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# RESEARCH ARTICLE





# Design and Validation of a Questionnaire about Risk Factors in Children with Cerebral Palsy

Diseño y validación de un cuestionario sobre factores de riesgo en niños con parálisis cerebral

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#### **Abstract**

**Objective.** To design and validate, in its appearance, a questionnaire to collect information on risk factors in children with cerebral palsy.

**Methodology.** The descriptive and methodological study included a design phase and a face validation phase of a questionnaire. The latter was carried out with the participation of 43 mothers and ten health professionals.

**Results.** Following Rutter's theoretical model of risk factors, a questionnaire was designed to collect information on pre-and perinatal conditions, which can be used as part of the documentation of the clinical history of children with cerebral palsy. Face validation of the instrument was performed, which suggested the acceptance of 17 items and the reformulation of 12, equivalent to 41.4% of the total number of questions of the FR-PC questionnaire.

**Limitations.** The sample size could have been larger. Similarly, more literature was needed to compare the results with similar studies.

**Value.** The product of this research is the FR-PC questionnaire. This tool facilitates the organization and integration of data from the child's clinical history with CP for decision-making. Furthermore, its content can be considered for developing health research projects.

**Conclusions.** The FR-PC questionnaire is a clear and understandable tool for collecting information on risk factors in children with cerebral palsy.



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conceptualization, data curation, formal analysis, research, methodology, project management, supervision, validation, visualization, writing: original draft, writing: review and editing.

# Keywords

Cerebral palsy; risk factors; validation study; questionnaires; physiotherapy; patient health questionnaire; brain injury; surveys and questionnaires; psychometrics; infant.

# Resumen

**Objetivo.** Diseñar y validar, en su apariencia, un cuestionario para recolectar información sobre factores de riesgo en niños con parálisis cerebral.

**Metodología.** Estudio descriptivo, metodológico, que incluyó una fase de diseño y otra de validación facial de un cuestionario. Esta última se llevó a cabo a través de la participación de 43 madres y 10 profesionales del área de la salud.

**Resultados.** De acuerdo con el modelo teórico de Rutter alrededor de los factores de riesgo, se diseñó un cuestionario que permite recolectar información sobre condiciones pre y perinatales, que puede ser utilizado como parte de la documentación de la historia clínica de los niños con parálisis cerebral. Se realizó la validación facial del instrumento, cuyos resultados sugirieron la aceptación de 17 ítems y la reformulación de 12, equivalentes al 41,4% de la totalidad de preguntas del Cuestionario FR-PC.

**Limitaciones.** El tamaño de la muestra pudo ser superior. De igual forma, no se encontró suficiente literatura que permitiera contrastar los resultados del estudio con otros similares.

**Valor.** El producto de esta investigación es el Cuestionario FR-PC, herramienta que facilita la organización y la integración de los datos de la historia clínica del niño con PC, para la toma de decisiones. Así mismo, su contenido puede ser considerado para el desarrollo de proyectos de investigación en salud.

**Conclusiones.** El Cuestionario FR-PC es una herramienta clara y comprensible para recolectar información sobre factores de riesgo en niños con parálisis cerebral.

# Palabras Clave

Parálisis cerebral; factores de riesgo; estudio de validación; cuestionarios; fisioterapia; cuestionario de salud del paciente; lesiones encefálicas; encuestas y cuestionarios; psicometría; infante.

#### Introduction

Cerebral palsy (CP) is defined by Rosenbaum as "a group of permanent developmental disorders of movement and posture, causing functional limitation. These are attributed to non-progressive disturbances produced in the developing fetal or infant brain" [1 p564]. It is usually diagnosed after two years and is the most common cause of physical disability in children. It has an estimated prevalence of 2 per 1000 live births, with multiple risk factors, each contributing to a different degree of severity in various individuals [1]. CP can be classified according to its distribution in the body and postural and movement characteristics, which guides the diagnosis and treatment of the child and allows for differentiated interventions or approaches [1-3]. The diagnosis depends on several elements, including the identification of prenatal, perinatal, and postnatal risk factors, as well as different social and cultural agents that may influence the development of this health condition, and there is still a wide field of exploration of this topic [4-8].



For their part, risk factors associated with health conditions have been studied in different fields for years. The World Health Organization has defined them as "any trait, characteristic, or exposure of an individual that increases his or her likelihood of disease or injury" [9 p106]. This article follows the previous concept and the proposal of Rutter, who classified them into three categories: 1. Biological, which refers to the physical nature of the events; 2. Organic, which refers to medical diagnoses; and 3. Environmental refers to cultural, social, and economic resources. In a complementary manner, Rutter proposes the following classification, which corresponds to the level of influence each risk factor may have on the person: 1. Proximal risk factors; 2. Medial risk factors; and 3. Distal risk factors [10,11].

In particular, risk factors associated with CP have been considered globally from three categories: prenatal, perinatal, and postnatal. The literature review by Himmelmann et al. [12] found a significant association between the development of CP and organic factors such as chorioamnionitis, maternal urinary tract infections, cytomegalovirus and neurotropic virus infection, and hyperbilirubinemia. In addition, it found that intrauterine growth deviations and multiple pregnancies represent a risk factor for CP. It is worth highlighting that from the environmental factors, their study reports an association between social deprivation and the development of CP in children.

Freire et al. [5] found that gestational hypertension and preeclampsia are risk factors for developing CP in children. This factor generates a limitation in the availability of nutrients and oxygen to the brain and restriction intrauterine growth. The above is due to the placental dysfunction associated with these conditions.

Derived from literature reports, Włodarczyk et al. [13] refer to the following factors as those associated with the risk of developing CP: maternal viral infections (STORCH), threatened abortion, gestational hypertension, pelvic delivery, preterm birth, low birth weight, placental insufficiency, forceps use, neonatal jaundice, respiratory distress syndrome, and other neonatal complications such as seizures, intraventricular hemorrhage, and sepsis.

The study conducted in Moldova by Bufteac et al. [14] found a correlation between the development of CP and the following risk factors: alcohol consumption during pregnancy, maternal arterial hypertension, maternal age over 35 years, maternal epilepsy, multiple pregnancies, breech delivery, cord circulation, and hyperbilirubinemia. From the environmental factors, the study draws attention to the results related to the rural origin and home-assisted childbirth, given their significance.

In addition to some organic and biological factors, such as APGAR less than seven at minute five and short stature for gestational age, Jöud et al. [4] found an understudied risk factor to be considered: maternal obesity.

Stoknes et al. [6] found an increased risk for CP as the number of associated factors increases; they state that the four main combinations of risk factors associated with CP are maternal illness and preterm labor, preterm labor and induction, maternal illness and induction, and maternal illness and APGAR less than seven at five minutes. This last combination yielded the highest correlation in their study.

Although CP has been extensively studied worldwide and significant associations have been found with risk factors, mainly biological and organic, it is not easy to find literature that reports questionnaires designed to collect information on pre-, peri- and postnatal biological,



organic, and environmental factors that may be related to the development of this condition in children. The latter becomes a knowledge gap that requires viable and well-founded solutions. This aspect is essential since prevention and intervention strategies can be appropriately oriented to the extent that the risk factors associated with lesions occurring in the immature brain are identified.

For this reason, there is a need to design an instrument to collect this information for approaching the child and family, including assessment, professional reasoning, diagnosis, and establishing and implementing intervention plans.

Considering the above, the objective of this research was to design and validate, in its appearance, a questionnaire to collect information on risk factors in children with cerebral palsy in order to have an instrument through which these factors can be taken into account, from the biological, organic and environmental fields, and provide the health team with a valuable tool to provide information and guide decision-making around the child with CP and his family (Annex: FR-PC Questionnaire).

# Methodology

A quantitative study of diagnostic test evaluation was developed through a design phase and another phase of face validation of a questionnaire. The latter was carried out through the participation of 43 mothers and ten health professionals, who formed the sample of the present study, that is, a non-probabilistic sample by convenience.

In this regard, it is essential to note that there is a wide variety of criteria for determining the sample size of test validation studies and, even more so, for face or appearance validation processes. Some authors suggest ten participants per item, some suggest five, and others suggest between two and three participants for each item contained in a broad instrument [15].

The design phase took into account the recommendations issued by Corral [16], Alonso et al. [17], and by Muñiz et al. [18] in terms of four premises: every questionnaire must be a reasonable and comprehensible document, sensitive to change concerning the phenomenon it measures, with justifiable and reasonable basic assumptions and clearly defined components. Similarly, this phase included four moments: 1) Determining the purpose of the instrument; 2) Defining the type of instrument to be used; 3) Conceptualizing the construct; 4) Operationalizing the construct.

Concerning the purpose of the instrument, it is expected to have a primary input through which the health team will have information on biological, organic, and environmental factors that will guide decision-making for the child with CP and his or her family.

The instrument analyzed in this research work is a questionnaire that allows the application of a series of questions on possible factors related to the development of CP. The questionnaire includes a mixed response type since it contemplates several response options, with closed, semi-closed, and open alternatives [16,17,19].

The conceptualization phase of the construct was carried out through a literature search guided by the PIOM strategy [20,21], which included the following keywords in Spanish and their correspondence in English: "Cerebral Palsy," "Questionnaires," "Risk Factors," "Validation Study (DeCS)."



This research considered the "Risk Factors that may be associated with Cerebral Palsy" as all those events or conditions of a natural, organic, or environmental order that occur before, during, or after birth and predispose an individual to develop cerebral palsy. According to their influence level, these can be proximal, medial, or distal.

According to the above, and bearing in mind both the purpose of the instrument and Rutter's proposal, Table 1 presents the operationalization of the construct.

After defining the construct and developing its operationalization, the formulation of each question (item) and response options continued, particularly for those with a closed or semi-closed structure. Thus, this led to the design of the questionnaire, oriented towards collecting useful information regarding factors that, proximally or distally, directly or indirectly, may represent a risk for the development of CP. The form contains 29 items or questions and is designed to be filled out by health professionals, following a structure that allows its alignment with the processes corresponding to the child's clinical history (Annex: FR-PC Questionnaire).

The face validation stage of the questionnaire involved the participation of 43 mothers and ten health professionals, selected by convenience, taking into account the following inclusion criteria:

Mothers: women who have been mothers residing in Colombia, with a basic primary school level that allows the completion of the face validation format of the questionnaire.

Health professionals: therapists, nurses, doctors, and psychologists, residents of Colombia, and with expertise in managing children's health conditions.

As part of the face validation process, two criteria were evaluated for each of the questions in the questionnaire: clarity and comprehension. About the above, the rating was established on an ordinal measurement scale, from 1 to 3, with its corresponding indicator (Table 2). It should be noted that the format for face validation recorded by professionals includes the 29 questions proposed by the FR-PC questionnaire. In contrast, the format applied to the mothers did not consider 3 of these, given their level of specificity (questions # 22, 23, and 24).

In order to allow the analysis of the information, the format for face validation of the FR-PC questionnaire was sent via e-mail to the professionals and was applied to the mothers. Following the procedure used in the study by Suárez-Acuña et al. [22], 80% acceptability was established as the minimum value to give rise to the acceptance of the question concerning each criterion evaluated; for questions with acceptance percentages below 80%, a new review process was projected, in order to obtain an adjusted version.

This research is part of the project "Cerebral Palsy, General Movements, Motor Development in Infants and Family Coping Strategies," endorsed by the Ethics and Research Committee of the Universidad de La Sabana, with code ENF-58-2020. The research took into account both the ethical and environmental guidelines established by the Universidad de La Sabana and the international guidelines related to the ethics of scientific writing and those to safeguard the integrity and confidentiality of the people who participated in the study, considering the principles of privacy and autonomy, established by the Declaration of Helsinki and the guidelines of Resolution 8430 of 1993 of the Colombian Ministry of Health.

The FR-PC questionnaire will be the instrument to be used to collect data related to biological, organic, and environmental risk factors of the children who are part of the study "Cerebral Palsy, General Movements, Motor Development in Infants and Family Coping Strategies."



	Table 1. Operationalization of the cons	struct FR-PC questio	nnaire
Dimensions (Factors by	Dimensions (Factors according to the level of influence)		)
category)	Proximal factor	Medial factor	Distal factor
	Mother's age during pregnancy (#1)		Mother's weight during pregnancy (#10)
	Type of birth (#5)		Number of mother's pregnancies (#14)
	Child of multiple pregnancies (#15)		
	Pregnancy risk level (#16)		
	Existence of threatened abortion (#17)		
Dialogical factors	Gestational age of the child at birth (#19)	Mother's emotional	onal
Biological factors	Child's birth weight (#20)	events during pregnancy (#12)	
	Child size at birth (#21)		
	Head circumference at birth (#22)		
	Chest circumference of the child at birth (#23)		
	Child's APGAR score at minutes 1 and 5 (#24)		
	Maternal use of or exposure to psychoactive, toxic, or highly polluting substances during or prior to pregnancy (#13)		
	Child's family history (health-related) (#27)	Mother's family history (health- related) (#27)	
Organic factors	Gestational complications of the infant (#18)	Number of abortions the mother has had (#14)	
	Complications of the infant at birth (#25)		
	Maternal illness during pregnancy (#18)		



Table 1. (continued)				
Dimensions (Factors by	(Eactors assording to the level of influ		nce)	
category)	Proximal factor	Medial factor	Distal factor	
	Number of prenatal checkups (#4)	Place of delivery (#6)	Mother's marital status during pregnancy (#2)	
	The person attending the delivery (#7)	Mother's occupation during pregnancy (#9)	Mother's level of schooling (#8)	
Environmental factors		Access to utilities (#29)	Conditions of hygiene and cleanliness of the mother during pregnancy (#11)	
		Income of the child's household (#28)	Accompanying a partner before and during pregnancy (#3)	
			Child's family unit (#26)	

Table 2. Criteria for face validation of the FR-PC questionnaire				
Criteria	Rating	Indicator		
Clarity	1. Unclear	The question needs to be clarified.		
Clarity refers to how transparent the language included in the question is; it needs	2. Somewhat clear	The question is straightforward but requires modification.		
to be simple, orderly, and concrete.	3. Clear	The question is clear		
Comprehension	1. It needs to be understood.	The question needs to be understood.		
Comprehension refers to how well the question is understood; the question needs	2. Somewhat understandable	The question is understandable but requires modification.		
to be answered without additional details.	3. It is understood	The question is understood.		



# Results

In general, the design of the FR-PC questionnaire was carried out, which response to the proposal on risk factors issued by Rutter, to the available evidence on the subject, and the premises and construction phases of Corral [16] and Alonso et al. [17].

The analysis of the face or perceived validity of the FR-PC questionnaire reported a total of 12 items with a lack of clarity and difficulty in understanding, identified as having obtained a percentage of acceptance lower than 80% (Tables 3 and 4).

Table 3. Analysis of the face validation of the FR-PC questionnaire - mothers			
Percentage of acceptance of items	Criteria clarity	Criteria understanding	Total acceptance percentage
	2 - 3 - 4 - 6 - 9 - 11 - 12 -		Over 90%:
Items with an acceptance percentage above 90%	14 - 16 - 17 - 18 - 19 - 20	2 - 3 - 4 - 6 - 9 - 11 - 12 - 14 - 16 - 17 - 18 - 19 - 20 - 21 - 25- 29	Over 90%: Clarity: 61.5% Understanding: 61.5%  Between 80 and 90%: Clarity: 23.1%
	- 21 - 25 <del>-</del> 29	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	Understanding: 61.5%
		1 – 8 – 15 – 26 - 27	Between 80 and 90%:
Items with an acceptance rate between 80 and 90%	1 – 8 – 13 - 15 – 26- 27	1-0-13-20-27	Clarity: 23.1%
			Clarity: 23.1% Understanding: 19.2%
		Below 80%:	Below 80%:
Items with an acceptance percentage below 80%	5 – 7 – 10 – 28	5 – 7 – 10 – 13 - 28	Clarity: 15.4%
, , , , , , , , , , , , , , , , , , , ,			Understanding: 19.2%

Note. Questions 22,23, and 24 were not included for mothers, given their level of specificity.

15.4% of the questions in the questionnaire were unclear, and 19.2% of the questions in the instrument were difficult for the mothers to understand (Table 3).

From the professionals' perspective, 34.5% of the questions in the questionnaire were reported as lacking clarity and being difficult to understand (Table 4).

In general, mothers reported five questions without clarity and difficulties understanding (# 5 - 7 - 10 - 13 - 28). On the part of the professionals, 11 questions arose with a need for more clarity and difficulties in understanding (6 - 7 - 10 - 13 - 14 - 15 - 16 - 17 - 18 - 27 - 28). Therefore, considering that some questions were reported with difficulties by both mothers and professionals, 12 questions were revised and adjusted, equivalent to 41.4% of the total number of questions in the FR-PC questionnaire. This adjustment took into account the comments and suggestions recorded by the participants in the study (Table 5).



Table 4. Analysis of the face validity of the FR-PC questionnaire - professionals			
Percentage of acceptance of items	Criteria clarity	Criteria understanding	Total acceptance percentage
			Over 90%:
Items with an acceptance percentage above 90%	4 – 5 - 25 4 – 12 - 25	4 – 12 - 25	Clarity: 10,3%
			Understanding: 10,3%
	1 - 2 - 3 - 6 - 8 - 9	1 - 2 - 3 - 5 - 8 - 9 - 11 -	Between 80 and 90%:
Items with an acceptance rate between 80 and 90%	- 11 - 12 - 19 - 20 -	18 - 19 - 20 - 21 - 22 - 23	Clarity: 55,2%
	- 29	- 24 - 26 - 29	Understanding: 55,2%
			Below 80%:
Items with an acceptance percentage below 80%	7 - 10 - 13 - 14 - 15 - 6 - 7 - 10 - 13 - 14 - 15 - Clarity: 34,5%	Clarity: 34,5%	
			Understanding: 34,5%

Table	5. Adjusting questions that are unclear and validation process with the participat	difficult to understand according to the face ion of mothers and professionals
# Item	Item or question according to its original formulation for the FR-PC questionnaire	Item or question reformulated and included in the final version of the FR-PC questionnaire
5	What type of delivery did you have?  Question issued without any clarification and the possibility of a closed answer	What type of delivery did you have?  Response options:  Non-instrumental vaginal  Instrumental vaginal  Surgical or cesarean section
6	Where was the delivery attended?  Question issued without any clarification and the possibility of a closed answer	Where was the delivery attended? Response options: Health care institution Another type of institution At home At another house Other location. Which one?



	Table 5. (cor	ntinued)
# Item	Item or question according to its original formulation for the FR-PC questionnaire	Item or question reformulated and included in the final version of the FR-PC questionnaire
	Who attended the delivery?	Who attended your delivery?
		Response options:
		<ul><li>Gynecologist</li></ul>
		Another doctor
7		• Nurse
,	Question issued without any clarification and the possibility of a closed answer	<ul> <li>Another health professional</li> </ul>
		• Doula
		• Midwife
		An inexperienced relative
		• Other. Who?
	How was your pregnancy weight?	Did your weight remain within the normal range throughout your pregnancy?
		• Yes
		• No
10	Question issued without any clarification and the	If you answered in the negative, please clarify below:
	possibility of a closed answer	<ul> <li>At some point during your pregnancy, your weight was lower than average.</li> </ul>
		• At some point during your pregnancy, your weight was higher than average.
		Before or during pregnancy, did you use or were you exposed to cigarettes, alcohol, or any psychoactive substance or any insecticide, pesticide, or high-polluting agent?
	Before pregnancy or during gestation, did you use or were you exposed to cigarettes, alcohol, or any psychoactive substance or any insecticide, pesticide, or high-polluting agent?  Question issued without any clarification and the possibility of a closed answer	• Yes
		● No
13		If you answered yes, please indicate what substance(s) you used or were exposed to and during what period of your pregnancy:
		Substance(s):
		Period of pregnancy during which you were exposed:



	Table 5. (co	ntinued)
# Item	Item or question according to its original formulation for the FR-PC questionnaire	Item or question reformulated and included in the final version of the FR-PC questionnaire
		How many pregnancies have you had in total?
	How many pregnancies have you had in total?  Question issued without any clarification and the possibility of a closed answer	Within these, have you had abortions?
14		• Yes
		• No
		If you answered yes, how many?
		Was your child the product of a twin, triplet, or other pregnancy
	Have you had multiple pregnancies?	• Yes
15	The question needs to be rephrased and oriented	● No
	exclusively to the child with CP.	If you answered yes, how many babies were born from that pregnancy?
		Was your pregnancy high-risk?
	Did you have any high-risk pregnancies?	• Yes
16	Question issued without any clarification and the possibility of a closed answer	● No
		If you answered yes, please mention the reason:
	Did you have a threatened abortion during	Did you have a threatened abortion during pregnancy?
17	gestation?	• Yes
	Question issued without any clarification and the possibility of a closed answer	● No
		Did you have any illness during pregnancy?
		• Yes
		● No
		If you answered yes, what illness(es) did you have?
18	Did you have any complications during your pregnancy?  Question issued without any clarification and the	Did the child present any complications during your pregnancy?
	possibility of a closed answer	• Yes
		● No
		If you answered yes, what complication(s) or illness(es) did your child have?



Table 5. (continued)				
# Item	Item or question according to its original formulation for the FR-PC questionnaire	Item or question reformulated and included in the final version of the FR-PC questionnaire		
		Does your family history include any of the following? Indicate which one, and consider your closest family nucleus, made up of your parents, siblings, grandparents and aunts, and uncles:		
		<ul> <li>Congenital malformations</li> </ul>		
		Abortions and stillbirths		
		• Cerebral Palsy		
	Does your family and child's history include any of the following? Indicate which one. (Closest family	<ul> <li>Central Nervous System Diseases</li> </ul>		
	circle, parents, siblings, grandparents, aunts, and uncles)	Other disabling conditions		
	*Congenital malformations.  *Abortions and stillbirths.  *Cerebral Palsy.  *Central Nervous System Diseases.  *Others.  *None.	• None		
27		Does your child's family history include any of the		
		following? Indicate which and consider the child's closest family nucleus, consisting of parents, siblings,		
		grandparents, and aunts and uncles:		
		<ul> <li>Congenital malformations</li> </ul>		
		Abortions and stillbirths		
		• Cerebral Palsy		
		<ul> <li>Central Nervous System Diseases</li> </ul>		
		<ul><li>Other disabling factors</li></ul>		
		• None		
		If you answered yes, please indicate which family member has the history.		
		How many people constitute the family nucleus of which you and your child are a part?		
	How much money did you and your immediate			
20	family receive during your pregnancy?	Of these people, how many receive a monthly income?		
28	Question issued without any clarification and the possibility of a closed answer.			
		How much did your household receive monthly income during your pregnancy?		



### **Discussion**

The design and validation of instruments for identifying risk factors in the diagnosis of CP is an essential aspect of research, evidence-based practice, health promotion, and decision-making and, as a primary goal, for the development of the child and his or her family.

According to the literature review process conducted within this study, it is evident that there are prenatal, perinatal, and postnatal biological, organic, and environmental risk factors that have been studied for many decades about the influence they may exert on the development of CP [7]. However, there needs to be more knowledgeable about the experience of research processes that have focused on the design and validation of a questionnaire aimed at collecting information on risk factors that could be associated with the development of CP.

Regarding the risk mentioned above factors, Wlodarczyk et al. [13] describe the main ones the following: 1. Prenatal: multiple pregnancies, vaginal bleeding, and chronic maternal infections; 2. perinatal: hypoxia, cesarean sections, premature rupture of membranes, and premature contractions; and 3. postnatal: respiratory failure, pneumonia, ischemic events, and sepsis. In addition, Tharaldsen et al. [23] report that APGAR score, congenital malformations, and prematurity should also be taken into account among the risk factors since they have been shown to have a strong association with the development of cerebral palsy in Norwegian children.

The design of the FR-PC questionnaire took into account the variables mentioned above because they are proximal factors, some of them biological and others organic, for the development of CP (Table 1).

The study by Bufteac et al. [14] proposes considering risk factors related to the mother, labor, and delivery. In doing so, it draws attention to biological, organic, and environmental factors, which have been included in the FR-PC questionnaire from different levels of influence (Table 1). Among these, maternal age, the mother's educational level, exposure to alcohol, and socioeconomic level are considered necessary, as well as maternal diseases, type of delivery, premature rupture of membranes, out-of-hospital deliveries, assisted vaginal deliveries, gestational age, APGAR score, multiple gestations, and birth weight.

On the other hand, Graham et al. [3] report neonatal asphyxia and preterm birth as the main risk factors associated with the development of cerebral palsy. Mainly, gestational age at birth is a variable inversely related to the possibility of developing cerebral palsy. The lower the gestational age at birth, the greater the possibility of developing cerebral palsy. For example, the risk in infants born before 28 weeks gestation is approximately 50 times higher than that of full-term infants. Both asphyxia and gestational age are proximal order variables, which are identified through the application of the FR-PC questionnaire. According to their category, these have been incorporated into the organic and biological factors, respectively (Table 1).

For term infants, variables include placental abnormalities, fetal growth retardation, neonatal depression with a low APGAR score, neonatal hyperbilirubinemia and jaundice, infections, and perinatal asphyxia, among others, are factors that have been associated with the possibility of developing CP [3]. Therefore, the FR-PC questionnaire considers questions aimed at collecting information on proximal organic factors, represented in this case by pre-, peri- and postnatal complications that may affect the development of the immature brain (Table 1).



According to Schneider et al. [7], maternal age is a factor to be considered within the broad spectrum of possible CP-related variables. Both advanced maternal and young maternal age are conditions related to the development of CP. This element is also part of the structure of the FR-PC questionnaire.

In addition to the biological and organic factors mentioned above, Chen et al. [24] draw attention to the possible relationship between parental education and the development of CP. The FR-PC questionnaire has items that will allow the collection of information on environmental factors, including variables such as the mother's level of education, occupation, access to public services, and household income, among others.

Based on the above, the FR-PC questionnaire has gathered evidence-based information that aims to relate biological, organic, and environmental factors of proximal, medial, or distal order to the development of CP. According to the results of the appearance validation process of the FR-PC questionnaire, questions 5, 6, 7, 10, 13, 14, 15, 16, 17, 18, 27, and 28 were adjusted because mothers and professionals reported them as being unclear and/or difficult to understand.

# Limitations

On the one hand, the sample size could have been larger; on the other hand, more literature was needed to contrast the study results with other similar studies.

# **Conclusions**

Based on the present study, a questionnaire (FR-PC Questionnaire) was designed and validated to collect information on possible risk factors that may be related to the development of CP. After its adjustment, the FR-PC Questionnaire is a clear and understandable tool that gathers pre-, peri- and postnatal biological, organic, and environmental elements that facilitate the organization and integration of data from the child's clinical history with CP for decision-making. Likewise, the FR-PC Questionnaire may be used in training, academic or research processes.

It is important to note that identifying the risk factors that influence the diagnosis of PC allows relevant decisions to be made, such as those related to the promotion of the health of individuals and groups. It also helps to guide the intervention processes between the interdisciplinary health team and the children and their families.

The research team intends to continue the present study through the content validation of the FR-PC Questionnaire.

#### References

- 1. Rosenbaum P. Cerebral palsy: is the concept still viable? Developmental Medicine & Child Neurology [Internet]. 2017 May 2;59(6):564–564. doi: http://dx.doi.org/10.1111/dmcn.13418
- Rosenbaum, PL, Bernard D. The Continuing Evolution of 'Cerebral Palsy. Annals of Physical and Rehabilitation Medicine. 2020 Oct;63(5):387–88. doi: https://doi.org/10.1016/j.rehab.2019.09.008.



- 3. Graham HK, Rosenbaum P, Paneth N, Dan B, Lin J-P, Damiano DL, et al. Cerebral palsy. Nature Reviews Disease Primers [Internet]. 2016 Jan 28;2(1). doi: http://dx.doi.org/10.1038/nrdp.2016.5
- 4. Jöud A, Sehlstedt A, Källén K, Westbom L, Rylander L. Associations between antenatal and perinatal risk factors and cerebral palsy: a Swedish cohort study. BMJ Open [Internet]. 2020 Aug;10(8):e038453. doi: http://dx.doi.org/10.1136/bmjopen-2020-038453
- 5. Freire G, Shevell M, Oskoui M. Cerebral palsy: Phenotypes and risk factors in term singletons born small for gestational age. European Journal of Paediatric Neurology [Internet]. 2015 Mar;19(2):218–25. doi: http://dx.doi.org/10.1016/j.ejpn.2014.12.005
- Stoknes M, Andersen GL, Elkamil AI, Irgens LM, Skranes J, Salvesen KÅ, et al. The
  effects of multiple pre- and perinatal risk factors on the occurrence of cerebral palsy. A
  Norwegian register based study. European Journal of Paediatric Neurology [Internet].
  2012 Jan;16(1):56–63. doi: http://dx.doi.org/10.1016/j.ejpn.2011.10.004
- 7. Schneider RE, Ng P, Zhang X, Andersen J, Buckley D, Fehlings D, et al. The Association Between Maternal Age and Cerebral Palsy Risk Factors. Pediatric Neurology [Internet]. 2018 May;82:25–8. doi: http://dx.doi.org/10.1016/j.pediatrneurol.2018.01.005
- 8. Robaina Castellanos GR. Prenatal risk factors of cerebral palsy. Rev Cubana Obstet Ginecol. [Internet]. 2010 Jun [citado 2022 Dic 06];36(2): 173-187. Disponible en: http://scielo.sld.cu/scielo.php?script=sci\_arttext&pid=S0138-600X2010000200015&lng=es
- 9. Aliaga P, Villarroel J, Cossio N. La Charla Motivacional; una Estrategia para Abordar el Desconocimiento de Factores de Riesgo Ergonómico en un Supermercado Chileno. Ciencia y Trabajo . [Internet]. 2016 May-Ago;18(56):106-109. Disponible en: https://doi.org/10.4067/s0718-24492016000200005
- 10. Portes JRM, Vieira ML, Crepaldi MA, More CL, Motta CCL. A criança com síndrome de Down: na perspectiva da Teoria Bioecológica do Desenvolvimento Humano, com destaque aos fatores de risco e de proteção. Boletim Academia Paulista de Psicologia, [Internet]. 2013; 33(85), 446-464. Disponible en: http://pepsic.bvsalud.org/scielo.php?script=sci\_arttext&pid=S1415-711X2013000200015&lng=pt&tlng=pt
- 11. Aguiar Andrade E, Acle Tomasini G. Resiliencia, factores de riesgo y protección en adolescentes Mayas de Yucatán: elementos para favorecer la adaptación escolar. Acta. Colomb. Psicol. [Internet]. 1 de julio de 2012 [citado 6 de diciembre de 2022];15(2):53-64. Disponible en: https://actacolombianapsicologia.ucatolica.edu.co/article/view/266
- 12. Himmelmann K, Ahlin K, Jacobsson B, Cans C, Thorsen P. Risk factors for cerebral palsy in children born at term. Acta Obstetricia et Gynecologica Scandinavica [Internet]. 2011 Jul 27;90(10):1070–81. doi: http://dx.doi.org/10.1111/j.1600-0412.2011.01217.x
- 13. Włodarczyk k, Domagalska-Szopa M, Serrano ME. Risk factors of neurodevolopmental disorders in preterm infant. Fizjoterapia Polska. 2020;20(4); 190-197. Available from: https://fizjoterapiapolska.pl/en/article/czynniki-ryzyka-zaburzen-neurorozwo-jowych-u-dzieci-urodzonych-przedwczesnie/



- 14. Bufteac Gincota E, Jahnsen R, Spinei L, Andersen GL. Risk Factors for Cerebral Palsy in Moldova. Medicina [Internet]. 2021 May 28;57(6):540. doi: http://dx.doi.org/10.3390/medicina57060540
- 15. Roco Videla Á, Hernández Orellana M, Silva González O. What is the appropriate sample size to validate a questionnaire? Nutrición Hospitalaria [Internet]. 2021 july-august;38(4):877-878. doi: http://dx.doi.org/10.20960/nh.03633
- 16. Corral Y. Diseño de cuestionarios para recolección de datos. Revista Ciencias De La Educación. 2010;20(36):152-168. http://servicio.bc.uc.edu.ve/educacion/revista/n36/art08.pdf
- 17. Alonso González R, Bayarre Vea H, Artiles Visbal L. Construcción de un instrumento para medir la satisfacción personal en mujeres de mediana edad. Rev Cub Salud Publica. 2004;30(2). Disponible en: http://scielo.sld.cu/scielo.php?script=sci\_arttext&pid=S0864-34662004000200006
- 18. Fernández JM, Pedrero EF. Diez pasos para la construcción de un test. Psicothema. 2019;31(1):7-16. doi: https://doi.org/10.7334/psicothema2018.291
- 19. Sarabia CM, Alconero AR. Claves para el diseño y validación de cuestionarios en Ciencias de la Salud. Enferm. Cardiol. [Internet]. 2019; 26(77): 69–73. Disponible en: https://enfermeriaencardiologia.com/media/acfupload/627a2069dc5b2\_Enferm-Cardiol.-2019-26-77-Art\_1-1.pdf
- 20. Cañón M, Buitrago-Gómez Q. La pregunta de investigación en la práctica clínica: guía para formularla. Revista Colombiana de Psiquiatría [Internet]. 2018 Jul;47(3):193–200. doi: http://dx.doi.org/10.1016/j.rcp.2016.06.004
- 21. Martínez Díaz JD, Ortega Chacón V, Muñoz Ronda FJ. El diseño de preguntas clínicas en la práctica basada en la evidencia. Modelos de formulación. Enfermería Global [Internet]. 2016 Jun 30;15(3):431. doi: http://dx.doi.org/10.6018/eglobal.15.3.239221
- 22. Suarez-Acuña CE, Carvajal-Carrascal G, Serrano-Gómez ME. Escala de incertidumbre en la enfermedad—forma padres/hijos: validación de la adaptación al español. Enfermería Intensiva [Internet]. 2018 Oct;29(4):149–57. doi: http://dx.doi.org/10.1016/j.enfi.2017.12.002
- 23. Tharaldsen G, Hollung SJ, Vik T, Andersen GL. High occurrence of perinatal risk factors and more severe impairments in children with postneonatal cerebral palsy in Norway. Acta Paediatrica [Internet]. 2022 Jan 31;111(4):812–9. doi: http://dx.doi.org/10.1111/apa.16240
- 24. Chen A, Dyck Holzinger S, Oskoui M, Shevell M, Andersen J, Buckley D, et al. Cerebral palsy in Canadian Indigenous children. Developmental Medicine & Developmental Medicine & Political Neurology [Internet]. 2020 Dec 13;63(5):614–22. doi: http://dx.doi.org/10.1111/dmcn.14776



# **Annex**

# FR-PC questionnaire for collecting information on risk factors in children with cerebral palsy.

The questionnaire aims to collect information on possible pre-, peri- and postnatal risk factors associated with cerebral palsy. This questionnaire was designed to be filled out by the health professionals through 29 simple questions to be asked to the mother; this information is confidential and must be treated according to the personal data treatment policies of the institution where the instrument is applied. Answering questions 20-25 may require support from the child's medical history records.

Mother's name:
Mother's identification:
Child's name:
Child's identification:
Name of examiner/health professional:
Identification of the examiner / Health professional:
Date:
Ask each of the questions below and record the mother's response:
1. How old were you when you became pregnant?
● 10 - 20 years
● 20 - 30 years
● 30 – 40 years
• > 40 years
Do not know/No response
2. What was your marital status during pregnancy?
• Single
• Married
• Divorced
• Widow
• Free union
Do not know/No response



3. Were you supported by your partner before and during the pregnancy?
• Yes
• No
Do not know/No response
4. How many prenatal checkups did you attend during your pregnancy?
<b>⊙</b> 0-1
<b>○</b> 2-3
<b>○</b> 4-5
<b>⊙</b> 6-7
● 8-9
• Ten or more
<ul><li>Do not know/No response</li></ul>
5. What type of delivery did you have?
Non-instrumental vaginal
Instrumental vaginal
<ul> <li>Surgical or cesarean section</li> </ul>
6. Where was the delivery attended?
Health care institution
<ul> <li>Another type of institution</li> </ul>
• At home
• At another house
• Other location.
Which one?
7. Who attended your delivery?
<ul><li>Gynecologist</li></ul>
<ul><li>Another doctor</li></ul>
• Nurse
<ul> <li>Another health professional</li> </ul>
<ul><li>Doula</li></ul>
<ul><li>Midwife</li></ul>
An inexperienced relative
• Other.
Who?



8. What level of schooling did you have at the time of delivery?
• Incomplete elementary school
• Completed elementary school
• Incomplete high school
• Completed high school
• Technical
• Technological education
<ul><li>University</li></ul>
Do not know/No response
9. What occupation did you have during your pregnancy?
<ul><li>Household</li></ul>
• Student
• Formal employment
• Informal employment
• None
Do not know/No response
10. Did your weight remain within the normal range throughout your pregnancy?
• Yes
● No
If you answered in the negative, please clarify below:
• At some point during your pregnancy, your weight was lower than average.
• At some point during your pregnancy, your weight was higher than average.
11. During pregnancy, did you have adequate self-hygiene measures daily? (such as daily showering, hand washing, and tooth brushing)
• Yes
● No
Do not know/No response
12. Did you experience any solid emotional event during pregnancy that generated stress uncertainty, or uneasiness?
• Yes
● No
Do not know/No response
If you answered yes, please indicate what type of event:



13. Before or during pregnancy, did you use or were you exposed to cigarettes, alcohol, or any osychoactive substance or any insecticide, pesticide, or high-polluting agent?		
• Yes		
● No		
f you answered yes, please indicate what substance(s) you used or were exposed to and during what period of your pregnancy:		
Substance(s):		
Period of pregnancy during which you were exposed:		
14. How many pregnancies have you had in total?		
Nithin these, have you had abortions?		
• Yes		
• No		
f you answered yes, how many?		
15. Was your child the product of a twin, triplet, or other pregnancy?		
• Yes		
• No		
f you answered yes, how many babies were born from that pregnancy?		
16. Was your pregnancy high-risk?		
• Yes		
• No		
f you answered yes, please mention the reason:		
17. Did you have a threatened abortion during pregnancy?		
• Yes		
• No		
18. Did you have any illness during pregnancy?		
• Yes		
• No		
f you answered yes, what illness(es) did you have?		
Did the child present any complications during your pregnancy?		
• Yes		
● No		
f you answered yes, what complication(s) or illness(es) did your child have?		



19. What week of gestation did you give birth?
• Before 28 weeks
Between 28 and 31 weeks
Between 32 and 36 weeks
Between 37 and 42 weeks
• Do not know/No response
20. What was the child's birth weight?
• < 1,000 grams
• 1.000 - 1.500 grams
• 1.501 - 2.500 grams
• > 2.500 gr
<ul><li>Do not know/No response</li></ul>
21. What was the child's size at birth?cm
22. What was the child's head circumference at birth?cm
23. What was the child's chest circumference at birth?cm
24. What were the child's APGAR scores at 1 minute and 5 minutes?
To one minute: At 5 minutes:
25. Did the child present any complications at the time of birth?
• Yes
• No
If you answered yes, please mention which complication:
26. According to the following family types, indicate which one refers to your child's nuclear family:
• The nuclear family (father, mother, and child(ren))
<ul><li>Single-parent family (mother and child(ren) or father and child(ren))</li></ul>
<ul><li>Homoparental family (homosexual couple and child(ren))</li></ul>
Composite family (parent(s), child(ren) and grandparent(s))
<ul><li>Extended family (grandparent(s), parent(s), child(ren), uncle(s))</li></ul>
• Reorganized family (at least one of the two parents brings children from the previous union).
Adoptive family
• Grandparent(s)' family
• Foster family
Do not know/No response



Onne:-	nucleus, made up of your parents, siblings, grandparents and aunts, and uncles:	
• Congenital m		
<ul><li>Abortions an</li></ul>		
Cerebral Pal		
<ul><li>Central Nervous System Diseases</li><li>Other disabling conditions</li></ul>		
If you answered	d yes, please indicate which family member has the history.	
	d's family history include any of the following? Indicate which and consider the family nucleus, consisting of parents, siblings, grandparents, and aunts and uncles	
• Congenital m	nalformations	
<ul><li>Abortions an</li></ul>	nd stillbirths	
• Cerebral Pal	sy	
• Central Nerv	rous System Diseases	
Otras discap	acitantes	
None		
If you answered	d yes, please indicate which family member has the history.	
28. How many	people constitute the family nucleus of which you and your child are a part?	
Of these people	e, how many receive a monthly income?	
How much did	your household receive monthly income during your pregnancy?	
29. During pre	gnancy, what public utilities were available to you?	
• Electricity		
• Gas		
• Water and se	ewerage	
• Water and se		

Thank you so much!