



Perceptions of the family facing the diagnosis and information about chronic disease in childhood

Vanessa Medeiros da Nóbrega, Kenya de Lima Silva, Altamira Pereira da Silva Reichert, Simone Elizabete Duarte Coutinho and Neusa Collet*

*Departamento de Enfermagem de Saúde Pública e Psiquiatria, Centro de Ciências da Saúde, Universidade Federal da Paraíba, Cidade Universitária, 58051-900, João Pessoa, Paraíba, Brazil. *Author for correspondence. E-mail: neucollet@gmail.com*

ABSTRACT. This study aimed to analyze the perceptions of the family to the diagnosis of chronic disease in childhood; and to assess, from the perspective of the families, the information provided by health professionals. This is a qualitative, descriptive-exploratory study based on the testimonials of families living in João Pessoa, State of Paraíba, whose children had been admitted to a public hospital. The empirical data was produced between November 2008 and January 2009 through participant observation and open interviews. In the analysis, the data were grouped into the following categories: perceptions and feelings of the families on the diagnosis of chronic disease in childhood; and information as a tool for the families deal with the adversities. The results revealed that, despite the long wait, the moment of the final diagnosis is hard and the families need support to overcome the situation and create coping strategies to play their new roles. The family needs to feel safe and confident in its ability to care for the child, which requires information. Shortcomings were verified in the communication between health professionals and family members, especially during hospitalization. The feelings that emerge in the course of chronic illness should not be ignored, but worked together with the family.

Keywords: child, nursing, hospitalization.

Percepções da família frente ao diagnóstico e às informações sobre a doença crônica na infância

RESUMO. Este estudo objetivou analisar as percepções da família, frente ao diagnóstico de doença crônica na infância e avaliar, na perspectiva das famílias, as informações fornecidas pelos profissionais de saúde. Estudo qualitativo, descritivo-exploratório, baseado no depoimento de famílias residentes em João Pessoa-PB, cujos filhos foram internados em um hospital público. A produção do material empírico ocorreu entre novembro de 2008 e janeiro de 2009, a partir da observação participante e de entrevista aberta. Na análise, os dados foram agrupados nas categorias: percepções e sentimentos das famílias sobre o diagnóstico da doença crônica na infância e informação como ferramenta para as famílias enfrentarem as adversidades. Os resultados revelaram que, apesar da longa espera, o momento do diagnóstico definitivo é difícil e as famílias necessitam de suporte para superar a situação e criar meios de enfrentamento para desempenhar seus novos papéis. É necessário que a família sinta-se segura e confiante na sua capacidade de cuidar do filho, necessitando de informação. Constataram-se lacunas na comunicação dos profissionais de saúde com os familiares, especialmente durante a hospitalização. Os sentimentos surgidos no curso da doença crônica não devem ser negligenciados, mas trabalhados juntamente com a família.

Palavras-chave: criança, enfermagem, hospitalização.

Introduction

In recent decades, the technological advances in some regions have contributed to early diagnosis of chronic disease. With this, the chronic illness gets a wider range in evaluations of public health problems affecting the world. This type of disease is featured by a slow course, and may be incurable, with consequent sequels and functional limitations (VIEIRA; LIMA, 2002).

However, these advances are not yet at disposal for many families, thus frequently they have to wait

a long time to get a final diagnosis of chronic disease (ANTON; PICCININI, 2010) and experience situations that overwhelm their members, triggering psycho-emotional disorders that adversely influence the coping of obstacles found during this process.

The chronic disease also affects growth and development of the child, since interfere in the functioning of the body for a long time, requiring ongoing assistance and monitoring by health professionals. Due to this situation, there is a limitation of daily activities, affecting the life and dynamics of

entire family (RIBEIRO; ROCHA, 2007). So when diagnosing a chronic disease in children, it is essential to include their family in the health care plan, since they are also influenced and changed by this circumstance.

This inclusion should help the family learn to live with the disease, become stronger in times of crisis that occasionally may occur in the course of the disease and adapt positively to this reality, in order to contribute to the continuous search for rebalancing the family system. Nevertheless, “[...] the lack of dialogue and sensitive listening has not contributed to the facing the situation” (SILVA et al., 2010, p. 365).

The family needs orientation and support by health professionals to help face the tough moments by which they have to go through during the course of the disease. Nevertheless, many families are unsatisfied with orientation provided by professionals by considering it insufficient (ARAÚJO et al., 2009; SILVA; CORREA, 2006).

The parents need to always be informed about the procedures that will be performed and to have their doubts solved. This presence and attitude should be encouraged and welcomed by health professionals, since the parents influence the child's response to facing the disease and their consequences can contribute to an appropriate care, less traumatic to child (MOLINA et al., 2009).

In this way, we highlight the importance of attentive listening and dialogue between the family and professionals when seeking the practical success of a health action (AYRES, 2007). This because, with an adequate interaction between family and health professional, it can be identified early the needs of the child and implement an exclusive and extended care, preventing unnecessary wear for both child and family.

The need to know the disease, its manifestations and implications, in addition to have stimulated the ability of care, is imperative to assist the child, preparing the family to develop a daily care with quality and autonomy, preventing relapses and health problems of children with chronic disease (ARAÚJO et al., 2009). In this way the family can feel safe, learn to master the situation, meet the needs to take care of the child, and make the child realize that is possible to live with the chronic disease without major fears.

The Resolution Number 41 of the National Council of Child and Adolescent (BRASIL, 1995, Article 10), guarantees the “[...] right of parents or guardians to participate actively in diagnosis, treatment and prognosis, to receive information about procedures to which the child will be submitted”.

Regarding hospital assistance, the nursing staff when developing their actions should include the family in the care, through an empathic relationship that favors the communication with the family-patient (MILIORINI et al., 2008). This empathic relationship with the family during the hospitalization period favors the dialogue, which contributes to the acquirement of new knowledge, solving their questions and concerns as for their competences to perform their new skills at home, slowly and gradually, easing the assimilation of information about the care needed by the child and adolescent chronically ill, by the family / caregivers (ALMEIDA et al., 2006). On the other hand, the lack of consistent and accurate information is one of the aspects that generates more concerns and anxiety in the parents, in addition to limit their participation in the care of hospitalized child (LIMA et al., 2010).

Given the above, the goals of this study were (i) to analyze the perceptions of the family facing the diagnosis of chronic disease in childhood, and (ii) to evaluate, from the family perspective, the information provided by health professionals.

The social scenario of this survey consists of families with children suffering from chronic disease, and how these families experience the diagnosis and information provided by professionals about the disease that affects their children. By understanding how the family is organized during this process is vital for nursing professionals to establish coresponsibilities in the construction of a care plan that meets the real needs of the family.

Material and methods

The design of this study was exploratory-descriptive with qualitative approach, based on testimonials of families whose children have a chronic disease. The research complied with the Resolution Number 196/96 of the National Health Council and the production of the empiric material started after approval of the project by the Research Ethics Committee of the hospital under the protocol number 090/08 (BRASIL, 1996). All participants signed a consent form.

Data collection occurred between November 2008 and January 2009. The inclusion criteria for this research were: be family of a child with chronic disease admitted in the studied hospital during the period of data collection; live in urban area of João Pessoa municipality; and accept to take part of the research. The study excluded families living outside the urban area of João Pessoa, Paraíba State and those with communication problems. Thus, the subjects of this research consisted in three families of children with chronic disease, whose access was

made by means of a survey performed in pediatric clinic of a public hospital, once this is a reference service for children with chronic illness in the State of Paraíba.

It was observed that more than 90% of children with chronic diseases hospitalized in pediatric clinic lived in other municipalities in the interior of Paraíba. This low demand from the municipality of João Pessoa is probably due to ambulatory monitoring provided in the hospital, which allows a more effective control of complications and appropriate treatment at home, preventing frequent hospitalizations of the children living in this city.

Data was collected through semi-structured interview performed during the permanence of the family in the hospital. All interviews were recorded, with consent of interviewees, in order to capture integrally the speech of the subjects. The script of the interview contained a part of characterization of the subjects (age, education, family income, profession/occupation, degree of kinship to the child) and of the children (gender, age, disease, and time of diagnosis) based on the guiding question: tell me about the chronic disease of your child, since the beginning of the first signs and symptoms of the disease up to nowadays.

The interviews lasted on average 40 minutes and were transcribed integrally; the data was processed from the principles of thematic analysis according to the following steps: ordination and classification of data, and final analysis (MINAYO, 2007). In this way, it permitted to organize and structure the parts, by relating them and identifying the units of meaning. Then, we grouped the data and extracted the following categories that compound the organized construction of empirical data: perceptions and feelings of the families facing the diagnosis of the chronic disease in childhood; information as a tool for families facing adversities.

To guarantee the anonymity of the participants, the families (F) were encoded by ordinal numbers in presentation, and in data analysis, according to the chronological order of the interviews, and identified within the text as (F1), (F2) and (F3).

Results and discussion

Among the families that participated in the study, two have nuclear composition with father, mother and child (or children), where the father figure is represented by the stepfather, and one has seminuclear composition, made up by a mother and her children. The children were male, aged 7, 8 and 11 years, suffering from pheochromocytoma tumor in the pancreas (C1), acute lymphoblastic leukemia

(C2) and sickle cell anemia (C3), respectively and at least one year of confirmed diagnosis; the income of their families were R\$ 530.00, R\$ 765.00 and R\$ 1,500.00, respectively.

The research subjects were three families, represented by mothers, because they were accompanying their children in the hospital during the collection period. The age group of the interviewees ranged from 28 to 39 years, two were housewives, and one was saleswoman. In relation to education, two had completed Elementary Education, and one, the High School.

The experience of the family in having a child with chronic disease begins to be experienced even before confirming the diagnosis. The family needs to feel competent to take care for the sick child, because the impact of the family when faced with the diagnosis of chronic disease in childhood may trigger destabilizing processes in both family dynamics and relationships, generating feelings of insecurity, fear and anguish.

Perceptions and feelings of the families about the diagnosis of chronic disease in childhood

The diagnosis of chronic disease is a time of suffering and despair for the family due to several factors, including beliefs related with chronic disease as being incurable and the person have to live with all uncertainties that involve its course, besides the fear of a sudden loss of their loved one. However, before the definitive diagnosis, the families spent a long waiting time:

[...] they just made us suspicious and nothing more; sent us to Recife and said that he had nothing. Sent us back and the boy only getting worse. Then they sent us to São Paulo where they discovered. Here (hospital) we only had suspicious, but in São Paulo, they confirmed. [...] all this was 3, 4 years ago, because he was almost 2 years old, and now he is 6 years. But since he was 8 months old he frequently was hospitalized, and when they discovered here was already late. He was about 2 years (F1).

[...] we lived in São Paulo, we stayed a little there, we came here and when we arrived, he had a very strong episode, then I took him to the (hospital). In São Paulo, he had those episodes, I took him to the hospital, but they never found anything. Here it was discovered (F2).

[...] when my son fell sick, we always went there, and they used to say it was a virus, that I should put my son to eat. They said that hospitalize him wouldn't work. They said: 'go home', and prescribed some medications to him [...]. My son spent six months going there and they sent him back home (F3).

This delay in diagnosis can be a result from the lack of time of professionals in hearing all the

complaints of the people under their care, due to the existing routine of daily health care. As asserted by Ayres (2009, p. 18),

[...] we should 'hear more'. Hear more because the report of people in orientation of diagnostic and therapeutic reasoning was progressively replaced by the striking arsenal of technologies for diagnosis, therapy and prognosis developed over the twentieth century.

The overvaluation and even the dependence of health professionals on technology underestimate something essential for diagnosing diseases: the dialogue for a more accurate assessment.

With the delay in diagnosis, there is a whirlwind of feelings that emerge, such as anguish, fear from uncertainty, in addition to stress, which disturb and disrupt the life and dynamics of families that stop at the timeline, due to the absence of a concrete response to what is being experienced by them. Pizzignacco et al. (2011), when studying the experience of cystic fibrosis from family context, reveal that the delay for defining the diagnosis may contribute to exacerbate negative feelings of guilty of parents that experience an episode, due to the difficulty to establish the diagnosis.

Besides the feelings caused by the long wait for a definitive diagnosis, when this is achieved, the families experience a new dilemma, now related to the chronic disease that according to their beliefs is associated with the idea of death:

[...] I was desperate because I was thinking that he could suddenly die or if he could live a normal life. [...] I was shocked because I thought it was an anemia that he took blood, did a proper nutrition and then he would get better. Then they said me it had no cure, explained me how it was, I was like this way [...]. At first I was very upset (F2).

It was shocking for me; if I could I would give my life for him [...] it made me very sad [...] (F3).

It was hard because they didn't explain to me, it was sudden. They came saying that C1 had a tumor and Lord, it was a shock. I cried, kicked, tapped like anyone would do, there is no human being who does not (F1).

The families associate directly chronic disease with finitude process, by being a health problem without cure. Souza et al. (2011) state that the expectation of loss gets closer to the family after the diagnosis. This is a tough moment and the families need support to overcome the situation, adapt to the new reality and accept the children disease in order to contribute with the treatment. In the process, the families begin creating coping strategies to allow them performing, as best as possible, their new roles

facing the diagnosis and care needs imposed by the disease.

The families also reported lack of support from a psychologist or someone willing to talk about the diagnosis and prepare them for next stages:

[...] I've never received a visit of a psychologist. Not even when the disease was discovered, when I was very upset. The doctors came to me and said 'there is no cure', directly you know? (F2).

There is no psychologist here to talk with us when the child's disease is discovered, or even a nurse prepared to sit and talk: 'mother, let's go right there, let's talk. Look, the disease of your kid is this way, this way. If you need, we can seek, we can strive [...]' no (they didn't do that) (F1).

The psychological support is classified by the families as being essential to help them facing the adversities that arise during the course of a chronic disease, for both the occasion of diagnosis and for the complications that emerge during the course of the disease. According to Vieira et al. (2009), the care demands to the child with chronic disease generate a social isolation of the family, enhancing the sensitivity and vulnerability to emotional disorders.

The chronic condition in childhood is hard to be faced by the family, so it is highlighted the importance of a social network that support all family members in this period, in order to maintain the equilibrium in the family system (NÓBREGA et al., 2010). When the family shares the experience with the disease, gives it a new meaning and only from the understanding from support networks and their functioning, the family will feel strengthened.

Humanization should occur in practices and from them. Therefore a humanizing practice in the attention to families of children with chronic disease is effective upon the opening of the other, in the care marked by otherness and contemplating how to be family, their wisdom, demands, and needs in this process.

Information as tool for families to face the adversities of chronic disease

For the family be able to meet the care needs of a child affected by a chronic disease, is necessary to feel secure and confident on its capability to perform new skills required during the treatment. To realize this, the family needs information about the disease, the treatment to be implemented, and the precautions to be followed to prevent complications to the child. Nevertheless in the statements below it is

observed the lack of information about the child's disease and its evolution.

Sometimes I miss to know something more about his disease. When something happens with C3. When he is in crisis and something happens and they don't explain to me why it is happening. Sometimes I even ask something, 'doctor, why is it happening? Why is he feeling this?'. Then I feel this lack of clarify the things for the mother. [...] I miss more explanation (F3).

[...] they should come and talk. I do the questions. Each time they discover something, they should come and say: 'mother it is like this'. But no, they hide the things (F1).

The lack of information has been one of the obstacles for the development of competences and skills in the family to take care of the child. The family is coparticipant in the care to the child, and therefore in the commitment with the process health-disease of the child. In this way, the information throughout the course of the disease is indispensable so that the family is able to process everything that is happening and to get organized to find the better path to follow, consciously and as balanced as possible, seeking the most coherent solution to each moment.

Study with families of children with malnutrition revealed the desire to learn about the illness that affects their families, so that they can intervene with the child. The authors emphasize that there is a complex universe of uncertainties about the influence of caring for the child as a result of ignorance, and that the lack of knowledge frequently occurs due to omission by health staff (FROTA et al., 2009).

All information about the child's health is significant for the family, however simple it may seem to professionals that assist these families. This because the family needs to know minutely the details of the disease and the care to be implemented to assist their child in their unique needs:

It is very superficial, sometimes they say: 'it's normal, it is the crisis'; but the reason why it is normal they don't explain. For me it is very meaningful to know everything that is happening with my son, to know why he is feeling a little pain in his nail (F3).

The lack of information generates a slow and silent accumulation of misunderstandings (HOLANDA et al., 2008). The knowledge acquired by means of adequate and understandable information contributes as an empowering source. In this study, it was observed a large communication gap between health professionals and family,

especially during the hospitalization period, when the professionals provide care but do not interact with the child and family. In contrast, the professionals should encourage family involvement during child hospitalization, to clarify doubts about the disease and treatment, besides give opportunity for the family to express anxieties and limitations (ROSSI; RODRIGUES, 2007; SILVA et al., 2010).

In this last time he got hospitalized, he went through 3 days with pain. Then the nurse came, gave food, medication, but the pain was still there. Why didn't she say to me it is normal? (F3).

[...] when the teachers (doctors) are teaching a class about the patients (for the university students), I was attentively hearing everything to know. When I hear words I don't know, I'll find out, look for in a book, ask someone to search the internet, but if it depends on them. When someone has a disease, a problem, they hide until the last moment, you know? (F1).

[...] he had this bellyaches, then came a doctor, I think he was expert in the subject, he touched my son's tummy and said it was normal, because the spleen was obstructed [...]. He said that if the pains didn't go away it would be necessary a surgery to remove the spleen. But I was not aware of this. I noticed the comments. I was not informed. I saw them talking among themselves and I was paying attention, just listening. So I think that they should clarify more, give more information to the mother, prepare, we need to be prepared (F3).

In this last statement, one realizes the importance of the family to be informed to organize for possible procedures during the treatment. The new challenge of health professionals is to increase awareness of population about the determinants of health through information (FROTA et al., 2009), since the lack of interactive dialogue weakens the bond between family and health professionals, which directly affect the children's treatment and may increase the vulnerability of their health. "[...] the doctor complained because I don't do a monitoring, [...] I don't take him every month. I just take him to the (hospital) when he is in a crisis [...]" (F3).

Every child with chronic disease needs a monitoring, regardless of diagnosed disease, so that the necessary interventions are implemented when detected any status alteration, and thus prevent future problems and/or hospitalizations. Given this, the outpatient follow-up is essential since if it is made adequately and on proper time, it contributes to reduce hospitalizations, due to a satisfactory management of chronic disease (DIAS-DA-COSTA et al., 2008).

In this study, the main responsible for the care of child with chronic disease was the mother, frequently the only family support that the child has during

hospitalizations. For this, these mothers need consistent and clarifying information so that they feel secure and able to promote security and tranquility to the child, “[...] the mother needs to know what is happening with her child to help him (F3)”.

The dialogue is a key in the management of everyday actions of health services. However, the typical dialogue with the purpose to gather information about the disease, when performing a classical anamnesis, does not change the assistance. This dialogue should be that one that provides a mutual knowledge, about something still unknown in the other, with share of experiences, conducted by a qualified hearing, effective communication and interpersonal relationship. Considering these attributes as a starting point for implementing actions and using technical procedures, the professionals can achieve the practical success desired (AYRES, 2007).

The lack of information from health professional leads the family to search knowledge about the child's disease in the internet.

[...] I knew that it was normal by the internet. Then I discovered that the child with this disease may have uninterrupted pain attacks, even about 8 days without stop feeling pain. But if it depended on her (doctor) I would never know (F3).

With computerization and current facility to access the internet, the families have acquired a lot of data about diseases and treatments. Nevertheless, it is necessary to have caution and be always close to the family to check if information is reliable and correct, clarifying possible misunderstandings thus preventing erroneous changes in the treatment. By keeping closer ties with the families, the health professionals can work favorably, elucidating errors in the knowledge achieved by the family, at the same time that the family's knowledge is valued in this process. According to Araújo et al. (2009, p. 504),

[...] the knowledge of specific aspects about the disease has enabled the family to relate and act facing the emergence of signs and symptoms of worsening condition. With understanding of information received, the family feels competent and has certain autonomy to care for the child.

Although the nurse recognizes that the assistance focus is the family, in practice this is not always accomplished. Nurses and other members of health staff need to understand the actual meaning of family assistance, in order to meet the demand from population and persist in the search of strategies that value the family as the center of the process (MARCON et al., 2004).

The humanizing reconstruction of health practices in this context requires everyone to be more sensitive and responsive, open to create links and

responsibilities, forming partnerships with the families and mobilizing possible social support networks (SILVA et al., 2010, p. 365).

Caring for family with chronic disease is more than intervene in a health problem, since it is an encounter of care, in which it is necessary to develop attitudes and create spaces of intersubjectivity.

Conclusion

The diagnosis of chronic disease is a challenging moment for all family members, and one way to overcome it is the dialogue and sensitive hearing between health professionals and family, preparing them for taking care of the child.

The feelings that emerge during the course of the chronic disease should not be overlooked, but worked with the family individually. The purpose is to cease or minimize them, in order to help the family to adapt to the new situation and collaborate with the welfare of the child and all members. If this management does not occur, the difficulties experienced can be somatized, overloading and stressing the family system.

One weakness found was the superficiality of information provided to the families. The family must receive accurate and adequate information to get conditions and knowledge to guide the whole process of chronic disease, both at home and hospital. This processed knowledge strengthens the family, since it feels confident to take care of the child.

Nursing, as a part of the health staff, can work satisfactorily by supporting these families along the process that permeates chronic disease, learning the meaning of the experience for each family and including them in the care given, so that they can accompany and assist the child's needs. In this perspective, the family has the subsidies to improve the quality of life of the child with chronic disease, which can also reflect positively in family balance and quality of life of the members involved in this process.

This study points out the importance of developing new researches, encompassing other subjects, contexts and situations, given the understanding that there is no universal reality. Furthermore, new studies can stand out elements to improve the quality of assistance provided to families of children with chronic disease.

Acknowledgements

To CNPq by financial support, Process no. 476666/2007-4.

References

ALMEIDA, M. I.; MOLINA, R. C. M.; VIEIRA, T. M. M.; HIGARASHI, I. H.; MARCON, S. S. O ser mãe de criança

- com doença crônica: realizando cuidados complexos. **Escola Anna Nery Revista de Enfermagem**, v. 10, n. 1, p. 36-46, 2006.
- ANTON, M. C.; PICCININI, C. A. Aspectos psicossociais associados a diferentes fases do transplante hepático pediátrico. **Psicologia: Teoria e Pesquisa**, v. 26, n. 3, p. 455-464, 2010.
- ARAÚJO, Y. B.; COLLET, N.; MOURA, F. M.; NÓBREGA, R. D. Conhecimento da família acerca da condição crônica na infância. **Texto e Contexto Enfermagem**, v. 18, n. 3, p. 498-505, 2009.
- AYRES, J. R. C. M. Uma concepção hermenêutica de saúde. **Physis**, v. 17, n. 1, p. 43-62, 2007.
- AYRES, J. R. C. M. Organização das ações de atenção à saúde: modelos e práticas. **Saúde e Sociedade**, v. 18, supl. 2, p. 11-23, 2009.
- BRASIL. Conselho Nacional dos Direitos da Criança e do Adolescente. Resolução n. 41/95. **Direitos da criança e do adolescente hospitalizados**. Brasília: Ministério da Justiça, 1995.
- BRASIL. Ministério da Saúde. Conselho Nacional de Saúde. Comissão Nacional de Ética em Pesquisa. Resolução n. 196/96. **Diretrizes e normas reguladoras de pesquisa envolvendo seres humanos**. Brasília: Ministério da Saúde, 1996.
- DIAS-DA-COSTA, J. S.; BORBA, L. G.; PINHO, M. N.; CHATKIN, M. Qualidade da atenção básica mediante internações evitáveis no Sul do Brasil. **Cadernos de Saúde Pública**, v. 24, n. 7, p. 1699-1707, 2008.
- FROTA, M. A.; MARTINS, M. C.; ALBUQUERQUE, C. M. Aspectos culturais no cuidado familiar à criança com desnutrição. **Acta Scientiarum. Health Sciences**, v. 31, n. 1, p. 9-14, 2009.
- HOLANDA, E. R.; COLLET, N.; COSTA, S. Children with Down's Syndrome: the meaning of the taking care in the perception of mothers. **Online Brazilian Journal of Nursing**, v. 7, n. 2, 2008. Available from: <<http://www.uff.br/objnursing/index.php/nursing/article/view/1443>>. Access on: Dec. 20, 2010.
- LIMA, A. S.; SILVA, V. K. B. A.; COLLET, N.; REICHERT, A. P. S.; OLIVERIA, B. R. G. Relações estabelecidas pelas enfermeiras com a família durante a hospitalização infantil. **Texto e Contexto Enfermagem**, v. 19, n. 4, p. 700-708, 2010.
- MARCON, S.; NOGUEIRA, L.; FONSECA, A.; UCHIMURA, T. Características da doença crônica em famílias residentes na região norte do município de Maringá, Estado do Paraná: uma primeira aproximação. **Acta Scientiarum. Health Sciences**, v. 26, n. 1, p. 83-93, 2004.
- MILIORINI, J. P.; FERNANDES, M. V.; DECESARO, M. N.; MARCON, S. S. A família no contexto hospitalar: apreendendo os anseios e expectativas relacionadas com doença crônica. **Revista da Rede de Enfermagem do Nordeste**, v. 9, n. 3, p. 81-91, 2008.
- MINAYO, M. C. S. **O desafio do conhecimento: pesquisa qualitativa em saúde**. 10. ed. São Paulo: Hucitec, 2007.
- MOLINA, R. C. M.; FONSECA, E. L.; WAILDMAN, M. A. P.; MARCON, S. S. A percepção da família sobre sua presença em uma unidade de terapia intensiva pediátrica e neonatal. **Revista da Escola de Enfermagem da USP**, v. 43, n. 3, p. 630-638, 2009.
- NÓBREGA, V. M.; COLLET, N.; SILVA, K. L.; COUTINHO, S. E. D. Rede e apoio social das famílias de crianças em condição crônica. **Revista Eletrônica de Enfermagem**, v. 12, n. 3, p. 431-440, 2010.
- PIZZIGNACCO, T. P.; MELLO, D. F.; LIMA, R. G. A experiência da doença na fibrose cística: caminhos para o cuidado integral. **Revista da Escola de Enfermagem da USP**, v. 45, n. 3, p. 638-644, 2011.
- RIBEIRO, R. L. R.; ROCHA, S. M. M. Enfermagem e famílias de crianças com síndrome nefrótica: novos elementos e horizontes para o cuidado. **Texto e Contexto Enfermagem**, v. 16, n. 1, p. 112-119, 2007.
- ROSSI, C.; RODRIGUES, B. The implications of the hospitalization for the child, his family and nursing team: a descriptive exploratory study. **Online Brazilian Journal of Nursing**, v. 6, n. 3, 2007. Available from: <<http://www.uff.br/objnursing/index.php/nursing/article/view/1110>>. Access on: Dec. 20, 2010.
- SILVA, F. M.; CORREA, I. Doença crônica na infância: vivência do familiar na hospitalização. **Revista Mineira de Enfermagem**, v. 10, n. 1, p. 18-23, 2006.
- SILVA, M. A. S.; COLLET, N.; SILVA, K. L.; MOURA, F. M. Cotidiano da família no enfrentamento da condição crônica na infância. **Acta Paulista de Enfermagem**, v. 23, n. 3, p. 359-365, 2010.
- SOUZA, I. V. B.; MARQUES, D. K. A.; LACERDA, O. R. M.; COLLET, N. Percepção das mães frente ao diagnóstico do filho com diabetes mellitus tipo 1. **Cogitare Enfermagem**, v. 16, n. 1, p. 43-48, 2011.
- VIEIRA, M. A.; LIMA, R. A. G. Crianças e adolescentes com doença crônica: convivendo com mudanças. **Revista Latino-Americana de Enfermagem**, v. 10, n. 4, p. 552-560, 2002.
- VIEIRA, S. S.; DUPAS, G.; FERREIRA, N. M. L. A. Doença renal crônica: a experiência da criança. **Escola Anna Nery Revista de Enfermagem**, v. 13, n. 1, p. 74-83, 2009.

Received on June 10, 2011.

Accepted on August 8, 2011.

License information: This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.