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## Children dependent on technology, a challenge in health education: a descriptive study

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### ABSTRACT

**Aim:** to verify how the health team of the Pediatric Intensive Care Unit (PICU) promotes the training of family caregivers of children dependent on technology (CDT); to identify the factors that interfere with family care for CDT in the PICU environment and at home; and to verify the health support system offered in home care to caregivers. **Method:** This is a qualitative-descriptive study with 14 CDT family caregivers. Thematic Content Analysis was used as a strategy of analysis and Symbolic Interactionism as a theoretical reference. **Results:** There is a deficiency in terms of caregiver support, disinformation and lack of knowledge related to complex care, and a disjointed and almost non-existent support system among the many factors that influence CDT care. **Conclusion:** there were gaps in the care setting for CDT, especially in the health education process of caregivers and in the follow-up and monitoring by the public services.

**Descriptors:** Home Nursing; Child Care; Nursing Care; Chronic Disease; Family.

## INTRODUCTION

Technological innovations and advances in public health policies have enabled changes in the Brazilian epidemiological profile, increasing the life expectancy of children with chronic diseases and of cases previously sentenced to death. Survivors often require medical and hospital devices to maintain their vital activities, and are called Children Dependent on Technology (CDT)<sup>(1)</sup>.

CDTs are in poor health condition and need continued attention. Among the technological devices most used to compensate for the loss of a vital function in pediatrics are mechanical ventilators, parenteral nutrition, tracheostomy, gastrostomy and peritoneal dialysis<sup>(2)</sup>.

A study conducted in the United States estimates that between 15% and 20% of children between 0 and 17 years of age survive with some special health needs<sup>(3)</sup>.

In Brazil, there are no records on the prevalence and characterization of CDT, only isolated records in some locations such as Rio de Janeiro and Santa Maria, making it difficult to infer an absolute number of such cases<sup>(4-5)</sup>. The scarcity of epidemiological data is a challenge for health professionals, making it difficult to plan and implement strategies directed at this clientele and their caregivers<sup>(6-7)</sup>.

CDTs are usually submitted to long and recurrent periods of hospitalization in Pediatric Intensive Care Units (PICUs). The hospital discharge is a process with chaotic meaning for the relatives, since the home care requires specific knowledge<sup>(6)</sup> not always worked in the ambit of hospitalization. The family begins to assume the role of caregiver, that is, the person who takes on the responsibility to meet the demands of care of the CDT<sup>(6)</sup>, without having been properly prepared for it.

Despite the changes that have taken place in the national scenario regarding the training of caregivers for the home environment, the offerings of public health services and programs, such as the *Programa Melhor em Casa* (PMC - Best Home-Based Program) and the *Programa de Assistência Domiciliar Interdisciplinar* (PADI - Interdisciplinary Home Care Program), are still very restricted.

In view of the above, the study had as its objectives: to verify how the health team of the Pediatric Intensive Care Unit (PICU) promotes the training of family caregivers of children dependent on technology (CDT); to identify the factors that interfere with family care for the CDT in the hospital and at home settings; and to verify the health support system offered in home care to caregivers.

## METHOD

Seeking to contemplate the family caregiver of the CDT as a subject who experiences the care of the child, it was necessary to resort to a theory that allowed to enter the empirical universe of this caregiver, revealing it from the symbolic interactions contained therein, Symbolic Interactionism<sup>(8)</sup>. Records were recorded with the aid of a digital recorder and each interview took, on average, 40 minutes; field notes, used as sources of information, were also performed. Subsequently, the information was transcribed in full and analyzed, based on the Bardin Content Analysis<sup>(9)</sup>. According to the author, this is an analytical strategy consisting of a grouping of techniques that are organized around three chronological poles: pre-analysis; exploitation of the material; treatment, inference and interpretation of results.

The pre-analysis composes the organization phase of the collected data. At this stage, the researchers performed a careful reading of the material in order to operationalize and systematize the data. In all, three readings of the collected material were carried out. In the first reading, also called "floating", we tried to know and analyze the text. In this opportunity, the authors had the first impression of the content expressed in the lines. The use of colored marker pens was used in order to identify themes or units in the essay, which were later regrouped according to a coding unit for the origin of the thematic units. Coding is a process in which raw data is aggregated into units, which allow an accurate description of the characteristics of the content. Then, another reading was performed to review the keyed units in order to ensure the correct identification of the essential aspects of the discourse. In the third reading, the information was organized taking into account the research objectives, and the data were codified<sup>(9)</sup>.

In the exploration of the information, the categorization was carried out, that is, the organization of the data. In this stage, the researchers performed associations, which, after being analyzed, allowed the analytical reading and inferences, resulting in one category and three thematic subcategories, which are respectively: meanings of the experience of family caregivers of CDT with the hospital environment; meanings attributed to the PICU; meanings of the qualification process for complex care; and assuming complex care.

The purpose of the symbolological approach was to seek the support that would lead to the identification of the meaning of taking care of a CDT, as well as the challenges encountered in learning and performing home care.

Working from the standpoint of Symbolic Interactionism allows reflections of human behavior based on meanings and the unveiling of the empirical world of caregivers in different contexts of their experience.

The study was carried out based on the PICU of a Teaching Hospital located in the northwest region of Paraná. Participants included 14 family caregivers of CDT included in the study at the time of the children's hospitalization. Data collection was performed by a single researcher in the second half of 2013.

The interviews were scheduled and took place in two different moments: the first during hospitalization in a reserved room at the PICU and the second at the home, within a period of approximately one week after discharge from the CDT. The data were collected through an interview with the application of a semi-structured script, consisting of questions related to the characterization of the subjects: 18 guiding questions for interview in a hospital environment and 16 guiding questions for interview in the home. The semi-structured interview script was prepared by the authors and previously applied to a group of five caregivers, not included in the study, to test their efficacy.

Inclusion criteria were: to be a preferential family caregiver of CDT admitted to the PICU during the period of the survey, to be 18 years of age or older and CDT with age compatible with the concept of a child according to the Statute of the Child and Adolescent, that is, the person who has not completed 12 years of age<sup>(10)</sup>. The single exclusion criterion was ethical-methodological, and consisted in the impossibility or refusal to participate in the study.

The development of the study met the formal requirements contained in the norms regulating ethics in research involving human

beings<sup>(11)</sup> and was approved by the Standing Committee on Ethics in Research with Human Beings of the State University of Maringá (CO-PEP), under opinion No. 131,658.

## RESULTS

Of the 14 caregivers interviewed, all were female, 13 were CDT mothers and one, maternal grandmother, two were between 20 and 29 years old, five were between 30 and 39 years old, four were between 40 and 49 years old, and three were between 50 and 59 years old. Seven caregivers (50%) were married, three (21%) reported having a stable relationship and four (29%) were divorced.

Eight participants (57%) had no employment relationship, indicating full dedication to the care of the CDT and household activities. The family income of nine caregivers (64%) was between one and three minimum wages, four (29%) were between three and five minimum wages and one (7%) did not know what the family's monthly income was. The schooling ranged from the absence of education, referred by two caregivers (14%), incomplete elementary school with seven indications (50%) and complete high school education referred by five interviewees (36%).

All children were between five months and seven years of age. The diagnoses related to the cause of the technological dependence were: genetic syndromes such as Werdnig Hoffman and West syndrome, respiratory insufficiency, cardiopathies, hydrocephaly, microcephaly, esophageal atresia, laryngomalacia and congenital toxoplasmosis. All the children had more than one diagnosis and among the technological dependencies were: tracheostomy, gastrostomy, use of mechanical ventilator, enteral and bladder probes.

The use of the public health system was reported by all families; however, some have used the private system at some stage in the clinical evolution of the child.

As we enter the empirical world of caregivers, we come across information that expresses the meaning of the experience during the period of hospitalization and after hospital discharge of the loved ones:

### *Meanings of the experience of family caregivers of CDT in the hospital environment*

- **Meanings assigned to the PICU:** When faced with a complex care environment, at first, caregivers manifested reactions motivated by feelings such as suffering, shock and despair.

I was shocked by all that; seeing him suffering and then being intubated... (e7)

When the doctor told me that she was going to the ICU I despaired; I thought she was dying. (e12)

The hospitalization in a PICU is a fact marked by negative meanings that are related to the idea of death.

I was pretty scared at first; afraid I would lose her soon. And I was afraid to stay here in the ICU, but the doctor said I had to stay. (e3)

When they talked about ICU, I used to think about a person on the verge of death. (e5)

The meaning attributed to the stay of the CDT in a complex unit, together with the treatment of a prolonged chronic illness, refers to the establishment of a framework of emotio-

nal fragility of caregivers. Fear and insecurity are favored by the environment itself, that is, by the common idea that characterizes a PICU, marked by the use of devices, by the isolation of the external world and by constant contact with other children in serious condition.

Because I didn't know what an ICU was like; I had only seen it on television; that great deal of medicine and a lot of equipment and everyone was almost dying. So I was very scared. (e1)

It was verified that caregivers initially appropriated the common sense knowledge about the meaning of ICU, until they actually entered into this reality, reframing it from their experience. Notwithstanding this re-signification, the lack of an accurate knowledge in terms of the pathology and the therapy instituted, added by the stress caused by the hospitalization, contribute to the changes of psychic and emotional order and fears related to the possibility of irreversible damages, such as the death of the CDT.

- **Meanings of the qualification process for complex care:** the participants presented several reactions to the learning of complex care. Among the meanings that emerged from the speeches and that refer to the process of instrumentalization, the most important are poor preparation, insecurity, and denial of care and fear of not knowing how to do it.

When there was a possibility of discharge they started to guide me. I got startled! Out of the blue they said I had to learn. I didn't want this to be true. (e2)

I still don't feel safe doing it alone (aspiration); I'm afraid of hurting everything him in the inner side. (e5)

The difficulties in the qualification process have sometimes included the lack of availability of the PICU's professionals to carry out teaching and guidance activities. Another aspect referred to is related to the late period in which this educational / informative activity takes place, usually on occasion or in a period very close to hospital discharge.

I have to learn alone, the nurse is never available to come and teach me. (e7)

I tried to escape all the time. I only got back to my senses when the doctor said that he was going to discharge him and at home I was going to deal with the gastro. (e8)

On the other hand, there was also a differentiated attitude on the part of one of the caregivers regarding the learning of complex care, which implies a responsibility inherent in her role as a mother, not something external to her.

They always complain about the lack of staff and we cannot leave everything to the nurses as a burden. Here there are also other children and other mothers who need to learn how to take care of their children. (e2)

- **Taking on Complex Care:** with regard to the period after hospital discharge, the difficulties reported by the caregivers referred again to the insecurity in terms of the execution of complex care, and still without the supervision of a specialized team, such as that made available during the period of hospitalization.

I know I can't be afraid or insecure. I did everything right in the hospital, but if I did something wrong a doctor would help me out. (e3)

The difficulties increased mainly due to the need to perform procedures such as aspiration of airways and manipulation of probes and drains. Fear, anxiety about the possibility of failure to perform the procedure and the feeling of unpreparedness were negative meanings prevalent in the discourse of caregivers.

I aspire, but when I realize she turns purple, I stop. It feels like I'm killing her. (e3)

They talked, but I didn't pay much attention, because it's one thing to be there, but here in my house it's different: I don't have all the devices of an ICU. (e7)

Here I do it the way I can, I can't be sure if it's right. (e12)

Structural difficulties, which constituted barriers to the effective implementation of care, were also reported. In the speeches, there are difficulties in acquiring the necessary inputs to the continuity of care.

I was informed that the health department should provide an aspirator. I went there, but they had nothing to lend me. I went to the promoter's office and they said it would take time and there was no specific waiting time. In December I went to Pinga Fogo (TV program and local radio), and got it on the same day. (e3)

I have to get the appliances, I mean, the nasal aspirator only. (e5)

According to the caregivers, this context is aggravated by the fact that they do not know where or in which instance of the public health network to find support for home care. It was also mentioned the lack of support from institutions that make up the basic health network (Family Health Strategy), evaluated by the interviewees as an absent network in relation to home care; and used exclusively for the acquisition of materials necessary for performing complex care.

The people at the health post came here a few days ago to see which materials he was using. (e11)

I just think the following: the health post is not very interested. I am responsible for her; if I want to see her well, I have to do everything myself. (e13)

## DISCUSSION

The study showed that the vast majority of the interviewees were mothers, replicating the results of research on caregivers and listing care as an activity of predominantly female responsibility<sup>(12-13)</sup>. Cultural determinants related to gender continue to take root in the concepts of caring.

From the perspective of Symbolic Interactionism, human beings are seen as social actors who communicate through symbols, that is, as social objects<sup>(14)</sup>.

The meaning of the impact generated by the hospital environment observed in this study confirms behavioral aspects found in

the literature on the subject. Fear is constant in the process of hospitalization and learning with the care offered to CDT. When they feel threatened, caregivers are predisposed to meanings of fear, insecurity, anxiety and worry, and can qualitatively compromise learning and care provision<sup>(15-16)</sup>.

The situation experienced by the caregivers in the PICU denounces the accessibility and reception deficiency during the educational process in health. It is clear from the analysis of the reports that, for the effectiveness of the care experience with a view to the preparation for the care of the CDT, the caregiver needs to develop a sense of security, even in a non-familiar environment such as the PICU, through care and interaction with the professional and adequate support to consider hospitalized children and their families in this context<sup>(1)</sup>.

Thus, considering that care for a CDT is a critical phenomenon in the lives of those who experience it, it is opportune to remember the importance of the health team in the technical preparation, leading the companion, as a potential family caregiver, to participate effectively in the actions that permeate care in the hospital environment.

Objects and interactions intentionally used in social interaction employ communication to represent something to others. In this perspective, in the interpretation of symbols, the receiver is the actor responsible for defining the situation and acting in response to the table according to definitions, following his/her perception<sup>(14)</sup>.

A review study on CDT care has shown that a barrier in the provision of care is the disbelief of health professionals related to this type of care<sup>(3)</sup>.

In the professionals' view, it can be understood that the family will not be able

to perform the care at home, a fact that predisposes to the decrease of ties and development of safety in the family caregivers to apply the information received, making the process more exhausting.

In this research, the insertion of family caregivers into the reality of the PICU is restricted to the role of mere companions, and health education is performed in a superficial and late manner, as the caregivers who classify the professional care received as below expectations. Planning for the discharge of these children is necessary, aiming at the learning of the caregiver, which must be acquired daily during hospitalization.

However, there was no blame on the members of the health team for this deficiency, attributed essentially to structural and organizational problems and the shortage of employees, since there is a protocol for health education proposed by the team in the unit in question.

These findings shed light on the professional performance of the nursing category, considering that the educational process represents one of the most important duties of the nurse and this is the professional who actively participates in the implementation of care for the CDT in a PICU<sup>(17)</sup>.

Communication is directly linked to language, be it verbal or symbolic. The success of the educational process depends on adequate communication, conducted in an individualized manner with each caregiver, so that the information is carried out in a clear language, enabling this family member to be the care agent.

Regarding the relationship between health professionals and accompanying caregivers, it is worth emphasizing that health education for hospital discharge aims to increase their autonomy, assisting them in building the

knowledge necessary for care, empowering them to exercise complex care<sup>(17)</sup>.

The preparation for hospital discharge should be started from admission, already foreseeing possible referrals and contact with other health units necessary for the maintenance of care in the home environment<sup>(18)</sup>.

As family members experience daily care and develop necessary skills, hospitalizations may be less frequent<sup>(19)</sup>. However, many services transfer responsibility for complex care to families, without a systematic and adequate planning. This transfer constitutes a potentially problematic attitude for two reasons: first, because the reality of hospital institutions does not have the structure and human resources necessary to adequately accommodate and provide support to caregivers, considering them as companions and not as a subject of care; secondly, because the services that constitute basic health care require a re-ordering of their actions, in collaboration with other institutions or care entities, with a view to the standardization of behaviors, aiming at the real inclusion of the informal caregiver in the educational assistance process.

The challenges faced by caregivers in home care were varied. The transfer of the hospital to the home resulted in a desire to "make correct" and contributed to the externalization of feelings related to insecurity and the difficulty of adaptation, aggravated by the lack of support for home care.

In the study, most caregivers live in the municipality where the hospital is located, with 100% coverage of the Family Health Teams. Despite this fact, all the interviewees said they did not receive home visits, as recommended by the Family Health Strategy. The services of the Basic Health Unit were restricted to the dispensing of materials inherent in care.

Thus, despite the existence of regulations for the creation of Home Health Care Services within the scope of the Unified Health System, regulated by ordinance No. 963 of May 2013, (20) according to contact and consultation with the Municipal Health Department, it was confirmed that the municipality does not have any Home Care Team implanted and the procedure is in the process of being studied.

On the other hand, there are initiatives to create non-governmental institutions, as evidenced in a study carried out in the city of Ribeirão Preto, where there are eight such institutions. They have the support of patients, health professionals, civil society and donations from third parties. It is noteworthy that these institutions offer a multi-professional service aimed at monitoring CDT<sup>(1)</sup>.

It is believed that the continuous monitoring of these caregivers can contribute to the amelioration of fear and insecurity in care. The results showed a worrying situation of the condition of care of the CDT, indicating gaps in the process of health education of caregivers and the poor follow-up and monitoring by the public services.

## CONCLUSION

It was verified that the main challenges faced by family caregivers in the execution of complex home care are a deficient instrumentation in the hospitalization, resulting in meanings of insecurity and fear, aggravated by the lack of a support network that contemplates the family of the CDT in their desires and needs.

Notwithstanding the limitations of the investigation, since this is a qualitative study and, therefore, without the pretension of generalizing its findings and conclusions, it

is believed that other studies related to the investigation of this growing reality in our society are also desirable. In this study, subjects do not know where to look for support. It is also important to strengthen reference and counter-referral networks in order to reduce the gaps between hospital care and basic care.

The contributions of the study are mainly related to the opening of a space for reflection on the educational and assistance role of nursing professionals, essential in this care setting, and essential to the process of building family autonomy for care, as a basilar aspect to the quality of life of these patients.

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