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Comprehensive Healthcare Model for Paediatric Patients Screened in the Retinopathy of Prematurity Program

Zoila Fariñas Falcón, C[1]*, Bárbara Toledo Pimentel, C[2], Mayda Morales González, C[3], & Yarianni Beltran Fariña[4]

1ISCMVC, Research Associate. Arnaldo Milián Castro Provincial Hospital
2Hospital Comandante Manuel Fajardo Rivero
3Villa Clara Medical Sciences Higher Institute
4Television social researcher. Telecubanacan. Santa Clara

***Corresponding author:** Zoila Fariñas Falcón ISCMVC, Research Associate. Arnaldo Milián Castro Provincial Hospital

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Abstract

Background: *Prematurity is associated with a higher prevalence of visual and neurocognitive impairments not only in the neonatal period but also in childhood and adolescence.*

Objective: *To design a comprehensive health model for pediatric patients screened in the National Program for the Care of Retinopathy of Prematurity.*

Methodological Design: *A multicenter, multistage, mixed-method approach was conducted. In the first stage, the clinical and epidemiological characteristics of the children screened between 2002 and 2018 were described. In the second stage, a longitudinal study was conducted in which 60 premature infants between 7 and 18 years of age were followed, 30 diagnosed with retinopathy of prematurity and 30 who did not suffer from it. Ophthalmological and neurocognitive sequelae were evaluated and treated. In the third stage, a comprehensive healthcare model was designed for pediatric patients screened in the program.*

Results: *A high percentage of patients presented ophthalmological, neurocognitive, and general disorders. The proposed model adopts a holistic and multidisciplinary approach, with four interrelated components focused on the child/adolescent and their family. Each component, in turn, generates interventions/actions and tools for clinical follow-up, aimed at improving the quality of care.*

Conclusions: *The healthcare model was rated as highly adequate by the experts consulted*

Keywords: Prematurity; Retinopathy of Prematurity; Sequelae; Care Model.

Introduction

Premature birth rates are increasing worldwide due to adolescent pregnancies, pregnancy at extreme ages, and risk factors such as hypertension, gestational diabetes, and multiple pregnancies resulting from assisted reproduction treatments [1,2].

ROP is a multifactorial, vasoproliferative, vitreoretinal disease in which normal vasculogenesis is disrupted, causing neovascularization and retinal detachment [3-7]. The main risk factor is vascular immaturity, with infants weighing less than 1500 g at birth (BW) or less than 30 weeks' gestational age (GA), or both [3-9].

The prevalence of blindness in the pediatric population varies

according to the socioeconomic development and mortality rates of each country [4-8]. Latin America accounts for two-thirds (24%) of children who are blind due to ROP [5-7]. In Cuba, a country with first-world healthcare services and the existence of neonatal intensive care units (NICUs), infants weighing less than 1250 g survive and infant mortality rates are low, with values below 7.9 deaths per 1000 live births [4-9]. The "ROP Blindness Prevention" project began in Cuba in 2000[8]. The national ROP rate in 2010 was 5.1%, and in 2021, it was 8.6% [4-9].

Villa Clara has a NICU that shows survival rates for newborns (NBs) weighing less than 1500 g above 70%. Partial statistical reports by [9] have reported a low incidence of ROP. The LBW rate in 2021 was 7.1%, with a 58.3% survival rate among premature infants and an infant mortality rate of 7.3%; this is a result of the implementation of the national research protocol and the scientific and technological development achieved in NICUs.

In the national and international literature review, there is little information on the sequelae in preschool, primary education, and adolescence. There are no articles related to comprehensive health care models for the follow-up of pediatric patients with these characteristics. These are stages in which the acquisition of skills and knowledge can lead to poor academic performance. Therefore, it is necessary for care for this population to continue beyond the age of 6.

The health model is a need created from different aspects of knowledge applicable to the sector with the aim of structuring standards and establishing them in terms of institutions and incentives, thereby favoring the development of the social response in health and avoiding uncertainty. It articulates individual and collective choices and must respond to the population's quality of life [10].

This research manages knowledge in the comprehensiveness of medical-social practice, clinical-epistemological, holistic, and multidisciplinary criteria necessary for care, actions, and skills that explain "how" to carry out this transformation during the school years and adolescence. The economic losses due to visual impairment are high, hindering the cognitive, academic, and social development of children and adolescents, affecting their self-esteem and access to certain professions. Therefore, we pose the following scientific problem:

How can comprehensive health care be achieved for pediatric patients screened in the Retinopathy of Prematurity program?

General Objective

To design a comprehensive care model for pediatric patients screened in the ROP program.II

Research Methodological Design

This is a multicenter, multi-stage study that follows a qualitative-quantitative or mixed methodological approach. It was conducted between 2002 and 2019 by a multidisciplinary team composed of specialists from the Arnaldo Milián Castro University Clinical and Surgical Hospital, the Mariana Grajales University Gynecological and Obstetric Hospital, the José Luis Miranda University Pediatric Hospital, and the Mental Health Center of the Chiqui Gómez-Lubián University Polyclinic in Santa Clara, Villa Clara. First stage: A retrospective descriptive study was conducted of patients included in the "Retinopathy of Prematurity Blindness Prevention Program" treated in the neonatal care unit of the Mariana Grajales Gynecological and Obstetric University Hospital from 2002 to 2018. The study population consisted of 1,020 newborns who met the inclusion criteria and the sample consisted of 58 newborns diagnosed with some degree of the disease.

Second Stage: Period from 2017 to 2019.

A longitudinal mixed-approach study was conducted with patients of pediatric age (between 7 and 18 years old); they received health interventions in the ophthalmology, psychology, and comprehensive care departments. Study population: 495 premature neonates born at the Mariana Grajales Gynecological and Obstetric University Hospital in Santa Clara, 45 of whom developed ROP. The sample was non-probabilistic by criterion: it consisted of 60 infants; 30 children with ROP and 30 without, and 60 parents or guardians. Sociodemographic and clinical variables were used; ophthalmological, psychological, and parental satisfaction variables; and pilot sample surveys were conducted with physicians specializing in IGM and ophthalmologists from the Primary Health Care System. Third stage of model design:

Preparation phase: Various aspects and evidence were considered:

The doctor's healthcare and research experience in the "National Project for the Prevention of Blindness due to ROP"; the results of the previous stages; document analysis: Program and International Classification for ROP. National ROP Program. ROP protocols proposed by the "Ramón Pando Ferrer" ICO from 2008 and 2018. Professional development plan of the Villa Clara University of Medical Sciences from 2017 to 2021. Health statistical yearbooks in their last five editions in Cuba. Office-level records for this age group. Systematic review of the health care model. Application of group techniques: nominal and focus groups. Ethical considerations were considered.

Model Design Phase and Expert Assessment

Results

Tabla1: Personal Pathological History of Infants

Antecedentes patológicos personales	Retinopathy of prematurity					
	Total	%	Si	%	No	%
Chronic lung disease	25	41,7	14	46,7	11	36,7
Epilepsy	14	23,3	11	36,7	3	10,0
SOMA deformities	7	11,7	5	16,7	2	6,7
Heart disease	7	11,7	4	13,3	3	10,0
Cerebral palsy	5	8,3	3	10,0	2	6,7

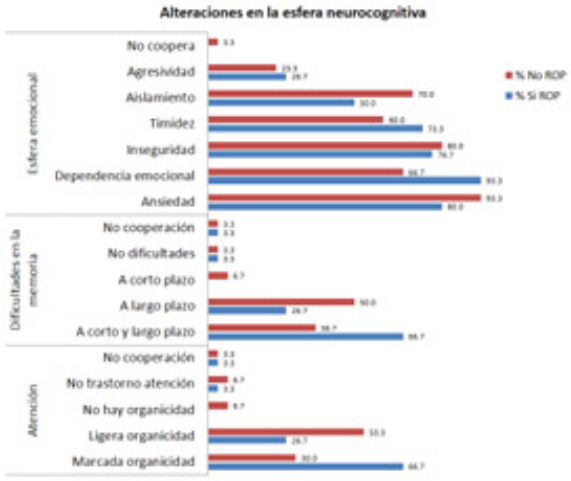
Genetic syndrome	5	8,3	2	6.7	3	10,0
Others	11	18,3	6	20,0	5	16,7
Neurocognitive pathological history	**Retinopathy of prematurity**					
	Total	**%**	**Si**	**%**	**No**	**%**
Speech disorders	11	21,7	8	26,7	3	10,0
Autism spectrum disorder (ASD)	2	3,3	1	23,3	1	3,3
Hearing loss	7	11,7	4	13,3	3	10,0
Psychological disorders	5	8,3	1	3,3	4	13,3

Table 2: Refractive Error and Degree of Rop In Infants

Refractive error	**Degree of Retinopathy of Prematurity**						
	Total	**%**	**1**	**2**	**3+**	**4a**	**No ROP**
Mild myopic astigmatism	21	35,0	3	7	0	0	11
High compound myopic astigmatism	14	23,3	2	3	4	1	4
Mild hyperopia	4	6,7	3	1	-	-	-
Mild hyperopic astigmatism	3	5,0	-	2	-	-	1
High myopia	2	3,3	-	-	-	-	2
High hyperopia	2	3,3	-	-	-	1	1
High hyperopic astigmatism	2	3,3	1	1	-	-	-
No defect	11	18,3	-	1	-	-	10
I don't cooperate	1	1,7	-	-	-	-	1

Source: Ophthalmological examination

Table 3: Neurocognitive Disorders.



Discussion of the Results

The most common diseases were chronic lung disease (41.7%), followed by epilepsy (23.3%), soma disorders and heart disease (11.7%), speech disorders (21.7%), hearing loss (11.7%), psychological disorders in five (8.3%), and autism in two (3.3%). Children with ROP were more affected in percentage terms for most of the reported diseases (Table 1). This is consistent with studies conducted by [4-12].

Mild myopic astigmatism was the most common ametropia in 21 children (35.0%) among those with ROP. High compound myopic astigmatism was next in order of frequency, with 14 patients (23.3%). No refractive error was observed in 11 children (18.3%) (Table 2), which was not different from the study by [7-12]. Difficulties in memory, attention, affective behavior, and language were noted (Table 3). Similar results were reported in their articles by and others who discussed this topic [5-7]. 80.0% of the children required ophthalmologic treatment, 90.0% for neurocognitive and psychological disorders [13-18]. 18.6% were treated by other medical disciplines. Follow-up was conducted, and stability and improvement of their sequelae were observed.

Phase III.

Comprehensive health care model for pediatric patients screened

in the Retinopathy of Prematurity program.

The Care Model has its conceptual basis in health systems based on the PHC strategy and the Chronic Disease Care Model for Children and Adolescents it positions PHC as an integrative setting for the provision of public health policies and gives them a role in intersectoral relations [10-19]. Cuba has a comprehensive strategy for the treatment of patients with chronic non-communicable diseases, which encompasses both promotion and prevention [20-23].

The systematization of experiences in the clinical ophthalmology service, knowledge of the country's current health situation, its social, political, and economic reality, the structural and functional characteristics of the Cuban health system, and the legal, bioethical, political, and strategic provisions regarding health are the foundational foundations for modeling ophthalmologic and comprehensive health care for infants screened in the ROP program. This foundation also contributes to adequate social integration and improved quality of life for these children in the province of Villa Clara.

Characteristics of the Model

Functional: simple, practical, and humanistic. It considers existing programs to enhance them with the model. It has a multidisciplinary and intersectoral approach and the coordinated activity of health and education professionals. It includes a care flowchart that specifies the function and progress at each stage, the patient's journey throughout the process, and the integration of PHC and well-organized hospital care. General Objective-To establish guidelines for the reorganization of health services to improve the quality of comprehensive care for premature infants in the ROP program.

Specific Objectives

To contribute to ensuring that the basic care needs of premature pediatric infants in the ROP program are met, ensuring their satisfaction and quality of life.
To ensure that patients are informed about the disease, the goals to be achieved, and their self-care.
To promote basic training and research in the care of premature pediatric infants in the ROP program to improve care for patients and their families.
To systematically evaluate the development of the model's implementation and its quality.

Principles of the Model

Basic rights regarding the rights of the child
Infant-centered
Comprehensive care
Continuity of care

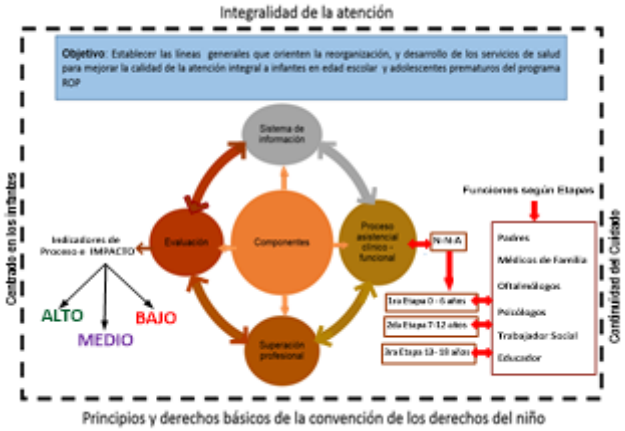
Components of the Model Composed of:

1. Clinical-functional care process
2. Professional development/research and publication
3. Information system
4. Monitoring and evaluation.

It Is Divided into Three Stages

Stage I. Care for children ages 0 to 6.
Stage II. Care for children ages 6 to 12.
Stage III. Care for adolescents ages 13 to 18. Each member has a role in each stage: from primary care to the MGI (Medical Institute), ophthalmologists, psychologists, other specialists, parents, children, adolescents, the MINED (Ministry of Education), and social work.

Comprehensive Health Care Model for pediatric patients screened in the Retinopathy of Prematurity Program



Conclusions

The comprehensive health care model for pediatric patients screened in the Retinopathy of Prematurity program positions PHC as an integrative setting for the provision of public health policies and the model for the care of chronic diseases in children and adolescents. It has a multidisciplinary and intersectoral approach that encompasses both promotion and prevention.
The proposed model was evaluated by expert consensus and was considered highly appropriate.

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