Residência RP Pediátrica
Publicação Oficial da Sociedade Brasileira de Pediatria

Submitted on: 09/01/2020
Approved on: 10/26/2020

ORIGINAL PAPER

Clinical-epidemiological profile of pediatric patients assisted by the interdisciplinary home care program of a reference hospital in Rio de Janeiro

Raquel Gomes Lot[1], Almiro Domiciano da Cruz Filho[1]

Keywords:
Home Care
Pediatrics
Chronic disease

Abstract

The Interdisciplinary Home Care Program of the Fernandes Figueira National Institute for Women's, Children's and Adolescents' Health (INSMCA Fernandes Figueira/FIOCRUZ) - PADI IFF - is pioneer in public pediatric home care (HC) in the state of Rio de Janeiro. It promotes safe dehospitalization, provides continuity of care in a multidisciplinary, comprehensive and individualized way, humanizing the care of children with technology-dependent complex chronic health conditions. The clinical-epidemiological profile of the patients in the program was described, analyzing: gender, age, date of admission, origin, residence, diagnoses, number of previous admissions, dependence on technologies, length of hospital stay before discharge from the program, readmissions during the HC, and outcome of the HC. There was no gender predominance; most are infants and preschoolers, residents of the city of Rio de Janeiro. The maternity of origin of these children is the INSMCA Fernandes Figueira in 70% of the cases. Clinical conditions were mostly composed of respiratory disorders and 90% of the patients have diseases related to the perinatal period (congenital malformations, genetic disorders, prematurity disorders). Chronic conditions were responsible for long periods of hospitalization, many of them originating in the neonatal period. All are dependent on at least two types of medical technology, and 80% have more than one diagnosis. The use of ostomies prevailed, with gastrostomy being the main device. 80% of the patients were dependent on oxygen therapy and 50% used mechanical ventilation. After dehospitalization, 40% of the children were never readmitted and two were discharged from the program.

[1] Fernandes Figueira National Institute of Women's, Children's and Adolescent's Health (INSMCA Fernandes Figueira/FIOCRUZ), Interdisciplinary Home Care Program (PADI) - Rio de Janeiro - Rio de Janeiro - Brazil

Correspondence to:
Raquel Gomes Lot.
Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira. Av. Rui Barbosa, 716 - Flamengo, Rio de Janeiro - RJ, 22250-020.
E-mail: raquelglot@gmail.com

DOI: 10.25060/residpediatr-2022.v12n3-460

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INTRODUCTION

FIn recent decades, there has been an epidemiological transition based on an increase in chronic health conditions and a reduction in infectious diseases. Previously, children died from dehydration in diarrheal conditions, vaccine-preventable diseases, malnutrition and infectious diseases. Among the causes for this phenomenon, the following stand out: immunization programs, better sanitary and environmental conditions, oral rehydration therapy, encouragement of breastfeeding, improvement of neonatal and premature care, surgical innovation to correct congenital malformations, development of drugs and medical technologies[1]. All these elements provided an increase in the survival of those who previously died in the absence of these interventions. With this new scenario, chronic diseases in pediatrics gained prominence.

Chronic diseases have different etiologies: metabolic, degenerative, hereditary, congenital, inflammatory, autoimmune, infectious that make them chronic. These are conditions expected to last at least one year; that produce sequelae (limiting organic functions, daily activities, social roles compared to healthy children of the same age from an emotional, physical and cognitive point of view); who require care from doctors and other healthcare professionals beyond what would be necessary for a given age group; that brings about dependence on medicines, technologies, devices, special diets and caregivers[2].

Within the pediatric population are children with complex chronic health conditions (CCCs). These are children in need of specialized care, affected by one or more chronic diseases (severe or with high morbidity/mortality), bringing limitations not only from an organic point of view, but also with regards to daily activities and community participation. In addition, they have diseases that generate dependence on medical technologies and an important demand for healthcare services (multidisciplinary and specialized follow-up, frequent and prolonged hospitalizations, multiple surgeries)[3,4]. Also in this group are technology-dependent children (TDC). They are those that, due to some physical limitation and/or loss of vital function, require technologies for survival such as tracheostomy (TCT), gastrostomy (GTT), ventriculoperitoneal shunt (VPS), long-term catheters, parenteral nutrition (PTN), peritoneal dialysis tube, enteral feeding tubes, bladder catheterization (BC), nasal oxygen catheter, mechanical ventilation (MV)[5].

Within these settings, it is essential to have a differentiated look at new demands, which mainly encompass multidisciplinary care and dependence on technologies. As a result of the needs produced by the chronic disease and the comorbidities that accompany it, there is a greater number of hospitalizations that tend to be longer, generating physical and psychosocial consequences for the patient and family[6]. In this sense, it is essential to seek to mitigate the harmful effects of hospitalizations and, when possible, prioritize care at home.

The PADI IFF was created in April 2001 with the aim of providing home care for pediatric patients at the Fernandes Figueira INSMCA with chronic and technology-dependent diseases, able to be monitored outside the hospital environment. During 2019, it assisted ten children in the metropolitan region of Rio de Janeiro via a multidisciplinary team composed of a doctor, a pharmacist, a nutritionist, a nurse, a physical therapist, a speech therapist, a psychologist and a social worker.

With regards to the field of pediatric HC, the PADI IFF is pioneer, being the only one in this modality in the public healthcare network of the state of Rio de Janeiro. It provides safe dehospitalization of TDC, reduces the length of hospital stay and ensures greater bed turnover. It also encourages prevention measures to reduce the risk of infections and avoid frequent readmissions, reduces treatment costs and articulates the care network close to the home. In partnership with the district's healthcare network and the Melhor em Casa Program, it provides comprehensive care, guides family members and the community about the basics of healthcare and appropriate activities for the good evolution of patients, enabling greater family participation in the act of caring, humanizing assistance and facilitating the insertion of TDC into their social nucleus.

METHODS

This is a quantitative, descriptive and cross-sectional study on the clinical-epidemiological profile of patients assisted by the PADI IFF, based on data from the active medical records of patients covered by the program between the months of January and October 2019, making up a total of ten patients.

The study variables were: gender, date of birth, date of hospitalization, origin (INSMCA Fernandes Figueira/FIOCRUZ or external), residence, diagnoses based on ten major categories according to the systems involved and the ICD-10, number of hospitalizations prior to HC, technology dependence, length of hospital stay before HC, readmissions during HC and HC outcome. The information was organized in an electronic database, using spreadsheets in Microsoft Excel, Windows version 2013 and submitted to a descriptive analysis, mediated by tables of absolute and relative frequencies.

A free and informed consent form was obtained from the person responsible for the study participant and an informed consent form for children up to 12 years old and for children and adolescents between 12 and 18 years old, in accordance with Resolution 466/2012, and we obtained approval from the Ethics Committee in Research at the Fernandes Figueira INSMCA/FIOCRUZ.

RESULTS

We studied ten patients – five females (50%) and five males (50%). Four are in the age group from 28 days to 2 years - infants (40%); four belong to the group from 2 to 6 years - preschoolers (40%); one belonged to the group from 6 to 10 years - one being schooling (10%) and one from 10 to 18 years old - a teenager (10%).

Eight live in the city of Rio de Janeiro (80%) and two (20%) live outside the city (in the metropolitan region of Rio de Janeiro).

As for the main diagnoses and ICD-10 classification (Table 1), three patients have neurological and/or neuromuscular conditions, fitting into congenital malformations of the nervous system (30%), all with Arnold-Chiari Syndrome type II (AC II) - one with Moebius Syndrome and another with CA II associated with the Edwards Syndrome. In cardiovascular conditions, two have congenital malformations of the circulatory system (20%) - Tetralogy of Fallot and Left Cardiac Isomerism with AVS.

Table 1. Distribution of diagnoses classified into categories/subcategories according to the systems involved.

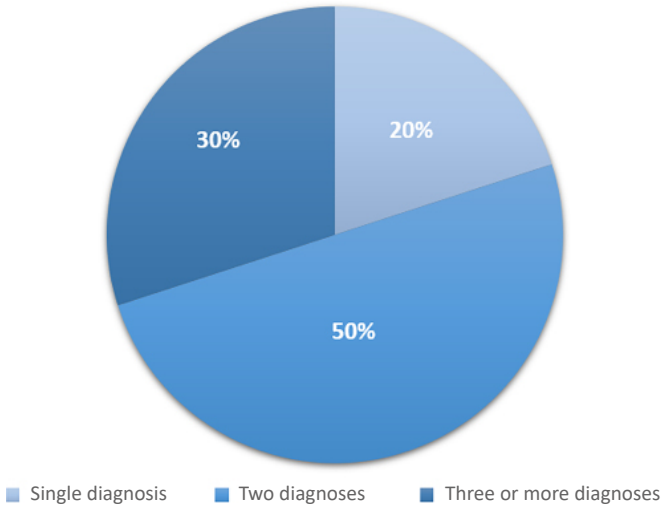
Diagnoses	*n (%)*
Respiratory Conditions	
Chronic respiratory diseases	6 (60%)
Neurological and/or Neuromuscular conditions	
Congenital malformations of the nervous system	3 (30%)
Renal and/or Urological conditions	
Chronic bladder conditions	3 (30%)
Cardiovascular conditions	
Congenital malformations of the circulatory system	2 (20%)
Conditions associated with prematurity of the neonatal period	
Respiratory diseases 2 (20%)	
Fetal malnutrition and delayed fetal growth 2 (20%)	
Extreme immaturity and/or newborn with very low weight	1 (10%)
Conditions associated with congenital anomalies or genetic defects	
Defects of the abdominal wall and diaphragm	2 (20%)
Chromosomal anomalies not classified in other parts	1 (10%)
Gastrointestinal conditions	
Other diseases of the digestive tract	1 (10%)

As for congenital anomalies/genetic defects, three were affected (30%): one being chromosomal anomalies not classified elsewhere (Edwards syndrome); two with abdominal wall and diaphragm defects - one with gastroschisis causing short bowel syndrome; another with omphalocele corrected in the neonatal period. One patient was categorized into gastrointestinal conditions by short bowel syndrome (10%).

Eight have diagnoses based on respiratory conditions (80%): one with chronic lung disease (CPD) due to surfactant deficiency; one with CPP secondary to bronchiolitis and recurrent pneumonia; three with cardiac malformations leading to chronic respiratory failure (CRF); one with central nervous system involvement evolving with CPP; two bronchodysplastic patients due to prematurity. Five patients (50%) are included in conditions related to prematurity and the neonatal period: two classified in the part of respiratory diseases due to bronchopulmonary dysplasia due to prematurity (20%); one extremely premature (10%); two with intrauterine growth retardation (20%). Three patients (30%) were affected by renal and/or urological conditions, by neurogenic bladder condition requiring intermittent bladder catheterization given their main diagnosis - AC II Syndrome.

As for the number of diagnoses, two children had only one underlying clinical condition (20%), five had two (50%), three had at least three (30%). Of these three children, two had three diagnoses and one had five diagnoses (figure 1).

Figure 01 – Number of diagnoses



All depend on technologies. As for the dependence type, all of them had ostomies. Eight of them had GTT (80%), five have TCT (50%) and one has an ileostomy (10%). Within the group of ostomized children, six had only one ostomy (60%) and four had more than one ostomy (40%). Nine patients (90%) were dependent on oxygen therapy and MV. Within these technologies, 55.5% of the patients were dependent on both. Regarding home oxygen therapy, eight patients were oxygen-dependent (80%). Three of these patients (30%) required invasive ventilatory assistance and two required non-invasive ventilatory assistance (20%). As for VPS, two patients had this device (20%). As for bladder catheterization, three patients (30%) needed this type of technology. Individualizing each device, the most used were GTT and oxygen therapy – 80% of the patients were dependent on each. Regarding the number of medical technologies used by each patient, five made use of two (50%) and the other five (50%) depended on at least three technologies to maintain their vital functions (Table 2).

Seven patients (70%) were born at the Fernandes Figueira INSMCA. Six patients (60%) remained hospitalized from birth at this location until the date of home discharge to the PADI IFF, after clinical stability. Only one child born at the institution was discharged home from the maternity hospital, but returned for hospitalization due to pneumonia/bronchiolitis. This hospitalization was prolonged until discharge to the program. The other three patients not born at Fernandes Figueira INSMCA were admitted to the institution because of pneumonia.

Table 2 - Dependence on medical technologies.

Types of technologies	n (%)
Ostomies	
Gastrostomy	8 (80%)
Tracheostomy	5 (50%)
Ileostomy	1 (10%)
Home oxygen therapy	8 (80%)
Invasive ventilatory assistance	3 (30%)
Non-invasive ventilatory assistance	2 (20%)
Bladder catheterism	3 (30%)
Ventriculoperitoneal shunt	1 (10%)
Number of technologies	n (%)
Two devices	5 (50%)
Three or more	5 (50%)

Considering the number of hospitalizations before discharge via PADI IFF (Table 3), eight patients had 1 to 2 hospitalizations (80%). Of these, six patients (60%) had only one hospitalization - which corresponded to hospitalization since birth. Two had two hospitalizations (20%). One patient had between 3 to 5 hospitalizations (10%) and one patient had more than five hospitalizations (10%). Regarding the duration of hospitalization before discharge, five patients (50%) remained hospitalized for more than 12 months. Three (30%) remained hospitalized for 6 to 12 months and two remained hospitalized for less than 6 months (20%).

Table 3 - History of hospitalizations.

Variables	n (%)
Number of hospital admissions before discharge to the PADI	
1 to 2 hospital admissions	8 (80%)
3 to 5 hospital admissions	1 (10%)
> 5 hospital admissions	1 (10%)
Duration of the last hospital stay before discharge to the PADI	
0 – 6 months	2 (20%)
6 months – 12 months	3 (30%)
> 12 months	5 (50%)
Readmissions after discharge to home PADI	
None	4 (40%)
1 to 2 readmissions	3 (30%)
3 to 5 readmissions	2 (20%)
> 5 readmissions	1 (10%)

As for the number of readmissions after hospital discharge, four patients were never readmitted (40%). Three had 1 to 2 readmissions (30%), two had 3 to 5 readmissions (20%) and only one had more than 5 readmissions (10%). Among the reasons for readmissions, there were: respiratory conditions (pneumonia, bronchiolitis, and pneumothorax), gastrointestinal conditions (gastroenteritis), urinary conditions (urinary tract infection), fever to be clarified, febrile convulsion, performance of GTT. Most hospitalizations were due to acute infectious diseases, especially those with respiratory causes. Of the patients analyzed, two had been discharged from home care during the study period (20%).

DISCUSSION

We can state that in the group assisted by the PADI IFF there was no predominance of one gender over the other, that most were infants and preschoolers and residents of the city of Rio de Janeiro. Mariani[7], in their study on the profile of children, adolescents and their caregivers assisted by a home care program in the city of Belo Horizonte, revealed that their sample was predominantly male, unlike the PADI IFF. On the other hand, the age group covered was 0 ¬¬6 years, similar to the PADI IFF population.

As for diagnoses, most are related to respiratory conditions (60%). Those linked to the neonatal period and prematurity are equivalent to 50%. Neurological, genetic and renal/urological conditions are equivalent in prevalence (30%). Marian also described that the main diseases were of neurological etiology, followed by respiratory, genetic and, finally, neoplastic. However, this difference, may be justified by several reasons – the reference article does not include conditions related to the neonatal period as a classification of hospitalization diagnosis, and it cannot be said that this type of involvement does not occur in the Belo Horizonte program; Fernandes Figueira INSMCA does not include oncology as a specialty; the renal/urological involvement mentioned in our profile does not appear as the main diagnosis, but secondary to the underlying condition – AC II with neurogenic bladder secondary to myelomeningocele – perhaps that is why it is more prevalent when compared to the article in question.

Vernier[8], in their paper on the characterization of children with special health needs and their caregivers at a Federal Hospital of Rio Grande do Sul, classified the diagnoses into perinatal and acquired conditions. Within the perinatal, there are those of congenital origin (malformations, genetic syndromes) and those acquired (prematurity, neonatal hypoxia, neonatal infection). The majority of children dependent on special care were affected by perinatal causes (58.5%). In the PADI IFF study, neurological, cardiac, gastrointestinal malformations and genetic syndromes are classified apart from conditions related to the neonatal period, being sectored by systems, based on the ICD-10. From the moment we group these conditions into neonatal/perinatal causes, this portion corresponds to 90% of the group. It can be inferred that the diseases that affect the assisted children are mostly related to perinatal causes, especially congenital malformations, if we classify in a similar way to the HC program in Rio Grande do Sul. This information corroborates the improvement of neonatal intensive care and technological advances in the surgical area in the correction of congenital malformations.

The respiratory etiologies present include: CPD caused by genetic alterations (surfactant deficiency); CPD secondary to recurrent pneumonia/bronchiolitis; CRF due to neurological disorders; lung disease secondary to congenital heart disease; bronchodysplasia of prematurity. The latter, in the study, is classified in a different category (conditions related to prematurity/neonatal period). Then, we notice that respiratory diseases would have a prevalence of 80% among the assisted patients if we consider bronchodysplasia due to prematurity within respiratory conditions, not classifying it within conditions related to the neonatal period.

Regarding the number of diagnoses, 80% had at least two underlying clinical conditions, which is similar to the literature when compared to the Mariani's group, in which the majority also had more than one diagnoses. The main diagnoses of children in the current analysis often involve secondary diagnoses and associated comorbidities, adding complexity to this patient profile. Included in the study population, for example, is a patient who had intrauterine growth restriction, with a chromosomal abnormality (Edwards Syndrome), associated with a malformation of the central nervous system (CA II). In this case, the child also has surgically corrected atrial and ventricular septal defect (secondary to Edwards), myelomeningocele and neurogenic bladder (associated with AC II), in addition to CPD.

Glendinning[9] mentions that in the late 1980s, it was estimated that in the United States there were about 100,000 technology-dependent children. In the UK, the estimate was, at the beginning of the year 2,000, of around 6,000 children. In Brazil, Drucker[10] states that there are no records on the prevalence of these children, but based on specific experiences, it is inferred the existence of a significant number of these children. All are dependent on medical technologies, precisely because it is a program that has this dependence as an inclusion criterion. Everyone needs at least two to maintain their vital functions in order to compensate for some functional loss. This fact can be explained by the complex diagnoses and associated comorbidities, with involvement of more than one system.

As for the type of technology, all are ostomized. GTT has a prevalence of 80%. Congenital malformations of neurological etiology (leading to delayed neuropsychomotor development, making oral feeding difficult) and prolonged hospitalizations (providing periods of parenteral or tube nutrition, without continuous stimulation from the oral route), may contribute to this high prevalence. Regarding TCT, the prevalence is 50%. We notice that all patients with TCT have neurological conditions and/or CPP, being involved with a history of prolonged intubation and difficult ventilatory weaning.

On the respiratory side, most need home oxygen therapy (80%). This is in line with the higher prevalence of respiratory conditions in the PADI IFF-assisted group: of patients with chronic respiratory conditions, all are dependent on supplemental oxygen. The group is heterogeneous: not only those with respiratory conditions of intrinsic pulmonary cause or secondary to prematurity, but also those with neurological diseases that progressed to CRF and those with congenital heart disease. As for MV, 50% of patients use it. Of these, 60% use invasive ventilation, while 40% use non-invasive ventilation. Comparatively, Alencar[11] showed that in the group assisted by the Melhor em Casa Program in the city of Curitiba, 62.5% of the patients are dependent on oxygen therapy and 68% use invasive ventilation.

As for origin, most were born at the INSMCA Fernandes Figueira. Although most children have only one hospitalization prior to HC, this corresponds, in 60% of the cases, to a hospitalization originating at birth. Until discharge to HC, most of these hospitalizations lasted for at least 12 months. This data can be explained by the high prevalence of perinatal/neonatal conditions, mainly congenital malformations and genetic syndromes. Precisely these children with prolonged hospitalizations are the ones with the greatest clinical complexity. In this sense, it is essential to think about the treatment plan from the neonatal period, considering the possibility of a future HC.

After discharge for follow-up with HC, 40% had no new admissions. Bernadá[12] describes that in a pediatric HC program in Uruguay, there was a reduction in the number of emergency consultations and hospitalizations, as well as a decrease in the length of hospital stay. Alencar[16] also showed a low incidence of re-hospitalizations. These data reflect the impact of dehospitalization by HC.

Readmissions were mostly related to respiratory, gastrointestinal and urinary infections. Respiratory conditions were the most common, justified by the prevalence of children's baseline respiratory conditions. On the other hand, technology, while it ends up compensating for the loss of a vital function, guaranteeing hospital discharge, also contributed to readmissions: pyelonephritis due to frequent bladder catheterization; recurrent pneumothorax in the chronically ventilated; hospitalization for gastrostomy.

During the study, two children were discharged from the PADI IFF (20%). This was due to the following factors: maintenance of clinical stability at home, no need for technological devices, autonomy of care, access to rehabilitation therapies available in the basic healthcare network and specialized monitoring in a tertiary hospital. The PADI IFF made it possible for there to be no readmissions in 40% of the cases. Without the program, hospitalizations would last longer, making it impossible for the child to remain in the family environment and in their social environment, making it difficult for the care to be autonomous.

Children with multiple diagnoses, dependent on medical technologies and with a history of prolonged hospitalizations were identified. Since most of these hospitalizations have their origin in the neonatal period, it is necessary to plan the process of dehospitalization of these potentially chronic patients from the neonatal intensive care unit to hospital discharge for HC. The PADI IFF is a safe option for pediatric patients with chronic and technology-dependent conditions who, even after stabilizing the baseline clinical picture during hospitalization, still need special resources and care by a multidisciplinary team. It aims to promote and maintain the clinical stability of the child, in addition to humanizing care.

It is therefore necessary to focus more on this type of health care, train professionals and create policies that encourage this type of practice in this new context of health care in pediatrics.

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