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# Technology-dependent children: the maternal care experience

CRIANÇA DEPENDENTE DE TECNOLOGIA: A EXPERIÊNCIA DO CUIDADO MATERNO

NIÑOS ADICTOS A LA TECNOLOGÍA: LA EXPERIENCIA DEL CUIDADO MATERNO

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## ABSTRACT

The objective of this study is to understand the maternal experience of caring for a technology-dependent child. We used the ethnographic case study approach, as well as the genogram, ecomap, open interview and observation methods as data collection instruments. The data were organized into three meaning units: the search for causes and culprits; hospital discharge and the demand for care; and the support networks. The study allowed for an understanding of the mother's experience of searching for explanations, as well as feelings of distrust, insecurity and dissatisfaction towards the health service provided. In addition, the mother's organization regarding the child's care and in terms of readying the home environment to receive the child, the use of support networks, and particularly the need for attachment with family and neighbors and the formal and informal search to assure the subsistence of her ill child as well as her other children were explored.

## DESCRIPTORS

Child  
Chronic disease  
Family  
Pediatric nursing  
Nursing care

## RESUMO

Este estudo tem como objetivo compreender a experiência materna no cuidado ao filho dependente de tecnologia. Utilizamos a abordagem do estudo de caso etnográfico tendo como instrumentos de coleta de dados os genograma e ecomapa, entrevista aberta e observação. Os dados foram organizados em três unidades de significado: a busca pelas causas e por culpados; a alta hospitalar e as demandas para o cuidado e as redes de apoio. O estudo permitiu conhecer a experiência materna em busca por explicações, bem como os sentimentos de desconfiança, insegurança e insatisfação relacionados ao serviço de saúde. Ainda a apropriação da mãe em relação aos cuidados à criança e no que se refere à organização do ambiente domiciliar para recebê-la, a utilização das redes de apoio, destacando a carência de vínculos com familiares e vizinhos e a busca formal e informal para garantir a subsistência da criança doente e dos demais filhos.

## DESCRIPTORES

Criança  
Doença crônica  
Família  
Enfermagem pediátrica  
Cuidados de enfermagem

## RESUMEN

Se objetiva comprender la experiencia materna de cuidado al hijo adicto a la tecnología. Utilizamos el abordaje de estudio de caso etnográfico, utilizando como instrumento de colecta de datos el genograma y el ecomapa, entrevista abierta y observación. Datos organizados en tres unidades de significación: búsqueda de causas y culpables; alta hospitalaria, y solicitudes de atención y redes de apoyo. El estudio permitió conocer la experiencia materna en búsqueda de explicaciones, así como los sentimientos de desconfianza, inseguridad e insatisfacción relacionados al servicio de salud. También la apropiación maternal relativa al cuidado del niño y en lo referente a la organización del ambiente domiciliario para recibirlo, la utilización de redes de apoyo, destacando la carencia de vínculos con familiares y vecinos y la búsqueda formal e informal para garantizar la subsistencia del niño enfermo y de los demás hijos.

## DESCRIPTORES

Niño  
Enfermedad crónica  
Familia  
Enfermería pediátrica  
Cuidados de enfermería

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## INTRODUCTION

As a result of advances in public policies and medical practices in care delivery to preterm children, children with congenital anomalies and chronic illnesses, a group of children emerged who need technological support to maintain their lives<sup>(1)</sup>. The members of this group are known as children with special health needs (CRIANES)<sup>(2)</sup> in Brazil and children with special healthcare needs<sup>(3)</sup> in international literature.

CRIANES are children who need individual and personalized care, of weak health and who need monitoring from health and social services that goes beyond what a healthy child needs<sup>(2-4)</sup>. These children's problems can be physical, developmental and behavioral, sometimes needing more sophisticated technologies to guarantee their survival. In these cases, the children are technology-dependent. The devices they can depend on range from high-tech items, like a mechanical ventilator, to low-tech items, like a colostomy for example.

Technological advances have imprinted transformations on care delivery to these children, which used to be attended and kept in the hospital environment, and now stay at home under their relatives' care, who perform technologically complex procedures<sup>(1)</sup>. Care delivery to a technology-dependent child entails different repercussions, which permeate the emotional, social and financial dimensions<sup>(1-7)</sup>.

Studies emphasize the feelings of exhaustion, stress and anxiety the parents report. They mention that the home environment needs to be reorganized due to the presence of equipment and support equipment. They report a feeling of solitude in view of a totally new reality, including new knowledge and new practices that need to be incorporated into their daily lives, as well as the access to services beyond health institutions, guaranteed by the child's civil rights<sup>(1,5)</sup>.

What motivates the development of this study is the need to understand how this process takes place, focusing on the maternal experience and articulating it with the experience of their child's illness, given that, after the hospital discharge, this mother goes through the reality of taking care of a *new child*, who demands care that differs from common-sense learning.

Based on these considerations, our theoretical option was to address the disease experience, which is how individuals position themselves and put themselves in the patient's place, attributing meanings and finding routine ways to deal with the distinct situations of the health-disease process and care<sup>(8)</sup>. This experience is so-

cially constructed, based and shared in the community the individual is inserted in<sup>(9)</sup>. The disease experience has been an important theme in socio-anthropological health studies, as it departs from the perspective that the health-disease process and care are a culturally determined phenomenon and that the disease experience is not a simple reflection of the pathological process, but an experience in which an individual or a group's values and expectations are expressed in the way they think or act towards the disease<sup>(8)</sup>.

The approach of the disease experiences permits recognizing important dimensions of the affliction and treatment, so as to gain further understanding of the disease phenomenon<sup>(8)</sup> and, consequently, enhance communication between health professionals and patients, positively influencing the quality of care.

Based on the above, the aim in this paper was to understand the maternal experience in care delivery to technology-dependent children, against the background of the disease experience.

... the disease experience is not a simple reflection of the pathological process, but an experience in which an individual or a group's values and expectations are expressed in the way they think or act towards the disease.

## METHOD

An ethnographic case study was accomplished<sup>(10)</sup>. The aim of this method is to study the phenomenon as a whole, allowing researchers to share experiences of the social world under analysis and, consequently, to get access to the meanings attributed and to the subjects' experience of the health-disease process<sup>(11)</sup>.

Considering the case study as a specific unit that consists of mutually integrated parts, in this research, participants were the mother of a technology-dependent child and two health professionals: the nurse and the Community Health Agent (CHA) from the Primary Health Care Unit (PHCU).

As the research involved human beings, the study was submitted to the Research Ethics Committee, in compliance with Resolution 196/96, issued by the National Health Council's National Research Ethics Commission, and received approval on September 10<sup>th</sup> 2009 under protocol number 405/2010. It is highlighted that, to preserve the study participants' identity, their names were not identified, using the terms mother, nurse and Community Health Agent in the quotes. In compliance with the orientations in the Informed Consent Term, authorization was requested to record the interviews.

This study was developed in an interior city in São Paulo State. The inclusion criteria were: being a mother or responsible caregiver for a child who depends on at least one technological device and being over 18 years of age. For the professionals, the criterion was to work in the cov-

erage area of the selected family and to have a bond with the child and family.

The choice of the case was intentional<sup>(12)</sup>. This option is justified by the fact that this mother was included when we witnessed the following situation: at an Emergency Care Unit where we were involved in teaching activities, we were present during a discussion between the nurse and the pediatrician, during which they debated on who was responsible for reintroducing a gastrostomy tube. At that moment, we got to know the child who participated in the study, who had not received food and water for more than six hours. We observed that the mother was manifesting signs of concern with the situation her child was going through and witnessed the health professionals' discussion.

After the situation had been solved, we approached this mother and invited her to participate in the study. We explained the purpose of the study and gave her the informed consent term. After selecting the case, we contacted the Primary Health Care Unit (PHCU) responsible for this family and held an approximately two-hour meeting with the nurse and the Community Health Agent (CHA), so as to get familiar with the study situation.

To produce the empirical material, we used the file to characterize the technology-dependent child based on the following indicators: gender, age, medical diagnosis, type of technological dependence, duration of the dependence, number of technological devices and services where the child is monitored. After establishing the characteristics, we started the second phase, in which we approached the ethnographic method to produce the empirical material about the experience of care delivery to the technology-dependent child. This phase involved four home visits, held in accordance with the mother's availability.

In line with the ethnographic research approach, the phenomenon needs to be investigated in the place where it occurs, as it is important for the researcher to get involved with the daily life of the group that will be studied, so as to be able to apprehend the meanings and the symbolic universe of the subjects involved<sup>(13)</sup>. Therefore, we selected the home environment, where interpersonal, social, educational and cultural relations take place between the mother and the members of her family.

The first home visit was aimed at recognizing the environment and scheduling the next meeting. We started the second meeting with the construction of the family's genogram and ecomap, as the use of this family nursing instrument played an important role as an initial *ice-breaker*. These instruments not only provide a graphic representation, but permit further approximation, knowledge and immersion in the field, as their elaboration demands social interaction between the researcher and the research subject.

During the second meeting, we also held the first in-

terview, based on the following guiding question: Tell me about your experience in care delivery for your technology-dependent child. The third and fourth home visit served to monitor specific care situations for the technology-dependent child, at different times, as well as to return to some situations that were not clear during the previous meetings.

To collect the data, participant observation and open interviews were used synchronically, as this is only possible for people sharing the same experiences<sup>(13)</sup>. Thus, the researcher took part in the observed reality and, thus, looked at the other person's perspective.

Concerning observation, we attempted to focus on the housing conditions (hygiene and cleaning, electrical network, sewage network, arrangement of the materials and technological devices), the relations among family members and how care was delivered to the child, including the handling of technological devices.

Data analysis started with the orientation of the empirical material into *narrative dossiers*<sup>(14)</sup>, containing the identification, fully transcribed interviews, observation records and patient file information. In compliance with the requirements of interpretative analysis, the narrative files were subject to exhaustive reading and, next, the data were systemized, so as to seek for common words, phrases and behaviors and possible differences, which constituted the units of meaning. Thus, the data were organized into three units of meaning: The search for the causes and people to blame; hospital discharge and care demands and support networks.

## RESULTS

To understand the essence of the data, initially, we describe the context involving the child and his family.

Case presentation: child, called Joãozinho, male, born in June 2005, lives with his 37-year-old mother and his two 13 and 15-year-old siblings. The mother says she has attended school until the fourth year of primary education and her children are taking the sixth and ninth year of primary education, respectively. The older siblings were conceived in the mother's first marriage, while Joãozinho was born from an unstable relationship. According to his mother, the father lives in another city and does not know him. After Joãozinho's birth, she had other relationships but, at the time of data collection, she was single. The three-room brick house is located in an unpaved alley, connected to the electricity and sewage networks, and is clean and organized. The child was born full-term, through a c-section, without problems and, until nine months of age, his development was adequate according to the information in his file, without any disease. The current diagnosis refers to unspecified encephalopathy of unclear cause. The PHCU professionals relate the condition to a

trauma, i.e. a fall from the stroller while the child was under the sister's care (10 years old at the time). The mother, however, indicates that her son's current conditions developed after being vaccinated against yellow fever. According to her, six days after the vaccine had been applied, the child manifested convulsive crisis and fever and was taken to the primary health care unit in the district primary health unit (UBDS), where he remained under continuous monitoring until he was transferred to the Intensive Care Unit of a tertiary hospital. At that service, the child presented cardiorespiratory arrest and demanded orotracheal intubation and mechanical ventilation. The child stayed at the Intensive Care Unit for two months and 15 days, when he was forwarded to the ward with a neurological impairment. He was discharged with a mic-key gastrostomy feeding tube for diet and medication infusion and a metallic tracheotomy cannula. The procedures the mother performs include bodily hygiene, enteral diet preparation and infusion, upper airway aspiration and tracheostomy, medication preparation and administration, including anticonvulsants, bronchodilators, corticoids and vitamin supplements. The child is monitored at a tertiary hospital in gastroenterology, neurology and pulmonology; attends childcare at the PHCU and also participates in physiotherapy and speech, language and hearing monitoring at the Association of Parents and Friends of Exceptional People - APAE. Rehospitalizations are frequent when the respiratory condition worsens and, according to the mother, he is hospitalized approximately three times per year.

### ***The units of meaning***

#### *The search for the causes and people to blame*

During the first meeting, Joãozinho's mother already described her trajectory in detail, from the conception of her son over pregnancy care, the birth process, until the arrival of her healthy son at home. Reminding this experience made her get emotional and return to her inquiries about the causes of the child's illness.

As mentioned, the etiology of the child's encephalopathy is questioned in the patient's file. The mother did manifest doubt when she discussed the possible causes. In that sense, she says:

... now I don't know if it's... some say it comes from the vaccine, others that it's because of the fall... (mother).

Although unsure of what really happened, the mother insists in finding someone to blame:

... I think that his diabetes was high and then he got this vaccine [yellow fever] and he became a special child" (mother), soon afterwards she reports: "My girl, when she saw the probe up his nose..., but she cried, cried. My husband said: It's your fault that Joãozinho got like that. But she, she knows... it's no use to try and get around something, when it was because of her, she know... but she cries, cries (mother).

In view of the possibility of some relation between the application of the vaccine and the child's illness, the relationship between the PHCU health team and the mother is troubled. Her testimony reveals the mistrust that holds out towards the institution:

I don't trust those people anymore... because they applied the vaccine to my son... after what happened to my son I don't trust anyone, nobody touches him, nobody... Then his head got the way it did, traumatized (mother).

During our meeting with the nurse and the Community Health Agent, they reported that the mother is confused and manipulative, that she is constantly trying to get benefits from her son's situation. According to them, several times, she even attacked the nursing auxiliary who administered the vaccine verbally.

The Community Health Agent intermediated the first visit to the home of the child's mother and, on our way to the home, confessed that, *...you can't do anything about that house... why go there?* (CHA).

When asked about the PHCU, the mother reports:

Over there [primary care unit], it's just to pick up medication, he doesn't go there... to tell you the truth, nobody came to visit, help, advise anything, even the people there from the hospital [professionals] charge me, asking if the people from the unit don't come to visit, to monitor... it's me and God and when he's bad I rush to the Cuiabá with him [district primary health unit]... the doctors over there already know his procedures, what needs to be done with him (mother).

The above testimony expresses the conflict between the health service and the mother. Besides medication, the service is also responsible for delivering materials like probes, gauze, saline solution and equipment. Although the mother affirms that she is not attended at the PHCU, the file registers various medical consultations for growth and development monitoring, besides different contacts with the hospital to obtain information about the child.

The nurse confirms that the Community Health Agents makes monthly home visits and that, at the time of the child's discharge from hospital, the nursing team made various visits, but they did not witness the execution of any technique/care, as the mother said she had already learned everything from the hospital nurse. According to the nurse, the nursing team observed that the mother did not want to demonstrate how she performed the procedures.

This conflict is one of the most delicate points in this relation, as different dimensions are interacting. We observed that this situation makes it impossible for the primary health care level to monitor this child, depriving the family from closer care and the creation of bonding with professionals in the primary network.

According to the nurse, this conflicting relation also happens with the hospital professionals, as exemplified next:

*When this mother is in hospital, she complains about the unit and, when she's at the unit, she talks negatively about the hospital (nurse).*

The same professional mentions that inter-institutional meetings have been held, involving the hospital, the guardianship council and the PHCU in the attempt to ... *untie these knots...* (nurse) and reach a similar care proposal among the services.

#### *Hospital discharge and care demands*

According to the data obtained in the file and the mother's report, the child stayed in hospital for approximately six months, i.e.

... two months and a half at the ICU and three months in pediatrics... (mother)

until he finally presented clinical improvement to be discharged from hospital. The mother's testimonies reveal the process experienced until her son arrived:

... it was a big controversy [referring to the hospital discharge]... pictures were taken to arrange his retirement... they arranged a bus ticket for me to arrange the documents, because my son did not have an identity card, no fiscal registration number (mother).

Besides gaining a benefit, other demands had to be guaranteed; among these, we underline the mother's appropriation of the child's care and also regarding the organization of the home environment to receive him.

Concerning the environment, we observed that, although small, the house is organized to attend to the technology-dependent child's needs. During the visit, we identified various pieces of equipment distributed across the house, including the hospital bed with an eggshell mattress, IV stand, inhaler, adapted child stroller, a cupboard full of aspiration probes, equipment, gauze, saline solution and medication.

According to this mother, the learning process for care was considered despairing, as she emphasized herself:

... then he took out the nasal probe, my heart started to speed up and I felt bad. My aunt said: 'don't lose hope, no, it's really like that'. I couldn't conform to that (mother).

João's mother got support from the hospital nurses to learn how to perform the procedures and confesses that, initially, she was very scared but that, over time, she adapted:

Fear of moving... I didn't have self-confidence to take care of him. Then, afterwards, over time, I gained experience, trust and adapted, little by little I adapted... Then I started to adapt, it went very well, no more twists occurred (mother).

The appropriation of the child's care shows to be closely related with the child's clinical conditions which,

according to the mother, in 2008, the child was re-hospitalized several times due to pneumonia. In this sense, she says:

... it has been more than two months since he last went to hospital... he's not getting ill, so it has been good for him... (mother).

In the family under analysis, changes in routines also took place as the mother became the full-time caregiver; the environment was adapted to receive the equipment and material needed for care; the financial difficulties emerged and the older children started to help with their brother's care.

Being a caregiver to a technology-dependent child demands energy and willingness. In the case of João's mother, she is directly involved in her son's care, whether in the accomplishment of hygiene care, food, like in the aspiration of secretions and medication administration. She is also responsible for domestic activities like washing clothes and keeping the environment clean or taking her son to the medical appointments or physiotherapy or speech, language and hearing therapy at least thrice a week.

The disease and care go beyond the sphere of the sick person and the individual, affecting the entire family, mainly the primary caregiver. Thus, with so many tasks, the mother reveals that she can't even get ill. She mentions:

... I cannot get ill, God help me ... I have to take care of my fatty, my little ball ... I got the flu, then I got a mask there at the unit and put it on so as not to cough on him, put saline solution in his nose and suddenly the flu went away (mother).

#### *The support networks*

The construction of the ecomap provided knowledge about the institutional network involved in care delivery to this child, as well as the support network of relatives and friends. In view of the graphic representations these instruments offer, we identified the different forms of social equipment that are considered as support; among these, the strong bond with the tertiary hospital and the secondary health service stand out, to the detriment of the PHCU, as mentioned earlier.

Among the benefits she receives, the mother listed the *Bolsa Família* (Family Support Grant), the Brazilian Social Security Institute – INSS pension, diapers and drugs she obtained due to the court case, free transportation for the child for medical monitoring and, in addition, political support from a city councilor who provides food and construction material to reform her house.

The information the PHCU health team provides are in accordance with the mother's report. They declared that she gets help from third parties to be able to support her family, as the mother confirms, telling that, whenever nec-

essay, she puts in action an influential politician in the city:

He [the city councilor] came here, he has given me vegetables, he's already given food packs and everything, when I've got no diapers they get them for me (mother).

Even a television program has gone to her house:

The social service of the wheelchair users wrote a letter to D.'s show and I didn't even know, but they surprised us, so unexpectedly. Then, there was a person who was there in her show who got touched by the case and donated the prostheses and she gave, I think 100 reais, I had no things at home and I went and bought them, I bought him milk, vegetables, meat, everything to make his food (mother).

Concerning family support, distancing is perceived between this nuclear family and relatives. Joãozinho's mother told us that they also have a lot of difficulties and their own problems, as reported next:

... my family, they don't help me with anything, I deal with my own difficulties, I put up my struggle with life... My sister doesn't help me at all, poor thing, she can't either (mother).

As for the child's father, he doesn't know him personally and does not offer any kind of financial help; the child was conceived in an unstable relationship. Relations with the neighbors are quite conflicting. According to the mother, they think that she does not take good care of her children and have already filed a complaint against her before the Guardianship Council, which is why she does not have any contact whatsoever with the neighborhood.

The primary reference for the patient, in this case for the family of the technology-dependent child, is the family and close friends. In Joãozinho's family, however, these relations seem to be fragile. Therefore, professionals' intervention is important to drive the development of the natural network's potentials and to seek support networks in the community.

## DISCUSSION

The disease experience is part of a person's existential movement and, therefore, takes place continuously, connecting us with a past and also remitting to a future, to a project<sup>(8)</sup>. In this perspective, reporting on the maternal experience in care delivery to technology-dependent children permitted identifying how the mother assumes her son's illness, what meanings she attributes to it and how she deals with the situation as part of her routine.

When she remembers her child's disease process, the mother returns to aspects related to the cause of the disease and the search for people to blame. In popular segments, the notion of causality is pluralistic though, and is united in the explanations that include natural, socioeconomic, psychosocial and supernatural aspects, representing distinct but linked, exchanging and non-contradictory

domains. Thus, the causal picture Joãozinho's mother develops includes behavioral, biological and relational factors, reaffirming the idea of an integrative plurality, translated into a unified discourse<sup>(15)</sup>.

The conflicting relation established between the mother and the community health service and the bond with specialized services are in line with a study about the disease experience in families of children with cystic fibrosis<sup>(16)</sup>, reinforcing and highlighting a pragmatic weakness of the system, which remains centered on care delivery to acute conditions, forwarding chronic conditions to the technologically more complex service and hampering bonding and trust with chronic patients and their family members.

The professionals involved in care delivery to this technology-dependent child, however, went beyond administrative requirements, as exemplified by meetings between the community health team, the specialized service team and the guardianship council. From a holistic care perspective, forwarding for care at other health system levels is insufficient to guarantee complementary and continuous care. Health professionals need to assume the commitment to establish communication that guarantees and monitors care, completing the gaps in care delivery and articulating the different levels<sup>(17)</sup>.

The findings reaffirm that transferring a technology-dependent child from hospital to the home environment represents a great challenge, to the extent that these children and their relatives go through complex medical, social and affective problems, which cannot be managed by a sole care unit<sup>(5)</sup>. In this sense, discharge planning together with the family and home visits for monitoring represent an important support source, involving information, individualized care and permanent monitoring, minimizing feelings of anxiety and fear<sup>(18)</sup>.

Despite a significant change in family dynamics, the nursing orientations provided throughout the hospitalization period and upon discharge were essential to construct this mother's autonomy for care delivery to her child, facilitating care continuity at home. In this context, nursing orientations represent an educative process inherent in nursing care, through dialogue, demonstration and permanent teaching, contributing to skills and knowledge development in home caregivers<sup>(19)</sup>.

The knowledge the disease experience provides, in addition to the family's values, beliefs and customs, support the attribution of meanings to the care form. The search for the formal health care sector, however, enhances the renewed assertion and inclusion of new care forms, valuing the biological aspects of the disease. Thus, the care structure is determined by the family's sociocultural context, with influence from the biological dimension.

When they take care of their children at home, the parents end up assuming the responsibility for performing

highly technical procedures, which formally only qualified professionals should perform, arousing feelings of exhaustion, stress and anxiety. In this sense, sleep is frequently interrupted and the parents experience difficulties to relax, considering that, in most cases, other family members or friends do not have the training needed to perform this complex care<sup>(1,5,7)</sup>. Recent studies reveal that frequent hospitalizations and the time spent to take care of a technology-dependent child at home entail important changes in the family dynamics, besides the family members' physical and emotional burden, especially the mother's<sup>(1-7)</sup>.

Family systems' sociocultural structure organize life; hence, the identification, integration and trust established between the family and its social context permit the construction and development of bonds and a solidarity network<sup>(6)</sup>. In the case under analysis, however, we observe a strong feeling of not belonging to the community, in the form of feelings of mistrust and insecurity towards neighbors and the health service.

The family is defined as people you can count on at times of difficulty and in disease situations, constituting a primary support source<sup>(6)</sup>. In this perspective, the lack of bonds, whether due to geographic distance or absence of affection, leads to an important lack of social support, making this family weaker in view of the disease experience.

The enormous efforts made to see to the children's demands and guarantee the other children's survival was also reported in a study about the social vulnerability of children with special healthcare needs<sup>(7)</sup>. Although disabled people are entitled to a continuous benefit of one Brazilian minimum wage, this resource only covers costs related to food, transportation and other elements necessary for the child's treatment. The large majority of the families, however, gain a family income that borders on or stays below the poverty line, exposing these children to greater social vulnerability.

Thus, the disease represents a problem situation, which affects the lives and demands restructuring and mobilization from the stakeholders, in search of new practices to deal with and explain the problem. Therefore, discourse related to the disease is marked by contradictions and imprecisions, reflecting the set of experiences they constructed and have been constructing, turning the disease experience into a fluid and gradual event<sup>(8)</sup>.

## REFERENCES

1. Kirk S, Glendinning C, Callery P. Parent or nurse? The experience of being the parent of a technology – dependent child. *J Adv Nurs*. 2005;51(5):456-64.
2. Wong D. *Enfermagem pediátrica: elementos essenciais à intervenção efetiva*. Rio de Janeiro: Guanabara Koogan; 1999.
3. McPherson MG, Arango P, Fox H, Lauver C, McManus M, Newachek PW, et al. A new definition of children with special health care needs. *Pediatrics*. 1998; 102(1):137-41
4. Cabral IE, Silva JJ, Zillmann DO, Moraes JRMM, Rodrigues EC. A criança egressa da terapia intensiva pediátrica na luta pela sobrevivência. *Rev Bras Enferm*. 2004;57(1):35-9.

## CONCLUSION

The maternal experience in care delivery to technology-dependent children is marked by the search for explanations for the causes of the child's illness, as well as feelings of mistrust, insecurity and dissatisfaction with the health service. Hospital discharge was conceived as a landmark in the mother's experience, involving the mother's appropriation of the child's care and the organization of the home environment to receive him. Knowledge resulting from her experience also directed the use of the support networks to take care of her child. To support the resources needed to continue treatment at home, as well as to guarantee their children's survival, they link up with formal care programs and turn to help from influential people in the city, picturing a situation of social vulnerability.

The use of the disease experience approach permitted going beyond the limits of the biomedical model and constructing a health-disease and care model in which we recover the meanings attributed to the experience of being a mother to a technology-dependent child. This, in turn, makes it possible to plan individual care in a closer and empathetic way, including greater possibilities to guarantee holistic, continuous and longitudinal care delivery to these children and their families.

Nursing plays a fundamental role in care delivery to technology-dependent children and their families and is committed to support them in the transition process to their home and further monitoring. We know that nursing care delivery to children and their families has been undergoing important modifications over time; we still need to advance in search of integral care though, based on co-operation and co-accountability.

As this is a case study, in which we explored the experience of a mother with a technology-dependent child, the impossibility to generalize results represents a limiting factor. The results can serve as support to devise the care process for children with special healthcare needs and their families. To achieve changes in public policies and in the work process of teams who deal with these children every day, further research is needed, which will help to construct articulated work among the different sectors involved in care.



5. Fracolli RA, Angelo MA. Experiência da família que possui uma criança dependente de tecnologia. *REME Rev Min Enferm.* 2006;10(2):125-31.
6. Silveira AO. Definindo o projeto de vida familiar: a família na transição para o cuidado domiciliar da criança com necessidades especiais [tese doutorado]. São Paulo: Escola de Enfermagem, Universidade de São Paulo; 2010.
7. Neves ET, Cabral IE. A fragilidade clínica e a vulnerabilidade social das crianças com necessidades especiais de saúde. *Rev Gaúcha Enferm.* 2008;29(2):182-90.
8. Rabelo MCM, Alves PC, Souza I. Experiência de doença e narrativa. Rio de Janeiro: FIOCRUZ; 1999.
9. Canesqui AM. Olhares socioantropológicos sobre os adoecidos crônicos. São Paulo: Hucitec; 2007.
10. Stake RE. The art of case study research. Thousand Oaks: Sage; 1995.
11. Cohn C. Antropologia da criança. Rio de Janeiro: Jorge Zahar; 2005.
12. Moreira H, Caleffe LG. Metodologia de pesquisa para o professor pesquisador. São Paulo: DP&A; 2006.
13. Geertz C. A interpretação das culturas. Rio de Janeiro: Guanabara Koogan; 1989.
14. Vila VSC, Rossi LA, Costa MCS. Experiência da doença cardíaca entre adultos submetidos à revascularização do miocárdio. *Rev Saúde Pública.* 2008;42(4):750-6.
15. Caroso C, Rodrigues N, Almeida-Filho N. "Nem tudo na vida tem explicação": exploração sobre causas de doenças e seus significados. In Leibing A. *Tecnologias do corpo: uma antropologia das medicinas no Brasil.* Rio de Janeiro: Nau; 2004. p. 145-73.
16. Pizzignacco TMP, Melo DF, Lima RAG. Estigma e fibrose cística. *Rev Latino Am Enferm.* 2010;18(1):139-42.
17. Silva RVGO, Ramos FRS. Processo de alta hospitalar da criança: percepções de enfermeiros acerca dos limites e das potencialidades de sua prática para a atenção integral. *Texto Contexto Enferm.* 2011;20(2):247-54.
18. Pinto JP, Ribeiro CA, Pettengill MAM. O processo de recuperação da criança após a alta hospitalar: revisão integrativa. *Acta Paul Enferm.* 2010;23(6):837-42.
19. Klassmann J, Kochia KRA, Furukawa TS, Higarashi IH, Marcon SS. Experiência de mães de crianças com leucemia: sentimentos acerca do cuidado domiciliar. *Rev Esc Enferm USP.* 2008;42(2):321-30.