital status also showed an association with the SPS experienced by the parents. Overall, the SPS-Scale proved to be a valid instrument to measure the SPS experienced daily by parents of children or adolescents diagnosed with ASD.

Keywords: Graded response model; Item response theory; Latent trait; Measurement instrument; Psychometric scale; Stress level.

1. Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental disorder characterized by difficulties in communication and social interaction, restricted interests, and stereotyped behavior patterns (American Psychiatric Association, 2013). Diagnosing ASD can be difficult because there is no specific medical test to diagnose this disorder. Parents often notice the child's atypical behavior, which helps doctors make the diagnosis. Although there are several studies on ASD, its causes are still unknown (Teixeira, 2016). Three levels of autism are indicated based on necessary support levels: level 1 (requiring support) is the mildest, while level 2 (requiring substantial support) and level 3 (requiring very substantial support) are the middle and most severe, respectively.

The great attention and high daily demand for care required by children with ASD often cause physical, financial, social, and emotional stress for their parents (Al-Oran & AL-Sagarat, 2016; Aguiar & Pondé, 2018). Mothers are generally the most affected (Kiami & Goodgold, 2017), as they usually assume the role of primary caregivers. Some common stressors are the child's behavior, difficulties with the work schedule, a great concern with the child's school stage, difficulties with the child's daily

care demands, and uncertainty about the child's future (Miranda *et al*., 2019).

To avoid exposing the child with ASD and their difficulties in participating and interacting in social activities and events, parents often feel forced to stay at home because of the challenges they experience with the child's behavior (McStay *et al*., 2014). Some parents also face prejudice in their social networks because of the child's behavior and often report changes in their social relationships with family and friends, making social interaction increasingly restricted (Whitman, 2015).

On the other hand, some parents of children with ASD are forced to leave the workforce (most often mothers) because they cannot obtain appropriate childcare or a flexible work schedule (Minatel & Matsukura, 2014). Those who remain at work are concerned with the workload that interferes with the time to practice activities that influence the child's development. Furthermore, employment decisions are often related to financial issues, which can also be a source of stress (Veld *et al*., 2017). The study by Ou *et al*. (2015) conducted in China with 459 nuclear families of children with ASD revealed that childcare problems greatly affected employment decisions of 57.5% of them.

The family's ability to adapt to the child's needs is also essential, as it can directly interfere with how the child with ASD will develop their skills (Miele & Amato, 2016). Therefore, offering support and professional help to parents of children with ASD and their family members is crucial to help them adapt to changes and deal with the child's care demands (Aguiar & Pondé, 2018).

Psychometric scales are valuable tools that can help assess ASD traits and their effects on parents' lives. Using objective instruments (questionnaires) for psychometric assessment, methods based on Item Response Theory (IRT) allow the construction of scales to measure latent traits (Sartes & Formigoni, 2013), i.e., traits that cannot be measured directly (such as attitudes, quality of life, patient satisfaction, amongst other attributes). IRT models can evaluate the relationships between the latent trait of interest and the items intended to measure the trait. For instance, the graded response model (Samejima, 1969) is appropriate when items have ordered response categories on a rating scale.

Several studies have shown the importance of IRT for psychometric assessment. For example, Sturm *et al*. (2017) used it to investigate the Social Responsibility Scale (SRS) psychometric properties and produce a reduced 16-item SRS short form that emerged as a more precise measure of ASD core symptom severity. Gardiner *et al*. (2019) also used methods based on IRT to assess the psychometric properties of the Family Resilience Assessment Scale, composed of 6 subscales that identify protective factors for parents of children or adolescents with ASD.

In addition, IRT methods were used by Zaitman-Zait *et al*. (2010) to assess the functioning of items in the Parenting Stress Index-Short Form (PSI-SF) to measure the stress of parents of young children with ASD. PSI-SF is a derivative of the PSI (Abidin, 1995) developed to measure parents' stress of typically developing children. It includes 36 items in three subscales (parental distress, parent-child dysfunctional interaction, and difficult child), each containing 12 items. The authors concluded that nine items showed poor functioning among parents of children with ASD. The reason is that children with ASD behave differently from typically developing children, and these items may not adequately discriminate the stress severity of parents of children with ASD. Two other studies that used the PSI-SF with parents of children with ASD also concluded that some items related to parent-child interaction and child's behavior could be perceived differently by parents of children with ASD and those of typically developing children (Zaitman-Zait *et al*., 2011; Dardas & Ahmad, 2014). Thus, the proposal of new instruments with items explicitly aimed at parents of children with ASD seems justifiable.

Social and Professional Stress (SPS) experienced by parents of children with ASD is a latent trait difficult to measure and not widely covered by existing scales. Thus, this study aimed to (1) propose an instrument to measure the SPS experienced by parents of children with ASD; and (2) investigate parental and child characteristics predicting higher levels of SPS. It is noteworthy that the instrument proposed in this study does not include challenges such as parents' fears about the child's future, as the focus is on social and professional (work) situations they experience due to the child's ASD condition.

2. Materials and Methods

2.1 The Instrument

The items to assess the latent trait "SPS experienced by parents of children/adolescents with ASD" were elaborated after reviewing existing scales, such as the PSI-SF (Abidin, 1995), Perceived Stress Scale (PSS; Cohen *et al*., 1983), Family Needs Scale (FNS; Dunst *et al*., 1988), Social Responsiveness Scale (SRS; Constantino & Gruber, 2012), Family Resilience Assessment Scale (FRAS; Sixbey, 2005), and the World Health Organization Quality of Life (WHOQOL; Fleck, 2000).

The instrument's items related to professional situations (P1 to P7, Table 1) ask about the influence of the child's ASD condition on the parents' professional life (e.g., in their work routine). In contrast, items related to social situations (S1 to S7, Table 1) ask about this influence on the parents' social life (e.g., social relationships and participation in parties and social events). The Portuguese version of the items is in Appendix A (Table A.1). Items having three or more ordered response categories were scored following a Likert scale (Likert, 1932), as shown in Table 1. The lowest and highest scores were assigned to the categories believed to cause the lowest and highest level of parental stress, respectively.

Table 1. The instrument for measuring the social and professional stress of parents of children with ASD

Are you currently working (paid employment)? If YES, answer all items. If NO, answer items S1 to S7.						
		Scores assigned to item categories				
Item	Description	1	2	3	4	5
P1	Do you have difficulties with your work routine because there is no one with whom to leave your child with ASD when you need it?	Never	Rarely	Sometimes	Often	Very often
P2	Do the daily care demands of your child with ASD make you tired, interfering with the development of your work activities?	Never	Rarely	Sometimes	Often	Very often
P3	How much do you dedicate to your professional life since your child's ASD diagnosis?	Too much	A little	Nothing	-	-
P4	Did you need to change your workload due to the daily care demands of your child with ASD? The change was	Favorable	There was no change	Unfavorable	-	-
P5	How often is your work routine affected by the daily care demands of your child with ASD? (e.g., missing work, arriving late, or leaving work early).	Never	Rarely	Sometimes	Often	Very often
P6	How much does your child's ASD condition affect your professional life?	Nothing	A little	Too much	-	-
P7	Is it easy for you to reconcile your child's daily care demands with your work schedule?	Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult
S1	When you go to parties or social events with your child with ASD, how much fun do you have and interact with people? ( ) I do not go to parties or social events (score = 3).	Too much	A little	Nothing	-	-
S2	Do you prefer to stay at home, avoiding going to places that interfere with the behavior of your child with ASD?	No	Yes	-	-	-
S3	Have you ever declined to go somewhere because of the behavior of your child with ASD?	Never	Rarely	Sometimes	Often	Very often
S4	Have you ever declined to go somewhere because you feel uncomfortable with comments or gestures from others directed at your child with ASD?	Never	Rarely	Sometimes	Often	Very often
S5	Has anyone declined to invite you to a party or social event due to your child's ASD condition?	Never	Rarely	Sometimes	Often	Very often
S6	How much does your child's ASD condition affect your social life?	Nothing	A little	Too much	-	-
S7	How much do the daily care demands of your child with ASD affect your social life?	Nothing	A little	Too much	-	-

Note: Items translated into the English language from the original Portuguese version. ASD: autism sprectrum disorder.

A group of specialists (psychologists, linguists, and statisticians) and some invited parents of children with ASD evaluated the first version of the instrument, aiming to test its format and function, clarity of the message, and language adequacy. The convenience and intentional sample of the pilot test consisted of 10 participants (seven women and three men), with a mean age of 39. The suggestions were incorporated after the pilot test, and none of the items needed to be excluded.

2.2 Participants and Recruitment Procedure

Participants were recruited through social networking sites, including Facebook, WhatsApp, Instagram, and Twitter. The questionnaire was edited into a Google Form®, and its web link remained available from February 1st to April 31st, 2020. Participants eligible for participation were parents of children or adolescents with ASD residing in Brazil aged 18 years or older. Participation was voluntary, and all participants who met the inclusion criteria and agreed to participate provided electronic informed consent. All parents with paid employment at the time of the survey completed all items (Table 1); otherwise, they completed items S1 to S7.

Participants were also asked about themselves and their children (see questions in Table A.2 of Appendix A). Two open-ended questions also allowed them to comment on the impact of the child's ASD condition on their professional and social lives. The data considered in the analysis were those of parents with paid employment at the time of the survey. The Research Ethics Committee of the Federal University of Parana, Brazil, approved the study (Protocol No. 3743074).

2.3 Data Analysis Based on Item Response Theory

2.3.1 Analysis of the IRT Assumptions

IRT methods assume that individuals vary along a dominant latent continuum. The necessary premises for unidimensional IRT models are unidimensionality, local independence, monotonicity, and item invariance. Since unidimensionality implies that only one latent trait is measured by the set of items in the instrument, factor analyses of the polychoric correlation matrices were first conducted to examine the essential unidimensionality. Scree plots of the eigenvalues of factors and principal components analyses were used to determine the number of factors or principal components to retain. Gorsuch (1983) recommends a ratio of the first to second eigenvalues equal to or greater than 3 to indicate essential unidimensionality. These analyses were carried out using the 14 items in Table 1. Several psychometric indices discussed by Rodriguez *et al*. (2016) were also evaluated. They are the omega reliability coefficients (omega and omega H), explained common variance (ECV), factor determinacy (FD), and construct replicability (H).

Local independence was evaluated using the local dependence (LD) G^2 statistic presented by Chen and Thissen (1997). Furthermore, the discrimination parameter of the Graded Response Model (which represents a slope) was also examined to assess possible violations of local independence. Items displaying excess dependence may have very high slopes (e.g., greater than 4) relative to other items on the measure (Nguyen *et al*., 2014). Item trace plots showing the items' characteristic curves (ICC) or items' operation characteristic curves (OCC) helped examine the monotonicity (i.e., that the probability of endorsing an item will continuously increase at higher levels of the latent variable).

Finally, the estimated item parameters were compared across different groups (e.g., gender and age groups) to test for item invariance. If the model fits, the anchor items must show no differential item functioning (DIF) in the parameters between different groups. In other words, item calibrations using different groups should yield similar parameter estimates (Nguyen *et al*., 2014; Fidalgo & Quintanilla Cobian, 2018).

2.3.2 Item Analyses Based on the Graded Response Model

Item analyses based on IRT parametric models are normative tests of item performance, providing a way to measure the quality of items. This study used the unidimensional Graded Response Model

(GRM) by Samejima (1969) to calibrate the items' parameters and select items with good performance. Under this model, the probability of an individual j with latent trait θ_j (j = 1, ..., n) endorsing the category equal to or higher than k from the i-th item is given as

$$P_{i,k}^{+}(\theta_j) = \frac{1}{1 + \exp\left[-a_i(\theta_j - b_{i,k})\right]} \quad (1)$$

for $k = 0, 1, ..., c_i - 1$, where c_i is the number of categories of the i-th item. Given that $P_{i,0}^{+}(\theta_j) = 1$, the parameter for the lowest category $b_{i,0}$ is not estimated. The probability of endorsing the category k is computed by subtracting the adjacent probabilities such that

$$P_{i,0}(\theta_j) = 1 - P_{i,1}^{+}(\theta_j) \text{ and } P_{i,k}(\theta_j) = P_{i,k}^{+}(\theta_j) - P_{i,(k+1)}^{+}(\theta_j), \text{ for } k > 0. \quad (2)$$

The discrimination parameter a represents a slope, which refers to how well the item response options discriminate (or differentiate) between parents with high and low levels of SPS. An item provides ample information about SPS differences across individuals if its discrimination is high. Otherwise, the item does not provide much information and may indicate that it needs to be adjusted or removed. The difficulty parameter b indicates where the item falls on the continuum of the latent trait. The parameters $b_{i,k}$ (i.e., threshold values) are interpreted as how high an individual's SPS level needs to be in order to have a 0.5 probability of endorsing that given response category or a higher category. In the present study, the selected items were those satisfying: $0.8 \leq a_i < 4.0$ and $-3 < b_{i,k} < 3$, with $b_{i,1} \leq b_{i,2} \leq \cdots \leq b_{i(c_i-1)}$. Response categories with a rate close to zero were regrouped to calibrate better the item's parameters (Sartes & Formigoni, 2013).

After estimating the GRM parameters using the maximum likelihood approach, the expectation a posteriori method was used to estimate the latent trait θ, assumed normally distributed with mean zero and unit variance (Embretson & Reise, 2000; Baker & Kim, 2004).

2.3.3 SPS-Scale Construction and its Interpretation

The SPS-Scale was constructed based on positioning the anchor or quasi-anchor items that characterize each scale point. Since the latent trait θ was assumed to be normally distributed with mean zero and unit variance, the items with the greatest discrimination were fixed on each scale unit, basically in the range of –3 to +3, with $x_{p-1} < x_p$ two consecutive levels of the scale. For category k of an item to be positioned at a certain level x_p of the scale, three conditions must be satisfied simultaneously: (1) the category k has a probability ≥ 0.6 of being endorsed by parents with $\theta \geq x_p$; (2) the category $(k-1)$ has a probability < 0.5 of being endorsed by parents with $\theta \geq x_{p-1}$; and (3) the difference of the probabilities associated with categories k and $(k-1)$ is ≥ 0.3.

Items that simultaneously meet all three conditions are called anchor items. As it is difficult to fulfill all of these conditions, items that met two conditions, called quasi-anchors, were considered (Barbetta *et al*., 2014). After positioning the anchor and quasi-anchor items on the SPS-Scale, the scale levels were defined and interpreted.

2.3.4 Parental and Child Characteristics Predicting the SPS-Scale

Linear regression was used to examine the parental and child characteristics predicting the latent trait θ. These characteristics are those addressed in questions Q1 to Q10 (Table A.2, Appendix A). All analyzes were performed in the R software (R Core Team, 2022) using the packages *psych* (Revelle, 2019), *BifactorIndicesCalculator* (Dueber, 2021), *mirt* (Chalmers, 2018), and *lavaan* (Rosseel, 2012).

3. Results

3.1 Description of Participants

The sample consisted of 255 parents, 222 mothers and 33 fathers aged 21 to 61 years (mean = 38, SD = 6.0). Overall, 78.4% were married, 91% were the primary caregivers, and 56.5% received support from their family or close people to help them with the child's daily care demands. The age of children or adolescents (217 males and 38 females) ranged from 1 to 18 years (mean = 6.5, SD = 3.7). Their age at ASD diagnosis ranged from 1 to 15 years (mean = 3.5, SD = 2.6).

3.2 Dimensionality Analysis

The Scree plot (Figure 1) suggests that one factor or principal component is sufficient to retain, with the ratio of the first to second eigenvalues ≥ 3 indicating essential unidimensionality. The omega reliability coefficients (omega = 0.89, omega H = 0.71) indicate that the general factor is the dominant source of systematic variance. The ECV of 0.58 also evidenced that the common variance is essentially unidimensional. In addition, high factor determinacy and construct replicability for the general factor (FD = 0.93, H = 0.89) suggest a well-defined latent variable. Then, the unidimensional GRM was considered for item parameter estimation and item analysis.

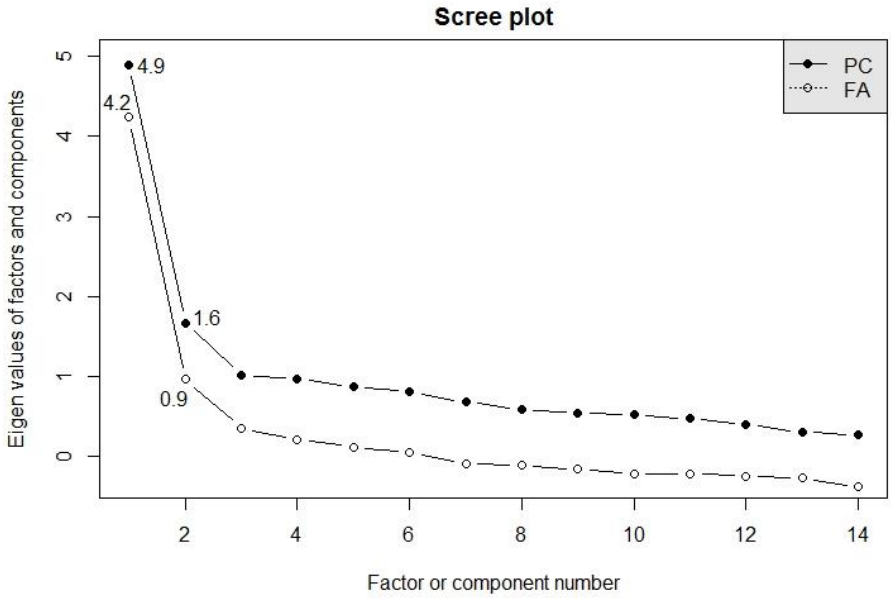

Figure 1. Analysis of the dimensionality of the 14-item instrument.
PC: principal components and FA: factor analysis.

3.3 IRT Parameters Estimation Based on the GRM

The IRT parameter estimates for item discrimination and item difficulty in Table 2 show that all items on the SPS instrument performed well ($0.8 \leq a_i < 4.0$ and $-3 < b_{i,k} < 3$). The difficulty parameters (threshold values) are on the same scale as the *Z*-scale, where a normal distribution is centered at zero with a unit standard deviation.

For example, item S3 has the following threshold values: $b_1 = -0.76$, $b_2 = 0.44$, and $b_3 = 1.5$. These values are the cutoff points that intercept the lines representing the probability of endorsing a category given a certain level on the latent trait represented by the x-axis in the trace plot shown for item S3 in Graph (a) of Figure 2. Thus, parents with an SPS level below the first threshold (–0.76) have a high probability of endorsing the category $k = 0$ (never or rarely) of item S3. In addition, parents with an SPS level between −0.76 and 0.44 are most likely to endorse the category $k = 1$ (sometimes), whereas those with an SPS level between 0.44 and 1.5 are most likely to endorse the category $k = 2$ (often).

Finally, those with an SPS level above 1.5 are most likely to endorse the category k = 3 (very often).

Graph (b) in Figure 2 shows the monotonicity of item S3 since the curves do not cross and continually increase at higher levels of the latent variable.

Table 2. Estimates of discrimination and difficulty parameters of each item

Item	a (SE)	Threshold response categories and parameters			
		b_0	b_1 (SE)	b_2 (SE)	b_3 (SE)
P1	1.20 (0.17)	Never or Rarely	Sometimes –1.57 (0.23)	Often 0.56 (0.15)	Very often 1.98 (0.28)
P2	1.16 (0.18)	Never or Rarely or Sometimes	Often –1.17 (0.20)	Very often 0.47 (0.15)	-
P3	0.96 (0.20)	Too much -	A little or Nothing –1.20 (0.25)	-	-
P4	1.03 (0.19)	Favorable or no change	Unfavorable –0.37 (0.16)	-	-
P5	0.96 (0.16)	Never or Rarely	Sometimes –2.27 (0.37)	Often 0.29 (0.16)	Very often 2.14 (0.35)
P6	1.08 (0.20)	Nothing or A little	Too much –0.16 (0.14)	-	-
P7	1.02 (0.17)	Very easy or Easy or Neutral	Difficult –0.23 (0.15)	Very difficult 2.20 (0.35)	-
S1	1.81 (0.25)	Too much -	A little –1.42 (0.17)	Nothing 1.05 (0.14)	-
S2	1.30 (0.23)	No -	Yes –0.97 (0.17)	-	-
S3	2.28 (0.28)	Never or Rarely	Sometimes –0.76 (0.11)	Often 0.44 (0.10)	Very often 1.50 (0.16)
S4	1.42 (0.20)	Never or Rarely	Sometimes –0.28 (0.12)	Often 1.12 (0.17)	Very often 2.35 (0.30)
S5	0.96 (0.16)	Never -	Rarely or Sometimes –0.49 (0.17)	Often or Very often 2.04 (0.34)	-
S6	2.65 (0.39)	Nothing -	A little –1.54 (0.15)	Too much 0.09 (0.09)	-
S7	2.64 (0.39)	Nothing -	A little –1.67 (0.16)	Too much 0.02 (0.09)	-

Note: a is the discrimination parameter and b_k (k = 1, 2, 3) are the difficulty parameters. SE is the standard error.

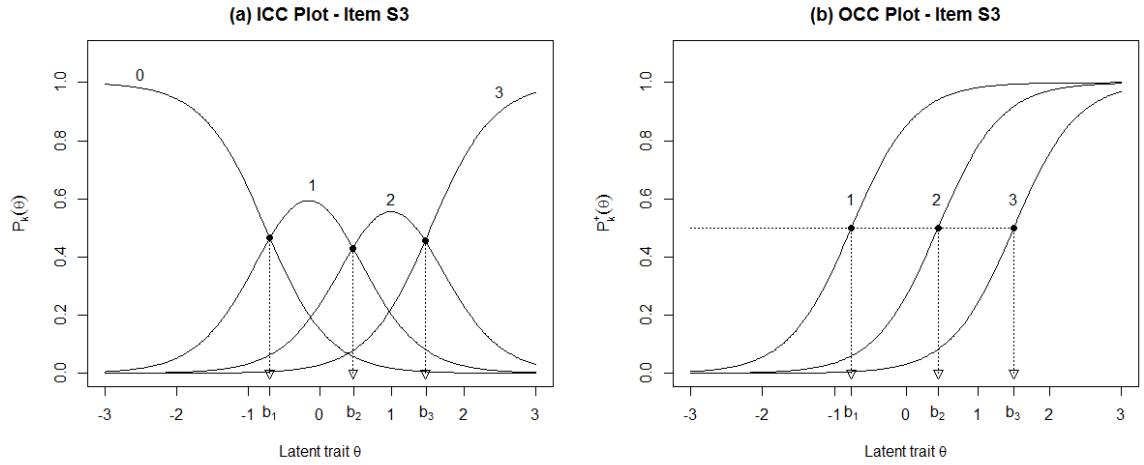

Figure 2. (a) ICC plot where each line reflects the probability of endorsing the category k (0: never or rarely, 1: sometimes, 2: often, and 3: very often), (b) OCC plot where each line reflects the probability of endorsing the category equal to or higher than k ($k = 1, 2, 3$), with b_1 = –0.76, b_2 = 0.44, and b_3 = 1.5 the thresholds values.

The trace plots for all items are displayed in Figure 3. They show the item-level information regarding the performance linked to each response category. Items with larger discrimination levels tend to provide information about the parents' SPS in a narrow range (e.g., item S6, which had the

largest discrimination value of 2.65). The test information curve shown in the last plot in Figure 3 indicates that the SPS instrument is best suited for measuring the SPS level in the range from –2 to 2 (where the curve is highest). Then, the SPS instrument provides more information (or assesses more accurately) parents with SPS in this range.

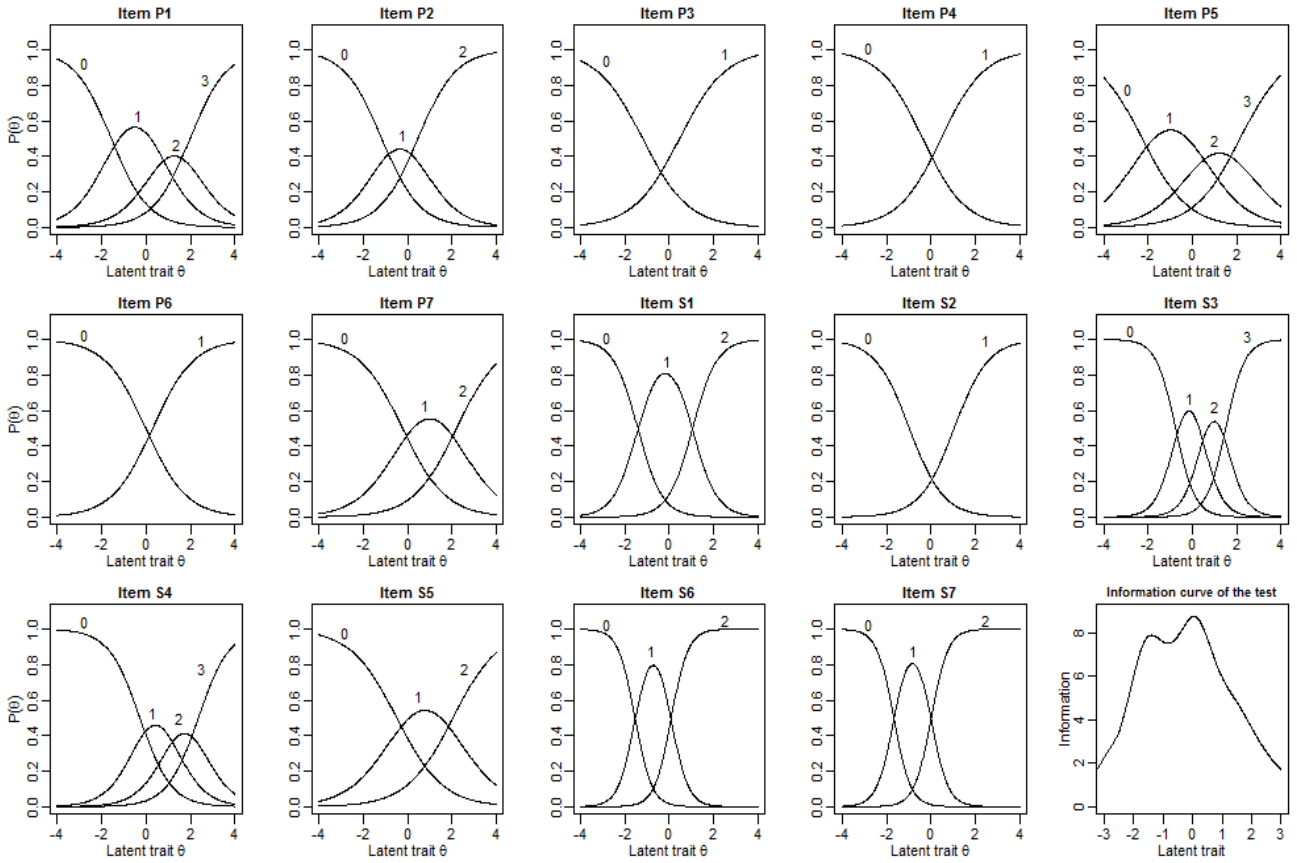

Figure 3. Item trace plots for items P1 to S7 where each line reflects the probability of endorsing an item response category k given the level on the latent trait ($k = 0, 1, \ldots, c_i - 1$, where c_i is the number of categories of item i). The information curve of the SPS instrument is shown in the last plot on the right.

3.4 Item Fit and Local Dependence

After controlling for the false discovery rate (FDR), a correction of multiple comparisons that is better suited in IRT models than the Bonferroni correction (Depaoli *et al*., 2018), the S-X^2 item fit statistic evidenced that the items fit the questionnaire well. There were also no issues with LD, as the local independence assumption among items on the SPS-Scale was supported by the LD G^2 test (p-values > 0.05), as well as by discrimination parameters smaller than 4.0 (Table 2).

Results (not shown) supported item invariance across age groups (≤ 38 and >38 years), indicating that parents of children with ASD of different ages similarly interpreted all items. Item invariance across gender could not be assessed because of the small number of fathers in the present study.

3.5 SPS-Scale Levels and Interpretation

The items identified as anchor items were: S1, S3, S4, S6, and S7, and as quasi-anchor: P1 to P7, S2, and S5. After positioning the items that characterize each scale point, five levels were defined for the SPS-Scale. These levels and their interpretations are shown in Table 3.

The scale levels in terms of the overall SPS score (OS) are also shown in Table 3. This score, computed by adding the responses of all 14 items in Table 1, ranges from 14 to 55. The higher the score, the higher the SPS level. In this study, latent trait estimates and overall SPS scores showed a correlation of 0.96 (95% confidence interval: 0.95 to 0.97).

Based on the five levels defined for the SPS-Scale (Table 3) and the estimated values of θ, 42 parents (16.5%) in the present study were classified as having a very low SPS level and 77 (30.2%) as having a low SPS level. For the moderate, high, and very high SPS levels, the number of parents classified on them was 101 (39.6%), 29 (11.4%), and 6 (2.3%), respectively.

Table 3. The five levels of the SPS-Scale and their respective interpretations

SPS level	Anchoring of items	Interpretation of the SPS-Scale at each level
Very low $\theta < -1$ $OS < 30$	$P1b_0$ to $P7b_0$ $S1b_0$ to $S7b_0$	At this level, there is a very low SPS. Parents of children with ASD are highly likely to endorse that their child's ASD condition has little or no impact on their professional life, and the same goes for their social life.
Low $-1 \leq \theta < 0$ $30 \leq OS < 37$	$P1b_1$ $P5b_1$ $S1b_1$ $S6b_1$ $S7b_1$	At this level, there is a low SPS. Parents of children with ASD are highly likely to endorse that: (a) *sometimes* have difficulties with their work routine because they have no one to leave their child when they need to; (b) the child's daily care demands *sometimes* affect their work routine (e.g., missing work); (c) when attending parties or events with the child, they can have a *little* fun and interact a *little* with people; (d) the child's ASD condition interferes a *little* in their social life, and (e) the child's daily care demands have *some* impact on their social life.
Moderate $0 \leq \theta < 1$ $37 \leq OS < 44$	$P2b_1$ $P3b_1$ $P4b_1$ $S2b_1$ $S3b_1$ $S4b_1$ $S5b_1$	At this level, there is a moderate SPS. Parents of children with ASD are highly likely to endorse that: (a) the child's daily care demands make them tired, which *often* interferes with their work activities; (b) they have been able to dedicate *little* or *nothing* to their professional life since the child's ASD diagnosis; (c) the change in their workload due to the child's daily care demands was unfavorable to them; (d) they *prefer* to stay at home to avoid places that interfere with their child's behavior; (e) *sometimes* they avoid going to certain places due to their child's behavior and comments aimed at their child, and (f) *rarely* or *sometimes* they are not invited to parties or social events due to their child's behavior.
High $1 \leq \theta < 2$ $44 \leq OS < 51$	$P1b_2$ $P2b_2$ $P5b_2$ $P6b_1$ $P7b_1$ $S3b_2$ $S6b_2$ $S7b_2$	At this level, there is a high SPS. Parents of children with ASD are highly likely to endorse that: (a) they *often* have difficulties with their work routine because they have no one to leave their child when they need to; (b) the child's daily care demands make them tired, which *very often* interferes with the performance of their work activities; (c) the child's daily care demands *often* affects their work routine (e.g., missing work); (d) the child's condition interferes *too much* in their professional life; (e) it is *difficult* reconciling their work routine with the child's daily care demands; (f) they *often* avoid going to certain places due to their child's behavior; and (g) the child's ASD condition and the child's daily care demands interfere *too much* in their social life.
Very high $\theta \geq 2$ $OS \geq 51$	$P1b_3$ $P5b_3$ $P7b_2$ $S1b_2$ $S3b_3$ $S4b_2$ $S4b_3$ $S5b_2$	At this level, there is a very high SPS. Parents of children with ASD are highly likely to endorse that: (a) they *very often* have difficulties with their work routine because they have no one to leave their child when they need to; (b) the child's daily care demands *very often* affect their work routine (e.g., missing work); (c) it is *very difficult* reconciling their work routine with the child's daily care demands; (d) when they go to parties or social events with their child, *cannot* have fun or interact with people; (e) they *very often* avoid going to certain places due to the child's behavior and comments aimed at their child, and (f) *often or very often* they are not invited to social events due to their child's behavior.

Note: b_0, b_1, b_2, and b_3 indicate the item's category after the regrouping presented in Table 3. OS denotes the overall SPS score computed by adding the responses of all 14 items in Table 1 (OS ranges from 14 to 55).

3.6 Social and Professional Satisfaction and the SPS-Scale

The professional and social satisfaction reported by parents in questions Q11 and Q12 (Table A.2, Appendix A) was negatively associated ($p < 0.001$) with the SPS-Scale (–0.37 and –0.52, respectively), indicating that the greater the satisfaction, the lower the SPS level. In addition, the self-assessment of stress in professional and social life addressed in questions Q13 and Q14 (Table A.2, Appendix A) was positively associated ($p < 0.001$) with the SPS-Scale (0.46 and 0.65, respectively).

3.7 Parental and Child Characteristics Predicting the Parents' SPS

Table 4 shows the linear regression results for the parental and child characteristics significantly associated with the parents' SPS. Primary caregivers' parents had a higher SPS level than parents who were not. Also, the higher the child's ASD symptoms, the greater the parents' SPS level. Fathers had a lower level of SPS than mothers, as did married participants compared to those with another marital status. A higher SPS level was suggested among parents of children aged 6-10 years than at other ages.

Table 4. Regression analysis of the parental and child characteristics

Description of the characteristic		*n* (%)	Estimates B [95%CI]	*p-value*
Q2	Primary caregiver			
	No	23 (9.0)	Reference	
	Yes	232 (91.0)	0.44 [0.05 to 0.84]	0.003
Q3	The participant's gender			
	Female	222 (87.1)	Reference	
	Male	33 (12.9)	–0.48 [–0.82 to –0.15]	0.005
Q4	Marital status			
	Married	200 (78.4)	Reference	
	Another status	55 (21.6)	0.42 [0.14 to 0.70]	0.003
Q5	The severity of the ASD symptoms			
	Mildest	150 (58.8)	Reference	
	Middle or severe	105 (41.2)	0.35 [0.12 to 0.57]	0.003
Q6	Age of the child with ASD (years)			
	1 to 5	128 (50.2)	Reference	
	6 to 10	85 (33.3)	0.24 [0.03 to 0.45]	0.046
	11 to 18	42 (16.5)	–0.09 [–0.36 to 0.18]	0.594

Note: B denotes the regression coefficient. CI: confidence interval. ASD: autism spectrum disorder.

4. Discussion

The instrument proposed in this study calibrated 14 items adequately (Table 2). The SPS-Scale presented good psychometric properties and high internal consistency reliability, indicating that it is a valid psychometric instrument to assess the SPS experienced daily by parents of children with ASD.

According to Pereira *et al*. (2017), parents of children with ASD experience a significant impact on social and professional life. The SPS-Scale reinforces this finding since, in our study, 53.3% had SPS from moderate to very high levels. A fact that explains the parents' stress concerning social life is that their child's behavior makes them uncomfortable going to specific places. Also, prejudice usually generates discomfort (Minatel & Matsukura, 2014). On the other hand, parents' professional stress is usually related to difficulties with the work routine due to their child's care demands and the need to leave the professional career in the background (Veld *et al*., 2017). In this study, 36% of parents reported difficulties with their work routine because, in some situations, there was no one with whom to leave their child. Also, having to miss work, being late, or leaving early due to the child's demands was reported by 44%. Moreover, 75% reported that the child's daily care demands make them tired, interfering with the performance of their work activities.

The severity of ASD symptoms also predicted a higher parent's SPS level, corroborating other studies (Bitsika & Sharpley, 2017; Tomeny, 2017). According to the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013), the ASD symptoms at middle and severe levels are the ones that generate the most difficulties and, therefore, more attention from caregivers is needed.

Mothers also had a higher level of SPS than fathers did, corroborating Kiami and Goodgold's (2017) finding, who reported a higher level of maternal stress. At the same time, McStay *et al*. (2014) and Miranda *et al*. (2019) reported a positive association between the child's behavior and parental stress, especially among mothers who assume the role of primary caregiver. In the present study, the primary caregivers' mothers also had a higher SPS level. It usually occurs because they have to assume

greater responsibilities, modifying their daily life and distancing themselves from social life. They are also often forced to reduce their workload or leave the workforce as they cannot obtain appropriate childcare or a flexible work schedule (Pinto *et al*., 2016; Minatel & Matsukura, 2014).

A higher SPS level was also suggested among parents with children aged 6-10. It coincides with school-age children, a transition period that can be stressful and challenging for parents due to the communication and social interaction difficulties of their children with ASD (Connollya & Gersch, 2016; Adams *et al*., 2020). In contrast, a lower SPS level was indicated among married parents, corroborating the studies by Hasting (2003) and Tehee *et al*. (2009). This may be because sharing the child's daily care demands and concerns with a partner can better balance the home environment, reducing stress (Aguiar & Pondé, 2018).

In addition, parents classified as having very low or low SPS levels (46.7%) reported positive feelings. They are very satisfied (or satisfied) with their social life, and the child's ASD condition has little or no impact on their social life. The reason is that maintaining a social life and having the support of friends and family can positively affect the parents' well-being (Bluth *et al*., 2013). According to Ooi *et al*. (2016), some parents feel self-confident about raising a child with ASD. However, they face several difficulties in social life, including the lack of information from other people about ASD. Many people judge the child's behavior with ASD as bad behavior, which often bothers the parents and causes negative feelings.

5. Final Remarks

The SPS-Scale proposed in this study has proved beneficial in assessing the SPS experienced daily by Brazilian parents of children with ASD. However, it is noteworthy that our findings may not be generalized to all parents of children with ASD. As this is the first study examining the theoretical structure and psychometric properties of the SPS-Scale, its application in other similar and different cultures would be valuable in order to provide additional foundations for its use.

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Conflicts of Interest

The authors declare no conflict of interest.

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Appendix A

Table A.1. Portuguese version of the items of the SPS instrument

Atualmente você tem um emprego remunerado? Se SIM, responda todos os itens. Se NÃO, responda os itens S1 a S7.						
		Escores assinalados às categorias dos itens				
Item	Descrição	1	2	3	4	5
P1	Você tem dificuldades com a sua rotina de trabalho por não ter com quem deixar seu filho(a) com TEA quando você precisa?	Nunca	Raramente	Algumas vezes	Com frequência	Com muita frequência
P2	As demandas diárias de cuidado do seu filho(a) com TEA o(a) deixam cansado(a), interferindo no desenvolvimento de suas atividades no trabalho?	Nunca	Raramente	Algumas vezes	Com frequência	Com muita frequência
P3	O quanto você se dedica à sua vida profissional desde o diagnóstico de TEA do seu filho(a)?	Muito	Um pouco	Nada	-	-
P4	Você precisou mudar sua carga de trabalho devido às demandas diárias de cuidado do seu filho(a) com TEA? A mudança foi …	Favorável	Não houve mudanças	Desfavorável	-	-
P5	Com que frequência sua rotina de trabalho é afetada pelas demandas diárias de cuidado do seu filho(a) com TEA? (por ex.: faltar ao trabalho, chegar atrasado ou sair mais cedo do trabalho).	Nunca	Raramente	Algumas vezes	Com frequência	Com muita frequência
P6	O quanto a condição de TEA do seu filho(a) afeta sua vida profissional?	Nada	Um pouco	Muito	-	-
P7	É fácil para você conciliar as demandas diárias de cuidado do seu filho(a) com seu horário de trabalho?	Muito fácil	Fácil	Nem fácil nem difícil	Difícil	Muito difícil
S1	Quando você vai a festas ou eventos sociais com o seu filho(a) com TEA, o quanto consegue se divertir e interagir com as pessoas? ( ) Não vou a festas ou eventos sociais (escore = 3).	Muito	Um pouco	Nada	-	-
S2	Você prefere ficar em casa, evitando ir a lugares que interfiram no comportamento do seu filho(a) com TEA?	Não	Sim	-	-	-
S3	Você já desistiu de ir a algum lugar por causa do comportamento do seu filho(a) com TEA?	Nunca	Raramente	Algumas vezes	Com frequência	Com muita frequência
S4	Você já desistiu de ir a algum lugar porque se sente desconfortável com comentários ou gestos de outras pessoas direcionados ao seu filho(a) com TEA?	Nunca	Raramente	Algumas vezes	Com frequência	Com muita frequência
S5	Alguém já deixou de convidá-lo(a) para uma festa ou evento social devido à condição de TEA do seu filho(a)?	Nunca	Raramente	Algumas vezes	Com frequência	Com muita frequência
S6	O quanto a condição de TEA do seu filho(a) afeta a sua vida social?	Nada	Um pouco	Muito	-	-
S7	O quanto as demandas diárias de cuidado do seu filho(a) com TEA afetam a sua vida social?	Nada	Um pouco	Muito	-	-

Note: TEA = Transtorno do Espectro Autista.

Table A.2. Questions asked to parents of children with ASD to gather additional information

Question	Description of the information / Descrição da informação
Q1	Age of the respondent (in whole years). _____ Idade do respondente (em anos completos). _____
Q2	Are you the primary caregiver of your child with ASD? ( )Yes ( )No Você é o cuidador principal do seu filho(a) com TEA? ( )Sim ( )Não
Q3	What is your gender? ( )Female ( )Male ( )Outro _____ Qual é o seu gênero? ( )Feminino ( )Masculino ( )Outro _____
Q4	What is your marital status? ( )Single ( )Married ( )Separated ( )Divorced ( )Widow(er) Qual é o seu estado civil? ( )Solteira(o) ( )Casada(o) ( )Separada(o) ( )Divorciada(o) ( )Viúva(o)
Q5	What is your child's degree of autism? ( )Mild ( )Moderate ( )Severe Qual é o grau de autismo do seu filho(a)? ( )Leve ( )Moderado ( )Severo
Q6	How old is your child with ASD? (In whole years) ___ Qual é a idade do seu filho(a) com TEA? (Em anos completos) ___
Q7	What is your child's gender with ASD? ( )Female ( )Male Qual é o gênero do seu filho com TEA? ( )Feminino ( ) Masculino
Q8	At what age was your child diagnosed with ASD? (In whole years) ___ Com que idade seu filho(a) foi diagnosticado(a) com TEA? (Em anos completos) ___
Q9	Do you have the help of a nanny or caregiver? ( )Yes ( )No Você tem ajuda de babá ou cuidador(a)? ( )Sim ( )Não
Q10	Do you receive support from family or close people with your child's ASD routine? ( )Yes ( )No Você recebe ajuda de sua família ou de pessoas próximas com a rotina do seu filho(a) com TEA? ( )Sim ( )Não
Q11	How satisfied do you feel with your professional life? ( )1.Very unsatisfied ( )2.Unsatisfied ( )3.Neutral ( )4.Satisfied ( )5.Very satisfied Quão satisfeito você se sente com a sua vida profissional? ( )1.Muito insatisfeito ( )2.Insatisfeito ( )3.Neutro ( )4.Satisfeito ( )5.Muito satisfeito
Q12	How satisfied do you feel with your social life? ( )1.Very unsatisfied ( )2.Unsatisfied ( )3.Neutral ( )4.Satisfied ( )5.Very satisfied Quão satisfeito você se sente com a sua vida social? ( )1.Muito insatisfeito ( )2.Insatisfeito ( )3.Neutro ( )4.Satisfeito ( )5.Muito satisfeito
Q13	How do you rate your stress level concerning your professional life? Level: ( )1 ( )2 ( )3 ( )4 ( )5 ( )6 ( )7 ( )8 ( )9 [very low = 1 to very high = 9] Como você avalia o seu nível de estresse em relação à sua vida profissional? Nível: ( )1 ( )2 ( )3 ( )4 ( )5 ( )6 ( )7 ( )8 ( )9 [muito baixo = 1 a muito alto = 9]
Q14	How do you rate your stress level concerning your social life? Level: ( )1 ( )2 ( )3 ( )4 ( )5 ( )6 ( )7 ( )8 ( )9 [very low = 1 to very high = 9] Como você avalia o seu nível de estresse em relação à sua vida social? Nível: ( )1 ( )2 ( )3 ( )4 ( )5 ( )6 ( )7 ( )8 ( )9 [muito baixo = 1 a muito alto = 9]

Note: ASD = Autism Spectrum Disorder. TEA = Transtorno do Espectro Autista.