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ORIGINAL ARTICLE

CHILDREN'S CHRONIC DISEASE: FAMILY NEEDS AND THEIR RELATIONSHIP WITH THE FAMILY HEALTH STRATEGY

Eliane Aparecida de Oliveira COSTA[a], Giselle DUPAS[b],
Etelvaldo Francisco Rego SOUSA[c], Monika WERNET[d]

ABSTRACT

The purpose of this study was to learn the perception that families of children with a chronic disease make of their relationships with the Family Health Unit (FHU). This qualitative study was performed using symbolic interactionism as the theoretical ground and narrative inquiry as the method. Data were collected through semi-structured interviews with seven families of children with chronic disease, enrolled in the FHU of a region with high social vulnerability, in São Paulo state, Brazil. Results showed that the family's relationship with the FHU is influenced by elements from their experience and trajectory, and that their experience as a family of a child with a chronic disease is strongly marked by their relationship with the health care services. This has great influence on the responses of the family, thus requiring a systematic and committed engagement of the health system in relieving their suffering, beyond merely treating the disease.

Descriptors: Family. Chronic disease. Child. Family Health Program. Primary health care.

RESUMO

Este estudo objetivou conhecer a percepção da família sobre a relação com a Unidade Saúde da Família (USF) na vivência com a doença crônica da criança. Em um desenho qualitativo utilizou-se o Interacionismo Simbólico como sustentáculo teórico, a Pesquisa de Narrativa como método e entrevistas com as famílias como instrumento para a coleta de dados. Os dados foram coletados por entrevista semiestruturada, com 7 famílias de crianças com doença crônica, cadastradas em USFs de uma região com alto índice de vulnerabilidade social, de um município do interior paulista. Os resultados mostraram como a relação da família com a USF é influenciada por elementos da experiência e trajetória familiar e como a vivência da doença crônica da criança é fortemente marcada pela relação com os serviços de saúde. Tal situação tem grande influência sobre as respostas da família, o que exige um engajamento sistemático e comprometido do sistema de saúde no alívio do sofrimento familiar, para além do tratamento pontual da patologia.

Descritores: *Família. Doença crônica. Criança. Programa Saúde da Família. Atenção primária à saúde.*
Título: *Doença crônica da criança: necessidades familiares e a relação com a Estratégia Saúde da Família.*

RESUMEN

Este estudio tuvo como objetivo conocer la percepción de la familia sobre su relación con la Unidad de Salud de la Familia respecto a su vivencia con la situación de la enfermedad crónica del niño. El diseño cualitativo utilizado fue el Interaccionismo Simbólico como base teórica, la Investigación Narrativa como método y entrevistas con las familias como instrumentos de recopilación de datos. Los datos fueron recolectados a través de entrevistas semiestructuradas con siete familias que tuvieron un hijo como miembro con una enfermedad crónica se matricularon en las Unidades de Salud de la Familia en una región con alta vulnerabilidad social, una ciudad de interior. Los resultados mostraron que la relación de la familia con la Unidad de Salud de la Familia está influenciada por elementos de la experiencia y del recorrido familiar, y la vivencia de la enfermedad crónica del niño es fuertemente marcada por la relación con los servicios de salud. Esta situación tiene una gran influencia en las respuestas de la familia, que requiere un compromiso sistemático y comprometido del sistema de salud para aliviar el sufrimiento de la familia, además de solicitar el tratamiento de la enfermedad.

Descriptores: *Familia. Enfermedad crónica. Niño. Programa de Salud Familiar. Atención primaria de salud.*
Título: *Enfermedad crónica del niño: necesidades familiares y su relación con la Estrategia Salud de la Familia.*

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[a] R.N. Master's Degree in Nursing by the Nursing Graduate Program of the School of Nursing, University of São Paulo. São Paulo, SP, Brazil. eli.apoc@gmail.com

[b] R.N. Master's Degree in Nursing by the Nursing Graduate Program of the School of Nursing, University of São Paulo. São Paulo, SP, Brazil. etelsousa@gmail.com

[c] R.N. Adjunct Professor at the Nursing Department of the Federal University of São Carlos. São Carlos, SP, Brazil. mwernet@ufscar.br

[d] R.N. Associate Professor at the Nursing Department of the Federal University of São Carlos. São Carlos, SP, Brazil. gdupas@ufscar.br

INTRODUCTION

Maintaining the family health is one of the most important demands for a society to survive. The literature indicates(1-3) the need to consider the family as a unit of care, which requires a broad look at their health needs, in the sense of a systemic view over its operation and intra- and extra-family relationships.

Chronic conditions are responsible for 60% of the overall onus resulting from diseases worldwide. It is estimated that, in 2020, 80% of the onus of diseases in developing countries will result from chronic problems(4).

The Family Health Strategy of the Brazilian Unified Health System (SUS, as per its acronym in Portuguese) has a health care model based on the family, territory and accountability(5). As a co-participant in the care process, the Family Health Strategy is seen as a possible articulator in the enablement and support of the family unit for coping with the child's chronic disease.

The quality of the bond between the health service – represented by its professionals – and the family constitutes an important condition in the prevention of complications and (re)hospitalizations(6), mainly in the home follow-up and ambulatory segment, which points to the need for studies contemplating this context. At the same time, it becomes vital to cast a glance at the experience of the family with the disease and the processes imposed in this situation(7), aimed at learning its operation and responses, and elaborating strategies capable of reducing the factors that affect the family health negatively.

This study had the purpose to learn the perception of the family regarding their relationships with the FHU in the process of child chronicity. This investigation contemplates the new challenges imposed to the Brazilian health care system in terms of how to understand, cope with and manage the changes in the patterns of occurrence of the diseases and the relationship with the family(8,9).

METHOD

This is a qualitative study, using the symbolic interactionism as theoretical lens, as it indicates that the constructed meanings suffer changes throughout the continuous interactive processes(10). The narrative inquiry with a holistic perspective and emphasis on the content was the methodological strategy chosen to reconstruct the meaningful elements that translate the interaction(11).

The study subjects were families living in a city in the interior of São Paulo, who were assisted by Family Health Strategy teams and complied with the following inclusion criteria: living in the same house with a child (or children) with a chronic disease, being enrolled in the FHU of the region and being indicated by the community health agent of the unit as a service user.

Data were collected between May and August of 2010, in the house of the families registered in the territory of the family health units, which were selected due to the large contingent of child population and because they belong to a region with high indexes of social vulnerability(12).

Exclusion criteria comprised: children who did not have a chronic disease, not being enrolled and/or a user of the selected FHU and not being indicated by the community health agent.

The contact with the FHU occurred once the study proposal was approved by the Human Research Ethics Committee of the Federal University of São Carlos, under protocol 452/2009. The identification and access to the families was initially mediated by the community health agent responsible for the microarea to which the family belonged.

All recommendations of resolution 196/96 of the National Health Council were observed(13). Interviews were the strategy adopted to access the narratives of the families of the children regarding the experience of care in the situation of chronicity(11). The families were invited to narrate their experiences based on the following triggering questions "What is it like for your family to deal with the chronic situation of (child's name)?"; and *"How does your family perceive the participation of the FHU in this process?"*. Other observations and questions were made in the identification of the need to broaden descriptions or to elucidate articulations of the aspects narrated.

Once the interviews were fully transcribed, an initial reading was made focused on the identification of the temporal aspects narrated and actions demanded from the families and professionals. More detailed readings were performed later to search for aspects of the context that enabled the access to the meanings attributed, causes and consequences of the facts narrated, which translated the concerns, suffering and aspirations of the interviewees [11].

RESULTS AND DISCUSSION

Interviews were performed with seven families, who experienced the chronic condition of their children in the home context and were being followed up by the reference FHU. Table 1 shows the general characteristics of the studied families and the time of enrollment to the reference FHU.

In the interpretative lenses[10] used, human beings define and act in a situation according to the constructed meanings, which emerge in social interactions and affect the attitudes, organizational forms and the intra- and extra-personal relationships established. The data analysis permitted to identify five categories based on the trajectory of the family and the relationships established with the professional health care system, which are presented as follows.

Knocking on many doors

The phenomenon of chronicity makes the relationship of the family with the health care system intrinsic to the existence of the family, since living with the chronic disease generates needs for resources that are beyond the internal context of the family unit and that, according to the current social organization, belong to the scope of health care services. Hence, this experience leads the family to seek the professional health care network in order to be supported in their demands[3]. Families in situation of social vulnerability, as it was the case with the families interviewed, are found highly dependent on the public service to assist them.

The family finds countless difficulties in the search for support to treat the disease of the child. The characteristics that permeate the disease and the sickening of the child predisposes the family to a peregrination that aims to find the signifiers of care and a support network that seems reliable and responsive to them.

> *It was really hard when we started searching for treatment... We didn't know, for instance, where to go, or how to do it... Besides that problem, knowing that it is something serious, having a sick child... not knowing where to go! I would go to a doctor, give a medication, then go somewhere else, to another doctor, who prescribed another medication, each doctor would say something different. [...] (Family I).*

A family reports a peregrination:

> *One day I took him to the emergency unit because he had a fever. At the unit, the doctor said: 'Are you treating the murmur yet?' I looked at her and said: 'what murmur?'... Then there was no doctor in the unit [FHU] and my husband told me to take him to the doctor's office. This doctor asked for a lot of exams and said: 'He certainly has a murmur and I think he also has bronchitis' ... I was able to do the exams at the SUS... But I didn't have the time to return to the doctor, because he was hospitalized... His dextro was at 570! I went to the hospital with him, he was hospitalized and transferred to the ICU. He was discharged and saw an endocrinologist who asked for all the exams and confirmed he had type 1 diabetes, child diabetes, then he made other exams and found the heart murmur... (Family V).*

Table 1 – General characterization of the interviewed families. São Carlos, SP, from May to August of 2010.

Characterization	Family I	Family II	Family III	Family IV	Family V	Family VI	Family VII
Pathology of the child	Marfan Syndrome	Phenylketonuria	Cerebral Palsy	Diabetes	Diabetes	Cerebral Palsy	Fetal Alcohol Syndrome
Age of the child	10 years	5 years	11 years	10 years	3 years	7 years	2 years
Time of diagnosis	6 years	5 years	10 years	6 years	11 months	6 years	2 years
Time of enrollment of the family in the FHU	3 years	5 years	2 years	3 years	3 years	3 years	3 years

An Australian study(7) that analyzed in detail the movements of resumption of life balance in families who experienced a chronic disease showed that the attempts to find balance were seriously harmed by fragmented services, which agrees with the findings of this study.

Feeling the repercussions of social vulnerability in child care

Brazilian social data(14) show that the lowest economical classes are more exposed to diseases and complications, less covered with preventive interventions, have a greater probability of becoming sick, lower resistance to diseases, worse access to health care services, lower quality of care received in primary health care services, lower probability of receiving essential treatments and less access to secondary and tertiary level services. The social context in which this study was developed made these conditions worse due to the child's chronicity.

The family perceives impacts on their quality of life and experiences the suffering of wanting something but not being able to have it, that is, they come across the needs of the child, become sensitive to them and, in face of the lack of financial and social resources, long to offer them, if not the cure, a better quality of life.

> *I think a lot about the resource, there is no money to fix it, to improve the situation* [referring to dental problems that the child presents as a result of the chronic disease] *(Family I).*

> *[...] We would like to have conditions, despite knowing he may not… be able to walk, to give him a better life, to make him able to move around, even if it is with a wheelchair. I wish I could take him to school every day, take him to the physiotherapy and aqua-aerobics sessions...* [the family does not have a vehicle and suffers with the precariousness of what is offered by the city government] *(Family III).*

A study(6) that relates the clinical frailty and social vulnerability of children with special health needs states that despite the existence of a legislation assuring the rights of the child, the unawareness of the families regarding these rights superposes it. The findings of the present study reveal the impact suffered by the family as a result of social vulnerability on the experience of living with the child's chronic disease, which evidences the need for legal and social empowerment of these families so as to subsidize them to cope with the needs resulting from the disease and, therefore, to offer better life conditions to the child(6).

At the same time, the family comes across the non-resolvability and slowness of health care services, showing that the dependence of the family regarding the public health care service is emphasized in face of the lack of resources.

> *What bothers me the most is not having resources to solve it and the fact that the government, the medicine in general, which we depend on, take a long time to solve a problem... In the case of this surgery,* [aortic aneurysm], *we waited for two years, he could have died before... and if we had money the surgery could have been made in 1 or 2 months (Family I).*

The vulnerability and suffering are emphasized as the disease of the child threatens deeply the sense of safety and competence of the family, and many of them are not able to engage alone in an active way in the process of restructuring and relief of the suffering(15). Part of these families' responses to the clinical condition of the child depends on the stage of family life, the impact on each member(16), their financial resources, the ability to identify support, mobilizing internal and external resources. In addition, the literature indicates that groups in face of social exclusion are weakened in their capability of reaction(17).

Comparing health care services and acknowledging the FHU as support

In their peregrination through the health care system, the family elaborates their perceptions regarding the service offered, comparing them as for their specificities, potentialities and deficiencies, as well as in terms of their quality, from the technical and relational point of view. By experiencing the several health care services, the family perceives the care provided by the FHU as different from the others, in terms of the proximity and interaction basically through the figure of the community health agent and the home visits.

> *Their system is different, I don't know… They visit us... In our case, there is a girl there, a psychologist, who came here just because the community health agent already comes, I didn't go looking for anyone (Family VI).*

By comparing the service provided by the FHU with that of other health care services, the family identifies a higher quality, as it perceives that by knowing the health history of the families and their members and following up closely the events of the chronicity, there are greater chances to know how they are dealing with the situation and to act according to the needs presented, which it does not identify in other services.

> *It is easier in the unit [FHU] because they already know your problem, they know what you're dealing with, but there I'm not sure... I hate going to that CEME* [Specialized Reference Service] *! I go there because I have no other option! (Family III).*

> *I used to take him to the emergency unit, which is closer to my house, but it is very hard to get an appointment, and there is even a pediatrician, there are more specialties than in the unit, but it is a lot more difficult to get an appointment, everything is more complicated. Different from the FHU, they already know my son there, they know me, they know his problem... (Family V).*

In the bonding with the reference FHU, the family shares needs and establishes partnerships, and by feeling the commitment of the team to satisfy their needs and the concern with their wellbeing, the family becomes more receptive to the team and acknowledges the support provided.

> *The community health agent used to come to my house, she was the one who provided the service [...] So this bonding with the family makes it easier, a lot easier (Family V).*

> *They* [the community health agents] *come to our house, they ask, they want to know how he is doing. I think that just the fact of coming here and wanting to know is a support to the family, because it would be worse if no one were interested in knowing how he is (Family VII).*

In the perception of the family, the FHU acts accelerating the process of access to the network of health care services, as by learning their reality and needs, it prioritizes the resolution of the demands imposed by the chronicity, mobilizing more promptly the internal resources of the team or the support network.

> [in other services]*... you have to see a nurse, so that later she sees your case, check how it is doing, and then refers you to a pediatrician or to another doctor who doesn't know the problem your family is going through. They know my son there* [at the FHU], *everyone knows me, they know I want something, I need something [...] they are one step ahead, they already know you, they know your problem (Family V).*

> *They participated, we needed a dental treatment, and when they found out it was a result of the surgery they got us an appointment very fast, everything was arranged in a week, and they help us in everything we need (Family I).*

> *They taught me a lot in the beginning, also because she studied in a school near the FHU, so she used to go there all the time (Family IV).*

The satisfaction of the family needs, in face of the child's chronic disease, goes through a transformation of the professional practice that allows an approach that is not only territorial, but also relational between the person who offers or provides the service and that who receives it(5, 9), so as to promote commitment, joint construction and solidarity, for family and professionals, from the necessary bonding to the comprehensive care(18), which is somehow favored in the care setting of the FHU.

In order to have the FHU recognized as a support system by the families, the process of bonding becomes salutary, as despite the limitations of the service, the interaction is what promotes trust, referencing and opens doors to the reflection-action of the team regarding their real potential of help/support to the family needs in face of the child's chronic disease(18). In this study, it was possible to observe that the family acknowledged the team as a referential for their needs when the family members were called by their names and the child was known by his/her care day-by-day.

Identifying the limitations of the FHU

The Family Health Strategy seems to produce a positive and progressive effect in the health conditions of the poorer population(5). In the context studied, it was possible to identify elements that lead the family to acknowledge it as a support and, at the same time, to face its limitations in the satisfaction of the family demands.

Being followed up by the FHU, the family approaches the service and becomes capable of identifying its limits, whether they are imposed by its structure, by the relationship with the network of services and the definition of its role in the health care system, or even by the interactive pattern established, that is, the bonding of the family to the FHU through its professionals.

> *They definitely don't have the resources necessary for the whole treatment of his case, they don't have the structure, they have the will, but not the structure [...] (Family I).*

> *They don't have many resources either [...] There is even a physiotherapy service* [physiotherapy intern], *but this type of physiotherapy they offer... They go to the person's house when he/she cannot leave home, in our case we can, we have a wheelchair, and it is too many people for only one physiotherapist... There is only one girl* [physiotherapy intern] *and she can't handle it, she can't. There are too many disabled people here, with all kinds of disability... (Family III).*

The care and the action outlined in the health needs of the family also demand the premise that any health care service or program must keep a direct relationship with the expectations and values of the assisted population(9). The family health units approached in this study were often limited in this area, as the needs resulting from chronicity require a broad action, and even the territorial proximity of the FHU is not enough to meet the needs when it is not connected and protected by intersectorial and multiprofessional actions, within a large social network(3,19).

CONCLUSION

The development of this study allowed to capture the perception of the family regarding their relationship with the reference FHU. In addition, the data also revealed the perception of the families regarding the health services as a whole, and how the experience of the family living with a child's chronic disease is strongly marked by the relationship with the health services.

In this sense, it was possible to identify that the perception of the family regarding the FHU is linked to their trajectory, throughout the course of the disease and the process of bonding, which the family was or is currently experiencing, also determining the feeling of being or not supported.

The structuring of the Brazilian primary health care and the definition of the role of the FHU establish a fluidity of health demands by different levels of care. In the practice, however, the family needs support to go through this transit in the health care system, as well as a service that, despite all the specificities and fragmentations of the service, serves as a broad, concrete and lasting reference in the coping with chronicity, which is potentially the role of the FHU.

The family voices, here presented, reveal that the experience of the family in the context of social vulnerability originates the need to break with the cycle of dependence – non-resolvability – family suffering, in the sense that the health care sector as a whole must assume its participation in the responsibility of social transformation, in light of principles such as comprehensiveness and equity, established in the SUS and planned to be executed by the Family Health Strategy.

At the same time this study provided answers, it also led to new questions regarding the intervention with families facing a chronic disease and suffering, because the results evidenced that this aspect is not a systematic and explicit component of the professional's role and, therefore, in many situations the relief of the suffering and the achievement of wellbeing is given due to the efforts of the family alone.

The trajectory of care taken by the families interviewed expresses suffering, struggle and challenge in face of the events, which produced and still produces impact on the family dynamics and wellbeing. In addition, the families consider the FHU an advance, but which still presents limitations.

Regarding the limitations of this study, it is important to mention the selection of families, as the units of the municipality did not provide an information system with clear records. The identification and access to the families with chronically ill children was limited to the reference of the professionals, the community health agent, who know the territory and have frequent access to the families. However, the perception of those who were not recognized or evidenced by the community health agent may be another perspective that needs to be recognized, which requires easy access to the identification, registration and maintenance of data regarding the families in this condition.

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Author's address / *Endereço do autor / Dirección del autor*
Eliane Aparecida de Oliveira Costa
Rua Caramboleira, 15, Cidade das Flores
06184-250, Osasco, SP
E-mail: eli.apoc@gmail.com

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