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ORIGINAL ARTICLE

EXPERIENCING A CHILD'S DIAGNOSIS OF CYSTIC FIBROSIS: A MATERNAL LOOK

VIVENCIANDO O DIAGNÓSTICO DE FIBROSE CÍSTICA DO FILHO: UM OLHAR MATERNO VIVENCIANDO EL DIAGNÓSTICO DE FIBROSIS CÍSTICA DEL HIJO: UNA MIRADA MATERNA

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ABSTRACT

Objective: to understand the mother's experience in face of a child's diagnosis of cystic fibrosis. **Method:** qualitative study, with a phenomenological approach, conducted with eight mothers of children with CF in Minas Gerais. Data were collected through open interviews. The project was approved by the Research Ethics Committee, CAAE: 02045712.9.0000.5142. **Results:** from the analysis, the following category emerged << The Being-there experiencing their child's diagnosis of cystic fibrosis >>. It was evident that professionals who serve these mothers at diagnosis moment are not sufficiently prepared. The diagnosis was given impersonally and without the proper information, which generated a significant impact and intense suffering. **Conclusion:** an enhancement of professionals that serve population, at this time of their lives, is necessary in order to offer them greater comfort and support in this period. **Descriptors:** Cystic Fibrosis; Mother-Child Relations; Diagnosis; Nursing Care.

RESUMO

Objetivo: compreender a experiência da mãe ao vivenciar o diagnóstico de fibrose cística do filho. **Método:** estudo qualitativo, com abordagem fenomenológica, realizado com oito mães de crianças com FC em Minas Gerais. Os dados foram coletados por meio de entrevistas abertas. O projeto foi aprovado pelo Comitê de Ética em Pesquisa, CAAE: 02045712.9.0000.5142. **Resultados:** na análise, emergiu a categoria << O Ser-ai vivenciando o diagnóstico de fibrose cística de seu filho >>. Evidenciou-se que os profissionais que atendem essas mães no momento do diagnóstico não estão suficientemente preparados. O diagnóstico foi dado de forma impessoal e sem as informações adequadas, o que gerou um impacto significativo e intenso sofrimento. **Conclusão:** é necessário um aprimoramento dos profissionais que as atendem, neste momento de suas vidas, no intuito de oferecê-las o maior conforto e apoio neste período. **Descritores:** Fibrose Cística; Relações Mãe-Filho; Diagnóstico; Cuidados de Enfermagem.

RESUMEN

Objetivo: comprender la experiencia de la madre al vivenciar el diagnóstico de fibrosis cística del hijo. **Método:** estudio cualitativo, con abordaje fenomenológica, realizado con ocho madres de niños con FC en Minas Gerais. Los datos fueron recolectados por medio de entrevistas abiertas. El proyecto fue aprobado por el Comité de Ética en Investigación, CAAE: 02045712.9.0000.5142. **Resultados:** en el análisis, emergió la categoría << El Ser-ahí vivenciando el diagnóstico de fibrosis cística de su hijo >>. Se evidenció que los profesiones que atienden estas madres en el momento del diagnóstico no están suficientemente preparados. El diagnóstico fue dado de forma impersonal y sin las informaciones adecuadas, el que generó un impacto significativo e intenso sufrimiento. **Conclusión:** es necesario un perfeccionamiento de los profesiones que as atienden, en este momento de sus vidas, el en intuito de ofrecerlas mayor confort y apoyo en este período. **Descriptores:** Fibrosis Cística; Relaciones Madre-Hijo; Diagnóstico; Cuidados de Enfermería.

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INTRODUCTION

The Cystic Fibrosis (CF) is a chronic, autosomal recessive and hereditary disease. The incidence in Brazil is 1: 8,500 live births¹. When it was discovered, life expectancy was five years; however, due to great technological advances and in research, it is currently around 30 years. However, still 15% to 20% of patients die before the tenth year.^{1,2}

In CF, a mutation of chromosome 7 occurs, which encodes the protein called Cystic Fibrosis Transmembrane Conductance Regulator (CFTR), responsible for conducting ions between intra and extracellular media.³ With disorder of ion transport in the cell membranes, absence of activity or partial operation of the chloride channel occurs, reducing excretion and, consequently, causing an increase in the sodium flux in an attempt to preserve the electrochemical equilibrium, which results in increased osmolality of the cell.¹

The increase in osmolality of the cell generates a dehydration of mucous secretions and increase in viscosity, leading to an inflammatory reaction and subsequent fibrosis process due to clogging of sweat and pancreatic ducts, bile ducts and airways, intestine and deferent vessels.¹ There are different manifestations of the disease due to over 1560 mutations in the CF gene, which leads to more or less intense symptoms, although there is always impairment of the upper airways and pancreas ducts.⁴

Respiratory symptoms present the highest morbidity and mortality, because the thick mucus remains attached to the lungs and becomes a culture medium for bacteria and microorganisms, causing recurrent pneumonia, bronchiectasis, pneumothorax. Another significant complication is the impairment of the gastrointestinal tract, especially, pancreatic insufficiency, which prevents the production and/or shipping of enzymes to the tract, causing poor digestion. This occurs mainly by non-absorption of fats, which causes steatorrhea and protein-energy malnutrition, affecting thereby the weight and structural development.⁵

Diagnosis can be made in pre-natal care, in newborn bloodspot screening test or during the course of life of individuals through the identification of at least one phenotypic finding or family history of CF, followed by positive result to sweat test or through positive nasal potential difference, or even through the presence of two mutations known to cause CF in the CFTR genes.⁶

The treatment of CF includes antibiotics, broncholytic agents, bronchodilators and anti-inflammatory drugs; airway hygiene and breathing exercises; oxygen support and vitamin supplementation⁶. It must be performed by a multidisciplinary, individualized team and preferably in specialized centers, and started as early as possible.^{2,7} It is evident that the therapeutic treatment is performed without valuing the being as a whole and the team's actions are often intended only for the individual's biological body, emphasizing only the technical aspects of care.⁸

The diagnosis of CF generates a significant impact on the lives of patients and their families because it is a systemic, complex therapy disease, with no cure and little known, that demands of individuals a routine constant care. The mother, more often, is the most involved in the care and monitoring the child, playing a fundamental role in the family structure, being one of the main responsible for education, parenting and socialization of children.⁸

After receiving a child's diagnosis of CF, the daily routine of mother is undergoing profound changes in order to spend more time with the child and provide support. Therefore, it is important that health professionals, especially nurses, take responsibility for the guidelines to mothers and that they have a close look at the bio-psycho-social issues involving the mother, the sick child and their entire family.

Receiving a diagnosis of a disease such as CF generates large impact on the thinking and acting of a mother, triggering numerous feelings and changing her routine life. Thus, revealing how these mothers experience the experience of their child's diagnosis of CF is essential for professionals to identify the real needs of this group and establish a continuous aid relationship. This study aims to:

- Understand the mother's experience in face of a child's diagnosis of cystic fibrosis.

METHOD

Article drawn from the dissertation << *Experiences of mothers of children with cystic fibrosis* >>, submitted to the Graduate Program in Nursing, School of Nursing, Federal University of Alfenas. Minas Gerais/MG, Brazil, 2013.

This is a qualitative study of Heidegger's existential phenomenological approach. The choice of this approach was due to our concern in unveiling how it is for mothers to experience having a child with CF. In addition to believing that phenomenology favors the

understanding of the phenomenon as it manifests itself to the person who experiences it and put as a starting point the reflection of the being who makes himself known, favoring the achievement of our goal.⁹

Participants were eight mothers of children carrying CF who met the following inclusion criteria: mothers of children with CF who had been diagnosed with the disease for more than a year from the interview day, believing that by this time they would have experienced the chronicity of the disease and could describe their experience with more details; being the primary caregiver of the child and being 18 years old or older.

The number of respondents was not defined *a priori*. Interviews were closed from the time the concerns of researchers were answered and the goal achieved, according to assumptions of qualitative phenomenological research.¹⁻¹⁰

In order to meet these subjects, it was used the "snowball" technique. It is developed so that the first interviewees, as researcher's acquaintances, indicate others and so on, until we reach the goal of the study.¹² Through telephone contact, we approached the first mother and from her we started contacts with other participants she indicated.

The collection of interviews was held from June to October 2012. All interviews were conducted individually in place and to me most convenient for each mother. All mothers chose to be interviewed at home because it was considered the place of greater peace and privacy to describe their experience. It used the open interview, without measured time, because the aim was to seize the existential time as horizon that made possible the emergence of responses to the concerns. The main question of the interviews was: I would like you to tell me your experience as mother of a child with CF. How is it to live the daily life of this experience? After this question, all mothers started their narratives reporting on the time of the search and discovery of the diagnosis, which showed the great need they had to talk about this period. So we decided to write a study that highlighted the impact diagnosis of CF to mothers accompanying the trajectory of their children's disease.

In order to preserve anonymity, the mothers were identified with the letter "I", from interview, followed by Arabic numbers from one to eight, reflecting the order in which they were performed (I1 to I8).

The path for organization and comprehensive analysis of the phenomenon was carried out according to methodological

assumptions of phenomenology.^{11,13} Initially, all material recorded was transcribed in full; and then, we performed successive readings of the material as a whole, still with no claim or concern with the interpretation of the data. New readings were made by the authors in search of meaning units, i.e., significant excerpts of speeches that addressed the research question and the study objective. The next step was the grouping by similarity of meaning units, composing this category and, finally, the interpretation and discussion of the data.

We borrowed some assumptions of existentialist framework of Martin Heidegger to support the interpretation of narratives, believing that the structures proposed by this author would serve as a guideline to support the interpretation of this important stage in the mother's life who experiences having a child with CF.

In order to meet the ethical aspects, the study was approved by the Ethics Committee on Human Research of the Federal University of Alfenas-MG, with the CAAE number 02045712.9.0000.5142 and approval protocol 017/2012. All research participants signed the Informed Consent Form(IC).

RESULTS AND DISCUSSION

♦ The Being-there experiencing their child's diagnosis of cystic fibrosis

Heidegger's approach indicates that the being-there is out in the world, subject to their existential factuality. In this world, they experience all the activities of being, they are born, grow, hate, love, witnesses death and life all the time.⁹ Thus, mothers of children with CF experience during their being-in-world the search for diagnosis. When faced with the impact of it, they experience feelings of relief, but at the same time, a fear of the unknown.^{8,14} It is a time of re-signification of their lives. So the world that is presented to these mothers is fraught with many difficulties and moments of reflection on the vicissitudes to which they are exposed in the course of their existence.

During the interviews, it became apparent the importance given by mothers to the stage of discovery of the diagnosis. When we began our meetings, mothers reported their trajectories in this process and unveiled, thrilled, their memories of the past before the confirmation that their child was diagnosed with a chronic illness.

We realized that, for them, receiving a diagnosis of CF for their child was despairing, since it represented a moment of interruption

of dreams; these dreams drawn before, with the perspective of the birth of a healthy child.

[...] In the beginning, it was very scary, it was my first child, my husband and I were still very young, I did not think she could have a disease; it was like someone had poured cold water on our plans. (I1)

We highlight one of the assumptions of Heidegger's concept, that the human being is not ready, but he is a task to be. And so he is subject, in his own existentialism, to gain or lose, just because the human being is the possibility. The encounter of the mother-being with their child's diagnosis of CF make her experience the beginning of new possibilities of life, maybe not those intended for them, but it is a new world that presents itself. The author states that it is through knowledge that we become aware in the world and experience our existence in it.⁹

The expected birth of a child is a very important event in the life of a woman, because for months, she waits anxiously for his arrival. It is a period of intense emotions and plans. The woman, in the position of mother, becomes more sensitive, suffers numerous physical and hormonal changes due to gestational stage. It arouses feelings of fear, doubt, anxiety about life and the future of that child.¹⁵ It is an event that becomes part, in a unique and special way, of the existence of a woman. The mother-child relationship begins even during pregnancy, when she builds an image of the ideal child. Faced with the newborn carrier of an illness, she presents emotionally shaken, with the fact that the child does not match her expectations and thus causing a threat that may endangers the mother-child bond.^{8,16}

The way the family reacts to child's chronic illness is related to some specific features that are unique and are presented differently in each household. Overcoming and living with the disease as something normal and inserted into their daily routine are directly related to the age at which the child is diagnosed; which the stage of disease is; treatment and its effects; the limitations imposed by the disease; the way society views it; the prognosis and the coping strategies that this family has.¹⁷

Discovering a child's chronic illness means a breakout in the existential projects of a mother.¹⁸ For them, it is difficult to understand that their children need special attention and that the demand of care to them will have to be expanded since the moment of the diagnosis. At that moment, they emerge in a reflection of the past, in search of every detail, something that could

be responsible for the current suffering, seeking reasons to justify the fact that their children had been born sick.

[...] We went to the psychologist, to try to understand, because we were shaken on we found out, because we hoped a healthy child, like my other children, then someone tells you that your child has a disease and that this disease has no cure, is it very difficult. (I2)

[...] It was so hard that we were thinking what my husband and I had done wrong, if we had gotten pregnant too soon. (I6)

A study conducted in Cascavel, Paraná, with mothers of children with CF, observed that these mothers, when asked about the patient's condition, referred to a sense of loss of the child, which, until diagnosis, had been conceived as a perfect child.⁸

During pregnancy, the parents come to verbalize their concerns and reflect on the possibility of something goes wrong with their child. Normally, however, this feeling is fleeting, especially if the pregnancy elapses without abnormalities or if family members had not experienced problems in other pregnancies, because living the daily life of pregnancy does not allow the mother to imagine that the child is ill or will not be perfect. Living daily objectively and very rushed, as most often occurs, prevents us from thinking about the various possibilities of life. And only with the existential anguish we realize those possibilities that can bring pain.¹⁸

[...] During all my pregnancies I was terrified of my children were born missing a body part or a serious illness, but I did not keep that in mind, no. (I2)

[...] When I heard, it was a shock. Until this day, if I remember it is a shock, I cry, I feel sad. Because I had a great pregnancy, did exercises, never had motion sickness. Neither my family nor the family of my husband had never experienced anything like that. (I8)

According to the speeches, we observed that the diagnosis is a watershed in the existence of each of these mothers. The impact of the diagnosis triggers a deep sense of fear, anguish and questions regarding the doubts related to treatment and their child's life course. It is a time of transition, of defining and redefining their role of being mothers front that child so expected.

[...] It was a very difficult time, from that day my life changed completely. (I4)

[...] In my life, everything changed after he was born. (I2)

Producing a child who may require more attention and care is something feared by

parents, since it demands an emotional effort to abandon the fantasized image of the expected child and changing family dynamics to offer the proper attention that he/she will need. When confirmed the child's diagnosis of CF, mothers of this study sought a new sense for their being, since their ideal child image was abruptly broken and the world presented a new being, sick, and that is on their constant vigilance and responsibility.

The being in the world is subject to possibilities of events that occur during its existence. The Dasein or being-there is faced with opportunities that he does not foresee. He is subject to changes that he does not know. He moves constantly in a state over which he has no control.⁹

Experiencing the child's diagnosis of CF may vary and be experienced in a very peculiar way by each mother. The first contact with the disease causes the mother and the whole family feelings of disbelief regarding the diagnosis:

[...] In the day the result came out, I was at home when I saw many nurses coming and saying that I had to go to Belo Horizonte that night. They arrived, it was 10 am, saying that that night I would have to go to Belo Horizonte because my son had cystic fibrosis, from that hour until the other day I just cried, you know? I felt lost, I could not believe. (I4)

[...] At the time of diagnosis it was very difficult, I would stay all the time in that hospital, I was alone, she and I, and she just sick, sick, she would go to ICU and get back. When she would go back there, I could not believe that was going to live it all over again. It was very sad. (I5)

Denial occurs as an attempt to escape from reality. This phase of not believing or denying the diagnosis has variable duration and prolonged denial may reflect on the whole family and cause an unsuccessful adaptation.⁸ As the being sees himself released to the "unknown" world and their experiences approach what they expected or not, denial appears as means of escape.

[...] Look, when he was born it was very difficult. You know? When you are producing a child you believe that he will be born perfect, right? Healthy, normal. And when I discovered his illness, it was a shock in my life. We desire a child to be perfect. When you are pregnant, you say, he will be like this, will be like that, he will be everything. And when you receive the news that your child is with an incurable disease, it is like everything you dreamed was thrown in the trash. (I3)

The moment of diagnosis causes the mother and the whole family to be shaken,

because though they are seeking an answer to the symptoms of the child, they do not expect to discover that the child has an incurable disease. At such times, they run through feelings of great fear and loss of control of the situation experienced. The fact that little was heard about the disease, ignorance about consequences thereof, about the treatment and the chances of cure, generate a sense of powerlessness in face of the situation presented to them.¹⁴

[...] I did not know anything about the disease. I had no idea how I was going to be mother of a child so sick. (I3)

[...] I do not know what it was cystic fibrosis, I had never heard. Then when they called me after the bloodspot screening test saying that he had this disease I was desperate. (I8)

For mothers, not having knowledge of the disease means not knowing how to proceed and react to everything that may occur in their life and their family's lives from that moment. Often, they do not understand what it is being said by health professionals, which can generate more inconvenience.

[...] After a few days we went to Belo Horizonte to do such a sweat test, I did not even know what it was, I thought I would they would burn him to do that test, in my mind they were going to hurt him to get the sweat, I kept thinking, thinking, how my life would be with my son, sick. (I2)

[...] When she was born and we found that she had fibrosis, we thought she was not going to be a normal child, would not walk and would not have a normal life. I always thought my daughter was going to be all the time in bed or in a wheelchair. (I6)

Study conducted with mothers of children with childhood cancer, whose objective was to understand the needs of these mothers, showed that uncertainty resulting from ignorance about the disease, coupled with the conviction that it is necessary to offer the best of themselves to protect the child, is a characteristic present in daily life these mothers since the diagnosis of the disease.¹⁹

In the mothers' reports in our study, we highlight that the fear arising from ignorance about the disease, since it was little known, is added to the fact that professionals who attended them in their city of origin know little about the disease.

[...] I talked to the doctor that I thought it was something wrong in newborn screening, but she said it could be wrong sample ... I went up and asked for nurses and nobody there could inform me what cystic fibrosis was. (I4)

It is important to point out that much of the reaction to the new reality will depend on

how the information will be received, how it will be presented and the professional's attitude that communicates. And the initial explanation is very important because it will determine how the sick child will be accepted within the family and how the mother and the whole family will react in face of this new moment in their lives.

[...] I remember well the day I received the news, I was in the hospital there in BH and the doctor called me apart, but there were other people waiting to talk to her, they had already announced her name several times in the hospital sound, then she called me, and told me that my son had CF, I do not get it right on time, I also did not have time to ask and she was soon telling me that the psychologist would talk to me after. (I7)

[...] When we did the newborn screening test and 5 days later this woman called me and said something had gotten wrong in his test and that I should take him there to do it again. I was desperate and started crying because she said that it been cystic fibrosis and I had never heard of this disease. (I2)

The communication of the diagnosis should be made as clear and cautious way, since it is an occasion that will significantly impact these mothers' lives. Often, they often do not understand and cannot assimilate all the information provided and may feel frightened before a prognosis that provides little lifetime for their children.

[...] At the time of my daughter's diagnosis, it was desperate, I was too afraid because the doctor told me that life expectancy was 5 years old, I thought she would not reach adolescence. It was a struggle. (I1)

The professional who communicates the diagnosis must be imbued with feelings of compassion and empathy, providing information and gradually identifying the phase that the mother and family are experiencing, so as not to leave them without direction or desperate. The statements unveiled that mothers felt lost when the diagnosis was communicated to them. The feeling of fear was the watchword at the moment.

[...] When I arrived in BH they released me that bomb, "your son is ill, and it is a serious disease. He will have to take enzyme every day, every time he is going to eat, he will have to take medicine. He may suffer a lot of pneumonia, and they may become more complicated". Wow! They talked all this, you know? (I4)

We believe that health professionals should reflect on the significance of this moment for mothers and their families, for the way information is understood is very important for the acceptance and assimilation of the

disease. It carries also a significant influence on how the mother will join and develop care during treatment. One must be aware of the uniqueness of their experience and realize that every family has a culture, an environment and beliefs and that each one will react differently.²⁰

Mothers need to be sheltered. When they feel like this, it means that professionals value them and this positively influences to provide an increase in safety throughout the treatment process that, after diagnosis, is inserted. They need a relationship with the professionals who care or will care for their children, that goes beyond a pathophysiological view and that considers all its difficulties and the influence of the child's illness in the family dynamics.¹⁹

From the reports of this study, we infer that many professionals are not prepared to provide the diagnosis to parents. Thus, we reaffirm the need for professionals to work with a more human approach, knowing how to make a communication of diagnosis without generating prejudices or reinforcing stereotypes about the child's condition. Professionals need to help parents to understand the nature of the problem and develop skills to face it.²⁰

The nurse, in this context, can help the mother and the whole family to understand the information provided, demonstrating they value that family. Valuing all the feelings produced by them, providing emotional care and safety for the care of their child, and helping them to identify the most important resources to deal with such an important moment in the experience of being-with the child.

FINAL REMARKS

Receiving the diagnosis of CF is a marking event in the life of women, permeated with suffering, anguish, sorrow, doubt and insecurity.

It was evidenced that the mother of children with CF presented care needs when receiving the diagnosis, especially in relation to the reception and clarification offered by professionals. Thus, health professionals, and especially nursing, must always be attentive to the customers' questions and needs, and willing to guide them and welcome them.

Although restricted to understanding the experience of a particular group and a particular moment of the trajectory of the disease, this study refers to important insights, and enables and encourages the development of new studies that envisage the

performance and understanding of professionals who serve these mothers.

Results of this study subsidize knowledge of feelings presented by this group, enabling the development of strategies that provide integral care, favoring, then, an improvement in the quality of care.

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REFERENCES

1. Firmida MC, Lopes, AG. Aspectos epidemiológicos da fibrose cística. Rev HUPE [Internet]. 2011 Oct/Nov [cited 2014 May 28];10(4):12-22. 2011. Available from: http://revista.hupe.uerj.br/detalhe_artigo.asp?id=70
2. Rosa FR, Dias FG, Nobre LN, Moraes HA. Fibrose cística: uma abordagem clínica e nutricional. Rev Nutr [Internet]. 2008 Nov/Dec [cited 2014 May 28];21(6):725-37. Available from: <http://www.scielo.br/pdf/rn/v21n6/a11v21n6.pdf>.
3. Jessup M, Parkinson C. "All at the sea": the experience of living with cystic fibrosis. Qual Health Res [Internet]. 2010 Mar [cited 2014 May 28];20(3):352-64. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/19955225>
4. Pizzinago TP, Mello DF, Lima RG. A experiência da doença na fibrose cística: caminhos para o cuidado integral. Rev Esc Enferm USP [Internet]. 2011 Jun [cited 2014 May 27];45(3):638-44. Available from: <http://www.scielo.br/pdf/reeusp/v45n3/v45n3a13.pdf>
5. Byrnes CA, Vidmar S, Cheney JL, Carlin JB, Armstrong DS, Cooper PJ et al. Prospective evaluation of respiratory exacerbations in children with cystic fibrosis from newborn screening to 5 years of age. Thorax [Internet]. 2013 Jul [cited 2014 May 27];68(7):643-51. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23345574>.
6. Dalcin PTR, Silva FAA. Fibrose cística no adulto: aspectos diagnósticos e terapêuticos. J Bras Pneumol [Internet]. 2008 Feb [cited 2014 May 27];34(2):107-17. Available from: <http://www.scielo.br/pdf/jbpneu/v34n2/v34n2a08.pdf>
7. Pfeifer LI, Silva MA. Avaliação da qualidade de vida de crianças com fibrose cística. Rev Nufen [Internet]. 2009 Aug/Nov [cited 2014 May 27];1(2):118-30. Available from: <http://pepsic.bvsalud.org/pdf/rnufen/v1n2/a08.pdf>
8. Tavares KO, Carvalho MDB, Pelloso SM. O que é ser mãe de uma criança com fibrose cística. Rev Gaúch Enferm [Internet]. 2010 Dec [cited 2014 May 12];31(4):723-9. Available from: <http://www.scielo.br/pdf/rngenf/v31n4/a16v31n4.pdf>
9. Heidegger M. Ser e tempo. Trad. revisada de Marcia de Sá Cavalcante Schuback. 4. ed. Petrópolis: Vozes; 2009.
10. Jesus MCP, Merighi MAB, Caldeira S, Oliveira DM, Souto RQ, Pinto MA. Cuidar da mãe idosa no contexto domiciliar: perspectiva de filhas. Texto & Contexto Enferm [Internet]. 2013 Oct/Dec [cited 2014 May 22]; 22(4): 1081-8. Available from: <http://www.scielo.br/pdf/tce/v22n4/26.pdf>
11. Merighi MAB, Jesus MCP, Domingos SRF, Oliveira DM, Baptista PCP. Ser docente de enfermagem, mulher e mãe: desvelando a vivência sob a luz da fenomenologia social. Rev Latino-Am Enfermagem [Internet]. 2011 Jan/Feb [cited 2014 May 27];19(1):164-70. Available from: http://www.scielo.br/pdf/rlae/v19n1/pt_22.pdf
12. Polit DF, Beck CT, Hungler BP. Fundamentos de pesquisa em enfermagem: métodos, avaliação e utilização. 5. ed. São Paulo: Artmed; 2004.
13. Josgrilberg RS. O método fenomenológico e as Ciências Humanas. Fenomenologia e análise do existir. São Paulo: Universidade Metodista de São Paulo; 2000.
14. Costa ASM, Britto MCA, Nóbrega SM, Vasconcelos MGL, Lima LS. Vivências de familiares de criança e adolescentes com fibrose cística. Rev Bras Crescimento Desenvol Hum [Internet]. 2010 Aug [cited 2014 May 27];20(2):217-27. Available from: <http://www.journals.usp.br/jhgd/article/viewFile/19960/22042>
15. Melo GM, Lélis ALPA, Cardoso MVLML, Farias LM, Balbino AC. Olhar materno sobre a dor do filho recém-nascido. Rev enferm UFPE on line [Internet]. 2014 Jan [cited 2014 May 28];8(1):8-15. Available from: www.revista.ufpe.br/revistaenfermagem/index.php/.../8286
16. Roecker S, Mai LD, Baggio SC, Mazzola JC, Marcon SS. Vivência de mães de bebês com malformação. Esc Anna Nery Rev Enferm [Internet]. 2012 Mar [cited 2014 May 24];16(1):17-26. Available from:

<http://www.scielo.br/pdf/ean/v16n1/v16n1a03.pdf>

17. Rodrigues CCM. Do impacto do diagnóstico à superação dos desafios: a mãe sendo-com a criança com doença falciforme. [Dissertação]. Campinas (SP): Faculdade de Ciências Médicas, Universidade Estadual de Campinas; 2009.

18. Ribeiro C, Madeira AMF. O significado de ser mãe de um filho portador de cardiopatia: um estudo fenomenológico. Rev Esc Enferm USP [Internet]. 2006 Mar [cited 2014 May 28];40(1):42-9. Available from: <http://www.scielo.br/pdf/reeusp/v40n1/a05v40n1.pdf>

19. Angelo M, Moreira PL, Rodrigues LMA. Incertezas diante do câncer infantil: compreendendo as necessidades da mãe. Esc Anna Nery Rev Enferm [Internet]. 2010 Apr/June [cited 2014 May 28];14 (2):301-8. Available from: <http://www.scielo.br/pdf/ean/v14n2/12.pdf>.

20. Gilbert MJ, Mello DF, Lima RAG. Experiências de mães de filhos com Doença de Hirschsprung: subsídios para o cuidado de enfermagem. Esc Anna Nery Rev Enferm [Internet]. 2009 Oct/Dec [cited 2014 May 16];13(4):793-801. Available from: <http://www.scielo.br/pdf/ean/v13n4/v13n4a15.pdf>

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