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ORIGINAL ARTICLE

DEMANDS OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS IN PRIMARY CARE IN RIO DE JANEIRO

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ABSTRACT

Objective: To analyze the demands of children with special health care needs, which implied some changes in the way of taking care at home. **Method:** Descriptive research implemented with data from Children with Special Health Care Needs Screener© - Brazilian version, integrated with the tri-centric study (Santa Maria – RS, Rio de Janeiro-RJ, and Ribeirão Preto – SP). We interviewed 589 families of children under 12 years old in 12 primary health care units. Data were treated with descriptive statistics. **Results:** According to the domain of special needs, the children's prevalence was 12,4%, being the chronic respiratory and cutaneous diseases the most predominant. In this group, 63% self-declared black and brown skin and 37% white color; 35,6% received benefits from programs of cash transfer (Bolsa Família Programme and Continuous Cash Benefit); 20,5% would live in a community wherein garbage and sewage were discarded at an open-air, with untreated water. **Conclusion:** The social conditions of vulnerabilities were added to the clinical one, affecting the way those children were taken care of at home. Knowledge regarding the needs, living conditions, care, and access demands can help restructure services and primary health care welcoming.

Keywords: Health Services Accessibility. Caregivers. Pediatric Nursing. Primary Health Care.

INTRODUCTION

In 2015 Brazil fulfilled the objective of the millennium development, which was to reduce the children's mortality rate achieving the index of 17.7 per 1.000 live births (LB). Comparing with the index of 52,5 per 1.000 LB, recorded in 1990, there was a decrease of 34.8 deaths per 1.000 LB[1].

This index was a result of, among other aspects, the improvement of neonatal care, the development of medical technology in health care, and poverty reduction.

However, many children older than one-year-old started living with some type of special health care need that implies some life-sustaining care, such as continuous use of medications and technological devices. These children require better support from health care networks, educational services, and social assistance. Some of them present changes in the quality of life due to unique needs; therefore, the care delivered by the family caregivers are based on new knowledge that is not present in their daily life[2-6].

Children and teenagers who have, or run a greater risk of having a physical, developmental, behavioral or emotional condition, including chronic and clinically complex conditions, require some specialized assistance from services and professionals (health care, education, and social assistance) for beyond the majority of children in general[2-6]. Due to these defining characteristics, in the United States,

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they were called Children With Special Health Care Needs (CSHCN) [3], in Brazil, Crianças com Necessidades Especiais de Saúde (CRIANES)[4], and in Chile, Niños y Adolescentes com Necessidades Especiales de Salud (NANEAS) [5].

Acknowledging the child as someone who has special health care needs contributes to the determination of real demands of health care in services, enabling a better organization and, consequently, offering better assistance. A survey carried out in the United States pointed that 15,1% of people aged between 12 months and 18 years old (children and teenagers) lived in the community with some special health care needs (SHCN)7. However, in Brazil, this group has little statistical visibility and prevalence data are geographically specific, especially in the cities of Rio de Janeiro (RJ), Santa Maria (RS) and the state of Paraná[2,8-9].

It is important to continue determining the prevalence and the profile of CSHCN in the community so that needs, care demands, and organization of network services is developed, being the primary health care the organizer of such networks[4-6, 7-10].

Health needs are made of a group of four structuring elements, that is, proper living conditions, access to technology, care autonomy, and a bond with the health care services. Such elements demand the primary health care network to coordinate care, organizing the health care services, the different levels, and areas of specializations[11-12]. Children with special health care, unique and differentiated needs require an organized and network assistance, due to their clinical fragility and social vulnerability. Therefore, the closer the caregiver families to health care services are, the greater the chances to solve these children's demands[13-14].

The exposed problem leads us to question: what health problems are recurrent among these children leading families to change the way of taking care of them at home? The objective was to analyze the demands of children with special health care needs that implied in some changes in the way of taking care of them at home.

METHOD

Data refer to the part of the sectional research implemented in the primary health care in Rio de Janeiro (Children with special health care needs in a primary health care unit: prevalence and access), involving two other cities (Santa Maria [RS] and Ribeirão Preto [SP]).

Sharing Data Bank is a current trend consisting of the process of granting or disclosing access to a research data 15. The data collection process consists of three stages: specification and design of data needs, collection and data processing, and disclosure and evaluation of results. This new concept has some advantages, such as more accessible information for everyone having access to data, better quality data, report load reduction, and the possibility of data collector agents to exchange information.

The following procedures were adopted to make the research database. For tracking the CSHCN in the community, we used the Brazilian version of the tool Children with Special Health Care Needs Screener© - CS©[8], composed of five items distributed in three dimensions. This tool includes a sort of variables related to the primary caregiver and the child. For sociodemographic, it was highlighted date of birth, sex, skin color/race, kinship relationship with whom they live, whether they go to school or daycare center. For health condition – medical or health diagnosis, types of units, and specialists they go to, history of hospitalization; information about birth – prenatal care, type of delivery, prematurity, birth weight). The variable care demand was assessed by three questions of the Screener CS©, and they were applied only in the city of Rio de Janeiro. They were the following: "Does the child have any health problems that changed the way you take care of them at home? Is this different care delivered due to any disease, health, or behavior problem? Has this health problem lasted, or is it expected to last a year or more?"

For data collection in Rio de Janeiro, we used the tool Screener CS© in 12 out of 15 Units qualified by PMAQ (National Program for Access and Quality Improvement in Primary Care), located in seven (7) programmatic areas (P.A 1.0, 2.1, 2.2, 3.1, 3.2, 5.2 and 5.3) in neighborhoods in the north, south, and west of the city. The sample of respondents was weighted by the number of children under 12 of each city integrating the tri-centric research, based on the IBGE Census of 2010, estimating a

total of 981 participants: 121 in Santa Maria, 286 in Ribeirão Preto and 574 in Rio de Janeiro[16-18].

The research fieldwork in Rio de Janeiro was performed from July 2016 to May 2017, when 589 family members of children under 12 were interviewed, who went to primary health care units (Family Clinic and Primary Health Care Units), searching for some type of assistance. These family members fulfilled the following inclusion criteria: be over 18 years old, family caregiver of children older than a week to 12 incomplete years old, living in Rio de Janeiro. People unaware of the current child's conditions, at birth and family's conditions, were excluded.

Data analysis was carried out with the program Excel for Windows®, and this study presented parameters based on descriptive measures. Therefore, the statistical analysis did not embody the structure of the sample plan of the tri-centric project.

This research was approved by the Research Ethics Committee of the Municipal Secretary of Health of Rio de Janeiro (CAAE nº 54885516.5.3001.5279, July 7, 2016), under the terms of Resolution nº 466, December 12, 2012, of the National Health Council.

RESULTS

The family members (n=589) who answered Screener CS© were aged between 18 and 76. Most of them were self-declared brown or black women who attended complete high school, housewives attending evangelical religions. These family members answered about 589 children; out of this total, 73 (12,4%) had some special and differentiated health care needs, which implied in changes in the way of providing home care.

Regarding the characterization of children with special health care needs, it was noticed that the majority had black or brown skin; 15/73 lived-in environments without access to water treatment, sewage, and without a proper garbage collection. Among the CSHCN, 25/73 depended on a federal government program of cash transfer, especially the Bolsa Família Programme and the Continuous Cash Benefit. Seven (7/73) children received one or more benefits deriving from a paternal pension, help from family members or church, and from the town hall of Rio de Janeiro (public transport card).

Forty-nine (67,1%) CSHCN had presented some recurrent health problems in the last 12 months that preceded the application of Screener but without a definition of the diagnosis of a disease, 24 (32,9%) waited for a vacancy in the National Regulatory System (SISREG) to be assisted by a specialist. Among the ones being regularly monitored by specialists, all of them were consulted in the Unified Healthcare System (SUS), 18 were also monitored by professionals associated with corporate healthcare insurance.

Despite having a defined disease diagnosis, 13 children were not regularly monitored by the specialized health care network of SUS.

Table 1. Children with special health care needs according to the quantity of diagnosed health problems and the health care system being monitored by specialists. Rio de Janeiro, Brazil, 2016-2017

Variables	N	%
Children with an already diagnosed health problems (n=49)		
Yes	49	67.1
No	24	32.9
Health care system monitored by specialist (n=36)		
Mixed (Private Health Insurance and Unified Health System)	18	50
Unified Health System (SUS)	18	50

Source: Created by the authors.

The health problems reported by the family members correspond to 61 disease diagnoses defined in 49 children, that is, each child presented from one to two diagnoses, increasing the clinical complexity of care for the family caregivers. The special health care needs related to the chronic diseases of the immune system, especially the respiratory and topical allergies, were diagnosed in 18 children; followed by the respiratory system ones (17 children), such as bronchitis, asthma, rhinitis, bronchiolitis and sleep apnea. Behavioral disorders such as attention deficit, attention deficit

due to hyperactivity and autism were diagnosed in six children.

Furthermore, the family members reported other special health care needs associated with chronic diseases of the endocrine, cardiovascular, digestive, nervous, skeletal, and hematological systems, and infections such as HIV / AIDS and chronic otitis. All diagnoses of chronic diseases and behavioral disorders implied in changes in the way family members took care of these children at home (Chart 1).

Chart 1. Health problems of children with special health care needs, reported by family members, with defined diagnosis, according to the disorder type and body system. Rio de Janeiro, Brazil, 2016-2017.

Defined diagnosis	N	Defineddiagnosis	N
RESPIRATORY (n=17)		**CARDIOVASCULAR (n=3)**	
Bronchitis	6	Heart diseases	3
Asthma	5		
Rhinitis	3		
Bronchiolitis	2		
Sleep apnea	1		
IMMUNOLOGICAL (n=18)		**DIGESTIVE (n=3)**	
Respiratory allergy	13	Diarrhea	2
Topical allergy	5	Constipation	1
DISORDERS BEHAVIORAL (n=6)		**NEUROLOGICAL (n=2)**	
ADHD	4	Epilepsy	1
ADD	1		
Autism	1		
ENDOCRINE (n=4)		**SKELETAL (n=1)**	
Cholesterolemia	1	Orthopedicdisorders	1
GrowthDisorder	1		
Obesity	1		
ThyroidChanges	1		
INFECTION (n=3)		**OTHERS (n=3)**	
Otitis	2	Phimosis	1
HIV/aids	1	Nonspecificsyndrome	1
		Hematologicalproblems	1

Source: Created by the authors.

Legend: HIV/aids– Human Immunodeficiency Virus/acquired immunodeficiency syndrome; ADHD - Attention Deficit Hyperactivity Disorder; ADD – Attention Deficit Disorder

Family members reported that 24 children (32,9%) had been recurrently sick in the year before the research, with several attendances at primary health care units, which were closer to where they lived. However, they still did not have a defined disease diagnosis or behavioral disorder. Among the health problems, the ones affecting the immune, respiratory, and endocrine systems stood out. The psychosocial systems include behavioral disorders, which were identified by the school where children studied, with psychosocial assistance demands (Chart 2). All of them require coordination of care delivered by the primary health care network, together with the other ones provided by SUS.

Such needs led the families to change the way they took care at home, changing the child's diet, removing curtains and carpets, visiting the emergency units and searching for vacancies to undergo surgeries and treatments through the National Regulatory System of Health Referee, as well as assistance in a children psychosocial care center.

Concerning the frequency of hospital admissions of children since their birth, 34 families answered that they were readmitted up to ten times. Half of them (17) were admitted at least once;11 were admitted from two to five times, and four were admitted between five and ten times. One child was readmitted more than 11 times.

Chart 2. Health problems of the child with special health care needs reported by a family member, with or without a diagnostic conclusion. Rio de Janeiro, Brazil, 2016-2017.

Health problems reported by the family member					
Type	**Conclusive diagnosis**	**without diagnosis**	**Type reported by family member**	**Conclusive diagnosis**	**Without diagnostic definition**
Respiratory Allergy (n=25)	13	12	Heart disorder(n=5)	3	2
Bronchitis (n=9)	6	3	social isolation (n=2)	-	2
Overweight/ Obesity (n=5)	1	4	Changing letters (Dyslalia)	2	2
Agitation (ADHD/ADD, Autism) (n=7)	6	1	Umbilical Hernia(n=2)	-	2
Rhinitis (n=8)	3	5	Severe burn sequelae(n=1)	-	1
Bronchiolitis(n=10)	6	4	High Cholesterol (n=1)	-	1
Seizure (n=4)	-	4	Sadness at the absence of the father (n=1)	-	1
Intolerance/Food Allergy (n=4)	-	4	Sinusitis (n=1)	-	1
Bowel disorder(n=3)	3	-	Reflux (n=1)	-	1
Recurring Pneumonia (n=2)	-	2	Suicidal Ideation (n=1)	-	1

Source: Created by the authors.
ADHD - Attention Deficit Hyperactivity Disorder; ADD – Attention Deficit Disorder

Specialized services were required to ensure comprehensive care for children with special health care needs. Several medical specialties and other professionals were mentioned as necessary for being available at those services. The same child may require monitoring by more than one specialty and by different professionals, totalizing 17 types of services or different specialties (Chart 3).

Chart 3. Specialties required by children with special health care needs, according to their families' report. Rio de Janeiro, Brazil, 2016-2017.

Specialties (n=17)			
Children in need of medical care (n= 43)		**Children with care needs for multi-professional specialties (n=11)**	
Immunology (allergy)	10	Speech Therapists	4
Pediatrics	8	Nutrition	3
Neurology	4	Psychology	3
Cardiology	3	Occupational Therapy	1
General practice (Family Physician)	3		
Psychiatry	3		
Ophthalmology	3		
Pneumology	2		
Otorhinolaryngology	2		
Endocrinology	2		
Hematology	1		
Genetics	1		
Dermatology	1		

Source: Created by the authors

Among the 36 children being monitored by specialized, public, and private services, ten were assisted by immunologists, eight by pediatricians, and four by neurologists. In some cases, the same child could be monitored by more than one specialist due to their several

diseases diagnoses and health care needs. Other specialties that require monitoring are dermatology, cardiology, general practice, psychiatry, ophthalmology, pneumology, otorhinolaryngology, endocrinology, hematology, and genetics. Of the 17 multi-professional specialties required by these children, four were monitored by the speech therapist, three by nutrition, three by psychology, and one by occupational therapy.

Chart 4. Relation among children's health problems, reported by family members, special health care needs, and care demand. Rio de Janeiro, Brazil, 2016-2017.

Reported health problems	Type of special health care need	Classification of care demand
Bronchitis, Rhinitis, Asthma, Bronchiolitis, Sinusitis, Allergy Respiratory, Allergies (Skin, Food)	Respiratory (A, B, AT, LC)	Modified quotidian care: Environmental management, feed control Care of drug administration: inhalation therapy, continuous use of drug therapy
Sleep Apnea	Sleep and rest (LC, A)	Modified quotidian care: Sleep and rest monitoring
HIV/aids	Continuous drug use (B, A, AT)	Care of drug administration: Adherence to Antiretroviral Therapy, management of continuous use drug therapy. Modified quotidian care: family preparation to reveal the condition to the child in a timely manner.
Obesity, High Cholesterol, Food intolerance, Growth Disorder Gastro esophageal reflux	Food and nutrition (LC, A)	Modified quotidian care: Feed control, Mixed Care: Treatment Adherence (drug and diet) Development care: Strict monitoring of growth and development Modifiedquotidian care: Semi-Fowler's position, Feed control
Constipation	Bowel elimination	Modified quotidian care: Food management, bowel habit regulation, diet control, hydration
Thrombocytosis, Cardiaccondition	Cardiopulmonary functioning (B, A)	Modified quotidian care: cardiorespiratory monitoring, learning resuscitation maneuvers Drug care: Continuous drug therapy,
Epilepsy	Continuous drug use (A, B, AT)	Care of drug administration: management of continuous use of drug therapy Modified quotidian care: knowledge about monitoring and controlling seizures
Social Isolation, Depression ADHD Speech disorder, Dyslalia	Behavioral, developmental and learning (B, LC)	Development care: Encouraging social inclusion, sports practice Modified quotidian care: Referral to speech therapy and resolution monitoring
Umbilical hernia, Coronary artery fistula, Congenital clubfoot	Surgical correction(AT, B)	Modified quotidian care: Referral for surgeon's assessment and resolution monitoring

A – Family caregiver autonomy; B – bond with the health care team network; LC – proper living conditions; AT – access to technology
Source: Created by the authors.

Chart 4 associates health care with special needs and care demand, with emphasis on the modified quotidian care, continuous use of drugs, development care, and mixed one.

DISCUSSION

The profile of children with special health care needs includes living in a vulnerable context due to some social determinants that increase the inequity and exposure to health problems with higher chances of becoming sick and being readmitted to the hospital. Among other aspects, lack of access to the sewage system, waste disposal in the open, and low family income stand out, some of which interfere in living conditions. Regardless of whether the race/color is black or brown or white, they are children who depend on the social protection network of the Unified Social Assistance System (SUAS) and the Unified Healthcare System (SUS), since they received some type of social benefit from the Cash Transfer Programme, especially Bolsa Família and Continuous Cash Benefit.

Both benefits are part of the childhood social safety net in Brazil, and they are intended for children whose families live in poverty and extreme social vulnerability.[4,19]According to the last demographic census of the Brazilian Institute of Geography and Statistics – IBGE, 2010, most of the Brazilian population had self-declared as having brown or black skin, which is explained because of the high level of miscegenation of races in our country[18].

The proactive action of the primary health care network of the Unified Healthcare System, as the coordinator of care and articulator with other care networks, needs to ensure the longitudinality and completeness of care. This contributes towards the decrease of hospital readmissions of acute cases, which are sensitive to primary health care[19,21]. The CSHCN are vulnerable and clinically fragile, leading their caregivers to demand a body of knowledge and practices based on technical-scientific knowledge to deal with these children's needs.[13] This group of children lives the "come and go effect," in a regular cycle of hospital admissions and readmissions, increasing the complexity of their care for both nursing professionals and their family caregivers[13, 21-22].

They are recurrently assisted in emergency units in Rio de Janeiro and are waiting for vacancies in the National Regulatory System (SISREG) for the definition of diagnoses related to the immune and respiratory systems.

Vulnerable situations expose children who are already clinically fragile to recurrent episodes of illness, which can become chronic and increase the health care needs, and require more attention from the specialized networks of the Unified Healthcare System (SUS). Both children being diagnosed with a disease, and the ones who presented recurrent episodes of illness, without diagnosis confirmation, need special health care. In both situations, their living conditions determined some changes in the way they were taken care of at home. The knowledge built from the observation of the child's behavior provides autonomy to the family caregiver, searching for access to the services network to define the diagnosis. The bond with the primary health care network of SUS does not prevent the wait for the National Regulatory System from releasing the assistance in the specialized health care network, which can retard the diagnosis of some conditions which demand early intervention. In our reality, these families attend the hospital network, where the child is monitored for their chronic condition, which does not connect with the available services at the primary health care.

The health care, social assistance, and educational services that deliver more complex assistance are more accessed by family caregivers when there are organized and available models of health care, as it is the case in Chile and the United States, for instance[5,7]. In turn, there are difficulties in accessing the presented health services to continue health treatment after hospital discharge[19, 20-22].

The absence of a referral and counter-referral system hinders the trajectory of family caregivers, leading them to search for creative strategies to continue taking care of this child in the network. For this group using SUS, the existence of networks formed by loose and fragmented meshes and the lack of articulation between the different levels of care compromise the application of the principles of integrality, longitudinal of the Unified Healthcare System[4-21-22, 24-25].

Clinically complex children groups have a high demand for specialized assistance, leading the family to value the child assistance in the primary health care, accessing this network as a reference for other services (access to SISREG, Brazilian name for the national regulatory

system of vacancy) and vaccination, for example[5-6,8-9].

Along with the year before the fieldwork of research, the children who had gotten recurrently ill and had still waited for specialized medical care to confirm the diagnosis and treatment. Children with a confirmed diagnosis of disease were not monitored by specialists, and the ones being monitored required different medical specialties (pediatrics, immunology, and neurology) and multi-professionals (nutrition, psychology, speech therapy, and occupational therapy). Multiple health problems put pressure on the provision of care by the specialized care network and converge on the definition of children with special health needs, as they demand specialized services, in number and quantity greater than children in general[2-3].

Those with modified quotidian care demands require some adaptations concerning care throughout life, such as the position to eat (gastroesophageal reflux) and avoiding bronco-aspiration, sleep and rest monitoring (sleep apnea), special handling in transport, personal hygiene (shower), getting dressed, adherence to drug use, application of immunizers, use of inhalers, etecetera[22-25].

The immune and respiratory systems disorders were the main causes of changing the way of taking care of these children at home, and the comings and goings to the emergency units closer to their homes. These needs are special and unique, implying in demands for some new knowledge so that this continuing home care is delivered correctly. Parents of children with problems resulting from chronic conditions have a strong desire to participate in their care.[9, 22-24] Care for this group impacts the family's life, as some changes in the family's everyday life are necessary, resulting in financial expenses and an increase in the clinical vulnerability and fragility.[10, 13, 24-25]

Among the diverse demands of the CSHCN, the modified quotidian care stands out, which is generated by sequelae of the therapeutic process associated with recurrent illnesses. It is a group with multiple health care needs that can imply changes or adaptations of the home environment to the child's daily needs, bringing about a challenge for their caregivers. This care changes according to the child's clinical conditions and their growth and development. Therefore, it is necessary to develop some actions of health education focused on the family, in all the process of the child's life. These caregivers always have new demands for knowledge to ensure the well-being, comfort, and safety concerning the child's care. Thus, there will be a need for continuous monitoring by a nurse to this child and family, to offer safe conditions for carrying out care at home[2, 24-25].

By sharing knowledge about procedural care, medication administration, those related to activities of daily life, development, among others, they provide more security for this family caregiver, reducing anxiety and stress. The primary health care nurse can be an essential link in this chain, articulating and creating bonds of the family caregivers and the children with the Family Health Strategy, making it possible to maintain the care longitudinal and comprehensiveness[24-25].

CONCLUSION

In Rio de Janeiro, 12,4% of the studied children had some type of specialized health care need, which provided families with some autonomy to change the way they took care of the mat home. Most of them lived in poverty and high social vulnerability affecting the proper living conditions and strengthened the bond concerning the care, especially in the primary health care networks, emergency units, and specialized care. The respiratory and immunological conditions, whether with defined diagnoses or not, pressured the demand for monitoring by different medical specialties (pediatricians, immunologists, neurologists, dermatologists) and other health professionals (speech therapist, nutritionist, and psychologists), to the time they demand for modified quotidian care, continuous use of drug, developmental and mixed from their families. The care actions inherent to these demands require new know ledge to take care of CSHCN at home.

Among the methodological limits of this study, the impossibility of accessing the primary health care services located in violent areas of Rio de Janeiro stands out, when developing field work in six previously programmed units.

For public health in general, we can better ensure care longitudinal, and comprehensiveness, effectively prioritizing the care of children enrolled in the National Regulatory System and who need to have anestablished diagnostic definition to start treatment and monitoring. The health needs of these children imply a higher demand for access and insertion in primary health care services, based on an assessment of social vulnerabilities and clinical fragility by nursing. Besides, the findings of this research an contribute to the nursing team of the family health strategy to monitor this child in the community, keeping their records active and updated, force fully and resolutely articulating the priority character of child care through specialized care.

DEMANDAS DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE SAÚDE NA ATENÇÃO PRIMÁRIA DA CIDADE DO RIO DE JANEIRO

RESUMO

Objetivo: Analisar demandas de crianças com necessidades especiais de saúde que implicaram em mudanças na forma de cuidar em casa. **Método**: Pesquisa descritiva implementada com dados do *Children with Special Health Care Neesds Screener*© - versão brasileira, integrada ao estudo tricêntrico (Santa Maria – RS, Rio de Janeiro-RJ e Ribeirão Preto – SP). Entrevistou-se589 familiares de crianças com menos de 12 anos, em 12 serviços da atenção primária. Dados tratados com estatística descritiva. **Resultados**: Segundo os domínios de necessidades especiais, a prevalência dessas crianças foi 12,4%, predominando as doenças crônicas respiratórias e tegumentares. Desse grupo, 63% era da raça/cor parda e preta e 37%branca; 35,6%eram beneficiados com programas de transferência de renda (bolsa família e prestação continuada); 20,5% viviam em ambientes cujo lixo e esgoto eram descartados a céu aberto, com água sem tratamento. **Conclusão**: As condições de vulnerabilidade social se somaram às clínicas que afetaram o modo de as crianças serem cuidadas em casa. Conhecimento sobre as necessidades, condições de vida, demandas de cuidado e de acesso podem auxiliar na reestruturação dos serviços e acolhimento na atenção primária.

Palavras-chave: Acesso aos Serviços de Saúde. Cuidadores. Enfermagem pediátrica. Atenção Primária à Saúde.

DEMANDAS DE NIÑOS CON NECESIDADES ESPECIALES DE SALUDEN LA ATENCIÓN PRIMARIA DE LA CIUDAD DE RIO DE JANEIRO

RESUMEN

Objetivo: analizar las demandas de niños con necesidades especiales de salud que conllevaron cambios en la forma de cuidar en casa. **Método**: investigación descriptiva implementada con datos del *Children with Special Health Care Neesds Screener*© - versión brasileña, integrada al estudio tricéntrico (Santa Maria – RS, Rio de Janeiro-RJ y Ribeirão Preto – SP). Fueron entrevistados 589 familiares de niños con menos de 12 años, en 12 servicios de atención primaria. Datos tratados con estadística descriptiva. **Resultados**: según los dominios de necesidades especiales, la prevalencia de estos niños fue 12,4%, predominando las enfermedades crónicas respiratorias y del sistema tegumentario. De este grupo, 63% era de la raza/color pardaynegray 37% blanca; 35,6% era beneficiado con programas de transferencia de renta (bolsa familia y prestación continua); 20,5% vivía en ambientes cuya basura y red de saneamiento eran descartadas a cielo abierto, con agua sin tratamiento. **Conclusión**: las condiciones de vulnerabilidad social se sumaron a las clínicas que afectaron el modo de cómo los niños son cuidados en casa. Conocimiento sobre las necesidades, condiciones de vida, demandas de cuidado y de acceso pueden auxiliar en la reestructuración de los servicios y acogimiento en la atención primaria.

Palabras clave: Accesibilidad a los Servicios de Salud. Cuidadores. Enfermería Pediátrica. Atención Primaria de Salud.

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