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

Habilidad de manejo de familias de niños con enfermedades crónicas para el cuidado en el hogar

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 habilidade de manejo em crianças com 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.

Corresponding author:
Melissa Joice de Abreu Felizardo
Email: melissajoice@gmail.com

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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. Changes have also been seen in health care, with emphasis on early de-hospitalization, with the family responsible for continuing care at home.

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

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.

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). 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.

The FMSF has been used in national studies and in international investigations related to different types of chronic conditions in childhood. In general, studies using the FMSF are mostly descriptive or exploratory and qualitative in approach. 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. 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.

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 care for their child.

METHOD

This is a convergent parallel type (QUAN-QUAL) Mixed Methods (MM) study. The theoretical framework of the Family Management Style was used as the theoretical framework of the study and the guidelines of the Mixed Method Appraisal Tools 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); 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. In most cases, normal patterns can be observed in the first two years of life.

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. 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.
The management capacity of the families

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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 for the maintenance of care were mentioned (M17 and P48), equivalent to 1.98 minimum wages at the time of data collection.

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.3,26

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.27,28

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.6,26

Mothers provide care while simultaneously learning the skills to deal with all the procedures and the therapy. This situation also
The management capacity of the families
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<table>
<thead>
<tr>
<th>Scale (score range)</th>
<th>Number of answers</th>
<th>Lowest Score</th>
<th>Highest Score</th>
<th>Mean Score</th>
<th>Median</th>
<th>Standard deviation</th>
<th>Qualitative Overview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management Skill*a (12-60)</td>
<td>53</td>
<td>34</td>
<td>57</td>
<td>44.49</td>
<td>44</td>
<td>5.31</td>
<td>“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?</td>
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<table>
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<th>Standard deviation</th>
<th>Qualitative Overview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives in Belo Horizonte* (n=16)</td>
<td>47.25</td>
<td>5.24</td>
<td>41</td>
<td>57</td>
<td>0.011</td>
<td>“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)</td>
<td></td>
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<tr>
<td>Does not live in Belo Horizonte* (n=37)</td>
<td>43.29</td>
<td>4.94</td>
<td>34</td>
<td>52</td>
<td>0.972</td>
<td>“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)</td>
<td></td>
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<tr>
<td>Lives with partner (n=41)</td>
<td>44.39</td>
<td>5.54</td>
<td>34</td>
<td>57</td>
<td>0.972</td>
<td>“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)</td>
<td></td>
</tr>
<tr>
<td>Lives without a partner (n=11)</td>
<td>44.45</td>
<td>4.65</td>
<td>38</td>
<td>52</td>
<td>0.972</td>
<td>“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)</td>
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<tr>
<th>Spearman’s Coefficient (r)</th>
<th>Value of p‡</th>
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<tr>
<td>Family income (n=53)</td>
<td>0.156</td>
</tr>
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</table>

*aScale positively related to family management. *Standard deviation. †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. ‡Student’s t-test for unpaired samples. †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.36

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”.29,30

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.11 A
positive correlation between the ability to manage the condition
and the health-related quality of life of thalassemic children was
also found.31

However, for others, more efforts are needed to maintain the
balance of the child’s health condition according to clinical status.11
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.32

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.27 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.27

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.28 Understanding the relationship between
socioeconomic factors and family management is necessary for
health professionals to promote interventions that improve the
living conditions of families.28

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.10

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.33
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.34

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.35,36 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.37,38

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.36 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.39

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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AUTHORS' CONTRIBUTIONS

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

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


Interpretation of results. Melissa Joice de Abreu Felizardo, Elysângela Dittz Duarte, Juliana Barony da Silva, Eliane Tatsch Neves.

Writing and critical revision of the manuscript. Melissa Joice de Abreu Felizardo, Juliana Barony da Silva, Eliane Tatsch Neves, Elysângela Dittz Duarte. Approval of the final version of the article. Melissa Joice de Abreu Felizardo, Juliana Barony da Silva, Eliane Tatsch Neves, Elysângela Dittz Duarte.

Responsibility for all aspects of the content and integrity of the published article. Melissa Joice de Abreu Felizardo, Juliana Barony da Silva, Eliane Tatsch Neves, Elysângela Dittz Duarte.

ASSOCIATE EDITOR

Aline Cristiane Cavachilli Okido

SCIENTIFIC EDITOR

Ivone Evangelista Cabral

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