
RELATIVES' PERCEPTION REGARDING THE STRESSORS RESULTING FROM THE CARE DEMANDS OF TECHNOLOGY-DEPENDENT CHILDREN AND ADOLESCENTS¹

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ABSTRACT: This qualitative study, guided by the System Model Theory was performed with the objective to identify the perceptions that relatives taking care of technology-dependent children and adolescents have regarding the stressors that affect their relationships, as a result from the care they provide to their children. Data were collected through semi-structured interviews, and then subjected to thematic categorical analysis. Nine women of different families participated. Three categories emerged: "I live for him/her now"; "Stressful situations happen all the time"; The man x woman relationship changed. Women identified the occurrence of multidimensional, everyday changes in their family life and, particularly, in their personal life, as they practically took over the whole care alone, abandoned their job, leisure, and "being a woman". It is concluded that in order to guarantee the accomplishments made possible by technological advancement, families warrant support, particularly for the women, through policies that permit them to take care of their child and also achieve personal fulfillment in other dimensions.

DESCRIPTORS: Family relations. Stress, psychological. Hospice care.

PERCEÇÃO DE FAMILIARES SOBRE ESTRESSORES DECORRENTES DAS DEMANDAS DE CUIDADO DE CRIANÇA E ADOLESCENTE DEPENDENTES DE TECNOLOGIAS

RESUMO: Estudo qualitativo, orientado pela Teoria do Modelo de Sistemas de Cuidado que objetivou identificar percepções de familiares sobre estressores nas suas relações, consequentes ao cuidado de crianças/adolescentes dependentes de tecnologia. Os dados foram coletados através de entrevistas semiestruturadas, e submetidos à análise categorial temática. Participaram nove mulheres de diferentes famílias. Três categorias foram evidenciadas: "Minha vida ficou em função dele(a)"; "Sempre estão acontecendo situações que estressam"; A relação homem x mulher mudou. As mulheres identificaram a instalação de mudanças multidimensionais, cotidianas, na vida de suas famílias e principalmente nas suas vidas, uma vez que assumiram quase que integralmente o cuidado, abdicaram do trabalho profissional, do lazer e de "ser mulher". Conclui-se que para garantir as conquistas possibilitadas pelo avanço tecnológico é necessário apoiar a família, especialmente a mulher, com políticas que permitam a ela cuidar da criança/adolescente e realizar-se em outras dimensões.

DESCRIPTORES: Relações familiares. Estresse psicológico. Cuidados paliativos.

LA PERCEPCIÓN DE LOS FAMILIARES SOBRE LOS FACTORES DE ESTRÉS COMO CONSECUENCIA DEL CUIDADO A NIÑOS Y ADOLESCENTES DEPENDIENTES DE TECNOLOGÍA

RESUMEN: Es un estudio cualitativo, exploratorio y descriptivo, basado en la teoría del modelo de sistemas de cuidado, con el objetivo de identificar la percepción de los familiares sobre los factores de estrés en sus relaciones, como consecuencia del cuidado a niños y adolescentes dependientes de tecnología. Los datos se recolectaron a través de entrevistas semiestruturadas, sometidas al análisis de categorías temáticas. Nueve mujeres de diferentes familias participaron. Se encontraron tres categorías: "Mi vida dependía de él (ella)"; "Siempre ocurren situaciones de estrés"; La relación hombre mujer cambió. Las mujeres identificaron la instalación de cambios multidimensionales, cotidianos, en la vida de sus familias, y especialmente, en sus vidas, ya que asumieron casi integralmente el cuidado, abandonaron su labor profesional, ocio y el "ser mujer". Se concluye que para asegurar los logros obtenidos por el avance tecnológico es necesario apoyar a la familia, especialmente a las mujeres; con políticas que le permitan atender a los niños y adolescentes y también realizarse en todas sus dimensiones.

DESCRIPTORES: Relaciones familiares. Estrés psicológico. Cuidados paliativos.

INTRODUCTION

The prevalence of children/adolescents who survive critical health situations, whether due to genetic or congenital conditions, traumas, infections, preterm birth or chronic diseases has increased significantly thanks to advanced technology and permanent care, which improve life expectancy as well as quality of life.^{1,4}

This new reality brought about a particular population referred to as technology-dependent children/adolescents, i.e., those with chronic diseases that warrant technological devices to attain clinical conditions compatible with recovery and/or survival, including in the home environment.³ Those devices can help with their nutrition, elimination, respiration or other functions, and are present in cases such as hemodialysis, peritoneal dialysis, mechanical ventilation, oxygen therapy, parenteral nutrition, tracheostomy, urostomy, ileostomy, colostomy, cardiorespiratory monitoring, in the form of catheters, tubes, cannulas and bags. Part of these children/adolescents makes use of more than one technological device, and are also dependent on some kind of medication.³⁻⁶

Besides the technical needs, which demand trained caregivers to apply and/or handle the devices, these children/adolescents require specific and prolonged care due to their baseline health conditions and the frequent clinical alterations.⁴

The development of smaller, portable and simplified devices, in addition to increasing survival rates, has made their handling easier, which allows for training lay caregivers. This has made it possible, and adequate, for technology-dependent children/adolescents to receive care at home.⁷

Families with technology-dependent children/adolescents live a different everyday life compared to families with "healthy" children. They have additional responsibilities and tasks, and endure changes resulting in multiple stressors.⁸⁻¹¹ One example is the transition of these children/adolescents from hospital to home, which implies a redefinition of the meaning of home, as the presence of medical supplies and equipment may decharacterize the family environment.⁴

The extensive and varied array of stressors associated with the situation lived by the technology-dependent child/adolescent has the potential

to affect all individuals that live with him/her. The changes in the family dynamics and relationships can emerge from the relatives' experiences and feelings.¹²⁻¹⁵ It is, therefore, considered that the interaction between family and technology surpasses the handling of devices.^{1,8}

Within this context, "the family is usually confronted with new demands, changes in their routine, constant adjustments and readjustments, which means the disease can affect several domains of the family: financial, occupational, personal, and interactions in and outside the family, alike".^{11,65}

In face of the established situation, i.e. the family having to cope with the new and multiple demands of care by the technology-dependent child/adolescent and the possibility of suffering an impact on family life, this study was developed with the objective to identify the perceptions that the relatives of technology-dependent children/adolescents have regarding the stressors resulting from their children's care demands.

THEORETICAL FRAMEWORK

In order to support the investigation process, Betty Neuman's System Model was adopted. In this model, the author follows the system concept, characterizing the forms of continuing interaction that take place between the environment and the client (human being, family, group, community); an interaction that can break stability due to the ongoing stressors.¹⁶⁻¹⁸ Stressors are intra-, inter- and extra-personal forces of nature, while reaction is the degree of energy that the client produces in order to face stressors and adapt.¹⁶

Interventions are actions that help the client achieve, sustain and/or reestablish a given stability of the system. There are three levels of intervention in face of the presentation of stressors: primary prevention, which can begin at any time when the stressor is identified; secondary prevention, which begins when the primary prevention was not successful, and the "client" already presents a reaction to the stressor, which purpose is to be an initial treatment of the symptoms, and attempts to strengthen the resistance lines to diminish those reactions. Tertiary prevention consists in reinforcing the resistance to stressors in order to prevent the recurrence of the reaction or regression.¹⁶⁻¹⁸

Reconstitution is the state of adaption of the stressful elements in an inner or outer environment, and can begin at any degree or level of reaction with the objective to establish a new well-being pattern.¹⁶⁻¹⁸

METHODOLOGY

This qualitative study was performed using an exploratory-descriptive perspective. The study took place at a reference pediatric hospital in Santa Catarina State, involving the treatment of children/adolescents in units B (surgical), C (cardiology and nutrition), D (pulmonology and nephrology) and E (neurology), where it is common to have children/adolescents as inpatients.

The subjects were the respective relatives accompanying technology-dependent children/adolescents hospitalized during the data collection period, which occurred between August and November of 2009. The relatives were older than 18 years and accompanied the referred patient in the hospital for at least 48 hours. The children/adolescents had been using the device for at least two months; a time considered necessary for the family to have lived the experienced of the care using that technology.

The study was approved by the ethics committee of the respective hospital (protocol number 045-2009), and complies with resolution 196/96 of the National Health Council.

The first contact with the relatives occurred at the hospitalization units, when they were introduced to the study and invited to participate. They were informed about their rights, according to all ethical principles, and signed the informed consent form.

Data collection was performed through semi-structured interviews, recorded on an mp3 recorder, and then transcribed. The interview script contained guiding questions based on the study objective, which included: how has your family life been since your child/adolescent had to begin using... (technological device(s))?, what care does your family have to take because...(name of child/adolescent) is now using the ... (technological device(s))?. For you, what stresses your family the most from (name of child/adolescent) having to use the... (technological device(s))?.

The mean duration of the interviews was 50 minutes, and they were performed in specific places of the hospitalization units where it was possible to provide privacy. The names of the

participants were replaced by numerals on the recordings.

The data were subjected to thematic categorical content analysis, adopting the following procedures: construct the body of data (transcribed interviews) based on the formulated questions, considered as pre-categories; perform successive readings of the obtained material, aiming at achieving a comprehensive understanding and envisage possibilities; mark, on the transcribed text, any words, phrases or groups of phrases with meaning related to the study objective (meaning units); divide the text and form meaning unit groups, considering the pre-categories, taking into consideration aspects such as homogeneity (not having dissimilar elements), exhaustiveness (exhausting the whole text), exclusivity (each element was included in one group), and adequacy or pertinence (adjustment to the objective and content). In this way, the pre-categories were formed, improved and/or modified, based on the adopted procedures. Finally, a generic title was assigned to each group (category). The resulting structure was inferred (deductions, causes, consequences) and interpreted.¹⁹

RESULTS AND DISCUSSION

All nine participants, companions of the hospitalized technology-dependent children/adolescents, were women (eight mothers and one sister).

Regarding their ages, three women were between 20 and 25 years, four were between 30 and 35 years, and two between 38 and 41 years. It is highlighted the women were all adults and within a working/active age group when they faced the need to take care of their technology-dependent children/adolescents.

Five women reported being housewives, three held a job that did not require formal training (janitor, saleswoman, seamstress) and one had a technical-level job (accounting). Two women did not have a partner, one lived with her boyfriend, five were married with the father of the child/adolescent, and one participant, who was the sister of the child/adolescent, was also married.

The following chart presents the age, time of device use, medical diagnosis and type of device used by the children/adolescents. The children/adolescents were represented using numerals; the same identification was used to represent the respective family member, adding the prefix "fam".

Chart 1 - Characterization of the technology-dependent children and adolescents, relatives of the participants, hospitalized between August and November of 2009 in a pediatric hospital in Florianópolis-SC

Child/ adolescent	Age	Time of device use	Medical Diagnosis	Technological device used
Nº1	1 year and 2 months	9 months	Down's Syndrome; Laryngotracheomalacia	Gastrostomy Tube (GT)
Nº2	2 years and 2 months	2 months and 15 days	Food allergy; Hypogammaglobulinemia	GT
Nº3	2 years	1 year and 10 months	Microcephaly; swallowing disorder	GT
Nº4	3 years	3 years (SVA) 2 months (GT)	Congenital hydrocephalus; Myelomeningocele; Neurogenic bladder; Bilateral grade V vesicoureteral reflux; Bilateral hydronephrosis	GT Intermittent Urinary Catheter (IUC)
Nº5	6 years	1 year	Chronic kidney disease (CKD); steroid-resistant nephrotic syndrome after Wilms Tumor	Tenckhoff catheter for CAPD
Nº6	7 years	7 years	Hydronephrosis; Neurogenic bladder	SVA
Nº7	11 years	8 months	Bladder exstrophy	SVA Mitrofanoff catheter (MC)
Nº8	12 years	12 years	CKD; Nephrotic syndrome	SVA MC
Nº9	14 years	14 (SVA) 15 days Mitrofanoff catheter	Myelomeningocele; Neurogenic bladder; Bilateral grade V vesicoureteral reflux evolving to bilateral hydronephrosis	SVA MC

From the obtained data, three categories emerged regarding the participants' perceptions of stressors in the family relationships due to the care demands of technology-dependent children/adolescents, which are presented below.

"My life changed because of him/her"

The participants mentioned facing various changes with different effects on the relatives' lives, but they consider that their life is the one that changed the most. They now devote their lives exclusively to their technology-dependent child/adolescent; some do so because they feel "obligated", others because they believe that it is worth sacrificing to provide the child with a better quality

of life. These data are similar to those reported in literature, regarding the fact that technology wins a central role in the lives of these families.³

The following statements portray the reported situation: *life changed, you know? It changed at home, in the care I gave [...], the expenses, it changed in every sense (fam9). In my case, I'm obligated to this [...] we always have one extra obligation, right? I'm really the one that does most of it (fam2). They have their lives, right? I'm the one left with most of the chores (fam5).*

The participants also stated they quit their jobs or reduced their hours because of the care demands and because of the time needed for the frequent visits to specialist health institutions and/

or social support. At home or in the hospital, while other relatives leave to go to school or work, they usually stay alone, devoted to caring for the child/adolescent. They perform repeated procedures several times a day that require regular intervals, and, therefore, they are under the pressure of keeping schedules. The highlighted procedures were: preparing tube feeding; cleaning the catheter insertion site; performing peritoneal dialysis; constant hygiene care; moving the device "delicately"; supervising the conditions of the insertion site of the device checking for leakage, inflammation or infection; obtaining the devices at health centers, city administrations and non-governmental organizations (NGOs).

The following statements refer to these activities: [...] *I live just for her, you know? [...] preparing her bottle every three hours, performing the dialysis [...] that's how I use my time [...] (fam5). At home I take the two tubes and wash them every time I use them, with very hot water, I put them away in a tightly closed container, dry it well and put it away, at least six times a day [...] (fam1).*

Another reported aspect, influenced by the omnipresence of the disease, technology and care, was the change of "being home" and "being a mother". They now live in an environment that is "half home and half hospital", stay long periods with their children/adolescents at health institutions and are called on to perform activities that require professional training, which they do not have, but acquire by performing the care every day. Because they have become "half professionals, half mothers", they cannot simply play the role of parents of "normal children/adolescents". These circumstances involve establishing a new and different family routine imposed by the dependence on technology, which produces the incorporation of functions that were once performed only by professionals and trained people.^{1,4,8,10}

Regarding leisure, the participants reported facing difficulties or impossibilities in this respect. The following statements illustrate these situations: *for me? There isn't (leisure) for me! There isn't time for that. My leisure is only my daughter, right?(fam2). Our "hobby" is going out and coming back quickly, because he needs all this care (fam8). The fact that he uses a tube, makes it a bit more difficult... It restrains us because... like...sometimes we do go out (fam6). [...] when you go out it's like packing to move. There's the syringe, the tube, the food (fam3).*

Literature⁵ highlights that caring for technology-dependent child/adolescent can lead the family

to social isolation, making severe restrictions to outdoor family activities, confining them to the house. It is also highlighted that this association is intensified by the fact that the family considers that leaving the house with all the necessary devices is a burden.^{1,13}

Usually there is no break in the care, and when respite does occur, it is accompanied by worries regarding the quality of the care that the designated person is providing.⁵ Participants who reported receiving more significant support from the family in the care, and are therefore able to enjoy a few hours of leisure or develop other activities revealed they find it hard to disconnect, and their thoughts are constantly drawn to the child/adolescent, as shown in the following statement: [...] *when I go out I call home all the time to know how he is doing [...] (fam9).*

"Stressful situations happen all the time"

This category reflects the relatives' perception that, besides changing their lives, the condition of the child/adolescent also changes consistently and keeps the family under constant tension. Likewise, the fact that the child/adolescent depends on the technological device to survive was referred as a significant source of stress. The following statements illustrate the referred aspects: [...] *if you have a child with problems at home, you know life is not stress-free (fam9). It's... everything is stressful, right? Because she was a healthy child, you know? Now she depends on this device, right? So everyone is stressed out [...] (fam5).*

On their first contact with the technological devices, fear and doubts emerge regarding their capacity to perform the care appropriately and this was highly stressful for them. The reports below reflect the situations perceived by the participants: *in the beginning it was a shock having to place the catheter there [...] (fam7). In the beginning I was afraid of the tube. When they talked about placing it [...] I shivered (fam3).*

After a certain period of handling the device, the family becomes adapted to it, and this first impact is reduced. By observing this movement through the lens of Betty Neuman's framework, we initially see the reaction to the stressor elements developed by the person and/or family followed by an activation of resistance and adaptation reflected on the movement of a normal line of defense to closer or farther from the baseline structure, but aiming to maintain the balance of the system.

The following statement illustrates the trajectory to reach success in handling the device: *in*

the beginning of using the gastrostomy everything was slow. Suddenly, when you realize it you are already prepared. Then it is easy because there is a little black stain on the tube, so you just match the black spot that connects to the tube. They you turn it this way and it locks, doesn't get loose? Then you go back, align the black spots and pull it out (fam3).

After becoming adapted to handling the device, the participants highlighted the evidence of stressors associated with the continuous care, which must be performed following regular schedules and intervals and with specific responsibility and techniques, with the purpose of avoiding complications. This form of care causes exhaustion on relatives/caregivers as a participant reported: *every hour, I mean, at the end I couldn't eat or sleep anymore (fam7).*

Some participants reported that certain relatives in addition to being afraid to handle the device also fear that they are not performing the care correctly and that this could cause problems to the child/adolescent, such as infections. They also stated that the constant supervision of the hygiene of the environment and of the location where the technological device is inserted is a persistent worry for everyone. One participant reported: *I always sterilize the room very well, I dust everything, I change the linens, I wash my hands well before passing the catheter in him[...] I'm afraid he can get an infection because imagine if it gets on that thing (catheter), right? [...] We are always that way [...] (fam7).*

Some situations involving infection episodes occur, despite, according to the reports, all the indicated care had been implemented. The continuous fear of infection, because it leads to hospitalization and/or can put the life of the child/adolescent at risk was referred as being a significant stressor that permeates the family life as a whole.

The perception that the child/adolescent was feeling pain associated with the use and/or handling of the technological device was also evidenced and can be confirmed in the following statements: *[...] she has complained about the gastro. She says it is painful, that it hurts, you know? [...] this worried us [...] (fam4). [...] sometimes she refuses to let us handle it, probably because it hurts too much. So... that is our greatest concern (fam2).*

Another stressor for the family, referred by the participants, was the compatibility with the activities of normal children/adolescents in the same age group, considering that some activities pose risks due to the use of the device. This is evidenced in the following statements: *[...] we*

didn't want him to play soccer because it could hit the [...] (fam7). I go to the pool, but then my husband has to stay outside with her because she can't go in because of the tube [...] how can you put her in a bathtub that you don't know how well it is washed? (fam3).

Literature refers to situations similar to those presented by the relatives, stating physical, emotional, social and financial burdens as consequences, particularly for women, who are the main caregivers, besides the fact that intense and prolonged stress is health hazardous.¹ The following similarities were highlighted: living with the reality of depending on a technological device to support the life of the child/adolescent¹³; the probability of health status changes due to complications causing readmission or putting the life of the child/adolescent at risk^{4,10,13}; the occurrence of pain associated with the use and/or handling of the technological device^{4,5,13}; the relatives' strangeness, unfamiliarity or deficiencies in handling the technologies^{4,10}; care that must be performed continuously and following regular schedule and intervals^{1,4,5,13}; and the compatibility with activities of children/adolescents of their age group with normal activities.¹³

The man x relationship changed

The movement of the family around the disease, handling the technological device and the woman's intense involvement in meeting the needs of the child/adolescent had a stronger effect, according to the participants, on the husband-wife relationship. Regarding the couple's other children, the participants consider they "go on with their lives", school, work, friends and family. Literature, on the other hand, refers a feeling of abandonment and emotional disorders, among other aspects, caused by an interruption or reduction in the care given to the other children.²⁰

The participants perceive that men and women are more worried, there are more elements causing tension, a large part of their conversations is about the situation of the child/adolescent, and about responsibilities and care. Conjugalinity is, therefore, affected because the "time for the husband" is reduced, and withdrawal is reinforced by frequent and often long absences of the woman, who is usually the one who accompanied the child/adolescent during hospitalizations, exams or specialist services. On participant says: *[...] we drew farther apart now, perhaps because we stay too long in hospitals, then we end up leaving that routine (fam2).*

The aforementioned data agree with those reported in a study stating that the burden caused by providing continuous care to these children/adolescents increase stress and family relationship problems. With time, communication between spouses can become composed exclusively of trivial elements, wearing the relationship, and they eventually no longer share their feelings.^{10,14}

Changes in the husband's mood and in "his" behavior were also mentioned as aspects that affect the couples' relationships. This is illustrated in the following statements: [...] *my husband is very nervous, you know? For him, everything is a fight. He gets this way when she is not well or when she is in pain (fam5). The change that occurred was my husband's behavior, because he was an excellent person... then he started to feel stressed, irritated, very nervous [...] He locked himself up and became isolated (fam2).*

The father was, in general, referred to as not being very helpful in performing the care, in spite of the woman recognizing that "he" is strongly concerned with the child/adolescents. They usually accommodate with the fact that "she" does everything, validating cultural aspects of the gender relationship in which men work outside the home and women take care of the house and the children.

Factors that can deteriorate the couple's relationship include conjugal disagreements resulting from a possible difference in task division, and the emotional and physical weariness of the caregivers, particularly women.⁴ The couple devotes less attention to each other and thus eventually compromise their moments of intimacy.¹³ The following statements address the issue of dividing the task and the correlated cultural aspects: *every now and then, when he is in a good mood, he even helps me give her a bath (fam2). [...] it's because he is used to working, putting food on the table those things you see? [...] It's not that he doesn't want to help me, it's because he thought I was the one who had to do that (fam7). [...] instead of his father helping me, he only disturbed me[...] (fam1). [...] when I have some things to do I say either help me or take a hike. So there are come times that we also end up feeling stressed out (fam2).*

FINAL CONSIDERATIONS

The hospital companions of technology-dependent children/adolescents revealed their perceptions about the occurrence of multidimensional changes in the family life permeated by stressors.

When they assume, and, on the other hand, are culturally assigned more responsibilities in the

care, in addition to performing numerous complex procedures, distributed and repeated along the days, and also in face of the limited amount of leisure and rest, they become more tired, more worried, and less available to other aspects of family relationships and social life. Recurrent medical visits and hospitalizations also affect the women's life with their partner and other relatives. The dimension of the woman being is concomitantly reduced to the strengthening of the mother/caregiver.

If on the one hand the development of technologies associated with family planning has boosted women's personal, social and professional growth, paradoxically, the technologies that promote the life support for children/adolescents with serious diseases imply that women must return home and assume the multiple responsibilities demanded by one member of the family. The care becomes the top priority in their lives, ratified by the cultural aspects of gender and, thus, participants define conjugality as an area of great influence on the stress they experience.

By observing the physical, emotional, and social demands involved in the care for technology-dependent children/adolescents, particularly on the women, we identify uncountable outer and inner forces that have the potential to change the existing balance, break the stability of the individual (woman) and/or family system, which can affect the baseline structure of energy resources and trigger the defense in the normal system, as indicated by the adopted framework by Betty Neuman.

For women, men suffer have more concerns towards the child/adolescent. Because of the condition of the child/adolescent, their mood and behavior changes. They become tense with the suffering endured by the child/adolescent. However, the women highlighted that the men do not collaborate much in face of the new demands; they fear and often refuse to deal with the technological devices.

Finally, though this study, it is understood that the stressors perceived by the participants regarding the care demands of technology-dependent children and adolescents were evidenced, as well as their effects on conjugality. The identified limitation of the study is the impossibility to evidence the perception of other relatives. In this sense, further studies should be conducted to address this aspect.

As stated by Betty Neuman, healthcare professionals should develop interventions that help families to recover and maintain the balance of physiological, psychological, sociocultural, developmental, and spiritual variables, so they are

capable of adapting and readapting to the situations that emerge in their lives, aiming to achieve health/wellbeing. Furthermore, to guarantee the achievements made possible through technological advancement, it is necessary to support the family, particularly the women, with policies that permit them to take care of the child/adolescent and also achieve personal fulfillment in their family relationships and as social subjects.

REFERENCES

1. Leite NSL, Cunha SR. A família da criança/adolescente dependente de tecnologia: aspectos fundamentais para a prática de enfermagem no ambiente hospitalar. *Esc Anna Nery Rev Enferm.* 2007 Mar; 11(1):92-7.
2. Fracolli RA, Ângelo M. A experiência da família que possui uma criança/adolescente dependente de tecnologia. *REME Rev Min Enferm.* 2006 Abr-Jun; 10(2):125-31.
3. Drucker LP. Rede de suporte tecnológico domiciliar à criança/adolescente dependente de tecnologia egressa de um hospital de saúde pública. *Ciênc Saúde Colet [online].* 2007 [acesso 2009 Mar 05]; 12(5):1285-94. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232007000500026
4. Wang KWK, Barnard A. Technology-dependent children and their families: a review. *J Adv Nurs [online].* 2004 Jan [acesso 2009 Mar 05] 45(1): 36-46. Disponível em: <http://eprints.qut.edu.au/2014/1/2014.pdf>.
5. Kirk S. Family's experiences of caring at home for a technology-dependent child: a review of the literature. *Child Care Health Dev.* 1998 Mar;24(2):101-14.
6. Gavazza CZ, Fonseca VM, Silva KS, Cunha SR. Utilização de serviços de reabilitação pelas crianças e adolescentes dependentes de tecnologia de um hospital materno-infantil no Rio de Janeiro, Brasil. *Cad Saúde Pública [online].* 2008 Mai [acesso 2008 Nov 10]; 24(5):1103-11. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0102-311X2008000500017&lng=pt&nrm=iso&tlng=pt
7. Glendinning C, Kirk S, Giuffrida A, Lawton D. Technology-dependent children In the community: definitions, numbers and costs. *Child: Care Health Dev.* 2001 Jul; 27(4):321-34.
8. Vidal M. Sobre a internação domiciliar: aproximações de uma nova modalidade de assistência. *Rev Polêmica [online];* 2007 [acesso 2009 Mar 05] Abr-Jun; (20). Disponível em: http://www.polemica.uerj.br/pol20/cquestoes/artigos/contemp_3.pdf
9. Castro EK; Piccinini CA. Implicações da doença orgânica crônica na infância para as relações familiares: algumas questões teóricas. *Psicol Reflex Crit [online].* 2002 [acesso 2009 Mar 10]; 15(3):625-35. Disponível em: <http://www.scielo.br/pdf/prc/v15n3/a16v15n3.pdf>.
10. Kirk S, Glendinning, C, Callery P. Parent or nurse? The experience of being the parent of a technology-dependent child. *J Adv Nurs.* 2005; 51(5):456-64.
11. Santos SV. A família da criança/adolescente com doença crônica: abordagem de algumas características. *Aná Psicológica.* 1998 Mar; 16(1):65-75.
12. Althoff CR, Renck LI, Sakae SVSS. Famílias de criança/adolescente s que necessitam de cuidados especiais: o impacto sobre a vida familiar. *Fam Saúde Desenv.* 2005 Set-Dez; 7(3):221-9.
13. Nunes MDR, Dupas G, Ferreira NMLA. Diabetes na infância/adolescência: conhecendo a dinâmica familiar. *Rev Eletr Enferm [online].* 2007 [acesso 2009 Mar 10]; 9(1):119-30. Disponível em: <http://www.fen.ufg.br/revista/v9/n1/pdf/v9n1a09.pdf>
14. Damião EBC, Ângelo M. A experiência da família em ter uma criança/adolescente com doença crônica. In: Gualda DMR, Bergamasco RB, organizadores. *Enfermagem, cultura e o processo saúde-doença.* São Paulo (SP): Ícone; 2004. p. 119-34.
15. Macdonald H, Callery P. Parenting children requiring complex care: a journey through time. *Child: Care Health Dev.* 2007; 34(2):207-13.
16. Cross JR. Betty Neuman. In: George JB, organizador. *Teorias de enfermagem: os fundamentos para a prática profissional.* Porto Alegre (RS): Artes Médicas; 1993. p. 227-40.
17. Leopardi MT, organizadora. *Processo de trabalho em saúde: organização e subjetividade.* Florianópolis (SC): Papa-Livros;1999.
18. Freese BT. Betty Neuman: modelo de sistemas. In: Tomey AM; Alligood MR. *Modelos y teorías en enfermería.* 5 ed. Madri (ES): Elsevier Science; 1988. p. 299-316.
19. Bardin L. *Análise de conteúdo.* Lisboa (PT): Edições 70; 2002.
20. Rabello CAFG, Rodrigues PHA. Saúde da família e cuidados paliativos infantis: ouvindo os familiares dependentes de tecnologia. *Cien Saúde Colet [online]* 2010 Mai [acessado 2010 Mai 25]; 15(2):379-88. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232010000200013

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