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NEGOCIAÇÃO DE CUIDADOS NUM SERVIÇO DE PEDIATRIA: DISCURSOS E PRÁTICA CARE NEGOTIATION IN A PEDIATRIC WARD: DISCOURSES AND PRACTICE NEGOCIACIÓN DE CUIDADOS EN UN SERVICIO DE PEDIATRÍA: DISCURSOS Y PRÁCTICA

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RESUMO

Introdução: A negociação de cuidados assume uma dimensão estruturante para o sucesso da interação entre pais, criança e enfermeiros durante a hospitalização. Contudo, constata-se uma escassa evidência científica sobre as perspetivas de pais relativamente ao processo negocial.

Objetivo: Compreender a negociação de cuidados desenvolvida entre enfermeiros e pais no serviço de Pediatria Médica.

Métodos: Estudo de abordagem qualitativa de tipo descritivo, que contou com a participação de 11 pais. A recolha de dados realizou-se através de entrevistas semiestruturadas e os dados analisados com recurso à técnica de análise de conteúdo segundo Bardin (2016).

Resultados: Dos discursos e perspetivas dos pais sobre a negociação de cuidados, emergiram cinco domínios. As condições estruturantes, e o conhecimento da criança e família, são alicerces para sustentar o processo negocial. Na negociação propriamente dita, confluem dois papéis, o parental, com a assunção e a adaptação à condição do papel parental, e o papel dos enfermeiros. Há comportamentos promotores da negociação, que tendem para a naturalidade do processo de negociar, não obstante, existirem também comportamentos por parte dos enfermeiros que inibem a negociação. O apoio após a alta é reconhecido como um importante suporte após o regresso da criança a casa.

Conclusão: Os achados permitem uma clarificação dos papéis dos diferentes intervenientes na negociação de cuidados, com potencial para contribuir para a implementação de ações favorecedoras do processo negocial de uma forma mais sustentada e intencional.

Palavras-chave: negociação; pais; criança; enfermeiros

ABSTRACT

Introduction: The negotiation process between parents, children, and nurses during hospitalization must be structured for a successful interaction. However, there is limited scientific evidence on parents' perspectives.

Objective: Understand the negotiation process that takes place between nurses and parents in the Paediatric Ward.

Methods: A qualitative descriptive study was conducted with 11 parents using semi-structured interviews. The data was analysed using content analysis techniques by Bardin (2016).

Results: Five domains emerged from the discourse and perspectives of parents regarding care negotiation. The structuring conditions and knowledge of the child and family serve as foundations to support the negotiation process. During the negotiation itself, two roles converge: the parental role, involving the assumption and adaptation to the parental role, and the role of the nurses. Some behaviours promote negotiation, aimed at making the process more natural. However, some behaviours on the part of the nurses could hinder negotiation. Post-discharge support is acknowledged as an essential extra support once the child returns home.

Conclusion: The findings provide clarification of the roles of the different participants in care negotiation, with potential contributions to the implementation of actions that improve the negotiating process in a more sustained and intentional manner.

Keywords: negotiation; parents; children; nurses

RESUMEN

Introducción: La negociación de los cuidados es un aspecto clave para el éxito de la interacción entre padres, hijos y personal de enfermería durante la hospitalización. Sin embargo, hay poca evidencia científica sobre las perspectivas de los padres en el proceso de negociación.

Objetivo: Comprender la negociación de los cuidados entre enfermeras y padres en el servicio de Pediatría Médica.

Métodos: Estudio de enfoque cualitativo de tipo descriptivo, que contó con la participación de 11 padres. La recolección de datos se llevó a cabo a través de entrevistas semiestructuradas y los datos fueron analizados mediante la técnica de análisis de contenido según Bardin (2016).

Resultados: De los discursos y perspectivas de los padres sobre la negociación de cuidados, surgieron cinco dominios. Las condiciones estructurantes y el conocimiento del niño y la familia se presentan como pilares para sustentar el proceso negociador. En la negociación propiamente dicha, convergen dos roles: el parental, con la asunción y adaptación a la condición del rol parental, y el rol de los enfermeros. Hay comportamientos que favorecen la negociación, que tienden hacia la naturalidad del proceso de negociar; sin embargo, también existen comportamientos por parte de los enfermeros que perjudican la negociación. El apoyo después del alta es reconocido como un soporte importante después del regreso del niño a casa.

Conclusión: Los hallazgos permiten aclarar los roles de los diferentes intervinientes en la negociación de cuidados, con el potencial de contribuir a la implementación de acciones favorecedoras del proceso negociador de manera más sostenida e intencional.

Palabras Clave: negociación; padres; niño; enfermeros

INTRODUCTION

The organisation and delivery of nursing care to children and families is increasingly based on models that value the involvement of the parents/family, both in the care provided and in decision-making.

Parental involvement in the care of their sick children is a crucial requirement for good paediatric nursing practice, based on models of care partnership and other theoretical references that focus on child- and family-centred care. In this context, negotiation assumes a structural dimension, and can be defined as a process of mutual understanding and coordination between parents and nurses about the care provided to the child (Sousa, 2012).

1. THEORETICAL FRAMEWORK

Care negotiation is a process by which families and health professionals establish a mutual agreement on care (Jonas *et al.*, 2022), having a sharing of information and expression of preferences, being a key strategy in the care partnership. It is a dynamic process, which can occur both tacitly and explicitly and is not necessarily linked to a specific clinical context (Nilou *et al.*, 2024).

The negotiation process should be seen as a structuring element of clinical practice, taking place in all contexts, but especially in complex situations of great uncertainty (Nilou *et al.*, 2024). As such, it is particularly relevant in situations in which children require complex and integrated care, that is, care for children with chronic diseases, who are clinically fragile, with significant functional limitations, and who require substantial support from various health services, having a huge impact on the family, the community and health resources (Cohen *et al.*, 2018; Brenner et *al.*, 2021).

Anne Casey's model of care partnership, and other references that favour family involvement, have been guiding the provision of care in the paediatric medical service for several years. The service has developed, along with said references, an organisation of care that allows its translation into practice, namely through the assumption of the method of work by the referring nurse for the most complex situations.

Negotiation as an analytical concept in different care contexts is still vague and little explored, and there is a lack of consensus (Nilou *et al.*, 2024). Recent literature provides some evidence that the negotiation of care and nurses' approaches towards it is often subordinated to the individual characteristics of the professionals, as well as the organisational context in which they are inserted (Cranley *et al.*, 2022). It is a process that is little planned and sustained in its intention, depending on the relationship established between family and nurses (Shields, 2017).

As the negotiation process is a crucial strategy in the care partnership, nurses play a key role in its promotion and operationalisation in clinical practice contexts (Sousa, 2012). However, although several studies discuss the importance of involving children and families in care and decision-making, how to do this effectively remains unclear (Jonas *et al.*, 2022; Nilou *et al.*, 2024).

In the Paediatric Medical Service, we perceive an apparent lack of consensus on the different roles that converge in the negotiation process. As we acknowledge the negotiation of care as a key to the success of the intervention during hospitalisation, we consider it important to study the different elements that make up said process. This understanding led us to the aim of this research: to understand the negotiation of care between nurses and parents in the Paediatric Department from the parents' perspective.

2. METHODS

Having established the general objective, the following specific targets were considered: to understand the perspective of parents on the negotiation of care established between nurses and parents; to analyse the difficulties and constraints to the development of the negotiation of care felt by the parents, as well as to analyse facilitating factors and barriers in the parents' ethics. In the light of the problems presented, we aim to answer the following research questions: How do parents experience the negotiation of care carried out by nurses? What are the difficulties and constraints felt by the parents? What do they consider to be the facilitating factors? This study is based on a qualitative, exploratory and descriptive approach that aims to understand the process of care negotiation through the optics of the parents, providing a more accurate view of the phenomenon under study.

2.1 Sample

Participants were selected by agreement according to the following inclusion and exclusion criteria:

- Inclusion criteria: parents of children with complex care needs, hospitalised for at least 7 days in the Paediatric Medical Service; parents with an age greater than or equal to 18 years; parents that understands and speak Portuguese fluently; parents that agree to participate in the study and assents to the informed consent.
- Exclusion criteria: parents of children with transitory and acute health needs; parents of children hospitalised for less than 7 days in the Paediatric Medical Service.

2.2. Data collection instruments

Taking into account the objective of the study, it became necessary to know the perspective of the parents in relation to the negotiation of care. Thus, the authors of the study constructed a semi-structured interview guide made up of seven open questions, duly validated in a subsequent phase by two senior researchers. The semi-structured interviews with the parents were carried out on the day of clinical discharge by two researchers who are part of the care team.

Prior to each interview, the parents were asked for their collaboration and voluntary participation in the study. We explained to the latter what the study consisted of and its objectives, as well as guaranteeing the confidentiality of the data. A declaration of informed consent was duly given, and a commitment was made that the audio recordings would be erased after transcription and validation. Emphasis was placed on the right to interrupt participation in the study.

The interviews took place between June 2021 and August 2022, and 11 interviews were conducted, for a total of 281 minutes. These were conducted in the office of the Paediatric Medical Service, reserved for said purpose. The audio of the interviews was transcribed in verbatim as they were being conducted, and the data collection was completed when it was understood that the theoretical saturation of the information had been reached, that is, when new information was no longer identified by conducting new interviews.

2.3 Data analysis

The analysis of the data was carried out through content analysis according to Bardin (2016). It involved processes of classifying, combining, as well as comparing the content in order to understand its meaning and implications, through three phases of content analysis: pre-analysis, exploration of the material and data processing (inference and interpretation). The pre-analysis began with a flowing reading of the interviews that allowed the occurrence of a set of initial impressions and orientations, facilitating the successive readings and, later, the construction of categories. This phase allowed a global perspective of the participants' perceptions. In a second phase, we proceeded to the analysis of the interviews, which was nothing more than the systematic application of the decisions made, through a deeper reading, transforming the raw data into units of meaning. These recording units allowed for the exact description of the relevant characteristics of the content. After their delimitation, these recording units were organised into domains, categories and subcategories.

The categories and subcategories emerged from an exploratory method, operationalised through a slow process of differentiation and regrouping, with the collaboration of the senior researcher. During said process, the principles that, according to Bardin (2016), should prevail in the construction of the categories were respected: mutual exclusion, homogeneity, relevance, objectivity and fidelity. In the third and final phase, the raw results were processed in order to be meaningful and valid. Inferences were made based on the identification of the domains and not on the frequency of their occurrence. This study had the favourable opinion of the Health Ethics Committee (CES) of the Coimbra Hospital and University Centre, No. 120/CES.

3. PRESENTATION AND DISCUSSION OF RESULTS

Eleven parents participated in the study, with an average age of 33 years, at the time of the interview, the youngest was 20 and the oldest 43 years old, ten female and one male. In terms of academic qualifications, four of the participants had higher education and seven had secondary education.

The children at the time of the interview had an average age of 7 months, the youngest was one month old and the oldest was two years old; five were female and six were male. Four of them had already been previously hospitalised in the Paediatric Medical Service. None of the interviewees had other children with complex care needs in their care.

The findings of the interview allowed us to identify five major domains in the understanding of the care negotiation process in the Paediatric Medical Service. The domain of structuring conditions and Knowledge of the Child and Family, which function as foundations to support the negotiation process. Two structuring roles come together for the negotiation itself: the Parental role and the Nurses' role. Support after discharge is a component that is widely regarded as an important support after the child returns home.

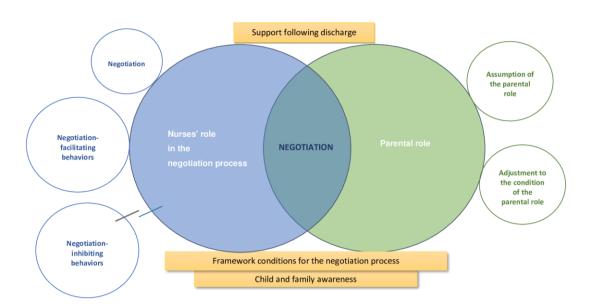


Figure 1 - Negotiation of Care in the Paediatric Medical Service

Child and family awareness

Parents say that the nurses' building of knowledge about the child and family is a factor that facilitates the negotiation of care, as it is a dynamic and evolving process "they get to know O. better, and they get to know the mother better too" (E6). There is not only a building up of knowledge about the needs of the child and family, but also about their personalities "they also know more or less the type of person they are dealing with" (E6). The intention of this construction is to achieve in-depth knowledge about the targets of care "Because you end up knowing M. and the family in a deeper way", which reveals the intentionality of "empathy" (E11), favouring the creation of a relationship of trust and the establishment of therapeutic communication, which facilitates the co-creation of a more personalised care project with the child and family.

The participants consider the assessment of their abilities to be equally important "They always asked me if I could do it" (E1) "And if we're not able to do it, you as professionals also assess it" (E10) and the assessment of willingness "The nurses always ask us if we want to do it" (E9) "(...) there were always some who asked if I wanted to do the bath or not" (E8). According to Sousa (2012), parents' desire to participate in care affects the success of the care partnership. Nurses' efforts should be directed towards assessing the parents' ability to provide care for the child, and it is also crucial to give them the freedom to be involved or not in the care process, depending on their wishes. The participants in this study thus identify two key aspects of the negotiation process: the careful and systematic assessment of the family's capacities and capabilities, as well as the assessment of their desire to participate in the child's developmental and/or complex care.

Framework conditions for the negotiation process

In line with other studies that identify the nurse reference method as favouring a partnership of care (Toivonen et al., 2020), the participants allude to the importance of the Nurse Reference, as an element that has a better knowledge of the child's and family's needs, favouring a more continuous follow-up "Being with the same nurse for several shifts? It's the follow-up, because from the beginning they follow V.'s clinical situation (...) and it also ends up making it easier" (E10), promoting the integration of the child and family in decision-making, ensuring greater family satisfaction (Parreira et al., 2021), and facilitating the negotiation of care "Having that person who knows us, who constantly knows some of our concerns... It's easier" (E11).

Parents see the sharing of information between nurses as a beneficial aspect of the negotiation process. "Because you end up passing on this information to each other about how you work with each child (...) you already knew it worked that way" (E1). This transfer of information ensured continuity of care, with a family-centred approach, through reflective and shared decision-making, conveying to the parents the nurses' concern for adapting the care plan to the individual characteristics and dynamics of each child and family. This contributes to a better understanding of the specificities of the targets of care, fostering greater confidence in the teams' ability to make judgements and decisions (Nonogaki et al., 2019).

According to Boland et al. (2019), health professionals identify the main environmental challenge to shared decision-making as a lack of time due to excessive workload. In the present study, the parents share these observations when they say that there is a limitation in the number of nurses that affects the time available to provide quality care "So care is provided, but maybe if there was more time it would be a better-quality service" (E11). The need for human resources was cited repeatedly by parents "I think there should be more people hired (...) the thing I think is most important is to have more people (professionals)" (E6). In addition, participants also emphasised the importance of increasing the number of nurses on the afternoon and night shifts "I think the afternoon and night shifts should have one or two more nurses, the morning ones do, the nurses don't divide in half" (E4). An increase in the number of nurses would allow for better planning and care management on the shifts, promoting more time for interaction with families, fostering a more favourable environment for the development of the negotiation process.

Parental role

From the parents' point of view, the assumption of the parental role is a crucial factor in the negotiation of care, where the belief in the parental role, the parents as experts in caring and the definition of limits by the parents are considered key dimensions. The participants expressed their belief in having to shoulder the parental role as their own responsibility and not that of the nurses "But I never had the perception that it was the responsibility of the nursing team, I always took it as my own" (E11). This active role of the parents in the care makes them feel fulfilled and satisfied with themselves "I wanted to do it myself (...) I really enjoyed being able to start T.'s hygiene". (E8), favouring closeness with their child "it's important for us parents and our children to feel closer" (E8).

Parents consider themselves to be better qualified for some aspects of caring, as they have more in-depth knowledge "as they know their children better, they know and are more attentive to all the signs" (E10). They also have more time, patience, and attention to detail "I don't think anyone is more patient and has more time to take care of small details" (E11) and are more willing to experiment with alternatives "and think of other possibilities that could improve M's situation" (E11). In the family-centred care and care partner models, parents are the best carers for their children, and as such nurses develop care planning by promoting the involvement of parents in the care process, not only by optimising their knowledge and skills for the development of their parental role, but above all by respecting and valuing their unique and valuable perspectives. On the other hand, the parents themselves set limits to their parental role, entrusting the care of their child to the nursing team when they feel they are unable to cope with their demands, giving up the care of their child "Whenever it's none of my concern, the team takes care of it" (E3).

In line with the statements regarding assumption of the parental role, adjustment to the condition of the parental role is also stressed as significant in the negotiation process. The perception of ability to perform the role is cited as a key point in this adaptation "the maintenance of the ileostomy, I think there was a perception that I would be able to do it, right?" (E11). This is a gradual and evolutionary process, in which the parents themselves gradually acknowledge their ability to perform the developmental and/or complex parental role "I found it more difficult at the beginning of the kinesiotherapy, but then over time, it ended up going smoothly" (E2). Through the gaining of knowledge and skills, but also through motivation. Partnership models of care promote parental empowerment, incorporating motivation (self-awareness and a sense of commitment), and the gaining of knowledge and skills (empowerment), enhancing involvement in care and shared decision-making (van den Hoogen & Ketelaar, 2022). This is a process that, depending on the unique characteristics of each child and family, can take different amounts of time, which must be respected when planning care.

It is interesting to understand that parents with previous experiences of hospitalisation report that they find it easier to adapt to the condition of the parental role "there are others who feel more at ease, as is my case, although I bring baggage from the past and there are parents who have no experience at all" (E7), as they identify such "baggage" as a facilitating condition that allows them to have greater levels of confidence and security in adapting to a new hospitalisation, being able to develop mechanisms that favour their ability to deal with new transitions. Indeed, identifying this facilitating condition helps to favour healthy transitions, both in terms of the developmental transition of parenthood and the situational transition of complex parenthood (Sousa, 2012).

Nurses' role in the negotiation process

It is well established that parents need the support of healthcare professionals to take an active role in decision-making (Gates et al., 2018), but there is evidence to suggest that this can be a significant challenge for nurses (Shields, 2017). As such, it will be valuable to understand how parents experience the negotiation process, what behaviours they consider to favour or hinder mutual decision-making, and how they experience the negotiation itself. From the parents' perspective, there are behaviours that promote negotiation, such as: the naturalness of the negotiation process; respecting parents' timings; respecting parents' opinions; creating a relationship of trust; creating bonds/nurses as family; valuing the paternal role; and sharing victories.

It was widely emphasised that the negotiation process is a gradual and evolving construction (Naturalness of the negotiation process) "In the Paediatric Medical Service everything is very simple, very easy to manage, because you also make us very comfortable (...) It's been building up... I feel it's been evolving" (E10). When parents feel involved as partners in care, they describe an interactive process, a flow that changes over time, both in terms of pace and involvement and participation "it's one day after another... It's gradual, we

get to a point where we feel more at ease, things flow differently" (E3) "it was immediately a very easy process, it went naturally" (E8).

Nurses' receptiveness to answering questions is also seen as crucial "great receptiveness on the part of the nursing team" (E8), not only in the sense of creating a relationship of trust with the family, "When we notice that there is empathy... I feel more at ease to ask certain questions and understand what I should do better with O." (E6), but also in terms of promoting the parents' self-confidence and the trust they place in the nursing team "The trust we have, it's a question that allows me to ask questions whenever there's any doubt... It's a factor that makes it easier" (E8).

One of the practices that favours this naturalness of the negotiation process is respect for the parents' timings "It wasn't straight away! It was important for me not to do it straight away, because I was still trying to understand what was happening" (E1). In this regard, the participants consider it crucial that the nurses don't put pressure on them to take over the care of their child "I was always asked, 'Look, does the mother want to do it? Do you want help?" (...) let the parents feel free " to do it". I don't think there should be any added pressure from the professionals" (E6). As well as fostering the development of knowledge and empowering parents, it is crucial that nurses endeavour to counterbalance the constant imbalance of power that may exist (Reeder & Morris, 2021), "I was always the one who asked to do it, and I was always told that if I didn't feel ready I didn't have to do it" (E9) "the fact that you don't put any pressure on them, saying 'take as long as you need'? it's very good" (E10).

For parents, it is crucial that nurses respect not only their timings, but also their opinions (Respect for parents' opinions) "I have never felt here in this service that my opinion about M.'s condition was dismissed... they valued what I said" (E11). The recognition of parents as partners in care involves this respect for their opinions, translated into active listening (Gates et al., 2018) "I've always talked to the nurses about everything and I don't think there's been a single nurse who didn't understand or who was disrespectful" (E9), which creates a feeling of understanding that favours the therapeutic relationship. This feeling of respect and understanding generates a dynamic relationship between parents and health professionals, in which neither assumes a dominant role, establishing a real partnership of care, with genuine shared decision-making (Pellikka et al., 2023).

Another aspect referred to as fostering negotiation is the nurses' concern for the child's well-being. The findings of the study show that the fact that nurses show their concern for the child's and family's well-being in its various dimensions, establishing personalised care, making them recognised as unique "who is not a ready-made patient, who is M.!" (E11), is reassuring care "trying to make S. more comfortable, that helps us a lot and is also very comfortable for us" (E3). Parents appreciate nurses' concern for the different circumstances of the family setting, including not only clinical aspects but also meeting the specific emotional and social needs of each child and family (Matthews, Puplampu & Gelech, 2021).

In addition to concern for the child's well-being, there is also reference to concern for the parents' well-being "they try to understand how we are, that's good, that helps..." (E1). More specifically, the parents consider it very positive that the nurses show concern and care for their wellbeing by actively listening to them, making it easier for them to express their emotions "I would get things off my chest... you were always the ones listening, you stayed and listened! Always!... how is that possible!" (E8). This finding differs from some literature (Evan, 2017) which suggests that parents may fear that nurses will take the focus off their child if they show concern for their own wellbeing. On the contrary, the participants in this study consider that this posture of understanding, empathy, and solidarity on the part of the nurses' favours. Not only their own comfort, but consequently also that of the child "parents have to be well to look after their children, and I'm very aware that you have this concern" (E11). In addition, the care shown towards the parents' need for "peace of mind" is pointed out: "I feel good here, I can at peace (...) very careful and attentive when we're down" (E4), favouring the parents' well-being, which fosters greater availability to carry out the parental role. Perhaps these valuations are due to the perception that parents and children can be cared for without this resulting in a loss for the children.

Although hospital institutions take into account the promotion of the paternal role, there is still little evidence to support this fact. Although it is mostly mothers who accompany their children during hospital stays, according to the participants, the paternal role is not devalued "I didn't feel excluded in any way, even though I'm a man, and there are mostly mothers here" (E11). Valuing the father's role by including them in childcare results in benefits for the child, for the fathers themselves and for the quality of family relationships (Yogman & Eppel, 2022).

Nurses play a decisive role in promoting fathers' self-confidence to fulfil their parental role (Reeder & Morris, 2021), a fact that the findings of this study attest to. These interventions are not only aimed at gaining knowledge and skills, "They always explained to me how to do it" (E9), but also at providing encouragement and positive feedback "They encouraged us" (E4), promoting parents' self-confidence to fulfil their role "I think you have a lot of confidence in us ... we feel good" (E8). This is a gradual process that takes place over time "I feel like it's been developing because I think you're also starting to put more trust in your parents" (E10). As there is greater emphasis on the potential of parents to look after their children, they become more confident in their parental role "I'd call the nurse and she'd say, "you can do it, I already know you can do it", and hearing this is good too! It's very good" (E8).

The results of this study support the importance of establishing a relationship between nurses and the family based on trust "it is vital to create trust in the relationship between parents and professionals (...) the key aspect of this relationship is trust" (E11), in line with

the generalised understanding that the negotiation of care and partnership models are based on the creation of trusting relationships between nurses and the family (Christian, 2020).

In 6 of the 11 interviews carried out, the creation of bonds is described as a determining factor in the negotiation process "I end up feeling better, and somehow cherished by the professionals" (E6). The relational environment created means that some parents even consider the nurses to be family members, building emotional bonds that contribute to achieving the main purpose, which is to ensure the child's well-being, "they have a close relationship with us (...) almost like family" (E1) "In essence, the creation of bonds with M. the care even! Feeling like a family working towards a common goal, which is M.'s well-being!" (E11). In fact, it is widely accepted that parents appreciate the creation of a close relationship with healthcare professionals (Toivonen et al., 2020; Matthews et al., 2021), with positive results in the therapeutic relationship (Reeder & Morris, 2021). In some cases, parents consider the Paediatric Medical Service a home "When I'm in the service, I feel like I'm at home, basically" (E10), where there is a facilitating tone for building bonds of trust and mutual respect that is structural for parents "The human warmth... The human part of this team, and I keep saying it! What saved us in all this were the nurses in this department!" (E8).

Sharing successes is perceived as a behaviour that promotes the negotiation of care "following his growth and sharing with us the successes he has" (E11). This exchange can create a feeling of co-operation and trust, which will favour a more successful negotiation process. Celebrating achievements is crucial for envisioning a promising future further down the road, maintaining hope that it is achievable, and generating encouragement and motivation (van den Hoogen & Ketelaar, 2022).

When nurses celebrate achievements with parents, they show their concern for them and their intention to keep them confident and motivated.

Negotiation is a crucial strategy in promoting better care practices and more fruitful interaction between nurses and parents (Sousa, 2012). The parents backed up this statement, identifying the ability to negotiate as an important tool in the process: "It was agreed by the whole team (me, the nurses)" (E10). Negotiating is in itself a highly complex endeavour, which not only makes it possible to achieve common goals, in a dynamic of mutual partnership, but also promotes the satisfaction of everyone involved "I feel totally at ease with you, if that day I don't feel comfortable doing something for V., I feel comfortable saying so" (E10). There's validation with the parents "It's the team going towards it a tad, '(...) what if we tried this? What if we did that?" (E3), which reflects effective negotiation.

At the same time, the study participants cite specific behaviours that inhibit the negotiation process, Negotiation Inhibiting Behaviours. There are some cases in which nurses take a unilateral decision without dialogue, adopting a position of power, imposing care "a nurse (...) who would come in and say "I'm the one giving the bath today! I don't want the mother to be upset, but I'm the one bathing the child!" ... So, at the end of the day, bathing every two days was one more little thing I could do, wasn't it?" (E8). In situations like these, there is a lingering autocracy in which parents don't feel comfortable talking or fear upsetting health professionals (Reeder & Morris, 2021), even if they want to clarify any doubts or participate in any care. In the nurses' takeover of power, a lack of questioning prevails, as they decide without asking "If they had asked, I would have said yes, but since they didn't ask..." (E8), and a lack of clarification "I didn't understand exactly why they thought it was early at that time (the start of the training)" (E11). The use of such behaviour constitutes a devaluation of the role and opinion of the parents "I feel that they didn't listen to me... they should consider this situation a little more, give more value to what the parents say" (E10). These responses are possibly underpinned by a perceived loss of control and power, which makes nurses reluctant to establish mutual agreements with parents (Shields, 2017). These behaviours contribute to a distancing in the relationship, as there is no questioning of the parents' needs and feelings "if I see that there isn't much willingness, I won't ask either" (E3), a key factor in negotiation "I've had situations with other nurses where I've tried to engage in conversation (...) the other side doesn't really show any reaction." (E6), such behaviour inhibits the creation of a relationship of trust and the promotion of partnership in care "they should talk to the mothers a bit more, they should try to understand" (E2). The study by Ryan & Quilan (2018) shows that when there are challenges in establishing a therapeutic relationship, parents seek support from their peers in order to empower themselves for the conflict with health professionals. Seeking this support is stressful and seems to result in a conflictual relationship and a non-collaborative "partnership" (Reeder & Morris, 2021).

Support following discharge

It is widely accepted that hospital discharge and the subsequent transition to returning home can be a complex process for parents, who often feel overwhelmed and distressed (Ronan, Brown & Marsh, 2020). As a provider of support during the discharge process, nurses are seen by parents as empowering (Brimble & McNee, 2021), promoting child and family satisfaction and confidence. In addition to this ongoing support during hospitalisation, parents also point out the importance of nurses showing availability and support after the child and family return home "if you need anything... you can contact us here, call us directly, and we'll try to help" (E6). This courtesy shown by nurses allows parents to feel more confident, secure and at ease when dealing with the new challenges that the transition to home care brings.

CONCLUSION

Acknowledging the negotiation of care as a structuring dimension in the implementation of family-centred care partnership models, we sought to dissect the negotiation process, identifying, exploring, and analysing the various elements that contribute, or not, to its success. We now take advantage of greater knowledge about the phenomenon under study, in the belief that this is the way to provide a voice and obtain the opinions of the main parties involved, rather than making presumptions about how the processes develop, which goes against the "a priori" and methodological definition of negotiation.

From the parents' perspective, there are five domains that converge in the development of care negotiation in the Paediatric Medical Service. In the first instance, the participants consider that there are structuring conditions for the negotiation process, of which we highlight the implementation of the method of providing care by a reference nurse, which favours the integration of the child and family in shared decision-making processes and continuity of care. Knowledge of the child and family is seen as a key factor in the negotiation process and is attained by constantly seeking out the unique needs and characteristics of each family, in a framework that evolves over time, which, according to the parents, promotes quality care.

There are two main fields involved in the negotiation process itself: the parental role and the role of the nurses. Regarding the parental role, the participants emphasise the responsibility of assuming their position, but also the definition of their limits. Whilst indirectly describing themselves as experts in caring for their child, they identified their deeper knowledge of the child, combined with their greater availability of time to experiment with care alternatives.

With regard to the role of nurses in the negotiation process, they report behaviours that promote and facilitate the naturalness of the negotiation process, especially the creation of bonds and relationships of trust between nurses and the family. Nurses are seen as family members who are respectful and value the different aspects of child/family care. In this environment, the parents feel that the nurses go above and beyond by pointing out and sharing achievements, making them believe and maintain a vision of hope for the future, playing on the same "team". However, some of the accounts mentioned inhibiting negotiation behaviours, which were genuinely counterproductive, creating difficulties and constraints in the negotiation process. In these cases, in particular, the nurses adopted a position of power, creating an imbalance in the established relationship. A hierarchical relationship thus persists, evident in the lack of questioning and/or explanation, resulting in a devaluation of the parents' role and opinions as well as a distancing between parents and nurses, which creates a major constraint on the care partnership.

Support after discharge is widely regarded as a key support after the child returns home, having a decisive role in the continuation of the negotiation process developed throughout the hospital stay.

Although this study was carried out in the unique context of the Paediatric Medical Service, which could be seen as a limitation of this study, we believe that the insights provided by clarifying some characteristic features of the negotiation process could be an opportunity for reflection in different contexts of clinical practice.

Clinical practice, training, and research concerns

We believe that sharing the results of this study, with an understanding of the negotiation process through clarification by those who experience it, will allow for a more purposeful and sustained nursing response, contributing effectively to the improvement of care practice. Notwithstanding the findings, we believe that this paper could be a stimulus to the pursuit of more formal knowledge on negotiation, namely in other care contexts, which would also allow for greater investment in the training of professionals and greater opportunities for nurses to share experiences.

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AUTHOR CONTRIBUTIONS

Conceptualization, C.N., C.F. and J.M.; data curation, C.N., D.B. and C.A.; formal analysis, C.N. and D.B.; investigation, C.N. and D.B.; methodology, C.N., D.B. and C.F.; project administration, C.N. and C.F.; supervision, C.N. and A.M.; visualization, C.N.; writing-original draft, C.N., D.B., C.F. and C.A.; writing-review and editing, C.N. and A.M.

CONFLICTS OF INTEREST

The authors declare no conflict of interest.

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