FAMILIES OF CHILDREN WITH CHRONIC CONDITIONS: PERCEIVED SUPPORT PROVIDED BY NURSES

Famílias de crianças com condições crónicas: perceção do apoio dado pelos enfermeiros

Familias de niños con enfermedades crónicas: percepción del apoyo prestado por los enfermeros

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ABSTRACT

Background: caring for children with chronic conditions and their families requires in-depth knowledge of families and their disease management process. **Objectives**: to describe the sociodemographic profile of the parents and the clinical profile of the children/adolescents with chronic pediatric conditions; to describe the parents' perception of the support provided by the nurses; and to explore the association between the parent's perception of the support provided by the nurses and the sociodemographic variables. **Methodology**: this descriptive-correlational study involved a sample of 237 parents who participated by answering an online questionnaire. The questionnaire included the *Portuguese version of the Iceland-Family Perceived Support Questionnaire* and questions about disease management and parents' perceptions of their own and their children's health. **Results**: the sample comprised mothers of adolescents with chronic physical illnesses and behavioral disorders. These parents reported a perception of support provided by nurses that was above the midpoint of the scale, with higher levels of perceived support in the cognitive domain. An association was found between the perception of support provided by nurses and the parent's level of education, age, children's age, and the parents' self-perception of health. **Conclusion**: these results may contribute to understanding the needs of these families, particularly in the emotional domain, and reinforce the importance of adapting nursing interventions for these families.

Keywords: chronic disease; child; family nursing; perception of support

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RESUMO

Enquadramento: cuidar crianças com condições crónicas e suas famílias requer um conhecimento aprofundado das famílias e do seu processo de gestão da doença. **Objetivos**: descrever o perfil sociodemográfico dos pais e clínico das crianças/adolescentes com condição crónica; descrever a perceção dos pais acerca do apoio dado pelos enfermeiros e explorar a associação entre a perceção de apoio e variáveis sociodemográficas. **Metodologia**: estudo descritivo-correlacional, no qual participaram 237 pais que responderam a um questionário online, utilizando a *Versão Portuguesa do Iceland-Family Perceived Support Questionnaire*, questões sobre a gestão da doença e a perceção dos pais sobre a sua saúde e a dos seus filhos. **Resultados**: a maioria dos respondentes eram mães de adolescentes, com doenças crónicas físicas e perturbações do comportamento, que reportaram uma perceção do apoio dado pelos enfermeiros acima do ponto médio da escala, maior ao nível do domínio cognitivo. Foi encontrada uma associação entre a perceção de apoio dado pelos enfermeiros e o grau de escolaridade dos pais, a idade dos pais, a idade das crianças e a autoperceção da saúde do pai/mãe. **Conclusão**: estes resultados podem contribuir para a compreensão das necessidades destas famílias, nomeadamente no domínio emocional e reforçar a importância de adequar as intervenções de enfermagem neste âmbito.

Palavras-chave: doença crónica; criança; enfermagem de família; perceção de apoio

RESUMEN

Marco contextual: el cuidado de los niños con enfermedades crónicas y sus familias requiere un conocimiento profundo de las familias y su proceso de gestión de la enfermedad. **Objetivos**: describir el perfil sociodemográfico de los padres y clínicos de niños/adolescentes con enfermedades pediátricas crónicas; describir las percepciones de los padres sobre el apoyo proporcionado por los enfermeros y explorar la asociación entre las percepciones de apoyo y las variables sociodemográficas. **Metodología**: es un estudio descriptivo-correlacional, participaron 237 padres, que respondieron al cuestionario online que incluía la *versión portuguesa del Iceland-Family Perceived Support Questionnaire*, preguntas sobre el manejo de la enfermedad y las percepciones de los padres sobre su propia salud y la de sus hijos. **Resultados**: La mayoría de los encuestados eran madres de adolescentes, con enfermedades físicas crónicas y trastornos del comportamiento, que informaron de una percepción del apoyo prestado por los enfermeros por encima del punto medio de la escala, mayor en el nivel del dominio cognitivo. Se encontró una asociación entre la percepción del apoyo dado por las enfermeras y el nivel de educación de los padres, la edad de los padres, la edad de los hijos y la autopercepción de salud de los padres. **Conclusión**: estos resultados pueden contribuir a la comprensión de las necesidades de estas familias, particularmente en el dominio emocional, y refuerzan la importancia de adaptar las intervenciones de enfermería para estas familias.

Palabras clave: enfermedad crónica; niño; enfermería de la familia; percepción del apoyo

INTRODUCTION

The number of children with one or more chronic health conditions has risen in recent years, largely due to advancements in pediatric medicine and healthcare technology (Huang et al., 2020; Romana et al., 2023). Chronic pediatric conditions are, by definition, health compromises that can be long-lasting and may include physical, developmental, behavioral, and/or emotional issues that children and/or adolescents may experience. These conditions have persistent effects and commonly require increased care compared to the general pediatric population (Huang et al., 2020).

In Portugal, the prevalence of chronic conditions in the pediatric population is not well-documented, but the literature suggests an increase in recent years (Lacerda et al., 2019; Romana et al., 2023). According to Lacerda and colleagues (2019), between 2011 and 2015, 15.5% of pediatric admissions to National Health Service Hospitals in mainland Portugal were of children with complex chronic conditions, the most frequent being oncological diseases and neurological/neuromuscular diseases (23% and 17.6%, respectively).

Although the most frequent admissions of children with complex chronic conditions are associated with the chronic condition itself, hospital admissions due to family issues, such as parental burnout, are becoming more significant. This highlights the importance of health professionals being attentive to the needs of these caregivers and promoting interventions to strengthen families facing the demands and specificities of managing pediatric chronic conditions (Romana et al., 2023). According to Lacerda and colleagues, they state that "Families who feel well in their daily lives, involved, supported and guided in complex care, are families who consume fewer health services" (2019, pp. 496). Understanding parents' perceptions of the support provided by nurses, considering their own and their children's characteristics, allows nurses to identify areas for improvement or development in an individualized manner that promotes family well-being (Shajani & Snell, 2023). Therefore, the objectives of the study were to describe the sociodemographic profile of the parents and the clinical profile of the children/adolescents with chronic pediatric conditions; to describe the parents' perception of the support provided by the nurses; to explore the association between the parent's perception of the support provided by the nurses and the sociodemographic variables.

FRAMEWORK/THEORETICAL FOUNDATION

When a child is diagnosed with a chronic condition, the family faces one of its greatest challenges, as their roles, routines, and functioning need to be adjusted to meet the needs of the entire family unit (Lummer-Aikey & Goldstein, 2020; Pinto et al., 2023). The family plays the primary role in the complex tasks of managing and maintaining the chronic pediatric condition (Pinto et al., 2023), so the healthcare that these children require places a significant burden on the family, with physical, psychological, and socio-economic repercussions for all its members (Spurr et al., 2023). This vulnerability can lead to a decrease in the parent's quality of life and family functioning, negatively impacting their ability to perform their roles (Emmamally & Brysiewicz, 2019; Pinto et al., 2023).

Considering the impact that this experience has on the lives of families, several studies have been dedicated to identifying protective factors that minimize negative family responses. In this context, social and family support (Yang et al., 2022), satisfaction with healthcare (Sigurdardottir et al., 2017), and family cohesion and resilience (Lummer-Aikey & Goldstein, 2020) stand out as predictors of family protection and well-being. Nurses play a crucial role in the healthcare team due to their close interaction in managing the illness and their collaborative relationship with the family unit. For this reason, nurses need to recognize the needs of these families, their specificities, and their illness trajectory to effectively implement quality interventions based on robust, current, and individualized scientific knowledge. Based on this premise, several family assessment tools have been developed in recent years, which help to understand the phenomena experienced by families in different contexts and improve the support offered to families of children with chronic conditions (Shajani & Snell, 2023).

Nurses' support for these families also contributes significantly to reducing family suffering (Emmamally & Brysiewicz, 2019). In a study by Svavarsdottir and Sigurdardottir (2013), it was found that the greater the perception of support received from nursing professionals, the better the patterns of intra-family communication and support. Family functioning has been proven as a powerful determinant of the quality of life and well-being of children with chronic conditions and their families (Mendes et al., 2022). Both cognitive and emotional support are important for achieving good functioning outcomes (Emmamally & Brysiewicz, 2019). Cognitive support includes interventions that nurses offer to inform or educate the family, empowering them to cope with the illness experience. Emotional support involves nurses providing opportunities for families to express how they are coping with difficult feelings related to the illness, reflect on their experiences as caregivers, and share their experiences of the illness (Shajani & Snell, 2023). For this reason, it is essential to provide nurses with validated scales that are easy to use in their clinical practice. With these tools, it is possible to understand how parents perceive the support provided by nurses, particularly cognitive or emotional support, and to tailor interventions to support these families more effectively.

METHODOLOGY

A descriptive-correlational study was conducted. The target population was parents of children/adolescents diagnosed with one or more chronic conditions who were followed up in the pediatric day hospital and/or pediatric outpatient clinic of four hospital institutions in the north of Portugal. Participants were selected through a non-probabilistic convenience sample, and data collection took place between May 2021 and January 2022. A total of 507 parents agreed to take part in the study, but only 237 answered the questionnaire, resulting in a response rate of 46.75%. The inclusion criteria were: being the parent of a child/adolescent with one or more diagnoses of a chronic illness and/or disorder, the diagnosis having occurred more than six months previously, and being proficient in Portuguese. The data collection instrument was an online questionnaire carried out using the REDCap (Research Electronic Data Capture) platform (Harris et al., 2019). The questionnaire consists of two parts: the first part, developed by the authors, includes questions on the sociodemographic characteristics of the parent, such as age, gender, marital status, level of education, and professional status. It also gathers sociodemographic and clinical data on the child/adolescent with a chronic illness and/or disorder, including diagnosis, time since diagnosis, number of hospitalizations, taking regular medication, and support from health professionals. Additionally, questions regarding the participant's self-perceived health and their perception of their child's physical and psychological health were included. The second part comprises the *Portuguese version of* the *Iceland-Family Perceived Support Questionnaire* (ICE-FPSQ), validated by Gouveia and colleagues (2019) and originally developed in Iceland by Sveinbjarnardottir and collaborators (2012), based on the conceptual framework of the Calgary Family Intervention Model (Shajani & Snell, 2023). This instrument provides insight into family members' perceptions of nurses' support in the cognitive and emotional domains when a family member has an illness. The questionnaire consists of 14 items subdivided into two subscales: (a) Cognitive Support (five items) and (b) Emotional Support (nine items) (Sveinbjarnardottir et al., 2012). This scale is scored on a Likert-type response scale ranging from 1 to 5, with one representing "almost always" and five representing "never." To facilitate the interpretation of the results, the scores of the scale items are inverted. The total scores range between 14 and 70 points, with higher scores indicating a better perception of the support provided by nursing professionals. The Cognitive Support subscale ranges from 5 to 25 points, and the Emotional Support subscale ranges from 9 to 45 points. The original scale achieved a *Cronbach's alpha* of 0.96 (Sveinbjarnardottir et al., 2012), while the Portuguese version, tested on a population of families with a member diagnosed with depression, achieved a *Cronbach's alpha* of 0.94 (Gouveia et al., 2019). The study was approved by the Presidents of the Boards of Directors, Ethics Committees, and Data Protection Officers of the four hospital institutions in Northern Portugal (approval numbers 52/2021, 38/2021, 16/2021, and 98_2021). This research complies with the ethical principles outlined in the Declaration of Helsinki.

For data collection, the researchers first contacted the relatives to explain the purpose of the study and provide an informed consent form, which was accepted by all participants involved in this research. After signing the consent form, the participants provided an email address where they received a link to access the REDCap (Research Electronic Data Capture) platform to complete the online questionnaire. The *Statistical Package for the Social Sciences* (SPSS), version 28.0, was used to analyze the data. Both descriptive and inferential statistics were employed. To study the association between variables, the *Student's t-test* (*t*) for independent samples was used, or the non-parametric *Kruskal-Wallis test* (H) when the assumptions of the parametric tests (normality and homogeneity) were not met. *Spearman's correlation coefficient* (r_s) was used to explore the relationship between two interval variables. The significance level was set at $p < 0.05$.

RESULTS

The results regarding the sociodemographic and professional characteristics of the participants and the children and adolescents are shown in Table 1. Most of the participants were mothers (86.9%), aged over 41 (65.8%), and in active employment (78.9%). Regarding self-perceived health, 211 parents reported good or very good health (74.7% and 14.3%, respectively).

Adolescents with one or more chronic conditions were the most common age group in the sample (53.5%), with diagnoses occurring between one and five years (36.7%). Hospitalization within the last year was reported by 56.5% of the sample, and regular pharmacological treatment was required by 71.7%. Parents' perceptions of their children's physical and mental health were positive, with reports indicating that their children were in good or very good physical health (73% and 17.7%, respectively) and good or very good mental health (38.4% and 51.5%, respectively).

Table 1

Socio-demographic characteristics of the participant and the child/adolescent

PARENT (PARTICIPANT)	n	(%)
Sex		
Female	207	87,3
Male	28	11,8
Missing	2	0,9
Degree of relationship		
Mother	206	86,9
Father	28	11,8
Other	3	1,3
Age (years)		
18-30	8	3,4
31-40	73	30,8
41-50	133	56,1
51-60	20	8,4
61 or over	3	1,3
Level of education		
Basic education	37	15,6
Secondary education	104	43,9
Graduate higher education	81	34,2
Postgraduate higher education	15	6,3
Professional situation		
Professional situation	8	3,4
Family support	19	8,0
Part-time work	156	65,8
Full-time work/study	12	5,1
Full-time work and second job	28	11,8
Unemployed	2	0,9
Retired	11	4,6
Missing	1	0,4
Marital status		
Married/marital partnership	194	81,9
Single/ Divorced	36	15,2
Widowed	6	2,5
Missing	1	0,4
Self-perception of health		
Very good	34	14,3
Good	177	74,7
Poor	24	10,1
Very bad	2	0,9
CHILD	n	(%)
Sex		
Female	114	48,1
Male	121	51,1
Missing	2	0,8
Age (years)		
1-3	33	14,0
4-6	24	10,1
7-10	53	22,4

11-18	127	53,5
Chronic condition (n=300)		
Respiratory tract	49	16,3
Gastrointestinal tract	37	12,3
Metabolic/endocrine system	32	10,7
Neurological	32	10,7
Immunological	22	7,3
Urological	16	5,3
Cardiovascular	11	3,7
Dermatological	5	1,7
Oncological	4	1,3
Ophthalmological	3	1,0
Hematology	2	0,7
Otorhinolaryngology	1	0,3
Behavioral disorders	50	16,7
Developmental disorders	6	2,0
Syndromes	30	10,0
Time since diagnosis of chronic condition (in years)		
<1	44	18,6
1-5	87	36,7
6-10	55	23,2
11-18	34	14,3
Missing	17	7,2
Recently hospitalized for the condition		
No	100	42,2
Yes	134	56,5
Missing	3	1,3
Number of hospitalizations (in the last year)		
Never	80	33,8
Once or twice	37	15,6
Three or four times	12	5,1
Five or more times	5	2,1
Missing	103	43,4
Parent's perception of child's physical health		
Very good	42	17,7
Good	173	73,0
Poor	19	8,0
Very bad	3	1,3
Parent's perception of child's mental health		
Very good	91	38,4
Good	122	51,5
Poor	17	7,2
Very bad	5	2,1
Missing	2	0,8
Takes medication regularly		
Yes	170	71,7
No	67	28,3
The person responsible for taking the medication		
Child/adolescent	30	12,7
Parent	2	0,8
Mum	78	32,9
Parent and child together	55	23,2
Other	5	2,1
Missing	67	28,3
Did you receive any information about the child's condition?		
Yes	217	91,5
No	17	7,2
Missing	3	1,3
Who provided this information (n=368)		
Doctor	215	58,4
Nurse	90	24,5
Nutritionist	35	9,5
Psychologist	21	5,7

Other	4	1,1
Occupational therapist	3	0,8
Current need for support from health professionals		
Yes	145	61,2
No	91	38,4
Missing	1	0,4
Professionals who provide support (n=294)		
Doctor	117	39,8
Nurse	68	23,1
Psychologist	49	16,7
Nutritionist	43	14,6
Other	17	5,8

Regarding the perception of support given by nurses, according to the Portuguese version of the ICE-FPSQ scale, the participants in this study obtained an average score slightly above the midpoint of the scale (M = 2.66; SD = 1.11). It was also found that the Cognitive Support subscale had a higher average score than the Emotional Support subscale (M = 3.33; SD = 1.24 and M = 2.29; SD = 1.22, respectively).

The study of the association between the ICE-FPSQ and sociodemographic variables is detailed in Table 2. The *Kruskal-Wallis* (H) test was used to establish the relationship between the independent variable of parents' level of education and perception of support. There was a significant difference in the Cognitive Support subscale (H(2) = 7.52, p = 0.023), which suggests that the higher the level of education, the lower the perception of support provided by nurses, particularly in the cognitive domain.

To study the association between variables such as parents' marital status (categorized as married or not married), diagnosis of a chronic condition in children/adolescents (or more than one chronic condition), episodes of hospitalization in the last year, regular taking medication, and the perception of support given by nurses in the Total Score of the ICE-FPSQ scale and its subscales, the *Student's t-test* was used. No statistically significant differences were found.

The study of the association between the results of the ICE-FPSQ scale and interval sociodemographic/professional variables showed a weak, negative correlation between the age of the parents and the Cognitive Support subscale (r_s = -0.160, p = 0.012), the Emotional Support subscale (r_s = -0.162, p = 0.012), and the Total Score of the ICE-FPSQ scale (r_s = -0.189, p = 0.003). This indicates that the younger the parent, the greater their perception of the support provided by nurses. Regarding the child's age, there was also a weak negative correlation between the Emotional Support subscale (r_s = -0.192, p = 0.003) and the Total Score of the ICE-FPSQ scale (rs = -0.159, p = 0.014), indicating that the older the child, the lower the perception of support given by nurses.

About the parents' perception of their health in general, there was a weak positive relationship, statistically highly significant in the Cognitive Support subscale (r_s = 0.174**, p = 0.007) and significant in the Total Score of the ICE-FPSQ scale (r_s = -0.166*, p = 0.011). This means that the better the parents' perception of their own health, the greater their perception of the support provided by nurses. No associations were found between the time of diagnosis of the chronic condition, the child's perception of physical and mental health, and the perception of support provided by nurses.

Table 2

Relationship between ICE-FPSQ and sociodemographic variables

	Cognitive		Emotional		Total Score	
Variables	***M(DP)***	**Statistics**	***M(DP)***	**Statistics**	***M(DP)***	**Statistics**
Parents: Level of education		H (2) = 7,52 ***p* = 0,023**		H (2) = 2,24 *p* = 0,326		H (2) = 4,12 *p* = 0,128
Up to primary school	3,78 (1,09)		2,51 (1,17)		2.96 (1.05)	
Secondary school and similar levels	3,36 (1,24)		2,26 (1,24)		2.65 (1.12)	
University degree and higher	3,14 (1,26)		2,23 (1,21)		2.56 (1.12)	
		Statistics		**Statistics**		**Statistics**
Parents: Marital status		t (234) = 1,43 *p* = 0,310		t (234) = 1,97 *p* = 0,356		t (234) = 1,96 *p* = 0,291
Married	3,38 (1,22)		2,33 (1,20)		2.70 (1.09)	
Not married/other	3,17 (1,31)		2,13 (1,28)		2.50 (1.18)	
Child: Diagnosis		t (235) = 1,68 *p* = 0,094		t (235) = 1,14 *p* = 0,256		t (235) = 1,47 *p* = 0,143
A chronic condition	3,38 (1,22)		3,38 (1,22)		3.38 (1.22)	
More than one chronic condition	3,17 (1,31)		3,17 (1,31)		3.17 (1.31)	
Child: Hospitalisation		t (232) = 1,43 *p* = 0,154		t (232) = 1,97 *p* = 0,50		t (232) = 1,96 *p* = 0,54
Yes	3,42 (1,35)		2,41 (1,26)		2.77 (1.15)	
No	3,19 (1,15)		2,10 (1,14)		2.49 (1.05)	
Child: Regular medication		t (235) = 1,77 *p* = 0,078		t (235) = 0,76 *p* = 0,447		t (235) = 1,31 *p* = 0,194
Yes	3,42 (1,26)		2,32 (1,29)		2.71 (1.17)	
No	3,10 (1,15)		2,20 (1,00)		2.52 (0.93)	
	Statistics		**Statistics**		**Statistics**	
Parents: age	r_s= -0,160 ***p* = 0,012**		r_s= -0,162 ***p* = 0,012**		r_s= -0,189 ***p* = 0,003**	
Parents: self-perceived health	r_s= 0,174 ***p* = 0,007**		r_s= 0,126 *p* = 0,052		r_s= -0,166 ***p* = 0,011**	
Parents: perception of their child's physical health	r_s= 0,021 *p* = 0,743		r_s= 0,029 *p* = 0,660		r_s= 0,027 *p* = 0,676	
Parents: Perception of their child's mental health	r_s= 0,093 *p* = 0,157		r_s= 0,064 *p* = 0,331		r_s= -0,085 *p* = 0,195	
Child: age	r_s= -0,035 *p* = 0,589		r_s= -0,192 ***p* = 0,003**		r_s= -0,159 ***p* = 0,014**	
Child: time since diagnosis	r= 0,087 *p* = 0,201		r= 0,053 *p* = 0,431		r= 0,072 *p* = 0,287	

Note: H = Kruskal-Wallis test; *t* = Student's t-test; r_s = Spearman's correlation coefficient.

DISCUSSION

In this study, it was possible to understand the sociodemographic characteristics of the parents and the clinical profile of the children/adolescents with a chronic condition. Additionally, the study explored how the parents perceive the support provided by the nurses and identified which sociodemographic variables had statistically significant relationships with the parents' perception of the support provided by the nurses.

Thus, considering the sociodemographic characteristics, the results of our study show that the maternal figure maintains a more active role in managing the processes associated with the chronic condition of children/adolescents, as seen in other studies (Mendes et al., 2022; Spurr et al., 2023). It should be noted that this study took place in a pediatric day hospital and/or outpatient clinic, and although the child/adolescent was accompanied by their mother, father, or both, the study participants were mainly mothers. This reflects the common scenario where mothers are primarily responsible for making decisions about the child/adolescent's healthcare (Lima et al., 2023; Pinto et al., 2023), as demonstrated by their greater involvement in administering the child/adolescent's medication.

The families in our sample have a high level of education, ranging from secondary school to a university degree, and most of them are still working. Considering that one of the main difficulties experienced by families of children with a chronic condition is related to the risk of the main caregiver losing their job temporarily or permanently (Toledano-Toledano & Luna, 2020), we found that only a small number of participants reported having their professional situation interrupted, for example, due to family assistance and/or unemployment. This may be related to the diversity of chronic conditions of the children included in the study, as a large proportion of the families recruited and who agreed to take part in the study were parents whose children had less complex health conditions. Families with children with more complex conditions showed less willingness to take part in the study, which is in line with the literature stating that the greater the complexity of the chronic condition, the greater the risk of parents being overburdened with caregiving and the less time available for other supplementary activities/tasks (Pinto et al., 2023).

In our sample, a considerable number of participants reported having more than one chronic condition, including children/adolescents with both physical illnesses and behavioral disorders. We can infer from the results that there is a similarity of diagnoses between our study and that presented in the study by Lacerda and colleagues (2019). However, it is important to note the difference in the type of health services where the data was collected. Lacerda et al. reported a higher frequency of children with complex chronic diseases, with a greater tendency in the relative proportion of respiratory conditions, other congenital/genetic anomalies, neurological/neuromuscular, hematological/immunological, metabolic, and gastrointestinal categories. The same authors found a significant increase in hospitalizations in recent years, with the northern region of Portugal having the highest absolute number (Lacerda et al., 2019). This upward trend in hospitalizations is also suggested by our results, which show that the majority of children/adolescents have recently been hospitalized for a chronic illness/disorder, some on more than one occasion.

Despite the challenges experienced by these parents, we found that they rated their own and their child's physical and mental health positively. These results may suggest that such positive beliefs contribute to family resilience and well-being, which has a protective effect on the family's psychopathological conditions (Lummer-Aikey & Goldstein, 2020; Toledano-Toledano et al., 2020).

Doctors and nurses were the health professionals who stood out the most when families were asked about who provided them with information about the child's condition and/or treatment. Most families also reported receiving support from health professionals, namely doctors, nurses, and psychologists. When managing a chronic condition, mothers, as primary caregivers, tend to have higher expectations of support from healthcare professionals (Emmamally & Brysiewicz, 2019). Understanding their expectations of support is important for developing care centered on the family's needs. Family members' perceptions of the benefits associated with the interventions they receive from professionals do not always align with the professionals' perceptions of the results of their clinical practice (Bruce et al., 2016).

Because we consider it important to understand the family's perspective on the support they received, we assessed their perception of the support provided by the nurses in terms of managing the illness. We found that the participants perceived greater support from the nurses in terms of the Cognitive Support subscale. In other words, the parents felt that the support given by the nurses primarily involved providing information and documentation. Regarding the Emotional Support subscale, parents perceived less support, a result similar to that obtained in a study of parents of children with congenital heart disease in Sweden (Bruce et al., 2016), but lower than that of a study conducted in Iceland with parents of hospitalized children (Sigurdardottir et al., 2017). This finding requires reflection, as perceived emotional support is recognized as extremely important for families to feel empowered to deal with the illness. In terms of the more general perception of the support provided by nurses, assessed by the Total Score of the ICE-FPSQ scale, we found that participants reported a very positive perception. This value was slightly higher than that obtained in studies carried out in Sweden but lower than that obtained in Iceland (Bruce et al., 2016; Sigurdardottir et al., 2017). According to the study by Sigurdardottir et al. (2017), parents tend to rate the support of professionals more highly when they believe that their suffering is recognized and valued by them, which also leads families to report higher levels of satisfaction with the care they receive.

In response to the last objective of the study, which was to explore the association between parents' perception of the support given by nurses and sociodemographic variables, an association was found between the perception of support given by nurses and the parents' level of education, the parents' age, the children's age, and the parents' self-perception of health. These relationships have been little explored in previous studies using this instrument, but evidence shows that the perception of support can be shaped by individual expectations, previous experiences, and the nature of the interaction between professionals and families (Yang et al., 2022; Von der Lippe et al., 2022). According to the results found in the systematic review carried out by Von der Lippe et al. (2022), the higher the family members' level of education, the greater their tendency to look for information in reliable sources, such as scientific journals or specialized professionals. This can sometimes make them experts on their children's condition, leading them to feel that some professionals' knowledge is based on outdated information. A lack of interest or consideration for parents' knowledge can lead to a deterioration in the relationship between parents and health professionals.

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In our study, we found that the younger the parents, the greater their perception of the support provided by the nurses. This result aligns with a study by Emmamally and Brysiewicz (2019), which found that older relatives of patients hospitalized in emergency departments reported a lower perception of support from healthcare professionals compared to younger age groups. Regarding the child's age, the closer the child gets to adolescence, the more developmental challenges there are for both parents and nurses (Shajani & Snell, 2023). This may explain why participants in our study with adolescent children reported a lower perception of support from nurses.

Finally, the positive association between parents' self-perceived health and the perceived support provided by nurses seems to reaffirm the role of social support provided by nurses as a protective factor in promoting the psychological well-being of caregivers of children with chronic illnesses (Yang et al., 2022). This highlights that the support provided by health professionals is fundamental in the family's adaptation to chronic pediatric illness (Lima et al., 2023; Mendes et al., 2022).

The results of our study can contribute valuable knowledge to clinical practice and encourage nurses to improve their collaborative relationship with families. Strategies such as engaging the family with the healthcare team in providing care, encouraging family members to take breaks from caregiving, helping family members recognize and normalize their emotional responses to adversity, valuing strengths, and praising family members (Shajani & Snell, 2023; Sveinbjarnardottir et al., 2012) are some strategies mentioned in the literature. This study has helped to improve nurses' understanding of what families truly feel and evaluate about the support they provide in terms of emotional and cognitive support for family functioning.

One of the limitations of the study is that, although the sample is large, it is not random, and it includes family caregivers of children/adolescents with a wide range of chronic conditions. Many parents who declined the invitation to participate cited being overwhelmed with caregiving responsibilities and having no time for additional activities/tasks. Additionally, many parents did not recognize their child's condition as chronic, such as in cases of obesity, and therefore did not agree to participate. Consequently, this study may have included a sample whose children/adolescents with chronic conditions present low to moderate levels of care demands for their caregivers. Secondly, the study participants were recruited from a region in the north of Portugal and were fluent in Portuguese (both Portuguese and Brazilian), which raises questions about the generalizability of the findings.

Future studies should investigate the usefulness of the variables included in this study for other samples and contexts to determine whether other sociodemographic factors could influence the experiences of families with chronic illnesses in terms of the support they perceive from nurses.

CONCLUSION

The results of this study show that the maternal figure plays a predominant role in managing the child's/adolescent's chronic condition. Despite the challenges encountered, the participants in our study reported having a good perception of their own health and the health of their children. Adolescents were the most represented group in our sample, with the most frequent diagnoses being chronic physical illnesses, specifically respiratory, gastrointestinal, and metabolic/endocrine diseases, followed by behavioral disorders. Participants highlighted doctors and nurses as the health professionals who provided information about the chronic condition and supported them in managing it.

When assessing the perceived support of the parent using the Portuguese version of the ICE-FPSQ scale, participants reported a good perception of the support given by nurses, particularly in the Cognitive Support subscale. Additionally, there was an association between the perception of support provided by nurses and the parents' level of education, the parents' age, the children's age, and the parents' self-perception of health.

Therefore, we can conclude that participants have needs in the process of family management of the illness, particularly in the emotional domain, which can be influenced by the sociodemographic variables of the families. This result is relevant for raising awareness among pediatric nurses, helping them to develop and implement interventions tailored to the specificities and needs of families experiencing a chronic pediatric condition, to maximize their quality of life and well-being.

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