

PERCEPTION OF THE CHILD AND ADOLESCENT IN RELATION TO BEING DEPENDENT ON TECHNOLOGY: FUNDAMENTAL ASPECTS FOR NURSING CARE¹

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¹ This work is part of the Conclusion Work of the Under-graduate Nursing Course at the Federal University of Santa Catarina (UFSC).

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ABSTRACT: Advances in healthcare technology in recent decades have increased the life expectancy of the population. The aim of this study was to investigate the experience of being dependent on technology for children/adolescents. It is a descriptive and exploratory study with a qualitative approach, conducted in a pediatric hospital in southern Brazil, in 2011. The study participants were six children and adolescents. An interview and daily interactions were used for the data collection. The results were grouped into three themes: coping with the technological device; overcoming the disease and the technological device, and the challenges experienced by the children and adolescents with the technological device at home and at school. It was evidenced that the technological dependence goes through moments of adaptation to meet the needs generated, therefore, it is important that the approach of the healthcare professionals, particularly the nursing professionals, contemplate the dimensions involved in caring for technology-dependent children/adolescents and their families.

DESCRIPTORS: Child. Adolescent. Pediatric nursing. Biomedical technology.

PERCEÇÃO DA CRIANÇA E DO ADOLESCENTE EM ESTAR DEPENDENTE DE TECNOLOGIA: ASPECTOS FUNDAMENTAIS PARA O CUIDADO DE ENFERMAGEM

RESUMO: Os avanços da tecnologia em saúde nas últimas décadas vêm aumentando a expectativa de vida da população. O objetivo deste estudo foi conhecer a experiência de estar dependente de tecnologia para crianças/adolescentes. Trata-se de estudo descritivo-exploratório, com abordagem qualitativa, realizado em um hospital pediátrico do sul do Brasil, em 2011. Participaram do estudo seis crianças e adolescentes. Utilizou-se a entrevista e interações diárias para coleta de dados. Os resultados foram agrupados em três temas: o lidar com o dispositivo tecnológico; a superação da doença e do dispositivo tecnológico, e os desafios vivenciados pela criança e adolescente com o dispositivo tecnológico em casa e na escola. Evidenciou-se que a dependência tecnológica perpassa por momentos de adaptação para suprir as necessidades geradas, assim, é importante que a abordagem dos profissionais da saúde, em especial da enfermagem, contemple as dimensões envolvidas no cuidado às crianças/adolescentes dependentes de tecnologia e suas famílias.

DESCRIPTORIOS: Criança. Adolescente. Enfermagem pediátrica. Tecnologia biomédica.

LA PERCEPCIÓN DEL NIÑO Y DEL ADOLESCENTE DEPENDIENTES DE LA TECNOLOGÍA: ASPECTOS FUNDAMENTALES DE LA ATENCIÓN DE ENFERMERÍA

RESUMEN: Los avances tecnológicos en materia de salud han aumentado la esperanza de vida de la población. El objetivo del estudio: comprender la experiencia de niños/adolescentes de ser dependientes de la tecnología. Es un estudio descriptivo exploratorio, cualitativo, realizado en un hospital pediátrico al sur de Brasil, en 2011. Participaron del estudio seis niños/adolescentes. Los datos se recolectaron por medio de entrevistas e interacciones diarias. Los resultados se agruparon en tres temas: el trato con el dispositivo tecnológico; la superación de la enfermedad y del dispositivo tecnológico; y los desafíos que experimentan los niños/adolescentes con el dispositivo tecnológico en el hogar y la escuela. Es evidente que la dependencia tecnológica pasa por momentos de adaptación para satisfacer las necesidades generadas, por lo que es importante que los profesionales de la salud y enfermería, consideren las dimensiones que intervienen en el cuidado del niño/adolescente dependientes de la tecnología y sus familias.

DESCRIPTORIOS: Niño. Adolescente. Enfermería pediátrica. Tecnología biomédica.

INTRODUCTION

Children are in a continuous process of growth and development with specific and unique needs in their biological, social and emotional dimensions. We think of children as individuals full of energy, hope, and happiness, who have a long time to enjoy life. This causes us to reflect on how difficult it can be when a serious illness occurs in childhood and how this becomes even more complex when there is a need for the use of technological resources and specialized care to live.

We find that the technological advances in healthcare over recent decades have increased life expectancy and survival in many individuals who would have previously been sentenced to death. However, the survivors often suffer from dysfunctions that require changes and readjustments in life, necessitating permanent special care.¹⁻² These children/adolescents are referred to as technology-dependent, since they require technological/pharmacological devices to substitute a vital function of the body, as well as continuous nursing care for their survival.³⁻⁴ The causes of this dependence can be attributed to congenital malformations, genetic conditions, chronic illnesses, or injuries, or even be associated with preterm birth, accidents, diseases or infections.⁵⁻⁷

Technology-dependent children/adolescents form part of the group known as Children with Special Healthcare Needs (CSHN), because they have special health conditions, represented by a requirement for continuous care, which may be temporary or permanent.⁸ The care requirements of these children are complex and involve developmental care, medication care and technological care.⁹

Studies involving technology-dependent children/adolescents can be considered recent. In the United States it is estimated that there are over 11 million children and adolescents with special health care needs, representing 15.1% of the population from zero to 17 years of age. Since 2000 that number has been growing in the country, as at that time it was estimated that approximately 13% of American children/adolescents had special health care needs.¹⁰

It appears that the registration of the worldwide prevalence of these cases is still precarious. It was estimated that at the end of the 1980s there were about 68,000 technology-dependent children and adolescents in the United States,¹¹ and in England in 2001, about 6,000 children and adolescents in this condition.¹² In Brazil these records are

precarious, however, from specific experiences it has been concluded that a significant number of children/adolescents are dependent on technology.⁶ The need for ongoing care for this population has generated changes in care practices, with them previously being cared for and staying in the hospital and now, remaining in their homes under the care of the family, who perform complex technical procedures.⁸

The care repercussions faced with a technology-dependent child or adolescent are diverse and permeate the emotional, social and financial dimensions. Given the complexity of this context, changes occur in the lives of the family members, which among other things, reflect on their quotidian, as they devote more time to the care of the child and must learn to cope with the technological device.² Some of the technology-dependent children/adolescents present mental, emotional and behavioral compromises, becoming totally dependent on continuous care, either from their parents or other family members.¹³

This study is justified due to the increasing number of children/adolescents who continuously use technological devices, and the eminent need to comprehend and appreciate the perception of these individuals regarding the device and its implications in their lives, aiming to provide care that meets their real needs. Another aspect is related to the scarcity of publications in the national literature focused on the theme. Mostly they address only the view of the family or healthcare professionals regarding technological devices and homecare and for technology-dependent children/adolescents, leaving gaps about the perception of the children/adolescents who experience this.

Based on these facts, we believe that in listening to technology-dependent children and adolescents, their experiences will be revealed, enabling the comprehension of the use of the technological device and thus contributing to the implementation of the nursing care. In this sense we formulated the following research question: what is the perception of being dependent on technology for the child/adolescent? To answer this question the general aim of the study was to investigate the experience of being dependent on technology for children/adolescents.

METHODOLOGY

This is an exploratory and descriptive study with a qualitative approach. It was conducted in a

pediatric hospital in southern Brazil, in inpatient units, from March to June 2011. This study was submitted to the Research Ethics Committee of the Institution under Protocol n. 064/2010. To ensure privacy and confidentiality, an identification system was used in which the real names of the interviewees were replaced by names of cartoon characters chosen by the children and adolescents.

The inclusion criteria for the study were: children and teenagers aged between seven and 15 years of age; who were hospitalized; with a technological device in use for at least a month, which did not prevent them expressing themselves and/or communicating; and with the acceptance of the parent/guardian responsible. The choice of this age limit was based on the fact that children older than seven years find themselves in the phase of logical and coherent thought, able to communicate their ideas verbally and attribute meanings to experiences.¹⁴

During the period of data collection we asked the nurses responsible for the inpatient units whether they had children/adolescents who met the inclusion criteria. From this, the participants of the study were six children/adolescents, four males and two females, aged between 10 and 13 years. The medical diagnoses were Human Acquired Immunodeficiency Syndrome (HIV), Neurogenic Bladder, Nephrotic Syndrome, Systemic Hypertension, Chronic Renal Failure, Hydrocephalus, and Myelomeningocele.

All the children/adolescents were attending elementary education, with three in the 5th grade and three in the 6th grade. Concerning the technological device used, we observed that one child was on continuous medication and vesical catheter, two were using vesical catheters, one using a urinary catheter, one a vesical catheter and a ventricular peritoneal shunt, and two children were using continuous medication. The length of use of the technological device ranged from one year to 11 years.

We used two strategies as data collection instruments: the open interview with a guiding question and a field diary in which we recorded the daily interactions conducted with the children/adolescents and their family members, highlighting the Significant Expressions (SEs) contained in the description and Reflection Notes (RNs). We initiated the acceptance of the children/adolescents through daily interactions that occurred in the room or leisure/recreation area (environments chosen by the child/adolescent) through games,

conversations about the quotidian, school, being at home, the hospital, and the use of technology in these environments. We gave the choice for the companion to participate or not in the meetings, however, for most them one was present. On average there were three to four interactions which lasted approximately 30 minutes each. After creating the bond with the children/adolescents, the open interview was scheduled with them and their parents, containing as a guiding question: Tell me how you feel using the (technological device name).

The interviews were recorded in mp3 format, with the consent of the participants or legal guardians, with transcripts produced later. The interpretative analysis of the data was structured from the following steps: pre-analysis, analysis of the expressed and latent meanings, and elaboration of themes that summarize the empirical data and final analysis.¹⁵

RESULTS AND DISCUSSION

From the data found, three themes emerged: coping with the technological device; overcoming the disease and the technological device; and the challenges experienced by the children and adolescents with the technological device at home and at school. These themes are discussed below.

Coping with the technological device

Children and adolescents in the process of living are faced with discoveries and challenges, and in this context, the existence of a disease or dependence on a technological device can affect their interactions with their environment and with their families. We realize that coping with the technological device has implications for the quotidian, promoting changes in the daily routine and impacting in different ways in their lives.¹⁶

The child/adolescent in the process of coping with the disease and the continued use of a technological device, shares with their family members the reality imposed by the need for complex and specific care, and this rigorous treatment that can promote feelings of insecurity, fear or discomfort for those involved. The children/adolescents sometimes showed discomfort in the use of the technological device, with the perception of the difficulty of being dependant on this device, verbalizing negative feelings and the "silent" presence of the pain, as in the following statements:

[...] *I feel bad, because I started to take medicine when I was four years old* (Little Mermaid, 11 years).

[...] *by catheter... I get scared, it hurts* [when asked why she felt disturbed] (Little Mermaid, 11 years).

It is noteworthy that in the case of the Little Mermaid, she starting using antiretroviral drugs at four years of age and at the same time her mother died due to HIV infection. This child, in the daily interactions performed, appeared shy and was sometimes sad, when remembering her mother, and at other times angry due to the disease, saying that she was afraid that what had happened to her mother would also happen to her. We believe, from this statement, that it was not only the dependence on medical care that led to the discomfort, but that it was also due to the fact that the medication will not provide a cure for the illness and the veiled fear of death.

We know that the dependence on technology provokes the need for complex care to be carried out by the family members and/or by the children/adolescents themselves,^{1,5} which can lead to their dependence on the caregivers for the performance of the technical procedures that are required, e.g. bladder catheterization. In the statements of Hommer, Chris and Little Mermaid, we highlight the following:

[...] *my mother* [the one who carries out the catheterization] (Hommer, 10 years of age; Chris, 10 years of age).

[...] *no, it's bad right...* [did not know how to insert the catheter] (Hommer, 10 years).

[...] *four... and my grandmother chooses whether it is in the morning or afternoon* [regarding the use of the bladder catheter] (Little Mermaid, 11 years).

We noted that the administration of drugs and the realization of more complex procedures in the home environment is primarily the responsibility of the caregiver. This requirement is reflected in routines coordinated by the family and also interferes in the process of autonomy of these children/adolescents, as they start to be ruled by the care imposed and by inflexible schedules, not only due to the necessity but also due to family routines and other significant demands of the care.

We have as an example of this, the statements of Little Mermaid, who during the daily interactions, reported the fear of relying on her grandmother to perform the catheterization procedure, and expressed a desire to participate more in the games with her friends and to be able to sleep at

their houses. Thus, the inflexibility imposed by the routine is evident, and the importance that the moments of interaction with other children have in the quotidian and in the identity construction process for this clientele is also demonstrated.

We also observed children/adolescents who had learned to perform the technical procedure, which gave them greater autonomy regarding the schedules and routines. We considered the statements of SpongeBob and Superman:

[...] *I take omeprazole at six in the morning, amiodipine is a little later than the omeprazole* [...] *I take prednisone in the afternoon* (Superman, 10 years).

[...] *also, I already know how to do the business of the machine* [...]. *First wash your hand well and then pass alcohol* [...]. *Sometimes it's me that does the dressing* (SpongeBob, 13 years).

We noted the knowledge of the technical rigor for the performance of the procedure. SpongeBob knew how to perform the procedures (automated peritoneal dialysis and catheterization) and described the antisepsis of hands needed in the procedure. In one of the interactions with this adolescent, we accompanied the preparation of the materials for the automated peritoneal dialysis and observed the individual's knowledge of the technique. In studies with technology-dependent children/adolescents it is possible to perceive that they acquire knowledge, skills and responsibility for taking care of themselves and the technological device used.¹⁷

From this, we see that the children/adolescents must also be included in their care and this must occur smoothly, safely, and in accordance with their capabilities. Healthcare professionals need to teach them how to handle the devices themselves, as this will provide autonomy in adulthood.¹⁸ This also appeared in the statements of the children/adolescents, i.e., they recognized the need to learn to perform the procedure with the device. Even with the restrictions in relation to the care and their own dependence, these children/adolescents managed to perform many of the activities that other children not dependent on technology perform, such as playing ball, running, playing video games, and flying kites, among various other games. However, they also showed that the dependence on technology imposes limitations regarding certain activities:

[...] *I can not play in the water, or on the sand in case I get an infection* (SpongeBob, 13 years).

[...] *in physical education you have to run and I cannot run* (Sandy, 12 years).

These statements illustrate the perception of the children and adolescents concerning the changes in their lives that are also related to the care arising from the concern with preventing complications, as in the following expression:

[...] *no, it's almost the same, but before I went to the beach right?... I'd go to the water park, this was all that bothered me. Now I'm used to it* (SpongeBob, 13 years).

The children/adolescents perceived these deprivations as necessary to maintain their health, which demonstrates that they understand the need to use the technological device. Therefore, to cope with the technological device reveals the changes in the quotidian of those involved and that this transcends aspects related only to the child'/adolescent's acceptance of the use of the device. With this it becomes necessary to look at the different dimensions of the meaning of being a technology-dependent child/adolescent.

Overcoming the illness and the technological device

The disease and the necessity of using a technological device was present in some of the children/adolescents from birth and accompanied them throughout the process of growth and development. Thus, we found that when the children/adolescents had used the device since early childhood, they reported not feeling different from other children/adolescents, as they showed themselves to be adapted to the use, as if the device were part of the body.¹⁹

The word "normal" was present in the statements of the children/adolescents in various aspects, representing how they felt themselves dependant on the technology. Normal is what is in the middle, in the center, neither to one side or the other, therefore, normal is to conform.²⁰ The quest for normality is something present in studies on chronic disease in childhood and on technology-dependent children/adolescents.^{17,21-22} We believe that the children/adolescents make reference to normality, or the desire not to be seen unequally or differently due to requiring complex healthcare, as a way of hiding their emotions.

In trying to trace the identity of being technology-dependent, we must not forget that identity is unstable, contradictory, fragmented, inconsistent and incomplete.²³ Therefore, in addition to normality, we also encountered other feelings, such as the difference, anger, fear, unacceptance

and dependence. We can identify this perception in the statement of Chris (10 years).

For God's sake, my God, it's bad... it's that I don't like to take medicine, you know? Me, I'd rather be normal! I'd prefer not to take medicine and to be normal. Understand? (Chris, 10 years).

Other feelings included, not being able to perform some activities like the "other" children:

[...] *because I can't do many things like other children...* (Sandy, 12 years).

It is also necessary to consider their perceptions about the "normal", the different, and the "other" children/adolescents. Some interviewees presented different and conflicting perceptions about how they felt about the technological device. Sandy (12 years) said she did not feel different from other children/adolescents, however, in another statement, she said that she felt a little different. We attribute this duality of perceptions to the desire to be the same, without the restrictions imposed by the diseases and technological devices. Some talked about changes in their self-image, however, did not treat this as a negative thing, or something that set them apart from the rest.

My stomach and my leg and... my foot, everything was swollen (Sandy, 12 years).

I swelled up too... I swelled up a lot (Superman, 10 years).

The results revealed that the children and adolescents comprehended the necessity for the use of the technological devices and that they also realized the implications that not using them could have. Understanding the implications of the use of the device helps with the insertion and interest of the child/adolescent in adapting their activities according to their needs.²⁴

I have to take my medicine to urinate... if I do not take this medicine, I don't urinate (Superman, 10 years).

Some children/adolescents showed some knowledge about their illnesses:

[...] *nephrotic syndrome, it's because I retain what was bad and passed everything out, there was protein in the urine, then I was swollen because of it, but I didn't have high blood pressure, then I got this high pressure problem* (Sandy, 12 years).

However, as well as the perception of the importance of the use of the technological device, we evidenced the fear of remaining dependent on technology in adulthood. We relate that this fear of dependence comes from the dreams that these

children/adolescents have for the future, as much as from the pain triggered by use of the device. Thus, the fear of dependence can also be derived from the fact that they do not want to feel pain throughout their lives.

We comprehend that the identity of being dependent on technology is complex, encompassing emotional, social and self-perception aspects, and presents the appeal of being treated as being indistinguishable from other children/adolescents. However, we need to share knowledge about their illnesses and technological devices, to thereby meet the individual needs and be able to offer nursing care according to the demands the individuals present.

The challenges experienced by the children and adolescents with the technological device at home and at school

The family members and the technology-dependent children/adolescents experience a daily challenge. They face major changes in the family routines with the need to adapt to the continuous use of a technological device. The home has its meaning transformed and there is a new organization of the family in various dimensions of their lives, in order to provide the care required by the technology-dependent child/adolescent.²

During the daily interactions with the children and adolescents, we realized that the main caregivers in the hospital environment were the mothers, and that they helped the nursing staff in the process of management and handling of the technological devices, demonstrating their skills and autonomy in this situation, as they deal with this reality in the home environment. This can enhance the opportunities that the children/adolescents have to experience situations appropriate for their growth and development, if the healthcare team and the family are prepared for it.²⁵ Thus, the intention of the homecare is to normalize the lives of these individuals, minimizing the impact of the disease on them and their families and promoting their growth and development.

Besides the mother figure, all the other members who compose the family and live in the same home also go through the process of adaptation to the new conditions of life. For the children and adolescents, during their journey through the process of growth and development, the family is their foundation. It is with the parents and siblings that they learn commonplace actions, and it

is them that the children miss when they have are hospitalized.

When we encounter the statements about how they miss the family, we perceive the extent with which the hospitalization process interferes with the psychological aspects of these children/adolescents. Not only with the hospitalization itself, but with leaving and returning to the hospital, forcing them into a reality not commonly experienced by children/adolescents of the same age group who are healthy. Consolidated in the literature are feelings of fear, helplessness, disability, suffering or even the finiteness of life brought about by the hospitalization, because during this, the child/adolescent abruptly moves away from their family, home and friends, i.e., from their routine, creating situations of great uncertainty for them. Furthermore, when the hospitalization period is prolonged, they are distant from activities that are essential for their growth and development, such as playing and socializing with friends from school.²⁶

Thus, as well as the changes undergone in the home and within the family, the children/adolescents of school age are faced with coping with being dependent on technology and not attending school regularly. They need support for their inclusion in various social contexts, especially in the school environment, since they require this inclusion to be healthy and satisfying.²⁷ In the school period, the children/adolescents develop their skills and express curiosity about each other and about their differences. Faced with this issue, when the technology-dependent child/adolescent returns to school, it is common for friends to ask questions and raise concerns regarding the use of the technological device. Here are some statements to this effect:

[...] *I already explained my problem to them [school friends] (Little Mermaid, 11 years).*

[...] *everyone there already knows... the teacher has already told them (SpongeBob, 13 years).*

Children/adolescents who need technological support may feel different from others, developing feelings of inferiority, which promotes self-isolation and hinders their learning process. When the actors of the school setting, such as the headmaster, the teacher and the classmates, know how to cope with the needs of these children/adolescents, respecting them, the environment is pleasant, natural and comfortable for regular teaching practices and child development.

Despite the many individual limitations, the children/adolescents speak for themselves and show their potential. During the moments of interaction they reported the school to be a fun space, where the friends are encountered, they play and study, also conveying the feeling of missing their colleagues.

It is essential that we legitimize the role of the healthcare team to include these children in their social contexts, especially in an active exchange with the school and teachers. We highlight the importance of the role of the nurse in the consolidation of information, and in the process of teaching, to stimulate and encourage the family caregivers in the importance of the use of the technological devices and their correct handling. With this, the technology-dependent child/adolescent will have the conditions for a healthier process of growth and development and will become protagonists in their own care.

CONCLUSION

Dependence on technology presents itself as a long journey for the child/adolescent and their families, in this journey are the strengths and weaknesses of these actors faced with the new life perspectives offered by the use of a technological device. In this context, we consider it necessary to understand the process of growth and development of the child/adolescent in order to comprehend the implications in their lives of the experience of the illness and the use of the technological device.

By "allowing" the children and adolescents to express themselves it was possible to unveil their perception of being technology-dependent, based on three themes. The first concerned coping with the technological device, in which the children and adolescents described the various changes in their quotidian and that these go beyond the acceptance or non-acceptance of the use of the technological device. Therefore, it is necessary to monitor each child/adolescent according to their capacity for understanding, translating their dependence on technology in a particular way. Furthermore, we can not view them excluding their previous experiences, children know the world through experiences, and therefore we must transcend the moment in which they are living today, considering them in their entire historical and situational context.

All children/adolescents are entitled to care that meets their real needs for the development of

their capabilities. In this sense, the care is shared between healthcare professionals and the family, and these individuals need to be prepared to cope with the difficulties due to the dependence on technology, in order to plan and implement actions to promote the development and maintenance of these children/adolescents considering their condition.

The second theme refers to overcoming the illness and the technological device. In this, the children/adolescents reported feeling no different to those that are not technology-dependent, as well as the pursuit of normality. The children and adolescents did not want to be treated unequally, they wanted to play, saw themselves as equal to the other children, had dreams for the future, and wanted to write their own history. We show that being, feeling and perceiving are mutable and therefore the identity of being technology-dependent is complex. We obtained different responses in relation to how they perceived themselves and this we attributed to concealment and silencing regarding their perceptions "of themselves", beyond the feelings experienced during the interactions with us.

The third theme referred to the challenges experienced by the children and adolescents concerning the technological device at home and at school, in which we highlighted their understanding, faced with the situations imposed and the change in their routine at school and at home, considering they depend on technology to remain alive. This theme reinforces the social isolation resulting from leaving and returning to the hospital, as well as highlighting the school as a place where fun and met friends. For this reason, it is essential to prepare the healthcare and education professionals for the inclusion of these children in this learning space. We believe that a fundamental aspect for nursing care is founded in the articulation and representation of the link between the healthcare professionals, the school, the family and the community.

The dependence on technology goes through moments of adaptation. Therefore, it is important that the approach of the healthcare professionals, especially those in nursing, is not only directed towards the demands of the illness and the devices, but also addresses the multiple dimensions involved in the care of technology-dependent children and adolescents and their families.

We highlight the need to avoid prejudices about technology-dependent children/adoles-

cents. We need to understand their feelings regarding themselves, how they see themselves, what troubles them, and what they really need, with this only being possible when we stop to listen to what they have to say. We highlight sensitive listening as a tool which allows us to overcome our own view and manage to take care of children/adolescents in their condition of being technology-dependent, suggesting ways to overcome and cope with the difficulties at different times in life. We emphasize that further research is needed with these clients and their family members, because, with the scientific advances, the trend is for increasing numbers of technology-dependent children/adolescents. As healthcare professionals, it is essential to reveal their requirements in order to make integral healthcare viable.

REFERENCES

- Hewitt-Taylor, J. Caring for children with complex and continuing health needs. *Nurs Stand*. 2005 Jun; 19(42):41-7.
- Leite NSL, Cunha SR. A família da criança dependente de tecnologia: aspectos fundamentais para a prática de enfermagem no ambiente hospitalar. *Rev Esc Anna Nery*. 2007 Mar; 11(1):92-7.
- Kirk S. Families' experiences of caring at home for a technology-dependent child: a review of the literature. *Child Care Health Dev*. 1998 Mar; 24(2):101-4.
- Guerini IC, Cordeiro PKS, Osta SZ. Percepção dos familiares de estressores nas suas relações decorrentes das demandas de cuidado de crianças e adolescentes dependentes de tecnologia [trabalho de conclusão de curso]. Florianópolis (SC): Universidade Federal de Santa Catarina; 2009.
- Fracolli RA, Angelo M. A experiência da família que possui uma criança dependente de tecnologia. *Rev Min Enferm*. 2006 Abr-Jun; 10(2):125-31.
- Drucker LP. Rede de suporte tecnológico domiciliar à criança dependente de tecnologia egressa de um hospital de saúde pública. *Ciênc Saúde Coletiva*. 2007 Set-Out; 12(5):1285-94.
- Moreira MEL, Goldani MZ. A criança é o pai do homem: novos desafios para a área de saúde da criança. *Ciênc Saúde Coletiva*. 2010 Mar; 15(2):321-7.
- Cabral IE, Silva JJ, Zillmann DO, Moraes JRMM, Rodrigues EC. A criança egressa da terapia intensiva pediátrica na luta pela sobrevivência. *Rev Bras Enferm*. 2004 Jan-Fev; 57(1):35-9.
- Neves ET, Cabral IE. A fragilidade clínica e a vulnerabilidade social das crianças com necessidades especiais de saúde. *Rev Gaúcha Enferm*. 2008 Jun; 29(2):182-90.
- National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the child and adolescent health measurement initiative, data resource center for child and adolescent health website. [acesso 2012 Out 06] Disponível em: <http://www.childhealthdata.org>
- U.S. Congress, Office of technology assessment. Technology-dependent children: hospital v. home care. a technical memorandum, OTA-TM-H-38. Washington, DC (US): U.S. Government Printing Office; 1987 May.
- 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.
- Floriani CA. Cuidados paliativos no domicílio: desafios aos cuidados de crianças dependentes de tecnologia. *J Pediatr*. 2010 Jan-Fev; 86(1):15-9.
- Hockenberry MJ, Wilson D. Wong: fundamentos de enfermagem pediátrica. 8ª ed. Rio de Janeiro (RJ): Elsevier; 2011.
- Gomes R. A análise de dados em pesquisa qualitativa. In: Minayo MCS, organizadora. *Pesquisa social: teoria, método e criatividade*. Petrópolis (RJ): Vozes; 2001.
- Guerini IC, Cordeiro PKS, Osta SZ, Ribeiro EM. Percepção de familiares sobre estressores decorrentes das demandas de cuidado de criança e adolescente dependentes de tecnologias. *Texto Contexto Enferm*, 2012 Abr-Jun; 21(2):348-55.
- Geraldi GS, Aruto GC, Silvano RS, Batista TB. A experiência de ser dependente de tecnologia na percepção da criança e do adolescente: contribuições para o cuidado de Enfermagem [trabalho de conclusão de curso]. Florianópolis (SC): Universidade Federal de Santa Catarina; 2010.
- Paula CC, Cabral IE, Souza IEO. O cotidiano de crianças infectadas pelo HIV no adolescer: compromissos e possibilidades no cuidado de si. *DST. J Bras Doenças Sex Transm*. 2008 Jul-Set; 20(3-4):173-8.
- Nobrega, RD, Collet N, Gomes IP, Holanda ER, Araújo YB. Criança em idade escolar hospitalizada: significado da condição crônica. *Texto Contexto Enferm*. 2010 Jul-Set; 19(3):425-33.
- Canguilhem G. O normal e o patológico. 5ª ed. Rio de Janeiro (RJ): Forense Universitária; 2000.
- Wang K-WK, Barnard A. Technology-dependent children and their families. *J Adv Nurs*. 2004 Jan; 45(1):36-46.
- Vieira SS, Dupas G, Ferreira NMLA. Doença renal crônica: a experiência da criança. *Esc Anna Nery*. 2009 Jan-Mar; 13(1):74-83.
- Silva TT. A produção social da identidade e da diferença. In: Silva, TT, organizador. *Identidade e diferença: a perspectiva dos estudos culturais*.

- Petrópolis (RJ): Vozes, 2000. [acesso 2012 Out 06]. Disponível em: <http://ccs.ufpel.edu.br/wp/wp-content/uploads/2011/07/a-producao-social-da-identidade-e-da-diferenca.pdf>
24. Lecussan P. A criança e o diagnóstico: o pediatra deve contar à criança doente seu diagnóstico? *Rev Assoc Med Bras.* 2001 Out-Dez; 47(4):282-3.
25. Picollo J. A criança dependente de ventilador: concepções e práticas do cuidado frente a suas necessidades de desenvolvimento [dissertação]. São Paulo: Universidade de São Paulo. Programa de Pós Graduação em Enfermagem; 2008.
26. Castanha ML, Lacerda MR, Zagonel IPS. Hospital: lugar para o enfermeiro cuidar do imaginário? *Acta Paul Enferm.* 2005 Jan-Mar; 18(1):94-9.
27. Nucci NAG. A criança com leucemia na escola. Campinas (SP): Livro Pleno; 2002.