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Factors associated with the quality of life of mothers of patients with Autism Spectrum Disorder

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Abstract

Autism Spectrum Disorder (ASD) is defined as a syndrome that interferes with neurodevelopment. Considered a chronic disorder, it requires special care from mothers and may compromise their quality of life. This study aimed to evaluate the factors associated with health-related quality of life of mothers of ASD children. This is a cross-sectional, descriptive, and analytical study. An instrument developed by the authors was used to assess the mother's sociodemographic variables and variables related to the child's health and the WHOQOL-Bref instrument to assess the mothers' quality of life. 77 mothers participated in the study. Most mothers were between 30 and 45 years old (60.6%), were white (61.04%), and had completed high school (52.9%). Concerning the children, 37.7% were between 5 and 10 years old, most without physical limitations (93.55%) and were male (77.92%). There was an association between the lowest score in the physical domain of the mother's quality of life and the male sex of the child (p=0.046); the variable single marital status was associated with lower scores in the psychological domains (p=0049) and social relationships (p=0.025). It is concluded that support measures are necessary to improve the physical, psychological, and social domains of mothers of autistic children, especially those who are single and do not have the support of a spouse.

Keywords: Autism Spectrum Disorder. Quality-of-life. Caregivers. Caregiver Burnout.

INTRODUCTION

Autism Spectrum Disorder (ASD) is defined as a syndrome that interferes with neurodevelopment, with manifestations occurring in the first years of life, and may present total or partial persistent deficiency in communication and social interaction, restricted and/or repetitive behavior patterns, and exacerbated interest for specific activities[1]. Individuals with ASD may have variable cognitive abilities, ranging from mental retardation to capacities above the population average[1].

There is no consensus in the literature on the causal factors that culminate in the development of the disorder, but current research has verified an increase in the prevalence and incidence of ASD in recent decades, reaching 1 to 2% of children[2,3].

Taking this reality into account, it is relevant to pay attention to the families of these individuals affected by ASD, especially mothers, as we know that in Latin culture, the role of caregiving is performed, in large part, by them. It should be noted that ASD is chronic,

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which requires special care from the family and multidisciplinary support so that affected individuals have an adequate functional capacity in adult life. Mothers, as primary caregivers, may feel mentally and physically overwhelmed[4].

An international study suggested that mothers who care for children with ASD present high levels of stress, due to their dependence on activities of daily living, the continuous demand for care together with the economic, social, and psychological impacts caused by the disorder on families[5].

In this context, it can be said that all changes in the routine of the mother who takes care of her child with ASD, as well as the stress overload imposed on her, can impact her quality of life.

The concept of quality-of-life is considered multidimensional, subjective, addressing both positive and negative aspects. The World Health Organization (WHO) defines it as: "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns"[6].

A study conducted in southern Brazil that aimed to investigate the quality of life and the presence of depressive symptoms in mothers of individuals with ASD found that the higher the levels of depression symptoms, the lower the quality-of-life scores were[7].

The present study was proposed taking into account the relevance of the impact of ASD on caregiver mothers and the scarcity of scientific literature when evaluating such impact on the quality of life of these mothers. Knowing these data is important to propose public policies aimed at these mothers as well as the development of health actions aimed at improving their quality of life.

Therefore, the objective of the present study was to evaluate the factors associated with the health-related quality-of-life of mothers with ASD children, using their sociodemographic variables and child variables such as age, time of diagnosis, communication, physical limitations, and gender.

METHODS

This was a cross-sectional, descriptive, and analytical study of the quality of life of mothers of individuals with ASD registered in the Autistic Association in a city in the rural region of Minas Gerais. This study was carried out between August and December 2019.

First, medical records from the institution of all children who had medical diagnoses of autism, according to DSM-5, were selected. Then, after the diagnosis was confirmed, the respective mothers of the children were contacted personally, and an invitation was made to participate in the study in an appropriate, private environment. After accepting the invitation, on a day and time scheduled with the participant in a reserved environment at the Association's building itself, all previous clarifications about the study were made and all doubts regarding participation were resolved, as well as the possibility of withdrawing consent or interrupting participation at any time.

Subsequently, mothers were asked to sign the Informed Consent Form. Inclusion criteria were individuals diagnosed by doctors according to DSM-5 and the only exclusion criterion was participants who had not yet had a closed diagnosis. 77 mothers participated in the study.

Then, the self-response questionnaires made by the researchers were delivered and were answered in front of them to help address any difficulties of the participants. First, the instrument related to the mothers' socio-demographic data was applied, containing closed questions. The independent variables of this questionnaire were those related to the mother (age, race, education, family income, salary, recipient of benefits, being the main caregiver of the children, and marital status) and those related to the child (current age, age at the time of diagnosis of autism, time elapsed since diagnosis, verbal or non-verbal communication, physical limitations, and gender).

Given the objective regarding quality-of-life, this was evaluated using the WHOQOL-BREF quality-of-life questionnaire, comprising the dependent variables. The WHOQOL-BREF questionnaire was validated by the World Health Organization and has good discriminant validity, test and re-test reliability, and internal consistency, which ranges from 0.66 to 0.87 (Cronbach's alpha coefficient). In this study, we also determined the Chronbach's alpha coefficient for the different domains of the questionnaire and verified that its values were between 0.91 and 0.93. Cronbach's alpha test value >0.7 has acceptable internal consistency[8].

The WHOQOL-BREF questionnaire has 26 questions: the first two questions (facets) are related to general quality-of-life and the level of satisfaction with one's own health. The remaining 24 questions are distributed in four domains: physical (7 facets), psychological (6 facets), social (3 facets), and environmental (8 facets). The level of satisfaction for each facet of the questionnaire was based on a 5-point Likert scale: 1: very bad, 2: bad, 3: neither good nor bad (neutral), 4: good, and 5: very good.

The raw scores for the WHOQOL-BREF domains were calculated and transformed to a scale ranging from 0 to 100 (transformed score (TS) 0-100). A score of 100 is the highest and 0 is the lowest quality-of-life indicator. Moreover, an overall quality-of-life score was calculated by adding the perceived quality-of-life scores with the four domains and then dividing by five. The mean score for each domain and the total score were calculated to categorize quality-of-life as good or poor. Therefore, individuals were categorized as having a good quality of life when scores were greater than or equal to the mean, while participants with a lower score than the mean were categorized as having a low quality of life for each domain. The transformations were performed according to the syntax for SPSS, proposed by the WHO[9].

Electronic databases were built using the Excel® program and then descriptive and inferential statistical analysis was performed. Qualitative variables were described by their absolute and relative frequencies. Quantitative variables were described by their means and standard deviations together with their minimum and maximum values.

Initially, the inferential analysis was univariate to verify outliers, and abnormal and asymmetrical values. Then, we proceeded with the multivariate analysis using the multiple linear regression test to determine the predictive variables for quality-of-life. Therefore, the non-standardized Beta coefficient was determined together with its standard error and its minimum and maximum values of the 95% confidence interval (95%CI). Then, the standardized beta coefficient and its degree of significance (p-value) were determined. For all statistical analyses, a significance level of 5% was considered (with a significance level of $p<0.05$) and analyses were performed using the computer program SPSS (Statistical Package of Social Science) version 20.0.0.

This research was approved by the Ethics Committee and Research with Human Beings of the University of Franca under the opinion number CAAE 24297119.4.0000.5495.

RESULTS

Table 1 shows the sociodemographic data and clinical characteristics of the mothers of children with ASD participating in the study.

Regarding the study participants, it was found that most were between 30 and 45 years old (50.6%), were white (50.6%), married (61%), and had a secondary education, that is, completed high school (52.8%). (Table 1)

Concerning family income, 52% had no income and 79.2% of mothers did not receive any benefits. It is noteworthy that most mothers were the main caregivers (79.2%). (Table 1)

The most prevalent age group of children was between 5 and 10 years old (37.7%), and the type of communication for the majority was verbal (71.4%). Most children had no physical limitations (93.5%). The most affected sex was male (78%). (Table 1)

Table 02 shows the distribution of numerical sociodemographic variables of mothers and children.

As for the mother's current age, the mean was 36.27±9.09 years. Regarding the current age of the child, the mean was 8.31±6.63 years, and the mean age at which the child was diagnosed was 3.87±2.43 years. Regarding the time of diagnosis, the average found was 4.47±5.99 years old. (Table 2)

Table 3 shows the mothers' quality-of-life scores.

Regarding quality of life, the highest score was observed in the physical domain (67.9) and the lowest in the psychological domain (56.7). The overall quality-of-life score was 61.35. (Table 3)

Table 4 shows the analysis of variables associated with the mothers' physical domain.

Regarding the physical domain of quality-of-life of mothers of children with ASD, there was an association between the lowest score in this domain and male children (p=0.046). Therefore, it can be implied that the male gender of the children is a predictor for lower quality of life in the physical domain. (Table 4)

Table 5 shows the analysis of the variables associated with the psychological domain of quality-of-life.

Single marital status was considered a predictor for lower scores in the psychological domain of mothers participating in the present study. (Table 5)

Table 6 shows the analysis of variables for the social relationships’ domain.

Concerning the mothers' social relationships domain, the lowest score was associated with the marital status of being single (p=0.025). (Table 6)

Multiple linear regression models for the variables associated with the Environmental and General Quality-of-Life domains were not presented, as no significant associations were found.

Table 1 – Shows the sociodemographic data and clinical characteristics of the mothers of children with ASD participating in the study.

Variables	Categories	Absolute frequencies	Relative frequencies (%)
Age Group	18 to 30 years	21	27.3
	30 to 45 years	39	50.6
	45 to 60 years	17	22.1
Race	White	39	50.6
	Brown	23	29.9
	Black	14	18.2
	Yellow	1	1.3
Marital status	Single	5	6.5
	Amasiada	16	20.8
	Married	47	61.0
	Separate	9	11.7
Education	Primary	15	19.5
	Secondary	33	52.8
	Tertiary	29	37.7
Family income	No salary	40	51.9
	Less than 1 salary	3	3.9
	1 salary	9	11.7
	2 to 3 salaries	18	23.4
	4 to 5 salaries	4	5.2
	Greater than 5 salaries	3	3.9
Receives income	Yes	37	48.0
	No	40	52.0
Recipient of government benefits	Yes	16	20.8
	No	61	79.2
The mother is the main caregiver	Yes	61	79.2
	No	16	20.8
Children's age range	Up to 2 years	4	5.2
	2 to 5 years	22	28.6
	5 to 10 years	29	37.7
	10 to 15 years	15	19.5
	Over 15 years	7	9.0
Children's type of communication	Verbal	55	71.4
	Non-verbal	22	28.6
Physical limitations	Yes	5	6.5
	No	72	93.5
Child's sex	Male	60	78.0
	Female	17	22.0

Table 2 – Distribution of numerical sociodemographic variables of mothers and children with ASD, Patrocínio, Minas Gerais, Brazil, 2019.

Variables	Mean and standard deviation (in months)	Minimum (in months)	Maximum (in months)	Mean and standard deviation (in years)
Mother's current age	435.2±109.1	252	672	36.23±9.1
Current age of the child	99.8±79.5	21	442	8.3±6.6
Child's age when diagnosed	46.1±29.1	12	144	3.9±2.4
Diagnosis time	54.5±71.9	1	406	4.5±6.0

Table 3 – Distribution of scores for the WHOQOL-BREF quality-of-life domains adjusted from 0-100 and categorized according to WHO recommendations, Patrocínio, Minas Gerais, Brazil, 2019.

Domains of Quality-of-Life	Mean ± Standard Deviation	Cronbach's Alpha	Poor		Good	
			n	%	n	%
Physical Domain	67.9±19.2	0.920	34	44.2	43	55.8
Psychological Domain	56.7±20.9	0.910	31	40.3	46	59.7
Social Domain	61.7±22.6	0.930	34	44.2	43	55.8
Environmental Domain	59.1±17.7	0.920	28	36.4	49	63.6
General Quality-of-Life	61.3±20.1	0.930	33	43.4	49	63.6

Table 4 – Multiple linear regression analysis of variables associated with the physical domain of the WHOQOL-BREF quality-of-life of mothers of children with ASD, Patrocínio, Minas Gerais, Brazil, 2019 (n=77).

Variables	Non-standardized coefficients		Standardized coefficients	Sig.	95.0% Confidence Interval for B	
	Beta	Standard Deviation	Beta		Inferior limit	Upper limit
Mothers						
Constant	32.33	25.70	0.000	0.213	-18.98	63.63
Age (months)	0.19	0.26	0.09	0.471	-0.33	0.71
Race (reference=white)	2.30	2.81	0.10	0.410	-3.32	7.92
Education (reference=secondary)	-3.64	3.42	-0.14	0.319	-10.87	3.59
Monthly Income (reference = 2 to 3 minimum wages)	-1.37	3.34	-0.12	0.683	-8.04	5.29
Monthly pay	7.08	12.29	0.18	0.567	-17.46	31.61
Recipient of government benefits	11.53	6.42	0.24	0.077	-1.28	34.35
Mother as the primary caregiver	-8.57	5.90	-0.18	0.150	-20.34	3.19
Marital status (reference=single)	5.26	3.25	0.20	0.110	-1.22	11.74
Children						
Constant	76.89	17.91	0.000	0.000	41.17	112.60
Current age (months)	0.04	0.03	0.17	0.148	-0.01	0.10
Age at diagnosis (months)	0.05	0.08	0.07	0.523	-0.10	0.20
Diagnosis time (months)	0.04	0.03	0.15	0.186	-0.02	0.10
Type of communication (reference=verbal)	-0.45	4.89	-0.01	0.926	-10.19	9.28
Physical limitations (reference=no limitations)	-6.10	8.93	-0.08	0.497	-23.90	11.69
Gender (reference=male)	-10.51	5.18	-0.23	**0.046***	-20.84	-0.19

*Demonstrated statistical differences.

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Table 5 – Multiple linear regression analysis of variables associated with the psychological domain of the WHOQOL-BREF quality-of-life of mothers of children with ASD, Patrocínio, Minas Gerais, Brazil, 2019 (n=77).

Variables	Coeficientes não padronizados			Sig.	95.0% intervalo de confiança para B	
	Beta	Standard Deviation	Beta		Inferior limit	Upper limit
Mothers						
Constant	11.04	24.69	0.00	0.691	44.23	66.32
Age (months)	-0.01	0.28	-0.01	0.967	-0.58	0.55
Race (reference=white)	2.91	3.03	0.11	0.310	-3.15	8.47
Education (reference=secondary)	-2.76	3.90	-0.10	0.483	-10.55	5.04
Monthly Income (reference = 2 to 3 minimum wages)	0.16	3.60	0.01	0.964	-7.02	7.34
Monthly pay	-7.28	13.24	0.18	0.584	-19.15	33.71
Recipient of government benefits	-13.65	9.92	0.27	0.053	-0.16	27.46
Mother as the primary caregiver	-7.61	6.35	-0.15	0.223	-20.29	5.07
Marital status (reference=single)	6.93	3.50	0.25	**0.049***	0.05	13.91
Children						
Constant	66.03	22.36	0.00	0.040	21.43	110.63
Current age (months)	0.01	0.03	0.04	0.751	-0.05	0.07
Age at diagnosis (months)	0.06	0.08	0.09	0.452	-0.10	0.23
Diagnosis time (months)	0.00	0.03	0.01	0.963	-0.06	0.07
Type of communication (reference=verbal)	2.01	5.30	0.04	0.706	-8.55	12.57
Physical limitations (reference=no limitations)	1.52	9.73	0.02	0.876	-17.86	20.40
Gender (reference=male)	-8.73	5.69	-0.17	0.129	-20.06	2.61

*Demonstrated statistical differences.

Table 6 – Multiple linear regression analysis of variables associated with the WHOQOL-BREF quality-of-life domain of mothers of children with ASD, Patrocínio, Minas Gerais, Brazil, 2019 (n=77).

Variables	Non-standardized coefficients		Standardized coefficients	Sig.	95.0% Confidence Interval for B	
	Beta	Standard deviation	Beta		Inferior limit	Upper limit
Mothers						
Constant	-1.79	29.94	0.00	0.953	-61.54	57.97
Age (months)	0.24	0.31	0.10	0.439	-0.37	0.85
Race (reference=white)	1.16	3.26	0.04	0.724	-5.38	7.71
Education (reference=secondary)	-6.18	4.22	-0.20	0.148	-14.61	2.24
Monthly Income (reference = 2 to 3 minimum wages)	-1.87	3.86	-0.08	0.784	-8.83	6.67
Monthly pay	13.55	14.38	0.30	0.347	-15.02	42.12
Recipient of government benefits	13.27	7.48	0.24	0.081	-1.66	28.20
Mother as the primary caregiver	1.94	6.87	0.04	0.779	-11.77	15.64
Marital status (reference=single)	8.69	3.78	0.28	**0.025***	1.14	16.24
Children						
Constant	82.20	25.84	0.00	0.002	30.67	133.74
Current age (months)	0.02	0.03	0.07	0.535	-0.04	0.09
Age at diagnosis (months)	0.03	0.09	0.04	0.727	-0.15	0.21
Diagnosis time (months)	0.02	0.04	0.06	0.590	-0.05	0.09
Type of communication (reference=verbal)	-3.64	5.72	-0.07	0.526	-15.04	7.75
Physical limitations (reference=no limitations)	-5.32	10.50	-0.06	0.614	-26.23	15.60
Gender (reference=male)	-4.14	6.22	-0.09	0.430	-17.33	7.49

*Demonstrated statistical differences.

DISCUSSION

Concerning the age of the mothers, a study carried out in Rio de Janeiro obtained similar results[10], as well as a study carried out in Zona da Mata Mineira[11]. In this age group, the woman is at their full productive working age, but when she becomes a caregiver of a child with ASD, she needs to give up working outside the home to dedicate herself to the child. This mother's feelings must be verified and monitored by the health team in order not to harm her health and quality-of-life.

Other studies corroborate the data that most mothers were married (61.04% married)[10-13]. However, this differs from an international study that argues that there is an increase in the number of divorces among couples with children in early childhood and when they have a child with ASD, and this risk is increased due to increased levels of stress[14]. The fact that most mothers were married in the present study is a positive fact, as family support for these children and for those who are their caregivers is important.

Most mothers had completed high school (52.9%), corroborating a study in Rio de Janeiro[10]. However, this differs from a study conducted in Bahia, where 43% of mothers had a higher education degree[12]. It is suggested that a higher level of education can facilitate the understanding of the act of caregiving for mothers. This statement is corroborated by research carried out with informal caregivers, which found that caregivers with a low education had difficulty in assimilating information and knowledge about the disease, impacting their health and quality-of-life[15].

Concerning family income, where 51.95% had no remuneration and 79.22% of mothers did not receive any benefits, a divergent result was found in a study carried out by Piovesan *et al.*[7] which found an income of 1 minimum wage for most mothers. The lack of income can be a source of stress for these mothers[15].

Most mothers were the main caregivers of children with ASD (79.2%). Not working outside the home is in line with the literature which describes that these mothers tend to leave the job market[10]. The literature also states that this situation can contribute to the increase in the stress of these mothers, who see their lives changed, having to leave their careers to become caregivers, which can lead them to frustration, as work is often considered a source of satisfaction, maintenance of autonomy, and elevation of self-esteem. Another fact that we must pay attention to is the loss of income and the reality this entails[16]. It is known that the person with ASD needs several special conditions, such as monitoring by several professionals and the use of controlled drugs, which is expensive.

The prevalent age group of children in this study was 5 to 10 years (37.7%), with a mean age of 8.31 years old. In Rio Grande do Sul, the age group found was higher (19 years)[7].

The fact that most of the children in the study can verbally communicate facilitates the care, and can positively impact the mothers, as well as the absence of physical limitations. For mothers, having a child with physical limitations generates a feeling of sadness, as it detracts from their hope, which was full of positive possibilities for this child. Another feeling is the concern and fear of what will be faced in the future[17].

Regarding the sex of the child, the majority being male corroborates the international literature, which shows that the incidence of ASD in such sex is 4.3 times higher than in females[18].

There are theories that try to explain the higher incidence of ASD in males. The first theory argues that circulating testosterone in males binds to brain receptors increasing brain arousal, making men more susceptible to stress and ASD[19]. The second theory reports that regions of the Y chromosome, present only in males, have some specific genes that can explain the higher incidence of ASD in such sex and use as an example, to justify this theory, the Sex Determining Region Y gene. This gene is responsible for the growth of the testes and modulates the breakdown of catecholamines and monoamines, and in individuals with ASD, the levels of catecholamines and their metabolites are altered[20]. Both take into account the genetic influence.

When assessing the mothers' quality of life, the highest score was found in the physical domain (67.9). Different from the study conducted by Piovezan *et al.*[7], which found a higher score in the psychological domain. The physical domain assesses, among other aspects, activities of daily living and work capacity[9]. Caring mothers obtained a higher score in this domain, which means that the act of caring is not negatively impacting their activities and that they are not feeling physically overloaded. Even with this result, it is important for the health team to accompany these mothers and guide them on how to perform this care so that over the years they do not become compromised in these aspects.

The lowest score was found in the psychological domain (56.7). In this score, aspects such as positive feelings, thinking, learning, and negative feelings are evaluated[9]. The main caregiver of a child with ASD goes through a process of adapting all their roles, namely: wife, family member, woman, professional, which makes her deal with the emotional consequences of this adaptation. This whole process can have significant short- and long-term effects on their mental, psychological, and physical health[18]. It is therefore suggested that psychological monitoring is essential so that she can adapt without harming her health and quality-of-life.

Regarding the physical domain of quality-of-life of mothers of children with autism, there was an association between the lowest score in this domain and male children. The highest percentage of ASD involvement is in males, a fact that may be related to this higher score[15,17]. A study carried out in the rural region of São Paulo did not find an association between the quality-of-life domains and the gender of the child or adolescent with ASD, but it found that all domains of caregivers for girls were lower than the scores for caregivers for boys, a result that is different from that found in the present study[21].

There was an association between the lowest score in the psychological domain of mothers and a marital status of being single (p=0.049). Another study with married mothers reported marital status as a predictor for better emotional, physical, and social support, given the fact of having a child with ASD[13]. Also, in relation to marital status, we can infer that there is a relationship with the financial situation, since it is known that for mothers not working, most of the family income comes from the spouse and when single, the mother does not have this financial support.

Concerning the mothers' social domain, their lowest score was associated with a marital status of being single (p=0.025). The lack of marital support in the act of caring can have a negative impact on the quality-of-life in terms of the social domain, as it assesses personal relationships, social support, and sexual activity[9]. It is believed that single mothers feel lonely both in the act of caring and sentimentally.

Another fact to be recalled is the feeling of this mother in relation to others, even the married ones complain of difficulty in social support, where they do not get the help and understanding in the way they expected[13]. For single women, this reality can become even more exacerbated, and they feel overwhelmed.

It is believed that there is a need for a different view of public policies in relation to the child with ASD, considering not only the child who needs special care, but also the caregiving mother who needs to receive adequate guidance and support so that she can effectively help in the development of this child without compromising their own health and quality-of-life.

One of the limitations of the present study is its cross-sectional nature, which makes it impossible to monitor these mothers over the years to verify whether there has been any change in the factors associated with their quality of life. Therefore, further studies with this same sample are suggested after a period for this follow-up.

CONCLUSION

The variables sex of the child and marital status were predictors for the worsening of certain domains of quality-of-life using the WHOQOL-BREF questionnaire. The male gender of children with autism spectrum disorder was a predictor for a poor quality-of-life of the mother in relation to the physical domain. Another predictor for a poor quality-of-life in the psychological and social domains of this mother was her marital status of being single. Single mothers can have a 24% reduction in their quality of life in the psychological domain (p=0.049) and of 28% in the social domain (p=0.025).

It is concluded that being a mother of an autistic child can impact their quality of life. Therefore, support measures are necessary to improve the physical, psychological, and social domains of mothers of autistic children, especially those who are single and do not have the support of a spouse.

Author statement CRediT

Conceptualization: Castro GG; Vieira ALS; Santos NMF. Methodology: Castro GG; Vieira ALS. Validation: Castro GG. Statistical analysis: Santos NMF. Formal analysis: Santos NMF. Investigation: Castro GG; Vieira ALS; Santos NMF. Resources: Castro GG; Vieira ALS; Santos NMF. Writing-original draft preparation: Castro GG; Vieira ALS; Santos NMF. Writing-review and editing: Castro GG; Vieira ALS; Santos NMF. Visualization: Santos NMF. Supervision: Castro GG; Santos NMF. Project administration: Castro GG.

All authors have read and agreed to the published version of the manuscript.

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