

CARE DELIVERY FOR THE CHILD TO GROW UP DESPITE THE PAIN: THE FAMILY'S EXPERIENCE¹

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This study aimed to understand the meaning of the experience of families having a child experiencing pain due to Juvenile Rheumatoid Arthritis and to construct a theoretical model representing this experience. Grounded Theory and Symbolic Interactionism were used as methodological framework and theoretical framework, respectively. Data were collected by semistructured interviews with 12 families. Data analysis allowed for the construction of the theoretical model Caring for the child to grow despite the pain, which describes an experience based on motivational elements: wanting to see the child without pain and wanting to see the child live a normal life, reviewing how the family lives the transition in its development cycles, retaking and integrating them in the family dynamic with the appearance of the disease and pain in the child. This theoretical model provides a framework for teaching, research and care, permitting advances in terms of theoretical nursing knowledge.

DESCRIPTORS: family; child; arthritis, juvenile rheumatoid, pain

CUIDANDO PARA QUE EL NIÑO CREZCA A PESAR DEL DOLOR: LA EXPERIENCIA DE LA FAMILIA

Este trabajo tuvo como objetivos comprender el cotidiano de la familia del niño que vivencia la situación de dolor consecuente de la Artritis Reumatoidea Juvenil y construir un modelo teórico representativo de esa experiencia. La Teoría Fundamentada en los Datos y el Interaccionismo Simbólico fueron utilizados como referenciales metodológico y teórico, respectivamente. Los datos fueron obtenidos por intermedio de entrevistas semi-estructuradas a 12 familias. El análisis de los datos permitió construir el modelo teórico Cuidando para que el niño crezca a pesar del dolor, que describe una experiencia estructurada en torno a los elementos motivadores: queriendo ver el niño libre del dolor y queriendo ver el niño llevar una vida normal, revelando como la familia vivencia las transiciones en sus ciclos de desarrollo, integrándolos en la dinámica familiar con la llegada de la enfermedad y del dolor en el niño. Este modelo proporciona un referencial que ayuda a la enseñanza, investigación y atención, permitiendo avanzar en el conocimiento teórico en enfermería.

DESCRIPTORES: familia; niño; artritis reumatoide juvenil; dolor

CUIDANDO PARA A CRIANÇA CRESCER APESAR DA DOR: A EXPERIÊNCIA DA FAMÍLIA

Os objetivos desse estudo foram compreender o significado da experiência da família da criança com dor decorrente de artrite reumatóide juvenil e construir um modelo teórico representativo dessa experiência. A Teoria Fundamentada nos Dados e o Interaccionismo Simbólico foram utilizados como referencial metodológico e teórico, respectivamente. Foram realizadas 12 entrevistas semi-estruturadas com famílias das crianças. A partir da análise dos dados, emergiu o modelo teórico "Cuidando para a criança crescer, apesar da dor", constituído por elementos motivacionais: querendo ver a criança livre da dor e querendo ver a criança levar uma vida normal, além de elementos intervenientes, revelando como a família vivencia as transições em seus ciclos de desenvolvimento, retomando-os e integrando-os na sua dinâmica com a chegada da doença e da dor na criança. Esse modelo teórico proporciona um referencial para as práticas de ensino, pesquisa e assistência, permitindo avançar em termos de conhecimento teórico para a enfermagem.

DESCRIPTORES: família; criança; artrite reumatóide juvenil; dor

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INTRODUCTION

For the family, the child's chronic pain represents an impact because its members experience a series of feelings, such as despair, anxiety, frustration and impotence in dealing with daily situations. Like adults, the child experiences the pain associated with diseases like Cancer, Juvenile Idiopathic Arthritis (JIA), Sickle Cell Disease, Hemophilia, accidental trauma and burns⁽¹⁻⁴⁾.

Results of a literature review highlight that research about chronic pain in children have focused on pain assessment, mainly its duration and intensity, neglecting its impact and functional consequences for the child and family, which are extremely relevant⁽⁵⁾.

Studies show that children's chronic pain generally changes family functioning through the new demands it creates, making it possible or not to create abilities for the family to overcome this event^(1-2,6).

In this perspective, further knowledge is needed about the experience of families of children with JIA, as research has only focused on aspects like: insecurity and impotence towards treatment and care for the child; the education mode that is offered; the family's feeling that its life is stagnated around the child's pain, besides the ambivalence between hope and conformism with the child's future physical condition^(3-4,7).

Some characteristics of JIA, including the fact that it is incurable and progressive, displaying an uncertain evolution for the child in terms of disability and physical dependence⁽³⁾, aroused our interest in obtaining knowledge about the family's experience of the pain situation in children.

In this sense, this study aims to: understand the meaning of the experience of families of children living in pain situations due to JIA and develop a theoretical model of the experience of families of children living in pain situations due to JIA.

THEORETICAL-METHODOLOGICAL APPROACH

Study characteristics

As a methodological reference framework, we used Grounded Theory, which consists in the discovery and development of a theory based on information that is collected and analyzed

systematically and comparatively. The authors highlight that the theory means "a strategy to work with research data, which provides ways of conceptualization to describe and explain". This method does not aim to establish a perfect description of the research area, but to create a theory that precisely justifies the reality of social interaction and its structural context in the light of an adequate theoretical reference framework⁽⁸⁾.

Symbolic Interactionism was chosen as the theoretical framework because it grants fundamental importance to the sense things represent for human behavior, and its meaning is seen as a social product that originates in symbolic interaction, in which the human being defines and interprets actions through the activities people develop while interacting⁽⁹⁾.

Place of study and subjects

The study was carried out at the pediatric specialty outpatient clinic, in the rheumatology sector of a teaching hospital in the city of São Paulo, which delivers care to children with JIA up to the age of 18. First, the research project was approved by the Institutional Review Board of the institution where data were collected.

Contact with the families was made at the outpatient clinic and each family was invited to participate in the study, including the children. If they were interested and available, the interviews were scheduled with the family and recorded with their consent. The selection was incidental and the medical team helped to identify the families, according to the form and severity of the child's JIA.

The number of families was based on the researcher's analysis of the testimonies and on her observations, and guided by sample groups⁽⁹⁾. The reflections could indicate that other data had to be collected in order to better develop the categories and make them denser as data analysis proceeded. Data were collected until theoretical saturation occurred, when repetition was found, as well as the absence of new data and the progressive understanding of the identified concepts.

Study participants were 12 families of children between 6 and 17 years old, who experienced the situation of pain as a result of JIA and were under follow-up at the Rheumatology Outpatient Clinic, as shown in Tables 1 and 2 below. In total, 27 persons participated: 12 mothers, 2 fathers, 11 children with JIA and 2 siblings.

Table 1 – Characterization of participant families according to age, civil status, religion, family income and education level

	Age	Civil status	Religion	Family income 1	Education level
Fathers	24-60	Married: 6	Catholic: 8 families	Up to 2: 4 families	Unfinished basic education: 9 fathers; 10 mothers
Mothers	28-48	Separated: 5	Evangelic: 1 family	Between 2 and 4: 3 families	Unfinished secondary education: 1 father; 1 mother
		Widowed: 1	No religion: 1 family	More than 7: 3 families	Finished secondary education: 1 mother
			Not informed: 2 families	Not informed: 2 families	Not informed: 2 fathers

¹ in number of minimum wages

Table 2 – Characterization of participant children according to age, gender, diagnosis time, JIA activity and education level

Child	Age (years)	Gender	Diagnosis time	JIA activity	JRA characterization	Education level
1	17	F	15 years	active	systemic, with pain, without limitation and deformity	Finished secondary education college entry exam
2	6	M	4 months	inactive	systemic, without pain, limitation and deformity	Preschool
3	8	F	2 years	active	systemic, with pain, limitation and deformity	1 st grade BE
4	11	F	1 year	active	systemic, with pain, limitation and deformity	4 th grade BE
5	13	F	4 years	active	systemic, with pain and limitation, without deformity	4 th grade BE
6	15	F	11 years	inactive	systemic, without pain, with limitation, without deformity	8 th grade BE
7	9	F	7 years	inactive	systemic, without pain, limitation and deformity	2 nd grade BE
8	12	F	4 years	active	polyarticular, with pain, without limitation and deformity	4 th grade BE
9	12	F	7 months	active	systemic, with pain and limitation, without deformity	7 th grade BE
10	15	F	11 years	inactive	systemic, without pain, with limitation and deformity	6 th grade BE
11	10	F	4 years	inactive	systemic, without pain, limitation and deformity	3 rd grade BE
12	7	F	4 years	inactive	polyarticular, without pain, with limitation, without deformity	1 st grade BE

BE= basic education

Data collection and analysis

Interviews and observations were strategies used for data collection, and were important resources to understand the family experience of children in pain due to JIA. The interviews were semistructured and guided by the following question: *“What has it been like for you to have a child in pain due to Juvenile Idiopathic Arthritis (JIA)?”*

Qualitative interviews aim to understand the person's experience and, thus, one experience is not truer than the other. We can find several versions of the same event and they can reflect distinct perspectives on the fact that occurred⁽¹⁰⁾.

Observation is another important strategy, as it allows researchers to have close contact with the subjects' experience, looking from their perspective, facilitating the understanding of the meanings subjects attribute to actions⁽¹¹⁾.

During data collection, carried out from September 2001 to August 2002, the family members' behavior was observed while they waited for the child to receive care, as well as their interactions with team members and other persons present there. All facts that happened were written down, which were called “observation notes”.

Data collection and analysis were done simultaneously, as recommended by Grounded

Theory. Data were collected until theoretical saturation occurred, when repetition was found, as well as the absence of new data and the progressive understanding of the identified concepts⁽⁸⁾.

The following steps were followed for data analysis: open coding, which consists in the identification and analysis of data obtained through interviews and observations, which are examined line by line and cut into units of analysis, called codes. After coding each interview, categorization was done, when the codes were grouped into categories, based on their conceptual similarities. Theoretical coding consists in an intense induction and deduction movement, in which data are compared and categories are made denser, permitting the identification of the central category that represents the link among all categories. This should be broad enough to express the essence of the study phenomenon and allow for the proposal of the theoretical model that describes the experience under study⁽⁸⁾.

RESULTS

Data analysis allowed for the development of the theoretical model *Care delivery for the child to grow up despite the pain* (Figure 1), which represents the family's experience of the situation of pain due to JIA in children.

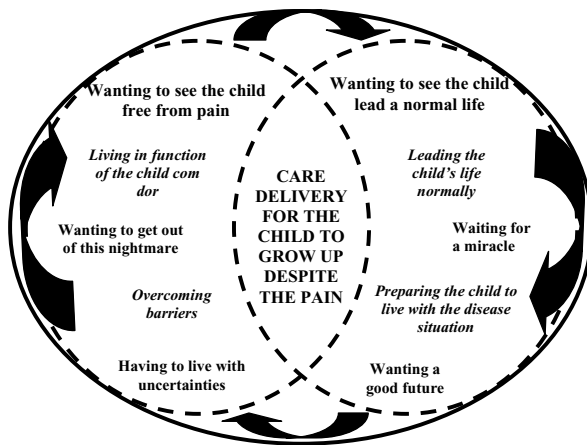


Figure 1 - The theoretical model: Care delivery for the child to grow up despite the pain

The experience that emerged from the integration of concepts reveals that the family lives a trajectory in which meanings and objectives interact all the time. This experience is structured around elements defined as motivational and intervenient and a central category, which appeared as an essential component in the daily lives of families that take care of a child with JIA.

In the family's interaction with the elements present in the experience, motivation is a key component in the family's interaction to perform actions in its daily reality. Thus, it is the strength that moves the family towards specific actions.

In the experience under study, the family's motivation and consequent actions were related with interactions that occur in two domains: the domain of the disease and, hence, the pain, and the child's domain as a being that grows and develops.

For these motivations to become reality, the family should use strategies and actions to execute the child's treatment and the attempt to reestablish normal life, affecting the life cycles of the disease, the family and the child.

When interacting with the child's disease, intentions are created to deliver care in the child's daily life. These reflect the actions performed by the family, which constantly interacts with the pain, seeking ways to relieve it and *wanting to see the child free from pain*.

The search for the child's diagnosis is not a calm trip, but often quite confusing and taking a long time. When discovered, it generates relief, besides feelings of fear and insecurity due to the fact that everything is unknown during this waiting period. This phase entails expectations for the family, suspending

its life and making it exclusively directed at the discovery of the diagnosis.

Life stopped for everybody when he was there, everything stopped, we just thought about the hospital, about him, oh dear, he's our first grandson, he's a son and a brother. (F2)

The family tries to reestablish the balance that was lost, during the transition phase experienced between the healthy child, the discovery of the diagnosis and life with a chronic disease. Its members live a new phase where they should learn to apply actions that help the child to live with his/her new living condition and need to develop ways of dealing with the child's fear about the future.

We are dealing with her, we already got used to it, you know. My mother deals with her normally, I do normally, I carry her, go out with her, we do a bit of everything for her. (F3)

The family needs to overcome the initial shock of receiving this diagnosis and develop ways of learning how to live with the unpredictability of the arrival of pain and, thus, of a crisis. Remaining on the alert, but nevertheless having to manage to live normally, the family remains attentive so that the other children do not feel neglected or left behind in function of the child with pain.

When I see that she lay down and slept, I say oh, she's not well today, when she's very quiet she's not well. (F4)

The change in family functioning starts by destructuring the former balance, leading to changes in the roles played by its members and putting an overload on somebody. These family rearrangements are not always discussed, but often imposed or considered automatic for the family member who already played this role before the disease event. As soon as the child's disease is installed in the family's life and starts to be a part of it, with the mother assuming all care, its members return to their previous life.

I'm the one who's concerned with her at home, you know what men are like, right, boys will be boys, they don't take interest like the mother. (F7)

The fact that the mother remains closer to care for the sick child than other relatives makes her perceive the child's fragility more clearly, trying to protect him/her and dedicating herself more to care delivery. This situation creates conflicts in family relations because the members do not understand this new dynamics imposed by the chronic disease, which demands a lot of attention to the child. The mother has to manage this dynamics and assume a conciliatory position among the family members.

All siblings were jealous of A. because she received all the attention. (F6)

During her experience of the child's illness, the mother is confronted with different kinds of adversities that need to be overcome in order to reach the big goal of delivering care for the child to grow up despite the pain. Prejudice and lack of consideration for the child's disease situation are the elements that most discourage her.

The boys keep on messing with her, making fun of her, calling her names, clone, 'robocop', because she walks in a stiff way, she doesn't run. (F5)

The second motivational element, *wanting to see the child lead a normal life*, represents the family's interaction with the child's domain as a being that grows and develops, besides experiencing the situation of chronic pain in the child, being obliged to perform actions to grant him/her a normal life, discerning his/her development across the life cycle in order to achieve a normal future like other people.

The family's motivation is to teach the child how to live with the pain, encourage his/her relation with peers in order to be able to participate in physical activities, such as playing, running, jumping, having social contact with other people, having friends, going to school and participating in other social activities.

During its experience of arthritis, the family learns that even children with a chronic disease can grow up normally, that is, with demands that are equal to those of healthy children, and is obliged to relate with the child in the best possible way, even if this relation is sometimes marked by difficulties in terms of unsuitable behavior, or in terms of the need to establish limits, which are as normal as in any other family.

Now she plays with everybody, talks, plays soccer, does a bit of everything. (F7)

In view of this new demand, the family needs to learn new strategies but, for this to occur, it should attempt to lead the child's life normally. This is a new normality, adapted to the child's limiting conditions.

I adapted the places to make it easier for her to walk around at home. (F9)

As the child grows up, the family will have to develop abilities to relate with him/her as, despite the chronic condition, (s)he has to live with peers and, therefore, some actions have to be developed so that the child can have a normal life like other children.

I teach her to dry the dishes, obliging her to make an effort to do some housework, taking care so that she doesn't think that she's an invalid. (F10)

The child's chronic condition demands a lot of learning from the family, as it should prepare him/her for the future, teach him/her to face the disease

and live with the limitations, encouraging him/her to perform the activities that are possible and stimulating his/her independence for adult life.

Now A. is already taking the preparatory course, she goes on her own, comes to the doctor alone. (F1)

The family believes that a future without the disease will happen, feels hope of finding the cure for the child, whether by the development of new drugs or by a miracle. The members are strengthened by religiousness, represented by a lot of faith in God.

We lead our lives as God wants it, but I hope that she'll be fine. (F8)

Another construct that makes up the theoretical model in this study are intervenient elements, called: *wanting to get out of this nightmare, having to live with uncertainties, waiting for a miracle and wanting a good future*.

The family's actions are influenced by the intervenient elements, which are its manifested desires, attempting to have its needs solved.

Wanting to get out of this nightmare is a desire that interferes negatively in the family, stimulating its members to persist in their desire for the child not to have a chronic disease, not to feel pain, have neither physical restrictions nor deformities nor suffering.

You feel anguished when you don't know if she's gonna get better soon and when you don't know the extent to which she's feeling pain, we know that the pain is strong but not how strong. (F2)

Having to live with uncertainties is another desire that reveals how the family spends most of its time, sometimes trying to understand the child's disease, sometimes having to live with doubts about treatment, about the next painful crisis, about a possible physical disability, about the child's possible physical deformities, generating a lot of suffering and insecurity for everybody.

You don't know, will she wake up well today, we get like, the fear that she won't wake up well. (F7)

The family always desires and dreams, *waiting for a miracle*, for the child to be cured, despite knowing that the disease is chronic and that it can only be controlled. Nevertheless, its members have faith and believe that God exists and that miracles can happen.

The doctors say that there's no cure, but I'm sure that there is one, I don't believe it's possible that there's no cure for this disease. (F11)

The family also attempts to think positively about the child's future, as if that attracted good vibrations and as if the disease would go away. *Wanting a good future* is the family trying to conquer

a life without pain and restrictions for the child, trying to obtain the cure by making the effort of the harsh treatment.

I am doing everything to avoid a bad future, nothing's impossible for God. (F9)

DISCUSSION

The results of this study revealed that the impact of the Juvenile Idiopathic Arthritis (JIA) diagnosis is enhanced by the abrupt change in the condition from normal to sick child. Besides, the pain appears as a constant precursor of the next crises, leaving the family submerged in an unknown universe. The family feels insecure and threatened by the child's unknown future, related to limitations and physical deformities.

In general, the disease appears unexpectedly and assaults the family, mainly when it affects a child. When hospitalization is needed, none of the two is prepared to deal with this sudden change in daily reality. For the child, the hospitalization represents fear of the unknown, physical suffering caused by the procedures and mental suffering related to all of the new feelings (s)he starts to experience. For the family, it means the feeling of losing normality, of insecurity in their function as parents, of financial change in the domestic budget, of pain due to their child's suffering.

The family's biggest concern is evidenced by the urgency to relieve the child's pain, adopting the child's needs as one significant focus, explained by the motivational element *wanting to see the child free from pain*.

It is considered essential to understand the family life cycle and the psychosocial demands determined by the JIA, as this constitutes particularly relevant elements in the family's experience, allowing us to identify how the family copes with the disease experience, as well as the crises that start to exist in the family's development while experiencing JIA.

In this study, the discovery phase of the pain and chronic disease experienced by the child's family is similar to the denomination of the crisis phase of chronic disease described in a study about the life cycle of the disease. The author highlights that this moment is characterized by the appearance of the symptoms, the occurrence of the diagnosis and the start of treatment, causing insecurity and fear in the family⁽¹²⁾.

In this study, it is observed that the child's disease imposed a movement of the family system

to incorporate its needs, leading to a crisis in the unit as a whole.

For the child's family, in most cases, the pain means experiencing moments of crisis they are confronted with across the life cycle, mainly when the child needs to be hospitalized, facing stressing situations⁽¹³⁾.

The impact of the child's chronic pain is very present in the marriage, as the mother generally carries the overload of giving up her job, home and housework in order to fully dedicate herself to the sick child, who now demands more care and attention, impairing the couple's intimacy⁽¹⁴⁾.

In this study, the mother acts, perceiving the need for intervention characterized by the other children's jealousy of the attention directed at the child in pain, finding herself obliged to harmonize family relations. The mother plays this conciliatory role as a family balancing factor, capable of mitigating the tensions that occur in the relationships among its members⁽¹⁵⁾.

The family's other motivational element, translated by *wanting to see the child lead a normal life*, shows how the family deals with the stress of the disease, at the same time as it develops as a family unit. In this sense, the following fundamental question also emerged: what is the way the family uses to achieve a functional level that is appropriate to the demands posed by the child's disease and to the available resources, as well as to the different dimensions of family life, in the context of the JIA, providing a normal life to the child?

The family performs the action of leading the child's life normally in the present in order to prepare the child to face the adversities that will come up in the future. This normality is definitely adapted to the child's conditions, but allows him/her to go to school normally and maintain life with his/her colleagues.

The family describes the difficulty it faces as the child grows up and becomes an adolescent. The adolescent puts to the test the strict treatment follow-up the family used to maintain until then, rebelling against it, putting the family in a vulnerable situation, as they know that the disease is progressive and that following the treatment is the only option to try and avoid its progression.

In this phase of development from child to adolescent, typical demands are generated. These require the family to promote transformations in the entire structure in order to leave the protection phase of this child and prepare him/her for adult life, exercising an emotional support function, in which the flexibility of family borders needs to increase⁽¹²⁾.

The appearance of the child's chronic pain, at the same time as the development of his/her life cycle, shakes up one of the basic objectives of growth, which is the conquest of adequate independence from the family itself. Thus, the extent to which the pain interferes in the activities performed outside the family and school environment needs to be assessed, trying to harbor a new normality for the child.

For the family, it is primordial to examine how the child's relation with his/her peers occurs in school, if (s)he has friends, if (s)he can participate in the children's games, how (s)he deals with the limitations and how (s)he feels about the questions colleagues ask about his/her condition, in order to have parameters to gradually prepare the child to live with the disease situation.

The disease cycle is added to the family's development cycle, incorporating the demands of the disease in treating the child with pain as normal, in dealing with the problems of each phase in the child's development. One of the family's most anxious desires is for their child to be normal like others and, to the extent that (s)he grows up with the disease, the family dreams that (s)he can do everything other children do, concurring with the others to work, and having a normal life like other people.

It is important to put the evolution of the chronic disease in a developmental context in order to understand the interface in the relationship between family dynamics and the child's chronic disease in different life cycles⁽¹²⁾.

CONCLUSIONS

This study advances by developing the theoretical model *Care delivery for the child to grow up despite the pain*, making it possible to attend the families of children in pain due to JIA, helping them to understand the start of the disease, managing to overcome the impact of the diagnosis more rapidly, accommodating the disease in the family, permitting the maintenance of family structure and coping with the children's chronic pain.

An important aspect of the existence of theoretical models of family experiences created on the basis of research results is the possibility to discuss the influence of these results on practice with families, providing a theoretical reference framework to guide teaching, research and care practices, advancing in terms of theoretical knowledge for the nursing area.

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