

Technology-dependent children and the demand for pharmaceutical care

Criança dependente de tecnologia e a demanda de cuidado medicamentoso

Niño dependiente de la tecnología y la demanda de atención médica

**Aline Cristiane Cavicchioli Okido^I, Suelen Teles da Cunha^{II}, Eliane Tatsch Neves^{III},
Giselle Dupas^{IV}, Regina Aparecida Garcia de Lima^I**

^I Universidade de São Paulo, Ribeirão Preto College of Nursing, Department of Maternal and Child Nursing and Public Health. Ribeirão Preto, São Paulo, Brazil.

^{II} Hospital Sírio-Libanês, Residency in Surgery. São Paulo, Brazil.

^{III} Federal Universidade de Santa Maria, Center for Health Sciences, Nursing Department. Santa Maria, Rio Grande do Sul, Brazil.

^{IV} Universidade Federal de São Carlos, Center of Biological and Health Sciences, Nursing Department. São Carlos, São Paulo, Brazil.

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ABSTRACT

Objective: to understand the experience of mothers of technology-dependent children as regards pharmaceutical care. **Method:** this was a qualitative, descriptive-exploratory study developed based on open interviews using a structured characterization tool, and applied during home visits to 12 mothers caring for technology-dependent children. The data was submitted to inductive content analysis. **Results:** this study is split into two themes: (i) maternal overload during pharmaceutical care, demonstrating the need to administer drugs continuously and the repercussions of this exhaustive care on the caregivers; (ii) the ease or difficulty of access to the medicines required, showing informal strategies and support networks. **Conclusion:** pharmaceutical care is a daily challenge expressed in maternal overload and difficulty accessing the drugs, made worse by failures in the care network and coordinated care. **Descriptors:** Pediatric Nursing; Caregivers; Child; Chronic Disease; Family.

RESUMO

Objetivo: compreender a vivência de mães de crianças dependentes de tecnologia em relação ao cuidado medicamentoso. **Método:** pesquisa qualitativa do tipo descritivo-exploratória, desenvolvida por meio de entrevistas abertas e aplicação de instrumento estruturado para caracterização, com 12 mães cuidadoras de crianças dependentes de tecnologia durante visita domiciliar. Os dados foram submetidos à análise de conteúdo indutiva. **Resultados:** organizados em dois temas: a sobrecarga materna diante do cuidado medicamentoso, que revelou a necessidade da administração de medicamentos de forma contínua e as repercussões desse cuidado exaustivo para as cuidadoras; e as dificuldades e facilidades no acesso aos medicamentos, apontando as estratégias informais e redes de apoio. **Conclusão:** o cuidado medicamentoso configura-se um desafio diário expresso pela sobrecarga materna e dificuldade de acesso aos medicamentos, potencializado por falhas na constituição da rede de atenção e coordenação do cuidado. **Descritores:** Enfermagem Pediátrica; Cuidadores; Criança; Doença Crônica; Família.

RESUMEN

Objetivo: comprender la experiencia de las madres de niños dependientes de la tecnología para la atención médica. **Método:** estudio cualitativo de tipo descriptivo exploratorio desarrollado a través de entrevistas abiertas y aplicación de instrumento estructurado para la caracterización, con 12 madres cuidadoras de niños que dependen de la tecnología durante las visitas a domicilio. Los datos fueron sometidos a análisis de contenido inductivo. **Resultados:** organizados en dos temas: la sobrecarga de la madre en relación a la atención médica, que reveló la necesidad de una administración continua del medicamento y las repercusiones de esta atención agotadora para las cuidadoras; y las dificultades y facilidades de acceso a los medicamentos, señalando las estrategias informales y

redes de apoio. **Conclusión:** la atención médica es un reto diario, expresado por la sobrecarga de la madre y la dificultad de acceso a los medicamentos, reforzada por las fallas en el establecimiento de la red de atención y la coordinación de la atención.

Descriptores: Enfermería Pediátrica; Cuidadores; Niño; Enfermedad Crónica; Familia.

CORRESPONDING AUTHOR

Aline Cristiane Cavicchioli Okido

E-mail: acc@eerp.usp.br

INTRODUCTION

A technology-dependent child is one with a chronic condition, fragile health, a complex medical-clinical situation, numerous stomas and dependent on technological devices for his/her very survival⁽¹⁾. These children need constant long-term care to maintain their health, and are included in the group of children with special healthcare needs (CRIANES)⁽²⁾. In this study, these terms are considered equivalent.

The complex care required by these children, such as oxygen therapy, tracheostomies with or without mechanical ventilation, enteral feeding, dialysis and the need for constant drug administration⁽³⁾ overburden home caregivers. Understanding the disease, treatment and technical aspects significantly reduces the levels of anxiety and stress among these caregivers. Thus, communication between the family and healthcare services is essential to provide knowledge and empower caregivers⁽⁴⁻⁵⁾.

Examples of the demand for care submitted include: development, meaning psychomotor and social follow-up with physical therapy and occupational therapy; modified normal care, including special care provided daily and go beyond the care required by a healthy child, such as constant monitoring of vital signs and oxygen saturation levels, technological upkeep, caring for the devices used to keep the child alive, and finally pharmaceutical care, as these children typically need constant medication⁽⁵⁾.

The most frequent of these therapies is pharmaceutical, both in the hospital setting and in the home. A study to describe technology-dependent children living in the city of Ribeirão Preto, SP showed that 90.2% of them demand pharmaceutical care. The medicines most often used on a daily basis are anticonvulsants, antibiotics, reflux medication, nutritional supplements and vitamins, steroids and muscle relaxants⁽⁶⁾.

As the demands of pharmaceutical care are frequent and require technical-scientific skills, this study was developed based on the following question: How do mothers experience the pharmaceutical care of their technology-dependent children? The goal is to understand their experiences as they relates to pharmaceutical care.

From this point of view, which includes this experience, we adopted the concepts of social network and social support to our theoretical approach. Although complementary, these concepts are different. Social networks refer to a structural dimension, such as religious organizations, the neighborhood, the healthcare system and social support. It is a people dimension, made up of the individuals in the social network that are actually relevant for a given family. Social support may be classified into emotional support, which focuses on the feelings of affection and concern, information support, meaning the data

and advice provided, and instrumental support, here comprising direct help in completing tasks, and financial support⁽⁷⁾.

METHOD

Ethical aspects

The study was undertaken under Brazilian and international standards for research involving human beings, and the requirements of the National Board of Health National Research Ethics Committee Resolution 196/96, subsequently replaced with Resolution 466/12. It was approved on August 10 2010, protocol number 405. In order to maintain the anonymity of the participants we chose to identify the mothers using an alphanumeric code based on the chronological order of the interviews as follows: Mother 1, Mother 2 and so forth. We asked for permission to record the interviews, as per the Statement of Free and Informed Consent.

Type of study

This is a qualitative, descriptive-exploratory study.

Methodology

Study scenario

This study was conducted in a city in the interior of the state of São Paulo, Brazil.

Data source

The empirical material is part of the database of a Ph.D. dissertation whose aim was to understand the maternal experience in caring for technology-dependent children. Thus, 12 mothers were intentionally selected to participate in the study, out of a sample of 102. The goal of using an intentional sample was to have a heterogeneous population made up of mothers with different experiences, either due to their socioeconomic status, marital status or time dealing with the disease. Inclusion criteria were mothers over the age of 18, with children 12 or under who depend on technology and continuously use medication. The number of participants was not stipulated up-front, but defined during the process of producing the empirical data, and as deemed by the authors to be sufficient to understand the phenomenon.

Data gathering and organization

We gathered statements dealing specifically with the experience with pharmaceutical care, ignoring the statements that made up the thesis. Data was gathered during home-visits performed between May and October 2011, using a structured questionnaire made up of characterization variables, and an open-ended interview, guided by the following question: Please tell me about your experience caring for your technology-dependent child. A

single researcher did all of the home interviews, each lasting about 90 minutes. We point out that, while we interviewed the mothers, in some situations other family members were present, such as the father, grandparents or siblings.

Data analysis

Analysis of the empirical material used the inductive content approach⁽⁸⁾. We started by organizing the characterization data and the transcriptions of the full interviews. We then proceeded to thoroughly read this material. The next step was to systematize and categorize the data looking for common words, phrases and behaviors, and possible differences. The data was

organized into two themes: a) Material load during pharmaceutical care, and b) Difficulty and ease in accessing medication.

RESULTS

The average age of the mothers was 34. Two of them held down formal jobs, and five helped the household budget by selling food or crafts. Five had a single technology-dependent child, and seven had between 3 and 7 technology-dependent children. The most frequent complaints were muscle pain, anxiety and depression. The time caring for the children ranged from 18 months to 11 years.

Box 1 - Description of the mothers participating in the study and their technology-dependent children

Mother					Child	
	Age	Education	Marital Status	Income	Technology devices	Medication
1	39	Secondary school	Divorced	R\$ 1.300,00	Gastrostomy Vesical catheter Tracheostomy with Bipap	Anticonvulsant Antibiotic Muscle relaxant Vitamins
2	31	Secondary school	Stable Partnership	R\$ 1.200,00	Gastrostomy Tracheostomy	Anticonvulsant Antibiotic Muscle relaxant
3	54	Secondary school	Married	R\$ 3.000,00	Gastrostomy Tracheostomy	Anticonvulsant
4	41	University Graduate	Married	R\$ 2.700,00	Gastrostomy	Anticonvulsant Muscle relaxant
5	30	University Graduate	Single	R\$ 1.000,00	Gastrostomy	Anticonvulsant Antibiotic Anti-hypertensive Corticosteroid
6	28	Secondary school	Single	R\$ 700,00	Jejunostomy	Anticonvulsant
7	36	Primary School	Married	R\$ 1.500,00	Gastrostomy	Anticonvulsant
8	22	University Graduate	Married	R\$ 2.000,00	Gastrostomy Oxygen therapy - nasal catheter	Anticonvulsant Antibiotic Anti-hypertensive Corticosteroid
9	41	Primary School	Married	Variable	Gastrostomy Oxygen therapy - nasal catheter	Anticonvulsant Antibiotic Corticosteroid Bronchodilator
10	34	Secondary school	Divorced	R\$ 2.500,00	Gastrostomy Oxygen therapy - CPAP Vesical catheter	Anticonvulsant Anti-reflux (proton pump inhibitor) Urinary antispasmodic
11	24	Primary School	Married	R\$ 2.300,00	Vesical catheter Intestinal lavage	Antibiotic
12	40	Secondary school	Married	R\$ 1.600,00	Gastrostomy Tracheostomy	Antibiotic Anticonvulsant

Maternal overload due to pharmaceutical care

One of the factors that generate this overload is the demand for intensive, full-time care of the child. In terms of medication, we point to the need to administer drugs at regular intervals day and night, requiring 24-hour care as revealed in the following statements:

... it starts at 6 am, then he gets medication at 7, then again at 8 and 11 am, then he gets medication at 3 pm, and so on ... every two hours. All through the night. (Mother 12)

Similarly, Mother 8 says:

...it starts at 6, and I don't ever get to bed before 1 am. That's because I have to give her a inhaler puff at midnight. If I don't, I'll have to wake up sometime before the morning to do so. [...] I start at midnight, change her, give her some milk, aspirate, give her an inhaler puff, and that goes on all day... That's what I do every day. [...] She is on Phenobarbital, Depakene®, Urbanil®, and Sabril®, these for crises... then she takes drugs for her lungs as well... It starts at 6 am, then at 7, 8, 10 and 11. That's because I split things up well (Mother 8)

In this sense, the caregiver describes a daily routine characterized by only a few hours of sleep, as the child cannot go for long periods without inhalation bronchodilators. Another important comment is the number of drugs they must manage over the course of the day.

To provide full-time care, these caregivers must incorporate numerous items in their daily routine that go beyond preparing and administering medication. These include upper airway aspiration, enteral feeding, regular changes in position to avoid bed-sores and deformities, and frequent trips to motor rehabilitation services. This further overloads the mothers.

Oh, it's a whole lot! Well, there is milk, his food, he needs aspiration in the morning, the catheter has to be placed, his teeth have to be scrubbed, his eyes cleaned and eye-drops put in. Between mil, and food there is juice, then there is lunch. Then he has to be aspirated and changed again, then in the afternoon he gets milk and then I bathe him. At dinner the catheter has to be placed again - that has to be done four times a day, he also requires aspiration four times a day. Tuesday and Thursday he gets physical therapy in the evenings. (Mother 1)

Domestic chores further enhance maternal overload.

Two or three times a day I change his clothes, then I have to clean this house, and it's not a small house, it's big. All of this before he wakes up, because then I have to bathe him, give him his inhalation, aspire him and exercise him, it's complicated. Then I rush to make lunch, there's my mother, she wants lunch and has her own medicine to take. (Mother 3)

Given this task overload, the time it takes to procure medicines adds an additional layer of complication.

This is something else I think should improve, as I said ... [access to] the drugs. Something, else, we have no time available and still have to go to the hospital to pick up the

medication. And then we have to wait 2 or 3 hours at the pharmacy. They could deliver it to our homes. (Mother 12)

We find that these mothers have anxiety and depression disorders due to the overload they experience. Thus they too need psychological and pharmaceutical care.

I take medicine in the morning and evening, plus fluoxetine for anxiety. When I am very tired I can't sleep, and that's bad. (Mother 9)

Problems procuring and difficulty accessing drugs

The care of a technology-dependent child produces an emotional and physical overload on their mothers, as shown above. Another dimension affected is financial, making it harder to purchase medicines:

I wanted to organize a Bingo, because sometimes things come up that are not in our budget and there is no way to pay for them. Every cent is accounted for. There is always something, almost every month. She had to take a R\$ 300,00 antibiotic. (Mother 8)

The Unified Health System (SUS) provides a number of medicines and inputs free of charge for the population in general, including technology-dependent children. However, in some specific situations, the clinical condition of these children demands additional drugs to better control their situation, in which case the medical professionals caring for them will prescribe non-standard, high cost drugs that require a formal petition for purchase.

Medication is the worst problem, imagine how we suffer. You go to the Ministry and pick up a piece of paper that you take to the doctor to fill out, then you take it back to the Ministry and if often comes back "turned down" because something wasn't exactly right. You spend the entire month carrying papers back and forth. I sent in four requests for medicine and they were all turned down. (Mother 12)

Because they are high-cost drugs, these mothers often must file a formal petition to have them purchased. The reports by the study participants show the problems and slowness of the process, described by Mother 9 as an embarrassing and humiliating process:

I had to beg to ask for a van [transportation], I had to beg to pay for the medicine, I had to beg to pick up the drug at the healthcare center. That's the right word, I'm sorry but it is. (Mother 9)

As a means of facilitating access to drugs, Mother 12 suggests:

I believe there should be a social worker who would come to our home, look at the prescription and authorize the purchase. Or someone like that to help us, the process is very laborious and we are already short of time. (Mother 12)

The following statements describe the battle these mothers go through to ensure access to medication:

There have been days when I got to the drugstore with him and they didn't even have dipyrone. In that time, you had to buy Clavulin®. Today you pick it up in the network, but I have never been happy, I am not ashamed of saying no. I went to the City Council, I went after the mayor. I couldn't pay for things but I would insist until I succeeded. (Mother 9)

...he was using a medicine for crises [convulsions], and we weren't able to get it... we couldn't buy it anywhere, the drugstores don't carry it. At the CTI they would give it to me once in a while. Then at some point, they said they couldn't give me any more. So there was nothing I could do. They didn't have it, I couldn't go to the healthcare center (posto), what was I to do? Then one day he got worse and started to have convulsions, I think it was lack of medication. We learned that there was a compounding pharmacy that could make it. So I started to buy it. But by that time he had been without the medicine for a long time, and he felt it. (Mother 1)

On the other hand, mothers mention some items they believe facilitate access to drugs, such as their legal right to the Benefit of Continued Care equivalent to one minimum monthly wage, to be used to fund the child's treatment.

By the time I found out he had the right to that benefit, he was already two years old. For instance, Sabril® cost R\$ 215,00 at the time, R\$ 215,00 each box. So it was either pay rent and eat or buy medicine. So I chased after the benefit. (Mother 9)

The bond that develops between mothers and the healthcare team may also be viewed as a facilitator, as these professionals are familiar with the child's situation and are able to quickly renew prescriptions:

Her medication is controlled. Dr. A writes the prescription for me if I needed it with no problem, he/she does it right then and there and gives it to me. (Mother 7)

Doctor, they are missing a medicine for him here, I don't have a prescription. ... "Go by my office and I'll leave you a prescription. (Mother 4)

Another facilitating strategy is mutual support, a network of solidarity among mothers is an informal form of support, where they support and help each other, including with medication:

We help each other. Sometimes J. runs out of medicine and she calls me, and sometimes A. runs out of medicine and I call her. So we exchange between ourselves. We help each other when we need something. (Mother 8)

DISCUSSION

Often these children require continuous pharmaceutical care, both at home and when hospitalized. According to the American Academy of Pediatrics, children with special health needs (CRIANEs) normally take five times the number of drugs that children in general⁽³⁾

Regular administration of medicines is a challenge as it increases maternal overload. When looking at the family networks of children with special health needs in the South of Brazil, researchers found that family care is focused on women⁽⁹⁾. Likewise, a study of the families of children with cystic fibrosis found that, when there is a child with a chronic disease, the mother is the main caregiver and therapy manager⁽¹⁰⁾.

Corroborating these results, studies have stressed feelings of exhaustion, stress, anxiety and depression. They talk about sleep that is frequently interrupted by equipment alarms or the need to give a child medicine through the night. Another situation is the difficulty parents have relaxing, as often other family members or friends do not have the training required to provide this complex care, resulting in caregivers falling ill⁽¹¹⁻¹⁵⁾. Here we find that instrumental and emotional support by the family network is weak.

Studies show that these mothers have emotional, social and physical problems such as trouble falling asleep, as they must wake up to check on the child or give it medicine, and they are socially isolated as well, scoring low on quality of life questionnaires⁽¹⁶⁻¹⁷⁾. A survey of mothers of children on mechanical ventilation found that 45% displayed the signs and symptoms of depression⁽¹²⁾. A study of the parents of children with special healthcare needs demonstrated that they are at higher risk for developing the symptoms of depression. Being single and unemployed also increases the probability of developing these symptoms⁽¹⁸⁾. Given this reality, it is important to strengthen the link with the healthcare system social network to provide effective and comprehensive support for these mothers who are vulnerable to mental illness.

Financial difficulties are also a recurring problem, as these children need much more from the healthcare services than children in general. This results in a significantly higher economic impact in terms of days absent from work. Medical expenses are also much higher - two or three times the expenses of a child without special needs⁽¹⁹⁾. A study to describe and analyze the experience of socially vulnerable families of children with cerebral palsy identified "Living with Financial Difficulties" to be a recurring theme, showing that limited financial resources result in feelings of anxiety by making it harder to continue or maintain treatment⁽²⁰⁾.

We find that instrumental support is also a major source of impact. The results of an international study show that socioeconomic factors make it harder to access drugs and specialized services, which affects quality of care and results in social vulnerability by children with special healthcare needs. This study also shows that 7.25% of the children requiring specialized care did not receive it. According to the authors, other factors such as household income, number of household members, ethnicity, material schooling and geographic location could be associated with this vulnerability⁽²¹⁾.

On the other hand, the facilities for purchasing medicines include the Benefit of Continued Supply. According to the Organic Social Care Law, people with special needs who are followed by rehabilitation services at specialized institutions have a right to this benefit, equivalent to one minimum wage⁽²²⁾. This amount is to be used to fund treatment,

including items such as food, transportation and medicines. However ignorance of this right means these children are unable to exercise their citizenship. In this case, support in the form of information is the moral duty and obligation of healthcare professionals.

The international literature further states that creating an integrated healthcare service network and coordinated care optimize access to services and inputs, reduce the volume of emergency care and hospitalizations, and lower hospital costs⁽²³⁻²⁴⁾.

Another facilitating factor mentioned is solidarity among the mothers of technology-dependent children, creating a new support network. The authors reiterate the importance of including caregivers in support groups that include other people who understand the physical and emotional pressure resulting from caring for technology-dependent children^(1,12). Thus, mothers are themselves the social support of other mothers.

Given the challenges of pharmaceutical care, nursing professionals have the possibility of providing social support by promoting comprehensive and resolute care with information, tools and emotional support. The literature values the exercise of these professionals, as they develop the knowledge and practices required to coordinate home-care⁽²³⁾, with the family as the unit of care⁽²⁰⁾. However, multi-disciplinary models are indicated to address the multiple facets of chronic conditions, with a better understanding of the psychosocial needs of these families^(1,12).

Study limitations

Regarding the limitations of this study, the results relate to the experience of twelve mothers of technology-dependent children in Brazil. However, these findings enable interlocution with international studies, helping position the problem within the global scenario.

Contributions for healthcare

Regarding practical application, the study can contribute to changes in the healthcare working process, focusing on comprehensive care, focusing on the family.

CONCLUSION

The experience of mothers with pharmaceutical care is permeated with daily challenges, among them maternal overload, and feelings of anxiety and depression caused by the exhaustive demands of caring for a child, made more complicated by the need to constantly administer drugs. We also point out the financial impact and the difficulty accessing these medicines, and the lack of a social network and coordinated care.

Thus, we warn of the importance of designing strategies to minimize maternal overload so that they have time for rest and leisure, with the implementation of a formal support system within the community itself. A strategy of this type already exists in developed nations, known as respite care. We also suggest that Nursing develop family-centric care, facilitating the process of finding other family members who could also be caregivers, and training these people. Nursing could also provide support in the form of information, such as schedules for administering drugs that provide gaps so that the mothers can perform other activities and rest for longer periods at night.

Regarding access to medicines, we recommend that the healthcare services be reorganized to provide comprehensive care, agile medication dispensing systems, and a network of professional support. For this, inter-sector activities that include healthcare services, the Public Ministry and social services can minimize the difficulties and slowness of the process to access medicines established in Brazilian legislation.

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