



## CHRONIC DISEASE IN CHILDREN: FAMILY EXPERIENCE IN DIAGNOSTIC RECEPTION

### DOENÇA CRÔNICA NA CRIANÇA: VIVÊNCIAS DA FAMÍLIA NO RECEBIMENTO DO DIAGNÓSTICO

### ENFERMEDAD CRÓNICA EN EL NIÑO: EXPERIENCIAS DE LA FAMILIA RECIBIENDO EL DIAGNÓSTICO

Giovana Calcagno Gomes<sup>1</sup>, Pâmela Kath de Oliveira Nornberg<sup>2</sup>, Bianca Contreira de Jung<sup>3</sup>, Camila Magroski Goulart Nobre<sup>4</sup>, Eloísa da Fonseca Rodrigues<sup>5</sup>, Daiani Modernel Xavier<sup>6</sup>

#### ABSTRACT

**Objective:** to know how the family experiences receiving the diagnosis of chronic disease of the child. **Method:** this is a descriptive and exploratory study, with a qualitative approach, with 15 family caregivers of children with chronic diseases. The technique used for the production of data was the semistructured interview, using a tape recorder. The responses were transcribed and analyzed according to the Thematic Analysis. **Results:** the family received the diagnosis of the child by the hospital doctor after childbirth or when the first symptoms of the disease appeared. Some were not informed, and the observation of signs of the disease was a source of stress and insecurity. **Conclusion:** receiving the diagnosis caused a strong reaction in the family that needed to modify their daily life to face the difficulties presented by the child and to find ways to take care of it effectively. **Descriptors:** Nursing; Child; Chronic Disease; Family; Diagnosis.

#### RESUMO

**Objetivo:** conhecer como a família vivencia o recebimento do diagnóstico de doença crônica da criança. **Método:** estudo descritivo e exploratório, de abordagem qualitativa, com 15 familiares cuidadores de crianças com doenças crônicas. A técnica utilizada para a produção de dados foi a entrevista semiestruturada, com uso de gravador. As respostas foram transcritas e analisadas de acordo com a Análise Temática. **Resultados:** a família recebeu o diagnóstico da criança pelo médico do hospital após o parto ou quando surgiram os primeiros sintomas da doença. Algumas não foram informadas e a observação dos sinais da doença foi fonte geradora de estresse e insegurança. **Conclusão:** o recebimento do diagnóstico causou forte reação na família que necessitou modificar seu cotidiano para enfrentar as dificuldades apresentadas pela criança e buscar modos para cuidá-la de forma efetiva. **Descritores:** Enfermagem; Criança; Doença Crônica; Família; Diagnóstico.

#### RESUMEN

**Objetivo:** conocer como la familia vive el recibimiento del diagnóstico de enfermedad crónica del niño. **Método:** estudio descriptivo y exploratorio, de enfoque cualitativo, con 15 familiares cuidadores de niños con enfermedades crónicas. La técnica utilizada para la producción de datos fue la entrevista semi-estructurada, con uso de un grabador. Las respuestas fueron transcritas y analizadas de acuerdo con el Análisis Temático. **Resultados:** la familia recibió el diagnóstico del niño por el médico del hospital después del parto o cuando surgieron los primeros síntomas de la enfermedad. Algunas no fueron informadas y la observación de los señales de la enfermedad fue fuente generadora de estrés e inseguridad. **Conclusión:** el recibimiento del diagnóstico causó fuerte reacción en la familia que necesitó modificar su cotidiano para enfrentar las dificultades presentadas por el niño y buscar modos para cuidarlo de forma efectiva. **Descriptores:** Enfermería; Niño; Enfermedad Crónica; Familia; Diagnóstico.

<sup>1</sup>Nurse, Ph.D. Professor, Graduation/Post-Graduation in Nursing/EscEnf/PPGENF, Federal University of Rio Grande/FURG. Rio Grande (RS), Brazil. E-mails: [giovanacalcagno@furg.br](mailto:giovanacalcagno@furg.br); <sup>2,5,6</sup>Nurses, Ph.D. students, Post-Graduation in Nursing, Federal University of Rio Grande/FURG. Rio Grande (RS), Brazil. E-mail: [pamelakathpko@yahoo.com.br](mailto:pamelakathpko@yahoo.com.br); [eloisadafonsecarodrigues@yahoo.com.br](mailto:eloisadafonsecarodrigues@yahoo.com.br); [daiamoder@gmail.com](mailto:daiamoder@gmail.com); <sup>3</sup>Nurse, Master, Substitute Professor Superior Magisterium, Federal University of Rio Grande/FURG. Rio Grande (RS), Brazil. E-mail: [biancajung@furg.br](mailto:biancajung@furg.br); <sup>4</sup>Nurse, Master student, Post-Graduation in Nursing, Federal University of Rio Grande/FURG. Rio Grande (RS), Brazil. E-mail: [kamy\\_magroski@yahoo.com.br](mailto:kamy_magroski@yahoo.com.br)

## INTRODUCTION

The Brazilian reality shows the growth of chronic diseases among children, reaching a rate of 9.3% in the 0-14 age group.<sup>1</sup> Pollution, consumption of fast food and inadequate diets contributed to the development of asthma, rhinitis, obesity and diabetes in children.

The chronic disease accompanies the person for a long period, presenting acute phases, moments of worsening or sensible improvement.<sup>2</sup> Generally, it has a slow development, being able to bring about biological, psychological and social changes, with evident prejudice of the people in conditions of greater social vulnerability.

In this sense, chronic diseases in childhood compromise the child and his family, who need adaptation to face the most adverse situations. Production on chronic conditions highlights that the age transitions, when a disease is diagnosed and treated from childhood, undergo transformations that include the way its flow between services and the changes that involve processes of discharge, and network construction that includes family, hospital, school, and rights-guarantee system.<sup>3</sup>

The birth of a child, which requires specific care, leads the family to enter into a new reality in which the child's diagnosis was possibly not expected, and this causes physical and psychological distress, especially for the family member, who may have feelings of fear, insecurity, depression, among others.<sup>4</sup> The relatives of these children become people with special needs since they need guidance on how to deal with the problem, about the reorganization of the family structure and the coping strategies of the disease and its sequels.

In this context, it is necessary to think about the family's role as a caregiver and ways to ensure that the childcare without compromising his physical and mental health, as this care will be given for a long time and in some of them permanently.

Studies with families of children with chronic diseases are relevant since they allow a better understanding of their experience in the process of caring for the child in their daily life, subsidizing health practices. In this sense, the question that guided this study was: how does the family experience the diagnosis of chronic child illness? Based on this question, the objective was to know how the family experiences receiving the diagnosis of chronic child disease.

## METHOD

This is a qualitative, exploratory and descriptive study with 15 family caregivers of children with chronic diseases hospitalized at the Pediatric Unit of a University Hospital (UH) in Southern Brazil. This is a reference hospital for maternal and child care. The Pediatric Unit has 18 beds intended for children between zero and twelve years old who are hospitalized for both clinical and surgical care.

The following selection criteria were used to select the study participants: to be the main family caregiver of the child in the hospital and the child to be five years old or older to ensure a long time of coexistence with the disease. Family members who, at the time of data collection, were identified as eventual caregivers of the child in the hospital were excluded. Thus, 15 family members participated in the study. This number was determined at the time when no new information appeared and the answers began to repeat.

Data collection was performed through semi-structured interviews in the living room of the Child-Friendly Hospital Program since it guaranteed comfort, privacy and was attached to Pediatrics. The interviews were conducted between March and August of 2013, recorded and transcribed. They had an average duration of 40 minutes. They were guided by the following questions: who gave you the diagnosis of the child's chronic disease? What was the impact of this diagnosis on the family? How did the family experience receiving this diagnosis?

The data were analyzed by the Thematic Analysis process, which includes the pre-analysis phase, material exploration, and treatment of results.<sup>5</sup> In the first phase, the "corpus" of the study was constituted, which is the organization of interviews according to an analytical table for its grouping, composed of columns distributed on the left for the numerical order of 1 to 15 and on the right under the fictitious names of the participants, corresponding the letter F and with material originating from their speeches.

In the material exploration phase, the interviews were carried out in an exhaustive way, and the units of registration were defined, that is words, phrases or paragraphs related to content and context (diagnosis, chronic disease, child, changes, birth, impact) and the analytical categories generated. The last stage of treatment of the results corresponds to the interpretation of the data, which resulted in two thematic categories:

Gomes GC, Nornberg PKO, Jung BC de et al.

the multifaceted discovery of the diagnosis and feelings produced before the diagnosis.

The research was approved by the Research Ethics Committee of the Health Area of the Federal University of Rio Grande (CEPAS/FURG) under number 106/2013 and CAAE 2311600285/22013-62, according to Resolution 466/2012, conducted by the ethical standards required. Participants signed the Informed Consent Term and also had their anonymity maintained, being identified by the letter F followed by the respective interview number.

## RESULTS AND DISCUSSION

The following is a description of the study participants and the categories generated from the data analysis.

### ♦ Characterization of study participants

Fifteen family members of children with chronic diseases participated in the study. The primary caregiver of all children was the mother, representing the families in this study. They were between 21 and 43 years old, most of them with a full second degree, the income of one to four minimum wages per month for the sustenance of three to seven people. As for the family income contributor, the father prevailed as the only provider, since the mothers had to stop working. They were helped to care for the child by the children's colleagues and grandparents, but some also cared for the child alone.

### ♦ The impact of receiving the diagnosis

For the relatives of this study, receiving the diagnosis meant a distinct, singular moment that happened in different chronological times. Most of the mothers' reports (F5, F6, F7, F9, F10, F14 and F15) expressed that the pediatrician was responsible for confirming the diagnosis of the child's chronic disease.

*The pediatrician was who diagnosed pulmonary stenosis shortly after birth. (F5)*

*Type of chronic disease; Asthma, since a baby. The pediatrician gave the diagnosis. I was told when he was born red. From birth, he stayed in the oxygen two days, purple, red, with two months. The doctor said he had asthma. (F6)*

*The pediatrician diagnosed asthmatic bronchitis. (F7)*

*He was born with the unformed lung, staying two months in the ICU. He was born six months pregnancy, and after two months I went home with my son. Today he has allergic bronchitis and shortening of the lower limb tendon. The pediatrician gave the diagnosis. (F9)*

Chronic disease in children: family experience...

*My child has recurrent urinary tract infection due to bladder reflux and convulsion. The diagnosis was given two days of life by the pediatrician. (F10)*

*He has had cerebral palsy since birth. He was in the neonatal intensive care unit when he was born. It was the pediatrician who gave the diagnosis. (F14)*

*My son was born with anal perforation, and he did an ileostomy. The diagnosis was given by the pediatrician. (F15)*

The findings of this study revealed how each mother discovered the diagnosis of chronic child illness at different times, presenting distinct feelings and having their lives transformed. Their routine and family dynamics were changed, and they had to look for ways to adapt to their new reality of life. In this context, the birth of a child with chronic disease and the receipt of his diagnosis can be an impactful, traumatic and painful experiment, representing a challenge for the whole family.<sup>6</sup>

The impact of receiving the diagnosis of the child was felt singularly by the mothers and marked by distinct moments that involved different chronological times. It was found that this news was given by the pediatrician and confirmed by different specialists. From this universe, aspects such as the lack of information on the health condition of the child (F2), the perception of normality conferred by the mothers (F1), the negation of the children's illness (F3) and knowing the child will not heal (F10).

The diagnosis of a chronic disease in the family feelings of fear, insecurity, discomfort, and tension, as often families are not prepared to deal with such an event. Thus, they are faced with a situation of suffering that can lead to a crisis in family dynamics.<sup>3-6</sup>

The predominance of the diagnosis was given as soon as the child was born (F5, F6, F8, and F14), at two days (F10) and two months old (F13). Diagnoses were given by different medical specialists (neurologist, traumatologist, hematologist, surgeon, ophthalmologist and neonatologist) according to the progression of the disease and the symptoms presented by the child.

*The diagnosis of encephalopathy was given by the physician when he was admitted to the neonatal intensive care unit. He arrived with 47 of bilirubin in the ICU. (F2)*

*The examination that was done by the doctor in the North, he just opened the blanket and looked at my son. Right after I went home. When he arrived, he began to scream, and his body was arch-shaped, lacking air, catatonic. (F1)*

Gomes GC, Nornberg PKO, Jung BC de et al.

Chronic disease in children: family experience...

*It was the neurologist who gave the diagnosis of encephalopathy. (F3)*

*The diagnosis of imperfect osteogenesis was given shortly after birth by the traumatologist. (F8)*

*It was the hematologist who diagnosed the presence of lymph nodes, but they were benign. (F11)*

*My son had intestinal volvulus and had short bowel syndrome. After the surgery, he removed almost the entire intestine. The diagnosis was given by the surgeon two years ago. (F12)*

*Four years ago, we had the diagnosis of osteogenesis confirmed by the traumatologist. However, blindness was at two months old by the ophthalmologist. (F13)*

The mothers (F2 and F4) reported a lack of information by health professionals about the child's health condition since F2 only discovered what the child had at random in a service for exceptional children and not by a specialist able to make the diagnosis. Another mother (F4) perceived the child's illness by witnessing the occurrence of seizures that made her seek health services frequently to obtain answers about the cause of the symptoms presented by the child. These experiences permeated moments of restlessness, of searching, of distrust, of observation, which naturally generated stress and insecurity.

*When he was born, I was not told what had happened. They just said it was a lack of oxygenation. I went to find out for myself what that meant. When I asked, they told me it was because he was premature. That was premature. I was very suspicious. I saw that it was not normal. I learned about the diagnosis when he was five years old at APAE. Another mother asked me if my son has an encephalopathy as well. (F2)*

*Who said it was encephalopathy was the neurologist. However, I went to find out when he started convulsing and I asked. (F4)*

The mothers (F2 and F4) reported that they were not informed about the child's chronic health condition. This may have been due to the lack of professional preparation since they are not encouraged to see the patient as a biopsychosocial being with their singularities and needs. This fact may have hindered to accept the child's diagnosis, generating doubts and uncertainties in the family, so the professional should be scientifically grounded both to perform the diagnosis and to program effective interventions that meet the child's real needs.<sup>7</sup>

Given the need to inform the child's diagnosis to the family, there is a need for professionals to provide individualized

attention to a better apprehension of this new condition, possibly preventing some caregivers from feeling insecure or guilty, feeling fragile and injured.<sup>8</sup> Upon receiving the diagnosis, the family member waits for health professionals to be sympathetic to their suffering, offering them the emotional support they need.

In this circumstance, the nurse must act as an educator, providing the child and family members with relevant and accurate information.<sup>9-10</sup> Knowing the possibility of progression, weakness or death caused by the disease, family members mobilize and even modify their habits of life for the health of the child.<sup>10</sup> Thus, the instrumented family contributes to the care of the child and the therapeutic plan at home.

The family may have difficulty understanding the child's diagnosis and found that they preferred to believe that it was a mistake. They tried to find a justification for the changes presented, not believing in the condition of chronicity of the child. In this sense, they denied the fact that the child needs support services, perceiving it as normal. They decided whether to use the medication prescribed for the child, according to what they thought was best for them, based on the signs and symptoms presented or even on the side effects of the drugs.

*I thought it was normal. He was small but seemed normal; I wanted to believe that he did not need to go to the APAE. (F1)*

*My daughter understands everything. I do not accept the APAE. (F3)*

*He is hyperactive. The neurologist prescribed Neuleptil, but as he slept a lot, I stopped giving it. I thought it was not necessary. I stopped giving it. (F15)*

A study involving families of children with cancer revealed feelings of denial about the diagnosis of the disease.<sup>11</sup> However, it is important to highlight this aspect as part of a process of elaboration of the disease situation and unpredictability imposed on the lives of children with cancer and their families.

The denial phase involves the first stage of a process that is triggered by unexpected news, such as the diagnosis of a serious illness or death risk situations.<sup>3</sup> It is used by many patients and their families, and they can be identified soon after the finding or sometimes in other stages of the disease, as the speech of F3 highlights, revealing the denial about the fact that the child needs support services.

For the mothers (F3, F10, and F13), the reality of having a child with the diagnosis of chronic illness meant living in a context of difficulties in which they could not accept the

Gomes GC, Nornberg PKO, Jung BC de et al.

disease and, consequently, the limitations imposed by it. The term accept was present in the testimonies and this gave rise to the reflection on how much the mothers have their particular universes shaken by the lack of a cure, resist this reality of difficult acceptance, showing a daily permeated by difficulties.

*I know I am very stubborn. I know she has problems, but it is so difficult that I still do not accept that she has to go to the APAE. I cannot accept it! (F3)*

*It is all right! I know I should get used to it. I have not gotten used to her illness yet. It sounds like a lie. She is seven years old, and I do not accept that she will not be well, that there is any cure. (F10)*

*I have many difficulties because he is six years old and walks with the help of the walker and he is blind. He is always on my lap. The doctor does not want to use a wheelchair, preventing him from walking. However, it is hard to accept all this. It's been six years, and it is still difficult. (F13)*

A study with American asthmatic children evidenced educational interventions offered by health professionals on how to deal with the disease at home. Thus, the educational role and sharing of information between professionals and parents reduce the causes of emergency care and hospitalizations.<sup>12</sup> For all mothers, the child's diagnosis has impacted and transformed the routine of their lives. Thus, recognizing that the caregiver mother also suffers impacts on her daily living with her other children, with her spouse, in the relationship with the world and becomes relevant to minimize the burden that the exclusive dedication to the child causes. It is up to the health team to articulate support networks so that the caring mother does not perceive alone in the face of the immensity of meanings that are attributed culturally to the disease and to care.<sup>13</sup>

It is believed that Nursing care allows the construction of a support network, providing information about the disease, adequate support for treatment and prevention of complications in the long term. Also, professionals should direct the look at the maternal personality, as it suffers along with the child with chronic illness, altering the emotional and social life of the mother.<sup>14</sup>

#### ◆ Feelings before diagnosis

It was verified that the diagnosis of chronic disease of the child beside being impacting to the family, causes a multiplicity of feelings. Regarding the child, caregivers are the people who suffer from this reality and manifest diverse feelings about the diagnosis of their children. Information on the diagnosis of the

Chronic disease in children: family experience...

child's illness caused a range of feelings such as shock, loss of hope, despair, sadness, worry, depression, moodiness, pain, bad and awful feeling and dread, as the mothers participating in this study pointed out:

*It was a shock to know the severity of the disease. The father (my husband) passed out when he visited his son in the ICU. At first, I was strong, I was a warrior. I thought it was not so much that he was normal. He was small but seemed normal. Then I collapsed, almost lost hope. (F1)*

*I went into despair because she was in a coma. (F3)*

*I did not know I was going to have a son like that with encephalopathy. The most difficult thing is for him to have this disease, it is very sad. (F4)*

*When I heard the diagnosis, I (mother) was terrified. (F5)*

*I was worried when I heard about the diagnosis of asthma. (F7)*

*It was an impact this diagnosis of imperfect osteogenesis! I do not know how to explain to you. The chances of survival were few, but he is nine years old. There is not much to do; one tells you something else says another. It was very difficult. At the time, we fill. (F8)*

*Soon after birth, I had depression. I did not feel like doing anything. I was always on the street. I did not want to go home without my son. He was born in six months and was admitted to the ICU and stayed in the hospital for two months. I only asked God to take care of him. (F9)*

*When I was diagnosed, I lost my ground. (F10)*

*I cannot explain it to this day. I do not understand how this can happen. He had no symptoms at all. He was healthy, and when it happened it was a shock. It was suddenly a shock. (F12)*

*Knowing his blindness was awful! It was a very bad feeling. We were alone in Porto Alegre, and we had no one in the family to share the pain when I got the news. When we learned about osteogenesis the father was present, but it was equally bad. (F13)*

*I was very sad at first. However, for her sake, I started to work and stimulate her. (F14)*

*I was terrified. At first, I did not understand the diagnosis. I thought they had pierced his anus during delivery. I did not know it was a malformation, which he had been born that way. (F15)*

The family member may experience several emotions: shock, despair, sadness, fear at the diagnosis of chronicity, even so, they must organize to care for the child.<sup>15</sup> These findings corroborate with those found in this study,

Gomes GC, Nornberg PKO, Jung BC de et al.

demonstrating how complex it is to have a child with chronic illness.

Another study on children with chronic diseases has revealed the demand for a longer time to define the diagnosis and, in certain cases, this delay may imply a reduction in the child's survival, as well as provoke feelings of anxiety and impotence in the family, needing the follow-up and support through the social network.<sup>16</sup> Some mothers (F2, F12, and F13) reported receiving the child's diagnosis after a few years after birth. They reported having perceived the signs and symptoms of the disease and the physical abnormalities imposed, but they were unaware of the actual health condition of the child, which made them seek other health services.

For mothers (F2 and F6), the diagnosis of their diagnosis did not have a negative impact due to chronic disease, possibly because it was not given soon after birth. In this way, the mothers gradually realized that the child had some problem, saying that they gradually assimilated the possibility of an illness. It is important to note that for F2, the diagnosis of the child represented a moment of tranquility and feeling good since it was already waiting for him, and with that, she was able to prepare better to deal with the new condition of life. However, the mother (F6) with previously experience in the care of the child with the same pathology and the definition of diagnosis facilitated care with the child.

*I received the diagnosis at APAE. He was five, but I expected it. Receiving the diagnosis made me feel good. I had a very difficult pregnancy because of the conditions of relationship with my son's father. (F2)*

*My oldest daughter has bronchitis. So, I was used to dealing with a child with asthma. (F6)*

Faced with the child's diagnosis, the feelings expressed by the mothers (F4 and F3) show the reality of suffering, of feeling guilty about the child's illness or being accused by the family of being guilty. In this case, mothers who are already fragile and responsible for care are the ones who seem to suffer most from the child's condition. Also, they may not receive the necessary support from the family to take care of him.

*I was in my son's shoes, watching him suffer. In my family, everyone was always united, but since they have no one to blame for my son's illness, they blamed me and walked away. (F4)*

*It changed everything, I did not tell anyone, I got stuck. Nobody helps. I ask God what I did? I feel guilty. (F3)*

Chronic disease in children: family experience...

In a study carried out on the perception of the relatives of patients with cow's milk allergy in relation to the treatment, they reported the existence of conflicts with the family, blaming the mother for the development of the disease, attributing to her genetic inheritance the child's illness and (F3) and the guilt attributed to them by the family (F4), which makes them responsible for their own by the child's illness.

The feelings produced before the diagnosis are expressed by the condition of acceptance of the chronic disease and the child with his limitations and problems. Despite the difficulties encountered in daily life, families manage to care for the child and reveal that they are not ashamed of it.

*I have to accept, so today he is well, attending APAE. I am not ashamed of him. He has social contact with other children. He has problems, but he has our affection; of the grandparents. The father does not give so much attention, but nevertheless, he adores the father. (F1)*

*I work hard. I accepted his condition. He has been visiting the traumatologist since last year. He attends him every three months. He will do foot surgery, and when performing tendon surgery, he will be able to walk normally. I will take good care of him. (F9)*

Therefore, the chronic disease imposes several needs besides the special care to the child, because it is necessary that the caregiver is also assisted by professionals and, especially, be clarified about the diagnosis and the limitations resulting from it. It is believed that negative feelings about the diagnosis can be minimized if family members receive the necessary guidance about the child's illness and the care they should receive.

## CONCLUSION

The study sought to know how the family experiences receiving the diagnosis of chronic disease of the child. Two categories emerged: the impact of receiving the diagnosis and feelings produced in the diagnosis. It was verified that the moment of receiving the diagnosis of the child, most of the time, generated great impact for the family and involved the confirmation by the pediatrician. However, other medical experts were also responsible for giving the news, after delivery or when symptoms of the disease appeared.

Mothers felt this moment in a unique way and in different chronological times since some children were only diagnosed years after birth. However, some mothers reported that they were not informed about the health

Gomes GC, Nornberg PKO, Jung BC de et al.

condition and diagnosis of the child by professionals and that the observation of signs and symptoms of the disease was a source of stress and insecurity.

The following feelings were expressed when they received the child's diagnosis: shock, despair, sadness, dread, worry, hopelessness, feeling of loss of the floor, pain, bad feeling, and guilt, but after a while, they reacted and started to manage the care of the child. Also, there was the denial of the diagnosis by the mothers and the feeling of guilt for the chronic condition of the child. It was also found that they were blamed by their family for the child's illness.

The data show that receiving the diagnosis of chronic disease of the child causes a strong reaction in the family, which needs to modify their daily lives and face several difficulties. They have to reorganize and adapt to live with the disease, the treatment, the way to rescue its routine, to plan the future and to be able to take care of the child of effective form.

In this context, the mother was the main caregiver, making child care a priority. Therefore, it is important to highlight the strong insertion of health professionals, especially nurses, who are active in the field of health education, who need to be involved in this context of guiding and clarifying the families about the real needs that a child with chronic illness will require.

## REFERENCES

1. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde. Departamento de Análises de Situação em Saúde. 20 anos de Sistema Único de Saúde (SUS) no Brasil, 2008 [Internet]. 2009 [cited 27 Oct 2016]. Available from: [http://bvsms.saude.gov.br/bvs/publicacoes/saude\\_brasil\\_2008.pdf](http://bvsms.saude.gov.br/bvs/publicacoes/saude_brasil_2008.pdf)
2. IBGE. Instituto Brasileiro de Geografia e Estatística. Pesquisa Nacional de Saúde 2013 [Internet]. 2014 [cited 28 Oct 2016]. Available from: <http://biblioteca.ibge.gov.br/visualizacao/livros/liv91110.pdf>
3. Moreira MC, Gomes R, Sá MR. Doenças crônicas em crianças e adolescentes: uma revisão bibliográfica. Ciênc saúde coletiva [Internet]. 2014 [cited 2016 Nov 11];19(7):2083-94. Available from: <http://www.arca.fiocruz.br/handle/icict/10479>
4. Roecker S, Mai LD, Baggio SC, Mazzola JC, Marcon SS. A vivência de mães de bebês com malformação. Esc Anna Nery RevEnferm

Chronic disease in children: family experience...

- [Internet]. 2012 Jan [cited 2016 Nov 11];16(01):17-26. Available from: [http://www.scielo.br/scielo.php?script=sci\\_arttext&pid=S1414-81452012000100003](http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1414-81452012000100003)
5. Bardin L. Análise de conteúdo. São Paulo (SP): Edições 70; 2011.
6. Souza MA, Melo LD. Sendo mãe de criança hospitalizada com doença crônica. REME rev minenferm [Internet]. 2013 [cited 2016 Nov 11];17(2):362-73. Available from: <http://www.reme.org.br/artigo/detalhes/655>
7. CestariVRF, CarvalhoZMF, Barbosa IV, Melo EM, StudartRMB. Assistência de enfermagem à criança com hidrocefalia: revisão integrativa da literatura. J Nurs UFPE on line [Internet]. 2013 May [cited 2016 Nov 11];5(6):4112-8. Available from: [http://www.repositorio.ufc.br/bitstream/riufc/6218/1/2013\\_art\\_rmbstudart.pdf](http://www.repositorio.ufc.br/bitstream/riufc/6218/1/2013_art_rmbstudart.pdf)
8. Martins EM, Frota MA, Silva DM, Ataíde MB. Vivência de mães no cuidado à criança diabética tipo 1. RevreneCeará [internet]. 2013 [cited 2016 Nov 11];14(1):42-9. Available from: <http://www.revistarene.ufc.br/revista/index.php/revista/article/view/1332>
9. dos Santos Pennafort VP, Silva AN, Queiroz MV. Percepções de enfermeiras acerca da prática educativa no cuidado hospitalar a crianças com diabetes. Rev gaúcha enferm online [internet]. 2014 Sep [cited 2016 Nov 11];35(3):130-6. Available from: <http://seer.ufrgs.br/index.php/RevistaGauchaDeEnfermagem/article/view/43313/31528>
10. Rubin O, Azzolin K, Muller S. Adesão ao tratamento de diabetes mellitus tipo 1 atendidos em um programa especializado em Porto Alegre. Medicina (Ribeirão Preto) [internet]. 2011 Dec [cited 2016 Nov 11];44(4):367-76. Available from: <http://www.revistas.usp.br/rmrp/article/view/47448>
11. Ramalho WS, Fernandes IC, Salge AK, Barbosa MA, Siqueira KM. A família da criança com câncer: percepções de profissionais de enfermagem atuantes em oncologia pediátrica. Ciênc cuidsaúde [internet]. 2012 Oct [cited 2016 Nov 11];11(4):784-91. Available from: <http://periodicos.uem.br/ojs/index.php/CienCuidSaude/article/view/21661>
12. Bucher JA, Thompson CW. Promoting Health in Low-Income Communities the Asthma Safe Kids Program Delivered by an Academic Nurse Managed Center. J AsthmaAllergy Educ [internet]. 2012 Oct [cited 2016 Nov 11];3(5):215-20. Available

from:

<http://jaa.sagepub.com/content/3/5/215.abstract>

13. Leite MF, Gomes IP, Moraes JD, Collet N. Impacto na vida de mães cuidadoras de crianças com doença crônica. *Revenferm UERJ* [internet]. 2015 SepT [cited 2016 Nov 11];23(4):501-6. Available

from:<http://www.e-publicacoes.uerj.br/index.php/enfermagemuerj/article/view/4966>

14. Dutra HS, Werneck LM, Gomes AL. Crianças com diabetes: percepções maternas. *RevenfermUFJF* [internet]. 2016 Aug [cited 2016 Nov 11];1(2): 195-203 .Available from:<https://enfermagem.ufjf.emnuvens.com.br/enfermagem/article/view/31>

15. Newton K, Lamarche K. Take the challenge: strategies to improve support for parents of chronically ill children. *Home Healthcare Now* [internet]. 2012 May [cited 2016 Nov 11];30(5):1-8. Available from:[http://journals.lww.com/homehealthcareonline/Abstract/2012/05000/Take\\_the\\_Challenge\\_Strategies\\_to\\_Improve\\_Support.9.aspx](http://journals.lww.com/homehealthcareonline/Abstract/2012/05000/Take_the_Challenge_Strategies_to_Improve_Support.9.aspx)

16. Araújo YB, da Silva Reichert AP, de Vasconcelos MG, Collet N. Fragilidade da rede social de famílias de crianças com doença crônica. *Revbrasenferm* [internet] . 2013 Sep [cited 2016 Nov 11];66(5):675-81. Available from:

<http://www.scielo.br/pdf/reben/v66n5/06.pdf>

17. Yonamine GH, Contim D, Castro AP, Jacob CM, Pastorino AC. Perceptionsofcaregiversofpatientswithcow's milk allergy regarding the treatment. *J Hum GrowthDev (Online)*. 2013 Sept [cited 2016 Nov 11];23(1):58-64. Available from:[http://pepsic.bvsalud.org/scielo.php?script=sci\\_abstract&pid=S010412822013000100009&lng=pt&nrm=iso&tlng=en](http://pepsic.bvsalud.org/scielo.php?script=sci_abstract&pid=S010412822013000100009&lng=pt&nrm=iso&tlng=en)

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### Corresponding Address

Bianca Contreira de Jung  
Universidade Federal do Rio Grande  
Escola de Enfermagem  
Rua General Osório, s/n, 4º piso  
Bairro Centro  
CEP 13025-155 – Rio Grande (RS), Brazil

English/Portuguese

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