ISSN: 1676-4285

OBJN
Online Brazilian Journal of Nursing
ENGLISH

Federal Fluminense University

AURORA DE AFONSO COSTA
NURSING SCHOOL

uff
Original Articles

Body hygiene of children with encephalopathy: a creative-sensible method for relatives

Katia Aparecida Andrade Coutinho[1], Sandra Teixeira de Araújo Pacheco[1],
Benedita Maria Rêgo Deusdará Rodrigues[1],
Juliana Rezende Montenegro de Moraes[2]

1 Rio de Janeiro State University
2 Rio de Janeiro Federal University

ABSTRACT

Aim: To describe practices related to body hygiene of children with encephalopathy at their homes. **Method:** This is a qualitative study using the creative-sensible method, with data generated from February to April 2014 through the dynamics "Corpo Saber", and with five family groups of children assisted in the clinic of a city hospital in the municipality of Rio de Janeiro; it was analyzed according to the French discourse analysis. **Results:** The body hygiene was contextualized by relatives in multiple dimensions, such as: the selection of the time for hygiene, location and necessary adaptations to perform the procedure, the affectionate dimension present during the bath, and the bath of child with gastrostomy. **Discussion:** For the relatives, body hygiene is presented as a complex care procedure, as it involves routines and adaptations related to the demand of children; however, it permitted to create moments of relaxation and play. **Conclusion:** The cultural traits of each family supported their caring practices, demonstrating the challenges created by the complexity of the care practice towards the demands of the children.

Descriptors: Hypoxia-Ischemia, Brain; Disabled Children; Child Care; Caregivers.

Coutinho KAA, Pacheco STA, Rodrigues BMRD, Moraes JRM. Body hygiene of children with encephalopathy: a creative-sensible method for relatives. Online braz j nurs [internet] 2016 Sept [cited year month day]; 15 (3):443-453. Available from: http://www.objnursing.uff.br/index.php/nursing/article/view/5533

INTRODUCTION

The scientific and technological developments started in the 1990s are reflected in the survival rates of children who were considered unlikely to live longer before. This demonstrated an increase in the number of children with chronic and/or incapacitating diseases, who require complex medical care and are dependent on technologies and home care beyond those offered to the majority of children and adolescents(1).

Many children that suffered perinatal asphyxia could benefit from the technological development. Perinatal asphyxia originates from a failure of the gas exchange system and it can develop to a hypoxic ischemic syndrome, which is characterized by generating multiple variations in the organism, especially the neurological compromise, thus becoming an important cause for morbi-mortality in newborns in term and in preterm(2).

The neurological lesions generated from perinatal asphyxia can have certain consequences that are considered irreversible. According to the location and size of the neurological injury, the child can have a poor prognosis, an impact on the individual's motor, intellectual, and behavioral abilities, needing physical and cognitive stimulation and permanent care from relatives(3).

In Brazil, there are few studies that investigate an exclusive incidence and prevalence of encephalopathy in children; however, based on information from other countries, it is possible to project the epidemiology in this country. Developed countries present an incidence around 1.5 to 5.0/1,000 born alive. In developing countries, the estimate is around 7/1,000 born alive. Such difference can be justified by the prenatal care conditions and by the primary care given to the mothers and the newborns(4).

Despite the fact that official numbers reflect a decrease in mortality by perinatal illnesses in Brazil, which between 2000 and 2008 was from 14.7 to 10.3 for every 1,000 born alive, this cause implicates in an expressive number of children that survived, thus presenting demands for special health care(4).

The chronicity generated by encephalopathy during childhood limits the participation of the child in regular activities for his age, affecting his own process of growth and development, thus requiring assistance and observation by many health professionals.

Hence, this child will require differentiated care, due to the limitations presented in the performance of his everyday life routines, such as self-care, and will depend on relatives to perform such functions(5).

Despite the fact some studies have already investigated the effects of encephalopathy in children(5), the understanding of the caregiver upon specific elements related to the disorder have not been completely explored.

As the limitations imposed by the illness upon their everyday lives and on the normal functions of their age manifest, these children present larger demands for continued (temporary or permanent) care, including in the set of children with special health care necessities (CRIANES, in Portuguese), as they are referred in Brazil(6).

In the Brazilian scenario, the number of CRIANES presents a direct correlation to avoidable illnesses that evolve to a chronic stage due to re-hospitalizations, perinatal diseases, and congenial malformations, thus requiring health support for an uncertain period of time(1).

In regards to the diversity and singularity of the care demands presented by the CRIANES, they must be considered as an emerging clientele for children's health care, which represents new challenges, not only to the health team, but also to the caregiving relatives that support the children at home(7).

Among the care demands presented by CRIANES with encephalopathy, there is the performance of hygiene care, a topic to be discussed in this research. In regards to the care of body hygiene, it is possible to observe the lack of publications that discuss the impact of hygiene care of children with encephalopathy in the daily family dynamics(8).

The caregiving relatives of the CRIANES need to acquire specific knowledge and practices for the home context of the procedure. The dialogues between health professionals and relatives must be one of the paths to be covered to negotiate the understanding, focusing on care practices.

Therefore, understanding the relevance of an approximation between nursing professionals with the caring practices performed by relatives of children with encephalopathy at home, and based on the countless demands for care presented by the CRIANES, this study aims to describe the relatives' practices with the body hygiene of children with hypoxic ischemic encephalopathy in home care.

METHOD

This research is a qualitative study, using the creative sensible method, which is supported by three elements: group discussion, participant observation, and group dynamics on creativity and sensibility as means to produce data(9). In order to measure the care of relatives to the body hygiene of the child with encephalopathy, this study adopted the group dynamics on creativity and sensibility, called "Corpo Saber"(10), in which through the metaphor of a drawn body, the caregiving relatives signify and re-signify the hygiene care provided to the child.

The artistic production was developed collectively, yet one piece was produced by family, together with debating questions: "Which hygiene care you perform with (name of the child) at home? How do you proceed?"

The scenario of the research was the home of the children supported in the follow-up clinic of a pediatric hospital located in the municipality of Rio de Janeiro, Brazil.

The participants of the research were five families, with a total of 12 relatives: five mothers, two fathers, one aunt, one grandfather, and three grandmothers.

To select the relatives, researchers used the registration forms of children assisted by the Follow-up Clinic for Chronic Patients, and the medical records filed in the Area of Medical Documentation of the referred hospital, in which there was data collection regarding the health background of the children.

The established criterion of inclusion was: to be the direct caregiver of children with hypoxic ischemic encephalopathy between the ages zero to two years old, during the period of data collection of the research. There were excluded caregiving relatives of hospitalized children during the stage of data collection.

The research project was approved by the Committee of Ethics in Research of the Health Municipal Office of Rio de Janeiro, under protocol #473005, on November 29th 2013. All participants signed the Free and Clear Consent Agreement, established according to the Resolution #466/2012, after they were aware of the aims of the study. To guarantee the anonymity of the participants, the relatives were only identified by their initials, and biblical names, as pseudonyms, were used for the children, as most relatives mentioned their children as a divine blessing upon them. Thus, they were identified as: Davi, Ana, Eva, Dídimo, and Elisa (in Portuguese).

The data was generated from February to April 2014. The discourses of the relatives during the dynamics were recorded with a digital recorder and then fully transcribed at the end of each meeting.

To finalize the field work, the eligibility of participants was used based on the criterion of inclusion established and on the standard prevalent in the discourses found after the transcription of the meetings. In this sense, all families that met the criterion of inclusion and accepted to participate in the study were included.

The path chosen to provide theoretical support to the present research was structured in the concepts of reflexive-critics, the process of awareness, and dialoguing education, according to Freire's concept(11).

Freire's theoretical concept(11) has its main axis as the development of a critical conscience in the individual, provoking a reflection upon the reality from the dialectics reflection-action-reflection, where the subject moves from awareness-raising to decision-making (full awareness).

This author also considers knowledge as mutable and unfinished, constructed and reconstructed from the problematization of concrete reality in the space of relationships through dialogue and the critical-reflexive analysis of the subjects (12).

Incorporating Freire's conceptions to the everyday life of the educational/caring practice of nursing enables the professional to transform or reconstruct the understandings inside of a group that does not have any technical-scientific knowledge, stimulating critical and reflexive thinking and intending for the understandings descending from the common universe.

The French discourse analysis(13) was the method used to treat the data, which was generated from the grouping of these analytical frames. On the first frame, the transformation was observed from a discursive object to a discursive process, and on the second one, the search was focused on the senses present in the discourse of the subjects, the use of analytical devices being fundamental in this process (paraphrasing, inter-discourse, and the unsaid) to have a full understanding of the meanings of the discourses.

RESULTS

In the process of analysis of the empirical material, regarding the hygiene practices of the CRIANES with encephalopathy, in the discourses of the relatives the following issues arose: the selection of the best time for hygiene, places and necessary adaptations to perform the hygiene of the child, the affectionate dimension used in the bath of the child, and the bath of the child with gastrostomy.

Selection of the best time for hygiene

When presenting in their discourses the body care performed with their children, the relatives report the selection of different periods of the day to perform the bath:

> (...) I bath him…/ Nine o'clock, eight o'clock and I bath him, (...) because that is the time to have a shower. (...) He wakes up, I bath him, and he calms down. (Mrs. P., mother of Dídimo).

> (...) and after lunch, I bath her, and she has a nap. (Mrs. J., mother of Elisa)

The discourses of the mothers of Dídimo and Elisa reveal their beliefs regarding the relaxing effect of bathing, which became a determinant factor to decide and establish the best time for hygiene.

Places and necessary adaptations to perform the hygiene of the child

The aspects related to the places where the bath of these CRIANES was performed, and the necessary adaptations to perform this care practice, were mentioned by the relatives:

> (...) I have to be careful with her in the bath tub, with very little water, as if she wants to lay down, playing in the tub, and then water goes into the ear – I have to be careful not to let the water into her ears (...) because the ear bothers her too much (Ana) and it is not good for her. For us adults, it is already something, for her it is new... (Mr. A., paternal grandfather of Ana)

> Well, when I bath her at home, I do not use the bath tub anymore, I use the regular shower, (...) I am only more careful to the area around the ears, and holding her to not let her slip. I do not use much soap, only a quick and thin soap layer. (Mrs. R., mother of Ana)

> In the bathroom, in the shower. (Mrs. P., mother of Dídimo)

Ana's family, a 24-month-old child under conditions to be using the shower, was using the bath tub with little water to her hygiene, as seen in the discourse fragment of her grandfather.

Inside the same family group, it was possible to observe different procedures for this care practice, once Ana's mother was at home she used the shower; however, she did so with little soap, focusing on the prevention of falling and water into the auditory meatus.

On the other side, the mother of Dídimo, a 20-month-old child who could not stand up due to his motor impairment, declared she baths her child under the shower, not justifying why she adopts such procedure.

Yet, in relation to the locations for the body hygiene of children, not only the bathtub and the shower were present in the discourses of the relatives:

> I bath him, but I do not take him to the bathroom, because he moves too much. I bath him in the laundry tub. (Mrs. T., maternal aunt of Dídimo)

> My care is the bath... (...) I place her in the bathtub, a big one. I take her to the water, and I wash her, holding her, (...) I turn her around, she always raises her head, she does not have a soft neck, and she is quite smart, (...) (Mrs. F., maternal grandmother of Eva)

When describing their practice to sanitize the child, Dídimo's aunt described the laundry tub as a necessary adaptation to bath him. The grandmother of Eva used, as a resource, a larger bathtub to better accommodate the girl and, because of that, a safer environment to handle the procedure because her 18 months old presented severe muscle spasticity, which impeded relatives to promote a transition from the bathtub to the shower.

Affectionate dimension used in the bath of the child

Besides the physical dimension of body hygiene of the child with encephalopathy, evidenced in the previous discourses, another signification was attributed to this care procedure; it is present in the discourse of Mr. R., father of Elisa:

> (...) sometimes I bath her. (...) She cries less with me, as she does not like water too much, so I clean her by playing, and she smiles and laughs. (Mr. R., father of Elisa)

By the speech of Elisa's father, bathing took another dimension, transposing the physical and sanitizing care procedure to add an affectionate dimension to it. For this individual during bath time, the child experienced moments of joy and pleasure.

Bath of the child with gastrostomy

Two families had children being fed through gastrostomy (Davi and Eva), but only Davi's family mentioned specific care with the technological device during body hygiene:

> They taught me at the hospital. They told me to be careful with the catheter during bathing, to not let the catheter get stuck on something (...) (Mrs. K., mother of Davi)

Mrs. K. pointed out the worries she has in avoiding traction upon the gastrostomy catheter, relating this attention to the possibility the catheter to pin something. For the relatives of this child, there were no references of special procedures to the ostium of the gastrostomy.

DISCUSSION

In regards to the selection of the time to perform body hygiene of their children, it is possible to see that, for the families that reported this issue, the bath is seen as a promotion of relaxation and, despite none of the mothers have clearly demonstrated the intention to promote this effect by choosing the time, their speech indicates that their practices are more directed to cultural background of their own families. This can be observed by the discursive formation of Mrs. P., mother of Dídimo, who reports that the boy calms down after the bath, and of Mrs. J., mother of Elisa, who baths her after lunch, a period most children of her age group (Elisa is 23 months old) usually nap.

The observations linked to the importance of a nap after lunch for children vary, thus enabling different theories and opinions. Some researchers defend the theory that children can have this practice up to three years old, and this should not only be considered a support to brain stimuli, but also as a practice that permits the child to have a physical rest(14).

There are few publications regarding body hygiene of children under a specific approach, in the details of ideal timing and mode of carrying it out, especially for children with encephalopathy.

A study related to the family routines and rituals of caring children shows that a degree of behavioral regularity is almost a universal characteristic of the families and that the continuity and stability to support the necessities of their members represent a critical dimension of the connection between social experience and health(10).

Besides that, daily routine habits, such as body hygiene, are strongly influenced by cultural standards and by the information that the individuals have access to throughout their lives. Therefore, it is necessary to know one's culture to understand one's behavior(10).

Consequently, the practice of the two families in establishing regular hours for the hygiene of their children demonstrated a behavioral pattern based on their own habits and culture, which is consistent with the idea that man is a being that has space-time roots, not being able to survive out of his own concrete reality. Hence, it is not possible to reduce mankind to an object without considering the context and the culture into which the individuals are inserted(11).

From the discursive fragment of Mr. A, grandfather of Ana, it was possible to see the proceedings used for the bath considering such necessities for care as taking into consideration the concrete experiences of water into the ear channel and the observations of the reactions of the child, followed by the inter-discourse used by various voices of children and adults, which, at some point they, all shared experiences of discomfort caused by the presence of water in the auditory meatus.

In this sense, the concrete existing situation, represented by the presence of water into the ear bothering the child, altered the care practice of this family member to a critical conscience, evidenced by the capacity of analysis. When the condition of critical conscience is present, the individual develops the capacity of dialogue. The autonomous and compromised thinking is characterized by the depth in which the individual interprets the problems and by the socio-political engagement it requires(15).

Ana's family group showed not only a preoccupation with the possibility of an otitis provoked by bath water, but also an attention related to the physical integrity of the child by the possibility of an eventual fall during the bath. Then, at the grandparent's home, her bath was in the regular bathtub; at her parent's home, her mother bathed her with little soap to avoid having the child slipping during the procedure.

The overprotection of Ana, who presented developmental conditions that permitted the transition from the bath tub to the shower, as her mother did, was evident in the discourse of her grandfather.

The clinical fragility presented by these children that presented chronic health conditions generates additional protective care offered by some relatives at home, trying to reduce the possible risks to their health. Thus, the overprotection also characterizes a mode of care performed by the relatives; however, in some situations, this conduct can lead to a social isolation and restrictions on the development of the child(16,17).

In regards to the family of Dídimo, it was possible to perceive that the mother, even though there were limitations, used the bath in a more habitual perspective when observing the age of the child; his aunt, based on what was unsaid, expressed her uneasiness, modifying the care procedure within her social reality, minimizing the challenges related to the demands of the child.

In the family of Eva, her grandmother, Mrs. F., demonstrated in the discursive fragment presented her naïve consciousness regarding the health framework of her granddaughter, as the child did not have movement in her cervical muscles the way the grandmother was reporting. On the contrary, the child presented muscle spams and rigidity of this part of the body due to a secondary hypertonia from the neurological impairment.

Because of the neurological and motor injury in children, the practice of bathing is a complex task, which increases the risks for accidents, imposing the necessity of caregivers to develop strategies that normalize the procedure as part of the daily routine of the child in the family.

Then, the care practices applied to children with encephalopathy are developed according to specificities and demands, which emerge from the challenges imposed by home care. In order to face these challenges, the caregiving relative searches for answers, learning and building a new way of care (building culture), which consequently changes the concrete reality (making history)(11).

Therefore, the routine of the families involves complex and continuous care practices in a predictable regularity throughout the family's lifespan(10).

The affective dimension that enables play during bathing, mentioned by Mr. R., father of Elisa, demonstrated not only the perception to the necessity for body hygiene care, but also the extended understanding of care, by promoting actions that contributed to the development of his daughter.

In a general sense, hygiene care of children is a source of pleasure and when the child is not a baby anymore, this moment represents the opportunity for joy and for relaxation, which enables a learning process no one can teach, related to one's world and how to deal with the environment, objects, time, space, structures, people, and the possibility to learn about one's self(18).

Play has an important role in the mental health of the human beings and deserves special attention from relatives and professionals that support children with special health necessities as they represent a venue of expression for the child. Besides, it is an exercise that helps to build a bond to the world and to the people around the child(19).

Furthermore, playing represents a resource for physical, emotional, cognitive, and social development. The use of ludic activities for children is recognized as an important tool to promote their development(19).

To understand the pleasure of playing for children, besides generating benefits for their own bio-psycho-social development, also benefits their relatives, who while observing the reactions and plays of the child are stimulated to continue searching to improve the child's health condition(19).

In this sense, playing represents a necessity for a healthy child and for the one with special health necessity, as it mediates the interaction of the child with the surrounding environment, permitting creativity, socialization, and learning, which makes this activity an important component in child development.

The body hygiene care of children with gastrostomy was presented by Mrs. K., mother of Davi. The inter-discourse of professionals, present in the speech of this mother, revealed the scientific knowledge transmitted by these professionals regarding the procedures to take during the bathing of the child due to the feeding device. However, in her speech, there are no guidelines on how to proceed, but warnings given in order to avoid possible complications.

In this regard, the scientific literature(20) reinforces the necessity of additional care with the gastrostomy catheter during bathing, evading excessive traction to avoid the enlargement of gastric stoma, which would lead to the extravasation of food content, generating injuries to peristomal skin.

For the mother of this child, who demanded technological care, the process of learning that started in the hospital was relevant; health professionals performed the roles of educators, intermediating their social speech, producing care practices, and demonstrating to this family the care procedures to be performed at home. However, the pedagogical model, in which there was only the transmission of information, contributed to the internalization of the knowledge in *how to* care, despite teaching *the reason this care was required*.

To exercise the critical and creative care, it is necessary to understand education as a means to support care, which cannot be used as a means to transmit information when the professional places himself as the bearer of the information with the power to infer and decide for the people of whom he is taking care. To educate properly, the professional must understand that education is a tool to enlighten and transform people, in which the measuring stick is the participation of the individual in the decision-making process(11).

Hence, the body hygiene of children was a topic that demonstrated multiple dimensions, demanding that the nursing professional, in his educator role, develop sensible listening to conduce it, according to the demands of CRIANES and their caregivers. The horizontality of the educational dialogic process can make flexible the relationship between the professional and the family, shortening the distances and socializing the understandings.

Through this research, it was possible to observe the reoccurrence and saturation of data, however generalization of the findings was not possible.

The everyday life of the relatives, regarding the body hygiene of the child with encephalopathy, showed much more than routine practices; it also demonstrated the beliefs and attitudes towards the care procedures of the children observed.

CONCLUSION

The process of care developed by the caregiving relatives of CRIANES with encephalopathy at home is supported by the knowledge acquired with the experiences generated by its practice. Thus, the child with special health needs leads his family to use special care and to search for various methods to perform the hygiene care.

The research revealed that, for caregiving relatives, the body hygiene of their children demanded the incorporation of new understandings, based on the overcoming of limitations and possibilities of their child's body. This process started with the understanding of care being unveiled and learned once relatives are involved in care procedures.

Despite the reduced number of relatives, which impedes the generalization of the findings, as it represented some limitations to the research, the everyday lives of relatives in care practices with the body hygiene of their child with encephalopathy demonstrated not only their daily procedures, but also their beliefs and values related to this care practice.

REFERENCES

1. Silveira A da, Neves ET. Vulnerability of children with special health care needs: implications for nursing. Rev. Gaúcha Enferm. [Internet]. 2012 [cited 2016 Feb 29]; 33(4): 172-80. Available from: http://www.scielo.br/pdf/rgenf/v33n4/en_22.pdf
2. Takazono OS, Golin, MO. Asfixia Perinatal: Repercussões Neurológicas e Detecção Precoce. Rev Neurocienc. [Internet]. 2013 [cited 2016 Aug 02]; 21 (1): 108-17. Available from:http://www.revistaneurociencias.com.br/edicoes/2013/RN2101/revisao2101/761revisao.pdf
3. Milbrath VM, Siqueira HCH de, Motta MGC da, Amestoy SC. The family of children with cerebral palsy: perception about health team orientations. Texto contexto - enferm. [Internet]. 2012 [cited 2016 Mar 12]; 21(4): 921-28. Available from: http://www.scielo.br/scielo.php?pid=S0104-07072012000400024&script=sci_arttext&tlng=en

4. Guimarães CL, Pizzolatto TCO, Coelho ACS, Freitas STT. Aspectos clínicos epidemiológicos de crianças com paralisia cerebral assistidas pela clínica escola de Fisioterapia UNIP-São José dos Campos. J Health Sci Inst. [Internet]. 2014 [cited 2016 Aug 02]; 32(3):281-85. Available from: http://www.unip.br/comunicacao/publicacoes/ics/edicoes/2014/03_jul-set/V32_n3_2014_p281a285.pdf
5. Dantas MSA, Pontes JF, Assis WD, Collet N. Facilidades e dificuldades da família no cuidado à criança com paralisia cerebral. Rev Gaúcha Enferm. [Internet]. 2012 [cited 2016 Feb 29]; 33: 73-80. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1983-14472012000300010
6. Pacheco STA, Cabral IE. Alimentação do bebê de baixo peso no domicílio: enfrentamentos da família e desafios para a enfermagem. Esc. Anna Nery [Internet]. 2011 [cited 2016 Mar 01]; 15(2): 314-22. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452011000200014
7. Neves ET, Silveira A da. Challenges for family caregivers of children with special health care needs: contributions of nursing. Journal of Nursing UFPE [Internet]. 2013 [cited 2016 Aug 02]; 7 (5): 1458-62. Available from: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/3229/pdf_2563
8. Baltor MRR, Dupas G. Experiences from families of children with cerebral paralysis in context of social vulnerability. Rev. Latino-Am. Enfermagem [Internet]. 2013 [cited 2016 Mar 12]; 21: 956-63. Available from: http://www.scielo.br/pdf/rlae/v21n4/0104-1169-rlae-21-04-0956.pdf
9. Soratto J, Pires DEP de, Cabral IE, Lazzari DD, Witt RR, Sipriano CA de S. A maneira criativa e sensível de pesquisar. Rev. bras. enferm. [Internet]. 2014 [cited 2016 Mar 14] ; 67(6): 994-99. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672014000600994
10. Fernandes GCM, Boehs AE, Rumor PCF. Rotinas e Rituais Familiares: Implicações para o Cuidado. Rev. Cienc Cuid Saude. [Internet]. 2011 [cited 2016 Feb 29]; 10(4):866-71. Available from:http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/18334/pdf
11. Freire P. Conscientização: teoria e prática da libertação. 3 ed. São Paulo: Centauro; 2008.
12. Müller EB, Zampieri MFM. Prática educativa com enfermeiras visando o cuidado humanizado ao recém-nascido no centro obstétrico. Texto & Contexto Enfermagem. [Internet]. 2014 [cited 2016 Mar 07]; 782-90. Available from: http://www.scielo.br/pdf/tce/v23n3/pt_0104-0707-tce-23-03-00782.pdf
13. Orlandi, EP. Análise de Discurso: princípios e procedimentos. 10 ed. Campinas: Pontes; 2012.
14. Guerreiro, DCR. A sesta em crianças em idade pré-escolar: influência na realização de uma atividade didática. Algarve. Dissertação [Mestrado em Educação Pré-Escolar] Universidade do Algarve. 2014.
15. Freire P. Educação como prática da liberdade. 14 ed. Rio de Janeiro: Paz e Terra; 2011.
16. Silveira A, Neves ET. Crianças com necessidades especiais em saúde: cuidado familiar na preservação da vida. Cienc Cuid Saúde. [Internet]. 2012 [cited 2016 Mar 07]; 11(1):74-80. http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/18861/pdf
17. Nishimoto CLJ, Duarte ED. Family organization for the care of children with chronic conditions, discharged from the neonatal intensive care unit. Texto contexto - enferm. [Internet] 2014 [cited 2016 Aug 02]; 23(2):318-27. Available from http://www.scielo.br/pdf/tce/v23n2/0104-0707-tce-23-02-00318.pdf
18. Depianti JRB, Silva LF, Carvalho AS, Monteiro ACM. Nursing perceptions of the benefits of ludicity on care practices for children with cancer: a descriptive study. Online Braz J Nurs [Internet]. 2014 [cited 2016 Mar 14]; 13 (2): 158-65. Available from: http://www.objnursing.uff.br/index.php/nursing/article/view/4314
19. Silva LF da, Cabral IE. Rescuing the pleasure of playing of child with cancer in a hospital setting. Rev. Bras. Enferm [Internet]. 2015 [cited 2016 Mar 14]; 68(3): 391-97. Available from: http://www.scielo.br/pdf/reben/v68n3/en_0034-7167-reben-68-03-0391.pdf
20. Hockenberry MJ, Wilson D. Wong fundamentos da enfermagem pediátrica. 9. ed. Rio de Janeiro: Elsevier; 2011.

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: 03/26/2016
Revised: 07/29/2016
Approved: 08/15/2016