EXPERIENCES OF MOTHERS OF TECHNOLOGY-DEPENDENT CHRONIC CHILDREN IN A PEDIATRIC INTENSIVE CARE UNIT*

HIGHLIGHTS
1. Fear of losing the child in the Intensive Care Unit.
2. Change in the family dynamics.
3. Negative feelings such as fear, insecurity, sadness, suffering.
4. Absence of a support network.

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ABSTRACT
Objective: to describe mothers’ experiences and repercussions of the hospitalization of technology-dependent chronic children in a Pediatric Intensive Care Unit on their personal and family life. Method: qualitative study conducted with 11 mothers of technology-dependent chronic children in a public hospital in the Federal District, Brazil. Data were collected by semi-structured interviews, recorded, later transcribed, coded, and subdivided into categories. Thematic content analysis was used as an analysis strategy. Results: were divided into five categories, which express the experiences of prolonged hospitalization, maternal feelings, difficulties/needs, coping strategies, and context of the pandemic, which highlighted the mostly negative repercussions that bring changes in the family dynamics in general, by needing to reinvent themselves and adapt to the conditions of the child and the hospital. Final considerations: the data show family vulnerability and reinforce the importance of nursing work for the adoption of a family-centered care model.

DESCRIPTORS: Hospitalization; Intensive Care Units, Pediatric; Child Health; Chronic Disease; Family.

HOW TO REFERENCE THIS ARTICLE:
INTRODUCTION

Technology-Dependent Children (TDC) are those who live in a chronic condition, with a fragile state of health, subject to a high level of medical complexity and dependence on technological products essential to their survival. These children require continuous, long-term, specialized care to maintain their health, making them an example of the subgroup of Children with Special Health Care Needs (CSHCN).

Although they have unique characteristics related to technological dependence, it is crucial to keep in mind that they, too, are social agents, builders of knowledge and culture. Research indicates that this group of children has revealed several factors related to the cultural context, with an effect on the quality of life of their families extrinsically related to the health-disease process of these individuals.

In addition, research conducted with children cared for in a Pediatric Intensive Care Unit (PICU), emphasizes anxiety, concern, and exhaustion, as the main factors to show the decline that these children present during treatment in the hospital environment. They emphasize that the care environment involving these children needs to be redesigned due to the presence of equipment and support personnel.

Thus, it should provide a sense of security, facing an entirely new reality, considering new knowledge and practices that must be incorporated into daily life, as well as access to services guaranteed by the child’s citizenship, rights outside the health institutions.

Based on these considerations, an approach to the experience of the disease was sought, the way in which individuals situate themselves and assume the position of being ill, attributing meanings and finding routine ways to deal with the different situations of the health-illness process and care in the PICU environment.

This experience is socially constructed, based on and shared in the community in which the individual is inserted. The experience of disease has been an important theme in social anthropological studies of health because it is based on the perspective that the health-illness process and care are a culturally determined phenomenon, and that the experience of disease is not simply a reflection of the pathological process, but rather, an experience in which values and expectations of an individual or a community are expressed in the way they think or act when facing a disease.

The approach to the disease experience allows us to recognize important dimensions of affliction and treatment, enabling a more comprehensive understanding of the disease phenomenon and consequent expansion of communication between health professionals and patients, with positive repercussions on the quality of care.

Based on the above, this article aimed to describe the experiences of mothers and the repercussions of the hospitalization of technology-dependent chronic children in a Pediatric Intensive Care Unit in their personal and family life, about the experience of the disease. In this study, the mother is understood as the main family caregiver, as she is the one who is continuously present in the care during the child’s hospitalization.

METHOD

Qualitative, descriptive research, conducted according to the Consolidated Criteria for Reporting Qualitative Research (COREQ), carried out in the PICU of a maternal and child hospital in Distrito Federal (DF), Brazil, with 11 mothers of TDC, using the Thematic Analysis proposed by Minayo.
Qualitative research aims to highlight the subjective factors pertinent to the thematic approaches of the proposed study, because it considers that there is a dynamic relationship between the real world and the subject, that is, an inseparable link between the objective world and the subjectivity of the subject that cannot be translated into numbers.

The inclusion criteria were being a mother aged >18 years, of TDC aged zero to 12 incomplete years, dependent on feeding devices (nasogastric/enteral tube, gastrostomy), elimination devices (relief bladder tube, ureterostomy, colostomy, ileostomy, and bowel lavage/irrigation), and breathing/oxygenation devices (tracheostomy in room air, with T-tube or mechanical ventilation, oxygen therapy with nasal catheter). Mothers with any impairment in comprehension or verbalization that made it impossible to answer the questions and to participate dialogically in the interview were excluded.

Data collection was carried out through semi-structured open interviews, with guiding questions that allowed an open description of the mothers’ experiences, after they agreed to participate in the research and signed the Free Informed Consent Form ICF. The interviews were audio recorded and took place from April to October 2022, in a reserved place in the PICU. They lasted an average of twenty minutes and were later transcribed in full and submitted to the qualitative analysis proposed by Minayo. The data were systematized using the thematic content analysis method, following the phases of pre-analysis, material exploration, treatment, inference, and interpretation of the results obtained. The anonymity and confidentiality of the participants were maintained, identifying the interviews in numerical form from (I1) to (I11) according to the order in which they were conducted.

The Microsoft Office Word and Excel packages were used to organize the interviews. Based on the systematization process, the empirical material was grouped by similarities and differences, enabling the emerging of thematic categories, namely: “Experiencing prolonged hospitalization”, “Maternal feelings”, “Difficulties and needs”, “Coping strategies”, “The context of the pandemic”.

This research was approved by the Research Ethics Committee of the College of Health Sciences (CEP-FS – in Portuguese) of the University of Brasilia (UnB – in Portuguese) and the Foundation for Education and Research in Health Sciences (FEPECS- in Portuguese) of the DF, under opinion no. 5,363,820.

RESULTS

The analysis of the narratives of the 11 mothers who participated in the research made it possible to identify the subjectivities of the repercussions of hospitalization on family life portrayed in five categories, which express the experiences of prolonged hospitalization, maternal feelings, difficulties/needs, coping strategies, and the context of the pandemic.

Category 1. Experience the prolonged hospitalization

Mothers of technology-dependent chronic children experience several challenges from the diagnosis to the reintegration of the child to family life, with the transition of care to the home. In this trajectory, the prolonged hospitalization emerges as the greatest difficulty in the maternal experience, since mothers assume the role of main caregiver, and most of the time, the child’s exclusive caregiver.

The hospitalization in the PICU distances the mother and hospitalized child from the home and from the rest of the family, leading the mother to live with the difficulties of being far from her husband/partner and from the other children and family members.
Some manage to minimize the effects of the physical separation by making constant telephone contact and meeting on weekends. They recognize that the other children feel and suffer with their absence, manifesting such absence through changes in mental and physical health such as changes in behavior, becoming more aggressive and nervous, and lack of appetite, eating habits, weight loss, getting sick and presenting fever.

To take care of these children during hospitalization, mothers need to activate and resort to family and informal support networks. It is common for the father/couple to continue their work routine, and the other small children are taken care of by their aunts, grandmothers, and friends. In this process, the mother finds herself stressed, having to choose which child she will take care of. The statements below show this experience for some mothers.

[...] the children who are at home, that they miss [12].

Very difficult because the whole family structure changed, the whole house routine changed. We, each time we stay in a corner, my husband works, my children stay at my sister-in-law’s house, I stay here [at the hospital], my children don’t know their [hospitalized] brother well, they only saw him once, so, it disrupted the whole family, many people noticed that the children are different, the way they suffer is different, each one has lost weight differently, it’s [...] everything changed, the education we used to give, they are all nervous, they are fighting, it seems that I must build everything again, if I can manage! When I get home, everything is different, so [...] [12].

My daughter came to see him, she had an emotional fever, my seven-year-old daughter, she also got sick, she called me crying, and then she couldn’t eat properly [13].

[...] we can’t stay together with the family anymore, when I go home, there is no way because my mother comes here, so we end up distancing ourselves, isn’t it [14].

I stay the whole week and weekend I go [...] Monday I come back. I leave the other daughters with a friend [16].

[...] One son is with my mother and the other son is with my mother-in-law, so everybody is separated, isn’t it, then sometimes, when I must stay with my mother-in-law’s son, I can’t stay with the one who is with my mother, I can never stay with them both at the same time [19].

I talk to them [the other children] by phone, but it is not the same thing as hugging, being close, the distancing affected a lot [...] they only ask when I will come back. But I usually go, this week my husband comes, and I will stay with them [111].

Category 2. Maternal feelings

In the maternal experience, before the prolonged hospitalization, negative emotional states predominate, of anguish, fear, nervousness, sadness and extreme insecurity and frustrated expectations, of improvement and of the child returning home. The mothers identify that this situation has repercussions on all the members of the family, affecting the way they relate to each other, the way they live together (when pre-existing), their patience, structure, dynamics, and routine. In this context, they are the ones who suffer the most with the overload, the changes, the restrictions, and the reorganization of their daily lives. They give up activities such as working, taking care of the house, and caring for their other young children.

There are times that I get anxious, I want to go away, I want her to get well so that we can go away [...] when we are anxious, we have no patience, we don’t understand the other person very much [11].
A feeling of sadness because he has been here, for so long, and never went home, then it is a distant feeling, of home, of missing home, missing his family, missing a home, I think he doesn’t have one, he doesn’t know what a home is, it is a feeling of sadness [I2].

Me losing him, you know [...] of total loss, or of me taking my son home, it’s [...] without me hearing his little voice, of him being totally debilitated on a bed, without walking, without talking, you know [...], without taking my hand and giving it a squeeze, so, this is my feeling that is scaring me the most, it’s really hurting me! [I3].

Then [...] fear, worried, anguished, feeling of impotence [...] [I5].

[...] I was afraid, sad, I had a tremor, just shaking, I was nervous [...] [I11].

You know, when we enter the hospital, we are like, will my son get out of this, will he leave here somewhere else, I don’t know, I am just so sad [I11]?

Category 3. Difficulties and Needs

The difficulties faced by mothers during hospitalization are related to the acceptance of their child’s condition, seeing him/her in the ICU bed in a state of suffering. In addition, they face financial difficulties, since many are single mothers and receive no financial help, in addition to not having a support network, facing difficulties to find someone to take care of their other children or even not being able to find another person to accompany the hospital stay. Many bring the distance from the family and the hospital isolation due to the clinical condition as difficulties experienced as well. In addition to not being able to stay away from the hospitalized child for a long time when they manage to go home or leave the hospital environment.

My biggest difficulty was because she always had strong crises, and they did not pass, right, and to accept her situation, that was my biggest difficulty [I1].

It is difficult to get people to exchange with me because when my husband is with the children, I am here, so for us to stay, it is kind of difficult to make this arrangement because he works, he can’t stay here. One day just for me doesn’t solve anything, today I have been here for almost three months already [I2].

All, because also like this, I depend on others to stay with my other daughters, so like this, I am ticking, asking one, asking another to stay with my other daughters, so I am having difficulties with this because nobody can stay with my other two daughters, understand [...] [I6].

Almost everything because I must be, like this is only me, I must take care of three children alone, then I must take care of everything, it’s only me! I have a family, but it is the same thing as not having one! [I6].

Initially, it was very difficult, because of the isolation, I wondered how I would manage. At first, I thought I couldn’t handle it, but then it was effortless [...] it was effortless. I had help from everybody, from the doctors, from the nurses, the problem was only at night, but there were always people with me. I had to be myself and that was it, but it passed, thank God. [I8].

The distance, that would be a difficulty [I10].

Category 4: Coping strategies

The measures found by the mothers interviewed were clinging to God, praying, going
to mass/chapel, going out of the hospital, going for a walk, manual activities, reading, changing companions when possible and meeting other mothers (also companions of other hospitalized children) in the living spaces, where the ways found to ease these problems.

I tried to crochet, did it for a few days, stopped, those things [11].

Go outside, have a snack, take a walk, go home occasionally [...] [12].

Go outside and speak with the girls, study a little, I also have books to read and take turns with my mother when I need to go out [14].

I am very anxious, and I can’t assimilate such a thing, depending on the state he is in, sometimes I can’t, it’s [...] stay by his side because I am very anxious, then [sister’s name] comes, it happened several times that I stayed outside, and she was here because I couldn’t. It’s [...] I can’t stay with him because I am very anxious, then [sister’s name] comes. It’s [...] I can’t! [15].

I go to get some air, positive thinking, I pray, talk to her too, it is complicated, it is I calm down, but then I will find a way to calm down because I need it isn’t it [15].

I am entrusting it to God isn’t it, I am praying a lot, understand, it’s... Furthermore, I am giving it to Him, that’s it! [16].

Sometimes I come... here [living room], and then I talk, right, with the mothers, right, and we have fun, we laugh, or we tell each other the story, right. [...] I like to attend mass, I like to go and be alone, to talk to God, right [...] I always go [...] I go, I am very catholic, right [17].

I have help from my family, isn’t it [...] they help me when I am here, and I can’t be with my children. So, they help me with this sense so that I can be more tranquil [...] [19].

Category 5. The context of the pandemic

The pandemic also brought some repercussions, both before and during the hospitalization of the chronically technology-dependent children. Many became pregnant in the context of the pandemic, social isolation interfered in communication and physical contact with other people, some of the providers of these children’s families became unemployed, altering their financial situation, the multi-professional accompaniment and consultations were lost or became more difficult to get, surgeries were delayed. Some of these repercussions interfered negatively in the health of these children, resulting in complicated and prolonged hospitalizations later.

I got pregnant with her during the pandemic, right. And when we were at home, we didn’t have much communication because people wouldn’t visit her, I wouldn’t let them, I wouldn’t go out with her, so it was always hospital, home, hospital again. We didn’t have much contact with other people in society [11].

My husband lost his job in the pandemic, we were [...] almost two years unemployed, he got a job at the end of last year. It was a shock without a job, then he got a job, and besides that, the fear of going out, of getting sick, fear of dying, fear of everything, so we were locked inside the house, the emotional was very shaken [...] [12].

The pandemic did affect us! Because he was not called to do his surgery because of the pandemic. So, if he had, the [...] from health would have called me because his name is already there, he should have already done it. If he had called me to be consulted, everything would have been fine, and he would have done it, this would not have worsened. So, yes, the pandemic did affect him [13].
Before the pandemic, he fit in a frame there, but afterward, because of the tracheotomy, and because there is no right position and so on, he doesn’t fit in any longer [...][15].

Yes, a lot! A lot! Because we stopped doing everything we used to do. We didn’t go to her appointments, the doctors didn’t come to the house, we became isolated inside the house, practically isolated. [18].

So, I had gone to Maranhão when I arrived, the consultations were slower, because of the pandemic, nobody could touch each other [111].

DISCUSSION

The results point to several consequences of the hospitalization of TDC in the PICU environment for the mothers (main caregiver), these repercussions are mostly negative and bring changes in the daily routine in general, because they need to reinvent themselves and adapt to the conditions of the child and the hospital.

In fact, studies point out that the hospitalization of a child is a critical and stressful event for the entire family nucleus, as it interferes in the routines and well-being, requiring adjustments to the challenges and demands that may arise, generating impacts in several areas of life, with many concerns and needs6.

The chronic condition itself already creates an impact on health care and family routine, due to recurrent prolonged hospitalizations, complications, need for specific care and subsequent rehabilitation, since the main caregiver is responsible for monitoring and living in the hospital environment full time. Thus, the whole family’s routine becomes exhausting, generating stress, social distancing, especially from the mother, who is usually the main caregiver and needs support networks to share feelings and the challenges of complex care7. Moreover, these impacts also generate emotional repercussions in those involved.

It’s worth pointing out that since the definition of the child’s diagnosis in chronic conditions, studies already point out a series of emotions experienced by the parents, such as confusion, anxiety, disbelief, turbulence, and loss of identity; however, these feelings dissipate over time8. During hospitalization, studies indicate that the parents’ experience is marked by fear, apprehension, anguish, impotence, anxiety, and guilt, resulting from several factors related to the clinical picture6.

In fact, the prolonged hospitalization makes the mothers of chronic children stay longer in the hospital, and this change affects the other family members, especially about the attention they devote to their other children because they end up being under the responsibility of others. However, this is not all, as other essential issues arise, such as new financial responsibilities, changes in the family budget, as many primary caregivers lose or give up their jobs due to recurrent and prolonged hospitalizations, which can interfere with the quality of the care provided9.

Moreover, the treatments given restrict the coexistence, unleash numerous sensations in the whole family, such as adjustment and confrontation of siblings, worries about the future, distance, interruption of routine activities, imposing a necessary condition of re-adaptation10. Thus, coping strategies emerge, the set of measures used by people to adapt to adverse circumstances, to mitigate the stressful effects and maintain well-being9.

About the coping strategies, a study points out that each caregiver develops his own mechanisms to deal with the situation, such as avoiding thinking about the disease, leaving the problems at the hospital when going home, comparison with other people’s more serious situations to feel better9.
Besides the aspects mentioned above, it is necessary to discuss the context of the COVID-19 pandemic, as mentioned by some mothers, which influenced the admission of their child to the PICU. Studies point out that the public health measures adopted to control the pandemic (closing schools, social distancing, cancelling appointments) resulted in unintended consequences for the health of children, especially for those with chronic diseases and living in vulnerable situations. In addition to the risk of contracting the virus, the social and medical consequences of the unprecedented public health measures required to slow viral spread may pose an even greater threat to children with chronic illnesses.

A study conducted in Sweden portrays that the impact of the pandemic on children with disabilities was described as a “triple jeopardy,” as they experienced the negative social impacts, the difficulty in accessing health services, and the increased risk of severe complications if they contracted COVID-19. Such aspects would contribute to the worsening of underlying pathologies without adequate multi-professional follow-up, thus resulting in hospital admissions and often in the PICU, exposing the child to the virus and other multidrug-resistant bacteria.

Such findings corroborate the results of the study conducted with 784 Canadian pediatricians, who reported an adverse health outcome due to interruption in health care delivery, such as interruption in the supply of drugs and equipment, interruption in family care, and interruption in community support.

Thus, we realize the real need for the entire health team to turn their eyes to the mothers of TDCs, especially in the pandemic context because many of the repercussions that were already known in this public can be exacerbated in the pandemic, thus requiring more profound monitoring. This study brings as a limitation the fact that it was carried out only in a general PICU and may not bring greater repercussions found in other settings.

**FINAL CONSIDERATIONS**

It was evidenced in this study that the main challenges faced by mothers are the complex social processes experienced in a PICU because the maternal experience in caring for the TDC is marked by the search for explanations about the causes of the child’s illness, as well as feelings of distrust and insecurity, the lack of a support network and change in family dynamics, caused by the distancing from other family members.

Therefore, it can be noticed that the family vulnerability evidenced reinforces even more the importance of adopting a model of care centered on the family, considering it as a system - its structures, historicity, life dynamics and subjective reactions present in the experiences that accompany the care trajectories to the TDCs, enabling a better bonding of nursing professionals, including these dimensions as part of the evaluation and intervention process to create strengthened spaces for the care processes, encompassing an expanded clinic, advanced practices, health education, and support in situations of greater clinical instability of the child, social and emotional instability of the families and providing greater adaptation, balance, and well-being.

Therefore, it is noted that nursing care is of fundamental importance as part of the support network currently, as there is a need for social intervention for the woman/mother, the child, and the family to have psychosocial stability outside the hospital setting.
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Experiences of mothers of technology-dependent chronic children in a pediatric intensive care unit.

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