SUFFERING EASES OVER TIME: THE EXPERIENCE OF FAMILIES IN THE CARE OF CHILDREN WITH CONGENITAL ANOMALIES[1]

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This study aimed to understand the experience of caring for a child with a congenital anomaly from the family's perspective. Symbolic Interactionism and Grounded Theory were the theoretical and methodological references, respectively. Data collection was carried out with eight families with children having congenital anomalies through semi-structured interviews and participating observation. Data analysis reached axial coding. Results revealed two phenomena in the experience of families in delivering care to children with congenital anomalies – Facing an initially difficult experience and suffering eases over time. We concluded that the understanding of this experience supports the need to reconsider the nursing care provided to families in the care of children with congenital anomalies.

DESCRIPTORS: nursing; congenital abnormalities; child; family

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EL SUFRIMIENTO AMENIZADO CON EL TIEMPO: LA EXPERIENCIA DE LA FAMILIA EN EL CUIDADO DEL NIÑO CON ANOMALÍA CONGÉNITA

El objetivo de este estudio fue comprender el significado de la vivencia del proceso de cuidar de niños con anomalía congénita bajo la perspectiva de la familia. El Interaccionismo Simbólico y la Teoría Fundamentada en los Datos fueron utilizados como marcos teóricos y metodológicos, respectivamente. La recolección de los datos fue realizada en ocho familias de niños con anomalía congénita, utilizándose la entrevista semiestructurada y la observación participante. El análisis de los datos fue conducido hasta la codificación axial. Como resultados, fueron evidenciados dos fenómenos en la vivencia de la familia al cuidar del niño con anomalía congénita: deparándose con una vivencia inicialmente difícil, y teniendo el sufrimiento amenizado con el tiempo. Se concluye que la comprensión de esa vivencia ofrece subsidios importantes para repensar la asistencia de enfermería a la familia que cuida de niños con anomalía congénita.

DESCRIPTORES: enfermería; anomalías congénitas; niño; familia

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O SOFRIMENTO AMENIZADO COM O TEMPO: A EXPERIÊNCIA DA FAMÍLIA NO CUIDADO DA CRIANÇA COM ANOMALIA CONGÊNITA

O objetivo deste estudo foi compreender o significado da vivência do processo de cuidar da criança com anomalia congênita sob a perspectiva da família. O Interacionismo Simbólico e a Teoria Fundamentada nos Dados foram utilizados como referenciais teórico e metodológico, respectivamente. A coleta dos dados foi realizada com oito famílias de crianças com anomalia congênita, utilizando-se a entrevista semiestruturada e observação participante. A análise dos dados foi conduzida até à codificação axial. Como resultados, foram evidenciados dois fenômenos na experiência da família ao cuidar da criança com anomalia congênita - deparando-se com uma experiência inicialmente difícil e tendo o sofrimento amenizado com o tempo. Conclui-se que a compreensão dessa vivência oferece subsídios importantes para se repensar a assistência de enfermagem à família no cuidar da criança com anomalia congênita.

DESCRITORES: enfermagem; anormalidades congênitas; criança; família

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INTRODUCTION

In recent years nurses have searched for a theoretical basis to better deliver care to children with congenital anomalies and their families through studies that focus on understanding the meaning of this experience so as to devise strategies of care delivery to meet their needs(1).

One of the studied aspects is related to the difficulties these families have to face when they have to care for children at home. Authors from one study(2) emphasize that orientation provided to families before hospital discharge does not take into account their needs. Consequently doubts and/or difficulties related to the care they have to provide at home emerge afterward. From this perspective, we recommend guidance to be provided before and after hospital discharge so as to reassure parents and minimize their anxiety.

The institution where the author has developed her activities is a central point of reference in delivering care to newborns with congenital anomalies. However, the participation of families in the care nof children during their hospitalization is still little encouraged because of the facility's poor infrastructure and lack of human resources to meet the large demand of patients.

Health professionals have recently tried to include families in the care of their children, accompanying and helping them to establish a more affective connection with their children. Thus, professionals have stimulated parents to talk to their babies, touch them, bring objects from home that are significant to children, and care for their hygiene and feed them. However, the difficulty in integrating the family when the child is a newborn is even greater because the team members themselves do not to know how to deal with the situation.

When parents receive the diagnosis of a congenital anomaly, they go through a very predictable sequence of stages regardless of the real nature of the condition. The initial stage or impact is of shock, accompanied by crying, feeling of helplessness and longing for escape; in the second stage there is disbelief and denial; sorrow and anxiety expressed through much crying and anger characterize the third stage; then people achieve balance through the acknowledgment of the condition and, at last, families reorganize their life, reintegrating and acknowledging their children(3).

Our concern was to understand the experience of caring for a child with a congenital abnormality for the family after hospital discharge. What are the difficulties and to what extent does the guidance provided during hospitalization help families to care for their children at home? We believe that understanding this experience can provide resources to better support families undergoing the process of caring for a child with a congenital anomaly and therefore devise better intervention strategies. Hence, this study aimed to understand the meaning of caring for a child with congenital anomaly at home from the family's perspective.

METHOD

Symbolic interactionism values that people interact, interpret, define and act in their daily life according to the meaning they attribute to the experienced situation(4). The use of the concepts and central ideas from symbolic interactionism in this study is pertinent because the family is composed of actors who play roles, act and interact among themselves, with their future, their community, with the professionals who care for them and at the same time evaluate the past and plan for the future.

Grounded theory (GT) is based on the social sciences, especially the symbolic interactionism tradition when it portrays society and its actions, then evaluates which aspects need to be investigated and how to understand social situations(5). The employment of this framework permitted the researcher to understand aspects of life as a subjective life.

Study Development

The study was conducted in an outpatients' facility for newborns with congenital anomalies hospitalized in the Neonatal Intensive Care Unit (NICU) of a school hospital.

Guidelines for research involving human beings established by Resolution n° 196/96 of the National Health Council were followed during data collection. Eight families totaling 12 family members, eight mothers and four fathers participated in the study.

Participant observation and semi-structured interviews were used in data collection. The genogram and ecomap were developed before interviews aiming to understand the families' history and dynamics.

The researcher recorded and fully transcribed all the interviews. The following question guided our study: What is it like to care for a child with a congenital anomaly at home? Other questions emerged during interviews aiming to facilitate the interviewees' verbalization of their experience and also to bring out the point of view of other family members: what difficulties have you faced in delivering care to this child at home? What elements facilitate it? As they answered, new questions emerged so to better clarify the aspects of their experience.

Data were analyzed simultaneously with its collection according to GT principles. Because this method is a form of managing data, it is in constant construction, which permits researchers to stop at any level of data analysis and report their findings(5). Although this method proposes the development of a theoretical model, this study reached the Axial Coding stage, which permitted the identification of two representative phenomena of the meaning of caring for a child with a congenital anomaly.

RESULTS

Two complementary phenomena emerged from data analysis concerning the family's experience of caring for a child with a congenital anomaly. The first phenomenon *Facing an initially difficult experience* and the second *Suffering eases over time* were permeated by an evolutionary process marked by moments of unbalance, physical and emotional stress and moments of strength, coping and overcoming. These phenomena emerged from the patients' reconstructions of their experiences, exposing facts from the child's birth up to the current time.

Facing an initially difficult experience represents the family's experience at the beginning, when it had to assume the child's care at home. This phenomenon is revealed through the categories that follow.

Feeling insecure to deliver care reveals the family's reactions at the moment it faces the child in need of special care at home. The family expresses its fears and concerns in relation to care, reporting inexperience and lack of practice to perform care actions.

...as soon as he got home, I was scared to death... of getting him in my lap...had to wash his little wounds... I was afraid of hurting him...Gee! I had to be very careful...had to clean his stitches...everything...(F4).

The family also reveals it keeps *suffering with the situation*. This suffering attests to the fact that they perceive that the child and the whole family have to learn how to live with the limitations imposed by the situation, such as the fear that the child will have a relapse and will be at risk of death, or will be hospitalized again.

...they told me that if he has a temperature, or any kind of infection, it can harm the valve. So I don't want him to be at the risk of being hospitalized again and everything...(...) ...my main concern is that he can't get an infection, any infection...(F8).

Suffering is coupled with the family *having an overload of daily demands*, having to live with the child's situation, which worsens previous difficulties such as the lack of financial resources and transportation.

...I'm running out of money to get here... I still have some, but how it'sn gonna be when I don't have any? So what? If I have no money, I'll have to get it, because I have no car... I need the money for transportation. If his treatment is not over soon, then, I guess it's going to be an obstacle (F1).

Families have to face unexpected situations in their daily routine such as doubts about special care demanded by their children's conditions. These conditions make feelings such as discomfort and disappointment to emerge in the families regarding the quality of care they receive; they become *disappointed* with the care delivered.

...when my child got out of the ICU they told me not to change or take out that thing he had on his back (hydrocolloid dressing)...So I didn't (...) Only that when I got to the neurosurgeon... he said that I'd had to take that out when I got home... that I should have washed it with soap, that I should have cleaned it up so it'd dry because it would never dry like that...(F4).

Aware that the child is depending on its care, the family neglects its own needs and tries to do anything so the child gets better, *promoting the child's well being*.

...I'll put anything aside so I can take care of him, both him (husband) and dinner at home. There's no obstacle for me. If he needs me, night and day... (...) ...I don't have a car, but even so, it doesn't stop me for coming here. I'll get him here...I try to be a super mom...(F1).

Suffering eases over time is the second phenomenon revealed in this experience. Having experienced a difficult time at the beginning enables the family to reveal its willpower to reacquire control, so family and child can have a normal life. Some categories that comprise this phenomenon are presented below.

The family feels more secure to deliver care to the child as they *acquire more experience to care for the child* due to its efforts to acquire knowledge and ability.

...then, with time you get used, you learn...(...) ...For me it is getting easier as time goes by...it's getting easier...(...)...Now I have more practice...(F7).

As the family becomes more self-assured in delivering care to the child, it feels more bonded to the child and expresses all its love with greater intensity. Caring for the child at home becomes more pleasurable, it accepts its condition, which favor *strengthened affective ties through care.*

...for me it's a pleasure getting home...see my child smiling...happy...getting him in my lap is a pleasure, kissing him...everything...(...)...to define it...it's a pleasure to have my child the way he is...(F3).

Feeling comforted reveals that the family is strengthened by the support provided by the health team, the extended family, friends, and faith in God. When the family is helped by people who welcome them with affection, it feels cared for.

...I also have God's support...I guess that God comes first, then the family, because I guess that everything is in His hands. So, if I want advice I have to ask Him...Anything my family cannot supply, I guess that only God can, you know (F5).

After feeling more capable to act and having lessened initial difficulties, the family permits itself to dream of a better future in which the child has the chance to overcome limitations imposed by his(er) condition, *believing in a new perspective on life*.

...right now, for me, I'll be very proud of my son when he gets to walk, because I do have faith he is going to walk!...(...)...my goal is to see him walking. It doesn't matter if he limps...as long as he walks with his own legs...This is my goal and I have faith I'll get there...(F4).

DISCUSSION

The results of this study permit initiating a process to acquire a better understanding of the experience of families with children with congenital anomalies.

When a family takes home his/her newborn child with a congenital anomaly, it experiences worries and anguish in face of the responsibility it now has to assume. Insecurity and doubt emerge during care, not only related to the care demanded by a special child but also the basic care required by any newborn child.

A study that focused on the experience of a family with a child who depends on technology$^{(6)}$ presents some similarities to this study. The family assumed the responsibility of performing oftentimes complex technical procedures, such as the administration of gastrostomy feeding at home. Because the family was already familiar with the process in the hospital context, it felt secure in performing this procedure at home, although it is common to feel unprepared for such responsibility in the beginning.

The transition from the care provided at the hospital to the care provided at home by family members has been a concept under study$^{(7)}$. Hospital discharge represents a symbolic landmark for parents, the beginning of a new phase in their lives when they become responsible for a child with special characteristics. Parents feel unprepared to assume the responsibility of caring for their children and unsure they will be able to continue the treatment initiated at the hospital. Thus, there is a need to prepare parents to care for their children at home.

The family perceives the limitations the disease imposes on the child during daily care and suffers with the prejudice they experience or perceive in society, acknowledging that a congenital anomaly many times compromises aesthetic concerns and makes social integration difficult.

The parents' concern about how the child is perceived by others is one of the categories revealed in a study$^{(8)}$ that focuses on the meaning of the experience of being a mother of a child with a congenital anomaly. It represents the way a mother feels in view of the child's insertion in the family and social context. The evidence of anomaly is perceived by the mother as a risk that the child will be rejected or discriminated against by people. Thus, she directs her mother's role and protective nature when she perceives her child is being rejected because of his anomaly.

The overload of daily demands coupled with suffering from living with a child's condition makes families vulnerable. The greatest difficulties are of a financial nature and cause hardships when resources needed to meet the child's needs are not available.

A study of families of children with chronic conditions focuses on the issue of families' lack of financial resources to deliver care. Financial resources become scarce over time, which might destroy family dynamics and distance family members$^{(9)}$.

Mothers, regardless of having support from other family members, assume their primary caregiving role, since for the society they play a central role in the family structure. This role meets the expectation mothers have for themselves and in order to play such roles they create strategies: they work adequate hours to meet their children's needs and activities, and also to attend the household routine; they even give up their jobs to meet the children's demands(10).

Coupled with difficulties experienced in its daily life, the family becomes disappointed with the care delivered in the health system. It experiences situations that make it feel harmed by the lack of education on how to deliver care to its child. The families also report that there are divergences in guidance provided by health professionals concerning the child's treatment and care.

This disappointment leads families to mistrust health services. It is not sufficient to simply offer the services; access to such services involves other aspects that are significant to maintain users' adherence to the service such as waiting time, physical distance from the service, availability of schedule, and the formation of ties and trust with health professionals(11).

Over time, the family feels more secure with its child and tries to care for him/her in the same way it would for a normal child as a way to cope and overcome the congenital anomaly. Although it cares for its child as if s/he was a normal child, it also understands and acknowledges that care has to be special and include the child's delicate nature and peculiarities.

Studies(6,8,12) focusing on chronic conditions reveal that families seek normal lives. They seek to integrate their children with chronic diseases in their daily lives and in society so they are seen and treated as normal children. Parents always reinforce the positive side, emphasizing that the child has a healthy appearance, stimulate their abilities and compare them favorably with other children, so they are not labeled as sick, different or abnormal.

Gradually, families overcome barriers related to the children's care, which generate feelings of closeness and satisfaction derived from the act of care and families enter a less tense and more affectionate relationship with their children. The child is seen as a child in his/her essence despite the anomaly, which encourages the family to love its child.

The care includes two basic meanings intrinsically linked. The first is related to an attitude of care, solicitude and attention toward the other and the second, concern and anxiety because the caregiver feels affectively involved and connected to the other(13).

A study(14) about the construction of parenting in the experience of a mother of a child with cancer reveals that she constructs her role based on the disease's demands and becomes *a mother of a child with cancer* so as to give meaning to her experience. She plays the role she considers to be hers toward her son, which is a role that improves over time.

We also perceived in this study how hard parents work to construct parenting over time. As they seek abilities to care for their child, they acknowledge emotions involved in the process and realize how pleasurable caring for their child can be since they are able to create bonds with the child and experience love, pride and satisfaction.

The support provided by health professionals, family members and friends strengthen the family and comfort them. This support helps them to create increasingly stronger ties with their child and overcome difficulties and suffering caused by their child's health condition.

Another study(15) focusing on the experience of family's interaction in the context of children's health care reveals that the interaction between health professionals and other families experiencing a similar situation is an important aspect in the family's experience. It feels welcomed when it shares its experience with other families because exchanging and receiving attention, affection and friendship is important for families during this process.

Another aspect that comforts families is related to their faith. Believing in God is a source of energy that strengthens the family trying to cope with the situation of caring for a child with a congenital anomaly.

There are studies in Brazil focusing on spirituality as synonymous with hope and life, courage to fight adversities and minimize suffering(16-17). A study about the experience of a father of a child with a congenital anomaly reveals that he places in God the cure for his child and his own suffering(18). It is in divine protection that he finds strength to overcome his limitations and face the situation.

Strengthening bonds through care experience, families keep making plans because they believe in a new perspective of life for themselves and their children. Even acknowledging all the difficulties, the family realizes that all its efforts are not in vain because the child's condition improves, so they plan to meet the child's needs and also ensure conditions to protect him/her in order to grow happy, away from risks so that in the future, both family and child can harvest the fruits planted with care and love.

WEAVING SOME REFLECTIONS

Understanding the meaning of the experience of families caring for children with congenital anomalies permits grasping and understanding behaviors and actions developed in care delivery. These events confer meaning and promote transformation of the family's perspective of care along its trajectory.

The difficulties experienced by the studied families in delivering care for their children with congenital anomalies led to the reflection about to what extent nurses and other health professionals are attentive to the needs of this clientele. The families' unpreparedness is directly linked to the experience they have during hospitalization. Hence, there is a need for interventions planned and systematized with a view to promote the care of children with this condition at home so as to minimize the overload of demands and suffering families experience.

In this perspective, we believe that the health team needs to care for families not only during their children's hospitalization at the neonatal ICU but also after hospital discharge so they receive support and are allowed to express their concerns in order to be better prepared to provide safe care for their children at home.

When we get close to families of children with congenital anomalies we have the opportunity to reflect upon the nursing profession's practice and acknowledge the need for these professionals to be present, especially in the daily routine of these families, helping them to cope, especially during the adaptation phase, aiding them, providing adequate information, suggesting solutions, facilitating access to services they need and especially developing a professional and personal practice of listening and welcoming them in moments of crisis.

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