

Avaliação da qualidade de vida, depressão, ansiedade e estresse de cuidadores de pessoas com ou sem Síndrome de Down: um estudo transversal
Evaluation of quality of life, depression, anxiety and stress among caregivers of people with or without Down Syndrome: a cross-sectional study
Evaluación de la calidad de vida, depresión, ansiedad y estrés de los cuidadores de personas con o sin síndrome de Down: un estudio transversal

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Resumo

O ato de cuidar, ser responsável pela sobrevivência e qualidade de vida de outro, representam atividades extras que podem provocar alterações socio emocionais a aqueles que executam esta função. Objetivo: Avaliar a qualidade de vida, depressão, ansiedade e estresse de cuidadores de pessoas com ou sem síndrome de Down. Metodologia: 144 cuidadores foram divididos em Grupo Controle (cuidadores de crianças típicas) e Grupo Síndrome de Down (cuidadores de pessoas com Síndrome de Down). O estudo transversal observacional controlado foi elaborado de acordo com a Declaração de Helsinque e aprovado pelo Comitê de Ética em Humanos. Para atingir os objetivos foram aplicados questionários validados relacionados ao tema. Os dados foram submetidos ao teste Qui-quadrado com post hoc Bonferroni modificado e de correlação de Rank ou Pearson. Resultados: O Grupo Síndrome de Down apresentou qualidade de vida relativa ao domínio psicológico menor e domínio do meio ambiente maior que o Grupo Controle. Nos grupos estudados a qualidade de vida e renda familiar apresentaram correlação positiva ($p=0,02$) e não houve diferença na depressão. O Grupo Controle apresentou maior índice de ansiedade e o Grupo Síndrome de Down maior índice de sintomas físicos de estresse; correlacionados com o grau de dependência do portador de Síndrome de Down ($p=0,04$). Conclusão: A renda familiar é fator importante para uma melhor qualidade de vida, sintomas de estresse físico reduzem a qualidade de vida no domínio psicológico e sintomas de estresse físico dos cuidadores estão correlacionados com um maior grau de dependência dos pacientes com Síndrome de Down.

Palavras-chave: Síndrome de Down; Qualidade de vida; Depressão; Ansiedade; Cuidadores.

Abstract

The act of caring, being responsible for the survival and quality of life of others, represent extra activities that can cause socio-emotional changes to those who perform this function. Objective: To assess the quality of life, depression, anxiety and stress of caregivers of people with or without Down syndrome. Methodology: 144 caregivers were divided into Control Group (caregivers of typical children) and Down Syndrome Group (caregivers of people with Down Syndrome). The controlled observational cross-sectional study was prepared in

accordance with the Declaration of Helsinki and approved by the Human Ethics Committee. To achieve the objectives, validated questionnaires related to the theme were applied. The data were subjected to the Chi-square test with modified Bonferroni post hoc and Rank or Pearson correlation tests. Results: The Down Syndrome Group had a lower quality of life related to the psychological domain and a higher environmental domain than the Control Group. In the groups studied, quality of life and family income showed a positive correlation ($p = 0.02$) and there was no difference in depression. The Control Group had a higher rate of anxiety and the Down Syndrome Group had a higher rate of physical symptoms of stress; correlated with the degree of dependence of the Down Syndrome patient ($p = 0.04$). Conclusion: Family income is an important factor for a better quality of life, symptoms of physical stress reduce the quality of life in the psychological domain and symptoms of physical stress of caregivers are correlated with a greater degree of dependence of patients with Down Syndrome.

Keywords: Down syndrome; Quality of life; Depression; Anxiety; Caregivers.

Resumen

El acto de cuidar, ser responsable de la supervivencia y la calidad de vida de los demás, representa actividades adicionales que pueden causar cambios socioemocionales en quienes realizan esta función. Objetivo: evaluar la calidad de vida, la depresión, la ansiedad y el estrés de los cuidadores de personas con o sin síndrome de Down. Metodología: 144 cuidadores se dividieron en Grupo de Control (cuidadores de niños típicos) y Grupo de Síndrome de Down (cuidadores de personas con Síndrome de Down). El estudio transversal observacional controlado fue preparado de acuerdo con la Declaración de Helsinki y aprobado por el Comité de Ética Humana. Para lograr los objetivos, se aplicaron cuestionarios validados relacionados con el tema. Los datos se sometieron a la prueba de Chi-cuadrado con Bonferroni post hoc modificado y las pruebas de correlación de Rank o Pearson. Resultados: El Grupo de Síndrome de Down tuvo una calidad de vida más baja relacionada con el dominio psicológico y un dominio ambiental más alto que el Grupo de Control. En los grupos estudiados, la calidad de vida y el ingreso familiar mostraron una correlación positiva ($p = 0.02$) y no hubo diferencias en la depresión. El Grupo de Control tuvo una mayor tasa de ansiedad y el Grupo de Síndrome de Down tuvo una mayor tasa de síntomas físicos de estrés; correlacionado con el grado de dependencia del paciente con síndrome de Down ($p = 0.04$). Conclusión: El ingreso familiar es un factor importante para una mejor calidad de vida, los síntomas del estrés físico reducen la calidad de vida en el dominio psicológico y los síntomas del estrés

físico de los cuidadores se correlacionan con un mayor grado de dependencia de los pacientes con síndrome de Down.

Palabras clave: Síndrome de Down; Calidad de vida; Depresión; Ansiedad; Cuidadores.

1. Introduction

Caregivers are considered people who carry full or most of the responsibility for the caring of relatives and/or patients (Etters, et al., 2008), dedicating most of their time to this care without being economically remunerated (Wilson, 1989) and without receiving guidance or adequate support in most cases (Amendola, et al., 2008).

The act of caring involves a radical change in the life of the caregiver, since it demands complex, delicate and painful tasks (Karsch, 2003) that, combined with other daily responsibilities, generate a change in the routine of the main caregiver that impacts their quality of life (Senses Dinc, et al., 2019). The subsequent overburdening can harm the caregiver's mental and physical well-being, leading to feelings of anxiety and uncertainty, existential angst, loss of perspective in life, development and long-term care (Senses Dinc, et al., 2019; Corrice & Glidden, 2009). Furthermore, it may cause social stress, as limitations to their social life isolate these individuals (Stephens, et al., 2001).

Quality of life is an individual's perception of his position in life, in the context of the culture and value system in which he lives and in relation to goals, expectations, standards and concerns (Whoqol group, 1994), representing the degree of satisfaction with regard to family, love, and social life, as well as the environment (Minayo, et al., 2000).

It is estimated that full-time caregivers face complications related to their mental health such as tiredness, sleep disturbances, a greater use of psychotropics, headache, weight loss, hypertension, and depression (Huang, et al., 2009); factors that can not only reduce the chances of the caregiver having an adequate quality of life (Bocchi, 2004), but also have a negative impact on the care provided to the person or patient with a disability (A'Campo & Spliethoff-Kamminga, 2010).

People with Down's Syndrome (DS) have various morbidities with several physical and social challenges (Startin, et al., 2020). When a child is born with DS, there may be a conflict between the "imagined" and the "real" child, leading to a situation of acceptance or denial by the parents, which can reflect on the family bond and care, as well as affect the child's development process and the parents' quality of life (Corrice & Glidden, 2009).

Assessing the quality of life, anxiety, stress and depression of caregivers of people

with DS can identify the need to develop public policies that favor individual and family quality of life, with improved health and social inclusion.

Thus, the purpose of the study was to assess and compare the quality of life, depression, anxiety and stress of caregivers of people with or without Down Syndrome.

Hypothesis

This study is based on the hypothesis that individuals in the Down Syndrome Group (DSG) have a lower quality of life and higher levels of depression, anxiety and stress than Control Group (CG) subjects.

2. Methods

This controlled observational cross-sectional study was carried out between September 2017 and March 2018, following the rules of the STROBE statement (Von Elm, et al., 2008).

Participants

The sample size was calculated from a finite population of 187 caregivers of patients with Down Syndrome under dental outpatient follow-up at Dental Assistance Center for People with Disabilities. The minimum sample required for an 80% confidence interval was 88 subjects per group, with a 5% error margin.

The study was conducted with a sample of 144 participants selected in 2 institutions: 82 individuals from a reference center in dental care for people with disabilities and 62 from a public school.

These participants were divided into two groups, one being the caregivers of typical children who attended a public school (4 to 8 years old), called the Control Group (CG). The other group was composed of caregivers of Down Syndrome patients, attending the Dental Assistance Center for People with Disabilities, referred to as the Down Syndrome Group (DSG).

The inclusion criteria for the study:

- DSG need to have Down's Syndrome and age range between 4 to 30 years,
- GC need to have age range between 4 to 8 years, do not have chronic diseases, neurological conditions or other changes that may need special care in the short or long term.

Caregivers of individuals who had other neurological complications besides DS and caregivers of patients who needed sedation to receive dental care were excluded from the research. In addition, participants who did not complete the completed questionnaires were excluded.

Caregivers were invited to participate in the study, and learned about the objectives and purposes of the study. In addition, they were made aware of the stages of research development, that the procedures adopted in this research complied with the Ethics Criteria in Research with Human Beings according to Resolution no. 466/12 of the National Health Council, and that the applied procedures offer a minimal risk to their dignity.

Following, the people who accepted the invitation signed the Free and Informed Consent Term as determined by Resolution CNS-196/96.

Data collection procedures

Data collection was performed by 2 applicators (MFA and GBC), previously trained in a pilot study.

When collecting data, the applicators followed an instruction sheet for the application of the questionnaires, in order to guarantee the standardization of this procedure. They explained to the participants all the objectives of the research, gave instructions on how to respond and guaranteed the anonymity of respondents. If a participant requested help to complete the questionnaire, the question and its alternative answers were read and the caregiver's statement was noted.

At Dental Assistance Center for People with Disabilities, the initial contact with the participants took place in the institution's waiting room when they were waiting for the consultation of DS patients. Upon their consent to participate in the research, they were sent to a room prepared for the application of the questionnaire. In the public school, this contact with the caregiver occurred during the monthly meetings with those responsible for the students.

Questionnaires

Initially, the participants were submitted to an initial questionnaire containing questions to situate the interviewee, such as name, age, address, city, gender, marital status, ethnicity, profession, the relationship with the patient, and if they were the only one to

exercise the responsibility of caregiver (dichotomous answer; yes or no). Furthermore, it was noted who helped most in the role (father, mother, grandparents, school, employees and others), the degree of responsibility of the caregiver, (primary, secondary, tertiary, others), which types of care the caregiver performed and the degree of dependence of this patient to perform activities that compromise their survival. They were also asked about their education level, whether they worked outside the home and their monthly family income.

Assessment tools

* World Health Organization Quality of Life (WHOQOL-Bref):

The abbreviated version of a quality of life assessment instrument developed by WHO, the World Health Organization Quality of Life (WHOQOL-100), created due to the need to assess the quality of life of patients undergoing medical treatment, was applied. The need for a shorter instrument led to the development of a shortened version containing 26 questions (WHOQOL-Bref) (Fleck, 2000; Rocha & Almeida, 2009)

The abbreviated questionnaire consists of two general questions, while the others (24 questions) represent each of the 24 facets that make up the original instrument. Thus, WHOQOL-Bref is composed of 4 domains: Physical, Psychological, Social Relations and Environment (Fleck, 2000; Rocha & Almeida, 2009).

* Beck Depression Inventory - BDI - (Beck Depression Inventory):

The Beck Depression Scale or Beck Inventory (Beck Depression Inventory, BDI, BDI-II), consists of a self-report questionnaire and is an instrument for measuring the severity of depression episodes validated to Brazilian Portuguese in 1996 (Gorenstein & Andrade, 1996).

The Portuguese version of the 21 items in the revised form of the BDI (BDI II) was used. The scale consists of items that include symptoms and attitudes, with intensities ranging from neutral to a maximum level of severity, classified from 0 to 3. The categories used were: 0-13 minimal depression; 14-19 mild depression; 20-28 moderate depression; and 29-63 severe depression (Gorenstein & Andrade, 1996).

* Beck Anxiety Inventory - BAI:

The Beck Anxiety Scale or Beck Anxiety Inventory (BAI), also developed by Beck, is a self-report questionnaire that measures the severity of an individual's anxiety, and was

validated for the Portuguese language (Quintão, et al., 2013).

It consists of 21 questions about how the individual has felt in the past week, expressed in common anxiety symptoms (such as fear of losing control and sweating). Each question has four possible answers, and the one that most closely resembles the individual's mental state should be flagged. The used categories were: 0-10 minimal anxiety; 11-19 mild anxiety; 20-30 moderate anxiety; and 31-63 severe anxiety (Quintão, et al., 2013).

* LIPP Adult Stress Symptom Inventory (ISSL):

The LIPP Adult Stress Symptom Inventory (ISSL) provides a measure of stress symptoms in adults and was validated for the Portuguese language (Lipp, 2005; Rossetti, et al., 2008). It consists of three frameworks to delineate the phases of stress, the first one referring to the physical or psychological symptoms that the person has experienced in the last 24 hours, being composed of 15 questions. The second framework refers to the symptoms experienced in the last 7 days, consisting of ten physical and 5 psychological symptoms. The third and final frame refers to symptoms experienced in the last month, consisting of 12 physical and 11 psychological symptoms. Some symptoms are repeated in more than one framework, but at different intensities (Lipp, 2005; Rossetti, et al., 2008).

The theoretical model of stress is quadriphasic, divided into the following phases: Alert Phase, Resistance Phase, Nearly Exhausted Phase and Exhausted Phase (Lipp, 2005).

The Alert Phase is the positive phase of stress, when the individual automatically prepares for action. If the Alert Phase is maintained for a long time or if new stressors accumulate, the Resistance Phase enters, in which the organism tries to prevent the total waste of energy and the individual unconsciously tries to reestablish the inner balance. The Near Exhaustion Phase (newly discovered phase) is when tension exceeds the limit of the manageable. At that point, the physical and emotional resistance begins to break, even though there are still moments when the individual can think lucidly, albeit with much effort. There is a lot of anxiety at this stage. The Exhaustion Phase is the most negative phase of pathological stress, with a great inner imbalance. The individual goes into depression and is unable to concentrate or work (Lipp, 2005). The following scores were assigned to determine the stress phase: 1 - No stress; 2 - Alert phase; 3 - Resistance phase; 4 - Near exhaustion phase; and 5 - Exhaustion phase. To determine the physical and psychological symptoms of stress, the scores were: 1 - Alert phase; 2 - Resistance / near exhaustion phase; and 3 - Exhaustion phase (Lipp, 2005).

Statistical analysis

For analysis, the data were tabulated and submitted to the Chi-square test with modified Bonferroni post-hoc test ($p \leq 0.05$) for group comparison, and the Spearman and Pearson correlation tests, depending on the type of variable under assessment ($p \leq 0.05$, $p \leq 0.001$).

Ethical aspects

This study is in accordance with the Helsinki Declaration (World Medical Association, 2013) and received approval by the Human Research Ethics Committee (Process n°: 2,522,646 - CAAE: 79244017.5.0000.5420).

3. Results and Discussion

After applying the exclusion criteria, some participants were excluded from the research because they did not complete the completed questionnaires, so the final sample for this study consisted of 144 participants. This total was divided into the CG ($n = 62$, 43, 05%) aged 18 to 61 years (34.2 years, 7.8 SD) and DSG ($n = 82$; 56,95%), aged 23 to 78 years (58.2 years; 10.8 SD) ($p = 0.0001$).

Table 1 shows the descriptive results about gender, marital status, race and education level in both groups (CG and DSG). According to the data, the majority of caregivers in both groups are female and married, but there was a significantly higher number of single caregivers in the CG, and widows in the DSG. Both groups were predominantly white (CG = 67.2%; DSG = 80.5%), and white DSG caregivers showed a significant correlation with DS, different from the black, brown and yellow races (rank correlation = -0.190; $p = 0.023$).

Table 1. Descriptive demographic data of the population studied in the control group (CG, n = 62) and the Down Syndrome group (DSG, n = 82).

Variable		CG (%)	DSG (%)
Gender	Man	24.6 A	18.3 A
	Woman	75.4 A	81.7 A
Marital status	Single	26.2 A	8.5 B
	Married	68.9 A	58.5 A
	Divorced	4.9 A	12.2 A
	Widower	0 A	20.7 B
Race	White	67.2 A	80.5 A
	Black	8.2 A	15.9 A
	Brown	24.6 A	3.7 B
Education level	Never attended	0 A	9.8 B
	Incomplete elementary school	19.7 A	40.2 B
	Complete primary education	24.6 A	17.1 A
	Complete high school	44.3 A	20.7 B
	Complete higher education	11.5 A	12.2 A

The statistical difference between the groups was determined by the chi-square test with modified Bonferroni post-hoc test. CG-Control group, DSG-Down Syndrome group. Different letters indicate a statistically significant difference between groups for each event. Source: Authors.

Table 2 shows data related to questions related to the child's degree of dependence and the degree of responsibility of caregivers in the two groups. Regarding the degree of responsibility, 91.8% of the CG and 91.5% of the DSG reported carrying primary responsibility for the care of their children, while 79% of the respondents in both groups perform all care for the children (GC- 82% and DSG- 76.8%). The data also showed a significant correlation between the degree of dependence for basic life functions and DS (rank correlation = -0.357; p = 0.0001).

Table 2. Degree of dependency and responsibility of caregivers in the control group (CG, n = 62) and in the Down Syndrome group (DSG, n = 82).

Variable		CG (%)	DSG (%)
What is your child's degree of dependence for activities that compromise his or her survival?	Low	34.4 A	14,6 B
	Medium	57.4 A	46,3 A
	High	4.9 A	23,2 B
	Extreme	3.3 A	14,6 B
Are you the only person responsible for your child's care?	Yes	19.7 A	54.9 B
	Not	80.3 A	45,1 B
Who else helps in the role?	Dad	47.7 A	29.3 B
	Mom	13.1 A	15.9 A
	Grandparents	98 A	4.9 A
	School	1.6 A	0 A
	Employees	0 A	1.2 A
	Nobody	27.9A	48.8 B

The statistical difference between the groups was determined by the chi-square test with modified Bonferroni post-hoc test. CG-Control group, DSG-Down Syndrome group.

Different letters indicate a statistically significant difference between groups for each event. Source: Authors.

Table 3 shows data about the current activities of caregivers, whether they work outside the home and family income.

Table 3. Activity, work outside the home and family income of caregivers in the control group (CG, n = 62) and in the Down Syndrome group (DSG, n = 82).

Variable		CG (%)	DSG (%)
Current activities of caregivers	Unemployed	14.8 A	0 B
	Employee	65.6 A	35.4 B
	From home	16.4 A	50 B
	Retired	1.6 A	14.6 B
	Student	1.6 A	0 A
Do you work outside the home?	Yes	63.9 A	28 B
	Not	36.1 A	72 B
What is the Family income?	Up to 1/4 of the minimum wage	3.3 A	0 A
	From 1/2 to 1 minimum wage	8.2 A	12.2 A
	From 1 to 2 minimum wages	63.9 A	36.6 B
	From 2 to 3 minimum wages	13.1 A	26.8 B
	From 3 to 5 minimum wages	4.9 A	15.9 B
	From 5 to 10 minimum wages	6.6 A	4.9 A
	From 10 to 15 minimum wages	0 A	3.7 A

The statistical difference between the groups was determined by the chi-square test with modified Bonferroni post-hoc test. CG-Control group, DSG-Down Syndrome group. Different letters indicate a statistically significant difference between groups for each event. Source: Authors.

In the anxiety assessment, the intensity of anxiety was significantly higher in the CG (Table 4), whereas the physical symptoms of stress were significantly higher in the DSG, in which 37.8% of the DSG caregivers were in the stress exhaustion phase (Table 4).

Table 4. Non-parametric correlation between BDI, BAI and LIPP of caregivers in the control groups (CG, n = 62) and Down Syndrome (DSG, n = 82).

Variabile		CG (%)	DSG (%)	Pearson's correlation	P Value
BDI	Minimum	73.8	78		
	Soft	19.7	20.7		
	Moderate	6.6	0		
	Severe	0	1.2	-0.08	0.46
BAI	Minimum	63.9	79.3		
	Light	9.8	13.4		
	Moderate	23	6.1		
	Serious	3.3	1.2	-0.22	0.018*
LIPP- presence	Stress				
	No stress	70.5	73.2		
	Alert	3.3	1.2		
	Resistance	24.6	19.5		
	Near exhaustion	0	1.2		
	Exhaustion	1.6	4.9	0.02	0,89
LIPP – physical symptoms	No physical symptoms	14.8	20.7		
	Alert	19.7	2.4		
	Resistance / Near Exhaustion	49.2	39		
	Exhaustion	16..4	37.8	0.13	0.032*
LIPP – psychological symptoms	No psychological symptoms	14.8	24.4		
	Alert	47.5	24.4		
	Resistance / Near Exhaustion	34.4	22		
	Exhaustion	3.3	29.3	0.15	0.115

* Significance values $p \leq 0.05$. Source: Authors.

In assessing quality of life, the DSG showed a lower quality of life relative to the psychological domain than the CG; and greater referring to the domain of environment (Table 5). Self-assessment of quality of life was positively correlated with family income (Pearson's correlation = 0.53; $p = 0.02$).

Table 5. Nonparametric correlation between data from the quality of life assessment questionnaire (WHOQOL-Bref) and caregivers in the control (CG) and Down Syndrome (DSG) groups.

Variables	CG Mean (SD)	DSG Mean (SD)	Pearson's correlation	P Value
WHOQOL physical domain	13.3 (1.75)	13.2 1.54)	-0.008	0.97
WHOQOL psychological domain	15.0 (2.43)	14.2 (1.73)	-0.20	0.012*
WHOQOL domain of social relations	14.5 (2.9)	14.8 (3.3)	0.04	0.29
WHOQOL domain of the environment	13.1 (1.9)	14.1 (2.2)	0.22	0.008**
Self-assessment of quality of life	14.6 (2.9)	15.1 (2.8)	0.08	0.38
TOTAL WHOQOL	13.9 (1.6)	14 (1.6)	0.05	0.62

* Significance values $p \leq 0.05$

** Significance values $p \leq 0.01$

Source: Authors.

In the DSG, there was a positive correlation between physical symptoms of stress and the degree of dependence of the person with DS, (Pearson's correlation = 0.23; $p = 0.04$).

4. Discussion

The present study compared the presence of stress, anxiety, depression and quality of life in caregivers of individuals with normal development and Down Syndrome, as well as its relationship with demographic factors and the personal characteristics of DS patients.

This study is limited to the collection of variables by interview, without a structured psychiatric assessment of caregivers. On the other hand, its main strength is the inclusion of a control group for comparison.

The age, educational level, work condition and family income are demographics characteristics that may influence the socio-emotional characteristics in a positive or negative way. The caregivers of patients with DS are older on average, with a more favorable economic situation and do not work outside the home. These factors bring a better conditions for coping with the daily family routine, which lead to a lower rate of anxiety. However, the higher age rate is commonly accompanied by physical changes typical of senility with reduced physical work capacity which added to the high degree of dependence of the children may have contributed to a greater physical stress (Lasheras, Petterson & Casado, 2001).

Regarding the level of education, the prevalence of incomplete basic education in the GSD and of complete high school in the CG corresponds to the findings of Eisenhower et al., 2009 that show less schooling among mothers of disabled children compared to that of typical children, a fact that may be associated with age; and in some cases, unhappiness, poor social relationships, low perception of self-care and health and sensory problems (Lasheras, Petterson & Casado, 2001), affecting the quality of life of these caregivers.

In the studied population, as expected, women and mothers predominate as the primary caregivers of their children, with or without DS (Baghdadli, et al., 2014), underlining the historical and cultural tradition of women bearing the main responsibility in the act of caring, regardless of the condition of the child receiving the care and the degree of kinship of the caregiver (Wegner & Pedro, 2010). Fathers generally play a secondary role in the care for children (Ricci & Hodapp, 2003), or sometimes no role at all, leaving the primary caregiver responsibility to the mother.

It is common sense that the presence of an individual with a mental disability in a family generates anxiety and doubts, reflecting on the caregiver's personal anxiety (Shapiro, et al., 1998). However, in this study the level of anxiety was higher in parents of children in the control group, which may be due to the fact that the families involved with DS in this research are embedded in an institutionalized context, which generates greater knowledge, security and tranquility. Interacting with other caregivers of patients with the same characteristic also allows for the exchange of information, experiences and mutual help, all of which enable them to face the situation more normally and without anxiety.

Additionally, feelings of sadness, anxiety and negative thoughts are common in mothers right at the beginning of pregnancy or the birth of a child with DS (Canbulat, et al., 2014; Hodapp, 2007), but these feelings tend to disappear after the adaptation period (Hodapp, 2007), which makes them more resilient and tolerant of difficulties (Choi & Yoo, 2015). In general, acceptance favorably influences the caregiver's psychological adaptation process, which may be one of the reasons for not having found high levels of stress, anxiety and depression in this study. The evaluated caregivers did not have babies and had likely already gone through the adaptation period. Caregivers of children without DS probably had greater anxiety associated with factors such as family income and working conditions.

Many studies have revealed that parents of children with DS have similar levels of stress as parents of typical children (Cless, et al., 2018). However, the present study shows that the presence of stress was low in both groups studied. Nonetheless, among caregivers with stress, it is observed that caregivers of patients with DS are in the most severe phase; the exhaustion phase, and show more physical symptoms related to stress. (Blacher, et al., 2013)

This is probably justified by the altered personal and family routine, as well as the caregiver's age. The primary caregiver suffers detachment from free time and increased physical labor (Crowe, 1993; Padelidau, 1998), leading to tiredness, fatigue and physical overburdening (Lim & Zebrack, 2004; Bourke, et al., 2008; Padelidau, 1998). Furthermore, the delay in the development of DS

patients increases their dependence, since it imposes limitations on basic daily self-care activities like getting dressed, performing personal hygiene, walking or talking (Daunhauer & Fidler, 2011). These factors require greater attention to aspects related to health, education and leisure (Bourke, et al., 2008). In addition, as caregivers of highly dependent DS patients become older, long term care activities can favor the occurrence of physical stress symptoms (Caicedo, 2014).

Thus, parents of children with DS may have a higher level of physical stress and lower quality of life than the parents of normal children (Hamlyn-Wright, et al., 2007; Hedov, et al., 2002, Roach, et al., 1999, Sanders & Morgan, 1997).

This study shows that the quality of life related to the psychological domain was lower and the one related to the environmental domain higher in caregivers of DS patients, unlike other studies that have revealed a decrease in QOL among parents of children with DS in many domains (Bourke, et al., 2008; Hedov, et al., 2000; Buzatto & Beresin, 2008; Oliveira & Limongi, 2011; Chan, et al., 2013; Marchal, et al., 2013; Senses Dinc, et al., 2019).

The caregiver's age can have a positive influence in the environmental domain (Corrice & Glidden, 2009), since older mothers are in a more mature phase (Oliveira & Limongi, 2011) and despite the difficulty, are better able to create solid family dynamics (Corrice & Glidden, 2009). They consequently have a better command of environmental factors than younger and less mature parents.

The reduction in the psychological domain of the main caregiver may be influenced by their low participation in leisure, social and personal activities. This, in turn, can adversely affect the mother's psychiatric condition (Bourke, et al., 2008), cause financial restrictions (Corrice and Glidden, 2009) and affect social support (Caicedo, 2014).

Although the average income of families in the SD group was higher, the high cost of caring for the child did put restraints on the family's budget (Bourke, et al., 2008), causing frustrations and dissatisfaction (Fernandes, et al., 2013).

The fact that most DS caregivers are married (Caicedo, 2014) may represent a potential for strengthening and support, as care activities can be divided between spouses (Amendola, et al., 2011). Nonetheless, marriage is not a guarantee, considering that many married people do not provide physical, financial and emotional support to their spouses.

Finally, the low percentage of caregivers with depression, anxiety and stress can be explained by the fact that they have gone through a process of psychosocial adaptation over the years and therefore carry a less negative perception of the situation (Barbosa, et al., 2012). In addition, the Dental Assistance Center for People with Disabilities is an Auxiliary Unit of Complex Structure whose objective is not only to provide multi and interdisciplinary dental assistance to patients with Down Syndrome, but also to psychosocially guide their relatives and develop socio-educational actions like cultural activities and other activities aimed at family and social integration.

Therefore, in view of this study's findings, it was possible to observe the importance of the need for planning, development and implementation of support programs and primary health care for

caregivers of people with DS. Prevention through a support program aimed at this population will contribute directly to the needs of caregivers and indirectly to the improvement of the care provided to the patient and other family members, minimizing anxiety, depression, stress and improving the quality of life.

5. Conclusion

DS caregivers showed worse symptoms of physical stress and a lower quality of life in the psychological domain than caregivers in the control group.

The symptoms of physical stress are related to the higher degree of dependence of people with DS, and the quality of life of DSG caregivers is directly related to family income.

Caregivers of people with DS did not show higher levels of anxiety and depression in this study.

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