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The influence of siblings with typical development on the burden and quality of life of parents of adolescents with Down syndrome

A influência de irmãos com desenvolvimento típico na sobrecarga e qualidade de vida de pais de adolescentes com síndrome de Down

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Abstract

Objective
The objective of this study was to evaluate the influence of the presence of siblings with normal development on the burden and quality of life of parents of adolescents with Down syndrome.

Methods
Cross sectional and correlational study with 25 caregivers divided in two groups: parents who had only children with Down syndrome and parents with other children with normal development. The caregivers were selected from a convenient sample and answered the World Health Organization Quality of Life, Zarit Burden Interview and Brazil's Economic Classification Criteria.

Results
It was found that both groups experienced moderate burden and regular quality of life for most families, with no significant difference.

Conclusion
It was concluded that the presence of siblings with normal development was not a factor influencing the burden and quality of life of parents of adolescents with Down syndrome.

Keywords: Caregivers; Down syndrome; Family; Family Relations; Quality of life.

Resumo

Objetivo

O objetivo deste estudo foi avaliar a influência da presença de irmãos com desenvolvimento típico na sobrecarga e na qualidade de vida de pais de adolescentes com síndrome de Down.

Métodos

Foi realizado um estudo transversal e correlacional, com 25 cuidadores divididos em dois grupos: pais com filhos únicos com síndrome de Down e pais com outros filhos com desenvolvimento típico. Os cuidadores foram selecionados a partir de uma amostragem de conveniência e responderam ao World Health Organization Quality of Life, ao Zarit Burden Interview e ao Critério de Classificação Econômica Brasil.

Resultados

Verificou-se que ambos os grupos apresentaram sobrecarga moderada e qualidade de vida regular para a maioria das famílias, não havendo diferença significativa.

Conclusão

Conclui-se que a presença de irmãos com desenvolvimento típico não foi fator de influência na sobrecarga e na qualidade de vida de pais de adolescentes com síndrome de Down.

Palavras-chave: *Cuidadores; Síndrome de Down; Família; Relações Familiares; Qualidade de vida.*

Down syndrome (DS) is the most frequent chromosomal abnormality and is among the main causes of Intellectual Disability. The prevalence of DS is 1 in approximately 730 births in the United States; it is a universal occurrence that can be present regardless of ethnicity and social class, and is often dependent on maternal age (Corona-Rivera et al., 2018; Souza et al., 2019).

Having a child with developmental changes can affect the family's Quality of Life (QoL) to a great extent. The QoL is related to people's own perception of their position in life, to the cultural values in which they live and may include indicators such as health, shelter, employment, security and education. The diagnosis of disability of a family member, even more so when it occurs in offsprings is usually one of the most unexpected and frightening revelations that can change the lives and dynamics of parents and family. At the beginning, parents tend to react with mixed feelings, such as fear, shock, guilt and uncertainty about the future. This reaction can be influenced by the way the diagnosis is given and, mainly, by the fact that many health professionals end up focusing only on the negative aspects of such condition (Abassi et al., 2017; Chambers & Chambers, 2015; Huiracocha et al., 2017).

Historically, care of people with some type of dependence is performed by their family members, who act as informal caregivers, do not get paid, have an affective bond with the person cared for and provide physical and emotional care. Many studies reveal that the mother is the figure who most often plays the role of caregiver. These caregivers deal with the pressure and burden of care and, if this stress is not handled well, it can negatively influence QoL, lead to anxiety and even to depression; in fact, the need to become a caregiver usually happens without prior preparation and can be considered a full-time job with a high demand, due to the vulnerability caused by the disease (Mohammed & Mustafa, 2016; Oliveira & Limongi, 2011; Toledano-Toledano et al., 2019; Wang et al., 2016).

Bearing in mind that DS is a disease with a high incidence that causes several changes in DS patients' physical and intellectual development which can increase the burden of caregivers and affect their QoL and, considering the literature surveyed, the objective of this study was to evaluate and correlate the influence of the presence of siblings with normal development on the burden and QoL of parents of adolescents with DS.

Methods

This study was cross-sectional and correlational, with convenience sampling. All ethical procedures were duly adopted and the research project was approved by the Ethics and Research Committee of Universidade Paulista on June 8, 2017, under opinion nº 2,109,032, CAAE 68169817.8.0000.5512

Participants

The study included 25 families who had a caregiver, whose inclusion criterion was to have a child with DS aged between 10 and 19 years, of either gender. These families were divided into two groups: (a) a group of parents who had only children with DS (GSDU) represented by 11 fathers or mothers and (b) a group of parents with children with DS and with another child or children with normal development (GSDI), represented by 14 mothers. Exclusion criteria were parents of institutionalized adolescents, in-patients and adolescents with other associated comorbidities and families with another member with a neurological disorder unrelated to DS.

Procedures

The place of data collection was an Institution of specialized care for people with disabilities in the metropolitan region of São Paulo. The Institution's representative also signed a term approving the research. The participants were invited by the investigator through an invitation letter containing explanations about the work, in addition to clarification of the ethical procedures. After acceptance, meetings were scheduled to collect data individually, on a day and time convenient to the participants lasting approximately 30 minutes, in which the free and informed consent form was signed and questions were answered. Participants also helped filling out an identification card and subsequently responded to three questionnaires.

Instruments

The identification card contained data such as: name, age, marital status, residence, number of children, number of people residing in the household, age of children, profession, current occupation and if still in the work market.

The instrument for assessing QoL was the World Health Organization Quality of Life (WHOQOL-Bref), which was translated and validated into Portuguese. This questionnaire consists of 26 questions and is subdivided into four domains: physical (7 questions), psychological (6 questions), social relationships (3 questions) and environment (8 questions). The first two questions of the WHOQOL-Bref concern the individual's perception of QoL and the individual's perception of health. All questions were asked using a five-point Likert-type scale, considering that the closer the answer to 1, the worse the QoL, and the closer to 5, the better the QoL. Thus, a score from 1 to 2.9 indicates that the QoL needs improvement; QoL is regular when the score ranges from 3 to 3.9; QoL is good when the score ranges from 4 to 4.9; Score 5 indicates a very good QoL. According to the scoring criterion, the numerical results of each question are summed up and grouped according to the domain to which they belong. Subsequently, the value of each domain is divided by the number of questions that compose that domain (Fleck et al., 2000).

Another instrument used was the Zarit Burden Interview Scale (ZBI), developed to assess caregivers' burden. This scale was translated into Portuguese and validated; it consists of 22 questions, which refer to the caregiver-patient relationship, assessment of health status, psychological well-being, finances and social life. On this scale, the score can range from 0 to 4, according to the presence or intensity of an affirmative answer. Questions 1 to 21 are organized according to the frequency of the feeling experienced by the caregiver and classified as never, rarely, sometimes and often. Question number 22 specifically addresses the burden, assessing the weight of the burden experienced by the caregiver. The total score of the scale is obtained by adding the score of all questions and can vary from 0 to 88. The higher the score, the greater the burden. The classification includes: no burden (score ≤ 21), moderate burden (score between 21 and 40 points), moderate to severe burden (score between 41 and 60 points) and severe burden (score ≥ 61) (Scazufca, 2002).

Finally, the *Critério de Classificação Econômica Brasil* (Brazilian Economic Classification Criterion), created by the *Associação Brasileira de Empresas de Pesquisa* (ABEP, Brazilian Association of Research Companies) was used to determine the socioeconomic level of families. It is based on the accumulation of material goods (possession of assets), on the purchasing power and on the level of education of the head of the family, classifying the person evaluated in six socioeconomic levels (A, B1, B2, C1, C2, D-E) (Associação Brasileira de Empresas de Pesquisa, 2015). For the present study, these classes were regrouped into three levels: A (A); B (B1+B2) C (C1+C2+D+E).

Data Analysis

The quantitative data recorded in the evaluation forms were transcribed to Excel databases and were later treated by the Minitab program, considering a significance level of 5%.

The characterization of the groups was carried out using descriptive statistics, with the numerical variables (age of parents and age of children with DS) summarized as a measure of position and dispersion, and the categorical variables (father or mother and children with DS gender, marital status, education level, paid work activity and socioeconomic level) presented through absolute and relative frequency.

The comparison of QoL and burden between the groups, as well as the comparison of the WHOQOL-Bref domains with, education, marital status and paid work, was performed using the Mann-Whitney test.

The correlation between the ZBI questionnaire and the WHOQOL-Bref domains for the groups was performed using Pearson's correlation test. Finally, the graphical presentation of QoL data was generated from the WHOQOL-Bref data processing program (Pedroso et al., 2010).

Results

Twenty-five caregivers participated in the study, 14 in the GSDI group and 11 in the GSDU group, called Participant 1 (P1), Participant 2 (P2) and so on, for both groups. The GSDU sample consisted of 11 caregivers in total, represented by ten mothers and one father. The age of caregivers ranged between 33 and 58 years (mean 47.72 years). For the GSDI, all participants were female, in this case the biological mother; and the age of the caregivers ranged between 34 and 54 years (average 50 years).

Regarding marital status, in the GSDU, 63% of caregivers were married or lived with a partner and the rest were single or divorced and lived only with their child. In the GSDI, 50% were married or lived with a partner, the other half were single or divorced and lived only with their children.

As for the level of education, caregivers in both groups completed elementary school up to high school, 63% in the GSDU and 92% in the GSDI. Regarding paid work, 54% of the caregivers in the GSDU had paid work out of home. For the GSDI, only two caregivers (15%) had paid work.

Considering the socioeconomic level, the caregivers of the GSDU were between class A (36%), B (27%) to class C and D (36%). In the GSDI, caregivers were classified between level B (35%) and C and D (64%).

The age of children with DS in the GSDU ranged between 10 and 18 years (average 13 years), with the majority (65%) being female and the remainder (25%) male. In the GSDI, the age of the child with DS ranged from 11 to 17 years (mean 13 years), with 50% female and 50% male.

WHOQOL-Bref and ZBI GSDU and GSDI results

Table 1 shows the average GSDU and GSDI scores on the WHOQOL–Bref questions. It was observed that although the score of Question 2 (Q2) and the physical domain came very close to the classification as good, the GSDU score was considered regular in the first two questions and in all domains of the scale. Likewise, it was observed that the average GSDI score was considered regular in the first two questions and in all the domains of the scale.

Table 1

Average of GSDU and GSDI participants in WHOQOL-Bref questions

Groups	Q1	Q2	Physical Domain	Psychological Domain	Social Relationships	Environment
				M		
Average GSDU	3.73	3.91	3.97	3.55	3.24	3.23
Average GSDI	3.50	3.57	3.86	3.64	3.29	3.17

Note: GSDU: Group of parents only with children with Down syndrome; GSDI: Group of parents with children with Down syndrome and with other child/children with normal development.

Considering the caregiver burden assessment, it was found that the mean ZBI score for GSDU was 28.72. In 18.18% of the caregivers, there was no burden, while 81.81% of caregivers had moderate burden. None of the caregivers presented moderate to severe or severe burden. For the GSDI the average ZBI score was 27.78. In 28.57% of the caregivers, there was no burden, while 64.28% of the caregivers indicated moderate burden. Only one mother (7.14%) experienced moderate to severe burden and no mother experienced severe burden. In the present study, the frequency of responses in the ZBI questionnaire was also evaluated. It could be noted that in some questions (9, 10, 13 and 18), the two groups (GSDU and GSDI) answered equally, that is, all 25 caregivers answered 'never' or 'rarely'. These issues are related to a lower burden value referring to: caregiver stress when he/she is close to his/her family member; damage to her health due to dedication to her family member; discomfort in receiving friends at home due to her family member condition; desire to transfer the care of her family member to someone else. It was observed that parents, even experiencing moderate burden, would not transfer the child's care to someone else.

Comparison of GSDU and GSDI scores for WHOQOL-Bref and ZBI

Participants 1 and 3 of the GSDU showed no burden, according to the ZBI. As for QoL, they both were classified as regular. The only participant (P8) of the GSDU with good QOL, presented moderate burden; and the participant (P6) who had the worst QoL, needing improvement, was classified as having moderate burden, being far from the score that would indicate moderate to severe, burden as shown in Table 2.

Table 2

Comparison between the ZBI and the WHOQOL-Bref in the two groups

Group / Participant	ZBI Score (*n*)	ZBI Classification	Average QoL	WHOQOL-Bref Classification
GSDU P1	20	Absent	3.846	Regular
GSDU P2	32	Moderate	3.923	Regular
GSDU P3	18	Absent	3.807	Regular
GSDU P4	34	Moderate	3.615	Regular
GSDU P5	30	Moderate	3.807	Regular
GSDU P6	26	Moderate	2.5	Need to improve
GSDU P7	36	Moderate	3.538	Regular
GSDU P8	31	Moderate	4.115	Good
GSDU P9	30	Moderate	3.576	Regular
GSDU P10	27	Moderate	3.153	Regular
GSDU P11	32	Moderate	3.153	Regular
GSDI P1	18	Absent	4.269	Good
GSDI P2	36	Moderate	3.307	Regular
GSDI P3	17	Absent	3.769	Regular
GSDI P4	26	Moderate	3.538	Regular
GSDI P5	27	Moderate	3.461	Regular
GSDI P6	33	Moderate	3.5	Regular
GSDI P7	38	Moderate	3.230	Regular
GSDI P8	25	Moderate	3.115	Regular
GSDI P9	26	Moderate	3.192	Regular
GSDI P10	19	Absent	3.615	Regular
GSDI P11	31	Moderate	3.576	Regular
GSDI P12	50	Moderate to severe	2.807	Need to improve
GSDI P13	23	Moderate	3.807	Regular
GSDI P14	20	Absent	3.884	Regular

Note: GSDU: Group of parents only with children with Down syndrome; GSDI: Group of parents with children with Down syndrome and with other child/children with normal development; QoL: Quality of Life; WHOQOL-Bref: World Health Organization Quality of Life; ZBI: Zarit Burden Interview.

The GSDI participants who showed no burden were 4 (P1, P3, P10 and P14), and out of these only one (P1) had good QoL. The others experienced regular QoL. Mother number 12 was the only one who presented moderate to severe burden, and was classified as needing to improve QoL, as shown in Table 2.

In the GSDU, 90.90% of the participants showed some change in the perception of QoL (score corresponding to "regular" or "improve") while 81.81% experienced some burden (score corresponding to "moderate" and "moderate to severe"). In the GSDI, 92.85% of the participants experienced some change in the perception of QoL, and 71.42% had some burden.

The environment domain is related to leisure, transportation, housing conditions and access to health services, and it was the one with the lowest average compared to the other domains in the two groups evaluated. This domain is usually associated with the parents' socioeconomic level and education level.

Correlation of quality of life and burden in the two groups

In the initial analysis, both groups revealed that the variables socioeconomic class ($p = 0.165$), marital status (0.689), education (0.133) and work activity (0.081) were independent from each other.

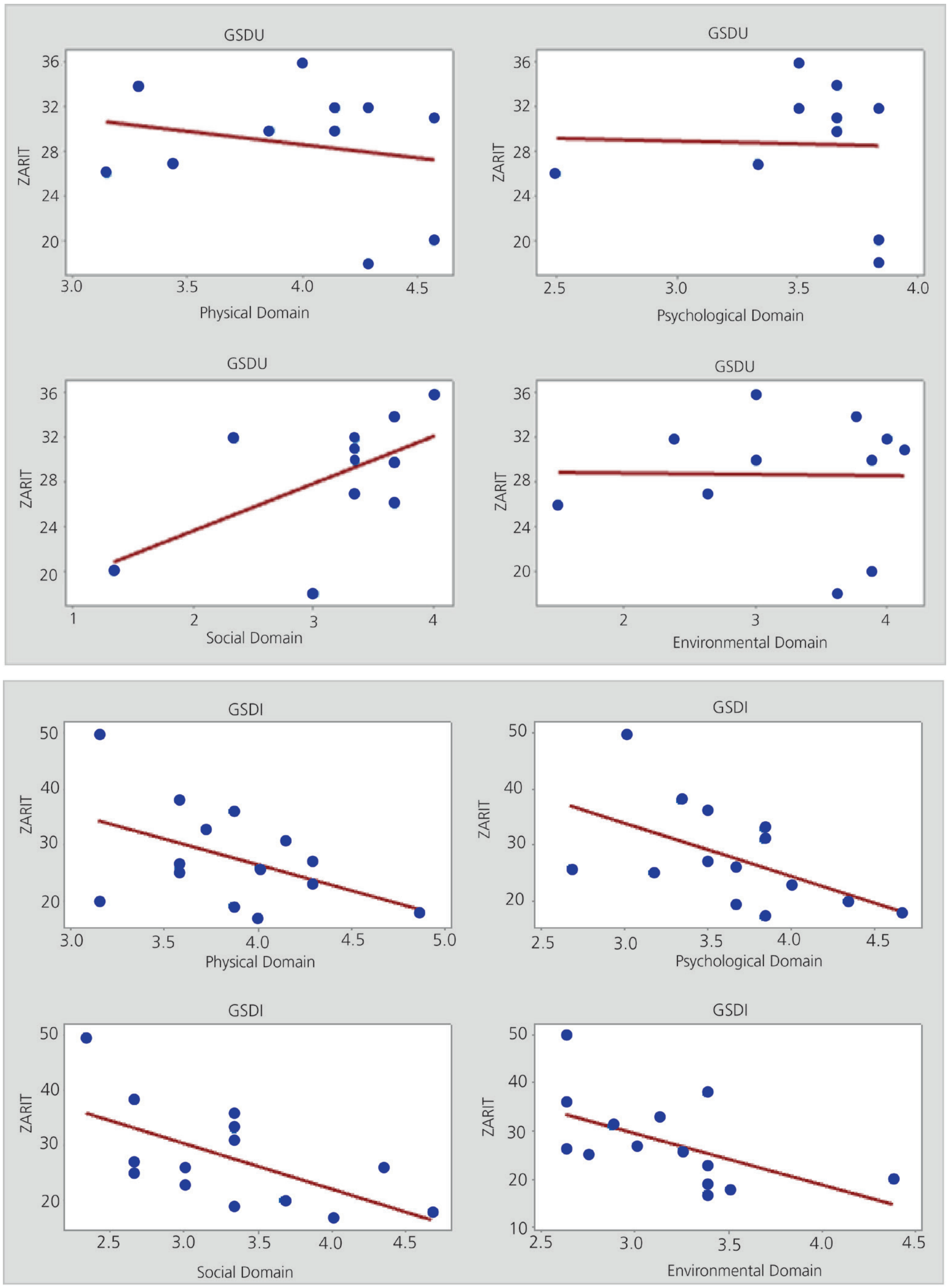
Analysis for the two groups

The correlation investigated between the ZBI score and the QoL domains of the WHOQOL-Bref for the GSDU group was not evidenced at the level of $p \leq 0.05$. The domain that came closest to this value was the social domain, with *p* = 0.068 (*r* = 0.569), indicating that this relationship can be better investigated in other groups. The other domains i.e. the physical domain *p* = 0.536 (*r* = -0.210); the psychological domain *p* = 0.924 (*r* = -0.033) and the environmental domain *p* = 0.962 (*r* = -0.016) did not present indexes indicating linear correlation,

In the GSDI, there was a linear correlation between the ZBI and the psychological domains *p* = 0.047 (*r* = -0.539), social *p* = 0.020 (*r* = -0.613) and environment *p* = 0.041 (*r* = -0.552) domains, except for the physical domain with *p* = 0.092 (*r* = -0.467). Figure 1 illustrates these results.

Figure 1

Correlation of WHOQOL-Bref Domains with ZBI for GSDU and GSDI



Note: GSDU: Group of parents only with children with Down syndrome; GSDI: Group of parents with children with Down syndrome and with other child/children with normal development; WHOQOL-Bref: World Health Organization Quality of Life; ZBI: Zarit Burden Interview.

Analysis for GSDU

The comparison of the four domains of the WHOQOL-Bref with the ABEP, marital status, education and paid work activity did not show a significant difference, with $p = 0.924$ between ABEP and WHOQOL-Bref physical domain; psychological domain ($p = 0.170$); social domain ($p = 0.241$) and environment domain ($p = 0.087$). The latter presented an approximate value of 0.05 and deserves further investigation in future studies.

The comparison between marital status and the WHOQOL-Bref domains also showed no difference, with $p = 0.505$ for the physical domain; $p = 1.000$ for the psychological domain; $p = 0.434$ for the social domain and $p = 1.000$ for the environment domain.

No differences were found for education either, with the physical domain $p = 0.924$; psychological domain $p = 0.096$; social domain $p = 0.328$ and environment domain $p = 0.296$.

Paid work activity showed $p = 0.054$ for the environment domain, and this value is considered very close to the reference value, $p \leq 0.05$, and should therefore be further investigated. For the physical domains ($p = 1.000$); psychological ($p = 0.218$) and social ($p = 0.571$) mean differences were not found.

The ZBI analysis also showed no difference with the ABEP results ($p = 0.254$); marital status ($p = 0.635$); education ($p = 0.342$) and paid work ($p = 0.233$).

Analysis for GSDI

The comparison of the four WHOQOL-Bref domains with ABEP, marital status, education and paid work activity showed a significant difference only between ABEP and the physical domain, with $p = 0.031$, psychological domain p=0.159, social domain $p = 0.416$ and environmental domain $p = 0.946$.

The means between marital status and the WHOQOL-Bref domains did not show differences, with $p = 0.796$ for the physical domain; $p = 0.403$ for psychological domain; $p = 0.948$ for the social domain and $p = 0.119$ for the environment domain.

Statistical treatment for education was not possible, as the GSDI sample had only one higher education participant.

Paid work activity showed no difference in means for the physical ($p = 0.854$), psychological ($p = 0.270$) and environment domains ($p = 0.404$). The social domain could not be tested because the two members who had paid jobs had equal means.

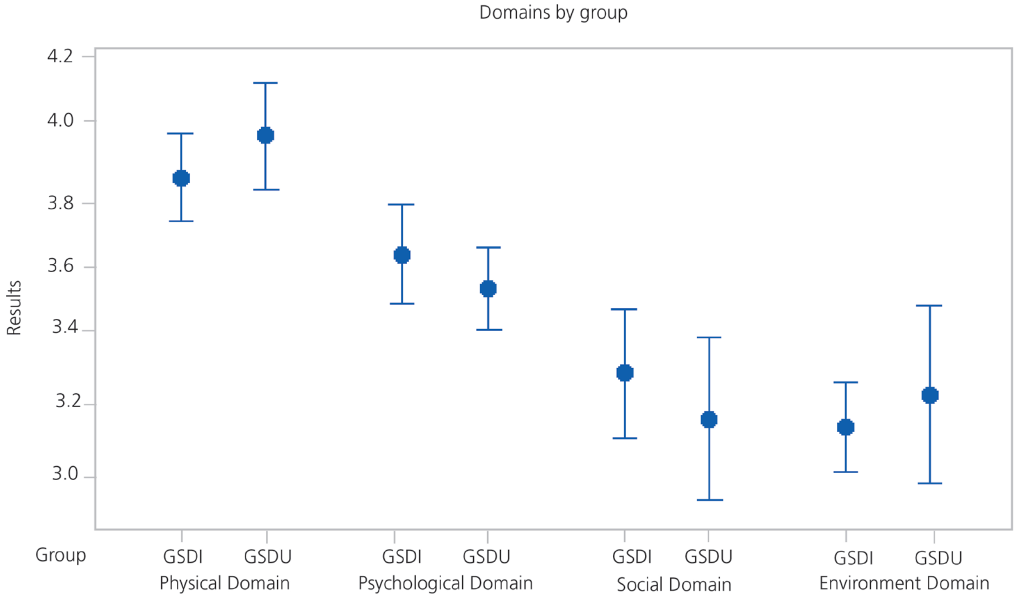
Comparison between the GSDU and GSDI groups

The comparison between GSDU and GSDI regarding the four domains of QoL assessed by the WHOQOL-Bref did not show a significant difference for any of the domains, with $p = 0.424$ for the physical domain, $p = 0.718$ for the psychological, $p = 0.867$ for the social and $p = 0.474$ for the environment domains. The comparison of the groups is reported in Figure 2.

No differences were found in ZBI scores between groups using the Mann-Whitney test ($p = 0.476$). Figure 3 shows the means found for the two groups and the standard error.

Figure 2

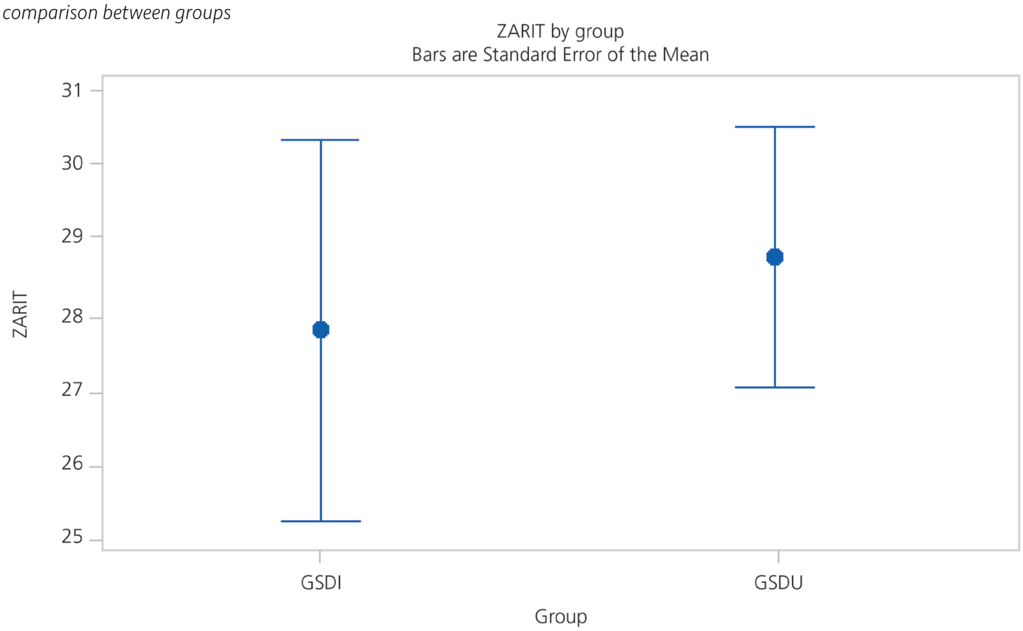
Comparison of WHOQOL-Bref Domains between groups



Note: The individual standard deviations were used to calculate the ranges. GSDU: Group of parents with only with children with Down syndrome; GSDI: Group of parents with children with Down syndrome and with other child/children with normal development; WHOQOL-Bref: World Health Organization Quality of Life.

Figure 3

ZBI comparison between groups



Note: GSDU: Group of parents only with children with Down syndrome; GSDI: Group of parents with children with Down syndrome and other child/children with normal development.

Discussion

Barros et al. (2019), used the WHOQOL-Bref and the ZBI to assess QoL and burden in primary caregivers of children and adolescents with and without disabilities. They observed a low level of education in most caregivers of children and adolescents with disabilities and, in addition, many parents were unemployed.

In the present study, 85% of the parents did not indicate any employment relationship. It was also observed that the GSDI had a lower socioeconomic level and only two mothers in this group had a job. This finding may indicate that, for the underprivileged social classes, taking care of a child with DS, reduces job opportunities on account of the dedication and time required for the care of the child.

In a study conducted in Brazil, on QoL and burden of female caregivers, the authors used the same instruments used in the present study with 224 informal caregivers. They found a sample predominantly of married women, with a low level of education and low purchasing power. However, the minority who received more than three minimum wages had a worse QoL score, that is, a greater purchasing power is not necessarily associated with a better QoL. The findings regarding burden were similar to those found in the current study, as most caregivers had moderate burden and the ZBI mean was practically the same as the mean of the two groups presented here. Finally, the authors also conclude that the greater the burden, the more the QoL of these caregivers will be impaired (Araújo et al., 2019).

Barros et al. (2017) also investigated the burden of caregivers of children and adolescents with DS, comparing them with the control group. It was found that all caregivers presented some level of burden (moderate), and the absence or little burden was predominant in the caregivers of the control group. The question about caregivers' stress when close to a family member with DS also yielded a negative answer in both groups, reinforcing the data found here.

The same authors also state that the low rate of caregivers with severe burden can be explained by the process of psychosocial adaptation over the years, which allows for a less negative perception of the situation. This fact may justify the findings of the current investigation, since the age group of the children in the studied sample was the adolescents' age and, thus, the parents had time to adapt to the situation and seek coping strategies.

In the study that evaluated predictors and risk factors for the burden of caregivers of children with chronic diseases, the authors found that children who are better able to perform daily activities and take care of their own health, reduce the demand for excessive care from mothers, thus reducing the mothers' burden. Hence the authors suggest that interventions and programs that can make children more self-sufficient can help alleviate caregivers' burden (Javalkar et al., 2017).

Caprini and Mota (2021) carried out a study on the psychological impact on family caregivers of children and adolescents with sickle cell anemia. Despite talking about another diagnosis, the authors make a comparison between the findings on caregivers adaptation in connection with the children and adolescents' age, and claim that families with younger children had greater difficulty in adapting, because the younger the child, the closer is the family to the shock of the diagnosis and the impact that the diagnosis of a chronic illness can have on that family.

Buzatto and Beresin (2008) evaluated the QoL of 30 parents of children with DS through the WHOQOL-Bref, of which 10.00% rated QoL as "very good", 60.00% as "good" and 30.00% as "neither bad nor good". Similar results were found in the present study, as most parents (64.28%) from the GSDI rated QoL as "good", 21.42% "neither bad nor good" and 14.28% "bad". In the GSDU, 18.18% of parents rated QoL as "very good", 36.36% as "good" and 45.45% as "neither bad nor good". In this group, most parents evaluated QoL as "neither bad nor good", which is not in agreement with the comparison with the first study nor with the GSDI. Buzatto and Beresin (2008) also found that the social domain had the highest score, while the psychological domain had the lowest score. This finding is not in agreement with the present study, since both groups presented the physical domain with the highest score and the environment domain with the lowest score.

Oliveira and Limongi (2011) evaluated the QoL of parents/caregivers of children and adolescents with DS, using the WHOQOL-Bref, and found that, out of the total of 31 caregivers, 84% rated their QoL as "good" and 16% as "neither bad nor good"; these data corroborate the study by Buzatto and Beresin (2008) and the GSDI of the present study. In the Buzatto and Beresin's study, the authors found that the environment domain had a lower average, which is in agreement with the results presented here, which had averages for the environment domain lower in both groups. Still in relation to the environment domain, in the article by Barros et al. (2019), it was also observed that the environment domain had the lowest average score for all groups assessed

For the sample evaluated here, the domain that presented the highest score is associated with pain, energy, fatigue, sleep, activities of daily living and medication dependence. It is interesting to note that this domain is the least commented on in the studies carried out with the WHOQOL-Bref, and that it may have been the one with the highest score for the age group of adolescents assessed, since it probably indicated less adolescents' physical dependence when compared to children.

A study carried out in Malaysia with 161 mothers of children and adolescents with DS aged up to 18 years belonging to different socioeconomic classes and of different ethnicities, found higher scores in the social relationships domain and lower scores in the environment domain, indicating lower satisfaction in this domain, which corroborates with the findings of the present study. The authors report that the lack of financial resources is strongly associated with families' perception of their QoL, with higher levels of stress and lower well-being (Geok et al, 2013).

Once again, when observing the 2019 study by Barros et al., the authors state that the presence of burden negatively influenced all the domains evaluated by the QoL scale, which leads to believe that individuals who present a greater burden, consider having a poorer QoL as a consequence.

The positive effect that a good relationship between parents, as partners, especially in caring, can facilitate and be a source of stress relief. In addition to the partner, a support network is essential. It is believed that social support, the amount of leisure time and time for themselves are important to improve the parents' QoL and, consequently, to reduce the stress arising from the task of caring (Marchal et al., 2013).

In another study by Graj et al. (2021), which aimed to describe the nature of the parents' QoL at the time of diagnosis and after seven months, it was observed that QoL was negatively affected at the very beginning; however, this acute stress did not influence the parents' QoL in the long term, as, after seven months, this QoL returned to the normal condition. And the domain that obtained a more profound improvement was the psychosocial domain. The parents' habituation to the disease after the initial temporary high stress denotes a resilience trajectory also highlighted in other studies on the subject. Habituation may have been the case in the present study as well, since our investigation was carried out with parents of already adolescent children.

Mothers of children with DS typically experience less stress and depression when compared to mothers who have children with other diagnoses that also lead to ID. Oliveira and Limongi (2011) corroborate this thought when they argue about some advantages that favor DS compared to other diagnoses. This supposed advantage was also addressed in the study by Ronca et al. (2019), in which they state that this can most likely occur because it is the most common genetic syndrome and consequently the most studied.

The group of caregivers participating in the study consisted of 25 individuals, mostly mothers, who answered the standardized questionnaires (WHOQOL-Bref, ZBI and ABEP). The data presented here proved to be complementary and serve as a basis for reflections on family planning and knowledge about the QoL and burden of these parents. However, the groups composed here represent a small sample of these families, and may not portray the reality of other groups. A limitation found and that could, perhaps, result in some difference, was the use of a burden questionnaire used both for formal and informal caregivers. Studies that focus on the mother-child or father-child relationship should be carried out and other instruments should also be tested, in order to promote greater knowledge about the needs of these families and their ways of coping with this situation.

Conclusion

We were able to evaluate and correlate, from the group assessed, the impact of the presence of siblings in the family of adolescents with DS. It is concluded that the presence of siblings with normal development can change the family structure and dynamics, yet not in a way to cause a reduction of the burden, or better of the QoL, since, for the sample assessed, both groups presented moderate burden and regular QoL for most families.

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R.P. RONCA contributed to the manuscript writing; conception, analysis and interpretation of the data; final approval of the version to be published. M.M. ROCHA and D. CAMPOS-POZZI: contributed to the critical content review; final approval of the version to be published. R. CYMROT contributed to the analysis and interpretation of the data; final approval of the version to be published. S.M. BLASCOVIS-ASSIS contributed to the conception, analysis and interpretation of the data; critical review of content; and final approval of the version to be published.