



The child with non-progressive chronic encephalopathy: impact of the disease on the caregiver

A criança com encefalopatia crônica não progressiva: impacto da doença para o cuidador

El niño con encefalopatía crónica no progresiva: impacto en el cuidado

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ABSTRACT

Objective: To know the perception of the primary caregiver regarding the disease and care for the child with Non-Progressive Chronic Encephalopathy (NPCE). **Methods:** *It is a descriptive field study, with a qualitative approach, conducted in October 2019 on the reality that involves the care process of patients with NPCE.* Nine caregivers of patients seen at a municipal physiotherapy clinic in a small town in the interior of Ceará, Brazil, were interviewed through semi-structured interviews, subsequently analyzed through content analysis, emerging the thematic categories: Limitations of the child with NPCE; Caregiver reactions to the child's diagnosis with NPCE; Future perspectives of the child with NPCE; Prejudice against the child with NPCE; The child with NPCE burdens the caregiver's health. **Results:** *The results indicate that the primary caregiver goes through critical phases, which start with the diagnosis, last during the care process, and bring future fears about the clinical condition prognosis, social acceptance, schooling, job market, and death.* **Conclusion:** This study highlights the need for support from health professionals for the treatment and guidelines for adequate care of this public.

Descriptors: Cerebral Palsy; Caregivers; Emotions.

RESUMO

Objetivo: Conhecer a percepção do cuidador primário quanto à doença e ao cuidado com a criança com encefalopatia crônica não progressiva (NPCE). **Métodos:** *Trata-se de um estudo de campo do tipo descritivo, com abordagem qualitativa, realizado em outubro de 2019 sobre a realidade que envolve o processo de cuidado de pacientes com NPCE. Entrevistaram-se nove cuidadores de pacientes atendidos em uma clínica municipal de fisioterapia de um município de pequeno porte do interior do Ceará, Brasil, por meio de entrevista semiestruturada, posteriormente analisada por meio da análise de conteúdo, emergindo as categorias temáticas: Limitações da criança com NPCE; Reações do cuidador ao diagnóstico da criança com NPCE; Perspectivas futuras da criança com NPCE; Preconceito com a criança portadora de NPCE; A criança portadora de NPCE sobrecarrega a saúde do cuidador.* **Resultados:** *Os resultados apontam que o cuidador primário passa por fases críticas, que iniciam com o diagnóstico, perduram durante o processo de cuidado e trazem receios futuros quanto ao prognóstico do quadro clínico, aceitação social, escolarização, mercado de trabalho e morte.* **Conclusão:** Este estudo evidencia a necessidade de apoio dos profissionais de saúde para o tratamento e orientações para o cuidado adequado desse público.

Descritores: Paralisia Cerebral; Cuidadores; Emoções.



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RESUMEN

Objetivo: Conocer la percepción del cuidador primario sobre la enfermedad y el cuidado del niño con encefalopatía crónica no progresiva (NPCE). **Métodos:** Se trata de un estudio de campo del tipo descriptivo de abordaje cualitativo realizado en octubre de 2019 sobre la realidad que comprende el proceso del cuidado de pacientes con NPCE. Se ha entrevistado nueve cuidadores de pacientes asistidos en una clínica de fisioterapia de un municipio pequeño del interior de Ceará, Brasil, a través de entrevista semiestructurada que ha sido analizada por el análisis de contenido del cual ha surgido las categorías temáticas a continuación: Limitaciones del niño con NPCE; Reacciones del cuidador sobre el diagnóstico del niño con NPCE; Perspectivas futuras del niño con NPCE; Prejuicio contra el niño portador de NPCE; El niño portador de NPCE sobrecarga la salud del cuidador. **Resultados:** Los resultados apuntan que el cuidador primario pasa por fases críticas que se inician con el diagnóstico, permanecen durante todo el proceso del cuidado y traen miedos futuros del pronóstico del cuadro clínico, la aceptación social, la escolarización, el mercado de trabajo y la muerte. **Conclusión:** Ese estudio evidencia la necesidad del apoyo de los profesionales sanitarios para el tratamiento y las orientaciones del cuidado adecuado de ese público.

Descriptores: Parálisis Cerebral; Cuidadores; Emociones.

INTRODUCTION

Cerebral palsy (CP) or non-progressive chronic encephalopathy (NPCE) is a set of disorders due to non-progressive disturbances, which limit several factors of functional capacity, including motor development, communication, and cognition⁽¹⁾.

Such alteration may be the result of an injury to the central nervous system (CNS), in the period of maturation and development, during the prenatal, perinatal, and postnatal phases, resulting in impaired muscle tone, motor skills, deformities, among others, which vary with the child's age and the location of the brain injury⁽²⁾. The child with NPCE requires much care and, after the diagnosis, the family starts to have another reality, being necessary to adapt the routine according to the need of the new family member⁽³⁾.

Even with medical advances for pre and perinatal diagnoses and interventions, NPCE is still a disabling disorder of the child's neurodevelopment⁽⁴⁾. In developed countries, the prevalence of PNEC ranges from 1.5 to 5.9/1,000 live births. The incidence in developing countries is estimated to be 7/1,000 live births. The number in developing countries, such as Brazil, may be higher due to poor prenatal care conditions and primary care for pregnant women⁽⁵⁾.

In the epidemiological survey, regarding the gestational history of mothers performing prenatal examinations, the vast majority were consulted by a specialized professional between 6 to 9 prenatal consultations. Prenatal examinations are relevant, as chronic encephalopathy can occur in the prenatal, perinatal, and postnatal phases, for numerous causes such as infections, AIDS, use of narcotics, tobacco, alcohol, malnutrition, and trauma^(6,7).

After the diagnosis of NPCE, in most cases, the mother is the primary caregiver, who, in addition to domestic activities, has the child as a burden, which requires total attention and dedication. The primary caregiver is defined as the one who has the main or total responsibility for the child's daily care, that is, the one who puts the patient's needs first and abdicates his / her life, thus fulfilling this role completely⁽⁸⁾.

Attention to the child starts to be doubled as he/she grows^(9,10). In some cases, the caregiver hardly participates in leisure activities without the child being present. Thus, in addition to physical overload, the primary caregiver suffers in several ways emotionally, since feelings, such as insecurity, impotence, guilt, and helplessness, by family members and even by health professionals, affect this caregiver and generate consequences, such as resigning your personal life to spend most of your time on behalf of the child. The act of caring, in this aspect, begins to have some negative repercussions for the caregiver's life, leading to interferences in health⁽¹¹⁾.

With the child's diagnosis, caregivers face difficulties in the daily routine of handling the child, eating, bathing, or dressing. The caregiver's concern with society's acceptance and prejudice are also factors that trigger their physical and psychological wear and tear⁽⁹⁾. The family's financial situation is also affected, as the child will need extra health expenses, for example, exams, medicines, professionals, basic needs, treatments, and care in general⁽¹²⁾. There is evidence that mothers of children with NPCE are more likely to develop anxiety and depression when compared to mothers of children without disabilities. Family conflicts are also part of this caregiver's life, generated by the adaptation that the whole family needs to experience^(13,14).

NPCE is widely studied, and most studies are focused on the child diagnosed with NPCE^(5,6), but among the problems caused to the child by the disease are also the needs of the subject providing care⁽⁵⁾. Research related to

the caregivers of these children is rare, who also need to live with dignity enabling them to perform their role with dignity^(12,15). Thus, this lack makes the present research necessary.

The Ordinance No. 2,446, of November 11, 2014, which redefines the National Health Promotion Policy (PNPS) as a set of strategies and ways of producing health, individually and collectively, determines that integrality in promoting health becomes a health production strategy⁽¹⁶⁾. Caregivers are configured here as part of the comprehensive care for children affected by NPCE⁽⁴⁾. In this context, the following guiding question was asked: how does the primary caregiver perceive the disease and care for his or her child affected by non-progressive chronic encephalopathy?

Thus, the objective of this research was to know the primary caregiver's perception of the disease and the care of children with non-progressive chronic encephalopathy (NPCE).

METHODS

It is descriptive type research with a qualitative approach^(17,18) on the reality that involves the care process of NPCE patients. The research field was the Municipal Physiotherapy Clinic of a small town in the interior of Ceará, Brazil, in which primary caregivers of children with NPCE participated in physical therapy in October 2019. All caregivers accompanying children treated at the clinic with the diagnosis of NPCE were invited to participate in the research.

Inclusion criteria adopted: primary caregivers of a child diagnosed with NPCE, of both sexes, and who are of legal age. All caregivers under the age of 18, primary caregivers who refused to participate in the research or who were not present during the collection period, and secondary caregivers, that is, who help on an economic level, support social and leisure activities among others, were excluded⁽¹⁹⁾.

All guests agreed to participate in the study, and all were at the clinic accompanying children with NPCE during the period analyzed. As this is qualitative research, the sample was limited by information saturation⁽²⁰⁾. Thus, the sample included nine participants.

A semi-structured interview⁽²¹⁾ was carried out, consisting of two stages: identification data of the primary caregiver with the variables relationship with the child and age, and with the following simple question, based on the objective: what is it for you to take care of your child with non-progressive chronic encephalopathy? The interview took place in a private environment, in which only the researcher and the caregiver met, while the child was attended by the clinic's physiotherapy service, lasting approximately 60 minutes, in a friendly atmosphere between the interviewer and the interviewee.

The content analysis method was used for data analysis, whose operation took place in three stages: pre-analysis, material exploration, and treatment of results⁽²²⁾. Furthermore, after analyzing the content of the interviews, categories emerged that summarize the responses: Limitations of the child with NPCE; Caregiver reactions to the child's diagnosis with NPCE; Future perspectives of the child with NPCE; Prejudice against the child affected by NPCE; The child with NPCE burdens the caregiver's health.

The research was submitted to the Research Ethics Committee of the INTA University Center (Uninta) and approved according to Opinion No. 3,635,099. Caregivers' participation was voluntary by signing the Free and Informed Consent Form (FICF). To maintain anonymity, the caregivers' names were replaced by the letters "CP", which refer to the expression "primary caregiver", followed by an Arabic numeral in the sequence of the interviews, giving total confidentiality to the participants.

RESULTS AND DISCUSSION

Nine primary caregivers participated in the study. They were all mothers, aged between 30 and 50 years old, who accompanied their children with PNEC during the treatment at the physiotherapy clinic. This data is corroborated by other researches when it affirms that the woman has always been responsible for the care, whether from the house or the children, even of the sick people, while the role of the man, many times, was to work outside to guarantee the financial provision of the family⁽²³⁾.

From the analyzed speeches, the thematic categories could be highlighted, grouped by their similarity of content. Excerpts of the caregivers speeches that represented each category were selected, as can be seen below.

Limitations of the child with NPCE

This category, limitations of the child with NPCE, deals with the difficulties children present in the mothers' point of view. What stood out the most were activities of daily living and, mostly, the difficulty of walking, as can be seen in the statements:

“One difficulty he has is getting the food in his mouth with a spoon. He already has other difficulties ... because he doesn’t walk either, right?! Yeah, don’t walk, don’t put the spoon in your mouth, that’s all, motor, that’s all.” (CP1)

“He has trouble getting dressed, doesn’t he?! He has difficulty speaking ... He has difficulty, sometimes, when picking up small things, when walking too, right?! He walks, but it is difficult ... (laughs).” (CP9)

“The difficulties for her? Well, it’s all things, because she doesn’t walk, it’s totally up to me, her movements are just like that, she moves with her arms, she moves her legs, but walking, she doesn’t walk.” (CP8)

“He doesn’t walk, he doesn’t speak, he doesn’t sit down, he has a lot of problems.” (CP4)

The caregiver’s speech highlights the patients’ motor and verbal difficulties. It is also observed that the levels of commitment differ from each other. Some children are affected in speech, have motor disabilities, such as walking, some have delayed cognitive development, while other children are not necessarily affected by all these limitations. These results corroborate another study, which identified that the biggest difficulty for children was to walk since most of them suffer from limitations; and some even need orthoses or a wheelchair^(24,25).

The unsatisfactory evolution of the patient’s clinical condition leads to the caregiver’s demotivation, becoming weakened by the negative aspects experienced. From the moment that the caregiver does not feel good about himself, he cannot focus on effective quality care. Thus, strategies that provide well-being are necessary so that the caregiver can offer more quality care to the child⁽²⁶⁾.

Caregiver reactions to the diagnosis of the child with NPCE

In this category, caregiver reactions to the diagnosis of the child with NPCE, the difficulty stood out amid denial, acceptance, and overcoming, as shown in the excerpts below:

“It was a little difficult for me, I didn’t know how to help her, but some people came and encouraged me to bring her here (Physiotherapy clinic).” (CP3)

“It was difficult, because we feel embarrassed, we feel rejected by society, especially in the family, I ... (crying) When I found out, I didn’t want to accept.” (CP2)

“At first it was horrible, because who is the mother who accepts to have a disabled child, right? Because in the beginning, when I found out, I wanted... Because we expect, during that pregnancy, to see the child walking, going to school like normal children, then, I don’t... At first, I didn’t want to accept it, I even wanted to ... Do that bullshit ... (suicide), but with faith in God, it’s not?! We face everything that comes from our children, whether normal or not, with faith in God we face.” (CP5)

The caregivers of the present study reported not knowing how to proceed with care after diagnosis. There was a feeling of powerlessness and reports of raising awareness of third parties who started to provide support and incentive to seek specialized care. Others reported rejection by society and even family members. Some referred to extreme despair at the diagnosis, having God as a way to face the situation, making it possible to identify the importance of the Municipal Physiotherapy Clinic for the treatment.

In general, the caregivers interviewed reported negative points as reactions to the diagnosis. Knowing that the news that the child has NPCE interferes in the life of the family and/or the caregiver, health professionals must contribute positively to a child’s relationships with their family members/caregivers, proposing changes in the family routine⁽²⁷⁾.

Care responsibility, when it is shared in harmony with other caregivers, reduces the workday and, consequently, becomes less exhaustive, which can positively contribute to the patient’s care and evolution⁽²⁶⁻²⁸⁾.

Besides, two primary caregivers (CP8 and CP5) reported that they suffered from social limitations, as they are unable to have a personal life, let alone general care for themselves:

“My life, since she was born, she is 21 years old, my life revolves around her. I can’t work, I can’t go out to have fun, much less study. This is my life, staying at home, taking care of her.” (CP8)

“I don’t have a social life, I just live for her and I see that my life is hers, for her, everything like that, you know? Then, I can’t go out, just to fix her things and go to church, and look there, but I don’t know how it will be in the future, because I don’t know how long I’ll be here, you know? But, as she only has me, I hand it over to God and He is the one who knows who is taking care, is not?!” (CP5)

After diagnosis, changes in social life are reported due to the need for constant care. There are reports that coping happens differently from individual to individual, as it varies according to how the person distinguishes and faces reality, either in non-acceptance or in denial related to the diagnosis⁽²⁸⁾.

The assessment of the burden of primary caregivers of children with NPCE shows that most caregivers feel exhausted due to the total responsibility for the child, limiting some aspects of this caregiver's life, as he ends up giving up his social life to live only life dedicated to the child^(8,28).

Future perspectives of the child with NPCE

In this category, future perspectives of the child with NPCE, the caregivers want to overcome the child amid society and autonomy, as observed in the following excerpts:

"A mother always thinks what is good for her child ... I think of him as a graduate ... (laughs) in a good job ... (laughs) ... Why not, isn't it?!" (CP1)

"May she become a better person, a good person who already is, a winner and may she achieve her dreams." (CP3)

"I imagine him as a great man ... (laughs) Studying, going to college, he wants to study in a professional course... ... He dreams very high. He said he will study to help me." (CP2)

"Hey! I imagine him as a prepared man, in the market, right?! He's already studying (...) graduated, whatever, I imagine him very well. I do not imagine him to be very sick, so dependent, not weak. I think of him better than he is today." (CP9)

Although the caregivers interviewed, having positive future expectations about the child, at the same time were insecure about success, current situation and because of the prognosis, they reported perceiving characteristics of the child's personality such as willpower and overcoming. Others had a desire for the child to reach higher education and graduate but were aware of the child's commitments, which would hinder the fulfillment of that desire.

As for the child insertion in the school, one of the difficulties is the exchange of information among students, teachers, employees, and even colleagues. The lack of knowledge about the disease at school, the lack of preparation or training of these professionals can hinder the child's development depending on the degree of their cognitive performance and degree of limitation. Another factor that can also interfere in this development is the parents' fear about the rejection of colleagues or people who are part of the environment, so that they end up saving the child from some situations or even from some activities, being "overprotective"^(25,29).

Fear of death of the child with NPCE or the caregiver

Regarding this category, fear of death of the child with NPCE or the caregiver, the caregivers interviewed stressed that the greatest fear of the future is to lose the child or die and leave the child alone in the world:

"What I'm most afraid of is her dying, losing her, and her health, isn't it?! What I care most about is her well-being. She being healthy, for me it's everything." (CP8)

"The fear is of losing her, isn't it, because we don't live forever, for the rest of our lives. Sometimes ... I think that these children, who have disabilities, do not live long, do not have life as we do. And that's my big fear, I don't even like to think, it's not?!" (CP5)

"His whole future, on his time being a man, I don't know, afraid of losing ... (long pause, shaky voice and compulsive crying) I have too much, I don't even like to talk, you know? Which is the fear that I have the most, because I know he won't have me all his life, right?! How will his life be." (CP1)

Among the future perspectives, the death of the child and the caregiver appears in some speeches, compromising the continuity of the child's care, with health as a primary point for physical and psychological well-being. One of the main concerns of family members of children with NPCE is the fear of death itself, considering that they are the main caregivers of the child or adult who, in these conditions, need basic and permanent care to survive. This concern generates anxiety and uncertainty about the future. In addition to death itself, there is the fear of experiencing the child's death⁽³⁰⁾.

Prejudice against the child with NPCE

In this category, prejudice against the child with NPCE, it is also highlighted that mothers fear how the child will react if any prejudice will arise in the future:

"Yes...Further ahead, some prejudice, some reaction to other people, the rejections that she may face in the future, not now, but we don't know when she goes to other schools, do we?! I don't know if there will be any

rejection, do I?! Against it ... with her ... that I can deal with it with her.” (CP 3)

“I’m afraid of how people will look at him differently, I’m afraid, because especially at school, isn’t it?! When he starts to study and notice that he is different, see him with some limitation ... Then, they will want to point to him and they will ... like exclude him ... Thinking that he is not normal, that’s what I think.” (CP7)

But the caregivers interviewed reported the fear about the school environment in the child’s future life. The statements also show an interest in facing adversities with the child. They report having fear that, due to physical conditions being noticeable, some type of exclusion will occur and this may compromise their self-esteem. It is known that prejudice and discrimination occur because it is a barrier that they are not always able to react to these prejudices, making them impotent. In this study, these barriers were also present, so that fear of the future due to prejudices generates concern in the primary caregiver⁽²⁸⁾.

The child with NPCE burdens the caregiver’s health

Among the difficulties experienced, this category, the child with NPCE overloads the caregiver health, was mentioned by the mothers a lot, with reports of physical overloads, such as pain in the back, arms, and limited movement:

“Me? I feel a lot of back pain, back pain. Sometimes, at night, I can barely sleep, pain in my arms, pain in my legs, then I even walk to see if I get better. The pain in my spine occurs just because I am lifting her, because she is already 14 years old, she is almost my size and very heavy. My feet swell sometimes, and at other times, she always snores. She has a very strong snoring, and I can’t sleep well, so I am afraid she will suffocate or choke to death a. Sometimes despair hits me and I even think about screwing myself (suicide), you know?” (CP5)

“So, I feel a lot of back pain, right, because it’s already very heavy, but you can take it, right?! I don’t know how long, because time is passing. We lose our strength, our movements, the pains appear and get worse, so I don’t know how it will be in the future, no. I’m afraid of the future.” (CP8)

Generally, overload, both due to the growing child’s weight and the excessive dedication the child requires, causes health problems for the caregiver, such as depression, spine problems, exhaustion, physical and mental tiredness. It was seen that, between the lines, they mention the desire to commit suicide. It is known that suicide is an emerging and multidimensional problem, and it is necessary for health professionals to broaden their knowledge on the subject and raise awareness to prevent and carry out appropriate management of the suicidal crisis, to promote health⁽³¹⁾, and also to have a humanized care with the caregiver.

Regarding the complaints mentioned by the caregivers, children with NPCE need help and support during the day, and this generates an overload on the caregiver, which can cause low back pain or other musculoskeletal symptoms, which may occur due to the daily locomotion that the caregiver exercises according to child’s needs⁽³²⁾. The caregiver will not necessarily experience pain or even feel overwhelmed to the extreme, on the contrary, there are cases in which they have a moderate burden due to family aids, which help in the child’s daily responsibility^(31,32).

Health professionals should guide and encourage the child’s mother to make her independent within her limits, clarifying them about the proper handling at home and the posture used during daily activities, preventing possible physical overload and problems postures, guidelines capable of promoting well-being^(29,32).

Even so, the caregivers interviewed reported “not feeling physically overwhelmed”, as can be seen in the excerpts below, as can be seen in the excerpts below, but it was noted that these reports come from the caregivers of children who are not totally dependent, that is, primary caregivers of children who do not have a total limitation. Others (CP6 and CP1) cited that, no matter how much they dedicate most of their time to taking care of their children, they do not present any complaints:

“No, I have no problem.” (CP6)

“No, I just feel tired sometimes, because it gets tired, but a physical problem, like that, not, even my mind clarified more, because ... because he (child) teach us many things, he teaches.” (CP1)

Despite the undeniable social, physical, and psychological burden that caregivers report, sometimes it is not noticed. Possibly, due to the total surrender to care, starting to consider the child’s pathological conditions as natural to the care process. Further studies on caregivers of children with NPCE are suggested due to the demand on the child and the lack of self-care, which compromises the physical and emotional aspects associated with child care^(4,32). The physiotherapist can assist by giving guidance on the position of the caregiver when handling the patient, providing improvements in complaints of musculoskeletal pain^(11,32).

The results of the present study are similar to other studies that identified that the lives of caregivers of patients with PNEC are unsatisfactory, especially in the physical and psychological domains, whereas, since the child's birth, they started to live according to them, putting their dreams and goals in the background, leading caregivers to be frustrated and dissatisfied with their own lives^(26,27,28).

The task of caring is complex and is often entrusted to individuals who are not prepared to perform such a function. Likewise, it is an activity permeated by diverse and contradictory feelings, given the need to perform specific functions that, often, caregivers were not prepared to exercise⁽¹⁷⁾, mainly because it is about taking care of a loved one, which involves emotions.

Such results can be applied to other realities where care is dependent, whether in the neuropsychiatry or adult neurology area. It is known that the health of people dependent on care is directly affected by the quality of care they receive and, for this, it is necessary to develop spaces to promote the empowerment of caregivers, so they can find support networks where they can share fears, difficulties, and successes in the performance of their duties⁽¹⁹⁾.

The Brazil's National Health Promotion Policy⁽¹⁶⁾ recommends the increase and expansion of primary care services, which can contribute to the prevention and promotion of individual and community health. Here, we highlighted that this neuromotor dysfunction in the child impacts the child, the family, society, and, above all, those who take care of the child since birth, who is usually the mother. Thus, the knowledge about this disease must be passed on from the prenatal period, and information about this disease is essential to assist in preventive actions, through health education, for women during pregnancy.

The current study was limited because it was carried out in only one place of study. We suggest the development of new studies involving caregivers of people with other pathologies so that they can identify their feelings and anxieties and, thus, the service aimed at this public is valued in terms of their needs, whether physical or psychic, praising not only the patient but sensitizing the multidisciplinary team and health managers so that they can give humanized attention to these caregivers.

FINAL CONSIDERATIONS

It is of great value to highlight, through the caregiver's look, what it is to care for patients with NPCE. It was seen that they reacted negatively to the diagnosis of the child's health condition and miss the support of friends and family.

Caregivers' willpower overcomes body aches and pains. It is convenient to have a different view of health professionals and managers, providing humanized care to these women caregivers, who go through critical phases since the birth of an NPCE child. The ways of coping differ from one caregiver to another, but they all need support from health professionals for treatment and guidance for the proper care of the child and self-care.

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INTEREST CONFLICTS

There were no conflicts of interest.

CONTRIBUTIONS

Érika Alves Germano and **Mara Dayanne Alves Ribeiro** contributed to the preparation and design of the study; the acquisition, analysis and interpretation of data; and the writing and / or revision of the manuscript. **Mauro Vinicius Dutra Girão** contributed to the acquisition, analysis and interpretation of data; and the writing and revision of the manuscript. **Edna Pinto Medeiros de Lima** contributed to the acquisition, analysis and interpretation of data. **Maria Dandara Alves Ribeiro** contributed to the writing and / or revision of the manuscript.

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