

# Family Management and socioeconomic situation of children and adolescents with neurological disorders

*Manejo Familiar e situação socioeconômica de crianças e adolescentes com distúrbios neurológicos*

*Manejo Familiar y situación socioeconómica de niños y adolescentes con trastornos neurológicos*

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## ABSTRACT

**Objectives:** to identify the relation between family management and socioeconomic situation of children and adolescents with neurological disorders. **Methods:** a descriptive and correlational study with 141 family members who answered a questionnaire on socioeconomic and family management information. Data collection took place between May and September 2016 in a pediatric neurology center. A descriptive and analytical analysis was carried out with the use of statistical tests in order to assess the relation of the variables researched. **Results:** a higher early childhood disease time was related with higher scores of management difficulty. There was relation between the highest family income and management skills and the lowest scores of family difficulty. The highest schooling level of mothers was associated with the lowest scores of disease impact view and family difficulty. **Conclusions:** family members with unfavorable socioeconomic situation had more difficulty with family management. **Descriptors:** Social Class; Nervous System Diseases; Child; Adolescent; Family Caregivers.

## RESUMO

**Objetivos:** identificar a correlação entre o manejo familiar e a situação socioeconômica de crianças e adolescentes com distúrbios neurológicos. **Métodos:** estudo descritivo, correlacional, com participação de 141 familiares, os quais responderam a um questionário sobre informações socioeconômicas e do manejo familiar. A coleta de dados ocorreu entre maio e setembro de 2016, em um Centro de Neurologia Pediátrica. Realizou-se análise descritiva e analítica, com uso de testes estatísticos para avaliar a correlação entre as variáveis investigadas. **Resultados:** o maior tempo de doença infanto-juvenil foi correlacionado a um maior escore de dificuldade de manejo. A maior renda familiar foi relacionada ao maior escore de habilidade de manejo e ao menor escore de dificuldade familiar. A maior escolaridade materna associou-se ao menor escore de visão do impacto da doença e dificuldade familiar. **Conclusões:** as famílias em situação socioeconômica mais desfavorável tiveram maiores dificuldades no manejo familiar.

**Descritores:** Situação Socioeconômica; Distúrbios Neurológicos; Criança; Adolescente; Cuidador Familiar.

## RESUMEN

**Objetivos:** identificar la correlación entre el manejo familiar y el estado socioeconómico de niños y adolescentes con trastornos neurológicos. **Métodos:** estudio descriptivo y correlacional con 141 miembros de la familia, que respondieron un cuestionario sobre información socioeconómica y gestión familiar. La recopilación de datos tuvo lugar entre mayo y septiembre de 2016 en un Centro de Neurología Pediátrica. Se realizó un análisis descriptivo y analítico utilizando pruebas estadísticas para evaluar la correlación entre las variables investigadas. **Resultados:** la mayor duración de la enfermedad infantil y juvenil se correlacionó con una mayor puntuación de dificultad de manejo. El mayor ingreso familiar se relacionó con un puntaje de habilidad gerencial más alto y un puntaje de dificultad familiar más bajo. La educación materna superior se asoció con una puntuación de visión más baja del impacto de la enfermedad y la dificultad familiar. **Conclusiones:** las familias en la situación socioeconómica más desfavorable tuvieron mayores dificultades en el manejo familiar.

**Descriptorios:** Situación Socioeconómica; Enfermedades del Sistema Nervioso; Niño; Adolescente; Cuidadores Familiares.

## INTRODUCTION

Neurological disorders in childhood are estimated to be a major cause of morbidity among chronic pediatric diseases<sup>(1)</sup>. Neurological disorders include conditions such as cerebral palsy, epilepsy, spina bifida, brain tumors and traumatic injuries. Neurodevelopmental diseases include the autism spectrum, among others. All these types of disorders are related to cognitive and motor deficits that compromise activities of daily living<sup>(2-4)</sup>.

Studies have shown that people with neurological and/or neurodevelopmental disorders require ongoing parental care<sup>(5-8)</sup>. Care demands of children with chronic diseases and effects of the disease on family life lead to the need for reorganization and adaptation to a new life arrangement. Each family manages its daily routine so that care for its members is incorporated into everyday life.<sup>(9-10)</sup>

It is important for health professionals to understand families' responses to chronic childhood conditions, because families' skills to meet the daily demands of childhood illness influences family health and child adaptation<sup>(11)</sup>. Health professionals are the agents with the greatest influence on family management<sup>(10)</sup>.

Nursing and health team interventions serve to support family adaptation. Moreover, these professionals must define what constitutes a successful adaptation and what facilitates it. When nurses recognize these factors, they can use their knowledge and skills to help children improve their health and help families adjust to chronic conditions. The use of theoretical models contributes to the development of nursing knowledge related to family responses to chronic childhood conditions.

One model is the Family Management Style Framework (FMSF), designed to identify household responses to chronic childhood conditions<sup>(9,12)</sup>. This consists of three main components: situation definition, management behavior and perceived consequences<sup>(9,12)</sup>. The theoretical model defines some factors that facilitate or hinder family management, such as social networks that support families, family resources, assistance from health professionals and education<sup>(10)</sup>.

During a FMSF conceptual analysis in 2012, the authors of the model identified few quantitative studies on demographic and socioeconomic factors that could influence the way family members define the situation of having a chronically ill child, the behaviors used to manage the disease, and perceptions about the disease consequences on family life<sup>(9,12)</sup>. FMSF explores factors that contribute or not to family management, which, in turn, influence the functioning of the sick individual and the family<sup>(9,12)</sup>.

FMSF and other family management studies advances required instrumentalization of the model. Thus, from the FMSF, the Family Management Measure (FaMM) was developed to assess how families manage chronic childhood disease and how they insert this condition into daily life<sup>(10)</sup>. In Brazil, family management has been investigated through FMSF in situations such as childhood cancer<sup>(13)</sup>, pediatric palliative care and in families of children who received liver transplantation<sup>(14)</sup>. The use of the quantitative tool is recent in Brazil. Family management mediates contextual factors and the functioning of children and families<sup>(10)</sup>. These aspects have important implications for interventions that can support families.

## OBJETIVES

To identify the relation between family management and socioeconomic situation of children and adolescents with neurological disorders.

## METHODS

### Ethical aspects

This research was approved by the Research Ethics Committee, under Opinion 1,299,529. The researchers respected the research involving human beings ethical principles, according to Resolution 466/2012 of the Brazilian National Health Board (*Conselho Nacional de Saúde*).

### Design, place, and period of study

This is a descriptive, correlational and cross-sectional study, conducted between May and September 2016. STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines were used to guide the methodology. The study site was a reference center for care for children with neurological diseases by the Brazilian Unified Health System (*Sistema Único de Saúde*) in the state of Paraná.

### Population, sample; inclusion and exclusion criteria

Participants were family members whose children/adolescents were undergoing treatment for autism spectrum disorder, epilepsy or cerebral palsy. A convenience sample was obtained, which was calculated using the largest number of medical appointments at the study site for the year prior to the planning of this research. These conditions defined the sample size, namely autism spectrum disorder: 35; epilepsy: 39; cerebral palsy: 67.

In this research, the inclusion criteria used were followed in the study, which assessed the psychometric properties of the FaMM tool, which the adapted version and validity was used in this study<sup>(11)</sup>: family members who lived in the same house with the children/adolescents and took care of these individuals (hygiene, food, mobility, mobility, elimination, health care, therapeutic support, socialization and protection); family members who provide care to children/adolescents diagnosed with the disease for at least six months before the survey; family caregivers of children/adolescents who were not hospitalized and did not receive emergency care in the two months prior to the survey. These criteria are justified by the search for family management in situations where there are no recent crises<sup>(11)</sup>. Family members whose children were under two years of age or over 19 were excluded, in addition to family members under 18.

### Study protocol

Data collection was conducted in two steps. In the first, data were extracted from medical records to identify children/adolescents in the age group foreseen for the study. In the second stage, family members were invited to participate in the research on the day of the child/adolescent's appointment.

Two tools were used, one of which was to collect demographic and socioeconomic data from families and the clinical situation of the child/adolescent; the other was the adapted and validated Brazilian version of FaMM<sup>(15-16)</sup>. In the first tool, the following demographic variables were collected: age and gender of family members and children/adolescents, and degree of relationship with the child/adolescent. Children and adolescents clinical variable was collected: time in which the child/adolescent lives with neurological disease. Finally, the variables of socioeconomic status were collected: access to early childhood education; type of education (regular/special); type of school (private/public); years of maternal education and per capita family income.

The second tool, FaMM, is made up of 53 items, 45 of which apply to all family members, while eight apply only to those with spouses/partners, subdivided into six dimensions. These dimensions were elaborated from the subcategories of the main FMSF components.

1. Child identity: indicates the degree of independence of the child; Higher scores indicate that the child is leading a normal life, from the perspective of family members.
2. Management skills: refers to the perception of parents about their skills to take care of their children; Higher scores indicate that parents feel better able to perform care.
3. Management effort: refers to the perception of the effort involved in disease management; the higher the score, the higher the effort.
4. Family difficulty: indicates parents' perception of the fact that having a sick child makes life difficult; the higher the score, the higher the difficulty.
5. Disease impact view: addresses the family's perception of the severity of the disease and the complications to the child's and family's health; higher scores indicate greater severity and concern of the family with the management of the disease.
6. Mutuality among parents: higher scores indicate greater reciprocity among partners in coping with the disease<sup>(11)</sup>. Answers to items were calculated on a Likert scale, with a score from one to five, with one indicating "I strongly disagree" while five indicating "I strongly agree"<sup>(11)</sup>.

### Analysis of results, and statistics

Descriptive analysis was used to present demographic data of families, children and adolescents, as well as socioeconomic status. There was decision to categorize these variables as absolute (n) and relative (%) values. Continuous variables were categorized and also presented as minimum, maximum and standard deviation (SD) values.

In estimating household per capita income, income from work-related activities and social benefits obtained from the government was included. Results were converted to minimum wage units, which corresponded to 880 *reais* (*reais* is the Brazilian currency; 880 *reais* is approximately 220 US dollars) in 2016. In Brazil, children and adolescents with disabilities, whose families have financial difficulties to support them, may receive the Government Continued Assistance Benefit. To grant it, children/adolescents must belong to families with per capita income

below one quarter of the minimum wage<sup>(17)</sup>, equivalent to 220 *reais* (about 55 US dollars) in 2016. In the present study, 49.60% (n = 70) of the families reported receiving this grant.

Family management dimensions were calculated according to the guidelines established by the researchers who elaborated the FaMM<sup>(18)</sup> and, subsequently, presented in mean score and SD.

To assess the relation between the variables, nonparametric statistical techniques were used, because the Shapiro-Wilk test showed that the variables did not present normal distribution. Spearman's correlation coefficient (Rho) was used to test the correlation between continuous variables (family management dimension score versus child/adolescent disease duration, years of maternal education, family per capita income). In this test, gross values were used.

The Mann-Whitney U test was used to compare the mean scores of each family management dimension according to the nominal categorical variables (type of education and type of school). The significance level was set at  $p \leq 0.05$ . Statistica 7.0 software was used for statistical analysis.

## RESULTS

### Demographic, and socioeconomic situation characterization

Demographic and socioeconomic situation data are presented in Table 1. The mean age of the family members was 37.8 years, with a minimum and maximum of 21 to 60 years, SD 2.1. The mean age of children/adolescents was 9.5 years, with a minimum and maximum of 2 to 17 years, SD of 1.7. There was a predominance of participants between 31 and 40 years old, female, who were mothers of the children/adolescents. Regarding children and adolescents, a predominance of males and age between two and ten years was identified. It was found that children/adolescents lived with the disease between five and nine years. Predominantly, they attended regular school, had access to public school, 43% of families had per capita income of up to ½ minimum wage, while 37% had ½ to minimum wage. In 47.5% of families, mothers had nine to eleven years at school, corresponding to elementary or high school.

**Table 1** – Demographic and socioeconomic situation data (n = 141), Curitiba, Paraná, Brazil, 2016

Variables	n	%
Demographic data		
Family members		
Age (years)		
21-30	25	17.73
31-40	69	48.94
41-60	47	33.33
Gender		
Female	121	85.82
Male	20	14.18
Relationship with child/adolescent		
Mother	117	83.00
Father	19	13.00
Other members	5	4.00
Children/adolescents		
Age (years)		
2-10	84	60.00
11-17	57	40.00

To be continued

Table 1 (concluded)

Variables	n	%
Gender		
Female	47	36.00
Male	94	67.00
Socioeconomic situation		
Time (years) of disease of children/adolescents		
<1	9	6.40
1-2	16	11.30
3-4	22	15.30
5-9	49	34.80
≥10	45	31.90
Access to early childhood education		
Yes	130	92.00
No	7	5.00
Not applicable <sup>a</sup>	4	3.00
Type of teaching		
Regular	80	61.54
Special	48	36.92
Mixed	2	1.54
Type of school <sup>b</sup>		
Public	119	92.00
Private	11	8.00
Per capita family income		
No income	2	1.00
Up to ½ minimum wage	61	43.00
½ to 1 minimum wage	52	37.00
1 to 1 and ½ minimum wage	18	13.00
1 and ½ to 2 minimum wages	5	4.00
2 to 5 minimum wages	3	2.00
Years of maternal studies		
0	1	0.70
1-4	19	13.50
5-8	33	23.40
9-11	67	47.50
12-15	19	13.50
16 and more	2	1.40

Note: <sup>a</sup>children who were not old enough to be compulsorily enrolled in Brazilian basic education (under four years old); <sup>b</sup>n = 130.

### Relationship of socioeconomic situation with family management

It was found that the longer the duration of childhood illness, the lower the child identity score, the higher the family difficulty score and disease impact view (Table 2). In relation to family management with per capita family income, it was found that the higher the income, the higher the management skills score, the lower the family difficulty score and the disease impact view. Furthermore, it was found that the higher the maternal education, the higher the child identity score, the lower the family difficulty and disease impact view scores.

According to Table 3, children/adolescents studying in regular education obtained higher mean scores in the child identity, management skills and mutuality among parents dimensions. In situations where children/adolescents attended special education, management effort mean scores, family difficulty and disease impact view were higher.

Table 2 – Relationship of family management dimensions with disease duration, years of maternal study and per capita family income (n = 141), Curitiba, Paraná, Brazil, 2016

Dimensions	n	Time of disease		Per capita income		Year of maternal studies	
		Rho <sup>a</sup>	p value	Rho <sup>a</sup>	p value	Rho <sup>a</sup>	p value
Child identity	141	-0.194	0.022*	0.144	0.087	0.169	0.046*
Management skills	141	-0.097	0.254	0.330	0.000*	0.147	0.082
Management effort	141	0.141	0.094	-0.058	0.493	-0.123	0.146
Family difficulty	141	0.260	0.002*	-0.224	0.007*	-0.224	0.007*
Mutuality among parents <sup>b</sup>	113	0.043	0.648	0.123	0.192	0.017	0.861
Disease impact view	141	0.175	0.038*	-0.191	0.022*	-0.284	0.001*

Note: <sup>a</sup>Spearman's correlation coefficient; <sup>b</sup>dimension applied to family members with partner/spouse (n = 113); \* p ≤ 0.05.

For those studying in public schools, mean scores for family difficulty and disease impact view were higher. In the case of those who attended private schools, the management skills score mean was higher (Table 3).

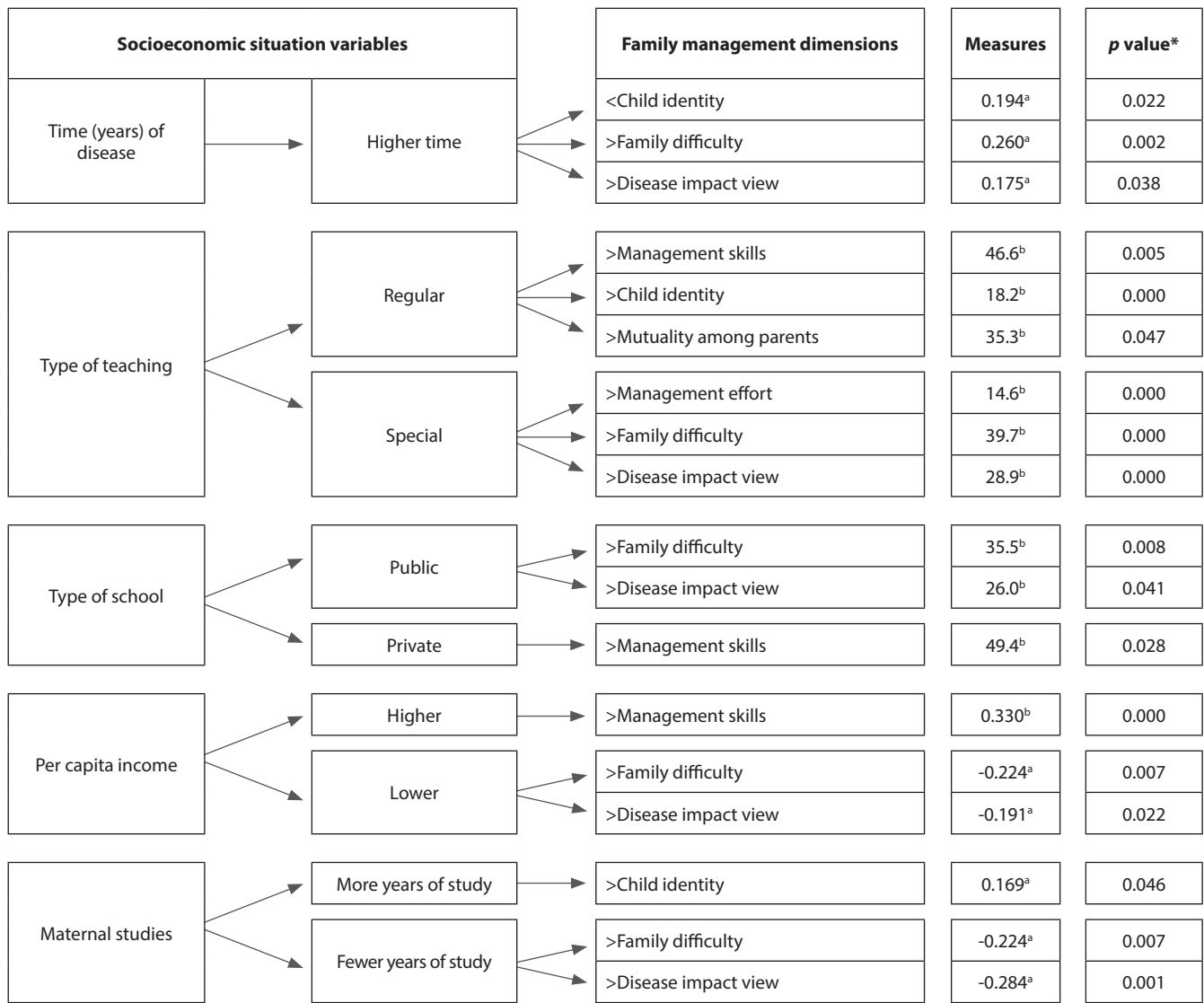
Figure 1 presents a synthesis of the variables researched. Families with greater difficulties in family management were those who had the following conditions: longer duration of childhood and youth disease; situations in which children/adolescents attended special education and had access to public schools; families with lower income and lower maternal education.

In the case of families whose children were in regular school, had access to private school, the per capita income was higher and the mothers had more years of schooling, and family management was more successful.

Table 3 – Descriptive analysis of family management dimensions with type of education and school of children/adolescents (n = 141), Curitiba, Paraná, Brazil, 2016

Dimensions	Type of teaching				p value <sup>b</sup>	Type of school				p value <sup>b</sup>
	n	Mean	SD <sup>a</sup>			n	Mean	SD <sup>a</sup>		
Child identity	Regular	80	18.2	5.15	0.000*	Private	11	18.2	4.78	0.172
	Special	48	13.2	3.95		Public	119	16.1	5.30	
Management skills	Regular	80	46.6	6.45	0.005*	Private	11	49.4	5.18	0.028*
	Special	48	43.5	5.68		Public	119	45.1	6.32	
Management effort	Regular	80	11.9	4.56	0.000*	Private	11	10.4	4.76	0.054
	Special	48	14.6	3.26		Public	119	13.3	4.24	
Family difficulty	Regular	80	31.3	12.47	0.000*	Private	11	25.7	11.89	0.008*
	Special	48	39.7	11.30		Public	119	35.5	12.60	
Mutuality among parents <sup>c</sup>	Regular	63	35.4	5.58	0.047*	Private	9	35.5	2.96	0.900
	Special	39	33.2	5.70		Public	95	34.5	5.86	
Disease impact view	Regular	80	23.6	6.35	0.000*	Private	11	21.7	7.62	0.041*
	Special	48	28.9	5.13		Public	119	26.0	6.21	

Note: <sup>a</sup>SD - Standard Deviation; <sup>b</sup>the difference between the means of the variables was assessed by the Mann-Whitney test (regular or special education and access to public or private schools); <sup>c</sup>dimension applied to family members with partner/spouse (n = 113); \* p ≤ 0.05.



Note: > highest score; < lower score; <sup>a</sup>Rho – Spearman's correlation coefficient; U Mann-Whitney test; \* p ≤ 0.05.

**Figure 1** - Synthesis of the relationship between socioeconomic situation and family management dimensions, Curitiba, Paraná, Brazil, 2016

## DISCUSSION

Children and adolescents with neurological diseases have complex needs that can challenge families in managing such conditions. Just as they report positive experiences in having a child with chronic illness, there are several stressors that play a critical role in how a family can continually manage their needs and those of those individuals<sup>(19-20)</sup>. The child's identity and impact view show the family perception of the child's/adolescent's abilities, which are linked to the understanding of the disease, as well as its demands and associated limitations<sup>(10)</sup>. The longer the child lives with the disease, the more noticeable are the signs of neurological impairment due to the particularities in child development<sup>(21)</sup>. Greater dependence on children generates greater demand for care, causing families to face difficulties and make intense efforts to manage them<sup>(22)</sup>.

Commonly, individuals with autism have changes in communication, social interaction and behavior, and in many cases other comorbidities<sup>(23)</sup>. Children/adolescents with epilepsy and

cerebral palsy may present physical, emotional, developmental, behavioral changes, among others, which require health care, exceeding routine ones<sup>(24)</sup>. In addition to health-related needs, these children/adolescents have educational demands. They are not always able to participate in the same activities as their peers due to limitations related to the disease, as well as structural barriers that prevent them from accessing environments<sup>(20)</sup>.

Families often seek regular education for children without developmental disorders. A study involving observation of functional and motor skills showed that more independent children and adolescents needed less school assistance<sup>(25)</sup>. On the other hand, those with lower functional and motor skills, intellectual, emotional and language disabilities attended special education<sup>(26)</sup> thus, they require more school assistance. A study in the United States showed that most children with comorbidities were enrolled in special education courses<sup>(25)</sup>.

Correspondingly, in Brazil, people with more serious health problems<sup>(27)</sup>, higher levels of physical disability and comorbid disabilities attend special education<sup>(28)</sup>. The results of these studies



converge with those of the current research, as they show that these children have greater restrictions and, therefore, family members invest more efforts and have difficulties in management, as well as in the perception of disease severity.

Regarding the type of school that children/adolescents in this study have access (public or private), for each enrollment in private school, 10 were observed in public schools, proportionally. Unlike in the Brazilian population, in 2014, every four enrollments in the public school found one in particular among individuals with at least one disability (visual, auditory, motor, mental or intellectual)<sup>(29)</sup>.

In a study on the determinants of education costs in Brazil, it was found that the decision of families to enroll their children in private schools is related to the level of maternal education, household income, school costs and availability of public and private schools in the region where they live. However, the most consistent predictive factor is household income, because the higher the income, the more likely children are to attend private institutions<sup>(30)</sup>. Thus, difficulties in the management by families of children who study in public schools may be related to the limitation of financial resources.

People with special educational needs require specialized physical and human resources from educational institutions<sup>(31)</sup>. This depends on financial support to maintain educational standards for this population, which is not always offered by the public education system<sup>(32)</sup>. The public school system may be the only way for children to be educated when they cannot afford to pay for private services, because in many situations family members need to stop working to take care of the child. Consequently, there is a reduction in the family's financial resources. Thus, they direct these resources to areas that they consider as priorities, such as housing costs and child health care, as well as indirect costs, such as transportation to take the child/adolescent to medical appointments, food, among others<sup>(20)</sup>. Thus, families may face difficulties in finding a financial balance.

A study conducted in the United States with family members of children with asthma showed an association between higher family income and greater management skills<sup>(33)</sup>, similar to the present study. However, lower income was related to greater family effort<sup>(33)</sup>. Low income is a difficulty faced by families of children/adolescents with chronic diseases. In addition to emotional distress, the lack of financial resources emerges as a stalemate for the desired treatment and recovery. Thus, families may feel helpless in the face of childhood illness<sup>(34)</sup>.

Lower-income families often depend on the public health system. Patients may be slow to access services because the demand for this type of care is higher<sup>(35)</sup> and thus families may face difficulties. In Brazil, in order to gain access to specialized services in the public health system, it is necessary to obtain the referral of professionals from the Basic Health Unit to specialized services, which may require waiting time.

On the other hand, families with higher incomes may have faster access to services and/or resources they want for child/adolescent care<sup>(36)</sup>. That way, they can be more satisfied and better able to manage available care resources.

Another important aspect related to family skills identified in this study was maternal schooling. Mothers with higher education have greater skills to seek resources for child/adolescent health and support networks<sup>(37)</sup>. Nevertheless, those mothers with fewer years of schooling may have greater difficulties in managing childhood

disease, and their child may have greater limitation related to the disease, as expressed in the disease impact view dimension.

In a study conducted in Greece, the correlation of sociodemographic characteristics with childhood neurological development was examined; Maternal higher education was found to be associated with better scores in childhood neurodevelopment<sup>(38)</sup>. A higher level of maternal education contributes to the understanding of children's health. In addition, mothers with higher education are more frequent users of health services, thus more closely monitoring the health of their children<sup>(39)</sup>.

### Study limitations

Despite obtaining a statistically significant correlation between the variables, associations were considered low to moderate. This fact limits the results of this study, which, therefore, should be interpreted with caution. Therefore, further studies with larger samples are needed to confirm the identified associations. Nevertheless, this study is considered relevant as it explores family management in culture outside the United States.

### Contributions to nursing, health and public policies

The relationship of socioeconomic aspects with family management provides health professionals with a knowledge base to support families in the organization of care, as well as broadening the support network to obtain resources to assist them in managing child therapy and family needs.

Public policies for early childhood education and social support are important forms of protection to ensure families access to services, enabling the broadening of the potential of care for this public, as well as achieving good child health outcomes and adapting families to chronic disease. The results from this study are relevant for policy makers and managers, as they can be considered in the development process and in the implementation of policies aimed at serving these families.

### CONCLUSIONS

Families with unfavorable socioeconomic conditions had greater difficulty in family management. Understanding the intersection between socioeconomic factors and family management is important to enable professionals to implement interventions to help these families.

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