


# Family-centered care on a physiotherapy course: case reports

*Cuidado centrado na família em uma disciplina de fisioterapia: relato de casos*

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## Abstract

**Introduction:** Family-Centered Care (FCC) is a philosophy that recognizes the family as a partner in the intervention process and currently constitutes one of the most important practices in pediatric physical therapy intervention. For this reason, FCC should be part of pediatric physiotherapy training so that future physiotherapists are able to include it in their clinical practice. **Objective:** To verify the feasibility of applying FCC as part of an undergraduate Physiotherapy course, focusing on the activity of children with different health conditions. **Methods:** This is a case report, based on information collected from medical records, on an intervention program carried out with 5 children and their families, in the home, once a week for seven weeks, by students of physical therapy in pediatrics. For pre- and post-intervention assessment of the children, standardized instruments were used: Gross Motor Function Measure (GMFM) and the Alberta Infant Motor Scale (AIMS). Reports were collected from families and students regarding the FCC experience. **Results:** The children with neurological impairment increased the GMFM target area score by more than 5%, indicating clinical improvement. A child at biological risk had a pre-intervention AIMS percentile of < 25 and a post-intervention percentile of 50, while another child with developmental delay did not alter his percentile. At the end of the intervention, families reported greater confidence in carrying out activities with their children and students reported the experience as relevant to their professional training. **Conclusion:** The practical application of FCC proved promising in the academic context of pediatric physical therapy.

**Keywords:** Child. Family. Higher education. Physiotherapy.

## Resumo

**Introdução:** O Cuidado Centrado na Família (CCF) é uma filosofia que reconhece a família como parceira no processo de intervenção e, atualmente, constitui uma das práticas mais importantes na intervenção fisioterapêutica pediátrica. Por este motivo, o CCF deveria fazer parte da formação em fisioterapia pediátrica de maneira que futuros fisioterapeutas pudessem inseri-lo em sua prática clínica. **Objetivo:** Verificar a viabilidade da aplicação do CCF em uma disciplina de graduação em fisioterapia, com foco na atividade de crianças com condições de saúde variadas. **Métodos:** Trata-se de um relato de casos, a partir de informações coletadas em prontuários, sobre um programa de intervenção realizado com cinco crianças e suas famílias no contexto domiciliar, uma vez por semana, durante sete semanas, por discentes da disciplina de fisioterapia em pediatria. Para a avaliação pré e pós-intervenção das crianças, utilizaram-se instrumentos padronizados: Avaliação da Função Motora Grossa (GMFM) e Escala Motora Infantil de Alberta (AIMS). Foram coletados relatos das famílias e discentes quanto à experiência com o CCF. **Resultados:** As crianças com comprometimento neurológico aumentaram a pontuação na área-meta do GMFM em mais de 5%, indicando melhora clínica. Uma criança de risco biológico selecionada apresentou AIMS percentil pré de < 25 e pós de 50, enquanto outra criança com atraso no desenvolvimento não alterou seu percentil. Ao final da intervenção, as famílias relataram maior confiança na realização de atividades com suas crianças e os discentes relataram a experiência como relevante na formação profissional. **Conclusão:** A aplicação prática do CCF mostrou-se promissora no contexto acadêmico da fisioterapia pediátrica.

**Palavras-chave:** Criança. Família. Ensino Superior. Fisioterapia.

## Introduction

The context in which the child is inserted and their interpersonal relationships, especially those established with their parents and other family members, have a significant impact on their development.<sup>1</sup> The presence of a child with atypical development influences the entire family routine and is often accompanied by feelings of guilt, vulnerability, and incapacity on the part of the family.<sup>2</sup> Therefore, recognition of the family's value and their insertion in the care of the child contributes to recognizing their capabilities, favoring family

empowerment, and, consequently, generating greater confidence in facing daily adversities. Thus, the physical therapy intervention should consider these aspects, understanding that the family is of central importance to the child's life.

In recent decades, a philosophical shift in care has been taking hold that "recognises the family as central to the child's life, sees the child in the context of his (unique) family, and supports family members in their role as caregivers".<sup>3</sup> Such a philosophy of care is known as Family-Centered Care (FCC). FCC is currently the most important practice in a pediatric physical therapy intervention program, being considered the approach which best contributes to children receiving comprehensive care, since childcare is included in the family's daily routine. In addition, collaboration between parents and therapists enables a more effective behavior plan.<sup>4,5</sup>

FCC is in line with the biopsychosocial model of the International Classification of Functioning, Disability, and Health (ICF),<sup>6</sup> in which functionality/disability is related not only to the health condition, but is also based on the perspective of the individual's body and society, that is, in the domains of body structure and function, activity, and participation; it is the result of the dynamic interaction between these components and contextual factors (environmental and personal).<sup>6</sup> Therefore, being central to the child's life, the family provides an important environment for the child and represents a central contextual factor.<sup>7</sup>

An early-intervention physical therapy program, which has FCC as one of its basic premises, found positive results both for the child and their family.<sup>8,9</sup> The authors found that, months after completing the intervention, the infants who had been undergoing the FCC program showed better functional skills, assessed by the Pediatric Evaluation of Disability Inventory (PEDI), when compared with the group that had received traditional physical therapy (child-centered).<sup>8</sup> In addition, in another study by the same group, the authors found improved outcomes over time in the children of families using coping and care strategies within the context of FCC.<sup>9</sup>

In Brazil, however, clinical physiotherapeutic approaches remain predominantly focused on the child's developmental changes and disabilities,<sup>10</sup> with child-centered interventions being practiced, with little family participation.<sup>11</sup> Brazilian studies making use of FCC within the physiotherapy context are scarce.<sup>12</sup>

Thus, considering the importance of FCC, this philosophy of care should be part of the syllabus of physiotherapy courses in the area of pediatrics. The pediatrics section (SoP) of the American Physical Therapy Association highlights FCC in the provision of child health care as one of the essential skills, that is, it is considered as basic knowledge for all graduates in physical therapy.<sup>13</sup> It is believed that one of the ways to incorporate FCC into Brazilian pediatric physical therapy would be to offer this content on undergraduate curricula, enabling future physical therapists to make use of FCC in their clinical practice. Thus, the objective of the present study was to verify the feasibility of applying FCC as part of an undergraduate physiotherapy course, focusing on the activity of children with different health conditions.

## Methods

This is a quantitative and qualitative, retrospective, descriptive case report, carried out in the second half of 2018, based on information and data extracted from the medical records of patients in the pediatric discipline of the physiotherapy course of the Universidade Federal dos Vales do Jequitinhonha e Mucuri (UFVJM). The study was approved by the Research Ethics Committee of UFVJM, decision 4.005.807/CAAE 30291920.8.0000.5108.

The study participants were three children with cerebral palsy being treated at a school physical therapy clinic, but without clinical evolution in the previous year, in addition to a child with developmental delay and another at biological risk, both of whom were on the waiting list.

Standardized assessment instruments were used to verify the result of the physical therapy intervention through FCC according to the health condition: Alberta Infant Motor Scale (AIMS) and the Gross Motor Function Measure (GMFM).

The AIMS is a scale validated for the Brazilian population, with adequate psychometric measures,<sup>14</sup> which assesses the gross motor skills of children from zero to 18 months of age. It consists of 58 items, divided into four subscales, described in the following postures: prone (21 items), supine (9), sitting (12), and standing (16). During the test, the evaluator observes the child's movement in the four positions and marks those observed and not observed. For each item observed, the

child receives 1 point and for items not observed, the child receives zero. The items observed in all positions are added together, resulting in a total raw score varying from 0 to 58 points, which is later converted into the percentile of the child's motor development compared to children of the same age.<sup>15</sup>

For children with cerebral palsy, the standardized GMFM scale was used,<sup>14</sup> referenced by criterion, and officially translated into Portuguese.<sup>15</sup> Version 88 was chosen because it has more items in supine and prone, and is, therefore, more suitable for children with severe gross motor function impairment. The GMFM is a system for assessing gross motor function over time or in response to an intervention, which is widely used in clinical practice in Brazil and in research work.<sup>14,15</sup> The GMFM-88 consists of 88 items divided into five dimensions: a) lying down/rolling over; b) sitting; c) crawling/kneeling; d) standing; and e) walking/running/jumping. Through observation, each item is scored from 0 to 3: 0 - child does not initiate movement; 1 - initiates the movement but does not complete it (performs less than 10% of the movement); 2 - partially completes the movement (10% to less than 100%); and 3 - completes the movement. The score for each item is added up and absolute values and percentages for each dimension are obtained. In this study, the percentage of dimensions determined as goal areas was used, that is, dimensions where greater changes are expected.<sup>16</sup>

Before starting the intervention program, the students were instructed in the theory and practice of FCC. Subsequently, an intervention program was developed in the home context with FCC, in which one visit was carried out per week, by groups of three to four students per family, with an average duration of 60 minutes each, for seven weeks, supervised by the two teachers responsible for the discipline. The number of visits, students per family, and the duration of the approach were defined based on the academic period, number of weekly classes, and number of students in the class, so that the strategies used during the intervention within FCC were fulfilled and that all students could experience the concepts of this approach in practice.

The intervention was carried out based on the family-professional collaboration model: (1) goals mutually agreed with the family; (2) shared planning; (3) shared implementation; and (4) shared evaluation.<sup>4</sup> The strategies used are presented below (Box 1).

**Box 1** - Strategies used during the intervention in the home context within family-centered care

<b>First visit</b>	<ol style="list-style-type: none"> <li>1. Initial presentation: open and informal dialogue with parents, breaking any hierarchy.</li> <li>2. Observation of familiar characteristics and resources in the home environment.</li> <li>3. Collection of personal data and main complaint from parents.</li> <li>4. Collection of the child's daily routine.</li> <li>5. Assessment (AIMS or GMFM).</li> </ol>
<b>Second visit</b>	<ol style="list-style-type: none"> <li>1. Establishment of goals, parents and therapist together, based on the ICF activity domain.</li> <li>2. Establishment of moments of activities between parents and children within the proposed objectives (completing the routine table with the new activities). The proposed activities must be within the daily care routine or in the moments reserved for parents to "play" with their children, that is, within parenting.</li> </ol>
<b>Third to sixth visit</b>	<p>From the third visit, in all sessions.</p> <ol style="list-style-type: none"> <li>1. Inquiry of the following questions: <ul style="list-style-type: none"> <li>- How have things been since our last visit?</li> <li>- What did your child like best? What was most difficult?</li> <li>- What did you (father/mother) like most? What was most difficult?</li> <li>- Has there been any change in your child's performance?</li> <li>- Do you have questions or concerns about carrying out the activities we have planned (play and self-care) for your family?</li> <li>- Do you think we should change the plan?</li> <li>- How do you think we should change the plan?</li> </ul> </li> <li>2. If necessary, adaptation of the approach based on the answers.</li> <li>3. Observation of how the parents were "playing with the child" (within the proposed objectives).</li> <li>4. Demonstration and suggestion, if necessary.</li> </ol>
<b>Seventh visit</b>	<ol style="list-style-type: none"> <li>1. Reassess the child using the GMFM or AIMS.</li> <li>2. Collection of the family's experience report in relation to FCC.</li> </ol>

Note: AIMS = Alberta Infant Motor Scale; GMFM = Gross Motor Function; ICF = International Classification of Functioning, Disability, and Health.

The results of this study are presented descriptively. The components described by the biopsychosocial model of the ICF were used to characterize each child. The assessment instruments were presented by the pre/post-intervention percentile or by the pre/post-intervention percentage score obtained. The graphs were created using GraphPad Prism/version 8.0. The families' and students' perceptions regarding the experience were extracted from the medical records and, after skimming, the content was analyzed, thus establishing the categories.

## Results

Characterization of the study participants regarding clinical condition, disabilities (body structure/function), activity/limitation and participation/restriction, and contextual factors, are presented in Table 1. Table 2 presents the main descriptions of the FCC stages for each child, according to the weekly strategies used.

The areas of the GMFM worked on with the children with neurological impairment were defined according to the main complaint of the parents and guided by the students. Child 1 had dimensions B (sitting) and D (standing) defined as goal areas in the FCC, while children 2 and 3 had dimensions A (lying down and

rolling) and B (sitting) as goal areas. Children 4 and 5, both with delayed neuropsychomotor development, had goals agreed with their parents within the range of acquisition of each child in the different postures (child 4: prone, supine, sitting and standing; child 5: standing).

Children 1, 2, and 3 had an increase in their scores in the previously established goal areas, as shown in Figure 1, in which the pre/post-intervention GMFM-88 graphs are presented. When considering the target dimensions, a percentage change of 9.30% for child 1, 10.29% for child 2, and 6.24% for child 3 is observed. When applying the AIMS, a change was observed in the percentile of child 4, while child 5 remained at the same post-intervention percentile (Table 3).

At the end of the intervention, families and students were asked about the experience (Table 4). Three main categories can be observed in the parents' reports: (1) they perceived the child's improvement; (2) they learned to know the child's abilities better; and (3) recognized their value and contribution to the child's intervention. Regarding the students' reports, the following categories stood out: (1) they observed the child's improvement; (2) the feeling of gratification of having seen the outcome of the interventions; (3) the rich learning experience; and (4) the barriers from a practical point of view, such as time spent commuting.

**Table 1** - Characteristics of the children according to the International Classification of Functioning, Disability and Health

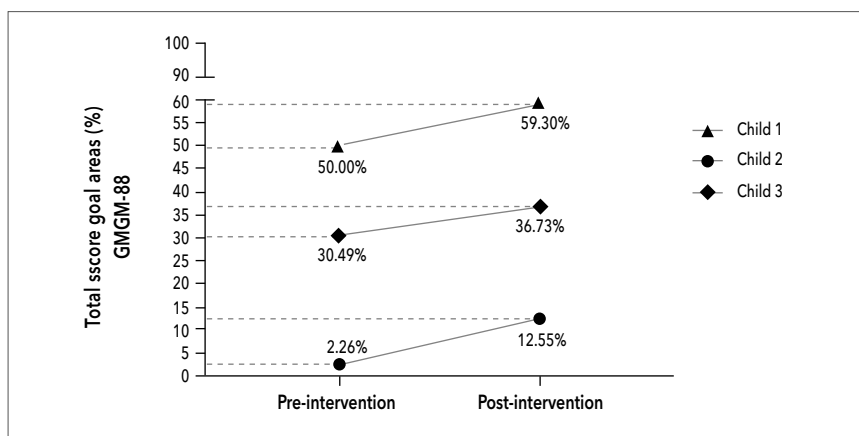
Child	Body function and structure		Activity and Participation		Contextual Factors
	Diagnosis and classifications	Deficiency of body structure and function	Activity and participation	Limitation and restriction	Personal and environmental
1	Spastic cerebral palsy (quadriplegia) GMFCS III, Mini-MACS II	Postural control deficit. Muscle weakness (in the lower limbs and trunk). Associated reactions. Right converging strabismus.	Sitting in the buddha position, he is able to pull himself up to a standing position with little assistance. Manipulates and reaches. Maintains the standing position with the support of hands and hips. Moves by dragging. Participates in outings with parents.	Does not perform forward and lateral gait. Does not assume the four-pronged position. Maintains sitting on the floor with one hand or with assistance, thoracic kyphosis, hip abduction, and knee flexion, but is unable to assume this position independently. Does not perform bimanual activities sitting on the floor. Doesn't ride his tricycle.	2 years and 11 months. Male. Cheerful, communicative, and motivated. Outings on weekends and late afternoons. Parents present and participative. Positive environmental characteristics (facilitators): access to regular school, home environment rich in stimuli and adaptations. Negative environmental characteristics (barriers): irregular surfaces in the external area of the residence that limit mobility.
2	Mixed cerebral palsy (quadriplegia) GMFCS IV, Mini-MACS IV	Dyskinetic-type hypotonia chorea. Scoliosis. Visual and hearing deficit. Muscle shortening (iliopsoas, tensor fascia latae, and hamstrings). Hip in flexion and abduction. Postural control deficit.	In the supine and prone positions, performs movement with the upper and lower limbs. Performs supine to prone roll.	Difficulty sitting without support and keeping the head at 45°. Limitation on transfers. Interaction difficulty.	3 years and 10 months. Male. Calm, collaborative. He has a 1-year-old sister. Outings on weekends. Positive environmental characteristics (facilitators): Participative and motivated mother, access to regular school and other health services, has an adapted bathtub. Negative environmental characteristics (barriers): domicile in a place of difficult access and city structure does not favor mobility with a wheelchair.
3	Hypotonic cerebral palsy (quadriplegia) GMFCS V, Mini-MACS III	Global hypotonia. Visual impairment. Macrocephaly.	Reaches objects in the midline. Manipulates. Rolls to both sides. In prone, maintains head position. Sitting, with hands supported, maintains control of head and trunk for a few seconds. Plays with the sister.	Does not assume a standing posture. Has limitations making transfers.	2 years. Male. Introspective, easily irritated. He has a 10-year-old sister. Positive environmental characteristics (facilitators): access to other health services. Negative environmental characteristics (barriers): Does not attend school, home environment with little stimulation, female single-parent family. The child does not interact with children of his age. Lives in a neighborhood with a high crime rate.
4	Biological risk (normal delivery with breech presentation and perinatal asphyxia )	Absence of deficiencies in the body structure.	In supine, keeps head oriented in midline, joins hands above chest, reaches for objects. In prone, maintains weight support in the forearm, elevates and supports the head for a few seconds. Standing, keeps her head in line with her body. She goes on late-afternoon walks with her mother.	In the supine position, maintains abduction and external rotation of the hips, flexion of the knees, dorsiflexion and ankle eversion. Less active lower limbs. Can remain, for a short period, with weight bearing on the upper limbs and thoracic kyphosis.	Four months. Female. Cheerful, but easily irritated. Positive environmental characteristics (facilitators): Educated and participative parents, access to health services. Frequent aquatic stimulation (once a week). Evening outings. Negative environmental characteristics (barriers): dimensions of the house limited for play.
5	ADNPM Psychomotor developmental delay	Absence of deficiencies in the body structure.	Pulls himself up to a standing position. Walks sideways. Makes transfers. Plays.	Does not walk independently. Does not speak. Does not interact with other children.	11 months. Male. Good-natured. Positive environmental characteristics (facilitators): nuclear family composed of father and mother, minimal financial conditions. Negative environmental characteristics (barriers): poor home environment in stimuli. Does not live with other children or adults.

Note: GMFCS = Gross Motor Function Classification System; Level III = Children sit alone or require at most limited external support to sit. MACS = Manual Ability Classification System, Level II = Child handles most objects, but with somewhat reduced quality and completion time.

**Table 2** - Description of the main points of the weekly strategies used in the FCC for each of the children and their families

Child	Week 1	Week 2	Week 3 to 6	Week 7
1	Parents' main complaint: "My child has difficulty standing and does not take steps, even when supported."	<ul style="list-style-type: none"> <li>- Mutually agreed goals: "get the child to stand up from sitting on the floor and increase the time in orthostatism."</li> <li>- The family established moments in the routine to stimulate the child.</li> <li>- They suggested games that encourage the child to reach the goals, such as placing toys at different heights so that the child tries to move to standing from sitting on the floor. They also encouraged the standing position during the bath.</li> </ul>	<ul style="list-style-type: none"> <li>- Main difficulty for parents: failing to support the child during position transfer.</li> <li>- Main facilities for parents: they allowed the child to try and make mistakes during the process. They understood that the child needed less support than was provided for position transfer. They motivated the child. The activities were varied and in different contexts. The parents built and acquired toys that helped to stimulate the achievement of goals and showed more autonomy in care and greater understanding of the child's condition over the weeks.</li> </ul>	<ul style="list-style-type: none"> <li>- In the evaluation shared with the parents, an improvement was observed in the child's ability to pull himself to a standing position from the buddha sitting position, in addition to greater interest of the child in playing in the standing position.</li> <li>- Parents recognized advances in their child's motor performance.</li> <li>- Parents stated that they were less overprotective and more patient in waiting for the child to respond to activities, in addition to having a better understanding of their child's health condition.</li> </ul>
2	Mother's main complaint: "I would like my child to have an improvement in sitting balance and stay in that position longer."	<ul style="list-style-type: none"> <li>- Mutually agreed goals: make the child stay in the sitting position longer, with as little support as possible, and improve alignment in the position.</li> <li>- The mother established moments in the routine to stimulate the child during daily care activities and during play.</li> <li>- The students helped the mother to think about how to overcome the limitations she presented so that she could have ideas for games to be developed with her child, until the mother suggested building a sensory mat for the child and suggested encouraging her to sit on a step, with her feet supported.</li> </ul>	<ul style="list-style-type: none"> <li>- Mother's main difficulty: maintaining the child's alignment in the sitting position. Due to low visual and auditory acuity, the mother reported difficulties in stimulating the child.</li> <li>- Main facilities of the mother: very attentive to the child's routine and in the implementation of stimuli as she learned more about the child's health condition. She made rugs with different textures so that the child could be stimulated in the position of all fours, on the mother's legs, and, thus, improve the activation of the spine muscles and the child's head control.</li> <li>- Over the weeks, the difficulties initially reported ceased to exist and the mother was more empowered and assertive in playing with her child.</li> </ul>	<ul style="list-style-type: none"> <li>- In the assessment shared with the mother, there was an improvement in the child's balance in the sitting position, which enabled him to considerably increase playing time without becoming destabilized, going from a few seconds (in the pre-intervention assessment) to a few minutes (in the post-intervention assessment).</li> <li>- The mother stated that she was more confident in the decisions made in relation to her son and easily perceived his greater interaction with her and with his younger sister, who was being involved in the games developed with her brother.</li> </ul>
3	Mother's main complaint: "I wanted my son to firm up his body more and put food in his mouth by himself."	<ul style="list-style-type: none"> <li>- Mutually agreed goals: to provide opportunities for the child to feed himself, giving him the necessary time. Play with the child on more stable surfaces to encourage better head and trunk control.</li> <li>- The mother was initially afraid to make suggestions as to moments in her routine when she could stimulate her child.</li> <li>- The students conducted the visit/treatment in order to eliminate hierarchies.</li> <li>- After understanding that the one who has the most knowledge about the child's health is herself, the mother was able to define, together with the students, the games to be played to stimulate the child and the best moments within the routine. A board with the routine was fixed on the wall of the house to help the mother remember.</li> </ul>	<ul style="list-style-type: none"> <li>- Main difficulties encountered by the mother: she was initially unable to develop activities, which made her feel discouraged with the approach. Main facilities: the mother was able to see the child's progress as she overcame the difficulties in giving him time to perform the tasks, so she became more participative and more motivated during the following sessions. The child's older sister was included in her brother's routine in order to contribute with games that stimulated him.</li> <li>- A clothesline of photos with the child in different positions and with encouraging phrases was prepared by the group of students to give visual stimuli to the family.</li> </ul>	<ul style="list-style-type: none"> <li>- In the evaluation shared with the child's mother and sister, it was observed that he spent more time in the sitting position with the support of his hands and presented better control of the head and trunk (from 5 seconds to almost 2 minutes). When stimulated, the child began to pivot to reach objects. As for putting food in the mouth, it was agreed with the family that the child needed more opportunities to explore food and be able to put it in his mouth.</li> <li>- Over the weeks, the mother and sister were more participative in activities with the child and more open to talking about their anxieties with the students.</li> <li>- The family was motivated not to give up encouraging the child in the first attempts at a new game, since the child needed trials and errors, and training was necessary for the proposed task to be carried out.</li> </ul>
4	Parent's main complaint: "My daughter moves her legs little compared to other children."	<ul style="list-style-type: none"> <li>- Mutually agreed goals: reach the feet in the supine position. Stimulate the child in the absence of the ecological cloth diaper to facilitate performance in the activity, since it was previously observed that the volume of the diaper made it difficult for the child to move.<sup>32</sup></li> <li>- Moments were established within the family's routine so that the child was stimulated, including during diaper changes, as suggested by the parents.</li> </ul>	<ul style="list-style-type: none"> <li>- Parents' main difficulty: the child's irritability in some postures made it difficult to carry out certain activities designed by the parents.</li> <li>- Main facilities: parents engaged in relation to different ways of stimulating the child. To overcome the child's irritability, the parents introduced musical resources, which enabled the daughter to remain calmer and stay longer in the postures defined for stimulation.</li> <li>- As the weeks went by, the child showed progress in motor development and new goals were set with the parents, such as playing longer in the prone position and, subsequently, stimulating the child in the cat position and to pull herself to a standing position.</li> </ul>	<ul style="list-style-type: none"> <li>- In the evaluation shared with the parents, there was an improvement in the child's gross motor performance with improvement in active movement of the lower limbs in all postures, good performance in rolling over, sitting without support, and in the use of the hands to reach and manipulate toys in the position.</li> <li>- Parents were even more engaged and assertive about ways to stimulate the child.</li> <li>- The mother stated that she was calmer about the child's condition, as she began to understand her condition better, and said that she understood that it was necessary to allow time for the daughter to respond to stimuli, which greatly reduced anxiety and fears about the child's future.</li> </ul>
5	Parents' Chief Complaint: "We want our child to take his first steps."	<ul style="list-style-type: none"> <li>- Mutually agreed goal: make the child pull himself to his feet, encourage the child to stay longer in orthostatism, promote anterior gait with the help of toys.</li> <li>- The parents, with the help of the students, identified factors that facilitated and hindered the performance of activities by the child.</li> <li>- The parents determined moments in the routine when they could play with the child, in order to achieve the goals and use facilitating elements to carry out the activities.</li> </ul>	<ul style="list-style-type: none"> <li>- Main difficulties for parents: establishing, within the routine, a time to play with the child during the week that could be effectively accomplished. They reported difficulty in meeting the goals agreed with the students.</li> <li>- Main facilities: as the sessions progressed, the parents became more creative in stimulating the child and began to try to overcome difficulties.</li> </ul>	<ul style="list-style-type: none"> <li>- In the evaluation shared with the parents, they mentioned that they realized the importance of letting the child play on the floor longer and how much their participation in games made the child more motivated and made him/her stay on his/her feet longer.</li> <li>- The parents, despite leaving the child a little freer to play on the floor, remained overprotective until the end of the visits. At the end of the treatment, the environment had more stimuli for the child and the parents adapted a stroller so that the child could push it and steps were encouraged.</li> </ul>





**Figure 1** - Evolutionary graph of the percentage scores of the goal areas of the Gross Motor Function Measure (GMFM-88) of the children (all with cerebral palsy) in the pre-intervention period and after 7 weeks of application of Family-Centered Care (post-intervention).

**Table 3** - Alberta Infant Motor Scales (AIMS) Score

	Child 4		Child 5	
	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention
Prone	4	8	21	21
Supine	6	8	9	9
Sitting	3	10	12	12
Standing	2	3	7	10
Total score	15	29	49	52
Percentile	< 25	50	10	10

Note: Child 4 - Biological risk; Child 5 - Psychomotor developmental delay.

**Table 4** - Families' and students' report at the end of the home intervention with Family-Centered Care (FCC)

Child	Family report	Student group report
1	"I understood better what to expect or not from my son, and how I could contribute to his development".	"The experience of participating in a family-centered home care program was rewarding and important to our academic background. Knowing the environment where the child lives, their routine, and their families helped us create a clinical perspective on the most diverse situations in everyday life, and to find simple ways to solve possible small problems when we know the environment where the family lives."
2	"I enjoyed the experience and thought my son was getting better."	"The experience was gratifying, as it was our first contact with a pediatric patient; it enabled us to learn a lot. The child's improvement at the end was clear and gratifying and we were very proud of our work. Unfortunately, the location of the child's house made it somewhat difficult; due to the rains and very hot sun, we had a bit of trouble."
3	"I was very happy with the evolution of my son, and I understood that it is very important to offer stimuli to the child."	"We found the experience interesting, as it is a way of closely observing a child who has a certain health condition and developmental delay as a consequence, thus enabling us to have a better idea of how to deal with these cases. Not forgetting also that the family-centered approach shows us that it is extremely important to know the personal, social, and environmental factors of the family, because only then will the care have stronger positive consequences for our patient and in this way his treatment will be effective."
4	"I noticed an improvement in my daughter's performance, and I learned to take advantage of moments within my routine to stimulate her."	"For us, being able to have a closer experience with a patient was beneficial, helping us in the relationship with the family and patient."
5	"For us, being able to have a closer experience with a patient was beneficial, helping us in the relationship with the family and patient."	"We observed that the intervention is extremely important for the child's development, not to mention that it strengthens the bonds between the parents and the child."

## Discussion

The present study demonstrated that it is feasible to use FCC within an undergraduate course in physiotherapy, considering the clinical improvement of children and the positive perception of the families and participating students.

Children 1, 2, and 3 showed an increase of at least 6% in total GMFM scores, considering the goal areas. Although the results were presented in a descriptive way, it should be considered that differences above 5% in GMFM scores are considered clinically significant.<sup>17,18</sup> Thus, in general, it is observed that the children with neurological impairment benefited from FCC. Regarding child 4, his inclusion in the study is the result of a recommendation for early intervention, due to the biological risk factors presented, and it was observed that he also benefited from FCC.

According to the interaction with the functionality/disability components, environmental factors can contribute as facilitators or barriers to the performance of the child's activities.<sup>6</sup> In this sense, important differences were observed in each of the families monitored, which may have contributed to the results found. Children 1, 2, and 4 had in common the fact of having participative and motivated parents and a home environment rich in stimuli. Even in cases where architectural barriers could restrict the child's participation, the parents would take them on daily or weekend outings. In this sense, it is known that family participation and cooperation in the treatment of children positively influence the results.<sup>18,19</sup>

Child 3 was initially characterized as a challenge to the implementation of FCC, considering some contextual factors such as the father's absence, the mother's lack of motivation, the child's irritability, and the scarcity of learning material and other resources in the home environment. That is, in addition to biological risk factors, the child lived in an unfavorable context, and was therefore also considered to be at psychosocial risk. Thus, associated biological and psychosocial risk factors make the child even more vulnerable to delays in development.<sup>20</sup> Nevertheless, during the sessions, the therapists conducted the treatment in order to eliminate hierarchies and make the mother more comfortable to expose her desires and ideas, in addition to encouraging the participation of the older sister during the sessions. Throughout the process, the family increased its participation and, with constant praise for

the performance of activities, mother and sister began to feel more confident. Studies indicate that one of the positive results of FCC is the empowerment of the family in the children's rehabilitation process.<sup>21</sup>

Some important barriers that impact the success of the intervention were observed in relation to child 5 and his family, which reflected in the absence of positive evolution, being the only child that did not present objective improvement on the applied standardized test. Considering the contextual factors, although the parents were receptive to the team in the home meetings, it was observed that they had difficulties establishing a time to play with the child during the week, according to the agreed goals. In this sense, according to the literature, families and therapists may have different beliefs/attitudes in relation to the intervention process. For some families, the care indicated by the therapist may come as a last priority, considering other social and family responsibilities,<sup>22</sup> which may have been the case for this child.

According to Brown et al.,<sup>23</sup> there are seven different levels of family involvement, ranging from the choice of "non-involvement" to "total control of the entire process". It is important to remember, therefore, one of the guiding principles of FCC: "the degree of involvement that families choose in relation to the treatment of the child must be respected."<sup>24</sup> Nevertheless, at the end of the seven weeks of follow-up, the parents of Child 5 reported realizing the importance of letting the child play on the floor longer and how much their participation in games made the child more motivated. Thus, it is worth noting that the change from a biomedical model perspective, in which the therapist controls the entire process, to a family-centered model, in which responsibilities are shared, is also a process that occurs gradually. It is possible that the family changes its position within the different levels of involvement over time and with the therapist's posture.<sup>23</sup>

Regarding the perception of the families at the end of the intervention, in addition to the subjective report of the children's improvement, the parents claimed to have obtained greater knowledge regarding their children's abilities. In addition, they found that they could actually contribute to developing activities that favor the child's participation in their daily routine. These reports are in agreement with studies found in the literature.<sup>21,25</sup> In his study on the opinion of parents in regard to the implementation of home programs according to FCC, Novak<sup>21</sup> reported that, through the guidance and



support they received from therapists, parents gained more confidence to help their children. Based on their experience with a family-centered program, COPing with and CARing for Infants with Special Needs, Zielgler and Hadders-Algra<sup>26</sup> observed that parents naturally began to make the home environment enriching for the development of their children, as observed in the families of most of the children involved in the present study.

According to the students' reports, the experience was of importance to their training, helping them understand the real context, resources, and potential of families, which facilitated the choice of activities suitable for the needs of each patient. The students emphasized that learning within the context of FCC is very broad and that the experience will be valid not only during graduation, but will impact upon their approaches as future professionals within the family environment or even within the clinical environment. Johnson et al.<sup>27</sup> found similar reports when verifying what medical students were learning when working with FCC during home visits, finding that students learned valuable lessons from the experiences and that direct contact with families provided better learning.

Nevertheless, although FCC has several positive points and is widely supported by the literature, it is also necessary to discuss the difficulties that may be encountered<sup>28</sup> and mention the possible negative impacts of the inclusion of FCC on the undergraduate curriculum. Litchfield and MacDougall<sup>28</sup> reported the results of a qualitative study with physical therapists who worked within FCC through home-based programs and highlighted practical barriers, mainly citing the time spent commuting to the residence. Similarly, despite praising the FCC experience, a group of students in the present study also encountered difficulties during the process due to excessive time spent traveling to the child's home, in addition to facing unfavorable weather conditions. It is important to emphasize that FCC is a philosophy of care, therefore, it can also be implemented within the physical therapist's clinical practice in any therapeutic environment, not just in the child's home. It is noteworthy, however, that one of its basic premises is that "the ideal behavior of the child occurs within a supportive family and community context" and one of its guiding principles is the involvement of all family members.<sup>3</sup> Therefore, intervention in the home environment is not mandatory, but preferential because it optimizes the child's ideal behavior and the involvement of the whole family.

Furthermore, it is also worth highlighting certain other points presented in the literature that can be considered as barriers to the implementation of FCC in the practice of pediatric physical therapy. FCC cannot merely be added to previous models,<sup>29</sup> as it would be necessary for the entire conceptual structure to be reorganized so that the change is effectively implemented to become centered on the family.<sup>27-29</sup> Another point is that the therapist may feel threatened by changes in their professional roles, where the family becomes ultimately responsible for the child's treatment.<sup>30</sup> In addition, FCC requires skills such as communication, honesty, respect, tolerance, and flexibility from the therapist.<sup>30</sup> Therefore, FCC is, in fact, a total change of conception and, for this reason, gaining experience in FCC while still an undergraduate is important, as it would enable the professional to have contact not only with the theoretical principles, but also with experiences that allow them to develop the necessary skills and competences.<sup>28,31</sup>

Some important limitations in this study are the number of participants, the short period using the approach, and the sample being composed only of participants from a single Brazilian municipality. Thus, future studies that address a greater number of participants over a longer period of FCC are necessary, as are studies that evaluate different sociocultural contexts. Another limitation that should be addressed in further studies is the use of standardized assessment instruments that can measure the change in parental empowerment, as well as other aspects beyond the activity, within functionality according to the ICF model. It is suggested that in future studies instruments are used that verify, for example, the child's participation. The present study, however, contributes to the discussion on the inclusion of FCC on undergraduate curricula, in addition to demonstrating the potential for the development of future studies with an adequate methodological design to verify a cause-and-effect relationship.

## Conclusion

In a relatively short period of time, most of the children in the present study reached the therapeutic goals and the families felt satisfied with the results achieved by their children. It was also observed that despite some barriers from a practical point of view, FCC has the potential to be included within a pediatric physiotherapy discipline. Considering the students' reports, the experience was

of great importance for their professional training in pediatric practice. FCC proved to be promising and future studies are suggested with other methodological designs that enable the analysis of a cause-and-effect relationship, in addition to those that can confirm the feasibility of its inclusion on the undergraduate physiotherapy curriculum.

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## Authors' contribution

RFMC was responsible for collecting the data from medical records and writing the manuscript. KBC and RLSM, professors and supervisors of the application of FCC, were also responsible for the study design, guidance and final review of the manuscript.

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