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## Rede social de apoio a uma criança dependente de tecnologia

Social network support for a child dependent of technology

Red de apoyo social para un hijo a cargo de la tecnología

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### ABSTRACT

This is a case study with the aims of presenting the history of a child dependent on technology and identify the social network to support the development of the children dependent on technology. The collected data were described using flowcharts as genogram and eco-map. It was observed the difficulty and complexity of maintaining the quality of life with a child who needs full time care. There is a need for more studies on this subject since there is the need to improve the care provided to these children, which is possible only through studies and research on the topic.

**Descriptors:** Disabled children, Social support, Pediatric nursing.

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## RESUMO

Trata-se de um estudo de caso com objetivos de apresentar o histórico de uma criança dependente de tecnologia e identificar a rede social de apoio ao desenvolvimento dessa criança. Os dados coletados foram descritos por meio de fluxogramas na forma de genograma e ecomapa. Observou-se a dificuldade e complexidade da manutenção da vida com qualidade de uma criança que necessita de cuidados em tempo integral. Fazem-se necessários mais estudos sobre a temática uma vez que existe a necessidade de melhoria na assistência prestada a essas crianças, que só será possível por meio de estudos e pesquisas sobre o tema.

**Descritores:** Criança com deficiência, Apoio social, Enfermagem pediátrica.

## RESUMEN

Se trata de un estudio de caso con el objetivo de presentar la historia de un niño dependiente de tecnología e identificar la red social para apoyar el desarrollo del niño depende de la tecnología. Los datos recogidos se describen utilizando diagramas de flujo como genograma y eco-mapa. Se observó la dificultad y la complejidad de mantener la calidad de vida con un niño que necesita cuidado a tiempo completo. Hay una necesidad más estudios sobre este tema, ya que hay la necesidad de mejorar la atención a estos niños, que sólo es posible a través de estudios e investigaciones sobre el tema.

**Descritores:** Niños con discapacidad, Apoyo social, Enfermería pediátrica.

## INTRODUCTION

With technological innovations in Neonatal Intensive Care Units - NeoICU it is observed increased survival of newborns at high risk. However, often these children are conditioned to uninterrupted use of devices that monitor and assist their vital functions in addition to monitoring of health and social services. These children are known as children with special health needs (CRIANES), children of the technology, or Technology Dependent Children (TDC), term arised from the international literature Children with special healthcare needs - by relying on technological and/or pharmacological devices.<sup>1-2</sup>

The support network is a link between the family and the services working in cooperation forming a care support, taking into account the emotional and subjective aspects involved in the care. Social networks represent the relationships between family members, friends, neighbors, communities, institutions, helping to overcome conflict, receive, use and distribute resources and even allow family reintegration.<sup>3</sup>

For some years the TDCs were attended only in the hospital. However, technological advances have ensured discharge. Thus, the complex technical procedures that once were performed in the hospital, now begin to be run by family. Provide care to these TCDs has several repercussions. Families report feelings of exhaustion, stress, anxiety, reformulation of the domestic environment to comport technological artifacts, loneliness and social isolation.<sup>4-5</sup>

Faced with all the implications for these families to provide care to a TDC, it is important to identify the

network that provides support to the child and their families. Through studies of the support network it may be remarked the personal and institutional dimension of the resources that generate emotional, physical and instrumental benefits for the members of this network. This work is justified by the need for nursing and other health areas perfecting more and more the assistance provided to these children, this improvement is only possible through studies and research on the subject. The guarantee of a normal life for these children is due to the multi-monitoring associated with family support.

Faced with this situation arises the question: what are the components of the social network to support the development of the child dependent on technology. This research presented at the 6th National Symposium, 2012, Rio de Janeiro. Annals of the 6th National Symposium Health care in the interdisciplinary perspective, in 2012.

Before the context presented the object of study: the social network to support the development of technology dependent children. The objectives are: to present the history of a child dependent on technology and identify their social support network development.

## METHOD

This is a case study since the focus of the investigation, the Technology Dependent Child, is a complex and contemporary social phenomenon. The case study is an exploratory research strategy that enables the evaluation of a social unit through deep analysis and intense human situations from real life.<sup>6</sup>

The contact of the researcher with the main caregiver of the TDC took place in one of the units where the child is multidisciplinary care with various specialties. The framework and medical history of the child has peculiarities as extremely low birth weight and significant prematurity, the caretaker was invited to participate. As the service unit is located in another municipality, the data collection was carried out in the educational institution attended by children which is located in the municipality of the family's residence. This institution does not have the Research Ethics Committee; therefore it was sent a request to the responsible nursery presenting the study objectives, rationale, procedures used and the day's schedule proposal and time for the interview with the caretaker. The location of the data collection was chosen by the caregiver and previously scheduled by the same.

The project is developed according to the provisions of Resolution CNS 196/96<sup>5</sup> the National Health Council that meets the survey questions with humans. Knowing that all research offers some risk to participants it is understood that this research presented minimal risk to participants.

<sup>5</sup> At the time that the project was referred to the Committee on Ethics in Research this was still the current resolution.

The project was submitted to the Research Ethics Committee of the study promoter institution (Federal University of the State of Rio de Janeiro) for consideration and was accepted under nº 09188512.7.0000.5285.

The element content, the child dependent on technology, was chosen for its extreme prematurity and low birth weight, range of health services that demands the attention network and small nuclear family. The caretaker was invited to participate and was properly oriented on the object, objectives, risks, methods and steps thereof. It was offered the term of free and informed consent and explained about the anonymity of the participants, the benefits and no detriments of the work.

Data collection was conducted through open questions at interviews directed to the proposed objectives whose answers were recorded and then entered into a database by the interviewer. The questions were answered by the primary caregiver of this child since it does not present sufficient cognitive development still, showing no verbal or nonverbal interaction that allows answering the issues raised.

The collected data were described and analyzed by flow charts in the form of genogram and eco-map. In genogram were woven the information that is configured in the household. For the construction of the genogram is necessary to choose a person content, in this case it was elected the child dependent on technology.<sup>7</sup>

The results were collected from the child's genogram and ecomap. The ecomap traces the relationship between the family and the community is structured from the broader relationships, child's external network to meet their demands. It evaluates the support networks that are effective, indicating the degree of need for nursing investment; a family with few connections with the community needs major interventions of nursing.<sup>7</sup>

Data analysis occurred in light of the Calgary Assessment Model of families. The family assessment involves the structural aspects of the family. This analysis is done considering the individual, the family system and the context as a suprasystem.<sup>7</sup>

The primary caregiver is the center of the network and articulator of support possibilities for the child's needs. They are the facing point of bureaucracies and conflicts and who consequently wears out.

The genogram, through their symbols and codes illustrates the people and the relationships that are limited in the family network, or internal structure of the caregiver (person index). Marital relations show up by horizontal lines of connection linking parents. The man is right, woman left. It should be taken into account in internal structure of the family relational ties are strong, superficial, medium, interrupted or conflictual.<sup>7</sup>

The relationship established between the family and the various elements of social network, was represented by dark, light, dashed and sinuous lines, which respectively mean links: strong, weak, broken and conflictive. The arrows next to each

row represent the return flow between the caregiver and the network elements. The arrows levied to both sides indicate that there is a balance in the flow of forces, while the arrows relate only to one side signal of an unbalanced flow forces.<sup>7</sup>

## RESULTS

The Genogram of caregiving is placed in a circle and from there are drawn relationships with family and the wider system, the ecomap. The dashed line indicates the relational ties and the flow of exchanges between the caregiver and the universe that was created by the fact that she has a child dependent on technology due to prematurity.

### Presented the Genogram

#### The person index

The construction of the eco-map and genogram of a child born has been held on 29 April 2010. This child resulted from the thirteenth pregnancy. Prenatal consultations were not carried out. The birth was considered miscarriage because it occurred at four months and 28 days of gestation. There were no measures of head circumference, abdominal or thoracic and length. The weight at birth was 0,370 grams, that low birth weight and low gestational date have undertaken the development of this child. After delivery, the child was abandoned in the hospital trash and later found by employees of the cleaning service, who developed septicemia.

At birth, he was for nine months in the Neonatal Intensive Care Unit (NeoICU) of a public hospital in the city of Petropolis. During the stay in the NeoICU, he was fed by a gastric catheter pray. At three months of age he presented hemorrhages in the retina and developed retinopathy of prematurity, that is a vascular proliferative disease that affects the retina of the newborn. Although its etiology is multifactorial, the most important factor is the immaturity of the retina due to the prematurity of the baby.<sup>8</sup>

It was made use of Dapakene until the ninth month of life in order to control and prevent the seizures that were later identified as abstinence crisis to crack which the biological mother did use during pregnancy. Being considered seizures, the child was contained in bed which caused him bone deformities on the toes that compromise until today his motor skills. There was a delay in psychomotor development. After his discharge, he was routed under the city shelter.

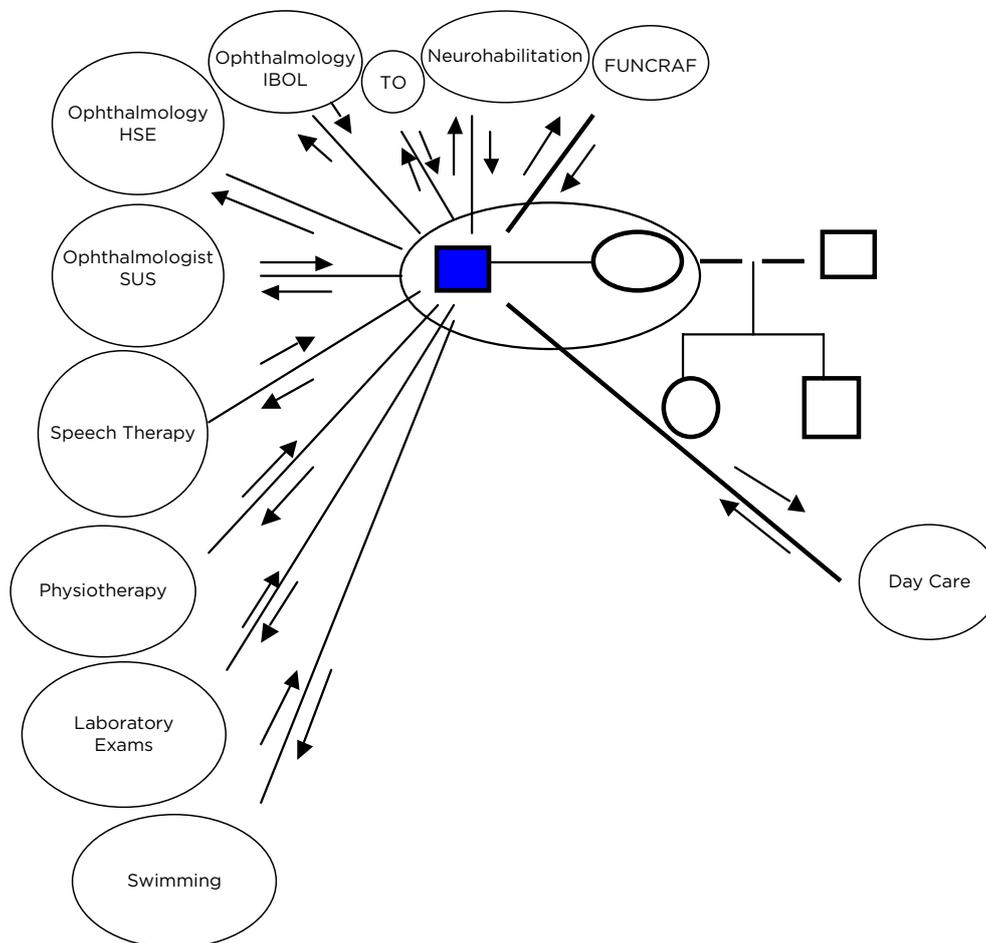
On the period of data collection, he was two years and seven months old and still ingested only pasty food for having difficulty swallowing solid foods as a result of a nine month feeding by oro gastric tube, the only milk that the child could drink was the Nestogeno 2.

The vaccination card was updated, two schemes have been carried out for Hepatitis B vaccine since at the hemogram it had not been observed antibodies to this virus after the first scheme. He presented reaction to BCG after

one year of application. He had candidiasis in pubic region with a year old. Patient was under misting several times a week because it had dyspnoea.

As for his development the child data collection revealed that he rolled with a year of life, sustained head at two, began to crawl at two years and seven months old, does not speak yet and presented dentition with a year old.

**Figure 1** - Genogram and ecomap, Prepared by the author, 2012



### The main caregiver

The main caregiver of the child, his adoptive mother, met the child because she works in the Health Department of their city. The judge ruled that this organ arrange medical specialties that the child demanded in a period of ten days. The foster mother then responsible for providing doctors ordered by the judge went to the orphanage where the child was found and asked the specific adoption hereof which was released within a week. She's 51 years old. Denies illicit drug use, as well as smoking and drinking. Has a family income of two minimum wages and denies receiving economic assistance for child care. However they have people close to, as neighbors and co-workers to care for the child. The person with whom she lives pays the health plan since the child cannot get the care which he needs at SUS. In the particular system, each session of physiotherapy and speech would come out to 70 reais and as often as he uses these services, which is three times a week, the health plan comes out less expensive than to pay for each session. The caretaker did not get the financial assistance by the INSS even if this benefit has been requested in court at the time of adoption. The mother

also has spending on private day care. The choice to take it out of municipal pubic nursery was made after learning that in the city nursery the child was put to sleep at lunch since it demanded too long to offer the meal.

Out of the 734 reais receiving salary, she separates 435 for rent. Living in the city of Petropolis in the state of Rio de Janeiro, she has two children from her first marriage; one of 21 and another of 25, both live in the city of Rio de Janeiro, but in separate houses. She lives with the child and another person. On weekends she goes to Rio de Janeiro and alternates between the homes of the two children. She is graduated and works in the administrative sector of the Petrópolis Health Department. This education favors the understanding of the information given to them. Their employment status, civil servant, also favors as she is dispensed at the times needed to take the child to the above health services.

### Introducing the ecomap

The companion to the caregiver pays 159 reais on health plan. The caretaker has two older children who attend higher

education and one of them is an academic in health, a fact that facilitates his understanding even of some pathologies.

The treatment for neurohabilitation is performed in the Sarah net, a federal institution, located in the west of the city of Rio de Janeiro. The medical institution found that the child has a cyst composed of liquor on the left side of the cerebellum and that it does not have the right brain mass. The neurologists can not yet explain the psychomotor development of children due to the involvement of these structures.

The mother sought the ophthalmology service in public institutions, but was not successful. The hospital in Rio de Janeiro that has retinopathy of prematurity experts, the Hospital of the State Server, has provided treatment to the child. For this reason the child is accompanied by the Brazilian Institute of Ophthalmology, a private institution with a cost of 500 reais per consultation. The caregiver did not get any assistance by SUS. Currently, consultations are every six months, but in the first months, they were every two.

The patient performs three times a week physiotherapy, occupational therapy three times a week, speech three times a week and once a month laboratory tests for constant anemia and consults the pediatrician two to three times a month. Swimming once a week.

He was on the Foundation for the Study and Treatment of Craniofacial Deformities - FUNCRAF in Mato Grosso do Sul for a consultation with an otorhinolaryngologist which indicated the cochlear implant but could not make this procedure to be carried out by SUS because there were no 100% guarantees of correction of hearing loss of the child.

The vaccines are administered in the epidemiology sector of Hospital Nelson Faearp, a municipal institution in the city of Petropolis. In addition to basic vaccines listed in the National Plan of the Ministry of Health of immunization, the child makes use of different vaccines that are available only in Immunobiology Special Reference Centers - CRIES. The caregiver had to go to another city to conduct a special scheme of hepatitis B in CRIES.

## DISCUSSION

A premature newborn or preterm is one born before 35 weeks gestational age. This child is more vulnerable to compromises in the development in areas such as learning, attention, behavior, interpersonal relationships, in addition to cognitive, motor and visual deficit by the immaturity of the neural system. For this reason, it is considered a high risk newborn. The low weight and gestational age are closely related to neonatal mortality, being greater the risk of morbidity when these factors are lower, being the extrauterine adaptation explicitly committed by the immaturity of the organs.<sup>9,10</sup>

There has not been observed in the literature a significant change of neurological problems especially in premature at 25 weeks or less. However, a multi-professional assistance to a normal life is necessary. As even premature without serious consequences need amparas interventions by families, it is

relevant to stimulate therapeutic and preventive treatment of psychomotor, cognitive, visual and social diseases.<sup>10-11-12</sup>

The family of TDCs undergo many changes. In the emotional sphere, there has been a physical and emotional burden. In the social sphere, a social isolation of the family is observed. And in the financial sphere support for raising funds is not guaranteed by the public health system.

It is observed an active search of the mother to broaden and solidify the support network. This search community support, the involvement of other family members as well as interactions with society through health institutions. This support is not always assured. Yet she performs self-care and needs to take care of others, that, in parts, depends on her own well-being. The task becomes even more difficult when the other depends upon it that their most basic rights are ensured.

There has been a wide network but with decentralized resources where support can be seen through the links and interactions with people who receive material support, affective, emotional and practical.

It is observed preferably female dedication reported in several studies. In seeking to be the main element that ensures the physical and emotional care of the child this limits their social network interaction with others that surround it. Thus renounces leisure activities and roles that fit her before.

This woman understands the importance of professional resource and seeks assistance not only in the institutions but also the professionals who compose it. Some professionals were highlighted by the hand but nursing was not mentioned at any time during the interview. Nursing is fundamental in the process of family adaptation to the new reality: receiving a child dependent on technology. It plays an interventionist role and ensures front support to the new reality installed. In this way, owns a great responsibility in this scenario nursing, family and also the support network.

It is believed that the knowledge of the social network of this group can contribute to improving the quality of life and the expansion of care. It can also highlight the religious and spiritual support as a way to support network as socio-cultural dimensions to give meaning to life processes and death.<sup>3-4</sup>

Combined with family and nursing, SUS' comprehensiveness principle is to complement the assistance provided to the TDCs. Through the search for a greater awareness for the needs of this group and looking for the best way to answer this need. Not only the most urgent needs of timely care and relief of suffering but also information and interventions that minimize problems to come.

## CONCLUSION

Through assessment tools of the support network of a TDC, it was noted the difficulty and complexity of maintaining the quality of life of a child who needs full-time care. In contrast to the relevant integral principle of SUS, access and availability to essential services for that child's life are scarce and flawed at times; but they are offset so far by an effectively support network that provides support to caregivers. There is a need of more studies on the subject as there is the need for nursing and other health areas increasingly to perfect the care provided to these children, this improvement is only possible through studies and research on the subject.

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