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ORIGINAL ARTICLE

Education and literacy program on prevention and care of pediatric patients with respiratory diseases and asthma

Educación y alfabetización en prevención y cuidado de pacientes pediátricos con enfermedades respiratorias y asma

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What do we know about the subject matter of this study?

Health education and literacy with a preventive approach are the mainstays of non-pharmacological management in patients with acute and chronic respiratory diseases.

What does this study contribute to what is already known?

This research is the first in Colombia to formally evaluate the short- and medium-term outcomes of the first five years of a structured health literacy program, aimed at caregivers of children with respiratory infections and asthma, in order to achieve greater emotional well-being, functionality, and prevention of acute episodes. Positive impact indicators are documented from the perspective of caregivers and patients participating in the program.

Abstract

Respiratory diseases, including bronchial asthma in children and adolescents, constitute a global public health problem. Educational strategies are an important tool for their control. **Objective:** To evaluate the impact of a health literacy program for the care and self-management of respiratory diseases and bronchial asthma after five years of implementation. **Patients and Method:** Prospective cohort study, non-probabilistic sample, and consecutive selection of patients < 17 years of age with asthma, recurrent bronchial obstructive syndrome, recurrent wheezing, or bronchiolitis, referred to the respiratory diseases literacy program in a pediatric hospital in Colombia during 2015-2020. Clinical, drug use, epidemiological history, risk exposures, and individual well-being data were collected. The impact was evaluated with the indicator of admission to the emergency room for resolution of respiratory crises, knowledge of the disease, and general well-being six months after leaving the program. **Results:** 2841 patients were included, mean age 7 years, 55% were male, and 86% had previous

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management by a pediatrician. 54% of a sedentary lifestyle, 48% of adherence to treatment, 66% of prevalence of at-home risk factors, and 11% of tobacco smoke exposure were detected. On leaving the program, parents reported good knowledge of the disease (99.7%), with a decrease in the number of admissions to the emergency department for crisis management from 25.4% to 6.3%. Health well-being showed an increase in the absence of negative feelings of sadness, upset, or anxiety generated by cough attacks from 53.3% to 72.5% (p = 0.006), sleep disturbances decreased by 20% (p = 0.059), the practice of physical activity increased by 14.6% (p = 0.030), and the feeling that the disease no longer controlled the lives of parents and children increased from 59% to 75.9% (p = 0.113). **Conclusions:** The literacy program improved health outcomes, general well-being, and empowered and promoted better self-management skills in children and caregivers.

Introduction

Respiratory diseases (RD) are a global public health problem[1], especially affecting children under 5 years of age, where infectious causes predominate, and with viral etiology accounting for 95% of cases. It is also well known that one of the most common non-infectious RDs affecting children and adolescents is bronchial asthma[1-6]. Despite that multiple clinical practice guidelines promote the implementation of educational interventions to improve adherence to RD treatment, crisis control, quality of life, and medication use technique[5], there are still difficulties in their design and implementation as an active element in individual care and education and literacy programs in prevention and care of children with RD and asthma.

Over the past decade, the World Health Organization (WHO) has emphasized the need to transform educational processes toward health literacy. Health literacy involves achieving a sufficient level of knowledge, personal skills, and confidence to improve personal and community health by changing personal lifestyles and living conditions[7]. More than just reading brochures and scheduling appointments, health literacy is about improving people's access to health information and their ability to use it effectively, which is fundamental to empowering patients and caregivers[8-10].

Uncontrolled RDs increase the risk of adverse events, morbidity, emergency room visits, and hospitalizations. They also have a negative impact on the economy and family dynamics, increasing school absenteeism and causing death in some cases, even in the young population[1,11]. Regardless of the nature of RD, its management is defined by the frequency and intensity of the symptoms, including the absence of sleep disturbances, maintaining physical activity, and other daily activities as normal as possible[5,12,13].

Several studies show that adherence to treatment in patients with RD, including asthma, is only 15-30%[14-16], and that such adherence only improves with education programs. Therefore, structured health literacy programs promote close contact with the patient and family, and allow to define and clarify concerns about the use technique of inhalers, side effects of medications, vaccination, feeding, crisis management, and other relevant aspects of patient care and self-control[17-19].

The objective of the study is to describe the impact of an educational program on the care and control of children with acute and chronic RD after the first five years of its implementation.

Patients and Method

Descriptive concurrent cohort study using a convenience sampling method from the Pneumology Department of a pediatric hospital in Bogota, Colombia. From January 2015 to March 2020, the following data were collected: clinical information, epidemiological data, family and personal history, individual well-being, medication use, risk exposures and habits of all patients included in the educational program, and management of RDs/bronchial asthma.

Criteria for inclusion in the program included being treated for an RD in patients aged < 17 years; diagnosis of asthma; recurrent obstructive bronchial syndrome (ROBS); recurrent wheezing with 5 or more episodes in a lifetime; being discharged from an intensive care unit for an RD and having a history of an asthma predictor index-IPA [+] at age < 3 years[20].

The research protocol was approved by the ethics committee of the *Fundación Universitaria Sanitas* (CEIFUS 713-19). No informed consent was required because we worked with data collected in the program's information system and was analyzed retrospectively.

Statistical analysis

Quantitative variables were analyzed by calculating measures of frequency, central tendency, and dispersion; categorical data were analyzed using proportions. The assumptions of normal distribution in quantitative variables were evaluated with the nonparametric Shapiro-Wilk test. Bivariate analysis was performed with Pearson's chi-square test or Fisher's exact test.

Depending on the nature of the distribution of the continuous variables, the t-student or Mann-Whitney U tests were applied. In the hypothesis contrast, values of $p < 0.05$ were considered statistically significant. The data were analyzed with Stata 16.0 software.

The spatial indexes of concentration and distribution of cases were calculated with the address and neighborhood of regular residence of each patient treated in the program, using the reference map of Bogota provided by the mayor's office of the city[21] and processing the spatial information with ArcGys software.

Program description

The children's respiratory disease/bronchial asthma program is a multimodal health literacy strategy for patients aged from 0 to 16 years, parents, and caregivers. It is a primary care program, outpatient, voluntary, belonging to a private health insurance that groups families of medium/high socioeconomic level and parents with professional education level (> 98%).

All patients discharged from the emergency services, hospitalization, or intensive care unit of private clinics in the city (with which the private insurer has an agreement for the care of its members) are beneficiaries of the program. Also, patients with these conditions who are seen in outpatient care by pediatricians or pediatric pulmonologists, those who are part of the health care teams provided by the private insurer for outpatient care, and those who are referred to the program to work in a coordinated and integrated manner on health literacy activities for patients, parents, and caregivers of children with these RDs.

The program includes patients diagnosed with bronchial asthma, recurrent wheezing, and ROBS. In addition, it educates the patient and family in different instances on the following topics: concept of the disease, modifiable risk factors, signs and symptoms, existing treatments, importance of adherence to treatment measured as attendance to medical check-ups, correct use of medications, non-pharmacological management such as diet, to exercise, and sanitation of the physical environment at home and school; warning signs, vaccination, diet, exercise, crisis management, and the necessary general training to promote the quality of life of the patient and family.

Once patients agreed to participate, they were evaluated by a physiotherapist trained in bronchial asthma, who surveyed the knowledge, attitudes, and practices of parents and caregivers about the diagnosis and control of the pathology (basic questionnaire designed by pediatricians, pediatric pulmonologists, respiratory therapists, and other professionals of the program's health team). The three literacy meetings with each patient and the focus groups with parents and caregivers take place throughout 6 to 8 months at times arranged for face-to-face or virtual activities. The program also carries out continuous biannual training in the literacy approach to the interdisciplinary group involved in the diagnosis (pediatricians and primary care physicians) and the management of patients (heads and auxiliary nurses, physiotherapists, physicians, pediatricians, pulmonologists, nutritionists, and psychologists). The program's goals include reducing the use of rescue medication, maintaining normal physical activity in children, improving their quality of life, reducing absences from school and work for parents, reducing non-relevant visits to the emergency department, and reducing hospital stays.

Impact assessment

Once the patients complete the program, an individual follow-up was initiated to identify the cases that required emergency care for respiratory crises or hospitalization. The level of knowledge about the disease of both parents and caregivers of the children in the program is also evaluated through the application of surveys via online (videoconference) or telephone interviews, in order to know the degree of health well-being of the people involved in the care of children and adolescents affected by RDs and bronchial asthma. The measurement of these three tracer indicators was carried out six months after leaving the program and is compared with the frequencies established in the baseline calculated at the entry.

Results

2,841 children under 17 years of age were included in the program during the study period (2015-2020). The average age at enrollment was 7 years and 55% were male. In 57% of parents and caregivers, a lack of clarity about an etiological or clinical diagnosis for the baseline RD with which the children were presented at the time of program entry was identified. 41% of cohort members had recorded positive asthma predicted index (API) when they were < 3 years of age. 25% of the children and adolescents required emergency care for the management of at least one respiratory crisis in the three months before the program entry (table 1).

Treatment was prescribed in 55.8% of the children and adolescents, and only half of the patients reported adherence to this prescription (48.9%). In rescue treatment, salbutamol was the first choice recommended to parents (96%) and ROBS (58%) in patients aged < years was the most frequent diagnosis. There was a high (66%) risk exposure in the home defined by parents or caregivers as the presence of dust mites, stuffed animals, residual dust, humidity in the home, and other environmental pollutants, accompanied by the pres-

ence of strong odors such as organic solvents and other chemical agents, including secondhand smoke due to the presence of smokers (table 2).

From an emotional perspective, acceptance of the diagnosis of bronchial asthma and other RDs was higher in parents of children > 5 years (57%) (p = 0.000), and general knowledge about children's health condition was reported as good by parents and caregivers (> 71%) (figure 1).

The impact of the program was evaluated through 3 indicators-tracers that compared the history of the 3 months before entering the program with the same variable at 6 months after leaving it. The first indicator referred to the need to visit an emergency service to resolve a respiratory crisis which showed a frequency reduction of consultation and management in acute RD wards in this service from 25.4% to 6% (p = 0.000) because of better control of the patients and better tools for both parents and caregivers to adequately manage crises at home.

We also evaluated the parents' and caregivers' level of appropriation of basic knowledge about RD because of the health literacy activities provided in the workshops of the program and correlated them with the other tracer indicators. Although the level of general knowledge was relatively good at entry (71.5%), it is important to mention that this percentage increased to 99.7% (p = 0.000) after the health literacy workshops.

Four elements were analyzed within the health well-being surrounding the caregivers of these children. The absence of negative feelings of sadness, upset, or anxiety generated by cough crises increased from 53.3% to 72.5% (p = 0.006). Sleep disturbances related to respiratory discomfort decreased by 20% (p = 0.059) and the practice of physical activity increased by 14.6% (p = 0.030). Finally, the feeling that the disease no longer controls their lives (parents and children) increased from 59 to 75.9% (p = 0.113) (figure 2).

According to the spatial analysis and with the use of distance-based models, choropleth maps were made with the cumulative density of patients related to the program during the first two years of activities, identifying that 67% of the patients were concentrated in an area of approximately 20 square kilometers around the hospital. A new measurement with accumulated data in the fifth year of activities showed that the same reference area concentrated only 51% of patients, evidencing the growth in the number of people seen and greater participation from more distant areas within the city (figure 3).

Discussion

This study sought to evaluate a health education and literacy program aimed at parents and caregivers of children with RD in Bogotá, Colombia. The results of the study identified positive reactions to the program, as well as increased confidence, knowledge, and development of caregiving skills, which maintained a level of recall and relationship with improved well-being and post-discharge outcomes.

Worldwide, RDs significantly affect children with significant repercussions for health institutions and

Table 1. Baseline characteristics of children and adolescents included in the program

Characteristics	Value	
	n	%
Sex		
Man	1587	55.8
Women	1254	44.2
Regular monitoring by a specialist		
Pediatrician	2455	86.4
Pulmonologist	1293	45.5
Pediatrician and Pulmonologist	1142	40.2
Diagnosis of admission to the program		
Not specified	1642	57.8
Recurrent bronchial obstructive syndrome	968	34.1
Recurring sibilant	231	8.1
Reported personal history		
None relevant	1509	53.1
Allergic rhinitis	444	15.6
Atopic dermatitis	357	12.6
Premature birth	244	8.6
Dust mite allergy	89	3.1
Allergy to some foods	78	2.8
Low birth weight	28	1.0
Low birth weight	28	1.0
Others	26	0.9
Drug allergy	21	0.7
Bronchiolitis	12	0.4
Asthma	5	0.2
History in the clinical record of an Asthma Predictive Index (API) when they were <3 years of age		
Positive	1176	41.4
No data	1042	36.7
Negative	623	21.9
Regular physical activity practice		
None	1535	54.0
No data	925	32.6
Yes	381	13.4
In the last 3 months and related to respiratory symptoms		
Requires emergency care	723	25.4
School absenteeism	489	17.2

systems; however, their management requires a multidisciplinary approach that is not easy to achieve due to several factors, especially in countries where resources are limited, both economic and human. Increasing adherence to treatment and the possibility of sustainably modifying some risk exposures at home and school in children and adolescents affected by these RDs is not an easy task, and the final success will be centered on the real possibility of closely and personally linking both patients and caregivers[22-24]. This task implies thinking that the philosophy of an educational program should incorporate the basic principles of health literacy and orient them towards person-centered care and not confuse it with the development of assistance activities or complementary to the clinical consultation, where basically instructions and alarm guidelines are given before any health contingency, and in whose absence usually causes poor control of acute or chronic

Table 2. Environmental risk factors, overall well-being, and disease awareness in children and adolescents upon entry into the program

Characteristics	Age groups in years			p	Total
	0 a 4 n = 688	5 a 9 n = 1.514	10 a 16 n = 639		n = 2841
Sex					
Man	402 (58.43)	833 (55.02)	352 (55.09)	0.296	1587
Women	286 (41.57)	681 (44.98)	287 (44.91)		1254
Diagnosis					
Recurrent bronchial obstructive syndrome	400 (58.14)	463 (30.58)	105 (16.43)	0.000	968
Recurrent wheezing	33 (4.80)	166 (10.96)	32 (5.01)		231
Not specified	255 (37.06)	885 (58.45)	502 (78.56)		1642
Risk exposure self-reported by caregivers					
Mites	275 (39.97)	1115 (73.65)	502 (78.56)	0.000	1892
Strong/irritating chemical odours	57 (8.28)	415 (27.43)	207 (32.39)		679
Animals	75 (10.90)	355 (23.45)	224 (35.05)		654
Cigarette smoke	37 (5.38)	184 (12.15)	93 (14.15)		314
Mold	9 (1.31)	51 (3.37)	20 (3.13)		80
Other fumes	9 (18.6)	45 (41.0)	23 (17.3)		77
Acceptance of the disease	261 (37.94)	897 (59.29)	369 (57.75)	0.000	1527
Updated pneumococcal vaccine	249 (36.19)	1079 (71.32)	483 (75.59)	0.000	1811
Updated influenza vaccine	162 (23.55)	868 (57.37)	368 (57.59)	0.000	1398
General knowledge of the disease upon admission to the program					
Well	439 (63.81)	629 (41.57)	220 (34.43)	0.000	1288
Regular	210 (30.52)	205 (13.55)	94 (14.71)		509
Bad	1 (0.15)	-	1 (0.16)		2
No data	38 (5.52)	679 (44.88)	324 (50.70)		1041
General well-being of caregivers upon program entry					
Well	488 (70.93)	613 (40.49)	263 (41.16)	0.000	1364
Regular	116 (16.86)	150 (9.91)	38 (5.95)		304
Bad	37 (5.38)	39 (2.58)	6 (0.94)		82
No data	47 (6.83)	712 (47.03)	332 (51.96)		1091
Disease control upon program enrollment					
Well	131 (19.04)	170 (11.23)	104 (16.28)	0.000	405
Regular	193 (28.05)	268 (17.70)	90 (14.08)		551
Bad	326 (47.38)	396 (17.70)	121 (18.94)		843
No	38 (5.52)	680 (44.91)	324 (50.70)		1042
Respiratory crises after discharge from the program	8 (10.0)	140 (18.02)	47 (10.71)		195
Crisis management					
Home	-	25 (3.22)	6 (1.37)	0.004	31
Emergency service	8 (10.0)	114 (14.67)	40 (9.11)		162

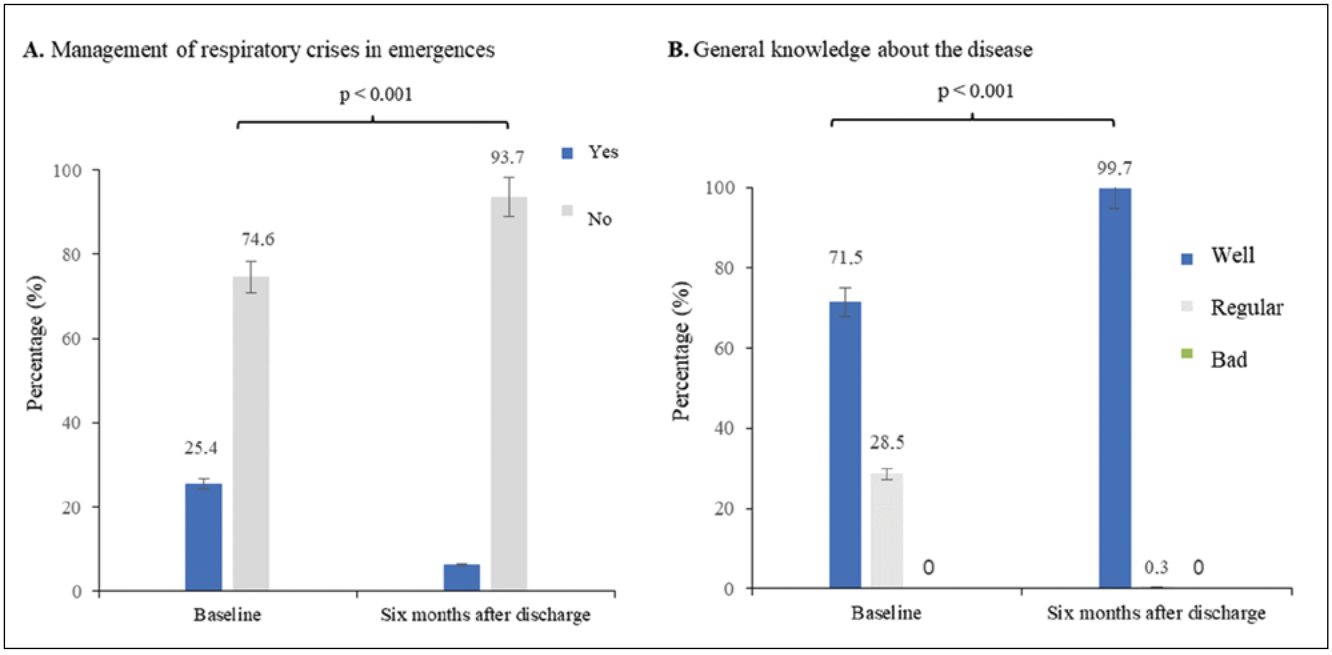

Figure 1. Admissions to pediatric emergencies for the management of respiratory crises and the level of knowledge of parents and caregivers about respiratory diseases, before and after the implementation of the educational program for patients and families in the prevention and care of respiratory diseases and bronchial asthma

respiratory conditions and greater use of medical care due to the poor understanding and inadequate use of health information by patients and their caregivers[25,26].

For the WHO, health literacy means more than being able to read brochures and make appointments; it implies the need to manage from a quality perspective focused on care, better access to health information, and the ability to use it; in other words, it requires a real and trust-building approach between patients, health personnel, and families[24,29-29].

This program showed improvement in several aspects, but we especially highlight the increase in emotional well-being conditions reported by parents and caregivers, which is fundamental in patient-centered approaches or humanization in health given that caregivers should also be favored by program strategies to avoid the mistake of ignoring their active role in care or even, as has been reported in the literature, turning them into second victims due to the psychological burden of the disease[30]. Although most of the literature reports that care programs for children and adolescents with chronic diseases focus on direct patient care, particularly for asthma, it is not convenient to forget the active role of parents and caregivers, nor that of the health care teams with whom it is necessary to maintain effective channels of communication from the literacy programs[31].

Although there is limited evidence on the results of this approach in the management of childhood RD due to the variety of strategies used for patient and caregiver literacy, the results of this study confirm that a literacy approach for patients and families, as well as for other members of the health care team involved in the care of RD, shows promise in improving disease awareness and acceptance, adherence to treatment, self-management of crises and risk exposures that result into reduced demand for emergency care and hospitalization, becoming a critical component of high-quality medical care[32,33].

The study showed high levels of sedentary lifestyles in children and a low acceptance of the disease upon entering the program, which coincides with the literature where the difficulties that exist to adequately perform physical activity, promote a healthy lifestyle, and educate the patient and family to better understand their pathology are analyzed with concern[34-38].

Bogota, the capital of Colombia, is located more than 2,600 meters above sea level and is the most densely populated city in the country with approximately nine million inhabitants, which generates a high demand for health services. Programs that require the patient and caregiver to travel to a hospital for face-to-face activities create a real barrier to access and a certain degree of inequity since all families do not have the financial resources to make several trips to comply with educational activities. Although the results of the study showed an expansion in the geographic coverage of children linked to the program over time and allowed to identify clusters of patients in certain areas of the city, it is necessary to innovate; for example, with an important resource derived from the

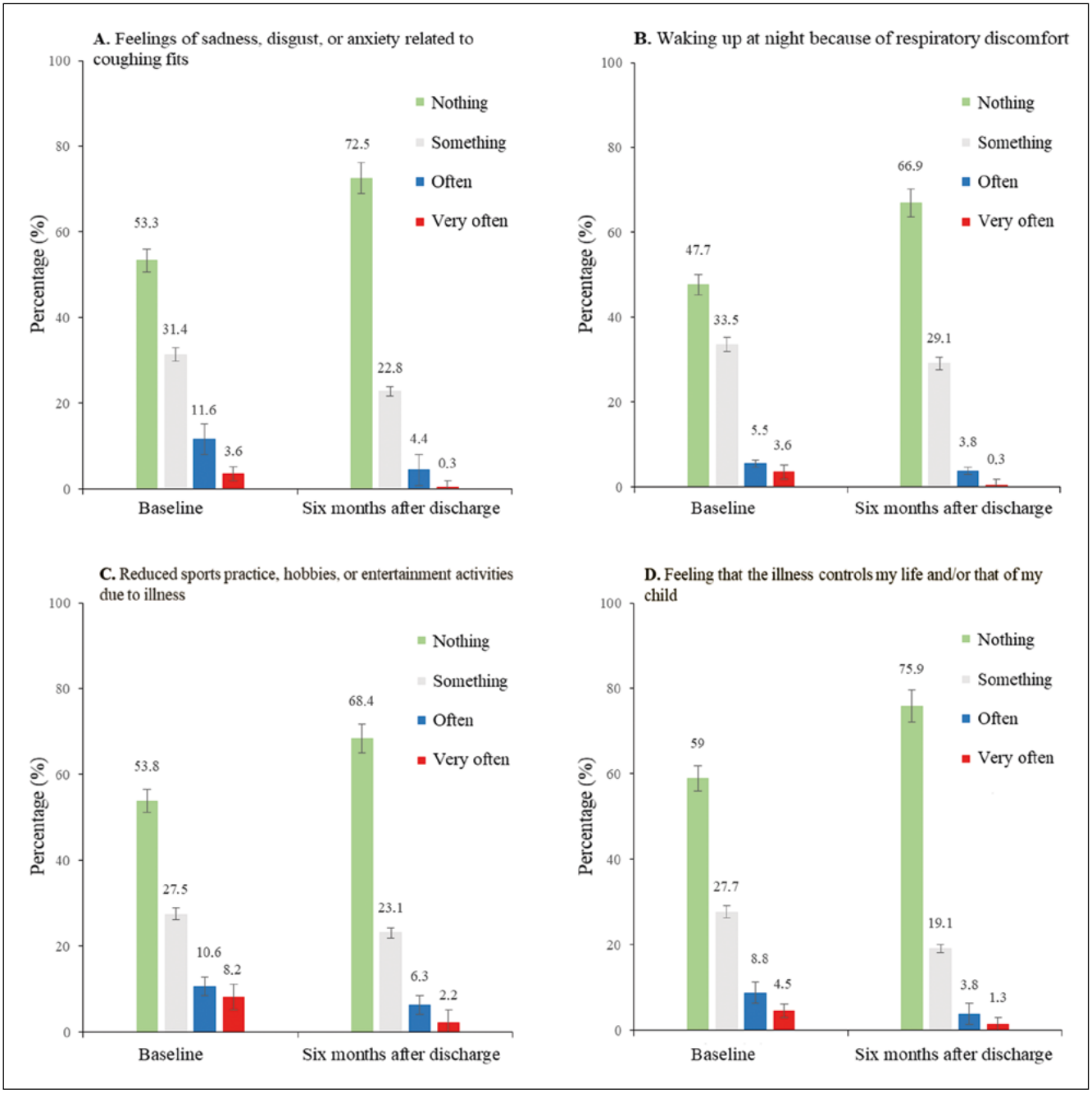

Figure 2. The frequency with which parents and children report negative feelings or emotions related to their respiratory condition, before and after the implementation of the educational program for patients and families in the prevention and care of respiratory diseases and bronchial asthma

COVID-19 pandemic such as the use of digital platforms that promote access, quality and greater equity for children and families affected by the conditions that are the object of care in the program[39-41].

Finally, the results of the study also suggest that the impact on clinical outcomes such as less demand for emergency services in the management of respiratory crises, together with the improved conditions of daily life in children, such as the increase in the practice of sports or recreational activities, improved sleep habits, and less school absenteeism observed during the follow-up and added to the decrease in negative feelings and experiences that affect caregivers, is a clear demonstration of the need and benefits caused by interventions aimed at strengthening the links between family, patient, and health team[42,43].

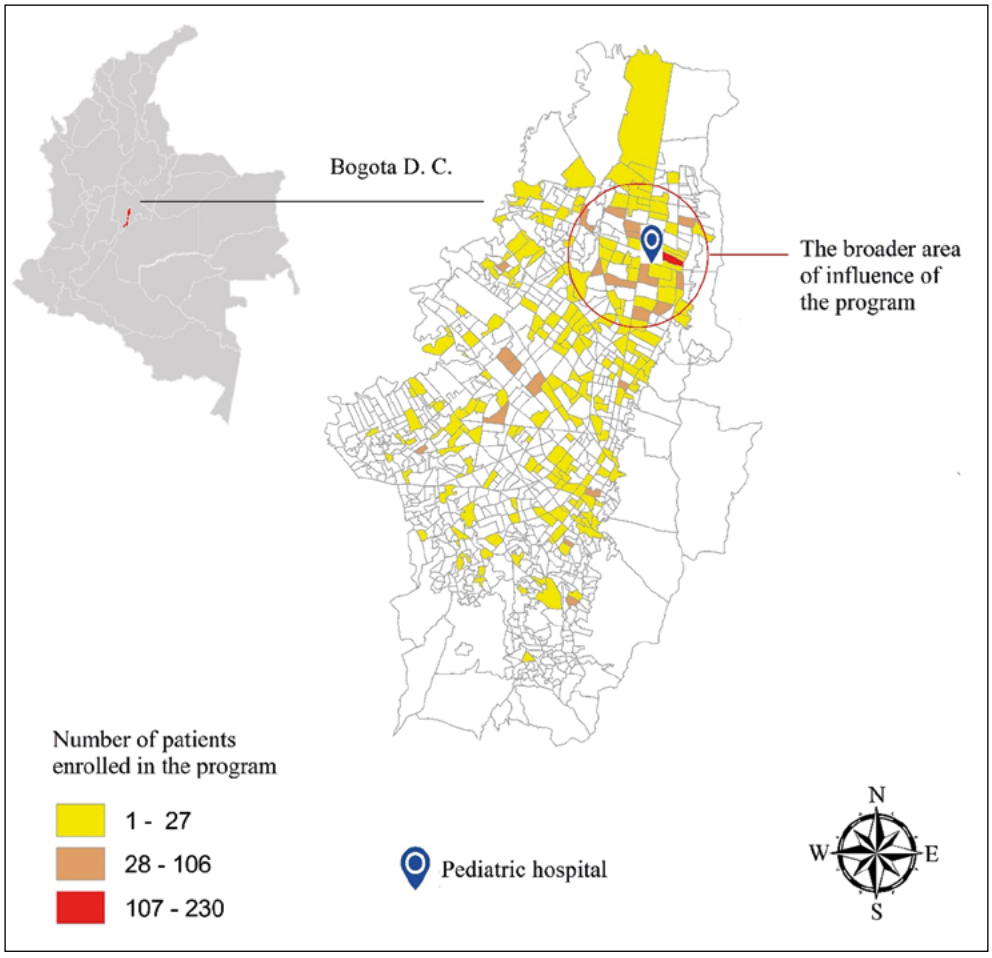

Figure 3. Accumulated spatial distribution of children and adolescents included in the program by neighborhood of residence. Bogota D.C., 2015-2020

Among the strengths of the study, we highlight that this is the first publication that approaches the implementation of an educational model under the conceptual approach of health literacy as a strategy that complements clinical care activities in children and adolescents with RD. We value the opportunity to work with a large sample size, heterogeneity in the age and base RD of the patients included, and a long period in the development of activities by the program. We also highlight the possibility of interpreting clinical outcomes from the perspective of the results and experiences reported by patients, parents, and caregivers (PREMs and PROMs)[24,44,45]. On the other side, we recognize as limitations the nature of the observational design, the conditioning to work with retrospective data recorded in the program's information system, the non-use of a control group, and the impossibility of evaluating the effectiveness of each intervention separately, as well as the measurement of clinical outcomes with a median time of more than six months as occurred in this cohort. More studies are still needed to evaluate which strategies can have a greater effect on the fulfillment of therapeutic objectives, to identify innovative strategies that allow greater coverage and quality in the implementation of literacy programs with the use of telemedicine, and even the need to validate the economic effects of interventions similar to the one described in this study in different contexts.

Conclusions

Educational programs that incorporate a health literacy approach enable healthcare providers to achieve better health outcomes for children, reduced demand for health services, and improved quality of life, and ultimately are essential to the quality of care that supports pediatric respiratory care.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed ac-

cording to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

Financial Disclosure

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