

# CHRONIC SUFFERING: MOTHER'S PERCEPTION OF CHILDREN DEPENDENT ON MECHANICAL VENTILATION

*Sofrimento crônico: percepção de mães de crianças dependentes de ventilação mecânica*

*Sufrimiento crónico: la percepción de madres de niños dependientes de la ventilación mecánica*

Original Article

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## RESUMO

**Objetivo:** Conhecer a percepção das mães sobre as principais dificuldades na assistência a uma criança com necessidades especiais, dependente de ventilação mecânica. **Métodos:** Pesquisa qualitativa, desenvolvida de agosto a novembro de 2013 no Hospital Dr. Waldemar Alcântara, em Fortaleza-CE. Os informantes foram sete mães de crianças sob ventilação mecânica. A coleta de dados deu-se através de questionários sociodemográficos e questões norteadoras, das quais emergiram categorias temáticas, analisadas pela análise de conteúdo, sendo os dados discutidos pela literatura pertinente. **Resultados:** A média das idades maternas variou de 18 a 36 anos. Seis eram casadas ou viviam união estável. O nível de escolaridade variou de analfabeta ao segundo grau completo. A renda familiar foi de no máximo um salário mínimo. As mães mencionaram angústia e medo diante do impacto inicial do diagnóstico, com pouca compreensão da linguagem biomédica e muitos questionamentos durante todo o período após o diagnóstico e durante a internação hospitalar. **Conclusão:** As dificuldades envolvem aspectos relacionados ao abandono familiar, ao distanciamento dos demais filhos em detrimento do cuidado ao filho deficiente, ao obstáculo em se relacionar socialmente e acerca do prognóstico e cuidados com seu filho. O ambiente hospitalar gera repercussões psicológicas diante da expectativa e da falta de esperança em relação à cura do filho, sabendo que este poderá ir a óbito. Os profissionais de saúde podem favorecer transformações incríveis, gerando um novo “cuidar”, mais amplo e humanizado, facilitando a recuperação/reestruturação familiar diante desse novo universo.

**Descritores:** Fisioterapia; Criança Hospitalizada; Humanização da assistência; Relações Mãe-Filho; Ventilação Pulmonar.

## ABSTRACT

**Objective:** To know the mothers' perception of the main difficulties in the care of children with special needs dependent on mechanical ventilation. **Methods:** A qualitative research conducted from August to November 2013 at the Dr. Waldemar Alcântara Hospital in Fortaleza, CE. Respondents were seven mothers of children under mechanical ventilation. Data were collected using sociodemographic questionnaires and guiding questions, from which emerged thematic categories that underwent content analysis, with data being discussed in the light of the relevant literature. **Results:** The average age of mothers ranged 18-36 years. Six were married or had formed a common-law marriage. Education level ranged from illiteracy to complete secondary education. Family income was up to one minimum wage. Mothers reported anguish and fear regarding the initial impact of the diagnosis, with little understanding of the biomedical language and a lot of questions during the whole period after diagnosis and during hospitalization. **Conclusion:** Difficulties involve aspects related to family abandonment, the distancing from the other children at the expense of the care of the disable child, the difficulty in engaging in social relationships, and the prognosis and care of their child. The hospital environment generates psychological repercussions on the expectation and hopelessness regarding the cure of their child, as they know they might die. Healthcare professionals can favor incredible transformations, generating a new “care”,

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*broader and humanized, facilitating the recovery/restructuring of the family within this new universe.*

**Descriptors:** *Physical Therapy; Hospitalized Child; Humanization of assistance; Mother-Child Relations; Pulmonary Ventilation.*

## RESUMEN

**Objetivo:** *Conocer la percepción de madres sobre las principales dificultades de la asistencia de un niño con necesidades especiales, dependiente de la ventilación mecánica. Métodos:* *Investigación cualitativa desarrollada entre agosto y noviembre de 2013 en el Hospital Dr. Waldemar Alcântara de Fortaleza-CE. Los informantes fueron siete madres de niños en ventilación mecánica. La recogida de datos se dio a través de cuestionarios sociodemográficos y preguntas norteadoras de las cuales surgieron las categorías temáticas analizadas por el análisis de contenido con los datos discutidos con la literatura pertinente.*

**Resultados:** *La media de las edades maternas varío entre 18 y 36 años. Seis eran casadas o tenían una unión estable de pareja. El nivel de escolaridad varió de analfabeta hasta la educación secundaria completa. La renta familiar era como mucho de un sueldo mínimo. Las madres relataron la angustia y el miedo delante el impacto inicial del diagnóstico con poca comprensión del lenguaje biomédico y muchas preguntas durante todo el periodo tras el diagnóstico y durante el ingreso hospitalario.*

**Conclusión:** *Las dificultades incluyen los aspectos relacionados al abandono familiar, a la distancia de los otros hijos en detrimento del cuidado del hijo discapacitado, del obstáculo de relacionarse socialmente y sobre el pronóstico y los cuidados con su hijo. El ambiente hospitalario genera repercusiones psicológicas frente la expectativa y la falta de esperanza respecto la cura del hijo, consciente que el mismo podrá morir. Los profesionales de la salud pueden favorecer transformaciones increíbles generando un nuevo "cuidar", más amplio y humanizado que facilite la recuperación/reestructuración familiar frente este nuevo universo.*

**Descriptor:** *Fisioterapia; Niño Hospitalizado; Humanización de la Atención; Relaciones Madre-Hijo; Ventilación Pulmonar.*

## INTRODUCTION

Motor development in childhood is classified into typical or atypical, referring to the process of maturation and development of the central nervous system - CNS<sup>(1)</sup>. This presents intense evolution, which begins in the fetal stage (around the 10th week of gestation) with myelination in the spinal roots, allowing a fetal reflex activity, and ends in childhood, when it reaches its peak of maturity<sup>(2)</sup>. Several pathologies can affect the neuropsychomotor development in childhood, such as cerebral palsy (CP), numerous syndromes, spinal muscular atrophy, neonatal asphyxias, and congenital malformations, with a potential to cause sequelae in children and make them likely to demand

special care from a multidisciplinary team in hospital units<sup>(1,2)</sup>. These pathologies are chronic and disabling, and require monitoring by specialized teams and the adoption of supportive measures, such as respiratory physiotherapy, which helps mobilizing secretions and reduces the incidence of respiratory infections, sometimes requiring the use of artificial airways, eventually associated with a long-term ventilatory support, classified as Invasive Mechanical Ventilation (IMV)<sup>(2,3)</sup>.

The initial procedure for a child in need of mechanical ventilation is tracheal intubation; this may be prolonged and require the indication of a tracheostomy, depending on the underlying disease and the child's age. Mechanical ventilation (MV) is one of the therapeutic resources most frequently used in neonatal and pediatric intensive care units<sup>(3)</sup>.

Whenever the medical team opts to perform a surgical procedure like the tracheostomy in a child, this is a complex decision that depends on several factors, including the severity of airway obstruction, intubation time, and the patient's clinical condition. Tracheostomy may also be indicated to facilitate the aspiration of secretions from the airways of children intubated for a long period<sup>(2,3)</sup>.

Children with major neurological deficits may have pathological breathing patterns and progress to respiratory failure due to the difficulty in maintaining the ventilation/perfusion ratio<sup>(3)</sup>. Acute respiratory failure (ARF) is defined as the inability of the respiratory system to obtain oxygen (O<sub>2</sub>) to supply tissue needs and to remove carbon dioxide (CO<sub>2</sub>) derived from the cell metabolism<sup>(4)</sup>.

In diseases involving neuromuscular disorders, respiratory failure is the result of a deficit in respiratory function, since the weakness of the respiratory muscles leads to changes in respiratory mechanics, followed by episodes of alveolar hypoventilation. Due to this process, a condition characterized by chronic hypercapnia and hypoxemia secondary to the rise in carbon dioxide partial pressure in the arterial blood (PaCO<sub>2</sub>)<sup>(5)</sup>.

The ventilatory support was a major therapeutic advance in recent decades and various ventilation techniques have been developed, thus becoming associated with the improved survival of patients with respiratory failure of various etiologies<sup>(5,6)</sup>.

A long stay in the hospital environment, especially in a Special Care Unit, may expose the child and the mother/caregiver to hospital infections and psychological disorders<sup>(7)</sup>. For the family, and especially for the mother figure, facing the unknown in a setting composed of many lights, devices, specialized professionals, and sound stimulation with many alarms and noises produces anguish, uncertainty and insecurity about the prognosis for their children<sup>(8)</sup>.

The moment of diagnosis is the most difficult for the family, experiencing this moment, however, is important to elaborate on the current reality, to rethink their experience with the arrival of a child who fails to meet the standards of something desired and expected in their imagination, and to seek understanding in order to deal with this child with chronic illness. In this case, the role of a multidisciplinary team in the first moment when parents face the disease is of great importance, and an attitude towards sheltering and dialogue should be adopted to generate a maturation before the disease acceptance and the resignation to a new way of life<sup>(9)</sup>.

Therefore, the mother-child bond has been the subject of scientific studies confirming the physiological and psychosocial benefits to the health of both mother and child. This contact calms the child down, and the mother becomes attuned, favoured by this moment, thus helping to stabilize the blood flow, the heartbeat and the child's breathing<sup>(10)</sup>. Scientific research shows that, beyond the search for a service that strengthens the mother's presence beside the child and the legitimacy conferred by the Child and Adolescent Statute (ECA - *Estatuto da Criança e do Adolescente*), strategies have been created to make it easier for the mother to stay by the child in situations where hospital care is needed. Offering a humanized care means using technologies other than those contained in the equipment, and caring for the mother is a methodology that should be incorporated as part of the child care<sup>(11)</sup>.

Thus, in developing this research, the aim was to know the mothers' perception about the main difficulties in the care of children with special needs, dependent on mechanical ventilation.

## METHODS

The research followed a qualitative type of methodology and was developed from August to November 2013 at the General Hospital Dr Waldemar Alcântara, located in Fortaleza, CE, classified as a secondary level hospital within the public health system. The study was carried out at the Pediatric Special Care Unit (*UCE PED - Unidade de Cuidados Especiais Pediátricos*), which comprises eight beds. At that unit, all the children present chronic diseases, requiring artificial airways (tracheostomy tube) and/or ventilatory support. The unit has a multidisciplinary team consisting of doctors, physiotherapists, nurses, speech therapists and nursing assistants.

The study participants were mothers of children on mechanical ventilation, hospitalized at the Pediatric Special Care Unit. The study included women aged over 18 years, who had children hospitalized at this unit and agreed to participate; mothers with severe hearing impairment that could affect the data collection were excluded.

Initially, information on the mothers was collected with use of a sociodemographic questionnaire composed of the following data: age, household income, education level, civil status, occupation, number of children, number of pregnancies and abortions.

After that, individual interviews were held in a private place (pediatric physical therapy room), ensuring the confidentiality of information, using guiding questions, and encouraging these mothers to make the free narrative about their lived experience, without interference from the interviewer, who kept in a neutral posture. The story was captured by a voice recorder for an unlimited period of time.

The guiding questions applied in the interview were: *“Describe how you felt when you learned that your son had special needs. Describe what you feel to be most difficult, due to your child's condition, in relation to your family and society. What do you know of the device used to assist your child's breathing? Do you remember which professional informed you about the diagnosis? How did he report the news? In your opinion, are the health professionals prepared to deal with this delicate moment to break this kind of news to the families?”*

After data collection, the interviews were transcribed verbatim and reliably, followed by the data and content analysis<sup>(12)</sup>, being discussed based on the literature concerning the subject.

Content analysis<sup>(12)</sup> has phases that are organized around three poles: 1. The pre-analysis; 2. The exploration of the material; and 3. The treatment of results: inference and interpretation. From the transcript of the interviews, the content was grouped by similarity of meanings and five thematic categories were unveiled: “Devastated”: the pain before the diagnosis; Professional competence in breaking the news; Care for the special child; The family and social context in chronic pain; and “That machine”: understanding of the mechanical ventilation.

The research followed the ethical precepts governed by Resolution 466/2012 of the National Health Council<sup>(13)</sup> and was approved by the Ethics Committee of the University of Fortaleza, under opinion No. 573532, on March 24, 2014.

This survey was held with seven mothers from a total of eight mothers at the unit, because one was absent during the collection period. Abbreviations were formed with initial M and Arabic numerals (1 to 7) and used to identify the participants.

## RESULTS AND DISCUSSION

After collecting the information of the sociodemographic questionnaire, the description of these data was used to identify the social and demographic context experienced

by these mothers, in order to allow later immersion in the subjectivity of each narrative, through the thematic categories.

The mean maternal age ranged from 18 to 36 years. Six mothers were married or in a common-law marriage and one was single, having been abandoned by her partner when he learned of the child's diagnosis. The level of education ranged from illiterate to complete high school. Family income was a minimum wage at the maximum. Prior to devoting themselves exclusively to the care of children, six of them used to work. All mothers had other children, and three of them had two children. Regarding abortions, only two mothers reported this experience.

### “Devastated”: the pain before the diagnosis

This category leads to the understanding of the maternal sensitivity as a central focus of the interactive process between mother and child in the early stages of development, favouring the formation of the bond between them, which is not separated from the socio-cultural context in which the mother-child dyad is inserted. The initial perception of the total dependence of a disabled child generates in mothers antagonistic feelings of love/hate, acceptance/rejection<sup>(14)</sup>.

Pregnancy is never a mere physiological and somatic process. The mother dreams of her child, creating a conscious and unconscious image of the child's body and personality, according to her wishes and experiences, creating expectations. Thus, the birth of a child with special needs can represent a disastrous event for parents and family, with rupture of the symbolic meanings of birth, generating feelings of fear and frustration<sup>(15)</sup>.

As to the moment of news, the mothers reported deep sadness when confronted to the lack of satisfaction of the idealized son desire. The statements reveal poignant experiences of mothers who manifested themselves absolutely confused for not knowing how to deal with a situation that is unexpected and considered extremely difficult.

A 27-year-old interviewee evidences her comprehensive dedication to care for her disabled daughter and her feelings towards her current experience:

*“[...] Very bad, because she was not like that; she was a healthy girl. She walked, played, studied, and it was discovered, all of a sudden, that my daughter had this disease. Then she was repeatedly hospitalized. I quit working; to take care of her, I could no longer work. Then now she depends on me. Now I can't work anymore, I just stay with her.” (M2)*

In her poignant speech, another mother shows her indignation to what she regards “medical error”:

*“I felt bad, you see ... because I didn't expect. At that time I got sad, you know, because I know it was due to a medical error. Because my son, who was supposed to be healthy, a perfect, normal child, he had cerebral palsy, had asphyxia, because of the complications in childbirth, and now he is a special child because of that.” (M3)*

Anguish permeates the speech of mothers that bemoan the fact that the children were not born healthy. However, the issue of spirituality provides guidance, as a way to accept this task, which, according to the following speech, should not be discussed, but because it was determined by a higher being<sup>(16)</sup>.

A young mother aged 22 years, with tears in her eyes, described how she felt at the time of the child's diagnosis:

*“Oh, I was devastated. I can't explain very clearly, you know, but when they told me he was going to be a kind of special, that he had this syndrome, you see, that I don't even know how to explain. I was so devastated, so devastated, and afraid of losing him, too. I don't know, you see, only God knows, but I know I'll lose him anyway.” (M4)*

The presence of spirituality as an aspect related to the quality of life is already something discussed by the World Health Organization (WHO). One can conceptualize spirituality as something related to a person with a non-material power of life or to a higher power. No rational explanation is needed to prove its existence. The spiritual dimension of care for these children appears as a way to face the adversities, veiled hopelessness and impossibility of cure<sup>(17)</sup>.

### Professional preparedness in breaking the news

This category evidences the initial reaction to the diagnosis, which can be influenced by the way the news is disclosed to parents. This should be broken in the least traumatic way possible. According to the Code of Medical Ethics, the doctor is the one with responsibility for the disclosure of the disease diagnosis; however, the multidisciplinary team should provide moments to clarify any doubts<sup>(18)</sup>.

Health professionals should be cautious when expressing themselves with individuals in vulnerable situations, whether physical or emotional. Therefore, the use of the term “cure” for chronic conditions should be avoided, thus preventing the generation of expectations on a purpose not achieved, but the children should yet be seen as beings with great potential for improvement<sup>(19)</sup>.

In her speech, one interviewee points out the lack of dialogue and understanding between mothers and health professionals:



*“He just said that the boy had a little problem in his head, some malformation in his brain, and that he couldn’t breathe by himself. They explain it many times, but they explain it in a different way, isn’t it, from our understanding.” (M1)*

Anthropology has been helping in the understanding of these phenomena with growing clarity but, in spite of that, the biomedical model is still brutally hegemonic, leading to a reductionist view of disease, seen as an exclusively biological process<sup>(20)</sup>. The biomedical model is oppressive in relation to the concepts and perceptions of the population<sup>(21)</sup>, and highlights its inability to provide satisfactory answers to many problems, especially regarding the psychological or subjective components that accompany any disease. Such model encourages the health professionals to adhere to an extremely Cartesian behavior in the separation between the observer and the observed, disregarding the popular knowledge, religious beliefs, and the cultural and social context in which the individual lives<sup>(21)</sup>.

Another study participant talks about the lack of professional training and the suffering generated by this “unpreparedness”:

*“Ah, it happened all out of nothing ... The only thing I asked her about was his little fingers. Then, she suddenly started saying: ‘No, mommy, this is the last thing to worry about, because he has a very serious syndrome. I have to warn you right away that your son won’t survive much longer; he’s bound to die at any moment.’ She said it like that, all at once. Oh, my, at that moment, I felt like the floor was falling out from under me, because it happened all of a sudden. She didn’t even prepare me.” (M4)*

A good doctor-patient relationship is one of the most important factors for therapeutic success. This relationship is capable of generating an attitude change in the patient against the suffering experienced. A relationship based on mutual exchange of trust, empathy and affection can trigger in both a profound change<sup>(22)</sup>.

Patient and health professional are subjects of a personal, family, and social context of their own, with personal and social needs interacting during an appointment or a therapeutic experience, and these needs are diverse and must be respected, mediated, and negotiated by both<sup>(23)</sup>.

### Care for the special child

This category refers to the cultural role played by the woman/mother, who is regarded the main caregiver in the household and takes more and more responsibilities, feeling pressured to take care of home and children, especially when they are disabled. Although the child’s condition reach the whole family group, the mother figure

is usually the most involved in providing care for the child. The caregiver then begins to live in full-time dedication to the child and its actions are primarily aimed at the child’s needs<sup>(24)</sup>. Talking about health care assigns to the term a sense already enshrined in the common sense, as a set of technically oriented procedures for the success of a certain treatment. However, originated from the Latin *cura*, care was used in an older, cohesive form, in the relationships of love and friendship, expressing an attitude of devotion and concern<sup>(25)</sup>.

A 20-year-old participant, mother of two children, emphasizes her feelings in caring for the child:

*“[...] We, as mothers, would never want to see our children that way, would we? But, as we know it’s for his good will, we have to do it. It’s almost one year now that he is with the tracheostomy tube, and then he needs to be aspirated. I’m not used yet to the life my son has. I feel very bad when I have to aspirate [...] what I find most difficult is the bathtime, see, because we have to bath him lying down. It’s a lengthy process [...]” (M6)*

From the perspective of the sick person or the close ones, the disease has an impact on the flow of their everyday life, radically changing their world, putting them in a situation of disorder and disruption<sup>(26)</sup>. The vulnerability of caregivers in the hospital environment, represented by physiological, emotional and cognitive disorders, results from the impact of the various existing stressors in that environment, like the work overload, constant contact with the others’ suffering and the unpredictability of the patients’ general state<sup>(27)</sup>.

Therefore, in an attempt to confront this difficulty, mothers become exclusively dedicated to the caring for children, to the detriment of performing their usual activities. Maternal care is also marked by renouncement. The self-renunciation for the sake of the other, the child<sup>(16)</sup>.

### The family and social context in chronic pain

This category shows how the disease turns the family and social context into chronic suffering. The possibility that the individual realizes the support received is a protective factor against physiological, psychological, and social problems, being understood as a predictor of health and individual adaptation, with potential to improve self-esteem and mood, decreasing stress and feelings of loneliness and failure<sup>(28)</sup>.

M3 shows how difficult it is to remain active in her social life, since she does not have assistance in caring for the disabled child:

*“And the social issue, I don’t have that anymore, understand? I can’t go anywhere. I have no one to take care of him while I’m away. It’s only me and my husband.”*

*It's hard; staying at home is the only solution.” (M3)*

Another interviewee, deeply touched, mentions how she and her other children become apart and reveals, weakened, the major anguish in her new life conditions:

*“Staying away from my family, you see? Because I have never gone through a thing like this, and now I'm living it. Even though I'm taking care of my child... there is also the other side, isn't there?” (M1)*

Another mother, aged 18, experiencing the suffering of her only child carrying an irreversible neurological disorder, makes a touching report of the experience of not having family support:

*“My parents are not by my side. The only one who stands by me, so far, is my husband. My parents, my uncles, they just don't care about me.” (M7)*

Family participation is critical to the success of the therapeutic process. However, it should be considered that in every family there are specific identities, with different beliefs, concepts, and forms of relationship. The presence of a disabled child in the family environment has an impact on all members of that family, resulting in changes in roles and relationships<sup>(29)</sup>.

### **“That device”: understanding of the mechanical ventilation.**

This category shows the understanding of the mechanical ventilation. The new maternal reality, faced with an environment full of unknown devices, watching her child in “that device” generates feelings of anguish and fear. The understanding of the mechanical ventilation, conveyed in a colloquial language, can help the mother to reach a greater comprehension of the improvement that this device can offer, avoiding muscle fatigue through the reduction in work of breathing and the re-expansion of poorly ventilated areas of the lungs<sup>(30)</sup>.

With some feeling of strangeness, M2 talks about the mechanical ventilation device:

*“That device over there, I just understand that it's to help her breathe. She can't, you know, but she still runs the risk with that machine. It requires more attention.” (M2)*

Caring for the “device” causes mothers to feel apprehensive while performing activities such as bathing or even holding the child in her arms, for fear of hurting them. It is often necessary to develop new skills, which requires a new learning experience regarding the various healthcare techniques<sup>(16)</sup>.

Another participant reveals anguish when faced with the daily life of her daughter in ventilatory support, and considers the “psychological disorders” a complicating factor during the machine weaning process:

*“My way of thinking is that she is not dependent on it, since she has breathed room air once [...], the doctor told to me that she has a chance to quit the machine, right? It only requires her help, because she is psychologically affected. She spent a week out of it, she was fine, truly well, then when she starts to get depressed, you know, it is very fatiguing.” (M5)*

Health information is a distant strategy from the everyday experience of mothers of children dependent on mechanical ventilation. There is a significant gap between the professionals' explanation and the perception of the recipient of that message. The subjects do not understand the technicalities of health professional language<sup>(31)</sup>, so it is important to adapt the language to something tangible within the reality of women in suffering for their children.

Technological advance has contributed to the development of medicines and high-end devices, increasing the survival rate of children with poor health status. In this context, in the family environment, and even out of it, these children require monitoring since they present some kind of chronic dependence. Therefore, the partnership with mothers is critical, as they are committed to ensuring better quality of life for children, whether in the pursuit of knowledge about their conditions, or by caring with dedication, love and exclusivity<sup>(16)</sup>.

## **FINAL CONSIDERATIONS**

The maternal narratives of everyday life with their children with special needs were filled with anguish and fear, especially regarding the initial impact of the diagnosis, the little understanding of biomedical language, and the many questions that arise during the entire period after diagnosis and during hospitalization. However, after the process of assimilation of the new reality, and having overcome the phase of denial of the symbolic loss of their perfectly healthy son, mothers show themselves committed to fighting for their child's survival and welfare. The difficulties perceived involve aspects related to family abandonment, the distancing from the other children at the expense of caring for the disabled children, the difficulty in connecting with society, and about the prognosis and care for the child.

The study showed that the mothers' stay in the hospital environment generates psychological repercussions, feelings of fear and anguish at the prospect and the lack of hope of healing, knowing that their child might die. The

knowledge of these weaknesses by the health professionals may favour incredible transformations, creating a new “care”, more comprehensive and humanized, facilitating the recovery/restructuring of the family within this new universe.

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