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RESEARCH

FAMILY VULNERABILITY OF CHILDREN WITH SPECIAL NEEDS OF MULTIPLE, COMPLEX AND CONTINUOUS CARE

VULNERABILIDADE FAMILIAR DE CRIANÇAS COM NECESSIDADES ESPECIAIS DE CUIDADOS MÚLTIPLOS, COMPLEXOS E CONTÍNUOS

VULNERABILIDAD FAMILIAR DE NIÑOS CON NECESIDADES ESPECIALES DE CUIDADOS MÚLTIPLES, COMPLEJOS Y CONTINUOS

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ABSTRACT

The aim of this study was to identify the family vulnerability of children with multiple, complex and continuous special needs. It is a cross-sectional study with families of 68 children. Data were collected from June to September 2015, through interviews conducted at home. Non-probabilistic sampling was used for convenience, and data were analyzed by means of descriptive statistics and Pearson's correlation. All families were vulnerable, however, 8.8% presented up to 40% vulnerability. In this study, it was identified a notable individual vulnerability due to the clinical fragility of the child, social exclusion, and programmatic regarding the precariousness of access to health services. Health care networks need to be re-evaluated by their managers in order to provide access and care to this population. It is also important to invest in the training of qualified professionals to work in primary care, who understand the context of the families and value their vulnerability in the implementation of care actions.
Keywords: Vulnerability Analysis; Health Vulnerability; Pediatric Nursing; Child Health; Family Nursing.

RESUMO

Esta pesquisa objetivou identificar a vulnerabilidade familiar das crianças com necessidades especiais de cuidados múltiplos, complexos e contínuos. Trata-se de estudo transversal, realizado com famílias de 68 crianças. Os dados foram coletados no período de junho a setembro de 2015, por meio de entrevistas realizadas no domicílio. Utilizou-se amostragem não probabilística por conveniência e os dados foram analisados por meio de estatística descritiva e correlação de Pearson. Todas as famílias apresentaram-se vulneráveis, contudo, 8,8% apresentaram até 40% de vulnerabilidade. Identificou-se, ainda, notória vulnerabilidade individual devido à fragilidade clínica da criança, social pela exclusão e programática relacionada à precariedade de acesso aos serviços de saúde. Faz-se necessário que as redes de atenção à saúde sejam reavaliadas por seus gestores, a fim de proporcionar acesso e atendimentos a essa população. Destaca-se a importância de investir na formação de profissionais qualificados para atuarem na atenção primária, que compreendam o contexto das famílias e valorizem a vulnerabilidade das mesmas na implementação de ações de cuidado.
Palavras-chave: *Análise de Vulnerabilidade; Vulnerabilidade em Saúde; Enfermagem Pediátrica; Saúde da Criança; Enfermagem Familiar.*

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RESUMEN

El objetivo de este estudio fue identificar la vulnerabilidad familiar de los niños con necesidades especiales de cuidados múltiples, complejos y continuos. Se trata de un estudio transversal realizado con familias de 68 niños. Los datos fueron recogidos en el período de junio a septiembre de 2015, por medio de entrevistas realizadas en el domicilio. Se utilizó un muestreo no probabilístico por conveniencia y los datos fueron analizados por medio de estadística descriptiva y correlación de Pearson. Todas las familias se mostraron vulnerables, el 8,8% presentó hasta un 40% de vulnerabilidad. En este estudio se identificó una notable vulnerabilidad individual debido a la fragilidad clínica del niño, social por la exclusión, y programática en cuanto a la precariedad de acceso a los servicios de salud. Es necesario que las redes de atención a la salud sean reevaluadas por sus gestores a fin de proporcionar acceso y atención a dicha población. Se destaca la importancia de invertir en la capacitación de profesionales calificados para actuar en la atención primaria, que comprendan el contexto de las familias y consideren su vulnerabilidad en la implementación de acciones de cuidado.

***Palabras clave**: Análisis de Vulnerabilidad; Vulnerabilidad en Salud; Enfermería Pediátrica; Salud del Niño; Enfermería de la Familia.*

INTRODUCTION

The greater survival of children living in limited conditions on life and who were born prematurely, with congenital malformations, syndromes or chronic health conditions gave rise to a group called Children with Special Needs of Health (CRIANES), whose children may present together or demand for four types of care: developmental, medication, technological and/or modified habitual care.[1,2]

On the other hand, the subgroup of CRIANES called children with special needs of multiple, complex and continuous care presents greater limitations in their neuro-psychomotor development and they need technologies to maintain basic daily activities. In these cases, usually, the mother or other family member is primarily responsible for home care.[3-5]

Such responsibilities are continuous and require the family to reorganize its dynamics and routine to exercise care with the child, often encountering the prejudice of society in the face of the condition of the child. CRIANES, and in particular those of the subgroup that present multiple, complex and continuous care, have weaknesses in the search for the guarantee of their rights as citizens, besides to suffering from social exclusion and the precariousness of access to health services, factors that determine situations of individual and family vulnerability.[6]

The vulnerability can encompass individual, collective, and contextual factors that predispose people to illness. The conceptual model for vulnerability proposed by Ayres et al.[7] is divided into three axes: a) individual, which consists of the existence of factors of the individual that cause the occurrence of the injury; b) programmatic, which considers access to health services, its organization, the relationship between professionals and patients, plans for prevention and control of diseases and resources offered to serve the population; c) social, referring to the environmental and economic conditions to which the individual is subordinate.

It should be noted that children with chronic conditions are susceptible to illness and worsening of their clinical condition when they do not have access to quality services and/or when health professionals do not recognize them in their context of vulnerability. Also, little access to basic sanitation; low parents' education level; working conditions and income; and the presence of people who demand more care in the family – the elderly and people with disabilities – are factors that intensify the vulnerability of the family.[8,9]

Also, studies show that the hospitalization of the child impacts negatively on the daily life of the family, since, besides causing suffering, families need to reorganize their routines to care for the child, and, family vulnerability factors may impair the treatment of the child. Thus, it is necessary for the multiprofessional health team to know the concepts of vulnerability and identify real situations in their areas of action to transform their practice, directing actions to the needs of families.[9-12]

Thus, identifying and knowing what types of vulnerability children with special needs, complex and continuous care and their families are exposed in the context of the community will enable the preparation of action plans to meet their real needs, preventing serious aggravations of their condition and providing support to their families. This is because there are few specific studies about them and those in the pediatric nursing area are carried out with families of hospitalized children.

In view of the above, the objective of this study was to identify the family vulnerability of children with multiple, complex and continuous special needs.

METHODOLOGY

This is a cross-sectional study with a quantitative approach carried out in the municipality of Maringá, located in the northwest region of the state of Paraná.

Participants in the study were family caregivers of children with special, complex and ongoing special care needs identified at a public educational institution specializing in rehabilitation. The inclusion criteria for participation in the study were: being a family caregiver (aged 18 years old and over) of children up to 11 years old, 11 months and 29 days who presented at least three of the four demands that characterize a child belonging to the group CRIANES - developmental care (need for psychomotor and social rehabilitation due to neuro muscular dysfunction), medication

care (that makes continuous use of medication), technological care (dependent on care technologies such as catheters, colostomy and/or uterotostomy bags, tracheostomy, among others) and modified habitual care (requires modification in routine care or tasks); and who resided in the municipality of Maringá-PR, since the institution also attends children residing in other municipalities that make up the 15th Regional of Health.[2]

The sample consisted of 68 children and their families, selected for convenience. It should be noted that the population of children with special needs of complex and continuous care is still unknown in the municipality of Maringá and the use of non-probabilistic sampling technique was the method that allowed to know the characteristics of the largest number of families in these conditions, being the most appropriate method for the development of the study.[13]

Initially, under the supervision of the social worker of the institution under study, the medical records of all those enrolled in this institution (251 individuals) were analyzed, and 91 children up to 12 years old who met the inclusion criteria in the study were identified. However, four were excluded due to the intervention of the school and the Tutelary Council in the family.[14]

Thus, families were initially contacted by a letter attached to the child's agenda, requesting authorization for telephone contact, but only 17 families responded to the request. Then, after authorization from the school director and the social worker, contact was made with all those responsible for 87 children, of whom 68 participated in the study, since 11 of them, despite being willing to participate, could not reconcile schedules of the home visit and eight refused to participate in the survey.

The data were collected from June to September 2015, through a semi-structured interview conducted in the families' homes, through prior scheduling, consent and availability. The instrument used in the data collection is a semi-structured type, elaborated by the authors and consists of five parts: a) socioeconomic characteristics of the family; b) the birth of the child; c) the demands for care (medication, technology, habitual modifications, and development); d) child health monitoring; e) individual and family vulnerability. An online electronic questionnaire was used to optimize the data collection containing the variables corresponding to the instruments used for the study, using the **Google Docs** application "forms" tool, which allowed the data to be automatically registered, tabulated and exported to the spreadsheet in Microsoft Office Excel 2010® software.

The variable care demands were adopted to identify the individual vulnerability of children. And the health monitoring variable was used to analyze the programmatic vulnerability, and this information was explored according to the concepts proposed by Ayres et al.[7]

The Vulnerability Index of Families of Paranaenses (IVFPR) was used to verify the vulnerability of the families, developed by the State Secretary for Family and Social Development (SEDS) through the Paranaense Institute for Economic and Social Development (IPARDES).[12] This instrument consists of 19 indicators distributed in four dimensions: a) **home adjustment**, consisting of five indicators that evaluate home aspects (up to 12 points); b) **family profile and composition**, which evaluates nine indicators corresponding to family members, their particularities and organization (up to 20 points); c) **access to work and income**, with two indicators related to work and monthly family income per capita (up to 13 points); d) **conditions of education**, which verifies the educational situation of the family members (up to eight points).

The vulnerability index in each dimension and the family vulnerability index were calculated according to the theoretical model: the sum of the points of the dimension divided by the maximum score that each dimension could reach; and the arithmetic mean of the indices of the dimensions, respectively. The values obtained ranged from zero to one, and the closer to one, the greater the family vulnerability and in each dimension.

The statistical analysis was performed using the free access software R version 3.1.2, using descriptive measures: absolute and relative frequency, mean (m) and standard deviation (SD). Pearson's correlation was used to verify if there was a correlation between the dimensions and the family vulnerability index.

The study was developed in accordance with the ethical precepts disciplined by Resolution 466/2012 of the National Health Council and approved by the Standing Committee on Ethics in Research with Human Beings of the State University of Maringá (Opinion 083705/2014, CAAE: 36505814.8. 0000.0104). All participants signed the Informed Consent Form in two copies.

RESULTS

Family caregivers of 68 children, aged between 22 and 70 years old (m = 36.6; SD=9.1), were mostly females and mothers of the children (98.5%). Most of them reported that they stopped working to take care of the child (76.5%), were white (73.5%), married (69.1%) and Catholic (58%). Considerable portion belonged to economy class C (48.6%) and 33.8% completed high school (Table 1). The number of residents per household varied between two and nine, with an average of four residents per household (SD = 1.3).

Family income ranged from one to 13 minimum wages (m = 4.5; SD = 3.4) and 45.6% of the children received the Continuous Benefit (BPC). Although most families were considered as having no high socioeconomic status, 83.8% of the children had a private health insurance - 63.1% of the cases had a co-participation plan, in which the family, in addition to paying the monthly fee, also needed to pay a percentage previously established on the value of medical consultations and outpatient examinations.

Table 1 - Sociodemographic profile of family caregivers of children with multiple, complex and continuous special needs. Maringá-PR, 2015

		N	%
Kinship degree	Mother	63	92.6
	Grandmother	4	5.9
	Brother	1	1.5
Marital Status	Single	8	11.8
	Stable union	7	10.3
	Married	47	69.1
	Widow	1	1.5
	Separated/Divorced	5	7.3
Gender	Female	67	98.5
	Male	1	1.5
Skin color	Yellow	2	2.9
	White	50	73.5
	Brown	15	22.1
	Black	1	1.5
Education level	Illiterate	1	1.5
	Incomplete Elementary School	11	16.2
	Complete Elementary School	7	10.3
	Incomplete High School	7	10.3
	Complete High School	23	33.8
	Incomplete Higher Education	4	5.9
	Complete Higher Education	15	22.0
Religion	Catholic	40	58.8
	Evangelical	24	35.4
	Spiritist	2	2.9
	Not practicing	2	2.9
Stopped working	Yes	52	76.5
	No	16	23.5
Economy Classification	A	6	8.8
	B	27	39.7
	C	33	48.6
	D	2	2.9

All children in the study had developmental and modified habitual care demands; 92.6% relied on technology to maintain basic daily activities and survival, and 72% used continuous medications. It should be emphasized that all children had at least three of the four care demands that characterize a CRIANES. Therefore, they had little or no autonomy over their own care needs, and it is essential to perform a full-time family caregiver (Table 2).

In 76.5% of cases, regular health monitoring of the child was carried out through the health insurance. According to family members, more than half of the children (58.8%) did not receive visits or follow-up from the Family Health Strategy (ESF) team, or even from the community health agent. It is noteworthy that 52.9% of the interviewees reported not having received guidance and/or training to carry out childcare at home, for example, on medications, care with the technological devices used, hygiene and feeding (Table 2).

Table 2 - Demands for care and access to care for children with multiple, complex and continuous special care needs. Maringá-PR, 2015

		N	%
Demands for care	Developmental	68	100
	Modified Habitual	68	100
	Medication	49	72
	Tecnhological	63	92.6
Health monitoring site	Outpatient	4	5.9
	Health insurance	52	76.5
	Basic health Unit	12	17.6
Receiving home visits from the ESF team	Yes	28	41.2
	No	40	58.8
Received guidance for child care	Yes	32	47.1
	No	36	52.9

Although 89.7% of the families lived in conditions considered minimal housing, six had a 17% vulnerability in this dimension, since the residence did not have a sewage network and they used a septic tank. One of these families accommodated more than three family members per room, which resulted in 25% of vulnerability (Table 3).

Table 3 - Parental vulnerability index: families of children with special needs of multiple, complex and continuous care. Maringá-PR, 2015

	%	N	%
Adequacy of home	0	61	89.7
	17	6	8.8
	25	1	1.5
Family profile and composition	5	28	41.2
	15	22	32.3
	25	14	20.6
	35	4	5.9
Access to work and income in the family	0	16	23.5
	15	25	36.8
	23	3	4.4
	31	3	4.4
	38	12	17.7
	54	2	2.9
	62	4	5.9
	77	3	4.4
Educational conditions	0	24	35.3
	25	29	42.6
	50	15	22.1

Continue...

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Table 3 - Parental vulnerability index: families of children with special needs of multiple, complex and continuous care. Maringá-PR, 2015

	%	N	%
Family Vulnerability Index	1-10	24	35.3
	11-20	24	35.3
	21-30	14	20.6
	31-40	6	8.8

Regarding **family composition**, all families had at least one condition that could affect family functioning and organization - the presence of at least one person with a disability residing at home. It is noteworthy that four families presented a 35% vulnerability in this dimension, with 17.6% of them being uniparental; 42.6% had a ratio between the number of children and adolescents and adults equal or greater than one; 22% of families had more than one disabled person residing at home; 5.9% had elderly living in an aggregate condition; and in 2.9% the head of the family was illiterate (Table 3).

The highest degree of vulnerability of the families under study was observed in the dimension of **access to work and family income** since 76.5% of the families reported having some difficulty in this aspect. In 11.8% of the families, less than half of the adults were working; 25% reported having a per capita income of half a minimum wage, and 10.3% had income less than a quarter of the minimum salary in force at the time (Table 3).

Regarding the **education level dimension**, it was observed that 22.1% of the families presented a vulnerability index of 50% (Table 3), with half of the children presenting at least three years of lag in the grades in which they were enrolled, and 24 adults in the study reported not having completed elementary school. The data show that all families presented vulnerability in this dimension. However, 8.8% of them had an index between 31 and 40%.

There was also a strong correlation between the dimensions of **access to work and income in the family** and **education conditions**, that is, the better the educational conditions, the greater the access to work and family income. Moreover, these dimensions were strongly correlated with family vulnerability, reinforcing that the greater the vulnerability of the family in the access to work and income, the higher the vulnerability in education conditions (Table 4).

However, **the family profile and composition** dimension exhibited a moderate correlation with the family vulnerability index.

DISCUSSION

The socioeconomic conditions presented by the families, the demands of the children's care, the lack of orientation to the parents, the fragile access and the precarious follow-up in the scope of the basic care represent a set of conditions that characterize the individual's vulnerability in the social and programmatic context,[15,16] corroborating the study carried out with family caregivers of CRIANES in a pediatric hospitalization unit of a teaching hospital in the South of Brazil.[6]

Programmatic vulnerability refers to the lack of elaboration, implementation, and evaluation of public policies and programs aimed at these children and their families in health services.[8] In this sense, together with the adequate management of resources from primary care, it is necessary to invest in the training of health professionals capable of intervening with vulnerable families ensuring quality care and access to the health service. It is highlighted that children have potential and recovery capacity when systematic, pertinent and timely interventions are carried out, including actions to protect and prevent injuries.[17]

A study carried out with seven families of children with chronic conditions and with a high index of social vulnerability showed that the life of these families is permeated by multiple experiences in the health services, raising reflections about the care centered in the family, with a technical-assistance premise in the basic care, especially for ESF.[18] In the practice, contribute professionals to act as facilitators of a family coping, sources of bonding and support, and as links with the other points of care of the health network.

It is also evident that children with chronic conditions, especially those with complex and continuous special needs of multiple care, are in a situation of programmatic vulnerability, since there is no information system that enables to locate them in health services or even a registry that provides information on the data of children and their families, as well as updating the demands for health care and health conditions.[18]

Table 4 - Correlation between the vulnerability indexes of families of children with special needs of multiple, complex and continuous care. Maringá-PR, 2015

Indexes	Adequacy of home	Family profile and composition	Access to work and income in the family	Education conditions	IVFPR
Adequacy of home	1	0.0320	0.0685	-0.0899	0.1448
Family profile and composition	0.0320	1	0.1669	0.0687	0.3688
Access to work and income in the family	0.0685	0.1669	1	0.6218	0.8963
Education conditions	-0.0899	0.0687	0.6218	1	0.8284
IVFPR	0.1448	0.3688	0.8963	0.8284	1

All the families participating in this study had some degree of family vulnerability. However, it can be seen that the most compromised and correlated dimensions with the general index of vulnerability of the families were: access to work and income in the family and education conditions, corroborating the findings of the study that validated IVFPR.[12]

It should be pointed out that in the families of this study the reduced number of people contributing to the family income is due to the fact that the children have many demands for care, which implies the need for one of the family members to stop working to take care of them, becoming most vulnerable families because of the financial resources.

It was also found that health conditions impair children's school and cognitive performance and, as a consequence, they have a large gap in the school grades, and special education is needed to assist them in their development. This finding, in addition to the fact that one-third of adults did not finish elementary school, influenced vulnerability in the dimension of "educational conditions".

The strong correlation between the dimensions "access to work and income in the family" and "education conditions" and their correlation with the IVFPR is possibly due to the fact that the education of the family head influences income and such data are reflected in the vulnerability family, that is, the higher the education level, the higher the family income and, consequently, the lower the vulnerability of the family.[19]

Due to the changing epidemiological profile of health in all age groups of the population and the increase of people with disabilities, some authors highlight the need to identify the vulnerability of the families that share this situation within the scope of the ESF to plan actions and mobilization resources for its implementation. According to these authors, it is necessary to devise actions to reduce family fatigue and direct existing resources in basic care so families fully care,[20] including through articulation and mobilization of existing resources in the network services, including education, social services, and mobility (moving to services within the family itinerary).[21]

In this line, the importance of assessing the vulnerability of children, based on a theoretical study on the adverse situations for children's development is highlighted, addressing aspects such as the commitment of the governmental instances in the planning and execution of policies, the insertion of the family in the social sphere to offer access to their rights of citizenship, relations that support the family structure and protection of the child's health.[22]

For nursing, it is fundamental to know the concepts of vulnerability and the instruments to identify it in the population, meeting the individual and collective needs, through actions directed and adapted to the complexity of each case.[23] For this, training of links between the professional and the family enables to identify the needs of the families and, together, subsidize the possible solutions to the problem, reducing overloads and increasing access to health services from a family-centered perspective of care.[24]

FINAL CONSIDERATIONS

The results of this study show that children with multiple, complex and continuous care special needs and their families present social, individual and programmatic vulnerability. This vulnerability was strongly related to the dimensions that approach the conditions of access to work and income in the family and education conditions. This highlights the fact that when a family member needs to stop working to care for the child, income decreases, and family vulnerability increases.

It is also worth noting that most families did not receive home visits from the ESF team, revealing serious failures in the work of primary care professionals to families of children with multiple, complex and continuous care needs. For this and other reasons, even with limited financial resources, families considered it necessary to contract a private health insurance to ensure access to children's health services, reinforcing the programmatic vulnerability of families.

The fact that the study informants were located from an institution constitutes an important limitation, besides the low availability of family caregivers to participate in the research because the family routine is exhausting because of the clinical fragility of the child, and also because the IVFPR only identifies the social vulnerability of the family. However, the results obtained are relevant to the public health of the municipality and the country, since information on the needs of this specific group of children and their families is scarce.

It should be emphasized that the work of the multi-professional team within the scope of the ESF, with the active participation of the nurse for health education, speech-language pathology, physiotherapeutic, pedagogical and occupational therapy, could allow more development and independence of the child, especially in the early phase of the disease, increasing autonomy for self-care, as well as psychological support and social assistance to families, reducing their exposure to social vulnerabilities.

Also, it is understood that there must be an empathic, longitudinal and integral link between health professionals and these families. This should be marked by the professional recognition of the commitment made by the family caregiver in the daily exercise of care, by the supportive posture and by the continuous and horizontal contact with the devices offered by the health and cross-sectoral network.

Thus, the need for research to identify the living conditions of these children, their families and needs are reinforced to propose health interventions and also to subsidize the management of public policies that are congruent with the real needs of children and families. Also, it is considered important

to invest in the training of professionals qualified to work in primary care, who understand and carry out family-centered care.

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