

SCORING INTERVENTIONS IN FAMILY RELATIONS REGARDING THE CARE FOR THE CHILD WITH A CHRONIC CONDITION¹

Daniele Castro Barbosa², Francisca Georgina Macedo de Sousa³, Joséte Luzia Leite⁴

¹ Article derived from the dissertation - Understanding the multiple interactions and retroactions for the organization of the family system in the care for the child with a chronic condition, presented to the Postgraduate Program in Nursing of the Universidade Federal do Maranhão (UFMA), with the support of the *Fundação de Amparo a Pesquisa e ao Desenvolvimento Científico e Tecnológico do Maranhão* and of the Coordination for the Improvement of Higher Education Personnel (CAPES), 2013.

² M.Sc. in Nursing. Brasília, Federal District, Brazil. E-mail: danielecastro_13@hotmail.com

³ Ph.D. in Nursing. Professor of the Undergraduate and Postgraduate Courses in Nursing, UFMA. São Luis, Maranhão, Brazil. E-mail: fgeorginasousa@hotmail.com

⁴ Ph.D. in Nursing. Tenured Professor of the Postgraduate Program in Nursing of the Anna Nery School of Nursing, of the Universidade Federal do Rio de Janeiro. Rio de Janeiro, Rio de Janeiro state, Brazil. E-mail: joluzia@gmail.com

ABSTRACT: The study aimed to reveal intervening conditions towards the care of children with chronic condition. The Complex Thought was used as theoretical framework and the Grounded Theory as methodological. Data were collected from January to August 2012, through semi-structured interviews in two follow-up services for children with chronic conditions and in the homes of participants. Participated 16 relatives of children with chronic conditions, divided into three sample groups. The category "Scoring the intervening conditions towards care of the child with chronic condition" reveals that multiple events experienced by the family in the care of children with chronic conditions are determined by the relationships and interactions of family members and influence the forms of organization for the care of child. Highlights the importance of the nurse to know and understand the multiple family experiences in order to encompass child and their family members as care units.

DESCRIPTORS: Nursing. Chronic disease. Family relations. Child.

PONTUANDO INTERVENIÊNCIAS NAS RELAÇÕES FAMILIARES FRENTE AO CUIDADO À CRIANÇA COM CONDIÇÃO CRÔNICA

RESUMO: O estudo objetivou desvelar as condições intervenientes para o cuidado da criança com condição crônica. Utilizou-se o Pensamento Complexo como referencial teórico e a *Grounded Theory* como metodológico. Os dados foram coletados de janeiro a agosto de 2012, por meio de entrevista semiestruturada, em dois serviços de acompanhamento a crianças com condições crônicas e nas residências dos participantes. Participaram 16 familiares de crianças com condições crônicas, distribuídos em três grupos amostrais. A categoria "Pontuando as interveniências no cuidado à criança com condição crônica" revela que os múltiplos acontecimentos vivenciados pela família no cuidado a criança com condição crônica são determinados pelas relações e interações familiares, influenciando as formas de organização do sistema para o cuidado da criança. Destaca-se a importância do enfermeiro conhecer e compreender as múltiplas vivências familiares para que possa englobar criança, família e seus membros como unidades de cuidado.

DESCRIPTORIOS: Enfermagem. Doença crônica. Relações familiares. Criança.

PUNTUANDO CONDICIONES INTERMEDIAS EN LAS RELACIONES FAMILIARES DELANTE CUIDADO DE LOS NIÑOS EN CONDICIÓN CRÓNICA

RESUMEN: El estudio objetivó revelar las condiciones intermedias para el cuidado de niños en condición crónica. Se utilizó el Pensamiento Complejo como el referencial teórico y la *Grounded Theory* como la referencial metodológica. La recolección de los datos se dio de enero a agosto de 2012, por medio de entrevista semiestructurada, en dos servicios de supervisión a niños con condición crónica, distribuidos en tres grupos de muestra. La categoría "Puntuando condiciones en el cuidado de los niños con condición crónica" revela que los múltiples acontecimientos vividos por la familia en el cuidado del niño con condición crónica se determinan por las relaciones e interacciones con la familia e influyen las formas de organización del sistema para el cuidado del niño. Se destaca la importancia de que el enfermero conozca e entienda las múltiples vivencias familiares a fin de que se pueda incluir el niño, la familia e cada uno de sus miembros como unidades de cuidado.

DESCRIPTORIOS: Enfermería. Enfermedad crónica. Relaciones familiares. Niño.

INTRODUCTION

The chronic conditions constitute the group of diseases which need continuous care and which persist over long periods, ranging from several years to decades.¹ When present in childhood, the chronic conditions are accompanied by certain specific characteristics, which impact intensely on the family. In this context, the family dynamic is altered, due to the need for repeated visits to the health service, for specific care, and for the use of medications, as well as to relapses and frequent episodes of inpatient treatment.² As a result, the chronic condition is characterized as a factor causing disorganization and deconstruction of the family, influencing both this system's internal relationships and its social relationships.³

Studies on this issue indicate that the family system, when it suffers abrupt changes, needs to reorganize, as caring for children affected by chronic illnesses is a task which requires a significant degree of family involvement.^{4,6} The family reorganization, in its turn, can be shaped so as to promote or maintain the well-being of the system.⁷ To this end, effective coping with the situation, adaptation to the changes, and the development of family and individual skills are necessary, in order to deal with the pressures, uncertainties, difficulties and anxieties which accompany a chronic condition in childhood. The reorganization of the family, therefore, requires the realigning of its members' perspectives, as well as changes in their behaviors. It is a process permeated by the valorization of feelings and attitudes such as affection, attention and dedication - which facilitate the interactions in the family system.^{4,5}

Thus, the movement of family reorganization leads to a reevaluation of the social roles performed by the family members, given that the child's chronic condition entails changes in the routine of all its members, producing needs in the reevaluation and redefinition of roles, even if temporarily. This redefinition of roles changes the process of intrafamily interaction, contributing to the family members redefining their own ways of acting in the light of the chronic condition.⁴ Factors which are external to the family system may also be considered in the process of reorganization resulting from the child's chronic condition, among which emphasis may be placed on the fundamental relevance of the social support networks, which are characterized as an essential resource in the assistance to the family during the various points of the health-illness-treatment-rehabilita-

tion process, and which can lead to more efficient and efficacious care.^{6,8-9}

It is understood, therefore, that this is a process which continuously involves order, disorder and organization, in an antagonistic and complementary dynamic. This relationship is part of the dynamic of each and every family, in particular those in which one of the children is experiencing a specific chronic condition, as irregularities, deviations and unforeseeable events are necessary such that the system may later achieve stability and organization.¹⁰ Taking these assertions into account, a chronic condition in childhood is characterized as a threat to personal, family and social functioning, and entails disorder of the system, which seeks new ways of interacting in order to achieve organization. The study was guided by the following problem: How do the interactive and retroactive processes for caring for the child with a chronic condition occur in the family?

Undertaking an investigation whose objective is related to the family dynamics and ways of organizing the family for the care of the child with a chronic condition could valorize the family relationships and facilitate the identification of the family system's needs, becoming closer to the comprehensiveness of the care and the family as a unit of care. Through this investigation, the aim was to reveal the intervenient conditions for the care of the child with a chronic condition.

THEORETICAL FRAMEWORK

The authors sought to detect the objective of the investigation in the light of Edgar Morin's Complex Thought, due to the understanding that the organization of the family system in the care for the child with a chronic condition is a phenomenon composed of multiple dimensions, and by a complex network of interactions, intrinsically linked to issues of order, disorder, and organization. This theoretical approach, in its turn, entails a process of disorganization, for the later organization of previously-established knowledge and conceptions, and is configured as a call to think about the nursing care for the families who experience the reality of caring for the child with a chronic condition. As a result, it is worth emphasizing that the complexity must be understood as a thought which unites and seeks the relationships between the various aspects of human life, as the problems can only be positioned and thought about correctly in their contexts, and these problems' context must be positioned in a planetary context.¹¹

To this end, thinking is necessary which covers the needs for the knowledge of the whole and of the parts of the whole; which recognizes the phenomena in their multidimensionality, without mutilatingly isolating their dimensions; which recognizes and addresses the contexts, which are, at the same time, supportive and conflictual; which respects the difference, at the same time as it recognizes the uniqueness of the phenomena. Thus, it is necessary to substitute simplifying thought, which isolates and separates, with complex thought, which unites and distinguishes.¹¹

METHODOLOGY

This is an exploratory study with a qualitative approach, guided by the assumptions of Grounded Theory (GT). GT has to do with theory derived from data, systematically brought together and analyzed through a research process. As a result, the theory derived from the data tends to resemble the reality more than a theory derived only from the bringing together of concepts, based in experience or in simple speculation. It also promotes greater discernment and a better understanding of the phenomenon investigated.¹²

Data collection was undertaken with family members of children with chronic conditions, between January – August 2012. The research settings were three services located in São Luís (in the State of Maranhão): the Santa Edwiges Clinical School of the Association of Parents and Friends of the Exceptional (APAE); the Mother-and-Child Unit of the Teaching Hospital of the Federal University of Maranhão (HUUMI-UFMA), and the participants' homes.

The technique used for data collection was the semi-structured interview, guided by the question: What happens or has happened in your family since the discovery of your child's condition? For selection of the study participants, the researchers sought people, places or facts which allowed the discovery of variations between concepts, making categories dense in terms of their properties and their dimensions.¹² Thus, a total of 12 mothers and four family members who were caregivers for children with chronic conditions participated in the study, divided into three sample groups. The first sample group was made up of seven mothers who cared for children with a chronic condition, who met the inclusion criteria of having been a caregiver for the child for a minimum period of one year. The second sample group was made up of five mothers who were caregivers for children with

chronic conditions, with greater purchasing power in comparison with the participants from the first group. The inclusion criteria defined for the second group were to have been the mother and caregiver for any child with any type of chronic condition for a minimum period of one year; and to have a family income of 5 to 15 minimum salaries/month, on the hypothesis that the financial situation would positively influence the organization of the family system. Finally, the third sample group was made up of members of two families who were caregivers for children with a chronic health condition. The interviewees from the first family were the child's father and maternal grandmother, and from the second family, they were the maternal grandmother and a maternal aunt. It is emphasized that the approach of the family caregivers occurred due to the closeness of the care which the same provided to the child. All the interviews were recorded on a digital recorder and transcribed immediately after being held. It is worth noting that, in order to define the sample, theoretical saturation was taken into account, as specified in GT.

Taking into account the assumptions of GT, the analysis of the data was initiated using the coding procedures, which cover three phases: open coding, axial coding, and selective coding. In the open coding, the raw data arising from the interviews were analyzed line by line, which allowed the construction of the preliminary codes. These codes, following rigorous processing using comparative analysis, were grouped by similarities and differences, giving rise to the concepts, which were again reorganized and grouped, allowing the development of terms with greater levels of abstraction, giving rise to the study's categories. Once the categories had been developed, the same were exhaustively compared with each other with the objective of achieving clearer and more complete explanations regarding the phenomenon investigated. This procedure characterized the stage of axial coding, which seeks to systematically develop the categories and to relate them. Once the categories had been constructed, the objective of the next step was to redefine them and integrate them until the development of the central category, characterizing the phase of selective coding.

In this way, the analytical process defined by GT made it possible to construct the organizational scheme used for classifying and developing the connections emerging between categories and sub-categories, this scheme being termed a paradigm, and possessing certain basic components, these

being: phenomenon, context, causal conditions, intervening conditions, and strategies.¹²

With a view to meeting the ethical criteria, the recommendations determined in Resolution N. 196/96, of the Brazilian National Health Council, which relates to research involving human beings, were followed. As a result, the study was evaluated and approved by the Research Ethics Committee of the President Dutra Teaching Hospital (HUPD)/UFMA, under Opinion n^o. 192/10. In order to undertake data collection, the participants were requested to sign two copies of the Terms of Free and informed consent. The participants' anonymity was guaranteed, with their identities being replaced with the names of flowers.

RESULTS AND DISCUSSION

The category "Scoring the interveniences in the care for the child with a chronic condition" was characterized as an intervenient condition of the theoretical model "Dealing with order and disorder of the family system in order to care for the child with a chronic condition", and revealed that the multiple occurrences experienced by the family, in the light of the care for the child with a chronic condition, are determined by the relationships and interactions of the family system's members in the light of the new context, and that these directly influence the ways of organizing this system for the care of the child. It is, therefore, important to identify and understand these, as they have the ability to increase or reduce the order or disorder experienced by the family system. It stands out that, in GT, the intervenient conditions have to do with the factors which alter the impact of the conditions and cause influences (causal conditions) on the phenomenon. Two subcategories made up the category in question: "Establishing the networks of interaction between the members of the family system and the child with a chronic condition" and "Indicating the multiple effects of the actions and interactions of the family system regarding the care for the child with a chronic condition".

Establishing the networks of interaction between the members of the family system and the child with a chronic condition

The first subcategory reveals the interactions established between the members of the family and the child with a chronic condition. It emphasizes the father's participation in the life and the care of the child, the behaviors adopted

by the family members in the care for the child, and the differentiated levels of links established between family members and the child. The father's participation in the care for the child with a chronic condition was present to a significant degree among some of the families interviewed. In some cases, the father was characterized as an important element in the life and care of the child, participating in the children's routines in various ways, whether this involved meeting the child's needs, taking responsibility for the care, or being present in the child's day-to-day. In this context, one point which deserves to be emphasized is the affection and the strong links present in the relationships between the fathers and their children:

my husband is always helping, he always finds a way. Our son only sleeps when he comes home, he snoozes, but he doesn't sleep, he waits for his father to come home from work. They are very close, when he [the husband] is at home, our son spends the whole day on top of him. [...] He does everything to be at home, if he is working and we need to resolve something for our son, he finds a way of managing to get some time off (Rosa).

my husband is very present, and they are very close. He helps to care for her all the time, really caring, making the infant cereal, changing nappies, he gets up very early, even now it is him who gets up early to make her infant cereal (Acácia).

The interactions established between father and child are characterized as an important factor for the child's development, and indicate that the fathers have the potential to be competent and involved in this care, besides demonstrating the desire to participate, actively seeking greater involvement in the care for the child.¹³ Hence, the figure of the father has been shown to be increasingly present in the children's lives, offering participation in the care and strengthening the links already existing.¹⁴ These attitudes can be explained by the social representation of the father itself, which has undergone intense changes over the passing of time. Formerly, the father exercised a role of authority, being the member who provided for the family. However, due to the entrance of the wife in the job market, this configuration has changed, determining new family arrangements. Within this perspective, the figure of the father is undergoing reconstruction, and in this process, the father exposes his affective face, being more present in the children's lives. Fatherhood, therefore, has acquired new values, emphasizing the role of the father in the search for the child's quality of life and in the recovery of the child's health.¹⁵

In this context, one study¹³ on the mothers' conception regarding fathers' participation in the care for the child demonstrated that 56% of the fathers were considered to be participants in the children's care, while 37% participated little, and only 7% seemed not to participate in the care for the child. This study addressed how the fathers participated in this care, and the results revealed that, in the majority of cases, the fathers were involved in various activities of care for the children, such as trips out, playing and basic care, with or without the mother's presence, such as giving baths and feeding.¹³ Other investigations have presented results which support those presented above, demonstrating that the fathers show themselves to be fairly involved in activities outside the domestic environment, such as trips out and medical consultations, as well as in daily activities such as giving baths, administering medications, and care with the child's sleep and rest.¹⁶ In relation to the father's participation in the life and care of the child with a chronic condition, it is important to stress that the same cannot be seen as supporting in the care for the child, but that he can be seen as an important member in the child's development, as he influences and is influenced in his direct interaction with his child.¹³

However, the father's participation in the care for the child with a chronic condition is fairly heterogeneous and is differentiated in practices and attitudes in the different families. In one of the accounts, the children had been totally abandoned by the father since they were small. The accounts below illustrate this reality:

my son was four months old, and since that time he has never again wanted to meet the boy, he doesn't participate in his life, he doesn't try to find out about the treatment, nothing (Verbena).

He just asked me to send me some photos of her [the daughter], so I sent some, he cried and everything, but that was all. Sometimes he wants to have news of her, but he doesn't call me, he calls an aunt of mine who lives in São Paulo, and she gives him information about the child (Tulipa).

In spite of the current configuration of fatherhood undergoing a process of transition, in which the father supports and participates intensely in the care of the child with a chronic condition, it is still possible to identify that the opposite sometimes occurs; the fathers distance themselves not only from care for the child, but also from the very act of living with the child.¹⁵

In contrast, the family members (grandmothers, uncles, aunts) who participate in the care for the child with a chronic condition reveal a constant concern with the treatment and with the child's health conditions and well-being. This participation is revealed by the closeness and bonds between the family members and the child, expressed through the constant offering of love and tenderness, and the activity of the family members in the care needs, as identified below:

They [family members] ask me about my son [mentions his name], about what is needed at the moment, how his life is, how his consultation went, what came up in his tests, they come with me too. There are times they come with me to hospital, they ring to find out what the doctor said, they come to fetch him [the child] at home so they can spend the weekend with him, they play with him, they take him out on trips (Margarida).

We go to the doctor together, for his treatment, and they [the family] play with him, and help in everything, in his activities, in his medications. Tenderness and love, sometimes they even give too much (Hortência).

We take care of him, we take responsibility, if something happens we are there, they are present in his day-to-day, if we notice something different, we talk and help in all ways (Orquídea).

However, the families identify different levels of bonds between their members and the child. There were those who were more participative and attached to the child, while others kept their distance, with weak links, as indicated in the accounts below:

some people concern themselves with him, but others don't. The closest people, such as his aunt and his grandmother, are very concerned with him, and his father and godmother as well, his godfather, they are very concerned about him (Papoula).

her father has another two children and I notice that his daughter, the oldest, keeps her distance somewhat from our child who is ill (Crisântemo).

In consonance with the data presented, one study which evaluated the participation of family members in the care for the child with a chronic condition emphasized – besides the figure of the mother – the grandmothers, the fathers, the uncles and the siblings as contributors in the care for the child, both in basic activities of care such as feeding, hygiene, rest and trips out, and in activities determined by the condition, such as visits to the doctor and the administration of medications.¹⁶

The care for the child with a chronic condition, however, requires more than attendance to her physiological needs. Touch, tenderness, cuddles, and affection are necessary, as attitudes which are positive for child development. This affective and interactive movement, in its turn, tends to occur more easily when there is a bond between the child and the family members.¹⁷

In this regard, the interactions undertaken between family members become important instruments for the development of bonds, which generates effects and positive feelings in the life of those involved, and consequently in the family system. In this way, the experiencing of the child's chronic condition, in a joint form by the family members, contributes to understanding, to collaboration, to love and to mutual care.¹⁴ This movement is characterized as a process of negative retroaction, in which the deviations are reduced and the system is stabilized,¹¹ that is, the development of bonds becomes positive for the family relationships, which leads to the development of positive actions of care for the child, thus contributing to the balance of the family system.

In this perspective, the nurse has an important role to perform with the families who live with the reality of the child's chronic condition. It falls to this professional to help the family to identify its strengths and potential, as well as its weak points and needs. In this way, in recognizing the family's importance in relation to the care for the child with a chronic condition, it is necessary to walk alongside it, supporting it and instrumentalizing it, such that it may care for the child in the best way possible.¹⁷

Indicating the multiple effects of actions and interactions of the family system in the light of the care for the child with a chronic condition

This second subcategory emphasizes the retro-active movement of strengthening family bonds, the weakening/breaking of the family bonds, and how families react in the light of these.

The most perceptible effect of these family actions and interactions regarding the care for the child with a chronic condition was the strengthening of the bonds between the family members. This retroactive movement, of deepening the family bonds, was shown to be of great importance for the family system, as it positively influenced the relationships of care with the child, as well as

the relationships established between the family members themselves:

after he was born, there were changes in my family, in the sense that it became more united. Today, my family is much more united, both my side of it and his [the husband]. Things which didn't happen before, happen now, such as that concern about telephoning to know how my son is, if he is okay. When he isn't okay, the whole family suffers, there is that affliction, everybody rings all the time wanting to know how he is. I had never brought my family close to the family of my husband, but today, we even go on trips together, his family came to visit mine, and that was very good because we really became united, and with each day we become more united (Hortência).

what happened in the family was that the help from everybody intensified, the union became more consolidated for him. We already had a good link, and he came to strengthen this link even more. The strengthening of the family occurred following the discovery of his heart disease, and is still maintained now (Orquídea).

When the families find themselves faced with the child's chronic condition, some important aspects can be observed, such as the act of the families in thinking about the context experienced. This movement allows them to reflect on the values and the relationships established among the members, and awakening to this reflection leads the families to outline new ways of living. In this regard, they rethink aspects relating to feelings and behaviors, processes which, in their turn, allow the strengthening of the family bonds through the changes in the relationships with the child and with the other members of the system.¹⁸

From this perspective, it is understood that the situation of the chronic condition involves not just the child, but the entire family system, and that it can be configured as unifying the family. The family members, faced with the child's chronic condition, seem to concern themselves with each other, seeking an articulation to promote mutual support. Thus, new family bonds can be constructed, and those already existing can be intensified. Another important aspect was of the family members, even those who were distant, who made themselves present, using various means of communication to be closer to the child and the other members of the system.¹⁹

This reality is in consonance with other studies¹⁶ on the reorganization of families of children with chronic conditions, which demonstrated stronger bonds after the diagnosis, revealed through support, concern, attention and the con-

stant search for information.²⁰ In these cases, the strengthening of family bonds was seen as positive, as it made it possible to mitigate the suffering and to value the already-existing relationships, perceiving them as long-lasting and sincere.

It is noteworthy that the role of the nurse consists of recognizing the relationships established by the family, as well as supporting them in the developing of new family relationships. If on the one hand it is necessary to encourage and promote new bonds between the family and the child, for the well-being of all the members of the system, on the other it is necessary to understand that this movement cannot be imposed – but, rather, must be encouraged, conquered, and promoted.¹⁷

In contrast, the weakening – and even breaking – of family bonds could be observed with a negative effect on the affective relationships of some of the families interviewed, as shown in the accounts below:

so he [the husband] started going out and leaving me alone, so I decided to separate. I thought it would be better, I was only concerned about my son, and I left him. Now he wants to come back, but I don't want him any more (Papoula).

It was so that my son would not get distressed, because we noticed that the more his condition progressed, the more he noticed [attitudes of prejudice from family members], so we decided to withdraw from them. As a result, we don't go much anymore to the house of family members who, we think, might say things to him that they shouldn't. We ended up withdrawing a little, and that's how we live, more just us, at home (Açucena).

The child's chronic condition is permeated by uncertainties, brings important repercussions for family life, and can cause significant impacts on the family relationships, as the changes which occur in the family context extend from the de-structuring of the system, caused by the parents' separation, through to the confusion of roles or ruptures in the family dynamic; often leading to the weakening or breaking of family bonds. Another fact which can favor the loss or weakening of family bonds is the uncooperative attitudes of its members. As a result, it is understood that the child's chronic condition can intensify relational difficulties.²¹

This dimension is close to the understanding of the recursive principle, proposed by Complex Thought,¹¹ as the changes of the family dynamic and the non-cooperation between the family members are configured as factors which influence the

relational difficulties, which in their turn continue to influence the first two, in a recursive process which will determine the families' forms of self-organization and which continuously involves order, disorder, and organization in an antagonistic and complementary dynamic.¹² These movements are part of the dynamic of each and every family system, however, they can be exacerbated in families where one of the children has a specific chronic condition, contributing to maintaining relational and interactional difficulties.

The process of weakening or breaking bonds, in its turn, inevitably influences some reactions of the family members, which may be more intense or more contained, as made clear in the accounts below:

when we separated, my family was totally de-structured, everybody was sad [...]. After the separation, my ex-husband and I argued, because after we separated he was jealous of me, so he assaulted me, me, with my son on my lap. My mother went there and he even assaulted my mother, after which he was arrested. After, my grandfather was upset and went to have it out with him, and he would still like to kill my grandfather. Since this happened, my family hasn't wanted even to let the boy go to his [the ex-husband's] house, because the father didn't want the boy anyway (Verbena).

in relation to the separation, nobody in my family showed their feelings, either positively or negatively, and also, it was a topic which I didn't want to bring home. I said that each one of us had decided to go their separate ways, and didn't ask for anybody's opinions, we took the decision and began to withdraw from them (Amarilis).

The family may be seen as an organized set of people who live in constant interaction, it being the case that each one of its members exercises a specific role which is determined by the relationships established among the family members themselves. Because of this, any alteration or change in one of the members of the family has repercussions for all the others; hence, the compromising of the child's health can lead to a crisis in the system, disorganizing the entire family structure.¹¹

When the crisis is installed, the family's response to the conflicts will have repercussions, positively or negatively, on the quality of life and well-being of both the system and of each one of the family members. Therefore, it is fundamental to understand the context experienced by the family in the light of the child's chronic condition, in order to encourage its strengthening in the face of adverse times.²¹ For this, it is necessary for the fam-

ily system to be seen in its multidimensionality, so there may be knowledge of the whole (family system) and of the parts (members of the family system) of the whole, avoiding that its dimensions should be excessively isolated.

CONCLUSION

The organization of the family system for the care for the child with a chronic condition is shaped under the influence of specific situations, which lead the family to experience a constant movement between order and disorder, and which will require of the system that it knows how to deal with this dialogic. The situations configured as intervenient were those which caused the organization of the family system for the continuity of care to the child with a chronic condition to increase or diminish. Some points could be emphasized as intervenient conditions for the family care of the child with a chronic condition, among which one finds the interactions, the bonds and the behaviors adopted by the members in the family system.

The results of the investigation reaffirm that strong and intense bonds transform the emotional climate of the family system, reduce the tensions and reduce risks of breaks, and that there is valorization of the affections, resulting in greater organization of this system, with a positive contribution to the care for the child with a chronic condition.

It is noteworthy that the family interactions and bonds were strategic conditions for the strengthening of the family system, at the same time that it made collaborative processes possible, these being so important for the permanent and continuous care required by the chronic condition. In this social and interactive context, the family achieves its caring role, enriched by the father's care.

However, the organization of the family system, in relation to the care for the child with a chronic condition, is constituted by opposing movements. On the one side, there are the interactions and bonds which produce affective and emotional support in the family for the care, while, on the other, there is the breaking of family bonds caused by conflictual interactions between the members of the system. These conditions significantly hinder the emotional health of the family unit, with negative consequences for the process of care in coping with difficulties, in defining roles, in communicating, and in affection between its members. These conditions, therefore, are intervenient, as they are reflected in the adaptive changes of

the family system, and determine the internal organization of the system in order to attend the care demands of the child with a chronic condition, as well as the individual needs of its members. Both conditions promote influences, which either intensify or moderate the occurrences, the interactions and the bonds and – consequently – produce retroactions for the order and disorder of the family system.

The interveniences in the care for the child with a chronic condition were the product of a rigorous process of analysis, enriched by the researchers' movements of deduction, induction, objectivity, sensitivity and creativity. This shows specific aspects of the family's experience regarding the child's condition, the difficulties experienced, the feelings revealed, the forms of support and coping for maintaining and providing continuity to the care and the attitudes of care, as well as the relationships, interactions and retroactions established by the family members in the caring process.

In the light of these aspects, one can emphasize the importance of the nurse being open to listening, and to communicating sensitively with the family caring for the child with a chronic condition, in the sense of knowing and understanding its multiple experiences, difficulties, conflicts, unions, relationships, interactions and retroactions, such that, in this way, it may encompass the child, the family and its members as units of care, addressing them in their multidimensionalities. Apart from the contributions for the functioning of the nurse, emphasis is placed on the opening of new paths for future research on the care for the child with a chronic condition, as the results presented here could complement and/or be complemented by new perspectives and findings regarding the family care for the child with a chronic health condition.

Approximation with the family system and with the child's chronic condition from the viewpoint of complexity made it possible to understand the multiple dimensions involved in the care, and redimensioned the need for a broader view regarding the occurrences, the relationships, the interactions and the retroactions produced in the family for the maintenance and continuity of the care. To this end, professionals, individually or as a team, must direct their attention as much to the family as to the family system, understood as the product of the relationships and interactions of its members.

To finalize, it is emphasized that the articulation between Complex Thought and GT allowed the emergence of various aspects regarding these families' context, making the understanding of the organization of the family system a rich and exalting experience for the nursing care and health care.

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