



ENGLISH

Federal Fluminense University

AURORA DE AFONSO COSTA
NURSING SCHOOL



Original Articles



Technology-dependent children: the meaning of home care – a descriptive study

Muriel Fernanda de Lima¹, Luis Fernando de Paulo², Ieda Harumi Higarashi¹

1 State University of Maringá

2 State University of Londrina

ABSTRACT

Aim: To highlight family strengths and weaknesses in terms of the care provided to children who are dependent on technology, and changes occurring following the return of these children to their homes; to discuss challenges and opportunities for family inclusion in the healthcare process. **Method:** This study uses a descriptive method that employs a qualitative approach, conducted with families of chronically ill technology-dependent children in a city in southern Brazil. The information obtained was treated according to the methodological frameworks of content analysis and thematic modality, and the theoretical framework of symbolic interactionism. **Results:** Data analysis was performed by distilling/separating data into five thematic categories, which were explored and discussed. **Conclusion:** The study gave an insight into the meanings that the family attributes to the experience of caring for a technology-dependent child, identifying the weaknesses of care and the gaps in the support provided by health services.

Descriptors: Home Care; Chronic Disease; Family Relations

INTRODUCTION

Chronic non-communicable diseases (CNCDs) have taken an important place in the agenda of the discussions around Brazilian public health. They are a global health problem, which qualitatively threatens health and human development⁽¹⁾.

The worsening of the population's CNCD-related health problems can be linked to the demographic transition and the epidemiological situation in our country, which has resulted in a reduction in the levels of fertility and mortality, especially in children and in the aging population, with the reordering of new health needs⁽²⁾.

The reduction in infant mortality rates can be easily explained by the technological advances relating to healthcare; on the other hand, there has been a relative increase in chronic diseases, along with attention paid to public policies aimed at children's health. In this context, a new set of demands in children's care has emerged, relating to technology-dependent children (TDC). These are children in need of medical devices—tracheostomies, gastrostomies, mechanical ventilators, enteral and bladder catheterization, specialized treatments (physiotherapy, speech therapy)—for the maintenance of inherent life activities⁽³⁾.

The level of commitment found in cases of TDCs is variable, and can range from children dependent on low technologies to those that require the use of mechanical ventilators⁽⁴⁾.

For families that experience chronic disease, the provision of care aimed at TDCs is a challenging task, given that the arrival of TDCs into the household demands numerous changes to the family's dynamics and everyday routine. Thus, this study has the following objectives: to highlight family strengths and weaknesses in the care of TDCs, and the changes occurring following the return of a child to the household;

and to discuss the challenges and possibilities for family relationships as they relate to the specialized care of chronically ill children.

METHOD

The theoretical orientation of the work is based on the tenets of symbolic interactionism (SI): a social science capable of portraying the actions of humans in relation to the world, focusing on the nature of interaction and social dynamics among individuals. We opted to use SI because it is a theory for which meaning is the central concept, and the interaction between people takes place within a social and symbolic structure, where individual action is meaningful for those who create and those who receive it⁽⁵⁾.

Content analysis⁽⁶⁾ was the methodological background used. This is a research method used in textual data analysis, which aims to provide knowledge and an understanding of the phenomenon studied. The systematic classification of the coding and identification process of themes consists of a subjective interpretation of the textual content.

The study was conducted with the families of the TDC, and the inclusion criteria were as follows: the interviewee should be the preferential caregiver of a TDC, hospitalized in the pediatric intensive care unit (PICU) within the survey period; they should be aged 18 years or older; and the TDC should be of the right age to be classed as a child, as defined by the Statute of Children and Adolescents, which extends to 12 years of age⁽⁷⁾. The PICU was chosen as part of the initial stage of the research, since it is from their experience of the care provided in the unit that a family is led to truly engage with the TDC's treatment.

The study took, as its starting point, a university hospital located in the northwest of Paraná, after the project had been approved by the Standing Committee on Ethics in Human Research of the State University of Maringá (COPEP) (Opinion 131.658/2012). Data collection took place following the caregivers' signing

of an informed consent form by the caregivers, during the period from March to June 2013.

Data were collected through non-participant observation in the PICU of the aforementioned hospital and by conducting interviews on two occasions: during hospitalization and at home. We used two semi-structured scripts containing, respectively, 16 and 18 guiding questions prepared by the researchers and previously tested with a group of three caregiving mothers who were not included in the study.

RESULTS

Of the 14 caregivers interviewed, 13 (93%) were mothers of TDCs and one (7%) was the maternal grandmother; two (14%) were aged between 20 and 29 years, five (36%) were aged between 30 and 39 years, four (29%) were aged between 40 and 49 years, and three (21%) were aged between 50 and 59 years. Seven caregivers (50%) were married women, three (21%) reported having a steady relationship, and four (29%) were divorced.

Eight respondents (57%) were not employed and provided full-time care to TDCs, alongside home activities. The family income of nine caregivers (64%) ranged between one and three minimum wages; four caregivers (29%) earned between three and five minimum wage; and one (7%) could not name their income. Schooling ranged from no formal education (14%), through incomplete primary education (50%), to five completed high school references (36%).

The TDCs were aged between five months and seven years. The medical diagnoses found to favor the installation of technological dependencies were syndromes of genetic origin, respiratory failure, heart disease, hydrocephalus, microcephaly, and others. All the children had more than one diagnosis, and among the technological dependencies found, we can highlight tracheostomy, gastrostomy, mechanical ventilator use, and enteral and bladder catheterization.

In order to address the central themes of the study, the research presentation has been divided into five categories. To ensure the anonymity of the participants, they are identified according to the order of realization, with the letter "I" and their interview number.

1) DELIVERING DIFFICULT NEWS

Receiving the news that the long-expected child must now depend on the aid of devices for the maintenance of their life represents a distressing situation for the family:

I thought it was the end. Nobody explained the problem correctly to me; the doctor said that lately the hospital was going through a bad harvest and that several children were born with disabilities... It sounded like he was talking about a damaged tomato crop. (I12)

This mother showed a great deal of outrage regarding the way she received her son's diagnosis (Field Diary).

According to the perception of the researchers, discourses emerged laden with meanings that denoted disappointment and indignation concerning the insensitivity of the health professionals.

For most mothers, a child's dependency on technology in order to keep it alive can lead to a sense of failure, arousing feelings and emotions permeated by fear, guilt and rejection. An insufficient or inadequate supply of information about the TDC ultimately accentuates these feelings of discomfort:

At first I was not aware of what was wrong with her. My other boy was born perfect; she also had to be perfect.

Had I done something wrong during pregnancy? (I13)

One mother reported her nonconformity and ignorance regarding the diagnosis of her five-year-old TDC. She insistently questions the researcher in an attempt to establish a justification for the use of tracheostomy (Field Diary).

The weakness of caregivers can be minimized through the health professionals' taking an appropriate approach to the moment of giving the news. Thus, the timing and the method of notifying the family about the diagnosis may represent an important milestone in the acceptance process and the family's adaptation to this new condition:

The nurse was so kind. She called me and my husband and explained that my boy had been born with a little problem and would have to undergo a tracheo. She took us to the ICU to show us other children who had also had tracheal and could lead a happy life. (I7).

Since it is a moment of high vulnerability, the participation of health professionals in welcoming and supporting the diagnosis of the TDC is a key factor in the emotional balance of the whole family.

2) READJUSTING THE HOME STRUCTURE AND FAMILY DYNAMICS

The arrival home of a TDC can impose conflicting and challenging situations onto family members. This stage is characterized by a succession of events, sensations and feelings that resonate within the family, especially the initial impact of non-acceptance of the TDC by other family members:

No one wanted to get too close and everyone was afraid of taking care of him. My oldest son came to say that he did not like him anymore. (I3)

These psychosocial effects appear frequently in the context of the initial strategies of coping with a chronic condition, affecting both marital and family relationships with varying degrees of intensity:

My husband did not care for her at the time. He said he only made perfect children and that the disabled girl was not his daughter. He disappeared in the world and I had to drop everything and start my life over. I became depressed. (I12)

One mother explained how she overcame difficulties in the course of caregiving, exhibiting her psychiatric prescriptions. She left work and now counts on a TDC retirement for the financial maintenance of her household (Field Diary).

The conflicting atmosphere illustrates the exclusive and exhaustive care dedicated to the TDC, and the beginning of conflicts emerging from the initiation of new household arrangements.

Concurrently, the need for a structural re-adjustment of the home emerged as a source of concern and anguish for family members:

I had to remodel a room and adjust some things. (I5)

One maternal grandmother showed us the renovated room, along with the creation of a bathroom and the expansion of space for holding belongings and appliances. This environment presented evidence of recent renovation, such as unpainted walls (Field Diary).

It was difficult to rearrange the room to fit the devices and the furniture in the necessary way (12).

Added to these adaptations in the home, or even as a result of such demands, there are financial difficulties that result from the acquisition of technological equipment and the materials necessary to maintain care:

It was hard to get this vacuum cleaner; I had to go on television because there weren't any such devices available in the health department. (13)

One mother showed us a recording made of the local news, presented on an open channel. By means of the program, she immediately received a donation of a secretion vacuum extractor. The purchase of the equipment was linked to the hospital discharge of the child (Field Diary).

3) THE PERFORMANCE OF COMPLEX CARE IN THE HOUSEHOLD

Faced with the reality of the need to provide TDC care, caregivers find themselves in a scenario marked by ignorance and misinformation in terms of the complexities of home care:

At the hospital they taught me quite a lot. Doubts appeared when I had to do everything by myself. (11)

In this statement, the meaning of this realization concerning the complexities of home care emerges. This is the experience expressed by the mother through her references to the fear and doubts that mark this situation.

Generally, the caregiver overcomes these difficulties by seeking skills for the implementation of care, based on the realization that

any difficulties or weaknesses that the TDC can present do not represent the guiding principles of the child's existence:

I thank God for having enabled me and given me the conditions to take care of my son. I don't see him as a sick child; the sick ones are those who say my son is sick. (18)

Besides the rejection of the child's disability, this mother constantly seeks qualifications to help her improve her TDC's care, demonstrating her course certificates to us. At home, several symbols denoting her attachment to religion are present, such as paintings with biblical messages in the entrance hall and in the TDC's room (Field Diary).

In contrast, some caregivers exert an approach care that could sometimes be considered excessive:

Only I take care of him. I don't trust anyone else to do it. I know I'm doing the right thing. (17)

It is noticeable that this mother carries out a thorough care routine. In the TDC's room, we could observe the presence of hygiene items in abundance, including alcohol gel, liquid soap, napkins and disposable procedure gloves (Field Diary).

4) PHYSICAL AND EMOTIONAL OVERLOAD

Being the caregiver of a TDC means abdicating of your own needs to live for the sake of your sick child. Caregivers are often consigned to social isolation and feel physically and emotionally overwhelmed, as illustrated in the following statements:

It takes me a long time. I do a follow up with a cardiologist, with the psychiatrist, and I also used to go to a psychologist twice a week. (I5)

His cradle is in my room and I have to vacuum it all the time. (I11)

Due to technological dependence and care in dealing with medicines, the cradle and the TDC's belongings occupy considerable space in the parent's room (Field Diary).

Another aspect of the interviewees' discourse, denoting the completeness of the caregivers' dedication to the complex demands of care, is based on their leaving work definitively and the resulting social isolation, a scenario in which the caregiver begins to live almost exclusively for the functions of the TDC:

I had to leave work to take care of him. I managed to provide for his retirement because, after I quit my job, everything was very difficult (I7).

The abandonment of work often appears to be the only viable approach to meeting the TDC's care demands and working through the difficulties emerging from the new conflicts imposed by the situation experienced. Emotions and feelings can be described as loaded with meanings relating to fear, insecurity and sorrow:

It was hard to adapt to this life, especially leaving work. I was very sick in the head. (I1)

When they feel limited, the caregivers become predisposed to anxiety, which gradually triggers psychological conflicts and psychosomatic illnesses. They face nontransferable experiences,

permeated by helplessness and a constant need to escape from reality:

I wonder how long I will have the strength to bear it all. I sometimes ask myself if I might wake up and see that everything has just been a bad dream. (I5)

The mothers often become exhausted, with tired faces and dark circles under their eyes (Field Diary).

The impact of living with a TDC can be a painful and conflicted process, manifested through speech or through other signs indicating the distress, exhaustion and overload related to care.

5) HEALTH SUPPORT NETWORKS: REALITY OR UTOPIA?

Health professionals are not always prepared to give a welcome to families that take care of chronically ill children with complex care needs. In their interviews, the meanings behind caregivers' disbelief emerge:

The only place I go with him is to the hospital. They already know his case there. I take him to the post just to get him vaccinated. (I7)

The health center people came here to sign her up when they learned that she was disabled and that I would need materials every week. They come here to replenish everything I use. (I12)

The second report reveals a very inadequate level of real assistance and a deficient network of professional support, which is restricted to the provision of materials and

supplies for the viability of providing care to the TDC. The superficiality of participation, and almost nonexistence of a primary care network, is even more evident when observing in the first report that the hospital is still depended upon for references and support relating to home care, while the basic health unit is responsible for routine actions, such as vaccinations. Thus, it is clear that the tertiary care referral service is the one which, in fact, guarantees assistance and priority services in the case of the worsening of the chronic disease. We were able to observe, therefore, a lack of reference provision in relation to TDC care within primary care, and the disconnection between reference services and counter-reference in health:

The doctor says that the fact that my son is going to a physiotherapist and a speech therapist is important for his recovery, since they have all these resources there in the hospital. But when it comes at the health center, there is never any availability of care (I11).

The helplessness reported by caregivers reveals an absence of places or assistance services and support aimed at caregivers. The reality of healthcare services offered by the municipality does not offer assistance support capable of carrying out the continuous monitoring of the TDC and his family.

DISCUSSION

The significant interpersonal interactions exchanged by caregivers over family care reverberate in their search for understanding, support and treatments suitable for their

children's chronic illnesses, and for successful ways to learn how to deal with complex care.

Corroborating previous studies on caregivers, among all potential relatives, mothers are more numerous in this sphere, finding themselves more often forced to assume the role of caregiver⁽⁸⁻⁹⁾. Maternal altruism greatly contributes to the prominence of mothers in home care, since they are traditionally responsible for the family's care provision. Thus, the provision of care, from its simplest to its most complex forms, seems to be the most natural solution for mothers in these scenarios.

From the reports relating to the TDC care experience, it was possible to identify the obstacles and mechanisms that had to be overcome by caregivers, as well as the meanings assigned to each key moment experienced in the course of childhood chronic illness. One crucial component to be initially considered is the impact of the news concerning the chronic disease and the insensitivity of some health professionals, as reported by the participants. Within the diagnosis period, the family experiences a shock reaction, giving rise to feelings and emotions intertwined with fear, anxiety and even denial; this is a crucial period in which the family needs all the support and clarification it can get from a qualified health professional⁽⁴⁾.

The attitudes of professionals reported in this research denote a lack of skill, empathy and sensitivity when announcing a chronic condition diagnosis that will have severe repercussions throughout the family nucleus. Following the impact of this diagnosis, the caregiver will establish a procedure for interaction and make gradual preparations concerning the child's condition, their new situation of health, and changes to family life, through interaction with family members and frequent communication with health professionals.

Lima MF, Paulo LF, Higarashi IH. Technology-dependent children: the meaning of home care – a descriptive study . Online braz j nurs [internet] 2015 Mar [cited year month day]; 14 (2):178-89. Available from: <http://www.objnursing.uff.br/index.php/nursing/article/view/5191>

This phenomenon leads the caregiver to associate the diagnosis with the meaning she assigns to this overall experience, taking as its starting point the announcement of the news by the health professional, as well as the way in which she receives the news.

Caregivers demonstrate their need to participate in and understand the diagnosis, and the importance of feeling welcomed and supported by the service and by professionals. Moreover, their questions regarding the chronic disease can lead them to feelings of helplessness, failure, guilt or rejection, generated by their having a child who is different from the child they might have desired^(4, 10).

The incentive for the participation and inclusion of the family during the TDC's diagnosis period is the responsibility of the health service, and some of its duties include ensuring emotional and physical support, as well as offering the human resources capable of providing care in times of fragility and vulnerability. However, this study found that, in reality, these services still have weaknesses in terms of family care, which become evident both at the point of diagnosis and in their monitoring practices.

Conflicting and challenging situations are established in the wake of a chronic condition diagnosis involving technological dependence. Initially, the family tends to become unstructured in its search for a realignment of its routine, in order to accommodate the child. It is a new experience, which commonly causes forcible changes to the personal dynamics of everyone involved. Concomitantly, there is a search for alternatives in order to achieve family stability, such as the division of tasks and a search for qualifications relating to the exercise of care. Such alternative dynamics generally proved to be a failure in this study, since the only person who gave up their

routine activities was the family's preferred caregiver, often the mother⁽¹¹⁾.

A lack of information regarding the diagnosis and the type of technology used by the TDC can fuel myths regarding care, leading to gaps in the caregiver's understanding of their own learning. As shown in the third category, misinformation on the part of the TDC's support services can sometimes lead caregivers to perform care excessively. Such an attitude constitutes a potential risk to both the TDCs and their mothers, since there is no guarantee that the care provided by these mothers will represent the care required by the child. Another obstacle created by the situation is social isolation, which is also harmful to both caregiver and TDC, bearing in mind that the caregivers alone cannot meet all their children's needs.

Overall, we can perceive that the provision of care includes different stages, each marked by its own strengths and weaknesses. Thus the presence of a single caregiver may constitute an obstacle to the clinical and psychological development of the TDC. Family caregivers tend to feel overwhelmed and socially isolated since care requires commitment, resulting in the physical and emotional exhaustion of those who perform it⁽¹²⁾.

Often health services provide the caregiver with a brief training course for practicing basic care, considered insufficient and surrounded by doubts and insecurities. Other services, however, credit the family caregiver with competences and responsibilities for which she is not properly qualified^(11, 13-14).

It is noteworthy that one of the greatest conflicts faced by caregivers is that of social relationships. A complex set of care responsibilities can determine the way in which caregivers relate to themselves, their partners, families, health professionals and the environment that surrounds them⁽¹⁵⁾.

Another important aspect of this scenario is the fact that caregivers who had previously financially contributed to the maintenance of their households were often forced to leave their jobs in order to take charge of caregiving as a full-time occupation.

Another condition imposed by this situation, and highlighted in the reports in this study, relates to marital status; dedication to childcare can mean the breaking of matrimonial ties, or else the mother ends up being forced to choose between childcare and marriage. Such a dilemma is based on a supposed incompatibility in the exercise of the social roles of women, whereby on one side there are the obligations concerning a woman's moral fulfillment of her role of mother and caregiver, and on the other, there is the pressing yet challenging need to seek the qualifications required to provide complex care⁽¹⁶⁾.

In the midst of this atmosphere of change is the need to readjust the structures of the home, as a way of seeking comfort and an environment conducive to the positioning of technological devices. However, the structural difficulties of the home emerge as a constant vulnerability, that is, the quality of life of the TDC is closely related to these physical and behavioral changes. In many cases, as shown in the survey, the family does not have the financial conditions to allow a restructuring of the physical environment, resulting in feelings of guilt and denial that force parents to make use of various means for the acquisition of materials.

Due to the need for individualized and specialized care, caregivers require the continuous monitoring of health services. We noticed the establishment of an adversarial relationship, or even a total lack of relationship, when the caregiver's association with their

basic health service was restricted to the simple dispensing of inputs for maintaining the technological apparatus.

The difficulty in creating bonds between health services and family caregivers reinforces the need for primary care restructuring, since the current structure is not sufficiently prepared to meet the growing demand from chronic cases, referring them instead to more complex services channels and hampering the provision of an integral and humanized assistance.

From the perspective of quality assurance and the necessity of offering comprehensive care to the TDC, there is the emergence of a need to articulate between the different levels attending to the continuity of care⁽¹⁷⁾. In the reality faced by the caregivers surveyed, a prior training is provided in the hospital that minimally prepares them for the performance of home care. From the statements, it is clearly necessary to continue this process of preparation and support, ensuring that assistance and the proper monitoring of the children's clinical course is offered.

In terms of continued attention, regular monitoring is needed that should be performed by a multidisciplinary team, qualified to provide care focused on the care demands of the TDC and family, within the principles of assistance humanization. Thus, it is understood that the Ministry of Health has been seeking strategies to provide grants to states and municipalities for the reorganization of home care networks, in order to accommodate the chronically ill and their family caregivers. This initiative was formalized with the establishment of Ordinance No. 963 of May 27, 2013, with a view to home care being consolidated within the ministerial program "It is Better at Home". Such an initiative has great potential for improving the patient's and family's

Lima MF, Paulo LF, Higarashi IH. Technology-dependent children: the meaning of home care – a descriptive study . Online braz j nurs [internet] 2015 Mar [cited year month day]; 14 (2):178-89. Available from: <http://www.objnursing.uff.br/index.php/nursing/article/view/5191>

comfort without the need for hospitalization, and for a consequent reduction in the overcrowding of hospitals and a reduction of risks such as nosocomial infection⁽¹⁸⁾.

This study has shown that not only is there a total absence of this type of assistance for families, but there is also an extremely superficial and incipient performance level of primary care service operations, preventing the maintenance of qualified care to the TDC at home.

A literature review on the care aimed at families who experience chronic illnesses has demonstrated some weaknesses in assisting families, according to the views of health professionals, such as a lack of space allotted in the patient's record for information relating to the provision of care by families⁽¹⁹⁾.

The need to include the family's perspective throughout the care process arises from the need to empower families to carry out home care, along with a follow-up of the family's teaching-learning process, which should be assured in the information records in all interactions with professional healthcare services. From this perspective, the caregiver should be instructed in relation to the nursing process, and could be evaluated by the team in order to receive a "hospital discharge" for the exercise of complex home care procedures, before having a subsequent follow-up with primary healthcare. However, such a level of assistance does not reflect the reality of Brazilian public health, due to certain limitations to assistance services relating to the precariousness of human, material and financial resources.

Knowledge, in terms of the family's experience in relation to complex care requirements, becomes essential when planning efficient care and educational interventions in support of domestic practice⁽²⁰⁾. The encou-

agement provided by studies and strategies geared towards the education of family caregivers aims to promote the autonomy and participation of the family, in terms of the care provided to the TDC, as well as the positive meanings of the individual and collective relationships established with the health services. Furthermore, this knowledge emphasizes the need to stimulate changes in the healthcare scenario of TDC care, and in the transition of this care process from the hospital to the household, in order to rescue the individual particularity of this experience and provide a good quality of life to the families facing chronic conditions.

CONCLUSION

The symbolic meanings attributed by caregivers—the protagonists in the provision of complex care—to their experiences demonstrate the obstacles and conflict situations arising in their search for well-being and the security assurances in the care offered. The level of integral and humanized care that takes TDCs' families fully into account still remains a challenge, requiring a paradigm shift from a care model centered on pathology.

In summary, the path taken by caregivers in understanding the diagnosis of TDC—and the complex care it requires—has enabled us to obtain the requisite knowledge relating to the obstacles that arise from this experience, amid a deficient and disarticulated public health system. It should be stated, however, that the results obtained and analyzed emerged from unique and specific experiences in the exercise of complex care.

In order to reverse this situation, numerous actions have been announced by the Ministry of Health, in order to organize and

regulate the attention afforded to the chronically ill in home care, through an appropriate valuation of the preferential caregiver. Given this issue, we must remain attentive to the necessity of developing actions that address the demands of training and monitoring caregivers at all levels of care.

REFERENCES

1. Schimidt MI, Duncan BB, Silva GA, Menezes NA, Monteiro CA, Barreto SM, et al. Doenças crônicas não transmissíveis no Brasil: carga e desafios atuais. In: *The Lancet – Saúde no Brasil*. [cited 13 set 2013]. Available from: <http://www.thelancet.com/series/health-in-brazil>.
2. Mendes EV. O cuidado das condições crônicas na atenção primária à saúde: o imperativo da consolidação da estratégia da saúde da família. Brasília: Organização Pan-Americana da Saúde; 2012.
3. Kirk S, Glendinning C, Callery P. Parent or nurse? The experience of being the parent of a technology – dependent child. *J AdvNurs*. 2005;51(5):456-64.
4. Okido ACC, Hayashida M, Lima RAG. Profile of technology-dependent children in Ribeirão Preto-SP. *J. Hum. Growth Dev*. 2012; 22(3): 291-296.
5. Blumer H. *Symbolic interactionism: perspective and method*. Englewood Cliffs: Prentice-Hall; 1969.
6. Bardin L. *Análise de conteúdo*. Lisboa: Edições 70; 2011.
7. Brasil. Presidência da República. Subchefia para Assuntos Jurídicos. Lei nº 8.069, de 13 de julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente. Brasília (DF); 1990 Jul 13.
8. Lima MF, Arruda GO, Vicente JB, Marcon SS, Higarashi IH. Crianças dependentes de tecnologia: desvelando a realidade do cuidador familiar. *Rev Rene*. 2013; 14(4): 665-73.
9. Rezende JM, Cabral IE. As condições de vida das Crianças com Necessidades Especiais de Saúde: determinantes da vulnerabilidade social na rede de cuidados em saúde as crianças com necessidades especiais de saúde. *R. pesq.:cuid. fundam. online*. [Internet].2010 [cited 2011 Out 16]; 2(Ed. Supl.):22-25. Disponível em: http://www.seer.unirio.br/index.php/cuidadofundamental/article/view/773/pdf_68.
10. Lima EC, Ribeiro NRR. A família cuidando do filho dependente de ventilação mecânica no domicílio. *CiencCuid Saúde*. 2009; 8(suplem): 110-16.
11. Leite NSL, Cunha SR, Tavares MFL. Empowerment das famílias de crianças dependentes de tecnologia: desafios conceituais e a educação crítico reflexiva freireana. *Rev. Enferm. UERJ*. 2011; 19(1): 152-6.
12. Pontes-Fernades AC, Peten EBL. Sobrecarga emocional e qualidade de vida em mães de crianças com erros inatos do metabolismo. *Psicolteorpesqui*. 2011; 27(4): 459-65.
13. Floriani CA. Home-based palliative care: challenges in the care of technology-dependent children. *J Pediatr (Rio J)*. 2010;86(1):15-20.
14. Rabello AFG, Rodrigues PH. Saúde da família e cuidados paliativos infantis: ouvindo os familiares de crianças dependentes de tecnologia. *Ciênc Saúde Coletiva*. 2010; 15(2):379-88.
15. Santo EARE, Gaiva MAM, Espinosa MM, Barbosa DA, Belasco AGS. Cuidando da criança com câncer: avaliação da sobrecarga e qualidade de vida dos cuidadores. *Rev. Latino-Am. Enfermagem*. 2011; 19(3): 9 telas.
16. Guimarães CA, Lipp MEN. Os possíveis porquês do cuidar. *Rev. SBPH [internet]*. 2012 [cited 2011 Oct 16]; 15(1): 249-63. Available from: http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1516-08582012000100014&lng=pt.
17. Silva RVGO, Ramos FRS. Processo de alta hospitalar da criança: percepções de enfermeiros acerca dos limites e das potencialidades de sua prática para a atenção integral. *Texto Contexto Enferm*. 2011; 20(2): 247-54.
18. Brasil. Presidência da República. Lei n. 963, de 27 de maio de 2013. Redefine a Atenção Domiciliar no âmbito do Sistema Único de Saúde. *Diário Oficial da república Federativa do Brasil, Brasília (DF)*; 2013 Ago 8.
19. Elsen I, Souza AIJ, Prospero ENS, Barcellos WBE. O cuidado profissional às famílias que

vivenciam a doença crônica em seu cotidiano. *CiencCuidSaude*. 2009; 8(suppl): 11-22.

20. Wang KWK, Barnard A. Technology-dependent children and their families: a review. *J Adv Nurs*. 2004; 45(1): 36-46.

All authors participated in the phases of this publication in one or more of the following steps, in According to the recommendations of the International Committee of Medical Journal Editors (ICMJE, 2013): (a) substantial involvement in the planning or preparation of the manuscript or in the collection, analysis or interpretation of data; (b) preparation of the manuscript or conducting critical revision of intellectual content; (c) approval of the versión submitted of this manuscript. All authors declare for the appropriate purposes that the responsibilities related to all aspects of the manuscript submitted to OBJN are yours. They ensure that issues related to the accuracy or integrity of any part of the article were properly investigated and resolved. Therefore, they exempt the OBJN of any participation whatsoever in any imbroglios concerning the content under consideration. All authors declare that they have no conflict of interest of financial or personal nature concerning this manuscript which may influence the writing and/or interpretation of the findings. This statement has been digitally signed by all authors as recommended by the ICMJE, whose model is available in http://www.objnursing.uff.br/normas/DUDE_eng_13-06-2013.pdf

Received: 03/17/2015

Revised: 05/11/2015

Approved: 05/20/2015