



## Original Article

### CARE TO CHILD WITH MUSCULAR DYSTROPHIES DEPENDENT OF HOME TECHNOLOGY: MOTHERS' CONCEPTION

*CUIDADO À CRIANÇA COM DISTROFIA MUSCULAR DEPENDENTE DE TECNOLOGIA NO DOMICÍLIO: CONCEPÇÃO DE MÃES*

*ATENCIÓN A NIÑOS CON DISTROFIA MUSCULAR DEPENDIENTES DE TECNOLOGÍA EN DOMICILIO: CONCEPCIONES DE MADRES*

Fabiola Sousa de Oliveira<sup>1</sup>, Viviane Mamede Vasconcelos<sup>2</sup>, Mariana Cavalcante Martins<sup>3</sup>, Ingrid Martins Leite Lúcio<sup>4</sup>

It was aimed to understand the mother's conception on care to child with muscular dystrophies dependent on technology. Descriptive study with qualitative approach carried out in a children's hospital of the tertiary net in Fortaleza-Ceará, Brazil, as well as in homes of children with muscular dystrophy assisted by the Home Ventilation Assistance Program. The informants were mothers of children with dystrophy aged between zero and four years old, admitted in the Special Patients Unit and assisted by this program. We performed semi-structured interviews and after analysis, the following categories emerged: Care of children with muscular dystrophy and Feelings and expectations of mothers of children with muscular dystrophy. We identified that some mothers consider the child's daily life within the normal patterns, and others report difficulties, creating anxiety and fear of death. Thus, we verify the importance of nurses in the training of these mothers for directed care enabling to overcome stressful moments.

**Descriptors:** Muscular Dystrophies; Mothers; Children.

Objetivou-se compreender a concepção de mães sobre cuidado a criança com Distrofia Muscular dependente de tecnologia. Estudo descritivo, com abordagem qualitativa, realizado em hospital infantil da rede terciária do município de Fortaleza – Ceará, bem como nos domicílios das crianças com distrofia muscular atendidas pelo Programa de Assistência Ventilatória Domiciliar-PAVD. As informantes foram mães de crianças com distrofia na faixa etária entre zero e quatro anos de idades, internadas na Unidade de Pacientes Especiais – UPE e aquelas que eram acompanhadas pelo PAVD. Realizou-se entrevista semiestruturada e após análise, emergiram as categorias: Cuidado a Criança com Distrofia Muscular e Sentimentos e Expectativas de Mães de Crianças com Distrofia Muscular. Verificou-se que algumas mães consideraram o cotidiano do filho dentro dos padrões de normalidade, e outras, referem dificuldades, gerando ansiedade e medo da morte. Assim, evidencia-se a importância do enfermeiro na capacitação dessas mães para o cuidado direcionado, possibilitando a superação de momentos estressores.

**Descritores:** Distrofias Musculares; Mães; Criança.

El objetivo fue comprender el concepto de madres sobre la atención a niños con Distrofia Muscular dependientes de tecnología. Estudio descriptivo, cualitativo, en hospital de la red terciaria de Fortaleza-CE, Brasil, y en hogares de niños con distrofia muscular tratados por el Programa de Asistencia Ventiladora en Hogares. Los informantes fueron las madres de niños con distrofia con edades entre cero y cuatro años, ingresados en la Unidad de Pacientes Especiales y los que fueron acompañados por el Programa. Se realizó entrevista semiestructurada y después del análisis, surgieron las categorías: Atención al niño con distrofia muscular y Sentimientos y expectativas de madres de niños con distrofia muscular. Algunas madres consideraron la vida diaria del niño normal y otras refrieron dificultades relacionadas a la ansiedad y miedo de la muerte. Es importante que enfermeros capaciten a las madres para la atención dirigida, permitiendo la superación de momentos de tensión.

**Descritores:** Distrofias Musculares; Madres; Niño.

<sup>1</sup> Nurse. Graduated from the Great Fortaleza Integrated Faculty (FGF). Fortaleza, CE, Brazil. E-mail: fabiola\_soliveira@hotmail.com

<sup>2</sup> Nurse. PhD student in Nursing from the Federal University of Ceará (UFC). FUNCAP Scholarship. Fortaleza, CE, Brazil. E-mail: vivienfermagem@hotmail.com

<sup>3</sup> Nurse. PhD student in Nursing from the Federal University of Ceará (UFC). Professor at the Nursing Undergraduate Course, Federal University of Ceará (UFC). Fortaleza, CE, Brazil. E-mail: marianaenfermagem@hotmail.com

<sup>4</sup> Nurse. PhD from the Federal University of Ceará (UFC). Professor at the Federal University of Alagoas (UFAL). Brazil. E-mail: ingrid\_lucio@yahoo.com.br

## INTRODUCTION

The Muscular Dystrophy is a genetic disease, caused by malformation or absence of proteins essential for the proper functioning of the physiology of muscle cells. It is characterized by progressive weakening of the muscles and the consequent damage to the movements<sup>(1)</sup>.

Duchenne Muscular Dystrophy (DMD) is the most severe form and appears in children from 0 to 5 years of age, being more frequent in males who, when affected by it, have frequent falls, difficulty in climbing stairs and running<sup>(2)</sup>.

In a professional experience with children with Muscular Dystrophy in a children's hospital of tertiary care in Fortaleza, one observed the need for family involvement in monitoring the development of these children, besides help in the hospital and home treatment, since these children are dependent on technology and on their mother's presence in care. So, the mothers' participation is fundamental during moments of orientation and training so as to enable them to perform invasive procedures such as aspiration of the airway without causing any harm to the health of the child.

In this context, we emphasize that the scientific technology advances significantly, since it is present in the hospital and depending on the disease, the house is adapted to this technological apparatus<sup>(3)</sup>.

Therefore, because of this dependence on technology imposed by serious diseases that make patients chronically ill, we developed a network of home care, Home Ventilation Assistance Program - HVAP, created in 2005, which aims to assist and keep children who are technology-dependent in the family, in order to optimize the quality of life of patients and caregivers, in this study, the mothers. They received training on the operation of the equipment that would be used in their

homes, how the children's care routine would be, and guidance on how to act in case of emergency<sup>(4)</sup>.

Home care is unquestionably more detailed, and several factors related to care and to infections are reduced, in order to strengthen the family relationships<sup>(5)</sup>. The HVAP aims to assist children with neuromuscular diseases, among them muscular dystrophy.

Thus, this study is relevant for showing, in several segments, the need for rapprochement between the nursing staff and mothers who take care of children with Muscular Dystrophy, dependent on hard technology, as well as for exposing the need to empower these mothers to provide care to their children, using technology. One adds that the equipment used by the children in this study were mechanical ventilators, also known as breathing machines, pulse oximeter, continuous infusion pump. In the hospital setting, the most common models were Inter 5<sup>®</sup> and Inter 3<sup>®</sup>. At home, they used BiPAP and LTV 1200.

Thus, this study aimed to understand the concept of mothers about the care to children with Muscular Dystrophy and who are technology-dependent, attended in a hospital of the tertiary network, reference in child care in the city of Fortaleza, Ceará, and assisted by the Home Ventilation Assistance Program - HVAP.

## METHOD

This is a descriptive study with a qualitative approach, by focusing on the universe of meanings, motives, aspirations, beliefs, values and attitude<sup>(6)</sup>. It was conducted in a tertiary public hospital, reference in child care, located in the city of Fortaleza, which had specialized care to clients through HVAP, where some children were receiving care at home, thus facilitating the living together and family interaction and/or caregivers.

Data collection happened at the hospital mentioned, specifically in the Special Patients Unit - EPU, place in the hospital mentioned where children were assisted with special care and with HVAP, thus it has been possible to approach the care of mothers in hospital and home environments. The study subjects were 11 mothers who accompanied children with Muscular Dystrophy and who were dependent on hard technology in the period stipulated for data collection.

One selected for the study: mothers of children aged from zero to four years old with muscular dystrophy who had been interned in the EPU, or who had been admitted during the collection, and those who were accompanied by HVAP; and mothers with age over or equal to 18. It is noteworthy that the age of the child, zero to four years old, was established due to the fact that the symptoms are more prevalent<sup>(7)</sup>.

The contact with the mothers occurred through the nurses responsible for the services, EPU and HVAP and the researcher made the selection of informants in accordance to the established criteria. Data collection was conducted in November 2010. To guide the interview one used a form with open questions, divided into two steps: first, identification data, socioeconomic aspects of the mothers, and the second phase was composed by the following questions: What is the routine of your child with Muscular Dystrophy like? How do you take care of your child with Muscular Dystrophy? How do you perceive the daily life of your child, depending on equipment to survive? What do you expect for the future of your child?

Data were categorized according to the proposed objective through referential thematic analysis<sup>(6)</sup> that addresses a discovery of meaning units evidenced from the themes discussed, consisting of three stages: pre-analysis: determination of registration units (keywords or phrases), context units and general theoretical concepts that guide the analysis, taking into account the purpose of the research, material exploration:

transformation of the initial data obtained, in order to understand the text from its meaning unit, and treating the results: data interpretation, already categorized and relating them with the theoretical reference that based the research.

The analysis and discussion of the results occurred by describing the characteristics of mothers participating in the study. Later, there was an evaluation form guided by a qualitative research form and, ultimately, the speeches of the interviews were transcribed and grouped by similarity of meaning, creating the thematic categories: Care to the Children with Muscular Dystrophy; Feelings and Expectations of Mothers of Children with Muscular Dystrophy. The project was submitted to the Ethics Committee of the Children's Hospital Albert Sabin (CHAS) for consideration and only after favorable opinion, under number 073/2010, data were collected and analyzed, in care recommended by Resolution 196/96, from the National Health Council.

## RESULTS AND DISCUSSION

### Description of informants

One interviewed 11 mothers of children with Muscular Dystrophy, aged between 19 and 40 years old, with an average of 27.81 years old. The predominant age group was between 20 and 25 years old. These data reported Muscular Dystrophy as a disease of genetic and hereditary character, therefore eliminating the determination of age of mothers for incidents of such pathology<sup>(1)</sup>.

The education of the mothers ranged from illiterate to graduated, and six had completed elementary school, and socioeconomic variation between them was a relevant factor for this purpose.

All the mothers were housewives, for choosing not to develop professional activities, dedicated only to house chores and child care, this happened because

they require special and integral care and thus, they were dependent, and families could not afford someone to help with the care. For this reason, one highlights the importance of considering the psychological aspects of the family, especially of the mothers who act as primary caregivers, being this their only activity<sup>(8)</sup>.

Another finding observed was religiosity that, consequently, has direct implications related to health-disease phenomena, besides being an important factor in emotional and informational support. Because of this, religion is relevant in the behavior and evolution of the disease<sup>(9)</sup>, because spirituality encourages family and produces feelings of hope or acceptance of the condition imposed by the child's illness. Given the above, it is worth noting that ten of the informants had predominant religion like Catholicism, only one was protestant.

Families lived with an average income of R \$ 1,348.48, ranging between R \$ 510.00 and \$ 5,000.00. The average household income in question corresponded predominantly to two minimum wages, and according to the references of the mothers interviewed, the salary came from the benefit of the child and the other parent, who worked. The number of children of these mothers ranged from one to seven, with an average of two children per mother. The amount of people in the family was composed of four people to each house.

The data obtained from this study was consistent with the National Research Datafolha, conducted by *Folha de Sao Paulo* in October 2007, in 211 municipalities, which set a new profile of the Brazilian family. According to research, the average number of people per household was 3.8, while 2.7 was the average number of children per family. About the income, 35% of the Brazilians received up to two minimum wages, and 24% received between two and three minimum wages<sup>(10)</sup>. Therefore, it was realized that the reality of the child with Muscular Dystrophy was

coherent with the profile of families in Brazil, there was no difference, especially in the financial aspect.

Ventilation was provided for children through tracheostomy. The portable vacuum was used to absorb secretions from the bronchial tree. Pulse oximetry was crucial because it was intended to measure heart rate and oxygen saturation of the children. The infusion pump was used only in hospital, at home food was administered in equipment of enteral infusion, and the route of administration was via gastrostomy. Mothers demonstrated negative impact of the respirator and other devices in their lives and in their children's lives; caregivers reported that the quality of life of their children, and their own, was affected.

### **Thematic categories**

#### Care to the children with Muscular Dystrophy

In the perception of mothers, the daily life of children with Muscular Dystrophy was considered normal, they reported that they performed activities like any other child, that they were not dependent on technology. *He is normal, he sleeps normally, wakes up normally, eats normally, it happens through the probe, but he is normal as any other child. He takes a shower, brushes his tooth (M1). Oh she wakes up smiling, if not all whiny, sly. Then I bathe her, tidy her hair, put her outfit on and she looks like a doll. Then she lays down and watches television (M7). He wakes up, has a session with the speech therapist, the physiotherapist, the occupational therapist, only after this he takes a shower, but I just give him a bath in the afternoon, and then I take him for a walk in the building's playground. He watches television, DVD movies, eats, sleeps (M9).*

It was noticed that actions related to basic human needs were done, particularly as related to the well-being of children with Muscular Dystrophy. However, it was noticeable that there are limitations imposed by the condition, thus the comfort position was limited to remaining lying or sitting. *Oh that's the way you're seeing, she stays only lying, not moving, I bathe her myself, I change sheets alone, I do everything alone. She has the milk through the probe, every 3 hours (M6). The poor little thing stays only lying, watching*

television. When she wakes up, she smiles, I bathe her, dress her up normally. She eats through a probe every 3 hours (M5).

The functional changes caused by muscle weakness become evident when children have early symptoms. Muscle strength is not enough to permit voluntary extension of the trunk when patients undergo their normal movements affecting the gear<sup>(11)</sup>.

Over time, muscle weakness occurs, which progressively gets worse, harming mobility and daily activities, as well as the muscles of respiration, requiring devices to function<sup>(12)</sup>. Therefore, the need of a caregiver is essential to assist in the normal and daily activities.

Faced with the impossibility of self-care, children perform their activities with the help of mothers, they take care of their children in the best way, providing a more consistent quality of life and facilitating the adaptation of the family relationship with the care of children dependent on technology. Care is a demonstration of affection and interest, and in this condition, one points to family care primarily related to the mother, which is unconditional and different from professional care, because this is driven by maternal love, the natural bond between mother and child<sup>(13)</sup>.

Due to this dependence on the mothers, they considered care as difficult, among other factors, as evidenced in the statements, because they dealt with unknown devices, and their children had become dependent on them forever. *It's complicated, it's difficult. We practically stop our lives to live for them. But I like to take care of her, just to see her smile now is my great reward* (M2).

Children with chronic pathology who are dependent on technology for some motor or respiratory impairment disrupt the whole family, especially when they are transferred to their homes. Mothers often leave their chores, change their professional routine and postpone their plans and commitments to stay with their children dependent on care<sup>(14)</sup>.

Even after discharge, there is still a dependence on devices, the main cause of mothers' resistance in

relation to care, because it is a different reality from what was desired throughout the gestational period, when they hoped to have a healthy child, within the standards of normality. *It's hard, because we hope to have a healthy baby, that will grow, will be running normally, and then we go through it, it's very difficult. It's always hard to look at her in that situation, knowing that she depends on the respirator to survive, that without it she would not be here* (M2). *It's a little embarrassing, you see that he is stuck to a technology you don't know how to use well, that's annoying, it gives a bad feeling, it is not easy* (M3). *She depends on that respirator to live, but thank God that such machines exist, otherwise my daughter would not be here* (M7).

The adaptation process of mothers is not instantaneous and it can change from one period of control to a situation of lack of control. Taking care of a sick child requires skills, knowledge about the disease and the devices to be used. The mothers need clear information from the health professionals and their doubts need to be clarified, so that the care to these children is performed safely and autonomously.

These caregiving mothers need to be oriented and informed about care that will be conducted at home, so this care must be observed and followed as it involves high technology. This support is accomplished specifically by the HVAP. Therefore, nursing has the opportunity to change the perspective of the family concerning the children's disease, the behavior directed to the concern and attention to the children becomes important to establish an empathetic and subjective relationship with the mothers, facilitating their participation in care<sup>(14)</sup>. Thus, with the support of the professional nurse, the patient and the mother will have a support in coping and relief of suffering, which will minimize the emotional stress of the family in taking care of the child<sup>(15)</sup>.

Feelings and expectations of mothers of children with Muscular Dystrophy

The conditions provided by the disease of the child with Muscular Dystrophy entail several feelings,

including fear and anxiety in the lives of mothers who are dedicated to caring for their children dependent on technology. *I went home a few times, and when I go I stay a few days, because I'm afraid of losing my daughter, she is everything for me (M6). I do not know what will happen to me the day I lose her, I hope she becomes a pretty big girl, but I want to take care of her until God allows me (M7). I'm afraid because I've been through a lot of judgment and many times I thought I was going to lose my son, and he was very weak, but at the same time strong (M10).*

One highlights that infant mortality is the main indicator of health status of a population and it also helps in defining health in developing countries<sup>(16)</sup>. The precariousness of health services offered to the population covers the socioeconomic and cultural situations, achieving high rates of infant deaths.

It is also pointed out that death is seen as a taboo, sometimes it represents failure mainly for people who deny it. The denial of death is remarkable in all the society, even among health professionals that refer to death as the end of all dreams, of all feelings<sup>(11)</sup>.

Besides the fear of death, the study highlights the anxiety as a factor that afflicts directly the quality of life of children and mothers, because before many situations reported by them, they become apprehensive for any sign that may result in death. *The concern I have on a daily basis is when the power goes out, then I'm afraid. It's for a short time, but we do not know how long it will last (M8). One day I got nervous because the machine stopped and the health team took two hours to arrive, then I took care of him until they arrived; it took too long, so my only fear is that (M10).*

From what was said by the mothers in previous moments, one highlights moments of stress experienced by them as a result of their children's condition, being afraid with the possibility of them not surviving, due to the malfunction of the equipment. The stressful events are those that are independent of the subject domain, regardless of their performance, such as the death of a person from the family, job loss, a chronic illness, these are stressors that trigger outbreaks eventually occurring mental disorders of psychiatric disorder. "If the response to stress generates a lasting or intense frequent

physiological activation, it can precipitate a depletion of the subject's resources with the appearance of various psychophysiological disorders; and it may predispose the appearance of anxiety disorders and other mental disorders..."<sup>(17:8)</sup>.

The feelings of distress, anxiety and crying are expressions of psychological suffering experienced by the mother. Tiredness is the barrier facing all these feelings. The hospitalization of a child is a difficult situation to a mother, which affects them psychologically, because this fact requires an adjustment to the hospital, a dark, obscure and unknown environment.

However, during the hospitalization of the child, it is desirable to cure the disease, so it is necessary that the condition is faced in the best way possible to alleviate suffering<sup>(18)</sup>. *I really want to take her home, because I have other children, I live in the country, then it is difficult to stay here with her all the time, and she will be better at home, near the family (M5). The first thing I do is thank God because He has helped me, bringing me home, there are days that I cannot believe that he's home, I think it's a miracle (M10). For me it is very difficult I'm already a long time in the hospital, more than a year, and always in the same situation (M6). From what I know, they did not use to live a lot, they died in the ICU, but nowadays they can go home (M1).*

The understanding of mothers is crucial, the information about the health status of the child, the forms of treatment, private care and their function as caregivers are very important for the children's care in the hospital and at home. Therefore it is necessary that the basic needs of families are met, so that the suffering facing this disease is not so embarrassing.

The desire of mothers to lead their children to family life is the need of bond and return to the comfort that was removed due to their pathology. Freedom of expression and autonomy are important for mothers, and these actions can be managed in the best way, in the family environment, together with the other members of the family.

The desire to make the children independent from technology care, children with a better quality of life and autonomy, was notable when the interviews were analyzed. The biggest hope was that the children could breathe without the aid of the respirator, become "normal" children as mentioned by the mothers: *I have faith in God that he will leave the machine (M10). I want to see my son walk, say a word, say mommy, daddy, that will be my joy, and getting out of this machine will be very good (M11).*

The quality of life is the vision of the subject concerning their life situation, involving the culture and values of the society where he lives, correlating with expectations, standards and concerns of life improvements (19). The evolution of muscular dystrophy is progressive, they start to miss or diminish the movements of the trunk, arms and legs, this condition causes desires, dreams and expectation of clinical improvement, among mothers who are caregivers. The mothers expressed: *They are strong, survive, struggle to live, along with the technology, fighting, their will to live is very big (M3). There were things he did not do, like moving the arm, moving his little leg, he holds his little leg, and he moves his little neck, many things that the doctors told me he would never do, for me I'm seeing the evolution of my son and to me this is everything (M8).*

These reports highlight that only palliative and not curative treatments are used to aid the survival of children with Muscular Dystrophy. Physical therapy is the main help in the treatment because it stimulates the movements that are restricted by the condition, and with such a practice, the child improves his breathing pattern and his limb movements<sup>(12)</sup>. Therefore, there is no treatment, no permanent cure for this disease. Therefore, before any sign of improvement in the child, day by day, mothers show happiness to follow their development.

The biggest hope reported by mothers was the establishment of the treatment or even the cure, with the use of stem cells. These statements showed that, although some mothers did not show deep knowledge about the subject, they knew it was possible and that

there was still hope of cure for their children. *I hope these stem cells work for my daughter, maybe she can get better, be normal, be a child like any other (M5). My greatest hope is in the stem cells, when they start testing on people I want them to test it with her too, it will be my greatest joy to see her come out of these machines and be a normal kid (M7). I believe that, in the future, the expectation is stem cells, we see so many cases on television, so for me it is hope (M8).*

Stem cells are defined as cells with strong competence of differentiation. During embryonic development, the stem cells of the blastocyst create progenitor cells which become restricted to specific cells. The adult stem cells have multipotent and pluripotent abilities, as evidenced in studies with mice in which hematopoietic stem cells from bone marrow were able to regenerate injured skeletal muscle tissue. In the same way, you can see the power of these cells to migrate from the marrow to the injured regions<sup>(20)</sup>.

The Biosafety Act allows, still with restrictions, that human embryos are handled, to collect stem cells. The regulation of this Law defines "non-viable embryos" those with proven genetic alterations, as they prevent the development due to lack of cleavage. The Brazilian law authorized research on embryos that are not used for breeding purposes after the procedure<sup>(21)</sup>.

For this, the faith of these mothers who take care of children suffering from Muscular Dystrophy and who are technology-dependent, in healing by stem cells, is reaffirmed by every piece of news that comes from studies in humans with a pathology similar to that of their children. However, such researches being carried still have very high financial cost.

#### **FINAL CONSIDERATIONS**

From this study, it is considered that mothers have different perceptions about the daily life of their children, to the extent that some consider it as within normal limits, while others point out the difficulties they face in their daily care to children suffering from

Muscular Dystrophy, especially because they depend on ventilatory support, considering that the lives of their children depend on them.

It is worth highlighting too aspects mentioned by the mothers, related to anxiety and fear of the death of their children. This happens due to several situations experienced at home and in the hospital, as the death of other children, severe clinical state of their child, aspects that generate insecurity and anxiety, seeking strength in spirituality and new treatments.

Given the above, one emphasizes the importance of nurses as health educators to empower these mothers to take care of their children and know how to deal with that reality around the dependence on technology, and be able to overcome stressful moments. However for legitimization of nursing in this field it is necessary continuous training of these professionals to handle these clients and their caregiving family, because besides direct patient care, there is the home care that involves physical, social, economic and cultural factors.

When mothers return to their homes, there is another transitional phase, when they will be alone to take care of the children and depending on the training that is provided by the team of HVAP, they may be able or not to go home. Besides training in relation to machines, mothers should receive psychological support, due to the lack of social interaction, thus affecting their normal activities that were developed before, emphasizing the upgrading of care related to their children. It is also suggested that labor activities of a social nature should be offered to the mothers of children with muscular dystrophy, when their children may be present, so that they can interact with other people, not forgetting to take care of their children.

## REFERENCES

1. Ministério da Saúde (BR). Biblioteca Virtual da Saúde. Dicas em Saúde. Brasília: Ministério da Saúde [Internet]. 2010. [citado 2010 mar 20]; [cerca de 4p.] Disponível em: <http://bvsm.s.saude.gov.br/html/pt/dicas/118distrofia.html>.
2. Ministério da Saúde (BR). Biblioteca Virtual da Saúde. Distúrbios musculares [Internet]. 2010. [citado 2010 mar 21]. Disponível em: <http://www.palabrero.com.ar/gestion/psicologia/index.php?tema=1595&/disturbios-musculares>
3. Nietzsche EA. Tecnologia emancipatória: possibilidade ou impossibilidade para a práxis de enfermagem? 1ª ed. Ijuí: Unijuí; 2000.
4. Conselho Regional de Medicina do Estado do Ceará. Parecer CREMEC nº 35/2010 [Internet]. 2010. [citado 2010 out 23]. Disponível em: [http://www.portalmedico.org.br/pareceres/crmce/pareceres/2010/35\\_2010.htm](http://www.portalmedico.org.br/pareceres/crmce/pareceres/2010/35_2010.htm)
5. Drucker LP. Rede de suporte tecnológico domiciliar à criança dependente de tecnologia egressa de um hospital de saúde pública. *Ciênc Saúde Coletiva*. 2008; 12(5):1285-94.
6. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 8ª ed. São Paulo: Hucitec; 2004.
7. Rocco FM, Luz FHG, Rossato AJ, Fernandes AC, Oliveira ASB, Beteta JT et al. Avaliação da função motora em crianças com distrofia muscular congênita com deficiência da miosina. *Arq Neuro-Psiquiatr*. 2005; 63(2a):298-306.
8. Freitas PM, Carvalho RCL, Leite MRS, Haase VG. Relação entre o estresse e inclusão escolar de crianças com paralisia cerebral. *Arq Bras Psicol*. 2006; 57(1/2):46-57.
9. Faria JB, Seidl EMF. Religiosidade e enfrentamento em contextos de saúde e doença: revisão de literatura. *Psicol Reflex Crit*. 2005; 18(3):381-9.
10. Instituto de Pesquisa Datafolha. Opinião Pública [Internet]. Família fica ainda mais importante para brasileiros. Folha de São Paulo, São Paulo, 07 jan 2007. [citado em 2011 ago 08]. Disponível em:

[www.cegente.com.br/upload/materialpesquisa/arq\\_159.pdf](http://www.cegente.com.br/upload/materialpesquisa/arq_159.pdf)

11. Gaudreault N, Gravel D, Nadeau S, Houde S, Gagnon D. Gait patterns comparison of children with Duchenne muscular dystrophy to those of control subjects considering the effect of gait velocity. *Gait Posture*. 2010; 32(3):342-7.
12. Mariano WS, Sevilha RCCC, Souto A. Aspectos genéticos, fisiológicos e clínicos de um paciente com distrofia muscular de Duchenne. *Ensaio e Ciência: C Biológicas, Agrárias e da Saúde*. 2009; 13(1):107-23.
13. Cipriano MAB, Queiroz MVO. Cuidado a criança portadora de mielomeningocele: vivência da família. *Rev Rene*. 2008; 9(4):72-81.
14. Molina RCM, Marconi SS. A percepção da família sobre sua presença em uma Unidade de Terapia Intensiva Pediátrica e Neonatal. *Rev Esc Enferm USP*. 2009; 43(3):630-8.
15. Morais GSN, Costa SFG. Experiência existencial de mães de crianças hospitalizadas em Unidade de Terapia Intensiva Pediátrica. *Rev Esc Enferm USP*. 2009; 43(3):639-46.
16. Frias PG, Lira PIC, Vidal AS, Vanderlei LC. Vigilância de óbitos infantis como indicador da efetividade do sistema de saúde - estudo em um município do interior do Nordeste brasileiro. *J Pediatr*. 2002; 78(6):509-16.
17. Margis R, Picon P, Cosner AF, Silveira RO. Relação entre estressores, estresse e ansiedade. *Rev Psiquiatr Rio Gd Sul*. 2003; 25(supl.1):65-74.
18. Milanesi K, Collet N, Oliveira RG, Vieira CS. Sofrimento psíquico da família de crianças hospitalizadas. *Rev Bras Enferm*. 2006; 59(6):769-74.
19. Melo EL, Valdés MT, Pinto, JM. Qualidade de vida de crianças e adolescentes com distrofia muscular de Duchenne. *Pediatrics*. 2005; 27(1):28-37.
20. Cabral ACV, Ângelo PC, Leite HV, Pereira AK, Lopes APBM, Oliveira MB, Borges KBG, Pardini VC, Ferreira ACS. Isolamento, diferenciação e aspectos bioquímicos de células-tronco de líquido amniótico. *Rev Assoc Med Bras*. 2008; 54(6):489-93.
21. Diniz D, Avelino D. Cenário internacional da pesquisa em células-tronco embrionárias. *Rev Saúde Pública*. 2009; 43(3):541-7.

Received: Sep. 9<sup>th</sup> 2012

Accepted: Aug. 8<sup>th</sup> 2012