



# Ability of management of families of children with chronic conditions for care at home

*Habilidade de manejo de famílias de crianças com condições crônicas para o cuidado no domicílio*

*Capacidad para gestionar familias de niños con enfermedades crónicas para el cuidado en el hogar*

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## ABSTRACT:

**Objective:** to analyze the relationship between families' living context and their management skills in caring for children with chronic health conditions. **Method:** a mixed, convergent parallel study, with the Family Management Style as the theoretical framework. Participants were family members of children with chronic conditions egressing from a Neonatal Intensive Care Unit in Southeastern Brazil. For the collection of quantitative data, the instrument Family Management Measure and a questionnaire of socio-demographic characterization were used. Quantitative data were analyzed using the Stata 15 statistical program. Qualitative data were produced by means of semi-structured interviews and submitted to the Directed Content Analysis. **Results:** the families presented a positive average score in the Management Ability scale, having greater ease to meet the care needs of the child with chronic condition at home. Favorable social and economic conditions contributed to the family's ability to care for the child with chronic health condition. **Conclusions and implications for practice:** it was concluded that there is a relationship between the context of life of the families and the ability to manage the child in chronic condition. Being able to count on a partner or other family members can improve the management skills of these families.

**Keywords:** Child Care; Chronic Disease; Nursing; Home Health Nursing; Family Nursing.

## RESUMO:

**Objetivo:** analisar a relação entre o contexto de vida das famílias e a sua habilidade de manejo no cuidado às crianças em condições crônicas de saúde. **Método:** estudo misto, do tipo paralelo convergente, tendo o Estilo de Manejo Familiar como quadro teórico. Participaram familiares de crianças com condições crônicas egressas de Unidade de Terapia Intensiva Neonatal do Sudeste do Brasil. Para a coleta de dados quantitativos, foram utilizados o instrumento Medida de Manejo Familiar e um questionário de caracterização sociodemográfica. Os dados quantitativos foram analisados por meio do programa estatístico Stata 15. Os dados qualitativos foram produzidos por meio de entrevista semiestruturada e submetidos à Análise de Conteúdo Dirigida. **Resultados:** as famílias apresentaram um escore médio positivo na escala Habilidade de Manejo, possuindo maior facilidade para atender às necessidades de cuidado do filho com condição crônica no domicílio. Condições sociais e econômicas favoráveis contribuíram para a capacidade da família em cuidar da criança com condição crônica de saúde. **Conclusões e implicações para a prática:** concluiu-se que há relação entre o contexto de vida das famílias e a habilidade de manejo da criança em condição crônica. Poder contar com o companheiro ou com outros membros da família pode melhorar a habilidade de manejo dessas famílias.

**Palavras-chave:** Cuidado da Criança; Doença Crônica; Enfermagem; Enfermagem Domiciliar; Enfermagem Familiar.

## RESUMEN

**Objetivo:** analizar la relación entre el contexto de vida de las familias y sus habilidades de gestión en el cuidado de niños con condiciones crónicas de salud (CCC). **Método:** estudio mixto, del tipo paralelo convergente (QUAN-QUAL), teniendo como marco teórico el Estilo de Gestión Familiar. Participaron familiares de niños con condiciones crónicas de una Unidad de Cuidados Intensivos Neonatales del sureste de Brasil. Para la recolección de datos cuantitativos se utilizó el instrumento Medida de Gestión Familiar y un cuestionario de caracterización sociodemográfica. Los datos cuantitativos se analizaron utilizando el programa estadístico Stata 15. Los datos cualitativos se produjeron a través de entrevistas semiestructuradas y se sometieron a Análisis de Contenido Dirigido. **Resultados:** las familias presentaron puntaje promedio positivo en la escala Habilidad de Manejo, teniendo mayor facilidad para atender las necesidades de cuidado del niño con condición crónica en el hogar. Las condiciones sociales y económicas favorables contribuyeron a la capacidad de la familia para cuidar del niño con condición crónica de salud. **Conclusiones e implicaciones para la práctica:** se concluyó que existe una relación entre el contexto de vida familiar y la capacidad de manejo de los niños con condición crónica. Poder contar con una pareja u otros miembros de la familia puede mejorar la capacidad de gestión de estas familias.

**Palabras clave:** Cuidado del Niño; Enfermedad Crónica; Enfermería; Cuidados de Enfermería en el Hogar; Enfermería de la Familia.

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## INTRODUCTION

The number of children with chronic conditions is growing, due in part to advances in health care, technology, and medicines.<sup>1-3</sup> Changes have also been seen in health care, with emphasis on early de-hospitalization, with the family responsible for continuing care at home.<sup>1-3</sup>

With the need for continued care for children, their families tend to have changes in lifestyle, overload of activities at home, and financial instability.<sup>1</sup> These factors are intrinsically related to the quality and maintenance of child care.<sup>4</sup>

Although there is concern about the need for the family to organize itself to cope with the demands, burdens of continued care and interference in the quality of life of its members, it has been found that many families who receive adequate resources and support grow stronger, thrive and care for their children.<sup>5,6</sup> The way each family responds to the demands of caring for the child with a chronic condition is defined as family management according to the Family Management Style Framework (FMSF).<sup>7,8</sup> This theoretical reference contributes to a more precise understanding of how family members insert the demands of the child in chronic condition into the family context. It also contributes to the clinical practice of health and nursing professionals in identifying weaknesses and potentialities in the management of the chronic condition.<sup>7,8</sup>

The FMSF has been used in national studies and in international investigations related to different types of chronic conditions in childhood.<sup>9-12</sup> In general, studies using the FMSF are mostly descriptive or exploratory and qualitative in approach.<sup>13</sup> Situations of chronic condition of children who survived hospitalization in the Neonatal Intensive Care Unit (NICU) are still little explored. This is a unique context of health and care conditions that deserves to be investigated.

According to the FMSF, contextual influences are factors external to the family that make it difficult or easy to manage the home care of the child with a chronic condition.<sup>14</sup> There are three main contextual influences: the financial resources needed to maintain care, the social support network as a source of support, and the trajectory of families seeking access to health care professionals and services for their child.<sup>14</sup>

Based on this understanding, this study seeks to answer the following research question: what is the relationship between the living conditions of families determined by socioeconomic variables and the families' ability to manage care? To this end, the following objective was formulated: to analyze the relationship between the families' living context and their ability to manage a child with a chronic condition.

## METHOD

This is a convergent parallel type (QUAN-QUAL) Mixed Methods (MM) study.<sup>15</sup> The theoretical framework of the Family Management Style was used<sup>14</sup> as the theoretical framework of the study and the guidelines of the Mixed Methods Appraisal Tools<sup>16</sup> for the preparation of the research report and the article.

The quantitative study design was of the cross-sectional type and the qualitative approach was of the descriptive type. Both approaches had the same weight assignment.

Inclusion criteria: for the family member - being responsible for most of the child's care, residing in the same household, being over 18 years old (except if they are the parents); for the child - presenting chronic conditions according to the Questionnaire for Identification of Children with Chronic Conditions - Revised (QuICCC-R);<sup>17</sup> having been admitted to a NICU soon after birth; being between two years and two years, 11 months and 29 days at the time of data collection. The age chosen took into account the fact that changes in the child's neuro-psychomotor development can be noted in this age group, as well as changes in motor skills, language, and cognitive and behavioral disorders.<sup>18</sup> In most cases, normal patterns can be observed in the first two years of life.<sup>18</sup>

The following exclusion criteria were adopted: family member with communication impairment; psychological or psychiatric alterations that would compromise the production of information for the research.

The participants were identified from two reference hospitals for maternal and child health care in Minas Gerais, here referred to as Hospital A and Hospital B.

Data collection was performed in the period from October 2019 to May 2020. Children who were discharged from NICUs in the period from December 2016 to December 2017 were identified from the admission records of the two hospitals, totaling 263 children in Hospital A and 852 children in Hospital B. Next, the family members of the 1115 children were contacted by telephone. Of these, 829 had changed their phone number or it was wrong, and the other 286 caretakers were successfully contacted. Of the 286 contacted, five children had died, 218 had no chronic conditions according to the QuICCC-R, and 63 children met the conditions set by the QuICCC-R. Of these 63 children, eight family members refused to participate. Thus, 53 family members participated in the research, corresponding to 54 children, one twin.

For data collection in the quantitative study, a questionnaire was used for the socio-demographic characterization of the families and the Family Management Measure.<sup>8</sup> The Brazilian Institute of Geography and Statistics (IBGE) was the reference used for the choice and classification of the sociodemographic variables. The main author read the questionnaire for sociodemographic characterization and also the Handling Skill scale during data collection to the participants. They answered the questions at the end of each item. The variables for the sociodemographic characterization of the families were: gender of the child (female, male); gestational age (weeks); age of the child at the time of data collection (years); gender of the family member (female, male); education of the family member (level of instruction); ethnicity (white, black, and others); profession; municipality of residence; family income (reais); religion; marital status (lives with a partner, lives without a partner, not informed); number of people in the same household.

This instrument was designed based on the FMSF and is composed of six scales, totaling 53 Likert-type items. The scales can be used separately and, for this research, the Management Ability scale (twelve items) was used. This scale indicates the family's ability to care for the child and its score has a positive correlation with Family Management. Therefore, the higher the score, the greater the capacity of families to insert therapeutic demands in their daily lives.<sup>13</sup> The scale items are related to the parents' ability to care for the child in the future, strategies and goals that family members have for helping the child to live with the chronic condition, financial condition for care actions, priority of the child in the family context, insecurity on the part of family members regarding care, and establishing a routine for caring for the child.<sup>13</sup> The version of the FAMM validated for Brazil showed a Cronbach's alpha of 0.89, and for the Handling Skill scale the value was 0.55, showing good adjustment in the validation tests, making the validation process acceptable.<sup>8</sup>

The qualitative stage data were collected through semi-structured interviews. The script was based on the dimensions of the theoretical framework of family management<sup>14</sup> and consists of the following questions: How is it being caring for (child's name) in the family context? What were the difficulties and facilities for carrying out the child's care in the family context? How is it for you to deal with the condition of (name of child)? Does the condition of (name of child) cause any interference in family life?

Participants were interviewed, individually, at home or by telephone call on a day and time of their choice. The duration of the interview ranged from thirty minutes to one hour and forty-three minutes, with an average of 52 minutes, including the collection of qualitative and quantitative data at the same time. The interview was conducted by one of the authors with experience in conducting interviews. For the telephone interviews, speakerphone was used for audio recording.

For the organization and analysis of the data, the steps described below were followed.

#### a) Quantitative study

The quantitative database was structured in the Survio<sup>®</sup> platform with double entry. For quantitative variables referring to socio-demographic components, means and measures of dispersion (standard deviation, minimum and maximum) were calculated. For categorical variables, absolute and percentage distributions were calculated. The calculation of the scores of the Family Management Measurement instrument, on the Management Skill scale, followed the guidelines of the authors.<sup>19,20</sup>

Correlations between the scale score and the quantitative variables related to children and caregivers were verified by Spearman's correlation test, once a non-normal distribution was identified in the independent variables. The statistical procedures were carried out in Stata software, v.15. The significance level adopted throughout the analysis was 5%.

#### b) Qualitative study

The 53 interviews were transcribed in full, typed in Microsoft Word, with a document formatted in A4 size, Arial font, size 12

and 1.5 spacing. The research corpus totaled 423 pages and was stored in the MAXQDA software, version 20.0. Quantitative variables were also exported to this software for later data mixing.

The interviews were numbered according to the order in which they were conducted and the participants' names were replaced by letters. The letters M for mothers, P for fathers, and T for great-aunt were used. The final identification of the interviews has the letter corresponding to the participant followed by the number in the order in which the interview was conducted (Ex.: M-22, M-34, P-01).

The transcription was carried out by two researchers, one of them being the main author of this study. The transcription of all interviews was checked by the first author of the study to certify the agreement between the audio and the transcribed content.

Directed Content Analysis was performed.<sup>21</sup> Two codes and three sub-codes were prepared based on the theoretical reference. For each of them, a definition was elaborated containing its meaning, what characterizes it and examples that would help identify them more precisely. The coding was carried out independently by the first author and an external researcher, and was validated by the last author of this study. The coding was performed with the support of MaxQDA<sup>®</sup> software, version 20.0, and a Kappa coefficient of 0.92 was obtained in the inter-coder validation.<sup>22</sup>

For the MM data mix, data correlation analysis (quantitative study) was combined with direct content analysis (qualitative study) for the convergence and corroboration of the results of the different methods and for the complementarity between them.<sup>23</sup>

The qualitative data were coded, seeking to identify the influences of the sociocultural context on the family's daily care. In this mixing stage, we tried to relate the content that made up the codes with the quantitative variables of the family context with the scores of management skills. Thus, the significance of the findings was amplified beyond what they could offer separately. The mixed data was interpreted in the light of the FMSF framework and the scientific literature in the area.

This project was submitted to the Research Ethics Committee of the institutions where the study was developed, and was approved with favorable opinion 3.508.414. The recommendations of Resolutions 466/12 and 510/2016 of the National Health Council were met.<sup>24,25</sup>

## RESULTS

Fifty-three family members of children with chronic conditions admitted to the NICU participated, 34 children from a philanthropic hospital (64.15%) and 19 children from a federal hospital (35.85%). Most children were male (66.04%), with a mean age of 2.73 years.

Mothers represented 88.68% (n=47) of the participants. Of the total number of participants, 77.36% (n=41) lived with their partner and 69.81% (n=37) lived within the state. Regarding education, 9.43% (n=05) had no education/incomplete elementary school; 18.87% (n=10) had complete elementary school/incomplete high school; the majority, 47.17% (n=25), had complete high school/incomplete college education; 24.53% (n=13) had complete college education. About occupation, 58.49% (n=31) declared

themselves in the technical/ manual labor category; 9.43% (n=9) declared themselves in the administrative category; 30.190% (n=16) declared themselves in the household category; 1.89% (n=1) did not inform their professional category. The mean age was 33.58 years, with a standard deviation of 7.67. The number of people living in the same residence was 3.90 people on average, with a 1.06 standard deviation. Family income, on average, was R\$2,076.83 (USD380.22), equivalent to 1.98 minimum wages at the time of data collection.

The average score of the Handling Ability scale was 44.49, with the median at 44.0, indicating greater ease of the participating families to meet the care needs of the child with a chronic condition at home (Chart 1). Among the 53 families who participated in the survey, four (n=4; 7.54%) families obtained a Management Skill score < 36. The rest of the families (n=50; 92.46%) obtained a score > 36, therefore, with positive Management Ability.

Thus, Chart 1 presents the integration of the quantitative and qualitative data, seeking to identify their convergences and divergences, as well as to broaden the understanding of the contextual aspects and their relationship with family management skills.

In the interviews, 18 participants expressed that the management skill resulted from the development of learning to care for their children, such as the correct administration of medications, the care with the child's body hygiene and the handling of technological devices and the adaptation regarding the type of feeding recommended for the child. Two referred to performing rehabilitation exercises with the child. All these participants had positive management skill scores with scores >38.

Participants M21, M34 and M35 reported difficulties in child care, considering that, with the advancing age of their children, the burden becomes more intense. This is because, in some cases, the children are still unable to verbalize, walk, develop comorbidities, and there is an increase in the number and complexity of the technological devices used and also the complexity of care.

The correlation between Management Ability and Family Income was not statistically significant ( $p=0.261$ ), not allowing us to affirm the influence of this contextual aspect on the family's ability. However, the fragments of the speeches allow us to identify the family's challenges to assume the costs of care at home. Expenses with the acquisition of materials necessary for the maintenance of care were mentioned (M17 and P48), the absence of a health plan, contributing to a greater expense with the child's health (M31) and the insufficiency in meeting the child's health demands when having a plan (M35).

The contribution of the companion to child care, considering the fact of "living with" or "living without" a companion, was not significant in relation to the Management Skill ( $p=0.972$ ). According to participants M15, M23 and M27, the companions perform care with the technological devices, the child's body hygiene, medication, play routine, accompaniment in consultations and decision-making.

The participants who do not live with a partner reported the presence of a social network formed by family members, who contribute as a source of security and support, helping to care for the child and taking him to specialized care (M6 and M34).

Living in Belo Horizonte showed a positive correlation with the Management Skill ( $p=0.011$ ). The fragments of the speeches show that the situations experienced in care related to the municipality of residence relate especially to the ease or difficulty of access to health services, considered necessary to guarantee care for their children in some situations. M4 (Management Skill Score = 55) lives in the same municipality where her child receives health care. She highlights the ease of access to health services due to the greater availability of resources to meet the children's needs.

## DISCUSSION

The results of this study demonstrate the potential of the FMSF for understanding families' experiences in caring for children with chronic conditions in their early years. The quantitative and qualitative data were consistent with results presented by other studies and contributed to the understanding of family management skill outcomes from the different life contexts of families.

The place where the families of children with chronic conditions live, how they organize themselves on a daily basis for care, who they can count on for the different tasks involving the child, their financial condition and the cultural and educational aspects of the caregivers form their life context and can favor the care of these children at home. Although only the variable "residence in the city of Belo Horizonte" was statistically significant in relation to the Handling Skill, the information reported by the participants during the interviews allowed us to recognize that the financial resources, social support and housing deserve attention for their potential to promote the Handling Skill. Most of the children's caregivers were their mothers, similarly to other studies that identify them as the main caregivers.<sup>3,26</sup>

The hospitals selected for the identification of children in chronic condition are reference hospitals for the population of the entire state. Therefore, faced with the possibility of a premature birth, pregnant women are referred to these institutions where they can have adequate access. This may explain the fact that a majority of participants (69.81%) live in a different municipality from where the child was born and have specialized follow-up.

Almost three quarters of the participants (71.7%) had completed high school, corresponding to 12 years or more of study. This characteristic of the population studied can contribute to a better understanding of the care to be performed and the engagement of caregivers to meet the demands of the child.<sup>27,28</sup> The occupation of the participants seems to reflect their level of education and is concentrated in technical/ labor activities (58.49%). It is also worth noting that 30.19% of the participants are engaged in domestic activities, which may result from the need for women to leave their jobs to take care of their children in situations of illness.<sup>6,26</sup>

Mothers provide care while simultaneously learning the skills to deal with all the procedures and the therapy. This situation also

**Chart 1.** Integration between quantitative and qualitative data in the convergent parallel approach. Belo Horizonte, MG, Brazil, 2020.

Scale (score range)	Number of answers	Lowest Score	Highest Score	Mean Score	Median	Standard deviation <sup>e</sup>	Qualitative Overview
Management Skill <sup>a</sup> (12-60)	53	34	57	44.49	44	5.31	<p>“So, like I told you, I am already getting used to her, you know? I am already getting used to the rhythm of taking care of her because she is a different child, right?”</p> <p>“Every day that passes, we find it a little more difficult to take care of her because she no longer wants to stay on our laps, she only likes to stay in the standing position. So, nowadays, I find it very difficult to take care of her by herself, because she is demanding more from me. (M34) (Negative Management Skill)”</p>
	<b>Mean</b>	<b>SD <math>\sigma</math></b>	<b>Min</b>	<b>Max</b>		<b>p-value<sup>¶</sup></b>	
Lives in Belo Horizonte <sup>¶</sup> (n=16)	47.25	5.24	41	57		0.011	“Then, sometimes we have to go by bus, right? So, we go by bus, sometimes my father takes me too, or we have to take an Uber...” (M33)
Does not live in Belo Horizonte <sup>¶</sup> (n=37)	43.29	4.94	34	52			“There is no support, right? He gets sick, I go to the hospital and take the car and go to Belo Horizonte. Here there is no support for him.” (M52)
Lives with partner (n=41)	44.39	5.54	34	57		0.972	“We both do the same things. I think both me and him. So, I probe, he probes...so one helps the other a lot. You know what I mean? So it doesn't get too dull, too tiring.” (M27)
Lives without a partner (n=11)	44.45	4.65	38	52			“My sisters, my mother, they help me A LOT, A LOT. My niece also helps me a lot. But the general care, like that, is myself.” (M10)
	<b>Spearman's Coefficient (r)</b>					<b>Value of p<sup>‡</sup></b>	
Family income (n=53)	0.156					0.261	“So, it is complicated in the financial issue, you know? Because...she spends more than the other because of the care, so the work ends up not being enough to maintain. So, you have to adjust everything according to her.” (P48)

<sup>a</sup>Scale positively related to family management. <sup>e</sup>Standard deviation. <sup>¶</sup>In this dimension, the results of 16 caretakers living in Belo Horizonte - Minas Gerais/ Brazil and 37 living outside Belo Horizonte - Minas Gerais/Brazil were analyzed. The marital status of a family member was not reported. <sup>†</sup>Student's t-test for unpaired samples. <sup>‡</sup>Spearman's Correlation Test. Source: survey data, 2020.

generates an overload for the women who sometimes need to deal with the condition of their child, with domestic chores, with care management, among other activities.<sup>26</sup>

The quantitative data of this study showed that families are able to meet the care needs of the child in chronic condition at home, with high scores of management skills. These data are consistent to affirm that, from the moment the caregivers manage the therapeutic routine and the home activities with cohesion, the condition itself becomes the closest to what the family considers a normal life.

From the knowledge of the main characteristics of the chronic condition, in which the family members know the permanent changes occurring in the child, the family members acquire autonomy to develop their functions and, together, seek to develop a sense of balance and control in face of the demands of care, which allows them to describe their situation as “normal”.<sup>29,30</sup>

Similar results were identified in a study with children with congenital adrenal hyperplasia, whereas management skills increased, the impact of the condition perceived by the family was less. In addition, the study showed that as the child's age advanced, family members were able to adapt to the care.<sup>11</sup> A positive correlation between the ability to manage the condition and the health-related quality of life of thalassemic children was also found.<sup>31</sup>

However, for others, more efforts are needed to maintain the balance of the child's health condition according to clinical status.<sup>11</sup> A study with parents of children with atopic dermatitis verified the difficulties in the family's ability to manage the chronic condition. The authors indicated that as the disease worsened, more effort was required to manage the disease and, consequently, there was a decrease in the perceived efficacy of mothers' ability to care for the child.<sup>32</sup>

Although the results show the absence of a significant relationship between the Management Skill and Family Income variables, the caregivers' discourse reveals how costly it is for the family to maintain care at home. A Chinese study found that the lower the income, the longer the duration of illness, and the more medication used, the more effort was required to manage the chronic condition.<sup>27</sup> The opposite was also verified. The higher the income, the lower the amount of medication used and the higher the maternal education, the higher were the levels of ability to manage care in daily life.<sup>27</sup>

The families of children in chronic conditions are financially more vulnerable due to the expenses involved with care, such as increased costs for transportation, medication, consultations, and diets, among others.<sup>28</sup> Understanding the relationship between socioeconomic factors and family management is necessary for health professionals to promote interventions that improve the living conditions of families.<sup>28</sup>

The data shows the absence of association between the marital status of family members and the Management Skill. It is important to report that, regardless of marital status, the participants described the presence of a social network that supported them in their care. This network consisted mainly of

family members. The participants who lived with their partner described that, besides their support in the daily actions of care and reciprocity in decision making at home, they also had the support of family members.

A study of parents of children with Down syndrome and parents of children with a chronic physical condition found that fathers and mothers who lived alone developed less ability to manage the condition compared to parents who lived with their partners. The results showed differences in relation to gender. Fathers made less effort to manage the condition when compared to mothers.<sup>10</sup>

One study found that the sociocultural context can influence family management. Thus, the family, by receiving a high level of social support, may experience less stress, and the caregiving actions become easier, even in the face of the challenges faced.<sup>33</sup> This is beneficial for the children's health, since the positive family bond solidifies the relationships and the children feel welcomed and supported by the family.<sup>34</sup>

The access to treatment at the various points of the health care network is seen as one of the challenges for families, meaning an exhausting journey.<sup>35,36</sup> When the Handling Ability dimension was associated with the Municipality of Residence, a significant correlation ( $p < 0.05$ ) was found between these variables. This means that families living in Belo Horizonte/Minas Gerais (Brazil) presented better Management Ability. Family members who live in the capital of Minas Gerais may have easier access to health services and professional monitoring, as well as easier transportation. In contrast, families from other cities in the state face challenges in ensuring the continuity of their child's follow-up, since they need to travel many miles to access services, as well as depend on transportation from their city hall, which is not always available.

Moreover, due to the more limited access to health services, the relationship between the family and health professionals becomes fragile or even nonexistent, which makes it difficult for the family to access information and for the professional to recognize the family structure, leading to a superficial relationship between the family and health professionals.<sup>37,38</sup>

As a result, families undertake a solitary and exhaustive search for health services that are effective in meeting the demands of children with chronic conditions, and need to define a therapeutic itinerary that minimizes the fragmentation of care.<sup>36</sup> In this scenario, the approximation of health professionals is necessary and can be corroborated through dialogue, the strengthening of the bond and the expansion of the support network.<sup>39</sup>

## CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

It was concluded that there is a relationship between the context of life of families and the ability to manage the child with chronic condition. Favorable social and economic conditions contribute to the family's ability to care for the child with chronic condition. Being able to count on the partner or other family

members for the division of tasks and support for care can improve the management ability of these families.

Over time, the ability to manage the care of the child improves, as families adapt and organize themselves to provide care, becoming increasingly able to meet the demands. However, in some situations, as the child grows, new demands may arise, which requires constant readjustment, so that new challenges can hinder the ability to manage.

The limitations of this study are that it was conducted with children with different chronic conditions and that the level of severity of the condition was not stratified as mild, moderate or severe. Thus, it is interesting to investigate the Management Skill of specific conditions, since different chronic conditions may result in different demands. Further longitudinal studies are also suggested, since the family's need for adaptation may change over time. In addition, the study participants were linked to a specific reality, being families coming from hospitals considered reference in maternal and child care. Thus, new studies covering different cultural contexts and health services are needed.

This study advances in the construction of knowledge by incorporating, in its design, different aspects that make up the life context of families such as their social, economic and demographic characterization, family composition and organization for care associated with the contextual aspects perceived by caregivers and expressed qualitatively through interviews.

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Study design. Melissa Joice de Abreu Felizardo. Elysângela Dittz Duarte.

Data collection or production. Melissa Joice de Abreu Felizardo. Elysângela Dittz Duarte.

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