

Parents of children with disabilities' perceptions regarding the quality of interaction with Health professionals working in early intervention: A qualitative descriptive study

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Abstract

Aims and Objectives: The aim of this study is to explore the perceptions of parents of children with physical disabilities concerning the quality of their interaction with health professionals in early intervention programs.

Background: Despite the consensus on the need for Patient and Family-Centered Care, there are still difficulties when executing such care. The quality of interaction among patients, families, and professionals is essential to facilitate the implementation of the programs.

Design: A qualitative descriptive study with thematic analysis using a Modified Grounded Theory approach.

Methods: Data were collected through seven focus groups with 28 parents of children with physical disabilities who were undergoing early intervention programs in three centres. The study followed the COREQ guidelines and checklist.

Results: Two themes emerged from the experiences: 'exchange of information and education', which included all the activities, procedures, exercises and skills taught by the professionals to help parents care for their child; and 'interpersonal skills', which focused on the way the professional relates with the child and the parents. Several subthemes emerged within each theme.

Conclusions: This study identified which elements of the professional-parent interaction are considered by parents when evaluating the quality of their interaction with the health care provider of their children.

Relevance to Clinical Practice: The results of this study bring to light certain behaviours and interactions that health professionals should consider in order to improve the perceptions of parents of children with disabilities regarding the quality of interaction in the context of early childhood intervention.

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Patient or Public Contribution: Parents contributed to the data collected. Early intervention professionals were involved in participant checking to ensure the rigour of the study.

KEYWORDS

children, disability, early intervention, focus groups, parents, patient and family-centred care, professional-patient interaction, qualitative research, quality of health care

1 | INTRODUCTION

Children with physical disabilities usually receive Early Childhood Intervention (ECI) Services. Despite the great consensus that currently exists on the appropriateness of applying Patient and Family-Centered Care (PFCC) in all fields of health, including paediatrics and rehabilitation (Clay & Parsh, 2016; Coats et al., 2018), many studies have shown that there are difficulties in implementing this model of care. Some authors argue that this may be due to the difficulties faced by health professionals when sharing information and establishing joint decision-making (Angeli et al., 2019; Clay & Parsh, 2016; Coats et al., 2018). Therefore, it is necessary for health professionals who work in ECI to know the needs of patients and their families. A good quality relationship between patients, families and professionals is essential for achieving this goal (Angeli et al., 2019). There is a lack of studies that analyse the perceptions and experiences of parents of patients treated in ECI regarding their relationship with the professionals involved. Knowledge of these perceptions could help improve the implementation of PFCC in this field.

2 | BACKGROUND

A large number of children worldwide live with physical disabilities. This significantly affects the child's ability to perform activities of daily living, such as independent feeding, communicating and mobility (World Health Organization & UNICEF, 2012). These children and their families usually have complex needs of support for functioning, that may be due to the characteristics of the children (e.g. level of disability, medical issues) or family (e.g. culturally or linguistically diverse groups, single parents, lack of support, low-incomes) (Ziviani et al., 2014) which can compromise the development of the child and the quality of life of the whole family. In order to reduce the impact of the disability and improve child development and family wellbeing, these children and their families often receive Early Childhood Intervention (ECI) (Eurlaid. The European Association of Early Childhood Intervention, 2019). As Moore states, 'The major purpose of early intervention is to enhance the competence and confidence of children's caregivers so children had the greatest likelihood of developing to their maximum potential' (Moore, 2012). These services are provided through interdisciplinary or transdisciplinary teams, composed by different professionals who generally work in coordination to provide support, information and resources to the child, the family and the environment. One of the main tools

What does this paper contribute to the wider global clinical community?

- This study can contribute to the body of knowledge on paediatrics with physical disabilities and their families receiving early childhood intervention.
- The study identified several factors that enhance the perceived quality of care, suggesting that an effective exchange of information with families, including education, and the use of good interpersonal skills with the family and child should be considered in the provision of early childhood intervention care.
- The findings of the study can help health care providers and managers of paediatric health services to improve the quality of care and their relationship with their patients and their families. These findings can contribute to facilitating health professionals to share information and implement joint decision-making with patients and/or their families and to facilitate and improve the implementation of Patient and Family-Centered Care.

that professionals use in ECI to provide support to the families are home programs. They are highly personalised for each family and include information, support, different interventions, procedures and strategies that are carried out at home by families and in other environments, to promote management and meet the needs of children and their families. ECI models have evolved over time, incorporating PFCC principles (Eurlaid. The European Association of Early Childhood Intervention, 2019; Novak & Berry, 2014).

The professionals who work in ECI come from different fields of knowledge and are trained in different skills (e.g. physicians, nurses, speech therapists, physiotherapists, occupational therapists, psychologists, preschool teachers and social services professionals, among others). Their interaction and collaboration within the teams and with families is a key axis for ECI (Eurlaid. The European Association of Early Childhood Intervention, 2019).

In fact, is not only technical knowledge but also professional interpersonal skills what defines the PFCC, which includes the following core principles in paediatrics: listening and respecting families and children, facilitating choice, sharing information, providing support, collaborating with families and children, and building confidence to participate in health care decision making (Committee

On Hospital Care and Institute for Patient-and Family-Centered Care, 2012).

The American Academy of Paediatrics (AAP) (American Academy of Paediatrics et al., 2006) describes PFCC as 'an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family in the patient's life'.

Indeed, not only for children but also for adults, there is a strong consensus that care should be based on the philosophy of PFCC (Clay & Parsh, 2016; Coats et al., 2018). Major professional organisations such as the American College of Critical Care Medicine (ACCM), the American Academy of Paediatrics (AAP), the Institute for patient and Family-Centered Care (IPFCC), the Institute for Healthcare Improvement (IHI), endorse these recommendations (American Academy of Paediatrics et al., 2006; Committee On Hospital Care and Institute for Patient-and Family-Centered Care, 2012). To be recognised by the Magnet Recognition Program, developed by the American Nurses Credentialing Center, hospitals must implement family-centred care (American Nurses Credentialing Center., 2016).

Several studies developed in paediatrics demonstrate that PFCC leads to important outcomes. Thus, studies have reported improvements in many areas, such as maternal knowledge and participation in infant caregiving (Neu et al., 2020), treatment outcomes (Coats et al., 2018; Kuhlthau et al., 2011), health status (Kuo et al., 2011), family functioning in physical functioning, communication and daily activities (Hsieh et al., 2016), family impact-cost (Kuo et al., 2011), parental perception of satisfaction, including health care satisfaction (Committee On Hospital Care and Institute for Patient-and Family-Centered Care, 2012; Hsieh et al., 2016; Kuo et al., 2011; Park et al., 2018), improved parent-professional communication (Kuhlthau et al., 2011) the relationship with health-care providers (Neu et al., 2020; Park et al., 2018), parents-professional collaboration (Coats et al., 2018; Segers et al., 2019), reduced intensity of stress, anxiety, depression of the caregivers (Knapp et al., 2010; Park et al., 2018), and among others.

For health-care providers, PFCC practices may reduce stress and burnout (Park et al., 2018), improve the staff's satisfaction (Committee On Hospital Care and Institute for Patient-and Family-Centered Care, 2012; Park et al., 2018) and quality of care, build positive relationships and engender trust between parents and care providers (Park et al., 2018).

Healthcare organisations that are patient and family-centred may benefit from improvements in efficient use of services, for example reducing admissions, readmissions (Knapp et al., 2010; Kuhlthau et al., 2011), improved access to care (Committee On Hospital Care and Institute for Patient-and Family-Centered Care, 2012; Kuhlthau et al., 2011), decreased length of the hospital stay (Kuo et al., 2011; Segers et al., 2019), and lesser health care costs (Clay & Parsh, 2016).

Despite the consensus and benefits, research studies reveal numerous difficulties in implementing PFCC (Angeli et al., 2019; Coats et al., 2018; Tallon et al., 2015). Literature shows that the model fails due to the difficulty for health care providers to share information and implement joint decision-making (Smith et al., 2015). According

to other authors, the model of PFCC is limited because it continues to focus solely in attachment theory (Tallon et al., 2015). Research findings also show that, despite the construction of therapeutic goals in a context viewed as collaborative between professionals and caregivers, there is discordance in collaborative goal setting, due, in part, to a lack of understanding of the care needs of patients and their families (Angeli et al., 2019). In fact, to understand the particular needs of each family, there must be a good quality of interaction between patients, families, and professionals. Indeed, several studies show that this interaction is the most important factor when establishing joint decision-making (An & Palisano, 2014; Angeli et al., 2019; Committee On Hospital Care and Institute for Patient-and Family-Centered Care, 2012).

There is evidence that a good interaction between health providers and patients or families can improve clinical outcomes (Kelley et al., 2014; Molina-Mula & Gallo-Estrada, 2020), the perception of overall quality of service (Bello, 2017; Molina-Mula & Gallo-Estrada, 2020), the satisfaction of patients, their families and health providers (Bello, 2017), and adherence to ECI (Lillo-Navarro et al., 2015, 2019; Medina-Mirapeix et al., 2017). ECI services, characterised by long-term interventions (lasting months or years) and regular meetings with families, often include programs in which parental collaboration is imperative (Novak & Berry, 2014). Thus, a continuous interaction between professionals and parents is necessary and certain aspects may influence this interaction (Novak & Berry, 2014).

In order to implement PFCC in ECI area, it would be useful to know which aspects of care affect the perception of the quality of the interaction between health care professionals and the parents of children with disabilities in ECI services. Although several studies have been conducted in paediatrics (Fisher & Broome, 2011), few have focused on ECI (Lillo-Navarro et al., 2015).

Therefore, this study aimed to explore the experiences of parents of children receiving treatment in ECI services, and to identify aspects of care that may influence their perceptions concerning the quality of their interaction with the therapists.

3 | METHODS

3.1 | Study design

The study is based on an explorative and qualitative design using focus groups, analysed thematically using a modified grounded theory approach. Qualitative methods usually highlight human experiences such as emotions, expectations, and attitudes (Morgan, 2019). We used focus groups to obtain a deeper understanding of the participants' experiences, considering that group interactions can trigger responses and build insights that may not arise during individual interviews. A modified grounded theory approach was adopted, which is inductive in nature, to allow the emergence of themes that were important to families related to perceived quality of care (Corbin & Strauss, 2015).

3.2 | Setting and participants

This study included parents of children with physical disabilities who were undergoing ECI programs at three centres in south-east Spain: (1) the infant rehabilitation service of a University Hospital; (2) a private clinic of ECI for children with disabilities; and (3) a parent association with ECI services for children with disabilities. The most common diagnoses of the children at these centres were Cerebral Palsy, Developmental delays, Encephalopathy of prematurity and hereditary diseases. The programs included recommendations to improve the daily routines of the child and family and were supervised by different health professionals (mainly physiotherapists, nurses, and occupational therapists). The care model was centred on the child, the family, and the environment (FCC).

Parents were included if their child was aged between 6 months and 6 years and were involved in an ECI program for more than 6 months. They were excluded if they displayed any type of inability to participate in the focus groups, such as non-Spanish speaking participants or if they presented communication impairments.

3.3 | Ethical considerations

The study was conducted following the Declaration of Helsinki (World Medical Association, 1964). Ethical approval for this study was granted by the Committee of Ethics and Research of the University of Murcia. At each centre, an assistant researcher handed selected subjects an invitation letter to participate in the meeting. This letter contained an explanatory statement about the project and its goals, issues about confidentiality, data protection as well as specifying the date and place for the meeting. The letter was not signed by any centre provider, in order to ensure that the subjects did not feel that they were under any pressure to participate. Parents were reassured of the confidentiality of their responses and informed about data protection before the start of each focus group session and were given the right to consent via a consent form. They were also asked for their consent to record the sessions, guaranteeing the confidentiality of their interventions. All participants gave their consent and agreed to the request to keep the discussion confidential, signing an informed consent. No conflicts arose between participants during the focus group sessions.

3.4 | Recruitment

Parents were identified at each centre after consulting a list of children referred to ECI treatment. The list contained relevant data concerning the child, such as the name, age, the parents' names, the diagnosis, and dates of the first ECI session. In-house professionals analysed the inclusion/exclusion criteria. In total, 54 parents were eligible to participate in this study.

A purposive sampling strategy with maximum variation sampling design was used to include parents of children of different ages,

gender, and clinical condition. This recruitment strategy is used to maximise the sampling heterogeneity, in order to identify and expand the range of variation or differences (Miles & Huberman, 2013). This enabled the selection of participants who could best provide insight into specific and personal experiences regarding the issues being examined, rather than obtaining a representative sample, as would be sought in quantitative research (Corbin & Strauss, 2015). The final sample size was dependent on the saturation of information, established as the point at which no new information was extracted from the focus groups.

One week after families received the invitation letter, a research assistant made telephone calls to determine the willingness of parents to participate and to clarify any questions. When several parents declined to participate, new parents presenting similar characteristics were invited, to ensure a minimum of four participants in each group.

Homogeneous and heterogeneous criteria were used to form the groups. Gender consistency was ensured, in order to avoid apprehension in discussing health issues in the presence of the opposite gender. In addition, we attempted to form heterogeneous groups by age as well as considering the clinical conditions of the children, to encourage a greater variability of experiences with the aim of stimulating discussion.

3.5 | Data collection

Focus groups were conducted face-to-face by three researchers who acted as a moderator and two assistants. They were unknown to the parents. Meetings were held in municipal premises, different from the ECI centres so that the participants felt free to express their opinions. A topic guide containing pre-determined questions was used (Table 1). This guide was initially formed based on a literature

TABLE 1 Thematic guide for focus group discussions

1. Service provision

- What interventions does your child receive/has your child received in the past?
- Has your child always had the same health care providers in early intervention?
- What aspects do you value in the interaction with your child?

2. Parent's involvement

- In which ways has the professional sought your collaboration?
- What activities has the professional recommended?
- Do you feel that you are able to perform these activities?
- What aspects can facilitate or hamper your ability to feel that you can perform these activities yourself?

3. Communication with the professional

- When do you usually talk with the health care professional that treats your child?
- What aspects do you value regarding the attitudes and behaviour of the professional during these conversations?
- What aspects do you think should be improved regarding the communication or service offered by the professional?

review (Committee On Hospital Care and Institute for Patient-and Family-Centered Care, 2012; Eurlayid. The European Association of Early Childhood Intervention, 2019). The following areas were included: service delivery, parent involvement and communication with the professional. Additional questions were included as themes started to emerge from the initial focus groups (Corbin & Strauss, 2015). During the focus groups, an audiotape, a videotape, and field notes were used for data collection.

All subjects participating in the focus groups were reassured of the confidentiality of their responses, accepted and gave written consent to be interviewed, audio and video recorded prior to the sessions. Data management followed the Regulation 2016/679/EU of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data. Data were stored in a database hosted securely at the University Miguel Hernandez, by the main researcher of the study. Seven focus groups were formed because categories were consolidated after these seven groups (Corbin & Strauss, 2015). Focus group sizes varied from three to seven participants, and the sessions lasted from 40 to 80 minutes. Each participant was assigned a numerical code for data entry. Notes taken during the interviews, and the moderator's reflections were included in a report for each focus group.

3.6 | Data analysis

The Atlas.ti v.8 qualitative analysis software (ATLAS.ti Scientific Software Development GmbH) program was used for data analysis (Muhr, 1991). All focus groups were transcribed verbatim for independent analysis. Participants' names were replaced by a pseudonym in the transcripts and quotations. This data analysis was undertaken using a modified grounded theory approach (Corbin & Strauss, 2015), incorporating data collection, coding, and analysis, and using a process of constant comparison without the component of developing a theory in light of the results (Morera-Balaguer et al., 2018).

Three authors (CLN, JMH, and FMM) independently reviewed the transcripts and coded sentences that contained units of meaning. These were labelled in categories, themes and subthemes using emerging codes. The three authors reviewed and compared their findings in order to reach an agreement on codes, categories, themes, and subthemes.

3.7 | Rigour

Three rounds of coding and discussion took place with the intention of enhancing credibility of the coding process and to develop clearer categories. This process was iterative with data collection from the data of subsequent transcripts. No new categories emerged at the end of the seventh focus group, which implied that saturation had

been reached. The next level of analysis involved identifying relationships between categories and the grouping of categories with uniformity into themes and subthemes with a higher conceptual level.

To verify the consistency of the final emergent themes and subthemes, two researchers (CLN, JMH) cross-checked their agreements through a blind review using codes for the same passages of two transcripts (Palinkas et al., 2015). Any disagreements between the two researchers were resolved by discussion. During each stage, an independent researcher (FMM) played the role of reviewer to verify whether the analysis was systematically supported by the data, with the intention of enhancing dependability, transferability and confirmability (Corbin & Strauss, 2015). The Guideline 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups' was used to verify the methodology of the study (Tong et al., 2007) (File S1).

3.8 | Research team

The research team was made up of seven researchers with extensive experience in qualitative research and in quality of health care. Three of them also had a broad experience in ECI, families, and caregivers.

4 | RESULTS

Thirty-seven subjects were sampled from a total of 54 eligible participants. Initially, 10 parents declined to attend the focus group, or were unable to attend it on the scheduled dates. Consequently, 10 new parents were added to the initial sample. Initially, 37 subjects were interested in attending the meeting upon the verbal reminder, however, not all of these participated in the focus groups. Ultimately, this study included 28 participants, who participated in seven focus groups, with two groups of fathers and five groups of mothers. Participants reported that their children received between one and three weekly sessions of 30 to 45 minutes of ECI programs at the centre, and that they also routinely received prescribed home programs for their children to perform. Generally, there was no specific scheduled time to talk to the health professionals. Parents usually talked to them in between or during the clinical sessions.

The programs included recommendations to improve the daily routines of the child and family: (1) exercises to enhance locomotion, postures, manual, and functional skills and (2) strategies to promote feeding, sleeping, dressing, and other daily activities. Families of premature children and other children with complex needs also received other recommendations of care, such as use of special equipment (for example breathing support and feeding tubes). The professionals who prescribed the home programs were mainly physiotherapists, occupational therapists, and nurses.

The characteristics of the participants and their children are displayed in Table 2. The characteristics of non-participants and participants were similar.

TABLE 2 Characteristics of study participants

Sociodemographic and health characteristics	n	%
Parents		
Gender		
Female	20	71.4
Male	8	28.6
Age		
≤30 years	7	25.0
>30 years	21	75.0
Children		
Age		
≤2 years	10	35.7
>2 years	18	64.3
Diagnosis		
Cerebral Palsy	8	28.5
Disease congenital or hereditary	5	18
Developmental delay	8	28.5
Obstetric brachial plexus injury	2	7
Encephalopathy of prematurity	5	18

The participants reported experiencing situations in which they perceived problems affecting the quality of the interaction between the professional and their child. These experiences were gathered into two emergent themes: (1) exchange of information and education and (2) interpersonal manners. Additionally, within each theme, several subthemes emerged. Each subtheme is presented below based on statements by participants (Table 3).

4.1 | Providing information and education

Most parents acknowledged that assuming the responsibility for the care of their child was frightening. There was consensus that the quality of the interaction with the professional was essential for coping with caring for their child and building confidence. Most parents valued the quality of this interaction based on their experiences, which can be classified into two sub-themes: exchange of information regarding the care plan, and teaching and reassuring skills.

4.1.1 | Exchange of information regarding the care plan

All participants agreed that their perception of the quality of interactions was dependent on building comprehensive care plans, as well as updated information concerning their child's health status, and the manner in which the professional interchanged information.

Participants perceived home care programs as being non-comprehensive when they received unspecific recommendations about the type, number and frequency of activities. According to

TABLE 3 Themes and subthemes

Subthemes	Code categories for statements
Theme 1: Exchange of information and education	
Exchange of information concerning the care plan	Comprehensive care plan
	Updated information
	Using clear language
	Justifying purposes of therapies
Teaching and reassuring skills	Everyday life
	Teaching while performing the child's program
	Correcting performance
	Monitoring performance
Theme 2: Interpersonal manners	
Supportive care	Answering parents' questions or concerns
	Appreciating parents' expertise
	Showing interest
Respectful communication with parents	Displaying friendly manners
	Providing enough time to talk
Caring and sensitive manners with the child	Being careful with the child
	Being sensitive to the child's behaviours

their comments, the lack of this information increased their anxiety as they were unsure of what to do with their child.

They (the ECI professionals) don't explain exactly which activities or how often they should do them every day. I don't know exactly what to do with my son, so I become very anxious...

(Mother of a 18-month-old girl)

Many participants who had attended ECI sessions over long periods of time reported a lack of more updated information in later phases. There was agreement that updated information was essential for coping with a child's care, especially for coping with activities of daily living such as dressing or feeding. Some parents also indicated that updated information should include advice on how to take care of their own well-being during their children's management as they become older.

For example, dressing, which I believe can be the most problematic. I remember that at first he (the occupational therapist) gave me guidance on how to hold my daughter in my arms and stuff ... but now that she is older he hardly teaches us anything.

(Mother of a 5-year-old girl)

The way professionals interchanged information was also relevant, especially at the beginning. Participants felt that interactions were good when professionals interchanged information

in clear and plain language that could be easily understood or when complementary written information was provided about the home program. Furthermore, the purpose of activities and advice adapted to the family's everyday life situations were also appreciated.

The nurse explains everything very clearly making it easy to understand, and that is very important to us.

(Father of a 3-year-old girl)

I would like the physiotherapist to give us a written sheet of recommendations, because, of the 10 activities that he asked us to do at home, in the end I only remember three ...

(Mother of a 2-year-old boy)

4.1.2 | Teaching and reassuring skills

Most participants reported that their perception of interaction quality was dependent on experiences concerning the professional's teaching method. What was most appreciated, with regards to quality, was receiving information while they were observing how the professional was doing the interventions with their child. This was considered important at the beginning in order to learn the skills better, and also as a way to communicate on a regular basis for reassurance and to confirm that the interventions were being practiced correctly.

She (the physiotherapist) teaches you recommendations while she is doing them with my daughter. Seeing how she does the recommendations gives me more confidence to be able to do them myself.

(Mother of a 2-year-old girl)

Participants also highly appreciated the teaching method when professionals not only demonstrated the new activities they were doing with their children but also when they could observe how the parents practiced the recommendations.

She (the physiotherapist) explained to me: 'look at this exercise'. Then she said: 'do you want to do it yourself? Please, come here and try it'

(Father of a 14-month-old boy)

A further aspect appreciated by parents was the feedback offered by the professionals when teaching the recommendations.

One day she (the nurse) explained to me how to do the recommendations and the next day she asked: 'do you have any questions concerning what I recommended yesterday?' If I had any questions, she would explain them again.

(Mother of a 4-year-old girl)

4.2 | Interpersonal skills

The way professionals related to the parents and their children was an important factor affecting perceptions of interaction quality. These perceptions were based on parents' observations of the professional's attitude towards their child and themselves. Three sub-themes emerged: supportive care, respectful communication with parents, and caring and sensitive manners with the child.

4.2.1 | Supportive care

Most parents mentioned that supportive care from professionals was essential to increase their sense of trust in themselves in relation to the child's long-term illness and to improve their ability to manage their child's care. This support was perceived during dialogues with the professional by observing their attitude when answering parents' questions or concerns about their child's health status, manifesting concerns or showing appreciation for the parents' ability to manage their child's care.

Some participants acknowledged that regular attendance and watching their child during therapy or procedures helped facilitate dialogue with professionals. However, other participants mentioned that attending therapy was insufficient in terms of their ability to ask relevant questions. They often avoided asking questions in the context of therapy in order to prevent interruptions. Participants reported that receiving answers to questions about their child's condition helped to gain trust and grasp what was happening, especially at the beginning of the programs.

It was as if I were blind early on in the sessions ... I asked her why my son did not sit-up or how come they still had not been able to correct the head [control]. And she answered it was because of the "problem" he had. But I did not know what the problem was exactly, and did not want to be stealing the short time of therapy by asking more questions. Then, at a meeting held at the center I asked the physiotherapist: but what is wrong with my child? I need you to clarify this for me...

(Mother of a 20-month-old boy)

Participants perceived that professionals showed interest when they asked them about aspects of their child's care related to other professionals or about their child's behaviour in other contexts. Many parents felt a greater sense of trust on these occasions.

...She says, if you find something new on the internet about your child's syndrome, action protocols or anything, bring these to me... You can see she (the occupational therapist) is interested and concerned about our problem.

(Father of a 2-year-old boy)

Participants also felt supportive care when the professional helped them to feel competent, as experts in their child's care, by appreciating their experience, knowledge, or caring skills or by being treated as an equal rather than just as the parent of a patient.

... I see that she (the nurse) trusts that I do things well.
That encourages me and provides me some comfort....
(Mother of a 6-year-old boy)

4.2.2 | Respectful communication with parents

All participants outlined that professionals behaved with respect and courtesy during conversations with them. Some participants emphasised their behaviours by making comparisons with other health professionals.

When you go to the doctor's office, he treats you with an attitude that is so distant and cold. Bad, very bad ... but when I go to them (the ECI professionals) they greet me politely and ask me how the appointment went.
(Father of a 19-month-old boy)

However, in some specific circumstances, participants revealed that professional's manners were less respectful, based on some of the answers given. In particular, some participants felt professionals dedicated too little time to listening to parents and answering their questions. These perceptions were especially related to when parents asked questions while another patient or parent was waiting for the professional or in between ECI sessions.

I wish that the physiotherapist would talk with us more and more calmly. Sometimes, after therapy I ask her things, but as there are children waiting for her, I feel she's in a hurry to end the conversation.
(Mother of a 3-year-old boy)

Many participants complained of the lack of a specific and regular slot in the professional's agenda for exchanging information, especially, parents that did not attend therapy to watch their child. The parents who attended ECI regularly agreed with this, however, they were also willing to conduct this exchange of information during the visits.

I understand that if there are other children after my child, I cannot take the time that belongs to another child by talking to the nurse. But I also think it would be nice if we had time just for talking with him.
(Mother of a 4-year-old girl)

4.2.3 | Caring and sensitive manners with the child

Parents greatly appreciated the humanity and personal interactions of professionals with their children. All parents reported that health

professionals treated their children with great care, especially in the case of babies. They appreciated that the professionals were able to adapt their treatment to the different stages of a child's life and their different behaviours.

...I see how they (the ECI professionals) treat my daughter...when they are so tiny and such babies, you see that they hold them with all the love in the world.
(Mother of a 6-year-old girl)

5 | DISCUSSION

Our study has provided insights into reported aspects of the experiences of parents of children receiving ECI care. These experiences guide parents' perceptions on the quality of interactions with their children's professionals. These findings provide experiential knowledge that may be used by healthcare providers to improve the therapeutic relationship.

In paediatrics, PFCC recognises that the family is the primary source of support and as such, the family's perspectives are fundamental in clinical decision-making (Committee On Hospital Care and Institute for Patient and Family-Centered Care, 2012). PFCC is used widely in different settings and programs working with children and their families, as ECI programs, hospitals and others (Dunst et al., 2007) yet implementation is still challenging (An & Palisano, 2014).

The families in this study received the ECI programs in different settings (hospital, private centre and parent association). Besides possible differences in the contents of the programs, their experiences and feelings may have differed depending on the setting but also the culture, professionals, and policies of the centre where they received the program. For example, families receiving the ECI programs at the hospital described more experiences regarding the nurses' interventions than those who received the programs at the parent association. This may be because, although nurses are part of the ECI teams who work for children with disabilities (An & Palisano, 2014; Eurlayd. The European Association of Early Childhood Intervention, 2019), they might not be still fully integrated into the ECI teams in all settings. In our study, in some cases, parents referred to ECI professionals in general, perceiving them as a team, but other times they spoke about a specific type of professional, especially when they explained experiences regarding the process of learning a specific procedure or an exercise. Previous studies have identified the 'formation of quality teams' (Ely & Ostrosky, 2018) and team coordination (Bruder & Dunst, 2008) as influencing factors on the efficacy and associated outcomes of PFCC in ECI. In our study, parents did not speak specifically about the training and team coordination, although in some of their statements it is possible to discern their vision of whether they perceive ECI professionals as a team. It would be necessary to study this aspect more thoroughly to understand to what extent it intervenes in their perception of the quality of care.

We performed seven focus groups in our study, five with mothers and two with fathers. Even though mothers may appear to be

overrepresented, they are usually the main caregiver and, in about 80%–93% of cases, the person who more often carried out ECI programs (McConnell et al., 2015; Medina-Mirapeix et al., 2017). PFCC aspire to respond to the needs of the whole family and not just the child's, however, in many cases, there is a lack of parental dedication. Furthermore, the families have been adopting different roles over time, depending on the intervention models in ECI, and the programs have also evolved (Eurlaid. The European Association of Early Childhood Intervention, 2019). According to some studies, it is estimated that between 50 and 80% of the therapy received by children with physical disabilities comes from performing home programs (Gmmash & Effgen, 2019). According to some studies, it is estimated that between 50% and 80% of the therapy received by children with physical disabilities takes place in the context of home programs. Thus, according to this model, the home program can be understood as: (1) a complementary intervention to the clinical sessions received by the children in the centres; (2) a resource used in transitory episodes; and (3) the basic and continuous way of providing services to families. In our study, most families received between one and three weekly clinical sessions of 30 to 45 mi at the centres and the home program was a complementary intervention, however, the time dedicated to performing the home programs at home was not registered.

Home programs of participants in our study were quite heterogeneous and highly individualised, mainly including information and education about exercises, procedures, and recommendations for daily life. Previous research also suggests that home programs must be developed in a personalised manner taking into account the needs of the child and the families, regardless of whether they are used as the main resource, or as a complement to other treatments (Campbell et al., 2006; Eurlaid. The European Association of Early Childhood Intervention, 2019; Lillo-Navarro et al., 2019; Piggot et al., 2003).

In our study, parents identified various aspects that influence their perception of quality, highlighting the exchange of information and education, and the interpersonal manners, suggesting that the relationship between health care professionals and families is as important as the application of knowledge and skills by the health professional. These issues have been reported in the literature as factors that directly affect users' perceptions of service quality in paediatric rehabilitation (Santer et al., 2014) and are fundamental for parents' satisfaction with paediatric services (King & Chiarello, 2014).

Among the aspects that influence their perception of quality, parents in our study highlighted the importance of exchanging comprehensive information on the child's treatment plan and other aspects. When families receive incomplete information about their home programs the relationship with their professional is seen in a more negative light (King & Chiarello, 2014). This perception can also decrease adherence to the programs by ninefold (Lillo-Navarro et al., 2019), depending on the nature of the recommendation, thus, recommendations that parents perceive as more difficult show decreased adherence. In contrast, when clear information is provided, this supports the positive outcomes, such as the continuity of care,

development of therapeutic skills and family engagement with programs (Fordham et al., 2012; McCarthy & Guerin, 2022; Schenker et al., 2016). A meta-analysis developed with children with physical disabilities showed that, when information is provided, health professionals usually focus more on information regarding the children's health conditions and development, whereas families would also like to receive more information regarding services and support (Almasri et al., 2018). Health professionals should consider the families' needs for information and consider other aspects of both the child's and the family's life.

Parents valued that the information received was updated accordingly for the child's age or changing needs. Some problems identified in this area were related to a lack of information on how to handle children during activities of daily living as they grew older. Studies in paediatrics have mentioned that training parents in activities of daily living increases their perception of service quality (King et al., 2003), promotes functional outcomes, reaches family-selected goals, empowers the families to deal with the child's issues, attenuates parent stress and anxiety, increases satisfaction, and parenting confidence and attachment, among other benefits (Johnson & Marlow, 2017; Mclean et al., 2022; Melnyk et al., 2006). One of the characteristics found in the literature on ECI programs is that they are not static, rather they are in continuous evolution according to children and family needs (Novak & Berry, 2014). Participants in our study clearly expressed their needs to update the program and include recommendations for activities of daily living. Furthermore, current models of ECI propose that, instead of acting as co-therapists, families might facilitate active exploration by children, encouraging their participation and learning during activities of daily living (Dirks & Hadders-Algra, 2011; Hadders-Algra, 2011).

Moreover, parents also appreciated it when the guidelines recommended by professionals were verbally supported by written guidelines. Receiving written recommendations on behalf of health professionals not only improves patients' perceptions of quality but also the adherence to these recommendations according to some studies (King & Chiarello, 2014; Sullivan et al., 2005). In contrast, other authors did not find that association (Medina-Mirapeix et al., 2017). Furthermore, it has been questioned whether in ECI parents are collaborating or just following instructions from the health professionals (McCarthy & Guerin, 2022).

This study also revealed that the importance that parents give to the information interchange with professionals regarding home programs is partly based on how these activities and/or skills are taught. This aspect was central to the perceived quality of interaction with the professional (King et al., 2003; King & Chiarello, 2014). In fact, coaching of parents might be a simple and effective means of promoting infant development (Akhbari Ziegler et al., 2021). For example, a trial carried out in premature babies with neurological abnormalities receiving physiotherapy programs, showed differences in long term motor outcomes when the interventions included a coaching program COPCA (Coping with and Caring for infants with special needs) following the principles of PFCC and focusing on education and communication with caregivers (Akhbari Ziegler

et al., 2021). Another trial developed with children with physical disabilities and families receiving home programs showed that an instructional course on communication strategies for therapists and parents to collaborate on goal setting, planning, and implementing interventions, led to a more active integration of an intervention into a family's daily routine in the experimental group, identifying problems, and modifying the intervention plans. This group also reported greater confidence for carrying out activities of the program during daily routines (An et al., 2019). In the literature, there are some other examples of interventions developed in the population of children with special needs and developmental delays that show how the improvements in communication carried out by health professionals can enhance family functioning, physical functioning, daily activities, parental perception of the child's health care, satisfaction and technical skills (Hsieh et al., 2016; Siller et al., 2018). However, both in our study and in the literature (Cunningham & Rosenbaum, 2014; McManus et al., 2020), parents detected problems in communication and interaction with the health professionals, including unspecific recommendations, lack of information about dosage or lack of specific time for communication, among others. Considering that this is such a key component of PFCC, communication skills and knowledge transfer to other adults are also desirable in ECI professionals and might be trained more deeply.

Similar to initial education, monitoring of recommendations was highly appreciated by parents, who valued when therapists corrected them if necessary. This helped increase the parent's self confidence in the ability to perform these recommendations. Previous studies have shown that this also positively affects scores of quality of the home environment and children's mobility participation (Hsieh et al., 2016). Furthermore, when health professionals monitor home programs and ask families about their difficulties, both adherence and satisfaction increase (Lillo-Navarro et al., 2019; Novak & Berry, 2014; Sullivan et al., 2005). However, when parents have difficulty following the program, they can sometimes perceive this follow-up as a source of stress, leading to feelings of guilt (Tipping et al., 2010). Professionals must offer sufficient understanding and support so that families perceive this follow-up as a source of help.

In our study, we identified a number of experiences related to the professional's interpersonal skills (treatment, support ...) which affected the parents' perception of quality. These experiences have also been reported in other studies as issues relevant to parents of children with disability (Fordham et al., 2012; King & Chiarello, 2014; Santer et al., 2014). The literature also defines capacity-building as desirable skills (Early Childhood intervention Australia, 2018). Via these practices, ECI professionals work in a collaborative partnership supporting parents and caregivers by using their existing abilities and developing new skills (Centre for Community Child Health (CCCH), 2011; Dunst & Trivette, 2009) so that they can progressively build their capacity to meet the needs of their children and other family members.

Generally, participants reported that professionals behaved with respect and courtesy during the dialogue established with

them. Furthermore, they acknowledged that the constant support offered by the professional helped them increase their self-confidence. These results are consistent with most studies that have been conducted in the field of rehabilitation (Morera-Balaguer et al., 2021).

Parents have highlighted certain aspects as being problematic for the quality of their interaction with the professional. For example, sometimes the responses of the therapists to their questions were not as respectful as usual. This occurred at times when the professional lacked the time to respond, and as a result, several parents said they missed having specific time allocated to this exchange of information between professionals and themselves. In fact, having enough time to share information is one of the fundamental pillars of ECI and PFCC. A paradigm shift has been made in many settings and it has been proven that the time spent exchanging information with families exponentially increases the intervention time received by the child, improving their results and those of the family, in many areas (Early Childhood intervention Australia, 2018; Eurlayid. The European Association of Early Childhood Intervention, 2019).

Literature shows that the most influential factors regarding perceptions of quality are related to processes and, especially, interpersonal relations (Fisher & Broome, 2011). We therefore believe that both professionals and administrators must increase their efforts to improve these interpersonal aspects, taking into account the influence this has on perceived quality, satisfaction, and the understanding that poor communication between parents and professionals can cause greater anxiety and depression which can lead to low adherence to treatment and poorer clinical outcomes (McConnell et al., 2015; Novak & Berry, 2014; Santer et al., 2014). In the opinion of the authors, greater importance should be given to these aspects during both undergraduate and graduate training.

It should also be noted that the parents positively valued when they were made to feel as a fundamental part of the team for the care of their child, feeling useful and helpful in their child's development. The progressive changes in the approaches in ECI are favouring a more active parental involvement and the facilitation of child skill generalisation beyond the centre. ECI services must therefore be provided in the family context (Eurlayid. The European Association of Early Childhood Intervention, 2019).

Our results are consistent with other studies in ECI on the quality of the interaction between care providers and parents (King & Chiarello, 2014; McConnell et al., 2015; Novak & Berry, 2014). However, both quantitative and qualitative studies are necessary to corroborate our findings and support generalisation of the same.

5.1 | Implications for research

This study reveals certain topics which open avenues for future research. Our participants discussed the value of being taught activities, skills, and tips to improve their ability to care for their children,

giving importance to the context of the same, all of which influenced their perception of the quality of care received. However, some studies show that the perceived quality and other outcomes vary according to the type of recommendation and advice provided (Lillo-Navarro et al., 2019). This is an issue that should be studied, because of the implications this may have on the relationship between professional practice and therapy outcomes.

5.2 | Study limitations

This study has used qualitative methodology to describe the experience of parents of children receiving ECI, using an objective sampling frame and heterogeneous sampling. Together with the use of rigorous methods, this suggests that these findings may be representative of the experience of the parents of children receiving ECI.

Nevertheless, our study presents several limitations, mainly related to the methodology employed. Concerning the design, the cross-sectional and retrospective nature of this study prevents the ability to study the parents' experiences during their children's treatment period. The perceptions and experiences of parents described in this study reflect a particular moment of the ECI process, which may have been influenced by numerous aspects. Other designs may allow parents to provide a more complete and detailed description of their experiences of rehabilitation treatment.

Moreover, regarding the homogeneity criteria for the formation of groups, we stratified the groups solely on the basis of sex, to avoid inhibiting parents in their comments to the opposite sex. Perhaps the stratification of the groups based on the moment children were in treatment would have helped us to identify common experiences among parents whose children undergo short- or long-term treatments.

Finally, given the sample size and participation of parents from some (not all) of the ECI centres in the area, mainly receiving rehabilitation programs in the centres complemented by home programs, we cannot generalise the findings presented in this study to other models of ECI and other samples. For example, families who use models of care based on programs that are developed at home to be used only in the family context, perceptions may differ.

6 | CONCLUSION

Our findings indicate that therapists' willingness to exchange information and provide education to the parents, and their interpersonal manners with the child and the parents, could influence parents' perceptions of the quality of interaction with professionals working in ECI. Results from this study contribute important information to the literature regarding features of professional-parent interaction, and can help the health care providers with the implementation of the PFCC model. Further research is required to study the influence of certain characteristics, such as the type of program and advice followed by parents, in relation to these perceptions.

7 | RELEVANCE TO CLINICAL PRACTICE

This study provides valuable insight into experiences that can help professionals and managers of ECI services to adopt certain behaviours and interactions in their services in order to ensure better perceptions of quality on behalf of parents. Concretely: (a) treat children, parents and families respectfully and with courtesy; (b) support parents and families by answering their questions using clear and straightforward language, being concerned about their health status, the care they receive from other professionals and their child's behaviour in other contexts, and showing appreciation for the skill, knowledge and experience of parents in caring for their children and treating them as equals; (c) provide ECI in the family context, interchange a comprehensive plan and up-to-date information about the treatment options and goals, and the care of both the child and the parent in everyday activities, using written information when necessary, and setting aside a specific time for the exchange of information, observing them when performing these activities, and providing them with feedback; and (d) provide children with a personalised treatment, displaying compassion, giving them their full attention and showing sensitivity to their behaviour.

Deficiencies regarding education, specific time for communication and program monitoring should be considered by professionals working with children with disabilities and their families, given the influence these have on the perceived quality and sense of satisfaction, and the fact that the attitude of the provider has demonstrated to be both a barrier and a form of encouragement for the engagement of parents in the treatment of their children.

AUTHOR CONTRIBUTIONS

All authors were substantially involved in the design of the study, and development of research and focus groups questions. C.L.N., F.M.M., and P.E.R. directed the focus groups. C.L.N., S.L.O.S., J.M.H., and P.E.R. transcribed the focus groups. C.L.N., F.M.M., and J.M.H. carried out initial analysis and coding of data, discussed the coding throughout the analysis, and were extensively involved in revising and confirming the themes. C.L.N. and J.M.B. wrote the article and prepared the manuscript for journal submission; all authors contributed substantially to editing the draft. All authors read and approved the final manuscript.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

CLN has full control of all primary raw data (focus groups transcripts) and allow the journal to review our data if requested. All raw data are written in Spanish. The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

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