

## Quality of Life of Caregivers of Children and Adolescents with Down Syndrome

**Bárbara Cristina Jorba Arantes, Ravena Maria Ribeiro Moura and Kátia Rodrigues Menezes\***

*Nursing Course, School of Health Sciences - ESCS (Escola Superior de Ciências da Saúde - ESCS), Brazil*

**\*Corresponding Author:** Kátia Rodrigues Menezes, Nursing Course, School of Health Sciences - ESCS (Escola Superior de Ciências da Saúde - ESCS), Brazil.

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### Abstract

**Objectives:** To identify the quality of life of caregivers of children and adolescents with Down Syndrome.

**Method:** This is a descriptive, cross-sectional and quantitative approach study with 107 assistants, from October 2018 to January 2019, in a unit specialized in the care of people with Down Syndrome in the Federal District, using sociodemographic questionnaire and the WHOWOL-BREF. Data were analyzed using the Statistical Package for Social Sciences software version 23, using descriptive analysis and nonparametric Mann-Whitney and Kruskal Wallis tests.

**Results:** From the analysis, it was identified that most caregivers (n = 97; 90.7%) were women, performing intra-household work, while 40 (37.4%) took care of extradomicile work. The caregivers described higher average in the psychological domain (3.61; SD = 0.62).

**Conclusion:** This study revealed that caregivers of children and adolescents with DS consider their quality of life to be good.

**Keywords:** *Quality of Life; Down's Syndrome; Caregivers*

### Introduction

Down Syndrome (DS) is a pathology of genetic origin characterized by a dysfunction during cell division, with the presence of an extra chromosome 21 [1,2]. Due to the genetic disorder, most people with Down Syndrome present congenital heart problems, hypothyroidism, immunological disorders and mental disorders that demand more attention in the promotion of care and consequent overload of stress, fatigue and isolation of caregivers [2,3].

Caregiver is the one who assumes the responsibility of caring for, supporting, or assisting some need of the person cared for, aiming at improving his/her health conditions [4]. The high demand of caring for children and adolescents with Down syndrome modifies the psychological and socio-environmental aspects of the caregiver's life, since it directly influences the physical, emotional, and financial health [3,5]. Such modifications can generate a stressful situation and directly interfere in the quality of life and social well-being [6].

Quality of life is understood as an individual and subjective feeling for the one that involves physical well-being, psychological state, social relations within and outside the family, environmental effects, and beliefs [7].

In view of the possible changes in the caregiver's life regarding social, financial, and emotional aspects, there may be an impact on his/her quality of life [3]. Taking into consideration the health promotion role of nursing professionals and the importance of knowing the reality of health care users to guarantee actions that effectively meet their real needs, the following guiding question was taken: how is the quality of life of caregivers of children and adolescents with Down Syndrome?

### Aim of the Study

Thus, the present study aimed to identify the quality of life of caregivers of children and adolescents with Down Syndrome seen at a specialized outpatient clinic of a public hospital in the Federal District.

### Method

This is a cross-sectional and descriptive study with a quantitative approach carried out in an outpatient unit of the Brazilian Unified Health System (SUS) specialized and reference in the care of people with Down Syndrome in the Federal District.

The research was developed as part of a Scientific Initiation Project funded by the Escola Superior de Ciências da Saúde, in the Federal District, Brazil, in accordance with resolution 466/2012 of the National Health Council and was approved by the Research Ethics Committee of the State Health Secretariat of the Federal District with process number: 2.885.704.

The sample was selected by convenience, with the inclusion criteria being to be the primary caregiver of children and adolescents aged 0 to 19 years as established by the World Health Organization (WHO), with Down syndrome, who had been followed by the sector for at least one month and was present at the time of data collection, agreeing to participate in the research by signing the Informed Consent Form (ICF). The caregiver who refused to participate in any stage of the research, to fill out and/or sign the Informed Consent Form and whose care in the mentioned unit started less than one month ago was excluded from the research.

Data collection was performed by the assistant researchers through the application of two structured questionnaires: a sociodemographic questionnaire, developed for this study and, to assess quality of life, the instrument developed by the World Health Organization Quality of Life - brief (WHOQOL-bref), and abbreviated by the WHO, was used. This instrument evaluates quality of life by means of 26 questions, two of which are related to the overall assessment of quality of life and general health perception, and the other 24 questions represent facets or areas related to quality of life that, in turn, are grouped into four domains, namely: physical, psychological, social relations, and environment.

Data analysis was performed using the software Statistical Package for the Social Sciences (SPSS) version 23. Descriptive data analysis was performed with frequency measures and measures of central tendency and dispersion. After the Kolmogorov Smirnov test, data normality was not verified, and non-parametric tests (Mann-Whitney and Kruskal Wallis) were applied to evaluate the relationship between the domains of quality of life addressed in the questionnaire and variables such as gender, age, marital status, family income, number of children, among others.

### Results

A total of 112 caregivers participated in the research, but 5 instruments were excluded because they did not reach the 80% response rate on the WHOQOL-bref questions. Thus, the final sample was composed of 107 caregivers of children and adolescents with DS, among whom 97 (90.7%) were women and only 10 (9.3%) were men. The caregivers' age ranged from 16 to 72 years, with a mean of 40 years (SD = 9.7). Regarding marital status, 50 caregivers (46.7%) were married and 57 (53.2%) had another marital status, i.e., single, separated, divorced, widowed or others.

Regarding education, 46 caregivers (43%) had completed high school, 29 (27.1%) had completed elementary school, and 29 (27.1%) reported having completed college.

As for family income, there was a predominance of monthly family income of 0 to 3 minimum wages for 66 (61.7%) interviewees, followed by monthly family income of 3.1 to 6 minimum wages reported by 14 caregivers (13.1%), and 27 of them (25.3%) reported income above 6.1 minimum wages.

In this research, (n = 89; 83%) caregivers reported having more than one child, presenting a mean of 2.63 children per caregiver (SD = 1.5), and of those who had more than one child, (n = 08; 9%) reported having another child with chronic health problems or syndrome. Most of the caregivers (n = 67; 62.6%) worked exclusively at home and (n = 40; 37.4%) did extra-homework. Of the caregivers who developed extra-domiciliary work, (n = 20; 50%) left the child with DS in the care of a family member or caregiver, while (n = 20; 50%) left their children in school or day care and, of these children, (n = 12; 60%) attended school full time.

As for the two general questions about quality of life in the WHOQOL-BREF instrument, the answers for “How would you rate your quality of life?” obtained a mean of 3.85 (SD = 0.7). From the total of 107 caregivers of children and adolescents with DS, 47.7% (n = 51) evaluated their quality of life as “good”, 28% (n = 30) “neither bad nor good”, 20.6% (n = 22) considered it as “very good” and 3.7% (n = 4) as “bad”. Regarding the second question, “How satisfied are you with your health?”, the mean was 3.48 (SD = 1.1). Of the total caregivers, 45.8% (n = 49) rated themselves as “satisfied” with their health and 15.9% (n = 17) said they felt “very satisfied.” In contrast, 15.9% (n = 17) of caregivers mentioned feeling “neither satisfied nor dissatisfied”, 15% (n = 16) declared themselves “dissatisfied” and 7.5% (n = 8) “very dissatisfied” with their health.

As shown in table 1, the quality of life measured by the WHOQOL-BREF (WHO) questionnaire in the sample studied obtained the highest mean in the Psychological domain (3.61; SD = 0.62), followed by the Social Relationships domain (3.44; SD = 0.96) and the Physical domain (3.36; SD = 0.65) with the lowest mean attributed to the Environment domain (3.25; SD = 0.70). Table 2 presents the relation of the domains of quality of life addressed in the WHOQOL-BREF questionnaire with study variables such as gender, age, marital status, education, family income, among others.

Domain	Average	SD	Median	Maximum	Minimum
Psychological	3.61	0.62	3.83	5	1.33
Social Relations	3.44	0.97	3,67	5	1
Physical	3.36	0.65	3.43	5	1.57
Environment	3.26	0.71	3.37	4.75	1.50

**Table 1:** Descriptive statistics of the domains of the WHOQOL-BREF questionnaire. Brasília-DF, 2019 (n = 107).  
Source: Research data, 2019.

Variables	Domains of quality of life in the WHOQOL-BREF questionnaire											
	Physical			Psychologic			Social Relations			Environment		
	Average	SD	p- value	Average	SD	p- value	Average	SD	p- value	Average	SD	p- value
Gender												
Male	3.7	0.6	0.046*	3.8	0.5	0.212*	3.9	0.9	0.075*	3.9	0.5	0.006*
Female	3.3	0.7		3.6	0.6		3.4	1.0		3.2	0.7	
<b>Age</b>												
<30 years old	3.5	0.5		3.8	0.4		3.6	0.6		3.4	0.5	

30 to 49 years	3.4	0.6	0.300**	3.6	0.6	0.644**	3.5	1.0	0.635**	3.3	0.7	0.624**
50 years or more	3.2	0.6		3.6	0.5		3.3	1.0		3.1	0.8	
Marital Status												
Married	3.4	0.7		3.6	0.6		3.6	0.9		3.5	0.7	
Separated/ Divorced	3.3	0.4	0.060**	3.7	0.5	0.749**	3.1	0.8	0.067**	3.1	0.8	0.014**
Single, widowed	3.2	0.6		3.5	0.7		3.2	1.0		3.0	0.6	
Other	3.9	0.3		3.8	0.4		4.0	0.7		3.3	0.5	
Level of education												
Up to elementary school	3.3	0.6		3.5	0.7		3.2	1.1		2.9	0.7	
High school complete	3.3	0.7	0.333**	3.7	0.6	0.389**	3.5	0.8	0.283**	3.3	0.6	<0.001**
Higher education or post-graduation	3.5	0.6		3.7	0.6		3.6	0.9		3.6	0.6	
Family Income												
0 to 3 minimum wages	3.3	0.7		3.6	0.7		3.3	1.0		3.0	0.7	
3.1 to 6 minimum wages	3.6	0.6	0.155**	3.6	0.5	0.719**	3.5	0.8	0.327**	3.4	0.6	<0.001**
More than 6.1 minimum wages	3.5	0.6		3.7	0.6		3.7	1.0		3.7	0.6	
Number of children												
One	3.2	0.4		3.6	0.6		3.7	0.8		3.3	0.5	
Two or three	3.5	0.6	0.135**	3.7	0.6	0.517**	3.4	1.0	0.413**	3.3	0.8	0.295**
Four or more	3.2	0.8		3.4	0.7		3.2	1.1		3.0	0.6	
Another child with health problems												

Yes	3.0	0.6	0.302*	3.4	1.1	0.657*	2.2	1.2	0.100*	3.1	0.5	0.873*			
No	3.5	0.7		3.7	0.6		3.3	1.0		3.1	0.8				
<b>Work</b>															
Domiciliary	3.2	0.6	<0.001*	3.5	0.7	0.024*	3.3	1.0	0.015*	3.0	0.7	<0.001*			
Extra-domiciliary	3.7	0.6		3.8	0.5		3.7	0.9		3.7	0.6				
<b>If extra-domiciliary profession the child stays in</b>															
Daycare or School	3.6	0.6		3.7	0.5		3.3	0.9		3.4	0.6				
Family or Caregiver	3.8	0.6	0.454*	3.9	0.4	0.449*	4.1	0.8	0.007*	3.9	0.4	0.018*			
<b>The child stays in daycare or school in the period</b>															
Morning or Afternoon	3.5	0.7	0.571*	3.7	0.3	0.384*	3.0	0.9	0.135*	3.1	0.6	0.031*			
Full Time	3.7	0.5		3.7	0.6		3.5	0.9		3.7	0.5				

**Table 2:** Relationship between the domains of quality of life of the WHOQOL-BREF questionnaire and study variables. Brasília-DF, 2019 (n = 107).

\*: p-value for Mann Whitney test.

\*\* : p-value for Kruskal Wallis test Source: survey data, 2019.

In the physical domain, the fact that achieved the highest mean (3.91; SD = 1.2) was “to what extent does your physical pain prevent you from doing what you need to do?” and the fact that achieved the lowest mean (3.06; SD = 1.2) was “how satisfied are you with your sleep?” In the psychological domain, the fact that achieved the highest mean (4.41; SD = 0.75) was “to what extent is your life meaningful?”, and the fact with the lowest mean (3.21; SD = 1.16) was “how much do you enjoy life?”.

The social relations domain showed the highest mean (3.45; SD = 1.39) in the facet “how satisfied are you with your sex life?”, and the fact that obtained the lowest mean (3.41; SD = 1.13) was “how satisfied are you with your personal relationships (friends, relatives, acquaintances, colleagues)?” The fact that obtained the highest mean (3.72; SD = 0.9) in the environment domain was “how available to you is the information you need in your daily life?”, while the facet with the lowest mean (2.55; SD = 1.16) was “to what extent do you have opportunities for leisure activities?”.

## Discussion

In the present study there was a predominance of female caregivers (n = 97; 90.7%), which corroborates other studies [7-9] in which the mother is the main caregiver, confirming that care falls on the mother or female figure [7]. In addition, mothers of children with disabilities have specific attributions, which can cause reactions and feelings that contradict the socially constructed ideal of motherhood,

which generates the risk of feelings of rejection, emotional detachment (despite the constant physical presence) and overprotection [10]. Such facts can directly contribute to the lower mean of quality of life of caregivers of children and adolescents with Down Syndrome, as evidenced in the present study by the analysis of the physical domain in table 2, where men obtained a higher mean in relation to women with statistical relevance.

The evaluation of the caregivers' marital status in this study revealed a prevalence of unmarried caregivers (53.2%), which differs from other studies [7,11] in which most of the caregivers were married. In the current research, single/widowed caregivers achieved lower mean scores compared to married caregivers in the environment domain, with this finding having statistical significance ( $p$ -value = 0.014). The issue of marital status can affect family dynamics and impact caregivers' quality of life. The presence of a partner can reduce the overload imposed on the family's main caregiver as well as minimize the physical and mental tension due to the division of responsibilities [8].

Regarding the education of the participants of this study, 43% ( $n = 46$ ) reported having completed high school, corroborating similar findings in the literature [7]. When relating education to quality of life, it was observed in this study that, although most of them reported having completed only high school, in the Environment domain, it was the caregivers with higher education or post-graduation who obtained the highest mean with statistical significance, and similar studies were not found in the literature.

As for the work performed by the caregivers of this study, there was a predominance of the intra-household work, which according to Marchal [11] may be related to a caregivers' choice of a less demanding career to be able to combine work with the care of the child. However, when relating the quality of life with the work variable, it was observed that caregivers who had an extra-household occupation had a higher mean in all domains related to quality of life. Such finding may be associated with the issue of personal accomplishment because work is pointed out as an element of extreme importance in human life, for influencing interpersonal relationships, leisure, personal satisfaction, and health perception [12].

In this study, when analyzing the answers of the two main questions related to the global assessment of quality of life and overall health perception, it was found that 47.7% ( $n = 51$ ) of caregivers of children and adolescents with DS assessed their quality of life as "good", which corroborates study [10] in which most caregivers assessed their quality of life as "good".

Some authors cite the term "DS advantage" when describing aspects related to caregiver stress that integrates some factors such as, for example, the recognition of the condition and early diagnosis [11,13,14]. There are also other causes resulting from model ideas about DS children because they are kind and friendly and, therefore, adapt more easily to situations. As some researchers' state, the degree of stress and health of the caregiver and the family are positively influenced by these ideal models about the child with DS [13,14].

In this study, the psychological domain presented the highest mean, proving that negative feelings such as stress, loneliness, and anxiety are not more frequent in caregivers of children than in caregivers of children who do not have any disability. The result found can be proved by the fact that parents of children with DS report a higher personal reward, besides a better quality of relationship with their children and subjective well-being when compared to parents of children with other disabilities [9].

In the Social Relationships domain, despite the result found in this research, Marchal [11] states that caregivers of children and adolescents with DS report difficulties in receiving support and understanding of the situation, since the DS child has a higher degree of dependence on the caregiver and, consequently, affects the quality of life and health of these caregivers [8].

The Physical domain is related to physical pain, medical treatment, daily energy, sleep, and ability to perform daily activities of caregivers. In the present study this domain had the greatest impact on the evaluation of the quality of life of caregivers, justified by the possible degree of involvement with the daily functional tasks performed with the children and adolescents with DS [9].

The Environment domain reached the lowest average among the domains, corroborating other studies [9,15]. This fact can be justified by the direct relationship with the socioeconomic level and the caregivers' level of education [9]. It is questioned in this domain about the recreation opportunities, which may have impacted the lower average, because the caregivers spend more time in the care of children and adolescents with DS than in recreational and social activities [15].

## Conclusion

This study revealed that the caregivers of children and adolescents with DS consider their quality of life good, especially in the psychological domain. Based on this research, we realize the need to study the aspects that involve this population and the environment in which they live, because understanding the impact on the quality of life of these people can greatly influence the comprehensive care for families.

Health professionals must always be attentive to the needs of the families of children and adolescents with DS, being willing to perform a qualified listening and understand their weaknesses, to simplify the coexistence of families and promote quality of life.

As a limitation of the study, the scarcity of literature on the evaluation of the quality of life of caregivers of children and adolescents with DS is highlighted, which made it difficult to compare the data analysis. It is suggested that further research be carried out in the area, with the purpose of investigating and analyzing the experience of the families of children and adolescents with DS.

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