

FEELINGS EXPERIENCED BY MOTHERS AND CHILDREN/ADOLESCENTS WITH SICKLE DISEASE IN THE CONTEXT OF THE COVID-19 PANDEMIC

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ABSTRACT

Objective: to know the feelings of children/adolescents with Sickle Cell Disease perceived by mothers and to identify feelings experienced by mothers of children/adolescents with Sickle Cell Disease after the emergence of the COVID-19 pandemic.

Method: qualitative study, developed in a city in the state of Bahia with the participation of 19 mothers of children and adolescents with Sickle Cell Disease. Data were obtained between March and April 2020 through semi-structured interviews via WhatsApp calls, which were submitted to thematic, factor and similarity analysis after transcription.

Results: the participants reported feeling overloaded due to dedicating themselves full time to the care of their children, who were more vulnerable and emotionally unstable due to social distancing. Therefore, strategies were adopted by mothers, intending to help adaptation and stress reduction - provided by the context of the pandemic - for themselves and in their children.

Conclusion: mothers of children/adolescents with Sickle Cell Disease need to be supported and instrumentalized in order to implement care centered on the psychoemotional dimension and seek specialized help, especially regarding feelings triggered due to the need to maintain the therapeutic routine of their children in the midst of the pandemic.

DESCRIPTORS: COVID-19. Sickle cell disease. Chronic disease. Emotions. Nursing.

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SENTIMENTOS VIVENCIADOS POR MÃES E CRIANÇAS/ADOLESCENTES COM DOENÇA FALCIFORME NO CONTEXTO DA PANDEMIA DA COVID-19

RESUMO

Objetivo: conhecer sentimentos de crianças/adolescentes com Doença Falciforme percebidos pelas mães e identificar sentimentos vivenciados por mães de crianças/adolescentes com Doença Falciforme após o surgimento da pandemia da COVID-19.

Método: estudo qualitativo, desenvolvido numa cidade do estado da Bahia com a participação de 19 mães de crianças e adolescentes com Doença Falciforme. Os dados foram obtidos entre março e abril de 2020 mediante entrevistas semiestruturadas via *WhatsApp*, as quais, após transcritas, foram submetidas a análise temática, análise fatorial e análise de similitude.

Resultados: as participantes referiram sentir sobrecarga ao dedicarem tempo integral aos cuidados dos filhos, que se mostraram mais vulneráveis e instáveis emocionalmente devido ao distanciamento social. Diante disso, estratégias foram adotadas pelas mães, tencionando a adaptação e a diminuição das tensões - proporcionadas pelo contexto da pandemia - nelas mesmas e em seus filhos.

Conclusão: as mães de crianças/adolescentes com Doença Falciforme necessitam ser apoiadas e instrumentalizadas para que se implementem cuidados centrados na dimensão psicoemocional e se busque ajuda especializada, principalmente diante daqueles sentimentos deflagrados em razão da necessidade de manter a rotina terapêutica dos seus filhos em meio à pandemia.

DESCRITORES: COVID-19. Doença falciforme. Doença crônica. Emoções. Enfermagem.

SENTIMIENTOS EXPERIMENTADOS POR MADRES Y NIÑOS/ADOLESCENTES CON ENFERMEDAD FALCIFORME EN EL CONTEXTO DE LA PANDEMIA DEL COVID-19

RESUMEN

Objetivo: conocer los sentimientos de los niños/adolescentes con Drepanocitosis percibidos por las madres e identificar los sentimientos experimentados por las madres de niños/adolescentes con Drepanocitosis después del surgimiento de la pandemia de COVID-19.

Método: estudio cualitativo, desarrollado en una ciudad del estado de Bahía con la participación de 19 madres de niños y adolescentes con enfermedad de células falciformes. Los datos se obtuvieron entre marzo y abril de 2020 a través de entrevistas semiestructuradas a través de llamadas de *WhatsApp*, que fueron sometidas a análisis temático, factorial y de similitud después de la transcripción.

Resultados: los participantes relataron sentirse sobrecargados al dedicar tiempo completo al cuidado de sus hijos, quienes se encontraban más vulnerables e inestables emocionalmente debido al distanciamiento social. Por lo tanto, las estrategias fueron adoptadas por las madres, con la intención de adaptarse y reducir las tensiones, proporcionadas por el contexto de la pandemia, en ellas y en sus hijos.

Conclusión: las madres de niños/adolescentes con Enfermedad de Células Falciformes necesitan ser apoyadas e instrumentalizadas para implementar cuidados centrados en la dimensión psicoemocional y buscar ayuda especializada, especialmente en relación a los sentimientos desencadenados por la necesidad de mantener la rutina terapéutica de sus hijos en la medio de la pandemia.

DESCRIPTORES: COVID-19. Enfermedad de célula falciforme. Enfermedad crónica. Emociones. Enfermería.

INTRODUCTION

The beginning of 2020 was marked by the onset of the Coronavirus Disease 2019 (COVID-19), caused by a new virus, called Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2)¹, which spread around the world, affecting a large number of people. The COVID-19 pandemic aroused fear around the world due to the lack of scientific knowledge regarding the origin of the disease and its effective treatment, mainly affecting the risk groups potentially subject to more severe conditions of the disease, such as people with Sickle Cell Disease (SCD).

When compared to the general population, people with SCD tend to be more severely affected by COVID-19, due to their preexisting chronic morbidities². It is known that people with SCD, especially in childhood, are a risk group for COVID-19 infection, since they suffer from reduced immune capacity to fight infections (functional asplenia). With the negative and constant impact on the immune system, the clinical management of SCD patients affected by SARS-CoV-2 infection must be fast and early³.

The management of SCD is stressful for parents and leads them to be overprotective, either because they feel helpless regarding the diagnosis or for fear of premature death of their child. Thus, the pandemic exacerbates these fears of illness and death for family members of children and adolescents with SCD, because they associate their previous vulnerability with a greater severity of the disease.

Firstly, a systematic search of scientific productions already published on this research subject was carried out from April/2020 to June/2020. A search was conducted in the Latin American and Caribbean Literature databases in Health Sciences (LILACS), SciELO, ScienceDirect and PubMed, using the descriptors "Sickle Cell Disease", "Feelings", "Children", "Adolescents" and "Coronavirus". However, no studies related to the object of the research were found through the descriptors in the databases or in ScienceDirect, which shows that there is a gap in the area and attests to the new nature of this object of study.

The present study highlights that it is necessary to know the feelings, reflections and concerns that emerge during the pandemic to create policies to cope with the health crisis with respect to the specificities of each collectivity⁴. With the emergence of the COVID-19 pandemic, it is evident that there is a need to fill gaps related to the pandemic in the daily life of risk groups with chronic health conditions, such as mothers and children/adolescents with SCD. Thus, it is important that all those involved in the care network - from professionals to health managers - aim to understand the feelings experienced by family members of children and adolescents with SCD during the COVID-19 pandemic. This knowledge will allow these groups to be better cared for by the nursing team, considering that they are part of the risk group and need comprehensive and holistic care, through care practices that consider the individual not only in the biological dimensions, but also in the prevention of psychoemotional disabilities.

Thus, this article was guided by the following research questions: "what are the feelings of children and adolescents with SCD perceived by mothers in the context of the COVID-19 pandemic? What are the feelings experienced by mothers of children/adolescents with SCD after the emergence of the COVID-19 pandemic?". The objectives of this study were to know the feelings of children/adolescents with SCD perceived by their mothers and to identify feelings experienced by mothers of children/adolescents with SCD after the emergence of the COVID-19 pandemic.

METHOD

A qualitative study developed with a group of family members of children/adolescents with SCD who attended a Municipal Reference Center for Sickle Cell Disease, located in the city of Feira de Santana (BA), and who had used the messaging application WhatsApp, before and after the pandemic.



Possible participants were approached through an invitation sent by message to the WhatsApp group of family members and professionals who support people with SCD and participants of extension projects developed by the research group (to which this research is also linked). The first female author conducted the interview and initially explained the objectives of the research, asking those who wished to participate by sending a message to the given telephone number to be used for communication between participants and the principal researcher.

All members of the group were invited, totaling 39 participants, but only 20 replied. Among these, 19 agreed to participate in the study; one of the participants in the group refused the invitation with the justification that talking about the theme COVID-19 would be uncomfortable, considering that one of her children was affected by the disease at that time. The following inclusion criteria was implemented among the guardians of children/adolescents with SCD: over 18 years of age; and to be the guardian of the child/adolescent with SCD aged between 2 and 15. The age range from 2 to 15 was chosen to identify changes that occur in the transition of care from childhood to adulthood in the various evolutionary phases. Those who did not live directly with the child at least five times a week were excluded.

The ideal number of participants in the qualitative approach corresponds to that which allows the achievement of knowledge regarding the study subject in depth. Thus, the interviews were conducted until theoretical saturation occurred, which was possible at the 16th interview. The theoretical saturation of data occurs when new participants are no longer included, considering that the data obtained begin to present a certain redundancy or repetition, and it is not considered necessary to persist in data collection⁵.

Empirical data were produced through the semi-structured interviews performed using the WhatsApp application between March and April 2020. The production of data through audio conversations on the WhatsApp application occurred due to the need to maintain social distancing and prevent the spread of the new coronavirus in the COVID-19 pandemic, considering that children and adolescents with SCD are part of a vulnerable group due to their chronic condition of the disease and immunosuppression. The use of audio messages via WhatsApp is also justified by facilitating communication with family members who had low levels of formal education (difficulty reading and/or typing).

The interview was guided by a semi-structured script composed of two parts: sociodemographic profile and guided questions: what are the feelings of children/adolescents with SCD after the emergence of the COVID-19 pandemic? How do you feel being responsible for a child/adolescent with SCD (risk group) after the emergence of the COVID-19 pandemic?

The audio messages with the interviewer's questions and answers of the interviewees lasted between 15 and 20 minutes. The answers were fully transcribed and returned to the participants for comments and/or correction. Afterwards, they were submitted to triangulation analysis techniques: thematic analysis, factor analysis and similitude analysis.

Thematic analysis is a recursive process, with movements that go back and forth as needed, throughout the phases⁶. The procedure took place in a non-linear manner, i.e., the order from one stage to the next stage was not followed. In the first phase, data familiarization took place, which consists of data transcription, reading and rereading the interviews and highlighting initial ideas; in the second phase, the relevant characteristics of the data were systematically coded throughout the set, observing the recurring patterns in the interviews; in the third phase, codes were grouped into potential themes, which were analyzed by observing the relationships between them; the fourth phase consisted of rereading and reviewing the themes, when it was verified whether they worked in relation to the coded extracts; in the fifth phase, the definition and naming of the thematic categories

and their respective subcategories was established; and in the sixth and last stage, the report was produced with analytical writing, involving the final analysis of the extracts and the interconnection of the most significant extracted themes⁷.

Regarding factor and similtude analysis (FA), the data were processed in the IRAMUTEQ software (Interface of R pour les Analyses Multidimensionnelles de Textes et de Questionnaires) 0.7 alpha 2⁸.

FA provides tools that analyze the correlations in a large number of variables, defining sets of strongly interrelated variables known as factors⁹, and generates a table that illustrates the convergence and opposition relationships of these variables (Figure 1). In turn, the analysis of similarity is based on graph theory and allows identifying co-occurrences and verifying indications of the connection between words, revealing in a tree-shaped image (Figure 2)¹⁰.

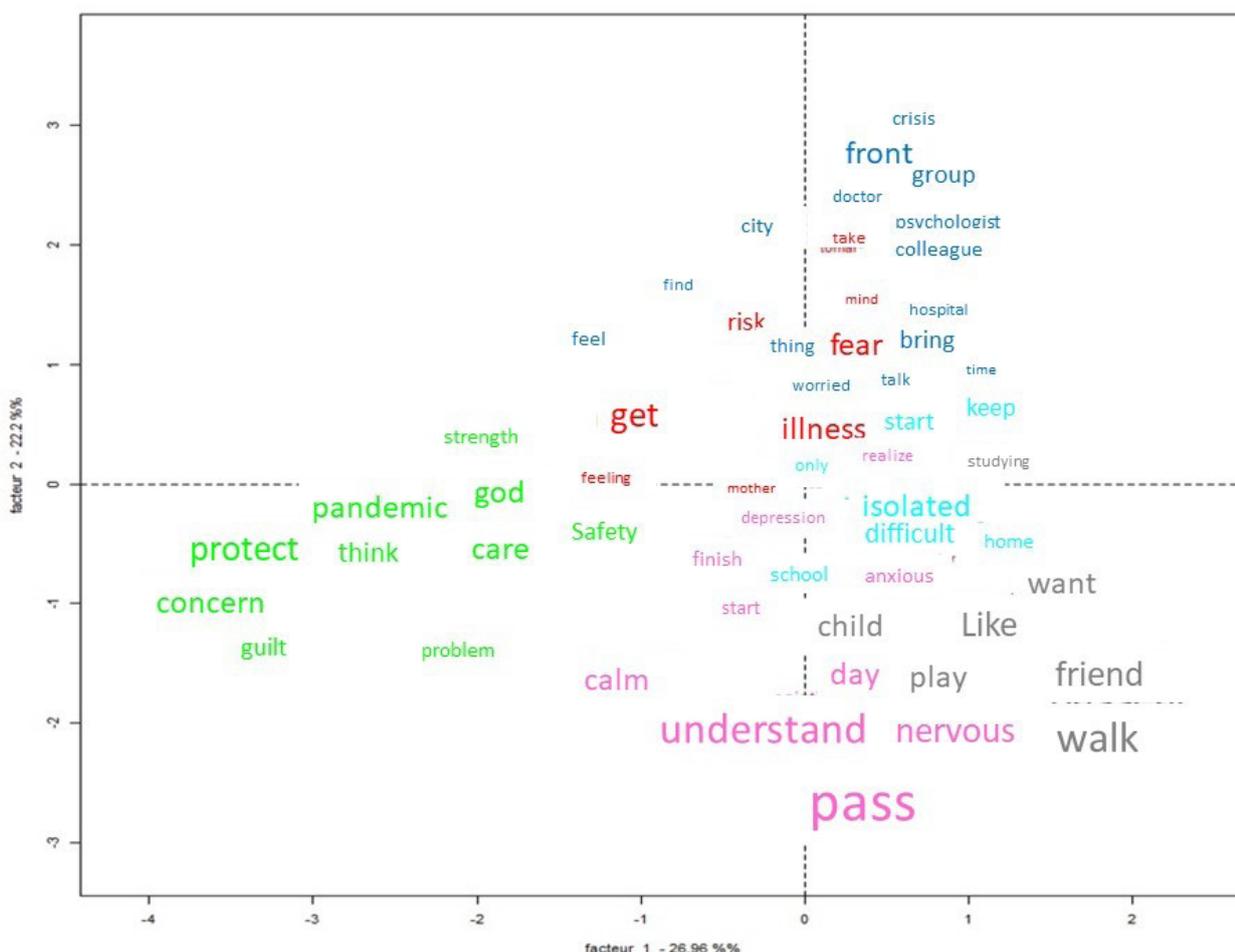


Figure 1 – Correspondence Factor Analysis about the feelings of mothers and children/adolescents with SCD in the context of the COVID-19 pandemic, Feira de Santana, BA, Brazil, 2021.

The themes obtained in the thematic analysis, the results of the FA and the Similitude Tree were evaluated, compared and validated by consensus by members of the research group (authors 1, 3 and 6) in two meetings held on the Google Meet platform.

The recommendations of Resolution No. 466/2012 were adopted, with a favorable opinion from the Research Ethics Committee (CEP), Resolution No. 510/2016 and Circular Letter No. 2/2021 of the National Research Ethics Committee (CONEP), which deals with procedures in research with any step in a virtual environment.

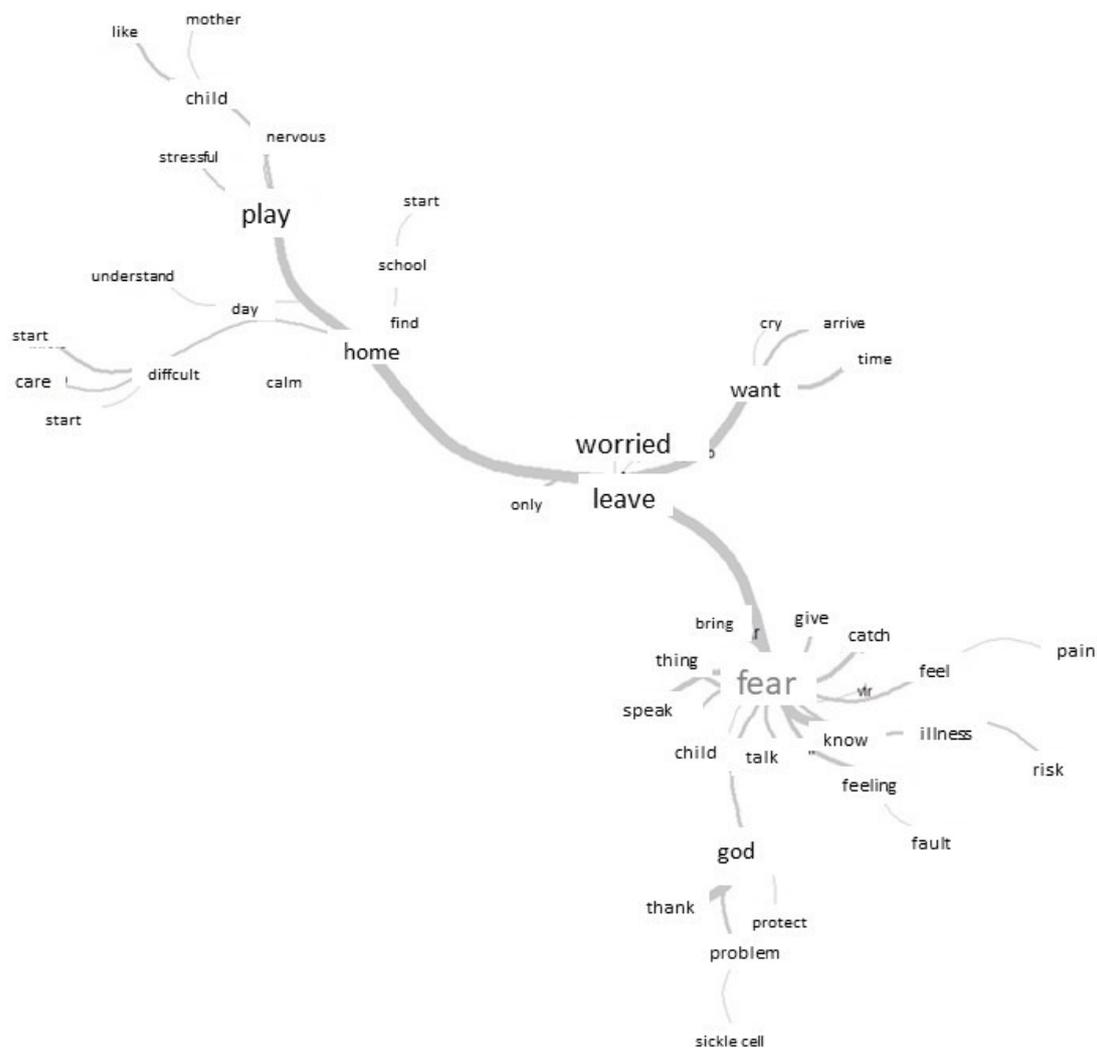


Figure 2 – Similitude tree regarding the feelings of mothers and children/adolescents with SCD in the context of the COVID-19 pandemic, Feira de Santana, BA, Brazil, 2021.

RESULTS

The study included 19 mothers of children/adolescents with SCD. The participants were between 20 and 49 years of age. Among them, 11 declared themselves as brown, seven as black and one as white. Regarding the level of education, 16 had completed high school, two completed higher education and one had not completed elementary school. Housewife was the predominant profession/occupation among the study participants, totaling 15. In addition, 17 mothers reported that, until that time, none of their family had tested positive for COVID-19. The ages of children/adolescents with SCD whose mothers were interviewed is illustrated in the Table 1 below:

Table 1 – Ages of children/adolescents with SCD (years). Feira de Santana, BA, Brazil, 2021.

E1	E2	E3	E4	E5	E6	E7	E8	E9	E10
12	4	7	10	6	14	7	9	13	11
E11	E12	E13	E14	E15	E16	E17	E18	E19	
10	9	11	2	9	12	15	11	14	

Source: Direct Search

The results were organized into two categories and into the images of the FA (Figure 1) and the Similitude Tree (Figure 2). The categories emerged from the thematic analysis and were confirmed with the CFA and the Similitude Tree, considering the frequency of words, the conformation of the word classes, the approximation of the terms of the X and Y axes and the organization of the axes based on the co-occurrence. The categories were entitled *Feelings of children/adolescents with SCD perceived by mothers* and *Feelings experienced by mothers during the pandemic*, which will be presented and discussed below.

Feelings of children/adolescents with SCD perceived by mothers

The interruption of school activities and the lack of interaction with other children was reflected in the behavior and emotions of children/adolescents with SCD. According to their mothers, this break in the child's routine caused stress, tensions and behavioral changes, with changes in the way they expressed affection, feelings of loss of freedom, distancing from the bodies and little verbal communication:

[...] *When I go somewhere and he sees a child, he wants to play, he cries to leave, because we know that children like to be with a children. And when the school closed he kept asking [imitating the child] 'Mommy, when are we going to school?'* (E2).

[...] *They became more distant from us, they didn't talk much, stayed more by themselves, because we talk a lot here the four of us, they stayed for a while like this when we didn't want to kiss, hug, touch, you know? [...] Before we cleaned everything on our body and the things that we brought from the street into the house we ask them not to touch us, now we let them touch, kiss, kiss, hug, talk, we talk a lot again, because they were feeling very excluded, you know?* (E6).

Mothers of children/adolescents with SCD reported that their children presented sadness and anxiety because they were prevented from playing and meeting with friends/other children. Social isolation made them emotional and resulted in constant nervousness and irritability. This irritability is the result of the misunderstanding about the limitations imposed due to risks regarding covid-19 constantly recalled by mothers.

[...] *He just wanted to be with me, he called me all the time to play, and he was also impatient, the two of them had no patience with each other sometimes, all the time they were talking [imitates son] 'I can't wait to go back to class so I can see my school friends'* (E9).

[...] *We couldn't say anything, he cried for everything, he was very upset sometimes because he wanted to go outside, there is a little park here, he wanted to play with the boys, I did not let him, his father would not let him go like this, so he cried all the time* (E16).

The mothers reported that the fear of leaving the house was perceived in children/adolescents with SCD. In addition, not having contact with friends/other children lead to sadness in children with SCD.

[...] *Every now and then he says he's in the mood to go back to school, and there are some colleagues who call him out the front, but he's afraid of the disease. They call him to play, he says "no, I can't leave no", he just replies this, 'I can't leave no', because he knows he's in the risk group. He's afraid to go out and play, but then every once in a while his cousins come home, they stay in here playing, talking* (E1).

[...] *At first it was very difficult, but now it's getting, at first we didn't really understand how to take care of ourselves in fact, but today it's easier. It was actually because he has respiratory problems and at first they talked about people with respiratory problem would be the worst cases. Soon after this, he [the child] and his sister was afraid to leave the house* (E9).

Associated with the child's fear of leaving home, the mothers reported that the fear of falling ill and dying was also present. Children/adolescents with SCD were frightened by the images presented by

the media that denoted frightening realities of the pandemic. The excessive news about the pandemic, associated with social distancing, increased the emotional discomfort of children/adolescents with SCD, as can be seen in the following statements:

[...] *Actually, he got really scared. There were a few days that he started crying, he told me that he was afraid to die, because we did not pay attention to the things on the television, we stopped watching television, because there were moments that he cried, he was afraid [...]* (E9).

[...] *He is very afraid, he has always been a child who has always liked to go out and today he refuses, even when we want to take him to a place in the open air, he feels afraid and does not want to go. He doesn't like us watching the news, because he says it's all a lie, but inside him I know he's afraid. He stays more at home, it gets in the way a little, because there's no other child and he's scared* (E13).

Feelings experienced by mothers during the pandemic

The mothers of children/adolescents with SCD reported feelings of guilt and fear that resulted in overprotecting their children. The mothers of children/adolescents with SCD reported that their responsibility increased because they need to protect their children from Covid-19:

[...] *With this disease, I get scared, I get more afraid of my daughter getting it, because she has a very low immunity, and also without physiotherapy to help with her immunity, because we cannot take her there* (E14).

[...] *It's apprehension and fear, it's a lot of mixed feelings* (E18).

The fear of the disease had a significant effect on sleep disorders in mothers of children/adolescents with SCD, as evidenced in the following statements:

[...] *It's because he doesn't have a spleen, his immunity is at risk, because the spleen produces immunity. He doesn't have a spleen* (E2).

[...] *At first I was very scared, very afraid, very worried about exposing him, that he wouldn't get infected, there was a period that I didn't even sleep right, I was so worried* (E4).

These mothers experienced negative feelings such as fear, anxiety and/or feelings of helplessness because of the inability to find a solution to the problem of social isolation in the context of the pandemic, as can be seen in the following statements:

[...] *At first I felt guilty, anger, incompetence, fear, it was an exaggerated fear. And that fear was that I could not protect him, as if I was to blame for them being high risk, and I could not protect him, forbidding him to go outside, especially when they saw the other children who could go outside and they could not* (E9).

[...] *We feel fear. [...] Insecurity, right? Because we have our hands tied, we can't do anything, what can we do?* (E11).

In view of the statements, it is evidenced that the fear of death was one of the first reactions of mothers of children in chronic illness in the scenario of the COVID-19 pandemic:

[...] *I am also afraid of her getting COVID and as she is in the risk group, I get very afraid [...] I'm panicking myself, I can't wait for this vaccine to come soon so that it can be a little better at least, because it panics me just to think about getting it. I don't even want to imagine such a thing, it's not been easy no, it's very difficult. It makes me feel helpless, that my biggest fear is of her catching it and losing her, because so many people who have died from this disease and doctors say that people in the risk group get sicker. My biggest fear is her getting it and dying, that's my biggest fear* (E5).

[...] *I'm quite afraid of my daughter getting this disease, I'm afraid of losing her, fear of her getting it and not getting better* (E7).

Through CFA, the terms that are closer to the zero point (Figure 1) - point of intersection with the two lines - indicate the higher occurrence of these among the study participants, such as “fear”, “catch”, “difficult”, “depression” and “die”, which confirms the fear of the mother in relation to infection and death of children with SCD as the center of their experience. However, this same fear seems to mobilize the mother to observe the behavior of everyone who approaches her and who may appear as an infection risk, aiming to preserve the child’s life.

By observing the Similitude Tree in Figure 2, it is possible to confirm that the tree is organized into three central lexical elements that are: “fear”, “home” and “leave”. The “leave” in the center is strongly linked to the terms “home” and “fear”, in addition to connecting with “God”, “crying”, “nervous” and “difficult”. The fear of leaving the house denotes the overload of the mother who, when staying at home to avoid COVID-19, in addition to assuming the tasks of caring for the child, witnesses the “crying” and “nervousness” of the child/adolescent. “Fear” is a consequence of knowledge about the risk of COVID-19 in people with SCD and the death of the child. This fear, found in the Y axis of CFA with frequency 54, was confirmed in the organization of the Similitude Tree as one of the axes, which demonstrates the force with which the fear of the child’s death filled the discourse of most mothers.

Fear in the Similitude tree organizes an axis with a large number of co-occurrences - “catch”, “disease”, “feelings”, “child”, “risk”, “protect”. Thus, it is possible to affirm that the idea that the death of the child could be another number in the statistics had repercussions on the suffering in mothers of children/adolescents with SCD. On the other hand, one of the interviewees mentioned her fear of catching COVID-19, dying and leaving her child alone, thus informing her that she feels like the only person capable of taking responsibility for the child’s care:

[...] I’m scared, yes, you know? I’m afraid of getting sick, leaving and him being here alone, alone in a way, because my son treats him like a son too, not like a brother. My son is already twenty-two years old, he was born ten years later, so the whole family cares for him, but my fear is to die and he stays behind, because I take care of everything, I am the person who has been with him since forever, so I’m afraid, really I’m afraid! (E1).

The fear that their child will get sick and have complications reverberates in the mothers’ discourse and emotions, reflecting on sleep and rest patterns that indicated the emergence of specific needs of these mothers during the pandemic. Fear can increase and panic can become pathological, especially in the face of social isolation and decreased interpersonal relationships, resulting in psychoemotional disorders.

[...] At first I panicked, you know? Because of my girl who has sickle cell anemia, so I panicked, I didn’t even want to go to the gate, I was so afraid when I went to work, [...] But to tell you the truth, I panicked and I’m becoming depressed, do you understand? (E19).

On the other hand, in addition to the mothers of children/adolescents with SCD adopting overprotective measures to prevent catching COVID-19, there was still the challenge of making other people aware of the protective measures to prevent the spread of the disease. The following speech shows that people in the extended family did not understand the need to be extra careful due to the child’s vulnerability and downplayed the mothers’ concerns when they adopted protective attitudes towards their children:

[...] You as a mother, you understand what the child has and you know it’s risky, but there are people who don’t understand that, they think you’re exaggerating [it imitates people]. It’s pretty complicated, because, besides doing your part, you still have to do the neighbors’ part. His father has his weekend drinks, goes out, goes out to bars, I talk to him, I think it is bad, I say: “what about your son”, but he does not understand, he just wants to enjoy himself, it is complicated (E11).

The term “leave”, strongly connected with the terms “only”, “worried” and “crying” is in the center with a greater number of branches in the Similitude Tree (Figure 2). This term shows that, for mothers, it is necessary to stay at home so as not to be exposed to the risk of the child contracting the virus, even contrary to the will of the child who was worried, angry and upset because of the restrictions employed by the mother. It is inferred that staying at home has a strong relationship with assuming the role of imposing limits on children/adolescents with SCD and maintaining the need to seek emotional support. In the branch above, words associated with “home” appear, which represent the actions of “care” and protection during the pandemic.

DISCUSSION

Among the feelings and emotions experienced by the mothers of children/adolescents in the COVID-19 pandemic, negative emotions prevailed: anxiety, depression, impotence, indignation and fear. A similar situation was experienced by several people during the process of social distancing, due to the feeling of uncertainty. By experiencing negative feelings and uncertainties, the person can also show a decrease in positive emotions such as happiness and satisfaction with life¹¹.

In this study, the overprotection of mothers is due to feelings of fear, guilt and uselessness. When they are encountered with a new and unknown situation of the COVID-19 pandemic, mothers of children/adolescents with SCD overprotect their children and feel frightened at the possibility of catching COVID-19 that may culminate in the death of their children. Pathological fear becomes harmful and can be a precursor to the development of mental disorders. In the context of a pandemic, fear increases anxiety and stress levels in healthy individuals and intensifies the symptoms of those with pre-existing psychiatric disorders¹². Adhering to social isolation is related to the fear of becoming infected and suffering financial and health damage¹³. In the case of mothers of children/adolescents with SCD, this fear is focused on the possibility of losing the child, more than that of anyone in the family group.

This study also showed that sleep alterations are common in mothers of children/adolescents with SCD, in view of the concern and fear surrounding COVID-19 that permeates their experiences. Quality of sleep tends to be deteriorated as a result of the impacts caused by social distancing, along with the fear of acquiring the disease and exposure to recurrent news reports of the pandemic¹⁴. In the context of social isolation in the context of social isolation, sleep problems during a pandemic are due to the introduction of several stressors, including loneliness due to social isolation, fear of contracting the disease, socioeconomic problems and uncertainty about the future¹⁵.

It was also found that the mother of the child with SCD fears falling ill from COVID-19 and leaving the child alone in case of her death. The fear of falling ill, dying, losing loved ones, and the reduction of formal and informal social support and the uncertainty about the future are present in families in the context of the pandemic¹⁶. The pandemic crisis causes uncertainty and fear of the unknown, but it can also be seen as an opportunity to develop resilience and wisdom¹⁷.

The results showed that the change in school routine and interpersonal relationships of the child caused stress and behavioral and emotional changes in children/adolescents with SCD. Children are more stressed due to mobility and contact restrictions with other important people in their lives and, therefore, can react more aggressively to external demands and requests from family members¹⁸. Children, especially those in preschool, do not understand the pandemic situation and end up reacting to the changes they perceive in the behavior of family members and in their day-to-day routine. Thus, the following symptoms may arise: changes in sleep pattern, feeding, crying, biting objects and people, sadness, apathy or distancing¹⁹. In addition, underage children tend to express more fear, while older children may ask many questions about the disease²⁰.

The fear of becoming ill and dying in children with SCD stems from the excessive news reports on the pandemic associated with social distancing, leading to emotional changes. The adoption of measures such as avoiding continuous access to news about the COVID-19 pandemic, for example, is an effective self-care measure for both adults and children. One should focus on attitudes that promote our well-being, such as the practice of physical activity and stretching²¹.

Family members should be instructed about the experiences of suffering and changes in children's behavior in the context of the pandemic, such as the presence of insomnia, agitation, increased communication difficulties, lack of appetite, loss of sphincter control and fear²². The pandemic has been responsible for the increase in cases of depression and anxiety in adults and increases in behavioral and emotional changes in children and adolescents. The manifestations present in children during the pandemic are irritability, concentration difficulties and greater dependence on parents or caregivers, as well as changes in sleep and eating patterns²⁰.

In this study, sadness was evidenced in children/adolescents with SCD due to the change in routine regarding being with their peers and even close relatives. Prolonged confinement, fear of infection, frustration, boredom, lack of contact with classmates, friends and teachers, lack of physical space in the residence for leisure activities and the financial loss of the family are factors that can result in more problems in children and adolescents²³.

When parents of children, especially those with chronic illness, need to work outside the home, the fear of being infected and transmitting the virus can cause there to be a disruption in close physical contact with their children. This affects the distancing of bodies, and the COVID-19 pandemic may affect mother-child and father-child relationships²⁰. For those who remain at home, this may also be a time of closer ties and a time to experience new patterns of interaction, learning and improving care²⁴. However, it is worth noting that attitudes of overprotection, common in the family interactions of people with SCD, may be hastened during the pandemic²⁵.

It is worth noting that the trend of reconfiguration of the pandemic phenomenon with the gradual return to face-to-face meetings, the reintegration into the social context and school activities, at the same time that new variants of the virus emerge, indicate that the challenges and stress in mothers/children with SCD tend to remain, given that SCD is a chronic condition that requires frequent visits to health units and increases vulnerabilities. This situation requires professionals to have a sensitive outlook at the new demands of care, the need to maintain respiratory barriers, the inclusion of vaccines, health education, social and psychoemotional support, and think about enabling and maintaining remote monitoring of this group.

Among the limitations of this study, we emphasize that exclusively accessing mothers located the phenomenon in their experience and perspective, but prevented us from reaching the perspectives of the children and adolescents themselves, as well as other subjects in the surroundings of their relationships. In addition, the access to experiences using WhatsApp limited the knowledge to subjective aspects and the unsaid during the interviews, which would be resolved by face-to-face interviews, on the other hand, this resource has made it possible to strengthen the bonds with the research team, to know and understand the challenges faced by mothers, meet the objectives of the study and understand how the COVID-19 pandemic affects the experiences of groups related to chronic health conditions.

CONCLUSION

The objective of the study was to understand the feelings experienced by mothers and children/adolescents with SCD after the emergence of the COVID-19 pandemic. Mothers of children/adolescents with SCD reported feeling overloaded when dedicating themselves full time to the care of

their children, who were more vulnerable and emotionally unstable due to social distancing. Therefore, strategies were adopted by mothers, with the intention of adapting and reducing tensions – provided by the context of the pandemic – in themselves and in their children.

This study emphasizes that mothers of children/adolescents with SCD need comprehensive care approaches in health services, with the aim to provide support during difficulties and positive changes to their experience in the context of the pandemic, in addition to reinforcing the importance of identifying changes in behavior and emotions in children/adolescents with SCD, in order to equip them for care and search for specialized support when necessary.

It is worth mentioning that the feelings of children/adolescents with SCD presented in this study were evidenced from the perceptions of their mothers, which highlights the need for future studies that will listen to the children/adolescents themselves in order to broaden the understanding of their experience during the pandemic.

These results contribute to nursing to the extent that they present aspects for reflection on the care of mothers of children/adolescents with chronic illness, implementation of therapeutic guidelines and updated information, emotional support, the offer of sensitive listening and supervision of care through face-to-face or online help groups (to support a network of solidarity and care), in addition to stimulating the adoption of positive coping strategies with situations related to the pandemic. Moreover, living with SCD in a post-pandemic scenario will be a great challenge in the face of amplified vulnerabilities, making it necessary for health professionals to have a sensitive outlook regarding the new care demands in this population.

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NOTES

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