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Arnaldo Milián Castro University Clinical and Surgical Hospital Comprehensive Healthcare Model for Pediatric Patients Screened in the Retinopathy of Prematurity Program

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Abstract

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

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

Methodological Design: A multicenter, multistage, mixed-methods study was conducted. In the first stage, the clinical and epidemiological characteristics of children screened between 2002 and 2018 were described. In the second stage, a longitudinal study was carried out involving 60 premature children aged 7 to 18 years-30 diagnosed with retinopathy of prematurity and 30 without the condition. Ophthalmological and neurocognitive sequelae were evaluated and treated. In the third stage, a comprehensive health care model was designed for pediatric patients screened in the program.

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

Conclusions: The health care model was considered highly appropriate by the experts consulted.

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

Abbreviations: ROP: Retinopathy of Prematurity; NICUs: Neonatal Intensive Care Units; LBW: Low Birth Weight; MGI: Medicina General Integral; PHC: Primary Health Care; MINED: Ministry of Education; TEA: Trastorno Del Espectro Autista

Introduction

Premature birth rates are increasing worldwide due to adolescent pregnancies, pregnancies at extreme maternal ages, and risk factors such as hypertension, gestational diabetes, and multiple pregnancies resulting from assisted reproductive treatments [1,2]. Retinopathy of prematurity (ROP) is a vitreoretinal, Vaso proliferative, and multifactorial disease characterized by an interruption of normal vasculogenic, leading to neovascularization and retinal detachment [3-7]. The main risk factor is vascular immaturity, typically in infants with a birth weight of less than 1500 grams or a gestational age under 30 weeks, or both [3-9].

The prevalence of childhood blindness varies according to each country's socioeconomic development and infant mortality rate [4-8]. Latin America accounts for two-thirds (24%) of childhood blindness cases due to ROP [5-7]. In Cuba, a country with first-world healthcare services and established neonatal intensive care units (NICUs), survival is possible for infants weighing less than 1250 grams, with low infant mortality rates of under 7.9

deaths per 1,000 live births [4,8,9]. The "Prevention of Blindness from ROP" project began in Cuba in 2000 [8]. The national rate of ROP was 5.1% in 2010 and increased to 8.6% in 2021 [4,7-9].

In Villa Clara, a NICU reports survival rates above 70% for newborns weighing under 1500 grams. Partial statistical reports by Fariñas Falcón et al [9]. have shown a low incidence of ROP. In 2021, the low birth weight (LBW) index was 7.1%, the survival rate for premature infants was 58.3%, and infant mortality was 7.3%. These outcomes reflect the implementation of national research protocols and technological advances in NICU care. National and international literature reviews show little information on the sequelae during preschool, primary education, and adolescence.

There is a lack of published articles proposing comprehensive health care models to follow up on pediatric patients with these characteristics-developmental stages where the acquisition of skills and knowledge can significantly impact academic performance. Therefore, care for this population must continue beyond the age of six. The health care model emerges from various knowledge streams applicable to the sector to structure regulations and institutional frameworks, supporting the development of a socially responsive health system and reducing uncertainty. It links individual and collective choices and should ensure quality of life for the population [10].

This study integrates medical-social knowledge using clinical, epistemological, holistic, and multidisciplinary criteria essential for delivering care, implementing actions, and developing skills that explain how to carry out this transformation during the school years and adolescence. The economic impact of visual disability is significant, hindering cognitive, academic, and social development in children and adolescents, affecting self-esteem, and limiting access to certain professions.

Therefore, we Pose the Following Scientific Question:

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 Retinopathy of Prematurity (ROP) program.

Methodological Design of the Study

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 comprising specialists from the "Arnaldo Milián Castro" University Clinical-Surgical Hospital, the "Mariana Grajales" University Gyneco-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 carried out on patients included in the "Blindness Prevention Program for Retinopathy of Prematurity," who were treated in the neonatal care service of the "Mariana Grajales" University Gyneco-Obstetric Hospital from 2002 to 2018. The study population consisted of 1,020 newborns who met the inclusion criteria, and the sample included 58 neonates who were diagnosed with some degree of the disease.

Second Stage

This phase covered the period from 2017 to 2019. A longitudinal mixed-methods study was conducted on pediatric patients aged between 7 and 18 years, who received a health intervention involving Ophthalmology, Psychology, and integrated care. The study population included 495 premature neonates born at the "Mariana Grajales" University Gyneco-Obstetric Hospital in Santa Clara, of whom 45 developed ROP. The non-probabilistic sample, based on specific criteria, consisted of 60 children, 30 who had ROP and 30 who did not-as well as 60 parents or guardians. Socio-demographic and clinical variables were assessed, including ophthalmologic, psychological, and parental satisfaction measures. Pilot surveys were also conducted with general medicine specialists (MGI) and primary health care (PHC) ophthalmologists.

Third Stage - Model Design Phase

1. **Preparation Phase:** Various aspects and pieces of evidence were considered:

- The clinical and research experience of the lead doctor in the "National Project for the Prevention of Blindness from ROP"
- The results from the previous stages

2. **Document Analysis:** National Program and International Classification of ROP, ROP National Program

- ROP protocols proposed by the "Ramón Pando Ferrer" ICO in 2008 and 2018
- The professional development plan of the University of Medical Sciences of Villa Clara from 2017 to 2021
- The latest five editions of national health statistical yearbooks in Cuba
- Consultation records for the targeted age group
- A systematic review of health care models
- Group techniques such as nominal and focus groups
- Ethical considerations were also addressed

Fase del diseño del modelo y Valoración por experto (Figure 1).

Discussion of the Results

The most frequent diseases were: chronic lung disease (41.7%), followed by epilepsy (23.3%), musculoskeletal abnormalities and congenital heart disease (11.7%). Speech disorder

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affected 21.7% of cases, hearing loss 11.7%, psychological disorders were found in five children (8.3%), and autism in two (3.3%). Children with ROP were more affected in percentage terms in most of the recorded diseases (Table 1). This aligns with findings from studies by Rodríguez, Manzitti J, and Ruiz Orosco [4,5,7,11,12]. Mild myopic astigmatism was the most common refractive error, seen in 21 children (35.0%) among those with ROP. High compound myopic astigmatism followed, present in 14 patients (23.3%).

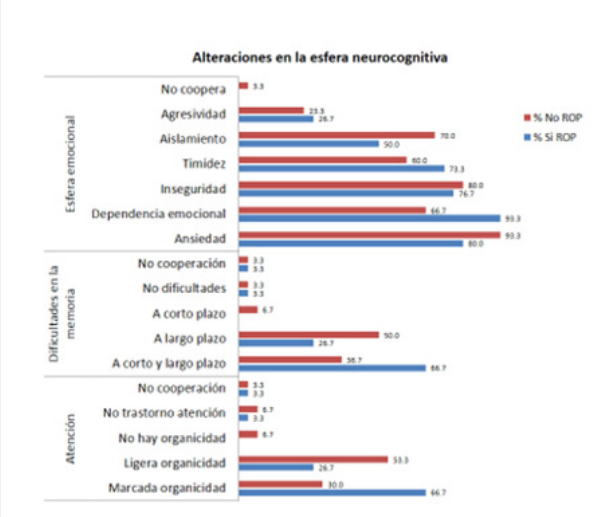

Figure 1: Alteraciones neurocognitivas.

Table 1: Personal pathological history of infants.

Personal Pathological History	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
Musculoskeletal 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

No refractive error was found in 11 children (18.3%) (Table 2), consistent with the findings of Ruiz Orosco H [7,11,12]. Difficulties were confirmed in memory, attention, affective domain, and language. Similar results were reported in articles by Manzitti J [5], Ruiz Orosco H [7], and others who addressed this topic [13-18]. 80.0% of the children required ophthalmological treatment, 90.0% required support for neurocognitive and psychological issues, and 18.6% were seen by other medical specialties. Follow-up care showed stability and improvement in their sequelae.

Phase III

Comprehensive Health Care Model for Pediatric Patients Screened in the Retinopathy of Prematurity Program

The care model is conceptually based on health systems that follow the Primary Health Care (PHC) strategy and the Chronic Disease Care Model for children and adolescents [10,18,19]. It places PHC as the integrating framework in public health policy delivery and gives it a central role in intersectoral collaboration.

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In Cuba, there is a comprehensive strategy for the management of patients with non-communicable chronic diseases that includes both promotion and prevention [20-23].

Table 2: Refractive error and degree of ROP in infants.

Refractive Error	Grade 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 Refractive Error	11	18,3	-	1	-	-	10
Did Not Cooperate	1	1,7	-	-	-	-	1

Source: Ophthalmologic examination.

The consolidation of experiences from clinical ophthalmology services, awareness of the current national health situation, the country's social, political, and economic reality, and the structural and functional characteristics of Cuba's health system, together with legal, bioethical, political, and strategic health guidelines, form the foundation for shaping an integrated ophthalmological health care model for children screened in the ROP program. This contributes to appropriate social integration and improved quality of life for these pediatric patients in Villa Clara province.

Model Characteristics

- **Functional:** Simple, practical, and human-centered. It incorporates and enhances existing programs.
- **Multidisciplinary and Intersectoral Approach:** Based on coordinated action among health and education professionals.
- **Care Flowchart:** Includes a clear structure of roles, steps in the care process, patient journey, and integration between PHC and hospital services.

General Objective

- To establish guidelines to reorganize health services and improve the quality of comprehensive care for premature children in the ROP program.

Specific Objectives

- Ensure that the basic care needs of premature pediatric patients in the ROP program are met, promoting satisfaction and quality of life.
- Empower patients with knowledge about their condition, personal health goals, and self-care practices.
- Promote foundational training and research on the care of premature pediatric patients in the ROP program to improve services for patients and their families.
- Systematically evaluate the development and quality of the model's implementation.

Model Principles

- Fundamental rights of the child
- Child-centered care
- Comprehensiveness of care
- Continuity of care

Model Components

- Clinical-functional care process
- Professional development / research and publication
- Information system
- Monitoring and evaluation

Stages of the Model

- **Stage I:** Care for children aged 0 to 6 years
- **Stage II:** Care for children aged 6 to 12 years
- **Stage III:** Care for adolescents aged 13 to 18 years

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Each participant in the system has a specific role at every stage, including PHC physicians (MGI), ophthalmologists, psychologists, other specialists, parents, children, adolescents, the Ministry of Education (MINED), and social workers. Comprehensive Health Care Model for Pediatric Patients Screened in the Retinopathy of Prematurity Program (Figure 2).

Figure 2: 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 Primary Health Care (PHC) as an integrative framework in the delivery of public health policies and in the care model for chronic diseases in children and adolescents. It adopts a multidisciplinary and intersectoral approach that encompasses both health promotion and disease prevention. The model proposal was evaluated by expert consensus and was considered highly appropriate.

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