REFACS

Original Article
Rev. Fam., Ciclos Vida Saúde Contexto Soc.
http://seer.uftm.edu.br/revistaeletronica/index.php/refacs/index
ISSN: 2318-8413 DOI*:* 10.18554/refacs.v10i3.5843

Assessment of family functioning of children and adolescents with chronic illness

Avaliação do funcionamento familiar de crianças e adolescentes com doença crônica

Evaluación del funcionamiento familiar en niños y adolescentes con enfermedades crónicas

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Received: 28/09/2021 **Approved:** 19/07/2022 **Published:** 30/09/2022

Objective: to assess the degree of family functioning of children and adolescents with chronic illness. **Methods:** a quantitative and cross-sectional study carried out in two reference services in the city of João Pessoa, PB, Brazil, between April 2017 and January 2018. Two instruments were used, one for registration and monitoring and the other for assessing family functioning. In the interpretation of data, correspondence analysis and weight of evidence were applied. **Results:** 79 caregivers of children and adolescents with chronic illnesses participated, in which 65% were classified as functional families and 35% as dysfunctional families, 50.6% were female children, 43% were under five years old, 59.5% were mixed raced. The main caregiver was the mother (93.7%), 66.1% mixed raced, 45.6% married, 68.4% unemployed, with a family income of less than two minimum wages and registered in a government social program (72.2 %). There was a relationship with a functional family: involvement in care, non-separation after the discovery of the illness, family union after the illness, child in later childhood (6-12 years), child/adolescent performing self-care, family income, receiving support and dependence of complex care. Family dysfunction was inversely linked to functionality factors. **Conclusion:** the ability to adapt and good family functioning are stronger when the family has better articulation with its social support network.

Descriptors: Child; Adolescent; Chronic disease; Family relations.

Objetivo: avaliar o grau de funcionamento familiar de crianças e adolescentes com doença crônica. **Método:** estudo quantitativo e transversal realizado em dois serviço de referências do município de João Pessoa entre abril de 2017 a janeiro de 2018. Utilizou-se dois instrumentos, um de cadastro e acompanhamento e outro de avaliação do funcionamento familiar. Na interpretação dos dados, aplicou-se análise de correspondência e peso da evidência. **Resultados:** participaram 79 cuidadores de crianças e adolescentes com doenças crônicas, na qual identificou-se que 65% foram classificados como famílias funcionais e 35% de famílias disfuncionais, 50,6% eram crianças do sexo feminino, 43% menores de cinco anos, 59,5% pardas. O cuidador principal era a mãe (93,7%), 66,1% pardas, 45,6% casadas, 68,4% desempregadas, renda familiar menor que dois salários mínimos e, cadastrados em programa social do governo (72,2%). Houve relação com família funcional: envolvimento no cuidado, não separação após a descoberta da doença, união familiar após a doença, criança na segunda infância (6-12 anos), criança/adolescente realizando autocuidado, renda familiar, no receber apoio e na dependência de cuidados complexos. A disfuncionalidade familiar esteve inversamente ligada aos fatores de funcionalidade. **Conclusão:** a capacidade de adaptação e bom funcionamento familiar são mais fortes quando a família possui melhor articulação com sua rede de apoio social.

Descritores: Criança; Adolescente; Doença crônica; Relações familiares.

Objetivo: evaluar el grado de funcionamiento familiar de los niños y adolescentes con enfermedades crónicas. **Método:** estudio cuantitativo y transversal realizado en dos servicios de referencia del municipio de João Pessoa, PB, Brasil, entre abril de 2017 y enero de 2018. Se utilizaron dos instrumentos, uno de registro y acompañamiento y otro de evaluación del funcionamiento familiar. En la interpretación de los datos se aplicó el análisis de correspondencia y el peso de la evidencia. **Resultados:** Participaron 79 cuidadores de niños y adolescentes con enfermedades crónicas, en los que se identificó que el 65% fueron clasificados como familias funcionales y el 35% como familias disfuncionales, el 50,6% eran de sexo femenino, el 43% menores de cinco años, el 59,5% pardos. El cuidador principal era la madre (93,7%), el 66,1% pardas, 45,6% eran casadas, el 68,4% no estaban empleadas, con ingreso familiar inferior a dos salarios mínimos y estaban inscritos en un programa social del gobierno (72,2%). Se observó una relación con la familia funcional: implicación en los cuidados, no separación tras el descubrimiento de la enfermedad, unidad familiar tras la enfermedad, niño en la segunda infancia (6-12 años), niño/adolescente realizando autocuidados, ingresos familiares, no recibir apoyo y dependencia de cuidados complejos. La disfuncionalidad familiar estaba inversamente relacionada con los factores de funcionalidad. **Conclusión:** la capacidad de adaptación y el buen funcionamiento familiar son más fuertes cuando la familia tiene una mejor articulación con su red de apoyo social.

Descriptores: Niño; Adolescente; Enfermedad crónica; Relaciones familiares.

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INTRODUCTION

Chronic illness is characterized by having a long or indefinite duration, with a prognosis that is in most cases doubtful, in addition to acute symptoms over time. Therefore, it requires continuous care, with a rigorous therapeutic plan, without, necessarily, the certainty of achieving a cure[1].

When the chronic illness affects children and adolescents, there is a change in the family routine, especially with regard to periods of crisis and exacerbations of signs and symptoms, resulting in a number of frequent hospitalizations during the progression of the illness, in addition to some limitations arising from complications and the need for specialized care[2].

The family, as the primary caregiver of the child/adolescent with a chronic illness, suffers an impact on its structure and functioning, needing to weave a support network to offer adequate care to this chronically ill child/adolescent. Thus, adequate management of resources and a readaptation of roles are essential, in the search for balance to face the new situation[3]. If this process of change is not successful, the so-called family dysfunction occurs.

Considering that each family is a unit of care, it is necessary to focus on the interaction between its members, and not just on the child or adolescent with a chronic illness. That is why, when dealing with a patient with a chronic illness, assessment and care must include the family[4].

There are many sensations and feelings experienced by the family, such as: frustration, insecurity, guilt, fear and hopelessness that arise in the relationship with a child/adolescent with a chronic illness[5]. However, for some families, it is an opportunity to unite and wait for a good prognosis, building a meaning for the illness, accepting it and seeking the possibility of making the family system more flexible[6]. For this, families restructure themselves to take care of the child/adolescent, with the mother usually being the main responsible for the care, who often gives up her routine activities and work.

In chronic illnesses, there is no possibility of cure, and the family learns to live with it, creating strong foundations for adaptation to the emergence of crises[7]. Thus, there must be a positive family environment, with family cohesion and less hostility, conflicts and communication problems, in order to maintain adequate family functioning[8]. On the contrary, a dysfunctional family presents a stressful environment for adapting to the new situation, and this affects the quality of life of its members, especially the member with chronic illness.

Chronic illness causes changes in roles, functions and the entire functioning of the family system. The family has the task of preparing its members to face crises produced both internally and externally, which may have structural and functional repercussions, reflecting on family well-being and health[9].

In times of crisis, the child/adolescent needs to undergo hospitalization, when behaviors different from those at home take place, as a result from the restrictions and norms of the hospital routine, which reduces the autonomy of family members, generating a feeling of impotence, loss of identity and their ability to make decisions. This can intensify when there is resistance among professionals, care is limited to individuals with chronic illnesses[10-11].

Evaluating family functionality allows the professionals to broaden their view and identify, in addition to health problems, vulnerabilities that may be subject to children/adolescents included in this nucleus[12-13]. One of the instruments for the family approach is the APGAR, whose name derives from the domains that compose it: "Adaptability", "Partnership", "Growth", "Affection" and "Resolves"). This instrument seeks to assess the perception of family members in relation to family functioning and their respective degrees of satisfaction according to the basic parameters of family function[14].

In this perspective, the following questions arise: *What is the degree of family functioning in families of children and adolescents with chronic illnesses? What are the demographic, socioeconomic, illness and family dynamics aspects that are related to the degree of family functioning in this specific population?* Thus, the present study aimed to assess the degree of family functioning of children and adolescents with chronic illness.

METHODS

This is a descriptive study, with a quantitative approach and cross-sectional design.

Data were collected in two public reference services for outpatient care and hospitalization of children and adolescents with chronic illness, one service linked to the federal sphere and the other to the state, both located in the municipality of João Pessoa, in the state of Paraíba.

The target population was all caregivers of children and adolescents with a confirmed medical diagnosis of chronic illness, who sought outpatient care or hospitalization between April 2017 and January 2018.

Only caregivers of children and adolescents aged between 0 and 18 years, with a confirmed diagnosis of chronic illness, were included in the study. In turn, caregivers of children/adolescents with a diagnosis under investigation were excluded.

An instrument was used to register and monitor children and adolescents with chronic illnesses[15]. This instrument included information on the course and stage of the illness, as well as information on family dynamics and sociodemographic aspects. Subsequently, the family APGAR questionnaire was applied, an instrument that assesses family functionality[16].

The family APGAR questionnaire consists of five questions referring to the components of family functioning and has three possible answers (almost never - 0, sometimes - 1, almost always - 2) each. The answers are quantified on a scale from 0 to 2. The sum will yield a result between 0 and 10 points and will characterize the family as: functional (7-10 points), moderate dysfunction (3-6 points) and severe dysfunction (0 points). -2 points)[16].

Data analysis was carried out using the Weight of Evidence (WoE) and Correspondence Analysis (CA).

WoE is a Bayesian statistical technique that, through probability distributions, calculates the influence of categorical explanatory variables on a given outcome, predicting its occurrence[17]. In the present study, we sought to verify the variables of influence on the Family APGAR.

In turn, CA is an exploratory technique, easy to interpret, which studies the relationship between qualitative variables and allows the visualization of associations through perceptual maps that offer a notion of proximity, thus allowing to verify the degree of interaction between the variables studied[18-19].

In both analyses, the main variable, that is, the outcome under observation, was the Family APGAR, which was transformed into a binary variable, being analyzed from two perspectives: family functionality and family dysfunction. Families with APGAR scores between 7 and 10 were considered functional, and those with scores between 0 and 6 as dysfunctional.

The following variables were related to the proposed outcome: age group of the child/adolescent; family income; stage of illness; ability to perform self-care on the part of the child/adolescent; whether there is involvement of family members, in addition to the main caregiver, in the care of the child/adolescent; presence of some kind of family support; dependence on complex care by the child/adolescent; and presence of family union or separation after diagnosis of the chronic illness. These variables were extracted from the instrument for registering and monitoring children and adolescents with chronic illness.

The research was evaluated and approved by the Research Ethics Committee of the Universidade Federal da Paraíba, and complied with the Guidelines and Norms for Research involving human beings, provided for in Resolution No. 466/12 of the National Health Council, under opinion number 1,939,103 with approval in 2017.

RESULTS

Profile of study's participants

79 caregivers of children and adolescents with chronic illnesses participated, in which 65% were classified as functional families and 35% as dysfunctional families.

Table 1 shows the sociodemographic profile and some health considerations of the children/adolescents: female (50.6%), brown (59.5%), in early childhood (0 to 5 years - 43%) , attended school (69.6%) and were in the chronic phase of the illness (73.4%).

Table 1. Sociodemographic profile of children/adolescents with CD – João Pessoa, 2018.

Variables		No.	%
Sex	Male	39	49.4%
	Female	40	50.6%
Race	White	26	32.9%
	Black	5	6.30%
	Mixed	47	59.5%
	Indigenous	1	1.30%
Age groups	Early childhood (0-5 years)	34	43.0%
	Later childhood (6-12 years)	21	26.6%
	Adolescence (13-18 years)	24	30.4%
Attends school?	Yes	55	69.6%
	No	23	29.1%
	Sometimes	1	1.30%
Current educational level	Nursery	2	2.50%
	Pre-school	8	10.1%
	Literate class	1	1.30%
	1st to 4th grafe	19	24.1%
	5th to 8th grade	18	22.8%
	High school	7	8.90%
Phase of illness	Initial	18	22.8%
	Chronic	58	73.4%
	Cure and Rehabilitation	3	3.80%
Has a disability?	Yes	18	22.8%
	No	61	77.2%
Depends on complex care?	Yes	30	38.0%
	No	49	62.0%
Performs self-care	Yes	51	64.6%
	No	28	35.4%
Has sequelae from the illness?	Yes	13	16.5%
	No	66	83.5%

Table 2 shows the profile, family and socioeconomic aspects of caregivers. The mother figure stood out (93.7%), the majority being mixed raced (66.1%) and married (45.6%), unemployed (68.4%), family income below two minimum wages, and registered in the government's social program (72.2%), with emphasis on the Bolsa Família and the benefit of continued provision.

Table 2. Sociodemographic profile of family caregivers. João Pessoa, 2018.

Variable		No.	%
Degree of kinship between child/adolescent and caregiver	Mother	75	93.7%
	Father	1	1.3%
	Grandmother	4	5.0%
Sex	Female	78	98.7%
	Male	1	1.3%
Race	White	14	17.7%
	Black	11	13.9%
	Asian	1	1.3%
	Mixed	53	66.1%
Marital status	Single	23	29.1%
	Married	36	45.6%
	Divorced	3	3.8%
	Civil union	17	21.5%
Employment status	Employed	17	21.5%
	Unemployed	54	68.4%
	On leave	3	3.8%
	Autonomous	5	6.3%
Family income	Under 1 minimum wage	21	26.6%
	1 minimum wage	18	22.8%
	Between 1 and 2 minimum wages	29	36.7%
	Between 2 and 4 minimum wages	7	8.9%
	5 or more minimum wages	4	5.1%
Registration in government social program	Yes	57	72.2%
	No	22	27.8%
Does the caregiver have any type of illness?	Yes	26	32.9%
	No	53	67.1%
Another family member caring for the child/adolescent	Yes	55	69.6%
	No	25	30.4%
Family receives some kind of support	Yes	39	49.4%
	No	40	50.6%
Separation after diagnosis of child/adolescent illness?	Yes	12	15.2%
	No	67	84.8%
Union after diagnosis of child/adolescent illness?	Yes	34	43.0%
	No	45	57.0%
Limitations in the family after illness	Yes	57	72.2%
	No	22	27.8%

Statistical Inference: Weight of Evidence and Correspondence Analysis

The WoE observed in Figure 1 points out the variables that have the greatest impact on the degree of family functionality. Among them, those that are identified as “Very Strong” on family functionality correspond to the family's involvement in care, that is, the existence or not of family support in the care performed by the main caregiver and family income. In turn, the variables “Strong” were the age group of the child/adolescent, the stage of illness and the ability of the child/adolescent to perform self-care.

Figure 1. Variables with the greatest impact on family functionality with the presence of children/adolescents with chronic illness, according to WoE – João Pessoa, 2018.

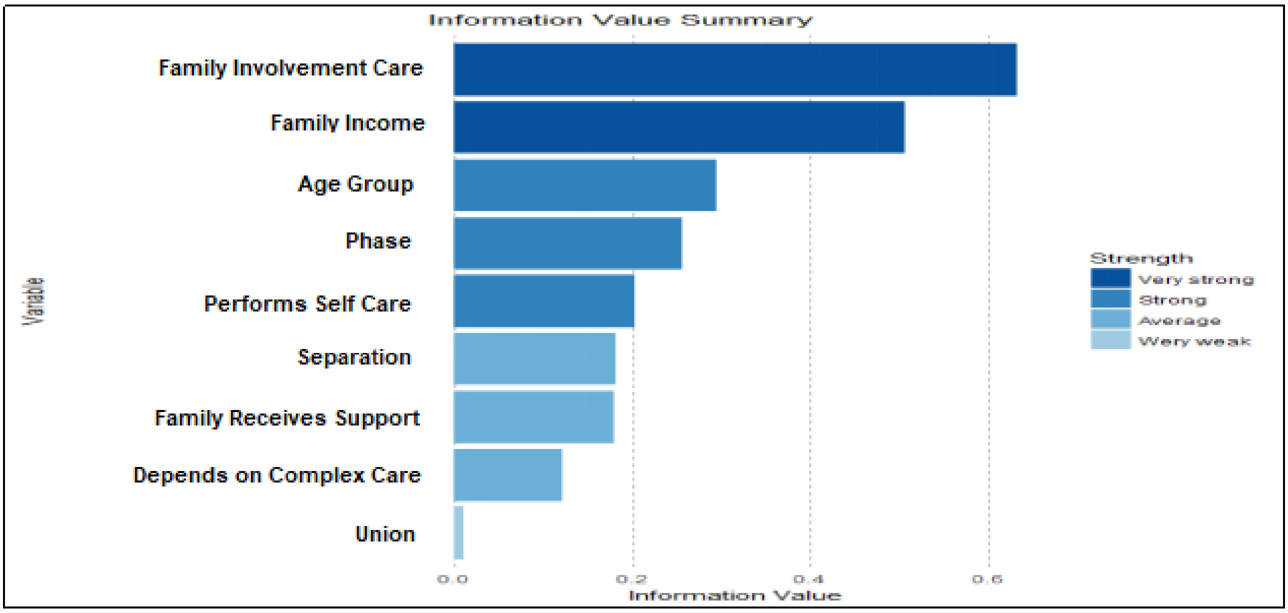
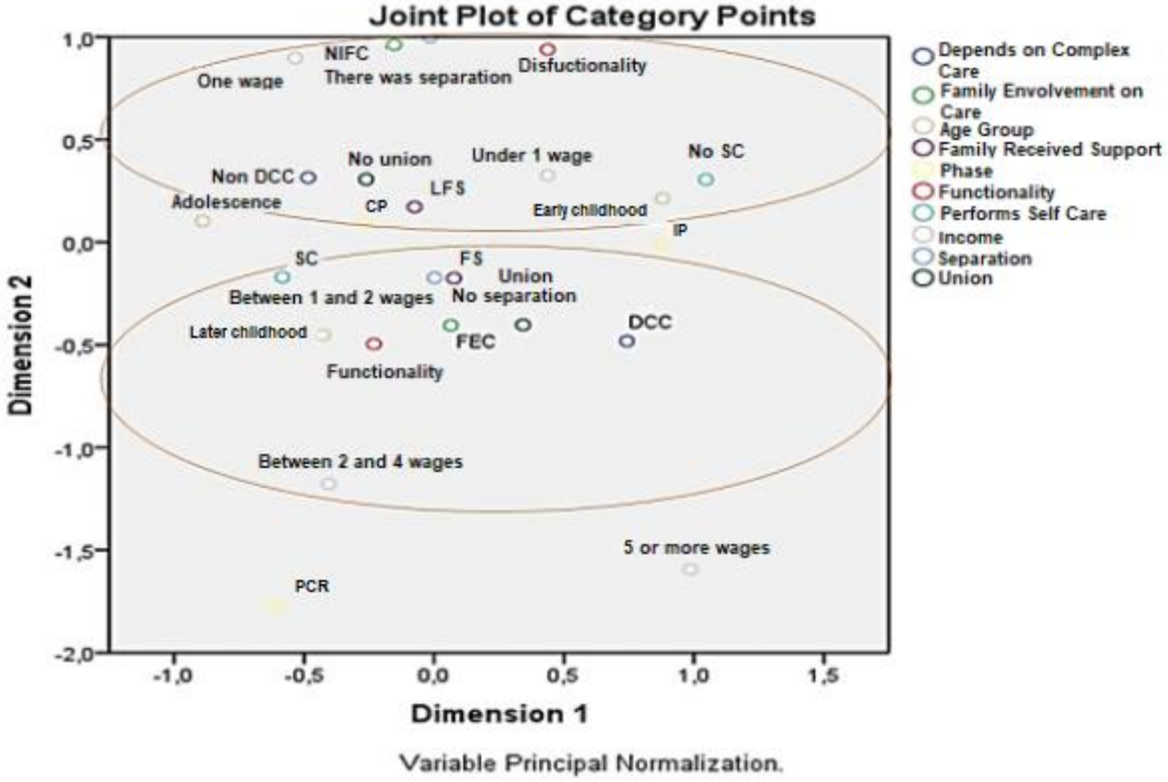


Figure 2 shows the correspondence analysis. In it, the closer the variables are, the greater the degree of association between them. Thus, it was found that the following situations are associated with family dysfunction: separation after the discovery of the illness, non-involvement of the family in care (NIFC), low family income (1 salary and less than 1 salary), non-union after discovery of the illness, non-performance of self-care by the child/adolescent (non SC), lack of support for the family (LSF), non-dependence on complex care by the child/adolescent (non DCC), child in early childhood (0 – 5 years), and child/adolescent in the chronic phase of the illness (CP).

Related to the functional family were the following situations: involvement in care (FEC), non-separation after the discovery of the illness, family union after illness, child in later childhood (6-12 years), self-care by the child/adolescent (SC), high family income (between 1 and 2 and between 2 and 4 minimum wages), family support (FRA), and child/adolescent dependence on complex care (DCC).

Figure 2. Variables most associated with family functionality and dysfunction according to Correspondence Analysis – João Pessoa, 2018.



DISCUSSION

As it was possible to identify in the results, one of the aspects that proved to be relevant in the profile of caregivers is that, in 98.7% of the cases, the main caregiver, the one who has more time for care, was marked by the female figure, so especially by the mother. They are the ones who suffer the main burdens imposed by the illness of the child/adolescent, above all, the burdens of a family nature. A study[20] points out that, historically, women have been assigned the responsibility of providing care to the sick within the family, which, in most cases, leads them to assume care alone as a socially constructed moral obligation.

It is true that, in the face of chronic illness, sometimes the family routine ends up going through a disorganization brought about by the illness and, for an effective confrontation, it is necessary that the roles of each member change. Constantly, many mothers assume the role of main caregiver of the sick child/adolescent, giving up the daily activities they previously performed, and the parents or another family member become responsible for taking care of the other children and providing for the needs of the house[21].

Thus, the existence of a social support network is of fundamental importance, as it reduces family burden, since it promotes health and reduces negative psychosocial effects and consequences during the care process in chronic illness[22]. The support network consists of the interaction between people or groups, which enable the establishment of a bond, capable of offering support, whether affective, emotional, material, contributing to mutual well-being and building positive factors in the prevention and maintenance of health[23].

In the analysis of the Weight of Evidence, the variable "*family involvement in the care of the child/adolescent*" had a very strong weight on family functioning, thus reinforcing how fundamental this involvement is for the family to be able to maintain a good functioning, because it deconcentrates the stressors on the main caregiver, and this is only possible when the family unites to face this new reality and each one assumes the co-responsibility of care. Also, the variable "*family income*" had a very strong weight on family functionality. This occurs because the need for multiple expenses is inherent to the chronic illness and, therefore, financial support is essential for the maintenance of family dynamics[3].

In the correspondence analysis, one of the highlighted variables was the receipt of support, related to better family functionality. The support offered to the family, be it financial, emotional or even the division of tasks and alternation in hospitalizations, helps the family to maintain homeostasis, strengthening the caregiver to face stressful situations that may influence family dynamics[21,24].

Higher income was directly related to good family functioning. It is known that problems and needs coexist in the family's daily life, and when there is no help to minimize them, it ends up becoming a stress factor. As the illness passes, the family's financial resources become scarce, due to the need for special care for the child/adolescent, treatment and expensive examinations that are often not offered by the public system. The expenses resulting from frequent hospitalizations generate in the family a feeling of helplessness in the face of the health condition of the chronically ill child/adolescent[3].

When the family has financial resources, it will face less difficulty compared to those with lower income, as the main caregiver often leaves their job to exclusively care for the child/adolescent[25]. This data corroborates the present research, where it was observed that 68.4% of the caregivers were unemployed, mostly due to the need to quit their job due to the need to care for the child/adolescent. In other words, having a child/adolescent with a chronic illness implies an increase in expenses, but this reality is often associated with a decrease in family income, which is more impacting on low-income families.

Children in later childhood had a better relationship with family functioning than children in early childhood. This result is directly related to the performance of self-care, since younger children generally do not yet perform basic activities alone, such as bathing, eating, dressing, among others, being dependent on their caregivers. Work on the profile of caregivers of patients with cystic fibrosis showed the need to prepare the patient for self-care in order to reduce the burden of tasks of caregivers who may be exhausted by the accumulation of responsibilities[26].

Contrary to previous findings, children dependent on complex care had a greater relationship with a functional family. Generally, when the child requires many hospitalizations and invasive procedures, generates a feeling of fear of losing the child[25]. This feeling of loss is one of the factors that predisposes to the strengthening of the family bond and, consequently, to its proper functioning.

An investigation carried out with mothers with children with meningomyelocele showed that the passage of a urinary catheter for relief brought both a negative connotation due to fear, insecurity and difficulty on the part of the caregiver, and a positive connotation due to the greater involvement of the family with the health team, which was actively close to the family in guiding care, enabling them to perform these procedures safely after hospital discharge[7].

The presence, involvement and support of the health professional seem fundamental in the family's coping with the chronic illness in childhood and adolescence. The bond established between professionals and family members, associated with actions that articulate the care network, contribute to the elaboration of an expanded care plan, aiming to improve family functioning.

CONCLUSION

It was found, through WoE, that family involvement in care, family income, age group of the child/adolescent and stage of the illness directly affect family functionality.

In turn, the correspondence analysis pointed out that one of the factors that predisposes family members to good functionality was family income greater than two minimum wages, that is, a favorable family income contributes positively to family functionality, because in a situation that demands financial resources, as is the case with chronic illness, the family is able to provide for the needs of the sick person and the house, reducing this stress factor.

When evaluating family functionality, the professional broadens their view and can provide comprehensive care, based on actions that are directed to the real needs of the child/adolescent-family binomial in the condition of chronic illness.

This study has limitations in the sense of generalizing the findings to other populations of children and adolescents in a context different from the one in which it was carried out.

Therefore, the use of WoE in future studies can deepen and verify new factors that influence family functioning.

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Associated Publisher: Rafael Gomes Ditterich.

Conflict of Interests: the authors declared there is no conflict of interests.

Financing: none.

CONTRIBUTIONS

Thalita Nóbrega Mendes collaborated in the design, collection and analysis of data and writing. **Érika Leite da Silva Cardoso** and **Nívea Trindade de Araújo Tiburtino Neves** participated in data collection and analysis, writing and revision. **Yana Balduíno de Araújo** and **Kenya de Lima Silva** contributed to the writing and revision.

How to cite this article (Vancouver)

Mendes TN, Cardoso ELS, Neves NTAT, Araújo YB, Silva KL. Assessment of family functioning of children and adolescents with chronic illness. Rev Fam, Ciclos Vida Saúde Contexto Soc. [Internet]. 2022 [cited in *insert day, month and year of access*]; 10(3):475-87. Available from: *insert access link*. DOI: *insert DOI link*

How to cite this article (ABNT)

MENDES, T. N.; CARDOSO, E. L. S.; NEVES, N. T. A. T.; ARAÚJO, Y. B.; SILVA, K. de L. Assessment of family functioning of children and adolescents with chronic illness. **Rev. Fam., Ciclos Vida Saúde Contexto Soc.**, Uberaba, MG, v. 10, n. 3, p. 475-487, 2022. DOI: *insert DOI link*. Available from: *insert access link*. Access in: *insert day, month and year of access*.

How to cite this article (APA)

Mendes, T.N., Cardoso, E.L.S., Neves, N.T.A.T., Araújo, Y.B., & Silva, K.L. (2022). Assessment of family functioning of children and adolescents with chronic illness. *Rev. Fam., Ciclos Vida Saúde Contexto Soc.*, 10(3), 475-487. Retrieved in *insert day, month and year of access* from *insert access link*. DOI: *insert DOI link*.