

## The parental care partnership in the view of parents of children with special health needs



*A parceria de cuidados pelo olhar dos pais de crianças com necessidades especiais de saúde*  
*La colaboración en cuidados según la mirada de padres de niños con necesidades especiales de salud*

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### How to cite this article:

Alves JMNO, Amendoeira JJ, Charepe ZB. A parceria de cuidados pelo olhar dos pais de crianças com necessidades especiais de saúde. Rev Gaúcha Enferm. 2017;38(4):e2016-0070.

doi: <http://dx.doi.org/10.1590/1983-1447.2017.04.2016-0070>.

doi: <http://dx.doi.org/10.1590/1983-1447.2017.04.2016-0070>

### ABSTRACT

**Objective:** To understand how the care partnership was experienced by parents of children with special healthcare needs.

**Method:** Qualitative, descriptive and exploratory study, carried out from December 2013 to February 2014. The method used was the narrative. The population corresponded to parents of children admitted to a medical service of a Pediatric Hospital in Portugal. The sample consisted of 10 parents. The data collection included the sociodemographic characterization and the ethnobiographic orientation interview. Once transcribed, the interviews yielded 10 narratives of partnership experiences between the parents and the nursing team.

**Results:** It was noted, as partnership opportunities, the training of parents and the collaborative decision-making, established in a dynamic, unique and ongoing relational process. **Conclusion:** The opportunities for partnership are key assumptions for the care delivery focusing on the child and on the parents as their resources.

**Keywords:** Child. Nursing. Chronic disease. Parents. Caregivers.

### RESUMO

**Objetivo:** Compreender como foi experienciada a parceria de cuidados pelos pais de crianças com necessidades especiais de saúde.

**Método:** Estudo qualitativo, descritivo e exploratório, realizado no período de dezembro de 2013 a fevereiro de 2014. O método utilizado foi a narrativa. A população correspondeu aos pais de crianças internadas num serviço de medicina de um Hospital Pediátrico em Portugal. A amostra foi constituída por 10 pais. A coleta de dados contemplou a caracterização sociodemográfica e a entrevista de orientação etnobiográfica. Depois de transcritas, as entrevistas originaram 10 narrativas de experiências de parceria dos pais com a equipe de enfermagem.

**Resultados:** Constatou-se, enquanto oportunidades de parceria, a capacitação dos pais e a tomada de decisão em parceria, estabelecidas num processo relacional dinâmico, singular e contínuo.

**Conclusão:** As oportunidades de parceria são pressupostos fundamentais para a prestação de cuidados com foco na criança e nos pais enquanto recursos da mesma.

**Palavras-chave:** Criança. Enfermagem. Doença crônica. Pais. Cuidadores.

### RESUMEN

**Objetivo:** Comprender la percepción experimentada por padres de niños con necesidades especiales de salud sobre su colaboración en los cuidados de enfermería.

**Método:** Estudio cualitativo, descriptivo y exploratorio, realizado entre diciembre de 2013 y febrero de 2014. El método utilizado fué la narrativa. La muestra poblacional abarcó a padres de niños internados en servicio de medicina de un hospital pediátrico de Portugal. La muestra fue constituída por 10 padres. La recolección de datos incluyó la caracterización sociodemográfica y la entrevista de orientación etnobiográfica. Después de transcritas, las entrevistas se produjeron 10 historias de experiencias de colaboración de los padres con el equipo de enfermería.

**Resultados:** Se confirmó la existencia de oportunidades de asociación, la capacitación de los padres y la toma de decisiones en conjunto, las cuales son establecidas en un proceso relacional dinámico, único y permanente.

**Conclusión:** Las oportunidades de asociación son condiciones fundamentales para la prestación de cuidados de atención en los niños, siendo los padres los medios del niño para obtenerlos.

**Palabras clave:** Niño. Enfermería. Enfermedad crónica. Padres. Cuidadores.

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## ■ INTRODUCTION

In the current reality of child and youth healthcare organizations, parents are considered partners of health professionals. It is part of their parental role to take care of their child, in health and illness, which is as important as feeding, educating, distracting or facilitating their development. The exercise of the parental role in populations in need of special healthcare is a challenge for them and requires nurses to design the care processes based on evidence-based practices, where the research assumes a growing and fundamental preponderance.

Children with special health needs (SHN) have chronic physical, developmental, behavioral, or emotional disorders, such as chronic renal failure, asthma, congenital malformations, oncological diseases, autism, or cerebral palsy<sup>(1-2)</sup>. Parents have to adapt in order to take care of the child at home, necessitating a broad network of family and social support, with the close involvement of health professionals<sup>(3)</sup>. As mentioned above, pediatric nursing care based on the philosophy of family-centered care and the partnership model of care are considered ideal to help parents fulfill the role they will play<sup>(2)</sup>.

International studies have shown that parents seem to value the interactions in which they felt that the nurse knows, understands and cares about the child and the family, namely in meeting the needs of care and development<sup>(3-4)</sup>. Parents also value the sensitivity and attention shown by the nurse in adapting real-life circumstances to the potential of the child and his/her family, both at the most superficial and concrete level of clinical aspects and in meeting specific emotional needs<sup>(4)</sup>.

In a systematic review of the literature<sup>(3)</sup>, nurses' attitudes, respect, trust, empathy, and advocacy were identified. These attitudes are described in the literature as attributes of the partnership model. The relationships established between the parents and the health professionals who meet these requirements were characterized as promoters of parents' training.

Likewise, gaps have been reported in the transmission of complete information to parents about the clinical situation, treatment and care of the child with SHN<sup>(5)</sup>. These gaps are extended to the communication and sharing of information between the different professionals of the institutions that provide healthcare to children with SHN, interfering with the appropriate coordination of the services, in order to respond adequately to the needs of the children and their families<sup>(3)</sup>.

The nursing care partnership model highlights the centrality of the child and the family in the care process, by their full integration in decision making<sup>(3)</sup>. "The partnership means

change, negotiation of the care to children shared with the family; support, teaching and involvement of the family as the result of a negotiation previously established"<sup>(3)</sup>.

The negotiation is based on the value of equality between parents and nurses; and once it is implemented, it values a collaborative dynamics in care planning<sup>(6)</sup>.

Despite the above, the contemporary research produced around this phenomenon points towards the deepening of the analysis of partnership experiences established between parents and nurses<sup>(2-3)</sup>. For this reason, we have developed a broader research study on the care partnership, aiming to better understand the model in use in a given context of care, which was constituted as a master's thesis<sup>(7)</sup>. It was outlined as a research question: what partnership opportunities do parents of children with SHN identify? And as objective: to understand how the parenting partnership of children with SHN was experienced.

## ■ METHOD

This study is qualitative, descriptive and exploratory. We analyzed the material obtained through ethnobiographic orientation interviews, focusing on the experiential event<sup>(8)</sup>. It was developed in a Pediatric Medical Service of a Pediatric Hospital in Portugal.

The population corresponded to the parents of children with SHN (father and mother), users of the research context. In continuity, we have used a non-probabilistic sample for convenience<sup>(9)</sup>, consisting of 10 parents of children with SHN. The sampling technique used was the intentional sample.

The inclusion criteria in the sample were: parents of children/adolescents whose individual condition fits in the group of children with SHN; diagnosis for more than one year of the health condition of the child/adolescent; parents who experienced previous hospitalizations, due to prior knowledge and time of contact with the nursing team; parents of children with SHN identified by reference element of the nursing team of the research context as having good communication skills.

As exclusion criteria: parents whose children were in the inaugural episode of their health condition, although they were part of the population of children with SHN; parents of children with transient and acute health needs.

Ten unstructured interviews were conducted with parents of children with SHN in the period from December of 2013 to February of 2014, which were transcribed after recorded in audio. After reading it in its entirety, 10 narratives were constructed from which, after having been written and read in full, it was possible to obtain a global perspective of

its contents. Essential process for the apprehension of the elements that stand out in the history experienced<sup>(10)</sup>.

The constituent elements of the ethnobiographic orientation interview were the following: initial question (I would like you to tell me stories that mention experiences in which you have had the opportunity to work together with nurses to provide care for your child along the way you have experienced); final phase of the interview, in which the content narrated was analyzed and new issues related to aspects that were not thoroughly explored or obscured, such as the theoretical aspects of the facts, related to the interviewees' feelings about the experiences reported<sup>(10)</sup>.

In the next step we resorted to content analysis. We performed the analysis of meanings, the codification, and the categorization of the data<sup>(11)</sup>. Given the uniqueness of each story, the analysis of meanings allowed to identify the global components of the contents, the common patterns, as well as to interconnect all the narratives and to investigate the way in which they answered the research question<sup>(10)</sup>. In continuity, the data obtained was coded. The coding is a process in which the data is systematically transformed and aggregated into units of analysis, which allow an accurate description of the relevant characteristics of the content. This transformation occurred by clipping, enumeration, classification, and aggregation<sup>(11)</sup>. We assigned a code to the participants (P1, P2, P3, P4, P5, P6, P7, P8, P9, P10) that we maintained in the identification of narratives and registration units. In the organization of the coding, we used the clipping to select the registration units and the context units; the enumeration, in which we defined as frequency counting rule the frequency of each unit of record in the text; classification and aggregation of the data by selecting the respective categories.

Since the categorization is a classification operation of the constituent elements of a set<sup>(11)</sup>, we performed the categorical analysis, regrouping the data by themes, categories, subcategories, context units, and registration.

This study was approved by the Ethics Committee for Health of the Health Institution. The approval was signed in letter No. 0161 with CES reference, dated of October 21, 2013. The participants involved in the study signed a Free and Informed Consent Term at the stage prior to the data collection, being guaranteed the confidentiality of the data, anonymity and the right to free choice when participating in the research.

## ■ RESULTS AND DISCUSSION

The health conditions of the children were related to Chronic Renal failure, which resulted in the need to per-

form peritoneal dialysis (4) and to have a bladder stoma (1); Hirschsprung Disease requiring gastrostomy (1); Cerebral Palsy (1); Short Bowel Syndrome (2) and Neuromuscular Disease requiring a tracheostomy (1). These conditions insert them in the group of children with SHN<sup>(1-2)</sup>.

The participants in this study were the mothers of children with SHN, aged between 20 and 49 years old, predominantly between 30 and 39 years old, whose education ranged from basic education, secondary and tertiary education, married and integrated in a nuclear family.

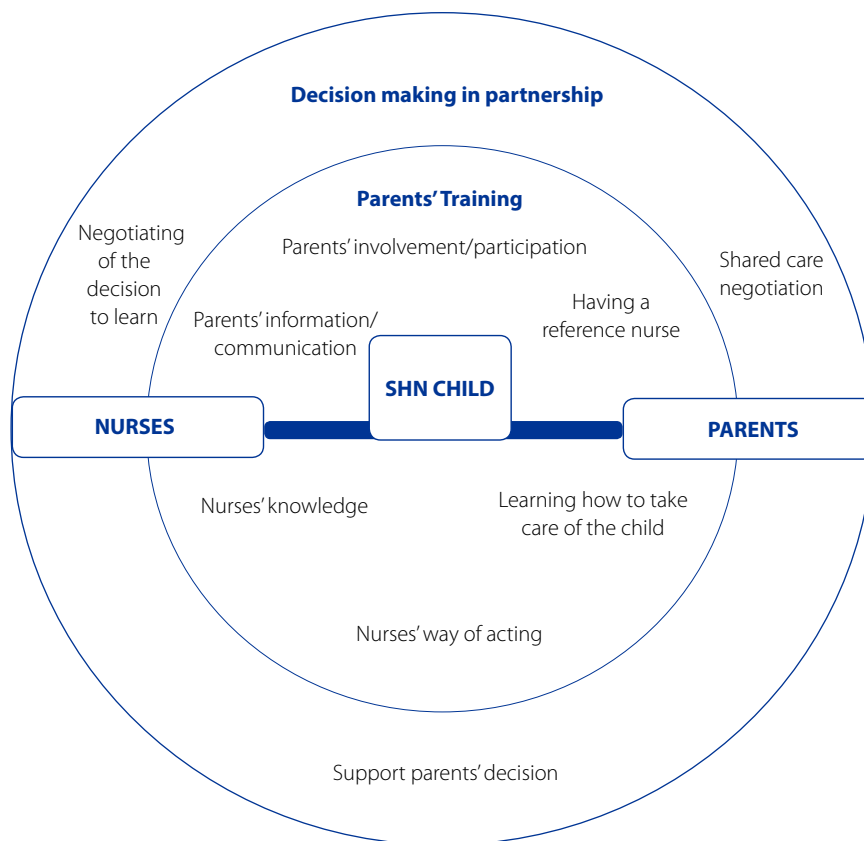
The process of content analysis of the narratives allowed the establishment of two categories, these being the parent training and decision making in partnership and respective subcategories. The parents' training category included parents' involvement/participation subcategories (10); information/communication with parents (9); having a reference nurse (7); learning how to take care of the child (5); the nurses' knowledge (4); nurses' ways of acting (3). In turn, three subcategories emerged from the decision-making partnership category: negotiation of the decision to learn (4); shared care negotiation (4); support the parents' decision (4).

With the results obtained from the analysis of the narratives, we built a schematic representation of partnership opportunities (figure 1).

The schematic representation shown in figure 1, set in circles, idealizes a human development system, which is open and dynamic. The background image was adapted from the bioecological model of human development presented by Bronfenbrenner and Morris<sup>(12)</sup>. These authors advocate models of human development that consider the diverse environments in which the person lives, relates, and develops. The subject/environment interaction is characterized by reciprocity, that is, one influences the other, it is a process of mutual interaction. The sharing of knowledge and experience results from processes that have contexts of working in partnership as the "stage".

The model is based on the premise that the human development is systemic, where no part makes sense without the vision of the whole. The whole can only be analyzed from its parts and the contexts are environments that influence and are influenced by the person. It considers four essential elements: the person, the process, the context, and the time. The person is significantly influenced by the interactions between ecosystems (context/environment) that overlap each other.

For our study, we considered it pertinent to use two ecosystems: the microsystem and the mesosystem. A microsystem is a pattern of activities, social roles, and interpersonal relationships experienced by the developing person in a given environment with particular physical,



**Figure 1** – Schematic representation of partnership opportunities from the perspective of parents of children with SHN

social, and symbolic characteristics that invite, allow, or inhibit sustained involvement in progressively more complex activities in interaction with the environment. A mesosystem includes the interconnections and processes that take place between two or more environments that contain the developing person. It emphasizes development as being directly related to the number of contexts in which the person participates.

The names presented: the child, the parents, and the nurses, are understood as active, dynamic subjects, who create and recreate progressively the environment in which they find themselves. The Human Being acts taking into account the meanings built from the social interactions that he develops, influencing his/her attitudes, forms of organization, and interpersonal relationships that he/she establishes<sup>(10,12)</sup>.

The child was in the central position of the partnership care<sup>(3,13)</sup>:

*It was good “[...]” to have learned “[...]”for the child (P3). And then “[...]”there was a nice little room for the boys to play, “[...]” it was the nurses who put the boys on the floor*

*for them to play “[...]” they “[...]” must be healthy (P6). “[...]”I saw that everything she had done “[...]” was just for his good (P7).*

The contexts in which the work in partnership was developed and the time it was spent were understood as resources for the mothers, who work together with the nurses to obtain gains in well-being, quality of life<sup>(1,14)</sup> and integral development of the children<sup>(5,13)</sup>.

*Since birth, she has lived the first 10 months inside the hospital and “[...]”the constancy was daily “[...]”to perform with the nurses, from knowing how to handle a baby with the wires attached to it, from the feeding (P6). This partnership I established with them was, it was very good (P8).*

The remaining terms presented in the schematic representation are results of the study. The parental empowerment and the decision-making in partnership arise as partnership opportunities, established within a relational, dynamic, singular and continuous process unfolded in the context of partnership.

## Parents' training and the establishment of a partnership relationship

In the data related to the category of parents' training, the development/participation in the child's care had as purpose their full capacitation. Over time, most participants wished to have the opportunity to learn how to deal with the complexity of children's health/illness situation<sup>(4)</sup>, that is, to gradually qualify. The learning opportunity has led to the development of mothers' knowledge and skills to care for their children<sup>(4,14)</sup>.

*"[...] I had to do [...] as if I were the nurse (P1). And after that day [...] it was step by step. While I did not feel able to do everything alone in the hospital, they did not send me away. (P3) [...] from day to night or night to day, I woke up with that desire that it had to be and that it had to start and that was it, I had to get it [...] I was a teacher in the process (P4). When we were doing the parenteral nutrition [...] we first had to see how they did it once or twice and then we started doing it and it went well (P9).*

The term parental involvement covers the caregiving and the decision making<sup>(6,15)</sup>. In this perspective, the mothers felt totally involved in the care they gave their children. When they felt empowered to take care of the child, they became involved, assuming full care.

*"[...] I became the nurse of A [...] 24 hours, the father was the nurse's assistant (P6). ... since I was there, it was me who cared for the child from beginning to end" [...] "they gave me this opportunity by being present (P8).*

When parents feel involved as partners, they describe it as an interactive process that resembles a "dance" in which the "choreography changes over time" as well as the rhythm of involvement and participation<sup>(4)</sup>.

The information/communication was valued in accordance with the results of studies in which parents were given increased importance as they had a wide range of information on the child's situation and the care to be given to the child<sup>(3,15)</sup>. Parents become specialists in child care and their knowledge and skills must be respected by nurses<sup>(3)</sup>.

In turn, having a reference nurse meant being able to enjoy the care of a person with extensive experience, which gave them peace of mind<sup>(16)</sup>.

*The first time I did it alone at home was on the phone with the [...] support nurse, to see if everything was fine and she said it was. I think it is important that we have some-*

*one to communicate with. It was a great opportunity and a great support that we had (P2). They are there [...] to inform us. They do not leave us worried, therefore, there is always, there is communication, in every sense, there is communication, they communicate and they listen to us [...] anything that happens at home, the first person I talk to [...] is always a nurse (P5). A nurse like her in the service [...] had a lot of experience and gave me a lot of peace of mind (P6).*

They said that learning how to take care of the child was critical to their empowerment. In the different partnership experiences established with nurses, in addition to valuing learning moments, they placed a special emphasis on nurses' knowledge about the condition of these children<sup>(4,17)</sup> and their ways of acting. Nurses' ways of action emerge with emphasis on the nature of the partnership based on interactive help processes<sup>(5)</sup>, making the relationship real and useful for both parents and the child.

*I had two nurses [X and Y] teaching me (P2). [...] I did an apprenticeship with each nurse [...] those details, those doubts that arise in the situation, that we do not know what to do with and ask the nurse [X] and she says: Look, this way is better [...] the ways in which each one works are different [...] to put together what each one knows [...] helped me [...] "it is all positive experiences (P5). [...] they teach us as the book says [...] it was fun to see the techniques of those people [...] by doing new things [...] we learned a lot "(P6) "... "they had knowledge" ... they have the necessary knowledge [...] they know the situations (P8). Each one has [...] in the end it's all the same, but each one has its own ways of doing and we have been picking up a way from one part of another and we have made our method, right " "And we do it at home (P9).*

Parents value the nurse's sensitivity and attention to working the real and potential life circumstances of the child and his/her family, both at the most superficial and concrete level of clinical aspects, and in meeting specific emotional needs<sup>(4)</sup>.

## The process of consolidating decision-making in partnership

Regarding the data obtained in the category of decision-making in partnership, we are in agreement with the results of studies carried out in Portugal, which demonstrate that there is, in general, availability for the establishment of negotiation of the decision<sup>(5)</sup>. However, some of

the mothers valued the shared care negotiation as part of the work in partnership with nurses, contrary to what happened in the previous subcategory.

*"[...] they also hear us, they also hear us. For example, wearing a nightdress and telling them no, it is easier to take them by the arm, they listen to us, they obey our opinion (P5). "... they were always open" [...] "if there was anything that would be harmful to him" [...] "they said" [...] and we understood [...] they gave us various alternatives to everything (P9).*

We found that as mothers felt empowered, they wanted to make the most decisions independently and/or in collaboration with the nurses, leading the decisions that involved managing the care for their children<sup>(4,14)</sup>. In this way, nurses should support the parents' decision, this being another subcategory to which mothers attributed value.

*The first time I popped the bags I pierced a bag and filled the bed with liquid [...] it was time to care for my daughter, but then I had another bag to warm [...] and do it only half an hour later [...] I then phoned the nurse [X] who is the reference nurse and she said it made no difference and that I could do it half an hour later. I think that [...] it is a great opportunity and a great support that we have (P2). A decision I made, in which [...] I was supported by my nurse (P5).*

The mothers felt comfortable with the support they received from nurses in relation to their decisions, in agreement with the conclusions of another study in which it is mentioned that despite the specific circumstances in which the partnership experiences occurred, it is important to discuss the decisions with the nurses<sup>(15)</sup>. However, "this care model requires a level of collaboration between parents and nurses, based on mutual respect and trust, impacting on self-confidence and the full capacity of parents to "live" with a child with SHN<sup>(3-4)</sup>. This assertion reflected the value of the participatory and relational aspect of the work in partnership with the parents, namely being heard, respected, and supported in their decisions.

## ■ FINAL CONSIDERATIONS

The parent empowerment and decision-making in partnership are opportunities valued by the mothers of children with SHN, since they have facilitated the fulfillment of their parental role. The elements of analysis, when val-

ued by parents, should be a reference for nurses, because they can facilitate the planning of the work in partnership.

Although the parents' training and decision-making were already part of the terms used in the partnership models, they were not identified as opportunities for partnership. New terms/expressions have been associated with the concept of partnership, denominated as constitutive elements: learning how to take care of the child, ways of acting of the nurses, having a reference nurse.

For the nursing care practice, the results of this particular study will enable nurses to develop care processes for children with SHN that encompass opportunities for partnership, reflecting the need to empower parents and involve them in decision-making. The elements associated with partnership opportunities are fundamental assumptions of the care partnership, with a focus on the child and parents as resources.

With implications in the management of the nursing care, the importance of the role of the reference nurse emerged, which was highly valued by the parents, namely in the support to the training and emotional support that the latter makes available to them. It was also clear that the use of the work method by the reference nurse is significant in the periods when the child and parents are hospitalized, but also when they are at home, because this professional constitutes an information/training support link, being able to articulate with other professionals and/or available resources. Nurses' knowledge and ways of acting were sensitive to the training of mothers, so we deduced that they should be the most qualified nurses with cognitive, technical-instrumental, and relational skills to play this role.

Finally, we highlight the possibility of continuity of this study in order to be able to answer the questions that derive from the discussion and interpretation of the obtained data, of which: which model of care partnership is significantly relevant for caring for children with SHN? What is the relationship between partnership opportunities to care for children with SHN and the quality of life of these children and their families?

Overall, the results of this study found a foundation in the theoretical frameworks of partnership models and in the practice of caring in partnership (model in use), for which it added a greater appropriation of the concept of partnership with implications for the nursing discipline and greater knowledge about the partnership opportunities.

As limitations of the study we were unable to obtain data from parents of children with SHN related to chronic respiratory problems, diabetes, and oncological, among the frequent health conditions in this pediatric population.

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Received: 12.31.2016

Approved: 07.27.2017