



TECHNOLOGY DEPENDENT CHILD: UNVEILING THE REALITY OF THE FAMILY CAREGIVER

CRIANÇAS DEPENDENTES DE TECNOLOGIA: DESVELANDO A REALIDADE DO CUIDADOR FAMILIAR

NIÑOS TECNOLÓGICAMENTE DEPENDIENTES: DESCUBRIENDO LA REALIDAD DEL CUIDADOR FAMILIAR

Muriel Fernanda de Lima¹, Guilherme Oliveira de Arruda², Jéssica Batistela Vicente³, Sonia Silva Marcon⁴, Ieda Harumi Higarashi⁵

This is a descriptive study, with a qualitative approach, with the purpose of comprehending the process of taking care of a technology dependent child, from the perspective of the preferential family caregiver and outlines the strengths and weaknesses of the family within the care process. Semi-structured interviews were conducted with nine family members living in Maringá, Paraná, Brazil in the first half of 2012. Data were analyzed based on Analysis of Content, thematic mode. It was identified that care is centered on the figure of the mother, who goes through a continuous process of learning, struggling with feelings such as fear and insecurity regarding care giving. The process of care imposed changes in the family routine and highlighted the need and importance of the support of the healthcare team to guide and clarify the doubts as well as the adoption of other coping strategies of this new routine.

Descriptors: Family; Child Care; Caregivers; Home Nursing.

Trata-se de um estudo descritivo, de abordagem qualitativa, com o objetivo de compreender como se configura o cuidar da criança dependente de tecnologia, sob a ótica do cuidador familiar preferencial, além de delinear as fortalezas e fragilidades da família no processo de cuidar. Foram realizadas entrevistas semiestruturadas com nove familiares residentes no município de Maringá, Paraná, Brasil, no primeiro semestre de 2012. Os dados foram analisados com base na Análise de Conteúdo, modalidade temática. Identificou-se que o cuidado é centrado na figura da mãe, que passa por um processo contínuo de aprendizagem, enfrentando dificuldades que implicam em sentimentos como medo e insegurança na realização dos cuidados. O cuidado impôs mudanças na rotina familiar, destacando a importância do apoio da equipe de saúde para orientar e sanar as dúvidas, bem como a adoção de outras estratégias de enfrentamento deste novo cotidiano.

Descritores: Família; Cuidado da Criança; Cuidadores; Assistência Domiciliar.

Estudio descriptivo, con enfoque cualitativo, con objetivo de comprender el proceso de cuidar de niño tecnológicamente dependiente, desde la perspectiva del cuidador familiar preferencial y describir los puntos fuertes y debilidades de la familia en el proceso de atención. Fueron realizadas entrevista semiestruturadas con nueve familiares que viven en Maringá, Paraná, Brasil, en el primer semestre de 2012. Los datos se analizaron basados en el análisis de contenido, modalidad temática. Se identificó que la atención se centra en la figura de la madre, que pasa por un proceso continuo de aprendizaje, luchando con sentimientos como miedo e inseguridad en la prestación de cuidados. El proceso de atención impuso cambios en la rutina familiar, destacándose la importancia del apoyo del equipo de salud para orientar y aclarar dudas, así como adopción de otras estrategias de afrontamiento de esta nueva rutina.

Descritores: Familia; Cuidado del Niño; Cuidadores; Atención Domiciliar de Salud.

¹RN. Master's Degree Student in Nursing by Universidade Estadual de Maringá. Maringá, PR, Brazil. E-mail: mflbio@hotmail.com

²RN. Master's Degree Student in Nursing by Universidade Estadual de Maringá. Maringá, PR, Brazil. E-mail: wilhelm_ibm@hotmail.com

³RN. Master's Degree Student in Nursing by Universidade Estadual de Maringá. Maringá, PR, Brazil. E-mail: jessicabatistela@hotmail.com

⁴RN. Doctor. Professor of Programa de Pós-graduação da Universidade Estadual de Maringá. Maringá, PR, Brazil. E-mail: soniasilva.marcon@gmail.com

⁵RN. Doctor. Professor of Programa de Pós-graduação da Universidade Estadual de Maringá. Maringá, PR, Brazil. E-mail: ieda1618@gmail.com

INTRODUCTION

More than a million children in Brazil are hospitalized annually due to different causes⁽¹⁾. These children, facing pathology, suffer changes in the routine of their daily activities and in their own style of living. The technological advance provides the modification of the epidemiological profile of the population, influenced by a greater number of survivors of premature children, with congenital malformation, chronic diseases and traumas. These children, when at home, demand continuous care of complex nature, constituting a challenge for their family caregivers⁽²⁾.

The birth of a child in the family provokes, generally, a transformation of the whole family unit, once they usually place a lot of hope around that new being. However, when such expectation is not confirmed, the family many times is surprised by an intercurrent health of a bigger complexity, demanding the immediate hospitalization of the child, in an intensive therapy unit⁽³⁾.

In the sequence of these events, the return of the child to the family and the resume of the daily life also comes as challenges to be faced by the family, keeping in mind that, not always everything turns to be the way it was before. The disease itself and the therapeutic process necessary to the recovery of the child can result in indelible traces, sequels which meet medical and nursing care which demand the continuity of the care for variable periods. So, the process of hospital discharge of a child who is dependent of complex care requires specific knowledge, once this patient represents a high risk of instability, of one or more physiological systems, with possible risks to health and very tenuous limits between life and death⁽⁴⁾.

In Brazil there are not data which allows evaluating how many children live in limitrophe conditions of life or surviving with the use of technology, which makes their treatment and the assistance to their family members difficult. When the child arrives at home

there is not the necessary adaptation for the due care of the technology dependent child (TDC). Furthermore, the family members are suddenly forced to develop care which previously only happened in the hospital unit by a specialized health team⁽⁵⁾.

So, in order to subsidize future strategies which allow the softening of the insecurity of the family/caregivers in these contexts, the present study aimed at understanding how the care of the TDC is established under the vision of the main family caregivers; also delineating the implication of the process of care related to the routine of life of the caregiver and the family dynamic structure, and it also makes clear the strengths and the frailties of the family in the care rendered to the TDC, from the preparation until the support for a care action.

METHOD

It is a descriptive qualitative study made with family members of technology dependent children (TDC). Nine caregiver mothers participated in the study, resident in the county of Maringá – Paraná – Brazil, in the areas of the scope of Basic Health Units (BHU) NIS Pinheiros and NIS Mandacarú. The choice of the referred units was justified by the fact that they are responsible for a wide area of urban scope in the county.

The data were collected in the first semester of 2012 through interviews which were previously scheduled and made in homes of the participating families. The criteria of inclusion were: caregivers whose families were selected in the BHU, they had to be the main family caregivers of the TDC in the age range from 3 to 12 years. The age range was established in order to exclude younger children and with high degree of dependence due to their age.

For the data collection, at first, in a visit to BHU, Health Communitarian Agents (HCA) of all the teams of the Family Health Strategy (FHS) acting in the referred

BHU were contacted. Such intermediation was chosen due to the fact that these subjects have a previous link with the families of interest of the research, thus favoring the approximation of the researcher with the families. Together HCA the survey was made, through Electronic Health Records, of the TDC within the scope of HCA, and their health history was collected. Later on, through telephone calls, the families were invited to participate in the study, and if they agreed, the work went on with the scheduling of the interviews in the homes of the families.

The interviews were guided by a semi-structured script, elaborated by the researchers and constituted by two parts: the first one was referring to a brief characterization of the participant (caregiver) and family; the second one was turned to the central theme of the study, in which the participants were invited to talk freely on the subject. The statements were registered with a use of a digital recorder, besides the register in a Record Book used for the notes of manifestations with the use of non-verbal language such as gestures, postures, facial expressions, etc.

For this analysis the statements were transcript and then edited for better clarity and comprehension, although the original sense was kept. Later on, they were submitted to the Analysis of Content, theme mode⁽⁶⁾, by separating the text into themes or units, which were grouped again according to a unit of codification previously established (theme unit).

The theme analysis establishes the division by team units⁽⁶⁾, which resulted in the configuration of three categories: 'Maternal care', regarding the care that the family renders to the child in the day-by-day, as well as the existence of competence for such care, 'Implications and feeling during care' which discusses the feeling that the family experiences in living with the child and the changes or routine resulting from this experience, and 'Frailties and Strengths: the role of net of support and pillar' which approaches the importance of the support

offered to the family, community and health team.

The research was developed after the authorization of the Secretaria de Saúde do Município (Health Department of the County) and approved by Comitê Permanente de Ética em Pesquisa (Permanent Committee of Ethics in Research involving Human Beings) of the Universidade Estadual de Maringá (COPEP /UEM), under administrative rule no. 41616 CAAE 03565012.6.0000.0104. In order to assure the anonymity of the informers the names of Angels were used to characterize the children, once they are divine messengers for the role of protection, orientation and sustaining in the more diversified circumstances. The choice is justified by the fact that the mothers interviewed brought with them the special son as a gift. In their statements they affirm that the TDC gives them the necessary courage and strength to lead their lives.

RESULTS AND DISCUSSION

Nine caregiver mothers participated in the study, resident in the county of Maringá – Paraná – Brazil, in the areas of the scope of Basic Health Units (BHU) NIS Pinheiros and NIS Mandacarú. They were between 27 and 46 years old, and all of them stated to be the main caregivers of the TDC, once they performed most or the totality of the care to the child. As to the family income and occupation, four mothers worked out of the house and five were exclusively dedicated to the full time care of the TDC. The causes of technological dependence found in the families were varied, prevailing the following medical diagnoses: meningomyelocele, cerebral palsy, renal insufficiency, and a diagnosis of a disease of genetic origin such as Tay-Sachs disease. Almost all the children included in the study needed the help of a wheel chair, vesical probing and nasoenteric probing, for the maintenance of physiological needs.

In most of the interviewed families, seven of them, there was only one who contributed for the family income. The schooling of the interviewed subjects varied

between illiteracy (one case) up to university level (one case), complete high school (one case), incomplete high school (one case), predominating the incomplete grade school (five cases). The houses visited were located in paved neighborhood with an average of four to five rooms, most of them made with brickwork and all of them with treated water, thus suggesting the average income. Despite the fact that all the families had a register at the BHUs, not all of them use the services offered by them.

Maternal care

The statements of the caregiver illustrate the configuration of care centralized in the maternal figure. The secular conception that care is the woman's responsibility makes the woman assume all the responsibility of the care with the child, imposing several changes to the life of this woman⁽⁷⁾.

Taking a care of a technology dependent child requires training and orientation from the health team, keeping in mind that it is up to this caregiver the responsibility of rendering care which until then was provided by a specialized team in a hospital. The following statements illustrate how the training for the care was configured. *I had the training, then I had to stay sixty days with him like that, every afternoon I would go to the hospital, we arrived at one in the afternoon and then, like, eight thirty, nine o'clock I was leaving the hospital. The days I was there I had the training. I had the training every day, in the last weeks I was taking care of Caliel alone, then they wouldn't come into the room anymore. They would say 'look, you are going to do what you can, because at home you are going to do this' (Caliel's mother). And from there I began to learn to prepare intermittent catheterism in the child, which I didn't do before. Until she was 2 years old I didn't do it, I didn't know how it works and I refuse to do it because I was afraid, then she taught me and said: here or in any other hospital you must use sterilized gloves in order not to contaminate the gloves and you need to have a complete asepsis with Povidine - that is what she taught me what to do - now, not at home. At home you wash your hands well, keep normal hygiene, don't touch on the tips and so we do the right thing (Hazel's mother).*

So we perceive the role exercised by the health team in order to provide subsidies for the construction of

the autonomy of these mothers for the care. Caring can be conceptualized as doing for the other something he can not do by himself, helping, orientating, teaching, supervising⁽⁸⁾. These cares are difficult to follow due to the lack of manual skills or even influenced by factors of emotional origin. *The first two times the doctor passed the probe, next month it will be me. She explained me everything and I am the one who is going to fix it. It is rather strange, isn't it? But I have to learn how to do it because one time or another I will have to do it. Ah... It is weird, isn't it? But I have to learn and gain experience. I stay with her the whole day...Ah, for me, the probe was the most difficult item to accept! But when the doctor fixed it I saw that it was better for her, she became stronger, more active, and she became another child....then I accepted. But it was difficult (Reyel's mother).*

The fact that there is only one caregiver can be a cause of overload. In a study⁽⁹⁾ made in Aracaju, Sergipe, Brazil, on the evaluation of the overload with 21 caregivers of children with cerebral palsy, become evident that the long period the mothers dedicated to care added to the performance of role of housewife generates an overload for themselves, once they can not get away from these tasks along their daily journey. The physical and mental cumulative wearing out, resulting from the care, can result, not rarely, in damage for the health of the caregiver and jeopardizes the performances of other activities⁽¹⁰⁻¹²⁾, leading her to being sick. *The hardest year for me was last year, when I got sick, wasn't it? It was like this: I got sick because I thought I was like this, strong to the extreme, right?! I thought I would never get sick! Then it is a very high stress (Daniel's mother).*

Such situations of weariness usually come up, as the result of the exclusive dedication to the care of the child, leaving to a second plan the care of oneself, in a relation of donation which finally develops great psychic suffering, affecting the structure and the welfare of the whole family. *I have to wake up because he wears diapers and I change them several times a night, because there is a lot of pee. He goes to the toilet several times but at night it is difficult. How is he going to wake to go the toilet so many times? So, in order to not let him wet, I wake up to change the diaper. I do my part (Caliel's mother).*

We learn from the observation of the difficulties

faced by these families, the need of a more effective professional contribution. In this sense, we point out the importance of the nursing team to understand how the process of taking care of a TDC is configured in order to be moved with the reality of these families, searching for ways of providing them humanized attention, in favor of the quality of life of the child and the caregiver.

Implications and feelings in the course of care

The arrival of a TDC in the family imposes to its members the experience of situations of impact, fear and insecurity, thus making evident the need of adaptation of the whole family to a totally new and unexpected situation. So, the peacefulness of the home is substituted by a routine which is many times severe, marked by the lack of comfort and by alternated moments of anguish and resignation⁽¹³⁾. *But then difficult appeared because...I divorced, stopped working and my father died four days later, and then I was in the hospital without work, without home and with a daughter* (Mehiel's mother).

It is common to the main caregiver to emphasize the exclusive dedication to the TDC, showing physical and emotional overload, abdication regarding herself, keeping away from work and the social interaction, as a way to guarantee full time care. In a general way the mothers, whose children depend continuously on technology, tend to develop depressive symptoms and also to experience instability within the family functioning⁽¹⁴⁾. However the keeping away from work and social interaction can have a repercussion in other spheres of family organization, for example, in the family income, which then becomes another generating source of anguish and worry. Such abdication is also resulting from the sensation of constant threat of loss of the TDC, which has as repercussion over protective attitudes and an excessive care in most of the times^(10,15). We must also consider that the mother shares the suffering caused by the disease and hospitalization with her children, in such a way that they need to be included in the assistential process during the hospitalization, they

can develop feelings of insecurity and doubts, which, in the last instance, make the taking and effectiveness of the care to the child difficult⁽¹⁰⁾. *Because you give up a lot of things in your life...you deny everything for yourself, in order to attend the child* (Ariel's mothers). *Yes, I had to quit my job to take care of her* (Reyel's mother).

According to what was previously discussed, the task of taking care of family members with health problems belongs predominantly to the woman. In the case of the TDC the role of preferential caregiver is almost always restrained to the mother. It is possible to learn from the mother's statements, manifestations of feeling such as love, caress, welcoming, support and sympathy. Besides that, due to the fact that the family caregivers followed their beloved beings for a long period of time, the clinical oscillations of the little patient, provoke a sensation of anxiety and constant expectation regarding the prognosis, in a such a way that the welfare of the child ends up being the welfare of the caregiver as well. *Because we love, don't we? We love our child the way she is! This for me is the best love, the unconditional love, right?* (Ariel's mother). *Ariel is a blessing for me I don't see her as a burden for me, I see her as a blessing for my life, you know? You can leave here happy for what I am saying is the truth for you* (Ariel's mother).

New problems can come up within the families who have a TDC to be taken care of. A very common challenge in this scenario is to keep the financial stability of the family, once they feel pressured to buy new medical hospital equipment, as well as to make adequacies in home environment, in order to better assist the needs of care of the child. Keeping in mind that in many of the cases such equipment is not available to public health, the threat of discontinuity of the care ends up generating restlessness, discomfort and feelings of helplessness in the family members once they can not offer the best to the sick child. *Ah, we have to adapt, don't we? We need to adapt the bathroom for him, but for now, we have not been able to build the bathroom* (Daniel's mother). The need to offer technological apparatus which provides support to the family care was also important in a ethnographic

study made in the countryside of the State of São Paulo highlighting the social vulnerability which may occur in the cases of families with low income⁽¹⁶⁾.

Among the challenges faced by the family members, besides the change of routine and structural adaptations to receive the TDC, we found loss of the structure of the family, the mother, as the main caregiver, feels the obligation to take care of the child full time, focusing her energy and spending a good deal of her time to the TDC. It is common that the mother neglects any questions related to her own care, as well as the moments of living and attention to the other members of the family, inducing her to a process of social isolation. *That is it, I stopped working, my husband didn't, but I stopped my whole life to take care of Ariel, so I don't have any income, I stopped everything to take care of Ariel* (Ariel's mother).

The focus of multi-professional attention in the care of the TDC must, besides other characteristics, be directed to the family members, in a way to allow the maintenance of the cohesion among its members and to stimulate the family to actively participate in the treatment. Such support ought to be able to instrumentalize this family to the care and at the same time make them understand and learn how to deal with internal conflicts. The main caregiver must bear in mind that he alone is not able to offer complete care of quality and when trying to do so he puts the TDC at risk and the family stability.

Frailties and strengths: the role of the net of support and help

The care of a TDC, besides being characterized as a generator of psycho emotional implication for the caregiver and the changes of the routine and family structure, is also within a net of support in health from which it receives positive and negative support regarding the caring action.

The mother's opinions on the support received from the health professional show diversities with reports which show the absence or discontinuity of the

educative-assistential process up to a closer relationship with the same especially in the initial phase of diagnoses and in the process of acceptance of the condition presented by the child. *The doctor had already warned me about this. Opposite to the first physician who only gave me the diagnosis and told me to go away. She didn't say anything else, didn't explain anything of the disease. Just told that he would die, and that's all* (Nithael's mother). *And the nurses there in the office, before, when he was very young they also came to our house and helped a lot. Now they stopped visiting, and they don't even come by* (Daniel's mother). *This physician, she was super super super, I mean, she couldn't be better! A lot of good people assisted Mikael in such a way! She was the one who discovered what he had* (Mikael's mother).

The statements of these mothers point out the importance of the professional accompaniment; from the first approach during the diagnosis of the child, until the adaptation, the orientation regarding the use of the technological devices, and regarding the differentiated care the set of this contribution evidences the need of initial orientation and the importance of the longitudinality of the link⁽¹³⁾. With that, we point out the relevance of the establishing of an empathy relationship between the health professional and the family members in a posture which reveals the worry of the health team with the capacity of the mothers to assimilate the provided orientation⁽¹⁷⁾.

The support of the family to the preferential, caregiver, when present, happens in different ways and under specific conditions in order to optimize the care or to allow that the child's mother can attend other needs while she temporarily designates her function of taking care to someone she trusts. But there is the absence of the family unit in the support of care can contribute to the frailty of the one who takes care. *They help to apply medicine in the probe. Everybody does everything, everybody helps and everybody cares. And sometimes when she ate in the mouth, nobody wanted to help. 'Ah no, and what if this girl feels something wrong and chokes'* (Reyel's mother). *When the purpose is to walk around, they don't like to stay. But when the matter is to take her to the doctor they never said no, right* (Ariel's mother). *When I need to go to the doctor, my niece comes and stays with Menadel and he likes this nurse a lot* (Menadel's mother).

In the sense to minimize the weariness and the tiredness naturally provoked by the stress associated to the care, the development of a solid family structure is indispensable⁽¹⁰⁾, in which the other member share their doings, becoming available to share the charge, thus contributing to the quality of life of everyone involved⁽¹⁸⁾. For that, it is very important that the caregivers have someone to share this care, facing the impacts of this overload on their health, not only the physical health but also the psychic-emotional health. The following statements show this need. *We share the care, but even then, I am quite tired, right?* (Daniel's mother). *I saw I had no one to count on, I asked the father of my son and he said: No! You will have to find a solution, because I already have my family. During the day, I can ever take care. But at night no – but it was difficult, but I went on. He (the former husband) gives me support, not in the beginning, but now he does* (Caliel's mother).

Among other possibilities of support and help, the mothers search for orientation in order to improve the care and for activities which benefit the children, such as horse back riding with the auxiliary therapeutic purpose, and facilitator of the social interaction of the child. The access to these activities happens through the appointment of the people or known professionals. *I saw on TV, and the doctor, the neurology doctor, and then he told me that it will be very good. The physicians give clues, don't they?* (Menadel's mother).

In this perspective, we can notice that the different components of the supporting nets and the help of family caregivers, can collaborate to the strengthening of the capacity and autonomy to care, making the care easier and softening the anguish, leading to the development of mechanisms of coping with the difficulties which may be presented in the trajectory of the families.

Frailties and difficulties, faced by the family, also permeate the care to the children. The reports on the context of care reveal obstacles imposed by the system of health, by the public means of transportation and accessibility (slopes, bus stair), by the impossibilities of family support and the misfortunes of life. *The SUS (Unified*

Health System) provides nothing to anyone, no! In order to get a vaccination for pneumonia, he has to take pneumomia23 vaccination, what a difficulty! They do not give support. Just like they told me: he only needs support! But they don't give any support (Nithael's mother). *To be honest with you, I see it like this: there is a lot of lack of accessibility* (Ariel's mother). *The only fault I see is that there is means of transportation but no one to help with this matter...is to board these busses with no help* (Menadel's mother). *At first I always asked the help from my mother-in-law, from my sister-in-law. But then, they also worked, so it was difficult for them to come at the time I needed it, I had to wait and such* (Mihael's mother).

The system of Brazilian health (SUS) is still unable to attend the population demand of families who need complex cares at home, thus occasioning the helplessness⁽¹⁵⁾ and the appearance of problems to be coped with, above all, by the families who are obliged to assume this care by themselves, as a result of the difficulty of accessing preventive and therapeutic resources.

Concerning the public areas, the mother referred to obstacles both related to transportation as well as the access to some places and public institutions. Because they need to move with heavy and difficult management health equipment, such as a wheel chair for example, the family members are faced with an exhaustive situation in which they become vulnerable to home confinement⁽¹³⁾.

CONCLUSION

The care of a TDC brings a series of implications to the family caregiver, requiring adaptations of the home environment in order to perform this care, as well as promoting drastic changes in the routine of the family. This process generates a range of feelings, such as fear, and insecurity facing the performance of the procedures and diverse doubts, leading to physical and emotional overload to this caregiver.

Regarding the net of support and health, we perceived a discrepancy in the opinions of caregivers regarding the role performed by the health professionals in the care to the child. The continuity of the following-

up, the adequate and sufficient orientation and the quality of the attention rendered by the health professionals are reported together with the presentations of inadequate postures, the discontinuity and the lack of attention and empathy to the family caregivers.

Thus, the mothers search for alternatives and support in the other members of the nuclear family, specially in the spouse and in the other children, or even in the extended family, health professionals and other institutions. Nevertheless, they trust above all, in the care they provide themselves anchoring their security in the acquired experience with the daily experiences of care, making themselves the protagonist of these daily tasks.

Frailties and difficulties of several matters make part of the context to care to the TDC by the family members and they require strategies of coping, in order to make it effective, however, without jeopardizing the family integrity. In this context the need of help of a health team is evident, orientating and enabling these caregivers thus minimizing their fears and anguish, and offering subsidies so that the family can adapt itself to the new routine within adequate patterns of quality of life.

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