Original Article
Artigo Original

Quality of life of parents/caregivers of children and adolescents with Down syndrome

Qualidade de vida de pais/cuidadores de crianças e adolescentes com síndrome de Down

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Keywords

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Quality of life
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ABSTRACT

Purpose: To assess the quality of life (LQ) of parents/caregivers of children and adolescents with Down syndrome (DS), as well as the influence of socio-demographic aspects on the results obtained. **Methods:** Participants were 31 parents/caregivers of children and adolescents with DS, divided into three groups: G1, caregivers of ten preschoolers (ages between 1 year and 5 years and 11 months); G2, caregivers of 11 school-aged children (ages between 6 years and 10 years and 11 months); and, G3, caregivers of ten pre-teens and adolescents (ages between 11 years and 15 years and 11 months). Parents/caregivers characterization: most of them were between 40 and 49 years old; high-school was the most common education level, followed by incomplete elementary school and college education; concerning the socio-economic class, most of them were from classes C and B2. The QL WHOQOL- *bref* protocol was administered. **Results:** Eighty-four percent of the parents/caregivers rated their QL as "good", and 55% reported to be "satisfied" with their health. The lowest average score was found for the Environment domain, which was found to be correlated with socio-demographic variables "education degree" and "socio-economic level". No difference was found between groups when age ranges were compared. **Conclusion:** The results suggest that the studied population consider their QL as "good", and is "satisfied" with their health. The Environment domain and the socio-demographic variables "education degree" and "socio-economic level" are the aspects that influence their quality of life.

Descritores

Síndrome de Down
Qualidade de vida
Cuidadores
Criança
Adolescente
Questionários

RESUMO

Objetivo: Avaliar a qualidade de vida (QV) de pais/cuidadores de crianças e adolescentes com síndrome de Down (SD) e a influência de aspectos sócio-demográficos nos resultados obtidos. **Métodos:** Participaram 31 pais/cuidadores de crianças e adolescentes com SD, que foram divididos em três grupos: G1, cuidadores de dez crianças pré-escolares (idades entre 1 ano e 5 anos e 11 meses); G2, cuidadores de 11 crianças em idade escolar (idades entre 6 anos e 10 anos e 11 meses); e G3, cuidadores de dez pré-adolescentes e adolescentes (idades entre 11 anos a 15 anos e 11 meses). Dados de caracterização dos pais/cuidadores: a maioria estava na faixa etária de 40-49 anos; o grau de escolaridade Ensino Médio Completo foi o mais freqüente, seguido de Ensino Fundamental Incompleto e Ensino Superior Completo; quanto à classe econômica, a concentração foi nas classes C e B2. Foi aplicado o questionário de QV WHOQOL-*bref*. **Resultados:** Dos pais/cuidadores pesquisados, 84% avaliaram sua QV como "boa" e 55% afirmaram se sentir "satisfeitos" com sua saúde. O domínio Meio Ambiente apresentou menor média quando comparado aos demais e apresentou correlação com as variáveis sócio-demográficas referentes ao "grau de instrução" e ao "nível socioeconômico". Não houve diferença entre os grupos na comparação das faixas etárias. **Conclusão:** Os dados obtidos apontam que a população estudada avalia sua QV como "boa" e está "satisfeita" com sua saúde. O domínio Meio Ambiente e as variáveis sócio-demográficas "grau de instrução" e "nível socioeconômico" são os aspectos que influenciam sua QV.

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INTRODUCTION

The Down syndrome (DS) is easily diagnosed at birth due to its peculiar characteristics, and the parents are informed about the syndrome early in the baby's first days of life. In the last few years, with the development of accurate diagnostic tests, the DS diagnosis has been established even during the gestational period, which has an impact on the whole family(1,2). The confrontation with the imagined and the real baby, when this image does not correspond to the idealized one, such as the case of infants with DS(3-5), lead to acceptance or denial behaviors that may influence the attachment bond and, consequently, the care provided to the baby, as well as the child development(5,6).

Authors(7) who have studied quality of life (QL) usually discuss concepts such as health and illness, influenced by changes on the morbimortality profile, and its relationship to advances in medical diagnostics and therapeutics. They point out that health and illness are processes that could be understood as a *continuum*, and are directly related to economic and socio-cultural aspects, as well as to life styles. The presence of an individual with special care needs will affect the family structure and its effects will also depend on which family member is affected, the period of permanence on the injury, and its severity(8). Regarding children with some kind of deficiency, the family has the important role to stimulate, provide attention, care, comprehension and protection(6,8). In that sense, the family can be defined as an organized group of people, influenced by socio-cultural aspects and individual needs, who participate into a relationship, in which each member plays a specific role.

Concerning children with DS, it is emphasized in the literature that these children have a lower rate of development, and they consequently demand grater dedication from their parents(4,5,9), influencing the family dynamics(2-4,6,8,10). Although its repercussion is extended to the whole family, the called primary caregiver is the one who has the responsibility of providing physical, emotional and drug assistance, and sometimes even financial support to the injured person(8). Many studies point out the mother as the family member who typically assumes the role of primary caregiver, concerning not only the direct child care, but also providing information about the child's global development, health and education(5,6,8-11), what is justified by the mothers' historically determined social role. Nevertheless, other researchers have considered both parents as equally involved in care-giving(3,4,12-15) .

The primary caregiver plays an important role in assisting the person with special care needs, as well as in keeping him or her as part of the community, preventing exclusion situations. However, the tasks assigned to the caregivers, often without adequate guidance and no health institutions and social support network, and also the changes in routine and the time spent in care-giving may directly interfere in caregivers' personal, family and social life, impacting on their QL(4,6-9,10,14,15). Several studies have reported the stress as an important factor related to that situation, which manifests itself in different ways and intensities on the family members, even on those members who are injured(1-4,15-17).

The presence of stress is pointed out as an important aspect concerning the family and its members' QL, even considering the DS, although in a smaller proportion when compared to other diseases such as autism and other psychiatric conditions, neurological disorders, and cognitive disabilities of nonspecific etiology(2,5,9-11,13,16). Generally, the stress is linked to behavioral problems, communication difficulties (receptive and expressive language), and cognitive deficits, which become more evident as the children get older(2,13). Fathers have more difficulties dealing with such situations than mothers(16).

Some researchers have mentioned some DS "advantages" concerning stress in the family, such as: early recognition and diagnosis; having a cromossomic cause (the cause factor is external to the parents); having large prevalence, being of common occurrence and recognition; having a lower rate of development, providing the parents with a longer period for adaptation to the children's behavior changes in their predictable course of development(2,5,6,8-10). Other pointed aspects are related to stereotyped ideas concerning children with DS, such as having docile behavior, being friendly and, consequently, being easily adaptable to different situations. Those stereotyped ideas have a positive influence on the stress level and well-being of family members, as affirmed by some authors(2,5).

The observation and identification of factors that influence the life style and the relationship among the family members, in which there is an member who is physically, emotionally or intellectually affected, led researchers to study the QL of individuals in such situations. The World Health Organization (WHO) defined QL, as reported in a Brazilian study(18), as "individuals' perceptions 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", whose concept implies the idea that the QL is subjective, multidimensional, and it includes both positive and negative evaluation elements(7,18-21). In order to carry out a worldwide QL evaluation, the WHO Quality of Life Group was created and a collaborative multi-centre research project was developed, resulting in the WHOQOL-100 (World Health Organization Quality of Life-100), which was composed of 100 items/ questions(18).

Based on this tool, the WHOQOL-bref was developed, comprising 26 questions, with the aim to measure the QL with the same effectiveness, but in a faster and easier way(18). The WHOQOL-bref presents two general questions concerning QL and more 24 questions, which represent each one of the 24 facets included in the original tool. It is arranged into four domains: physical health, psychological, social relations, and environment. Authors carried out a study aiming to compare both tools in test and re-test situations in transplantation-liver disease patients, and high correlations were found between the tools, except for the social relations domain(22).

Both WHOQOL forms are validated and available in Brazilian Portuguese(19,23). They have been used in both analytical studies about QV evaluation tools(7,18,20) and researches concerning its administration in different populations(4,8,11,15). Regarding the DS, such tools are also used by Brazilian researchers(4,8,11). In the international literature, there are a great variety of tools for QL assessment, even related to DS, composed of different types of questionnaires(1,2,5,9,10,13,16,17) .

The aim of the present study was to evaluate the QL of parents/caregivers of children and adolescents with DS, as well as the influence of socio-economic aspects in the results.

METHODS

This research was approved by the Research Ethics Committee of the School of Medicine of Universidade de São Paulo (CEP-FMUSP), under protocol nº 237/10. All subjects have their consent form signed.

This is a quantitative study, descriptive and exploratory in character. Thirty one parents/ caregivers of children and adolescents with DS attending the service participated in this study. The inclusion criteria involved: being responsible for the children/adolescents' daily care; children/ adolescents aged up to 15 years and 11 months.

All the children and adolescents are under medical follow-up, carried out in health services to the family's preference, and audiological follow-up, carried out in the institution.

Based on other authors' proposal(24), the caregiver was considered as the person who usually took the child to the speech-language therapy, carried out in the Speech-Language Pathology Laboratory in Syndromes and Sensorimotor Deficits of the FMUSP (LIF-SASM). The caregiver received all the information and guidance related to the treatment, and should be part of the child's nuclear family, that is, the caregiver should live with the child and be responsible for his or her daily care (25). In this study the caregivers were 22 mothers, seven fathers and two grandmothers.

For comparison purposes, the parents/caregivers were arranged into three groups, according to the children/ adolescents' chronological age: G1, composed of caregivers of ten preschoolers (ages ranging between 1 year and 5 years and 11 months; mean chronological age: 3 years and 8 months); G2, composed of caregivers of 11 school-aged children (ages ranging between 6 years and 10 years and 11 months; mean chronological age: 8 years and 5 months); and G3, composed of caregivers of ten pre-teens and teens (ages ranging between 11 years and 15 years and 11 months; mean chronological age: 8 years and 5 months).

The WHOQOL-bref questionnaire was administered to the parents/caregivers by the examiner, a speech-language pathologist who had no prior contact or information about the children and adolescents, thereby avoiding influences on data gathering. Although the WHOQOL-bref is a self-administered tool, we preferred to use the interviewer-administered form, in order to avoid problems concerning understanding the questions. In case of parents/ caregivers' doubts, a general explanation was given, without mentioning examples.

For analysis purposes, this study followed the tool's design(19,22). In the statistical descriptive analysis, we used specific syntax, with transformed scores from zero to 100. The data concerning the parents/caregivers' socio-demographic profile, considering their age, education and socio-economic levels, were organized according to the ABEP CCEB(26) (Table 1).

For the statistical analysis, we used the Friedman, Wilcoxon, Spearman Correlation and Kruskal-Wallis non-parametric tests. To complement the descriptive analysis, we used the Confidence Interval for the mean. The significance level adopted was 0.05.

RESULTS

Regarding the two general questions about QL, the answers for " How would you rate your quality of life?" indicated that 84% (n=26) of the 31 parents/ caregivers of children/ adolescents with DS rated their QL as "good", and the other 16% (n=5) rated their QL as "neither poor nor good". Concerning the question "How satisfied are you with your health?", 55% (n=17) of the parents/ caregivers declared to be "satisfied" and 16% (n=5) affirmed to be "very satisfied", while 19% (n=6) felt themselves "dissatisfied" and 10% (n=3) "neither satisfied nor dissatisfied".

The comparison among WHOQOL-bref domains showed significant differences among them (p<0.001) (Table 2).

The comparison between the means and medians of each domain allows verifying that the sampling distribution is symmetric, since those values are similar for all domains. Besides that, the standard deviation shows that the data are homogeneous.

The Environment domain was the one with the lowest average score (53.33 ± 5.05), what shows that this domain is the most affected.

The domains were also compared in pairs (Table 3).

The results showed significant differences between the Environment domain and each of the other domains.

The correlation analysis was carried out between each domain and each socio-demographic variable (parents/ caregiver's age, education degree, and socioeconomic level) (Table 4).

Positive significant correlations were found only between

Table 1. Socio-demographic profile of parents/caregivers of children and adolescents with Down syndrome (DS)

Education	n	(%)	Economic class	n	(%)	Age range (years)	n	(%)
No education	1	(3)	E	0	(0)	20-29	1	(3)
Incomplete elementary school	7	(23)	D	1	(3)	30-39	5	(16)
Complete elementary school	4	(13)	C	12	(39)	40-49	17	(55)
Incomplete high school	1	(3)	B2	10	(33)	50-59	6	(19)
Complete high school	11	(36)	B1	5	(16)	+60	2	(7)
Incomplete college education	0	(0)	A2	3	(9)			
Complete college education	7	(22)	A1	0	(0)			

Table 2. Comparison among the results obtained for the WHOQOL-bref domains

WHOQOL-bref	Physical	Psychological	Social relations	Environment
Mean	65.09	69.89	69.62	53.33
Median	67.9	70.8	75.0	56.3
SD	15.31	13.03	16.74	14.34
Q1	57.1	62.5	66.7	45.3
Q3	75.0	79.2	75.0	65.6
n	31	31	31	31
CI	5.39	4.59	5.89	5.05
p-value	<0.001*			

* Significant value (p≤0.05) – Friedman test

Note: SD = standard deviation; Q1 = 1st quartile; Q3 = 3rd quartile; CI = confidence interval

the Environment domain and the socio-demographic variables education degree and socioeconomic level.

The groups were compared for each WHOQOL-bref domain (Table 5).

The statistical analysis revealed that the groups are homogeneous concerning the all the WHOQOL-bref domains.

DISCUSSION

The proposal for studying QL and its relationship with the health sciences has intensified in the past few years and motivated conceptual and methodological research reviews(12,21,23), even considering the state of the art in Brazil(7,20,27), besides discussions and studies in several health areas with different populations. These studies mostly aim to provide better conditions for individuals development and greater facilities for reaching such goals, whether they are functional, psychological, cultural, social or economic(3,5,7,9,10,16,17,27).

Table 3. Comparison between the WHOQOL-bref domains, by pairs

	Physical	Psycological	Social relations
Psychological	0.088		
Social relations	0.171	0.942	
Environment	<0.001*	<0.001*	<0.001*

* Significant values (p≤0.05) – Wilcoxon test

In studies concerned with these aspects and that involve populations with global development deficits(10), nonspecific intellectual disabilities(13), or belonging to the autistic spectrum(15), the term parents and/or caregivers is used in a general way, not necessarily making reference to data that characterize each one of these individuals or compare them. In studies about QL in DS, the authors have intended to present findings that involve parents/caregivers, and generally, the studied population is mostly composed of mothers(2,4-6,8,10). In a few cases, the objective is to study the male element as caregiver, that is the father(16) or the own injured individual(1,11,17). In the present study, the goal was the caregiver, as defined in the methods, comprising mostly mothers, although seven fathers and two grandmothers also took part of the studied population.

Even though the inclusion of these nine non-mother caregivers could lead to some interference on the obtained results, the mixed and not totally controlled composition of the interviewed subjects can be justified by the fact that it reflects the

Table 4. Correlation between the WHOQOL-bref results and the variables age, education degree, and socioeconomic level

		Physical	Psychological	Social relations	Environment	Age	Education degree
Psychological	Corr	37.1%					
	p-value	0.040*					
Social relations	Corr	42.6%	34.9%				
	p-value	0.017*	0.054				
Environment	Corr	59.4%	54.9%	33.3%			
	p-value	<0.001*	0.001*	0.067			
Age	Corr	-8.4%	1.8%	-3.7%	-28.5%		
	p-value	0.654	0.924	0.844	0.120		
Education degree	Corr	16.4%	22.5%	-12.6%	53.9%	-45.7%	
	p-value	0.379	0.224	0.500	0.002*	0.010*	
SEL	Corr	27.7%	21.2%	15.8%	45.1%	-31.4%	65.2%
	p-value	0.132	0.253	0.396	0.011*	0.085	<0.001*

* Significant values (p≤0.05) – Spearman Correlation test

Note: SEL = socio-economic level; Corr = correlation

Table 5. Comparison among groups concerning the WHOQOL-bref domains

	Group	Mean	Median	SD	Q1	Q3	n	CI	p-value
Physical	Group 1	63.93	67.9	19.88	62.5	67.9	10	12.32	0.850
	Group 2	65.58	75.0	15.43	53.6	76.8	11	9.12	
	Group 3	65.71	67.9	10.94	58.0	74.1	10	6.78	
Psychological	Group 1	71.25	68.8	11.53	63.5	77.1	10	7.15	0.678
	Group 2	65.91	70.8	16.33	56.3	79.2	11	9.65	
	Group 3	72.92	75.0	10.25	63.5	78.1	10	6.35	
Social relations	Group 1	70.83	70.8	11.95	66.7	75.0	10	7.41	0.931
	Group 2	68.18	75.0	18.94	66.7	75.0	11	11.19	
	Group 3	70.00	75.0	19.72	66.7	81.3	10	12.22	
Environment	Group 1	53.13	53.1	14.73	45.3	64.1	10	9.13	0.208
	Group 2	57.67	62.5	15.08	57.8	65.6	11	8.91	
	Group 3	48.75	48.4	13.03	38.3	57.8	10	8.07	

Kruskal-Wallis test ($p \leq 0.05$)
Note: SD = standard deviation; Q1 = 1st quartile; Q3 = 3rd quartile; CI = confidence interval

reality found in the service in which the children and adolescents were placed. In some occasions, the mothers assume the role of family economic provider, once the fathers, for any different reasons, have no stable economic activity. The same can be said about the grandparents. The economic aspect as a factor that interferes in family dynamics, when considering individuals with DS, is seldom examined and usually analyzed in a general way(5,10).

Concerning the QL self-rating ("very poor", "poor", "neither poor nor good", "good" or "very good"), the majority of parents/ caregivers rated their QL as "good". This data is supported by results found in other studies(4,8) and it can be addressed to the Social Relations domain. According to some authors(2,5), the ideas about individuals with DS, as presenting a docile behavior, being friendly and easily adaptable to situations, encourage social attitudes, making it easier for parents/caregivers to participate in social interactions. These same authors explain that although positives, those ideas are stereotyped and do not necessarily correspond to the reality of all individuals with DS.

Other aspect that may reinforce the mentioned findings and that also corroborate the score obtained for the Psychological domain found in the present research, can be related to the called "DS advantage". According to some studies(2,5,9,10), the parents of children with DS have reported a greater personal reward, higher quality in their relationship with their children, and subjective well-being when compared with parents of children with another disabilities. Other studies have reported that parents/caregivers of children with DS, although presenting signs of stress, these signs are less intense comparatively to other pathologies, and they are justified by factors, such as: possibility of following the children development, despite the clinical and intellectual difficulties; adaptation to children's conditions during the development period, which is slower; because the parents are mostly older, the family would be more adapted in their dynamics(1-3, 5,9,17). Another factor highlighted by some authors is the identification of intellectual deficits. According to these studies(9,13), the fact that parents know that the cognitive deficits found in DS are part of the phenotype would result in less stress, when compared with parents whose children present this feature in a nonspecific way.

Considering the Physical domain, whose score was closer to the Psychological and Social Relations domains than to the Environment domain, the findings are corroborated by other studies(4,11,28). It is interesting to note that in both national and international literature, few analysis concerning the facets that compose this domain are found, what is also highlighted in other study(28). In that sense, the influence of stress in factors as health, energy and fatigue, sleep and rest, capacity for working, and treatment dependence related to caregivers, is not always carefully analyzed(3,9,16).

In a study carried out with mothers of individuals with DS, with ages ranging from birth to 25 years, the authors(28) observed that the greatest impact in the mothers' physical health is associated to the degree of involvement in daily functional tasks carried out for their children. Thus, the more independent the child become, the better is the physical condition presented by the mother. These authors also emphasize that the presence of maladaptative behaviors has impact on mothers' psychological health, which is evidenced by the presence of stress. Other authors(10) point out that one important factor to the physical health of mothers of individuals with DS is the optimism related to the good expectations concerning their children's development. As argued by some authors(1,2,10), there is a close relationship among the social, psychological and physical aspects considered in studies about the QL, as also observed in the present research.

The Environment domain, which is related to leisure, to the access to health services, transportation and housing conditions, presented the lowest average score when compared to the other domains, corroborating studies concerning both DS(8) and children with autism(15). In a review paper about the theme QL, the discussed aspects also emphasized the importance and influence of the environment in this issue(21). However, when considering the same population studied in the present research, the authors found the Environment domain as the second lowest average score, being supplanted by the Psychological domain(4). In a study focusing leisure, the authors(14) emphasized its importance for parents/caregivers of individuals with DS as a way of reducing stress and increasing the physical and psychological well-being, besides favoring social relationships and family harmonization. This issue can be considered of difficult achievement based on data from both the present research and other studies(8,12).

The significant correlation found for the Environment domain indicates that this domain is mainly related to the parents/ caregivers' education degree and socioeconomic level. This result corroborate findings from other studies, which point out that the cultural and socio-economic disadvantage may interfere in the parents/caregivers' stress levels, resulting in a worse relationship between parents and children(9,20). Authors also highlight that the caregivers' (especially mothers) education degree and cultural perspectives (concerning the couple) are associated to the degree of optimism with which they build their lives(10,11,13).

In the present research, no significant correlation was found between parents/caregivers' age and the domains. In studies related to this fact, authors(5,10) have observed that the age, generally concerning the mothers, can be considered a positive factor for both the relationship between the parents/ caregivers and their children and the QL enhancement. In general, the mothers are older and are in a more mature phase of life. Unfortunately, the results of the present research do not allow data analysis in this direction, although it is important to be aware of these comments.

In the present research, the domains were also compared according to children and adolescents' ages, with the aim to verify possible differences in the results, as pointed out in some studies(13,16,17). No differences between groups were found, suggesting homogeneously in the studied population. Otherwise, as observed by these same authors, the questionnaire is administered to parents/ caregivers or other professionals, who can consider other variables as more important, such as the presence of maladaptative behaviors.

In a review study regarding researches about QL in health care carried out in São Paulo, the authors(20) point out, besides the existence of two ways of measurement, specific and generic, the importance of this kind of research to our reality. They indicate the use of the WHOQOL that, as a generic tool, covers important aspects regarding health and reflects the influence or impact of some disease existence in the life of an individual or in his/her family's life. In that sense, other studies(4,7,11,15,20,22,23,27) in both national and international literature, involving different pathologies, agree with such commentary and mention that the WHOQOL-bref presents adequate psychometric characteristics for the QL evaluation. In the present research, the differences found among the domains corroborate such findings.

A study carried out(23) with the purpose of validating the brief version of the WHOQOL, proved its effectiveness, although reporting that the correlation for the Social Relations domain is not so high when compared to the other domains. Concerning the questionnaire administration and the comments found in the above mentioned studies, a study(21) draws the researchers' attention to the need of using short questions in simple and accessible language when speaking to the participants.

The present study brings some important considerations to be made. One of them refers to the study's contribution to the comprehension of the effects on the QL of parents/caregivers of children and adolescents with DS and its influence on therapeutic intervention proposing. The other refers to some limitations that should be considered, such as the small sample size, what limited the generalization of findings. In that sense it would be interesting to carry out a longitudinal study in order to follow the evolution of parents/caregivers ratings as well as possible changes in the aspects related to the Environment domain and socio-demographic data influences.

It is also important to refer the fact that the data presented in this research were not compared with data from the population of parents/caregivers of children and adolescents without developmental complaints. Such comparison could add interesting observations for studying. In the literature, when the QL issue is considered, even if assessed using different tools, one can found studies that compare groups of individuals with different pathologies(2,5,10,16) or studies that do not use this methodological design(9,13-15,17). The same is observed concerning this theme addressed to DS, using the WHOQOL-bref (4,8,11).

We can neither deny the importance of the WHOQOL-bref as a tool for measuring the QL and for providing information about an individual or a group of people, which will be useful for therapeutic process adequation, nor dismiss the importance of intrinsic and extrinsic factors to the individual, which can influence data gathering and analysis. Many studies(7,19-21,27) emphasize such issue.

CONCLUSION

The results suggest that the studied population rated their QL as "good" and they are "satisfied" with their health. The Environment domain and the socio-demographic variables "education degree" and "socio-economic level" are the aspects that have influenced their quality of life.

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