



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

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Abstract

Introduction: 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 study was conducted 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 conducted, following 60 premature infants between 7 and 18 years of age, 30 diagnosed with retinopathy of prematurity and 30 without. 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 with ophthalmological, neurocognitive, and general impairments. The proposed model has 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 monitoring, aimed at improving the quality of care.

Conclusions: The health model was rated as highly appropriate by the experts consulted.

Keywords: Prematurity; Retinopathy of prematurity; Sequelae; Care model

Introduction

Premature birth rates are increasing worldwide due to teenage pregnancies, pregnancies at the extremes of maternal age, and risk factors such as hypertension, gestational diabetes, and multiple pregnancies resulting from assisted reproductive treatments [1,2]. ROP is a vitreoretinal, Vaso proliferative, and multifactorial disease in which there is an interruption of normal vasculogenesis, leading to neovascularization and retinal detachment [3-7]. The main risk factor is vascular immaturity, children with a birth weight (BW) of less than 1500 g or less than 30 weeks of gestational age (GA), or both (3-9). The prevalence of blindness in the child population varies according to the socioeconomic development and mortality rate of each country.

(4-8) Latin America accounts for two-thirds (24%) of blind children due to ROP (5-7) In Cuba, a country with first-world health services and the existence of neonatal intensive care units (NICUs) , children weighing less than 1250 g survive, and infant mortality rates are low, with values below 7.9 deaths per 1000 live births (4, 8, 9).The “Prevention of Blindness due to ROP” project began in Cuba in 2000 [8]. The national rate of ROP in 2010 was 5.1%, and in 2021, it was 8.6%. (4,7-9). In Villa Clara there is a NICU that shows survival rates in newborns (NB) weighing less than 1500 g of over 70%. Partial statistical reports by Farinas Falcon [9] have reported a low incidence of ROP. The BPN index in 2021 was 7.1%, with a 58.3% survival rate for premature infants and an infant mortality rate of 7.3%; a result of the implementation of the national research protocol and the

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scientific and technological development achieved in the NICUs. In the national and international literature review, there is little information on the consequences in the preschool, primary education and adolescent stages; there is no evidence of articles related to models of comprehensive health care for the follow-up of pediatric patients with these characteristics, stages in which the acquisition of skills and knowledge can condition low school performance; therefore, it is necessary that the care of this population, continues beyond 6 years. The health model is a necessity created from different branches of knowledge applicable to the sector in order to structure norms and establish 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 quality of life of the population [10]. This research manages knowledge within the comprehensive medical-social practice, clinical-epistemological criteria, and a holistic and multidisciplinary approach necessary for the care, actions, and skills that explain "how" to carry out this transformation during school age and adolescence. The economic losses due to visual impairment are significant, hindering the cognitive, academic, and social development of children and adolescents, and affecting their self-esteem and access to certain professions. Therefore, we pose the following research problem: How can we achieve comprehensive healthcare for pediatric patients screened in the Retinopathy of Prematurity program?

General Objective

Design a comprehensive care model for pediatric patients screened in the ROP program.

Methodological Design of the Research

This is a multicenter study that follows a mixed-methods (qualitative-quantitative) approach. It was conducted between 2002 and 2019 by a multidisciplinary team of specialists from the "Arnaldo Milián Castro" University Clinical Surgical Hospital, the "Mariana Grajales" University Gynecological-Obstetrical 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.

The study is considered multi-stage

First stage: A retrospective descriptive study was carried out on the patients included in the "Program for the prevention of blindness due to Retinopathy of Prematurity" treated in the neonatal care service of the "Mariana Grajales" University Gynecological-Obstetrical Hospital from 2002 to 2018. The study universe consisted of 1020 newborns who met the inclusion criteria and the sample consisted of 58 newborns who were diagnosed with some degree of the disease.

Second stage: Period from 2017 to 2019. This is a longitudinal, mixed-methods study of pediatric patients (ages 7-18) who received comprehensive healthcare interventions involving ophthalmology, psychology, and general care. The study population consisted of 495 premature infants born at the "Mariana Grajales" University Gynecological and Obstetrical Hospital in Santa Clara, 45 of whom developed retinopathy of prematurity (ROP). The non-probability sampling method comprised 60 infants (30 with ROP and 30 without) and 60 parents or guardians. Sociodemographic, clinical, ophthalmological, psychological, and satisfaction variables were collected. Parents and pilot sample surveys to: medical specialists in MGI and ophthalmologists of the APS.

Third stage: Preparation phase: Various aspects and evidence were taken into account:

Clinical and research experience of the doctor in the "National Project for the Prevention of Blindness due to ROP; the results of the previous stages; analysis of documents: International Classification and Program for ROP. National ROP Program. The ROP protocols proposed by the ICO "Ramón Pando Ferrer" in 2008 and 2018. Professional development plan of the University of Medical Sciences of Villa Clara from 2017 to 2021. Statistical health yearbooks in their last five editions in Cuba. Office-level records for this age group. Systematic review of a healthcare model. Application of group techniques: nominal group and focus group. Ethical considerations were taken into account. Model design phase and Expert assessment.

Results

The most frequent illnesses were: chronic lung disease (41.7%), followed by epilepsy (23.3%), somatic disorders and heart disease (11.7%), speech disorder (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, in most of the recorded illnesses (Table 1). Mild myopic astigmatism was the most frequent refractive error in 21 children (35.0%) among those affected by ROP. High compound myopic astigmatism the next most frequent finding was 14 patients (23.3%). No refractive error was observed in 11 children (18.3%) (Table 2). Difficulties were observed in memory, attention, affect, and language. 80.0% of the children required ophthalmological treatment, and 90.0% required treatment for neurocognitive and psychological impairments. 18.6% received care from other medical disciplines. Follow-up was conducted, and stability and improvement of their sequelae were observed (Figure 1).

Comprehensive health care model for pediatric patients screened in the Retinopathy of Prematurity program

The Care Model has its conceptual starting point in health systems based on the Primary Health Care (PHC) strategy and the

Child and Adolescent Chronic Disease Care Model; it positions PHC as an integrating environment in the delivery of public health policies and assigns it a role in intersectoral collaboration.

ophthalmological and comprehensive health care in the infants screened in the ROP program; and contribute to an adequate social integration and the improvement of the quality of life of these children of pediatric age in the province of Villa Clara (Figure 2).

Model Features

Functional: simple, practical, and humanistic. It incorporates existing programs to enhance them with the model. It has a multidisciplinary and intersectoral approach and emphasizes the coordinated activity of health and education professionals. It implicitly includes a care flowchart that specifies the function and evolution at each moment, the patient's journey during the process, and the integration of primary and hospital care that is well organized.

General objective

- Establish guidelines to direct 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 needs of care for premature pediatric infants in the ROP program are met, with satisfaction and quality of life for these children.
- To obtain an informed patient about the disease, the goals to be achieved and their self-care.
- To promote basic training and research in the care of premature infants in the pediatric ROP program, in order to improve care for patients and their families.
- Systematically evaluate the development of the model's implementation and its quality.

Principles of the model

- Basic rights regarding children's rights
- Child-centered
- Comprehensive care
- Continuity of care.

Model components

Composed of:

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

It is divided into three stages

Stage I. Care for children from 0 to 6 years old. Stage II. Care for children from 6 to 12 years old. Stage III: Care for adolescents

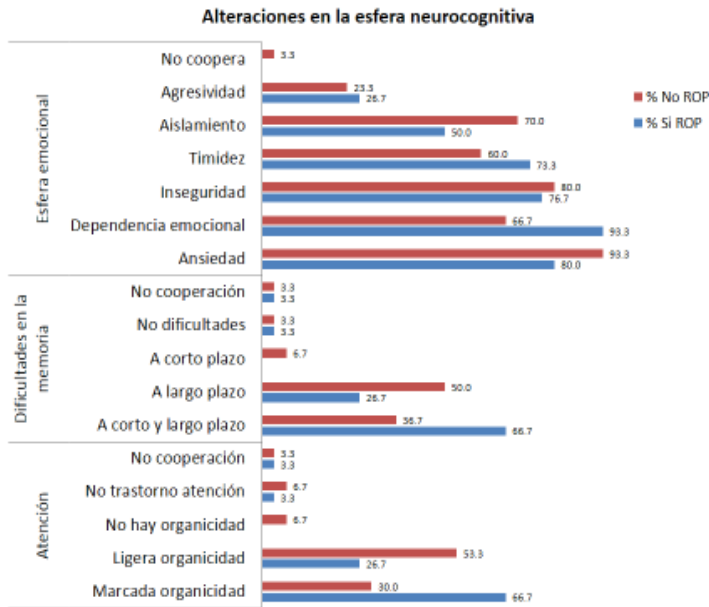


Figure 1: Neurocognitive alterations.



Figure 2: Comprehensive Health Care Model for pediatric patients screened in the Retinopathy of Prematurity Program.

In Cuba, there is a comprehensive strategy for the treatment of patients with chronic non-communicable diseases, encompassing both health promotion and disease prevention. The systematization of experiences in the clinical ophthalmology service, the knowledge of the current health situation of the country, its social, political and economic reality; the structural and functional characteristics of the health system in Cuba, together with the legal, bioethical, political and strategic provisions in health matters, are the basic supports to model the



aged 13 to 18. Each member has their role in each stage; from Primary Health Care with the Family Medicine Specialist, ophthalmologists, psychologists, other specialists, parents,

children, adolescents, the Ministry of Education, and Social Work. Comprehensive Health Care Model for pediatric patients screened in the Retinopathy of Prematurity Program.

Table 1: Personal medical history of the infants.

Personal medical history	Retinopathy of prematurity					
	Total	%	Yeah	%	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	%	Yeah	%	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 do not cooperate	1	1.7	-	-	-	-	1

Conclusions

The comprehensive health care model for pediatric patients screened in the Retinopathy of Prematurity program positions

primary health care as an integrating environment in the provision of public health policies and the model of care for chronic diseases in children and adolescents; it has a multidisciplinary and intersectoral approach that encompasses both promotion and



prevention. The evaluation of the model proposal by expert criteria; by consensus it was considered very adequate.

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