

The perceptions of families with children having chronic diseases and their relationships with healthcare professionals

PERCEPÇÕES DA FAMÍLIA DA CRIANÇA COM DOENÇA CRÔNICA FRENTE ÀS RELAÇÕES COM PROFISSIONAIS DA SAÚDE

PERCEPCIONES DE LA FAMILIA DEL NIÑO CON ENFERMEDAD CRÓNICA FRENTE A LAS RELACIONES CON LOS PROFESIONALES DE LA SALUD

Marja Rany Rigotti Baltor¹, Ana Paula Keller de Matos², Monika Wernet³, Noeli Marchioro Liston Andrade Ferreira⁴, Giselle Dupas⁵

ABSTRACT

The prevalence of chronic disease in childhood has increased, placing families in constant contact with health professionals. In such situations the relationship with health professionals has an important role. Few scientific studies address this theme, in spite of its being highlighted as fundamental for effective interaction. The aim of this study was to characterize how the family of a child with a chronic disease perceives its relationship with health professionals. Twenty caregivers for children with chronic diseases were interviewed. The theoretical and methodological frameworks were, respectively, symbolic interactionism and thematic content analysis. The analytical process revealed four themes: role of the caregiver, stressful relationships, services and professionals, and seeking welcoming relationships. The outcomes of this interactional process, which show an incongruity of expectations and behaviors between professionals and families, are poor and generate feelings of abandonment. These can be eased through listening and understanding by other families in similar situations.

DESCRIPTORS

Child
Chronic disease
Communication
Professional-family relations

RESUMO

A prevalência de doença crônica na infância tem aumentado, impondo à família contato contínuo com profissionais de saúde, ocasião em que a relação desempenha papel relevante. Raras explorações científicas abordam tal temática, apesar de ser apontada como núcleo fundamental para a interação efetiva. O objetivo desse estudo foi caracterizar como a família de criança doente crônica percebe sua relação com os profissionais de saúde. Foram entrevistados 20 cuidadores de criança com doença crônica. O referencial teórico e metodológico adotados foram, respectivamente, o Interacionismo Simbólico e a análise de conteúdo temática. O processo analítico revelou quatro categorias temáticas: papel do cuidador, relações angustiantes, serviços e profissionais e buscando relações acolhedoras. O resultado deste processo interacional que apresenta incongruência de expectativas e comportamentos entre profissional e família é falho e gera sentimento de desamparo, o qual é amenizado pela escuta e compreensão de outras famílias em situação similar.

DESCRITORES

Criança
Doença crônica
Comunicação
Relações profissional-família

RESUMEN

La prevalencia de la enfermedad crónica en la infancia ha aumentado, requiriendo la familia un contacto continuo con los profesionales de salud, momento donde esta relación juega un papel importante. Existen pocas exploraciones científicas que traten este tema, a pesar de ser identificado como núcleo fundamental para la interacción efectiva. El objetivo de este estudio fue caracterizar la percepción de la familia del niño con enfermedad crónica sobre la relación con los profesionales de la salud. Fueron entrevistados 20 cuidadores de niños con enfermedades crónicas. El referencial teórico y metodológico adoptados fueron el Interaccionismo Simbólico y el análisis del contenido temático, respectivamente. El proceso de análisis reveló cuatro categorías temáticas: rol del cuidador, relaciones angustiantes, servicios y profesionales y; buscando relaciones acogedoras. El resultado de este proceso de interacción que presenta incongruencia de las expectativas y comportamientos entre el profesional y la familia es deficiente, y genera un sentimiento de abandono, que es atenuado por la escucha y la comprensión de otras familias en situaciones similares.

DESCRIPTORES

Niños
Enfermedad crónica
Comunicación
Relaciones profesional-familia

¹RN. Masters degree candidate at Federal University of São Carlos. CAPES fellow. São Carlos, SP, Brazil. ma_baltor@hotmail.com ²Student of Nursing at Federal University of São Carlos. FAPESP fellow. São Carlos, SP, Brazil. anakeller@hotmail.com ³RN. Adjunct professor in the Department of Nursing at Federal University of São Carlos. São Carlos, SP, Brazil. monika.wernet@gmail.com ⁴RN. Retired Professor of the Department of Nursing at Federal University of São Carlos. São Carlos, SP, Brazil. noeli@ufscar.br ⁵RN. Associate Professor of the Department of Nursing at Federal University of São Carlos. São Carlos, SP, Brazil. giselle.dupas@gmail.com

INTRODUCTION

With the epidemiological transition⁽¹⁾ in Brazil, there has been an increase in the number of chronic medical conditions, including in childhood, which means that the health system and its professionals must resolve the needs of those who live with these conditions, especially the family⁽²⁾.

A family living with a chronic condition suffers changes to its everyday life, in order to meet the demands of the illness. It is common for one family member, often the mother, to assume responsibility for care of the child⁽³⁾. This person is usually designated the primary caregiver.

During the trajectory of care for these children, families encounter and have relationships with numerous professionals and services. The way in which such relationships are experienced may provide comfort and security for the family⁽⁴⁻⁵⁾. However, lack of dialogue and attachment are highlighted as critical aspects that must be considered, with a view to focusing on the family's coping and promoting humanized care⁽⁶⁾.

In situations where listening, dialogue and the offer of comprehensive and contextualized information takes place, partnerships are established that contribute to decision-making, and to maintaining hope in difficult times⁽⁷⁾.

An integral part of the interactional process, communication is a means of sharing and understanding the messages sent and received between the professionals and the family, in a way that maintains the relationship and contributes to mutual enrichment⁽⁸⁾. In spite of its importance, however, obstacles in this area are emphasized in the experience of the families that live with the child's chronic illness⁽⁹⁻¹¹⁾.

In light of the problem described above, this study had the objective to know how the family that has a child with a chronic illness perceives its relationship with health professionals, from the perspective of the primary caregiver.

METHOD

The study followed a qualitative approach which, because it focused on relationships between professionals and families, adopted symbolic interactionism (SI) as its theoretical framework. According to this framework, it is *in and through* social interactions that meanings are established and determine the participants' behavior. SI deals with a dynamic and continuous process in which meanings and actions are transformed⁽¹²⁾.

With a view toward creating a detailed picture of the phenomenon and promoting its understanding, we adopted the strategy of a collective, semi-structured interview for the collection of data. This type of interview is

recommended for situations in which there are people in similar circumstances (in this case, relationships with health professionals, given the condition of chronic illness of the child). Having a group configuration promotes narrative and dialogue⁽¹³⁾.

The study involved 20 caregivers of children aged 1 to 18 years who met the following criteria: the primary caregiver of a child with a chronic illness, in outpatient care, and aged at least 18 years. Twelve participants were mothers, six were grandmothers, one was a grandfather and one was the father of the child. The medical diagnoses of the children were: cerebral palsy (ten children); meningomyelocele (four); Down's syndrome (three); encephalic vascular accident (two); and West's syndrome (one). With the exception of two children, all were diagnosed during their first year of life.

Data collection took place through five group interviews carried out between October and November 2010, which were completely recorded and transcribed. Each interview brought together four caregivers, lasted about 60 minutes, and began with the following question: *How have your*

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relationships with health professionals been throughout your and your children's lives? During the interview other questions were used in a contextualized manner, with the intention of amplifying the description of the phenomenon under study. No caregiver was interviewed more than once, and s/he was identified by a color and the group number in which s/he participated.

The empirical evidence generated underwent the analytical processes recommended by the thematic content analysis⁽¹⁴⁾.

This method is part of the group of techniques used to analyze communication, and the content is taken to be a way of understanding the meanings implicit in the messages. Analysis of the material encompasses three phases: pre-analysis (flowing reading and the formulation of hypotheses), exploration of material (codification and classification into categories), treatment of the results obtained and interpretation (process of reflection)⁽¹⁴⁾.

The recommendations of resolution 196/96 relating to research involving human subjects were followed. It is worth emphasizing that this study integrated the research project *Social support network in coexistence with the chronic illness of the child*, approved by the Research Ethics Committee of Federal University of São Carlos under protocol number 164/2010.

RESULTS

The perceptions of the family member regarding relationships with professionals while experiencing the chronic illness of the child are described based on the four thematic categories: role of the caregiver, stressful relationships,

services and professionals, and seeking welcoming relationships. These are presented below, along with some representative statements.

Role of the caregiver

This category concerns the meaning of being a caregiver, and details the counterpoint of this meaning on the part of the family member and the healthcare professional, from the perspective of the family member. It is composed of two subcategories: *conceiving of oneself as a caregiver* and *being seen as a caregiver*.

In the mind of the caregiver, it is his/her role to defend the rights of the child and to seek to do everything s/he can for him/her, i.e., to seek to meet their needs and to dedicate him/herself completely to finding and maintaining the best care. During this process they experience variations in the child's state of health and care needs, with constant transformations and interurrences appearing that affect the family's ability to meet those needs.

The caregivers are always ready to cope with this scenario, in spite of the suffering and the feeling of lack of social support. To be a caregiver is a complex, difficult, solitary experience, full of surprises and uncertainties. It is challenging, with daily, endless solitary struggles.

...this path is long and it is not easy, no! (Blue, G2).

What don't we do for them? We go to the moon if needed.... we confront fire, water... (White, G1).

We go to various appointments. And for each one there is an expectation and we don't know what is going to be the response. It is a difficult situation. (Green G1).

The everyday life of the family, especially the caregiver, is directed towards the child and its care. This affects their personal relationships, which are limited to the child, members of the family, the professionals, and to caregivers of other children in similar situations. Of these, the latter are highlighted as those with whom relationships are the closest, most frequent, and that best promote coping.

The reality is (...) we stay at home, it is difficult to go out, and you withdraw! So your life is with the mothers! (Blue, G2).

Honestly we speak more among the mothers! We resolve our doubts among the mothers... (Purple, G1).

Being seen as the caregiver

The caregiver perceives that most of the professionals think the family should follow their decisions completely, that is, they charge the family with the faithful execution of the therapy they prescribe. They relate to the caregiver by transmitting information, ordering recommendations and behaviors, and making demands. They perceive that they are seen as the means by which the therapeutic prescription will be guaranteed. However, they are focused on the child's illness, without considering the historical, social,

cultural and economic context of the family. Added to this is the lack of consideration by the professional about what is said and contributed by the caregiver, disregarding almost everything that is not related to the prescribed therapy.

... I get there and say that my son is like this, like that, but they say right away that I am not a doctor! But if I live with him, I know what his symptoms are! I want to tell other things that are important (Brown, G5).

...I am saying that the boy is like this and no one hears... (Violet, G1).

there is one doctor who gets mad if you ask any questions (Red, G5).

It was like I wasn't there! My only duty is to listen to what he wants to say, what he orders. Of course, to do everything correctly later. I think that they think that we are obliged to do everything they ask. It is our duty; it seems as though they think like this (Blue, G2).

The thematic category *stressful relationships* deals with the caregiver's feelings, derived from contact with the healthcare professionals, in which they live with contempt and lack of humanized care. They reveal that the availability of the professional is correlated to the financial component. The subcategories *Lack of appreciation of the caregiver*, *Abandonment in their need*, and *Economic factor interfering in the relationship* explain the elements of this category.

Lack of appreciation of the caregiver

In their relationship with the professionals, especially the physician, the caregiver's observations are not valued. She feels that what s/he says about the child's situation is not listened to or recognized. S/he feels unappreciated, seen only as a resource that promotes the care of the child, as well as a depository for commands and duties.

Added to this is the broad use by healthcare professionals of technical terminology that is not understood by the caregiver. This dehumanizes the interaction, blocks dialogue and does not contribute to the shared care sought by the caregivers. In reaction to this, the caregiver ends up omitting him/herself because s/he feels coerced into silence, listening and responding only to that which the professional wants to ask and hear. They point out that they understand, from the attitude of the professionals, that there is no desire to establish partnerships, to build a space for dialogue, asking questions and making observations. In light of this attitude, the caregiver opts to remain silent, because s/he is afraid of the consequences the child could suffer. Some caregivers tolerate this situation, but simultaneously seek another professional to care for the child.

depending on the professional that you get, you want one thing and you can't have it, you can't understand what he says, you don't understand anything and can't even ask, because they get angry...you can't ask, you just have to listen, obey (Blue, G-2).

Sometimes you are afraid of saying something and harming that care, the person (professional) does not come anymore, doesn't want to look at the child anymore, and it is what you created. So we stay quiet (Blue, G2).

Helplessness in need

Professional interactions with little sensitivity to or appreciation of each family's uniqueness create a sense of insecurity and helplessness. Such feelings result from the lack of a complete connection with the healthcare professionals and inefficient communication with them, as well as disrespect for the child, the family and the caregiver. Caregivers feel stressed because they feel they must invalidate themselves in order to guarantee some care for the child. That is, they focus on the benefits that the professional brings to the child, and try to manage and bear the discomfort and intense anxiety they feel. However, they eventually seek a professional who will welcome them more, as they need to find someone who is capable of understanding them and supporting them according to their needs.

They confirm that in the context of chronic illness it is difficult to find humane professionals that actually desire to establish caring partnerships. They experience relationships of imposition and demand with regard to prescriptions made, which, because they are decontextualized and centered exclusively on the child, may become inefficient. Finding someone who values them, who has an interest in the uniqueness of their situation and who promotes their autonomy as well as that of the family to care for the child, is seen as a solution to the anxiety and insecurity they feel in their relationship with the professionals.

...I wanted to resolve my doubts, because I am the one providing the care. And she didn't look at me, the doctor, only when giving orders about what I have to do. It isn't just this that we need (Blue, G2).

He doesn't do the minimum, doesn't look at me directly, doesn't give any explanation and 'that's it, time's up, you're excused.' It's always like that. There is never conversation. Sometimes they ask 'how are you?' but it's never from the heart, they don't want to know anything about this, only if we did the exercises, gave the medicine, if this, that. It causes anxiety, a lot of anxiety (Green, G4).

Economic factor interfering in the relationship

This subcategory identifies the difference in the interest and professional involvement in the care offered to the child and family when the appointment/therapy is paid for. The family reports that when it is unable to resolve a problem, or is very insecure about what has been prescribed for the child, it resorts to paying for an appointment or treatment. They confirm that when they pay, their experience in terms of listening, valuation and problem resolution is more satisfactory.

Faced with such experiences, some families end up contracting private medical plans, even if their ability to

pay for it is limited, in order to feel more secure, supported and less anxious. They believe that only those with private care are recognized as people and as having rights. Hence they question whether the actions of the professionals are motivated solely by financial interest, to the detriment of the care offered. Unsatisfied with this, but reasoning that it is their only recourse in the face of their suffering, the family accepts the situation for the good of the child.

...in every place I have already been to there have been rude people! Now I am on a private health plan, and for the time being I don't have any complaint! (Red, G5).

...I got a health plan for (child) in order for me to feel like, more secure...to resolve my doubts and for me to be more secure, less anxious... (Red, G5).

The more surgeries they do, the more they earn! That's the way it is; always about money (White, G1).

They highlight some situations with regard to the public health service in which they have experienced quality care, both technical and in relationship terms.

The doctors here are really good...some people say to get one (private health plan), but I say no, that the SUS doctors are good, that they provide good care, that I was referred to any doctor that I wanted (...) People talk about paying, but you just need to be patient, because it takes a while to get an appointment. You can pay, but that is going to take time as well! You pay for an appointment and want it to be right away, but that is not an option... (Brown, G5).

The categorical theme *services and professionals* describes the obstacles experienced by families in their relationships with services and professionals, with direct implications for their search for the best care for the child. The subcategories *lack of consensus among professionals* and *lack of resolution of services* describe these aspects.

Lack of consensus among professionals

The implications of the different concepts and behaviors among the professionals and health services are discussed here. In relationships with the professionals, these differences are perceived and sometimes explained, which places the family in a dilemma: in whom should they believe and trust? This interferes with the connection as well as breeding insecurity about the care being given to the child.

You go to one (doctor) who says one thing, and go to another who says something else. (Blue, G2).

When the doctor went to speak about the orthotics, he was like, Oh, the physiotherapist doesn't know anything, I know my area. But the physiotherapist knew more about the problem than he did. So it was that dispute: I am the doctor, he is the physiotherapist (Rose, G4).

Lack of resolution of services

In the relationship between services themselves, the lack of any connection is explicit and the family does not

receive guidance on the process, who to seek and where to go. This affects the family because it promotes the sense of loss of direction.

He has to come to you and say: I am very sorry, but I have to tell you. You are going through this, this and this. Because then the family is oriented and already knows the alternative that it must take. What should I do? You should do this, that and this. Who should I seek? So and so of such, in such sector, he is going to solve your problem. That's it. And we can move on with confidence (Green, G4).

...To tell you the truth we were confused, and didn't know what to do (Rose, G3).

In some situations, the bureaucracy involved in accessing appointments makes treatment unfeasible and has irreversible consequences for the child.

You wait and wait and wait, and my son is all crooked... he feels a lot of pain...so the waiting lists are what kill us! (Blue, G2).

The case of (child) was negligence here in [names town], it was a really big bureaucracy! (...) we were here for almost ten years without doing anything! (Magenta, G5).

Seeking welcoming relationships

Finding a welcoming relationship brings comfort and helps resolve difficulties. The caregiver mobilizes to find this type of interaction, which is achieved with few professionals but with many peers. This thematic category is divided into the subcategories experiencing support with peers' and reassuring professional relationships.

Experiencing support with peers

Informal conversations between caregivers in similar situations are the main resource for support and information, which encourages them to seek other professionals. By sharing their experiences, feelings and difficulties, they discover resources and ways to access them. Thus, the caregivers support each other both emotionally and with information, providing hope and comfort and a tendency to motivate and improve the functioning of each specific caregiver and family.

Simultaneously, they perceive this mutual help, which increases their feelings of self-worth and self-esteem. Recognizing one's value brings happiness and a sense of satisfaction. This aspect brings caregivers closer and increases their potential as partners, becoming a mutual resource for support and social contact. They feel openness, understanding and tolerance in this contact, which is conceived as limited but complete.

...I went [treatment in another town] because of the recommendations from other mothers. I trust what they tell me (Burgundy, G1).

...it is a struggle, huh? And if [another mother] needs anything, she knows that she can count on us! (Yellow, G2).

Reassuring professional relationships

In their search for health and care for the child, the caregivers may find professionals with characteristics recognized as comforting, which combine technical and interpersonal competence. There is the description of the diagnostic and therapeutic capacity of the professional, associated with the establishment of a relationship in which the experiences, efforts, potential and difficulties of the child, caregiver and family are recognized, which tends to direct the relationship toward important centers of care.

The professional interest shown extends to the family members and is understood as comprehensive, humane care. These relationships are thought of as bringing support, confidence and security, as well as hope for improvements in the current situation. This mobilizes the family's resources, energy and dedication to continue. This aspect is triggered primarily through the sense of having been recognized for their efforts, clarified and informed in regard to the situation of the child, for being considered in the planning of the proposed treatment, and their perceived honesty in this process. Thus the family is kept up to date with therapeutic recommendations, and its achievements are valued in the uniqueness of its situation, which tends to keep it strong. Hope helps the family to manage the adversities of their situation.

These professionals have charisma, which expresses commitment, involvement and dedication in the performance of their profession. They demonstrate availability and interest in the particularities of the family and child. This attitude is perceptible and can be differentiated from that of others who do not show such involvement in their work.

...we end up trusting more because if he [the professional] explains, makes you understand...he is giving you security! The other one sits down, says that s/he needs to perform a surgery, schedules the surgery and that's it! And that is not what we want! (Violet, G1).

Even though the family is going to suffer, [the doctor] must be categorical, must be sincere. He at least needs to clarify. Clarify, and if he doesn't know what to do, refer us to someone who does! (Green, G4).

It is something that you feel inside and you like! (...) So empathy when you arrive, you talk, she laughs....you can tell she likes us! (...). She is always concerned about things... that is nice, there has to be contact! (Blue, G2).

...they are professionals who work with love (Green, G4).

...her humanity with us...for caring about the case, us. I say that she is a complete package (...) she asks how we are, to me and my husband, she interacts a lot with [child], she does tests, she is not rushed in the appointment (...) she revises the medicine that she prescribed (Burgundy, G1).

When the family finds a professional who welcomes them, they make an effort to continue that contact. They move to distant towns just to be cared for by these

professionals, just to experience comforting professional relationships.

There is no security and serenity like Dr. P! There is no other pediatrician like her. [child] has already been sick twice, I brought her to another appointment, but afterwards, when I got home, I had to call Dr. P to see what she thought. (Green, G4).

DISCUSSION

The comprehensiveness of care for people, groups and the community implies perceiving the subject in his/her historical, social, political and family context⁽¹⁵⁾. Thus, it is the professionals' duty to aim to understand the particular experience of each subject and his/her family. Interaction and communication are a way of reaching this goal⁽⁸⁾.

In this study, the professional relationship was characterized as vertical, centered on the information and determination of behaviors and actions idealized by the professionals, with a strong emphasis on their judgment. Such interactions do not permit comprehension of the family's needs and actions, in addition to compromising care, because they prevent the family being a source and depository of information⁽¹⁶⁾.

The lack of connection, security and trust is due to the lack of space for dialogue between the professional and the family, strongly permeated by the negative attitude of the professional, which impedes the establishment of a therapeutic relationship. The theoretical model of family strengthening⁽¹⁷⁾ points to the professional domain as a place to begin the interaction with the family, which is transformed by the possibility of participation and collaboration, so that their potential, needs and coping strategies are revealed and strengthened.

The relationship needs to be understood by the professional as a way of understanding the specific experience. It is carried out in the context in which s/he can recognize how the family perceives and acts in the world, its beliefs, values and needs, elements that guide care. Therefore, the challenge is for professionals to recognize that communication is itself a therapy⁽¹⁸⁾.

The difficulties and suffering present in the course of a chronic illness may encourage coping when interactions with the health professionals are respectful and value the family's strength. They favor the discovery of capabilities and resources, making their potential known, and intentionally using them. Therefore, professional interactions can promote resilience^(3,18).

As in other studies^(4,6,10), support between peers was also specifically highlighted as a resource to deal with stressful relationships with professionals, as well as for finding strategies to break with such professionals and sharing recommendations for more human professionals.

To promote this sharing of suffering and support, the therapy of group meetings is recommended, albeit little used⁽¹⁸⁾: one international study states that its use is only 4.8%⁽¹⁹⁾. Health professionals should value these spaces with the intention of amplifying social support⁽²⁰⁾.

Among these findings, disrespect is also highlighted, associated with the professionals' failure to listen to or attempt to understand the needs of the children and families. The professional attitude of not valuing the family and not identifying it as a partner in the child's care generates a sense of abandonment, a finding from another study that also associated this fact with lack of communication, understanding and imposing demands⁽²⁰⁾.

The World Health Organization⁽²¹⁾ emphasizes that chronic health conditions require cooperation and integration between health systems in order to guarantee the sharing of information in different situations. In Brazil, the unified health system (*Sistema Único de Saúde – SUS*) proposes such comprehensiveness⁽¹⁾ – yet this study shows the opposite. The families report difficulty in accessing treatment and guaranteeing its continuity, which compromises the concept of comprehensiveness and line of care.

The bureaucracy surrounding care is a critical aspect to be reflected upon, since when dealing with children with continuous care needs, any delay or lack of welcoming may have irreversible consequences for the child. This can be characterized as negligence by the professional and the SUS, in addition to imposing such occurrences on the family.

Based on these explanations, this study finds that the care offered to the family of a child with a chronic illness should be rethought, making critical analysis of the relationship between professionals and families necessary. Currently, professional competence is solely in the sphere of technicality, leaving a gap to be filled with interpersonal skills, for effective, humane and comprehensive care. The identification of gaps in communication allows for greater understanding and the possibility of improvements in the care offered to families.

CONCLUSION

This study identified that the relationships with health professionals are perceived as disrespectful, given their lack of recognition of the family's efforts to guarantee that the child's care needs are met. The family places expectations on the healthcare professional to provide such care. Thus, the family tries to express its needs to the professional, although it often does not encounter a sensitive, listening attitude. It receives responses that are incongruent to its needs, and feels abandoned. This feeling of abandonment is eased by listening and understanding from families in similar situations. This

interaction promotes the search for more human professionals and services.

The fact that the interviews were carried out with the users of one outpatient care center may limit their applicability to other services or municipalities. Therefore, replication of this study in other situations, or new qualitative explorations into the interactions between families of children

with chronic illnesses and professionals, may provide more depth and broaden the elements revealed here.

This study demonstrates that communication with the family of the chronically ill child should be reconsidered, mainly with regard to professionals' interpersonal skills. Ineffective communication compromises humane and comprehensive care.

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